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»When I was on the ward«: The contribution of patient narratives to public involvement in health care decision-making

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Abstract

Aims: This paper sets out to provide an account of the forms of knowledge and expertise participants brought to a representational form of public involvement in healthcare. The findings are drawn from a two-year ethnographic study of an initiative by an acute hospital in the UK that aimed to involve members of the local community in health care decision-making, through the creation of a patient and public council.
Methods: Data triangulation was achieved by a multi-method approach to the conduct of the fieldwork. The methods consisted of: a) Observation of all council meetings (42 hours), b) Individual and focus group interviews with councillors (n=17) and c) Interviews with hospital staff and managers (n=35).
Results: Councillors drew almost exclusively from their experiential knowledge to construct and advance their agendas for the work of the council. Experiential knowledge and narratives was found to be very influential in constructing the types of contributions from the patient councillors. The patient councillors narratives provided a direct and largely unanticipated challenge to the agendas promoted by the health care workers. This resulted in particular tensions between the patient councillors and professionals concerned with the nature of expertise and the form of patients' contribution to health care delivery. The paper outlines these contested areas and describes the ways in which both patients and staff moved to create a shared set of understandings in order to progress the work of the council.
Conclusions: The paper highlights the contribution of personal narratives to public participation and the value that knowledge derived from personal experiences can have for service development. A key finding relates to the importance of professional repositioning and training vis-à-vis the credibility of patients' narratives, as a starting point for shared understandings and the development of improvements in service organisation.
However situated and experiential knowledge cannot be treated as unproblematic, instead an understanding of the partiality of such knowledge needs to be created and consequently where such knowledge can be appropriately drawn upon.

Key words: User involvement in policy and planning, public participation, public empowerment, patient narratives, ethnography

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Introduction

Western health care systems are facing increasing demands for health care provision from a less deferential public. Incorporating the *user voice* and achieving a partnership with patients has been perceived as one means of resolving key contested areas of health care delivery through making the service both more accountable and more responsive to user definitions of need [24].
At the level of the consultation approaches which recognise that the patient brings a form of expertise concerning his or her own health status, have consistently demonstrated improved health outcomes [15, 22] particularly in the management of chronic conditions such as diabetes and asthma. Significantly, the expertise that patients bring to the successful health care encounter is grounded in an embodied experiential knowledge base, not normally accessible to practitioners [4, 10, 26]. This patient centred perspective contends that the skills and competencies necessary for managing health and illness are distributed between patients and professionals.
Collective and representational forms of public participation encompasses the involvement of members of the public or local community, (usually patients or their carers) in strategic decision-making, resource allocation and decision making about the enhancement of quality [7, 8]. The claim that there are positive benefits to patient involvement at the representational level has been attributed to the value offered by having the input from patients and carers own experiential knowledge attained through their encounters with services. Through employing knowledge gained from their experience of receiving care patients can generate creative solutions and ideas that benefit the organisation

as a whole [21]. Moreover at the strategic or policy level of health care decision-making experiential knowledge 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 [7, 8].

However, in relation to the representational level of involvement, the exact nature and impact of user expertise, the effectiveness of user contributions and how far patients can be involved in policy and strategic decision-making are particularly unclear [11]. In spite of such an absence of clarity, comparatively little attention has been given to evaluating the processes which enable user knowledge at the representational level to actually impact on health care decision-making and identifiable change in service delivery [3, 13, 14, 25].

The findings presented in this paper are drawn from an evaluation of an initiative by an acute general hospital in the UK, that aimed to establish a mechanism for public involvement in strategic and policy decision-making, notably a patient and public council. This paper aims to provide an exploration of the forms of knowledge, and input patient members brought to the process of health care decision-making. Tensions concerned with the nature of expertise and the form of service users' contribution to health care delivery are then described. The paper outlines these contested areas and details the ways in which both patients and staff moved to create a shared set of understandings in order to progress public participation.

The implementation of the Patient and Public Council

The patient council was established as part of a hospital wide patient and public involvement. The council was set up with the deputy director of nursing acting as chair and link to the hospital managerial structures. The council had access to part-time administrative support (4 hrs per week) and an additional health care professional who acted as a co-ordinator. Councillors were not paid for their time, but expenses were reimbursed.

The advertised remit of the council was to encompass both the *promotion* of patient participation for individuals at the level of the consultation and involvement in policy and strategic decision-making about the character and quality of services. The activity of the council was constructed partly from referred work, in the form of requests from staff for the council to have an input on an issue, and partly by councillors raising items for the agenda.

The patient and public council 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. The final 16 members of the council reflected the tendency for such initiatives to be largely supported by older adults with few members of minority communities. Only four of the original members 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 a predominately middle class one, 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.

Evaluation methodology

The external evaluation team were appointed prior to the recruitment phase, consequently the evaluation covers the full first two years of the life of the council. The methodology involved observation of all council meetings (14 three hour meetings, audio, video and verbatim notes= 42 hours), interviews with councillors (n=17), including a final group interview of remaining councillors and interviews with key staff within the hospital (n=35). A documentary review and mapping of the council actions was also undertaken. The data was analysed via Atlas.ti, using a grounded theory approach.

All patient members of the council and staff involved were aware of the evaluation and written consent was obtained from all participants. All participants have been anonymised in this paper.

The contribution of the councillors: insisting on a patient perspective

The issue of representation is an intensely debated issue within public participation, with members of socially and economically disadvantaged groups being perceived as less likely to participate [5]. However this perception has been challenged by research that suggests local concern and levels of interest in an issue are likely to be stronger indicators of high public participation rates than either demographic variables or economic advantage [12, 16, 18]. The importance of personal concern as a positive variable influencing participation rates was also reflected in the findings from the patient and public council evaluation. The councillors were found to represent a *community of interest* in so far as the primary motivating factor for all members was to be a voice for patients and, in particular, to improve service delivery. A motivation that was exclusively linked to their own or their families' experiences of health care services. The main reasons councillors' choose to participate in the council were as follows:

1. »No blame«: Learning from adverse events: The majority of the councillors reported some negative personal health care experiences, which in some cases had exacerbated their presenting illnesses. However they expressed a strong desire to use their own negative experiences not to complain, but to prevent a repeat occurrence medical and organizational failures to deliver quality care. As one councillor explained:

> »I just wanted to make sure that what happened to me, won't happen to any one else. I can rest easy knowing it won't ever happen again.« (Council member)

2. Altruism: A further four of the councillors expressed an altruistic desire to support a service that had helped to restore their health, to »give something back«, was, in these cases, the main motivating factor in joining the council:

> »So the hospital has been good for me, […] so you try and put something back don't you?« (Council member)

3. An empowering agenda: The third approach was characterized by a desire to empower patients with knowledge to enable them to manage their own health care encounters and experience of hospital services more effectively. A particular focus for these councillors was to improve the provision of evidence based patient-centred information. Moreover, councillors were keen to assist directly with increasing the role of patients in the decision-making process, particularly through improved patient information.

> »People can't speak up to consultants; they can't ask questions they would like to ask and I'd like to help that.« (Council member)

In summary then, participants were concerned with the development and enhancement of the quality of the patient experience and the delivery of care. Even those who were critical of their personal experiences of care, were concerned less with a complaints led agenda than they were with pursuing patient empowerment and improving services through their contribution rather than complaining. Consequently from the very beginning of the existence of the council experiential knowledge was being drawn on by participants to shape the operation of the council.

The remainder of the paper focuses attention on the forms of narratives and experiential knowledge councillors brought to the process of public participation and the impact of such contributions.

»Telling the story«: Contributing Experience-Based Knowledge

In terms of the knowledge base for the councillors contribution it can be seen from exploration of their motivation to participate that experiences of care held a significant place in individuals decision-making. Councillors in interview, consistently expressed the belief that their experiential patient knowledge was the most important, if not the only form of knowledge that validated their right to participate on the council:

> »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.« (Councillor)

Observation of the council meetings confirmed the significant role experiential knowledge played in the users contribution to the participation process. During the first five council meetings all the issues raised by councillors, (not specifically concerned with the operation of the council), were overtly drawn from either the councillors or their families experiences of receiving care within the hospital. This resulted in the following issues being promoted as items for the council to address: The quality of patient information, use of car parking, sign-posting and the difficulties caused by the hospital delaying or cancelling operations

In the early meetings experiential knowledge was displayed in all but one instance through personal narratives that recounted experiences of care. Participants were observed to raise these personal narratives during the council meetings as strategies that served as a »voicing« technique; to initially raise an issue or to supportively »second« an issue being raised through another councillor's narrative. In the »voicing« and »seconding« forms personal narratives appeared to be employed to provide explanatory force or credibility for an issue that was perceived to require either action or placing on the council's work agenda. In recounting narratives of health care encounters the councillors appeared to be concerned with explicitly conveying the reality of the patient experience, so that professionals could know what it was like to receive services or care. This strategy of »telling it like it is« was frequently employed as a means to exemplify how an individual experience was generalisable to other patients or carers encounters. In the following account, (below) the story indicates how organisational procedures fail to take into account that achieving an admission to hospital is for patients located in a highly complex set of extra-ordinary arrangements.

> »Particularly where she's told to ring the hospital at 7 in the morning and you ring at 7 – or everything's arranged so that she can be brought in, but then it's – »sorry we don't know yet, we might know at 11«. And you ring at 11 and they say »well we're not quite sure yet but it might be later on« – so how do you keep on rearranging everything. You know, people work; people have children to collect.« (Council member – caring for older relative observation recording meeting 1)

The above example was highly typical of the way that narratives were employed to illustrate the absence of a patient perspective in either hospital procedures or professional attitudes. Although the accounts were critical, the councillors' narratives did appear to be serving a broader purpose than simply complaining about services. It has been suggested that personal narratives are constructed in relation to experiences where there has been a fracturing between the »self and society« and between »ideal and real« [20]. In the context of the patient and public council it appeared that councillors were attempting through their story telling, to create a bridge between the reality of their experiences and their belief that professionals were unaware of the existence of such experiences. Narratives became a way of highlighting problematic areas of care and service organisation, that the councillors perceived as warranting change and therefore worth including on the council agenda for action.

The professional reaction

Dominant professional and organisational work place norms influenced how health care professional responded to patient councillors attempts to raise agendas. Negative reactions 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 professional 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 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 councils' operation health care professionals 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.

Towards shared understandings and agendas

This section explores how the council and 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?«
> *Councillor 1:* »Jolly useful!«
> *Councillor 2:* »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.«
> *Councillor 3:* »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'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 […]«
> *Councillor 4:* »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 nursing staff 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 manager. Interview data)

Moreover senior staff argued that the very way public and patient participation was defined and therefore understood by 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 manager. Interview data)

Significantly, a need for a re-positioning of staff approaches and understandings concerning patient and public participation was also a consistent feature in the councillors' interviews. Frequently, interview respondents argued that health care organisations needed to commit to providing the staff support and training they 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)

The impacts of patient narratives: contributing the »view from the outside«

As a result of conveying their narratives in the council meetings sub-groups of councillors formed with common interests in issues such as, cleanliness and housekeeping, who were then prompted to visit the wards to assess current situations. In this context the councillors translated narratives into agenda items that helped them to construct areas for action. As a direct consequence of the ward visits and meetings with staff, councillors employed their external status to raise as problematic aspects of organisation of care health care, aspects that staff had previously accepted as permanent feature of their working lives. Agenda and work items for the council became derived from a combination of their knowledge drawn from personal experience (for example hospital stays during which they witnessed elderly patients without adequate bedding) and evidence gleaned from meticulous touring of ward areas to identify laundry provision, meal allocation and cleanliness. As the following example illustrates, this approach was associated with the identification of practical solutions to local organisational problems such as the availability of laundry bags, blankets and pillows:

> »When the nurses are working on the ward they accept that there are never any (laundry) bags, you know, but they don't realise that somebody should say to somebody ›there aren't any bags‹, because they work with it day after day. And when we came along and we said ›well why aren't there any bags?‹ And so they bought some.« (Council member)

The councillors felt that they achieved practical solutions by asking what appeared to be, from a patient point of view, the obvious why question; i.e. »why is it like that? And why don't we do something about it?« Lack of knowledge of hospital budgets, hierarchies and organisations was perceived as a strength by the members of the council, rather than a weakness as they are free to challenge such issues from a patient-centred perspective and importantly achieve a change in service delivery or organisation: as the following interaction from a focus group with councillors illustrates:

> *Respondent 1:* »Cutlery was altered as well, wasn't it?«
> *Respondent 2:* »Cutlery was altered for disabled people, yes, because the health care assistants were saying, ›it's no good sending us a knife, fork and spoon, we need two spoons.‹ And it was very simple but nobody had thought about it before until we asked them, why?« (Focus group with the council)

The activity of the council also adds support to the interpretation that experiential knowledge is likely to have a role in the construction of the impacts of representational forms of public participation. Overall, from participation on hospital working parties to developing patient surveys that focused on the quality of care and information, as opposed, »To things about bedpans or the volume of TVs« (Councillor interview) the work of the council encompassed a wide portfolio of activity that reflected »experiential agendas«. Table 1 illustrates that the experientially driven themes of patient information; cleanliness and issues relating to the care of older people were all particularly evident in the hospital wide subgroups and projects that the councillors volunteered to join.

Limitations of the patient narrative: is equity at risk?

A noted drawback of user involvement in planning service delivery is that user groups have been found to be less concerned than professionals with equity in service provision [11, 23]. Findings from this study suggest that the »equity issue« may in fact arise as a result of limitations with agendas derived from experiential knowledge, as even when grounded in knowledge of local communities, such »experiential agendas« may have an inbuilt partiality [19]. Although (as noted in previous sections) personal experiences generated energy and enthusiasm among councillors to pursue issues, a gap in specific areas of experience was problematic in so far as it resulted in some areas generating little energy or enthusiasm. At the very least a gap in personal knowledge resulted in a low response from councillors to volunteer to take up some work that was referred as they felt they did not have the relevant experience or any real interest in the issue:

> »Like this midwifery they've said they've got to have outsiders views, well it's obvious they've come to us, but with that I think, they would have been better off going to a doctor's surgery and asking if there were any pregnant women, or women that had had children in the last

Group / working Party	Councillors involved	Notes on activity Undertaken
Audit Group	5	Audits undertaken: ■ Complaints ■ Cancelled operations
Patient Questionnaires	2	Surveys of: ■ Outpatients ■ Trauma and Orthopaedics ■ Surgery ■ Radiology ■ Obstetrics
Patient information and Communication group	2	Involved in a number of activities from advising on leaflets from patient perspective to responding to the results of the patient surveys
Environmental group	4	Two Councillors concerned with the patient and hospital environment, e. g. review of linen services Two Councillors for review of food services
Sub-groups concerned with development of specific Trust Policies	2 – 5	Policies Included: Uniform Policy (nursing staff) Carers Policy Smoking Policy
Publicity and awareness of the council	5	On-going Including planning for an awareness day
Medicine Cleanliness and Hygiene Group	4	New – on-going
Frameworks of care for Older People	2	Advice on implementation

Table 1: On-going council activity in working parties/sub-groups (18 months after council implementation)

> 5 years. (The chair) picked me to do that, and Helen, because we were the two youngest members in the group, but the last time I gave birth was 12 years ago tomorrow, you know.«
> (Councillor commenting on her involvement in the development of strategy for midwifery education)

At its most extreme lack of experiential knowledge led to an absence of empathy for issues that fell outside of personal experiences. For example, in response to national concern that children's educational attainment as well as their emotional well being was suffering as a result of being in hospital, the hospital installed a computer to enable school children to be taught from school during hospital stays and to maintain relationships with their peer group. However some councillors who were, almost exclusively at that point, not parents of school age children, viewed this development as having a very low priority.

> *Councillor:* »We have dirty hospitals and elderly patients neglected and dirty and they are putting a computer in the paediatric unit so that they (children) can email their friends!« (Observation recording: meeting 6)

The response of the council to issues of equity was however an evolving one, that was shaped through the process of participation. Although effective accountability to a wider constituency of patients and even knowledge of others experiences' remained a challenge for the council, particularly in relation to issues of concern to younger patients and maternity care. The council did prioritise and expend considerable time and energy in attempting to reach out to their constituency through patient surveys that focused on the quality of care.

Discussion

This paper set out to explore the nature and form of knowledge and expertise that members of the public brought to the process health care decision-making at the representational level. The evaluation reported here demonstrates that within public involvement initiatives, experiential knowledge is likely to have a pervasive quality, as members of the public seeking to contribute to representational forms of public involvement will be both strongly influenced and directed by such knowledge. Experiential knowledge also appeared from this study to function as a primary motivator for participation and as a factor in sustaining continued commitment to the process.

The findings highlight the significance of narratives as a means of displaying experiential knowledge and to develop subsequent strategies for action. Narratives were also found to have an important role in creating a sense of shared understandings and a consensus among other patient representatives in terms of agenda prioritisation.

This study demonstrated that knowledge held by patients can act as a resource to support the generation of valuable changes to the organisation and delivery of health care, providing both an inspiration and validity for patient driven agendas. Moreover the experiential agendas of the councillors were not simply parochial issues of relevance only to local communities, indeed the agendas promoted by the councillors were in many cases key issues for the health service as a whole, for example, the importance of addressing issues of cleanliness in hospitals are very much coming to the fore with concerns over the transmission of infections [1, 17].

Working with patient narratives is clearly a new experience for many healthcare professionals, particularly in terms of policy and strategic decision-making. This study highlighted that staff also need support and training to understand the meaning to patients of such narratives and the value of engaging with them.

Although effective at being a catalyst for change, the partiality and consequently, the limitations of knowledge drawn from patients' narratives was evidenced in the operation of the patient and public council. In particular the negative consequences for resource and work prioritisation were made apparent. However such partiality need not automatically discredit patient based experiential knowledge; medical sociology has for example, demonstrated that professional knowledge is also partial and partisan. Instead the strengths, limitations and how to employ such knowledge appropriately, needs to be understood more clearly. Health care organisations may also be able to ameliorate the negative consequences of partiality by ensuring that strategies for accountability to a wider constituency of patients are put in place. Models that create opportunities for reflection on the complexity of priority setting by providing patients with ways to input their own experiential knowledge, but also to gain access to organisational knowledge may prove to be an effective means to maximising the potential of patient contributions [6, 9].

Overall the findings from this study illustrate how experiential knowledge can be a constructive force within public involvement and as such should not be easily be dismissed or negated as »intolerable subjectivity«, located in singular vision. Instead the voicing of personal experiences can provide a valuable conduit for service patients to construct agendas and action for change.

In order for representational forms of participation in health care decision-making to be effective, there needs to be greater understanding of how those involved in public participation initiatives are likely to display and employ their knowledge.

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