Defining the user role in infection control

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SUMMARY

Background: Health policy initiatives continue to recognize the valuable role of patients and the public in improving safety, advocating the availability of information as well as involvement at the point of care. In infection control, there is a limited understanding of how users interpret the plethora of publicly available information about hospital performance, and little evidence to support strategies that include reminding healthcare staff to adhere to hand hygiene practices.

Aim: To understand how users define their own role in patient safety, specifically in infection control.

Methods: Through group interviews, self-completed questionnaires and scenario evaluation, user views of 41 participants (15 carers and 26 patients with recent experience of inpatient hospital care in London, UK) were collected and analysed. In addition, the project’s patient representative performed direct observation of the research event to offer inter-rater reliability of the qualitative analysis.

Findings: Users considered evidence of systemic safety-related failings when presented with hospital choices, and did not discount hospitals with high ‘red’ flagged rates of meticillin-resistant Staphylococcus aureus. Further, users considered staff satisfaction within the workplace over and above user satisfaction. Those most dissatisfied with the care they received were unlikely to ask staff, ‘Have you washed your hands?’

Conclusion: This in-depth qualitative analysis of views from a relatively informed user sample shows ‘what matters’, and provides new avenues for improvement initiatives. It is encouraging that users appear to take a holistic view of indicators. There is a need for strategies to improve dimensions of staff satisfaction, along with understanding the implications of patient satisfaction.

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Introduction

On patient involvement, the recent All-Party Parliamentary Groups’ Report in England highlights a need ‘to change the clinical paradigm from “what’s the matter” to “what matters to you”’ (p.6). This necessary ‘shift in culture and power’ has
been highlighted across clinical areas including patient safety. There is a well-established discourse surrounding the potential role and benefits of involving service users in co-designing healthcare services and delivery through consultation, followed by feedback and evaluation to improve services.

Here, users constitute members of the public (as potential users of services), patients as current users, as well as carers and relatives of patients. Involvement of patients in decision making around their own individual treatment plans can result in enhanced self-management, and better health outcomes through increased self-efficacy. Decision making at the organizational level in hospitals may be viewed as a logistical extension of such user involvement, if users are viewed as secondary stakeholders or as 'temporary members' of the hospital. Even within a hospital setting with its clearly defined organizational boundary, patients have varying degrees of membership as inpatients, outpatients or those with long-term conditions with complex, blended patient pathways.

Whilst policy makers and academics advocate and evaluate user roles, some aspects of this participation remain inadequately defined. Further research is required regarding the skills and decision-making process employed by users to define their own role in patient safety, specifically in infection control. When thinking of roles, issues of responsibility and blame arise, and clarity of information and checking understanding is crucial. In-depth qualitative research has revealed that surgical site infections were perceived by patients to be as a result of chance or as a result of their own neglect in postoperative care; conversely, meticillin-resistant Staphylococcus aureus (MRSA) was viewed as avoidable and hence the result of deficiencies in hospital management and care. Users are exposed to a lot of information and indicators about rates of healthcare-associated infections (HCAIs) via hospital websites as well as the media, but it is not known how users make sense of this information. Additionally, it is not completely clear how users view the espoused and potential roles promoted for them by healthcare organizations. The Chief Medical Officer’s 2006 annual report in England talked about 'strengthening the patient’s hand’ (p.19) in response to low compliance with hand hygiene practices by hospital healthcare workers (HCWs). Some hospitals have sought involvement of patients in infection prevention and control practices at the point of care, specifically by monitoring and reminding HCWs about hand hygiene compliance. Some of these practices encourage patients to ask HCWs, at the point of care, ‘Have you washed your hands?’ This ubiquitous strategy for patient involvement has been reviewed previously.

It is a fitting time to reflect upon positioning patients to monitor and question healthcare staff when, 10 years after the initial Francis report, challenges persist for National Health Service (NHS) staff to ‘speak up’.

This paper explores users’ self-perceived roles in patient safety, specifically in infection control, describing the information needs of users and potential adverse effects, with the aim of generating useful evidence before the resourcing of large-scale, controlled, relevant studies.

Methods

In May 2014, a sample of 41 participants (15 carers, 26 patients) was recruited from across London. Recruitment was by quota sampling on ethnicity and satisfaction (measured on a five-point Likert scale) with received care. In order to minimize respondent desirability bias and conflict of interest, participants were recruited via an independent market research organization, and individuals who had received care at the host organization were excluded. To minimize knowledge and confidence bias, HCWs were also excluded. Informed consent was obtained, and participants were reimbursed for their time.

User views were sought through a five-hour consultation event held at Hammersmith Hospital, London. Discussions were organized in groups of seven to nine participants, with an experienced facilitator at each table. Group interviews, self-completed questionnaires, scenario evaluation and discrete choice activities were used to collect data. Following open questions about the meaning of patient safety, open and closed questions were investigated in four main domains: responsibility for patient safety; role of patients in patient safety; specific role of reminding HCWs of hand hygiene; and use of publicly available infection data in hospital choice (Figure 1).

Participants were asked to write free text or fill out short questionnaires before group discussion for each question to capture individual views. Non-participant observers also took notes at each table. Plenary sessions were led by a facilitator from the independent organization to minimize bias. The plenary included an infection control information and 'questions and answers’ (Q&A) session to determine if this had any immediate/short-term impact on perceptions; this session was led by an infection control research nurse (ECS) and infection control doctor (WZ). The content of the session is set out in Table 1. The multi-disciplinary research team, comprising infection control practitioners, healthcare management researchers and patient representatives, took observation notes and analysed the data. In addition, the project’s patient representative (FH) provided inter-rater reliability during data analysis. All discussions were audio recorded and transcribed. Quantitative analysis of the self-completed questionnaires comprised descriptive analysis. An integrated approach to analysis was used for the qualitative data, where an organizing framework or ‘start-up’ list from the literature is followed by an inductive analysis.

Results

Participants talked freely about their hospital experiences and sources of influence, including experiences of friends and family.

Patient safety: meaning and expectations

Participants brought up a number of aspects of patient safety, ranging from structural issues such as levels and consistency of staffing, processes such as cleanliness of the environment and information sharing, and wider cultural aspects of a safe and friendly atmosphere.

Dimensions of patient safety which were seen as important by the participants, in order of prevalence to the open question, ‘What does patient safety include?’ were as follows: emphasis on cleanliness of the environment, staff and visitors; protecting patients from adverse incidents (e.g. misdiagnosis and wrongly prescribed drugs, infections); having well-trained
and trustworthy staff; providing appropriate medical treatment; and ensuring safety/security of patients and their belongings.

In this opening question, participants spoke about the preventative measures of hygiene, as well as making references to HCAIs more generally:

‘mixture of infection patients with no-infection patients’ (User 3, male)

‘... not to go in with one illness and contract another’ (Carer 2, male)

Only one participant made specific reference to a particular HCAI (in this case, MRSA). Respondents focused mainly on care in hospitals, with only two individuals referring to postoperative care and no mention of primary care.

A significant number of participants spoke about personal safety from other patients and feelings of vulnerability. These worries were exacerbated by perceived low levels of staffing and overstretched staff who ‘do not know what is going on’. Consistency of staffing was seen as important to minimize information loss and avert adverse events such as misdiagnosis and incorrect prescribing. In addition to these potential adverse events, concerns about ‘feeling vulnerable’ and ‘worried will not be listened to’ were highly prevalent in accounts across age groups.

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Trust A</th>
<th>Trust B</th>
<th>Trust C</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoidable infections:</td>
<td>Observed: 9</td>
<td>Observed: 1</td>
<td>Observed: 5</td>
</tr>
<tr>
<td>Incidence of meticillin-resistant Staphylococcus aureus</td>
<td>Expected: 2.58</td>
<td>Expected: 2.75</td>
<td>Expected: 2.59</td>
</tr>
<tr>
<td>Risk?: Elevated risk</td>
<td>Risk?: No evidence of risk</td>
<td>Risk?: No evidence of risk</td>
<td>Risk?: No evidence of risk</td>
</tr>
<tr>
<td>Emergency re-admissions following an elective admission (cross-sectional)</td>
<td>Expected: 1763.26</td>
<td>Expected: 1014.07</td>
<td>Expected: 1019.61</td>
</tr>
<tr>
<td>Risk?: No evidence of risk</td>
<td>Risk?: No evidence of risk</td>
<td>Risk?: No evidence of risk</td>
<td>Risk?: Elevated risk</td>
</tr>
<tr>
<td>Meeting physical needs:</td>
<td>Observed: 7.01</td>
<td>Observed: 6.59</td>
<td>Observed: 7.38</td>
</tr>
<tr>
<td>Inpatient Survey 2012 Q32: ‘Were you involved as much as you wanted to be in decisions about your care and treatment?’ (score out of 10)</td>
<td>Expected: –</td>
<td>Expected: –</td>
<td>Expected: –</td>
</tr>
<tr>
<td>Risk?: No evidence of risk</td>
<td>Risk?: Risk</td>
<td>Risk?: No evidence of risk</td>
<td>Risk?: No evidence of risk</td>
</tr>
<tr>
<td>Overall experience:</td>
<td>Observed: 69.96</td>
<td>Observed: 48.31</td>
<td>Observed: 69.75</td>
</tr>
<tr>
<td>Risk?: No evidence of risk</td>
<td>Risk?: Risk</td>
<td>Risk?: No evidence of risk</td>
<td>Risk?: No evidence of risk</td>
</tr>
<tr>
<td>Staff survey:</td>
<td>Observed: 68.27%</td>
<td>Observed: 63.58%</td>
<td>Observed: 51.56%</td>
</tr>
<tr>
<td>NHS Staff Survey: the proportion of staff who would recommend the trust as a place to work or receive treatment</td>
<td>Expected: 65.19%</td>
<td>Expected: 65.19%</td>
<td>Expected: 65.19%</td>
</tr>
<tr>
<td>Risk?: No evidence of risk</td>
<td>Risk?: No evidence of risk</td>
<td>Risk?: No evidence of risk</td>
<td>Risk?: Elevated risk</td>
</tr>
<tr>
<td>Staffing – staff vs bed occupancy:</td>
<td>Observed: 1.29</td>
<td>Observed: 2.26</td>
<td>Observed: 2.1</td>
</tr>
<tr>
<td>Ratio of all nursing staff to occupied beds</td>
<td>Expected: 1.82</td>
<td>Expected: 1.82</td>
<td>Expected: 1.82</td>
</tr>
<tr>
<td>Risk?: No evidence of risk</td>
<td>Risk?: No evidence of risk</td>
<td>Risk?: No evidence of risk</td>
<td>Risk?: No evidence of risk</td>
</tr>
</tbody>
</table>

Data representing three trusts differentiated for five out of six indicators were presented, and participants were asked to state their preferences, given that all other dimensions (travel time, cost etc.) are equal. The indicator for ‘staffing – staff vs bed occupancy’ (ratio of all nursing staff to occupied beds) acted as a ‘control’, rated green (no evidence of risk) across the three trusts, to minimize bias, as this issue had been the focus of media attention close to the data collection period.

Source: Care Quality Commission Intelligent Monitoring Reports.

**Figure 1.** Risk profiles of three trusts: based on publicly accessible process and outcome indicators, participants had to choose a trust for personal care. NHS, National Health Service.
Responsibility for patient safety

In response to the open question, ‘Who is responsible for patient safety?’, patients were perceived to be devoid of responsibility, while visitors and carers were deemed responsible (20%). Additionally, little responsibility was apportioned to macro-actors such as the UK Government or commissioners, with an emphasis on ‘all staff in hospital’ and ‘healthcare staff in hospital’ being responsible for patient safety (Figure 2). All responded positively to the follow-up direct question, ‘Do patients have a role in patient safety?’ The nature of involvement was contingent on a number of factors including severity of illness and ‘type of hospital’, which was elaborated upon in the group discussions to mean, ‘Will we be listened to?’ Ideas for participation included anonymous (electronic) feedback.

Reminding healthcare staff about hand hygiene

None of the participants had previously asked this question of HCWs for themselves or for others. Approximately half of the participants reported commenting previously to staff about visible lack of environmental cleanliness. The information and questions & answers session seemed to have some impact on participants’ confidence about this aspect, as a minority (36%) of participants said that they would ask the prospective, intentional question, ‘Would you ask a HCW, have you washed your hands?’

Figure 3 shows that the younger and older participants reported a higher intention to ask than participants aged 30–60 years. No association between sex and intention to ask was found. Equally, no differences between carers and patients were observed. The analysis did reveal interesting patterns according to level of satisfaction of received care. None of the highly dissatisfied participants answered ‘Yes’ to this question. A minority (10%) of these participants said that they may ask under certain conditions, whilst 90% said that they would not ask. However, for those at the other end of the spectrum (‘satisfied’ or ‘very satisfied with care’), the majority would ask under certain conditions (77%), and the remaining 23% said they would ask. So, in contrast, none of the satisfied participants ruled out the possibility of asking.

Reasons provided for unwillingness to ask ranged from feeling uncomfortable, avoiding disrespect toward HCWs, and assuming that HCWs were competent:

‘I would consider the doctor/nurse to be a professional in their field. I think it would be rude and inappropriate to tell them to wash their hands.’ (User 25, male)

‘It’s difficult to stop somebody from doing something — I’d even feel uncomfortable about asking somebody in a catering facility — I’d expect them to take offence.’ (User 6, female)

Almost one-third of the participants empathized with staff being busy and having to deal with challenging situations; this was another rationale for not asking.

For some of those with an intention to ask, the importance of observing hand hygiene was stressed:

‘Yes — wash hands… I wouldn’t want them touching me or taking my blood without me seeing them do this.’ (User 15, female)
For 35% of participants (classified as ‘Y/N with qualifier’ in Figure 3), a number of conditions would determine their participation in hand hygiene monitoring behaviours. These circumstances included the staff member concerned [‘I would not ask a doctor, no I would not’ (Carer 2, female)]; the patient concerned [‘Definitely would for my child’ (User 40, female); ‘Elderly patients are too scared to ask such questions’ (User 29, female)]; or the health status [‘If I was in severe pain or distress, no as last thing on my mind — so “no” but if in mild pain, routine exam, I would say, “Have you washed your hands?” though this could be insulting... maybe’ (User 3, male)].

Two participants were explicit about the renewed thoughts following the information session:

‘I wouldn’t have had, but may do so, now it’s been highlighted I think I definitely will.’ (User 5, female)

‘Not sure, depends on circumstances, probably would now.’ (Carer 12, male)

In contrast, when participants were presented with a different scenario about patient safety (missed medication dose of a diabetic patient), the majority were willing to ‘speak up’ as this was associated with immediate danger to health. Ninety percent stated that they would interrupt two HCWs to alert them to a missed dose of medication.

**Hospital choice based on performance indicators**

Participants took some time trying to make sense of the numbers and the associated (red, amber, green) coding (Figure 1), with discussion about thresholds between amber and red. For example, a higher objective rate above the ‘expected’ rate is not always coded red. During discussion, it became apparent that understanding that red can be attributed through quite small deviations for certain indicators was useful.

The exercise provided good insight into the level of information that participants were willing to engage with when provided in the context of shared information, views and opinions. It was also apparent that information provided ‘cold’ would be somewhat unhelpful, and unlikely to be used to ‘rate’ hospitals, aid decision making or indeed alleviate fears. In this context of information exchange, aggregate results for the participants show that the hospitals were ranked in order of preference as follows: first preference was shared between Trusts A and B, and many respondents stated that they ‘just would not go’ to Trust C:

‘Trust C — it would appear that staff are unhappy and avoidable infections are more than half which rings alarm bells.’ (User 11, female)

‘Trust A — reason is that, overall, the hospital scores highly, taking into consideration that people can get an infection in all NHS [National Health Service] hospitals.’ (User 39, male)

‘I would trust A though it has one red, but it can be easily countermeasured and fixed. The other points of A are green. So they need to fix the problem for the first point. B and C have more than one problem, and it is tough and time consuming to fix. So A, B, C.’ (User 25, female)

On the NHS Staff Survey, the indicator ‘proportion of staff who would recommend the trust as a place to work or receive treatment’ was viewed as important by the majority of the participants. This indicator was perceived to be more important than the Friends and Family test.

The elevated risk (‘red’) of HCAIs in Trust A was discussed by participants in the context of the other indicators, and did not, by itself, deter users. Participants viewed HCAIs as ‘unavoidable’ in some situations, and looked for explanations to why this was the only issue. In addition, there was discussion about the period over which the data were relevant, and if the elevated risk was a ‘peak’ value or a consistent risk over a longer period. Overall, Trust C was perceived as a ‘problem’ trust with systemic patient safety failings.

**Discussion**

This research engaged users with experience of inpatient hospital services to afford an opportunity to explore their

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**Figure 3.** Response to ‘Would you ask a healthcare worker, have you washed your hands?’ SD, standard deviation. Blue bars indicate ‘Yes’, orange bars indicate ‘Yes/no (with qualifier); grey bars indicate ‘No’.
decision-making process, including appraisal of infection control fitness of hospitals. The findings are limited in generalizability by the sample size, and because data relate to participants’ intentions and opinions rather than actual behaviours.

Participants did not recognize an immediate role of users in patient safety, or align themselves within the generic remit of ‘infection control as everybody’s responsibility’. However, on direct questioning, the majority felt that patients have a role in patient safety. Their main concern referred to ‘not being listened to’. Follow-up after discharge was the point when patients reported feeling very vulnerable, and examples of negative and positive experiences emerged. Findings indicate that a positive experience with overall care may lead to better engagement because patients may feel that their concerns will be listened to.

As in previous studies on the specific role of patient involvement in increasing hand hygiene compliance, a minority of participants said that they would interpolate HCWs about this at the point of care.\(^1\)\(^5\)\(^,\)\(^2\)\(^2\)\(^,\)\(^2\)\(^3\) The findings in the current study are particularly important as the views were taken after a detailed presentation of the risks of hospital-acquired infections, and the critical role of hand hygiene in addressing this avoidable harm. Reasons for not asking included fear of repercussions for future care, respect of professional knowledge and competence, and empathy for a busy, over-stretched workforce. Organizations may find it helpful to use hand hygiene as a ‘tracer’ to understand how patients perceive their hospital and staff, abounding on the notion that optimal organizational patient safety may reflect overall quality of care.\(^1\)\(^,\)\(^2\)\(^4\)\(^,\)\(^2\)\(^5\) In addition, complete absence of engagement intention in the dissatisfied users may serve as an important proxy indicator for hospitals when embarking on interventions.\(^2\)\(^5\)

There may be something particularly uncomfortable about questioning an individual’s ‘hygiene’, as anecdotal accounts from the practitioners and patient’s representative corroborate, but there is also a temporal dimension. Culturally, comparing hand hygiene as a basic tenant of infection control to smoking on hospital premises (another primary prevention measure), we are decades from having institutionalized or internalizing infection control. In this context, putting the onus on patients may not be the way forward. Health system financing and delivery structures position users at varying degrees of control, as do individual factors such as education and health literacy.\(^2\)\(^6\) However, these do not seem to translate into levels of comfort with the suggested role of questioning or reminding.\(^2\)\(^9\)

This research suggests that users engage in a sophisticated (or more complex than hitherto considered)\(^2\)\(^7\)\(^,\)\(^2\)\(^8\) appraisal of the information related to HCAs provided in hospital websites. An ‘elevated risk’ of acquiring an HCAI (visually coded red) along with ‘no evidence of risk’ (green) for five other indicators did not deter users from this hospital. Hospitals with systemic problems were seen as unsafe, and hospitals where improvement would be more challenging. Hospital staff need time and resources to enable meaningful conversations with patients and carers about the information that is already out in the public domain. Clinicians and organizations must consider the health literacy of patients before proposing or promoting the participation of these patients. Assessment by the service users in the current study aligns well with the wider suite of organizational performance and capacity indicators needed to assess optimal infection prevention and control.\(^2\)\(^9\)

Whilst users span primary, secondary and tertiary care through the life course, infection control outside of hospital care did not feature in accounts in this study. In hospitals, users are included in governance activities through membership of governance councils in NHS Foundation Hospitals and membership of Patient-Led Assessments of the Care Environment (PLACE).\(^3\)\(^0\) Generic evaluation tools are in routine use, but employment of these data to improve care is still suboptimal.\(^3\)

From an organizational perspective, user views can help to shape care which is responsive to people’s individual abilities and preferences.\(^9\) From a health systems perspective, it is useful to bear in mind the aspirational ‘fully engaged’ scenario,\(^3\)\(^1\) the contribution of patient safety efforts towards this goal, but also to stop and think about the nature of this engagement.

‘Levels of public engagement in relation to their health are high. Life expectancy rises considerably, health status improves dramatically and people are confident in the health system and demand high-quality care. The health service is responsive with high rates of technology uptake, particularly in relation to disease prevention. Use of resources is more efficient.’ (p.4)\(^3\)\(^2\)

**Conclusion**

Encouragingly, this study found that users take a holistic view of indicators, and are interested in what is behind publicly reported numbers. The study explains why interventions that involve observing, monitoring and challenging healthcare staff are inconsistent with what users feel capable or comfortable with. New approaches that involve a more collaborative approach through sharing and interpreting information is one suggested avenue.

Strategies to improve the dimensions of staff satisfaction along with understanding implications of patient satisfaction are required. Intelligent use of routinely reported feedback may therefore be useful at the organizational level. From a human factors perspective, staff satisfaction itself is an important indicator to gauge resilience or fatigue at the unit level. In addition, higher levels of staff satisfaction may result in better staff engagement with new initiatives, in a more sustainable way.

This in-depth analysis of views from a relatively informed user sample shows what matters and provides new avenues for improvement initiatives.

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