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# Should I stay or should I go? Patient understandings of and responses to source-isolation practices

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### Abstract

Isolation of patients, who are colonised or infected with a multidrug-resistant organism (source-isolation), is a common practice in most acute health-care settings, to prevent transmission to other patients. Efforts to improve the efficacy of source-isolation in hospitals focus on healthcare staff compliance with isolation precautions. In this article we examine patients' awareness, understandings and observance of source-isolation practices and directives with a view to understanding better the roles patients play or could play in transmitting, or limiting transmission, of multidrug-resistant organisms (MRO). Seventeen source-isolated adult surgical patients and two relatives participated in video-reflexive ethnography and interviews. We learned that, although most of these patients wanted to protect themselves and others from colonisation/infection with a MRO, they had a limited understanding of what precautions they could take while in isolation and found it difficult to obtain ongoing information. Thus, many patients regularly left their source-isolation rooms without taking appropriate precautions and were potentially contributing to environmental contamination and transmission. Some patients also interacted with other patients and their personal belongings in ways that exposed other patients, unnecessarily, to colonisation/infection risk. By not providing patients with adequate information on infection risk or how they could contribute to their own safety or that of others, they are denied the opportunity to fully engage in their healthcare. To improve the efficacy of source-isolation and contact precautions in general, patient care providers should consider colonised or infected patients as active partners in reducing transmission and involve patients and relatives in regular, ongoing conversations about transmission prevention.

### Keywords

Patient involvement, patient experience, patient engagement, patient- and family-centred care, source-isolation, MRSA, infection prevention and control, qualitative methods, health literacy

### Note

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## Introduction

Source-isolation of patients, colonised or infected with multi-drug resistant organisms (MRO), is commonly implemented in acute-care settings,<sup>1</sup> although there is some ongoing debate around its effectiveness because of incomplete staff<sup>2,3</sup> or, to a lesser degree, visitor<sup>4,5</sup> compliance. Studies examining effectiveness of isolation precautions are often based in intensive care units<sup>6-9</sup> where patients are confined to bed. Studies have also examined adverse physical and psychological impacts of isolation on non-intensive care patients<sup>10,11</sup> Isolation can be a very lonely experience; however, except in conditions for which quarantine is legally required, patients are not physically confined and many are ambulant. To date, there has been no specific investigation of whether, when or why mobile patients initiate movements across source-isolation barriers for reasons unrelated to their medical care. The activities of source-isolated patients and the roles they may be able to play in preventing infection transmission presents another factor for consideration in debate around the effectiveness of source-isolation.

The potential contribution of patients<sup>12-14</sup> to environmental contamination and MRO transmission,<sup>15</sup> has been explored in the literature and there are increasing calls for attention to patient hand hygiene as a means to prevent infection.<sup>14,16-18</sup> However, some researchers have suggested that deficits in patients' knowledge and understanding of MRO transmission and infection prevention and control (IPC) strategies, such as hand hygiene and source-isolation, may influence patient adherence.<sup>19-23</sup> The aim of this paper is to explore patients' awareness, understandings and observance of source-isolation practices and directives. Such insights may broaden clinicians' understandings of patient activities that impact upon IPC and may encourage them to support patients as more active partners in reducing infection transmission.

## Methods

### *Design*

The findings in this paper are a subset of a larger ethnographic doctoral study designed to explore patients' broad experiences, understandings and enactments of IPC. Our theoretical perspective acknowledges patients and family members as already playing active roles in recognising safety issues and enacting safety; often in ways not realised by their healthcare providers.<sup>24</sup> Thus, we sought to use methods that enabled patients to identify and articulate their own issues of concern and to share

their particular points of view about IPC. Alongside 300 hours of ethnographic observations we also engaged in interviews with patients, relatives and clinicians, and collected 11 hours of video footage that was used in video-reflexive sessions (video-reflexive ethnography).<sup>25</sup>

### *Video-reflexive ethnography*

Video-reflexive ethnography is an interventionist method that involves videoing care episodes and showing these back to participants to stimulate discussion about problems and potentials embedded in practices.<sup>25</sup> In this study, patients were initially offered an opportunity to be filmed during methicillin resistant *Staphylococcus aureus* (MRSA) screening (nasal swabs) and then to watch this footage back with the researcher to explore, in real-time, their behaviours, beliefs and strategies around IPC. Through this process patients also identified previously unrecognised infection risks arising from their interaction with healthcare professionals and developed new strategies for having their IPC needs met. The reflexive sessions were also video or audio recorded. This part of the study is described in more detail elsewhere.<sup>26</sup>

### *Interviews*

Some patients did not wish an episode of care to be filmed but agreed to participate in a 20-50 minute interview, which was video or audio recorded with their consent. Unstructured interviews<sup>27</sup> were employed so as to avoid leading questions and to encourage spontaneous generation of patient perspectives. However, broad questions were used to provide focus. Examples include: "From your perspective what was the purpose of the procedure [e.g. nasal swab]?"; "What were you thinking/feeling when it was being done?"; "What does infection control mean to you?"

### *Setting/participants*

The setting was a 66 bed, adult surgical unit in a metropolitan hospital in Sydney, Australia. This study took a purposive sample of 83 patients who were approached by the researcher (first author), informed about the study, given an information sheet, and offered a range of options for involvement. 21 agreed to an interview, 12 agreed to MRSA screening being videoed, and six agreed to participate in video-reflexive sessions following this. Two relatives also agreed to an interview. At a later date two other patients asked to be involved in video-reflexive activities: one patient viewed footage of her wound dressing being performed; another watched video footage of general activities filmed over one morning in his isolation room.

Human research ethics committees of the University of Technology, Sydney and Western Sydney Local Health District approved the study. A continuous consent process was adhered to. Consent for observation, interviews and videoing were obtained in writing. Subsequently, consents for videoing and the use of footage in other settings were requested at each stage. Participation was voluntary, and those involved could withdraw from the study or ask for videoing to be stopped at any time. Each participant was given a pseudonym unless they asked to use their own name.

### ***Data collection and analysis***

Fieldwork took place between March 2013 and April 2014. Observations, interviews and video-reflexive sessions were carried out in overlapping cycles. The overarching aim of using video-reflexivity in particular was to engender reflexivity and thought in participants. As such patients involved in video-reflexivity guided the analysis and interpretation of data as they viewed their own footage. Recordings of these reflexive sessions and the unstructured interviews were transcribed as soon as possible after taking place. Through an inductive process, the researcher identified themes and subthemes using Dedoose qualitative data analysis software. Ongoing analysis informed subsequent interviews and reflexive sessions. The themes were also discussed with participants as well as the wider research team and refined over time.

### **Findings**

MRSA acquisition and environmental contamination were relatively common at this research site and 17 patient participants were source-isolated in a single bedded room due to MRSA colonisation or infection at the time the research took place. Four isolated patients participated in a video-reflexive session and 13 isolated patients and two relatives (from the same family) participated in an interview at the patient's bedside; all but two of the latter were audio-recorded. The exceptions were an interview involving an interpreter and one with a patient who did not wish to be recorded; notes were taken during these interviews. One patient, who could not speak, scribed his dialogue, which the researcher read aloud to the video recorder. One patient had been recently cleared of MRSA but remained in an isolation room. Another was unaware of her recent MRSA colonisation status at the time of interview. During their interviews or reflexive sessions all of these patients volunteered insights about source-isolation practices.

Three main themes emerged: Understanding isolation and transmission; managing isolation boundaries; direct contact with other patients. Together, these insights show how patients' problems with receiving and understanding information given to them about isolation and transmission can lead to behaviours that are highly variable

regarding the ways in which they manage (or ignore) their isolation and the ways in which they might themselves be directly transmitting MROs to other patients.

### ***Understanding isolation and transmission***

At the research site, ward nurses were responsible for moving patients into isolation and providing initial education. Infection control professionals (ICP) discussed isolation precautions with patients on daily rounds but this was not always possible. Patients were often unavailable when ICPs arrived and return visits were not often possible due to heavy demands on the infection control department. A patient information sheet was available for ward staff to provide and discuss with the patient.

Most patients understood basic transmission processes and why they were isolated.

*I mean it can spread – like if I've got an infection and...nurses are handling me and then they go to the next patient, again not gloved up and that and handle them. Or vice versa they could have handled Joe Blow next door and brought something to me. (Fiona)*

Others were unsure of transmission mechanisms or the difference between colonisation and infection and some were anxious about the risk they might present to others.

*If I just breathe on someone are they going to get it?... even if I touch, does have to be an open wound? (Sidney)*

*You can just catch it from even just speaking to your Mum, like I was speaking to you just outside the door (Edie)*

*They told me that it was to do with my nose. But what's MRIS (sic) got to do with the nose? (Mary)*

*Well that's another thing I'm not sure of...I'm not kicking everybody with my [infected] foot. I'm not touching the wound either. ... So in that case I don't really know how I would be spreading it. (Rob)*

A few participants claimed they had never received information about MROs or source-isolation. Others had received some information from an ICP, ward nurse or doctor, but would have appreciated more regular, ongoing conversations with ward staff.

*Researcher: How often... would you like that information?*

*Miller: Regular updates on if I still have the infection or not, you know, or how long it's going to be for, that type of thing.*

Most participants did not remember being told whether they could leave their isolation room. According to ICPs, patients could leave isolation if they performed hand

hygiene and avoided communal areas, but most participants could not recall having been told this. Exceptions included Miller, who remembered being told it was best not to visit other patients, and Norris, who was told he could smoke outside.

Some participants reported difficulties getting information even when actively asking.

*Because I asked for [an information sheet] Saturday. I asked dad to get one Sunday. We asked for one Monday. ... [Nurse Unit Manager] brought it down to us on Tuesday. And my auntie had been here on Friday and even she said she was talking to the nurses and they wouldn't say anything; they wouldn't tell her anything. (Karin – daughter of patient)*

Some patients were resourceful and approached other patients. Before receiving information from staff, Karin had borrowed an information sheet from another isolated patient. Miller also learned about contact precautions from another patient.

*Miller: Well because I was being told by the guy who had [MRSA] that it shouldn't be happening. He was telling me all about MRSA.*

*Researcher: So you learned from him really?*

*Miller: A lot more from him than I learned from the nurses.*

Obtaining information was more difficult for Greta, who spoke little English. She cried as she recounted her confusion and fear when she was taken into isolation. She could not understand the nurses' explanations. She was not offered written information in her own language. She had no information until her daughter visited the next day.

Most participants had either not received the information sheet or did not find it helpful.

*It's old as the hills. (Cameron)*

*I've been given bits of paper that hardly explain anything. (Miller)*

Ann felt calmer after reading the brochure but could not recall any information from it.

*Ann: It sort of calmed me down a bit.*

*Researcher: Can you remember some of the things you read in the brochure?*

*Ann: No. But it's in the drawer if you want to have a look at it [laughs].*

The MRSA information sheet did provide information about the distinction between colonisation and infection as well as modes of transmission. However, the pamphlet

provided rather vague information about isolation precautions and how patients could prevent transmission. It stated for example that *occasionally* patients *may* be placed in a single room and that staff *may* wear personal protective equipment (PPE). One paragraph encouraged patients to perform thorough hand hygiene, especially after using the toilet, but did not suggest that patients should stay in their room or take special precautions if leaving it. There was mention that health care workers should wash their hands upon entering and leaving isolation rooms. It was suggested that patients could ask clinicians for more information, but, as is shown above, these conversations rarely happened. When they did, some patients were given partial or misleading information.

*There's nothing you can really do about it. The doctor says it's everywhere this MRSA. It's in the cleaning products, it's everywhere...and then once you go out into the fresh air in the sun, within 2 hours it's off you. (Norris)*

Many had learned about isolation practices from watching staff, but were confused by inconsistent practices, leading them to believe that isolation was not that important.

*I haven't put a great deal of importance on it because hospitals haven't put a great deal of importance on it. Except for this [contact precaution] sign. (Morgan)*

*Sidney: Nearly everyone who comes in wears a gown and gloves. Some people don't. ... I suspect they feel that the actual risk of contagion is maybe not that high. They don't seem to worry.*

*Researcher: So you're not worried if they're not worried?*

*Sidney: No.*

In contrast, Michael and Norris felt that staff was generally adherent with hand hygiene and PPE.

### **Managing isolation boundaries**

Apart from 4 bedbound patients, all 13 others had left their rooms of their own volition.

*I just hop in a wheelchair and go ... downstairs ... and tomorrow ... all three of my friends are going to take me downstairs for lunch, so that's an outing. (Eden)*

*Go and get the paper, read it outside. Come up. Go outside to have a smoke. (Norris)*

Some worried that in doing so they might spread infection.

*I'm in isolation control here but I can leave this room, go across to the kitchen, get a juice out, use the microwave, make myself a cup of coffee, cup of tea, contaminate that whole room. (James)*

Others had not considered that they would spread bacteria or felt that IPC was mainly the clinicians' responsibility.

*They're higher than me; they have a better position than I'll ever have. They're supposed to be smart ... they should be the first ones to be aware of the situation ... And I think that's a good starting point for your looking at stopping the spreading of the disease. Because obviously they're the ones doing it. They're touching me and they're going to touch somebody else and they're going to touch somebody else. And there it goes through the hospital ... So you have to ask yourself. Who's the one who's transmitting it? It may be not necessarily the patient. (Rob)*

Rob suspected he should limit his movements outside the room but hoped he would not be asked to do so. Only Miller said he mostly stayed in his room to stop spreading MRSA. James stated he would stay, if asked.

Mary did not mention her existing MRSA-colonisation status on admission to hospital because she did not want to go into isolation.

*They had me on one floor with four people ... and then I heard this nurse say, "But she didn't tell us she had it". And I said, "Hey why am I going to tell you I've got it, so you can segregate me?" So I don't say anything, see? (Mary)*

Morgan was so focused on her emergency condition that she forgot to mention her MRSA status. Both Mary and Morgan realised that MRSA alert systems do not always connect between hospitals and it could take some time before a patient was identified and isolated. To Mary, this meant she could 'get away with it' for a while. When pressed to explain she said:

*When I don't say anything nobody knows unless they go on the computer. And it wasn't in this [current hospital A] computer. It was in [hospital B computer] and it wasn't in [hospital C computer]. (Mary)*

Other patients notified staff as soon as they were admitted, sometimes to ensure they received the correct care, but often because they knew it would ensure a private room (not wanted by Mary but sought after by many). When Norris was informed about his healthcare associated infection (HAI) the ward staff even suggested that it could be viewed as advantageous.

*Then they said, "Well you get your own room," and I was like, "OK, sweet!" [Laughs] (Norris)*

However, despite securing a single room these patients still left them regularly; some did not take precautions when leaving, while others developed creative strategies in an attempt to reduce the risk of transmission.

*Gary: I'd make sure I didn't walk along dragging my hand along the handrails and so forth. When I actually opened and closed doors I actually tried to use my elbow, even though I don't know how much use that would have done because the MRSA was probably on the skin and everything. Also [try] not to touch or do things. Made it difficult when you wanted to go down to the TV room and sit down and read magazines and watch TV.*

Researcher: *But you still managed to do that?*

Gary: *Yeah.*

*When I go downstairs and then come back from having a coffee and that, I stop at the thing there [alcohol-based hand rub] and put some on my hands before I come back into the ward. (Michael)*

*I do feel funny when I go make a cup of tea from that kitchen room. Like even though it's all bandaged up (infected finger) ... just a cup, it's like, "Oh, careful not to touch two." You know? Someone else has got to use that other one. (Norris)*

*Straight in the [communal patient kitchen] door there's paper towels and I always take a paper towel and I always try and touch everything, like doors and everything like that, with a paper towel. (James)*

### **Direct contact with other patients**

During field observations, patients, not on isolation precautions, were seen sitting on each other's beds, sharing belongings and socialising in communal areas. Karin observed that her mother had had close contact with other patients in a four-bed room.

*Because Mum couldn't get up and walk and the other two were friendly and there were looking after her. ... one was filling out mum's breakfast menu and stuff. And mum would say, "Here is my New Idea"... [patient] would come over and watch the TV...*

Karin had also taken home laundry for these patients. She became concerned when these fellow patients were subsequently identified as MRO positive and isolated a few days later. Shortly after, Karin's mother was also found to be MRO positive.

Participants also mentioned having direct contact with known MRO-colonised patients. At the time of research Miller told how, on his previous admission for a surgical procedure, he had shared a two-bed room with a patient on contact precautions for MRSA, despite not being colonised himself. This was due to a lack of isolation rooms. He recounted:

*You might punch them on the arm, something like that ... or you might handle something in their room ... books, you know, pencils, whatever.*

Shortly after discharge home, Miller's wound showed signs of infection and breakdown. When he returned to hospital he was found to be infected with MRSA.

## Discussion

A small but growing number of papers have explored patients' knowledge and perceptions of risk around HAI<sup>22,28</sup> and the negative and positive elements of patients' experiences of source-isolation.<sup>11,29</sup> Our findings contribute to this literature. For example, consistent with other research, patients in our study found it difficult to obtain IPC information and generally lacked knowledge of MROs. However, our findings and analysis go further; linking these experiences and understandings (or lack thereof) to patient infection control behaviours around source-isolation, and to the potential impact these behaviours may have on infection transmission. In particular, the hitherto unexplored finding that, at this site at least, patients frequently left their isolation rooms for reasons unrelated to their medical care, underscores the need to attend to the activities of patients and the roles they may be able to play in preventing infection transmission.

We argue that when mobile patients are not aware of their MRO colonisation/infection status and/or modes of MRO transmission they may engage in direct contact with other patients or their belongings and expose them to *unnecessary* risk. The two family members involved in this study also revealed some of the ways in which immobile patients may be exposed to infection risks from direct contact with other patients. Furthermore, these family members shed light on visitor activities that can impact on infection transmission, such as borrowing information sheets from colonised patients and taking home laundry for undetected patients. It is essential that patients and visitors be informed about the risks of MRO colonisation, its relationship to HAI risk and direct and indirect modes of pathogen transmission. This should not, however, be the responsibility of ICPs only.<sup>30,31</sup> Infection control departments are often stretched and all patient-care providers should be able to discuss IPC practices, regularly, with patients under their care.

Many participants wanted to learn about IPC and contribute to their own safety and that of others.<sup>11,30</sup> We know that patients who are involved in their own care are: 'more likely to share important information, engage in productive plans of action, adhere to these plans, utilise communication technologies, engage with other patients/patient communities, and, ultimately, positively influence the course and trajectory of their health status'.<sup>32</sup> However, patients reported having difficulty obtaining information, even when actively trying. Consistent with other research, we found that a lack of accurate, accessible

and timely information about MROs contributed to frustration and confusion about IPC.<sup>10,11,22</sup>

Most participants in this study felt they had not been adequately informed about how they could prevent MRO transmission. This does not necessarily mean they were not told at some point; they may have been overwhelmed by their illness or the impact of being placed in isolation, so information may not have been retained.<sup>28</sup> Some patients were given partial or incorrect information. As in other studies,<sup>23,33</sup> inconsistent IPC practices by staff confused patients and led some to believe that isolation precautions were not overly important. Participants did not find generic patient information sheets particularly helpful, as they did not provide explicit instructions around leaving isolation; the assumption was that staff at each facility/ward would convey local policy to patients. The inclusion of local contact details for patients who want more detailed information could be made available. More importantly, patients and families should be involved in discussions about how to improve content and modes of delivery of IPC information.

We confirmed the suggestion of Newtown *et al.*<sup>21</sup> that inadequate understanding may affect patients' adherence to isolation practices. In contrast to research reporting patient self-isolation in community settings,<sup>34</sup> many patients left their isolation rooms for social reasons, without taking transmission precautions, and may have unwittingly contributed to environmental contamination in communal areas of the ward/hospital. Clearly, telling patients once, about MROs, is inadequate to address this.<sup>23</sup> Rather, well-informed, ongoing conversations about IPC are needed, throughout a patient's stay. As reported elsewhere,<sup>26</sup> in the absence of explicit instructions from staff, some patients developed personal strategies in an attempt to reduce transmission.

This study also highlighted the potential impact, on MRO transmission, of measures taken by some patients to achieve their personal preferences. Some were happy to have a private room<sup>21,35</sup> so volunteered their MRO status on admission. On the other hand, some patients withheld information about their MRO status to avoid being placed in isolation until an alert was activated. Patients need to be aware of the significance of their colonisation and the potential risk to other patients. Furthermore, without routine admission screening – which is not always recommended or appropriate – many colonised patients will go undetected<sup>36</sup>; therefore *all* patients should be provided with information about the risk of MRO colonisation and how to prevent transmission.

Once colonised with MRSA, patients are at increased risk of subsequent invasive infection<sup>37-39</sup> and, consequently, increased mortality.<sup>40,41</sup> So it was disturbing to find that



some clinicians emphasised the perceived benefit of a single room, over these potentially serious implications of colonisation, when explaining MROs. Perhaps this was due to discomfort around discussing HAI.<sup>22</sup> Healthcare providers need support and strategies to communicate the implications of colonisation, including ways to avoid subsequent infection and to reduce transmission, to patients, without unduly frightening them.<sup>42</sup>

There have been recent calls to limit source-isolation for certain MRO-colonised patients in endemic, non-outbreak settings and some US hospitals have abandoned it in favour of greater emphasis on compliance with standard precautions, especially hand hygiene.<sup>8</sup> However, most authorities accept that properly implemented isolation and transmission-based precautions, in addition to standard precautions, can reduce MRO transmission. Nevertheless, no matter how a facility approaches the care of colonised or infected patients, the effectiveness of IPC measures will be sub-optimal unless we pay attention to the activities of *all* patients and their visitors and engage with them as active partners in reducing MRO transmission. By not giving patients appropriate and accessible information, on HAI risk and how they can contribute to their own and others' safety, we deny them the opportunity to fully engage in their own care.<sup>42</sup> Our findings and the epilogue to this paper show that some patients are very willing to engage with this complex safety issue.

### Conclusion and recommendations

Given the burden of cross-infection on patients, staff and services, it is critical that we design better and more consistent ways to detect, respond to and communicate about patients' MRO colonisation and infection risks. Source-isolation is common practice in most acute healthcare settings. Based on our findings, to improve the efficacy of source-isolation and to reduce infection transmission in general, we make the following recommendations:

1. All patients and visitors need information about HAI and IPC strategies - not just those who are colonised or infected with MROs. Patients' awareness of risks prior to, or on, admission may assist them to make informed choices and take actions that could reduce their chances of MRO acquisition.
2. Patients and families should be involved in discussions about how to improve content and modes of delivery of formal IPC patient information. ICP contact details should be available on/in materials for patients who want more detailed information. Information in languages other than English is essential and should be easily accessible.
3. In addition to formal patient education, all patient care providers should engage patients in regular, ongoing conversations about IPC. Clinical staff could capitalise on moments where they are engaged in IPC

practices such as hand hygiene, wound dressings and donning PPE, to model effective behaviours and discuss with patients the reasons for, and the impact of, IPC practices. Such activity should create space for patients to ask questions and to build on their knowledge over their hospital stay.

4. At the same time, patient care providers should consider patients as active partners in reducing transmission. They can pay attention to patient and family feedback about their perceptions of infection risk and to the strategies patients and family members develop to keep themselves and others safe. This may broaden providers understanding of IPC risks and the roles patients can play in reducing transmission.
5. Further research is required to explore patients' and visitors' perceptions and behaviours around source-isolation and the ways that they would like to partner with healthcare providers to reduce HAI.

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### **Patient Epilogue: Gary reflects on HAI and being involved in research**

*I have had several admissions to hospitals for surgical procedures over the last 5 years and in that time I have suffered from two surgical site infections due to MRSA. One of these resulted in [MRSA] septicaemia – a horrific experience that I would not wish on anyone. I don't know where or when I first acquired MRSA and, prior to my involvement in this research, I knew very little about it except that it is a resistant bacterium and is hard to treat.*

*I first became involved in this research project in March 2013 when Mary interviewed me about my understanding of infection control. I was in hospital for a routine surgical procedure. Although I had had MRSA in the past, on this admission I was not placed on contact precautions so I assumed I was clear. I was discharged without complications, but 3 weeks later developed an MRSA wound infection and returned to hospital for treatment. I am still not sure if this was related to my previous MRSA colonisation or if it was a new infection. I was discharged after 2 weeks on antibiotics but a few days later developed septicaemia. Both times I was re-admitted I contacted Mary and we had further conversations about MRSA and infection control. Over the years we have met many times and continued these discussions. Through my connection with Mary, and because of the profound effect MRSA has had on my life, I became a consumer member on several committees, one of them specifically dealing with infection control. I was also involved in preparing this journal article for publication.*

*These conversations, committees and writing opportunities have helped me to better understand infection transmission and prevention, what happened to me, and how I could take better care of my health in the future. I now know the difference between colonisation and infection and the steps I can take to reduce the risk of both. I am more acutely aware of the importance of hand hygiene and this has spilled over into my home life.*

*I believe that patients should be told the truth about HAI. Sure, it's scary to find out that hospitals aren't as safe as you thought they were, but don't sugar coat the facts. I think I deserved to know that colonisation could become an infection and that infections can be life threatening. No one told me and it was a shock when it happened. Had I known, I could have been more alert for signs of infection or sepsis myself. And, had I known how, I would have taken more appropriate care not to spread MRSA when I was in hospital, so that what happened to me would not happen to others.*

*I believe that staff and patients should work as a team to reduce HAI. Treat us with respect and recognise that we have the intelligence to be part of this team. And realise that we have the most at stake here and are keen to avoid complications!*

*That said, being involved in writing this journal highlighted for me the range of knowledge and attitudes that patients can have about infection control. Some are complacent, others highly concerned and everything in-between. So how can you get through to everyone? I would stress that just one formal education session or one handout is not enough. What is needed are regular informal conversations about infection control that open up dialogue and room for questions. For example, when you are doing a 20sec hand rub at the bedside explain to us why we too should be washing hands regularly and show us, by example, how to do it properly. When you see us sitting on another patient's bed, explain to us why we shouldn't. When doing our dressings, explain why we shouldn't touch our wounds. When inserting cannulas tell us about signs of infection and when the cannula should be replaced so that we, if we are able, can take some responsibility for ensuring good cannula care.*

*Not everyone will comply – but you might just find that with a shift in approach we can all work together to reduce healthcare associated infections.*