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### Cover Page Footnote

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# Patients' perceptions and knowledge of source isolation for multi-resistant organisms in an Australian metropolitan hospital: A bedside interview with questionnaire study

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## Abstract

The aim of this study was to explore perceptions and knowledge of source isolation among hospitalised patients colonised or infected with multi-resistant organisms, to identify if information provided and delivery method are helpful and appropriate, and to identify areas for practice improvements. Purposive sampling was conducted. Between November 2019 and January 2020, bedside interviews with structured questionnaires (combining multiple-choice and free-text questions) were conducted with adult in-patients requiring isolation for multi-resistant organisms in a 180-bed metropolitan hospital in Brisbane, Australia. Data analysis included quantifying multiple-choice responses and thematic analysis of free-text responses. Thirty participants completed the interview questionnaire. Lack of awareness and understanding of multi-resistant organisms was evident. Participants reported a preference for face-to-face education (96.7%) and information brochures (86.7%), rather than phone call (33.3%) or informative video (0%). Qualitative responses revealed communication and information deficits exacerbated patients' negative psychological impacts including embarrassment, loneliness, abandonment, confusion and fear. Participants identified that clinicians need better communication skills and knowledge of multi-resistant organisms to recognise and ameliorate the effect of source isolation on patients. In conclusion, patients in source isolation reported that they do not receive adequate information. Enhancing clinician knowledge of multi-resistant organisms and improving communication skills may help address the psychological needs of these patients.

## Keywords

Patient experience, patient perceptions, patient knowledge, source isolation, infection management, communication

## Introduction

Preventing and controlling the spread of infection is a priority for healthcare organisations worldwide, particularly as multi-resistant organism (MRO) infections are associated with increased mortality and higher healthcare costs.<sup>1</sup> Transmission-based precautions in addition to standard precautions, including isolation of hospitalised patients with MRO colonisation or infections, are considered best practice to reduce the risk of organism transmission.<sup>2</sup> A large Australian study pre-COVID-19 found that approximately 12% of hospital patients were managed with transmission-based precautions that required the use of personal protective equipment (PPE), including gowns and gloves, surveillance, and source isolation, often in a single room due to MRO infection or colonisation.<sup>3</sup> While source isolation of infected or colonised patients is necessary to protect other patients and healthcare workers (HCW), repeated reviews have shown that isolation can elicit negative patient emotions, including loneliness, depression, anxiety, stigma, fear, and hostility.<sup>4-12</sup> Moreover, higher rates of adverse events, such as patient falls, for patients in isolation have been

attributed to a reluctance on the part of HCW to don PPE and enter patients' rooms.<sup>13,14</sup>

Psychosocial challenges of isolation vary, depending on the organism and required precautions. In general, transmission-based precautions include placement in a single room (if available) with the door closed and limited transport and movement of patients outside the room, in addition to PPE worn by all staff entering the room.<sup>2,15</sup> Droplet and airborne organisms also require HCWs (and at times the patient) to wear a mask to reduce spreading the infectious agent.<sup>2,15</sup> Susceptible staff and visitors may be restricted from entry, depending on the organism and their own immune status.<sup>2</sup>

Empowering patients as partners in infection prevention requires HCWs to provide relevant and appropriate information to patients.<sup>16</sup> This is particularly important for patients diagnosed or suspected of having an MRO, to promote compliance with infection prevention measures. Providing timely, accurate and appropriate information for patients may improve patient experience and compliance

with source isolation and infection prevention procedures.<sup>17</sup>

This study was conducted in a 180-bed adult teaching hospital in Brisbane, Australia, admitting over 35,000 patients annually. Hospital Infection Prevention and Management Services (IPMS) perform routine daily surveillance screening for patients with laboratory evidence of MRO, including methicillin-resistant *Staphylococcus aureus* (MRSA), non-multi-resistant methicillin-resistant *Staphylococcus aureus* (nmMRSA), Vancomycin-resistant enterococci (VRE), Carbapenemase-Producing Enterobacterales (CPE), and Extended Spectrum Beta Lactamase (ESBL) *Klebsiella Pneumoniae*. Patients are identified through the state-wide surveillance database (Multiprac), which logs an alert when a patient with a previously identified MRO has an encounter at the facility or there is a new laboratory result for an MRO. When an MRO is confirmed, ward staff are advised and information including a brochure is provided to patients in hospital by an IPMS team member. After hours, patient education is the responsibility of ward staff and discharged patients are sent a letter and information brochure via mail.

As part of a local quality initiative, a review of infection management procedures undertaken by the lead author (IPMS nurse) identified that it was unclear if current methods of patient education about MROs were helpful and appropriate for affected patients. Therefore, this study had three aims: (i) to explore hospital patients' perceptions and experiences of source isolation for MRO; (ii) to identify if information currently being provided and the method of delivery is appropriate and helpful; and (iii) to identify areas for practice improvements in management of patients requiring source isolation.

## Methods

### *Study Design and Setting*

Bedside interviews with structured questionnaires were conducted with medical and surgical in-patients requiring source isolation for MRO in a 180-bed adult teaching hospital in Brisbane, Australia, between November 2019 and January 2020.

### *Data collection tool*

The questionnaire contained eight questions: a mixture of multiple-choice, yes/no, and free-text/open-ended (Appendix Supplement 1). A literature review guided construction of the questions, which were formulated to gain insight into patients' perceptions of their treatment and understanding of MRO. Prompts to elicit patient input included '*Something else?*' or '*Other feelings?*' and an open-ended question, '*Do you have any suggestions on how staff could improve the care of patients with MROs?*'. Following consultation with an ethicist, questions were structured to minimise participants' potential distress while creating an

opportunity for them to discuss their experiences and perceptions of care and to contribute suggestions for ways their care could be improved.

### *Data collection methods*

All interviews were conducted by the lead author and retained the same structure and format for each participant. After obtaining consent, the interviewer checked the patient's electronic medical record to confirm age, gender, admission stream (medical or surgical), and MRO. Participant demographics were not recorded. The interviewer sat with the patient and read each question aloud, documenting the patient's answers directly onto the questionnaire form. The interviewer then read each response back to the relevant participant at the time of the interviews to minimise errors. Responses to the open-ended questions were audio-recorded on a handheld device, with the interviewer asking gentle probing questions to encourage responses or clarify statements (e.g., "Can you tell me more about that?", "What was that like?", "How did you feel about that?").

Each interview took approximately 10–20 minutes to complete and was completed once per participant (regardless of repeat admissions during the study period). Participants could withdraw consent at any time during the interview without further questions. At the completion of the interview, the interviewer asked participants if they had any questions relating to their MRO, and if so, they could elect to have an IPMS nurse speak to them at a mutually agreed time. To ensure confidentiality of responses, the IPMS referral was completed on a separate form (containing the patient's name, date of birth, and current location) and phoned through to the service. As the questionnaires did not contain any identifiable details, participants were advised that study withdrawal was not possible once the interviewer had left, as there was no way to identify individual forms. No additional follow-up was required.

Multiple-choice responses were entered into Microsoft Office Forms and exported to Excel. All electronic data was password-protected and held on a secure server hosted by the health service. All paper forms were shredded immediately after the data had been entered; audio recordings were deleted following transcription.

### *Sample size and criteria*

A sample size of 30 participant interviews was selected based on data sufficiency expected from previous related studies.<sup>1,11,17-19</sup> English-speaking patients with an MRO requiring isolation and capacity to consent were eligible for inclusion. Exclusion criteria were <18 years of age, culturally and linguistically diverse, mental health management, acute deterioration, cognitive impairment, or palliative care.

### **Sampling strategy**

Purposive sampling was conducted. Between November 2019 and January 2020, admitted patients with laboratory evidence of an MRO were screened for inclusion during daytime hours. When a potential patient was identified, the project lead consulted the patient's primary nurse to determine if the patient met study criteria. Potentially suitable patients were invited to participate in a structured interview about their MRO experience. Patients were provided with a study information sheet and offered time for questions before being asked for verbal consent to participate.

### **Data analysis**

Descriptive statistics (overall numbers, percentages) were calculated for multiple-choice responses using Excel. Free-text responses were transcribed verbatim from the audio recordings. A predominantly inductive qualitative analysis was performed as per Braun and Clarke's model of reflexive thematic analysis.<sup>20,21</sup> That is, two researchers independently read each transcript several times to familiarise themselves with the data. Coding was completed manually by generating initial codes, collating data for each code, and then exploring for potential themes. Themes identified by previous authors were flagged; however, we also identified themes not encountered in previous literature, such as patient perceptions of how staff could improve the care of patients with MRO. The researchers then met several times to discuss and explore their subjective interpretations of the data, review and compare the identified themes in relation to the entire data set and make refinements where necessary. Any participant

statements themed differently by researchers during analysis were discussed until agreement was reached. Finally, themes were labelled, and relevant data extracts were organised under each theme. As all participant data was collected anonymously, member checking of transcripts was not done.

### **Ethical considerations**

Ethical approval for the study was obtained from hospital (LNR/19/QMS/57351) and university ethics committees (GU 2019/824; Tasmania Health and Medical HREC Project ID 23665). No identifiable patient data was collected.

## **Results**

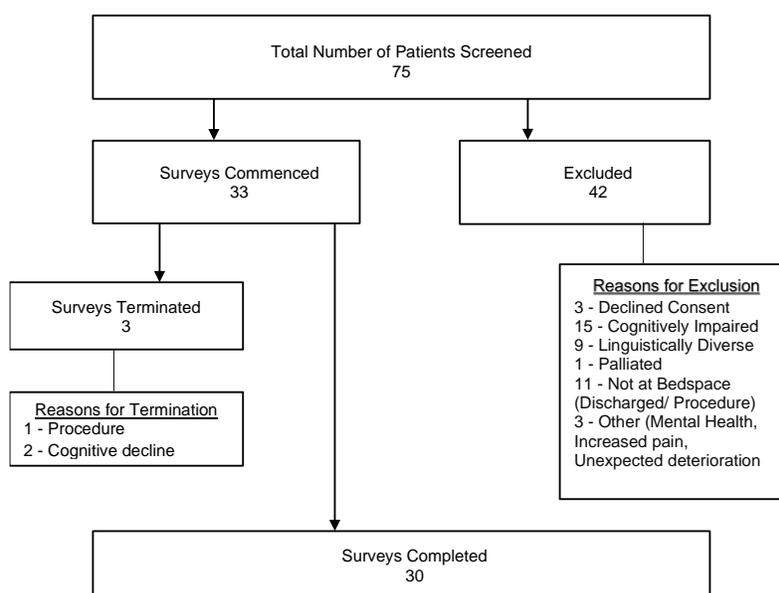
### **Demographics**

We screened 75 inpatients with MROs, of whom 33 consented to participate; however, one interview was abandoned for a patient procedure and two were halted when it became clear that the patients were cognitively impaired. Therefore, 30 patients (median age 67 years) participated in the study. Figure 1 details the screening procedure and Table 1 provides participant demographics.

### **Quantitative responses**

No participant reported a good understanding of their MRO, with the majority (70%, 21/30) stating that they knew nothing about their infection. Ten (33%) participants did not know they had an MRO, and a further seven (23.3%) did not know how long they had it. Two-thirds (20, 66.7%) of participants did not recall being notified of the MRO. Only five participants recalled a discussion with

**Figure 1. Patient screening flow diagram**



**Table 1. Participant characteristics (N=30)**

Demographics	N (%)
Gender	
Female	13 (43%)
Male	17 (57%)
Admission stream	
Medical	14 (47%)
Surgical	16 (53%)
Age (years)	
Median (range)	67 (19–91)
Multi Resistant Organism	
nmMRSA	19
MRSA	5
VRE Van B	3
ESBL Klebsiella	2
ESBL Klebsiella and nmMRSA	1

nmMRSA, non-multi-resistant methicillin-resistant *Staphylococcus aureus*; MRSA, methicillin-resistant *Staphylococcus aureus*; VRE, Vancomycin-resistant enterococci; ESBL, Extended Spectrum Beta Lactamase

an IPMS nurse; others reported receiving an information brochure (n=7) or letter in the post (n=3) notifying them of the infection. Nearly all participants felt in-hospital discussions with staff and information brochures were the most helpful ways of receiving information, while more than half suggested follow-up discussions with their GP would potentially be helpful, and one-third reported a likely benefit in receiving a phone call. Four participants requested follow-up with IPMS at survey completion. The majority (87%, 26/30) of patients had been nursed in a single room and two-thirds (20/30) had experienced multiple bed moves since having an MRO. No participant believed that their treatment was better, with almost one-third (8/30) suggesting that their treatment was in fact worse. The multiple-choice responses about participants' awareness and understanding of MRO and experiences of care are shown in Table 2.

### **Qualitative responses**

Three major themes were identified: 1. Emotional impact and perception of being treated differently; 2. Lack of knowledge; and 3. Desire for more information and better communication. Exemplar quotes with gender and age are included in italics.

#### **1. Emotional impact and perception of being treated differently**

Almost all participants reported emotional distress during hospitalisation with an MRO, with a strong perception of being treated differently. Participants expressed feelings of embarrassment and shame: *"Treated like you are a leper. Feel terrible and really self-conscious when barricades and signs are put up to warn people from coming in. It's embarrassing"* (F-71). Some participants noted the short cuts HCWs took to avoid

donning PPE: *"Some staff just talk from the door: that feels weird"* (M-54).

A sense of isolation and abandonment was prevalent, particularly for those in single rooms. Two-thirds of participants had experienced multiple bed moves during admission, with 87% having been in a single room. Many expressed feelings of anxiety, loneliness, fear, and abandonment at being in a single room: *"I felt abandoned. I was very upset, and I cried. No one was around. No one comes in to visit. When the door is closed it's very frightening"* (F-91), and *"They say I'm infected, but I feel affected because I get shut away"* (M-83). Others highlighted the powerlessness that occurs with isolation (*"I feel as if my voice isn't heard"* F-66), with a reluctance to speak up: *"I've been a bit lonely, but you don't want to complain, do you?"* (F-63).

Several participants commented on the time it took to receive attention: *"Sometimes I worry that I won't see the nurses for a long time. I worry that they might have forgotten about me"* (M-58), and *"It takes a long time to get a nurse to help you. It's probably because I'm so far away and they have to put all that gear on"* (F-45). Some participants indicated the delay in receiving attention was problematic, suggesting the need for *"More staff in busy periods so it doesn't take as long for people to get to you"* (M-33).

#### **2. Lack of knowledge**

As the multiple-choice results showed, no participants had much understanding of their MRO (*"I didn't know anything about it and I'm sure I'm not alone"* (M-86)), with two-thirds unable to recall being notified of the infection. One in three participants did not know they had an MRO: *"I've never really been told, and I never thought to ask"* (M-85). Participants reported not having the information they

**Table 2. Participants' perceptions and understanding of multi-resistant organism infection**

Question and multiple-choice responses	N (%)
How long have you had a Multi Resistant Organism infection?	
I didn't know I had an infection	10 (33.3%)
Just this admission	2 (6.7%)
In the last year	4 (14%)
More than a year	7 (23.3%)
Not sure	7 (23.3%)
What do you feel is your level of understanding of this?	
Know nothing	21 (70%)
Know a little	9 (30%)
Know a lot	0 (0%)
If/when you were notified of the MRO, what did you receive? *	
A visit from a nurse from the IPMS to discuss the organism	5 (16.7%)
An information brochure	7 (23.3%)
A letter in the post	3 (10%)
No notification	15 (50%)
Don't recall	5 (16.7%)
What method/s of information delivery do you think might be most helpful to patients? *	
Phone call	10 (33.3%)
Short video	0 (0%)
Chat in hospital with a nurse from IPMS	29 (96.7%)
Discussion with your GP	17 (56.7%)
Information brochure	26 (86.7%)
Have you experienced any of the following since having an MRO? *	
Better treatment	0 (0%)
Worse treatment	8 (26.7%)
Multiple bed moves	20 (66.7%)
Single room	26 (86.7%)
Other feelings	29 (96.7%)
Do you feel that having an MRO has had an impact on your family, carers, or visitors?	
Yes	0 (0%)
No	28 (93.3%)
Other	2 (6.7%)

MRO, Multi-Resistant Organism; IPMS, Infection Prevention and Management Service; GP, General Practitioner; \* Multiple responses permitted

needed and not knowing who to ask: *"I'm not really sure what's going on or if I should be worried, but I am a bit"* (M-60). For some, the lack of knowledge compounded the emotional impact: *"I feel dirty when I hear the nurses say, 'she's buggy'. I don't really understand what that means"* (F-54).

Lack of attention to patient information needs was perceived pertaining to initial notification (*"I felt it was handled really poorly. Slapping a sign on the door that said 'Stop' without even talking to me about it was really bad"* (F-66)), intermittent information (*"It's a bit awkward actually, but no one talks about it, so I don't want to bring it up"* (M-48)), and upon hospital discharge (*"I assumed when I was discharged that I didn't have the infection, so I need to know that that's not right"* (M-50)).

### **3. Desire for more information and better communication**

Suggestions for improving care of patients with MROs revealed an overwhelming desire for more information and better communication. Participants indicated that

having information would help them feel more involved with their care: *"I don't even know what I'm infected with – and do I still have it? The signs are on the outside of the door so I don't know what people should be wearing. If they told me, maybe I could help"* (M-83). Several participants requested education about the clearance process (*"Better communication, especially about clearance"* (F-66)), with information repeated at least every admission: *"We need more in-depth information. Maybe remind us when we are re-admitted what is going on with our infection"* (M-50).

Communication overall was perceived as lacking, and participants expressed frustration and disappointment at the inconsistent messages from HCWs (*"I'm not quite sure who to ask for the truth. Everyone seems to say something different"* (M-71) and a perceived element of disregard for their information needs: *"Staff assume we are imbeciles. They don't talk to us about it, even though you are the one that has it, you're not told. You overhear conversations, but they should come straight to you to talk about it, not just talk about you and not include you"* (F-68). One participant suggested staff were not well

equipped to educate patients about MROs and proposed “*Education of the hospital staff*” (F-66).

Several participants requested more engagement from HCWs (“*I think if the nurses came to check on patients to make sure they have the information they need, it would be good*” (F-60), with a strong desire for regular updates about their condition: “*Talk to us about what’s going on. A lot of things happen when I’m in hospital – it would be good to have someone update me about what’s going on*” (F-54).

## Discussion

This study of patients’ experiences and knowledge of source isolation identified that the negative emotional impact of isolation was exacerbated by patients’ lack of knowledge of the MRO and their perceptions that HCWs were not adequately equipped to provide meaningful information.

*Emotional impact and perception of being treated differently* was a prominent theme, with negative emotions including embarrassment, stigma, loneliness, confusion, fear, and frustration reported by most. The adverse impact of isolation has been documented in previous studies of patients’ experiences of source isolation for MRO,<sup>1,8,11,12,17,18,22-26</sup> with higher rates of anxiety and depression in these patients compared to control groups<sup>27</sup> and a recent meta-analysis confirming source isolation entails additional psychological burden.<sup>5</sup> Studies examining patient perceptions relating to care in isolation have reported loneliness and a sense of abandonment as prevalent.<sup>1,11,17,23,24</sup> Loss of independence and control associated with being in isolation has the potential for unintended damage to patients’ psychological welfare, which can present in many ways, including loneliness and anger.<sup>18</sup>

Several participants stated they felt embarrassed, dirty, or like a ‘leper’: specific terms evident in other studies.<sup>1,8,11,18,19,22,23,28</sup> Acute awareness of stigma associated with MRO increased feelings of shame, embarrassment and guilt and contributed to perceptions of *being treated differently*. Our results correlate with research findings that patients in isolation perceive they experience worse care.<sup>7,29,30</sup> In particular, several respondents noted reduced contact time with HCWs and a delay in staff responsiveness, in part attributed to the additional time required for donning PPE. Other studies have identified the added risk this presents for patients in isolation, who received less medical attention, care or treatment when opportunities for interpersonal interactions were reduced.<sup>11,13,23,31</sup> Studies have reported an association between delays in staff responsiveness and patients perceiving adverse issues with their care, resulting in negative feelings and decreased satisfaction.<sup>3,7,8,11,19,29,32-34</sup> The reduced opportunity for, and quality of, interactions

with staff and other patients exacerbates perceptions of social isolation and limits the ability to voice concerns or ask questions that would normally enable patients to receive information and alleviate their concerns.<sup>1,17,18,28</sup> Furthermore, an increase in preventable adverse events (including falls and pressure injuries) is associated with decreased HCW contact time and isolation.<sup>1,6,18,28,34</sup>

*Lack of knowledge about the MRO*, regardless of the organism or duration of infection, was reported by over two-thirds of participants, with only one-third having any recollection of the initial notification. Our findings correlate with studies that identified patients have little insight into the purpose or necessity of transmission-based precautions or isolation.<sup>11,17,24</sup> Again, this lack of knowledge and understanding, and a corresponding desire for more information, is prevalent in the literature.<sup>11,17,23,35,36</sup> Knowledge deficits likely contributed to the feelings of confusion, uncertainty, fear, concern, and anxiety expressed by study participants; research suggests that a lack of information or comprehension may amplify distress, anxiety and depression.<sup>1,11,17,18,22-24</sup> While not identified as a significant concern by participants in this study, a lack of certainty has been associated with frustration leading to anger in similar studies.<sup>17,18,23</sup>

A corresponding *desire for more information* featured strongly, suggesting that information provided was often perceived as inaccurate and/or insufficient, leading to confusion and frustration and exacerbating the psychological impact of isolation, as shown previously.<sup>17,18,37</sup> Having accurate and timely information could improve understanding, reduce anxiety and distress, result in greater compliance with restrictions, and enable more effective coping.<sup>11,12,17-19,26</sup> Prior research has rarely explored patients’ knowledge needs about MROs. Participants in this study suggested information could include updates about their infectious status each admission, notification if/when this changes, information about the clearance process, and guidance on where to get more information. Although participants in this study expressed a clear preference for a face-to-face discussion with an IPMS nurse and an information brochure, research by Gudnadottir et al.<sup>35</sup> identified a variety of information preferences. Hence, we must not assume that all patients want or need the same information, delivered in the same way. Information packages and delivery should consider the patient’s education, cultural background, and social supports.<sup>35</sup> Benefit would be gained from increased consumer engagement, particularly through the involvement of patients and carers in creating information packages and developing policies relating to care of patients with MROs.<sup>26,36</sup>

*A desire for better communication* was expressed by several participants. Improving communication and quality of information at the time of MRO diagnosis was a priority

for patients in this and other studies.<sup>18</sup> Participants recognised that donning and doffing PPE was an added burden for busy staff, who often stood at the door, rather than entering the room. However, this behaviour reinforced perceptions of inadequate communication with HCWs and being treated differently. Communication is the most significant factor influencing perceptions of care, with research highlighting the need for effective and comprehensive communication between HCWs and patients in isolation to ensure appropriate education is provided to facilitate patient engagement in care.<sup>10,18,35-37</sup> Researchers have identified the need to improve HCW communication, acknowledging it is often ineffective and inadequate, particularly relating to the infection status of patients and the necessity of precautions.<sup>32,35,38</sup> Study participants reported a preference for obtaining information from staff; however, research suggests that HCW inadequacies with communication and education may exacerbate patients' feelings of isolation and confusion.<sup>8,10</sup> Shortfalls in HCWs' understanding of MROs may result in inconsistent messaging, and patient education consequently is neglected and avoided.<sup>39-41</sup> However, if patients receive adequate education about isolation and precautions they are more likely to accept the requirements.<sup>7,19,38,42</sup> It is therefore essential that HCWs are appropriately educated about transmission precautions so that a consistent level of care can be delivered.<sup>17</sup>

The HCW's perspective on communicating with patients in source isolation has been inadequately researched, although a recent study<sup>41</sup> reported that nurses recognised the emotional toll on patients, but some nurses blamed heavy workloads and system flaws for the negative experiences associated with source isolation, such as loneliness, a perception of sub-optimal care, and a lack of autonomy. Improving HCW understanding of MROs is essential to reduce stigma and provide the emotional and social support these patients need.<sup>10,11,17,18,28</sup>

### ***Strengths and limitations***

Patient experience of isolation for MROs has been widely reported, mostly from large metropolitan hospitals in North America,<sup>19,29,30</sup> Europe,<sup>1,25,37</sup> and Australia.<sup>3,17</sup> This study was performed at a smaller hospital, offering fresh insights from previous studies. Reduced available resources in smaller facilities (including isolation beds and staffing) means that challenges can be different and at times intensified. For instance, single rooms in smaller hospitals are often in short supply, resulting in frequent bed moves for patients with MROs due to competing needs for isolation.<sup>3</sup> Furthermore, all participants in this study required contact precautions. Other infections such as varicella, measles, tuberculosis or SARS-Cov-2 require airborne transmission precautions, including isolation in a negative pressure room (not available in many smaller facilities), which could alter patients' perceptions of care,

especially with the additional precautions required for these infections.

As with similar studies,<sup>1,17,22</sup> patients with diverse cultural and linguistic backgrounds were excluded from participation. Ideally, future studies could include these populations because the appropriateness of information given to patients whose first language is not English is currently unknown. Furthermore, it is possible that patients from diverse backgrounds have different support and information needs, particularly in relation to family and visitors. Level of education and socioeconomic status could possibly affect patients' knowledge and perceptions of MROs and the need for isolation, and this should be considered when designing patient education materials and discussing MROs. Patients with mental health conditions were also excluded from this study, but with the well documented psychological impact of isolation, this cohort of patients would benefit from better representation in future initiatives when considering the treatment of patients with MROs and the way information is delivered.

This study did not consider the frequency or duration of isolation, nor did it consider the primary reason for the current admission. Conceivably, these factors may contribute to patient perceptions of care, as one study identified a direct correlation between the length of isolation and anxiety scores.<sup>1</sup>

### **Conclusion**

In the past decade, numerous studies have reported negative patient perceptions of isolation for MRO. Yet patients continue to experience the emotional impact of being treated differently, and they remain starved of the information and level of communication that would likely alleviate the adverse psychological effects associated with isolation. This study has provided insight into improvements patients perceive as potentially valuable, such as improving the content and frequency of MRO education, improving the standard of communication to ensure greater quality of information transference, and creating time and opportunity for patients to ask questions and receive accurate information. Improving the education and confidence of HCWs relating to MROs would enhance the quality of information delivered to patients. Fostering consumer engagement and collaborating with patients with MROs during the development of infection management guidelines, hospital policies, and information packages would promote patient-centred care and deliver better patient outcomes.

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## Appendix

### Supplement 1. Interview questionnaire and data collection form

Questions	Answers
1. How long have you had a Multi Resistant Organism (MRO) infection or colonisation?	<ul style="list-style-type: none"> <li><input type="radio"/> I didn't know I had an infection</li> <li><input type="radio"/> Just this admission</li> <li><input type="radio"/> In the last year</li> <li><input type="radio"/> More than a year</li> <li><input type="radio"/> Not sure</li> </ul>
2. What do you feel is your level of understanding of this?	<ul style="list-style-type: none"> <li><input type="radio"/> Know nothing</li> <li><input type="radio"/> Know a little</li> <li><input type="radio"/> Know a lot</li> </ul>
3. If/when you were notified of the MRO did you receive:	<ul style="list-style-type: none"> <li><input type="radio"/> A visit from a nurse from the Infection Prevention and Management Service (IPMS) to discuss the organism?</li> <li><input type="radio"/> An information brochure?</li> <li><input type="radio"/> A letter in the post?</li> <li><input type="radio"/> No notification</li> <li><input type="radio"/> Something else (<i>Document response</i>)</li> </ul>
4. Did you find any of the above helpful?	<i>Record response</i>
5. What method/s of information delivery do you think might be the most helpful to patients?	<ul style="list-style-type: none"> <li><input type="radio"/> Phone call</li> <li><input type="radio"/> Short video</li> <li><input type="radio"/> Chat in hospital with a nurse from Infection Prevention and Management Service</li> <li><input type="radio"/> Discussion with your GP about the organism</li> <li><input type="radio"/> Information brochure</li> <li><input type="radio"/> Something else (<i>Document response</i>)</li> </ul>
6. Have you experienced any of the following since having an MRO?	<ul style="list-style-type: none"> <li><input type="radio"/> Better treatment</li> <li><input type="radio"/> Worse treatment</li> <li><input type="radio"/> Multiple bed moves</li> <li><input type="radio"/> Single room</li> <li><input type="radio"/> Other feelings (<i>Document response</i>)</li> </ul>
7. Do you feel that you having a MRO has had an impact on your family, carers, or visitors?	Yes/No If yes, <i>Record response</i>
8. Do you have any suggestions on how staff could improve the care of patients with MROs?	<i>Record response</i>