



**Health**  
Illawarra Shoalhaven  
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**The Rural Research Capacity Building Program 2009  
Final report for research project:**

**Do You Know How You Just Made Me Feel? :  
Patient's experience isolated in contact precautions for MRSA in a regional setting – A  
qualitative study**

Principal Researcher:

Annmaree Wilson  
Infection Prevention and Control Clinical Nurse Consultant  
Infection Management and Control Service (IMACS)  
Illawarra Shoalhaven Local Health District  
Rural Health Directorate  
Shoalhaven District Memorial Hospital  
Telephone: 02 44239318  
Fax: 02 44214967  
Email: [Annmaree.Wilson@SESI.AHS.HEALTH.NSW.GOV.AU](mailto:Annmaree.Wilson@SESI.AHS.HEALTH.NSW.GOV.AU)

## **Table of Contents**

<b>Content</b>	<b>Page Number</b>
Acknowledgements	3
Glossary of Terms	4
Abstract	5
Key words	5
Executive Summary	6
Introduction	8
Background	8
Rationale	9
Literature Review	10
Aim of research	13
Method	13
Participant Selection	14
Findings	18
Discussion	24
Limitations	27
Conclusions and recommendations	27
References	29
Appendix 1 - Participant Information Sheet	34
Appendix 2 - Participant Consent Form	38
Appendix 3 – Interview Guide	40
Table 1: Reasons for non-participation	15
Table 2: Patient Demographics	16

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## **Glossary of Terms**

Colonisation	Organism present on patient but not causing an infection
Cohorted	Patients with the same strain of MRSA placed in multi-bed room
Golden Staph.	In this report refers to MRSA
HAI	Healthcare Associated Infections
HCF	Health Care Facilities
ISLHD	Illawarra Shoalhaven Local Health District
MRSA	Methicillin Resistant <i>Staphylococcus aureus</i>
PPE	Personal Protective Equipment
RHD	Rural Health Directorate
RRCBP	Rural Research Capacity Building Program
SESIAHS	South Eastern Sydney Illawarra Health Service

**Don't you know how you just made me feel?**  
**Patient's experience isolated in contact precautions for MRSA in a regional setting – A Qualitative Study**

**Background:** Contact precautions are the most frequently utilised strategy in reducing the transmission of infectious diseases and multi-resistant organisms within healthcare facilities. The patient experience in isolation for infection control reasons has been the subject of studies conducted in tertiary or large metropolitan facilities as well as specialised units. These studies have shown that isolated patients are at higher risk for preventable adverse events, they are less satisfied with their care, and have less contact with healthcare workers.

**Aims:** This qualitative study describes the experience of patients isolated for MRSA in regional health care facilities.

**Study Design:** A phenomenological approach was utilised and data was collected via semi-structured interviews (N= 6). Interviews were recorded using audio digital technology and field notes were recorded immediately following the interview. All interview recordings were transcribed verbatim and open coded. Axial coding assisted the development of themes and extensive field notes augmented analysis of the transcripts.

**Results:** Three major themes were identified

1. *'They will not talk about it': Information about Methicillin Resistant Staphylococcus aureus (MRSA):* Participants lacked information about MRSA and described poor notification practices, their inability to obtain concise information from healthcare workers as well as the reluctance of healthcare workers to discuss MRSA.
2. *'Locked in these rooms': Care in hospital:* Participants described both positive and negative aspects of being isolated in a single room
3. *'What can I do about it? Nothing': Surrendering to MRSA:* Participants reported persistent concerns of transmitting MRSA to their families and being conscious of their own hygiene practices

**Conclusions:** The experience of patients isolated for MRSA in regional settings mirrored those of previous studies conducted in tertiary or metropolitan facilities. Inconsistent staff practices and compliance with infection control practices were highlighted as concerns. Participants reported feeling lonely, bored, embarrassed and ashamed.

**Key Words:**

Contact precautions, multi-resistant organisms, MRSA, infection control, regional health setting

## Executive Summary

### Background:

Worldwide MRSA is the causative organism for many healthcare related infections. Isolation or additional precautions are key strategies in the management of MRSA and multi-resistant organism transmission within healthcare facilities (HCF). On identification of MRSA, patients are placed in contact precautions and an alert is placed into the electronic medical records. These electronic alerts identify that the patient requires contact precautions for any future episodes of care. Previous studies have demonstrated that isolation results in negative psychological impact, increased adverse events and dissatisfaction with healthcare.

### Aim:

This study aims to explore and understand the experience of patients who have MRSA and are isolated in contact precautions in a regional healthcare setting. Anecdotal information given to the principle researcher from both patient and healthcare workers related to isolation precautions have fuelled the search for further understanding of the patient experience.

### Study Design:

A qualitative study design with a phenomenological approach was employed for this study. The experiences of six participants in isolation for MRSA in regional healthcare facilities were explored via semi-structured interviews.

Interviews recordings were transcribed by the principal researcher. Transcripts were analysed using open coding to identify emergent themes. This analysis lead to the development of key categories and links to subcategories ' axial coding'<sup>(50)</sup>. This second level of coding revealed the key themes and sub-themes for this study<sup>(50,52,58)</sup>.

### Findings:

Three key themes were identified following analysis of the transcripts

1. 'They will not talk about it': Information about MRSA – identified sub- themes were
  - Notification of MRSA
  - Receiving and timing of information
  - Not being notified – finding out accidentally
  - Staff knowledge – “staff don't know anything about it”
  - Other sources of information
2. 'Locked in these rooms': Care in hospital – within this major theme the following sub-themes were highlighted
  - Isolation – positive and negative aspects
  - Inconsistent staff practices
  - Cleaning and Catering
  - Embarrassment and Discrimination
3. 'What can you do about it? Nothing': Surrendering to MRSA – sub-themes within this key theme were identified as:
  - “Don't want to make others sick - concern for family and others
  - “Learning to be careful” - effects on life and hygiene practices
  - “Everyone's got it” - resigned to having MRSA
  - “Leprosy or the plague” - having to tell healthcare workers all the time

**Conclusions:**

Findings of this study were consistent with previous studies conducted in tertiary and metropolitan healthcare facilities. Participants reported both positive and negative aspects of being isolated in a single room.

All participants felt that they were not adequately notified that they had MRSA and not received any verbal or written information that would assist them in understanding MRSA or helped alleviate their concerns of passing on MRSA to their families.

Staff knowledge and inconsistent practices with infection control strategies were also highlighted as issues for the participants of this study. Although staff had been educated on MRSA, isolation precautions and accessing information this knowledge had not been translated into practice.

Participants felt stigmatised or discriminated against and reported feeling dirty, lonely, locked in, embarrassed and ashamed.

**Recommendations:**

Patients should be notified of their MRSA status and given accurate information immediately that the MRSA has been identified by the laboratory. For those patients whose MRSA results are available after they have been discharge from hospital a formal notification process should be developed in conjunction with local medical officers. This would ensure that this group of patients are notified of their MRSA results and that they receive both written and verbal information.

Barriers to healthcare workers compliance with infection prevention and control practices require investigation in order to improve current practice. Development of strategies to improve the care of patients in isolation is required.

## Introduction

The purpose of this report is to guide clinical practice in caring for patients who are placed in contact precautions for MRSA in a regional setting. Current literature indicates that there is both the potential for physical and psychological adverse outcomes for patients isolated in hospital. The report outlines the rationale for conducting the current study; the process utilised during the research and will conclude with recommendations to improve the patients experience in isolation.

Anecdotal information from patients and healthcare workers regarding the experience in isolation for infection control purposes provided the catalyst for the principle researcher.

## Background

Patients are isolated for a variety of reasons. The basis for the use of isolation precautions (also known as additional precautions) is to prevent the transmission of multi-resistant organisms (MRO) or infectious diseases within the healthcare facility. Isolation or additional precautions is recommended for the management, of infectious diseases and multi-resistant organisms within NSW <sup>(1,2,7)</sup>, Australia <sup>(3)</sup> and internationally <sup>(4,5,26,60)</sup>. There are three categories of additional precautions; contact, droplet and airborne. Contact precautions are the most frequently used category of isolation and is utilised for patients with MROs of which MRSA is the most prevalent.

Worldwide MRSA is the causative organism for many healthcare related infections. There is significant morbidity <sup>(9-13)</sup> and mortality associated with MRSA infections. Mortality rates associated with MRSA blood stream infections can range from 10% to 50% <sup>(3)</sup>. It is estimated that in most countries the percentage of MRSA within healthcare facilities is between 20 – 75% <sup>(26)</sup>. In NSW Intensive Care Units (ICU) MRSA colonisation and infection rate in 2008 was 3.8% per 1000 bed days <sup>(8)</sup>.

The implementation of the NSW Health policy directive in 2007 on management and prevention of multi-resistant organisms (MRO), has resulted in active screening in patients with chronic wounds and indwelling medical devices as well as those scheduled for elective orthopaedic surgery such as hip and knee replacements and patients admitted to intensive care units <sup>(2,7)</sup>. As a result of active screening increased numbers of patients are now being identified as being colonised or infected with MRSA.

Once identified as being colonised or infected with MRSA contact precautions are implemented <sup>(1,2,7)</sup>. Contact precautions require that the patient be cared for in a single room, with signage on the door indicating that precautions are in place. These precautions include the use of personal protective equipment (PPE) such as gloves and gowns by clinical staff entering the patients room to provide care and the restriction of the patients movement within the ward <sup>(1-6)</sup>.

Identification of MRSA has ongoing implications for patients, once a patient is identified as colonised or infected with an MRSA an alert is placed in their electronic medical records (EMR) as well as the patient information systems (IPM). These electronic alerts ensure that contact precautions are initiated when the patient represents for any future episodes of care. The alerts remain in the electronic systems until the patient has been cleared by an infectious disease physician, clinical microbiologist or infection control officer <sup>(2)</sup>. The clearance criteria as outlined by NSW Health <sup>(2)</sup> in most instances is difficult to meet with few patients being cleared.



The NSW Health State Plan: Towards 2010<sup>(15)</sup> aims to improve clinical practice and reduce the risk of infections within in the healthcare setting. The plan states that it will achieve this by developing effective working relationships between clinicians, consumers and carers in the development of policies, planning and delivery of healthcare by redesigning the patients journey to build in safety. This study hopes to provide an insight into the consumer perspective to assist in the redesign objective.

## **Rationale**

Studies on the care of patients and their experiences have reported adverse outcomes and low satisfaction with care when isolated. These studies have been conducted in specific patient groups<sup>(23,24)</sup>, specialised units<sup>(18,21,22)</sup>, metropolitan and tertiary hospitals, as well as large teaching<sup>(25)</sup> or university facilities<sup>(16)</sup>. No studies were found that had been conducted in a rural or regional setting.

This study was designed to explore the patient experience in a regional healthcare setting (due to lack of available research conducted in the rural or regional healthcare setting). It was also anticipated that this would highlight any differences that had been experienced by patients in studies that had been conducted in tertiary and metropolitan facilities, as well as identifying if there is a difference for patients admitted to their local healthcare facilities and living in smaller populated areas. The question being asked is "Does having MRSA change how these patients interact with others?"

This study is also in keeping with the NSW Health plan to improve the patient journey.

## **Literature Search Strategy:**

A literature search was conducted utilising the Clinical Information Access Project with Medline, Pubmed, Cinahl databases searched. The date range was from 1996 to the present and the search terms included MRSA, isolation, contact precautions, patients experience and seclusion.

The literature review was repeated in June 2011 prior to completion of the report to determine if any additional articles were available. Two items were located<sup>(37,44)</sup> and incorporated into the literature review. Studies were located on all search terms listed.

Assistance was obtained from the Local Health District librarian in conducting the original literature search and the follow up review in June 2011 to ensure an accurate and detailed search.

## **Literature Review:**

The search terms utilised discovered numerous articles related to various aspects of the patient experience in isolation and their perception of care. Studies obtained included qualitative and quantitative studies which included systematic reviews on rationale and effectiveness of isolation as well as the patients experience in isolation.

The literature review highlighted several themes, the most frequently occurring themes were information<sup>(14,28,29,30,33,34,36,41)</sup>, communication<sup>(28,29,30)</sup>, understanding of MRSA<sup>(30,31,36,40,41)</sup>, isolation<sup>(5,30,31,35,36)</sup>, contact with staff<sup>(32)</sup>, consequences<sup>(31,39)</sup>, adverse events or harm<sup>(37)</sup>, psychological effects of patients in isolation<sup>(36)</sup> and staff compliance with precautions<sup>(11)</sup>. All of these themes contribute to the patients overall experience in isolation and will be discussed in this review.

The theme '*information and understanding*' of MRSA was featured prominently<sup>(14,28-30)</sup> and the studies reviewed found that participants lacked information about MRSA<sup>(28-30,33)</sup>, the causes<sup>(31)</sup>, transmission<sup>(32)</sup>, consequences<sup>(31)</sup> and isolation precautions<sup>(33)</sup>. The information given was reported to have failed to meet the need of the patients<sup>(28)</sup>. Madeo's<sup>(28)</sup> study found that the information varied and concluded that the participants level of knowledge depended on whether the participants knew someone who also had MRSA. Alternatively Newton<sup>(31)</sup> found that participants despite being given both written and detailed verbal information did not have a clear understanding of MRSA.

In Gill et al's<sup>(38)</sup> study on perceptions and awareness of MRSA the media was cited as a source of information on MRSA for 68% of patients and 24% of employees. In this study television (42%) and newspapers (26%) were listed as the most frequent sources. Burnett et. al<sup>(38)</sup> found as well as being a source of information the media also influenced views among their participants on the cause, which then lead to decrease in confidence of healthcare.

A recurring recommendation in previous studies is that both written and verbal information on MRSA and reasons for isolation be given to patients<sup>(13,29,33,38)</sup>. It also recommended that communication and information be adapted to meet the specific needs of individual patients as this assists with the information being understood<sup>(38)</sup>.

A lack of information that the patient understands on isolation and MRSA management as well as poor communication in healthcare are frequently found to be the underlying cause of patient complaints and decrease levels of patient satisfaction<sup>(16,19,42)</sup>. Inconsistent information or mixed messages from healthcare providers causes confusion<sup>(30)</sup> and undermines the patients confidence in the healthcare service. Providing accurate information to patients on their care and medical management has been demonstrated to improve satisfaction as well as decrease anxiety particularly in patients<sup>(28,29)</sup> placed in isolation.

Isolation of patients has been reported as having significant psychological effects, such as increasing symptoms of anxiety and depression<sup>(20,36,42,44)</sup>, fear and anger<sup>(42,44)</sup>. Frequent mood disturbances have been noted<sup>(33)</sup> and have been found to occur after only one week of isolation<sup>(20)</sup>.

Conversely a small pilot study examining the psychological impact of spinal cord injured patients isolated because of MRSA infections<sup>(21)</sup>, found that there was no significant difference in anxiety and depression scores between the isolated patients and the control group. The only difference found was that the isolated patients scored significantly higher levels of anger than the control group. However a limitation of this study as noted by the researchers was the specific population (spinal cord injured) under study, so therefore their findings could not be generalised<sup>(43)</sup> to other patients groups and that perhaps studies involving different groups might may find isolation has greater impact on the psychological well being of the patients<sup>(21)</sup>.

Wassenberg et. al<sup>(6)</sup> also investigated the psychological impact on patients who were isolated in the short-term for infection control reasons that included MROs, infectious diarrhoea or contagious diseases such as herpes zoster. Patients in this study were in isolation for at least 24–48 hours. This study demonstrated no differences in the anxiety and depression levels, between the control group of non-isolated patients and isolated patients and concluded that there were no negative effects in psychological well-being due to short term isolation.

Patient safety was raised as an issue with isolated patients reported to have longer length of stay and higher rates of preventable adverse events. Stelfox et. al<sup>(16)</sup> concluded that patients in isolation were eight times more likely than the control group to experience falls, pressure ulcers, and electrolyte imbalances. Patients have also reported that they felt isolation had impeded their recovery and rehabilitation<sup>(18)</sup>.

In a study conducted by Skyman et al<sup>(30)</sup> patient safety issues were also identified. Patients in this study felt they had been denied treatment or therapy for their illness as a result of having MRSA. These patients felt that they did not receive the same level of care as other non-MRSA patients. Patients have also reported that they have less contact with healthcare workers<sup>(17,31,32)</sup>, and experience delays in care.

Patients in contact precautions are reported to be examined less frequently by their physicians<sup>(25)</sup> than patients not isolated. However this study did not report on the normal examination practices of the physicians in the study, for example, would they have been normally examined if they had not been in isolation.

Isolation has been perceived as having both a positive and negative impact<sup>(28,31)</sup>. Positive aspects of being isolated have been reported as greater privacy, greater freedom from the routine<sup>(31)</sup> and improved care<sup>(19)</sup>. On the negative side of isolation patient's experienced isolation as being limiting and violating<sup>(30)</sup>. Other patients reported feeling bored<sup>(29)</sup>, lonely<sup>(31)</sup> and unclean<sup>(13)</sup>. The use of PPE also contributes to the patient feeling unclean. Patients are touched with hands that are gloved; clothes are covered with aprons or gowns. If masks are required, patients are unable to see staff members faces properly<sup>(46)</sup>. In addition face masks hinder communication with patients especially those with hearing impairments

Staff practices and behaviour are also noted throughout the literature. Practices relating to compliance with infection control practices<sup>(11)</sup> such as the use of PPE, hand hygiene and knowledge were frequently commented on by patients. Level and adequacy of cleaning of rooms<sup>(47,48)</sup> and equipment was also noted in several reports to be a concern to patients in isolation and the topic of numerous journal articles related to MRSA<sup>(26)</sup>, other multi-drug resistant organisms and isolation precautions<sup>(27)</sup>.

The consequences for patients once identified with MRSA are not only being placed in isolation when receiving inpatient care but also issues related to living with MRSA on discharge from hospital. Relationships with family and friends have been reported to be adversely affected with patients reporting their relatives made them feel unwelcome, or they were excluded from seeing family or participating in family functions<sup>(30,32,36)</sup>. Patients have expressed overwhelming concern about being a risk to others<sup>(36)</sup> and passing MRSA to others<sup>(32)</sup>.

Patients infected or colonised with MRSA described discriminatory behaviour from healthcare professionals<sup>(30)</sup>. Patients reported they were instructed by staff that they were unable to sit in the waiting room of the emergency department with other patients and were required to wait outside in the emergency department for hours before seeing a doctor<sup>(30)</sup>. Braut and Holt<sup>(44)</sup> identified similarities with this type of behaviour and that towards HIV positive patients, when HIV was first identified in the 1980s.

Ethics related to isolation, healthcare associated infections and staff compliance were uncovered within the search parameters of the literature review. Cole and Lai<sup>(5)</sup> state that the isolation is justifiable on the basis that it produces benefits to non-infected patients that outweigh the potential for harm and adverse outcomes for the patients who are isolated. This irony between preventing the transmission of MRSA, protecting the non-MRSA patients and patient safety for those patients in isolation has been compared to violation of rights, and the ethical principles of non maleficent and beneficence<sup>(37)</sup>.

Gilbert et al<sup>(45)</sup> commented on the ethical implications of avoidance of harm to patients and included within their debate the issues of organisational systems failure and non-compliance of healthcare workers with evidence based practices, such as hand hygiene. They discussed the moral obligation of health care workers to "do no harm" and propose that compliance with

infection control policies be a condition of professional registrations and employment as well as advocating for penalties for non-compliant staff.

The issue of patient experience whilst under contact precautions for MRSA is a complex one. The literature review reveals both positive and negative aspects such as how isolation impacts upon patients, contact with healthcare staff, adverse events, staff practices, cleaning and ethical considerations. The literature review did not identify any studies that had been conducted in a regional setting.

### **Aim of Research**

The aim of this research study was to explore the patient experience with contact precautions for MRSA in a regional healthcare setting.

### **Method**

The principal researcher is a female infection prevention and control coordinator on the South Coast of NSW and authorised to practice as a registered nurse.

### **Study Design:**

A qualitative study was planned with participants being invited to participate in semi structured interviews to explore their experience of being isolated for MRSA during their hospital admission. Interviews were coded and thematically analysed to reveal major themes.

A phenomenological theoretical framework was utilised for this qualitative study. Phenomenology describes the lived experience of the participants or what the experience means to those who lived it<sup>(52)</sup> and explores participants feelings and beliefs<sup>(49)</sup>. This approach allowed for the research to explore the experience of participants and insight into the meaning that they placed on being isolated for MRSA.

### **Study setting:**

The study sample was restricted to patients who resided within the Shoalhaven Local Government Area which extends from Gerroa to North Durras<sup>(55)</sup> on the NSW South Coast and classified as inner regional<sup>(56,57)</sup> under the Accessibility Remoteness Index of Australia criteria<sup>(62)</sup>.

The Shoalhaven Local Government Area had an estimated population of 86,650 in 2006 with 68.8% of the population 18 years and over<sup>(55)</sup>. Aboriginal and Torres Straight Islanders make up 3.8% of the population with 2.4% of the population from a non- English speaking background<sup>(55)</sup>.

The healthcare facilities that service the area are comprised of three hospitals; a 30 bed rehabilitation and palliative care facility, a 35 bed acute hospital; and a 196 bed acute facility. Participants in this study had been inpatients in either of the two acute facilities and isolated in single rooms between November 2010 and June 2011.

Patients were not recruited from the rehabilitation and palliative hospital as this site is over 100 hundred years old and has Nightingale style wards. Patients within this facility are not placed in single rooms for isolation.

### **Participant Selection:**

Purposive sampling was used for participant recruitment. Patients eligible for inclusion in the study were over 18 years of age, intact cognition.

To reduce perceived power relationships or concerns about coercion, patients were excluded from the study if they were receiving any ongoing health services on discharge such as community health, ambulatory care or hospital in the home services.

### **Recruitment:**

Patient's selection for recruitment was conducted via an independent third party consisting of the Infection Management and Control Service (IMACS) Nurse Manager and an Administrative Assistant. A report of inpatients with MRSA was compiled from the Electronic Medical Records (EMR) system. The IMACS Nurse Manager and the Administrative Assistant selected every second patient on the list. Participants were contacted in groups of four.

Originally contact letters and participant information sheets (Appendix 1) were given to the potential participants on the day of their discharge from hospital. This process proved to be unsuccessful in recruiting participants. The reason for amendment was because patients, when contacted via telephone four to five days following their discharge, had either not read the information or had thrown away the contact letters. Potential participants stated that they thought it 'was just more information' given to them when discharged or that the information was intended for their Local Medical Officers.

All participants signed a consent form (Appendix 2) after verbal explanation, that informed them that participation was voluntary, their information would be de-identified, they could withdraw for the study at any time prior to the analysis of the data and if they chose to decline the interview it would not affect any care or treatments from the health service now or in the future. Participants were given the opportunity to read the consent prior to signing. Participants were also given the option of retaining a copy of the consent form, all participants declined (Patient Consent Form Appendix 2).

Ethics approval was granted to interview between eight to twelve participants. There were twenty four patients contacted who were identified as potential participants for the study. Table 1 outlines the reasons for patients declining to participate and interviews not being conducted.

Eight patients agreed to participate in the study with six interviews conducted. Two interviews were not conducted for the following reasons:

- One participant was re-admitted to a healthcare facility prior to interview appointment
- One interview was suspended as the participant was not aware of having MRSA and had not been cared for with contact precautions during his last admission so therefore did not meet the eligibility criteria. This participant was given information regarding MRSA and did not experience any adverse effects or require any additional services e.g. counselling from Social Work

Table 1: Reasons for non-participation and interviews not conducted

<b>N=24</b>		
<b>Patients given information at time of discharge</b>	8	did not read information -3 threw information away – 2 thought information was for LMO - 3
<b>Patients declined</b>	4	Reason cited – still unwell 2 Did not wish to participate 2
<b>Discharged with ongoing health care</b>	3	
<b>Moved outside of geographical area</b>	1	
<b>Patients agreed participate and interviews arranged</b>	8	
<b>Number of interviews conducted</b>	6	
<b>Interview cancelled</b>	1	Patient re-admitted to hospital
<b>Interview terminated</b>	1	Patient unaware of MRSA status and was not isolated during hospitalisation

#### **Interview Setting:**

All interviews were conducted at the participant's home as this was the participants preferred location. This ensured that the participant was comfortable and reduced the burden of travelling on the participant.

The participant's partner or carers were also able to be present at the interview. Three participants choose to have their partners or carers present for the entire interview. Due to other commitments, three participants had their partners or carers present for part of the interview process. All of the partners or carers participated in the interview process and offered support and assistance to the participants.

Table 2: Participants number of admissions and length of stay in isolation following identification of MRSA

<b>Participant</b>	<b>Age</b>	<b>Sex</b>	<b>MRSA First Identified</b>	<b>No admission since MRSA Identified</b>	<b>Average number of days in Isolation since identification of MRSA</b>
<b>1. Abe</b>	76	Male	Jan 2009	2	6.5
<b>2. Ben</b>	71	Male	Mar 2008	4	12.5
<b>3. Chuck</b>	60	Male	Jun 2009	4	4
<b>4. Rita</b>	38	Female	Oct 2008	3	5
<b>5. Sue</b>	77	Female	Feb 2011	2	8
<b>6. Tina</b>	54	Female	May 2007	23	17

Four participants were from an English speaking background, one from non-english speaking European background who has resided in Australia for over 25 years and did not require an interpreter, one participant was from an Aboriginal Torres Strait Island background. These were incidental recruitments.

### **Data Collection:**

Data was collected via semi-structured interviews utilising an interview guide (Appendix 3) and field notes written immediately following the interview. Semi-structured interviews allow participants to express themselves in their own words<sup>(50,59)</sup> allow for a broad range of topics to be covered utilising an open-ended questions outlined in an interview guide<sup>(50)</sup>. The interview guide also ensured consistency with all interviews, as well as keeping both the researcher and participant on track. Interview guides ensure that the researcher covers the same topics and ideas with each of the study participants<sup>(51)</sup>.

A pilot interview was conducted to test the interview guide<sup>(58)</sup> and to allow the principle researcher to identify any issues with interview technique. The pilot participant was a 51 year old female, identified with MRSA in 2009 and has had ten admissions to hospital since MRSA has been identified, with an average length of stay in isolation of 9.6 days. The pilot participant was well known to the principle researcher and would have been excluded from the study due to ongoing healthcare following discharge from hospital. Duration of pilot interview was forty minutes. No amendments were made to the interview guide

Six participants were interviewed with saturation of themes occurring at the fifth interview. Five interviews were conducted in May 2011 with the sixth additional interview conducted June 2011. Interview duration was between 21 to 56 minutes with a mean interview time of 32 minutes. At conclusion of all interviews additional information was given and participant's questions were answered.

All participants agreed to have the interview recorded. The audio digital recordings of the interviews were transcribed by the principal researcher. Both the interview recordings and transcriptions were electronically secured in a password protected file. Immediately following the interview field notes were documented in a journal. All participants consented to allow the inclusion of field note data for analysis. Post interview the journal was secured in locked filing cabinet which only the principle researcher having access.

Participants were given the option of reading the transcripts, five participants declined the offer. The sixth participant indicated at interview that they would like to read the transcript but later declined when contacted after the interview had been transcribed. Pseudonyms have been used in order to de-identify participants and their partners, carers and family when quoted in the report.

The potential risks identified for the participants included anxiety and emotional distress. Consideration was given to reduce these risks by allowing the participant to express their feelings, set the pace of the interview<sup>(58)</sup> and conducting the interviews in the participants home.

## Data Analysis:

All interviews were transcribed by the principle researcher. All coding and analysis were completed by hand. Both the interview recordings and transcript were analysed for emergent themes to allow open coding. This was next followed by axial coding where data was organised together by making connections between major categories and sub-categories<sup>(51)</sup>. The main categories became the major themes which comprised of the grouped sub-categories<sup>(50,51,59)</sup>. The first interview was reviewed by an independent researcher to ensure consistency with themes and coding. Discussion and agreement of themes and data occurred with an independent researcher. This also allowed for objectivity and ensured validity and rigour of analysis<sup>(50)</sup>.

## Ethics Approval

Research ethics approval was granted by the Human Research Ethics Committee of the University of Wollongong and South Eastern Sydney Illawarra Area Health Service on 29<sup>th</sup> July 2010 (reference number:HE10/094; AU RED: HREC/10/ WGONG/28). Site specific approval was granted on 11<sup>th</sup> October 2010 (reference number: HE10/094; Trim D10/5613).

## Findings:

Analysis of the transcripts revealed three major themes and as well as sub-themes identified in each major theme. The major themes identified were:

- “They will not talk about it”-Information about MRSA
- “Locked in these rooms”-Care in hospital
- “What can I do about it? Nothing.-Living with MRSA

### **Theme 1: ‘They will not talk about it’ - Information about MRSA**

Included within this theme is the initial notification to participants of their ‘having’ MRSA. Participants describe being informed of having MRSA, the lack of information they received or even having to ask for information. One participant described being moved from a multi-bed room (four bed) into a single room and was not informed of the reason until she asked.

*“I was in a shared room when they did that swab... umm as soon as they got the results back, I got moved into a single room” and “I said what am being moved for, he (the nurse) said for MRSA and I said but I didn’t have MRSA and he (the nurse) said you have now”.*  
Tina

Appropriateness of the time and location that participants were informed of their MRSA was discussed by one participant, who had been notified at home via telephone following discharge from hospital.

*(It) “wasn’t ‘til I got home I got a phone call that night, that my husband had taken to say that they had taken a swab, I remember them taking a swab of my nose, under my arm and somewhere else I can’t remember now and they said that the swab from my nose came back saying that there was MRSA and they just told me to be careful”.*  
Rita



The timing of information to participants was also highlighted by Abe who stated he did not remember receiving information about his MRSA but his family knew about it as they were expected to comply with precautions. Abe had been in the intensive care unit.

*"I can't remember that they ever told me I had the golden staph in me ... because at the time the first two or three days (in hospital) I wasn't even conscious of anything you know".*  
Abe

One participant reported that she found out by accident she had MRSA in her wound while having her dressings changed.

*"I just heard the nurses talking, as they were (changing the) dressing"*  
Sue

Participants in this study felt that they should be informed of their MRSA status by their medical officers with either their doctor in hospital informing them or their local medical officer. Abe believed that his local medical officer should have told him about his MRSA and Sue who discovered she had MRSA by accident, believed the doctor should have told her.

*"I think Dr X should have said 'you've got staph. and now we've gotta do this' but they just said it was 'just' an infection"*  
Sue

Participants also reported that they had asked hospital staff for information about MRSA and had received a variety of responses and at times conflicting information from different staff members as well as staff refusing to discuss MRSA.

*"...they won't talk about it if you asked them if you ask a doctor about it they change the subject and umm and they will not talk to you about it".*  
Chuck

Chuck also believed that the staff would not speak to him about MRSA because they themselves had no knowledge about it.

*"The staff don't know anything about it ..... well they tell you they don't know anything about it".*  
Chuck

Some participants reported obtaining information regarding MRSA from other sources such as internet, friends and family. Sue and her husband had located information about MRSA from the internet and commented on the antibiotics that were used to treat her MRSA infection.

*"the stuff that they put her on is ahh what they use for people with leprosy".*  
Sue's husband

*"Yeah so I was on them for about over six weeks when I got home".*

Sue

Two participants reported that they had family members who worked in healthcare (nursing staff) at the hospitals in the study as well as one participant who stated she was aware of MRSA.

*"My father died of MRSA infection so I knew what MRSA was, he died ..... they didn't have vancomycin then"*  
Tina

## **Theme 2: 'Locked in these rooms': Care in Hospital**

Being in isolation was portrayed by participants as have being both positive and negative. Positive aspects of being in isolation were privacy, own room, own bathroom and toilet, ability to have lights and television on during the night, able to have more than two visitors and easier for young children to visit.

*"I preferred isolation because I was on my own, own bathroom that kind of thing.... I could please myself what time I go to sleep, what time I wake up "* Ben

*"I enjoyed every minute of it I had visions, of being in a ward there, with half a dozen others".* Abe

*"The fact that I had my own room was quite good actually... I had my own bathroom, my own television".* Rita

Negative aspects of being isolated were reported in this study as not having anyone to talk with until visiting hours and loneliness.

*"If you're in a shared room, you know, you get to talk to someone you know but the only ones I get to talk to are my family when they come in so I think you feel a bit alone".* Tina

*"I'm one of the worst talkers you've ever seen in your life, I gasbag I can't help it I talk to anyone and I, you know you lay there for hours, hours day and night never anyone to umm talk to,(the)nurses coming in, they haven't got time to talk to you".* Chuck

Restriction of activities to room was reported as concerning to the participants, especially when in hospital for several days and they were encouraged by medical staff to get up and move around.

*"and they go are you getting plenty of exercise and I go what? Around the bed... like I get up and move around but how much exercise can I get around the bed you know?"* Tina

*"I duck my head around the corner and was talking to this old gentleman in the room beside me and they came (nursing staff) and went ahhhhhh, you just can't, can't umm talk to anybody, we weren't touching or anything I'm standing at the doorway .... Nup not allowed .... You're not allowed out there you've got to stay (in your room)".* Chuck

The duration of time that patients were in hospital and isolated was discussed as an issue by Tina who had several admissions stated that she felt frustration at being restricted to her room.

*"I think it's like 'cabin fever', that's what it feels like and even this time I was in there for three and a half weeks but you still get that .... well I mean I have this here (indicating home) and I, we are on five and a half acres I have plenty of room and then they put you into a room you know".* Tina

Chuck referred to being in a single room when talking about isolation as

*"Being locked in these rooms"*

Chuck

Although being in isolation was discussed as ensuring privacy ironically it was also seen as issue with for maintaining privacy.

*"So they (doctors) are talking to you from outside the door where everybody else can hear what's going on, outside the door, so it doesn't feel private or that you know".*

Tina

*"Some of the doctors wouldn't come in, they just stood at the doorway and shouted across, couldn't be bothered dressing (putting on PPE)".*

Ben

Participants reflected that this was no worse than if they had been in a four bed room, with just the curtains pulled however the difference was, they felt that the corridor, was a more public place and this behaviour contributed to them feeling unclean or dirty.

*"I think I probably felt more embarrassed because I think I'm unclean and that's why everyone has to do that".*

Tina

Inconsistent staff practices and compliance with infection control was a major concern for participants. Some staff would always wear PPE while others would not. This behaviour was not confined to one professional group.

*"They put these plastic like glad wrap things on and then when they'd go they'd just rip it off and put it in the bin and then wash their hands. The young doctor he did when he came in but, Dr P he just came in ....had a look at me that umm he didn't come very often".*

Sue

*"One nurse said I'm not touching your foot (wound had MRSA) so I'm not going to glove up so he'd just come in and he would want to know what my BSL (blood sugar level) was or do my temperature and he was like I'm not going near your foot and your foot is wrapped so there's no need for me to do that, but he would walk out and pump, wash his hands and all that"*

Rita

*"nurses are the only ones who carry it out there, like even in the middle of the night when there is no one around they come to your door ask, check see that you don't need something there and then immediately and then they will glove up and... there excellent with, doctors refuse, doctors don't follow".*

Chuck

Other inconsistent practices noticed by participants also included the fact that they had been isolated and restricted to a single room but on the day of discharge they were allowed to wait in a common area – discharge lounge with other patients who had not been isolated, they were somewhat confused by this occurrence.

*" I was coming home and umm, they had patients coming in so I had to leave my room early and then we had to wait for the doctor and everybody to signs paper so I was sent up umm we ended up in another waiting room, TV room somewhere".*

Sue

Practices related to the delivery of meals, morning and afternoon teas was discussed by four of the participants as being a negative aspect of being in isolation. Catering staff would not deliver meals into the rooms but would leave them outside the door and nursing staff would then bring the meals into the room. Participants and their support person present at interview commented on cold meals as a result of this practice with one participant citing an incident that occurred at a referral hospital.

*"Yeah by the time you got them (meals) when someone came along to bring it into you it was stone cold I didn't like that much ... I mean I used to spend most of my day with Ben. I used to go and bring the meal in but if I wasn't there he'd wait for ages".*

Ben's wife

*"Umm the girl went past with the tray (catering staff) and she said 'Oh would you like a drink' and 'I said I'd love a juice' and she said, she threw one into the room.... Yeah I caught it, I caught it,... she couldn't come in there was a big sign on the door not to come in unless you got permission from the head nurse, sister or something".* Sue

Cleaning was commented on by all participants and was seen as both a negative and positive aspect of being isolated. Participants felt that cleaning was better in isolated rooms and with some stating that the cleaning in isolation needs to improve.

*"Hospitals are too dirty they're not looked after well. Those rooms (isolation rooms) are kept spotless on a daily basis, they're kept spotless... and all there's no shirking by anyone".*

Chuck

*"I was there for five days not one cleaner came in and cleaned my table top, like the feeding tray or whatever it is, I didn't clean anything, they came in and cleaned the ensuite, as in ran a mop over it every day, but as for my room they did not mop it once".*

Rita

The cleaning of the hospital was linked to the participants concerns about their condition worsening or experiencing complications from the illness that had brought them to hospital in the first place. One participant was so concerned about the cleaning she spoke to a cleaner about their routine practice of cleaning her room.

*"I said how many rooms have you done with that bucket and he said well I've done the previous room and I said well you go and empty that bucket and start again please..... And I umm I said to him (the cleaner) you don't realise I've got Golden Staph. and umm I've got an infection in my foot and I've got to walk from my bed to that bathroom and if you're not doing that properly it gunna cause me to lose my foot".*

Rita

Four participants reported embarrassing or humiliating events experienced in hospital that they believed were because they had MRSA. Sue reported having to wait a long time for assistance after showering.

*"I couldn't get up and walk... to get my clothing, so you just sit there and wait. And there was one day I was in tears because umm the girls were so busy I had buzzed but one of the young men came in and he said "do you mind" (to have a male helping her to dress) and I said "no can you just help me"*

Sue

Tina reported incidents that occurred in front of her family that were embarrassing for her and her family member present.

*“one girl (nurse) came marching in and I said “Oh stop I’m MRSA”,... so she said” oh great!”...she went “ohh” and my kids were there and they were just (daughter) was there and she was just astounded, cause she (nurse) went “Oh great now I’m dirty, now what am I supposed to do, they should have signs up” and I thought Do You Know How You Just Made Me Feel... she made me feel dirty”.* Tina

Participants also discussed having their surgical procedures cancelled and although they understood that the cancellation was due to the need for an emergency surgical procedure to be performed they felt that having MRSA had contributed as they had been placed last on the theatre list. Tina recounted an incident where her minor procedure was performed in her isolation room.

*“There were about three or four theatre staff and they came around all gowned up and their machinery. And what do I do? I burst into tears –only because not only did it draw my attention that something was going on, everybody else in the ward and every other room..... it was just how I perceived it at the time, I felt embarrassed, and I think I felt dirty.”* Tina

Tina then went on to explain that she was upset and frightened as the last time she had a surgical procedure there had been some problems

*“What if something goes wrong?... When I think back now I was just totally humiliated I think, do you know what I mean I Felt Like I Had The Plague*

Tina

### **Theme 3: ‘What can I do about it ? Nothing’: Surrendering to MRSA**

Overwhelmingly participants were apprehensive of MRSA causing health problems for their families.

*“The only thing I worry about every time, I go in there, I ask is my family OK can they get anything and they just keep telling me No they can’t get it”.* Chuck

Although participants reported that MRSA had not altered anything for them outside of the hospital some reported that they were now particular about their hygiene practices

*“I’m super conscious, super conscious even with the kids, I always use antibacterial on their hands and like I carry a thing of bacterial, antibacterial you know ... I’m just so careful and like I nearly drive my husband nuts because I strip the bed like every second day...I’m just paranoid, paranoid that’s it I’m paranoid and like I don’t want to make anybody sick, but like for me I’m just scared of any germs.”* Tina

Other participants in this study reported that having MRSA had not affected their interactions with their family, friends or hindered any of their normal activities within the local community. Chuck stated he did not have any problems with having MRSA as he felt that everyone had MRSA.

*“What I’m finding out is just about everyone, who comes into hospital has got it, all the people who that come in on a regular basis. I’ve got a whole group of people who are just like me, that are in and out of hospital all the time and every last person is like it.”*

Chuck

One participant reported that he had resigned himself to the fact that he had MRSA and the only ongoing consequence of having MRSA meant that he would have problems with wound healing.

*“What can I do about it? Nothing. And its well there, what can you do about it? I have to accept it.... The only thing I heard about it, if you carry a bug like that, if you’ve got wounds or something, if you injure yourself it takes longer (to heal), now that I think about it that’s correct”.*

Abe

Frequently participants reported having to provide information to health care workers about their MRSA status when they re-presented to hospital for care.

*“In the emergency (department) they did ask me if I had MRSA and that’s when I said “what’s MRSA” and “I said I’m not sure, I wouldn’t have a clue”*

Rita

This was somewhat annoying to the participants at times with two participants recounting an episode of being transferred to a referral hospital for care where they felt that the staff were under the impression that they (participants) stated they had ‘MRSA’ because they just wanted a single room.

*I had my discharge letter with me and they argued with me and they argued with (daughter)....they think you want a private room and they said you’re making this up (having MRSA) and I said NO I’m not making this up”*

Tina

## **DISCUSSION:**

### **‘They will not talk about it’: Information about MRSA:**

Participants in this study had expectations that medical officers would inform them that they had MRSA this would not be usual practice as microbiology results are not always available at the time medical officers conduct their rounds and contact precautions are initiated immediately MRSA is identified.

Despite having had at least one admission following identification of MRSA all participants had limited accurate information on the organism itself and transmission of MRSA. Previous studies have concluded that level of knowledge depended on whether participants knew someone who also had MRSA <sup>(28)</sup>. Three participants felt they were well informed on MRSA as they had family members; working in health who had given them information on MRSA and one participant had searched the internet for information. However in this study it was demonstrated, that even the participants whose family members worked in health care demonstrated limited knowledge of MRSA.

Lack of knowledge by doctors and nurses on MRSA was described by one participant as the reason, staff refused to discuss any issues related to the organism or gave inconsistent information<sup>(32)</sup>. This reluctance to discuss MRSA with the patients leads to patients acquiring

some times inaccurate information related to MRSA and to also conclude that healthcare workers are trying to cover up how they acquired their MRSA.

Gill et al<sup>(38)</sup> in their study reported that none of the employees within their facility had recognized the education they had received in particular induction or orientation, as a source of knowledge and questioned the effectiveness of current education programs presented to staff on this subject. Similar to Gill et al findings, staff within in the hospitals participating in the study had received education on multi-resistant organisms both at orientation and annual mandatory updates. This education also included how to access patient information sheets on resistant organism. Although written information sheets were available at both hospitals in the study none of the participants reported receiving information sheets during their hospitalisation<sup>(38)</sup>.

The timing of information was discussed by some of the participants with one not recalling at all that he had been notified that he had MRSA. He reported that at the time he was informed he was very ill in the intensive care unit, another participant reported being contacted on discharge by phone and message left with her husband that she had MRSA as well as a participant stating she just overheard staff talking. This method of notification undermined the participants confidence in the health system and left them with numerous unanswered questions that increased their anxiety and concern for their families well being.

Patients should be given both written and verbal information at the time that MRSA is first identified. All participants in this study were given both written and verbal information at the completion of their interview as well as contact details if they required any further information.

## **Theme 2: 'Locked in these rooms': Care in Hospital**

Participants described positive and negative aspects of care while in isolation. Participants in this study reported the positive aspects as not having to share a room with other patients, bathrooms and the ability for more family including children to visit. This is consistent with studies previously conducted<sup>(28,31)</sup>.

The negative aspects of isolation were related to being restricted to their rooms was especially an issue with those participants with a long length of stay in hospital. Contradictions in care with being in isolation were highlighted in interviews when participants reported they were expected to exercise by walking but were also restricted to their rooms. This confusion and mixed messages has been demonstrated in studies to increase worry, anxiety and decrease patient satisfaction with services<sup>(16,19,28-30,42)</sup>.

Participants reported inconsistent staff practices related to wearing or not wearing of PPE. This are issues that have been consistently highlighted within the literature<sup>(11)</sup>. The wearing of PPE is mandatory as part of contact precautions if there is to be any contact with the patient or their environment<sup>(1-4)</sup> clearly this is a compliance issues that requires addressing within the healthcare system.

Not wanting to wear PPE or being too lazy to put it on was reported by the participants as being the reason for staff standing at the doorway and speaking to them. Participants found this behaviour to be rude and distressing as well as impinging on their privacy.

Cleaning and Food services were commented on by most of the participants in this study. Comments related to cleaning levels were both negative and positive, with participants in this study also commented on the cleaning standards at both the hospital in the study as well as tertiary and metropolitan hospitals were they had been referred to for care. Cleaning of patients rooms and patient care equipment have been discussed as contributing factors in outbreaks of multi-resistant organisms<sup>(48)</sup>. Two participants within this study were concerned about the quality of cleaning and the negative impact it could have on their current condition.

### **Theme 3: 'What can I do about it? Nothing': Living with MRSA**

In this theme participants reported they were concerned about their families, one participant reporting that he consistently asks hospital staff at every admission to confirm that his family is not at risk from his MRSA. No participant reported having changed anything other than hygiene practices as a result of MRSA.

Although participants reported that having MRSA had not altered any of their interactions with their family, friends or activities within the local community, however all participants reported that they were now more particular about handwashing and their hygiene practices. Participants reported that they had 'learnt to be careful' so they would not get sick or make other people sick. These feelings of concern for family and being a risk to others have been reported in several studies<sup>(32,36)</sup>

The stigma of having MRSA is reported in several studies and journal articles<sup>(13,17)</sup>, as was the shame and embarrassment of having MRSA was reported by participants in this study. All participants in this current study used the terms 'leprosy' or the 'plague' when referring to MRSA and reported that they believed staff were fearful of picking up MRSA from them. Having to constantly tell or remind staff that they have MRSA and being placed last on theatre lists was seen by participants to be part of 'just living with MRSA'.

#### **Study Strengths:**

This research project aimed to compare the experience of patients reported in studies that had been conducted in tertiary and metropolitan hospitals to those experienced by participants in a regional hospital. Aspects reported in previous studies were also reported by participants within in this study, such as lack of information, inconsistent practices and issues with cleaning. Participants also felt angry, lonely and embarrassed.

An additional strength of this study is that participants recruited were from English speaking, non-English speaking and Aboriginal Torres Straight Islander background. Incidental recruitment of these groups are broadly representative of the local community.

A second opinion on themes and codes by an independent researcher to ensure consistency and rigour was a strength of this study.

#### **Study Limitations:**

The limitation of this study was that the participants did not include anyone between the ages of 18 -36 years, so generalisation is limited to those aged 37 and older.

Qualitative research findings are the results of data interpretation and can be presented in several ways and the skills and experience of the researcher play a role in the data interpretation<sup>(60)</sup>.

The experience of the principal researcher is also seen as a limitation to this study. The principal researcher is a novice researcher but experienced healthcare worker with 30 years experience.



## **Conclusions**

This study has demonstrated that the experience of patients isolated in contact precautions in a regional healthcare setting is similar to those studies conducted in tertiary and metropolitan hospitals. Care in isolation had both positive and negative aspects for participants.

Numerous studies have identified information and communication as pivotal issues for patients in isolation and have recommended that information be adapted to meet the specific need of the patients<sup>(38)</sup>. This study found that information was not given to participants and that there expectation was that they would be informed of their MRSA results by their medical officers.

One interview was cancelled as the potential participant was not aware that they had MRSA despite results being available prior to discharge and the information noted in the discharge summary. This information was not relayed to the potential participant from either the healthcare workers or the local medical officer. Patients who are identified with MRSA after discharge should be notified of their results. They should receive both written and verbal information from the hospital healthcare worker or their local medical officers.

Attention to staff attitudes or the stigma around MRSA has been highlighted in this study as well as others, and although some practices have an unintended discriminatory practice such as placing patients with MRSA last on the theatre list which then means they are the first to be dropped of the theatre list these practices requires; lessons learnt from past campaigns that have reduced discriminatory practices within health should be reviewed for the applicability to Multi-drug resistant organisms.

Education of healthcare workers on multi-drug resistant organisms requires review to improve its effectiveness. Barriers to compliance with infection prevention and control practices require investigation in order to improve current practice.

## **Recommendations**

1. Education of all healthcare staff on MRSA-topics should include transmission of MRSA, isolation precautions
2. Monitor healthcare workers compliance with contact precautions and amend practice of staff speaking to patients in isolation from the doorway
3. Ensure patient information sheets are accessible and utilised by healthcare workers
4. Explore and implement plan to overcome barriers preventing healthcare workers from discussing MRSA with patients
5. Check prior to discharge that known MRSA patients have received written information on MRSA and contact details if they have any questions
6. Collaboration with local medical officers to ensure patients identified with MRSA after discharge receive both written and verbal information.
7. Investigate ways of decreasing isolated patients anxiety and potential adverse psychological effects through such things as volunteer programs for patients who have no visitors. And access to diversional aids such as magazines, books and television
8. Educate local medical officers on how to obtain clearance status for MRSA patients

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## Appendix 1:



**SOUTH EASTERN SYDNEY  
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**NSW HEALTH**

## PARTICIPANT INFORMATION SHEET

### Patient's experience in isolation for MRSA in the rural setting.

#### Invitation

You are invited to participate in a research study investigating the experience of **patients who have had MRSA** and were isolated in hospital.

The study is being conducted by Annmaree Wilson, who is an Infection Control Coordinator at Shoalhaven and Milton Ulladulla Hospitals, part of the South Eastern Sydney Area Health Service (phone 442397318).

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

#### 1. 'What is the purpose of this study?'

The purpose is to investigate how people who are placed in isolation for MRSA feel about it and what the care was like from your point of view.

#### 2. 'Why have I been invited to participate in this study?'

You have been invited to participate because **you have had MRSA** and were in isolation during your last stay in hospital and live in a rural area.

#### 3. 'What if I don't want to take part in this study, or if I want to withdraw later?'

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide **not** to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with The South Eastern Sydney/Illawarra Area Health Service, Shoalhaven, Milton or David Berry Hospital or associated community health centres within the Shoalhaven region.

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason. However, it may not be possible to withdraw your data from the study results if these have already had your identifying details removed: the researcher will be happy to discuss this further with you if you wish, before you give consent.

## Appendix 1:



**SOUTH EASTERN SYDNEY  
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**NSW HEALTH**

### **4. 'What does this study involve?'**

This study will be conducted at your home and will involve a taped interview with you. The interview will last for about one hour. The study itself will run over one year and is due for completion in June 2011.

If you agree to participate in this study, you will be interviewed in your home.

Prior to the interview:

- You will be contacted by phone and a few questions will be asked about your home to ensure the safety of the researcher
- A date and time convenient to you will be organised between you and the researcher

Prior to the interview a brief discussion will occur between you and the researcher about the research process. It is important that you feel comfortable during the interview, so it is best to choose a time of the day when you feel at your best.

If you wish to participate you will be asked to sign a consent form; this will be clearly explained to you by the researcher and the form will be provided to you for signing on the day. Any questions you have about the project can be discussed with the interviewer on the day. The signed consent form will be retained by the interviewer and you will be provided with your own copy of the consent.

### **5. 'Will I benefit from the study?'**

This study aims to further our knowledge about how patients feel about being in isolation for MRSA during their stay in hospital.

Although the study is unlikely to benefit you directly, benefits from this study are likely to be seen in the future through discussion, publications and further research into this area.

The study may benefit you by enabling you to share your views and feelings.

### **6. 'Are there risks to me in taking part in this study?'**

If you decide to participate in the study, you need to be aware that the interview will take about 1 hour of your time.

The researcher/study team has taken steps to minimise any risk to you by protecting your privacy by de-identifying data, so you will not be linked personally to any of the data collected. As with any research, there may also be risks associated with the research that are presently unknown or unforeseeable.



## Appendix 1:



**SOUTH EASTERN SYDNEY  
ILLAWARRA**  
**NSW HEALTH**

### **7. How will my confidentiality be protected?**

Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. Only the researchers named above will have access to your details and results that will be held securely at Shoalhaven District Memorial Hospital in Nowra NSW.

### **8. 'What happens with the results?'**

If you give us your permission by signing the consent form, we plan to discuss the results at conferences and scientific meetings and publish the study results in peer reviewed professional journals.

In any publication, information will be provided in such a way that you cannot be personally identified. Results of the study will be provided to you, if you wish.

### **9. 'What happens if I suffer harm, injury or complications as a result of the study?'**

If you suffer any harm or complications as a result of this study, you should contact the researcher as soon as possible, who will assist you in obtaining appropriate counselling or treatment.

### **10. 'How is this study being paid for?'**

The study is being sponsored by The Rural Institute of Clinical Services and Teaching as part of the Rural Research Capacity Building Program.

All of the money being paid by the sponsor will be deposited into an account managed by South Eastern Sydney Illawarra Area Health Service. No money is paid directly to individual researchers.

### **11. 'Will taking part in this study cost me anything, and will I be paid?'**

Participation in this study will not cost you anything apart from your time, for which we thank you. You will not receive any monetary payment.

### **12. 'What should I do if I want to discuss this study further before I decide?'**

When you have read this information, the researcher, Annmaree Wilson will discuss it with you and any queries you may have. If you would like to know more at any stage, please do not hesitate to contact her on 02 44239318.

## Appendix 1:



**SOUTH EASTERN SYDNEY  
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NSW HEALTH**

### **13. 'Who should I contact if I have concerns about the conduct of this study?'**

This study has been reviewed by The University of Wollongong and South Eastern Sydney Illawarra Area Health Service Human Research Ethics Committee. If you have any complaints about the conduct of this study you should contact the University of Wollongong Ethics officer who is the person nominated to receive complaints from research participants.

The Ethics officer can be contacted on 02 42214457 or  
The University of Wollongong and South Eastern Sydney Illawarra Area Health Service  
Human Research Ethics Committee  
Research Services Office  
University of Wollongong  
Level 1, Building 20,  
Northfields Avenue  
Wollongong NSW 2522  
Tel 02 42214457

**Thank you for taking the time to consider this study.**

**This information sheet is for you to keep.**

## Appendix 2:



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**NSW HEALTH**

### CONSENT FORM

#### Experience of adult patients in isolation for MRSA in rural hospital settings

##### **The researchers seek your consent to participate in the above research**

Please remember that your decision to participate is voluntary; you do not have to consent if you do not wish to participate. If you decide not to participate you do not have to give a reason.

##### **The research team is:**

Annmaree Wilson,  
Infection Prevention and Control  
Rural Health Directorate,  
Shoalhaven District Memorial Hospital  
PO Box 246  
Nowra NSW 2541

Phone - 44239318

### CONSENT

#### **As a participant in the above-named study:**

- I have had the purpose of the research and any related benefits and risks explained to me by the researcher.
- I am aware that the research will involve an interview in my home or usual place of residence that will be recorded electronically for analysis
- If I choose after the recorded interview not to participate, my recorded interview will not be able to be deleted as it will have been de-identified by the researcher
- I understand that as part of the study any information collected about me, as well as my personal details, is confidential, and that neither my name nor any other identifying information will be published
- I understand that I am free to withdraw from the study at any time. If I wish to withdraw I should contact any of the research team to let them know.
- I understand that if I choose to withdraw at a late stage after my interview it may not be possible to remove my data from the study results if it has already had identifying details removed.
- If I do withdraw this will not affect my relationship with the researchers or with the health care organisation where the study takes place, nor will it affect any health care treatment that I receive now or in the future.

**Appendix 2:**

- I have read and understood the written explanation provided to me on the participant information sheet and have been given this sheet to keep.
- I am aware of who to contact if I have any complaints about the conduct of the research and that these contact details can be found on the participant information sheet.
  
- I agree to participate in the above-named study

**(Print) NAME**

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**Signature**

**Date**

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### Appendix 3:



#### Interview Guide

Experience of adult patients isolated for MRSA in rural hospital settings

Semi structured interview – try to cover following topics, but follow leads as they arise.

#### Ethics requirements

The purpose of this interview is to explore your experiences as a person **who has had MRSA** (commonly known as ‘golden staph’) and placed in isolation.

Your participation in the study is entirely voluntary and you have the right to withdraw from the study at any time. If you decide not to participate in this study or if you withdraw from the study, you may do this freely. You are free not to answer any questions you may choose. I am only noting the date of the interview. Any reports, papers or discussions with others will be confidential and no identifying information will be revealed to anyone outside the research team.

I would like to electronically record this interview so I can concentrate on our conversation instead of taking large amounts of notes. The interview will be transcribed word for word (verbatim) to make sure all of the discussion is accurate and complete.

Are you willing to have me electronically record our conversation?  
yes                      no                      (please circle and researcher to initial)

Are there any things you would like to ask me about this project?  
yes                      no                      (please circle and researcher to initial)

(2 consent forms provided – one for patient to sign and return to researcher and one for patient to keep)

#### Identifying data

1. Date of interview: \_\_\_\_\_

#### Leading questions:

- Can you tell me the reason you were admitted to the hospital?
- When were you placed in isolation?
- How did you feel about that?
- What were the good things (positive aspects) and bad things (negative aspects) about being in isolation?
- How do you feel you were treated while you were in isolation?

#### Further Themes to be explored

#### How did you feel about the information given to you

- *When you first found out you had MRSA-* Where you told about MRSA results? How did you feel about this?

### Appendix 3:

- *Verbal communication* – Did staff talk to you about your MRSA? If so who? If not who would you have liked to speak to? Why?
- *Written communication* – Did you receive any written information? If Yes did it help?

#### Isolation

- *Where you admitted straight into a single room? How did you feel about that?*  
*Or*
- *When you were transferred into a single room – What were you told about having to be moved into a single room? How did you feel about this?*
- *How was the care you received while in isolation? (seeking patients perception of level of care)*
- *What precautions (e.g. gowns, gloves, masks, etc) were used by staff? How did you feel about the precautions?*
- *What precautions were used by your visitors? How did you feel about the precautions?*

#### Healthcare

- *How would you feel about having to go back to the hospital? Inpatient care or outpatient care?*

#### Attitudes about MRSA

- *Attitudes of others* – What do you think other people think about MRSA? What have other people commented to you about MRSA? What sort of things did they say? How did this make you feel?
- *Own beliefs* - What do you think having MRSA means?

#### After Discharge

- *Has MRSA affected you at home? Have you changed anything? Has it affected your interactions with your family? Has it affected your interactions with friends? Has it changed any activities that you do within your local community?*

Are there any other things about having MRSA you would like to tell me about?