

**An exploration of patient experiences accessing an
Emergency Department for mental health crises.
An untold story.**

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Abstract

Emergency Departments (ED) of general hospitals are often used by people for assistance when experiencing a mental health crisis. There are a number of studies regarding mental health care in general hospital emergency departments. These studies are limited to patient satisfaction with specific ED psychiatric-liaison services or only reporting on the effectiveness of such a service. The studies are not designed to address the subjective experience: What does it feel like to come to a busy emergency department, with little space for privacy, to get help for a problem that still bears significant stigma?

A qualitative study design based in phenomenology intended to explore and understand those who have lived the experience of going to an ED for a mental health crisis.

A research protocol was developed to conduct unstructured in-depth interviews. Potential participants were invited to join the study through advertisement in local newspapers. Two in-depth interviews were conducted.

Due to the low number of participants, data saturation could not be achieved and data analysis was incomplete. It was determined that publishing the very small amount of existing data would reduce anonymity of participants. The study was terminated at this stage as it was unable to be completed as intended.

This report contains an overview of the intended study and includes the challenges and experiences of the researcher as a novice. It is anticipated that the experience of the researcher on this project highlights learning opportunities for both the researcher and others in future research.

Keywords: mental health, psychiatric, emergency, experience, client satisfaction, consumer satisfaction

Executive Summary

This research project aimed to find out from the patient perspective what it is like to go to an emergency department for a mental health crisis. The study findings were not able to be disseminated in this report. Low participant numbers resulted in incomplete data analysis and publishing the small amount of data gathered may reduce anonymity of the participants. This report provides an overview of the intended study and includes the experiences of the researcher as a novice.

The research design was based in phenomenology, a qualitative method typically employed for use in studies aiming to understand experience. The protocol outlined the use of unstructured in-depth interviews to gather data with participants being invited to join the study through advertisements in local newspapers.

In addition to the low numbers of participants, there were a number of external issues impacting on the option to continue the research. These factors included the media strategy not following the proposed recommendation and the researcher obtaining an appointment to a health service external to the local health district where the study was being undertaken. Not taking these factors into consideration contributed to the decreased ability to amend the recruitment strategy and the decision to terminate the study.

What this project did show was the importance of the subject matter. The patient experience must not be shadowed by an incomplete study. The experience of the researcher has been considered and lessons have been learned from this attempt to learn from others.

Recommendations:

Future research of this subject should be attended and consideration given to including in the protocol:

- a. A hierarchical range of alternate recruitment strategies specific to the subject matter and with regard to a willingness to participate, ability to give informed consent and that the individual's current mental status doesn't preclude their ability to understand the process and risks of the study.
- b. Formalised indicators for actions by departments not directly involved in the study though whose action or inaction will affect its progress need to be included in the project milestones.

About the researcher

At the time this study was undertaken, the researcher Kim Edwards was employed as a Clinical Nurse Consultant Grade 2 in the Mental Health Emergency Care and Support Centre (MHECSC) for the Southern NSW LHD. At the commencement of the project, the researcher had 19 years' experience as a Registered Nurse; 17 of these years spent in mental health services including acute adult inpatient, community mental health, child and adolescent mental health, mental health phone triaging services and most recently mental health emergency care.

Mental health emergency care is of significant interest to the researcher whose principal role was to facilitate specially designed two day workshops aimed at educating staff of general hospital departments to increase their capacity in assisting people presenting with mental health crises. Mental health consumer advocates employed by the service participated by detailing their role and by sharing their personal journey of recovery from mental illness. Such sessions were evaluated by staff participants as being of the highest value and 'most powerful' session. This prompted reflective discussions with staff resulting in the research question and an application to participate in the program.

The researcher did not have any direct relationship with the participants prior to the study and was not aware of any direct relationship with MHECSC. Potential study participants were aware of the professional background of the researcher. Outside being a participant in prior studies as a mental health nurse, this was the first research project the researcher led.

Introduction

The move to promote emergency departments as entry points to care and treatment for individuals experiencing mental health crises has seen various impacts on staff, services and consumers (Kalucy, Thomas and King, 2005). This is particularly true for rural and remote areas where health care services are historically under-resourced and physical facilities are poorly designed and isolated from specialist psychiatric services (Mental Health Drug & Alcohol Office, 2006). Emergency departments were not designed for this role and general hospital staff were reporting a lack of confidence, skill and knowledge with regard to management of mental health presentations (NSW Centre for Mental Health, 1998). Recommendations were made to develop mental health specific triage guidelines and training programs to increase the capacity for general hospital staff in emergency departments to respond to and effectively manage mental health presentations (NSW Centre for Mental Healthy, 1998).

Mental health presenting problems and diagnoses are many and varied. The spectrum of defined mental disorder historically and currently continues to be debated, reviewed and evolved from simple terms of 'lunacy' and 'insanity' to the complex formal classification systems with various editions of the International Classification of Diseases (ICD) and Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association, 2000). Mental health crisis is usually indicated by the presence of changes in behaviour, emotions or thoughts or a combination of these: such common mental health presentations to emergency departments include suicidality or self-harm, confusion and not making sense, bizarre behaviour and speech, sad, depressed or distressed, hyperactive and elevated or nervousness and panic (NSW Health Department, 2009). It is said that the ongoing challenges in defining and classifying mental disorder may be attributed to variations in emphasis on phenomenology, aetiology and course of the disorder (American Psychiatric Association, 2000). That is, the individuals experience and perception contributes to defining the problem. Mental health crises cannot be entirely defined by external description. It is important to be mindful that people experiencing a mental health

crisis may not have, and may never develop a defined or classified mental disorder. There is no one definition of what constitutes a mental health crisis and for this study; the definition comes from the person themselves and their experience.

The consumer experience in health care has become highly important in service planning and development, and it has provided us with opportunity to expand our understanding of healthcare delivery from definitions and processes toward meaningful experience. Organisations vested in health care innovation have adopted this very important aspect in order to address service delivery from the patient perspective: The Picker Institute, founded in 1994, is a US-based organisation well known for their extensive research of patient experiences and patient-centred care (Picker Institute, 2011). In Australia, the Australian Resource Centre for Healthcare Innovations (ARCHI) has adopted the Patient and Carer Experience project as part of NSW Health's Clinical Services Redesign Program (ARCHI, 2011). In mental health care in NSW, consumer involvement is highlighted in major changes brought about by the NSW Mental Health Act (2007) where the rights of consumers and their carers to be involved in treatment have been specifically outlined (Mental Health Drug & Alcohol Office, 2010). Consumer participation in policy, planning and treatment is cited as the 'hallmark of a quality mental health system' (Australian Health Ministers, 2003). Here, and after the reviews of the First and Second National Mental Health Plan, consumers have been fully recognised as having expertise and a unique understanding because of their experiences.

With this research activity, patients who have experienced a mental health crisis will be given the opportunity to describe what they felt, saw and heard; how staff engaged with them, whether they were involved in decisions about their care, how they made their choices during their journey through the emergency department and what that felt like and meant to them. The study was undertaken within the Southern NSW Local Health District.

There are twelve emergency departments in various localities of Southern NSW LHD. The localities chosen included Goulburn, Queanbeyan, Yass and Crookwell. According to the levels of emergency medicine in public hospitals in NSW, these localities include hospitals with one emergency department at level 4, one at level 3 and two at level 2 (NSW Health Department, 2002). The acuity and capacity for these EDs is described as being from small hospitals generally dealing with minor injury and ailment with access to mental health resources (level 2) to purpose designed EDs that can manage most emergencies and have access to 24hour on-call liaison psychiatry (level 4) (NSW Health Department, 2002).

Aim and expected outcomes of the study

This project intended to explore and understand the experiences of adults who are accessing care in an emergency department for mental health crises. This research question was generated from discussions and reflective practice that considered increasing the body of knowledge and enhancing understanding with regard to this specific experience; the movement towards consumer involvement in health care service planning and delivery; and the impact upon EDs of general hospitals are being used as a portal to access mental health care for crises.

It was expected that this project would ascertain any implications for clinical practice and service planning and that such diverse and rich descriptions of patient experiences could complement current training and education packages provided to general hospital staff about mental health crises in the emergency department.

Ethics

The ethical aspects of this research were reviewed and approved by the Greater Western Human Research Ethics Committee of the Western NSW Local Health District (Reference HREC/12/GWAHS/68).

Literature Review

Gaps exist in the literature about this particular kind of experience. A search of Embase, CINAHL, ProQuest, PsychINFO and Medline databases was conducted between August to October 2011. The search was limited to English only texts. Key search terms were: *mental health or mental health services, mental disorders or psychiatric patients or psychiatric symptoms, hospitals and emergency services, client satisfaction or client attitudes.*

There were a small number of research articles examining patient satisfaction with a particular mental health care service in emergency departments. These types of studies use a mix of survey and open questions about a very specific service. These studies are limited to reporting on a specific psychiatric emergency service and do not explore the broader issues about attending a general emergency department in crisis. Little to no results returned for explorations of the experience of such patients.

There are significant differences between patient satisfaction and the patient experience with regard to healthcare service provision. The evaluation of patient satisfaction tends to elicit responses based on structured surveys designed with a specific agenda and have a more scientific approach. The limitations noted in the literature (Wilcock et al., 2003; Coulter, Fitzpatrick and Cornwell, 2009) include questions being set by the service provider which can indicate potential biases; questions restricted to a particular service; results are typically used to justify continuation of a service rather than inform improvements in care and patients are not usually aware of specific standards that a service should be meeting. The patient experience inclines to be a narrative that gives a richer understanding of healthcare by including information about 'gaps' that exist in the journey from admission to discharge (ARCHI, 2011, Coulter, Fitzpatrick & Cornwell, 2009). The patient story tells us what actually happened in their words rather than rating what happened.

A Canadian study used focus groups with mental health patients to determine satisfaction with care received in a regional emergency department (Clarke, Dusome and Hughes; 2007). This paper while capturing the system issues pertinent to the patient group, like ED waiting times; was limited in reporting the deeper experience of the patient. It also emphasised the evaluation of the role of the psychiatric emergency nurse. One of the three questions used to facilitate the focus groups asked patients – “What was missing from the range of emergency psychiatric services?” While this question is directly aimed at evaluation, it assumes that for those patient’s something was missing – prompting discussion on services and issues rather than experience.

Similarly, O’Regan and Ryan (2009) measured satisfaction of a specific emergency service using a survey and included qualitative data to obtain a more ‘in-depth view from the patient’s perspective’. This data analysis resulted in findings about factors that led to patient’s being dissatisfied with the service and so was limited to procedural issues rather than an exploration of the personal experience.

Two studies have used telephone interviews to rate patient satisfaction with a mental health service provided in emergency departments (Summers and Happell, 2003; Wand and Scheaken, 2006). In an analysis of qualitative data that was obtained in the study by Summers and Happell, some patients briefly described their experience: “felt imprisoned”, “positive experience”, “she didn’t talk about my problems”. These were grouped into themes at this stage. Further exploration of those experiences could provide further insights and context; for example, “feeling imprisoned” could be related to being in a small room in the ED. The use of mental health legislation to invoke involuntary status or use of seclusion may also be the reason behind the expression of that description. Furthermore the patient may have felt the limitations to confidentiality in an emergency department and felt unable to express concerns openly. These qualitative themes are important aspects of satisfaction surveys however in this study, it was unclear what “feeling imprisoned” was about. For in-depth exploration, phone interviews could also be limiting to the range of additional

data available including participant's emotional expression and engagement with the researcher during the interview.

The research process

This qualitative study was conducted using a phenomenological approach whereby participants are able to reflect upon their experience and provide their meaning to that experience. A target population was identified as people aged 18 years or over who have accessed a regional and rural emergency department in Southern NSW Local Health District for the purpose of seeking assistance for a mental health crisis. Exclusion criteria were considered in order for participants to be able to give informed consent to participate; participants should not be currently considered an Involuntary status under the NSW Mental Health Act 2007 (i.e. not currently detained in a declared mental health facility; not currently treated under a Community Treatment Order). Potential participants were invited to join the study through local newspaper advertisements including an article outlining discussion about the research (Appendix 1 and 2). This is a 'typical case sampling' strategy that, as a form of purposive sampling is consistent with phenomenological methodologies (Patton, 2002).

The approved media strategy discussed with the appropriate Media Affairs Officer was to submit the advertisement and media release to four identified local newspapers. The choice of publications within localities within the Southern NSW Local Health District geographical region was based on including experiences of visits to emergency departments of differing sizes and acuity.

Two participants contacted the principal researcher in response to the advertisement. The first participant contacted by phone. The second participant made contact by email. The participants were asked if information about the study could be mailed or emailed to them and permission was granted for the researcher to make a follow-up phone call as with the 'Phone Contact Guidelines' (Appendix 3). Participant information sheets (Appendix 4) and consent forms (Appendix 5) were emailed to each potential participant. The researcher initiated second contact by phone one week

later to confirm receipt of the information, address any questions expressed and confirm a wish to be included in the study. At this contact, once willingness to participate was established, mutually agreed locations where the interviews could take place were decided. At both the interviews, participants brought their signed consent form to the interview and this was confirmed prior to commencing.

Unstructured in-depth interviews were conducted by the researcher and audio recorded. At both interviews, only the researcher and the participant were present in the room. For safety reasons, an identified person was made available at both locations for assistance should they be required. Assistance was neither requested by both participants nor required by the researcher at any time. Interviews were conducted in office settings, with the duration between 48-68 minutes. A guide to interviews (Appendix 6) was developed as part of the research protocol with introductory comments and prompts designed to discover deeper information and meaning. Reflective notes were also collected by researcher at the end of each interview.

No more participants

After receiving the two responses to advertisements within two weeks of the advertisement being circulated in one local newspaper (6th May 2013), there were no further responses received. The intention to interview between six to twelve participants was not able to be achieved. Guest, Bunce & Johnson (2005) concluded that theme identification was complete and stable after 12 interviews even after incorporating new data; and fewer interviews were required if the study aimed to find less specific, overarching themes. Data analysis commenced with verbatim data transcribed from the interviews. On preliminary analysis data saturation could not be attained with the two interviews conducted.

The plan for recruitment was not implemented as intended. A review of the media strategy in June 2013 concluded that as advertisements were not circulated as

planned, the visibility and circulation of the proposed research and invitation to participate were grossly limited. Only one advertisement in one newspaper was confirmed as being circulated. Being an employee of NSW Health with specific media policies and guidelines, the strategy required various levels of approval. This was met with support and without challenge and therefore did not hinder the initial process. As a media release was to accompany the advert, it was informed that payment would not be necessary. Attempts were made to contact the Media Affairs Officer to no avail. On the 24th June 2013, an email was received advising that this position had been vacated. Contact was made with the next incumbent in August 2013. A request to re-run the strategy as planned was made at this time and again the planned strategy was not carried out.

Shortly after, the principal researcher was notified of a successful appointment elsewhere that precluded further recruitment to the study. In discussions with the Health Education and Training Institute's Rural Research Program Officer a decision was made to discontinue the study as the researcher could no longer access the intended target group. A final report would be submitted which detailed the research that was undertaken and the reflections of the researcher.

Whose experience? Reflections of the researcher

This research project was not able to satisfy the study aims. I have not been able to analyse and deeply understand what the specific experience was like for people going to an ED in a mental health crisis. I have not been able to convey this message to others. What this research did provide were valuable insights into my research experience and the challenges I faced as a novice researcher.

I applied to participate in the program because for the first time as a senior clinician, the call for applications initiated reflecting on my career and that I could build on the limited research skills and theory learnt during both my undergraduate and post-graduate studies. To effectively reveal the lessons learned on this project, it is

necessary to revisit my original application to the program. I had listed goals to increase my confidence with research through investigation of a key clinical question and that presenting the study and findings for peer review and presentation would enhance my current practice as a senior clinician. I also noted an interest in continuing study at PhD level as suggested by a lecturer during my Master's Degree award and that this program may give me skills, knowledge and confidence to work towards that. In addition to evaluating this project against my original goals, I found that I experienced a number of feelings and thoughts about the study itself. Of particular note was grappling with what I term 'ethical recruitment'. I was also very aware of not meeting the program milestones and in not concluding the study itself, I was confronted with very strong guilt.

As a researcher working in mental health emergency care at the time, I was in a position to access records in which to select 'information rich' cases and considered a mail-out approach as a recruitment strategy. Purposive sampling is by definition for a purpose, and selecting information rich cases is the recommended method for phenomenological studies (Patton, 2002). Questions stirred. Could I do this? Is this ethical? Health organisations are bound by privacy laws and regulations: we collect and use information for primary and secondary purposes and mail-outs are common in health research. To select, because of my position who I should mail invitations to didn't seem courteous in the least. From the beginning, I felt that persons who attended EDs for a mental health crisis would not be expecting to be mailed a letter inviting them to participate in research.

Furthermore, I questioned what makes one person's experience more valuable than another? How could the process give equal opportunity to many who have had this type of experience and minimise the possibility of perceived pressure to participate by direct recruitment? After lengthy soul searching and discussions with research mentors, I believed the recruitment strategy employed would be less confronting and truly give potential participants the power to choose to be a part of the study. This

strategy also meant that I didn't need to 'select' specific cases based on my interpretation of a 'rich' experience.

Unlike potential participants, much comment and advice from colleagues related to the strategy was forthcoming. "People with mental health problems won't read the newspaper." "You should have mailed invitations." "Why didn't you or your team recruit potential participants when they attended the ED?" "You should have advertised in community mental health centres." "That strategy with that population group was never going to work." Of note here is the assumption that people who attend an ED in mental health crisis must have some sort of mental disorder or illness that requires ongoing care and treatment. Indeed I had to respond to a similar assumption made by the ethics committee during the application process. People who attend EDs in mental health crisis do not necessarily become diagnosed with a mental illness or disorder. I was also left wondering if I had been given the opportunity to simply pay money for the advertisements from the small budget allocated to each researcher in the program, that at the very least the recruitment strategy would have been implemented as planned giving wider opportunity for potential participants to consider the invitation. I then received news of successful appointment to a more senior role in another LHD. On reflection, this news was somewhat bittersweet – I had a lot of loose ends to tie up.

It was becoming apparent to me that I was not meeting key objectives outlined early in the program. It was at this point I noted feelings of failure – I was failing to stick to the plan, I was failing those running the program and my colleagues and employer who supported me to participate. There was also defiance and then determination. A further decision had to be made. Do I abandon the program all together? To me, that was certainly the easy option. Two people had the interest and took the time to participate by telling stories of their experience in emergency departments when in crisis. I could not discount this and to me, opting to leave the program felt I lacked respect for this effort. While I could not use the data in the manner for which was planned, I could finish the program by writing this report. I could be open about the challenges experienced and my limitations as a novice researcher. I was also not

meeting my personal professional goals. I wanted to say I could lead a research project. I wanted to be able to bring more meaningful information to training and education delivered to nurses across the district. For the first time ever, I considered I may have a chance at being published in a peer review journal. And while I may not have achieved those goals, strangely I do feel more confident in my ability to 'do research'.

To be fair to the participants and the supporters of the project it is necessary to discuss the time this has taken. Time was grossly underestimated and I have always known this while not entirely aware of it. The time factor was always there. Time to produce the protocol, submit ethics, re-submit responses to questions raised, submit the site specific application, liaise with the media office, wait for advertisements to be printed, data collection, interview transcription and complete this report. The consequences of underestimating time have been conveyed well throughout the program at workshops, teleconferences and through mentorship. This is an element of research that I learned is also inherently linked to the researcher. Despite being in a holding pattern over factors out of my control, there are other intrinsic dynamics impacting on time management I am aware of but don't yet fully understand. When I think about the possibility of leading or engaging in future research projects, it feels as though I have a handle on this now through what I have learned about myself and the research process. I guess only time will tell.

Recommendations or lessons learnt?

Future research of this subject should be attended and consideration given to including in the protocol:

- a. A hierarchical range of alternate recruitment strategies specific to the subject matter and with regard to a willingness to participate, ability to give informed consent and that the individual's current mental status doesn't preclude their ability to understand the process and risks of the study.

- b. Formalised indicators for actions by departments not directly involved in the study though whose action or inaction will affect its progress need to be included in the project milestones.

A final note

Through the challenges of research and limitations of the researcher, a story about one thing transformed into lessons learned about another.

Personally I found this experience invigorating yet overwhelming; valuable yet a burden. I have increased my knowledge about general research, phenomenology, ethics applications and more so about the subject matter. I may not have been able to convey the message so that others who haven't experienced what it is like to go to an ED in mental health crisis may begin to see, feel, appreciate and understand it. However I, myself have learned about two of those experiences. It is hoped that others attempting research projects may take something away from this story. It is hoped that my intimate knowledge of two specific experiences will enhance my compassion and sensitivities to the needs of health care consumers, enhance advocacy and involving consumers in health service planning.

Of the struggles on the way, ethical dilemmas remain. It occurred to me in concluding, that this report has the ability to relieve me of the burden of this research project. There is a sense of finality. Only it's not quite the feeling I anticipated. On deeper reflection I find that I should probably not feel such relief. The original question remains unanswered. Theirs remains a story untold.

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Appendix 1: Research Advertisement Version 2

RESEARCH: Understanding what it's like to go to an emergency department for mental health problems.

We are looking for volunteers aged 18 years or over to take part in a study about going to an emergency department for care for a mental health problem.

Your participation would involve telling me about your experience at a confidential audio-recorded interview for approximately 1 hour.

In appreciation of your time, light refreshments will be available at the interview.

For more information about this study, or to volunteer to participate, please contact:

Kim Edwards, Clinical Nurse Consultant
Mental Health Emergency Care & Support Centre
Southern NSW Local Health District.
Ph.: 0408 677 063
Email: kim.edwards@gsahs.health.nsw.gov.au

To minimise any potential calling costs to you, a message can be left and the call will be returned to you at your convenience. Please suggest a suitable time to be called back when you leave a message. Alternatively, you may email me your interest.

The ethical aspects of the research have been reviewed and approved by the
Greater Western Human Research Ethics Committee (HREC)
Western NSW Local Health District
PO Box 143
Bathurst NSW 2795
Ph.: (02) 6339 5601

Appendix 2: Media Release Version 2

Friday 13th July, 2012

THE PATIENT PERSPECTIVE: RESEARCHING MENTAL HEALTH CARE IN EMERGENCY DEPARTMENTS.

It is important for health staff to understand what it is like for people in a mental health crisis to seek help from a hospital emergency department. Leading this research project is local nurse Kim Edwards. “We know what it is like as health workers providing care in emergency departments, but we don’t understand what it is like to be a person on the receiving end of that care” she said.

Our hospitals are working hard to provide patients with the best care. The focus on good mental health care includes encouraging people to access that care. We know that people experiencing mental health problems find it hard to seek help. Ms Edwards explains that “by conducting this kind of research, we can get deeper insights into the experience of getting help at an emergency department for a mental health problem and understand exactly where we can improve in order to make positive adjustments and respond in a way that is least distressing for people accessing that type of service”.

Ms Edwards said that other studies about mental health care in emergency departments have been about patient satisfaction or satisfaction with a specific kind of service. “With this project, we want to uncover and describe the nature of the experience for those patients and present the information in a way that those who haven’t experienced this may begin to see, feel, appreciate and understand it.”

The NSW Ministry of Health’s Health Education & Training Institute (HETI) together with Southern NSW Local Health District is supporting this research. Ms Edwards would like to interview people aged 18 years or older who have recently visited an emergency department in NSW for mental health concerns.

If you have had this type of experience and would like more information; or you are interested in participating in the research project, you are welcome to contact Ms Edwards by either phone or email:

0428 677 063

kim.edwards@gsahs.health.nsw.gov.au

To minimise any potential calling costs, a message can be left for a return call at a time convenient to you.

ends

FOLLOW-UP CONTACT GUIDELINES

Understanding what it's like to go to an emergency department for mental health problems.

To be used at the time potential participants make contact with the Researcher to join the study.

INITIAL CONTACT:

Call/email received – response below:

- Thanks for making contact about this research?
- Are you interested in participating in interviews?
- Can I mail/email out the PIS? (Note: If mail – include self-addressed stamped envelope for return)
 - If yes, can I confirm your mail/email address?
 - If no, would you like to go through this on the day of the interview?

Note responses and confirm choice to participate.

Participation confirmed: Can I call you in 1 week to see if the information arrived, and answer any questions you have?

FOLLOW-UP CONTACT:

Call / email placed – responses below:

- Introduction – HI, its Kim Edwards calling about joining the research that I am doing. Did you receive the patient information sheet?
 - If yes, were you able to have a chance to look over it?
 - If no, would you like to go through this now?

Note responses and confirm continued interest for continued NO responses.

- Will you be participating in the study?

For those who choose to withdrawal at this point, thank them for their time.

For those who would like to continue

- Would you like to make suitable arrangements for the interview now?
- Can I send a reminder text message / email the day before?

Text / email message reminder day before.

PARTICIPANT INFORMATION SHEET

Understanding what it's like to go to an emergency department for mental health problems.

I am doing research into understanding what it is like to go to an emergency department for a person who is seeking help for a mental health problem.

I am doing this research as part of my participation in the NSW Ministry of Health's Health, Education & Training Institute: Rural Research Capacity Building Project.

I am inviting people who have had this type of experience to join with this research project.

The study is being conducted by:

Kim Edwards, Clinical Nurse Consultant, Mental Health Emergency Care & Support Centre (Researcher)

Before you decide whether or not you wish to join 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 learn about and understand the experiences of adults who are accessing care in an emergency department for a mental health problem so that this new knowledge can be used in training and service planning in the future.

2. 'What does this study involve?'

You will be asked to:

- Participate in one audio-recorded anonymous interview at a mutually agreed place and time, and attended only by the researcher and yourself.
- The interview will take about one hour.

If you agree to join this study, you will be asked to sign the Participant Consent Form.

3. 'What if I want to withdraw later?'

- If you decide not to participate, it will not affect the treatment you receive from health services within Southern NSW Local Health District now or in the future. Whatever your decision, it will not affect how the staff care for you now or in the future.
- If you wish to withdraw from the study once it has started, you can do so up until your data has been de-identified and joined with other people's data.
- To maintain anonymity, the information you provide is not identified with your details. Once analysis commences, it is not possible to remove your information from the study results.
- If you withdraw from the study prior to the analysis, all information you provide will be destroyed and not included.

Appendix 4: Participant Information Sheet Version 2

- You do not have to provide a reason for deciding to withdraw from the study.

4. 'How is this study being paid for?'

The study is being guided by the Health Education and Training Institute (HETI) with support from the Southern NSW Local Health District.

This study is being done as part of the researcher's work for Southern NSW LHD.

5. 'Are there risks to me in taking part in this study?'

All research involves some risk to the participant.

The known risks of this study are:

- Becoming emotional when recalling your experience during the interview.
- You tell the researcher about serious illegal activity that the researcher is legally obliged to report
- You may receive negative attention from other's if they find out you have joined a research project
- You may be a patient of the researcher in the future.

If you have any further questions or if you are unsure, you are encouraged to contact the researcher to discuss this further.

7. 'What happens if I become upset or distressed during the interview?'

An appropriate professional support person will be made available at the time to help with any distress that may happen during the interview should you decide you would need it.

You are able to bring along a friend or support person to the interview although they will not be able to participate.

At the start of the interview, the researcher will go over the risks with you at which point you may choose to leave the study.

Your anonymity regarding participation is of the utmost importance and will not be breached by the researcher; or the professional support person if you ask for their help during the interview.

If in the unlikely event you need help in an emergency department in the future and the researcher is called to attend, you will be given an opportunity to decline and an alternative professional will be arranged at if you want it.

8. 'Will I benefit from the study?'

It is important for health professionals to understand what it is like from a consumer's perspective to access help for a mental health problem in an emergency department. With greater understanding the health service can improve planning services for these situations and also provide education for the staff who work there on what these experiences are like for consumers.

Appendix 4: Participant Information Sheet Version 2

Some people participating in this kind of research find that telling their story is beneficial however there may be no direct benefit to you.

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

Participation in this study will not cost you anything. You will not be paid to join this study.

The interview will include light refreshments for you.

10. 'What will happen to my taped information after it has been used?'

The information you provide during the interview will be stored separate to any identifying details. The digital recordings and separated identifying details will be stored on a password protected computer for 5 yrs. The typed transcripts and your consent form will be stored separately in a locked cabinet, in a locked room, in a locked building for 5 yrs. Both sets of information will be destroyed after 5 years.

Your personal information will not be used outside of this study.

11. 'How will my anonymity be protected?'

Only the researcher, and the professional support person, if you choose to use this service will know whether you are participating in this study. The audio-recorded interviews will only be heard by the researcher.

The professional support person is bound by the same confidentiality agreements pertaining to this study as set by NSW Health.

12. 'What happens with the results?'

We plan to discuss and publish the results with:

- Southern NSW Local Health District and the Health Education and Training Institute
- Professional research mentor
- Publication in a peer reviewed journal.

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

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

When you have read this information, the principal researcher Kim Edwards will discuss it with you and any queries you may have.

You are encouraged to ask questions or raise concerns at any time about the nature of the study or the methods being used.

Appendix 4: Participant Information Sheet Version 2

If you would like to know more at any stage, please do not hesitate to contact Kim on 0428 677 063 or by email: kim.edwards@gsahs.health.nsw.gov.au

To minimise any potential calling costs to you, a message can be left and the call can be returned to you at your convenience.

14: ‘Who can address any concerns or complaints I may have during the project?’

The ethical aspects of this research project have been reviewed and approved by the Greater Western Human Research Ethics Committee (HREC) of the Western & Far West NSW Local Health Districts.

If you have any concerns or complaints please contact:

The Executive Officer
Greater Western Human Research Ethics Committee
Western NSW Local Health District
PO Box 143
Bathurst NSW 2795

Ph.: (02) 6339 5601

PARTICIPANT CONSENT FORM

Understanding what it's like to go to an emergency department for mental health problems.

Thank you for agreeing to join this study.

This form is used to record your consent to join this study. By signing below, you understand the following:

- Participation in this study is voluntary
- Participation involves telling us your experience at an audio-recorded interview for about one hour at a mutually agreed place.
- You can withdrawal from the study until your data has been merged with other people's data.
- You are aware that the results will be discussed with Southern NSW Local Health District, the Health, Education & Training Institute and the Researcher's professional mentor. The results may be published in a peer-reviewed journal.
- The researcher must report any serious illegal activity that may be divulged during the research.
- By signing this you indicate that you have read and understand the full details and have considered the risks as outlined on the Participant Information Sheet.

I HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND AGREE TO PARTICIPATE IN THIS STUDY:

Participant Name: _____

Participant Signature: _____

Date: _____

GUIDE TO INTERVIEW

Understanding what it's like to go to an emergency department for mental health problems.

This guide has been adapted from the NSW Clinical Redesign Project "Collecting Patient Stories" available from the ARCHI website:
http://www.archi.net.au/resources/patientexperience/collect_stories

Introductory comments

- This study aims to improve the experience of patients.
- It is very important that I understand what your experience was like and how the systems work from the point of view of consumers.
- I am very grateful you have agreed to talk to me about your experience. Please be as honest and constructively critical as you can.
- I reassure you that we will protect your identity.
When I describe your experiences to colleagues, I will do it in a way that protects your identity. I will never reveal your name or where you come from.
- Would you like to ask me any questions before we get started?

Prompts only – not designed to be structured:

1. Please describe your experience of going to the emergency department to get help for a mental health problem from the beginning.

Prompts: What triggered the need to go to the ED?
What were the steps along the way?
What did you see, hear, and feel?

2. What were the best or most positive aspects of your experience?

Prompts: Was there any part of your experience that was particularly reassuring for you?
How did the situation affect you emotionally and physically?

3. What did not work so well for you during your health care?

Prompts: Was there anything you expected that did not happen?
What were you most concerned about?
How did the situation affect your emotionally and physically?
What was that like?