

COLLECTING PATIENT AND CARER STORIES

PARTICIPANT INFORMATION SHEET

Invitation

I would like to invite you to participate in a discussion as part of our project being undertaken by our Health Service to improve the patient and carer experience. This is an important project in which health systems are being redesigned to improve the experience of patients and their carers. We are interested in hearing about your experience so that we can identify ways to improve our service.

You have been randomly invited to participate in this discussion with representatives from NSW Health as you recently experienced the delivery of our health services.

Before you decide whether you wish to participate in this discussion, it is important for you to understand why we would like to speak with you 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 these discussions?

A priority in the NSW State Health Plan 2006-2010 is to “Create Better Experiences for People Using the Health System”.

The delivery of many health services in NSW are currently being reviewed using the terms of reference below. We would like to discuss your health care experience using the following:

- Access to care
- Respect for patients values, preferences, and expressed needs
- Coordination and integration of care
- Information and education
- Transition and continuity
- Physical comfort
- Emotional support and alleviation of fear and anxiety
- Involvement of family and friends

We are conducting interviews with a wide range of people who have recently received health services to understand better ways to improve our systems so that they meet the expectations listed above.

2. Why have I been invited to participate in a discussion?

You have been randomly invited to participate in a discussion as you have recently experienced the delivery of health services. Therefore, you can provide valuable feedback regarding health services which are currently being reviewed.

3. What if I don't want to take part in a discussion, or if I want to withdraw later?

Participation is entirely your choice. Whether or not you decide to participate, your decision will not disadvantage you in any way and will not affect your relationship with the hospital/community health centre, any health staff or any other aspect of your health care. If you decide to participate, you may withdraw your comments at any time without giving a reason.

4. What will a discussion involve?

If you agree to participate in a discussion, we will arrange a time that is convenient to you, to either meet in person or talk by phone. If you are willing to tell us about your experience, we will ask you to sign the Participant Consent Form.

We encourage you to have a family member or carer with you if you wish – someone who has supported you on your journey through the health care system and can also offer insights about the experience. This person will also be asked to sign the Participant Consent Form.

The discussion will take approximately one hour. We will not ask you detailed questions about your medical treatment or results – we want to know how the health system works and communicates information to you and how you (and your carer) feel about your experience.

5. Will taking part in the discussion cost me anything, and will I be paid?

You will not be paid to participate in the discussion. However, we will arrange all discussions at a time, date and location to suit you, so that you do not incur any expenses through participation.

6. How will my confidentiality be protected?

Any information that we collect about you in connection with this discussion will remain confidential, and will be disclosed only with your permission.

However, under exceptional circumstances we may be required to disclose information you have provided. This might occur where either:

- Disclosure is required by law. For example, if you were to advise us that you were the victim of a criminal act while you were receiving health services.
- If mandatory policy directives within NSW Health compel us to do so. For example, if you advise us of serious misconduct or negligence by a staff member.

While these circumstances are extremely rare, these provisions exist to ensure that all unsatisfactory conduct within the NSW health system receives appropriate attention.

In sharing your insights about the health system, we will remove or change any details which may identify you (e.g. names, where you live). We will also invite you and your carer to nominate an 'alias' so that references to the information you provide us will never identify you.

7. What happens with the results?

Your insights about your experience will be used in our reports and submitted to NSW Health. We also expect to present findings at professional conferences and on a website that is used by health professionals involved in redesign initiatives (www.archi.net.au). Publication in academic and professional journals may follow.

While we may talk about aspects of your experience, individual participants will not be identified in any reports, presentations or papers arising from the project.

You will also receive a written copy of your discussion with us to ensure that we have accurately captured your journey.

8. What should I do if I would like further information regarding this discussion before I decide to participate?

The name of the lead person who will meet with you is attached in the Participant Consent Form. Should you have any questions after reading this information, please contact this person in the first instance. Similarly, if you would like any further information, please do not hesitate to contact this person.

9. Who should I contact if I have concerns about the conduct of this discussion?

If your questions are not satisfactorily answered or if you have concerns prior to, during or after the interview, you can contact the following Health representative for this project:

{Insert Name}
{Insert Designation}
Phone:
Mobile:
E-mail:

Thank you for taking the time to consider sharing your experience within the NSW health system.

Should you wish to participate in an interview with us regarding your experience, please sign the attached Participant Consent Form.

This information sheet is for you to keep.