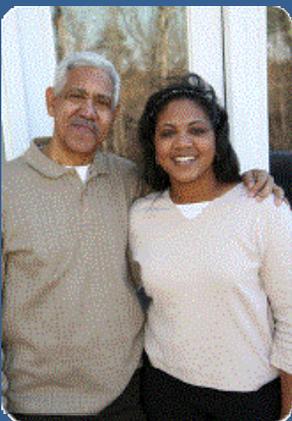


# Collecting Patient & Carer Stories

A Guide for Frontline Health Service Staff who wish to Understand and Improve Patient and Carer Experience

Updated February 2014



This guide is complemented by:

- E-learning module available at GEM
- Resources available at:

<http://www.archi.net.au/resources/patientexperience>





# Table of Contents

About this Guide .....	5
Acknowledgements.....	5
1. Introduction .....	6
1.1 Why should we talk to patients and carers? .....	6
1.2 Who is a “Carer”?.....	7
1.3 Do managers need to seek ethics approval to talk to patients and carers?.....	7
1.4 How do we go about talking to patients and carers?.....	8
1.5 How are patient rights to privacy protected?.....	9
1.6 Are patient satisfaction surveys useful? .....	9
2. Planning to Collect Stories .....	10
2.1 How do we define our sample? .....	10
2.2 How do we avoid bias in our sample? .....	10
2.3 How many patients and carers should we talk to?.....	11
2.4 How do we invite patients and carers to participate?.....	11
• For people in hospital .....	11
• For people who receive health care services in the Community.....	11
• Special advice regarding people with mental illness .....	12
2.5 Should we talk to patients and carers together?.....	12
2.6 Who should collect the stories?.....	12
3. Collecting the story .....	13
3.1 Introductions.....	13
3.2 Creating a suitable environment .....	13
3.3 Active listening.....	14
3.4 Verbal and non-verbal communication .....	14
3.5 Time allocation.....	14
3.6 Question style .....	15
3.7 Demonstrating empathy .....	15
3.8 Maintaining structure and direction.....	16
3.9 What to do when you encounter:.....	16

- Difficult/angry patients/carers.....**Error! Bookmark not defined.**
- Emotional patients/carers .....**Error! Bookmark not defined.**
- Overly Agreeable Patients/Carers..... 18

3.10 What if the person is dissatisfied with their care and wants to complain?..... 18

3.11 What if the person reveals adverse information, which requires a response?..... 18

3.12 Closing the discussion ..... 19

4. Analysing the stories ..... 20

4.1 What patients and carers value ..... 20

4.2 How can we analyse patient and carer stories? ..... 20

5. Service improvement..... 21

5.1 How can we find out whether or not we have improved patient and carer experience? ..... 21

5.2 What if the person we talk to wants feedback about the impact of their comments? ..... 21

6. Trouble Shooting..... 22

6.1 Debriefings ..... 22

6.2 What if the person we talk to raised other issues? ..... 22

6.3 What if a patient or carer changes their mind and wants to withdraw consent?..... 22

6.4 Practical Tips ..... 23

7. Contribute Your Patient and Carer Story to ARCHI..... 23

APPENDIX 1: Patient and Carer Story Collection ..... 23

## About this Guide

NSW Health aims to deliver better patient journeys by improving

- Access to care
- Safety
- Patient and carer experience

This guide provides advice and resources for health service Staff who wish to

- Collect patient and carer stories
- Understand the patient and carer experience
- Develop solutions for improving the experience.

The guide contains:

1. A summary step by step guide to collecting the stories of patients and carers
2. Answers to frequently asked questions
3. Resources to support the collection of patient and carer stories

For further information, please contact the Patient and Staff Experience Team at ACI at [pse@aci.health.nsw.gov.au](mailto:pse@aci.health.nsw.gov.au)

## Acknowledgements

This guide was updated from the previous version which was created in September 2008 by staff members at the NSW Ministry of Health.

# 1. Introduction

There is now a widespread realisation that patients' involvement in care improvement is not optional but essential to achieving high quality of care. Understanding the patients' perspective about their experience in the health services can offer great insight to the gaps in service delivery and ways to improve it.

NSW Health has developed a method of collecting and analysing stories about patient and carer experiences. **This method of enquiry can be used regularly by all staff members.** The method deliberately goes beyond questions of satisfaction, and explores patient and carer perceptions of their care and what they actually experienced.

When it is skillfully employed, the method enables staff members to:

- Understand what is currently working well and where patient and carer experience can be improved
- Collect "mobilising narratives" that help inspire health teams to improve their service.

The method involves discussions with a number of patients and carers of a particular service who have had recent contact with the service, e.g. within the past month. The method features:

- A lightly structured discussion using open questions;
- Discussions conducted in the patient and carer's own home or venue of their choice;
- Facilitation by suitably skilled staff

Patients and carers are informed about the intention to understand and improve their experience of the health service. They're invited to describe their recent health care experience, reflect on the most positive aspects of their experience and offer constructive criticism. They are reassured about the benefits their input will bring to improving the NSW Health system and the fact that their privacy will be carefully guarded. Their story is produced in their words, de-identified and validated by the storyteller.

This guide has been developed to support staff collecting patient and carer stories and includes links to practical tools and resources that complement the information herein.

## 1.1 Why should we talk to patients and carers?

Patients and carers are not only the "customers" who experience our services; they are often the only people with a perspective on their entire journey. Their experience is a product of our systems and processes and the way they interact. Patients have valuable insights on how well our systems are working and what we could do to improve.

There are many reasons for talking to carers about their experience supporting the patient. They can help provide a complete perspective of the journey because they are often responsible for imparting information to health care providers; making decisions; helping to navigate the patient through the journey; and providing care and support at home. If a patient is too unwell to participate in interactions with health care professionals, they sometimes (at least temporarily) leave this role to their carer.

Helping people to remain healthy at home often requires the active support of their carers. By listening to carers, we will discover ways of supporting them better, and therefore supporting patients better.

If you talk to a patient and their carer together, and listen carefully to what they both say, you are likely to obtain a very complete picture of their experience.

## 1.2 Who is a “Carer”?

In general, Carers Australia defines Carers as people who provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged. Carers can be parents, partners, brothers, sisters, friends or children. Some carers are eligible for government benefits while others are employed or have a private income.

However, for the purposes of this guide, the carer is the person or persons who supported the patient during their health care journey. In this context, the role of “carer” may be temporary – only until the patient recovers.

Carers are those involved in receiving information and helping the patient make decisions, and generally providing day to day support for the patient during their health care journey.

## 1.3 Do staff need to seek ethics approval to talk to patients and carers?

Contacting patients and carers for quality improvement purposes is accepted practice in health care. This guide outlines a way to collect the stories of patients and carers for service improvement purposes, and with due respect for the ethical principles of

- Avoiding undue pressure or coercion to take part
- Informed consent
- Privacy and confidentiality
- Providing a mechanism for withdrawing a story

The method outlined in this guide focuses on the patient and carer perceptions, experiences and feelings. It does not seek to discover confidential information about their medical condition, medical history, clinical treatment or clinical outcomes.

Ethics approval is required in situations in which people will be asked for confidential information about their condition, medical history, clinical treatment or clinical outcomes. For further information please see [NSW Health guideline document number: GL2007\\_020 -Human Research Ethics Committees - Quality Improvement & Ethical Review: A Practice Guide for NSW](#)

However for each health service it is recommended to follow the local ethics guidelines.

## 1.4 How do we go about talking to patients and carers?

This guide outlines a simple, practical method for collecting and analysing patient and carer stories. Essentially, the method involves holding discussions with a number of patients and carers and drawing out the most positive and negative aspects of their experience. In summary, the steps in the method are set out below:

Step by Step	Points to consider	Resources available to you on <a href="http://archi.net.au">archi.net.au</a>
1. Identify and invite individual patients and carers to participate	<ul style="list-style-type: none"> <li>Define target population.</li> <li>Invite them to take part</li> <li>Decide how many to talk to avoid bias</li> </ul>	<b>Sample:</b> Participant Invitation Letter
2. Set up the meetings	<ul style="list-style-type: none"> <li>Where to hold the discussion</li> <li>Who should attend</li> <li>How long it will take</li> </ul>	<b>Sample:</b> Participant Information Sheet
3. Facilitate the discussions	<ul style="list-style-type: none"> <li>Skills required</li> <li>Introductions</li> <li>Skilful listening and questioning</li> <li>What patients/carers value</li> <li>Ending the discussion</li> </ul>	<b>Sample:</b> Participant Consent form Story Collection Process What Patients and Carers Value Pie Chart
4. Record and analyse the stories of patients and carers	<ul style="list-style-type: none"> <li>How and where to record patient and carer insights</li> </ul>	What Patients and Carers Value Definitions
5. Present the results	<ul style="list-style-type: none"> <li>How to present Qualitative insights</li> <li>Compare with other data sources                             <ul style="list-style-type: none"> <li>➤ Patient Survey</li> <li>➤ Complaints &amp; Compliments/IIMS</li> <li>➤ Tagalong/ observations</li> </ul> </li> </ul>	Patient and Carer Story Record Analysis Spreadsheet Report Template
6. Use the knowledge: to improve patient and carer experience	<ul style="list-style-type: none"> <li>Target the most significant problems (as shown by data)</li> <li>Use insights to design solutions</li> <li>Who else needs to know/act?</li> <li>Discuss your solutions with patients and carers</li> </ul>	Step by step guide and resources at <a href="http://archi.net.au">archi.net.au</a>
7. Re-measure to see if your solutions worked		
8. Read the literature (optional)		

Some people ask if they should audiotape patient and carer discussions. While this has the advantage of improving transcription, it may also act as a barrier to open discussion and make the discussion too formal. Therefore, recording discussions is not generally recommended.

## 1.5 How are patient rights to privacy protected?

The confidentiality of patient and/or carer information is critical. In the first instance, discussions will only be undertaken with patients/carers who have provided informed consent after being provided with a formal invitation to participate, as well as a Participant Information Sheet and Participant Consent Form. These documents also provide further contact points within the Local Health Districts/Specialty Health Networks should the patient and/or carer have any questions or concerns.

At the beginning of the discussion, staff are encouraged to reiterate the purpose of the discussion and confirm the mechanisms to protect the confidentiality of the patient/ carer story. They can also answer any questions the participant may have, and ensure they understand and formally consent to participation.

Patient/carers are invited to nominate an 'alias' for use in their story. Example: John Smith nominates 'Fred' as his alias because that is his middle name.

## 1.6 Are patient satisfaction surveys useful?

### Yes

Patient satisfaction surveys are an extremely useful mechanism for eliciting information, particularly from large groups of people. They are often conducted annually. A good survey provides actionable data and free text comments from respondents.. Patient and carer stories can add richness to survey data and give insight into survey results.

Further comments on this subject are from the Picker Institute (<http://www.pickereurope.org> )

We can learn something from patient satisfaction studies, in particular about specific likes and dislikes, but we cannot be sure that they capture the most pertinent or salient issues from the patient/public point of view.

Health care providers in Europe and the USA have been measuring patient satisfaction for many years, but often these surveys have been conceptually flawed and methodologically weak. They have tended to focus on managers' or clinicians' agendas rather than on the topics which are most important to patients and they are frequently too 'broad brush' to produce actionable results. The complexities of modern health care and the diversity of patients' expectations and experiences cannot be reliably evaluated by asking global rating questions such as "How satisfied were you with your care in hospital X?" nor by focusing solely on food and amenities while ignoring patients' concerns about their illness and clinical care. Typically such surveys elicit overwhelmingly positive ratings that do not reflect reported experience. Patient satisfaction surveys have often been used simply as marketing tools, with providers making claims on the basis of poorly designed and badly conducted surveys that "95% of our patients are satisfied". More rigorous methods are required if quality improvement efforts are to become truly patient-centred.

The critiques of patient satisfaction surveys have led to a new emphasis on measuring patients' experience rather than satisfaction. Instead of asking patients to rate their care on a Likert scale (e.g. excellent, very good, good, fair, poor), they are asked to report in detail on their experience of a particular provider at a specific point in time by responding to questions about whether or not certain processes or events occurred during the course of a specific episode of care. Responses to these types of questions are intended to be factual rather than evaluative.

## 2. Planning to Collect Stories

This section provides practical information regarding how to effectively plan patient and/or carer discussions including identification of your target group, inviting participation and selecting a facilitator.

### 2.1 How do we define our sample?

It is important to define your target population according to the service or patient journey you are aiming to improve and target a group of people who experienced the service recently (ideally within one month).

For example:

#### **Goal: Improve Patient Flow**

Talk to patients who met the following criteria at X Hospital within the previous 4 weeks:

- Admitted via the Emergency Department;
- Transferred to an Inpatient ward; and
- Stayed more than 24 hours
- Transferred home

#### **Goal: Improve Cardiology Experience**

- Talk to Cardiology patients who, within the previous 4 weeks, were:
- Treated within the Emergency Department at x hospital for chest pain
- Experienced booked cardiology treatment at x hospital.

#### **Goal: Improve Community Mental Health Services**

Talk to clients who were visited at home by the X Community Mental Health team within the last 30 days.

### 2.2 How do we avoid bias in our sample?

The logistics of organising discussions are usually complex. People may not be available when you call; may not return your calls; or other more subtle obstacles can get in the way.

You may be tempted to schedule the 'easiest' discussions and leave out patients or carers with whom communication is more difficult. For example, you might find it "easier" to approach and organise discussions with non-working adults living independently; people who can hear well; those who quickly understand the objectives of the program; those who seem confident about participating; and people for whom English is a first language.

However, if we only talk to these people, we will not get a fair picture of patient and carer experience.

Some patients may wish to take part in a discussion, but may particularly need the involvement of a carer for example:

- People with developmental disabilities;
- Young people;
- Older people with hearing impairment or another communication difficulty.

Similarly, challenges may be experienced scheduling discussions with:

- People who work full time may only be available to talk after hours.
- People residing within aged care facilities
- People from a culturally and linguistically diverse background. Enlist the help of your local interpreter service for such discussions. They usually charge a very modest fee.

It is important that you try to overcome the barriers to including different types of people. To ensure the integrity of this method, any implicit or explicit bias in your sample should be noted.

### 2.3 How many patients and carers should we talk to?

This is a qualitative analysis technique, involving collecting the stories of a random sample of patients and carers who have experienced a particular patient journey within the past month. At some point you will reach 'saturation point' when the same themes emerge repeatedly and it is not necessary to collect more stories.

It is impossible to predict when you will reach this 'saturation point', so there is no 'right' number. However, our experience suggests that you collect at least 10 different patient and/or carer stories before you begin a service improvement project and the same number after implementation.

If after 10 stories no obvious themes emerge or unable to identify the top 3 positive and negative dimensions from the eight dimensions, it would be advisable to capture additional patient and carer stories.

This method does not provide statistically valid data. What it will do is provide both data and qualitative insights, which will enable service managers to meaningfully evaluate the positive and negative aspects of patient and/or carer experience and consider solutions accordingly.

This method may also be complemented by other data for example:

- Patient survey
- Compliments and complaints
- IIMS data
- Observation and tagalongs

### 2.4 How do we invite patients and carers to participate?

There are many strategies for inviting patients and carers to participate in a discussion. The following strategies take patient privacy matters into account.

#### • For people in hospital

Visit patients in hospital with some information about your service improvement project and invite the patient and carer to arrange a time to talk to you after they return home. Include a check box on the Referral for Admission form – patients can advise whether or not they are willing to be contacted when they return home. Gain the support of nurses who actually admit patients to hospital. Ask for their help for, say, one week. Ask them to briefly explain your project and encourage participation from every person admitted for that week. The nurse can note this on the Referral for Admission form. Provide an 'invitation to participate' and Participant Information Sheet to every patient and/or their carer for a specific period of time. Follow up by phone.

#### • For people who receive health care services in the Community

Select a random sample of clients and send an invitation letter asking if they and their carer would be willing to talk about their experience. Follow up by phone. Ask Community Health workers to talk to every client they visit for a period of one week and provide you with the names of people who agree to take part. Contact the local support group and ask if you can attend a meeting to tell people about the project and invite individuals to take part in discussions.

- **Special advice regarding people with mental illness**

To ensure the patient's wellbeing is taken into consideration asks the Mental Health Service to provide a risk assessment on the patients in your sample. Participation of the carer in the discussion maybe particularly important-either together with the patient or separately.

Engaging people known to the target group (such as Community and Support Workers) can also be helpful in facilitating access to individuals who may otherwise be difficult to speak with.

Once random samples of patients and/or carers have been identified, each can be contacted and formally invited to participate. At this time, they must be provided with the following (if they have not already received these):

- An invitation to participate
- A Participant Information Sheet
- A Participant Consent Form

Samples of these resources are available on the following location and can be tailored to your specific project:

[http://www.archi.net.au/resources/patientexperience/collect\\_stories](http://www.archi.net.au/resources/patientexperience/collect_stories)

It is preferable that the patient and/or carer sign and return a Participant Consent Form prior to the discussion. This minimises the risk that a patient and/or carer may decline to provide consent at the time of discussion and provides adequate time in which case any questions may be answered prior to the discussion. It is acknowledged that this will not always be possible.

## 2.5 Should we talk to patients and carers together?

There are advantages and disadvantages to talking to both the patient and carer together.

By talking to both, you often hear the complete story from both perspectives all at once. However, the relationship between the patient and carer may make it difficult for one or the other to be completely forthcoming. For example, carers may not be completely honest or provide adverse information about the journey for fear of upsetting the patient. Be guided by the preference of the patient and carer.

## 2.6 Who should collect the stories?

A skilled person who will make best use of this time-intensive technique. The objective is to obtain rich insights about our system and ideas about how to improve.

Choose a person who:

- Is both a good listener and skilful communicator (e.g. notices 'weak signals' and skillfully, gently invites the patient or carer to elaborate);
- Genuinely cares about improving patient and carer experience (authenticity shows);
- Engages people effectively;
- Is not biased toward the information that may be received
- Will draw out patient and carer insights that will inform your project.

Ideally we recommend that you arrange for 2 people to attend each discussion. Having a second listener and recorder of responses helps to eliminate bias and capture pertinent information. It may also be helpful to consider having one clinical and one non-clinical person present as they will detect different signals and provide a complementary analysis of feedback.

*Please Note: To ensure safe practice, it is important to adhere to your local safety policy when visiting*

*patients and carers in their homes.*

## 3. Collecting the story

### 3.1 Introductions

It is essential that the first interaction between you and the patient and/or carer, is courteous and professional.

The following summary can be used as a guide:

- Please introduce yourself using full names, position titles and service. Wherever possible, business cards can be provided.
- Shake hands in an appropriate manner with the patient and/or carer.
- Ask the patient and/or carer what name they would like you to use for them, e.g. their first name only, title and surname, etc.
- Provide an overview of the specific project being undertaken within your Health Service and why you would like to collect this person's story.
- Clarify what the involvement of the patient and/or carer entails. I.e. Explain the valuable nature of information regarding their experience and how this information will be used as part of your project.
- Reiterate that all information provided by patients and carers will be de-identified prior to being used. Confirm that their identity will never be revealed.
- Explain that two people are present for the discussion in order that one can pay full attention to the patient and/or carer and the other can record notes. These will then be typed up and a copy forwarded to the patient and/or carer for their records and to validate its accuracy.
- Ask if the patient would like someone to sit in on the discussion (e.g. partner, family member, and carer). If they planned to have a carer with them for the discussion and the carer is not present, ask if they will be joining you and reinforce that they are welcome to do so.
- Ask the patient and/or carer to sign a Participant Consent Form if they have not already done so. All aspects of the Participant Consent Form should be explained. The patient and/or carer should have sufficient time and feel comfortable reading this prior to signing it. A Participant Information Sheet must be left with the patient and/or carer.
- The patient and/or carer should be asked if they have any questions before commencing the discussion.
- Explain what you would like to cover in the discussion and clarify the time allocation (i.e. usually a maximum of one hour).
- Explain what will happen to the information once you have finished with it. (storage / disposed)

### 3.2 Creating a suitable environment

It is essential that discussions are conducted at a time and location of the patient and/or carer's choice. Some patients/carers will prefer to participate in a discussion at their home or a neutral location, while others may like to hold the discussion at a facility (particularly if they need to return for treatment). Be flexible in your approach to scheduling discussions and sensitive to the preferences of the patient/carers for both discussion time and location.

No matter where the discussion is held, it is important to create a comfortable space for the patient/carers. Below are a few suggestions for creating an optimal physical environment in which the patient/carers will feel relaxed and comfortable in discussing their experience:

- Try to create an informal space with the patient and/or carer by minimising barriers between

you. E.g. If the discussion is taking place over a rectangular table, it is preferable to position yourself and participant around one corner in order that the table is not perceived as a barrier. Where several people are present, adopting a circular seating arrangement may be helpful.

- Create an equitable space by sitting at the same height as the patient and/or carer and avoid sitting either too close or too far away.
- Minimise noise and distractions and maximise privacy during the discussion. This may be simply achieved through closing a door when conducting the discussion in a patient and/or carer's home. In a facility, the preferred option is that a separate office is used for the discussion, also with a closed door for privacy. Alternately, drawing the curtains to create a private space around a patient and/or carer and controlling the volume of the discussion is a last resort within a facility.

*Turn off or silence your phone*

### 3.3 Active listening

To demonstrate that you are actively listening to the patient and/or carer use the following strategies:

- Face the person;
- Maintain eye contact;
- Nod your head to acknowledge information;
- Allow the participant to provide information without interrupting;
- Use short silences to enable participants to gather their thoughts without feeling pressured;
- Paraphrase information the participant provides in your own words to ensure you have clearly understood it.
- Encourage participants to elaborate on key information by 'mirroring'. E.g. If a patient says "I was worried about that", you could respond inquisitively with "worried? can you tell me more about being worried?" You should always attempt to identify key words or phrases with unclear implications or emotional content, and explore these further.
- Expect to talk for less than 10% of the time. Once the story is underway let the patient do the talking.

### 3.4 Verbal and non-verbal communication

All verbal communication with participants should occur in a clear and audible tone of voice. Try to adopt the same tone, pitch and pace to that of the participant. You need to be particularly alert to identify whether a participant is experiencing difficulty hearing, e.g. older persons or people who may require the use of a hearing aid.

Avoid using technical language or jargon unless it is adequately explained and adopt language which is tailored to the patient and/or carer.

Non-verbal communication sends messages which are equally as strong as verbal communication. Therefore, it is important that you are aware of any cultural, sexual and individual differences which may exist and any personal habits or tensions which may affect your non-verbal communication.

The following may be used as a guide to inform non-verbal communication:

- S** Sit facing the participant as this indicates your active involvement and interest
- O** Open and friendly, posture and body language
- L** Lean towards the participant a little when speaking and listening to show interest
- E** Maintain regular eye contact; don't stare or look away
- R** Relax and smile appropriately

### 3.5 Time allocation

Patients and carers will not open up to people who are perceived to be too busy to listen. So allow

sufficient time and ensure that your body language indicates that you are keen to listen and value what the patient and/or carer has to say. Discussions will take approximately one hour, and though some discussions may take less than an hour, some may take longer.

Ensure that you have allowed sufficient time for the discussion. It is important that you are able to complete a discussion which has been started. Similarly, if a patient and/or carer are upset after they tell you their story, remain with them until they are feeling better or until someone can stay with them (e.g. a neighbour or family member).

### 3.6 Question style

Though discussions are lightly structured, and a framework for discussions has been proposed, you can tailor the discussion framework to suit your needs, remembering our goal is to find out what matters to patients. Be aware of the different styles of discussion questions available.

#### *Open questions*

Open questions provide a lot of scope and encouragement to participants to provide information in their own way and at their own pace. They usually begin with 'how' or 'what', e.g. 'What was it like when you went into the ward'? The defining feature of open questions is that they cannot be answered with a 'yes' or 'no'.

Open questions are particularly useful for opening a topic, encouraging elaboration on a topic, changing to a new topic or gathering information on a sensitive or personal topic. You will note that the proposed discussion record utilises open questions to derive the maximum amount of information from a participant perspective and follows the logical course of a conversation.

#### *Closed questions*

Unlike open questions, closed questions are used when specific information or clarification is required. They elicit concrete information, which is usually brief, and can be answered with a 'yes' or 'no'. Closed questions restrict the amount and nature of information a participant can provide in response. E.g. 'Would you have preferred that the doctor give you written materials'?

Open and closed questions both perform important and complementary roles. A discussion will generally commence with open questions; move into closed questions; change topics with an open question; followed by closed questions; but should always finish with an open question, such as "is there anything further you would like to add, or do you have any questions"? Where possible, open questions are preferable as they enable participants to direct the discussion and maximise opportunities to explore the information being supplied.

#### *Elaborating and clarifying questions*

Open and closed questions are supported by two further types of questions. *Elaborating questions* encourage the participant to tell you more about their experience. E.g. 'What happened next?' *Clarifying questions* get the participant to be more specific and expansive about certain aspects of their story. E.g. 'You said you were worried about that. What sort of things worried you?'

### 3.7 Demonstrating empathy

During the course of a discussion, a patient and/or carer may reveal overly positive or negative information, in response to which it is appropriate to demonstrate empathy.

Empathy is the process of observing the world from another person's perspective and accurately perceiving their feelings. Equally important is the ability to communicate this understanding back to the person. Effectively conveying empathy essentially means 'putting yourself in someone else's

shoes' or 'seeing the world from their point of view'. Empathy can be demonstrated in response to positive or negative situations.

Empathy is different to sympathy, in which you convey concern, sorrow or pity towards another person. Sympathy is essentially an expression of one's own feelings about another person's predicament.

Demonstrating empathy helps patients and carers feel that they are respected and understood and is reinforced by your non-verbal behaviour. It is therefore appropriate to demonstrate empathy throughout a discussion. In order to do this, it is essential that you have understood the core message provided. Try to use short, rather than long-winded responses and tailor your response to the tone of the patient or carer. When a patient or carer reveals something significant, you should always respond, and a failure to respond may send the wrong message.

When demonstrating empathy, there are several things you should not do, including:

- Using clichés, such as 'lots of people feel like that';
- Responding to information with a question, such as "how long did that feeling last";
- Providing advice and attempting to solve problems

An example of demonstrating empathy may be 'I hear that you became more and more angry because each time the surgeon made her ward rounds you were in the shower or off having a test'.

### 3.8 Maintaining structure and direction

It is helpful to think of a discussion as a formal structure with a beginning, middle and end. While it is important to give patients and carers the time they need, and responding appropriately to each individual situation, try to stick to the agenda as much as possible. It is also helpful to maintain a 'picture' of where you are in the discussion at any stage, where you need to go next and the time remaining. Below are several tips for maintaining structure and direction:

- If a patient and/or carer raises an issue which is relevant, but not at that stage of the discussion, note it down for discussion at a more appropriate time, you may like to say, can we come back to that and make sure you do so;
- If a patient raises an issue which is not relevant to the discussion, acknowledge the issue and ask them to raise it again after the formal part of the discussion is complete;
- Use questions to redirect the patient and/or carer back to the topic at hand, e.g. 'getting back to what happened in the Emergency Department ....'

### 3.9 What to do when you encounter:

#### a. Patients or carers who become angry or difficult

During the course of a discussion, a patient and/or carer may become angry. Indeed, some patients/carers may have agreed to participate in a discussion because of the anger they feel as a result of their experience with the health system. There are several types of difficult/angry emotions that you may encounter:

Withdrawn/secretive/vague	may limit information as a form of control
Critical/negative	feel that everything is wrong
Intimidating	may be highly sarcastic and use cutting language to illustrate their point
Sad	dwell on their experiences and make others feel guilty

When dealing with difficult/angry situations, it is important to remember that anger:

- Is a common and normal reaction.
- Often results from a loss of control and feelings of powerlessness.
- Can be justified and should be managed accordingly.

There are also several positive features of patient and/or carer anger:

- It signals an important problem which needs attention.
- It acts as a motivator to find solutions and bring about change.

There are several ways to identify when someone is angry, including:

- Raised voice/shouting
- Flushed face
- Wild gesticulations
- Angry words
- Rigid body
- Withdrawal from
- Sarcasm
- Dismissive comments
- Gritted teeth, clenched jaw

#### b. Patients and Carers who become emotionally distressed

Dealing with strong emotional responses can be extremely challenging. You the need to maintain a balance between calm professional detachment and becoming too involved, too distressed or expressing inappropriate emotion. An inappropriate emotional response can stop you thinking and acting clearly and takes the focus away from the patient and/or carer in distress. Similarly, patients and/or carers will not disclose emotional content to someone who is trying to avoid discussing such content.

Therefore, always ensure that your demeanour is as comfortable as possible in order that the participant will also be put at ease.

### Strategies for managing difficult situations

There are a range of strategies available for dealing with difficult situations

#### Do:

- Stay calm and take deep breaths.
- Acknowledge the emotion. Name it and recognise its origin.
- Focus on the issue. Take it seriously and pay full attention to what the patient is saying. Try to understand the source of their anger / distress.
- Acknowledge and explore the patients and/or carer's emotions. Make the patient and/or carer feel that you have heard what they have said and not judged them. E.g. 'I can see that you are very upset and I would like to find out more about what happened to make you feel that way'.
- Listen actively and maintain eye contact. Always listen without interrupting. You can then paraphrase the information supplied and ask clarifying questions.
- Identify the patients and/or carer's key concerns. E.g. 'Can I just check that I have heard you correctly ... you said that ...'
- Apologise if appropriate. E.g. 'I can see why you're upset and I would be too. I'm sorry that happened to you in hospital'.
- Move on to suggestions regarding how the problem can be overcome and the situation improved.
- Recognise if you have been hearing about a situation that requires further action / reporting and work with the patient / carer to support this process.

#### Don't:

- Take it personally as this is not about you. Patients and/or carers who appear difficult or angry are acting this way as their needs have not been met. Try to visualise angry comments going

through you as a messenger only.

- Get defensive. Don't challenge or criticise the patient and/or carer. It is more important that you try to understand the root cause of the anger.
- Get into an argument or yell back at a patient and/or carer.
- Be tempted to fix the problem before the patient and/or carer has finished talking.

#### c. Patients/Carers who seem overly agreeable

It is possible that some patients and/or carers may be too agreeable in a discussion. This may take the form of saying very little; providing only positive information; or providing information that they think you want to hear.

If you encounter a patient and/or carer who appears to be too agreeable, it may be helpful to follow the aforementioned suggestions regarding maintaining structure and direction. Other suggestions include:

- Re-focussing the patient and/or carer's attention on the discussion of negative as well as positive aspects of their journey and ways to improve this.
- Use normalisation statements to encourage a balanced discussion. E.g. 'some patients have said that they didn't have such an easy time when they came to hospital ... was that the case for you?'
- Explore subtle statements like: 'They are very busy....' Or 'I expect to wait' .....as they may contain deeper information
- Try asking what their carer, partner or relatives thought about what happened. E.g. 'Does your partner also agree that everything went well in hospital?'

### 3.10 What if the person is dissatisfied with their care and wants to complain?

First, you can reassure the person that by talking to you, they are providing direct input into a program that aims to fix the system problems they encountered and make sure that future patients and carers have more positive experiences.

Second, you can tell people they can phone or write to the manager of the service in which they experienced problems. If their complaint is about their entire journey, they can write to the Clinical Governance Unit of their Local Health District/Specialty Health Network.

Make sure you are aware of your Local Health Districts/Specialty Health Networks protocols for complaints handling before you embark on these discussions. You should also be able to provide patients and/or carers with relevant contact details at the time of a discussion should they wish to lodge a complaint.

### 3.11 What if the person reveals adverse information, which requires a response?

Under prescribed circumstances you may be required to disclose information provided by patients and/or carers in the context of a discussion, which would otherwise be confidential.

This might occur where:

- Disclosure is required by law. For example, if a patient and/or carer advised that they were the victim of a criminal act while receiving health services.
- Mandatory policy directives within NSW Health compel us to disclose information. For example, if a patient and/or carer divulged details 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. The Participant Information Sheet which is provided to all patients and/or carers clearly conveys this information.

If, after conducting discussion, you are unsure as to whether information provided in a patient/carer discussion should be disclosed, advice should be sought from your manager. The identity of the patient and/or carer, and the facility involved must remain confidential until a decision is reached regarding disclosure based on the nature of information supplied.

All staff have a responsibility to be aware of relevant policy directives, manuals and guidelines governing situations which may arise in a patient and/or carer discussion. These are available on the Ministry of Health Intranet and are accessible using the following link:

<http://www.health.nsw.gov.au/policies/pages/default.aspx>

As at February 2013, relevant NSW Health documentation includes, but is not limited to the following:

- Child Related Allegations, Charges and Convictions against Employees (PD2006\_025)
- Complaint or Concern about a Clinician – Principles for Action (PD2006\_007)
- Complaint Management Policy (PD2006\_073)
- Criminal Allegations, Charges and Convictions against Employees (PD2006\_026)
- Incident Management Policy (PD2014\_004)
- Code of Conduct - NSW Health (PD2012\_018)
- Privacy Manual (Version 2)- NSW Health (PD2005\_593)
- Reportable Incidents Definition under Section 20L of the Health Administration Act (PD2005\_634)

### 3.12 Closing the discussion

Prior to closing a discussion, it is important to summarise the key points covered and check to ensure that you have correctly understood what the patient/carer has said. After discussing their health care experience, patient/carers are invited to help categorise the positive and negative aspects of their journey using the NRC+PICKER eight dimensions in the pie chart below. Based on the frequency with which each of these are reported, we can make informed inferences about what is working well for patients and carers and what needs to be improved. A discussion should always conclude with 'is there anything else you would like to say about ....' and 'do you have any questions for us ....'?

It is also important to reiterate with the patient and/or carer:

- How their information will be used;
- They can withdraw their consent at anytime and their story will no longer be used;
- Contact details for both the Health Services and Ministry of Health should they have any questions or concerns about the discussion or use of their information;
- The alias that has been assigned to their story (and ensure that this has been recorded on their copy of the Participant Consent Form).

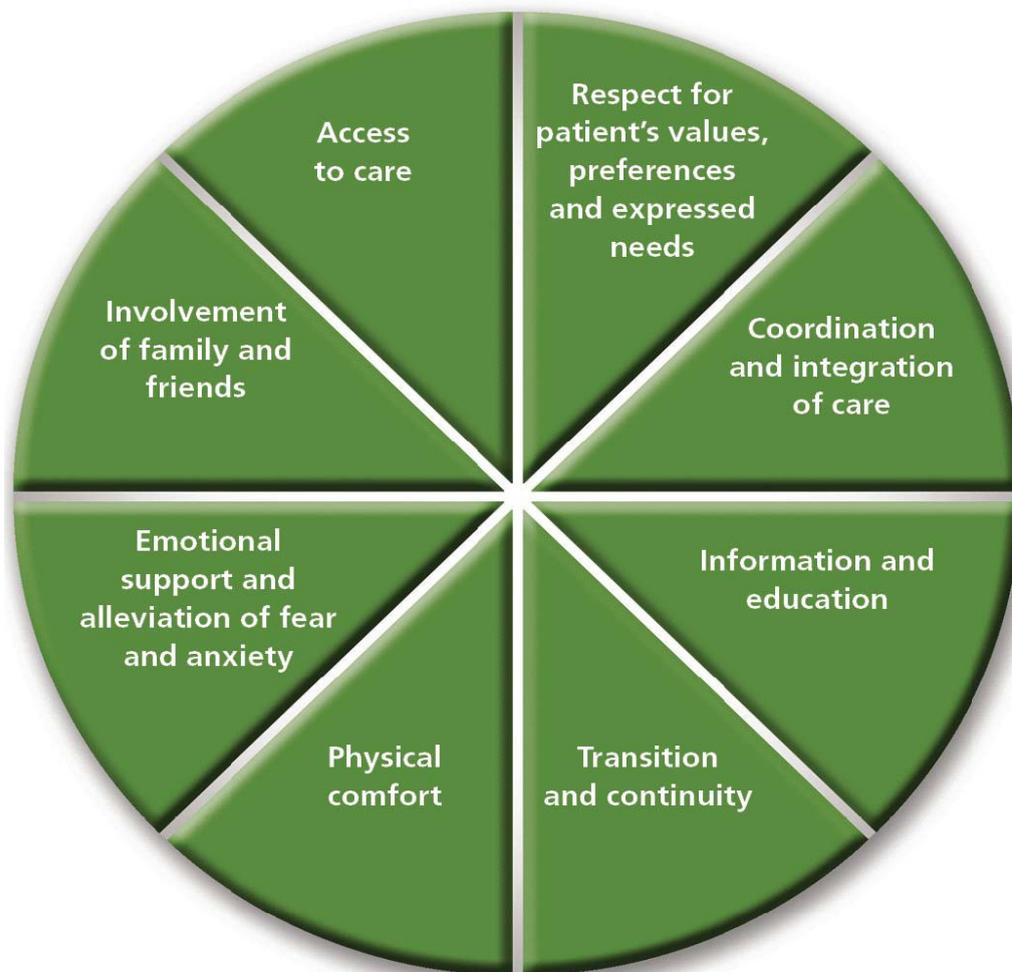
Let patient/carer know you will post a copy of their story for validation and allow time for them to add or edit the story if required.

Shake hands with the patient/carer prior to leaving and thank the patient/carer for their time and willingness to share their story.

## 4. Analysing the stories

### 4.1 What patients and carers value

Research from the NRC+Picker Institute show patients and carers value the following:



#### NRC+PICKER Dimensions of Care Valued by Patients

### 4.2 How can we analyse patient and carer stories?

The most significant positive and negative dimensions of care should be identified to assist in discerning the key positive and negative aspects of their journey. Most journeys include high points and low points, so patients and carers are encouraged to consider the aspects of the journey that were most important or had the greatest impact on them, and use these to identify the most positive and negative aspects of the journey as a whole.

You can use the information from the stories to identify areas for improvement as well as acknowledging the areas where you are doing well. This can be done using the spreadsheet available on ARCHI ([www.archi.net.au](http://www.archi.net.au)) which tallies the positive and negative aspects reported by patients and carers. The graphs generated from the spreadsheet will enable you to determine the positive

and negative dimensions of care.

We then identify the direct quotes from patients and carers that add richness to the analysis and describe how we could improve the systems and processes that affect the patient and carer experience.

These insights are then shared with our teams to assist in setting goals for improving patient and carer experience and informing the design of solutions.

## 5. Service improvement

Service Improvement is a rich topic in its own right, for more information in this area see ARCHI website, your Clinical Governance, Quality and Redesign Units as they may be able to help you.

### 5.1 How can we find out whether or not we have improved patient and carer experience?

By repeated measurement.

After the implementation of project solutions, it is recommended that you collect a similar number of stories from recent patients. If patients and carers no longer identify the same negative aspects of “what patients value” as the first group, this is arguably an indication that you have improved patient and carer experience on that issue.

If this seems too simple, consider the advice of Norman and Streiner in “Biostatistics – The Bare Essentials”

*“All this stuff about randomising folks to groups, although now de rigueur for medical research, goes against a lot of intuition. A much more natural experiment is to measure something, do something to make it better, and then measure it again.”*

Of course, other indicators like patient survey and complaints monitoring results can also be used

### 5.2 What if the person we talk to wants feedback about the impact of their comments?

It is likely that some patients and carers will want to know whether, and how, their input has affected the project. This is true of all of the people you engage in your project –clinicians, administration staff, patients and carers.

Accordingly, it is good practice to:

- Send the patient and/or carer a copy of their story in order that they may verify its content or add any information previously overlooked.
- Keep a database of everyone who participates in your project (including staff members, patients and carers, and other stakeholders) and invite them to a final presentation about the outcomes of the project. Several considerations associated with this are as follows:
  - Patients and/or carers to be asked if they would be interested in attending a presentation or would like further information on the project in the first instance.
  - Any information or invitation forwarded via e-mail should use the blind carbon copy (BCC) function to preserve patient and/or carer confidentiality.
  - Ensure that patients and/or carers are not introduced to other stakeholders as participants in a patient and/or carer discussion.

These strategies will maximise the involvement of patients and carers, but not inadvertently compromise their privacy where they choose to be involved in the project beyond a discussion.

Where patients and/or carers would like further information or involvement, send a copy of the final project report to patients and carers with a letter of thanks and explanation about the main outcomes of the project. Make sure the letter and/or report clearly explains key issues raised by patients and carers and summarises how patient and carer experience has been improved through the project.

## 6. Trouble Shooting

### 6.1 Debriefings

#### *Patient*

Be mindful that patients and/or carers may experience a range of emotions during the course of a discussion and remain emotional at its conclusion. Where this is the case, it is important that you:

- Don't leave until the patient and/or carer has calmed down and you are sure they are feeling comfortable.
- Ask if there is someone they would like to be with them after you leave (e.g. a carer, family member, friend, neighbour).
- Check on them via telephone later that day or early the next day.
- Where a patient and/or carer have been particularly distressed, follow up with them via telephone again.
- Where you suspect that a discussion has had an adverse effect on a patient and/or carer and they require additional support or assistance, you should bring this to the attention of your manager who will be able to recommend appropriate options.

#### *Team Member*

Just as patients/carers may experience a range of emotions during a discussion, it is important to be mindful of the effect that discussions have on them. It is therefore important to:

- Acknowledge your own emotional state, rather than trying to fight it.
- If discussions are likely to be/have been emotionally draining, spread out the timing of discussions and take turns as the leader of the discussion.
- Arrange for a suitable colleague or supervisor to be available for debriefings as required.
- Ensure that if emotionally laden material is raised in discussions, it is channelled into constructive criticism and feedback to health service managers.

### 6.2 What if the person we talk to raised other issues?

Patients and carers provide an enormous amount of valuable information during discussions and it is important that this information is not lost because it falls beyond the scope of your project. If a patient and/or carer reveal information which is beyond the scope of your area this information should be:

- Retained for consideration at a more appropriate time; and/or
- Forwarded to a more appropriate area/person for consideration.

In both of these instances, the patient and/or carer's confidentiality must be maintained. Staff are responsible for ensuring that information retained or provided to another person/area could in no way identify the patient and/or carer.

### 6.3 What if a patient or carer changes their mind and wants to withdraw consent?

There is a 'revocation of consent' section on the consent form to be signed and retained by patients and carers. If they change their mind about participating, they can simply sign it and send it in without having to explain their reasons. At the time of writing, the authors have not experienced any withdrawal.

## 6.4 Practical Tips

Practical tips when collecting stories:

- Take a clipboard to support you as you write (as you may be sitting on a lounge during the discussion).
- Take extra pens.
- Ask the participant if they have any pets and ensure it will be safe for staff to enter the participant's residence.
- To consider some staff maybe affected by cigarette smoke and pets when making arrangements.

## 7. Contribute Your Patient and Carer Story to ARCHI

ARCHI is hosting a patient story library to bring perspectives of patients and carers to Australian health professionals. Over time, we hope to find common themes and share this knowledge with the goal of helping to guide health system improvement.

No matter who you are or where you are from, you are welcome to contribute your patient/carer experience story using this form. The information you enter in the "Describe your experience" section will be published on our site. The information in the Details section is for our records only, and will not be published.

If you would like to contribute your patient and carer stories to the story library on ARCHI visit [http://www.archi.net.au/e-library/patientexperience/story\\_builder](http://www.archi.net.au/e-library/patientexperience/story_builder)

## APPENDIX 1: Patient and Carer Story Collection Resources

The following resources have been designed to support your personal contact with patients and carers:

1. Sample invitation to participate in a discussion
2. Participant Consent Form
3. Participant Information Sheet
4. Story Collection Form
5. What Patients Value – Patient Centred Dimensions of care
6. Analysis Spreadsheet
7. Discussion Flow Chart

These resources are available as both Word and PDF documents on [ARCHI website](http://www.archi.net.au/resources/patientexperience/collect_stories) on the following link: [http://www.archi.net.au/resources/patientexperience/collect\\_stories](http://www.archi.net.au/resources/patientexperience/collect_stories)

For further information or clarification please email the Patient & Staff Experience Team at ACI on [pse@aci.health.nsw.gov.au](mailto:pse@aci.health.nsw.gov.au)