Patient Stories

A toolkit for collecting and using patient stories for service improvement in WA Health

October 2008
Introduction

What are ‘Patient Stories’?

Service improvement and innovation activities aim to enhance health services so patients move smoothly though a coordinated system to ensure they receive high quality care. This involves looking at different ways to organise services around the needs and preferences of patients, rather then the needs and preferences of services. The end result will be to ultimately enhance the patient experience by improving the delivery, quality and flow of care, by reducing delays to the patient’s journey and by improving access across key areas of the public health service.

Patient Stories involves interviewing patients directly to gather their insights on the service they have received either as part of a particular service redesign project, or to complement WA Health’s broader program of service improvement. Although satisfaction surveys have been collated and analysed for more than 10 years by WA Health (through the Patient Evaluation of Health Services), Patient Stories build on the survey information by allowing patients to give the qualitative insights needed for service improvement projects.

Collecting Patient Stories is an important component in understanding how patients’ perceived the health care they have received in the WA Health system and how we can improve on the many different aspects of service delivery in our hospitals, and in our community-based health care programs.

How to use this toolkit

This toolkit has been produced to assist WA Health staff to collect Patient Stories for the purpose of improving services provided by the WA health system to ensure that key insights from patients are captured and used to inform service improvement projects and programs.

This toolkit includes:

- Part A: How to use Patient Stories for service improvement
- Part B: How to collect and use your own Patient Stories
- Part C: How you can share Patient Stories across the system
- Part D: Templates and additional resources

If you require further assistance or information on Patient Stories, please contact the Health Reform Implementation Taskforce at hrit@health.wa.gov.au
Part A: How to use Patient Stories for service improvement

To examine the patient journey

The metropolitan Area Health Services are already coordinating a number of service improvement initiatives (such as those underway through the Clinical Service Redesign Program), that take into account the patient journey. This includes redesigning and improving care according to patients’ needs, where every step in the patient journey will be examined and improved.

Clinical service redesign involves using methods such as LEAN Thinking, constraint theory and 6 Sigma to foster continued quality improvement. In these projects, Patient Stories have been used as a means of data collection, either to identify or verify the problems and issues discovered through the service redesign process.

To understand the patient experience

Patient Stories may also be collected across the system for the purpose of understanding patients’ feelings as they navigate the system, rather than examining one aspect of their journey. They can provide valuable insights on how we can improve on many different aspects of service delivery and care in our hospitals and in our community-based health care programs. Patient Stories assist staff in improving the experience for patients and can assist staff through education and reflection.

These Patient Stories can also provide insights into what happens between episodes of clinical care, such as time waiting at home for an appointment or time spent recovering on a ward. During these times patients can develop strong perceptions of the health system, the interactions (or lack of interactions) between the patient and health care staff.

To monitor service improvements

Patient Stories may also be collected over time following the implementation of a particular improvement to a service. Interviewing patients at this time may support an audit of the impact the changes have made to the patients’ journey or experience, and where the improvements have been sustained over a period of time.

Patient Stories may also be used as a means of benefits realisation, to promote the achievements of the service improvement activity using tangible evidence from the stories provided by the patients’ themselves. Sharing the lessons learned and the processes for successful implementation of improvements is a valuable way of spreading the learnings throughout the organisation.
Part B: How to collect and use your own Patient Stories

How can I collect and use Patient Stories for my project/program?

Patient Stories should be collected as part of a service improvement project to gain the most value from the experience. Once the aims of the service improvement project are clear, you will need to determine how collecting patient stories will enhance the project and ultimately provide the best outcome for the patient.

Patient Stories can then be collected in the health care environment or once patients have returned to their residence after treatment. Interviews can be conducted face-to-face, over the phone, in a focus group situation, and can be audio or hand recorded by the collector.

Patients talk about what they felt, saw, hear, the emotions that were evoked and how this affected their experience within the WA health system. These insights are an important component in understanding how we can improve on many different aspects of service delivery and care in our hospitals and in our community based health care programs.

Once the stories have been analysed, it is important to use the data to action the service improvement. Equally, it is important to share the information and lessons you have learned through the process across the system to assist other service improvement projects occurring in WA Health.

Suggested steps

Once you have defined the aims of your service improvement project you can determine the kind of patient you wish to involve in the collection of Patient Stories.

<table>
<thead>
<tr>
<th>Identify patients to participate</th>
<th>▪ Current patients/clients</th>
<th>▪ Approach while in care with information and request to interview</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>▪ Recent patients/clients</td>
<td>▪ Send a letter with information</td>
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<td>▪ Follow up with a phone call</td>
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<td>▪ Invite to focus group session, interview over the phone or arrange on-to-one interview</td>
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# WA Health’s Patient Stories

## Select random samples
- Contact local support groups
- Attend meetings to tell people about the project and invite people to participate

## Decide on interview method
- Face to face
- Telephone
- Focus group
- Written responses
- Recorded - audio
- Recorded - video
- Written responses
- Recorded responses
- Recorded - audio
- Recorded - video

## Use resources and templates
- Patient information sheets
- Consent forms (see note below)
- Information on why stories are being collected and how they will be used

## Interview prompts
- Write scripted questions
- Lightly structure questions
- Create interview prompts
- Have them rate aspects of the service delivery
- Ask them to relate their recent healthcare experience
- Ask for comment on best or worst aspects of care
- Ask for suggestions for improvement

## Analyse
- Transcribe story
- Identify issues for improvement
- Create solutions
- Look at themes
- Target main issues
- Measure improvements

## Share Knowledge
- Work out who else would benefit from the information
- Share lessons learned

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**NOTE:** There may be exceptional circumstances where staff would be required to disclose information about the patient. This might occur where:

- Disclosure is required by law. For example, if patients advised that they were the victim of a criminal act while they were receiving health services.
- If mandatory policy directives with WA Health compel staff to do so. For example, if a patient advised staff 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 WA health system receives appropriate attention. Staff should be aware of the processes for complaints for their individual work units, if required.
Part C: How you can share Patient Stories

Not all WA Health staff trying to improve care processes will have the access, skills, time and ability to run patient focus groups, undertake telephone surveys or interview patient groups. It is important, therefore, to ensure that the stories that are collected are shared around the system, to ensure knowledge, learnings and solutions are transferred across sites experiencing similar issues.

If you have already conducted (or you are planning to conduct) interviews with patients for a service redesign project or as part of data collection for service improvement, please consider sharing these stories across the system. Stories may be submitted in the form of written transcripts, digital recordings, or patient surveys where qualitative comments have been provided.

These submissions will be added to the Patient Stories database for WA Health staff to access via the website www.health.wa.gov.au/hrit/patientstories. If patient insights have been used specifically to inform a solution to a redesign or improvement project, please also indicate what the insights were, how the solution was developed, and how the solution was implemented.

All submissions of Patient Stories and information on solutions developed as a result of patient stories can be emailed to: hrit@health.wa.gov.au. All Patient Stories submitted for inclusion on the Patient Stories webpage must obtain consent from patients, and must use an ‘alias’ to protect patients’ rights. Refer to Section D for links to examples and suggested templates for patient consent forms that you may choose to use.

How can I use a Patient Story from the database?

If you have identified a particular patient story on the website that you feel will be relevant to your area of work or service improvement project you may download the transcript or sound file, providing that:

1. The story is not altered or modified in any way to ensure the integrity of the story is maintained.
2. That the project team that provided the patient story is acknowledged if the story is disseminated widely.
3. That you inform the Patient Stories team via email (hrit@health.wa.gov.au) when a patient story has been used and whether the story was successful in achieving the desired result.

If would like any promotional materials to gain support for conducting Patient Stories in your Area or branch, please contact hrit@health.wa.gov.au
Part D: Templates and additional resources

The following templates, tools and links may be useful to staff interested in collecting and recording Patient Stories for use in a service improvement project.

**Information and consent forms**

- i. Participant information sheet and consent form - community-based service
- ii. Participant information sheet and consent form - hospital service

**Interview guides**

- iii. Interview prompt sheet - for community-based staff
- iv. Patient stories considerations and guiding questions - for community-based staff
- v. Interview prompt sheet - for hospital staff
- vi. Patient stories considerations and guiding questions - for hospital staff

**Promotional material**

- vii. Patient Stories flyer (A4)
i. Participant information sheet and consent form - community-based service
PARTICIPANT INFORMATION SHEET

Patient experience interviews - “Patient Stories”

You are invited to take part in a short interview to help us improve our services. We are interested in hearing about your personal experience so that we can identify ways to continue to improve our service to patients and clients here and at other sites across the State.

You have been randomly chosen to participate in a short interview with representatives from WA Health as you recently experienced the delivery of community-based health services.

Your insights about your experience will be shared with other WA Health staff across the health system and also placed on WA Health’s website. While we may talk about aspects of your experience, you will not be identified on the website, in any reports, presentations or papers arising from the project.

In sharing your insights about the health system, any information that we collect about you in connection with this interview will remain confidential, and will be disclosed only with your permission.

We also invite you to nominate an ‘alias’ so that references to the information you provide us will not identify you.

Who should I contact if I have further questions about the interview?

If you have questions after your interview, you can contact the following WA Health representative:

Contact name:

Position/title:

Phone:

E-mail:

Thank you for taking the time to share your experience with the WA Health system. Please keep this page for future reference.
PARTICIPANT CONSENT FORM

I agree to participate in an interview regarding my recent experience with the WA Health system.

I consent to taking part in the discussion and have understood the information contained within the Patient Information Sheet, a copy of which I have been given to keep.

I understand I can withdraw my comments at any time and do not have to give any reason for withdrawing. I also understand that I may be contacted in the future as part of an evaluation of this patient interview method and my telephone number has been requested for this purpose.

I understand that my personal information will remain confidential as outlined in the Patient Information Sheet.

PATIENT

Print Name: ________________________  Date:   __________________
Signature: ________________________  Telephone:  __________________
Alias:  ________________________

Name of Interviewer:  _______________________    Signature: ____________________

Contact details for WA Health representative:

Name:  __________________________
Position:  __________________________
Phone:  __________________________
E-mail:  __________________________
Address:  __________________________
________________________________

I have informed the above person about this interview and I am sure that they understand the content of both the Participant Information Sheet and this Participant Consent Form.
ii. Participant information sheet and consent form - hospital service
PARTICIPANT INFORMATION SHEET

Patient experience interviews - “Patient Stories”

You are invited to take part in a short interview to help us improve our services. We are interested in hearing about your personal experience so that we can identify ways to continue to improve our service to patients and clients here and at other sites across the State.

You have been randomly chosen to participate in a short interview with representatives from WA Health as you recently experienced the delivery of services here in the hospital.

Your insights about your experience will be shared with other WA Health staff across the health system and also placed on WA Health’s website. While we may talk about aspects of your experience, you will not be identified on the website, in any reports, presentations or papers arising from the project.

In sharing your insights about the health system, any information that we collect about you in connection with this interview will remain confidential, and will be disclosed only with your permission.

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I understand that my personal information will remain confidential as outlined in the Patient Information Sheet.

PARTICIPANT

Print Name: ________________________  Date:   __________________
Signature: ________________________  Telephone:  __________________
Alias:  ________________________

Name of Interviewer:  _________________________  Signature: ___________________

Contact details for WA Health representative:

Name:  __________________________
Position: __________________________

Phone:  __________________________
E-mail:  __________________________
Address:  __________________________
_____________________________

I have informed the above person about this interview and I am sure that they understand the content of both the Participant Information Sheet and this Participant Consent Form.
iii. Interview prompt sheet - for community-based staff
INTRODUCTION:

- WA Health is focusing on service improvement to deliver better experiences for patients and clients by improving on many different aspects of service delivery and care.
- We are reviewing many systems involved in delivering health care including our staff, our processes and our technology and how they all work together to provide health care services to you.
- We are conducting interviews with a range of people who have recently received community based health care to better understand ways to improve the experience for patients like you in the future.
- Thank you for agreeing to talk to us about your health care experience. Please be as honest and constructively critical as you can.
- Your privacy will be protected; we will not reveal your name or where you came from.

Real Name of Patient:

Alias Name:

Date:

Name of Interviewer:

Prompts:

1. What was your health care experience?
2. What were the best or most positive aspects of your health care experience?
3. What do you think we could do to improve the service delivered to you?
iv. Patient stories considerations and guiding questions - for community-based staff
The seven dimensions of client care in the community

The seven dimensions displayed in the client care pie below are adapted from the seven scales provided in the WA Health Patient Satisfaction Survey, and represent the areas of the patient experience that may be considered in developing patient interview questions.
Guiding questions that may be used to develop Patient Stories interviews

The following questions provide a framework for the types of questions you may ask a client in collecting their story. Depending on the area you wish to examine or the outcome you wish to achieve, you may choose a few of the questions from a range of areas, or multiple questions from one specific area.

The following questions are intended as a guide only, as other questions may be created to suit your needs.

Access to facilities WA

- Was your appointment date arranged so that you could easily keep it?
- When you got to the facility did you know where to go?
- Was there adequate parking?
- Was there adequate sign posting to help you get around the facility?
- Describe the assistance provided to you to get to the facility
- Were you asked if you had any cultural or religious beliefs that might affect the way you were treated?
- Were you asked who, other than staff, could be given information about your care?
- Did you have access to an interpreter if you needed one?
- Were you told everything you needed to know when you arrived at your first appointment?
- Did anyone check that you understood the information provided?
- Did introduce themselves at each appointment?
- Was information given about your planned care?

Information and communication

- Were you given information about the purpose of treatment?
- Were you given information about your progress?
- Was information given to your family about your progress?
- Describe the way health care professionals answered your questions.
- Describe the way health care professionals explained your condition and treatment.
Time and attention paid to clients’ care
- How long did you wait for a referral or appointment when it was needed?
- Did the health care professional spend adequate time on your care and treatment?
- Did you have confidence in your health care professional (s)?
- Describe the attention to your care given by the health care professional.
- Did you feel you could get help if you needed support/reassurance?

Meeting personal as well as clinical needs
- Did you feel you were able to ask for information if you felt anxious about something?
- Were you treated with politeness and consideration?
- Were you shown respect while being examined or interviewed?
- Was your right to an opinion respected?

Involved in decisions about care and treatment
- Were you involved in decisions about your care and treatment?
- Were you encouraged to ask questions about your condition and treatment?
- Were you given time was given to consider any consent form you needed to sign?
- Did you feel you could refuse the proposed treatment?
- Were any problems and complaints dealt with promptly/adequately?

Links to appropriate services
- Were the details about the services you needed correct?
- Was there an adequate range of services included?
- Describe the usefulness of the services you were offered
- Were you referred to the services closest to where you live?
- Were your means of transport taken into account by staff when suggesting services?
Continuity of care

- Was there communication between doctors, nursing staff and other health care professionals about your treatment?
- Were you given information on how to manage your condition at home?
- Were you told the arrangements with your doctor and others about continuing with care?
- Were you told/given access to extra support you may have needed?
v. Interview prompt sheet - for hospital staff
INTERVIEW PROMPT SHEET - HOSPITAL

Introduction:

- WA Health has a service improvement program to improve the experience of patients by improving the delivery, quality and flow of care.

- We are reviewing many systems involved in delivering health care including our staff, our processes and our technology and how they all work together to provide health care services to you.

- We are conducting interviews with a range of people who have recently received health care to better understand ways to improve the experience for patients like you in the future.

- Thank you for agreeing to talk to us about your health care experience. Please be as honest and constructively critical as you can.

- Your privacy will be protected; we will not reveal your name or where you came from.

Real Name of Patient:

Alias Name:

Date:

Name of Interviewer:

Prompts:

1. What was your health care experience here at the hospital?

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

3. What did not work so well for you during your time here? What do you think we could do to improve things?
vi. Patient stories considerations and guiding questions - for hospital staff
The seven dimensions of patient care

The seven dimensions displayed in the patient care pie below are adapted from the seven scales provided in the WA Health Patient Satisfaction Survey, and represent the areas of the patient experience that may be considered in developing patient interview questions.
Guiding questions that may be used to develop Patient Stories interviews

The following questions provide a framework for the types of questions you may ask a patient in collecting their story. Depending on the area you wish to examine or the outcome you wish to achieve, you may choose a few of the questions from a range of areas, or multiple questions from one specific area.

The following questions are intended as a guide only, as other questions may be created to suit your needs.

**Getting into hospital**

- Once at hospital, how long did you wait before taken/sent to room or ward?
- Describe the time you waited to get into hospital. Was information sent before admission on how to prepare for your hospital stay?
- Was your admission date arranged so that you could easily keep it?
- When you got to the hospital did you know where to go?
- Was there adequate hospital parking?
- Was there adequate sign posting to help you get around the hospital?
- Describe the assistance provided to you to get into the hospital
- Were you asked about your dietary needs?
- Were you asked if you had any cultural or religious beliefs that might affect the way you were treated?
- Were you asked who, other than hospital staff, could be given information about your condition?
- Did you have access to an interpreter if you needed one?
- Were you asked if you were currently taking medication?
- Were you told everything you needed to know when you arrived at your ward?
- Did anyone check that you understood the information provided?
- Did the nurse in charge introduce themselves at each shift change?
- Was information given upon arrival on the ward about your planned treatment?
Information and communication
- Were you given information about the purpose and results of tests?
- Were you given information about medications?
- Were you given information about your progress?
- Was information given to your family about your progress?
- Describe the way health care professionals answered your questions.
- Describe the way health care professionals explained your condition and treatment.

Time and attention paid to patients’ care
- How long did you wait for a doctor when it was needed?
- Did the doctor spend adequate time on your care and treatment?
- Did you have confidence in your doctor(s)?
- Did you have confidence in the nursing staff?
- How long did you wait for a nurse after using the call system?
- Describe the attention to your care given by nursing staff.
- Were you given assistance when you required it (e.g. toilet/showers)?
- Did you feel you could get help if you needed support/reassurance?
- Were you given pain relief when it was required?

Meeting personal as well as clinical needs
- Did you feel you were able to ask for information if you felt anxious about something?
- Were you treated with politeness and consideration?
- Were you shown respect while being examined or interviewed?
- Was your right to an opinion respected?
- Did you have screens around the bed when being examined to ensure privacy?
- Did hospital staff use low voices when interviewing or examining you so others couldn’t overhear?
- Did you feel safe and secure while in hospital?
Involved in decisions about care and treatment

- Were you involved in decisions about your care and treatment?
- Were you encouraged to ask questions about your condition and treatment?
- Were you given time was given to consider any consent form you needed to sign?
- Did you feel you could refuse the proposed test/treatment/procedure?
- Did you feel you could ask for a second opinion about the proposed test/treatment/procedure?
- Were you told you could refuse to have medical/nursing students present?
- Were any problems and complaints dealt with promptly/adequately?
- Were you told about your patient rights, the hospital complaint service and Office of Health Review?

Food and residential aspects

- How would you describe the quality of the food?
- Was there adequate range and appeal of menus?
- Was the temperature of the food appropriately hot/cold?
- Was the quantity of food provided appropriate?
- Was your bed comfortable?
- Describe the cleanliness of the surroundings.
- Was the noise level around the area comfortable?
- Was the position of the call for help button easy to reach?
- Were adequate supplies for your baby provided? (Maternity only)

Continuity of care

- Was there communication between doctors, nursing staff and other health care professionals about your treatment?
- Were you given information on how to manage condition/recovery at home?
- Were you told the arrangements at discharge with the doctor and others continuing with care?
- If you needed special equipment/aids did the hospital staff organise them at discharge?
- Describe the time you waited for a doctor to discharge you from hospital.
- Were you told/given access to extra support you may have needed?
vii. Patient Stories flyer (A4)
What are ‘Patient Stories’?

Patient Stories involves collecting stories from patients’ personal experiences to understand how they perceived the health care they have received in the WA Health system. Patients talk about what they felt, saw, heard, the emotions that were evoked and how this may have affected their decisions and actions during their journey.

These insights are an important component in understanding how we can improve different aspects of service delivery and care in our hospitals and in our community-based health care programs.

How can ‘Patient Stories’ be used?

Patient Stories involves looking at different ways to organise services around the needs and preferences of patients, rather then the needs and preferences of services. Stories can therefore be used:

- to examine aspects of the patient journey, through data collection for a clinical service redesign project;
- to understand the whole patient experience to assist staff through education and reflection; and
- to support an audit of the impact a service improvement and innovation project has made to a patient’s journey/experience, and whether improvements have been sustained over time.
The end result will be to ultimately enhance the patient experience by improving the delivery, quality and flow of care, by reducing delays to the patient’s journey and by improving access across key areas of the public health service.

How can I collect and use ‘Patient Stories’ for my project/program?

Patient Stories should be collected as part of a service improvement project to gain the most value from the experience. Once the aims of the service improvement project are clear, you will need to determine how collecting patient stories will enhance the project and ultimately provide the best outcomes for the patient.

Patient Stories can be collected in the health care environment or once patients have returned to their residence after treatment. Interviews can be conducted face-to-face, over the phone, in a focus group situation, and can be audio or hand recorded by the collector.

Once the stories have been analysed, it is important to use the data to action the service improvement. Equally, it is important to share the information and lessons you have learned through the process across the system to assist other service improvement projects occurring in WA Health.

Where can I find more information on ‘Patient Stories’?


- Information on which Area Health Services have previously conducted projects which included gathering Patient Stories;

- Access to transcripts of previously collected Patient Stories; and

- A step-by-step toolkit for conducting your own Patient Stories, including templates.

If you have collected patient stories as part of a service improvement project and would like to share your stories and learnings with other WA Health staff, please email your details to hrit@health.wa.gov.au.