

TOOLKIT

CONSUMER EXPERIENCE

National Quality and Risk Managers Group

June 2012

Preliminary comments

This Toolkit describes 11 methods for capturing consumer experience. It was designed to be used with the *Guide for Developing a Consumer Experience Framework*, which provides information on selecting the most appropriate methods. The Toolkit is not a comprehensive list but provides a selection of methods commonly-used for collecting information from individuals and groups.

The following information is provided about each method:

- **Title**
- **Purpose**
- **What is it and how can it help?**
- **Practical suggestions**
- **Things to consider**
- **More information & resources**

The terms *patient* and *consumer* are both used in this document for people who receive health or disability services. Providers of health services also engage with a range of others in providing these services including family, whānau, caregivers and friends. All of these people have valuable knowledge and insights into the way services are and could be provided.

Consumer Engagement

The tools and methods included in the Toolkit are focused on collecting feedback from consumers about their experience of using health services. It is important to recognise that consumer experience is only one aspect of consumer engagement and these methods should be used in conjunction with other forms of consumer engagement, such as those aimed at empowering and building partnerships with consumers. An example of this is Consumer Representation, which serves to provide a strong and viable voice for consumers and the community on all aspects of health service planning and delivery. The Canterbury DHB established its Consumer Council in 2008 and chose the slogan 'nothing about us, without us' to demonstrate the importance of consumer involvement in all organisational activities. Similarly, a Community Panel was established at Counties Manukau DHB in 2005 as a forum for staff to access community perspectives on a range of issues and to inform the development plans, policies, and procedures.

Consumer Rights and Privacy

When engaging patients and families to gather information on their experience of the health system, health teams are reminded to behave in a manner which is mindful of the Privacy Act and the Code of Rights. Individuals must be treated with dignity and respect, and information shared for the purposes of improvement should not be identifiable or repeated as to identify the individual or family.

Communication with participants must be open and honest and the participants must clearly understand how the information will be used, where it is going to be stored and who will have access to it. Before using any patient story or other information, consent must be obtained from the individual. It is also important to confirm that they are happy with the completed product before publication. Total trust between the parties will result in a long and successful relationship.

Refer to the Code of Rights for more information on the rights of health and disability services consumers: <http://www.hdc.org.nz/the-act--code/the-code-of-rights>

Health Service Co-Design

Co-design is a term widely used in healthcare to describe programmes for planning or improving health services in collaboration with consumers. One such programme developed by Waikato DHB is Health Service Co-Design:

<http://www.healthcodesign.org.nz/>

Co-design is not discussed in detail in the Toolkit, however it is a great idea to make use of this and other similar resources in developing a consumer experience framework.

The Consumer Experience Project

The Toolkit has been developed by the Consumer Experience Project Team consisting of consumers and Quality and Risk Managers (Appendix 1). The Team worked on behalf of the National Quality and Risk Managers Group and was supported by the Health Quality and Safety Commission. Literature, practice experience from the DHBs and national and international examples form the basis of the current Guide and the Toolkit. The Toolkit is a living document and will be updated based on feedback and experiences.

Online Discussion Forum

Purpose

To collect consumers' views and encourage discussion between consumers in order to gain a deeper understanding of an issue

What is it and how can it help?

Discussion forums can be used to pose questions to participants in order to collect more in-depth information about a particular topic, for example an issue identified in a survey or questionnaire. Discussion forums are a great way to engage with consumers who may have difficulty accessing other methods of providing feedback as they are open all times for many days or weeks.

Examples of online discussion forums are Reo Ora Health Voice used by Auckland DHB and WebEx, a widely-used webinar forum.

Also see the description for *Focus Group*.

Practical Suggestions

- Develop an initial range of questions. These can be revised or expanded on to further develop emerging ideas.
- Forums can be open to public or by invitation, and moderated or un-moderated. It is advisable to develop rules of participation and moderation and to make these clear to all members, including advice on who will see and hear their comments.
- Consider developing a regional approach.

Things to consider

Preparation of a business case and engagement with your IT team may be necessary to establish discussion forums.

More information and resources

Tates e.a (2009). Online focus groups as a tool to collect data in hard-to-include populations: examples from paediatric oncology. BMC Medical Research Methodology 9:15

<http://www.wikihow.com/Start-an-Online-Discussion-Community>

Purpose	To collect in-depth information from consumers about identified issues
What is it and how can it help?	<p>A focus group is consumer discussion about specific topics lead by a facilitator. Focus groups are popular for discussing certain aspects of patients' experience of a service. Interaction between consumers is possible, creating a comfortable environment for consumers to provide in-depth feedback. The facilitator asks open-ended questions in order to build on emerging ideas throughout the discussion.</p> <p>See also the description of the tool <i>Online Discussion Forum</i>.</p>
Practical Suggestions	<ul style="list-style-type: none"> • Issues can be identified from complaints or surveys • Advise attendees who get the information
Things to consider	Focus group facilitator must be experienced and well-trained and clear criteria is needed for participants.
More information and resources	<p>http://assessment.aas.duke.edu/documents/How_to_Conduct_a_Focus_Group.pdf</p> <p>http://managementhelp.org/businessresearch/focus-groups.htm</p> <p>NHS Quality Tools – Patient Perspectives 2. Focus Groups:</p> <p>http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/patient_perspectives.html</p>

Purpose	To capture consumers' experiences in their own words and to get in-depth information about their views
What is it and how can it help?	<p>In-depth interviews are useful if you want detail about a person's experience or want to explore new issues in depth. Interviews can be used in place of a focus group if a potential participant does not feel comfortable talking openly in a group. They can be conducted over the phone or face to face.</p> <p>To get an in-depth understanding of the consumer's views, use a list of open ended questions on your particular topic</p>
Practical Suggestions	<ul style="list-style-type: none"> • Ethical approval may be required for interviews if you are going to identify the consumer. • Consumer must be given the opportunity to review the interview transcript before it is used.
Things to consider	Conducting, transcribing and analysing interviews is a time-consuming process.
More information and resources	<p>A guide for designing and conduction in-depth interviews: http://www.pathfind.org/site/DocServer/m_e_tool_series_in_depth_interviews.pdf https://edis.ifas.ufl.edu/fy393 NHS Quality Tools – Patient Perspectives 3. Semi-structured patient Interviews: http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/patient_perspectives.html</p>

Purpose	To collect detailed information about the consumer experience throughout the process of care.
What is it and how can it help?	A patient diary is a record of events throughout a consumer's healthcare experience. The diary involves the consumer in their own care and in the development of health care services. Diaries can be brief, reporting descriptive or reflective experiences and can focus on the entire consumer journey or only one element of their experience (eg pain management).
Practical Suggestions	<ul style="list-style-type: none"> • It is important to provide information to the consumer about the reason the diary is to be kept. Diaries can be completed using a number of methods (written diary, computer or tablet, audio recording, drawing or collage, storyboards). • Provide feedback to the consumer in relation to their help and any improvements made (eg better management of pain relief)
Things to consider	Confidentiality and consumer consent are required.
More information and resources	<p>Stensland P and Malterud K. Unravelling empowering internal voices - a case study on the interactive use of illness diaries. <i>Family Practice</i> 2001; 18: 425—429</p> <p>http://webcache.googleusercontent.com/search?q=cache:ysFTHI2QP5EJ:www.midlandcancernetwork.org.nz/file/fileid/37124+patient+diary+nz&hl=nl&gl=nl</p>

Patient Journey – Process Mapping

Purpose	To gain a common understanding of the consumer journey and the elements that drive the consumer experience
What is it and how can it help?	<p>Patient Journey Process Mapping is a method of documenting of a consumer's journey through the health system. A working group, supported by a facilitator, is assembled to map the journey of the consumer. The mapping process consists of three critical elements:</p> <ol style="list-style-type: none"> 1. Mapping the process visually with all of the activities' elements of the journey (step by step) 2. Identifying 'Moments of Truth' which are the moments when a consumer makes an immediate judgement on that part of their experience 3. Value analysis: value adding (things that consumer perceives as improving their experience), necessary non-value adding (activities and features that consumers not directly perceives as enhancing their experience), waste (anything that the consumer does not require)
Practical Suggestions	<ul style="list-style-type: none"> • Walk the journey and talk to the participants and customers of the process to find out what really happens – even if you think you already know • The journey must be a true reflection of the current consumer's experience, not what should happen in the best-case scenario. • Patient Journey Maps are meant to be used. Establish practices that make them living documents that are updated when improvements are made.
Things to consider	A skilled and trained facilitator is required.
More information and resources	<p>Patient Journey Mapping (Health Service Co-Design): http://www.healthcodesign.org.nz/03_explore_b.html</p> <p>NHS Quality Tools – A Conventional Model of Process Mapping: http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/process_mapping_-_a_conventional_model.html</p>

NHS Quality Tools – Process Mapping – Alternative
Conventional Methods:

http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/process_mapping_-_alternative_conventional_methods.html

Purpose

To capture a consumer's experience in their own words in order to provide a personal, emotive perspective on the impact of positive and negative experiences

What is it and how can it help?

Consumers or their family/whanau are interviewed and the stories are captured on video, audio recordings or in writing. The stories show first-hand and in a personal way the patient journey and experience. Stories can be focused on a particular topic, and can be both positive and negative. They can be used for educational purposes, placed on a website (see links below) or used in a meeting with health care providers. Patient stories can be captured in writing, on video or audio recording, or depicted using images on a storyboard.

Also see *In-depth Interview*.

Practical Suggestions

- Develop guidelines for a standardised approach for recording, editing, moderating, and using the stories.
- Select an environment for the interview where the participant is comfortable, such as their home or other familiar place.
- Obtain the consumer's consent to use the final edited version of the story and inform them of how it will be used.
- Ensure necessary action is taken in response to the story and that those telling the story have a means to get appropriate feedback from the organisation.

Things to consider

A nominated and skilled person is required to facilitate, coordinate, and moderate the process.

More information and resources

http://www.healthcodesign.org.nz/03_explore_d.html

http://www.archi.net.au/documents/resources/patient_stories/patient-carer.pdf

http://www.health.wa.gov.au/hrit/docs/A_toolkit_for_collecting_and_using_patient_stories.pdf

<http://www.wales.nhs.uk/sitesplus/865/opendoc/191187>

Patient Shadowing / Tracking

Purpose

To collect detailed information about the obstacles, experiences and position of the consumer during the consumer journey

What is it and how can it help?

The 'shadower' (observer) accompanies consumers during the journey through the health system. The shadower, who can be another patient, volunteer or staff-member, joins consumer in all activities to get an objective view from perspective of consumer. Questions can be asked to get a better understanding. Observations can be recorded as field notes or on a checklist.

Practical Suggestions

- The consumer needs to be well informed in advance about the purpose and role of the shadower.
- Shadowing is easy to combine with other methods like in-depth interviews or patient diary.
- Preferably the shadower does not have in-depth knowledge of the process

Things to consider

Procedure must be developed to recruit and train shadowers

More information and resources

Patient Shadowing (Health Service Co-Design):
http://www.healthcodesign.org.nz/03_explore_a.html

NHS Quality Tools – Patient Perspectives 4. Patient Shadowing:

http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/patient_perspectives.html

Purpose

To collect comments from consumers on their experiences and suggestions, compliments or complaints

What is it and how can it help?

Suggestion boxes can be used to collect feedback from consumers and organisations in the community. A suggestion box can be a physical box, but may also exist in an electronic form on the organisation website. A comment card, template or brief questionnaire is provided to get feedback.

Suggestion boxes create an opportunity to quickly and easily provide feedback. They also allow for anonymous input, which is an advantage when you want to get the opinion of less outspoken groups. Comment cards can also be more directed, asking an open question or for patient stories.

Practical Suggestions

- Suggestion boxes or posters should be placed in public high-use areas (eg hospital foyers, waiting rooms)
- Electronic suggestion boxes can also be used to cast a wider net for responses
- Comment cards/templates should have the opportunity to leave contact details and relevant service or division.
- Complaints should be redirected to the Complaints Management process

Things to consider

Suggestion boxes are relatively low-cost and low-tech, simple and easy to use

Time is required to read, respond, or redirect comments

An electronic system may be more costly but less labour intensive

Purpose	To collect information from consumers about identified topics in a specific timeframe
What is it and how can it help?	Surveys and questionnaires are used to collect information on set questions from a sample of the patient population. Surveys are an effective method of collecting quantitative feedback from a large group of consumers and identifying topics for further exploration using other methods, such as focus groups, in-depth interviews or online discussion forums. Surveys can be on paper or electronic.
Practical Suggestions	<ul style="list-style-type: none"> • Demographic information (eg age, sex, gender) should be collected and analysed to determine if respondents are representative of the total consumer populations. • Consider using short surveys (3–5 questions) on the spot (eg, in waiting rooms) and be creative in the implementation
Things to consider	<p>Survey questions must be externally validated (eg standard Picker questions) or internally validated through pilots and focus groups.</p> <p>Open-ended free text questions can be used to provide more detailed information, however these questions should be carefully selected as the responses are more difficult to analyse.</p>
More information and resources	<p>http://www.ihi.org/knowledge/Pages/Tools/ShortSurvey.aspx</p> <p>Experienced-based Surveys (Health Service Co-Design): http://www.healthcodesign.org.nz/03_explore_c.html</p> <p>NHS Quality Tools – Patient Perspectives 1. Questionnaire: http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/patient_perspectives.html</p> <p>http://www.pickereurope.org/surveys/</p>

Purpose	To collect information from consumers regarding their experiences through text messaging
What is it and how can it help?	Texting can be used as a method to collect feedback from patients. Text messages can be sent to consumers to ask them for feedback or signs can be posted requesting consumers to text general or more specific feedback to a particular number.
Practical Suggestions	<p>In order to gain specific and constructive feedback:</p> <ul style="list-style-type: none"> • designate a unique number or code for each department or service to be included in the text • request text feedback relating to a particular campaign or initiative (eg, hand hygiene, consumer safety) • request text feedback relating to a particular aspect of service (eg, communication, waiting times)
Things to consider	<p>There is a cost for consumers to send a text.</p> <p>Consumers may expect a real-time response to their text.</p>
More information and resources	www.texsys.co.nz (Texsys)

Purpose To raise the profile of the organisation and enter into a two-way online dialogue with consumers and community members

What is it and how can it help?

Internet-based social media websites, for example Facebook or Twitter, can be used to facilitate interaction between consumers and health and disability service organisations. Consumers and community members can be involved by becoming followers or friends with the organisation and then commenting on or sharing posted information and stories.

The organisation can also publish links to relevant resources (patient stories, online surveys, or discussion forums) and pose questions to collect feedback on particular topics.

Practical Suggestions

- Post a constant stream of interesting stories to keep consumers engaged.
- Encourage employees and consumers from all services to get involved.
- Let people have their say by prompting followers to respond, share stories, and provide feedback.

Things to consider

Social Media is free to set up.

Assign a facilitator to manage the upkeep and integration of all social media for the organisation, and moderator content to ensure external posts are not abusive or defamatory.

More information and resources

<http://www.changefoundation.ca/docs/socialmediatoolkit.pdf>

<http://www.changefoundation.ca/docs/socialmediaguidepart2.pdf>

<http://www.lvntrn.net/20-cool-uses-for-twitter-in-health-and-medicine.html/>

<http://www.facebook.com/pages/Create-your-own-Page-for-your-Business-Organization-Teamor-Personal-Page/50939744258>

APPENDIX 1: Main Resources

Literature

Balik B, Conway J, Zipperer L, Watson J. (2011) *Achieving an Exceptional Patient and Family Experience of Inpatient Hospital Care*. IHI Innovation Series white paper. Cambridge, Massachusetts: Institute for Healthcare Improvement (available on www.IHI.org)

Binkhorst T, Posma E, Lobenstein S. (2009) *Patiënten betrekken bij de zorg in het ziekenhuis*. Utrecht, The Netherlands: CBO (available on www.cbo.nl)

Davies E, Cleary P D. (2005). Hearing the Patient's Voice? Factors Affecting the Use of Patient Survey Data in Quality Improvement. *Quality & Safety in Health Care* 14(6):428–32.

National Resource Centre for Consumer Participation in Health (2004). *Information series: Methods and models of consumer participation*. Victoria, Australia: La Trobe University,

NHS Modernisation Agency (2005). *Improvement Leaders' Guide: Involving Patients and carers: general improvement skills*. London, UK: NHS

Patient and public empowerment (2009). *Understanding what matter: A guide to using patient feedback to transform service*. Leeds, UK: Department of Health. (available on www.dh.gov.uk/publications)

Picker Institute Europe (2009). *Using Patient Feedback: a practical guide to improving patient experience*. Oxford, UK: Picker Institute Europe. (available on <http://www.pickereurope.org/usingpatientfeedback>)

Tayside Improvement Network. *Service User Feedback Toolkit*. Dundee, Scotland: NHS Tayside. (available on [http://www.knowledge.scot.nhs.uk/media/CLT/ResourceUploads/23632/Patient%20to%20olkit\[1\].pdf](http://www.knowledge.scot.nhs.uk/media/CLT/ResourceUploads/23632/Patient%20to%20olkit[1].pdf))

Frampton, S. editor (2008). *Patient-centered care: Improvement Guide*. Cambden, USA: Planetree, Derby, USA & Picker Institute.

Websites

<http://www.cahps.ahrq.gov/Quality-Improvement/Improvement-Guide.aspx>

<http://www.ihl.org>

www.pickereurope.org/improvingpatientexperience

www.hqsc.govt.nz