

Agenda

Health Consumer Council

Venue: Property Services Meeting Room

Date and Time: Tuesday 10 October 2018 at 10:30am – 1:00pm

Item No.	Item	Page
1	Apologies	
2	Presentation Introduction to Maori members of HCC (we are hopeful they will attend) 2.1 <u>Health Quality & Safety Commission</u> - Deon York – 10:30am	
3	Minutes of Meeting - 12 September 2018	2
4	Matters Arising	4
5	Papers for Decision - Nil	
6	For Discussion 6.1 <u>Consumer Engagement Framework</u>	5
7	Papers for Noting 7.1 <u>Correspondence for Noting</u> - Nil	
8	General Business 8.1 <u>Patient Experience Survey</u> – if time allows Averil will present results and outcomes	
9	Next Meeting - Wednesday 14 November 2018	

Minutes of Health Consumer Council

Venue: CEO Meeting Room

Date: 12 September 2018

Attendees: John Powell (Chair), Susan Horne, Julia Genet, Rosalie Liddle Crawford, Tessa Mackenzie, Susan Matthews, Maz McKeivitt, Lisa Murphy, Florence Trout, Adrienne von Tunzelmann, Averil Boon and Cherie Martin

Item No.	Item	Action
1	<p>Meeting opened with a Karakia by Susan Horne</p> <p>Apologies Apologies were received from Wol Hansen.</p>	
2	<p>Presentation</p> <p>2.1 <u>System Level Measures Improvement Plan</u> – Sarah Davey and Sarah Nash</p> <p>Averil will present results and outcomes of the Patient Experience Survey at next meeting.</p>	Averil
3	<p>Minutes of Meeting</p> <p>Resolved that the committee receive the minutes of the meeting held on 8 August 2018 and confirm as a true and correct record.</p> <p style="text-align: right;">Moved: A von Tunzelman Seconded: R Liddle Crawford</p>	
4	<p>Matters Arising</p> <p><u>Is there an alternative to the word patient</u> Averil will circulate the updated version for approval/comment by the committee, asking the Board to consider the word “Tangata Whaiora” and noting Regional Maori Health have yet to have input.</p>	Averil, Adrienne, John
5	<p>Papers for Decision</p> <p>5.1 <u>Draft Terms of Reference</u> Agreement was reached after discussion. Averil will circulate the updated version for approval/comment prior to this being submitted to the CEO for final sign off.</p>	Averil

Item No.	Item	Action
6	<p>Papers/Items for Discussion</p> <p>6.1 <u>Draft BOPDHB Emergency Medicine Services 5 year Strategic Service Plan 2018-23</u> Members will send individual comments/recommendations to John Powell by Monday 17 September. John will collate in MSWord</p>	
7	<p>Papers for Noting - Nil</p>	
9	<p>General Business</p> <p>It was suggested that the meeting could start an hour earlier 10am – 1pm if we can find a meeting room.</p> <p>Members are to come to the next meeting with an issue to test against the terms of reference.</p> <p>An email was received from Graeme Norton who was the ex-chair of Hawkes Bay Health Consumer Council. He is trying to set up a National group. More information will be available next month when information from other Councils is collated.</p> <p>It was suggested that a glossary of acronyms be compiled.</p>	Cherie
10	<p>Next Meeting – Wednesday 10 October 2018</p>	

The meeting closed at 1:28pm with a Karakia.

The minutes will be confirmed as a true and correct record at the next meeting.



Health Consumer Council

Matters Arising – October 2018

Meeting Date	Item	Action required	Action Taken
08.08.18	9	Wol to present other options for Karakia at next meeting	
12.09.18	2	<u>System Level Measures Improvement Plan</u> Averil will present results and outcomes of the Patient Experience Survey at next meeting.	
12.09.18	4	<u>Is there an alternative to the word patient</u> Averil will circulate the updated version for approval/comment by the committee, asking the Board to consider the word “Tangata Whaiora” and noting Regional Maori Health have yet to have input.	Averil, Adrienne and John
12.09.18	5	<u>Draft Terms of Reference</u> Averil will circulate the updated version for approval/comment prior to this being submitted to the CEO for final sign off.	Averil

BOPDHB Consumer Engagement Framework

2016

Bay of Plenty District Health Board
Quality & Patient Safety



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BOPDHB Consumer Engagement Framework

CARE – Compassion, Attitude, Responsiveness and Excellence

Section 1: Introduction

1.1. Background

The Bay of Plenty District Health Board (BOPDHB) is one of 20 District Health Boards (DHBs) in New Zealand, and one of five DHBs in the Midland region. BOPDHB is charged with the responsibility of delivering health services for the people of the Bay of Plenty.

In 2011 the BOPDHB introduced CARE - Compassion, Attitude, Responsiveness and Excellence as their Values and made a commitment to deliver patient and family centred care that puts the needs of patients and carers at its heart. Health Excellence is our commitment to performance excellence, using the internationally recognised *Health Care Criteria for Performance Excellence* framework. The vision for health excellence is 'striving to achieve the highest quality healthcare' and is a practical tool to guide continuous improvement, delivering a positive patient experience and our organisational culture based on quality outcomes.

The [He Pou Oranga Tangata Whenua framework](#) was developed by Māori Health Rūnanga with BOPDHB (2007) to provide organisations with a framework that can assist in the expression and application of kaupapa Māori principles to reflect traditional tangata whenua values are recognised as key indicators of *toiora*: optimum health and well-being.

This Consumer Engagement framework demonstrates BOPDHB's commitment across the whole of the organisation and provides a mechanism to coordinate, prioritise and share consumer engagement activities and resources across BOPDHB's many services and sites.

The vision for consumer engagement at BOPDHB is to be a health service that integrates consumer engagement into every part of the organisation, so that consumers are active partners in how BOPDHB undertakes business and care provision. BOPDHB want consumers to be given meaningful opportunities to actively engage and ensure that the consumers' perspective is listened to and valued in the planning, service delivery and evaluation of our health service. BOPDHB is committed to fostering a positive organisational culture where consumers and staff have access, support and the tools they require for active consumer engagement.

1.2. Defining consumer and community engagement

Consumer engagement refers to the wide range of strategies in which consumers are involved in the planning, service delivery and evaluation of our health care. It covers partnerships between health professionals, patients and their family and/or carers when care is planned and provided. This can be at an individual, service, network and/or system level.

There is growing evidence about the importance of engagement with patients, consumers, families, carers and the community for health service planning, delivery and evaluation. Whilst consumer and community engagement are commonly used terms, they are rarely defined in the health literature. The New Zealand (NZ) Health Quality and Safety Commission (HQSC) have defined consumer engagement as:

'... a process where consumers of health and disability services are encouraged and empowered to actively participate in decisions about the treatment, services and care they need and receive. It is most successful when consumers and clinicians demonstrate mutual respect, active listening and have confidence to participate in full and frank conversation. Systems that support consumer engagement actively seek input from consumers and staff at all levels of an organisation.'

There is no 'one size fits all' approach for consumer engagement, and good communication is the cornerstone to effective engagement at all levels. There has been some willingness demonstrated to

engage with our local communities and BOPDHB has some established engagement processes which provide an excellent basis for ongoing engagement. This framework aims to maintain and enhance the channels of communication and engagement between our facilities/services and the consumers and communities we serve.

1.3. Legislation and strategies that underpin consumer engagement

- Health and Disability Consumer Rights
- Treaty of Waitangi
- NZ Health and Disability Service Standards
- NZ Triple Aim
- NZ Ministry of Health Framework for Health Literacy
- Criteria for Performance Excellence Health Care
- BOPDHB Strategic Priorities
- BOPDHB Integrated Care Strategy
- BOPDHB Annual Plan 2015
- BOPDHB Clinical School Education Strategy
- He Pou Oranag Tanagata Whenua
- Whānau Ora

1.4. Purpose, scope and benefits of consumer and community engagement

The purpose of this framework is to strengthen and improve consumer engagement processes across BOPDHB. It identifies BOPDHB's current position regarding the significance and value of engaging with consumers and community, provides guidance and resources and is written for all employees.

As BOPDHB seeks improved health outcomes and healthier lifestyles for the Bay of Plenty population, the patient is a critical stakeholder and must become an engaged partner. Even the most capable and caring of clinicians cannot unilaterally improve a patient's health without their engagement; it is a team effort involving providers, patients, families, caregivers and health plans. Involving patients in making decisions about their own care and not treating them merely as passive recipients of health care is the basic building block for consumer engagement (ACSQHC, 2011).

Research has shown that together, the multiple individual benefits of patient and family engagement can improve multiple aspects of hospital performance, including quality, patient safety, financial performance, patient experiences of care and patient outcomes. Patient and family engagement strategies also help improve employees' satisfaction with their work and this, in turn, leads to higher levels of staff retention and an improved ability to recruit quality talent.

1.5. Health literacy

Health literacy is the extent to which consumers can obtain process and understand information about their health care, services and health system. It also refers to a consumer's capacity to effectively use that information to make decisions about their own health care. This includes, but is not limited to, consumers with limited English proficiency, those from a culturally and linguistically diverse (CALD) backgrounds, children and young people.

The traditional view of health literacy has been focused on changing the skill level of the patient or consumer. However, recent research suggests that to effectively make improvements in health literacy organisations need to look at strategies that focus on activities that minimise the complexity of healthcare as well as those that focus on improving individual skills.

People with poorer levels of knowledge and limited understanding about their condition, are less likely to attend appointments, are less adherent to medication regimens and health behaviour advice, make more medication errors and perform worse at self-care activities. Studies have shown that those with poor health literacy and are not able to effectively exercise their 'choice' or 'voice' when it comes to making health care decisions.

More information:

Ministry of Health: Framework, Review and other publications

- <http://www.health.govt.nz/publication/framework-health-literacy>

Health Quality & Safety Commission: Three steps to better health literacy booklet, *Let's PLAN for better care* leaflet

- <http://www.hqsc.govt.nz/our-programmes/partners-in-care/work-streams/health-literacy/>

Section 2: Key components of consumer and community engagement

The framework includes a set of nine principles; a model which describes five elements and four levels of engagement across four domains of health service operation; and a set of practice examples to support effective engagement.

2.1 Principles of Consumer Engagement

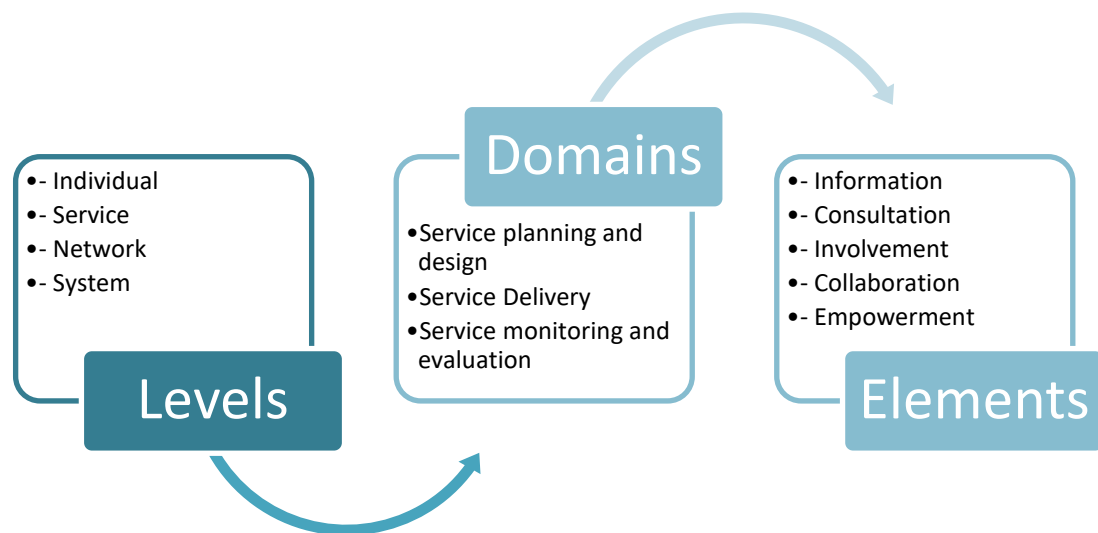
There are nine principles of consumer and community engagement contributes to enhancing the services and healthcare that is delivered by health service organisations.

PRINCIPLE	PRINCIPLE STATEMENT	PRINCIPLE IN PRACTICE
1. Participation	Consumers and communities participate and are involved in decision making about the health care system.	BOPDHB involves consumers and communities in decision making and demonstrates how it uses consumer and community feedback to plan, design, deliver and monitor and evaluate services.
2. Person-centred /whānau-centred	Engagement processes are consumer and community centred	BOPDHB enhances the way it undertakes engagement in a way that is person-centred and values the needs of consumers, their families/carers and the community.
3. Accessible and inclusive	The needs of consumers and communities who may experience barriers to engage effectively are considered to enhance their accessibility and inclusion.	BOPDHB examines barriers that consumers and communities experience to engage meaningfully and develops strategies to increase access and inclusion for people who are marginalised and experience poorer health outcomes.
4. Partnership	Consumers, community and BOPDHB work in partnership.	BOPDHB partners with consumers and the community at all levels of engagement around the planning, designing, delivery and monitoring and evaluation of services.
5. Diversity	The engagement process values and supports the diversity of consumers and communities.	BOPDHB understands the different populations of consumers and communities and engages with a diverse range of individuals and groups, for example people with a disability, older persons, Māori, young people, people with a mental illness and people from culturally and linguistically diverse backgrounds.
6. Mutual respect and value	Engagement is undertaken with mutual respect and valuing of each other's experiences and contributions.	BOPDHB works with consumers and communities in a respectful way that values the contribution consumers and communities bring to improving service planning, provision, monitoring and review as well as overall system outcomes.
7. Support	Consumers and communities are provided with the support they need to engage meaningfully with the healthcare system.	BOPDHB undertakes a process to understand the needs of consumers and the community, and implements processes to provide them with the support that they need to engage.
8. Influence	Consumer and community engagement influences health policy, planning and system reform, and feedback is provided about how the engagement has influenced outcomes.	BOPDHB utilises the information and feedback gained through engagement to improve health policy, planning, and service delivery and design, and ensures that consumers and communities are provided with feedback about the changes their input has achieved.
9. Continuous improvement	Consumer and community engagement is reviewed and evaluated to drive continuous improvement.	BOPDHB uses information from the review and evaluation of its engagement activities to improve future engagement and share learnings and knowledge with staff members of the organisation.

2.2 Levels, Domains and Elements of Consumer Engagement

The BOPDHB Consumer Engagement Framework supports:

- Engagement occurring at all of the four organisational levels on an ongoing basis;
- The involvement of consumers and community throughout the continuum of the engagement process, from planning, commencement of initiatives/activities through to the monitoring, evaluation and review phases;
- The use of a variety of mechanisms and methods that are tailored to meet the needs and purpose of the engagement;
- The engagement of consumers that are representative of the population that accesses and utilises any service, including culturally-diverse and marginalised groups;
- Early engagement of consumers, enabling the identification of objectives and focus of the activities to achieve positive outcomes;
- The provision of information to consumers and communities within BOPDHB using a supportive, mentoring approach;
- The provision of feedback to consumers and communities about how their contribution has influenced the end results.



2.3 Levels of Consumer Engagement

Partnering with consumers and the community can occur on different scales and levels of engagement. The four scales of engagement are Individual, Service, Network and System.

Level of engagement	Where the engagement level occurs	Explanation of level
1. Individual/whānau	<ul style="list-style-type: none"> • Individual /whānau healthcare 	This level focuses on engaging with the individual consumer and/or their family/carer as partners in their own healthcare, support and treatment.
2. Service	<ul style="list-style-type: none"> • Programme delivery • Service delivery • Facility / hospital 	This level focuses on engaging with consumers and the community to have input into how programmes, services, or facilities are delivered, structured, evaluated and improved.
3. Network	<ul style="list-style-type: none"> • Local BOPDHB healthcare and Community Services networks 	This level focuses on how health service organisations engage with consumers and community at the regional level.
4. System	<ul style="list-style-type: none"> • Local government • Midland Region DHBs • Hapu/Iwi • National government 	This level focuses on how consumers and communities engage to influence and input on health policy, reform and legislation at the system level across local, Midland and National jurisdictions.

2.4 Elements of the Public Participation Spectrum

Engaging with Consumers; a guide for district health boards (NZ HQSC) has adapted the International Association for Public Participation (IAP2) spectrum of public participation table (below) showing increasing levels of consumer impact that relates to health consumers engaging in decisions about their care and health services. The elements of engagement occur along a spectrum, and involve an increasing level of consumer and community participation from information through to empowerment.

INCREASING LEVEL OF CONSUMER IMPACT

	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
Public participation goal	To provide consumers with balanced and objective information to assist them in understanding the issue, alternatives, opportunities and/or solutions.	To obtain consumer feedback on issues, alternatives and/or decisions.	To work directly with consumers to ensure that consumer concerns and aspirations are consistently understood and considered.	To partner with consumers in each aspect of decision-making, including in the development of alternatives and identification of the preferred solution.	To place final decision-making in the hands of the consumer.
Promise to consumers	We will keep you informed.	Consumer councils working in parity with clinical governance.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how consumer input influenced the decision.	We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.
Example techniques	Information fact sheets, websites.	Consumer feedback and comments, focus groups, patient experience surveys, community meetings.	External advisory groups, focus groups, patient experience surveys, shared decision-making.	Consumer councils reporting to clinical governance, consumer representation in clinical governance.	Consumer councils working in parity with clinical governance.

Section 3: Current informal and formal BOPDHB mechanisms

There are many existing mechanisms in use across all levels of the organisation and these should be considered as a possible source to obtain consumer feedback information before initiating a new process. The table below includes many of the informal and formal mechanisms currently in use but there may be more.

LEVEL	TYPE
Individual: Patients / Families / Carers	<ul style="list-style-type: none"> • Assessment and care planning • Intentional Patient Rounding • Bedside Handover • Case Management • Tracer methodology (audit) • National Quarterly & BOPDHB Fortnightly Patient Experience Surveys • Mental Health - Marama Real Time Feedback • Ad hoc Surveys / Feedback • Collection of patient / family / carer stories • Feedback received by online form, email, verbal (phone & in person), paper (letter & Do you want to tell us something forms)
Department level: Unit / Ward / Team	<ul style="list-style-type: none"> • Ad hoc Surveys / Feedback • Intentional Patient Rounding • Bedside Handover • Focus groups • Co-design projects • National Quarterly & BOPDHB Fortnightly Patient Experience Surveys data • Mental Health - Marama Real Time Feedback data
Service / Cluster	<ul style="list-style-type: none"> • Ad hoc Surveys / Feedback • Focus groups • Co-design projects • Mental Health Community Advisor • National Quarterly & BOPDHB Fortnightly Patient Experience Surveys data • Mental Health - Marama Real Time Feedback data
Provider Arm	<ul style="list-style-type: none"> • Ad hoc Surveys / Feedback • Focus Groups • Co-design projects • Advisory Groups – Volunteer Patient Advisor Group, Community Health Liaison Group • Consumer representation on organisational committees • Volunteers • National Quarterly & BOPDHB Fortnightly Patient Experience Surveys data • Mental Health - Marama Real Time Feedback data
DHB	<ul style="list-style-type: none"> • He Pou Oranga Tangata Whenua Framework • Stakeholder consultation • Consumer representation / focus Groups / projects • Co-design projects • BOPDHB Pulse Employee Survey • National Quarterly & BOPDHB Fortnightly Patient Experience Surveys / Mental Health - Marama Real Time Feedback data

Section 4: Using the Consumer Engagement Framework



4.1 Involving consumers

Why involve patients and the public? The simple answer to the question is because it is their Health Service.

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.

In order to involve patients and the public in a truly meaningful and sincere way, first of all it is necessary to be aware of what actually matters to them - what do they care about and what do they consider to be important elements of service that can make the difference between an excellent patient experience and an average one or a poor one?

NHS research has shown that there are several elements of what matters to patients and that they fall into two categories – Functional and Relational:

<i>What matters to patients? Themes from patient interviews</i>			
		Functional	Relational
Being treated as a person, not a number			<input checked="" type="checkbox"/>
Staff who listen and spend time with patient			<input checked="" type="checkbox"/>
Individualised treatment with no labelling			<input checked="" type="checkbox"/>
Using language that is easy to understand			<input checked="" type="checkbox"/>
Finding out about the latest technologies and innovations medications		<input checked="" type="checkbox"/>	
Feeling informed, receiving information and being given options			<input checked="" type="checkbox"/>
Patient involvement in care and being able to ask questions			<input checked="" type="checkbox"/>
More public awareness about condition		<input checked="" type="checkbox"/>	
Efficient processes		<input checked="" type="checkbox"/>	
Knowledgeable health professionals			<input checked="" type="checkbox"/>
Aftercare support			<input checked="" type="checkbox"/>
Positive outcomes		<input checked="" type="checkbox"/>	
Continuity of care			<input checked="" type="checkbox"/>
Good relationships and positive attitudes among staff			<input checked="" type="checkbox"/>
The value of support services			<input checked="" type="checkbox"/>

4.2 Prepare and plan

Preparing and planning for any consumer and/or community engagement is essential to success. The table below summarises the key features to consider when preparing, planning, engaging, implementing and evaluating.

CONSUMER AND COMMUNITY PARTICIPATION	
Prepare and plan	<ul style="list-style-type: none"> Identify and understand the aims and objectives to be explored and how the stakeholders are affected. Identify risks and benefits Identify internal and external stakeholders – consumers, carers, community, organisations and seek advice and feedback as appropriate Identify health literacy requirements and any health literacy tools Consider timeframe e.g. minimum of six weeks but could be longer depending on complexity of issue
Design	<ul style="list-style-type: none"> Identify communication strategies, agenda, issues, expectations, resources, tools and methods
Engage and report	<ul style="list-style-type: none"> Identify the method of engagement (see Method selection table below), forums, feedback mechanisms and action/task list to meet the objectives through the engagement plan with the stakeholders
Implement	<ul style="list-style-type: none"> Identify time, budget and milestones in accordance with engagement plan and identify lessons learnt
Evaluate	<ul style="list-style-type: none"> Evaluate and assess against the expected outcomes for BOPDHB and stakeholders against the specific aims and objectives Share the learning and integrate the outcomes into relevant practice

Adapted from the Queensland Health Consumer and Community Participation Toolkit 2002

When planning any project, consider any existing mechanisms to capture feedback that may have data/information available for use in quality improvement projects e.g. BOPDHB Patient Experience Surveys, online feedback form, Quality and Patient Safety email address, staff, “Do you want to tell us something” forms etc.

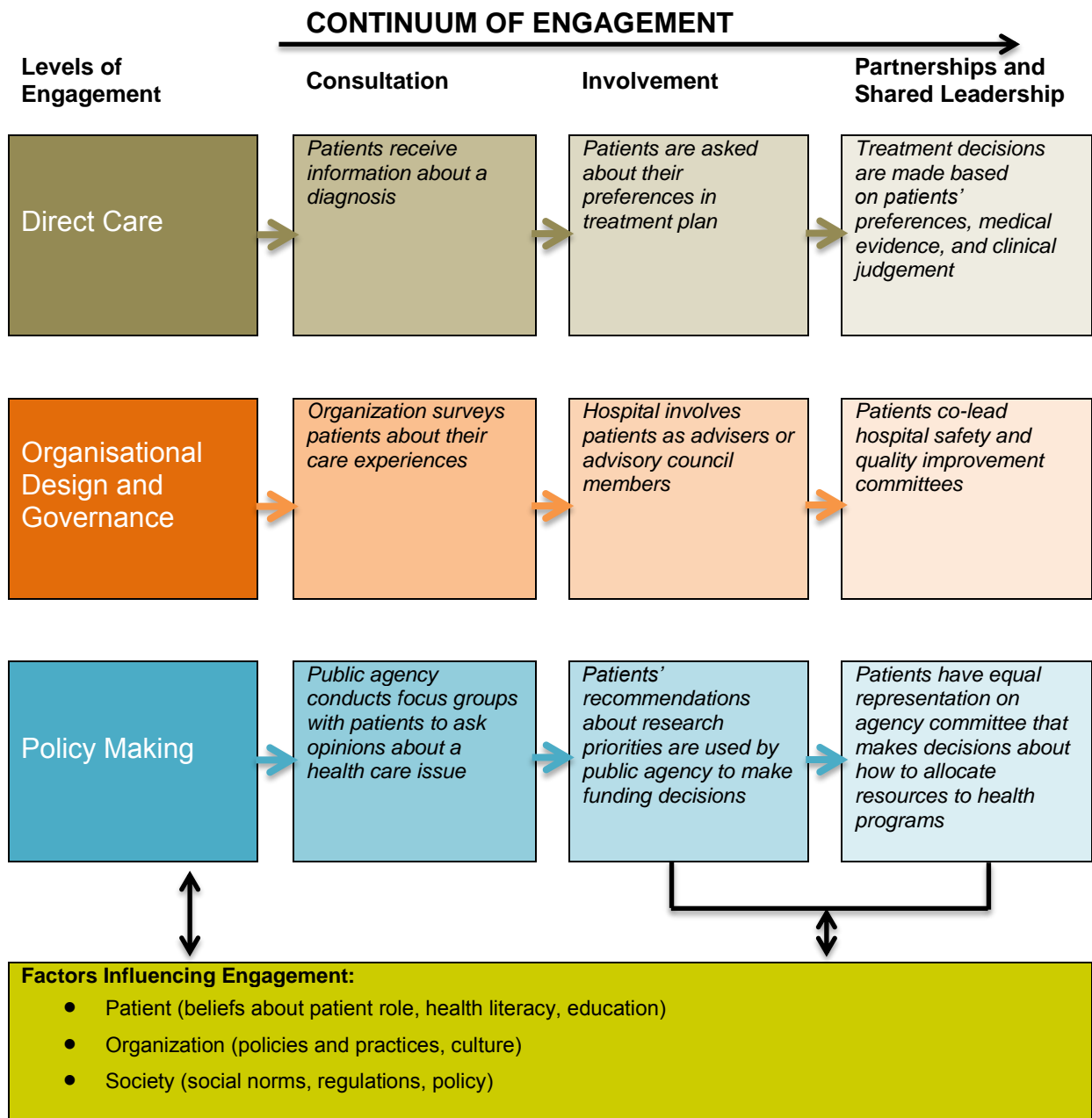
4.3 A Multidimensional Framework Tool for Patient and Family Engagement in Health Care

This multidimensional framework tool demonstrates that patient and family engagement exists in multiple forms along the continuum of engagement. Traditionally, consultative interaction has taken place solely on the lower end of the continuum of engagement. However by moving along the direct care continuum, patient input and shared decision-making increases to involvement and, finally, leads to partnership and shared leadership. The partnership and shared leadership at the higher end of the continuum has communication moving in both directions, and responsibility for decision making is shared. Moving along either the level of engagement or the continuum of engagement axis requires culture change that consists of support and commitment of leadership and providers, patient education, and potential changes to workflow, policies, and procedures.

The framework tool highlights that engagement is not confined to individual health behaviour or direct care interactions, but can include organisational design, governance, and policy making. Consumers can interact in a variety of settings, including community-based services, clinics, and hospitals. Patient and family needs, desires, and preferences can be included in each of these settings along the continuum of engagement.

Using the blank framework tool at the end of this document can assist planning the level of consumer engagement required for any project.

4.4 Continuum of engagement



Source: Kristin L.Carman, Pam Dardess, Maureen Maurer, Shoshanna Sofaer, Karen Adams, Christine Bechtel, and Jennifer Sweeney, "Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies,"Health Affairs" 32, no. 2 (2013): 223-31.

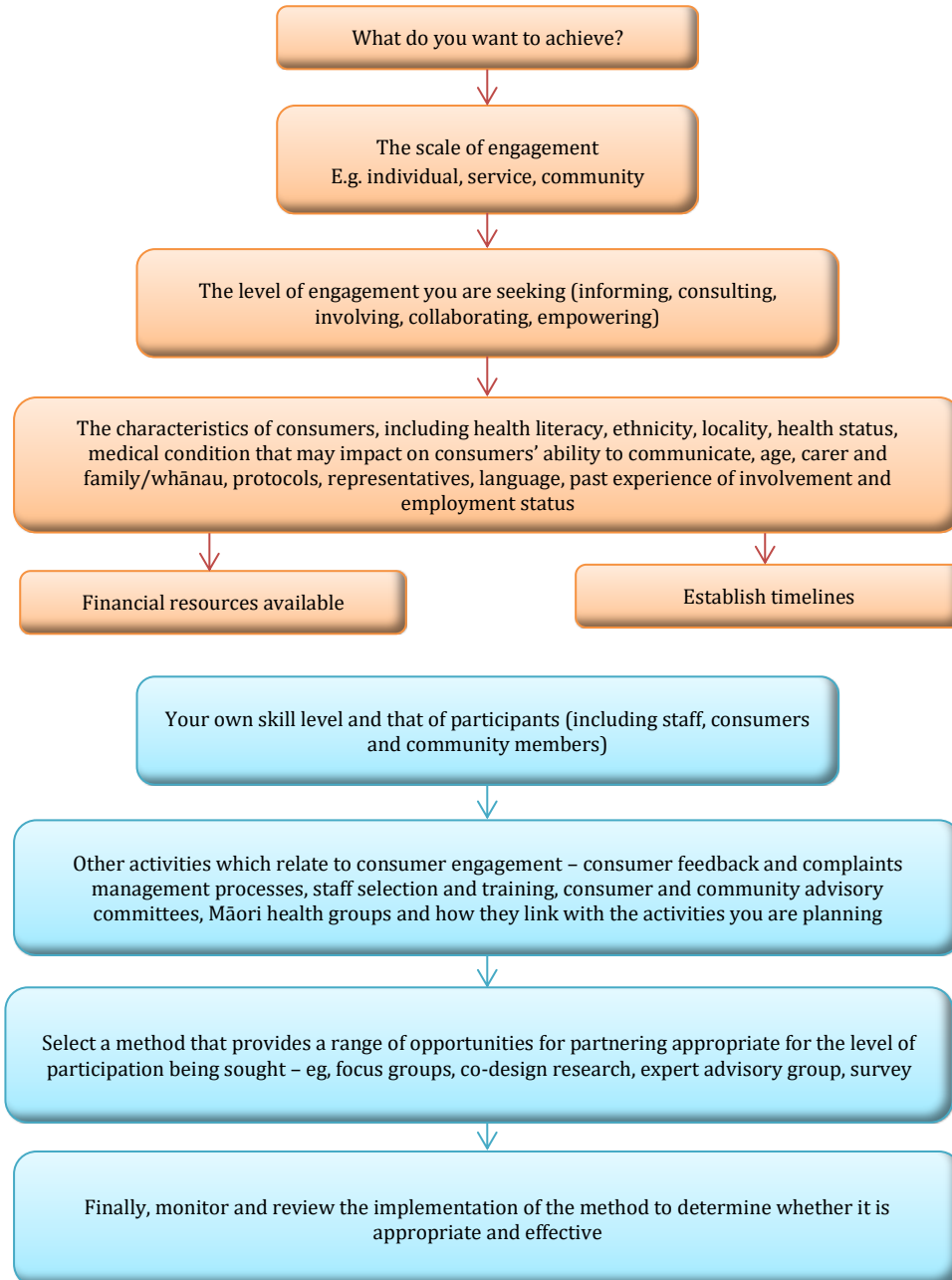
4.5 Method selection

This method selector table is adapted from the Consumer and Community Participation Toolkit, Queensland Health, 2002 and describes some of the more commonly used methods, their strengths and limitations along with tips for their use:

METHODS	STRENGTHS	LIMITATIONS
Survey – can be written, telephone, Email, face to face	<ul style="list-style-type: none"> Email and mail out questionnaires are inexpensive Can cover a wide geographic area Useful for gathering quantifiable information 	<ul style="list-style-type: none"> Questions need to be structured, straight forward and unambiguous Literacy may be an issue Often low response rates Limited opportunity to probe in telephone/written surveys Consumers may not be able to afford or access internet facility.
In-depth interviews	<ul style="list-style-type: none"> Useful to follow up specific issues Provides in-depth information from selected stakeholders 	<ul style="list-style-type: none"> Requires skilled interviewer Time consuming Small numbers – requires careful selection of consumers
Focus groups	<ul style="list-style-type: none"> Quick and low cost Allows exploration of issues identified through surveys Useful for collecting information on a specific issue 	<ul style="list-style-type: none"> May not be representative of consumers Not suitable for information dissemination Not suitable for decision-making Requires skilled facilitator Language barriers
Public meetings and forums	<ul style="list-style-type: none"> Opportunity for anyone to attend New networks created A forum for debating issues Opportunity for information dissemination and sharing 	<ul style="list-style-type: none"> Poor attendance Confidentiality issues Risk of domination by particular individuals or groups Not representative of population or views May be difficult to stay focussed on issue Requires skilled facilitator People with a disability may be disadvantaged (hearing, sight, language)
Consumer representatives on Committees	<ul style="list-style-type: none"> Medium to long term perspective Encourages debate Ensures accountability 	<ul style="list-style-type: none"> Requires orientation and ongoing support Costs / reimbursements Requires organisational commitment to meaningful participation
Workshops	<ul style="list-style-type: none"> Can develop a shared approach to a specific issue Brings together selected people from diverse groups Structured session can produce a plan or recommendations 	<ul style="list-style-type: none"> Small numbers – needs careful consideration of participants Requires skilled facilitator Participants may need particular skills, knowledge or experience
Social Media	<ul style="list-style-type: none"> Effective tool to help engage and disseminate information and resources to large audiences Delivers messages to those who want to receive it Can amplify messages and Celebrate successes Can build and strengthen reputations 	<ul style="list-style-type: none"> Organisational confidentiality and privacy guidelines extend to use of social media Low cost, low time commitment, no advertising required Limited current BOPDHB use of social media (2015)

4.6 Decision Tree

The decision chart below has been adapted for New Zealand by the HQSC and may help you plan for your consumer engagement co-design projects. The selection of methods and techniques will take into account a range of issues including the level of partnering sought, desired outcomes, resources available, views and the needs of consumers and the community, the locality and the skill levels of participants.



4.7 Method Guides

4.7.1 Patient Experience Surveys

All BOPDHB staff can access to the BOPDHB Patient Experience Survey Dashboard through direct login on OnePlace and this is an extremely useful mechanism for inviting feedback from a large number of people using our services. The survey results including free text comments from respondents are available for use and may provide the information you are looking for.

- The National Adult Inpatient Experience Survey is undertaken quarterly when 400 inpatients discharged in the previous two weeks are invited to complete a survey.
- BOPDHB also conducts the fortnightly survey using the same questions

Additional questions can be added to the survey for a period of time. There is a cost involved but this may be of use for large projects to provide a baseline or evaluate results. For more information about the surveys contact your service's Quality & Patient Safety Coordinator.



4.7.2 Co-design Resources

A comprehensive New Zealand co-design resource is available <http://www.healthcodesign.org.nz/> which provides practical information regarding how to effectively plan co-design projects with patient, family and/or carer focus groups/discussions including identifying your target group, inviting participation and selecting a facilitator. There is a hard copy version of this resource available through BOPDHB Tauranga and Whakatane Hospital libraries.

Other external toolkits and sources of information:

- HQSC Partners in Care: <http://www.hqsc.govt.nz/our-programmes/partners-in-care/>
- The Kings Fund Experience Based Co-design: <http://www.kingsfund.org.uk/projects/ebcd>
- NHS Experience Based Design: [http://www.institute.nhs.uk/quality_and_value/experienced_based_design/the_ebd_approach_\(experience_based_design\).html](http://www.institute.nhs.uk/quality_and_value/experienced_based_design/the_ebd_approach_(experience_based_design).html)

4.7.3 Collecting Patient Stories

a) Patient rights, privacy and ethics approval

Contacting patients, families and carers for quality improvement purposes is accepted practice in health care and this framework outlines different ways to engage with patients, families and carers for service improvement purposes while maintaining due respect for the ethical principles of:

- Avoiding undue pressure or coercion
- Informed consent
- Maintaining privacy and confidentiality
- Providing a mechanism for withdrawing

Collection of patient stories can only be undertaken with consent. The consent and registration form included in this framework. At the beginning of any discussion, staff are encouraged to ensure the participant fully understands the process and formally consents to participation. Staff should explain the purpose of collecting a story, answer any questions the participant may have, confirm the mechanisms available to protect the confidentiality of the story and ensure the participant knows how to withdraw their consent if required. Participants can also nominate an 'alias' for use in their story if they prefer.

Ethics approval is only 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 contact BOPDHB Ethics Committee.

b) Staff Responsibilities

Any staff member collecting patient stories is responsible for:

- Gaining consent and registering the collection of the story with the Quality and Patient Safety Administrator (qualityandpatientsafety@bopdhb.govt.nz).
- Recognising own limitations and acknowledging when they need advice and support

If the participant reveals something during the interview that may necessitate further discussion, investigation or action, the BOPDHB Complaints and Incident Reporting policies should be followed:

- Recognising when issues revealed need to be acted on and how to do so
- Discontinuing the interview if the participant is distressed and indicates that they wish to terminate the interview
- During the interview the interviewer will not react at the time, but may raise an issue again once the interview is completed
- If immediate action is required, the participant can be asked whether they have raised their issue/concern with anyone in the organisation and provide information to the participant on how this may be done
- Information obtained at the interview is confidential, it may not be appropriate for the interviewer to take matters forward without the participant's specific consent to do so.
- For more support or advice please contact the Quality and Patient Safety Team.

c) Sharing Patient Stories

Not all BOPDHB staff trying to improve care processes will have the access, skills, time and ability to run patient focus groups, undertake surveys or interview patient groups. It is important, therefore, to ensure that any stories that are collected can be shared to ensure knowledge, learnings and solutions are to be shared with other areas experiencing similar issues.

If you have already conducted (or you are planning to conduct) interviews with patients please consider gaining the participants permission to share these stories across the organisation. Once consent is gained stories may be submitted to Quality and Patient Safety in the form of written transcripts, and/or patient surveys where qualitative comments have been provided. Notation of audio or digital (AV) recordings can also be stored but these files will be stored by the Digital Communication Team.

All submissions for inclusion on the Patient Stories database must include a completed consent and registration form, information on when and how they have been collected, how they can be used and emailed to: qualityandpatientsafety@bopdhb.govt.nz.

Staff accessing a Patient Story from the request a transcript or file, providing that:

1. The story is not altered or modified in any way
2. Acknowledgement is given to the project team that provided the patient

3. Feedback is provided to the Patient Stories team via email when a patient story has been used and whether the story was successful in achieving the desired result (qualityandpatientsafety@bopdhb.govt.nz).

d) *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 from both perspectives at once, however, the relationship between the patient and carer may make it difficult for one or the other to be completely forthright. For example, carers may not be completely honest or provide adverse information about the journey for fear of upsetting the patient or vice versa. Be guided by the preference of the patient and carer.

e) *Guidance for Video or Digitally Recorded Stories*

Videoining or audio-recording conversations may have some advantages in improving transcription; however it may also act as a barrier to open discussion and make the process too formal. Therefore, recording discussions is not generally necessary or recommended. This method of recording stories should only be chosen when the desired finished product is a video or audio recording of the patient/family member/carer talking about their experiences e.g. a video of the patient (video story), or as a photographic slideshow overlaid with an audio recording of the patient (audio story). There are additional issues to be considered by both the story taker and participant.

- ***Technical issues***

In order to record good quality audio-visual (AV) material, the interviewer will need to work with a Multi-Media Designer. Equipment to produce the recording may include a video camera with inbuilt microphone, an external microphone and an audio field recorder. As the set-up and use of AV equipment is a specialist role in its own right, interviewers must approach and organise with appropriate staff with the time and skills to assist them, advice can be sought from the BOPDHB Digital team.

- ***The interviewing space***

As the equipment will record all sound as it is heard within the interviewing space, a number of issues become significant. The identified space should be quiet and unlikely to be disturbed, away from sources of noise, such as photocopiers, ticking clocks and loud computers or busy roads outside the window. Consideration should also be given to the weather, as rain on the roof or a howling wind will also affect the sound recording. The space must also be acoustically suitable, in that the space does not echo e.g. spaces with soft furnishings have fewer echoes than spaces with hard surfaces and windows.

All of the above apply to audio recordings. If the story is to be video recorded, the space should also have a plain wall or suitable backdrop for the video and be well and softly lit, so that harsh shadows are not cast.

- ***Interviewing techniques suitable for audio-visual recording***

As a good digital story will not give any indication of the interviewer, the importance of asking open questions is paramount while remembering that whatever is said by the interviewer will also be recorded, and so the interviewer must avoid things like giving verbal encouragement to the storyteller. Before starting the interviewer should encourage the storyteller to phrase their story in whole sentences as this makes the editing work easier.

- ***Translation and bilingual issues***

Participants may want to give their stories in their own language of choice, options for translation should be discussed with the participant and they should be matched with an interviewer who is able to communicate with them in their language of choice and has the ability to translate if required (<http://oneplace/Org/Pages/Interpreters.aspx>). Some of the issues encountered may be:

- a. Participants who are fluently bilingual may be happy to record their experiences in different languages, which will ensure that the participant's own words and emphasis are retained.
- b. Dubbing another language over the video or photographic slideshow will require the original story to be transcribed verbatim, translated and then recorded in another language by a fluent speaker. This new audio track will then need to be edited with the video to create a new version of the patient story.

- c. Subtitling the original story will need transcribing and translating and then edited into the video by a Multi-Media Designer or transcribing to provide as a bilingual written version.

f) Timescales

Producing a video or audio story can be a time consuming process. An hour-long interview may be cut down to two or three minutes of the most powerful material and additional time will be required to edit the recording.

g) Formats, storage and archiving

To make digital patient stories as accessible as possible across the organisation, each finished story is saved both as an .AVI file at high resolution, and as a .mpg lower resolution file that can be played by Windows Media Player. Stories which have been produced purely on audio, with no accompanying video or graphic images, are saved in mp3 format.

Both the finished product and the original recording are saved to a designated standalone space held by the digital team, or to DVD. Consideration should be given to the confidentiality and sensitivity of the information of both the original and finished story when arranging how to save and store the files, as well as any specific instructions the participant has given as to the handling of their story. A copy of the finished product on DVD can also be sent to the Patient Stories Administrator, Quality and Patient Safety

For further Information about collecting your patient audio-visual (AV) story please contact the BOPDHB Digital Team.

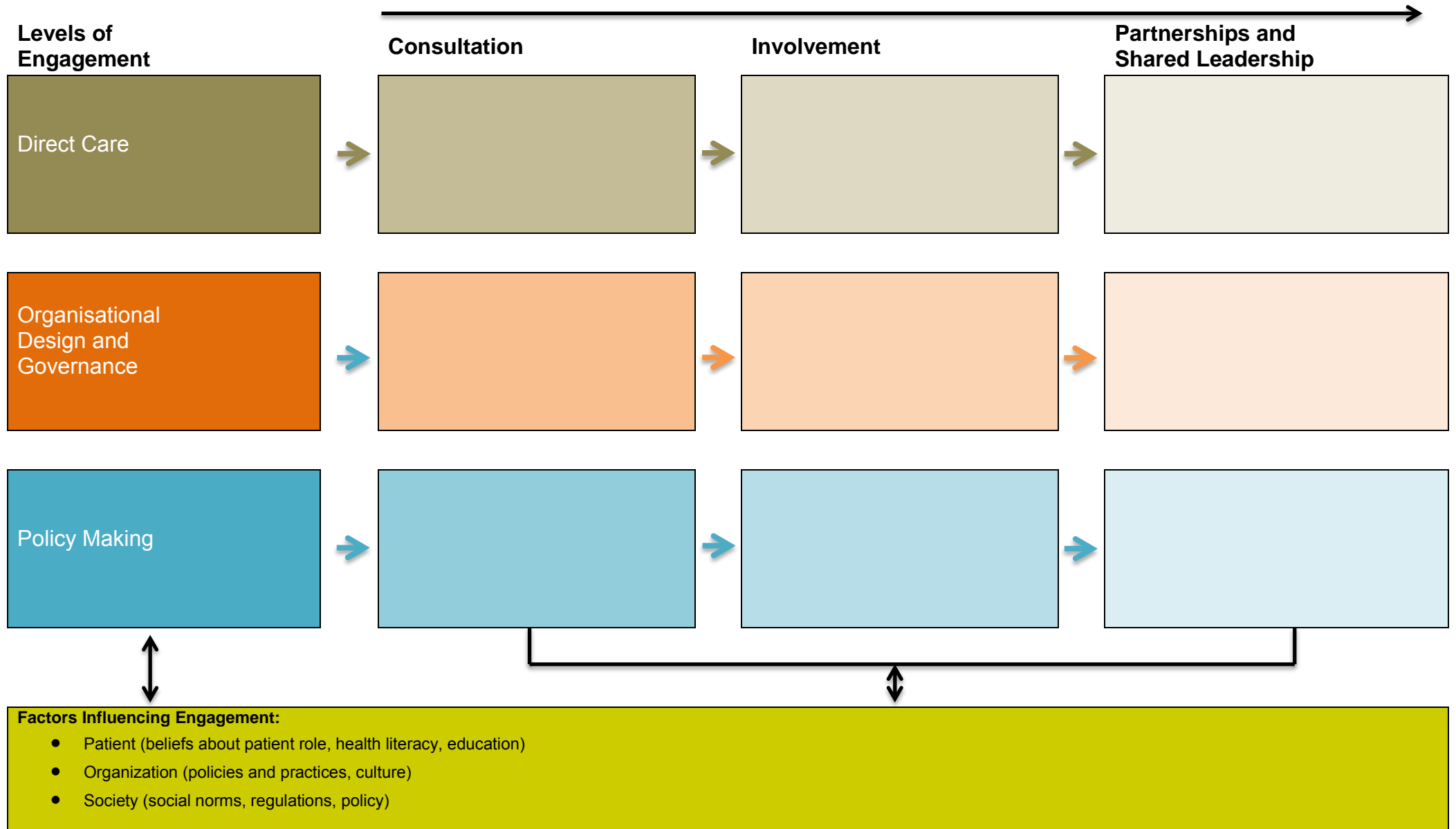
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Consent and Authority to use Patient Story Form			
<i>Copy for patient/Carer and copy to Quality and Patient Safety</i>			
<p>1. I have read and understand the Patient Stories - Information for Patients sheet and have had the opportunity to consider the information, ask questions and have these answered satisfactorily.</p> <p>2. I understand that my participation is voluntary and I am free to withdraw at any time and I can ask for any comments I have made on tape, in writing or on film to be removed.</p> <p>3. I understand that my story (or part of it) may be used in different formats such as video, paper and/or electronic and be share with others for the benefits of designing services and education.</p> <p>4. I understand that transcripts of my story will be stored in a safe environment and disposed of in a confidential manner.</p>			
Patient / Carer Name:		Contact number:	
Address or email:			
Patient / Carer Signature:		Preferred Alias	
Signature of witness:		Date:	
For Internal Use Only			
Staff member (print name):			
Department / Service		Extension:	
Email:			
Staff member Signature:		Date:	
Purpose and planned use of story collected:			
File name and location:		Content identifier:	
<p><i>Completed Patient Stories Consent and Registration forms must accompany all submissions of Patient Stories – scan and email to: qualityandpatientsafety@bopdhb.govt.nz</i></p>			
<i>Date consent withdrawn by storyteller:</i>		<i>Date story removed from database and disposed:</i>	

A Multidimensional Framework Tool for Patient and Family Engagement in Health and Health Care

CONTINUUM OF ENGAGEMENT



Source: Kristin L. Carman, Pam Dardess, Maureen Maurer, Shoshanna Sofaer, Karen Adams, Christine Bechtel, and Jennifer Sweeney, "Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies," *Health Affairs* 32, no. 2 (2013): 223-31.

Capturing Patient Stories – Quick Guide

Checklist for Opening Discussion	Capturing Patient Stories – Quick Guide		Checklist for Closing Discussion
<ul style="list-style-type: none"> • Introduce yourselves (name, position/role, business unit) • Thank participant(s) for their time, honesty and willingness to speak with you • Advise participant how their story will be used, confirming that their information will assist in developing solutions to improving services, provide overview of project • Refer to contacts within the consent form if they have any questions or concerns and reaffirm their privacy will be protected and confirm their ability to withdraw their story at any time by returning portion of consent • Obtain written consent if not already received • Ask if participant has any questions or concerns prior to conducting the discussion 	1. Contact the Patient &/or Carer Telephone / Letter / in person	<ul style="list-style-type: none"> • Thank the participant • Explain the process of what will happen next and that a draft copy of the story will be sent to them for verification and/or editing • Ensure participant has copy of consent form and Patient information sheet • Ensure you have obtained a signed copy of consent from participants prior to departure • Ask if participant has any questions or concerns prior to concluding the discussion 	
	2. Schedule Discussion Invite patient/Carer to determine date, time & venue Schedule two staff to attend, allow at least an hour		
	3. Conduct Discussion Ensure a quiet, private space to maintain confidentiality		
	4. Resources to take Identification, mobile phone (in silent mode), transcript & consent form		
	5. Analyse Results Write up the story in the patient & carers voice using as many direct quotes and phrases as possible Follow up on any issues or concerns raised within agreed timeframes		
	6. Provide Feedback Send Thankyou letter to patient/carers with a copy of their story for verification and/or editing – enclose postage paid envelope to facilitate return of amended story		
	7. Contact the Patient &/or Carer Complete Patient Story Registration & Transcript forms Scan & email all with consent form to qualityandpatientsafety@bopdhb.govt.nz		
	Practical Tips <ul style="list-style-type: none"> • Take extra pens • Take a clipboard to support you as you write • Ask the participant if they have any pets and ensure it will be safe for staff to enter the participant’s residence (if required), also consider that some staff may be affected by cigarette smoke and pets when making arrangements • Choose attire that is professional and will not be intimidating to the patient/carers 		

