An evaluation of the co-design programme 2014–15

Prepared by Ko Awatea’s Evaluation Officer – Brooke Hayward

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Finally, thanks to Ko Awatea’s Director of Innovation, Lynne Maher. Lynne is the programme facilitator for the co-design programme and was highly valued by consumers, team members and sponsors alike for her skills, availability and ‘going above and beyond’ in the support she provided to project teams.
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Executive summary
This evaluation applied qualitative data collection methods to gain in-depth information from team members, sponsors, consumers and the programme facilitator to meet evaluation objectives. The evaluation aimed to:

- describe the challenges and solutions by participating teams to increase the engagement of consumers to co-design of health services
- describe how the approach is being embedded into daily practice, and identify opportunities to increase sustainability of the approach
- determine the level of leadership support provided to team members and how this impacts on the achievements and learning experiences of teams
- produce simple but effective advice on how to engage consumers in the co-design of health services.

It involved the participation of the programme facilitator, nine team members, five sponsors and four consumers in either semi-structured interviews (N=17) or written feedback (N=2). Consultation with the Consumer Council from Counties Manukau Health provided further consumer insights on engaging consumers in co-design projects. Written materials from project teams were also provided as a source of data for this evaluation.

The strongest themes emerging in consumer and team members accounts regarding consumer engagement included:

- the importance of relationships and networks from project conception to completion
- tailoring of engagement approaches – there is no ‘one right way’ to approach consumers; engagement should be tailored to specific individuals or consumer groups. Likewise, consumers should have more than one way to provide feedback or share their consumer experience
- consumer engagement is value driven and highly personal.

Consistent with previous evaluations, team members continue to feel they do not receive enough support from sponsors or senior leaders to make the most out of their participation in the programme, with 63 percent of project teams being unsatisfied with the level of support received by project sponsors. A key challenge for sponsors who support project teams was finding time to dedicate to projects as they manage several competing commitments. Buy-in and engagement from senior leaders was fundamental to project teams being able to secure release time to work on their project, validate the EBD approach, overcome barriers to change, and implement recommended solutions.

There were a number of opportunities identified to increase sustainability of the experience based design (EBD) approach, related to increased buy-in and engagement from frontline health care professionals, sponsors and senior leaders, alignment with broader projects, priorities or policies and systems or culture change.

Key areas for improvement were identified as part of this evaluation including:

- utilising more than one approach method for reaching consumers
- engaging more than one consumer to work with at project level
- building rapport between consumers and project teams (rather than one health care professional), to enable ongoing engagement in the event of workforce turnover
- providing assurance to consumers about the contributions they are making, and feedback on how their contributions have been applied, implemented solutions, and impact on other consumers engaged in health care services
- sponsors regularly ‘checking in’ on support needs of project teams
- team members asking for help when they need it and communicating support needs
- securing financial resources for the implementation of EBD solutions
- increasing attendance of the masterclass by all team members
- increasing presence of project sponsors through increased engagement in project meetings, informal discussions and WebEx sessions
- developing more structured and formalised methods for sharing EBD skills across health care organisations to increase capacity amongst the health care workforce.

Key areas for improvement, instead of evaluation recommendations, were made in recognition of the existing work and partnership approaches committed by Ko Awatea and the Health Quality & Safety Commission to continuously improve the co-design programme.
Introduction

The Partners in Care programme was developed by the Health Quality & Safety Commission (the Commission) to support health care organisations in delivering its stated aim to ‘improve quality, safety and experience of care’ and to ‘increase the engagement of consumers in decision-making about the services they use, and to increase consumer literacy and capture consumer experiences’. Part of this work has involved the funding of the co-design programme, which has several core principles including:

- to achieve a partnership between patients, staff and carers
- an emphasis on experience rather than attitude or opinion
- narrative and storytelling approach to identify ‘touch points’
- an emphasis on the co-design of services
- systematic evaluation of improvements and benefits.

Ko Awatea’s Director for Innovation, Lynne Maher, was recruited by the Commission to deliver the co-design programme, under the auspices of the experience-based design approach (EBD) to co-design, for its third iteration from October 2014 through to the end of April 2015. In this iteration, Lynne has worked with nine health care organisations to deliver content around core principles of the programme. Participants in this iteration of the co-design programme were encouraged to select project areas that supported the Commission’s national patient safety campaign, Open for better care, which is a current focus area of the Commission.

The experiences that patients, the public and health care staff have when they receive or deliver health care services are a valuable source of information that can be used to improve safety of care and transform services. The co-design programme has been designed to support and enable consumer engagement and participation across the health and disability sector in decision-making about their own health and the delivery of health and disability services in New Zealand. Consumers are encouraged and supported to participate at a level appropriate to their needs, skills and experience.

Participants in this co-design programme are able to take advantage of the latest developments in utilising patient experience to improve safety through the co-design of health care processes and services. This programme also contributes to vision and values assumed by many health care services to work in partnership with their communities to deliver person or patient-centred care.

Background

The EBD approach (used interchangeably with ‘co-design’) was developed by the National Health Service in England. It ‘uses patient and staff experience to design better health care services’, and was successfully used to support delivery of the co-design programme by Ko Awatea in 2012, 2013 and now 2014–2015. The EBD approach is an evidence-based approach¹ applied within health care services in England,² Canada, the USA and New Zealand,³ contributing to various health care system changes for improved consumer experiences. The approach utilises various tools to draw out or capture the subjective and

personal experiences of consumers and carers who use health care services, and subsequently ensures that health care professionals understand experiences from the perspective of staff, consumers and carers.

The EBD approach entails the use of a specific range of tools/resources applied across several stages, captured in Figure 1 below.

**Figure 1: Summary of project phases for the co-design programme projects**

<table>
<thead>
<tr>
<th>Prepare</th>
<th>Capture</th>
<th>Understand</th>
<th>Improve</th>
<th>Measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Introduction EBD</td>
<td>• Capture consumer experience</td>
<td>• Understand the experience</td>
<td>• Improve the experience</td>
<td>• Measure the improvement</td>
</tr>
<tr>
<td>tools, roles and</td>
<td>• Use tools to help people tell their stories</td>
<td>• Tools for understanding consumer</td>
<td>• Tools to turn experience</td>
<td>• Tools for measuring and evaluating</td>
</tr>
<tr>
<td>structures</td>
<td></td>
<td>and staff experiences</td>
<td>into action</td>
<td>improvement</td>
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</table>

**Programme content and activities**

Participation in the co-design programme commenced with team members and consumers from each of the project teams attending one of two masterclasses (a one-day training delivered twice – once in Wellington and once in Hamilton). The masterclass aimed to increase participants’ competencies in the following areas:

- Understanding the context, value and evidence base for working closely with patients and their families.
- Awareness of a staged process to engage patients, capture their experiences of care, organise and identify themes for improvement and to co-design future services.
- Increased knowledge of a range of specific customer service design methods including observation, shadowing, interviewing, emotion mapping and co-design.
- Application of these methods to the context of improving safety in health care linking to the national patient safety campaign work streams.

The masterclasses included a mix of presentations, group work, and discussion so that participants could maximise their learning.

Over the seven-month course duration, seven one-hour WebEx sessions were delivered by Lynne Maher, which incorporated formal teaching by Lynne, and opportunities for
An evaluation of the co-design programme 2014–2015

participating teams to share their progress and ask questions. In addition to the formal teaching delivered at the initial masterclass and subsequent WebEx sessions, participants are also invited to contact Lynne whenever needed. Lynne facilitated ‘coaching’ calls and email to a number of participants throughout the programme duration.

During the programme, participants also completed written programme requirements including a workbook and case study template. Workbooks were completed by each project team twice throughout the programme period to capture learning over the duration of the programme. These were reviewed twice by the Programme Facilitator to provide feedback and direction as teams’ progressed through the programme. Workbooks aimed to capture the following:

- Evidence of each project teams’ work and feedback from each phase of the EBD approach.
- Practical experience of utilising approaches that increase the engagement of consumers and lead to co-design of health services.
- Stories/narratives that demonstrate the impact of working closely with consumers.
- The impact that participating in this programme has on them as an individual, patients/consumers they are working with, other people working with them and the organisation they work for.

The completion of the case study template captures a 500-word case study describing their project.

Co-design programme participants have access to a wide range of resources and learning material through the Commission website. This includes relevant peer reviewed papers, other helpful documents and website links about consumer experience. They can also share their own learning resources and useful documents with other participants through this website.

**Previous evaluation findings**

The first iteration of the co-design programme was delivered from May 2012 to February 2013, and the second from October 2013 to June 2014. Both iterations of the programme were evaluated with an aim to:

- understand more about participants’ experience of the co-design programme/EBD programme
- capture any learning and experiences that can be shared amongst all of the project teams
- identify any potential areas of concern that may require additional support
- consider ways in which the programme may be improved.

Previous evaluation findings included a description of team members’ view of the EBD approach, emotional experiences over the duration of the programme, and satisfaction with various programme components such as the masterclass, distance learning approach, web based learning seminars, EBD ideas and concepts, and quality of supporting material and ongoing support.

**Support**

Previous evaluation findings identified some problematic aspects of sponsorship or support of project teams. Securing support from senior staff for their project and/or arranging meetings with senior staff was a challenge for several project teams. Moreover, lack of
regular engagement from senior leaders ‘could have a detrimental effect on [the] sustainability of some projects’ (p11).

While it is clear that, historically, not all teams obtained the level of leadership support they would like, there is limited discussion about what an ‘ideal’ level of support looks like. Gaining clarity around support needs for project teams is an important step in being able to clearly communicate support requirements to senior staff, and meet the needs of team members.

The level of support received from colleagues and other staff members has varied across project teams and over each programme iteration. Evaluation findings from the first iteration of the programme suggested there was some lack of collegial support: 8 of 24 respondents (33 percent) ‘disagree’ or ‘strongly disagree’ that staff were enthusiastic about the EBD approach. Further, seven respondents ‘disagree’ or ‘strongly disagree’ that staff willingly supported the co-design projects, and were willing to participate in the project (for example, being interviewed or filmed).

Evaluation findings from the second iteration state that engagement of other staff was generally positive. Eight of nine evaluation respondents described staff as being enthusiastic, actively involved, or willing to participate in aspect of the project. Overall, team members from both iterations of the project describe their colleagues as supportive of (i) offering quality care to their patients and (ii) the EBD approach for improvement work. The lack of enthusiasm or support experienced by some team members across both iterations of the programme most often related to staff/colleague participation in interviews or videos.

**Sustainability of the EBD approach**

From previous evaluations, we know that team members are utilising the tools and resources provided to them throughout the programme duration. The tools used by participants of the second iteration of co-design programme to capture consumer experiences are summarised in Table 1 below. However, we do not yet have a clear understanding of how these tools may be applied to other co-design projects in the future.

**Table 1: Tools used by evaluation participants to capture consumer experiences throughout the second iteration of the co-design programme**

<table>
<thead>
<tr>
<th>Description of tool</th>
<th>Participants who reported using it:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observation</td>
<td>2</td>
</tr>
<tr>
<td>Filming</td>
<td>1</td>
</tr>
<tr>
<td>Interview</td>
<td>3</td>
</tr>
<tr>
<td>Discussion</td>
<td>0</td>
</tr>
<tr>
<td>Emotion questionnaire</td>
<td>2</td>
</tr>
<tr>
<td>Emotion mapping</td>
<td>2</td>
</tr>
<tr>
<td>Wordle</td>
<td>1</td>
</tr>
</tbody>
</table>

Anecdotally, previous evaluations suggest that the programme may be inspiring further co-design work in the health sector: ‘I have heard that this programme has generated many other co-design projects in the sector and created quite a wave of enthusiasm for co-design in the health sector’ (p21); ‘This programme is leading to a general increase in consumer

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involvement in my organisation\textsuperscript{4} (p14). The extent of skill sharing and embedding of EBD approaches is currently unknown. From self-reports, it is clear that the confidence of team members to engage with consumers in co-design processes increases over the programme duration. Self-reports also indicate that team members demonstrate a high level of enthusiasm to share their learning with others to spread EBD practice locally. Building on this evidence, it is now important to identify opportunities to further embed EBD approaches into localised practice in health sectors, and identify committed resources to enable this.

**Engaging consumers**

Drawing on team members’ experiences, previous evaluations contributed a number of recommendations for engaging with key stakeholders, including consumers. These are summarised in Table 2 below.

**Table 2: Summary of recommendations for engaging with consumers from previous evaluation reports**

<table>
<thead>
<tr>
<th>Recommendations for engaging with consumers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Timing of engagement</strong></td>
</tr>
<tr>
<td>Engage key stakeholders at the earliest opportunity (sponsors, consumers, and your team).</td>
</tr>
<tr>
<td>Focus on building and maintaining relationships throughout, particularly by devoting time to get patients to express their needs and views.</td>
</tr>
<tr>
<td><strong>Communications</strong></td>
</tr>
<tr>
<td>Maintain open and honest communication during initial engagement phases, as well as providing regular updates to keep stakeholders informed of progress.</td>
</tr>
<tr>
<td>Have a clear understanding of what you are asking of consumers and what commitments they have to make.</td>
</tr>
<tr>
<td>Use patient stories to make engagement with staff and senior leadership more powerful and effective.</td>
</tr>
<tr>
<td><strong>Patient centred</strong></td>
</tr>
<tr>
<td>Do not make assumptions about the needs of consumers, their family/whānau.</td>
</tr>
</tbody>
</table>

Experiences of team members attempting to engage with consumers highlight that their availability, locality, enthusiasm and competing commitments can make it difficult to maintain regular contact. Further, team members could find it difficult to recruit consumers when they were unclear what commitments they were asking for: ‘It was really challenging to recruit a consumer, we were not entirely sure of how the project would run and therefore describing the co-design programme\textsuperscript{6} (p14). Challenges faced by team members whilst engaging with consumers also included:

- identifying a consumer to work with the team at a ‘project’ level
- identifying a consumer who has the time to commit
- illness of consumers during the project duration.

Despite the challenges experienced by team members in approaching and maintaining engagement with consumers, previous evaluation findings have shown that consumers (as well as team members) are highly motivated and enthused about being involved in the programme: ‘We have not encountered a negative comment and 100% of those invited have accepted’. However, evaluations need further exploration of consumer experiences of participating in the co-design programme. Though the second evaluation did include telephone interviews with 12 consumers, recommendations for future co-design
programme participants has been largely oriented around the enhancing experiences for staff or team members, with more room to include recommendations to improve the experiences of consumers.

The current evaluation
Building on the findings of the two previous evaluations, the current evaluation focuses on the transition from theory to practice, exploring the experiences, challenges and solutions that teams encountered while engaging with consumers in their projects.

Evaluation objectives
- To describe the challenges and solutions by participating teams to increase the engagement of consumers to co-design of health services.
- To describe how the approach is being embedded into daily practice, and identify opportunities to increase sustainability of the approach.
- To determine the level of leadership support provided to team members and how this impacts on the achievements and learning experiences of teams.
- To advise on how to engage consumers in the co-design of health services.

Methodology
The evaluation framework for the co-design programme 2014–15 was developed in collaboration with Lynne Maher, Commission staff and the research and evaluation team of Ko Awatea, Counties Manukau Health. The agreed evaluation framework seeks to gain in-depth information about the experiences of staff and consumers navigating a co-design approach to change in health care systems, while minimising evaluation demands on participants and intrusions in daily practice of clinical staff. The evaluation focuses on obtaining information from several key audiences including:
- consumers engaged in the co-design programme
- project team members
- project sponsors (senior leaders who have supported project teams at each site)
- programme facilitator.

Evaluation design and methods
This needs evaluation applied qualitative data collection methods to gain in-depth information from key stakeholders to meet evaluation objectives. This design does not seek to produce generalisable results, but rather provide a thorough examination of consumer, team member and sponsor experiences of the co-design programme through qualitative data collection methods which will be revealing about the programme in its entirety. The following data collection methods were utilised throughout this evaluation process:
- Study and analysis of teams’ workbooks and other relevant materials.
- Semi-structured interviews with team members and sponsors.
- Semi-structured interviews with consumers.
- Semi-structured interview with the programme facilitator.

Workbooks are an appropriate source of data as they are completed as a programme requirement and therefore do not place any additional burden on staff to participate in evaluation activities. They provide various insights including learning and reflections of
project team members. Other relevant materials which are generated by team members include:

- presentations for contributions to WebEx sessions
- completed case study templates.

Semi-structured interviews are typically applied in qualitative research as they provide an opportunity for the collection of rich, in-depth information, honest conversation, flexibility and rapport building between researchers and participants. Due to the location and preferences of evaluation participants, all participant interviews with sponsors, team members and consumers were conducted over the phone. Interview schedules are provided in Appendices A–C. A face-to-face interview was held with the programme facilitator (Appendix D).

**Participant recruitment**

Completed workbooks from each team were provided directly to the Evaluation team by programme facilitator Lynne Maher, with the consent of team members, twice throughout the programme period (January and June 2015). As Lynne has been involved with all project teams and is known to team members, sponsors and consumers, she also facilitated initial contact, via email, with all potential interview participants.

The purpose of this initial contact was to introduce the lead investigator, and communicate evaluation objectives and key points around typical evaluation queries potential participants may have. The contact details for the lead investigator were also provided so that participants could contact the lead investigator directly with any questions, concerns or complaints they may have about the evaluation.

Following initial contact through Lynne, all potential evaluation participants were followed up, via email, by the lead investigator. This email contact provided participant information sheets (see Appendices E–G) detailing the evaluation objectives, participant requirements, risks, and use of information, and requested that all those interested in participating responded directly to the lead investigator. For those who did not respond, follow-up contacted included email reminders and phone contact. For those who did response, a short survey was sent to assist with interview scheduling, with interviews later confirmed by phone.

**Analysis**

A written record of each evaluation interview was developed and sent to all participants for them to verify and highlight any missed points. These interview records were then de-identified to protect the confidentiality of evaluation participants in reporting. The interview records were thematically analysed. Thematic analysis is a widely applied method for the analysis of qualitative data which involves identifying underlying patterns or themes in narrative or written materials.

Thematic analysis is a process whereby the research and evaluation team:

1. familiarise themselves with the data
2. code the data to identify important features relevant to evaluation questions
3. search for significantly broader potential themes, or patterns of meaning, within coded/collated data
4. review the potential themes with another member of the team
5. define and name these themes before commencing writing of the evaluation report.
Workbook materials were filtered for relevance to evaluation questions and thematically analysed alongside interview data.

**Limitations**
As interviews are a verbal exchange, effective interviews are largely dependent on the communication skills of interviewers.\(^6\)\(^7\) Our interviewers have significant experience conducting interviews, and will therefore use various techniques such as pausing, probing, prompting and allowing free conversational flow to encourage sharing of experiences and insights related to the co-design programme.

Due to the voluntary nature of participation in this evaluation, there are limitations regarding the number of evaluation participants. Having clinical staff participate in evaluation activities is difficult given their limited time capacity during the working hours. Interview times were offered as early as 7am, and as late as 8pm to facilitate participation.

**Evaluation findings**
Evaluation findings are presented in several sections:

- Team profiles
- Consumer engagement
- Leadership and support
- Sustainability of the EBD approach.

In total, 17 semi-structured interviews were conducted for this evaluation, involving seven team members, five sponsors and four consumers. A further two team members provided feedback in written form. Completed workbooks were obtained for eight of nine health care organisations participating in the co-design programme. Due to staff turnover, one health care service was unable to complete the final workbook. Finally, Counties Manukau Health’s Consumer Council also provided feedback around consumer engagement in co-design projects.

**Team profiles**
There were nine participating health care providers in this iteration of the co-design programme:

- Counties Manukau Health
- Capital & Coast DHB
- Northern DHB
- Waikato DHB
- Lakes DHB Pharmacy
- St Johns (Mount Wellington)
- Taupo Hospital
- Island Bay Medical Centre
- Waikanae Health.


This involved the participation of approximately 56 staff across health care providers, and 17 consumers working at ‘project level’ alongside participating project teams.

There were two levels of consumer engagement for projects as described below:

- Consumers who contribute feedback, information or their perspective about their health related experience for use by the project team.
- Consumers who play a dual role in contributing feedback, information or their perspective about their health related experience, but also actively participate at project level to contribute to ongoing communications and decision making alongside the project team.

The aims of projects which teams have embarked on are described below in Table 3.

**Table 3: A summary of project aims of participating teams**

<table>
<thead>
<tr>
<th>Project aims</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improve understanding of the advance care planning (ACP) process and resources from Pacific health workers and Pacific patients’ perspective.</td>
</tr>
<tr>
<td>Support improved way-finding by consumers through consumer perspectives about the effectiveness of signs from the hospital gateway to their destination, and finding their way back out to the carpark.</td>
</tr>
<tr>
<td>Identify the most appropriate ambulance response for patients who have fallen but do not need transport to the emergency department, but may require assistance to get off the floor and assessment of their ongoing risk of falls.</td>
</tr>
<tr>
<td>Reduce the overall harm related to opioid use in orthopaedic theatre patients by 50 percent by June 2016.</td>
</tr>
<tr>
<td>Provide an outpatient hysteroscopy service, which:</td>
</tr>
<tr>
<td>1. improves patient experiences as there will be no general anaesthetic involved, thus clients can plan time off work or for childcare more easily as it only involves a short clinic timeframe</td>
</tr>
<tr>
<td>2. reduces main theatre list space, which in turn would reduce post anaesthetic care unit and ward bed space significantly</td>
</tr>
<tr>
<td>3. reduces waiting times for the patients on the gynaecology wait list</td>
</tr>
<tr>
<td>4. reduces main theatre list space, which in turn would reduce post anaesthetic care unit and ward bed space significantly.</td>
</tr>
<tr>
<td>Investigate patient experiences of referral processes into our service. We want to find out how the patients feel about being referred to our service, their experience of being recipients of the District Nursing Service, and how we can foster relationships with consumers of the service.</td>
</tr>
<tr>
<td>Increase the engagement of consumers in decision-making about the services they use, and to increase consumer literacy and capture consumer experiences.</td>
</tr>
<tr>
<td>Identify high risk vulnerable patients, develop shared care plans for these patients, identify emerging issues, and establish proactive care planning that can be accessed by all services. This is to provide a streamlined health service where important health information is shared between patient, family and providers.</td>
</tr>
<tr>
<td>To capture the experience of youth using support clinics, and also their experiences of the previous child and adolescent mental health services.</td>
</tr>
<tr>
<td>Work as a multi-disciplinary group with consumers to improve communication with patients.</td>
</tr>
</tbody>
</table>
Project aims

around falls risk and reduction initiatives with the ultimate aim of reducing the incidence of falls. We are focussing predominantly on the inpatient environment, specifically the wards with a high incidence of falls.

As at June 2015, projects were at varying levels of completeness. Not all project teams have been able to implement recommended solutions due to challenges such as lack of funding for recommended solutions. However, all project teams have succeeded in applying EBD approaches to engage with consumers and capture consumer experiences – which is key in building and applying these new skills with programme participants.

To ensure evaluation responses remain confidential, participating health care providers will no longer be identified through the remaining of the evaluation report. Perspectives and experiences of consumers, team members and sponsors in this evaluation are aggregated into summary form. Although health care providers may be unique in their capacity, resources and demographic groups served, information collected as part of this evaluation has informed recommendations intended for application at any health care provider attempting to engage consumers in the co-design of health services.

Consumer engagement

This section describes the perspectives of both team members and consumers in discussing challenges and solutions to increase the engagement of consumers in the co-design of health services. Team members continue to feel challenged by recruiting consumers to work with. For many, the EBD approach incites initial stress and anxiety as they are required to utilise new skills, challenge conventional ways of doing things, and manage competing demands on their time. Likewise, consumers can find being approached a stressful, albeit exciting experience – for vastly different reasons, however. Consumers worry: What can I offer? Will I be useful? How can I help others? Will this project really result in change? The need to contribute and help others is an emotional experience for consumers which is felt not only throughout the programme duration, but before as a decisive factor influencing their involvement, and long after as they reflect on everything they have contributed and achieved.

Findings for this section are presented in three stages of consumer engagement including: planning phase, the first encounter, and maintaining consumer engagement. The strongest themes emerging in consumer and team members accounts consistent across these stages of engagement include:

- the importance of relationships and networks from project conception to completion
- tailoring of engagement approaches – there is no ‘one right way’ to approach consumers; engagement should be tailored to specific individuals or consumer groups. Likewise, consumers should have more than one way to provide feedback or share their consumer experience
- consumer engagement is value driven and highly personal.

Since this iteration of the co-design programme concluded, the Commission has produced a resource on consumer engagement entitled Engaging with Consumers: a guide for District Health Boards8 which highlights the benefits of consumer engagement, communicates principles of consumer engagement and provides advice on facilitating consumer engagement in health care organisations.

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Planning phase
Before engaging consumers, all of the project teams prepared by:

1. defining the scope, direction or issue to address for their project (to varying extents)
2. planning pathways for approaching consumers and different experience capture tools
3. considering key consumer characteristics which were relevant to their project.

Consumer characteristics which were considered fundamental to enable project contributions included that the consumer had:

- a recent experience with the relevant health service or procedure
- advocacy/communication skills or the ability articulate their story
- interest, availability and willingness to be involved
- in some cases, a particular demographic quality such as age, gender or ethnic group (for example, a woman would be more relevant in respect to women's health services).

In the following quote, a team member describes how these considerations were central to decision making around consumers they approached: ‘We knew who would be a good patient in this…they were vocal, available and a good advocate for themselves’. The team member went on to describe that the consumer had experience navigating the hospital system, represented/advocated for other dependents well, and was able to ask lots of questions. This project also had particular personal significance to the consumer, who wanted to change a few things about their own journey through the health system, such as having to constantly repeat their story to a range of health care providers. This anecdote highlights the how consumers’ personal experiences and characteristics are central to their engagement in the co-design programme.

An agreed understanding of key consumer characteristics needed for each project team was used functionally by team members to determine who they would approach, and conversely who they wouldn’t. This process also provided reassurance to team members that the consumers approached would be relevant in their experiences and subsequently potential contributions to the project teams. In the following summary, one consumer representative describes the benefit of having well-defined inclusion criteria before approaching consumers:

‘Pressure on the project team to find consumers quickly meant that a wide range of consumers were initially approached. In hindsight, it would have been better to make the boundaries for inclusion stricter. This would have resulted in fewer consumers participating, but we would have captured more relevant consumer experiences.’

Ensuring that consumers have a relevant health experience to capture was essential for team members to best connect consumer experience to potential changes or recommendations for health care services. However, project teams also acknowledged the risk of reducing diversity in the consumer experiences captured.

A key challenge identified by team members was to secure a diverse range of consumers and consumer experiences to contribute to their project. Whilst, team members felt they were able to reach consumers who were (i) interested, (ii) available, (iii) capable of articulating their story, and (iv) had a relevant consumer experience with the service involved in the project, this was often at the cost of excluding those most ‘disengaged’ or ‘health illiterate’ consumers. Further, because the involved consumers were health literate and had good advocacy skills, they were often complementary in their perspectives and experiences of the health care services. Positive stories were valuable in identifying ‘what is working’ and
provided a valid consumer perspective, but team members found negative consumer experiences particularly useful in identifying key areas for change. As summarised by one team member: ‘we know we are not perfect, there is room for improvement somewhere’.

Planning how, who by, and when consumers would be approached about the programme was a key part of the planning phase. In hindsight, some team members identified this part of the planning phase as integral to increasing the diversity of consumers and consumer experiences. In approaching consumers, most team members (85 percent or six of seven) reported utilising only one strategy. Upon reflection, team members considered having more than one strategy for approaching consumers and capturing their story as a useful way to increase the diversity of engaged consumers and subsequently experiences captured:

‘There is more than one way to approach patients in the capture phase. Teams should have alternative plans to utilise if you don’t capture any patients in your first approach...and how you get patient feedback should be tailored to the particular patient...In the planning phase, explore a few different options and offer alternatives to patients so they can provide feedback in a way they are most comfortable with’.

Across project teams, a number of platforms for contacting potential consumers were utilised as summarised in Table 4 below. The summary shows that consumers across the project teams were approached both directly (face-to-face or a phone call) and indirectly (for example, through group invitations or promotional materials in public spaces), in planned or opportunistic contacts.

**Table 4: Summary of contact platforms used by team members to ‘reach’ consumers**

<table>
<thead>
<tr>
<th>Summary of contact platforms used by team members to ‘reach’ consumers</th>
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<tbody>
<tr>
<td><strong>Face-to-face</strong></td>
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<tr>
<td><strong>Phone contact</strong></td>
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<td></td>
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<tr>
<td><strong>Email contact</strong></td>
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<tr>
<td><strong>Promotional approaches</strong></td>
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<tr>
<td></td>
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</tbody>
</table>
Summary of contact platforms used by team members to ‘reach’ consumers

| Through promotion of the project through existing consumer networks (for example, Consumer Council’s) (email, face-to-face, or over the phone) who can voluntarily delegate consumer involvement. |

All of the above ways to reach consumers were successful in securing consumer engagement in the co-design projects – though consumers certainly advocate for a personable approach.

In considering platforms for communication that are not presented in Table 4 above, it is apparent that some approaches may be underutilised. For example, throughout the evaluation there were no examples where text or social media such as Facebook or Twitter were utilised, which may be appropriate for younger age groups. As further explained in ‘The first encounter’, there are more avenues for reaching consumers that are currently underutilised by project teams.

The need to tailor approaches based on consumer groups or individuals was a strong theme in the interviews of both team members and consumers. Similarly, tailored approaches in the way consumers can share their experience means consumers are provided with options which enable them to share in a way they are most comfortable with. As explained by one team member: ‘Patients were encouraged to share their stories in a variety of ways. “If you can’t describe it in words, use photos, or just give me some key words”’. Planning more than one strategy to capture consumer experience is an important part of the planning phase.

Getting prepared for consumer engagement also involved developing experience capture tools. For example, experience questionnaires, experience interview questions or photo-boards. A key learning from one team member described in their workbook was the value in developing experience capture tools in partnership with consumers: ‘Preparing the survey document in conjunction with consumers [ensured] it was ‘usable’ for them, [in terms of] language, question structure and relevance’.

In summary, team members recommended:

- identifying consumers who could contribute
- planning multiple strategies for approaching consumers
- tailoring consumer approaches based on consumer groups or individuals
- planning more than once option for capturing consumer experiences.

The first encounter

The most persistent theme emerging in the accounts of team members was networking and relationships. Networking and relationships were central to project from conception to completion – from securing buy-in from senior level management or leadership, developing the right relationships with staff to influence change, knowing who to talk to or where to turn when facing barriers, and building relationships with consumers to work alongside. Having positive relationships with consumers supported team members not only to initially identify and approach consumers, but enabled honest and critical feedback of health care systems.

Drawing on pre-existing relationships was a valuable leverage point in approaching consumers. All four of the consumers who participated in this evaluation were approached by a known health professional – someone who had been involved in their care or the care of their family or, through existing consumer groups or complaints processes. Members of
Counties Manukau Health’s Consumer Council highlight the importance of rapport, trust and respect in consumer-health professional interactions – all of which are built and maintained over time in ongoing relationships.

In consumers’ experience, being approached by someone familiar to them provided them with the reassurance they needed to accept their offer of involvement with little hesitation. Having a known health professional approach consumers made a difference in their willingness to get involved, particularly if contact was made over the phone instead of more personally face-to-face.

One consumer described having a really positive pre-existing relationship with the nurse who had initially approached her. She recalled: ‘She’d helped me through a couple of difficult periods… The fact that I knew her helped’. This familiarity and trust from a pre-existing relationship was paramount in the consumer coming on board with limited understanding and information in regards to the programme and what was actually involved.

Team members encountered challenges in approaching consumers when their service did not afford ongoing contact or rapport building with consumers. For example, where consumers are admitted to an emergency service but have only very brief medical interactions with staff. Another challenging area is in ambulatory services, where health professionals are only involved in the short transition of consumers to acute care settings, where others then care for them. These limited interactions left team members feeling uncertain about the most appropriate way to reach consumers.

A clear theme emerging in consumer accounts is that there is no one ‘right way’ to approach consumers. While having an established relationship helps, this is not always the reality of consumer-health professional interactions, and rapport and trust needs to be built and maintained over time regardless of pre-existing relationships. This was particularly evident when team members sought to engage beyond their main ‘project level’ consumer, to capture the experiences of a wider range of consumers – many of whom were not personally well known.

In trying to reach consumers, team members utilised existing consumer groups (such as Consumer Councils), and worked together as a project team to draw on extended care networks. Health-based community groups were not utilised but could be of value in connecting consumers with health professionals, for example, Diabetes NZ, Kidney Society and the Mental Health Foundation. Team members could also move beyond known patient networks to reach consumers through community based groups (for example, church, schools or other social groups). The Commission also has its own consumer network which could be accessed.

Regardless of the nature of the relationship between consumers and the health care professionals who approached them about the project, consumers communicated the importance of health professionals:

- being personable and approachable and committing to rapport building with consumers
- providing consumers with space to think about their involvement (not expecting a response straight away) and reflect on their contribution
- making it okay to say no, and not pushing for their involvement if the patient is not interested
- explaining in simple, non-medical jargon, what co-design is and expected outcomes
- being honest and transparent about consumer involvement (including time commitments, how the information will be used, and any compensation available)
• assuring consumers they have a worthwhile contribution to make
• really listening without judgement and validating the experiences of consumers
• being genuine and empathising where you have similar experiences
• using simple language that is not full of medical jargon.

Communicating project details
Due to the preparation work committed, all team members interviewed had a reasonably well defined project focus or direction for action before approaching consumers, which assisted in preparing an explanation of the project to consumers. When approaching consumers to capture experiences that did not require ongoing engagement with the team at project level, team members where more easily able to articulate details such as how much time consumers would require to dedicate to the project, whether they would receive compensation for their time, and how their information would be used.

Communicating clear project details was more challenging for team members when approaching consumers to work alongside the team for a more extended period of time. In such cases, team members felt uncertain about what they were actually asking consumers to do, and often reported wishing that they could have been more upfront about what was involved, and clearer about the consumer role and the time they would have to dedicate to the project. Given the evolutionary nature of the projects, however, such details were not always possible to anticipate. This is often the case for co-design project teams:

‘Clinicians and managers scope out a project thinking that we know what is needed. When you gather information from the patients or users of the service we discover different things which effectively disrupt our initial assumptions. [This is] a “gift” because it provides us the ability to redesign services in a way that will really meet the needs of the users although sometimes it feels hard’.

Contrary to the discomfort of team members in trying to communicate clear project details, the immediate response of consumers who worked at project level with the team was feeling honoured about being approached: ‘[My first thought was] this is neat. This is a real privilege’. The consumers were passionate about being involved in the projects because of their own experiences with the health care services (both good and bad), and their interest in seeing service improvements. Consumers reported that helping to inform changes which could result in better experiences for other consumers was a unique, rare and rewarding opportunity that is not often available for consumers. Initially, appealing to consumers’ sense of humanity and altruism was enough to secure involvement on the premise of communicating further project details as these were clarified with the team alongside engaged consumers. Initially, what was most important to consumers was:

• being given an opportunity to help
• being reassured that they can help and have a worthy contribution to make
• understanding the importance of patient perspectives in co-designing health care services.

To maintain ongoing engagement, however, all consumers, regardless of their level of involvement, needed an awareness of the commitment they were making. This is further discussed in ‘Maintaining consumer engagement’.

Timing of consumer approaches
In making the first approach to consumers, timing is an important consideration. Team members recognised it was important to not leave contact too long, but also acknowledged
that there are inconvenient or inconsiderate times to approach consumers. Consumers identified the following as inappropriate times to be approached:

- at vulnerable times – for example, in acute care settings where they could be experiencing pain, or be focussed on their health condition and recovery
- for some, when they have whānau, family or friends visiting to whom they would like to spend time and dedicate their attention. Although some consumers may like to discuss this when they have support people available.

One team member also advocated that afterhours work was important for increasing consumer reach: 'Having allocated time outside of work hours would have allowed a greater "involvement" with consumers.'

For consumers working at project level, two team members highlighted the value of the consumer being involved as early as possible in the project development, so they are familiar with and contributing to decisions made. These team members argued that early involvement would provide the consumer with great context around why a particular solution was being pursued: ‘Knowing a project inside out makes it easier to understand what is happening now.’

Whether or not consumers decided to get involved came down to their availability, their interest and personal connection to the project, and personal values.

**Maintaining consumer engagement**

Majority of team members (85 percent or six of seven) found that consumers were extremely receptive to the offer of being involved in co-design projects. In talking to consumers, this message was reinforced. As earlier highlighted, consumers felt that the opportunity to be involved was a privilege, and an opportunity to help others who in the future will go through similar health experiences. In the initial stages of the project, consumers were motivated by their altruistic and community values in getting involved. As summarised by one consumer in the following quote: ‘If you can make a comment which improves things, that is all you wish for.’

To maintain ongoing consumer engagement, however, consumers recommended:

- regular communication (email, phone or face-to-face, simply being ‘in touch’)
- advance notice on meetings and consumer commitments for the project
- providing regular assurance or feedback to the consumer that they are making a worthwhile contribution.

Consumers recommend advanced planning for meetings and other project commitments. While consumers are willing to help, they too have competing demands on their time which can inhibit participation when things aren’t planned or agreed in advance. Moreover, feeling like they were an integral part of the project team was important to consumers. One consumer reported being paid for her contributions to the project, but what was more important than the monetary value of this compensation for their time, was feeling that their contributions were being taken seriously: ‘Being paid isn’t the be all or end all…[but it did make me feel that] they were taking this seriously…[and that] my contributions counted for something’.

Key challenges for team members in maintaining consumer engagement included:

- availability of the consumer and competing demands on their time
• consumers being too unwell to participate, or having health conditions which inhibited their involvement (for example, cognitive impairment or issues with short- or long-term memory).

Engaging more than one consumer to work at project level with the team was identified as a solution to challenges with consumers being unable to contribute on a long term basis to the project (for various reasons such as their health, availability, or familial commitments). For example, one project team commenced the project with three committed consumers working at project level, but over time, had one consumer who contributed actively throughout the project period.

In this evaluation, visibility of the end result has emerged as a critical factor in consumer engagement and satisfaction with their involvement in the co-design projects. All of the consumers (100 percent) reported having a lack of information about current project progress or outcomes, which can leave them feeling frustrated or dismissed: ‘Their need of me is gone I suppose… Maybe something else will come up that I can be involved in.’ Consumers relayed that this lack of communication was often the result of workforce turnover, competing priorities and reassignment to other projects which resulted in changes to clinical staff whom they previously identified as project drivers and key contacts: ‘The [project manager] has been dragged into some other project, they have about 5 on the go at once.’

Of particular note, lack of communication about the project outcomes was disappointing for consumers because, in juxtaposition to their need to help others, they felt unclear about how they had helped, whether their input had made a difference, and how others might have a better experience of health care services as a result of their work. Consumers’ evaluation interviews demonstrate that consumer interest/investment in the projects do not desist at the conclusion of the formal programme period. Consistent with their motivation for getting involved, consumers remain emotionally invested in the projects. Follow-up and ongoing contact with consumers about changes and progress would be highly valued.

A summary of consumer engagement findings, with illustrations to capture consumer experiences of the co-design programme, is provided on the following page.
Summary of consumer engagement findings
Consumer participation in co-design project teams is value driven and highly personal. Consumers get involved because they care and want to help others, not because a staff member was able to communicate every detail of the project from day one (this just doesn’t happen sometimes, and consumers may benefit from clarifying some of this alongside project teams). Co-design is transformative on many levels, changing health care services and consumer experiences, but also consumers themselves who feel ‘worthwhile’ and ‘useful’ as a person through their involvement. Giving consumers the opportunity to be part of change is extremely empowering.

Healthcare professionals should not underestimate how relationships and trust are central to meaningful consumer engagement. Establishing trust through rapport building with consumers makes it okay for them to say ‘no’ when they don’t want to be involved, and to be open and honest when sharing. Rapport building means taking the time to explain and listen, really listen – validate the experiences of consumers without judgement or assumptions. Being personal, approachable and genuine really does make a difference for consumers. Healthcare professionals should build relationships and trust so consumers can feel as comfortable sharing as they would with their closest confidants – best friends or family/whānau.
There is no ‘one size fits all’ approach to consumer engagement and story capture. Tailoring your approach to consumer engagement and story capture to specific individuals or consumer groups is a must. There are lots of ways that consumers can be approached and provide feedback – utilising more than one option means consumers can communicate in a way they are most comfortable with, whether this is through a questionnaire, interview, photo-board, video or other options. Providing choices increases the diversity of consumers and consumer experiences that are captured.

Remembering that consumers are motivated to get involved because they want to help others, don’t forget to assure them they are helping, and communicate how they have helped. Maintaining consumer engagement over the project duration comes down to planning, communication and how you make consumers feel about their involvement. Consumers want to see change and feel they are helping others – anything less is a waste of their time and efforts. Unfortunately, consumers are often left wondering what has come of all the hours of work they have committed.

Acknowledgements to Cory Illustrates for capturing these important consumer experiences for the co-design programme 2014–15.
Leadership and support

Previous evaluations of the co-design programme have shown that historically, team members encountered challenges securing the level of leadership and support they felt was needed to make the most out of this programme. For example, lack of regular contact from senior leaders, and difficulty securing meeting times. To date, however, there have been limited insights from evaluation as to what kind or level of support is needed by project teams.

During the current evaluation, team members and sponsors were asked about support needs, the level of support received/offered, and any associated challenges. From these discussions a clear idea emerged of leadership attributes which assist team members in getting the most out of their participation in the co-design programme. This section of the evaluation aims to discuss:

- what support was provided
- what support was needed
- key challenges in obtaining support
- a description of needed sponsor attributes to support co-design projects.

Support provided by sponsors

The support provided to project teams from sponsors takes many forms and varies over the duration of the programme. For example, initially, some sponsors provided assurance to team members about their project scope as they worried that their project may be ‘too big to deliver’. Some also provided encouragement to team members who felt anxious about approaching consumers. However, later in the project phases some team members indicated that they needed more support around mitigating barriers to solution implementation. It was clear that the support needs of team members differed across project phases and project teams. This emphasises the need of sponsors or senior leaders to ‘check in’ regularly and seek clarification around support needs.

During this evaluation, one team member commented that ‘It was a little unclear what the role of the sponsor was’, which resulted in some reluctance to approach the sponsor when encountering barriers. This has highlighted the dual responsibility of leaders needing to understand and deliver their support responsibilities, and team members needing to be proactive in engaging with their leader and requesting help when needed.

In discussions with sponsors, examples of the support provided to project teams by sponsors included:

- assuring and confidence building around different project aspects (such as approaching consumers)
- securing staff release time for project meetings, WebEx sessions and other programme related activities/events
- securing financial resources for staff time, interventions, or reimbursement to consumers
- problem solving alongside project team members when they encountered barriers to project progress and solution implementation
- directing team members to the right people to assist and navigate barriers
- mentoring around relationship building or influencing skills
- contributing to project meetings, the initial training, or WebEx attendance
- technical support, for example, connecting to WebEx sessions
• distributing project updates to staff or senior management
• validating the EBD approach to other staff or senior leaders
• maintaining open communication channels with the project team.

The biggest challenge for sponsors in supporting project teams was finding the time. As explained by one sponsor, ‘[I] wear many different hats’ – this often meant being out of the office or addressing other priorities. Competing priorities made committing time to the project difficult: ‘It becomes another job in all the jobs you have to do’.

In hindsight, two sponsors suggested scheduling structured support and project management time. For example, regular catch-ups with time allocated in advance. This would ensure that time is dedicated to the project, and was not ‘eaten up juggling other priorities’. Some sponsors also suggested they could have been more proactive in following up team members to see if any support was required. As advocated by the programme facilitator, there is a dual responsibility in maintaining open channels of communication – both sponsors and team members should initiate contact and provide needed updates on the project progress.

One sponsor spoke about the role sponsors could play in supporting sustainability of the EBD approach: ‘Managerial staff could have assisted in the project becoming wider reaching than the few staff who were involved’. Sponsors or senior leaders have decision making power that could assist in increasing the availability of promotional and training opportunities, platforms for sharing skills amongst staff and so on.

**Support needs of team members**

In the above section, sponsors have identified the kind of support delivered to project teams. This is not representative of the level of support delivered to everyone, however. When discussing the support provided to team members, it was clear that there was a discrepancy between what was needed in terms of support to project teams, and what was delivered. Five of eight projects (63 percent) who completed the co-design programme expressed dissatisfaction with the level of support provided by their sponsors.

The leadership and support required by teams to progress their project varied significantly depending on the knowledge, skills and experience of staff who made up project teams. For example, one team member reported having significant network knowledge of the health care organisation that the team operated in, and therefore required less direction around who to talk to when encountering barriers. For staff other staff, however, more support around networks and relationships may be needed. Another project team had a mix of clinical, quality improvement and communications staff, who together provided a vast array of medical and technical skills such as computer skills, presentation skills and medical and health service knowledge, which was high beneficial when it came to producing documents such as questionnaires, or photo-boards.

**Securing resources**

All team members who participated in this evaluation reported needing sponsors or senior leaders who secured the staff release time needed to dedicate to each project. Finding the time to commit to projects was a key challenge for team members, and impacted the ability for other service staff to contribute to projects alongside their peers: ‘At first it is difficult to get started and it is difficult at times to encourage staff to do something else in their already busy day.’ Securing staff release time is important for structured programme events such as WebEx sessions and project team meetings, but also needs to extend beyond this to include the general project management work completed by team members to maintain project

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9 This calculation excludes one project team who did not complete the co-design programme.
momentum such as consumer engagement, project updates to other staff, developing presentations, planning, follow-up and so on.

Beyond the need of project staff to be able to commit their own time to dedicate to projects, other resources were also needed by project teams. For example, some of the interventions or recommendations made required a funding commitment to secure resources such as time from other staff or new equipment. Some teams also provided payment to consumers, either monetary in value for their time contributed, or petrol or taxi chits to compensate for travel to and from project meetings. One consumer identified these taxi chits as a key enabler in their ability to contribute to the project.

At the outset of their projects, team members could not always anticipate in advance the financial cost of addressing problems revealed in the stories of consumers, which was a challenge in later phases of the programme when it came to implementing recommended solutions. Team members were creative in making no – cost improvements for their health care service (for example, updating written communications to consumers or changing verbal communications with consumers). However, two of the project teams participating in this evaluation reported being unable to implement their recommended solution to health service problems due to lack of committed funds.

**Barrier mitigation or problem solving**

Team members also identified the need for sponsors or senior leaders to assist them in breaking down barriers to change. This involves problem solving alongside project teams, directing team members to the right personnel to engage with whom could support change, or validating the EBD approach with other staff (from frontline to management).

**Technical support**

As their participation in the programme required team members to develop story capture resources, write project plans, engage in the online WebEx sessions, and formally present their project progress, technical and computer skills were utilised. Some team members found this difficult and suggested this could be an area of additional support. One team member explained that having a team spanning clinical areas, quality improvement and communications ‘was particularly helpful when it came to producing and formatting documents, working with photos, and pulling content into a poster. This was a huge support to the clinical staff involved, who do not necessarily have the time, skills or contacts to easily complete these tasks’.

**Buy-in or engagement**

A key overarching theme in all of the support needs identified by team members was buy-in and engagement from sponsors and senior leaders. Having buy-in and engagement from sponsors or senior leaders was a huge support for team members and impacted progress of the project team across all programme phases. Buy-in and engagement could look like:

- Understanding the EBD approach and socialising this with other staff from all levels of the organisation.
- Being directly involved in project meetings or WebEx sessions to demonstrate their support and awareness of project progress.
- Securing resources such as staff release time or funding for solutions.
- Problem solving with project teams when they encountered barriers.
- Maintaining a presence with project teams through contributing to discussion, planning and consumer engagement.
In reflecting on their experience, several team members spoke about the need for increased engagement and buy-in from senior leaders. When sponsors or senior leaders were disengaged or did not perceive the value in the EBD approach, this impacted project progress:

‘Co-design is new to the [organisation] and whilst the senior management team is supportive there is lack of understanding of the value for our services and therefore capacity to carry out the project is limited due to competing priorities.’

Similarly, another team member explained that, although sponsors and senior leaders agreed to the scope of their project prior to commencing the work, due to competing priorities and limitations in the time capacity of staff ‘we couldn’t stay as committed as we believed we could at the start’.

Buy-in from senior leaders and staff was particularly challenging when project teams were required to work with staff across organisational boundaries, as is captured in a summary from one team member:

‘It is difficult to implement changes and secure commitment from project staff at an organisation outside your own – particularly when unable to pay for their commitments.’

In their interview, team members also spoke about the need for buy-in and support from fellow colleagues, team members, or health care professionals from the relevant services involved:

‘Staff were a little apprehensive at first because many felt that patients were mostly happy with their experience. Further reiteration of the aim for us to know what works well for patients in order to continue to provide a great service [was needed]. We also needed to know what does not work well so we can improve the areas that are identified as lacking or can improve. Once we attended the study day on co-design, staff got a better understanding of what we were trying to achieve.’

As further discussed in the section on ‘Sustainability of the EBD approach’, time and energy could be wasted by team members trying to convince others about the importance of the approach. The understanding, willingness and energy of staff was a great support to project teams: ‘The progress of the projects relies heavily on the enthusiasm and creativity of medical and nursing staff and [other health professionals], going the extra mile’.

It would be of value for project teams to increase buy-in and engagement from their peers. The following were identified as opportunities to do this:

- have all team members attend the masterclass training delivered by the programme facilitator
- demonstrate the value of patient voices in real life examples
- give them an opportunity to see the approach in practice (sharing through observational and experiential approaches).

**Leadership attributes that support co-design project teams**

Table 5 is a summary of attributes of effective sponsors or senior leaders to support project teams. These attributes emerged from the perspectives of both team members and consumers in reflecting on their experience of leadership and support throughout the co-design programme.
Table 5: Attributes of effective sponsors/senior leaders for co-design project teams

<table>
<thead>
<tr>
<th>Summary</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>Power</strong></td>
<td>In a position of influence to provide an authorising environment for staff time committed to the projects, and to support proposed interventions/changes to systems or services.</td>
</tr>
<tr>
<td><strong>People</strong></td>
<td>Existing relationships and network knowledge of the relevant health care system. This was pivotal for sponsors’ ability to direct team members to who they needed to talk to when trying to influence change and mitigate barriers.</td>
</tr>
<tr>
<td><strong>Passion</strong></td>
<td>Sponsors or senior leaders who were passionate and energetic about the EBD approach and therefore had a vested interest in the project and progression through project phases.</td>
</tr>
<tr>
<td><strong>Presence</strong></td>
<td>Someone with availability to meet regularly with the project team, who is proactive in ‘checking in’ on project progress, who can be approached as a ‘sounding board’ for project direction and advice when needed, and attends project meetings or web ex sessions to maintain engagement, visibility and show support.</td>
</tr>
<tr>
<td><strong>Problem Solver</strong></td>
<td>Engage with project teams to find solutions to barriers that they encounter throughout project phases.</td>
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</tbody>
</table>

**Summary of leadership and support**

Consistent with previous evaluations, team members continue to feel they do not receive enough support from sponsors or senior leaders to make the most out of their participation in the programme.

A key overarching theme in all of the support needs identified by team members was buy-in and engagement from sponsors and senior leaders. Buy-in and engagement from senior leaders was fundamental to project teams being able to secure release time to work on their project, validate the EBD approach, overcome barriers to change, and implement recommended solutions. Lack of buy-in or engagement resulted in loss of project momentum as team members continually needed to advocate about the value of patient voices in redesigning health care systems.

Key support needs identified by team members included:

- securing resources
- barrier mitigation
- technical support
- buy-in or engagement by sponsors and senior leaders
- having willing and committed peers.

Team members and consumers identified key attributes for effective sponsorship of co-design projects: power, people, passion, presence and problem solving skills. This section also identified that sponsors could play more of a role in supporting dissemination of EBD skills across their respective health care organisations.

**Sustainability of the EBD approach**

The following section describes how project teams currently share and promote the EBD approach, and opportunities for increased sustainability of the EBD approach which team
members and sponsors have identified. The health care organisations where project team members practice clinically on a day-to-day basis are at various stages of ‘readiness’ to sustain the EBD approach in daily practice. As demonstrated in the stories below, for some this requires a cultural as well as system change in the way consumer voices are valued and utilised when addressing problems or improving health care services. Many of the themes emerging around sustainability of the EBD approach were consistent across support and leadership needs for project teams also. For example: buy-in, leadership and relationships. This section discusses the use of tools and resources provided throughout the co-design programme, buy-in, leadership and relationships, alignment, and systems or culture change.

**Tools and resources**

Throughout the co-design programme, team members, consumers and sponsors were provided with a vast array of resources and tools to support their learning, project development and engagement with consumers. During evaluation interviews, team members were asked about the use of these tools, and their ongoing (or lack of ongoing) application in the co-design of health care services. Without prompting team members, the tools they spoke about are summarised in **Table 6** below.

**Table 6: Tools and resources discussed by team members as being particularly useful and rationale for why they were useful**

<table>
<thead>
<tr>
<th>Tool or resource</th>
<th>Rationale</th>
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| **Masterclass training**                                   | • The masterclass brought clinicians and consumers together under this agenda for the first time – so was an opportunity to meet and get to know each other as well as learn.  
• The masterclass training was also identified as important for ensuring everyone understood the value of patient voices in co-designing health care systems – getting all team members ‘on the same page’. |
| **Consumer experience capture tools** (for example, experience questionnaire, photo stories) | • The tools provided richer information about patient experience beyond what is routinely collected in a patient satisfaction survey: ‘Capturing experience is vastly different to surveying for patient satisfaction.’ |
| **Tools for visually displaying patient stories/ feedback** (for example, Wordle, video) | • These tools were powerful for summarising patient experiences to communicate to others and promote the project. This could be very powerful when advocating for change to senior management or other staff. |
| **WebEx sessions**                                         | • For learning and reflection.  
• Maintaining project momentum and ‘keeping us on track’.  
• An opportunity to ask questions, get answers and connect with other project teams. |
<p>| <strong>Workbook materials</strong>                                     | • For learning and reflection on project phases: ‘[The workbook helps staff to] reflect on where you started and where you are going.’ |
| <strong>Programme facilitator</strong>                                  | • The programme director was identified as a |</p>
<table>
<thead>
<tr>
<th>Tool or resource</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>valuable ‘sounding board’ for support and advice.</td>
<td></td>
</tr>
<tr>
<td>The ‘5 whys’</td>
<td>• Provides understanding around cause and effect.</td>
</tr>
</tbody>
</table>

Seventy percent (five of seven) of team members reported that the above tools are currently being applied to new co-design projects. A further two team members reported that the tools are not currently being used, but there are plans to use them on upcoming projects. The ongoing use of the tools by majority of the project teams supports sustainability of the EBD approach. Team members identified that ongoing use of the tools is supported by the fact that the tools:

- can be easily adapted for localised use in other health care services, specialist areas or consumer groups
- are provided with examples of how they can be used
- can be easily understood and used by consumers (and in some instances designed in partnership with consumers).

Of particular note from Table 6 above, excluding the masterclass training, programme facilitator and WebEx sessions, all of the tools are accessible to project teams on an ongoing basis, and not dependent on funding or delivery of the programme.

**Buy-in, leadership and relationships**

As highlighted earlier, buy-in, leadership and relationships are consistent themes across many project areas. In terms of project sustainability, buy-in, leadership and relationships were recurrent themes in the responses of team members or sponsors in regards to:

- supporting visibility or promotion of the project
- supporting distribution of skills the EBD approach
- endorsing the approach
- enabling change.

When discussing how they have shared the approach with others, all team members spoke about promoting project progress, for example, providing project updates, through some of the following communication channels:

- clinical governance meeting updates
- team or peer meetings updates
- staff email updates
- monthly newsletter targeted at various frontline or managerial staff
- promotional materials such as posters or photo-boards
- weekly staff bulletin
- dissemination of project materials (such as experience questionnaires)
- DHB Quality Awards applications
- accreditation processes
- consumers sharing their experiences at the clinical governance board level.
One team member reported that promoting their work through the above channels did stimulate interest in their project from other staff. The accounts of team members show that often sponsors or other senior leaders had a role to play in distributing these communications. Team members spoke about these communications as integral to stimulating interest, gaining support in principle and increasing awareness of the EBD approach. However, opportunities to directly teach or transfer skills learnt by sponsors or project team members were not as readily identified.

In making the approach more sustainable, all team members and sponsors relayed the importance of sharing their new skills with others. However, beyond the promotional work described above, sharing their new skills gained on the co-design programme was not yet occurring through any structured dissemination or training approaches. Rather, this is occurring through the conceptualisation of new projects enveloping more staff, and day-to-day interactions between staff and consumers in which application of new skills may be observed by other staff. Observation and experiential learning, or breathing life into the approach through its application in other projects, were identified by team members as preferred approaches to share skills with others. As asserted by one team member: ‘It feeds and grows by having other people observe it’. Similarly, another team member spoke about embarking on a new project with a different part of their service, which provides an opportunity for sharing the approach and tools more widely across the service to ‘bring more people on the journey by showing them the tools in practice’.

Project teams could be creative in getting more people to come on board with EBD projects. Increasing engagement from health professionals is an obvious option, but sponsors also spoke of building consumer leadership teams, training consumers to engage with other consumers, and involving students or volunteers in co-design projects. Doing so requires initial investments in time and staff resources, but subsequently results in increased capacity in people, and a wider group of people, with skills to take an EBD approach. Team members, sponsors and the programme facilitator argued that observation and experiential learning takes the skills and knowledge acquired through promotional avenues beyond ‘awareness’ of the approach and consumer voices, to a deeper understanding of the approach and its application in day-to-day clinical practice.

The value of patient voices was the most common learning discussed by team members when reflecting on their learnings after each capture phase. Reportedly however, not all team members, sponsors or senior leaders involved in this iteration of co-design programme perceived the value of the consumer voices, which was a major barrier to sustainability of the EBD approach. As explained by one team member:

‘I think it would have be useful to have included [all project team members] in the group on the training sessions. We spent some time persuading others that capturing stories will assist us in making improvements that patients want and need, not just what the heath professional think are needed’.

Wasting time in having to defend or legitimate the need for ongoing consumer involvement in projects was frustrating for team members who understood the value of patient voices. Although, it could be argued this is not wasting resources, but a core component of this work in socialising and sharing EBD approaches.

Sponsors and senior leaders have a role to play in validating or endorsing the EBD approach and value of patient voices. This was particularly relevant where senior leaders or sponsors needed to play a functional role in supporting the project. For example, one project involved a charge nurse of the service taking responsibility for facilitating the experience capture process. The charge nurse delegated staff for each shift to explain the feedback process to patients when they were admitted to the service, and later followed up with patients to...
provide an experience questionnaire from which consumer feedback was obtained. The experience questionnaires were then collected weekly by a member of project team.

As discussed in ‘Leadership and support’, senior leadership can be pivotal in the plausibility of project team members to mitigate barriers and achieve or implement person centred solutions to problems identified with health care services. That envisioned changes often sit beyond the capacity, authority and scope of project teams to change is a barrier to sustainability of the EBD approach. As explained by one team member in their interview summary:

‘It is difficult to make changes that are beyond your control/out of scope of your authority or leadership. There were several people involved in this project who impacted outcomes, or had to provide consent or approval for changes, as we well as international standards to consider.’

Similarly, a sponsor from another project team stated:

‘A key challenge of the co-design approach was that a select group of staff worked on improvement, but instigating changes required the collaboration of a much bigger group of staff, from frontline to management….We significantly underestimated how extensive the communications should be.’

The project teams in this discussion required the support of senior leaders to endorse the changes. The experience of one sponsor interviewed during this evaluation demonstrated that fear of change is very real for some health professionals. The EBD approach challenges conventional clinical practice and requires ‘letting go’ of power and preconceived ideas about the role of both health professionals and consumers in designing health care systems. When people are not ready for change, relationships became important in advocating for a different approach. The field of human resources provides a vast amount of existing literature which demonstrates the importance of this.\textsuperscript{10}

Earlier in this evaluation report, the importance of involving more than one consumer and more team members were identified as solutions to staff turnover and consumer attrition from projects. Involving only one consumer became challenging when that consumer was away, had other commitments, or was too unwell to participate. This could disrupt project momentum. Likewise, when staff turnover occurs project work can be re-delegated to other staff members, ‘however, it is more difficult for other staff to maintain the special connection with [the health care service] that the patient and their family have developed [with a specific member of staff]’. Staff attrition was described by this sponsor as being ‘disappointing’ for the consumer and the consumer's family. Involving more than one team member to build relationships across several staff is one approach to increase sustainability recommended by this sponsor. In regards to this same issue, building relationships with significant others who know consumers best to increase programme sustainability was also raised. In the experience of this sponsor, the project team came to realise that it was actually the social worker who knew the consumer best and had a well-established relationship with the consumer. Having the social worker involved increased engagement and trust with the project team.

A team member and sponsor commented on the impact participating in this programme has had on staff relationships – strengthening relationships and knowledge of the other services. For example, ‘project staff emerged with a new appreciation for how primary and secondary care operate’. That participation in the co-design programme can assist in nurturing

relationships between health professionals further supports sustainability of the EBD approach.

**Alignment**

Sponsors suggested that aligning projects within policies or broader projects supports sustainability of the projects and EBD approaches – particularly as priorities, workloads and focus for clinical teams continuously change. Both team members and consumers commented on the competing priorities and projects that occur in health care systems, and how this impacts on the ability of team members to dedicate their time to their co-design project. As highlighted earlier by a consumer, team members often ‘have about five on the go at once’. Alignment with broader projects or policies would also assist when engagement from sponsors or senior leaders was complicated by conflicting agendas or directions in which they push project teams from different individuals in positions of power – this was the experience of one team member.

One of the co-design projects in this iteration was connected to a broader project spanning several DHBs. This provided a unique opportunity to share the approach more widely with other DHBs, but also ensured that at a local level, the project would continue to be a priority for participating team members.

Sponsors also suggested embedding the EBD approach in written policy or procedural standards which provide best practice standards for clinical staff. There are not many examples of where this is already occurring in evaluation participants’ discussions, though some health care services did have a consumer policy. One team member relayed that EBD approaches have been integrated into evaluation methodologies processes, so that now when evaluating or reviewing services, methodologies may be better critiqued, and reporting would include patient voices and quotes. Alignment could also come through training or learning and development services provided by the DHBs or services. Ko Awatea is a great example of this, or other learning and development teams, where existing training that is offered to health professionals could incorporate EBD methodologies.

**Systems or culture change**

Throughout interviews, there were countless examples of how systems or culture change support the sustainability of EBD projects and/or approaches, and conversely, where lack of system or culture change can threaten sustainability of the projects and/or approaches.

Some of the system changes implemented as part of the co-design projects by their very nature demand a commitment to sustained EBD approaches and change in clinical practice of staff. For example, one sponsor talked about changes in the handover process, which now occurs at the consumer bedside, rather than in isolation from consumers. This provides an opportunity for consumer input on handover discussion which was unavailable prior to this change. A whiteboard placed at the consumer bedside gives consumers the opportunity to write their own information/messages or concerns. This also provides consumers with readily accessible information about their condition and how it may be changing or improving. This sponsor also recalled recommendations made for a professional development programme for clinical staff, and was able to secure 0.2 FTE to incorporate a portfolio around patient stories for quality projects in nursing. This change appeals to the perspective of team members, who suggested that ‘GP’s’ and Nurses’ time for their contribution to their projects need to be funded to support sustainability’.

Another team member relayed how advocacy from the project team has led to higher engagement with the pre-existing consumer council. The team member stated the consumer council is now more actively involved in changes around the health service which impact on patient experiences. Two team members spoke about the establishment of a consumer
council, or increased engagement with consumer councils, which they believe is occurring as a result of the co-design programme is a system change providing new pathways for engagement of consumers.

In discussing system changes which support the sustainability of EBD approaches, evaluation participants talked about what has happened, as well as what still needs to happen. Two team members spoke about the need for a central database or forum for quality improvement projects to support sharing across different health care providers, and minimise 'reinventing the wheel'. Basic parameters such as project description, timelines and key contacts could be included to enable others to contact health professionals to find out what has happened with the project and share any insights. This system change would assist in reducing duplication of the work committed by project teams across various health care services.

Not having the right IT platforms was identified as a key issue threatening sustainability of one co-design project in this iteration. Lack of integration between primary and secondary health care services, for example, undermines the intent of multi-disciplinary team (MDT) meetings trialled by one project team, in which both health care professionals and consumers came together to discuss care provided, any problems with care, and agree on a shared care plan. Getting the most of future meetings depends largely on the ability for IT systems between primary and secondary care to ‘talk to each other’, so that all stakeholders are able to access and amend information: ‘If we had had an unlimited budget and access to an agile IT provider then we really could have witnessed some innovative electronic shared records’. Moreover, trialling MDT meetings with an engaged consumer on the project team provided great insights on what this experience was like for consumers (it was in fact quite confronting and overwhelming for the consumer).

Direct evidence of cultural change is not within the scope of this evaluation; however, sponsors have shared some anecdotes about their observations of cultural change within their health care service. Cultural changes identified included where team members or sponsors had observed a change in attitudes or behaviour of clinical staff. For example, one team member reported that staff are more person-centred and have a more collaborative approach with consumers – visiting them more, and asking for their perspectives more. This team member shared a story about a consumer who simply wanted a shower while in the care of a health service. Previously, this request would have resulted in a referral to another service managing personal care, which would have subsequently resulted in a significant amount of waiting time for the consumer to have a shower. Now, ‘we understood that this wouldn’t happen quickly enough for the patient’. A nurse attended directly to this request by going to the site and assisting the consumer with a shower.

Similarly, another team member commented ‘four years ago no-one talked about having consumers involved’. The team member compared this with their culture of consumer involvement now, recognising there have been many changes with the establishment of a consumer facilitator role, updating of a consumer policy, and consumers sharing their stories at the Clinical Governance Board level.

**Sustainability summary**

Team members and sponsors had many ideas about increasing the sustainability of the EBD approach as summarised in **Table 7** below.

<table>
<thead>
<tr>
<th><strong>Summary of ideas to increase sustainability of the EBD approach</strong></th>
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</thead>
<tbody>
<tr>
<td><strong>Table 7: Summary of ideas from team members and sponsors to increase sustainability of the EBD approach</strong></td>
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<td>---</td>
</tr>
</tbody>
</table>
• Promoting the projects and increasing visibility of this work and patient voices within health care services to support cultural change around consumer voices.

• Disseminating skills more widely across health care systems by creating opportunities for experiential learning, or learning through observation with new co-design projects.

• Building ‘people power’ through engagement with students, volunteers or others who could be involved in projects.

• Increase buy-in from sponsors or other senior leaders to enable or endorse (a) consumer engagement approaches, and (b) changes recommended by project teams.

• Involving more consumers and team members in project teams to maintain momentum and mitigate staff turnover or consumer attrition from projects.

• Continue building relationships with consumers and other health professionals to share this approach with an ‘opportunity’ based, rather than ‘fear based’ response.

• Align projects with broader/wider projects or strategic directions of health care services.

• Embed the approach within policy or procedures or other system changes.

• Embed the approach in pre-existing training and development opportunities already funded for health care professionals.

• Seek funding opportunities to secure time of clinical staff to contribute to quality projects around patient stories/consumer voices.

• Dedicate adequate resources for funding of interventions.

• Increase staff and leadership engagement in the masterclass training for increased buy-in and understanding of the value of consumer voices.

Key barriers to sustainability of the EBD approach identified included: consumer attrition from co-design projects, staff/workforce turnover, lack of buy-in from staff and senior leaders, lack of secured resources to implement solutions or dedicate staff time to projects and systems or cultures within health care organisations that fail to properly promote the value of consumer engagement.
Evaluation summary

This evaluation focused on:

- describing the challenges and solutions by participating teams to increase the engagement of consumers to co-design of health services
- describing how the approach is being embedded into daily practice
- identifying opportunities to increase sustainability of the approach
- determining the level of leadership support provided to team members and how this impacts on the achievements and learning experiences of teams.

Some simple advice on how to engage consumers in the co-design of health services has also been provided.

Key challenges encountered by project teams to increase engagement of consumers included:

- securing a diverse range of consumer and consumer experiences to turn experiences into action
- reaching and approaching consumers in the absence of pre-existing relationships
- communicating clear project details and commitment requirements to consumers when projects were still evolving and such details were unknown
- availability of the consumer and competing demands on their time
- consumers being too unwell to participate or having health conditions which inhibited their involvement (for example, cognitive impairment or issues with short or long term memory).

In exploring consumer engagement, consumers and team members proposed many solutions to the above challenges. These included drawing on pre-existing relationships, consumer and community groups to connect with consumers, tailoring approach and story capture methods, and committing to rapport building with consumers regardless of the nature of pre-existing relationships. To maintain consumer engagement across the duration of the programme, consumers made some important recommendations including improving communications, planning in advance and providing assurance or feedback about consumer contributions to projects. All of the consumers were value driven by their motivation to help others, but were not provided with project feedback to communicate what was implemented as a result of their involvement, or how they had helped others.

Consistent with previous evaluations, team members continue to feel they do not receive enough support from sponsors or senior leaders to make the most out of their participation in the programme, with 63 percent of project teams being unsatisfied with the level of support received by project sponsors. Buy-in and engagement from senior leaders was fundamental to project teams being able to secure release time to work on their project, validate the EBD approach, overcome barriers to change, and implement recommended solutions. Lack of buy-in or engagement resulted in loss of project momentum as team members continually needed to advocate about the value of patient voices in redesigning health care systems. Team members and consumers identified key attributes for effective sponsorship of co-design projects: power, people, passion, presence and problem solving skills.

Team members and sponsors identified many opportunities for increasing the sustainability of the EBD approach. As with many other project aspects, increased sustainability relies heavily on the buy-in and engagement of sponsors, senior leaders and frontline staff from...
health care organisations. All team members spoke about promoting project progress to stimulate interest and awareness of the EBD approach. Directly sharing this approach with others, however, was not occurring through any formal training opportunities, but through the conceptualisation of new projects enveloping more staff, and day to day interactions between staff and consumers in which application of new skills may be observed by other staff. Seventy percent (five of seven) of team members reported that co-design tools are currently being applied to new projects. Continued use of the tools is enabled by the fact that tools are:

- easily adapted for local use in other health care services, specialist areas or consumer groups
- provided with examples of how they can be used
- can be easily understood and used by consumers (and in some instances designed in partnership with consumers).

Alignment and culture and systems change were also identified as cornerstones of increased sustainability of the EBD approach.

**Key improvement areas**

Key areas for improvement, instead of evaluation recommendations, were made in recognition of the existing work and partnership approaches committed by Ko Awatea and the Commission to continuously improve the co-design programme. These areas include:

- utilising more than one approach method for reaching consumers
- engaging more than one consumer to work with at project level
- building rapport between consumers and project teams (rather than one health care professional), to enable ongoing engagement in the event of workforce turnover
- providing assurance to consumers about the contributions they are making, and feedback on how their contributions have been applied, implemented solutions, and impact on other consumers engaged in health care services
- sponsors regularly ‘checking in’ on support needs of project teams
- team members asking for help when they need it and communicating support needs
- securing financial resources for the implementation of EBD solutions
- increasing attendance of the masterclass by all team members
- increasing presence of project sponsors through increased engagement in project meetings, informal discussions and WebEx sessions
- developing more structured and formalised methods for sharing EBD skills across health care organisations to increase capacity amongst the health care workforce.

**Concluding comments**

This evaluation has highlighted that team members need to get better at maintaining communications with consumers, assuring them of their input or contributions to projects, and advising how their input has resulted in change for future consumers. It has also shown that support of team members is a persistent issue for participating co-design teams needing attention. Increasing sustainability of EBD approaches required cultural and systems changes from health services providers, of which there are many opportunities across health care services. Across all areas of discussion, there were a number of overarching key themes in the accounts of team members, sponsors and consumers, including the importance of buy-in or engagement, leadership and relationships.
Appendix A: Interview schedule for team members

Interview aims:

- To describe the challenges and solutions by participating teams to increase the engagement of consumers to co-design of health services
- To describe how the approach is being embedded into daily practice, and identify opportunities to increase sustainability of the approach
- To determine if the level of support provided to team members is sufficient to achieve a positive learning experience
- To collect a range of stories/narratives that demonstrate the impact of working closely with consumers and that could be used as case-studies for other teams.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Question/statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff experiences approaching consumers</td>
<td>Describe your experience approaching patients about their participation for the first time</td>
</tr>
<tr>
<td></td>
<td>What was easy/ and what was uncomfortable/hard about approaching patients?</td>
</tr>
<tr>
<td></td>
<td>Do you think you have been able to reach a range of people, including those who may be unengaged?</td>
</tr>
<tr>
<td></td>
<td>Were any patients not able or not interested in participating?</td>
</tr>
<tr>
<td></td>
<td>[Depending on response above] How did you respond and feel when patients were not interested or able to participate?</td>
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<tr>
<td></td>
<td>How would you feel now about approaching patients to participate in co-designing services?</td>
</tr>
<tr>
<td></td>
<td>Was working with your patients in this way rewarding for you? How/why?</td>
</tr>
<tr>
<td>Securing participation from consumers</td>
<td>How did your patients react when you approached them to participate?</td>
</tr>
<tr>
<td></td>
<td>What do you think it was about how you approached them that led them to react this way?</td>
</tr>
<tr>
<td></td>
<td>Did you adapt your approach to different patients and how?</td>
</tr>
<tr>
<td></td>
<td>In hindsight, would you approach them differently in the future?</td>
</tr>
<tr>
<td>Guide for approaching consumers</td>
<td>In hindsight, what kind of information would have been useful for you to know prior to approaching consumers?</td>
</tr>
<tr>
<td></td>
<td>What would you like to know from a patient’s perspective about approaching them?</td>
</tr>
<tr>
<td>Learning and sustainability</td>
<td>What was your biggest learning curve during this programme?</td>
</tr>
<tr>
<td></td>
<td>Of the tools and resources provided, which did you use? (free recall)</td>
</tr>
<tr>
<td></td>
<td>Which tools do you still use/ intend to use and why?</td>
</tr>
<tr>
<td></td>
<td>Has this programme impacted how you engage with patients generally? How?</td>
</tr>
<tr>
<td></td>
<td>Has the programme impacted how others in your place of work (who weren’t part of the programme) engage with patients?</td>
</tr>
<tr>
<td></td>
<td>What do you think will happen to your project at the end of the Programme? Is there any opportunity to continue this project or working in this way?</td>
</tr>
<tr>
<td></td>
<td>In your opinion, what is the biggest benefit of working with your patients through a co-design process?</td>
</tr>
<tr>
<td></td>
<td>What are your plans for the future when the Programme finishes?</td>
</tr>
<tr>
<td>Theme</td>
<td>Question/statement</td>
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<tr>
<td>-------------------------------</td>
<td>-----------------------------------------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>What budget or other resources are available to continue this work?</td>
</tr>
<tr>
<td></td>
<td>Have you shared your skills/learning with others in any way?</td>
</tr>
<tr>
<td></td>
<td>In what ways can you share your new skills with others?</td>
</tr>
<tr>
<td>Support from sponsors</td>
<td>What do you need most in terms of support to make the most out of this programme?</td>
</tr>
<tr>
<td></td>
<td>How did your sponsor support/fail to support you throughout this programme?</td>
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<td></td>
<td>What would you have your sponsor do differently if they were involved in the project again?</td>
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<tr>
<td></td>
<td>What role can support from peers play in the Programme?</td>
</tr>
</tbody>
</table>
Appendix B: Interview schedule for sponsors

Interview aims:
- To describe how the approach is being embedded into daily practice, and identify opportunities to increase sustainability of the approach
- To determine the level of leadership support provided to team members and how this impacts on the achievements and learning experiences of teams.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Question/statement</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Support offered</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Describe your experience working with staff on the Partners in Care Programme</td>
</tr>
<tr>
<td></td>
<td>Describe the supporting role you offered to your designated project team</td>
</tr>
<tr>
<td></td>
<td>What kind of challenges did team members encounter and how did you respond?</td>
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<tr>
<td></td>
<td>Describe any capacity issues you had in supporting project teams</td>
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<tr>
<td></td>
<td>How might your support differ if you were involved in the Programme again?</td>
</tr>
<tr>
<td></td>
<td>What would make your supporting role easier (if anything)?</td>
</tr>
<tr>
<td><strong>Learning and sustainability</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>What did you learn from being a sponsor?</td>
</tr>
<tr>
<td></td>
<td>What benefits of working with patients through a co-design process have you observed?</td>
</tr>
<tr>
<td></td>
<td>Have you observed any changes in the way staff engage with their patients resulting from the Partners in Care Programme?</td>
</tr>
<tr>
<td></td>
<td>What are your plans for the future when the Programme finishes?</td>
</tr>
<tr>
<td></td>
<td>What budget or other resources are available to continue this work?</td>
</tr>
<tr>
<td></td>
<td>Would you support the sharing/dissemination of this new approach across other staff?</td>
</tr>
<tr>
<td></td>
<td>In your organisation, what would work best to facilitate skill/knowledge sharing with others?</td>
</tr>
</tbody>
</table>
## Appendix C: Interview schedule for consumers

**Interview aims:**
- Inform some advice for staff on how to engage consumers in the co-design of health services
- To collect a range of stories/narratives that demonstrate the impact of working closely with consumers and that could be used as case-studies for other teams

<table>
<thead>
<tr>
<th>Theme</th>
<th>Question/statement</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Approaching consumers/patients about the co-design programme</strong></td>
<td>Describe your experience being approached about participating in the programme for the first time</td>
</tr>
<tr>
<td></td>
<td>What were your initial impressions/reactions about the programme?</td>
</tr>
<tr>
<td></td>
<td>Did these impressions/reactions change over time? How and why?</td>
</tr>
<tr>
<td></td>
<td>Initially, did you understand what the programme was about and what your involvement would mean?</td>
</tr>
<tr>
<td></td>
<td>Could the programme be better explained and how?</td>
</tr>
<tr>
<td></td>
<td>In a perfect world, how would you like to be approached about participating in the programme?</td>
</tr>
<tr>
<td></td>
<td>How might people from [your culture] want to be approached differently to others?</td>
</tr>
<tr>
<td></td>
<td>How might people [in your age group] want to be approached differently to others?</td>
</tr>
<tr>
<td></td>
<td>If you could give your doctor/nurse one piece of advice about working with patients for next time, what would it be?</td>
</tr>
<tr>
<td><strong>Motivators and disincentives for participation</strong></td>
<td>What made you decide to get involved in the programme?</td>
</tr>
<tr>
<td></td>
<td>Was there anything that made getting involved a hard decision for you?</td>
</tr>
<tr>
<td></td>
<td>How did your nurse/doctor motivate you to get involved?</td>
</tr>
<tr>
<td><strong>Participating in the programme</strong></td>
<td>Tell me about the project you worked on and what you were trying to achieve</td>
</tr>
<tr>
<td></td>
<td>Who do you think you represent; yourself or the patient collective?</td>
</tr>
<tr>
<td></td>
<td>Do you have any way to seek opinions/experiences from fellow patients relevant to this project?</td>
</tr>
<tr>
<td></td>
<td>What did you enjoy most about the programme?</td>
</tr>
<tr>
<td></td>
<td>Would you change anything about your experience?</td>
</tr>
<tr>
<td></td>
<td>Was participating in this programme rewarding for you? How/why?</td>
</tr>
<tr>
<td><strong>Outcomes</strong></td>
<td>What impact has this programme had on you?</td>
</tr>
<tr>
<td></td>
<td>Would you ever consider getting involved in a Programme like this again? Why/why not?</td>
</tr>
<tr>
<td></td>
<td>What is happening with the project now? Did you get the outcome you hoped for?</td>
</tr>
<tr>
<td></td>
<td>Would you be willing to participate in a focus group session to further develop the guide for staff?</td>
</tr>
</tbody>
</table>
Appendix D: Interview schedule for programme facilitator

Interview aims:

- To describe how the approach is being embedded into daily practice, and identify opportunities to increase sustainability of the approach.
- To collect a range of stories/narratives that demonstrate the impact of working closely with consumers and that could be used as case-studies for other teams.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Question/statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff experiences approaching consumers</td>
<td>In your observations, how did staff overcome challenges for getting consumers to participate?</td>
</tr>
<tr>
<td></td>
<td>How did staff reach the unengaged?</td>
</tr>
<tr>
<td></td>
<td>What benefits of working with patients through a co-design process have you observed?</td>
</tr>
<tr>
<td>Learning and sustainability</td>
<td>Have you observed any changes in the way staff engage with their patients resulting from the Partners in Care Programme?</td>
</tr>
<tr>
<td></td>
<td>How does the model in NZ compare with other localities?</td>
</tr>
<tr>
<td></td>
<td>What are your plans for the future when the Programme finishes?</td>
</tr>
<tr>
<td></td>
<td>What budget or other resources are available to continue this work?</td>
</tr>
<tr>
<td></td>
<td>In what ways can ebd skills be shared/ distributed with others?</td>
</tr>
<tr>
<td>Support</td>
<td>What support needs of staff do you think are met?</td>
</tr>
<tr>
<td></td>
<td>What support needs continue to be unmet?</td>
</tr>
</tbody>
</table>
Appendix E: Participant information sheet for team members

You are invited to take part in an evaluation for the co-design programme 2015. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and whether or not you participate in the evaluation won't affect your participation in the programme, or relationship with the course staff.

This Participant Information Sheet will help you decide if you would like to participate in the evaluation by providing information about why we are doing the evaluation, what your participation would involve, what the benefits and risks to you might be, and what would happen after the evaluation ends.

This document is four pages long, please make sure you have read and understood all the pages. If there is anything you don't understand or if you have any further questions about the evaluation please do not hesitate to contact the Lead Investigator, Brooke. Brooke’s contact details are provided at the end of this information sheet.

WHAT IS THE PURPOSE OF THE STUDY?

The co-design programme evaluation 2015 aims to:

- Describe the challenges experienced and solutions identified by participating teams to increase the engagement of consumers to co-design health services
- Describe how the EBD (Experience Based Design) approach is being embedded into daily practice, and identify opportunities to increase sustainability of the approach
- Determine the level of leadership support provided to team members and how this impacts on the achievements and learning experiences of teams
- Collect a range of stories/narratives that demonstrate the impact of working closely with consumers that could be used as case-studies for other teams
- Produce simple but effective advice on how to engage consumers in the co-design of health services

This evaluation is funded by the New Zealand Healthy Quality and Safety Commission, and is being led by the Research and Evaluation team at Ko Awatea, Counties Manukau Health, who are responsible for the evaluation design, data collection, analysis and reporting.

This evaluation is approved by the Counties Manukau Health Research Office.

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

All project team members have been invited to participate in this evaluation to gain insights from their direct involvement in the programme.

Your contribution to this evaluation will involve:

- Participating in a face-to-face or telephone interview with Brooke who is the Lead Investigator.
- Providing feedback on a written summary of the evaluation interview (sent via email) to ensure that your thoughts and perspectives have been summarised as you intended to communicate them.
- The opportunity to provide feedback on a draft evaluation report within a defined timeframe. While feedback from team members is welcomed, this is not compulsory.
Whether interviews are conducted face-to-face or over the telephone will depend on the availability and accessibility of team members, and will be decided on a case by case basis in consultation with each participating team member. It is expected that the interview will take up to one hour of your time and will be conducted within a three week period spanning June 2nd-23rd. Topics of discussion throughout interviews with team members will include:

- Your experiences of initially approaching consumers
- Your experiences of working closely with consumers
- The progress you have been able to make and how this has contributed to any outcomes/impacts you have observed
- Your thoughts on what opportunities there are for ongoing sustainability of the EBD approach
- Your feedback regarding the support available throughout the Programme

Interviews will be conducted in a conversational style, guided by a number of pre-determined interview questions. During the interview, there will also be opportunities to add your own comments and insights should these not be raised in response to the interview questions asked.

A summary of your evaluation interview will be sent to you, via email, within one week of your interview. It is important to make sure the summary reflects what you wanted to say. Responding to your interview summary should take only 10-20 minutes of your time, depending on the length and depth of your interview discussion. Responding involves: (i) reading through your interview summary and (ii) letting us know if you are happy with the summary, providing feedback about any aspect that you are not happy with, and advising about any missed points. Feedback can be provided through email or by telephoning Brooke who is the lead investigator.

The evaluation also involves analysis of teams’ workbooks and other relevant materials, interviews or focus groups with consumers/patients, and interviews with project sponsors/senior leaders.

WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF THIS STUDY?

This evaluation will benefit a wide audience including: team members, sponsors and consumers who are currently participating, or in the future will participate, in the co-design programme. This evaluation is expected to contribute to ongoing programme improvement and refinement, and also be a resource for future project team members to more effectively and confidently approach consumers about participating in the co-design of health care services. More broadly, health care services may benefit from this evaluation through sharing of the findings which will raise awareness of our learning, potential outcomes/impacts and opportunities to embed EBD approaches.

There are minimal risks to team members who decide to participate in this evaluation. Any reporting or publications developed will contain only de-identified information. For example, evaluation participants will be identified as a ‘team member’, ‘consumer/patient’ or ‘sponsor’; there will be no inclusion of names or any other personal details. However, for those readers who are familiar with the programme and project teams, there is some risk that they may be able to identify individuals or teams due to their thorough knowledge of experiences and perspectives presented in the evaluation.

Highlighting both positive and negative aspects of your experience enables balanced evaluation reporting. Communicating where experiences may have been less than satisfactory can be uncomfortable for some, but this is an important part of refining and
improving programmes. All evaluation participants are encouraged to be open and honest in their feedback and discussions of their experiences participating in the programme. We would like to assure all participant groups that anything raised during interviews will remain completely de-identified in any evaluation reporting, and in long term data storage.

**WHAT ARE MY RIGHTS?**

Participation in this evaluation, while greatly appreciated, is strictly voluntary. You are free to decline to participate without this affecting your involvement in the co-design programme and relationship with any of the programme team.

All participants have the right to access information about them collected as part of the evaluation. You may also withdraw from the evaluation at any practical time. It would be impractical to withdraw any time after interview findings have been already been incorporated with others into evaluation reporting.

As previously highlighted, team members can contribute feedback on a draft version of the evaluation report within specified time frames. All evaluation participants will be provided with a copy of the finalised evaluation report.

**WHAT HAPPENS AFTER THE EVALUATION IS COMPLETED?**

It is expected that an evaluation report will be available in September 2015. A final version of the report will be emailed to all evaluation participants at this time. De-identified data from the evaluation will be stored, on a password protected database at Ko Awatea, for a period of up to three years.

**WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?**

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Name: Brooke Hayward  
Title: Evaluation Officer  
Phone: (09) 250 9868  
Email: Brooke.Hayward@middlemore.co.nz

If you want to talk to someone who isn't involved with the study, you can contact:

Name: Luis Villa  
Title: Research and Evaluation Manager  
Phone: (09) 250 2065  
Email: Luis.Villa@middlemore.co.nz
Appendix F: Participant information sheet for sponsors

You are invited to take part in an evaluation for the co-design programme 2015. Whether or not you take part is your choice. If you don’t want to take part, you don’t have to give a reason, and whether or not you participate in the evaluation won’t affect your participation in the programme, or relationship with the programme staff.

This Participant Information Sheet will help you decide if you would like to participate in the evaluation by providing information about why we are doing the evaluation, what your participation would involve, what the benefits and risks to you might be, and what would happen after the evaluation ends.

This document is four pages long, please make sure you have read and understood all the pages. If there is anything you don’t understand or if you have any further questions about the evaluation please do not hesitate to contact the Lead Investigator, Brooke. Brooke’s contact details are provided at the end of this information sheet.

WHAT IS THE PURPOSE OF THE STUDY?

The co-design programme evaluation 2015 aims to:

— Describe the challenges experienced and solutions identified by participating teams to increase the engagement of consumers to co-design health services
— Describe how the EBD (Experience Based Design) approach is being embedded into daily practice, and identify opportunities to increase sustainability of the approach
— Determine the level of leadership support provided to team members and how this impacts on the achievements and learning experiences of teams
— Collect a range of stories/narratives that demonstrate the impact of working closely with consumers that could be used as case-studies for other teams
— Produce simple but effective advice on how to engage consumers in the co-design of health services

This evaluation is funded by the New Zealand Healthy Quality and Safety Commission, and is being led by the Research and Evaluation team at Ko Awatea, Counties Manukau Health, who are responsible for the evaluation design, data collection, analysis and reporting.

This evaluation is approved by the Counties Manukau Health Research Office.

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

All sponsors or senior leaders of project teams have been invited to participate in this evaluation to gain insights from their direct involvement in the programme. Your contribution to this evaluation will involve:

— Participating in a face-to-face or telephone interview with Brooke who is the Lead Investigator.
— Providing feedback on a written summary of the evaluation interview (sent via email) to ensure that your thoughts and perspectives have been summarised as you intended to communicate them.
— The opportunity to provide feedback on a draft evaluation report within a defined timeframe. While feedback from sponsors or senior leaders is welcomed, this is not compulsory.
Whether interviews are conducted face-to-face or over the telephone will depend on the availability and accessibility of sponsors and/or senior leaders, and will be decided together on a case by case basis. It is expected that the interview will take up to one hour of your time and will be conducted within a three week period spanning June 17th-July 8th. Topics of discussion throughout interviews with sponsors and/or senior leaders will include:

- Your experiences supporting staff participating in the co-design programme
- Exploring your role as a support person
- Challenges encountered by project teams
- Any outcomes/impacts you have observed
- Your thoughts on what opportunities there are for ongoing sustainability of the EBD approach

Interviews will be conducted in a conversational style, guided by a number of pre-determined interview questions. During the interview, there will also be opportunities to add your own comments and insights should these not be raised in response to the interview questions asked.

A summary of your evaluation interview will be sent to you, via email, within one week of your interview. It is important to make sure the summary reflects what you wanted to say. Responding to your interview summary should take only 10-20 minutes of your time, depending on the length and depth of your interview discussion. Responding involves: (i) reading through your interview summary and (ii) letting us know if you are happy with the summary, providing feedback about any aspect that you are not happy with, and advising about any missed points. Feedback can be provided through email or by telephoning Brooke who is the lead investigator.

The evaluation also involves analysis of teams’ workbooks and other relevant materials, interviews or focus groups with consumers/patients, and interviews with project team members.

**WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF THIS STUDY?**

This evaluation will benefit a wide audience including: team members, sponsors and consumers who are currently participating, or in the future will participate, in the co-design programme. This evaluation is expected to contribute to ongoing programme improvement and refinement, and also be a resource for future project team members to more effectively and confidently approach consumers about participating in the co-design of health care services. More broadly, health care services may benefit from this evaluation through sharing of the findings which will raise awareness of our learning, potential outcomes/impacts and opportunities to embed EBD approaches.

There are minimal risks to sponsors and/or senior leaders who decide to participate in this evaluation. Any reporting or publications developed will contain only de-identified information. For example, evaluation participants will be identified as a ‘team member’, ‘consumer/patient’ or ‘sponsor/senior leader’; there will be no inclusion of names or any other personal details. However, for those readers who are familiar with the programme and project teams, there is some risk that they may be able to identify individuals or teams due to their thorough knowledge of experiences and perspectives presented in the evaluation.

Highlighting both positive and negative aspects of your experience enables balanced evaluation reporting. Communicating where experiences may have been less than satisfactory can be uncomfortable for some, but this is an important part of refining and improving programmes. All evaluation participants are encouraged to be open and honest in their feedback and discussion of their experiences participating in the programme. We would
like to assure all participant groups that anything raised during interviews will remain completely de-identified in any evaluation reporting, and in long term data storage.

**WHAT ARE MY RIGHTS?**

Participation in this evaluation, while greatly appreciated, is strictly voluntary. You are free to decline to participate without this affecting your involvement in the co-design programme and relationship with any of the programme team.

All participants have the right to access information about them collected as part of the evaluation. You may also withdraw from the evaluation at any practical time. It would be impractical to withdraw any time after interview findings have been already been incorporated with others into evaluation reporting.

As previously highlighted, sponsors/senior leaders can contribute to providing feedback on a draft version of the evaluation report within specified time frames. All evaluation participants will be provided with a copy of the finalised evaluation report.

**WHAT HAPPENS AFTER THE EVALUATION IS COMPLETED?**

It is expected that an evaluation report will be available in September 2015. A final version of the report will be emailed to all evaluation participants at this time. De-identified data from the evaluation will be stored, on a password protected data base at Ko Awatea, for a period of up to three years.

**WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?**

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Name: Brooke Hayward  
Title: Evaluation Officer  
Phone: (09) 250 9868  
Email: Brooke.Hayward@middlemore.co.nz

If you want to talk to someone who isn’t involved with the study, you can contact:

Name: Luis Villa  
Title: Research and Evaluation Manager  
Phone: (09) 250 2065  
Email: Luis.Villa@middlemore.co.nz
Appendix G: Participant information sheet for consumers

You are invited to take part in an evaluation for the co-design programme 2015. Whether or not you take part is your choice. If you don’t want to take part, you don’t have to give a reason, and whether or not you participate in the evaluation won’t affect your participation in the programme, or relationship with staff from your health service.

This Participant Information Sheet will help you decide if you would like to participate in the evaluation by providing information about why we are doing the evaluation, what your participation would involve, what the benefits and risks to you might be, and what would happen after the evaluation ends.

This document is four pages long. Please feel free to read it by yourself, or together with family, whānau or friends if you would prefer. If there is anything you don’t understand, or if you would like to ask any questions about the evaluation, please contact the Evaluation Leader, Brooke. Brooke’s contact details are provided at the end of this information sheet.

**WHAT IS THE PURPOSE OF THE STUDY?**

The co-design programme evaluation 2015 aims to:
- Describe the challenges experienced and solutions identified by participating teams to increase the engagement of consumers to co-design health services
- Describe how the EBD (Experience Based Design) approach is being embedded into daily practice, and identify ways to make this sustainable
- Determine the level of leadership support provided to team members and how this impacts on the achievements and learning experiences of teams.
- Collect a range of stories/narratives that show the impact of working closely with consumers that could be used as case-studies for other teams
- Produce simple but effective advice on how to engage consumers in the co-design of health services

This evaluation is funded by the New Zealand Healthy Quality and Safety Commission, and is being led by the Research and Evaluation team at Ko Awatea, Counties Manukau Health, who are responsible for the evaluation design, data collection, analysis and reporting.

**WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?**

All patients who have been involved in co-designing health care services with staff are welcomed to participate in this evaluation to gain insights from their direct involvement in the programme.

Your part in this evaluation will involve:
- Participating in a face-to-face or telephone interview with Brooke who is the Evaluation Leader.
- Providing feedback on a written summary of your evaluation interview (sent via email) to ensure that your thoughts and perspectives have been summarised as you intended to communicate them.
- The opportunity to provide feedback, in a group discussion or through telephone or email, on a draft guide for staff to help them better approach patients. Providing feedback on the draft guide is really appreciated, but this is optional.
Interviews will be conducted face-to-face or over the telephone depending on your availability and location. Patients and the Evaluation Leader can decide together what will work the best. It is expected that the interview will take up to one hour of your time and will be completed sometime between June 17th and July 10th. The main things we will talk about in the interview include:

- Your experience of being approached by staff at your health care service about the programme
- Why you wanted to get involved in the programme (motivators), and what made getting involved harder
- Your experiences working closely with staff at your health care service
- The progress you have been able to make and any changes
- What you got out of the programme (personal rewards)

The interview will be just like having a conversation with someone, but guided by a number of pre-determined interview questions. During the interview, there will also be the chance to add your own comments and insights should these not be raised in response to the interview questions asked.

A written summary of your evaluation interview will be sent to you, via email, within one week of your interview. It is important to make sure the summary reflects what you wanted to say. Responding to your interview summary should take only 10-20 minutes of your time, depending on the length and depth of your interview discussion. To respond, we ask that you first read through your interview summary. You are welcome to do this by yourself, or with the support of family, whānau or friends. After reading the summary, let us know if you are happy with it, and if there is anything that you are not happy with. Please also point out any missed points. Feedback can be provided through email or by telephoning Brooke; whatever suits you best.

There will also be the option to provide feedback on a draft guide being written for staff to help them better approach patients about the co-design programme in the future. You may provide feedback by participating in a group discussion, or by telephoning or emailing Brooke. We can talk about this at your interview and you don’t have to do this part of the evaluation if you would prefer not to.

The evaluation also involves interviews with team members and sponsors/senior leaders (all the staff on the programme who have been involved), and analysis of workbooks and other programme materials.

**WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF THIS STUDY?**

This evaluation will benefit many people including: team members, sponsors and consumers who are currently participating, or in the future will participate, in the co-design programme. This evaluation is expected to contribute to ongoing programme improvement and refinement, and also be a resource for future project team members to more effectively and confidently approach consumers about participating in the co-design of health care services. More broadly, health care services may benefit from this evaluation through sharing of the findings, which will raise awareness of our learning, potential outcomes/impacts and opportunities to embed EBD approaches.

There are minimal risks to you if you decide to participate in this evaluation. Any reporting or publications made will not include your names or other personal details. For example, we will call evaluation participants ‘team member’, ‘consumer/patient’ or ‘sponsor’ only, rather than using your names. However, for those readers who are familiar with the programme and project teams, there is some risk that they may be able to identify individuals or teams due to their thorough knowledge of experiences and perspectives presented in the evaluation.
Highlighting both positive and negative aspects of your experience improves our evaluation reporting. Communicating what you didn’t like can be hard, but this is a great way to improve the programme for others. Everyone is encouraged to be open and honest in discussing their experiences participating in the programme. Please remember that anything raised during interviews will remain completely de-identified (you will not be identified) in any evaluation reporting, and in long term storage of the information.

**WHAT ARE MY RIGHTS?**

Participating in this evaluation would be appreciated but is your choice. You are free to decline to participate without this affecting your involvement in the co-design programme and relationship with any of your health care providers.

All participants have the right to access information about them collected as part of the evaluation. You may also withdraw from the evaluation at any practical time. It would not be possible to withdraw any time after interview findings have been already been incorporated with others into evaluation reporting.

As previously highlighted, patients/consumers can provide feedback (within specified time frames) on the draft guide for staff to assist them in better approaching consumers about the programme. All evaluation participants will be provided with a copy of the finalised evaluation report.

**WHAT HAPPENS AFTER THE EVALUATION IS COMPLETED?**

It is expected that an evaluation report will be available in September 2015. A final version of the report will be emailed to all evaluation participants at this time. De-identified data from the evaluation will be stored, on a password protected data base at Ko Awatea, for a period of up to three years.

**WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?**

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Name: Brooke Hayward  
Title: Evaluation Officer  
Phone: (09) 250 9868  
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If you want to talk to someone who isn’t involved with the study, you can contact:

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