



HEALTH QUALITY & SAFETY  
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*Kupu Taurangi Hauora o Aotearoa*



*Institute for Innovation  
and Improvement*

## **New Zealand Health Safety and Quality Commission Partners in Care Experience Based Design Programme**



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experience based design

**Review Report  
December 2012**

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## Review summary

The Partners in Care programme was developed by the New Zealand Health Safety & Quality Commission (HSQC) to support healthcare organisations in delivering its aim to *“Increase the engagement of consumers in decision-making about the services they use, and to increase consumer literacy and capture consumer experiences.”*

The NHS Institute for Innovation and Improvement, (part of the English National Health Service) was commissioned by HSQC to deliver its Experience Based Design (ebd) approach to the 31 healthcare organisations participating in the Partners in Care programme. As ebd *‘uses patient and staff experience to design better healthcare services’*, it was seen as the ideal approach to support delivery of this programme.

The ebd programme, which began in May 2012 and ends in February 2013, includes an introductory masterclass, a series of ten web based learning seminars and email support from Dr Lynne Maher, the NHS Institute’s programme director. Participants also have access to all ebd resources and learning material through the HQCS website.

To be eligible for the ebd programme completion certificate a health sector and consumer representative from each healthcare organisation is required to participate in all elements of the programme, implement an ebd project in their own organisation and complete a workbook to demonstrate their learning.

An interim review has been carried out to understand more about participants’ experience of the Partners in Care ebd programme, capture any learning that can be shared amongst all of the project teams, identify any potential areas of concern that may require additional support and consider any ways in which the programme may be improved.

Review data have been captured through four different methods: review of web seminar recordings; review of the 22 (out of potentially 31) workbooks that had been completed; twelve telephone interviews with programme participants and an online survey sent out to all participants. Twenty nine (out of a potential total of 62) survey questionnaires were returned.

The majority of survey respondents describe their current situation as ‘actively participating in the ebd learning programme’ and their projects are either ‘progressing well’ (11) or ‘progressing slowly’ (15). Three are still actively participating in the learning although their projects are temporarily on hold. Five teams have withdrawn from the programme, mainly as result of time constraints or lack of resources to complete the ebd work.

Participants’ overall view of the ebd approach is very positive. They have found it a powerful way of engaging consumers and understanding what their experience of healthcare services are really like. The importance they place on consumer engagement has increased as a result of the programme.

Twenty seven (out of 29) rated their overall experience of the ebd programme as ‘excellent’ or ‘good’ and the majority thought the ebd masterclass, ideas and concepts included in the programme, and quality of supporting materials are ‘excellent’ or ‘good’.

Participation in the web seminars has been high and these are also viewed as ‘excellent’ or ‘good’. The most highly rated and most enjoyable web seminars were those on driver diagrams, sustainability and three seminars when participants shared their experiences with the entire group.

Fifteen survey respondents have experienced technical difficulties in joining the web seminars, although on the whole, these have been resolved. There have been some reports of poor sound quality and some difficulties accessing web seminar recordings and

resources on the HSQC website. We have recommended providing web links to the web seminar recordings and re-issuing passwords and instructions for accessing the HSQC website.

Almost all survey respondents found the workbook questions either 'very relevant' or 'somewhat relevant' to their own project. The majority found them 'quite challenging' to complete. Feedback about workbook completion included comments about its length and format, repetitive questions and underestimating the time required to complete it.

The teams were at various stages of implementing their ebd projects with most having completed the 'preparation stage' and currently working on 'capturing experience' to which they are applying a range of ebd tools to gather data from staff and consumers. The most frequently used/most preferred ebd tools include: interviews to gather patient/staff stories, which some have videoed, observations and surveys to capture emotional experiences. Twenty five out of 29 survey respondents rated the ebd tools as 'excellent' or 'good'

A significant amount of time and effort has been dedicated to engaging senior leaders, staff and consumers and teams report having made good progress. Most teams have successfully engaged with senior leaders, some have been surprised by their enthusiasm and support. Several teams have found it challenging to arrange meetings with senior leaders and/or they have not gained the level of leadership support they would like.

Overall, consumers have been enthusiastic about participating in ebd projects and none of the teams experienced any difficulties or resistance. Consumers have actively helped with gathering information and they have provided contacts to engage more consumers.

Whilst some teams have found that staff are supportive of the ebd approach and are willing to participate, others have had difficult experiences and they have met with staff resistance and cynicism. For three or four teams, this has been extreme and has significantly delayed their project's progress.

Other challenges that have, at times, delayed projects include: gaining clarity on project aims, which has been an iterative process and many teams have had to reconsider and redefine their project aims; underestimating the scale of the task, which has also led to redefining aims and starting with smaller pieces of work to build confidence; clarifying roles and responsibilities of project team members; and ensuring sufficient resources are in place at the start of the project. The amount of time required to carry out the ebd work has been by far the greatest challenge and it has caused concern for almost all of the participants. They suggest that the time required should be made clear at the outset of the programme.

Participants' key recommendations are that it is essential to: dedicate sufficient time, effort and resources to the planning stage, be flexible and willing to consider alternative options; anticipate obstacles and remain determined when things do not always go according to plan. The amount of time and effort dedicated to the preparation stage is strongly correlated with the degree to which participants felt adequately prepared to move on to later stages in the ebd process with clarity and confidence.

Overall, participating in the programme has been a positive and rewarding experience for the overwhelming majority. The most rewarding/enjoyable aspects have been the value of new knowledge gained, first experiences of working directly with consumers, success in overcoming challenges and personal development opportunities. Everyone who responded to the survey strongly agreed/agreed that they would recommend the ebd approach and the partners in care programme to others and they are now keen to share their learning to spread ebd locally

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# Partners in Care Experience Based Design Programme

The English National Health Service's (NHS) Institute for Innovation and Improvement is delivering an Experience Based Design (EBD) programme on behalf of the New Zealand Health Safety and Quality Commission (HSQC). The ebd programme, which forms part of HSQC's Partners in Care programme, was launched in May 2012 and will continue until February 2013. An interim review of the programme has recently been carried out and the aim of this report is to present the review findings.

## 1. Background to the Partners in Care programme

The New Zealand Health Safety & Quality Commission has identified an aim to:

*"Increase the engagement of consumers in decision-making about the services they use, and to increase consumer literacy and capture consumer experiences."*

The Commission has developed the Partners in Care programme to support healthcare organisations across New Zealand in achieving this aim. Partners in Care has been designed to support and enable patient and consumer engagement and participation across the health and disability sector. It aims to increase people's participation in decision-making about their own health and about the way health and disability services in New Zealand are delivered. This participation must be safe, meaningful and occur at all levels, from policy to practice and patients and consumers will be encouraged and supported to participate at a level appropriate to their needs, skills and experience.

The NHS Institute for Innovation and Improvement, which is part of the English National Health Service (NHS) was commissioned to deliver its Experience Based Design (ebd) approach to 31 healthcare organisations across New Zealand that are participating in the Partners in Care Programme. See appendix 1 for list of participating organisations and details of their ebd projects.

## 2. Introduction to the Experience Based Design Approach

The Experience Based Design approach (ebd) *'uses patient and staff experience to design better healthcare services'*, and it was therefore seen as the ideal approach to support delivery of the Partners in Care programme. EBD provides an exciting new way of bringing patients and staff together to share the role of improving care through the re-design of services. It is a proven methodology, which provides a range of tools that can be used to effectively increase the engagement of consumers in decision making about the services they use.

Figure 1 illustrates the four stages of the ebd approach: Capture; Understand; Improve; and Measure. A set of specific tools can be applied to each of these stages. A project that involves the ebd approach would also require teams to complete a 'preparation' stage before starting on stage 1: Capture the experience.

**Figure 1: Four steps of the EBD approach**



### **EBD programme content and delivery methods**

The ebd element of the Partners in Care programme is being delivered by Dr Lynne Maher, who developed the ebd approach and is director of Innovation and Design at the NHS Institute for Innovation and Improvement. Additional input is being provided by NHS Institute colleagues with expertise in specific topics that support delivery of ebd.

The Partners in Care ebd programme includes a one day introductory masterclass, a series of eleven web based learning seminars and email or telephone support from the NHS Institute's programme director. Participants could attend the master class either at Auckland on 16<sup>th</sup> May or Wellington on 17<sup>th</sup> May 2012. The web seminars began on 29<sup>th</sup> May 2012 and will be held approximately once a month until February 2013.

The web seminars cover topics that have been shown to support the design and delivery and of ebd projects. They also provide opportunities for the 31 Partners in Care project teams (62 participants) to discuss their experiences and share their learning with each other and to raise any issues or concerns. There is sufficient flexibility in the programme to include additional topics that participants feel will be of benefit to them and during each web seminar they are encouraged to suggest topics for future sessions.

A summary of the topics covered in the masterclass and the eight web seminars that have already been held is shown in table 1 (page 3). The remaining web three seminars will be held between January and March 2013 ( dates are Jan 15<sup>th</sup>, Feb 12<sup>th</sup> and March 8<sup>th</sup>).

Partners in Care programme participants have access to all ebd resources and learning material through the HQCS website. They can also share their own learning resources and useful documents with other participants through this website.

### **Eligibility criteria for ebd programme completion certificate**

A health sector and consumer representative from each of the 31 participating healthcare organisations are required to attend the masterclass, participate in all web seminars and complete a workbook (one for each project) to be eligible for a 'certificate of completion'. The web seminars are recorded to give participants the opportunity to 'catch up' on any missed sessions.

Tale 1 Summary of EBD Programme content delivered up to end Nov 2012	
Event	Content covered
EBD Masterclass	<ul style="list-style-type: none"> <li>• Introduction to the EBD approach</li> <li>• Planning for Action</li> <li>• Outline of the programme and work requirements for certificate of completion</li> </ul>
Web seminars	<ul style="list-style-type: none"> <li>• Introduction to web seminars and review of EBD approach</li> <li>• 15 Steps challenge: introducing a new ebd tool</li> <li>• Measurement: 7 steps to measurement for improvement</li> <li>• Sharing experience on progress</li> <li>• Driver diagrams(additional)</li> <li>• Sustainability</li> <li>• Stories and narratives</li> <li>• Sharing experience and review of progress to date</li> </ul>

The workbook is designed to support Partners in Care teams to capture their learning over the duration of the programme and to share and contribute to the web-based learning sessions. Specifically through this workbook and participation in the web-based learning session, the ebd programme director will acquire assurance of the teams' learning about applying the concepts of the ebd approach and their ability to implement a project/programme with patients/consumers to improve experience of care. Going through this experience will then result in the team members being able to support others to also *“increase the engagement of consumers in decision-making about the services they use, and to increase consumer literacy and capture consumer experiences.”*

Completion of the programme and workbook will provide the evidence of learning and understanding. Participants are expected to:

1. Provide evidence of their work and feedback from each different phase of the ebd approach
2. Illustrate practical experience of utilising approaches that increase the engagement of consumers and leads to co-design of health services
3. Gather a range of stories/narratives that demonstrate the impact of working closely with consumers
4. Demonstrate 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

All project teams were required to submit their workbooks during August and September for a review of their progress during the first few months of the programme. They will be expected to submit them again in February 2013 before the end of the programme.

A certificate of completion will be issued on successful completion of all elements of the programme.

### 3 Partners in Care review: Aims and methods

The purpose of this review is to understand more about participants' experience of the Partners in Care 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 and consider any ways in which the programme may be improved. We would like to stress that its purpose is *not* to assess how well project teams are doing and

data collected will not be used to determine whether participants will be awarded the certificate of completion.

## Methods used

To achieve the review's aims, data have been captured through four different methods:

- 1 A review of the Q&A sessions and on line 'chat' from the first eight web seminars to identify any emerging themes
- 2 Analysis of the workbooks to identify key learning points, achievements and challenges. Twenty two workbooks (out of a potential total of 31) had been submitted in time for inclusion in this review
- 3 Telephone interviews with a sample of twelve consumer and health sector representatives
- 4 An online survey, which included fixed choice response questions (e.g. strongly agree/agree/disagree/strongly disagree) and some open ended questions. Although four teams (8 participants) are known to have withdrawn from the Partners in Care Programme, we wanted to learn about *everyone's* experience (including the challenges some may have encountered that had led to them withdrawing) and therefore, we asked *all* of the original 62 participants to complete the questionnaire. Twenty nine questionnaires were returned, which represents a response rate of just under 50%.

Data from each of the above sources have been analysed to identify key learning points and any emerging themes.

The remainder of this report focuses on the review findings. It presents information about:

- Participants' views of the ebd approach
- Experience of participating in the Partners in Care ebd programme
- Implementing and ebd project
- Challenges, reflections and key learning
- Greatest achievements and most enjoyable experiences
- Recommendations for future participants

The figures that appear in the following tables relate to the number of survey respondents that expressed a particular view, rather than a percentage.

## 4 Participants' view of the ebd approach

Participants' overall view of the ebd approach is very positive. They said that it is a powerful way of understanding consumers' views and what their experiences of healthcare services are really like. It is an effective way of engaging consumers in healthcare improvement from the outset and provides a powerful method for engaging with and gaining staff support.

*'It's been particularly exciting to discover a new perspective in the most routine interactions'*

*'This is a powerful process with the capability of enhancing services and outcomes for clients'*

*'Ebd can be applied in many varied instances to better a variety of services. It brings fresh ideas and approaches outside the normal ways projects have been managed before'*

One team has already recognised the opportunities for ebd in future improvement projects.

*'Undoubtedly EBD is going to be a common way of approaching planning for the future with plans to incorporate it in a number of projects from here on in. ... the changes promise to be profound'.*

Table 2 shows how participant's views on the importance of co-designing services have changed as a result of the ebd programme, with the majority (23) indicating that they now see it as essential.

<b>Table 2: the importance of co designing health services</b>				
	<i>Essential</i>	<i>Very Important</i>	<i>Of some importance</i>	<i>Not at all important</i>
Which best describes your view of the importance of co-designing health services <i>before</i> you participated in the programme?	6	9	14	
Which best describes your view <i>now</i> ?	23	5	1	

### **Emotional words reflecting participants' feelings**

We asked participants to indicate which emotional words reflected their feelings at the start of the programme and at the time of completing the questionnaire (table 3)

An equal number (17) felt challenged at both points in time although this figure may not relate to the same respondents (i.e. a participant may have felt challenged at the outset and may no longer feel that way and vice versa).

There has been a slight decrease in the number of respondents who feel excited (21 to 15) although this is still relatively high and represents 50%. Although another decrease (23 to 19) the majority has remained enthusiastic.

Eight feel overwhelmed now (none of them did at the outset) and there has been an increase in the number of respondents feeling pressured (increasing from 5 to 14). Other data sources (i.e. interviews and workbooks) suggest that the time required to complete ebd work alongside their regular 'day job' has resulted in these changes in feelings.

Fewer respondents feel intrigued, which is understandable, as they now have eight months experience of the programme and are no longer anticipating what it might involve.

Participants were encouraged to add emotional words that described their feelings both at the start and the time of the review. Words that described their feelings at the start of the programme include, honoured, passionate, daunted, curious and eager. At the time of completing the survey they wrote, disillusioned, involved, engaged, motivated, valuable, uncertain and frustrated.

<b>Table 3. Emotional words describing participants' feelings</b>		
	<i>How did you feel about being involved in the programme when you first 'signed up' as a participant?</i>	<i>How do you feel about your involvement in the programme now?</i>
Challenged	17	17
Overwhelmed		8
Apprehensive	5	3
Intrigued	15	10
Excited	21	15
Pressured	5	14
Disinterested		1
Enthusiastic	23	19
Supported	17	14

## 5 Experience of participating in Partners in Care ebd programme

### Information, resources and support

Participants' views on the masterclass, ebd ideas and concepts, quality of supporting material and ongoing support were generally extremely positive, with the majority rating these as either 'excellent' or 'good'. Additional comments support the positive findings shown in table 4

*'Access to excellent on line resources – HQSC website and Lynne's material has been incredibly helpful – we continue to use this frequently'*

*'Loving the partners in care page on the HQSC website. Great to keep all the info in one place.'*

<b>Table 4: views on information, resources and support</b>				
<b>What are your thoughts about:</b>	<i>Excellent</i>	<i>Good</i>	<i>Fair</i>	<i>Poor</i>
Information you received about the programme before it started	11	11	5	2
The ebd Masterclass	19	9		
The ideas and concepts covered throughout the programme	21	8		
Ease of access to supporting material and resources	12	9	6	
Quality and usefulness of supporting material and resources	15	9	2	
Ongoing support and advice	18	9	2	

*NB not all respondents answered all of these questions*

Seven respondents rated the information received about the programme before it started as 'fair' or 'poor'. Six rated ease of access to supporting materials and resources as fair and seven respondents made additional comments about the difficulty in accessing material from the HSQC website. We explored this during the interviews and found that the problem is due mainly to 'password' issues or technical problems with participants' own IT systems.

As the problem had still not been resolved for some participants, which means that they are not able to access valuable resources, we recommend that instructions for accessing the HSQC website and passwords are resent to all participants.

## Distance learning approach

Although distance or remote learning (i.e. through web seminars and email support) is a new experience for many participants, feedback shows that, overall, it has been a positive and valuable learning experience. It has enabled them to learn from experts in the English National Health Service, when, because of the distance, more traditional face to face learning events would not have been possible.

Twenty seven out of twenty nine respondents rated their overall experience of distance learning as 'excellent' or 'good' and over half made additional comments about the quality of the programme.

*'Web conferences and support from Lynne and HQSC staff have given us the confidence to try new tools knowing there was supervisory resource if we needed it'*

*'One of the best learning programmes I've been involved in'*

*'I found it a bit strange at first –li prefer face to face learning – but I got the hang of it and it's been great'*

Table 5: Views on distance learning approach				
	<i>Excellent</i>	<i>Good</i>	<i>Fair</i>	<i>Poor</i>
How would you rate your overall experience of the distance learning approach?	15	12	2	

## Web learning seminars

The ebd web learning seminars combine presentations on ebd tools and ebd related topics with opportunities to interact through regular 'questions and answers' sessions. Three of the sessions have been set up to allow some teams to present and share their experiences with the entire group. Participants can also interact with the presenter and each other through a 'chat' facility and they are encouraged to make comments and raise questions throughout each session.

## Web seminar participation

Overall, participation in the web learning seminars has been high, although there are conflicting messages between the different data sources (e.g. survey responses, web seminar data and workbooks).

On the one hand, survey data (representing approximately 50% of Partners in Care participants) show that *all* respondents are joining/ listening to the recordings of all the web seminars or between five and seven of them. On the other hand, we have noticed a decrease in the number of participants 'logged in' to live web seminars although we do recognise that they may be listening to the recordings. However, workbook data also

suggests a steady decline in participation as the programme has progressed. We also found a correlation between web seminar participation and 1) whether workbooks were submitted on time and 2) the amount of information/level of detail provided in the workbooks.

### **Web seminar experience**

All of the survey respondents (29) rated the web learning seminars as 'excellent' or 'good'. The comments below, which are typical of those expressed by interviewees and survey respondents also confirm that overall, the majority has found them a positive and valuable learning experience. Despite participating remotely, the level of interaction during each session has been high and participants have regularly posed questions to the presenters and to one another and they have shared their own experiences and offered to share their own material and resources.

*'Web seminars provide opportunities to raise any concerns, learn from each other and share resources. Supportive relationships can be developed through these virtual learning methods'*

*'I find Lynne's enthusiasm during the web seminars really motivating'*

*'The webinars are really useful, it keeps our interest in the project high and it's like we are all working towards a common goal'*

*'The chat box is great – the slides are great'*

The web seminars that participants enjoyed the most included those on: measurement, sustainability and driver diagrams. The most popular sessions were those where Partners in Care participants shared their own experiences and in particular the one held at the end of November.

*'The last one on sharing projects (in November) – it's great when they have an example of a project and then also add a little bit of theory to that'*

In response to the question 'are there are web seminars you didn't particularly enjoy?' the majority either said 'no' or they 'enjoyed them all'. A minority did not enjoy the earlier sessions, which they felt were 'slow' and 'duplicated what we're already learned' and some did not enjoy the early sharing sessions.

Whilst the distance learning approach has, overall, been a positive experience for most of the Partners in Care participants, four said that they it does not fit with their preferred learning style. They prefer face to face interactions and although they have found the presentations useful, they have found it difficult to interact.

Fifteen of the survey respondents have experienced some kind of technical difficulty, including problems connecting to the live web seminars (especially the first few sessions), poor sound quality and interference or they have been unable to access the recordings. Typical comments include:

*'I didn't find the instructions to join easy and I can't access the recordings'*

*'A few times I couldn't hear – quite frustrating with a lot of background noises. It really slowed things down and at times made it hard to stay attentive'*

*'I have had lots of problems trying to replay the sessions I missed'*

*'I still haven't managed to get a sound link through my computer so that I can talk to other participants'*

Whilst some of these problems are due to local IT systems and are therefore beyond the control of Partners in Care directors, if survey responses are typical of all Partners in Care participants, then almost half have experienced some problems. This may explain why web seminar participation has declined.

The majority of the connection issues appear to have been resolved through local IT solutions, however, there are still problems accessing recordings via the HSQC website and it may be worthwhile emailing details of web links for all the web seminar recordings. This appears to have been more successful than accessing them through HSQC website. Some participants are frustrated by poor sound quality and they may need to connect via their laptops/computers *and* their phones. Reminding everyone to mute their phone at the start of each web seminar may further improve the sound quality.

Appendix 2 provides a more detailed account of the key learning points and issues raised for each web learning seminar.

## Ebd workbooks

As table 6 shows, almost all the survey respondents found the workbook questions either 'very relevant' or 'somewhat relevant' to their own project and the majority found them 'quite challenging' to complete.

<b>Table 6: ebd workbooks</b>				
	<i>Very relevant</i>	<i>Somewhat relevant</i>	<i>Somewhat irrelevant</i>	<i>Not all relevant</i>
How relevant are the questions in the workbook to your own project experience?	11	11	1	
	<i>Very easy</i>	<i>Quite easy</i>	<i>Quite challenging</i>	<i>Very challenging</i>
How easy or challenging was it to complete the workbook?	1	7	15	

NB three respondents did not complete these questions

Additional comments about workbook completion were divided between positive and negative. On a positive note, it was viewed as a useful experience to reflect on progress and the lessons learned

*'Overall, I found the questions/structure of the workbook forced us to take stock of where we had come from and what we had accomplished'*

*'A useful process, making us reflect on the experience to date'*

*'The value of the workbook is in the reflection of learning'*

Negative comments related mainly to the workbook format, its length and repetitive nature and lack of guidance as to what information was required

*'It is not use friendly e.g. the font keeps changing and the tables/bullets go haywire'*

*'The workbook is quite repetitive. Reduce the page count and make it more succinct'*

*'Would be useful to have a few more prompts about what is expected'*

Other feedback on the workbook related to lack of time due to other work pressures or not appreciating the time that would be required to complete it, with a suggestion that it would be helpful to outline the time requirements for this task at the start of the programme.

*‘Only challenge has been finding the time to do it’*

*‘It would be worth letting participants know that they need to put aside half a day a month for the webinar and workbook’*

## 6 Implementing an ebd project:

This section focuses on project teams’ experience of actually implementing their ebd projects.

### Stages of the ebd process

Whilst our aim was not to assess how individual projects are progressing, we wanted to provide a sense of what stage in the ebd process the teams are at and what their main achievements have been.

As table 7 illustrates, the majority are either ‘capturing experience’ (14) or ‘understanding the experience’ (9). Four teams are now at the stage of ‘improving the experience’ and one team is ‘measuring the improvement’.

Preparation stage	1
Capture the experience	14
Understand the experience	9
Improve the experience	4
Measure the improvement	1

In terms of how survey respondents view their current situation, 11 report that they are ‘actively participating in the ebd learning programme and their project is progressing well’, 15 are actively participating and their project is ‘progressing slowly’. Three respondents indicate that they are actively participating in the ebd programme (i.e. joining the web learning seminars) although their project is temporarily on hold.

We know from email exchanges that five teams (10 participants) have withdrawn from the programme. None of these participants returned the questionnaire and therefore, we are unable to report on the specific challenges they encountered that led to them withdrawing. Email correspondence suggests that time constraints and lack of resources are the primary reasons.

Active participant in ebd learning programme and our project is progressing well	11
Active participant in ebd learning programme and our project is progressing slowly	15

## Applying Ebd tools and methods

All except one survey respondent rated the ebd tools that they had used as 'excellent' or 'good'.

**Table 9: use of ebd tools**

	<i>Excellent</i>	<i>Good</i>	<i>Fair</i>	<i>Poor</i>
Overall, how would you rate the tools that you have used?	16	9	1	

**NB Three respondents did not complete this section and three had not used any of the tools**

We asked participants to list the ebd tools they have used and tell us which ones they have found the most useful/ enjoyed using the most. As the teams are at different stages in their ebd projects, it is understandable that their use of ebd tools varies significantly. For example, three teams have not yet used any of the tools; five teams have used just one of the tools and four report having used most or all of them. About half (15 respondents) have used two or three of recommended ebd tools and four said they have adapted tools (e.g. the emotion questionnaire) to fit the context of their project.

The most frequently used ebd tools include: staff and patient interviews to listen to their stories (9 respondents), which some have videoed (4); observations (6); questionnaires (8); driver diagrams (4) and 'Wordles' (3)

Tools that respondents have found 'most useful/enjoyed using the most' include listening to staff and patient stories (the most popular response) videoing staff and patients telling their stories, driver diagrams and 'Wordle'.

*'Teams loved concept of using "wordle" to provide non-threatening feedback'*

*'Use of surveys to identify touch points was quickly accepted'*

*'Videoing patients and staff telling their stories has provided such rich information – it's been a great experience'*

*'First client interviews have proven very rich, perspective changing and powerful'*

Overall, the response rate to this question was low (eight respondents did not complete it) and therefore a wider range of ebd tools may have been used than the figures above suggest

## Engaging key stakeholders

Although some project teams are now capturing experience and analysing data, much of the data gathered throughout this review (in particular workbook data) related to the preparation stage. During this stage, one of the most important tasks is to engage with key stakeholders at the earliest opportunity and participants were specifically asked about their experiences of engaging with senior leaders, staff and consumers.

It is clear that the majority of teams has dedicated considerable time and effort to this task and that overall, significant progress has been made.

## Engaging with senior leaders

Most teams have successfully engaged with senior leaders and they have been encouraged (a few surprised) by their enthusiastic responses and the high level of support they have received for the ebd approach. As the figures in table 10 show, the majority 'strongly agree/agree' that 'senior leaders are enthusiastic about the ebd approach' and 'they have actively supported projects'.

Table 10: Senior leadership engagement				
	Strongly agree	Agree	Disagree	Strongly disagree
Senior leaders are enthusiastic about the ebd approach	13	8	4	
Senior leaders have actively supported our project	11	12	3	

NB three consumer representatives did not respond to these questions

The following comments provide further examples of the strength of senior leadership support for the ebd approach

*'Extremely supportive. They have also provided excellent flexibility when time is required to work on the project'.*

*'Immediate support from CEO and DON. The project was seen as worthwhile and would add value to relationships between the Hospital and the Consumers we serve'.*

*'Information about the project was published from the CEO in the weekly staff newsletter'*

*'We were pleasantly surprised how ready the senior leadership were to support the project'.*

The process of engaging with senior leaders demonstrated to project teams how necessary it is to gain their support and how this can be instrumental in moving projects forward.

*'This gave us 'permission' to get started and, importantly, indicated senior leadership's trust and buy-in. Had this not occurred, it would have been impossible to proceed'*

*'Achieving management cooperation early on paves the way for a successful project especially when (not if!) unexpected challenges occur down the track'.*

However, as a few of the teams discovered, engaging senior leaders proved to be quite a challenge. They had not anticipated it being so difficult to book time in senior leaders' diaries and their experience has shown that meetings with senior leaders need to be planned well in advance, especially if they are required to have an input into the project.

*'Some of the senior management team were hard to pin down and convince'*

*'We have not yet had dedicated time to present EBD co-design concepts to all the members of the senior management team'.*

*'I under estimated just how long it took to gain approval (from senior leaders) for the documentation I wanted to use in the presentation folder for clients'*

Four teams found that although senior leaders supported ebd in principle, they did not provide the support that was required to help overcome obstacles.

*Although senior leaders said they were supportive, when staff declined to participate (e.g. filming) the senior leaders vanished and did not support me*

A key learning point for some was to ensure that project aims and objectives are really clear before presenting to leadership team.

*'There were no barriers to gaining leadership support but in terms of this initiative it may have been better if we identified project aims sooner'*

Other factors that were shown to have a positive impact on senior leadership engagement were: aligning project aims with the organisation's strategic objectives; demonstrating the potential benefits; providing the right level of information and ensuring that senior leaders receive regular updates on the project's progress

*'Management support initiatives if they align with the originations over all goals'*

*'It is essential to be clear and honest with senior leadership about proposed activities, including the value/benefits to the organisation and budget'*

*'Keep senior management abreast of all developments'*

## Engaging staff

Whilst overall, the level of staff engagement is generally high, it has been more problematic for some teams than senior leadership and consumer engagement. As table 11 shows, not all staff are enthusiastic about the ebd approach or are willing to support or participate in projects.

<b>Table 11: Staff engagement</b>				
	<i>Strongly agree</i>	<i>Agree</i>	<i>Disagree</i>	<i>Strongly disagree</i>
Staff are enthusiastic about the ebd approach	3	13	5	3
Staff have willingly supported our particular project	5	13	6	1
*Staff have been willing to participate in the project (e.g. be interviewed, filmed) 5 n/a as consumers	3	13	6	1

**\*Five consumers felt this question was not relevant to their experience**

Interview and survey comments suggest that generally, staff want to offer quality care to their patients and are supportive of an approach that involves them and provides an evidence base for improvement work. One consultant immediately asked if the approach could be trialled in his clinic.

*'She (nurse manager) was focussed on providing the best possible care to her patients and was looking for evidence of the issues she believes they face'*

*'We met with our Maternity Manager and she just said go for it!! We were immediately given the scope and encouragement, the strategy is definitely go and do!!!*

*'Were really easy to engage. Very keen on model, liked the proactive nature of the EBD approach. One orthopaedic consultant immediately asked if we could trial the approach at this OP clinic*

*'Once we started disseminating information, we became a bit overwhelmed with the enthusiasm across the teams. Everyone wanted it now'*

Even more encouraging for some of the projects teams, staff willingly helped out and proactively supported projects.

*'Staff have been co-operative in giving feedback and offering critique to the plan and questionnaire phases. Staff also willingly participated in a series of focus groups'*

*'Middle management who have been involved have been very accommodating and supportive in liaising with their staff about the project and co-ordinating staff and consumers for interview'*

As with senior leadership engagement, participants recognised that gaining staff's support and trust is essential for moving projects forward and that sufficient time has to be allocated to the engagement process.

*'Without positive engagement, we risk losing their trust and may not be able to access service users for the consumer focus groups and the project will fail'*

*'Without taking time to take this step, the project will not get off the ground and we risk failure'*

It is primarily in relation to staff's willingness to actually participate in ebd projects, for example interviews and filming, that the partners in care teams encountered mixed reactions from staff. Some teams described positive experiences in which staff were eager to participate and to offer their skills and knowledge.

*'Key workers readily gave consent to a video interview and participated well'*

*'In one video interview a staff member was able to share with the consumer her thoughts and aspirations for the future. This was a positive experience for the consumer'*

However, it proved more difficult for other teams and they encountered cynicism and resistance. Suggested reasons for staff resistance are feeling threatened and/or fear that they may be judged.

*'They felt nervous about the idea of being videoed and criticised about their work'*

*'Presentation of concept of an exit interview conducted by ex-patients to team members was met with an atmosphere of cynicism and doubt.*

*'It seems that we have not 'fired' the staff with the concept of consumer involvement*

*'Staff can be nervous and harder to persuade than patients – other staff are nervous at the prospect of being videoed*

*'Staff can feel threatened by 'outsiders' undertaking a project on 'their' patients'*

One participant suggested that staff may be concerned about the impact of the ebd project on patient safety and clinical effectiveness.

*'Staff need assurance that the project will support the programmes they are undertaking and will not interfere with patient safety and clinical effectiveness. This is all about gaining staff's trust'*

It was suggested that it is important to explain and reassure staff that the aim of the interviews, videos etc is to gather information for the purpose of improving patient services rather than a method of judging their performance and the safety of their patients will not be compromised in any way.

Teams advised that adequate preparation is essential before attempting to engage with staff. The concepts of ebd should be carefully explained and staff should be given sufficient time to take these on board. Drawing on staff's own experiences and involving them in project design were also suggested as useful ways to engage them and gain their support.

*'Be better prepared especially when presenting a novel idea to staff'.*

*'Preparation is key for persuading people, especially staff'*

*'Take more time to explain the project rationale; and allow staff to consider this in relation to other work projects'*

*'Co-design principles need to be promoted to staff in an environment where there is enough time to get people on board'*

*'Maybe drawing a bit more on their (staff's) own experiences of listening to consumers and their whānau'*

## **Engaging consumers**

According to survey, interview and workbook data, consumers have responded enthusiastically when approached about the Partners in Care programme and none of the teams reported any negative or difficult experiences. Some teams found that the first consumers on board with the ebd project subsequently provided useful contacts to engage more consumers.

*'Consumers were excited about work'*

*'We have not encountered a negative comment and 100% of those invited have accepted'*

*'Engagement with initial consumers enabled us to seek their suggestions for other vital contacts to engage with this project'*

*'All the consumers have been absolutely fantastic, obliging to get us going'.*

*'Some natural leaders were 'discovered' through the process. We will maintain relationships and communications with these young people to keep them engaged in the project going forward'*

Participants described some very positive experiences of working in partnership with consumers to capture patient stories and gather information.

*'Consumers have participated in shadowing, observation, focus group and questionnaire activities'.*

*'Consumers participated readily in the video interview'*

*'During the 'shadowing' consumers expressed their appreciation about being asked for their opinion (almost as though we were doing the favour – not the other way around)'.*

They also reflected on missed opportunities for engaging with consumers at an earlier stage in the ebd project, suggesting that whilst it may take courage, they intend to be bolder in the future.

*'Could have identified more opportunities to engage with consumers earlier. We will be 'bolder' in future but it took some courage to approach consumers and ask for their help in the first instance'.*

*'Once out there discussing and introducing the model to consumers there was a real enthusiasm for engaging with this way of working'*

*'Patients are keen to help – don't hold back from asking them'*

However, whilst it was generally agreed that consumers should be engaged at the earliest opportunity, it was also pointed out that it may be helpful to have some of the processes in place before involving them as not all consumers want to get involved in the detail of the 'set up' phase

*'We could have had more processes up and running before involving our consumers who have limited energy for initiating the set up phase of a project.'*

Several teams described the benefits of existing relationships between themselves or their organisations and consumer groups. They found it easier to engage with consumers if a good relationship had already been established.

*'We had existing relationships with cancer society & other patient support groups. It was easier to explain and recruit for the project, as the group had originally raised an issue as a difficult experience, and they were keen to help'*

*'Mental Health Services were really helpful as already have consumer and family advisory roles that were keen to assist in creating opportunities to engage the wider group'.*

Like staff, consumers also like to be well informed about a project they are asked to take part in and three teams found that more consumer information was required than they had first thought

*'Consumers liked to have more information about the project – this has now been added to the questionnaire as staff found themselves repeating the same aim – risk in that was that 'different' staff may offer a slightly different perspective'.*

Overall, the process of engaging consumers has been a positive experience and as a result, the confidence of the project teams has increased and there has been an overall increase in consumer engagement across the participating organisations.

**Table 12: Confidence and increase in consumer involved**

	<i>Strongly agree</i>	<i>agree</i>	<i>disagree</i>	<i>Strongly disagree</i>

My confidence in engaging with consumers has increased as a result of this programme	16	3	1	
This programme is leading to a general increase in consumer involvement in my organisation	16	3	3	

3 consumer representatives did not complete these questions

## Key learning from the engagement process

Some common themes emerged from project teams' experience of the entire engagement process.

Firstly, they identified the need to engage with *all* key stakeholders at the earliest opportunity

*'Speak to the senior management team, staff and consumer groups early'*

*'Inform key stakeholders at an earlier stage of the project'*

*'Involve them all from the beginning'*

Secondly, they found that actively involving consumers and using patient stories throughout the engagement process were powerful and effective ways to increase staff and senior leadership support for the ebd approach.

*'I think it could have helped for me (the patient) to be there at the time people needed persuading'*

*'If staff hear the experience first-hand they are more likely to engage'*

*'Don't underestimate the value of the consumer experience in gaining support'*

Thirdly, they stressed the importance of focusing on building and maintaining relationships throughout the entire engagement process.

*'The process of gaining senior leadership support showed us the paramount importance of trust and the value of relationships'*

*'Without trust and established relationships, getting a project started would have been much more difficult, including time consuming'*

*'Be aware to work on relationships first or be clear that relationships as well as tasks are important'*

Finally, project teams repeatedly emphasised the need for open and honest communication during the initial engagement phase and when providing regular progress updates to ensure that high levels of support are sustained throughout the project's duration.

*'Keep communication open and as often as possible'*

*'Have become increasingly aware that we need to keep the Partners in Care project at the front over everyone's attention'*

*'You need good communication and a willingness to be open minded – listen to other people, understand the constraints under which each participant is operating'*

*'Project partners must also communicate clearly and honestly with staff so they feel well informed, involved and keen to participate rather than pushed in to it. We cannot assume that although we think they have been informed they actually understand and support the process'*

## 7 Challenges, reflections and key learning

Participants' reflections reveal some of the challenges they have encountered in implementing ebd projects. These are discussed below, together with some of the ways in which they have overcome them and their suggestions for how they might do things differently next time.

### Clarity of project aims

As well as engaging with key stakeholders, the preparation stage is also the stage during which project teams need to clearly define their project aims and measures of success. In the earlier stages these aims may be broad aims but as one team pointed out

*'We need to be able to describe what success will look like – if we can't, we can't expect people to buy in to this work and more importantly, know if we've achieved it'*

Whilst all of the teams had identified project aims at the outset of the Partners in Care programme, many of them recognised that as their work progressed, they needed to step back, reconsider their aims and get more clarity about what, specifically, they are trying to achieve. In some instances, lack of clarity delayed the start of their work. Some of the aims were initially too broad and could not realistically be achieved within the timescales. Others were not defined clearly enough and could not easily be described to someone outside of the project team and some were too narrow and described a specific intervention or improvement method rather than an aim.

*'We possibly needed a clearer sense of purpose from the beginning'*

*'We had not devoted enough attention to the real aims and what success would look like and how we will measure this'*

*'It is important to have succinct messages about the aims of our project ready at hand for when there are opportunities to communicate with staff and patients'*

Participants' feedback shows that the web seminar sessions, specifically the two that focused on driver diagrams and measurement, provided valuable learning that enabled them to develop much more clearly defined and potentially more achievable project aims. As the programme has progressed, they have also become more confident and more reassured that it is quite normal for these to get shaped and changed as projects progress. The advice they frequently gave is:

*'The project needs to be flexible, i.e. priorities and deliverables could change, depending on what happens'*

*'Step back, consider and review what can be achieved and get clear about the aims and the methodology being used'*

And one team pointed out, if the aim is to use an ebd approach in its purest sense, then it is the patients rather than staff who should select the project

*If it is truly to be based on patient experience, they (patients) need to identify what is a meaningful project*

## **Underestimating the scale of an ebd project**

At the outset of any project, it can be difficult to know exactly what will be involved and with a new and unfamiliar approach, such as ebd, it is understandable that many of the teams underestimated the scale of the task. In some instances, this led to a loss of enthusiasm and slower progress than originally anticipated.

*'We misjudged the magnitude of the task ahead of us in setting up a novel approach leading to initial group membership attrition.'*

*'While there was lots of early enthusiasm, the consumer group went quickly off the boil, as again project too big and we hadn't chunked things well enough to start. A bit too much of a scattergun approach'*

*'Concerned about the extent of the project. It appears the more we progress, the more we can see we will need to do',*

*'We were slow to start, a bit overwhelmed with the size of the project.'*

The advice some teams have given is to break down the project into smaller and more manageable chunks and not be deterred by the scale of the overall project but instead, make a start on something small and allow confidence to develop.

*'It was decided quite early on that this was a massive piece of work, probably outside our scope in this time frame. We then agreed to select something more manageable, something which we still felt would fit within the framework concept'*

*'Develop 'bite size' chunks that are more likely to succeed'*

*'A breaking down of the components of the project into simpler, less complex stages needs to occur'*

*'Starting small and allowing confidence to build was important'*

## **Underestimating the time required**

The time required to carry out the ebd work was without doubt the issue that participants were most concerned about. All of the interviewees spoke about time constraints and it was a recurring theme throughout the workbooks, survey and web seminar 'chat'

More specifically, the time challenge was mentioned most frequently in relation to having to fit the ebd project work in with other work commitments. Other participants said they underestimated the timescales involved to bring clinicians and consumers together and/or they had not appreciated the time it takes to change culture and ways of thinking.

*'Team co-ordination of this project has been challenging because of time constraints & the competing demands of a busy work and home life'*

*'We must be realistic about how time consuming each task will be for each stage and make generous allowances for time frames'*

*'Time management – do not under-estimate the time required for a quality approach to planning partnership projects'*

*'Gaining simultaneous dedicated time from the consumer and clinician for work on the project is proving problematical at present and delaying progress to a degree'..*

*'The time factor to achieve the cultural shift in thinking in our DHB was not appreciated'.*

*'We have significantly underestimated the time investment required'*

The survey asked participants to describe their greatest challenge and 14 of the 21 respondents who completed this section wrote about time related issues. Several participants suggested (either through the survey or workbook) that if the Partners in Care programme is repeated, the time requirements should be made clear before the programme begins.

### **Clarifying roles and responsibilities**

Projects were sometimes delayed because roles and responsibilities were not clearly defined. When it is not clear who is responsible for which task and the timescale by which they need completing, things can get overlooked. To avoid unnecessary delays, participants advised other teams to ensure that everyone involved in the project is clear about their own role and the tasks they are responsible for.

*'There was some negotiation of duties and responsibilities required'*

*'The need to ensure understanding around roles and responsibilities (specifically in this instance, whom in the team was responsible for identifying suitable consumer reps and bringing them on board)'*

*'Ensure people are clear about roles and responsibilities, including their own and others and team members have their deliverables top of mind between meetings'*

### **Ensure sufficient resources in place**

Several teams recommended that it is worth taking time to consider the resources (including staff resources) that will be required and wherever possible, ensuring that these are in place before starting the work. Inevitably, things will emerge that cannot be anticipated at the beginning of a project, however, if some of the more obvious things are overlooked, it may lead to unnecessary and avoidable delays.

*'Having a dedicated staff resource in place from the outset is important in going forward'*

*'Don't start any project without all resources confirmed, allocated and in place beforehand'*

### **Spend time in the 'planning' stage**

One of the conclusions that has been drawn from this review is that, whilst it may be tempting to begin the more interesting work of 'capturing information' (e.g. gathering patients stories, doing interviews and surveys) it is essential to dedicate sufficient time and effort to the 'preparation' stage. Participants' specific suggestions for success include: flexibility and

a willingness to consider alternative options and determination to keep going when things don't always go according to plan.

*'Our overall learning, spend time in planning stages'*

*'You can't do too much groundwork'.*

*'And be determined to keep going*

*Be flexible and generate alternatives in the face of opposition*

*Be prepared for obstacles and don't be discouraged – be reassured that it will lead to better patient outcomes*

Partners in Care teams' experience demonstrates that, the amount of time and effort dedicated to the preparation stage is strongly correlated with the degree to which they felt adequately prepared to move to the next stage with clarity and confidence.

## 8 Greatest achievements and most enjoyable experiences

There is no doubt that participating in the partners in care programme has been a rewarding, although at times a challenging experience. Table 12 includes some examples of participants' greatest achievements and most enjoyable experiences. These include: the value of new knowledge gained throughout the programme, first experiences of working directly with consumers, success in overcoming challenges and personal development opportunities. One inspiring story is from a team whose first consumer event was so successful that consumers stayed for more than an hour after it was due to end and they asked if they could attend the Christmas party.

**Table 12: Examples of greatest achievements/ most enjoyable experience of the programme overall**

- Generating excellent material to use for consumer engagement.
- Seeing the staff become aware and actively seeking out consumers to engage within their own programmes.
- 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
- Talking with the consumers (families and patients) about their experiences
- Seeing the way staff have bought in, e.g. as a direct outcome of this project a consumer now sits on a Service Level Alliance for planning respite care.
- Experiencing the power of a Driver Diagram process.
- Designing the poster and seeing it up on the wall of my department!
- Proud of the work we have done
- It has opened a new window for me
- Helping staff confidence and excitement in the process grow over the course of our work together
- The confidence that the health sector is taking on the message of the value of consumer input
- A fantastic focus group with consumers who had so much fun – they asked us if they could back for a Christmas party! We had allowed an hour so that people would be leaving at 5.00pm). At 6.30pm they were all still with us.
- The fact that I am running a pilot project for a National Organisation, without this programme, the guidance, education and support provided by the programme, I would not have had the confidence or know how.
- My own professional development has been enhanced, as well as a positive outcome for the organization

- Stepping aside from leadership to engage in partnership.

## 9 Recommendations for future participants

Finally, the success of the Partners in Care programme is clearly demonstrated in the figures shown in table 13. Everyone who responded to the survey strongly agreed/ agreed that they would recommend the ebd approach and the partners in care programme to others and with the exception of one respondent, all strongly agreed/agreed that they are now keen to share their learning to spread ebd locally.

As a further testimony to its success, when we asked what improvements could be made to the programme, twelve respondents said 'none they could think of'. All of the other comments related to 'a preference for face to face learning' although they also acknowledged that this is unrealistic, or to logistical and technical issues such as the timing of the web learning seminars and IT problems in their own organisations

<b>Table 13: Recommendations and spreading the learning</b>				
	<i>Strongly agree</i>	<i>Agree</i>	<i>Disagree</i>	<i>Strongly disagree</i>
I would recommend the ebd approach to others	22	5		
I am keen to share my learning with others to spread ebd practice locally	22	4	1	
I would recommend participation in this programme to others.	22	5		

## Appendix 1

### Organisations participating in Partners in Care ebd programme

Project Title	Organisation	Project description
1. Advanced Care Planning in the home care sector	Access	Implement Advanced Care Planning within the home healthcare sector, with consumer experiences helping to design the care pathway
2. Family Are Not Visitors / Family as Partners in Care	Auckland DHB	Work with consumers to implement a "Families as Partners in Care" approach.
3. Organisational implementation of sensory modulation in partnership with consumers	Auckland DHB	Facilitate a collaborative and strategic approach to the implementation and embedding of sensory modulation as an evidence-informed approach to practice across mental health and addiction services.
4. Consumer Voice - Raising concerns and getting a timely response	Bay of Plenty DHB	Work with consumers and clinicians to identify an escalation process for patients and families to raise concerns and issues so they can be resolved in a timely and appropriate manner at the lowest level.
5. Inform BBRIS group members on function and aim of the group	Brain Injury Rehab Service, Burwood Hospital	Develop a brochure to inform potential members of the Burwood Brain Injury Rehabilitation Service advisory group on the purpose and aims of the group.
6. Hear me! Facilitating communication, to improve outcomes, for those with an intellectual disability	Canterbury DHB	Address communication issues by using Picture Exchange Communication [PEC] system of communication, a recognised communication system which is currently used only for a limited number of service users in the Intellectually Disabled Persons Health Service
7. Improving the Wellbeing Programme in the Acute Inpatient Service	Canterbury DHB	Enlarge and improve the therapeutic programme available in Te Awakura (acute inpatient ward) by incorporating a recovery orientation and principles, increasing the range and number of activities available to consumers, and incorporating greater peer and adult community mental health team provision into programme delivery.
8. Making the message matter	Canterbury DHB	Develop and roll out a messaging package for diabetes patient across Canterbury about upcoming changes to diabetes care in July 2012.
9. Promoting Consumer Focus Groups (CFG)	Canterbury DHB	Review Canterbury DHB's CFG policy to successfully demonstrate the delivery of CFGs and to demonstrate their value to improving patient care, including developing a 'train the trainer' model to support use of CFGs throughout the Canterbury Health System.
10. Behind the Mask: Understanding and improving oncology patients' experience of the radiation mask	Capital & Coast DHB	Research evidence around managing anxiety related to use of the thermoplastic mask, identify strategies to help with anxiety, and produce an information resource for patients about coping with the mask.
11. Patient & Family Centred Care in ICU	Counties Manukau DHB	Work in partnership with patients to identify specific areas for improvement, aims and measures, with the aim of "making our critical care complex the place where we want our family to be cared for".
12. Series of patient education fact sheets regarding patient safety	Counties Manukau DHB	Arm patients with the knowledge to protect themselves and their family by developing fact sheets to avoid medical errors, diagnosis and common surgical procedures
13. Enhance consumer experience	Hawkes Bay DHB	Review and recommend strategies to improve consumer engagement in delivery of health services for HBDHB
14. One Stop E-Shop – Partners in Care: Engaging Consumers in HQSC Work	Health Quality & Safety Commission	Set up a system for patients and consumers to express interest in being representatives on Commission work programmes, and develop an intranet site for staff to provide best practice guidance for working in partnership with consumers in their policies, programmes and projects.
15. Safe use of insulin and consumer engagement/health literacy	HQSC/Waitemata DHB	Identify the information consumers require to use insulin safely and assess the issue of safe insulin use from the consumer perspective. This will enable assessment of information currently available to see if it meets consumer needs.
16. Implementing optimal discharge from hospital	Hutt Valley DHB	Tidy up the discharge process within the hospital and consider opportunities for wider healthcare system support for earlier discharge and minimal re-admissions.
17. Optimising the surgical patient pathway	Hutt Valley DHB	Deliver an optimal, streamlined model of care for surgical patients which recognises the value of their time and minimises duplication of effort, whilst making the very best use of available resources.

Project Title	Organisation	Project description
18. Understanding alert terminology - an opportunity for patient engagement	Mercy Hospital, Dunedin	Establish patient views on the most acceptable wording to be used in questions asked on admission, relating to allergies, sensitivities or intolerances, with a view to reducing incidence of adverse drug reactions and allergy/intolerance problems suffered by patients admitted to hospital.
19. Enabling patient involvement in the management of their chronic inflammatory arthritis condition	Nelson Marlborough DHB	Involve patients/consumers in the service design component of a review that's underway to improve rheumatology service delivery
20. Case management and consumer and whanau involvement	Northland DHB, Mental Health and Addiction Services	Introduce a partnership-oriented model for services, based around better communication with patients and whanau, within the service and across services (including NGOs) to clients and whanau.
21. Co-designing community care services: Nurse Maude stoma clinical treatment service	Nurse Maude	Work with consumers to review current delivery of stoma services and re-design the service so that it better meets the patient's expectations around quality, safety and the experience, and optimise the clinician's capacity and capability.
22. Presenting quality and safety measurement and evaluation to consumers	Patients First	TBA
23. Patients' engagement with and response to blood clot (venous thromboembolism; VTE) information and risk self-assessment tool	Southern Cross	Explore the personal and subjective experiences of patients in the VTE risk study and identify the touch points (where the patient's experience is most powerfully shaped) in the care pathway relating to VTE risk.
24. Tala Pasifika – engaging Pacific young people in tobacco control advocacy	Tala Pasifika, Heart Foundation	This project aims to build Pacific young peoples' understanding, excitement and desire to be involved in achieving the Government's 2025 smoke free goal.
25. Consumer engagement framework for Waikato District Health Board	Waikato DHB	Develop a recommendation for executive sign off for a consumer engagement framework for Waikato DHB, which may include recommendations for the type of consumer engagement model.
26. Develop a patient satisfaction survey for rollout in medical and health of the older person and potentially DHB wide	Waitemata DHB	Use the results from a recent review of the complaints process to implement a DHB-wide patient satisfaction survey system
27. Influencing model of care and hospital design through introducing the consumer perspective	West Coast DHB	Provide a consumer perspective into the new model of care being developed by West Coast health services
28. Patients' stories driving quality in health	West Coast DHB	Use patients' experiences and stories to improve/design systems and processes, to put patients and their families at the centre of health care services provided.
29. Build capacity to integrate "Peer Support" across the mental health and addictions continuum	Whanganui DHB	Improve the quality of life for service users and their whanau living with mental health and addiction issues; find healthier relationships within the community as the integrated "intentional peer support" services collaborate across all clinical services.
30. Effective Consumer Engagement into Systems Re-design	Whanganui DHB	Project seeks to identify: attributes of an effective consumer; enablers for effective consumer engagement; mechanisms locally to engage Maori And Pacifica consumers; development of a set of agreed principles for consumer partnership and a way of working when co-designing service or clinical models of care; qualities sought in a consumer voice in co-design and how to grow such individuals; and an agreed process for engagement

## Appendix 2

### Key themes emerging from web seminars

Web seminar	Key themes/learning
<p><b>Web seminar 1</b>  <b>29<sup>th</sup> May 2012</b>  <i>Introductory web seminar:</i>            Overview of the stages of EBD projects and important issues to consider</p>	<ul style="list-style-type: none"> <li>• Recognising that senior leadership support is essential and that gaining and maintaining their commitment is an ongoing process that requires sustained effort from the project team. It is important to maintain dialogue with senior leaders and this requires adequate planning to ensure regular meetings take place</li> <li>• Recognising that the EBD approach provides an opportunity to deliver improvements in safety and clinical outcomes as well as improving the patient experience. Drawing attention to this helps create a persuasive argument to engage with and gain commitment from senior leaders and clinicians</li> <li>• Gathering baseline data is essential to be able to later demonstrate improvement</li> <li>• The vital importance of patient stories and the different ways in which their stories can be gathered</li> <li>• Some project teams have encountered challenges in gaining ethical approval. Others have found more creative ways around this and it is important for teams to learn from and draw on the experiences of those who have successfully gained approval</li> </ul>
<p><b>Web seminar 2</b>  <b>29<sup>th</sup> June</b>  <i>15 steps challenge</i>            introduction to a new tool for teams to use            Ethical issues to consider            Workbook expectations</p>	<ul style="list-style-type: none"> <li>• Recognising the importance of the consumer perspective and their input into projects</li> <li>• Understanding the need to see things through 'fresh eyes' – recognising the limitations of tunnel vision and learning to broaden our own vision</li> <li>• 15 steps challenge provides a framework for observation, a way to look through fresh eyes and gain multiple perspectives on the same experience – to recognise touch points – walking and feeling the patient's journey through observations</li> <li>• It is a way of building confidence, identifying what works well, what can be improved and supports sharing of good practice</li> <li>• Teams (staff, patients, carers, managers and leaders) rather than individuals should be included in the observations</li> <li>• Continuous feedback and review of information gathered, ongoing discussions and reporting are vital to project success</li> <li>• Strategic alignment of projects is important</li> <li>• People (staff and patients) can be sensitive to change - adopting a 'softly softly' approach can help overcome these challenges and help make change more acceptable</li> <li>• Ethical approval can be complex and has been a challenge for some project teams. It is important to identify and make the distinction between research involving patients and EBD and if ethical approval is necessary point out the differences to ethical committees. Project teams can learn from and build on each others' experiences. Use of compacts can provide a helpful solution</li> </ul>
<p><b>Web seminar 3</b>  <b>19<sup>th</sup> July 2012</b>  <i>Measurement</i>            Introduction to 7 steps to measurement for improvement</p>	<ul style="list-style-type: none"> <li>• Gained a better understanding of why measurement is critical – have to be able to measure improvements</li> <li>• Measuring improvement is easier if you have a clearly defined process – 7 Step process provides this</li> <li>• Recognised the importance of having clear, measurable objectives and the need to take a step back if necessary to ensure objectives are clear</li> <li>• Recognising that data can be presented to tell a compelling story</li> <li>• Collecting baseline data is essential to be able to measure improvement</li> <li>• Essential to identify the right measures and to have clear definitions to ensure that everyone on the team shares the understanding and is measuring the same thing</li> </ul>

	<ul style="list-style-type: none"> <li>• Data can be collected for a sample of patients as long as the sample is representative of the whole group of patients</li> <li>• It is important to identify different types of variation and work only on variations (common cause) that can be removed through process improvements</li> <li>• Developed a better understanding of PDSA cycles and the importance of getting started with smaller projects, testing things and repeating PDSA cycles rather than starting too big</li> <li>• Driver diagrams are a very useful way of articulating a goal and its measures</li> </ul>
<p><b>Web seminar 4</b>  <b>Date 8<sup>th</sup> august 2012</b>  <i>Sharing (1)</i>  Opportunity to hear from and share the learning from two project teams</p>	<p><b>Key learning for project teams sharing their experiences</b></p> <ul style="list-style-type: none"> <li>• Process of sharing helped clarify aims and assess progress and recognise how much has already been achieved</li> <li>• Further evidence of the need for leadership support from the highest level. Bottom up support is also required</li> <li>• Firsthand experience of the need to be clear about the project aims – original aims were initially potential solutions</li> <li>• There are benefits in taking things slowly to ensure learning is captured and it is important to take time out to learn from experiences</li> </ul> <p><b>Key learning for participants</b></p> <ul style="list-style-type: none"> <li>• Recognising that there is much to be learned from sharing for both the sharer and sharee</li> <li>• Further emphasis on the need for strategic alignment of projects, which also helps with sustainability</li> <li>• Further confirmation of the need to really clarify project aims and to keep reviewing and if necessary, redefining the aims to incorporate learning. It is useful to develop an ‘elevator pitch’</li> <li>• Further evidence of the benefits of developing driver diagrams</li> <li>• Recognising that a well developed process will build trust and credibility with staff</li> <li>• Emphasised the need for project team members to commit to meet as frequently as possible to strengthen team relationships.</li> <li>• Essential to keep people informed and engage staff in the process</li> <li>• Reassuring to hear that others have changed their approach and have redefined objectives as a result of experience and learning</li> <li>• Reassurance for some that projects are ‘on track’ and provided additional ‘food for thought’</li> <li>• Encouragement to overcome disappointments and keep going</li> <li>• Presentations could be more succinct in future sharing sessions</li> </ul>
<p><b>Web seminar 5</b>  <b>5<sup>th</sup> September 2012</b>  <i>Sharing 2</i>  Opportunity to hear from and share the learning from two more project teams  Update on key themes emerging from workbooks on progress to date</p>	<ul style="list-style-type: none"> <li>• Sceptics and resisters of change should not be dismissed – they offer valuable learning and can be helpful in identifying risks</li> <li>• Elevator exercise is a useful method for getting clarity on project aims and communicating them to other people</li> <li>• Developing a shared meaning of who can be considered a "consumer" rep is fundamental. Managers and clinicians may see themselves as patients but they have very different perspectives of a service. Recognise the value of the experience that staff members bring to the project <i>and</i> also recognise that consumers will not have this level of experience</li> <li>• It is important to develop a common language that staff and patients both understand and avoid healthcare jargon</li> <li>• Contextualise the work for different teams</li> <li>• Recognise the differences between consumers</li> <li>• It is important to engage consumers in fun and interesting ways.</li> <li>• Staff are often asked to give feedback through surveys, interviews and meetings and new and interesting ways of engaging them are needed</li> <li>• Overall, the presentations and participant contributions provided some useful reference resources</li> <li>• Participating in the EBD programme had raised awareness of what a service is like from the user’s perspective and this learning will be valuable in all future projects</li> </ul>

<p><b>Additional Web seminar</b>  <b>26<sup>th</sup> September 2012</b>  <i>Driver diagrams</i></p>	<ul style="list-style-type: none"> <li>• Demonstrated the value of having a real live example to learn about a new topic</li> <li>• Reinforced the need for senior leadership support and awareness that without this, individual projects would not be able to achieve the planned outcomes – outcomes could not be sustained</li> <li>• Demonstrated the power of diagrams and helped make the distinction between aims, primary and secondary drivers and interventions and measures</li> <li>• Helpful way of further refining project aims – recognised that proposed drivers may actually be aims. Demonstrated the need for some teams to revisit and redefine aims and drivers before identifying interventions</li> <li>• Drivers need to be clearly defined and potentially measurable</li> <li>• It is important to avoid jumping to solutions too quickly and before really examining what the problems may be</li> <li>• Raised awareness that an aim of reducing complaints may not always be appropriate – focusing on a particular area may initially increase complaints. It is important to examine whether the cause of the complaints is dealt with through improvement interventions</li> </ul>
<p><b>Web seminar 6</b>  <b>3<sup>rd</sup> October 2012-11-01</b>  <i>NHS Sustainability Model</i></p>	<p><i>Comments from questions and web chat only</i></p> <ul style="list-style-type: none"> <li>• Recognised the relevance of the sustainability model to Partners in Care projects</li> <li>• Sustainability model is a useful way of stepping back and considering whether planned approaches are likely to be the most effective and making changes to approaches if necessary</li> <li>• Recognised that sustainability depends on leadership 'buy in'</li> <li>• Recognised the importance of demonstrating the personal benefits of a project to different stakeholder groups and individuals – without evidence of benefits (what's in it for me) it can be difficult to engage people</li> <li>• Raised awareness of the need to improve communication within the project team and wider. Use methods that make information (updates on progress etc) as visible as possible. Use data and graphs creatively</li> <li>• Emphasised the importance of regular communication with senior leaders to ensure continued support</li> <li>• Recognised the need to present information in different formats for different groups e.g. clinicians may prefer data as graphs whilst senior leaders may prefer written reports.</li> <li>• All relevant stakeholder groups and individuals have to be included – exclusion will have a negative impact on 'buy in'</li> <li>• People who may originally be sceptical can be great supporters and influencers once they have 'bought in' to the project</li> <li>• Although the model does not incorporate the role of consumers, project teams could apply the same engagement strategies to consumers as they do to staff and senior leaders – what can consumers offer, what is important to them? This is about working effectively together and getting clear about what each stakeholder group can best contribute</li> <li>• Sustainability of projects can be difficult when the national drivers e.g. funding) are not aligned to support new models of service delivery. It is important to consider how organisational strategies support the project</li> </ul>
<p><b>Web seminar 7</b>  <b>30<sup>th</sup> October 2012</b>  <i>Review of programme</i>  <i>Project sharing</i></p>	<ul style="list-style-type: none"> <li>• Some project teams continue to experience difficulties in gaining staff agreement to the experience questionnaires and to be filmed. Some staff feel threatened by the EBD approach and may feel they will be judged</li> <li>• It is important to share positive stories of consumer experiences to engage staff, especially those who do feel threatened</li> <li>• Widespread agreement that Wordle is a fun and effective way of engaging staff and consumers.</li> <li>• Some project teams are moving in to the 'capture experience' stage and are using a wide range of tools to gather information on consumer experience. These include: observations, emotional questionnaires</li> </ul>

	<p>and other staff and patient questionnaires, administered face to face, via telephone and email and on line, interviews, filming of patient interviews, consumer journey mapping, discussion and shadowing patients</p> <ul style="list-style-type: none"><li>• Consumers have volunteered willingly and overall, it has been a positive and enjoyable experience. Cancer patients in particular 'love to think they are helping, the next person coming along'</li><li>• Some project teams are concerned about completing their projects within the timescales.</li></ul>
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