New Zealand Health Quality and Safety Commission Partners in Care Programme

Review Report
July 2014

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Review summary

The Partners in Care programme was developed by the New Zealand Health Quality & Safety Commission (HQSC) 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."*

Lynne Maher from Ko Awatea was commissioned by HQSC to deliver content based on the Experience Based Design (ebd) approach to twelve healthcare organisations participating in the Partners in Care programme.

The core principles of the Programme are described as follows:

- 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

The Partners in Care programme commenced in October 2013 and ended in June 2014. It included two introductory master classes, a series of eight web based learning seminars, individual coaching calls and email support from Dr Lynne Maher. Participants also had access to a wide range of learning material through the HQSC website.

This review has been carried out to understand more about participants' experience of the Partners in Care ebd programme and to specifically capture any learning that may impact on future programmes.

Review data have been captured through three different methods: review of the workbooks that had been completed by participants; six telephone interviews with participants and an online survey sent out to all participants.

Summary

Eight teams consisting of a staff member and a consumer, sixteen participants in total completed the programme

Participants' overall view of the Partners in Care Programme is very positive with 88% stating that they have been very motivated by the programme. The same number (88%) also said that their confidence in engaging with consumers had increased as a result of this programme.

All participants have communicated information about their project to others and seven (77%) have used more than one mechanism. Most communication was through presentations to a range of colleagues including general staff groups, specific cultural groups and formal groups such as strategic and governance boards. The use of newsletters and articles in local press were also featured mechanisms.

55% of participants rated the web sessions as 'excellent' or 'good'. The most enjoyable web seminars were those where colleagues shared their progress and where there was a significant amount of online 'chat'. Those describing the phases of Capture, Understand and Emotion mapping were also highlighted.

Participation in the web seminars was challenging for some who had difficulty with the technology. Six survey respondents have experienced technical difficulties in joining the web seminars, although on the whole, these appear to be due to local difficulties.

All survey respondents found the workbook questions either 'very relevant' or 'mostly relevant' to their own project. Feedback included that the workbook 'kept me focussed', 'helped me to reflect on the journey' and 'provided structured progression'. Two respondents found the workbook 'very challenging or challenging' to complete. Feedback about workbook completion also included underestimating the time required to complete it.

The most frequently used/most preferred tools include: interviews to gather patient/staff stories, which some have videoed, experience surveys and mapping techniques, a Wordle tool to display emotion words and observations.

Most teams have successfully engaged with senior leaders, some have been surprised by their enthusiasm and support. Three teams had senior leadership support overall but said that the leader did not regularly engage with the project team.

Engagement of other staff has also been generally positive with 8 of the 9 respondents saying that staff were either enthusiastic, actively involved or willing to participate in aspects of the project for example being interviewed or filmed.

All teams had consumers who were directly working with them on the project or who supported the project where they were able. Participants have very much enjoyed working closely with consumers.

Challenges have included the amount of time required to carry out the ebd work. Most of the participants did not have dedicated time and needed to carve slots out of their usual work pattern to undertake their projects.

Contents

Partners in Care Programme

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.

Dr. Lynne Maher, Director for Innovation at Ko Awatea was commissioned by HSQC to deliver content based on the Experience Based Design (ebd) approach to twelve healthcare organisations participating in the Partners in Care programme. Over the course of the programme four teams withdrew their participation. The reasons they cited included unanticipated workloads, severe illness of the staff member or the consumer.

The core principles of the Programme can be described as follows:

- 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
- Review of improvements and benefits

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) was developed within the NHS in England. It *'uses patient and staff experience to design better healthcare services',* and it was successfully used to support delivery of the Partners in Care programme in 2012 and 2013. This approach provides an exciting way of bringing patients and staff together to share the role of improving care through the co-design of services. It is a proven methodology in England, Canada, USA and in New Zealand, which provides a range of tools that can be used or adapted and used to increase the engagement of consumers in decision making about the services they use.

Figure 1 illustrates the four stages of the core ebd approach: Capture; Understand; Improve; and Measure. A set of specific tools are available at each of these stages. A project that involves the ebd approach also requires teams to complete a 'preparation' stage before

starting on stage 1: Capture the experience. This preparation phase includes engaging key stakeholders such as senior leaders, consumers and local staff.

Figure 1: Four steps of the EBD approach
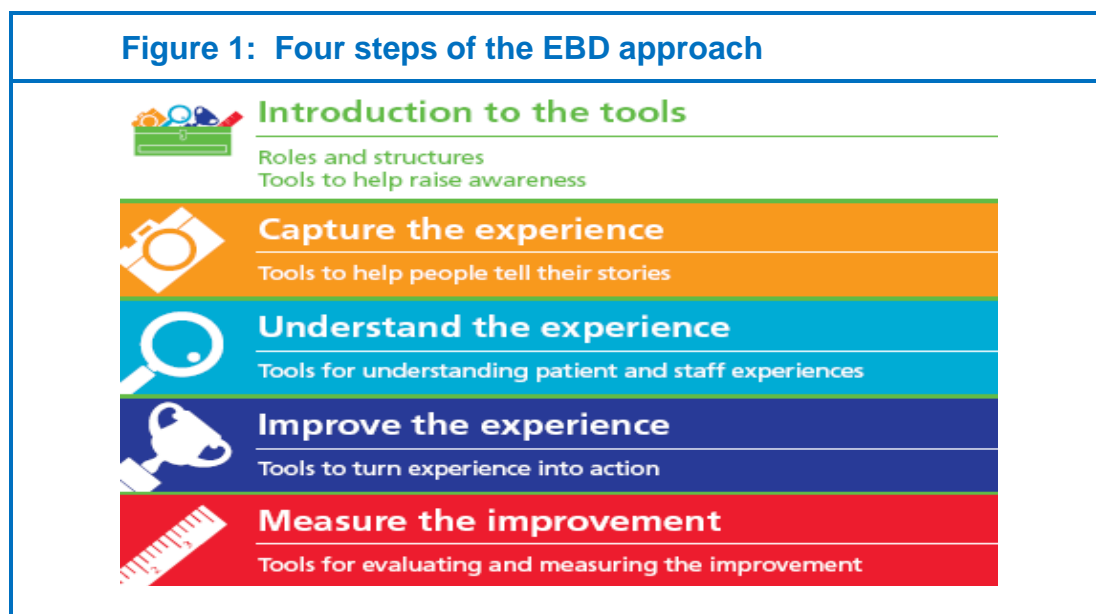
Partners in Care programme content and delivery methods

The Partners in Care programme included two, one day introductory master class's, a series of eight web based learning seminars and telephone coaching and e mail support provided by Lynne Maher. Participants could attend one of the master class's either in Auckland on 7th October or Wellington on 9th October 2014. The web seminars began on 31st October 2014 and were held approximately once a month until June 2014.

The web seminars covered topics that have been shown to support the design and delivery of consumer experience projects. They also provide opportunities for the project teams to discuss their experiences and share their learning with each other and to raise any issues or concerns. There was sufficient flexibility in the programme to include additional topics that participants felt would be of benefit to them and during each web seminar they were encouraged to suggest topics for future sessions.

A summary of the topics covered in the masterclass and the eight web seminars that were held is shown in table 1 (page 3).

Partners in Care programme participants had access to a wide range of resources and learning material through the HQCS 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.

Eligibility criteria for the programme completion certificate

A health sector and consumer representative from each of the participating healthcare organisations are required to attend the masterclass, participate or listen to all web seminars and complete a workbook (one for each project) to be eligible for a 'certificate of

completion'. The web seminars were recorded to give participants the opportunity to 'catch up' on any missed sessions.

Table 1 Summary of Programme content delivered up to end June 2014	
Event	**Content covered**
Master class's	- Introduction to the EBD approach - Planning for Action - Outline of the programme and work requirements for certificate of completion
Web seminars	- Introduction to web seminars and starting for success - Using the sustainability model and planning for sustainability - Measurement or improvement driver diagram's and the model for Improvement - Stories and narratives - Sharing experience on the capture phase - Understanding experience- participants sharing progress - Understand and improve - Review and next steps

Programme Workbook

The workbook is designed to support Partners in Care teams to capture their reflection and learning over the duration of the programme. Specifically through this workbook and participation in the web-based learning session, the programme facilitator has acquired 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. One team applied the tools and learning within a project to develop, deliver and evaluate a training programme on de-escalation practice within the field of mental health.

 It is anticipated that going through this experience will 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 has provided the evidence of learning and understanding. Participants were 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 initially during January for a review of their progress during the first few months of the programme. Each team received a detailed review summary which provided general feedback and helpful suggestions. The final submission was in June 2014 and again participants received feedback and suggestions to help teams continue to progress.

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, 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.

Methods used

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

1 Analysis of the workbooks to identify key learning points, achievements and challenges. Eight (out of a potential total of 12) have been submitted.

2 Telephone interviews with a sample of six consumer and health sector representatives. These interviews were conducted by two independent individuals who are not part of the Partners in Care Delivery Team.

3 An online survey, which included fixed choice response questions (e.g. strongly agree/agree/disagree/strongly disagree) and some open ended questions.

   Nine questionnaires were returned, which represents a response rate of 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 co-designing with consumers
- Experience of being involved in the Partners in Care ebd programme
- Different stages of the programme
- Challenges, reflections and key learning
- Greatest achievements and most enjoyable experiences
- Recommendations for future participants

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4 Participants' view of co-designing with consumers

During the programme participants view of how important co-designing with consumers changed. Before participating in the programme only two people felt that co- design was essential. At the end of the programme this had increased to seven (77.8%).
They said;

'The experience based design approach, focusing as it does on emotions, is an exciting way of bringing patients and healthcare staff together to share the role of improving care and re-designing services'.

'I was very excited about the concept of co-design'.

'I loved working with the consumer/advocate'.

'Great consumer partner'.

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

5 Participants' view of being involved in the programme

We asked participants to indicate how motivated they felt at the start of the programme and at the time of completing the questionnaire. Table 2 shows how participant's views have changed as a result of the ebd programme. There has been a significant shift from only three (33.33%) being very motivated at the start of the programme to eight (88.89%) feeling very motivated at the end of the programme.

Table 2: How did you feel about being involved in the programme?				
	Very motivated	*Mostly motivated*	*Little unmotivated*	*Very unmotivated*
How did you feel about being involved in the programme when you first signed up as a participant?	3	5	1	0
Which best describes your view *now*?	8	1	0	0

At the start of the programme comments indicated some anxiety was present. This included a level of uncertainty about exactly what was going to be involved.

'Very excited but unsure of what was involved'.

'Bit anxious about how it would work'.

'I wasn't sure if I was the right person for the task'.

'The only reason I have not said 'very motivated' is because it came at a very busy time'.

However, it was clear that programme participants gained more confidence as the programme went on. They particularly enjoyed the new learning, new tools and methods. One person would have liked the programme to continue and one is delighted to tell others about the programme.

'It was refreshing to use new skills'.

'It has been an honour to be part of the course and to engage with patients and families using ebd'.

'Working through the programme has reassured me that the work is vital and that we must continue'.

'I found the support and content stimulating'.

'Am disappointed the programme is finishing would like it to continue on for a bit longer'.

'Delighted to tell people I have been involved'.

6 Experience of participating in Partners in Care 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'.

Table 4: views on information, resources and support				
What are your thoughts about:	*Excellent*	*Good*	*Fair*	*Poor*
Information you received about the programme before it started	3	5	0	1
The initial ebd Masterclass	7	2	0	0
The teaching covered throughout the programme	6	3	0	0
Ease of access to supporting material and resources	3	4	2	0
Quality and usefulness of supporting material and resources	5	4	0	0
Ongoing support and advice	9	0	0	0
Web based learning sessions	2	3	3	1

Eight respondents rated the information received about the programme before it started as Excellent or Good while one person found it to be poor. Comments included a wish to have more information about the role of a consumer and of other similar projects in New Zealand. There is significant information about consumer roles and short case studies of previous Partners in Care projects on the HQSC WebPages and early signal of this might be helpful in future projects.

'Provision of more information about the consumer role could be provided at the beginning of the programme'.

'More information about other projects in New Zealand'.

'Loved the information that was given beforehand so I was prepared'.

'I don't think there is anything that would have made this programme better'.

The initial ebd masterclass, teaching covered throughout the programme and on-going support were rated as 'excellent' or 'good' by all nine respondents. One person suggested that a second day would have been helpful. Two people rated ease of access to supporting materials and resources as 'fair' and seven thought it to be 'good' or 'excellent'.

> *'The master class was good, a second day would have been helpful to really get people started'.*

> *'It was interesting to meeting the other colleagues on the study day. She and her partner (consumer) could see we had something in place but could do better. I was fascinated. I though it was great'.*

Although distance or remote learning (i.e. through web seminars and email support) is a new experience for some participants, feedback shows that, overall, significant learning has taken place.

The ebd web learning seminars combine presentations on ebd tools and ebd related topics with opportunities to interact through regular 'questions and answers' sessions. Four of the sessions enabled teams to present and share their experiences with the entire group and these were identified as 'highlights' by others. Participants could 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.

While five respondents said the web sessions were 'excellent' or 'good' and four respondents felt that they were 'fair' or 'poor'; all respondents experienced some level of technical difficulty. This ranged from an inability to connect to poor sound quality.

> *'I underestimated the technical issues with using web based learning as it was my first experience. It detracted from my learning and caused me a lot of frustration'.*

> *'We did not always have very good reception and often had to sign in several times throughout the session so it was quite frustrating as we missed whole sections when we were not linked up'.*

> *'The webinar only worked properly once'.*

> *'The technology didn't always work. We often lost connection during the webinar – so missed parts of the sessions'.*

> *'The web sessions were plagued with technical connection issues'.*

Two respondents felt that the technical difficulties were from 'their end' and another three respondents said that receiving the power point presentations and resource literature before the scheduled sessions was helpful.

> *'It was good that the team had sent all the slides beforehand so they could print them off and "knew what we were in for. I thought that was excellent'.*

> *'Having the slides beforehand made all the difference'.*

> *'The information we could get before the web sessions were a lifesaver'.*

Despite some of the challenges of participating remotely, participants have found the sessions useful. In addition they regularly posed questions to the presenters and to one another and they have shared their own experiences, materials and resources.

> *'Took a while to get used to them but have confidence now and feel that the group are interacting well and that sharing of ideas and resources has been really beneficial'.*

> *'It's a great way of doing it through the webinar. We were informed beforehand when the next webinar was and what information was required of us'.*

> *'All of them were useful and provided fresh motivation, advice and support- just when required'*

> *'They were all useful'*

The web seminars that participants enjoyed the most included those where their colleagues on the programme shared their own experiences:

> *'Session 4 due to the mapping completed by Whangarei- good model and sharing/participation'.*

> *'The feedback from Whangarei'.*

> *'Session 4 because I found it very practical'.*

> *'I liked the patient stories from Bay of Plenty'.*

> *'The mapping example from Northland was great'.*

> *'I particularly liked the session on 'Hello my name is', it really struck a chord'.*

> *'I learnt a lot from the team from Taranaki when they told us about their patient family/whanau framework'.*

Other comments included:

> *'I enjoyed the first two sessions as they were very relevant to my work i.e. Capturing and Understanding the patient experience'.*

> *'The last one because I feel as a group that we engaged well with questions in the text box etc'.*

In response to the question 'are there any web seminars you felt did not add value? the majority (6) either said 'no' or they 'enjoyed them all'. One respondent identified session five as not enjoyable. This was a session that had to be abandoned because of technical difficulties and one did not enjoy session three because of the style of the guest presenter.

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

Programme Workbooks

As table 5 shows, almost all the survey respondents found the workbook questions either 'all relevant' or 'mostly relevant' to their own project and the majority found them 'very easy' or 'fairly easy' to complete.

Table 5: Programme workbooks				
	All relevant	*Mostly relevant*	*Few relevant*	*None relevant*
How relevant are the questions in the workbook to your own project experience?	6	3	0	0
	Very easy	*Fairly easy*	*challenging*	*Very challenging*
How easy or challenging was it to complete the workbook?	3	4	1	1

Additional comments about workbook completion were mostly positive and it was viewed as a useful experience to reflect on progress and the lessons learned.

> *'Most relevant, guided the experience'.*

> *'Kept me focussed as I progressed forward in the learning experience'.*

> *'It was good to track our progress and the questions made you think about and assess things'.*

> *'It provided a good guide that helped to keep focussed, including a timeline'.*

> *'We found it no trouble working on this together-this was one of the good parts of the process as it showed us where we had come from and what we had learned on the journey'.*

> *'Found the workbook intuitive and easy to follow'.*

Some respondents cited flow, repetition and time as more challenging aspects of completing the workbook.

> *'Completing the workbook did not seem to flow with the project for some reason. There were responses that straddled sections, felt bitty- and I was always wondering where to put certain elements into which section'.*

> *'Well laid out – good questions although some felt repetitive.*
> *Balancing the documentation requirements of the programme and doing the actual project work on improving consumer engagement was a real challenge'.*

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'.*

7 Tools and methods used within the ebd project:

This section focuses on the tools and methods most frequently used by participants.
As table 6 illustrates, participants have used a variety of the tools and methods available to them. However, within the questionnaire participants were only able to choose one tool or method so the results of the Survey Monkey questionnaire do not fully reflect respondents use of the tools and methods available. In future questionnaires it would be better to enable a multiple choices.

Table 6: What tools and Methods have been used	
Observation	2
Filming	0
Interview	3
Discussion	0
Emotion Questionnaire	2
Emotion mapping	1
Wordle	1

Respondent stated:

'*This box would only let me 'tick' one. We used observation, interviews and discussion*'.

'*We used Patient stories, interviews, emotion questionnaires, Wordle in various ways*'.

'*Can't seem to tick other- so used emotion questionnaire and emotion mapping, questionnaire and structured conversation too*'.

'*Patient stories are easy to get, you just have to start and ask staff for a suggestion of whom to interview*'.

'*Interviews mapping and wordle*'

'*All bar film*'.

Through their workbooks participants have also identified the wide use of tools and methods, these include: patient/staff interviews/conversations (6 respondents), which some have videoed (2); observations (2); experience questionnaires (6); experience mapping (5); driver diagrams (2) and 'Wordles' (4). Many had used at least two different tools and some had used three or four. This is encouraged within the programme in order to gather breadth and depth of patient, staff and family perspectives.

'*There are great tools and resources available to use and modify for your own purpose and organisation*'

'*We are now aware of the patient experience tool and how we could use it at the beginning of a new initiative as one means of gathering patients experience*'.

'The interviews with patients/carers went really well and were easy yet provided us with some really rich information'.

'The patient experience questionnaire provides a way of measuring the subjective aspect of a process'.

'The consumer mapping session was a rich source of information and it was really valuable to hear what consumers thought of our processes and to make suggestions about what might work better'.

'Pinpointing the emotions of the patients and the touchpoints stands out in the whole programme. The questionnaire that the patients get with the emotions was really good'.

'Utilising the emotional touch points is incredibly powerful in respect to engaging others, and in collating other consumer feedback recently has been useful in respect to how we approached the mapping out and sharing of this information with our team as well. So we are taking the learning forward in respect to other areas of our work'.

'Very beneficial to take the time to map out and then simplify the information from the 'understand' phase and to look for both similarities and differences'

The team working on the staff training programme specifically used observation, a survey monkey questionnaire and interviews with their participants:

'She (consumer partner) was able to look at the delivery with a fresh eye and was able to identify several areas that didn't work to the best needs of the class'.

'Survey Monkey gave some useful data from which to further investigate'.

'Interviews with both the deliverers' of the course and the participants helped highlight some issues not noted previously'.

8 Engaging key stakeholders

During the initial preparation 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 have dedicated considerable time and effort to this task and that overall, significant progress was made.

Engaging with senior leaders

Most teams have successfully engaged with senior leaders and they have been encouraged (a few surprised) by their enthusiasm. However three responses indicate that while enthusiastic some senior sponsors were not regularly and actively engaged. This could have a detrimental effect on sustainability of some projects.

Table 7- Senior Sponsor Engagement	
Senior sponsor is enthusiastic and has actively supported the approach	5
Senior sponsor is supportive but not regularly and actively engaged	3
It has been difficult to engage a senior sponsor	0

The following comments provide further examples of the strength of senior leadership support;

> 'Our sponsor, Director of Nursing was supportive and actively encouraged us throughout the process'.

> 'We were strongly supported throughout by senior management and staff".

> 'Support form senior leadership was gained and there was enthusiasm for the project'.

> 'Having the COO/ Director of Nursing as a member of the Clinical Board, and the Quality Risk Manager on our sub-group, was extremely valuable in gaining EMT (Executive Management Team) endorsement'.

> 'The importance of gaining key leadership support should not be underestimated'.

> 'It's essential to identify the "people of influence and authority" within your organisation and to get them on your side so they support the plan and will back us when things get tough'.

> 'It would have been better to have had the time to discuss our project with the leadership team'.

Engaging staff

Overall, the level of staff engagement was generally high. As table 8 shows, staff have been either enthusiastic or willing to support or participate in projects.

Table 8- Engagement of other staff	
Staff are enthusiastic about the approach	3
Staff have willingly supported our particular project and have been actively involved	2
Staff have been willing to participate in aspects of the project (e.g. be interviewed or filmed)	3
It has been difficult to engage staff	0

Good preparation is needed before engaging with staff and teams also noted the importance of spending time with staff as early in the project journey as possible to ensure their understanding of the project and to reduce any anxiety they may have.

> *'You must get "buy-in" from key staff so that they do not feel threatened'.*

> *'Earlier engagement of staff and consumers in our project would have been beneficial'.*

> *'The need for long lead-in times. The need to socialise staff and use repetition so they understand concepts. The need to ameliorate fear of change'.*

> *'Lots of support from staff to change, once they understood the project'.*

> *'We could have spent more time doing this (engaging staff), to ensure understanding from staff as to the principles of co-design and the content of our project. However, their time was limited, as was ours'.*

One project team described how misunderstandings can occur despite an extensive range of communication methods;

> *'Face to face meetings rather than email communications were more effective in terms of getting our message across, though a follow up by email was also sometimes necessary'.*

> *'Even after face to face meetings there were still some misunderstandings. Therefore, we found it was important to check back that people really understood what the project was about'.*

> *'We were also aware that some staff misunderstood our motivation and therefore felt threatened'.*

> *'We felt staff were apprehensive that our project might mean more work for them. It was a challenge to mitigate this, and more thought could have gone into this'.*

Engaging consumers

According to survey, interviews and workbook data, consumers have been supportive to teams and generous with their time. Some of this support has been at the project level where consumers have participated in the initial ebd master class and some web sessions. Others reported that consumers have engaged more in terms of actively sharing experiences through interviews, the completion of questionnaires and taking part in focus group discussions.

Table 9- Engagement of consumers	
We have had a key consumer working directly with us on the project	4
Consumers have supported the project where possible	5
Consumers have not been available to participate.	0

A small number of teams did face some challenges in engaging consumers. These ranged from difficulty in identifying someone particularly to work with the team at 'project' level, identifying someone who subsequently could not commit the time or illness of consumers during the project.

> '*At the beginning of the project we struggled to identify a consumer to be a part of the process and while we did identify 2 people there have been challenges with them being involved. They both live in the mid north and have busy lives and while for the first half of the project I kept in regular contact that has largely dropped off. Instead we have found that we have tended to source patients on the ward*'.

> '*It was really challenging to recruit a consumer, we were not entirely sure of how the project would run and therefore describing the Partners in Care programme and what commitment we were asking of consumers was extremely difficult*'.

> '*The consumer I was working with unfortunately has been unwell*'.

> '*Our consumer partner has recently resigned her position to take up other opportunities*'.

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 10 - Experience of engaging consumers	
My confidence in engaging with consumers has increased as a result of this programme	8
This programme is leading to a general increase in consumer involvement in my organisation	1

'

Key learning from the engagement process included:

> '*My confidence in engaging with consumers has increased as a result of this programme*'
>
> '*This programme is leading to a general increase in consumer involvement in my organisation*'.
>
> '*Engagement with consumers about process yields highly valuable information that can inform change*'.

One respondent said that the programme had not added anything to their existing expertise;

> '*This programme has not helped with my experience of engaging with patients*'.

Despite some challenges many participants have said that working with consumers has resulted in very positive experiences.

> '*She was so helpful; I could not have done this without my consumer partner*'.

> '*I loved working with my partner. She was such a joy to work with*'.

> "*We found the longer we talked with patients, the more constructive feedback they seemed to give, and the more open they seemed to become*'.

> '*Never assume you know what patients and their families in your own community want. In future the aim has to be to ask them to tell their stories about their overall experience of care, and they will provide health care professionals where improvement needs to focus*'.

9 Challenges, reflections and key learning

Participants' reflections reveal some of the challenges they have encountered in implementing their 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.

Underestimating the time required

The time required to carry out the ebd work was an issue that most participants were concerned about and this was the reason given when two teams withdrew from the programme. Specifically, the time challenge was mentioned most frequently in relation to having to fit the ebd project work in with other work commitments. Participants also said they underestimated the timescales involved, including time to find a consumer to work with and to bring stakeholders together. Some also mentioned that on reflection they wish they had brought stakeholders together earlier in the process.

> '*Time to do the work- not enough of it*'.

> '*Finding someone to be our lead consumer-a number of issues related to our patient population, geography and not really understanding what was required of them*'.

> '*Our key learning? Start sooner than you think you need to, and don't be discouraged when it doesn't quite go to plan*'.

> '*With my other workload in the DHB, I found it somewhat difficult to maintain the momentum. I was no less passionate about our project*'.

> '*We were both very busy with competing priorities, and finding the time to do the work was a challenge for both of us. In addition, my consumer partner was in hospital for 9 days and this impacted on the time we had to spend on the project*'.

> '*Having more time, this took time and it felt rushed*'.

> '*More lead in time in starting the project would have allowed for senior leadership to have better understanding of the project*'.

Recognising that some key stakeholders could not always work to the projects timescales was an important lesson. This also links to the need to consider resource needs as a whole (including staff resources) that will be required and wherever possible, ensuring that these are in place before starting the work.

> *'It was a challenge getting the sub-group to meet regularly in order to develop the framework. This took significant time as there was so much information available to review. We got a bit stuck for a while and then decided to "keep it simple" so that it was achievable'.*

> *'Getting others to express their views and needs takes time.'*

> *'The (name withheld) team provided very useful input into the final version of our work. Gaining this feedback in a timely manner was challenging and it required a number of attempts by phone, person, email and help from other senior staff to finally receive the amended version back from the team after a number of months. This created some stress for us both. In hindsight we should have begun this consultation earlier'.*

10 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
a. *Hearing the stories, needs, wants and expectations of Maori elders. It was an honour and a joy to being the presence of 10 elders full of wisdom and spirit.*
b. *Communication, communication, communication.-If you do it properly (timely, appropriate etc) the patient engagement commences from the first word and the patient's journey is then what the patient needs and not what is imposed on them.*
c. *I think this has been described in detail in the workbook. I am proud to have co-lead the delivery a consumer engagement framework to the organisation and I am extremely proud of the successful launch event we organised, which could not have gone any better. It is very gratifying to have the COO and CMA congratulate and thank us at a Clinical Board meeting with the CEO present.*
d. *Just finding that small things can make huge changes and improve the lot for staff and patients.*
e. *Most enjoyable - working in partnership with consumer. Greatest achievements – increased understanding by staff of patient experience.*

> f. *The patient vs staff mapping, involving the more junior members of our team in the collection of data but also finding out what patients truly value and want from our service.*
>
> g. *To know that our team is considered to be the go-to-people for consumer advice.*
>
> h. *Producing a new product that has support of participants being able to work collaboratively with a Consumer.*
>
> i. *Seeing the faces of the patients when they got their story back in a booklet with photos!*

11 How have you communicated information about this project to others?

Table – Communication to other staff	
Through departmental or organisational newsletter	3
Through presentations to staff groups within my organisation	9
Through presentations to groups outside of my organisation	1
Through articles in local press	2
Through articles published elsewhere	1

There is significant evidence to show that respondents are sharing there work with others within their organisation and externally.

> *'I have only reported this learning with some of my staff of my organisation. .Hopefully next year I can share the Capturing and Understanding tools at our conference'.*

> *'The Nurse Manager had a staff training day and has made changes based on our findings'.*

> *'Is being adopted across the organisation'.*

> *'I act as a resource for staff who are leading other projects which assist in ensuring project teams have consumer involvement from the beginning of projects'.*

> *'The changes are in all wards in the hospital block that the Nurse Manager oversees'.*

> *'There are plans to do similar projects in two DHB residential facilities.. We are looking at how we will spread co-design across the DHB'.*

> *'A staff member wants to use the methods for the experience capture for her Masters'.*

One team have adapted utilised the methods to support a hospital Chaplaincy service to better understand their consumers.

12 Final thoughts

During the programme participants provided a number of insightful and encouraging comments which are shared below.

From my personal perspective even if nothing came of the project that we are working on, just recording the patient experiences and engaging with them outside the usual complaints process has given me wonderful insight into the patient journey from an holistic viewpoint and I can already see that I have made changes in how I engage with patients when I am dealing with complaints.

I wouldn't say I was a better person for the experience (I am leaving my run a bit late for that) but I am certainly a more understanding person. So, thanks to Lynne and HQSC for the opportunity to learn the theory and apply the practice.

Very clearly the thing that has been very evident through our participation in this programme has been that what we think is important is not the same as what patients think is important.

We need to consider how we are going to consistently and regularly get feedback from consumers. At present we rely heavily on complaints – whether that be formal or informal as a measure about the service we provide however we need to devise a way of regularly surveying our consumers as well as considering consumer input when we are redesigning a process.

Understanding the consumer perspective will ultimately improve the engagement that we have with consumers and should impact on the quality of care that is provided

As health professionals we need to understand what is important to consumers with regard to their inpatient stay and give strong consideration to this when prioritising or planning changes to the way we work.

We were surprised at the number of patients who were very satisfied with services provided, despite there being some obvious problems e.g. wait times. Their level of acceptance told us something important about the level of poor service that people are prepared to accept from a public health service.

Never assume you know what patients and their families in your own community want. In future the aim has to be to ask them to tell their stories about their overall experience of care, and they will provide health care professionals where improvement needs to focus.

Participating in this programme has influenced the way that we redesign processes in our area. Where a process touches patients in any way we are trying to include patients and/or carers in giving us feedback about what we are planning to do.

We feel confident that we have the skills and knowledge to work effectively in this area. We will use the resources of HQSC to extend our knowledge and also use self-directed learning. We will also use feedback from consumers and staff to inform our work and to maximise the chance of success.

Appendix 1
Organisations participating in Partners in Care ebd programme

Organisation	Aim of the project
Waikato DHB	The aim of the project is to deliver a process and to change practice to improve the experience for the patient and their family/whaanau during this critical time, by the following changes.
Waikato DHB	To answer the question- How would service users like to access information / the system for compliments and complaints? To earn the reputation as a service people trust with their loved one's care. (Service Goal).
Bay of Plenty DHB	Our aim is to have patient information that is designed to enhance patient communication.
Taranaki DHB	To improve Consumer Participation through the - Development and launch of the Taranaki DHB Patient and Family/Whaanau-Centred Care Framework.
Northland DHB	To understand and improve the patient and family experience of discharge.
Waitemata DHB	To improve the Older Persons Healthcare Experience: From Listening to Action.
Canterbury DHB	To create a consumer/clinician partnership that develops, delivers and evaluates a course to train new graduate clinicians to have effective prevention and de-escalation skills that they apply to everyday practice.
Waikato DHB	To understand and improve the use of Call Bells.

Appendix 2
Key learning and themes emerging from web seminars

Web seminar	Key learning and themes
Web seminar 1 Introduction to web seminars and starting for success	- The need for understanding of the need for change and how the change will benefit the service users, staff, and the organisation is fundamental to sustaining change. - For us it was the importance of taking time to do the preparatory work and set the parameters of what we wanted to achieve. - The need for active engagement of senior leaders. - Key learning was around planning to tackle scepticism. - Essential to motivate staff for change or the project is unlikely to succeed. - Communication and influencing stakeholders is key to success of project. - Key takeaway was to involve key persons, including groups such as nurse consultants who had a vested interest in the course and had previously been instructors.
Web seminar 2 Using the sustainability model and planning for sustainability	- This session focused on sustainability for improvement, use of the PDSA cycle and defining the aim, change, and measure, and discussed the capture phase of experience based design. - It was really helpful to think about sustainability issues from the very outset – I hadn't really done this before, and I think it's a useful habit. - This session focused on measuring for success and emphasised the importance of SMART – specific, measurable, attainable, realistic and timely - goals for our project. - Identifying the strengths and weaknesses in terms of sustainability of the project and addressing those in order to succeed. - Very useful in terms of thinking about how we would collect stores and thoughts from patients and staff.
Web seminar 3 Measurement or improvement driver diagram's and the model for Improvement	- A key take away point for us was the use of a driver diagram to assist us to visualise our ideas and the importance of testing these ideas. - The concept of the driver diagram really appeals, but again, it requires time and planning up front. I think it cannot be overemphasised how important this is. - We learnt about the Model for Improvement and PDSA Cycles. - We were encouraged to think about what we are trying to accomplish through change, and how we will know that a change is an improvement. - Working through "The Model for Improvement & Developing a

	Theory of Change" was interesting.
	• Test our ideas to ensure that they will work – using the PDSA cycle to check the ideas and our identified solutions, fine-tuning them as we go to ensure the end result can easily be implemented.
	• Three types of measures – outcome measures, problem measures and balancing measures.
Web seminar 4 Stories and narratives	• The importance of the patient's story and their emotions as they tell the story and what they felt at the time in their journey which may now have a different impact on the patient.
	• The Mapping Session completed by Northland District Health Board, Whangarei, was a brilliant example of carers and patients participating together.
	• We learnt from others about capturing patient experience.
	• From the sharing example we heard about the mismatch between the things that staff thought were issues about discharge and the things that patients/families identified as issues about discharge.
	• That patients' concerns were often quite different from those of the staff.
	• Great examples of patients experience.
	• Listening to a patient story compiled by Bay of Plenty team was insightful.
	• I found this session very interesting and learnt a great deal from it. Getting patients and staff together in focus groups worked really well and we will probably try to adapt some of this method in our project.
	• We have learned that, as the charge nurse at Whangarei explained, you need to ask the people who use the service, from their experience, what needs improvement.
	• I like the usefulness of the various 'capture' methods including mapping of processes/decisions.
Web seminar 5 Sharing experience on the capture phase	This session was abandoned due to technical difficulty. However one of the teams who were due to present shared via e mail their presentation and other information.
Web seminar 6 Understanding experience-participants sharing progress	• The need to find emotions and touch points, not just the verbatim content was important.
	• Learnt about the use of patient experience questionnaires, patient interviews, experience mapping
	• I particularly enjoyed the part about using post-it notes for the mapping process – I think it is a great way to identify and pick out themes.
	• Identifying emotions, touch points, emotional mapping.
	Really want to do this with our information when we get it. I am

	- excited about how this will look. "hello my name is" emphasis – brought home the importance of what is just a common courtesy. " #hellomynameis.org.uk" was a real winner for me. - We found the session particularly helpful as it related to emotional mapping and linked in well with previous reading following web session 3.
Web seminar 7 Understand and improve	- I had come into this project thinking of something concrete that we could 'do' to improve the use of the call bell, but as we worked through the interview responses to our questionnaires and saw the themes that emerged, it completely changed my (Pat) way of thinking and on what I had thought the kind of outcome we would end up with would be. - It was very interesting to hear from the team about the call bell project. - Learning from the example of patient experience co-design project related to the use of the call bell. - Our learning was around the movement from gathering experience to placing this in themes so that improvement can be made. - The team from Taranaki told us about their patient family/whaanau framework – about the launch and its endorsement by their Board. - Liked the examples of understanding patient's experience. - Plenty of support offered. - Keep workbooks up-to-date with 5 weeks left.
Web seminar 8 Review and next steps	- It is our intention to share the information about the ebd approach further within our teams. We have done small snippets as we have progressed. - Key themes celebrate, spread, communicate and carry on. - It was great to reflect on all of our work, and take stock for the on-going challenges ahead. Pat and I have really enjoyed working on this together. - Our project will be shared at OPR Governance Group this month. - I need to consider how will this be communicated within my organisation – newsletters, presentations at groups. - For us the final comment said it all. ***"The ebd approach is about sharing and understanding the experiences of patients, carers and staff together to design better services."*** - Key takeaway point- This would have to be "perseverance"! I was very gratified to see this mentioned today, as I am facing the next few months with a renewed vision and sense of "yes, I can do this.