

Co-Design Programme 2015–16

Report of the evaluation survey and interviews



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KO AWATEA
HEALTH SYSTEM INNOVATION AND IMPROVEMENT

Most or a lot of professionals think we know what's best for the patient but we don't always... For me that's why co-design is important. When we look back at history, health professionals and management in health services design things to suit themselves, not to suit the people who use it. (Staff member)

Acknowledgements

This reflection on the Co-Design Programme was funded by the Health Quality & Safety Commission New Zealand (the Commission) and completed by Ko Awatea's Research and Evaluation Office. Our thanks go out to the consumers and staff who generously dedicated their time to complete a survey or participate in an interview. A special thank you is also extended to Dr Lynne Maher (Co-Design Programme facilitator at Ko Awatea) and Chris Walsh (Director, Partners in Care at the Commission) for their feedback on this report and continued support of co-design.

Executive summary

This iteration of the Co-Design Programme was delivered in two New Zealand district health boards (DHBs) over an eight-month period from October 2015 through to the end of May 2016. Reflections on the Co-Design Programme for 2015–16 were contributed by 20 people through a post-programme survey (including two consumers and 17 staff members) and five interviews (with one consumer and four staff members).

Interview findings show these participants have a comprehensive understanding of what co-design means in the context of health and health care transformation. Consumers and staff alike recognise co-design as an opportunity to move away from tokenistic engagement with consumers, to a more meaningful model of engagement and partnership in which consumers and staff together define the challenges to their current experiences of delivering or receiving care, and co-design solutions.

While learning about the co-design approach, a range of tools and resources is available to support project teams across the stages of co-design. The programme facilitator was identified as the single most useful tool or resource available to programme participants. Other particularly useful tools included masterclass training and tools for visually displaying consumer feedback.

Consumers felt they were ‘important’ or ‘very important’ members of the project teams they worked in partnership with, and that their inputs were ‘valued’ or ‘highly valued’ by other members of their teams. However, consumer survey responses show consumers had differing views about communication and how useful they felt as a team member. While one consumer reported ‘always’ receiving updates about project progress, the other reported ‘never’ receiving an update throughout the project duration and feeling ‘not at all useful’ with their contributions to the project team.

Despite project teams recognising the benefits of co-design, application in practice was not without challenges. Consumers and staff identified coordination of people with differing commitments as one key challenge. Further, consumer engagement and attrition from project teams continues to be a challenge for staff participants of project teams.

Seventy-six percent (n=13) of staff members surveyed felt they had an adequate level of support from project sponsors or senior leaders. The passion, enthusiasm, availability and knowledge of project sponsors were identified as supportive factors. However, securing staff release time, competing priorities and working with senior leaders who had limited knowledge of the co-design approach and expected benefits were more challenging aspects.

The most significant theme which emerged regarding programme and project impacts was the improved knowledge and awareness of staff, particularly in regards to consumer experiences and how these can be used to inform health care transformation. Staff anecdotes show that co-design disrupts conventional roles and interactions between consumers and health care professionals, ultimately leading to (reported) changes in how programme participants engage with consumers in their daily clinical practice.

Eighty-four percent of staff surveyed (n=16) reported that working with consumers to co-design is 'rewarding' or 'highly rewarding', and this supports continued application of the approach. Sharing and distribution of the co-design approach is occurring through application of the approach in practice within health care settings. This 'learning by doing' and role modelling of the approach provides opportunities for other staff and consumers to observe or participate in co-design as it is applied to future projects. However, there is limited systematic or structural integration of the co-design approach into organisational training and development, policy or strategy.

This report has identified a number of learnings. These offer potential future opportunities to increase the sustainability of co-design approaches through:

1. embedding co-design within existing organisational training at DHBs, for example, the improvement advisor programme, safety programmes and other general improvement training
2. delivering focused workshops on areas of the co-design process participants have found challenging, such as effectively engaging with consumers
3. identifying programme participants who may need additional support to train or teach colleagues and connect them to existing training or mentorship in their organisation that can assist in developing these skills
4. considering different modalities for the delivery of programme content which teams can access within timescales that suit their needs, for example, e-learning programmes
5. increasing support for senior leaders to understand co-design and expected benefits, and how co-design can fit within their organisational strategy, values and priorities, potentially through targeted training or communications to senior leaders
6. support senior leaders and sponsors to play a more active role in sharing the co-design methodology, in particular, advocating for co-design to be embedded within broader organisational policies or strategy.

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Introduction

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

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

The experiences that consumers, the public and health care professionals have when they receive or deliver health care services are a valuable source of information that can be used to improve safety of care and transform services.

The Co-Design Programme has been designed to support and enable consumer engagement and participation across the health and disability sector in decision-making about their own health, and the delivery of health and disability support services in New Zealand. Consumers are encouraged and supported to participate at a level appropriate to their needs, skills and experience.

Ko Awatea’s Director of Innovation, Lynne Maher, was contracted by the Commission to deliver the Co-Design Programme, under the auspices of Partners in Care, for its fifth iteration from October 2015 through to the end of May 2016. In this iteration, Lynne has worked with two district health boards (DHBs) (MidCentral and Nelson Marlborough) to deliver content around core principles of the programme.

This is the first time the Co-Design Programme has been delivered on site in the DHB setting. Previous recruitment for the programme has involved seeking expressions of interest from health providers and staff nationally. As a result of past evaluations, it was felt that a more localised programme with leadership, support and closer networking of participants would improve completion and sustainability.

A full description of the programme evidence base, content and participant requirements is available in [previous evaluation reporting](#) on the Commission website.

Method

Two tools were used to gather information about Co-Design Programme experiences, including a post-programme survey distributed to participants, and post-programme interviewing.

Post-programme survey

The post-programme survey was developed by Ko Awatea's Research and Evaluation Office in partnership with Lynne Maher (Ko Awatea Programme Facilitator) and Chris Walsh (Director, Partners in Care). The survey includes a combination of closed¹ response (multiple choice, Likert scales) and open response questions oriented towards gaining information about consumer and staff experiences with different programme aspects, including: consumer engagement and satisfaction, programme tools and resources, support, and sustainability of the co-design approach. A copy of the survey questions is in Appendix A.

The survey was programmed on SurveyMonkey and emailed to staff and consumers. Using this method, there were six named programme participants who were not able to be contacted due to not having provided an email address. An information sheet was distributed prior to the survey, which provided information about the purpose of the survey, how the information would be used, accessibility of the information and key contacts, should potential survey participants have any questions. This information sheet is available in Appendix B.

Confidentiality of participants' responses was assured by omitting information in reporting that might lead to identification of individual participants, and through restricting access to survey and interview data. Survey data is accessible only through the Ko Awatea SurveyMonkey registration designated for use by the Research and Evaluation Office and Learning and Development. This is not accessible by any Ko Awatea staff associated with the delivery of the Co-Design Programme. Downloaded survey data and interview data are stored on a password-protected computer in the Research and Evaluation Office.

The survey was voluntary, and although all programme participants were encouraged to complete it, they were also advised they were under no obligation to do so. Participants were advised that survey completion was their choice, and that their decision to participate or not would not impact on their participation in the programme or their working relationship with the programme facilitator or director.

The survey was distributed on Monday 2 May 2016 to a total of 40 potential respondents. On Monday 16 May, two weeks after the initial distribution, a reminder to complete the survey was distributed to 28 potential respondents who had not yet completed the survey. On Monday 23 May, the survey was closed and a thank you message distributed to the 19 respondents who completed the survey.

¹ Closed or 'forced' response questions provide a range of pre-determined response options from which a respondent must select one which best fits with their experience, perception or opinion.

Survey data was analysed in a number of ways, depending on the question response structure. Closed response questions, such as multiple choice or Likert Scales, were analysed through descriptive statistics, such as response percentages and totals. Open response options were thematically analysed with the aid of a qualitative software package, NVivo.

Post-programme interviews

Five semi-structured interviews with programme participants were conducted. These were formal interviews guided by pre-established questions or an 'interview schedule' (see Appendix C) that was followed, but also allowed for topical flexibility. Where appropriate and relevant, conversations were more free flowing; encouraging participant experiences to emerge. The interview questions were predominantly open-ended to facilitate discussion.

As described with the survey questions, the development of the interview schedule was a collaborative effort led by Ko Awatea's Research and Evaluation Office. The Commission identified two preferred interview participants who were contacted first, by email, and provided with an information sheet about the interviews (see Appendix D) and an invitation to participate. An information sheet and invitation to participate in an interview was then emailed, to the remaining programme participants, with an aim to complete five interviews. The remaining interviews used quota sampling methods, with an intention to ensure inclusion of consumers, senior leaders or project sponsors, and health professionals that were a part of the working team. Five people responded and agreed to participate in an interview, which meant there were no respondents who agreed but were not able to be interviewed.

Interviews were scheduled via email, to be completed during 2–20 May. All survey participants provided a telephone number for the final interviews. Four interviews were conducted over the phone by Ko Awatea's Research Officer and recorded for transcription and analysis. All participants provided permission for interviews to be recorded. One interview was conducted face-to-face at Middlemore Hospital. This interview was also recorded with the permission of the interviewee.

Interview records were transcribed and then thematically analysed with the aid of qualitative software package, NVivo.

Findings

The following chapter presents findings from the post-programme survey and interviews organised into five main sections:

1. consumer experiences
2. staff experiences
3. sustainability of the co-design approach
4. programme impacts and finally
5. making sense of co-design.

Staff survey responses are presented graphically where relevant. Overall, there are two unique consumer participants included in these findings. Both consumers completed the survey, and one also participated in an interview. Due to having only two survey responses from consumers, consumer responses are not presented graphically.

The survey was distributed to a total of 40 people, including five consumers and 33 staff members.² A total of 19 people completed the survey, including two consumers and 17 staff members – an overall response rate of 47.5 percent. Respondents were from both participating DHBs, including nine from MidCentral DHB and 10 from Nelson Marlborough DHB. Five interviews were completed, including one consumer and four members of staff (two sponsors and two other staff). Four of the five interview participants were also survey respondents. As this is a small participant group of 20 individuals in total, respondents will be referred to merely as ‘staff member’ or ‘consumer’ throughout.

Consumer experiences

The consumer who was interviewed talked about how co-design is a process in which consumers can be engaged in a meaningful rather than tokenistic way.

Participating in this just really made me re-evaluate what the role of a consumer rep is, and what it can be, and how to be heard. A lot of times a consumer rep is considered to be [of little value]... We have to have one [on the team to meet a requirement], rather than really involve the consumer rep [as a partner].

This view is consistent with survey results, which highlight that the consumers felt valued and important throughout the co-design process.

Survey findings show that consumers felt their thoughts, experiences and opinions were ‘valued’ or ‘highly valued’ by the project team. Being ‘considered as an equal partner in the project’ (consumer) was one explanation for what made consumers feel highly valued throughout the co-design process. The consumers also reported feeling they were an



² The final two people in the distribution group were not categorised as either staff or consumer.

‘important’ or ‘very important’ part of the project team. They were able to feel important through maintaining ‘full involvement’ (consumer) in the project throughout the project.

While both consumers felt their thoughts, opinions and experiences were valued by the project team, one also felt their contributions to the project were ‘not useful at all’. Findings under the section on ‘communication throughout the project’ suggest this consumer experienced some challenges with ongoing communication throughout the project which could have impacted on how useful they felt their contributions were.

Initial engagement

Both consumers were known to health professionals and invited to participate in their respective co-design projects through a consumer panel group or a ‘specific invitation’ (consumer). Information about the co-design project and getting involved was first provided via email to both consumers.

Support throughout the project

Financial support to participate in the co-design project was offered to both consumers, one in the form of travel allowances, and the other a small remuneration from the DHB. Overall, one consumer felt there was ‘lots of support’ available to them during the project, while the other felt ‘neutral’ about available support – inferring that additional support would have been preferable.

Communication throughout the project

Consumers reported that getting information from the team about the co-design project when they felt they needed it was ‘okay’ or ‘really easy’. Consumers’ ability and comfort to ask for information is important so that all team members communicate in a language that is understandable for others:

I think you just [have to] be yourself and if you’re with the right group you can ask questions that they all know the answers to but you don’t. You need to find out for yourself. The right group are more than happy to give you that information at the right level. (Consumer)

While engaged in the co-design project, both consumers reported having a dedicated person whom they could contact, and who supported them on the co-design project. However, one consumer reported being able to contact any member of the project team; the other consumer had only one contact.

The regularity of project progress updates provided to consumers varied between the two consumer respondents. While one consumer reported ‘always’ receiving updates about the project progress, the other reported ‘never’ receiving an update throughout the project. Similarly, one consumer reported being completely uninformed of the project outcomes. This question did not apply to the other consumer, who responded ‘N/A or project not yet complete’.



Participation

One consumer recalled they were 'sometimes' part of the project team meetings, and the other 'regularly'. The consumers felt respectively 'welcome' or 'very welcome' to attend.

A key challenge in participating in project meetings or other commitments (for example, WebEx sessions), was coordinating times that accommodated all team members:

I suppose one of the biggest [challenges] was getting people together, finding a time that worked for everybody. With those who are actually working within the health business, just trying to find an hour here or an hour there when everybody was able to go – it was a challenge. We actually shared a lot via email. (Consumer)

The difficulty of co-ordinating team members to participate in various project aspects was also a theme in the accounts of staff members. Overall, four of five interview participants identified this as a challenge.

Both consumers reported that they were the only consumers in their project team.

Staff experiences

Survey responses indicate that staff members generally find working with consumers to co-design is a rewarding experience (Figure 1).



Figure 1: Likert scale responses for 'To what extent was working with consumers to co-design rewarding for you?' presented as total number of responses per response option

In staff responses, there are examples of the potential for the programme to inspire staff, to reaffirm their work in the health care industry and to change the way they perceive health care services and their relationship with consumers: 'It has been a different perspective to have problems identified by the consumers, often not what staff would expect'; 'The feedback you get is always worthwhile and the connection reminds you why you work in public health system to help people'; 'It fits my understanding of humanity. I think we have to do more and more of this in health and I delighted in being able to be part of this small, empowering step'.

Engaging with consumers

Half of respondents (53 percent, n=9) rated engaging with consumers about participating in co-design for the first time as 'neutral' or below ('neutral', 'difficult', 'really difficult'), as depicted in Figure 2.

Expanding on this, staff explained that difficult aspects included: reversing roles from advisor and expert to listener; knowing where to start; health concerns of consumers that may inhibit participation; and small sample size of potential participants. Supportive aspects included: having a good existing relationship with the consumer; community connections; and availability of the consumer.

Fifty-nine percent of staff (n=10) felt they were able to connect with a diverse range of consumers, including those who may be 'harder to reach', while 41 percent of staff (n=7) felt the range of consumers they connected with was 'limited'. For instance, one respondent explained that reaching particularly vulnerable consumer groups, such as mental health consumers,³ was difficult due to lack of relationships and trust with this consumer group: 'It will take time to build relationships with our mental health consumer groups. We have to be patient' (staff member). During interviews, one staff member reflected on how the difficulty of increasing and maintaining consumer engagement over long periods of time impacts on the diversity of consumers involved in co-design, and the need for strategies and support to enable diverse consumer representation.

Otherwise you're only going to be limited to certain groups of people that have the availability whereas you want to be able to capture the people that work Monday to Friday; you want to be able to capture the shift workers and others. (Staff member)

Most staff (88 percent, n=15) found consumers to be 'interested' (53 percent, n=9) or 'very interested' (35 percent, n=6) in participating in the co-design project. Despite initial interest in participating in co-design projects, consumer attrition was a key challenge raised by interview participants. The health and availability of consumers, and their other commitments, were discussed as impacting consumer involvement and project momentum.

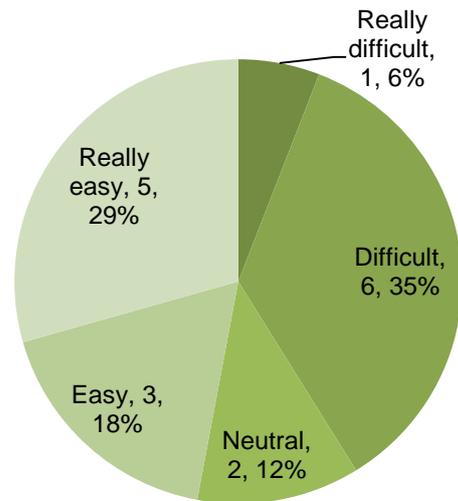


Figure 2: Likert scale responses for 'How did you find engaging with consumers about participating in co-design for the first time?' presented as total number and per cent of responses per response option

³ This group was changed to protect the identity of the survey respondent.

We've been through four different consumer reps now... you know one had gone overseas for a couple of months so was very involved in the very beginning but not later in the project. We had one [consumer] who unfortunately had her father become terminally ill so she had to pull out. We had one person who said 'Yes, I'll come to the meetings' but never came... It just meant that we had to go and find the consumer voice in other ways. It slowed [the project] down because you had to then re-orientate to what we're doing and all the time. (Team member)

Resources utilised by staff

Survey respondents were asked to rate how useful a selection of tools provided for the Co-Design Programme were, including: masterclass training, consumer experience capture tools, WebEx sessions, workbook materials, tools for visually displaying consumer stories and the programme facilitator (see Figure 3).

The programme facilitator was identified as the single most useful tool or resource available for programme participants: 'Lynne was the biggest support, you know if it wasn't for her leadership and the way she goes about what she does, I think probably we wouldn't have progressed really' (staff member). Support from the programme facilitator was available to programme participants at regular monthly intervals through WebEx sessions and coaching phone calls as and when needed by project teams.

The masterclass was also considered 'useful' or 'highly useful' by all respondents.

In regards to specific tools, one interview participant stated they had found mapping and clustering exercises a useful tool for managing information from various stakeholders. One interview participant also commented the tools were modifiable to fit local needs or circumstances.

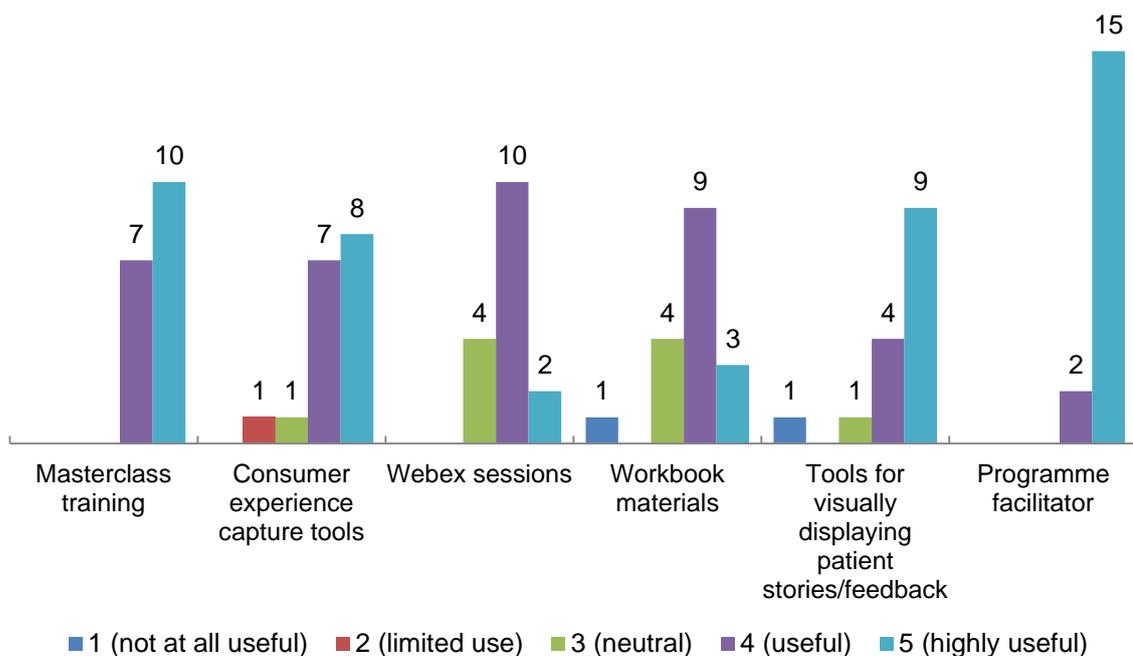


Figure 3: Likert scale responses for 'How useful did you find the following tools and resources?' ranging from 'not at all useful' to 'highly useful'

Leadership and support

As indicated in Figure 4, most survey respondents (76 percent, n=13) felt they had an adequate level of support from project sponsors or senior leaders while participating in the Co-Design Programme. Open responses characterised one project sponsor as 'approachable, passionate and responsive' (staff member). Project sponsors or senior leaders were also viewed favourably when they were 'interested and involved'; 'enthusiastic and knowledgeable'; 'they took time to listen and ask and promote progress' (various staff members).

Similarly, two interview participants highlighted the importance of passion and enthusiasm amongst senior leaders.

The director of that area is very positive about it and very encouraging, very enthusiastic and I think that that's a key ingredient. But if you haven't got the willingness to consider change at the top then you're not going to get anywhere, are you? (Staff member)

They are people who have a passion and enthusiasm and also know that making the commitment is a pretty big thing. The second part of that is that they have the support of people – their manager and their wider team and also the support of the organisation to do this work. (Staff member)

These quotes reflect the need for passion and enthusiasm to be supported by higher level management.

Challenges with support from sponsors or senior leaders that were identified included:

- securing staff release time (identified by two survey respondents and two interview participants)
- senior leaders just beginning to learn about co-design and expected benefits (identified by two interview participants)
- competing priorities (identified by one interview participant and one survey respondent).

For one survey respondent, lack of release time to participate in WebEx sessions resulted in having to commit unpaid hours to complete all of their project work: 'I came in for meetings in my own time, worked on the workbooks in my own time [and] watched WebEx meetings in my own time' (staff member). Another staff member described participation in the programme as a 'stretch' for staff who were supported

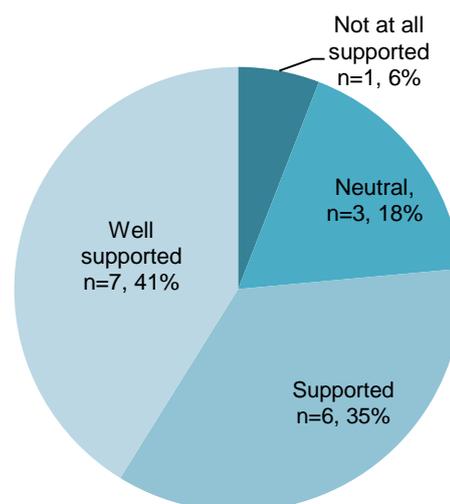


Figure 4: Likert scale responses for 'To what extent did you feel supported by project sponsors or senior leaders while participating in the project?' presented as total number and per cent of responses per response option

'in principle' by their managers, but expected to maintain the same working commitments and workload.

Sustainability of co-design approaches

Sustaining the co-design approach was an area of discussion in all interviews, as well as an area of survey questioning. We aimed to establish how the co-design approach was being integrated into clinical practice and shared more widely among DHB staff and consumers.

Most survey respondents (65 percent, n=11) reported they were able to develop more structured methods for sharing co-design skills across their health organisation by/at the end of their project (Figure 5). By 'structured methods' we sought examples around how sharing or applying the approach has gone beyond other staff (or consumers) observing co-design in practice (by way of role modelling from programme participants), to becoming embedded in organisational training and development, improvement methodologies or organisational policy.

However, despite the great future visions of programme participants, there are limited examples of this having been achieved. One interview participant discussed their organisation's commitment to increased consumer representation on committees and in quality reporting, while another said they are hoping to establish a consumer council in the near future (this was in motion prior to the Co-Design Programme).

Two interview participants discussed their future intent to have the co-design approach incorporated into policy and organisational development programmes. Their confidence in their knowledge and understanding of the approach enabled this, in that they could teach and deliver some of the programme content themselves. Incorporating the approach into the organisation's strategic plan was perceived as fundamental to sustenance of the approach.

My ultimate aim would be this is part of a wider change to the way we think and the way we work and the medium to long term and we're working on our strategic plan here at the moment with our new CEO. We're certainly ensuring that co-design has a place in that strategic plan. I think that this work that we're doing now will start to build a foundation for what we need to do moving forward in the medium to long term. (Staff member)

Current success in sustaining the co-design approach has largely come through application of the approach to future projects: 'The people who have been involved in this programme are now getting involved with other pieces of work as well' (staff

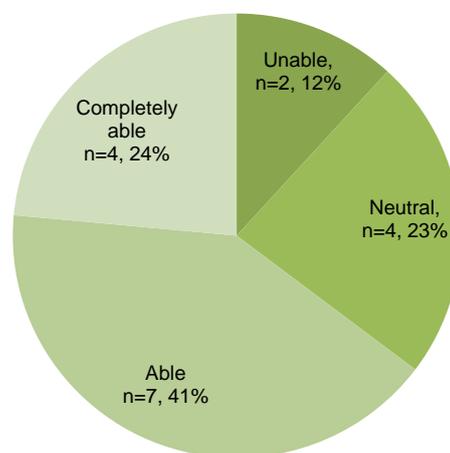


Figure 5: Likert scale responses for 'To what extent were you able to develop more structured methods for sharing co-design skills across your organisation by/at the end of the project?' presented as total number and percent of responses per response option

member) – giving staff the opportunity to ‘learn by doing’. Three (of four) staff who participated in interviews shared examples of how co-design is shared and distributed through its application in practice (within and beyond the clinical field).

I’ve already done it with the rest of the team here at the hospital and I know that the department staff themselves have been sharing amongst their team so from here I guess it’s just a matter of when the next project comes up to help out and provide that support. (Staff member)

Further, two interview participants described how their organisations have been promoting the approach and project outcomes through media and other communication avenues, for example, news pieces, email updates or e-newsletters.

Our operations director has set up a regular newsletter that’s already going out to all of staff about all of the projects and kind of key learnings from there and we’re reporting back up to the board as well as far as the project and what we’ve achieved. (Staff member)

Communication and promotional opportunities through Twitter were also raised by one interview participant.

Some staff found it difficult to share the approach/skills more widely beyond their project team (12 percent or n=2 were ‘unable’, and 23 percent or n=4 were ‘neutral’), citing time constraints, competing priorities and staff turnover as barriers to sharing co-design skills. One respondent also identified they do not yet feel ready to be able to share with others: ‘I did not get enough practice to develop further’ (staff member). Moreover, not all staff were able to identify opportunities for skill sharing: ‘At this time I cannot see any avenue to take my knowledge of co design out to a wider audience’ (staff member).

Participant interviews indicated the following factors could increase the sustainability of the co-design approach.

- Buy-in and engagement from senior leaders, with specific reference to senior leaders needing to have knowledge of co-design processes and expected benefits. One participant identified the benefits of co-design are a ‘knowledge gap’ (staff member) among senior leaders.

The benefits probably need to be described at the top table so it becomes the way they we do business going forward... [The programme has educated staff] at the coal face, I do wonder if there is a need to go away and provide some education, a master class for boards and senior leaders giving them some insight into what co-design is and why we should be adopting it. (Staff member)

- Continued communication and promotional activities as earlier highlighted. One interview participant suggested these could incorporate evaluative findings about the impact and benefits of co-design.

I think more of those examples of what co-design has achieved in the world and in DHBs and the voice of the consumers who have been involved in it themselves. What differences that approach and the outcome to it has made for them and/or their families or the community. Because if it’s not the

consumers that speak up we're still going to be seen to be saying what we think has made a difference but in actual fact it probably needs to be pushing that barrier. (Staff member)

- Interdisciplinary collaboration was particularly important to one team member, who highlighted the advantage of involvement across speciality groups or services.

[The experience] reinforced the value of other organisations being part of the change... They have a community pharmacist on that team and a general practitioner. [Most] teams have one or two people external... There's a real value in widening that approach. (Staff member)

- Creating the right language for different stakeholder groups was also suggested by one interview participant, who suggested a change in language to appeal to medical officers.

I think it's trying to find the language in some ways that's sort of makes this sexy for doctors. Patient involvement makes it very sexy for nurses, nurses go 'I get that'. I'm not sure what the switch is for medical staff, it'd probably be data; you know, 'this is the difference it makes when you do it'. (Staff member)

Programme impacts

Discussion about the impact of the Co-Design Programme and subsequent projects was oriented around four key themes: consumer engagement, knowledge and awareness, improved communications and therapeutic effect, as summarised in Figure 6.



Figure 6: Key themes in discussion about programme and project impacts or outcomes

Most staff who completed the survey reported that the programme has impacted how they engage with consumers 'to some extent' (41 percent, n=7) or 'to a great extent' (53 percent, n=9) (see Figure 7). Forty-seven percent (n=8) of staff respondents also believe the programme has impacted how others in their place of work engage with consumers 'to some extent', while one staff respondent thought it had 'to a great extent'. Forty-one percent of staff (n=7) responded 'neutral' (23 percent, n=4) or thought it had 'very little' impact on others in their place of work (18 percent, n=3).

The previous section has outlined opportunities for increased sharing or distribution of the approach to enable a wider impact on health care professionals, consumers and health care services.

In the survey, we sought examples of how the programme had impacted the way in which participants (or others such as colleagues) engage with consumers – 12 staff responded. The most significant theme in these responses was improved knowledge and awareness of consumer stories or journeys and their relevance to health care transformation. For example: '[This programme] has made me make the patient journey my priority'; 'Great to change our mindset from "this is what we think needs to change for patients" to "how can we change our service to provide you, our patient or consumer, a better service experience?"' (staff members).

A discussion of programme or project impact during interviews also

highlighted changes in the knowledge or awareness of staff: 'The two-day workshop was an extremely good experience. It raised a lot of things that I'd never really thought of before and certainly opened my eyes big time to what it looks like from the other side around' (staff member). In another example, a staff member stated:

I firmly believe that people come to work to do a good job but I also believe that we sort of put on our 'I'm at work' glasses. The blinkers are there, we've always done it this way and until you're actually challenged around your thinking, you think what you're doing is providing excellent care. It's not until it's actually challenged, you sort of go 'we do that' 'oh no, we don't – you learn.

Completed projects delivered tangible changes to written communications with consumers, such as pamphlets or brochures with health information. Four interview participants discussed how they have refined consumer information to make it more understandable for consumers utilising their health care services. Further, some work continues to facilitate other changes to health care services, including, for example, the adaption of cancer pathways to improve consumer flow through radiology services.

Finally, during interviews, one staff member discussed the therapeutic impact that co-design may have on consumers of health care service.

Obviously there are the benefits for the patients themselves which can't be underestimated. For a lot of them the fact that they were involved was huge for them. For them to tell their story about how horrific their experiences were,

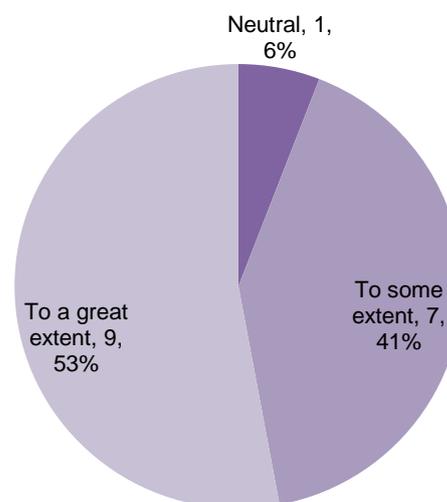


Figure 7: Likert scale responses for 'To what extent has this programme/project impacted how you engage you consumers?' presented as total number and percent of responses per response option

not necessarily in terms of care but not being prepared for the horrific surgery that was involved, telling their story and being able to feedback has been therapeutic for the patients.

Making sense of co-design

To ascertain how co-design is understood by programme participants, interview participants were asked what co-design means to them. Participant responses demonstrate an informed and comprehensive understanding of what co-design means in the context of health and health care transformation. Participants use their own language to describe co-design; key themes that underpin their understandings are summarised in Figure 8.

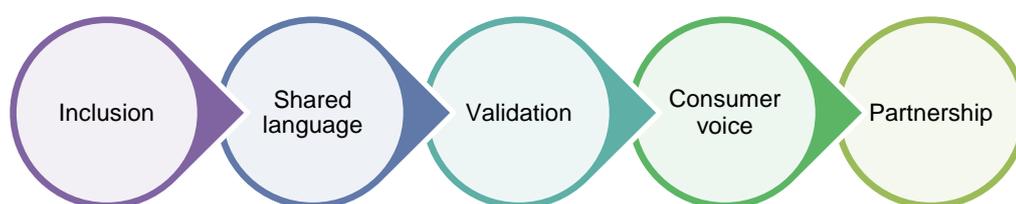


Figure 8: Key values or themes underpinning participant understandings of ‘co-design’

Co-design to me is about the equal voice of the service user or consumer along with our staff. It’s not necessarily a priority of one over the other. It’s about ensuring that we have a consumer voice. I don’t mean just a professional consumer sitting around the table... [Co-design is ensuring] that consumers are part of determining what the real problem is and what we want to do... Co-design to me is about engagement with consumers at every level, everywhere about everything. Whether it be co-designing a service, a whole of service or some bigger thing in an organisation, or something that’s really small that might only be for a very small number of people who use that particular service or need that particular procedure. (Staff member)

In the above quote, a staff member explains co-design as creating an equal voice for consumers alongside the voice of health care professionals. Similarly, another staff member commented: ‘For me, co-design is about everybody being able to say “from our point of view this is how it would affect us”’.

One participant also drew attention to co-design being an intricate process of meaningful (rather than tokenistic) engagement, for the purpose of identifying core issues and creating health care transformation.

[Co-design is] not just coming together to share ideas and come up with a solution... [With co-design] you need to go through the process of actually engaging consumers first so that they can actually tell you their *real thoughts* and then you capture that and then later on you further understand what they were trying to say in order to *figure out the core issues* and that’s where you involve everybody coming up with a solution in the end. (Staff member)

In all of the above quotes, staff touch on the genuine partnership that is created in co-design, through the validation of consumer experiences, thoughts and opinions as a legitimate and invaluable source of information to transform health care services.

Responses also highlighted an implicit benefit of reducing assumptions about consumer experience through the process of co-design.

Most or a lot of professionals think we know what's best for the patient but we don't... Don't you think they are the people who need to tell you what will work best for them? That for me really sums it up. They're the patients, they need the service and they know what's going to work best for them... When we look back at history, health professionals and management in health services design things to suit themselves, not to suit the people who use it. (Staff member)

During discussion about the meaning of co-design, one participant referred to patient-led services, which is further explored in the discussion of this report.

Discussion

The interview and survey findings presented in this report are consistent with the more extensive findings presented in the [evaluation of the Co-Design Programme 2014–15](#). The current findings suggest there are some aspects of the co-design programme which continue to challenge participants, including:

- engaging with consumers about participating in co-design
- consumer attrition from co-design projects
- embedding co-design into organisational training and development, policy or strategy
- securing release time from work to commit to projects.

Although there was a limited number of consumers involved in this survey and interview process, some of their insights were consistent with challenges raised in previous evaluation reporting, including:

- consistency of project updates and being informed of project outcomes
- having only one staff member as a key point of contact. As per previous evaluation findings, this may impact sustainability and consumer satisfaction when reallocation or staff turnover disrupts a consumer's connection with a co-design project team.

In response to 2015 evaluation findings and recommendations, updates to the programme content were made to address some of the challenges experienced by staff and consumers. For instance, the content was adapted to further support staff to engage consumers in co-design. An enhanced section on the importance of using existing relationships with consumers and/or taking the time to develop relationships prior to the programme journey was incorporated. The content was also adapted to incorporate the inclusion of prompts to provide regular feedback to consumers about progress and impact even if they are no longer actively involved in the project. That staff still find engaging with consumers difficult is to be expected given that co-design disrupts conventional roles and relationships between health professionals and consumers.

Extending on previous findings, this post-programme surveying and interviewing has offered some new insights pertaining to:

- sharing of the co-design approach
- confidence in teaching skills and the co-design methodology.
- the language in which co-design is 'sold' to others
- how programme participants have come to understand co-design
- the need to work with staff from different organisational levels to increase knowledge of co-design among senior leaders.

Throughout the programme period staff and consumers were equipped with co-design skills. However, interview findings suggest not all staff are confident in their ability to teach or share skills with others, nor able to identify opportunities for

disseminating their knowledge more widely. These findings have demonstrated that to support dissemination of the approach among health care professionals, programme participants need to feel:

1. confident in their knowledge of the co-design approach
2. confident in their teaching and sharing skills
3. able to recognise avenues or opportunities for dissemination.

Confidence in sharing and teaching skills will vary amongst programme participants. The potential for participants to embrace this approach in a way that means further co-design will take place could point to the need for more development around teaching and sharing skills.

Previous evaluation findings have highlighted that lack of 'buy in' from sponsors or senior leaders can impact on project momentum and a project team's ability to overcome barriers and implement solutions they have co-designed. The current findings have highlighted that such challenges may occur when senior leaders have limited knowledge about co-design and expected benefits. As project teams are typically comprised of frontline staff to whom the masterclass, WebEx sessions and other programme content are predominantly delivered, it is reasonable to expect sponsors or other senior leaders may not have the same extent of knowledge about the co-design approach and expected benefits. This suggests that learning material may need to be more accessible and amenable to sponsors or senior leaders.

These findings have explored how programme participants have come to understand 'co-design' and its application in health care settings. Interview participants' responses indicate a comprehensive understanding of what co-design means in the context of health care transformation. One participant's reference to 'patient led' services, however, highlights a danger of health care service design swinging from being predominantly focused on the views and expertise of health care professionals, to being predominantly patient led. While co-design aims to redress the imbalance, it is about ensuring the expertise and experiences of all involved in a process are validated; enabling both staff and patients to be involved in the design of solutions or improvements. Co-design is a process for providing an equal voice to all parties, and acknowledging that both staff and patient views offer valuable expertise.

These findings, together with previous evaluation findings, have demonstrated that programme participants most often share the approach by applying it in practice on other projects which ideally will involve other health professionals. Systemic or structural embedding of the co-design approach, while perceived as valuable by interview participants, has not been achieved.

Limitations

There was only a small population of potential consumer participants and a low consumer response rate throughout surveying and interviewing. While there is a lot to learn from even one consumer it is not possible to ascertain to what extent particular consumer experiences may be similar or relevant to other consumers who participated in the Co-Design Programme. Although an overall response rate of 47.5

percent is reasonable for an online survey, we are unaware of the experiences of non-responders, which may differ from those who agreed to participate.

Survey responses and anecdotes shared during interviews provide an indication of how the approach is being applied in practice. However, these are self-reported, and we have not undertaken any direct observation of changes in clinical practice.

Conclusions

These findings have highlighted a high level of passion and enthusiasm for the co-design approach across programme participants. Participant responses suggest that application of the co-design approach to future projects is the main avenue through which others, through observation and 'doing', learn about co-design and its role in health care transformation.

The lack of systemic or structural integration of the co-design approach into organisational training and development, policy or strategy leaves the co-design approach open to the risk of poor sustainability. This is compounded by competing organisational priorities and need for increased senior leadership or management knowledge of co-design and expected benefits of the approach. These findings suggest that knowledge about co-design needs to filter to higher organisational levels.

Future considerations for the Co-Design Programme

This report has identified a number of learnings. These offer potential future opportunities to increase the sustainability of co-design approaches through:

1. embedding co-design within existing organisational training at DHBs, for example, the improvement advisor programme, safety programmes and other general improvement training
2. delivering focused workshops on areas of the co-design process participants have found challenging, such as effectively engaging with consumers
3. identifying programme participants who may need additional support to train or teach colleagues and connect them to existing training or mentorship in their organisation that can assist in developing these skills
4. considering different modalities for the delivery of programme content which teams can access within timescales that suit their needs, for example, e-learning programmes
5. increasing support for senior leaders to understand co-design and expected benefits, and how co-design can fit within their organisational strategy, values and priorities, potentially through targeted training or communications to senior leaders
6. support senior leaders and sponsors to play a more active role in sharing the co-design methodology, in particular, advocating for co-design to be embedded within broader organisational policies or strategy.

Appendix A: Survey questions

In question one, we ask which district health board (DHB) you worked with, or are employed by. We ask this so we can check that people from both DHB's have responded to this survey. This information is not used to identify responders in any way.

1. Which district health board (DHB) were you employed by or working with during your co-design project?

- MidCentral DHB
- Nelson Marlborough DHB

2. Are/were you a consumer or member of staff on your co-design project?

- Consumer
- Member of staff

Questions directed at consumers only

Section title: How you initially got involved in the co-design project

3. How did you first hear about the co-design project? (Please tick one option):

- Through a health care worker I have known for some time
- Through a health care worker I have known for a little while
- Through a health care worker I had not met before
- Through a group invitation or promotional material (such as a poster or brochure) in a public space
- Other (please specify)

4. When you first heard about the co-design project, how was information about getting involved given to you? (Please tick all that apply):

- Face to face while staying in a ward
- Face to face while visiting a clinic as an outpatient
- Face to face in a community setting such as home, church or other place
- Face to face while attending an existing consumer group (for example, Consumer Council)
- Face to face while attending an existing community group (for example, church, a volunteer group)
- Contacted by telephone
- Contacted by email
- Written information, for example, a pamphlet or brochure
- Written information in an email
- Other (please specify)

Section title: Being part of the project team

5. While working on the co-design project, how valued did you feel your thoughts, experiences and opinions were by the project team?

Not at all valued Of little value Neutral Valued Highly valued

6. Please share with us what made you feel your thoughts, experiences and opinions were (or were not) valued while working on this project: (Write your response in the space provided).

7. To what extent did you feel like an important part of the project team?

Not at all important Of little importance Neutral Important Very important

8. Please share with us what made you feel like an important (or not very important) part of the project team: (Write your response in the space provided).

9. Did you attend project meetings with the team?

- Yes, I was regularly part of project meetings
- Yes, I was sometimes part of project meetings
- No, I was not part of project meetings at all.

10. How welcome did you feel to attend project meetings?

Unwelcome Not very welcome Neutral Welcome Very welcome

11. Please share with us what made you feel welcome or unwelcome to attend project meetings: (Write your response in the space provided).

12. Did you receive any financial payment or other support for participating on the co-design project?

- Yes, please specify:
- No

Section title: Information and communication throughout the project

13. How easy was it for you to get information from your team about the co-design project when you felt you needed it?

Really hard Hard Okay Easy Really easy N/A

14. Did you have a dedicated person (a specific person you could get in touch with) to support you on the co-design project?

- Yes
- No
- Not sure

15. How many people from your project team were you able to contact? (Please write your response in the space below):

16. How regularly did you get updates about the progress of your co-design project?
(Please select one response on the scale below)

Never Not very often Often Always N/A

17. To what extent do you feel informed by staff about project outcomes (what happened or changed as a result of your work)? Please rate on the scale below.

Completely uninformed (not aware of outcomes) Not very informed Neutral
 Informed Well informed N/A or project not yet complete

Section title: Working with other consumers during your project

18. Were there other consumers involved in your project team?

Yes
 No
 Not sure

19. How many consumers were involved in your project team? (Please write your answer in the space below)

20. Were you in contact with any of the other consumers?

Yes – regularly
 Yes – sometimes
 No

Section title: Overall satisfaction with the project

21. Overall, to what extent did you feel that an appropriate level of support was made available to you during the co-design project? (Please rate on the scale below):

No support Hardly any support Neutral Some support Lots of support

22. How useful did you feel your contributions to the project were? (Please rate on the scale below):

Not at all useful Not very useful Neutral Useful Very useful

Questions directed at staff only

Section title: Engaging with consumers

23. How did you find engaging with consumers about participating in co-design for the first time?

Really difficult Difficult Neutral Easy Really easy N/A

24. Please expand on your answer for the above question:

25. To what extent were you able to connect with a range of consumers, including those who may be harder to reach?

Not at all Limited Neutral To some extent To a great extent N/A

26. Please expand on your answer for the above question:

27. To what extent were the consumers you or your team approached interested in participating?

Not at all interested Little interest Neutral Interested Very interested N/A or not sure

Section title: Resources and support

28. How useful did you find the following tools and resources provided for the co-design project:

	Not at all useful			Highly useful	
Masterclass training	1	2	3	4	5
Consumer experience capture tools (for example, experience questionnaire, stories)	1	2	3	4	5
Tools for visually displaying patient stories/ feedback (for example, wordle, video, emotion mapping)	1	2	3	4	5
WebEx sessions	1	2	3	4	5
Workbook materials	1	2	3	4	5
Programme facilitator	1	2	3	4	5

29. To what extent did you feel supported by project sponsors or senior leaders when participating in the project?

Not at all supported Poor support Neutral Supported Highly supported
 N/A not sure

30. Please expand on your answer for the above question:

31. To what extent are you able to develop more structured methods for sharing co-design skills across your health organisation at the end of the project?

Completely unable Unable Neutral Able Completely able N/A not sure

32. Please expand on your answer for the above question:

Section title: Project outcomes

33. To what extent was working with consumers to co-design rewarding for you?

Not at all rewarding Of little reward Neutral Rewarding Highly rewarding
 N/A

34. Please expand on your answer for the above question:

35. To what extent has this programme impacted how you engage with consumers generally?

Not at all Very little Neutral To some extent To a great extent

36. To what extent has the programme impacted on how others in your place of work engage with consumers?

Not at all Very little Neutral To some extent To a great extent

37. Please provide an example of how the programme has impacted how you or others engage with consumers in your place of work?

Final questions (consumers and members of staff)

38. Is there anything else you would like to add about your experience?

39. Would you like to receive a copy of the survey results?

Yes please

No thanks

Thank you for your contributions.

Appendix B: Information sheet about the Co-Design Programme survey

Survey contact person: **Dominic Madell**

Email: Dominic.Madell@middlemore.co.nz

Contact phone number: (09) 276 0279

You are invited to complete a survey about your participation in the Co-Design Programme 2016, facilitated by Lynne Maher at Ko Awatea (Counties Manukau Health). This survey has been sent to staff and consumers who were part of a co-design project team at all participating DHBs including: MidCentral DHB and Nelson Marlborough DHB.

This information sheet will help you decide if you would like to complete the survey by providing information about why we are doing the survey, the types of questions included in the survey and what happens with the information collected. Completing this survey or not is **your choice**. If you decide not to, you don't have to give a reason, and whether or not you participate in the survey won't affect your participation in the programme.

If there is anything you do not understand, or if you would like to ask any questions about the survey, please contact the Ko Awatea's Research Officer - Dominic.

KEY THINGS ABOUT THE SURVEY YOU SHOULD KNOW

The collection, analysis and reporting of this survey data is funded by the Health Quality & Safety Commission New Zealand (the Commission), and is being led by the Research and Evaluation Office at Ko Awatea, Counties Manukau Health.

The information received from this survey will be compiled into a report for the Commission, for the purposes of monitoring and improving outcomes and participant experiences of the Co-Design Programme.

Participation in this survey is anonymous, meaning that survey responses cannot be connected with the person providing them. Reporting or publications made will not include the names or other personal details of programme participants. Survey respondents will be identified as 'staff members' or 'consumers' only. However, for those readers who are familiar with the programme and project teams, there is some risk that they may be able to identify individuals or teams due to their thorough knowledge of experiences and perspectives presented in reporting. While it is important to understand that participation in the survey is optional, because survey responses are not connected to you, we would not be able to withdrawal your responses should you later decide you would prefer not to take part.

It is expected that it will take up to 10-15 minutes of your time to complete the survey. Highlighting both positive and negative aspects of your experience improves our reporting. Communicating what you did not enjoy or like can be hard, but this is great

way to improve the programme for others. Everyone is encouraged to be open and honest in discussing their experiences participating in the programme.

It is expected that a report of survey findings will be available in June 2016. A final version of the report will be publically accessible on the HQSC website. You may also request a copy through the survey questions (we ask at the end if you would like to receive a copy). De-identified data from the evaluation will be stored, on a password protected data base at Ko Awatea, for a period of up to three years.

CONTACT DETAILS FOR STAFF

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

Name: Dominic Madell
Title: Research Officer
Phone: (09) 276 0279
Email: Dominic.Madell@middlemore.co.nz

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

Name: Luis Villa
Title: Research and Evaluation Manager
Phone: (09) 250 2065
Email: Luis.Villa@middlemore.co.nz

Appendix C: Interview schedule

Proposed interview questions with team members, sponsors and consumers

1. Please share with me your experience participating in the co-design project:
 - a. What did your project focus on?
 - b. What did you aim to achieve?
 - c. How did you go about doing this?
2. What does 'co-design' mean to you?
 - a. Unprompted.
 - b. Clarify understanding.
 - c. In the context of health
 - d. Anything else?
3. Did anything about the project or method surprise you?
 - a. Participation.
 - b. Buy-in.
 - c. Process.
 - d. Outcomes.
4. What were key successes of your project or the co-design approach?
 - a. What was good/successful?
 - b. How did that make you feel?
 - c. Were these unique to the project context?
5. What were the main challenges you experienced while participating on this co-design project?
 - a. Identify challenges.
 - b. How were challenges resolved?
 - c. Were any unresolved?
 - d. How did they impact project outcomes?
6. Please share with me your impression of any impact being involved in this programme has had: for....
 - a. Team members
 - b. Other consumers
 - c. Other staff
 - d. DHB
 - e. Sustaining the co-design approach
7. What would you change about the approach you took?

Consumer specific questions

8. How were you involved as a member of the project team?
 - a. Did you feel you contributed?
 - b. What level of involvement were you happy and comfortable with?
9. Over the duration of the project, how involved did you stay?
 - a. What changes in your involvement may have occurred over time?
 - b. What enabled continued involvement?
 - c. What lead to becoming more uninvolved?
 - d. What could be done differently to maintain involvement?
10. How valued did you feel you were as a team member?
 - a. Your thoughts, perspectives and experiences
 - b. How was being valued expressed (or not expressed)?
 - c. How can consumers feel more valued?
11. What advice would you give to other consumers about working with health professionals to co-design?
12. What advice would you give to health professionals about working with consumers to co-design?

Team member specific questions

13. What are the key lessons you have learned from your involvement in co-design?
14. Would you approach re-design differently now?
 - a. How?
15. How do you go about maintaining this change in practice?
 - a. What are limitations to this?
16. How will you share information about your co-design project with others?
17. How will you share your learning of specific tools and methods with others?

Sponsor specific questions

18. What needs to happen for co-design to become a normal part of the way consumers and staff look at service delivery?
 - a. Resources
 - b. Culture
 - c. Buy-in
 - d. Leadership
 - e. Policy
19. How can we get people to understand what co-design is and how it works?

Appendix D: Information sheet for the Co-Design Programme interviews

Survey contact person: **Dominic Madell**

Email: Dominic.Madell@middlemore.co.nz

Contact phone number: (09) 276 0279

You are invited to participate in an interview about your participation in the Co-Design Programme 2016, facilitated by Lynne Maher at Ko Awatea (Counties Manukau Health). We are aiming to complete five interviews with programme participants, including health care professionals and consumers.

This information sheet will help you decide if you would like to participate in an interview by providing information about why we are doing the interviews, topics of conversation you can expect and what happens with the information collected. Deciding whether to take part in an interview is **your choice**. If you decide not to, you don't have to give a reason, and your decision won't affect your participation in the programme.

If there is anything you do not understand, or if you would like to ask any questions about the interview, please contact the Ko Awatea's Research Officer – Dominic Madell.

KEY THINGS ABOUT THE INTERVIEW PROCESS YOU SHOULD KNOW

The collection, analysis and reporting of interview findings is funded by the Health Quality & Safety Commission New Zealand (the Commission), and is being led by the Research and Evaluation Office at Ko Awatea, Counties Manukau Health.

The information shared during interviews will be compiled into a report (along with survey data that is also being collected) for the Commission. This report helps to monitor and improve outcomes and participant experiences of the Co-Design Programme.

The HQSC have identified preferred participants for an interview about their experience with the Co-Design Programme. This means HQSC staff will know who was interviewed. If this worries you or makes you feel less comfortable about sharing, please feel free to discuss this with the Interviewer – Dominic. Sharing what you did not enjoy, or what did not work, can be difficult in a small group of identifiable participants. Everyone is encouraged to be open and honest in discussing their experiences participating in the programme and make us aware of anything you are not comfortable being included in reporting.

Reporting or publications made will not include the names or other personal details of interview participants. Participants will be identified as 'staff members' or 'consumers' only. However, as there is only a small group of five people being interviewed, it is

likely that readers who are familiar with the programme and project teams will recognise individuals and/or teams.

If you do participate in an interview, you can withdraw your interview record only before they are incorporated into reporting with findings from other participants. Please contact us within three business days of your interview if you would like to withdraw.

It is expected that it will take between 30 minutes and up to one hour of your time to participate in an interview. A report of survey and interview findings will be available in June 2016. The report will be made publically accessible on the HQSC website at this time. De-identified data from the evaluation will be stored, on a password protected data base at Ko Awatea, for a period of up to three years.

CONTACT DETAILS FOR STAFF

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

Name: Dominic Madell
Title: Evaluation Officer
Phone: (09) 250 8279
Email: Dominic.Madell@middlemore.co.nz

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

Name: Luis Villa
Title: Research and Evaluation Manager
Phone: (09) 250 2065
Email: Luis.Villa@middlemore.co.nz