HEALTH QUALITY & SAFETY
COMMISSION NEW ZEALAND
Kupu Taurangi Hauora o Aotearoa

Ngā Poutama survey for consumers of mental health and addiction services, their families and whānau

National report

July 2020

Document purpose

This is a national report for the Ngā Poutama survey for consumers of mental health and addiction (MHA) services, their families and whānau.

The survey was conducted by the Health Quality & Safety Commission, as part of the MHA quality improvement programme, between September and November 2019.

Mobius Ltd was contracted to deliver the cognitive testing and fieldwork components of the survey.

This report was written by the Health Quality & Safety Commission.

For more information, please go to: www.hqsc.govt.nz/MHA-consumer-survey

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Available online at www.hqsc.govt.nz

Enquiries to: MentalHealthAddiction@hqsc.govt.nz

Acknowledgements

Thank you to the consumers, families and whānau who participated in this survey, and to all the district health board staff who supported the fieldwork.

Executive summary

This is the national report for the Ngā Poutama survey for consumers of mental health and addiction (MHA) services, their families and whānau. This survey was conducted for the Health Quality & Safety Commission's (the Commission's) national MHA quality improvement programme.

When consumers have positive experiences engaging with health services, they are more likely to have better recovery outcomes.[1] A positive experience is also an important end in itself. This survey focuses on the experience of consumers, families and whānau using MHA services. Survey questions include topics such as being treated with respect, listened to and being actively involved in care plans.

A total of 267 people took part in the Ngā Poutama survey for consumers of MHA services, their families and whānau. The estimated consumer response rate was 3.3 percent. There has been feedback on the survey's final sample size, which was smaller than expected, and on shortcomings in its planning and methodology. We acknowledge that the survey process could have been better. In particular, during survey planning, we did not engage with DHB MHA leaders thoroughly enough or early enough to ensure the survey met their needs and that delivery requirements would fit alongside existing demands on services. In addition, the sampling and collection methodology had not previously been used in an MHA environment. Although these methods are used in the Commission's other, well-established patient experience surveys[2], the adaptations required for the MHA context had greater ramifications than initially appreciated. The adapted methods were not able to be tested sufficiently within the survey timeframe. These issues meant that many DHB staff struggled to support Ngā Poutama despite their best endeavours.

The Commission is an improvement organisation and we have learned from this experience. After the survey period ended, we held debrief sessions with leaders from DHB MHA services in order to understand their specific challenges and their ideas to improve future versions of the survey. Appendix 2 of this report details lessons learned in these discussions, and recommendations to improve future survey iterations, including a longer lead-in period, greater engagement with sector leadership and more support for DHBs to embed survey processes. We will work collaboratively with DHBs to improve the survey methodology and uptake in future iterations of the survey.

Despite the limitations of the survey, the results at the national level can inform change. The findings align closely with comparable international survey results with larger sample sizes, and the 267 voices of those who took part contain important messages for everyone in the MHA sector. Interesting and relevant key findings include:

- The two questions with the highest percentage of positive responses were about being treated with respect and staff explaining things in a way that was easy to understand (both 59 percent).
- The questions with the lowest percentage of positive responses related to cultural and spiritual needs, such as, where appropriate, use of te reo Māori by staff (14 percent) and access to traditional Māori healing practices (15 percent). Other low-rating responses related to access to peer-support staff (24 percent) and staff communicating well with one another (37 percent).
- About one-third of people who took part in the survey felt they, or their family or whānau member, experienced harm while using services. The most common type of harm reported was

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[1] Wong EC, Collins RL, Breslau J, et al. 2019. Associations between provider communication and personal recovery outcomes. *BMC Psychiatry* 19(102). URL: https://bmcpsychiatry.biomedcentral.com/articles/10.1186/s12888-019-2084-9.

[2]

emotional or psychological harm. People who reported harm had a lower percentage of positive responses across most experience questions. These differences were statistically significant.

When comparing the experience of service between different groups of people, some statistically significant differences were found.

- People were more positive about their experience of community-based MHA services across many questions, compared with those who had used inpatient services.
- Across many experience questions, older people reported a more positive experience compared with younger consumers.
- People under compulsory treatment were less likely than those under voluntary treatment to agree that they felt warmly welcomed into the service and were able to have a support person during sessions with staff.

The important next step for the MHA sector is to translate these survey results into real service improvements for consumers, families and whānau.

The Commission is here to inform, help and support MHA service providers. We will continue to work with the sector on how to include more voices in future surveys. In the meantime, we encourage providers to use the national results in their quality improvement of MHA services.

Contents

Introduction

Survey objectives

The Ngā Poutama consumer, family and whānau survey generates feedback that can be used to monitor and improve the quality and safety of mental health and addiction (MHA) services.

This is a new national survey conducted as part of the Health Quality & Safety Commission's (the Commission's) national MHA quality improvement programme.

The objectives of the survey are to:

- use consumer, family and whānau experiences to help providers improve the quality of MHA services
- complement the findings of the Ngā Poutama staff survey,[3] conducted in August 2018, which focused on the quality and safety culture of MHA services. Together, the surveys allow for comparisons of staff and consumer perspectives to some extent
- monitor improvements in consumer, family and whānau experience. The 2019 survey was intended to serve as the baseline, to make comparisons against when the survey is repeated. However, given the low uptake, this survey serves as a snapshot and is unlikely to be comparable to any future survey with modified methodology.

Methodology

This survey was for:

- consumers who used district health board (DHB) MHA services in Aotearoa New Zealand (either inpatient or community services), who were discharged or transitioned between 1 September and 15 October 2019
- their families and whānau (including chosen support people, who may not be biologically related).

All eligible consumers[4] received a survey invitation from the contracted survey provider either by email, SMS text or by post.

The final sample size was 267 people. This included 228 consumers and 39 family and whānau members. A total of 6,977 consumers were invited to participate. This means the estimated consumer response rate was 3.3 percent.[5] The final sample size and response rate were considerably lower than expected. The Commission sought feedback from DHB MHA leaders on the methodology and other survey processes. Recommendations for future surveys include a review of the methodology, a longer lead-in period, greater engagement with sector leadership and more support for DHBs to embed survey processes. All feedback, lessons learned and recommendations are summarised in Appendix 2.

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[3] www.hqsc.govt.nz/our-programmes/mental-health-and-addiction-quality-improvement/projects/quality-in-context

[4] All eligible consumers with valid recorded contact details.

[5] This response rate is an estimate only, and likely to be an underestimate because many contact details (emails, mobile numbers and addresses) are likely to have been invalid or out of date. The response rate is calculated by the number of emails and SMS texts sent (minus 10 percent due to immediate bounce-backs) and the number of letters posted.

The demographic profile of the sample profile does not fully reflect the broader population profile of all MHA consumers and whānau. For example, the sample over-represented females and under-represented Māori respondents. This limits how the sample can be generalised to the experience of the broader population. Please keep this in mind when interpreting survey results.

For a full description of the methodology, see the separate technical report. The survey questionnaires are also available. For both, see Other resources available.

Experience of service

In the following sections we summarise the survey results at the national level.

Appendix 1 includes detailed data tables. Individual DHB results (sample size permitting) are also available online (see Other resources available).

Question reporting

Scale reporting

Respondents rated the experience questions against a 1–7 Likert agreement scale. Two scales were used (ranging from 'Strongly disagree' to 'Strongly agree'; or from 'Never' to 'Always').

A score of 6–7 on the Likert scale was coded as a positive response.

Results in this report reflect the percentage of positive responses for each question, unless otherwise specified. 'Not applicable' responses were excluded from the percentage denominator.[6]

Survey question reporting

There were two sets of survey questions, one for consumers and the other for family and whānau members. Most survey questions contained the same concept, tailored for the respondent. For example, consumers were asked, 'My care and support met my individual needs', whereas family and whānau members were asked, 'My whānau member's care and support met their individual needs'.

There were five experience questions asked only of consumers, and two experience questions asked only of family and whānau members.[7] All demographic questions were the same, except only consumers were asked to report their age group.

Results in this report combine the respondents for both consumers and family and whānau members, unless otherwise specified.

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[6] Respondents who also did not answer the question have been excluded from the percentage denominator. Appendix 1 includes a table to show the percentage of positive, neutral, negative, don't know and not applicable responses for each experience question.

[7] In the family and whānau question set, some questions were asked about their experience and other questions about their view on the consumer experience. For example, 'I was treated with respect' asked whether they, as a family or whānau member, felt treated with respect. Another example was their view on the consumer's experience, eg, 'My whānau member's care and support met their individual needs'. See specific questions in the questionnaires under Other resources available for detail.

Overall results

Figures 1 and 2 show the national results by question in order of level of agreement.

Experience questions with higher levels of agreement (where people were more likely to give a positive response) included the following.

- Staff explained things in a way that was easy to understand (59 percent rated positively).
- Treated with respect (59 percent).
- Able to have support person during sessions with staff (53 percent).
- Whānau included, as appropriate, throughout journey (52 percent).
- Cultural needs respected (50 percent).

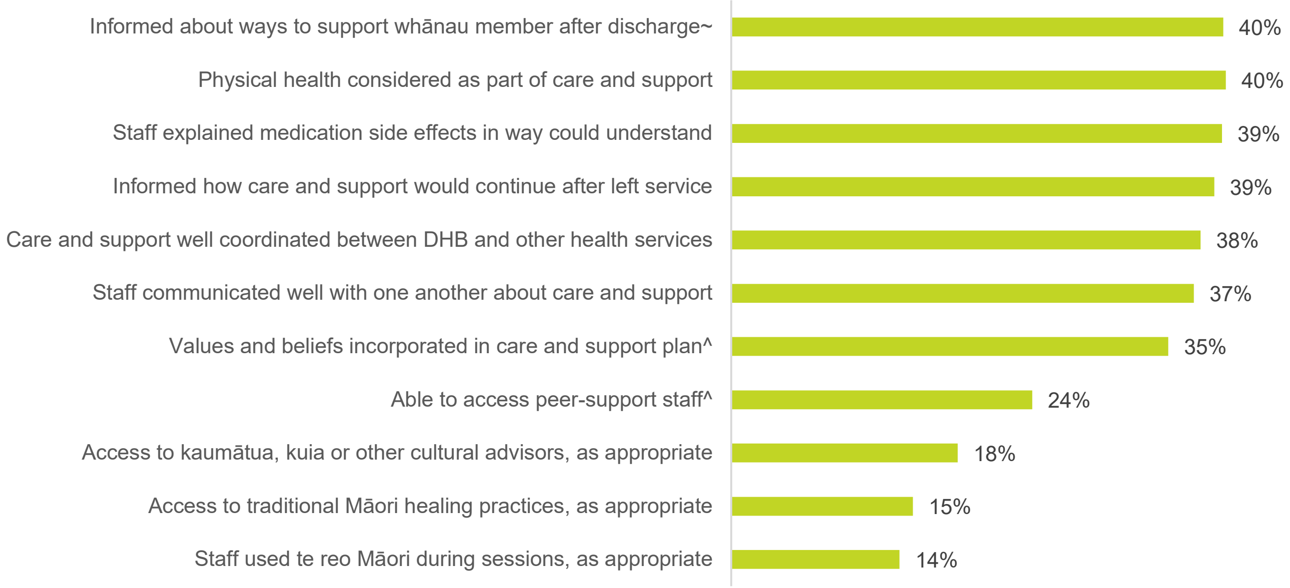
Experience questions with lower levels of agreement (where people were less likely to give a positive response) included the following.

- Staff used te reo Māori during sessions, as appropriate (14 percent rated positively).
- Access to traditional Māori healing practices, as appropriate (15 percent).
- Access to kaumātua, kuia or other cultural advisors, as appropriate (18 percent).
- Able to access peer-support staff (24 percent).
- Values and beliefs incorporated in care and support plan (35 percent).

Figure 1: National results (above 40 percent agreement)

^ Questions only answered by consumers, not by family and whānau members.
~ Questions only answered by family and whānau members, not by consumers.

Figure 2: National results (under 40 percent agreement)



^ Questions only answered by consumers, not by family and whānau members.
~ Questions only answered by family and whānau members, not by consumers.

Experience of harm

The survey included a subsection about the experience of harm.

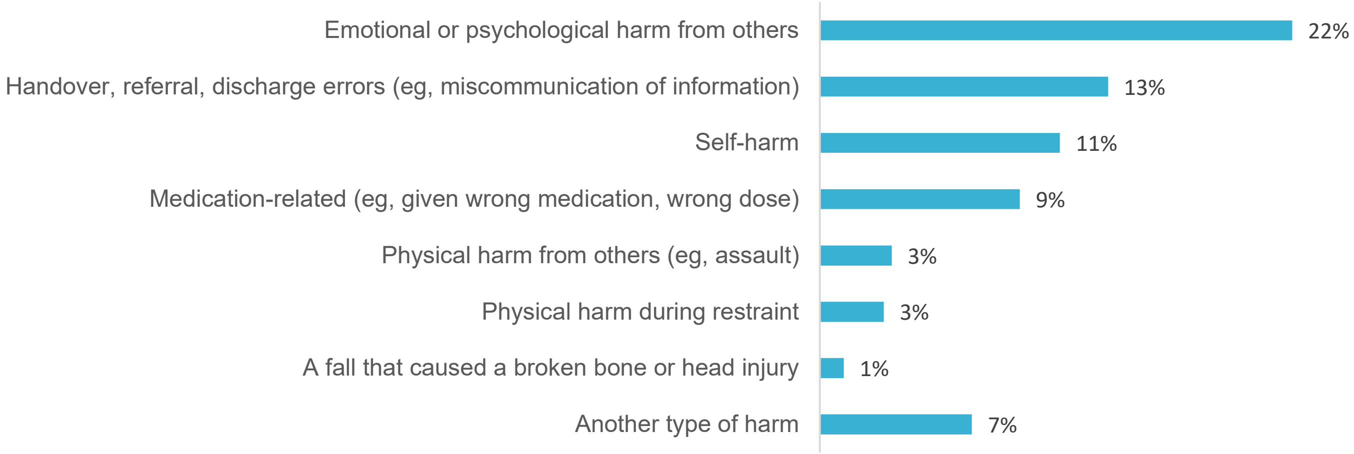
Overall, 33 percent of respondents felt that they, or their family or whānau member, experienced harm while using services. This question used a ‘Yes’ or ‘No’ response option rather than the Likert response scale.

Respondents who reported they experienced harm were asked to indicate the type/s of harm by selecting from the options shown in Figure 3. The most common type of harm was ‘emotional or psychological harm from others’ (22 percent of all respondents), followed by ‘handover, referral, discharge errors (eg, miscommunication of information)’ (13 percent) and then ‘self-harm’ (11 percent).

The definition of ‘harm’ was left open in these questions; respondents could answer based on any aspect of their experience that they considered harmful. The questions did not ask respondents to say whether the harm could have been avoided, nor to provide additional details about the impact, severity or duration of harm experienced. In interpreting these results, please note the potential for variation between respondents.

Note also that these questions are a measure of experiences of harm, as distinct from measures of harm as an outcome (eg, reportable events/incidents, lost disability-adjusted life years, surgical site infections). The two should not be conflated or directly compared.

Figure 3: Type of harm experienced

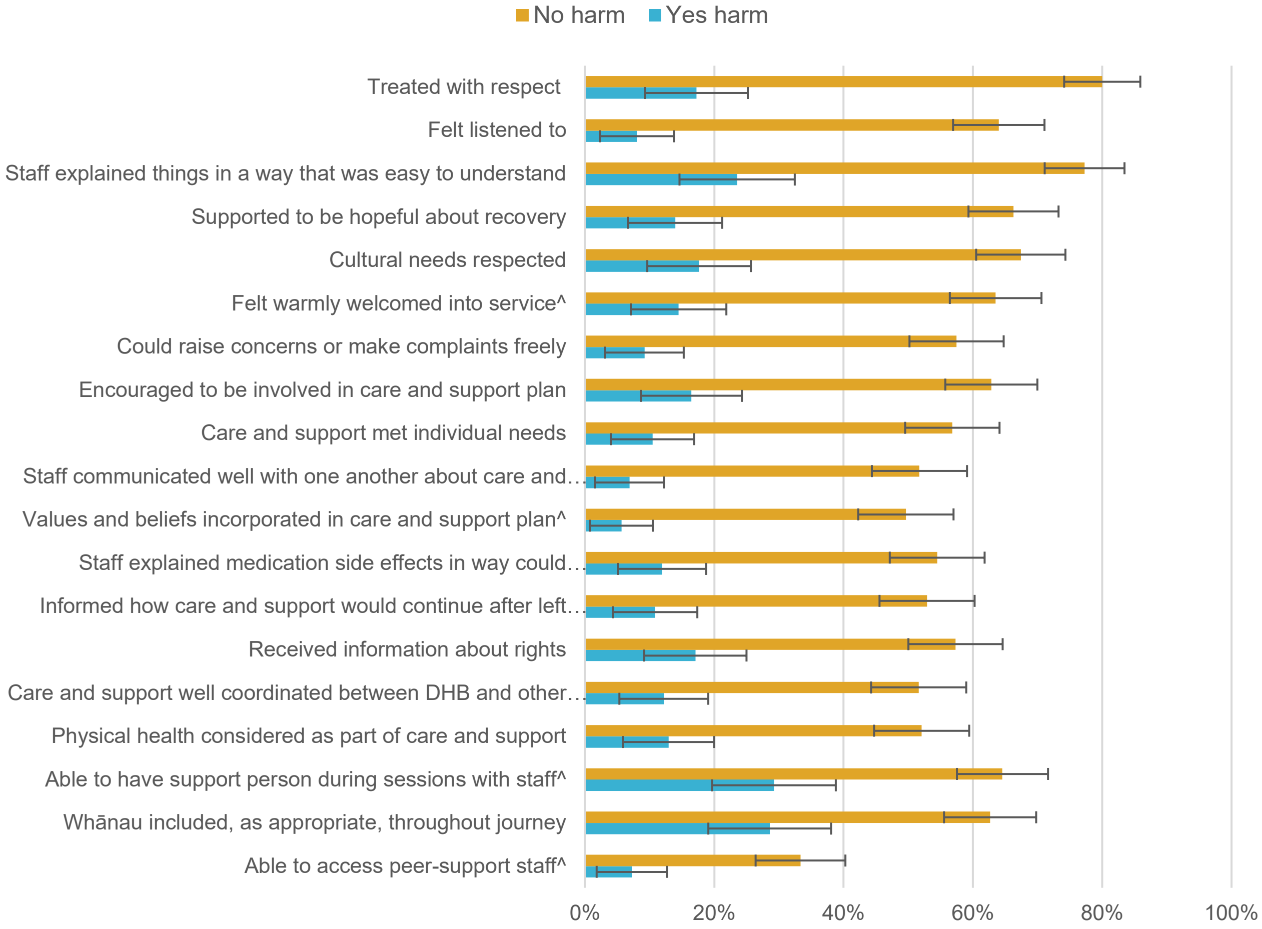


The options shown in Figure 3 were a multiple selection list where respondents could select as many types of harm as were applicable. Of people who reported experiencing harm, 40 percent selected one harm category, 27 percent selected two harm categories and 33 percent selected three or more harm categories.

There were many statistically significant differences between respondents who self-reported harm compared with those who self-reported no harm across nearly all experience questions. For example, 17 percent of people who self-reported harm said they were treated with respect, compared with 80 percent for people who self-reported no harm.

Comparisons of experience by self-reported harm are shown in Figure 4.

Figure 4: Experience responses by whether self-reported experiencing harm



^ Questions only answered by consumers not by family and whānau members.
Errors bars show the 95 percent confidence interval.

People receiving compulsory treatment under the Mental Health (Compulsory Assessment and Treatment) Act 1992 (the Mental Health Act) self-reported a slightly higher experience of harm (40 percent) than consumers receiving voluntary treatment (31 percent), however this difference is not statistically significant.

Service type – community and inpatient

Respondents were asked whether they had been using DHB community or inpatient services. The following questions had a higher percentage of positive responses from people using DHB community services than from people using inpatient services. The differences were statistically significant.

- Physical health considered as part of care and support (44 percent rated positive for community services compared with 31 percent for inpatient).
- Able to have support person during sessions with staff (63 percent rated positive for community services compared with 35 percent for inpatient).
- Felt warmly welcomed into service (53 percent rated positive for community services compared with 36 percent for inpatient).
- Access to traditional Māori healing practices, as appropriate (23 percent rated positive for community services compared with 0 percent for inpatient).
- Treated with respect (65 percent rated positive for community compared with 49 percent for inpatient).
- Staff explained things in a way that was easy to understand (64 percent rated positive for community compared with 51 percent for inpatient).

Service area – mental health and addiction

People who had used addiction services were **more likely** to agree they felt warmly welcomed into the service than those who had used mental health and all other service types combined ('mental health combined') (67 percent for addiction services compared with 44 percent for mental health combined services).[8]

This was the only experience question with a statistically significant difference in responses from people using addiction services compared with those using mental health combined services.

Mental Health Act – voluntary and compulsory treatment

Respondents were asked whether they or their family or whānau member had been receiving compulsory treatement under the Mental Health Act. For the following two questions, people were **less likely** to give a positive response if the treatment had been compulsory rather than voluntary.

- Able to have a support person during sessions with staff (30 percent rated positive for compulsory treatment compared with 53 percent for voluntary).
- Felt warmly welcomed into service (30 percent rated positive for compulsory treatment compared with 52 percent for voluntary).

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[8] Sample sizes were too small to allow us to report separate results from forensic, child and youth, and older persons services. For this analysis, results from people using these services were combined with results from people who selected 'mental health' as their service area.

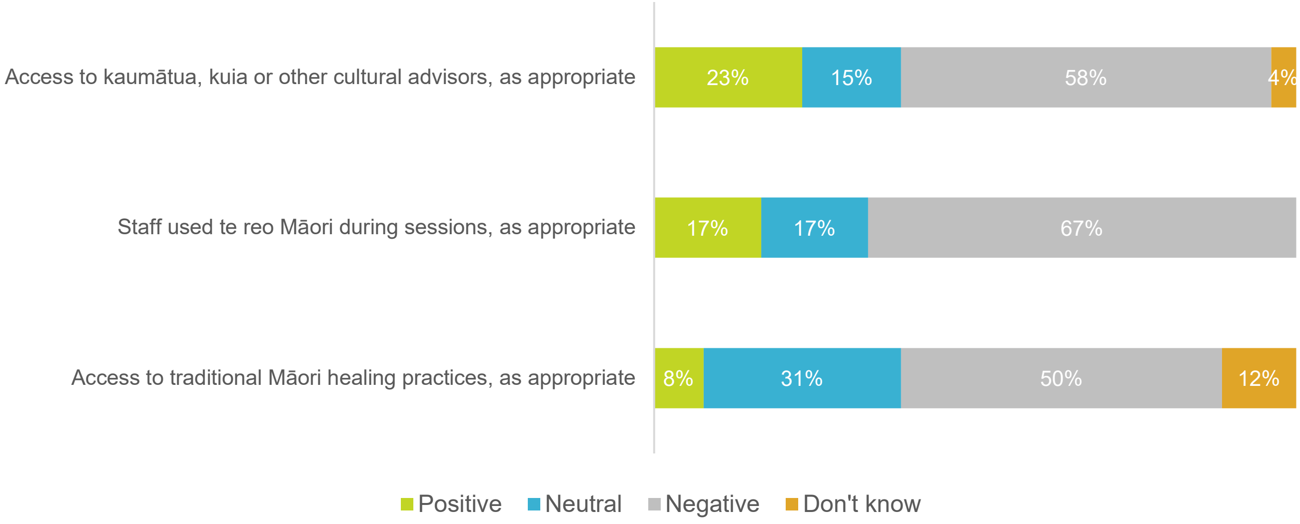
Ethnicity

Māori were **less likely** to give a positive response that they were able to have a support person during sessions with staff (35 percent for Māori compared with 55 percent for non-Māori). This was the only experience question with statistically significant differences between Māori and non-Māori.

The survey included three questions about the cultural competence of the service, with regard to te reo and tikanga Māori.

Figure 5 shows how Māori respondents answered these three questions. This shows, for example, 67 percent of Māori respondents answered negatively that staff used te reo Māori during sessions, as appropriate.

Figure 5: Cultural competency questions for Māori respondents[9]



The sample size was not large enough for us to report separate results for kaupapa Māori services and other services.

Gender

Males were **more likely** than females to give a positive response to the following questions.

- Could raise concerns or make complaints freely (51 percent for males, 38 percent for females).
- Felt warmly welcomed into service (58 percent for males, 42 percent for females).
- Supported to be hopeful about recovery (60 percent for males, 42 percent for females).

The sample size was not large enough for us to report separate results from people of non-binary or other genders, nor to report results by trans status

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[9] For this analysis, responses to the seven-point Likert scale were converted to 1–3 = negative; 4–5 = neutral; and 6–7=positive.

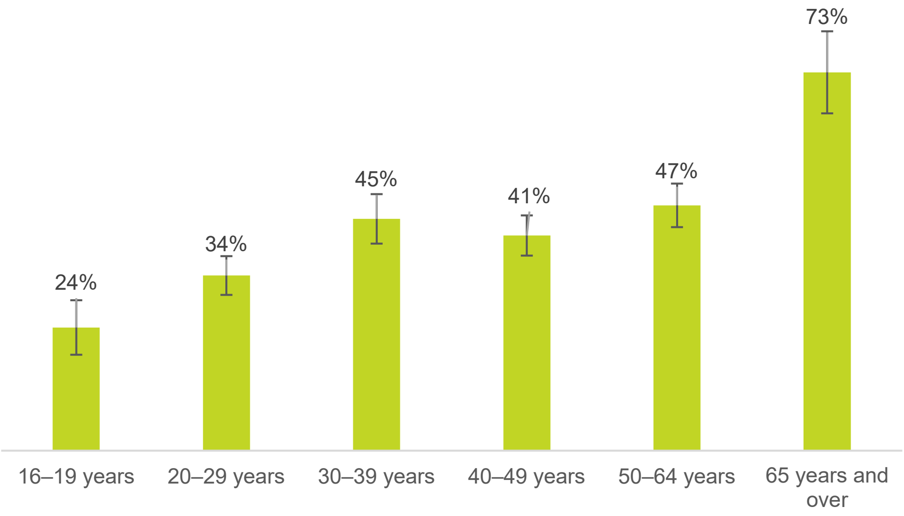
Age

Across many experience questions, younger people were **less likely** to give a positive response compared with older people, as the following examples show.

- Care and support met individual needs (22 percent of 16–29-year-olds rated this positively compared with 40 percent of 30–49-year-olds and 62 percent of people aged 50 years and over).
- Staff communicated well with one another about care and support (20 percent of 16–29-year-olds rated this positively compared with 36 percent of 30–49-year-olds and 51 percent of people aged 50 years and over).
- Felt could raise concerns or make complaints freely (23 percent of 16–29-year-olds rated this positively compared with 39 percent of 30–49-year-olds and 56 percent of people aged 50 years and over).
- Felt listened to (25 percent of 16–29-year-olds rated this positively compared with 42 percent of 30–49-year-olds and 67 percent of people aged 50 years and over).

Figure 7 shows the average percentage of positive responses across 19[10] experience questions for consumer respondents by age group. Note that only consumers were asked their age group, so these results do not include family and whānau responses.

Figure 7: Average percentage of positive scores across most experience questions by consumer age group



Errors bars show the 95 percent confidence interval.

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[10] Three of the 22 consumer experience questions were excluded from analysis because they had a low sample size for some age groups (< 5 denominator). The questions excluded were: access to traditional Māori healing, use of te reo Māori and access to kaumātua, kuia or other cultural advisors.

Consumer, and family and whānau

There were no statistically significant differences between consumer responses and family and whānau responses. This is partly due to the low sample size for family and whānau, which reduces the ability to detect statistically significant differences.

The following two questions in the survey were asked only of family and whānau respondents.

- Told about the support available for whānau (42 percent of family and whānau members gave a positive response).
- Given information on how to support whānau after discharge (39 percent of family and whānau members gave a positive response).

Length of time using services

There were no statistically significant differences when comparing experience responses by length of time using services.

Action and change

This survey is about consumers, family and whānau sharing their experience of service, so this experience can inform quality improvements. Hence the important next step for the MHA sector is to translate the survey results into real service improvements for consumers, families and whānau. The Commission is here to inform, help and support MHA service providers.

This report includes important messages for everyone in the MHA sector. There are some positive findings and areas for improvement.

Despite the low sample size, the survey results at the national level can inform change. The findings align closely with international survey results with larger sample sizes. For example, the New South Wales 'Your Experience of Service (YES)' survey[11] found that being treated with respect was a higher-scoring question, and access to peer support was a lower-scoring question. The YES survey also found similar differences of experience between groups of people; for example, people treated in hospital settings reported less positive experiences compared with those treated in community services. The YES survey also found older people reported a more positive experience than younger people, and people with involuntary legal status reported a less positive experience than voluntary consumers.

We will continue to work with the sector on how to include more voices in future surveys. In the meantime, we encourage providers to use the national results in their quality improvement of MHA services.

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[11] NSW Ministry of Health. 2017. *Your Experience of Service: 2016–2017*. Sydney: NSW Ministry of Health. URL: www.health.nsw.gov.au/mentalhealth/Documents/yes-survey-report-2016-2017.pdf.

Other resources available

Other resources containing results from the Ngā Poutama survey for consumers of MHA services, their families and whānau are available at: www.hqsc.govt.nz/MHA-consumer-survey.

The stage one results include:

- a summary of key findings
- a technical report
- individual DHB reports (sample size permitting)
- survey questionnaires for consumers, families and whānau.

Stage two results will contain further results such as qualitative analysis from the open-ended questions and comparisons of results between the Ngā Poutama staff survey and the Ngā Poutama consumer, family and whānau survey.

For information not contained in the above resources, please contact the Commission MHA team at: MentalHealthAddiction@hqsc.govt.nz.

Appendix 1: Data tables

All survey results in the following data tables are given as percentage positives (scores of 6–7 on the Likert scale).

An asterisk (*) next to a percentage in a table indicates the score represents a statistically significant difference – either to the percentage of the group in the column alongside or the national results, as noted below the relevant figures.

This is a survey, so all percentages are subject to sampling error. The margins of error for the survey results are: national results +/– 6.0 percent.

To calculate the margin of error for the other categories based on their sample size (*n*) and proportion ($\hat{p}$), the following formula can be used:

$$\sqrt{\frac{\hat{p} \times (1 - \hat{p})}{n}} \times 1.96$$

Experience of harm

Table 1: Percentages of positive responses by harm

	Yes experienced harm	No experienced harm
	n = 87	n = 177
Self-determination		
Care and support met individual needs	10*	57*
Encouraged to be involved in care and support plan	16*	63*
Supported to be hopeful about recovery	14*	66*
Respect		
Treated with respect	17*	80*
Communication		
Felt listened to	8*	64*
Staff explained things in a way that was easy to understand	24*	77*
Cultural and spiritual needs		
Cultural needs respected	18*	67*
Values and beliefs incorporated in care and support plan^	6*	50*
Felt warmly welcomed into service^	14*	64*
Access to traditional Māori healing practices, as appropriate	5	21
Staff used te reo Māori during sessions, as appropriate	7	19
Access to kaumātua, kuia or other cultural advisors, as appropriate	11	25
Involvement of family, whānau and support networks		
Whānau included, as appropriate, throughout journey	29*	63*
Able to have support person during sessions with staff^	29*	65*
Able to access peer-support staff^	7*	33*
Coordination and continuity		
Staff communicated well with one another about care and support	7*	52*
Informed how care and support would continue after left service	11*	53*
Care and support well coordinated between DHB and other health services	12*	52*
Physical needs and human rights		
Received information about rights	17*	57*
Physical health considered as part of care and support	13*	52*
Safety		
Could raise concerns or make complaints freely	9*	57*
Staff explained medication side effects in way could understand^	12*	54*

* Statistically significant difference between the two categories.
^ Questions only answered by consumers not by family and whānau members.

Service type – inpatient and community

Table 2: Percentages of positive responses by service type

	Community	Inpatient
	n = 174	n = 93
Self-determination		
Care and support met individual needs	45	35
Encouraged to be involved in care and support plan	51	43
Supported to be hopeful about recovery	52	44
Respect		
Treated with respect	65*	49*
Communication		
Felt listened to	49	40
Staff explained things in a way that was easy to understand	64*	51*
Cultural and spiritual needs		
Cultural needs respected	52	48
Values and beliefs incorporated in care and support plan^	38	30
Felt warmly welcomed into service^	53*	36*
Access to traditional Māori healing practices, as appropriate	23*	0*
Staff used te reo Māori during sessions, as appropriate	18	7
Access to kaumātua, kuia or other cultural advisors, as appropriate	24	7
Involvement of family, whānau and support networks		
Whānau included, as appropriate, throughout journey	48	57
Able to have support person during sessions with staff^	63*	35*
Able to access peer-support staff^	26	22
Coordination and continuity		
Staff communicated well with one another about care and support	39	34
Informed how care and support would continue after left service	42	32
Care and support well coordinated between DHB and other health services	42	30
Physical needs and human rights		
Received information about rights	46	40
Physical health considered as part of care and support	44*	31*
Safety		
Could raise concerns or make complaints freely	45	35
Staff explained medication side effects in way could understand^	43	34

* Statistically significant difference between the two categories.
^ Questions only answered by consumers not by family and whānau members.

Service area – mental health and addiction

Table 3: Percentages of positive responses by service area

	Mental health[ǂ]	Addiction
	n = 219	n = 23
Self-determination		
Care and support met individual needs	39	52
Encouraged to be involved in care and support plan	46	65
Supported to be hopeful about recovery	45	65
Respect		
Treated with respect	56	65
Communication		
Felt listened to	42	61
Staff explained things in a way that was easy to understand	58	61
Cultural and spiritual needs		
Cultural needs respected	49	50
Values and beliefs incorporated in care and support plan^	33	33
Felt warmly welcomed into service^	44*	67*
Access to traditional Māori healing practices, as appropriate	10	-
Staff used te reo Māori during sessions, as appropriate	13	-
Access to kaumātua, kuia or other cultural advisors, as appropriate	18	-
Involvement of family, whānau and support networks		
Whānau included, as appropriate, throughout journey	51	47
Able to have support person during sessions with staff^	50	63
Able to access peer-support staff^	22	30
Coordination and continuity		
Staff communicated well with one another about care and support	35	35
Informed how care and support would continue after left service	37	41
Care and support well coordinated between DHB and other health services	36	42
Physical needs and human rights		
Received information about rights	43	43
Physical health considered as part of care and support	39	50
Safety		
Could raise concerns or make complaints freely	40	48
Staff explained medication side effects in way could understand^	36	40

* Statistically significant difference between the two categories.
^ Questions only answered by consumers not by family and whānau.
ǂ Includes mental health, forensic, child and youth, and older persons services.
\- Unable to be reported as denominator due to < 5 responses.

Mental Health Act – voluntary and compulsory treatment

Table 4: Percentages of positive responses by Mental Health Act

	Voluntary	Compulsory
	n = 161	n = 60
Self-determination		
Care and support met individual needs	43	33
Encouraged to be involved in care and support plan	50	44
Supported to be hopeful about recovery	49	43
Respect		
Treated with respect	59	50
Communication		
Felt listened to	46	40
Staff explained things in a way that was easy to understand	61	52
Cultural and spiritual needs		
Cultural needs respected	50	44
Values and beliefs incorporated in care and support plan^	36	28
Felt warmly welcomed into service^	52*	30*
Access to traditional Māori healing practices, as appropriate	11	20
Staff used te reo Māori during sessions, as appropriate	18	8
Access to kaumātua, kuia or other cultural advisors, as appropriate	21	23
Involvement of family, whānau and support networks		
Whānau included, as appropriate, throughout journey	51	46
Able to have support person during sessions with staff^	53*	30*
Able to access peer-support staff^	26	15
Coordination and continuity		
Staff communicated well with one another about care and support	38	35
Informed how care and support would continue after left service	41	32
Care and support well coordinated between DHB and other health services	36	43
Physical needs and human rights		
Received information about rights	46	36
Physical health considered as part of care and support	44	32
Safety		
Could raise concerns or make complaints freely	44	37
Staff explained medication side effects in way could understand^	41	27

* Statistically significant difference between the two categories.
^ Questions only answered by consumers not by family and whānau members.

Ethnicity

Table 5: Percentages of positive responses by ethnicity

	Māori	**Non-Māori**
	n = 37	**n = 210**
Self-determination		
Care and support met individual needs	35	44
Encouraged to be involved in care and support plan	43	51
Supported to be hopeful about recovery	43	50
Respect		
Treated with respect	54	60
Communication		
Felt listened to	35	48
Staff explained things in a way that was easy to understand	51	61
Cultural and spiritual needs		
Cultural needs respected	44	52
Values and beliefs incorporated in care and support plan^	31	36
Felt warmly welcomed into service^	41	49
Access to traditional Māori healing practices, as appropriate	8	24
Staff used te reo Māori during sessions, as appropriate	17	10
Access to kaumātua, kuia or other cultural advisors, as appropriate	23	15
Involvement of family, whānau and support networks		
Whānau included, as appropriate, throughout journey	42	54
Able to have support person during sessions with staff^	35*	55*
Able to access peer-support staff^	19	25
Coordination and continuity		
Staff communicated well with one another about care and support	33	39
Informed how care and support would continue after left service	38	40
Care and support well coordinated between DHB and other health services	35	40
Physical needs and human rights		
Received information about rights	44	45
Physical health considered as part of care and support	41	41
Safety		
Could raise concerns or make complaints freely	32	44
Staff explained medication side effects in way could understand^	32	40

* Statistically significant difference between the two categories.
^ Questions only answered by consumers not by family and whānau members.

Gender

Table 6: Percentages of positive responses by gender

	Female	Male
	n = 175	n = 74
Self-determination		
Care and support met individual needs	39	47
Encouraged to be involved in care and support plan	44	57
Supported to be hopeful about recovery	42*	60*
Respect		
Treated with respect	56	64
Communication		
Felt listened to	43	50
Staff explained things in a way that was easy to understand	59	58
Cultural and spiritual needs		
Cultural needs respected	48	56
Values and beliefs incorporated in care and support plan^	33	38
Felt warmly welcomed into service^	42*	58*
Access to traditional Māori healing practices, as appropriate	14	7
Staff used te reo Māori during sessions, as appropriate	14	10
Access to kaumātua, kuia or other cultural advisors, as appropriate	21	18
Involvement of family, whānau and support networks		
Whānau included, as appropriate, throughout journey	50	54
Able to have support person during sessions with staff^	50	54
Able to access peer-support staff^	21	29
Coordination and continuity		
Staff communicated well with one another about care and support	36	37
Informed how care and support would continue after left service	37	41
Care and support well coordinated between DHB and other health services	39	38
Physical needs and human rights		
Received information about rights	41	50
Physical health considered as part of care and support	39	45
Safety		
Could raise concerns or make complaints freely	38*	51*
Staff explained medication side effects in way could understand^	36	44

* Statistically significant difference between the two categories.
^ Questions only answered by consumers not by family and whānau members.
Sample size does not allow for separate reporting of results for non-binary genders and trans status.

Age

Table 7: Percentages of positive consumer[ł] responses by age group (95% CI upper bound, lower bound)

	16–29	30–49	50+	National*
	n = 67	n = 77	n = 73	n = 267
Self-determination				
Care and support met individual needs	22 (12, 32)	40 (29, 51)	62 (50, 73)	42 (36, 47)
Encouraged to be involved in care and support plan	30 (19, 41)	49 (37, 60)	61 (49, 72)	48 (42, 54)
Supported to be hopeful about recovery	32 (21, 44)	44 (33, 55)	67 (56, 78)	49 (43, 55)
Respect				
Treated with respect	46 (34, 58)	52 (41, 63)	77 (67, 86)	59 (53, 65)
Communication				
Felt listened to	25 (15, 36)	42 (31, 53)	67 (56, 78)	46 (40, 52)
Staff explained things in a way that was easy to understand	52 (40, 64)	56 (45, 67)	70 (59, 80)	59 (54, 65)
Cultural and spiritual needs				
Cultural needs respected	36 (23, 49)	52 (40, 64)	53 (39, 67)	50 (44, 57)
Values and beliefs incorporated in care and support plan^	21 (11, 31)	32 (22, 43)	48 (36, 61)	35 (29, 42)
Felt warmly welcomed into service^	33 (22, 45)	45 (34, 57)	60 (49, 71)	47 (41, 54)
Access to traditional Māori healing practices, as appropriate	8 (0, 24)	9 (0, 26)	0	15 (5, 25)
Staff used te reo Māori during sessions, as appropriate	8 (0, 24)	13 (0, 35)	0	14 (2, 25)
Access to kaumātua, kuia or other cultural advisors, as appropriate	31 (6, 56)	10 (0, 29)	0	18 (7, 30)
Involvement of family, whānau and support networks				
Whānau included, as appropriate, throughout journey	45 (32, 58)	53 (41, 65)	57 (45, 69)	52 (45, 58)
Able to have support person during with sessions with staff^	50 (37, 63)	50 (38, 62)	52 (40, 65)	53 (46, 60)
Able to access peer-support staff^	16 (6, 25)	21 (11, 30)	34 (23, 45)	24 (18, 30)
Coordination and continuity				
Staff communicated well with one another about care and support	20 (10, 29)	36 (26, 47)	51 (39, 62)	37 (31, 43)
Informed how care and support would continue after left service	24 (13, 34)	37 (26, 48)	47 (35, 58)	39 (33, 45)
Care and support well-coordinated between DHB and other health services	25 (14, 36)	39 (28, 50)	43 (30, 55)	38 (32, 44)
Physical needs and human rights				
Informed about rights in way could understand	32 (21, 44)	47 (36, 59)	49 (38, 61)	44 (38, 50)
Physical health considered as part of care and support	28 (17, 39)	43 (32, 55)	49 (37, 60)	40 (34, 46)
Safety				
Could raise concerns or make complaints freely	23 (13, 33)	39 (28, 50)	56 (45, 68)	42 (36, 48)
Staff explained medication side effects in way could understand^	31 (19, 44)	36 (25, 48)	45 (33, 58)	39 (32, 46)

[ł] Age group question only answered by consumers not by family and whānau members.

*National percentages include responses from consumers who did not give an age group.

Consumers, and family and whānau

Table 8: Percentages of positive responses by consumers, and family and whānau

	Consumers	**Family and whānau**
	n = 228	**n = 39**
Self-determination		
Care and support met individual needs	42	41
Encouraged to be involved in care and support plan	47	54
Supported to be hopeful about recovery	50	44
Respect		
Treated with respect	60	57
Communication		
Felt listened to	46	43
Staff explained things in a way that was easy to understand	61	53
Cultural and spiritual needs		
Cultural needs respected	48	63
Values and beliefs incorporated in care and support plan^	35	-
Felt warmly welcomed into service^	47	-
Access to traditional Māori healing practices, as appropriate	12	21
Staff used te reo Māori during sessions, as appropriate	11	22
Access to kaumātua, kuia or other cultural advisors, as appropriate	15	27
Involvement of family, whānau and support networks		
Whānau included, as appropriate, throughout journey	53	46
Able to have support person during sessions with staff^	53	-
Able to access peer-support staff^	24	-
Told about support available for whānau~	-	42
Coordination and continuity		
Staff communicated well with one another about care and support	36	41
Informed how care and support would continue after left service	38	44
Care and support well coordinated between DHB and other health services	36	47
Given information on how to support whānau after discharge~	-	39
Physical needs and human rights		
Received information about rights	44	44
Physical health considered as part of care and support	40	38
Safety		
Could raise concerns or make complaints freely	40	49
Staff explained medication side effects in way could understand^	39	-

^ Questions only answered by consumers not by family and whānau members.
~ Questions only answered by family and whānau members not by consumers
- Question not applicable

Experience responses

Table 9: Percentage of positive, neutral, negative, don’t know and not applicable responses

Note these percentages do not align with the other percentages in this report because for all other reporting, ‘not applicable’ responses were excluded from the percentage denominator.

	Positive	Neutral	Negative	Don’t know	Not applicable	Total
Self-determination						
Care and support met individual needs	41	18	39	1	1	100
Encouraged to be involved in care and support plan	47	18	32	1	1	100
Supported to be hopeful about recovery	48	22	27	0	2	100
Respect						
Treated with respect	59	26	14	0	1	100
Communication						
Felt listened to	45	25	28	0	1	100
Staff explained things in a way that was easy to understand	59	23	17	0	1	100
Cultural and spiritual needs						
Cultural needs respected	39	14	21	3	23	100
Values and beliefs incorporated in care and support plan^	32	24	32	4	7	100
Felt warmly welcomed into service^	47	21	29	2	0	100
Access to traditional Māori healing practices, as appropriate	3	3	7	4	82	100
Staff used te reo Māori during sessions, as appropriate	2	1	9	1	86	100
Access to kaumātua, kuia or other cultural advisors, as appropriate	3	2	9	3	84	100
Involvement of family, whānau and support networks						
Whānau included, as appropriate, throughout journey	46	21	22	0	11	100
Able to have support person during sessions with staff^	45	13	22	5	14	100
Able to access peer-support staff^	22	14	42	13	9	100
Told about support available for whānau~	41	10	46	0	3	100
Coordination and continuity						
Staff communicated well with one another about care and support	37	21	33	8	1	100
Informed how care and support would continue after left service	37	16	42	1	3	100
Care and support well coordinated between DHB and other health	34	14	39	3	10	100
Given information on how to support whānau after discharge~	38	5	54	0	3	100
Physical needs and human rights						
Received information about rights	42	18	31	4	4	100
Physical health considered as part of care and support	38	23	33	2	4	100
Safety						
Could raise concerns or make complaints freely	41	17	39	1	1	100
Staff explained medication side effects in way could understand^	33	16	35	0	15	100

^ Questions only answered by consumers not by family and whānau members.
~ Questions only answered by family and whānau members not by consumers

Appendix 2: Lessons learned and recommendations

Summary

The survey uptake was lower than expected. To understand and learn from this outcome, the Commission held debrief sessions with leaders from DHB MHA services.

This appendix summarises the challenges raised in these discussions, along with recommendations for the future. Individuals and DHBs are not named. We will work collaboratively with DHBs to improve the survey methodology and uptake in future iterations of the survey.

Recommendations

For the Commission:

- Review survey methodology, including:
  - who can take part: consider including consumers prior to discharge or transition
  - survey delivery mode and timing: consider using tablet devices onsite and/or other approaches to gather feedback such as hui with shared food
  - consider offering incentives to take part
  - assess ongoing collection of MHA consumer experience
  - revisit methods for family and whānau participation.
- Allow longer lead-in time for DHBs to implement survey processes
- Greater engagement with sector leadership, particularly early on in the development of survey methodology and processes.

For DHBs:

- Ensure IT functions and processes support collection of consumer email addresses.
- Encourage a focus on the collection of consumer email addresses, and verification of other contact details, leading up to and during survey periods.
- Align MHA privacy statements with DHB privacy statements to specify that consumer information may be used to monitor service quality.
- Align MHA policies with DHB policies on the sharing of consumer contact information for experience surveys.
- Use existing collections of consumer experience to inform quality improvement.

Post-survey debrief sessions

Overview

The Commission invited each DHB MHA general manager, clinical director and survey contact person to a survey debrief session. These sessions were conducted remotely (via videoconference) with the Commission's Ngā Poutama survey and programme managers. Twelve DHBs attended debrief sessions.

The purpose of the sessions was learning rather than judgement. The sessions included an open discussion on what worked, what did not work and the learnings for the next time the survey is repeated. We thank all those who took part in the debrief sessions for sharing constructive suggestions on what could be improved.

This appendix collates and synthesises the debrief findings.

Findings

All DHBs told us that processes had been put in place to support the survey. During the survey lead-up period, each DHB had identified and named a champion to promote the survey throughout their services. However, DHBs experienced numerous challenges, including difficulties in gaining staff and consumer support for the survey, local system and technical limitations, incompatibilities with existing DHB policies and processes, and in some cases ongoing review of policies surrounding information collection and use.

Staff capacity and behaviour

The survey methodology relied on MHA service staff to hand out the survey invitation flyer and encourage consumers to take part. However, there was considerable variation among staff in their willingness and ability to do this. Challenges included the following.

a. Awareness and support from staff to promote survey

This was a new national survey for MHA services, and teams told us that raising awareness and addressing concerns took time. Some staff were reluctant to ask consumers to take part in ‘yet another survey’.

Furthermore, some staff were not as engaged in service improvement, or were not clear on the survey processes and purpose. This contributed to survey processes not always being followed (eg, flyers were left on tables in waiting rooms rather than a direct conversation taking place between the staff member and consumers about the survey). Nearly all DHBs were unsure whether flyers were distributed to all consumers within the eligibility period.

b. Low capacity

Some DHBs spoke about how the survey was a low priority among the busy workloads of clinicians and other staff. ‘Staff feel stretched and this was just one more thing.’

Consumer attitudes and needs

Even among consumers who received an invitation, there was a lower than anticipated uptake of the survey. Challenges for consumers included the following.

c. Survey/consultation fatigue

Consumer advisors shared that consumers are a frequently consulted group. Many feel over-surveyed (‘surveys done to death’) and are sceptical about taking part. This challenge relates to consumer fatigue from other types of consultation such as local patient safety initiatives and the Government Inquiry into Mental Health and Addiction.

d. Perceived impact

Debrief participants noted that, historically, consumer feedback has not always been acted on and/or improvements not fed back to consumers. They said that if consumers can see tangible changes as a result of giving feedback then there will be greater participation next time.

e. Timing relative to service interaction

We were told by some consumer advisors that consumers do not want to be reminded of their episode of being unwell. Consumers who feel this way are unlikely to take part in a survey once they have left the service.

Technical

f. Lack of digital inclusion

DHB staff said that emailed invitations and the online survey delivery were inappropriate for a large proportion of consumers. Many do not have an internet-capable device, do not have an email address and/or do not have readily available internet access. The survey provider also sent survey invitations via post and text message, and consumers were offered the option of completing the survey on paper or over the phone. However, email invitations and online completion were prioritised due to higher expected response rates, lower cost and greater privacy.

Because this perception is widespread among staff, many staff were sceptical about the value of collecting consumers email addresses for the survey.

g. Email collection not routine

The DHBs who provided the most email addresses for survey invitations (> 40 percent of eligible participants) were those already using email for other purposes, such as appointment reminders. Some DHBs do not routinely collect or use consumer email addresses and had a much lower collection of emails – some DHBs had no emails collected. These DHBs told us that it takes a long time to embed change.

h. Email collection difficult within patient management systems

Some DHBs said the email field within their patient management system was a few layers in or separate to other systems used for clinical notes. Without email recording being easy, clinicians or administrative staff were unlikely to fill it in.

i. Contact details not regularly verified

For consumers with recorded email addresses and mobile numbers, there was an estimated 10 percent immediate bounce-backs from the survey invitations, and a further unknown number with out-of-date or incorrectly recorded details. Many DHBs do not audit or verify the accuracy of consumer contact details.

j. Data extract was expensive, or service was not resourced to extract data

One DHB said that, due to the outsourcing of IT support, they had to pay about $2,000 for the coded specifications of the data extract. Another said the business analyst team was going through a significant period of change and could not deliver the data extract as per requirements.

Policies

k. Privacy statements

Some DHB MHA services do not have privacy statements advising consumers how their personal information will be used. For services that do use privacy statements, not all statements specify that health information may be used to monitor quality (which includes experience surveys).

All DHB MHA services need to provide consumers with a privacy statement, including reference to the use of information for monitoring quality, in line with guidance from the Ministry of Health and Office of the Privacy Commissioner.

Processes

l. Complex processes

DHBs told us there was some confusion about the survey processes. DHB staff were asked to hand out flyers, collect email addresses and discuss the survey with consumers. We were told that asking multiple things from staff led to some confusion. For example, some staff were unclear on who was the right person to hand out flyer – administrative staff or clinical.

We also heard that the eligibility criteria (discharged or transitioned between 1 September and 15 October 2019 with some exclusions) was complex for staff to follow.

m. Relatively short lead-in time

Many teams felt that the lead-in time was too short. The first formal correspondence to DHBs took place in May 2019, with the survey starting in September 2019. Many DHBs felt this needed to be longer and that if there had been communication earlier in the year they could have put resources in place to support the survey.

For this reason, some DHBs were slow to implement survey processes. Others did not receive the flyers with enough time prior to the survey start date. We also heard that because many of the survey workstreams were happening in parallel, due to the tight timeframes (eg, finalising survey methodology in parallel to finalising the survey questions), it was difficult to promote the survey without staff having the final survey question set.

n. Flyers and posters

Some teams told us that the survey flyers and posters contained too much information, needed to be more accessible and could have had a clearer call to action.

Recommendations for the next survey

Commission

The following are recommendations for the Commission to consider, including a review of the survey methodology, having a longer lead-in time and engaging more with sector leadership.

1. **Review survey methodology**

   Before this survey is repeated, we recommend there is a thorough methodology review on how best to balance the privacy, cost and survey quality considerations, alongside maximising response rates. Different ideas raised by DHBs during the de-brief sessions include the following.

   a. Who can take part: consider including consumers prior to discharge or transition.

      In the rolling adult inpatient patient experience survey run by the Commission, people are invited to take part after leaving the service. This methodology proved particularly challenging for MHA staff and consumers in the Ngā Poutama survey.

      An alternative model is to let people take part before they have left the service. During the development of Ngā Poutama, this model was rejected because it could compromise the quality of the survey data, as well as the relationship between consumer and provider. There would not be enough time for the respondent to collect and compose their thoughts about what they have experienced. Further, there could be increased concerns among consumers about the anonymity of the survey. Consumers who feel their responses are not anonymous may believe that what they say could negatively affect the treatment they receive from the service. Consumers could then give unrealistically positive responses.

While this rationale holds, the response rate of the Ngā Poutama survey shows there was very little uptake in the experience survey once an MHA consumer had left the service. Anecdotally we heard from consumer advisors that once a consumer leaves the service, they want to move on with their recovery and are not that interested in taking part in a survey about prior service use. We also heard that the complicated criteria for participation made it hard for staff and consumers to understand who should take part.

Many teams support changing the survey to be about 'your journey so far'. Adding a question about whether the survey was completed at the time of discharge or during ongoing service use would allow us to separate the results. Other safeguards could be put in place for in-situ collection, such as consumer advisors or peer support workers helping to administer the survey, rather than clinicians.

b. Survey delivery mode and timing: consider using tablets within services

Many DHBs supported integrating the Ngā Poutama survey with Mārama Realtime Feedback (RTF). Mārama RTF is in use in most DHBs around the country. Teams saw Ngā Poutama and Mārama RTF as complementary, but distinct, ways of collecting consumer experience. However, we also heard comments such as, 'anything stand-alone doesn't work'.

One idea is that tablet delivery could automatically direct respondents into different surveys depending on their responses to a first question on whether they are being discharged or are still receiving services. Those being discharged would then be presented with the Ngā Poutama survey, while those still receiving services would be presented with Mārama RTF. The Ngā Poutama survey could then use a smaller question set rather than the full 22 questions, which people could fill in more quickly in-situ. Alternatively, the tablet could switch from Mārama RTF to Ngā Poutama questions at regular intervals (eg, a fortnight every quarter). This again would need to be supported by consumer advisors or peer support workers helping to administer the surveys (with associated resourcing implications), along with other recommendations to reduce any negative effects of integrating the surveys.

c. Survey delivery mode and timing: consider other approaches such as face-to-face hui

DHBs in the debriefs suggested an approach outside the traditional patient experience survey methodology. This could include morning teas or pizza evenings to bring people together to feed back their experience. Face-to-face approaches are more appropriate for Māori consumers and whānau.

Some DHBs suggested providing a paper questionnaire with a pre-paid return envelope at the time of discharge. Any repeat of the survey would need to balance the additional costs associated with this, and the improved uptake of the survey.

Other suggestions included greater use of social media platforms and increased advertising to promote survey.

d. Survey delivery mode and timing: consider providing incentives for participation

There was no incentive for people to take part in the Ngā Poutama survey, due to perceptions that the survey would no longer be anonymous if respondents entered their contact details for a prize draw alongside their experience responses; and it could encourage consumers to take part in the survey more than once.

However, due to the low survey response rate, we recommend reconsidering how to incentivise participation for greater uptake. One suggestion we heard is that incentivisation is done locally rather than nationally (eg, a box to put contact details in for the prize draw, separate from the tablet-based survey).

e. Assess ongoing collection of MHA consumer experience

Many DHBs said the set-up of the Ngā Poutama survey was challenging – the survey was new for MHA and many of the processes were not routine (eg, collecting email addresses and sharing contact details with a third party). An ongoing survey would embed these processes within DHBs.

Some DHBs welcomed the idea of ongoing collection of MHA consumer experience, while others raised questions and concerns. The latter included 'risk that Mārama RTF efforts get diluted if Ngā Poutama is rolling' and finding the right balance between ongoing feedback and the burden for consumers to take part.

f. Revisit methods for family and whānau participation

A very low number of family and whānau members took part in the Ngā Poutama survey. Alongside the review of methodology to improve consumer uptake of the survey, we recommend considering whether and how to appropriately include family and whānau members.

2. **Allow longer lead-in time and more engagement with sector leadership**

DHBs told us about challenges with process changes taking time and that they need longer lead-in time for these changes. We recommend having a longer lead-in time and more support for DHBs to introduce change processes. DHBs also suggested the survey and required process changes were put on the agenda at key MHA leadership group meetings including those of general managers, clinical directors and directors of nursing.

DHBs

If the 2019 methodology (extracts of contact details provided to the survey provider to invite survey participation) is used again, the following are recommendations for DHBs to embed process changes now to prepare for future survey iterations.

1. **Ensure IT functions and process support collection of consumer email addresses, and encourage a focus on the collection of consumer email addresses, and verification of other contact details, leading up to and during survey periods**

This includes ensuring there is an email field in patient management systems that is easy to access, collecting email address on admission forms, setting up processes to receive current contact details (eg, for GPs to include email addresses in referral letters to MHA services).

2. **Align MHA privacy statements with DHB privacy statements to specify that consumer information may be used to monitor service quality**

This should include privacy statements on admission forms, along with posters and brochures. We suggest adding collection of email addresses to these notices, to increase uptake and awareness of this by consumers and staff.

Some DHBs asked for standardised privacy statements and brochures across the country, with direction from the Ministry of Health.

3. **Align MHA policies with DHB policies on the sharing of contact information for experience surveys**

   Make MHA policies consistent with DHB policies on how and when consumer contact details can be used and shared with a third party.

4. **Use existing collections of consumer experience, including the Ngā Poutama national results, to inform quality improvement**

   DHBs that use existing information on consumer experience will support culture change for consumer and whānau voices to be central to quality improvement work. Consumers may also be more likely to participate in the next iteration of the survey if they can see tangible changes as a result of providing feedback.