Co-design Partners in Care case study

Youth admissions to hospital for self-harm: What is the data telling us and how can this inform quality improvement projects in the future? (Christchurch Primary Health Organisation)

Context

Canterbury has an increasing number of young people seeking assistance for mental health concerns, and the complexity and level of acuity of presentations is of concern. Christchurch Primary Health Organisation (CPHO) provides a range of mental health services to its general practices in Christchurch. According to recent data provided by the Ministry of Health, CPHO has a high rate of young people enrolled at its six-member general practices who are admitted to hospital after self-harming.

Youth (ages 15–24) constitute approximately one third of the total CPHO enrolled population. Three of the six general practices provide youth-specific services. Two of these practices are situated in tertiary educational institutes and one is a youth-specific service for people aged between 10 and 24 years old. Two of the three practices are also very low cost access practices. This could explain the high rate of hospitalisations within CPHO, as youth who are experiencing mental health concerns may be more likely to present where they feel supported in a youth-friendly environment. However, further investigation was warranted to identify if there were other reasons for the high hospitalisation rate.

Project aims

- Investigate the data to understand the reasons for the high rate of youth admissions.
- Confirm whether CPHO is an outlier.
- Complete a literature review to develop knowledge relevant to the topic area.
- Engage with experts/health practitioners to gather their knowledge related to self-harm.
- Identify consumers who would be willing to assist in identifying the questions we should be asking related to the data, based on their lived experience.
- Identify any areas for future service improvement.

Start up

Our small team came together to clarify our purpose and scope within the co-design quality improvement project. We agreed a key principle was to ensure the safety of young people and to work within ethical boundaries. This was very important given the sensitive nature of self-harm.

We were able to access data from the Ministry of Health relating to youth hospital admissions for the period of 31 March 2016 to 30 March 2018, which indicated the actual youth self-harm hospitalised rates per 10,000 population for CPHO's six general practices had risen from 182 in 2016 to 308 in 2018. Further practice-level data was requested and investigated to identify trends that would explain the high rates and if these were isolated to specific individuals, practices, or due to multiple presentations for the same people.

After investigating the data and identifying trends, we then commenced a literature search to gather more information about self-harm to inform our work. Current literature indicates that there are a variety of reasons why young people self-harm, including emotional dysregulation, trauma, and high-stress environments, and that such behaviours are not necessarily due to suicidal ideation (Robinson et al 2018; Robinson et al 2017; Wilson et al 2015). Trauma is a common factor for some that self-harm, especially those who have had adverse childhood experiences, such as physical abuse, sexual abuse and/or neglect, and trauma can be linked to negative adult physical and mental health outcomes, including depression and attempted suicide (Sun et al 2017). Those who require hospitalisation often have complex and long-term mental health concerns that need a coordinated and specialist approach to decrease the likelihood of the 'revolving door', where there are frequent repeat hospitalisations.

These findings have been further supported by health professionals who were interviewed as part of the co-design project.

Taking this into consideration, the focus of further investigation has been on the experiences of young people in relation to the services they have engaged with and were supported by prior to their admission and following discharge. The purpose was to identify any gaps or areas for improvement within these services with the long-term goal to decrease the number of youth being admitted to hospital due to self-injury.

The original scope changed from working with consumers to understand self-harm from their perspective to working with consumers to understand their experience of support services. We felt that engaging in conversation about a very traumatic period could trigger emotional distress, and this was not congruent with the principles of our project, which were to ensure the safety of young people and to work within ethical boundaries. We also considered who we needed to engage with to understand clinical/social/community perspectives. This included input from:

- Canterbury suicide prevention coordinators
- clinicians from two distinctly different youth focused services – a Youth One Stop Shop service and a university health centre
- a population health specialist
- CPHO's mental health team – experts in the field of mental health and wellbeing
- a CPHO social worker
- a Canterbury District Health Board (CDHB) data analyst
- a school nursing service
- a member of the Child and Youth Mortality Review Committee
- a primary care service integration facilitator.

Engage

To most effectively engage with people, we developed information about the purpose of the project to encourage their involvement in the co-design process. This information was in the style of 'elevator pitches', which are short narratives about a project that can be used to engage people and help them to understand the reason for the work and how they might contribute.

Areas of elevator pitch refinement

It has been important to acknowledge the two different groups we have engaged with – health practitioners and consumers. Therefore, both groups required different language and focuses as part of the elevator pitches. For consumers, the emphasis was on their input into ways of supporting the prevention of youth self-harm and identifying areas where there could be positive changes made to current mental health services. The focus for health practitioners was on their input into identifying gaps and supporting future quality improvement. Clear confidentiality boundaries were also accentuated for both consumers and health professionals.

As the project progressed, the elevator pitches, scope and aims changed as we learnt more about self-harm. It was also necessary to narrow the scope to ensure the project was manageable and achievable within time and resourcing constraints. The aims were always kept at the centre of the project, which was vital to keeping it on track.

Consumer (young person) elevator pitch

'Hello, my name is … and I work for the Christchurch Primary Health Organisation (CPHO). We provide a range of mental health services to six general practices in Christchurch. We have recognised that the number of young people who are self-harming and are being admitted to hospital is increasing. We are working on a project to look into this. Part of the project will involve talking to people who have had these experiences to better understand what worked well, what was not so good, and how we could make these services better, including if there was anything that could have been done to help people which would prevent them from self-harming. This is where your input is really important.

Would you be willing to have a chat with us about this? We do have some specific questions to ask but you can tell us anything about your experiences of being hospitalised and after discharge from hospital.

Any information you share will be treated in strictest confidence. You will not be identified, and specific information shared will not be included in the final report that we will write. At any stage during the interview/project you can choose not to continue to participate and information you have shared will not be used.

If you are happy to help us, we will ask you and the person who has a chat with you to sign a consent form. This will outline the plan for the chat and how the information will be recorded. If you would also like to view the questions before agreeing to participate, we can get them to you.'

Expert (health practitioner) elevator pitch

'Hello, my name is … and I work for the Christchurch Primary Health Organisation (CPHO). We have recognised that the number of young people who are self-harming and are being admitted to hospital is increasing. We are working on a project to look into this. Part of the project will involve talking to health professionals working closely with individuals who have engaged in self-harming behaviours. We want to better understand what current support services work well, what is not so good and how we could make these services better, including if there is anything that would prevent individuals from self-harming that is not being done currently. This is where your input is really important.

Would you be willing to have a chat with us about this? We do have some specific questions to ask but you can tell us anything about your experience as a health practitioner that is relevant to our project. Any information you share will be treated in strictest confidence. You will not be identified, and specific information shared will not be included in the final report that we will write. At any stage during the interview/project you can choose not to continue to participate and information you have shared will not be used.

If you are happy to help us, we will ask you and the person who has a chat with you to sign a consent form. This will outline the plan for the chat and how the information will be recorded. If you would also like to view the questions before agreeing to participate, we can get them to you.'

Capture

To understand the reasons for the rising number of youth being admitted to hospital following self-harm, we examined a variety of data sources, including:

- Ministry of Health System Level Measures data regarding youth hospital admissions due to self-harm (31 March 2016 to 30 March 2018)
- CDHB Data Analysts: System Level Measures data on youth admission rates for self-harm (1 July 2017 to 1 September 2018)
- CDHB Planning and Funding Data Analyst:
  - assisted the co-design team to understand the data and provide this at a practice level
  - shared information Using national health index (NHI) information such as demographic data that identified practices with the highest rate of hospitalisations and if there were multiple admissions
- literature review.

Interviews with health professionals

We undertook face-to-face interviews with 20 people, including medical directors of two youth general practices; a nurse manager of a youth practice; general practitioners (GPs); nurses; a collaborative care coordinator; social workers; a population health specialist; youth support services; a suicide prevention team; a mental health support team including counsellors; members of the Child and Youth Mortality Review Committee; a Māori provider; and a school nursing service.

We also shared the elevator pitches and aims of the project with the following three Canterbury primary health advisory groups and sought their feedback:

- Te Kāhui o Papaki Kā Tai
- Pacific Reference Group
- Culturally and Linguistically Diverse Communities Health Advisory Group.

Initial interviews with 10 health practitioners provided information that led us to re-examine our questions, scope and elevator pitches. Revised questions that included some common themes were used in subsequent interviews with both health professionals and consumers.

Key learnings from health practitioners

- There were concerns around gaps in the provision of information consistently shared back to the practices following admission to the Emergency Department (ED) or when people are discharged from community-based secondary care services.
- Youth may not be hospitalised for self-harm – however, warning signs and cues need to be identified to provide early intervention and alternative coping strategies to reduce hospital presentations and admissions.
- Insight into different cultural perspectives on suicide and self-harm are necessary to address the high rates of non-suicidal self-injury and suicide in Māori and Pacific youth. This is supported by Kingi et al (2017), who suggest that the international understanding of, and interventions for, self-harm are grounded in definitions and models based on a worldview that, for some rangatahi Māori (Māori youth), differ from their own lived experience, and the potential for traditional knowledge to enable whānau to understand self-injury in a cultural context needs

to be further explored. Whakapapa (genealogy) emphasises the importance of relationships and the understanding that all people are connected. Therefore, rangatahi who are engaging in self-harm may be lacking in some critical relationship with their whānau.

- Hospitalisations are just the tip of the iceberg, and more emphasis needs to be placed on presentations to ED and appropriate and timely follow up to support young people.
- Practice-level audits of individual presentations identified that the high number of admissions were mainly due to single individuals being re-admitted after multiple incidents of self-harm. These were concentrated at one practice, and the individuals were known to both the practice and secondary care as frequent attenders.
- Early recognition and intervention of self-harming behaviour is vital, particularly as the age of young people self-harming is getting younger. The new Mana Ake service and current Social Workers in Schools will help address some of these issues, but a coordinated effort between health, education and other services is needed as well as adequate funding. The role of school nurses and pastoral care cannot be overstated.
- There is a need for youth-specific services, separate crisis intervention for youth (crisis café/drop-in centre) and the development and implementation of a youth hub with wrap-around services (not just related to health but to address the social determinants of health). Plans for a youth hub are currently underway but will require financial support and investment to become a reality.
- Lack of acute plans: Whilst there are usually crisis plans completed with consumers if they have been seen in secondary services, these are not always shared with other health professionals. There are different databases holding information about consumers within the hospital, primary care and secondary mental health services that are not available to all health professionals involved in consumers' care. Acute plans are available to be completed and shared on an electronic platform called Health Connect South (via HealthOne); however, these are not always discussed or completed with patients, particularly with youth who may not visit their GP that often. Some information in HealthOne may be protected under a security/privacy seal. This begs the question of weighing up the right for patient privacy versus the need to maintain the person's safety and decrease clinical risk. Sharing of plans with consumers is another area for further discussion.
- Self-harm behaviour can be a mode of communication used by young people and needs to be taken seriously.
- High acuity and complex issues post-discharge/presentation are of particular concern since the events of 15 March 2019 in Christchurch, which has seen an increase in the severity and complexity of people presenting with mental health concerns and an increase in people (particularly youth) accessing the mental health help lines. The Government and CDHB have responded to this increased demand with interim additional funding for mental health services; however, most services prior to this tragic event were already oversubscribed and under-resourced.
- Repeat presentations are an issue. Most of the people who had repeat presentations were known to both primary and secondary services and have complex mental health concerns.
- Cost and timeliness of seeing a health practitioner is a barrier:
  - *'Costs involved with returning to GP is another hurdle for patients to jump.'*

Health practitioners also highlighted:

- the value of sharing practice-level NHI data to identify any further themes and gaps in service provision, including communication gaps between primary and secondary care
- issues related to engaging with consumers and differentiating between self-harm as an emotional regulator and self-harm with suicidal ideation
- the need for education of health professionals in identifying cues that indicate a young person may be self-harming and being able to ask the right questions

- the importance of health professionals being able to connect and advocate for people with mental health concerns
- the value of formulating a process map focusing on people aged 18–65 years to identify where there may be gaps in service
- the need for further process mapping to identify service provision and pathways for young people aged 10–18 years and any gaps
- the need for more services that are Māori and Pacifica specific and greater cultural competency among health professionals and support services.

Interviews with consumers

The team chose not to engage with consumers who had recently self-harmed because of the risk of trauma in recalling the experience. We did approach a consumer whose experience was less recent but encountered difficulty in engaging with them despite endeavouring to create environments and strategies to support them during and after completion of any discussion.

Some consumers agreed initially to participate but later withdrew, and we honoured that decision. The engagement was happening during the period of December 2018 to February 2019, which may have influenced engagement in terms of people being with family and on holiday during this time. However, we did have success in engaging with a health professional who was a consumer and a consumer who has spoken about their journey of self-harm in the public arena, as well as a family member of a young consumer.

We also identified some useful social media sites (eg, Voices of Hope and Life Matters New Zealand) where consumers provide insight into their experiences of mental health issues, including suicide. Our mental health team also provided some anecdotal narratives from consumers of their services.

Whilst we endeavoured to gain more consumer input to ensure that we were being true to the core principles of co-design, this process proved to be one of the biggest challenges of the project.

Key learnings from consumers

Consumers provided the following insights:

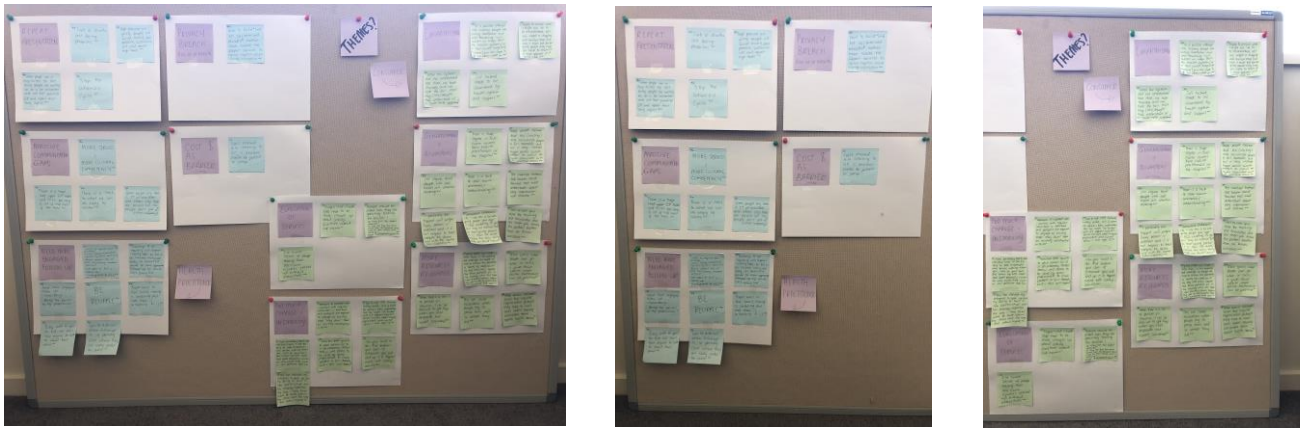
- There is too much change and instability within services.
  - *'Transition from youth to adult services is an extremely stressful time ... and seems to be used by some to scare patients into sorting themselves out.'*
- Cost and timeliness of access to counsellors are barriers.
- Health professionals provide conflicting information.
- Consumers are having to tell their story multiple times because information is not being shared.
  - *'When people are in deep distress the last thing they are wanting to do is be vulnerable and call their practice/GP and repeat their story again.'*
  - *'I have personally had to wait in ED only to talk to someone who knows nothing about you, none of your past, and comes up with ideas that didn't previously work ... so why would they work in this particular case?'*
  - *'We kept telling the same story. Nothing gets passed on, we kept repeating … it was like they're not listening.'*
- Families need to be strong advocates to get things done.
  - *'We were at the hospital all day ... told we could take her home now … we refused … we got things done because we stood up.'*
- Health practitioners need to ask the right questions and engage with consumers in a non-judgemental manner.

  - *'Support staff/health staff need to be more straight up about asking questions about self-harm.'*
  - *'They didn't seem to get anywhere ... perhaps they weren't asking the right questions.'*
- Generalisations and assumptions are made about people who self-harm.
  - *'There is a lack of self-harm awareness. Stigma that people who self-harm are attention seeking.'*
- Families of young children need support and need health professionals to listen as they are the ones that live with mental health 24/7.
- Finding a person that you connect with is vital.
- Having support when children are young may prevent serious issues arising later on.

Understand

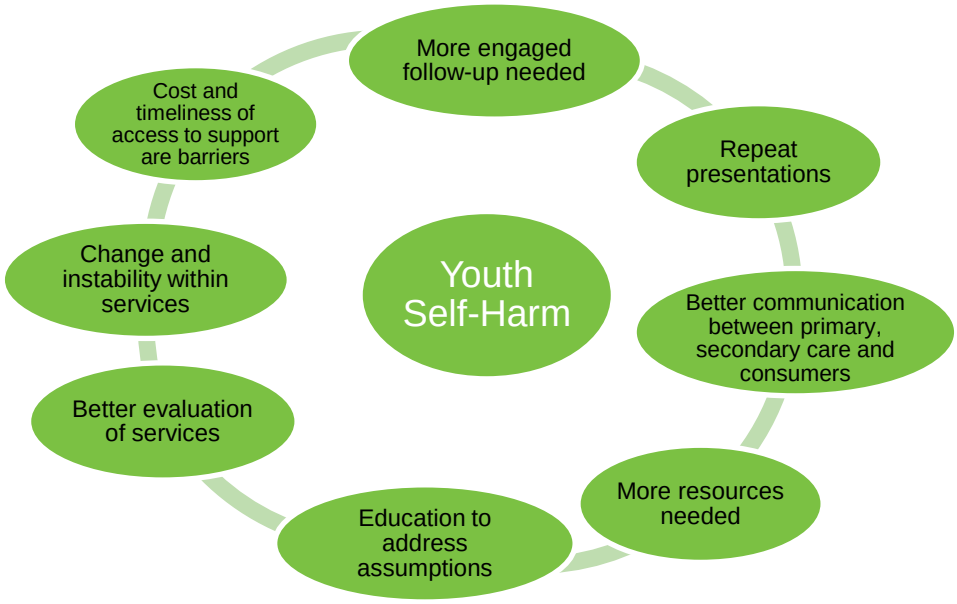
We took all the data we had gathered through discussions with people, the literature review, system-wide and local data sources, and key learnings from consumers and health professionals and started to organise it into themes.

Mapping of themes from interviews with health practitioners and consumers



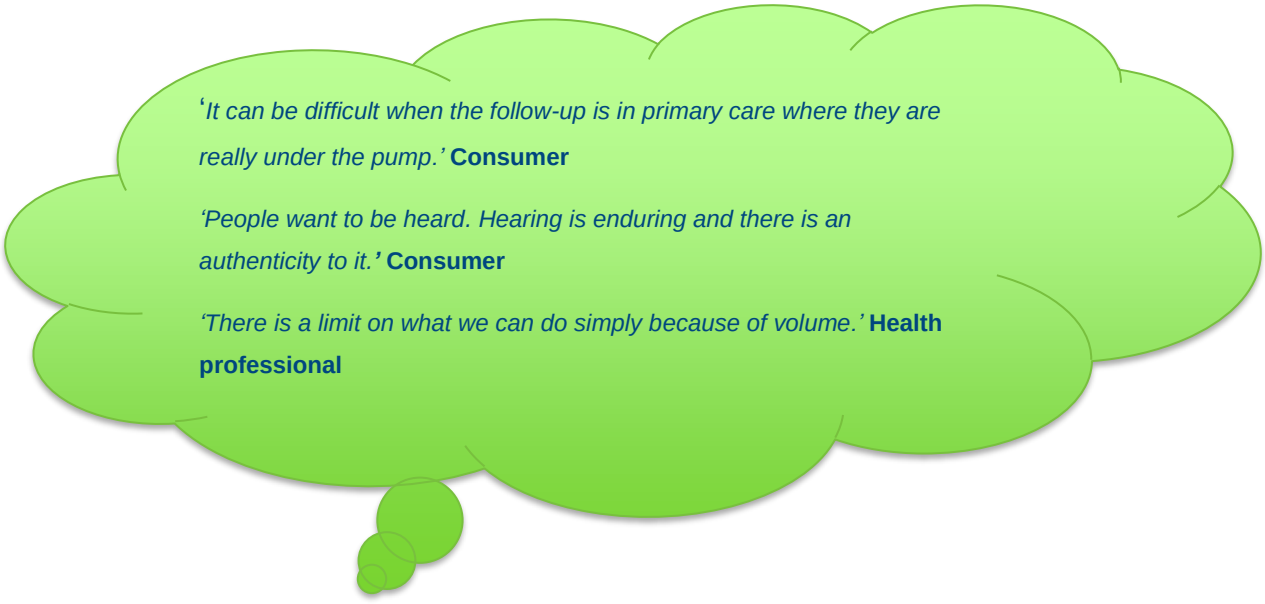
To synthesise the large amount of data collected, we looked for recurring themes and added narratives to illustrate these more fully. The data from consumers and health professionals were rich and congruent with each other. Common themes with both health professionals and consumers were discussed to further identify priorities for addressing issues raised.

Common themes



Narratives to support the themes

1. More engaged follow-up is needed



Consumers felt strongly that they needed to connect with health professionals and feel like they were being taken seriously and listened to. Provision of appropriate support/contacts after an acute presentation was also important, particularly for those who may not have been admitted.

Follow-up in general practice presents challenges, particularly if there are high acuity and complex needs to discuss and management plans need to be made, given that an average consultation time is 10–15 minutes. There is currently funding for general practice mental health extended consultations (for a further 15–20 minutes); however, there is usually a co-payment required for the first part of the consultation, which can be a barrier for some. More funding is required to ensure

consumers receive appropriate support in an environment that encourages them to engage and is culturally appropriate.

One consumer suggested that there should be a post-presentation/discharge standard policy across practices to ensure consistency in follow-up and management in primary care.

2. Repeat presentations need to be addressed.

'We need to stop the whānau cycle.' **Consumer**

There is a need for further examination of the link between trauma, particularly adverse childhood experiences, and the intergenerational effects this has on physical and mental health and wellbeing.

Several health professionals expressed their desire for the system to change to address issues for those with long-term mental health concerns who are in a cycle of the 'revolving door' and feature highly in the admissions/discharge statistics for primary and secondary care. Whilst the 'revolving door' may keep people out of hospital and prevent institutionalisation, it may not effectively address the actual cause of their mental health condition/s. A more beneficial intervention could be intensive specialist services that provide a range of treatment modalities in a secure environment. This model of care has been trialled in Nelson and may provide an alternative to current treatment modalities.

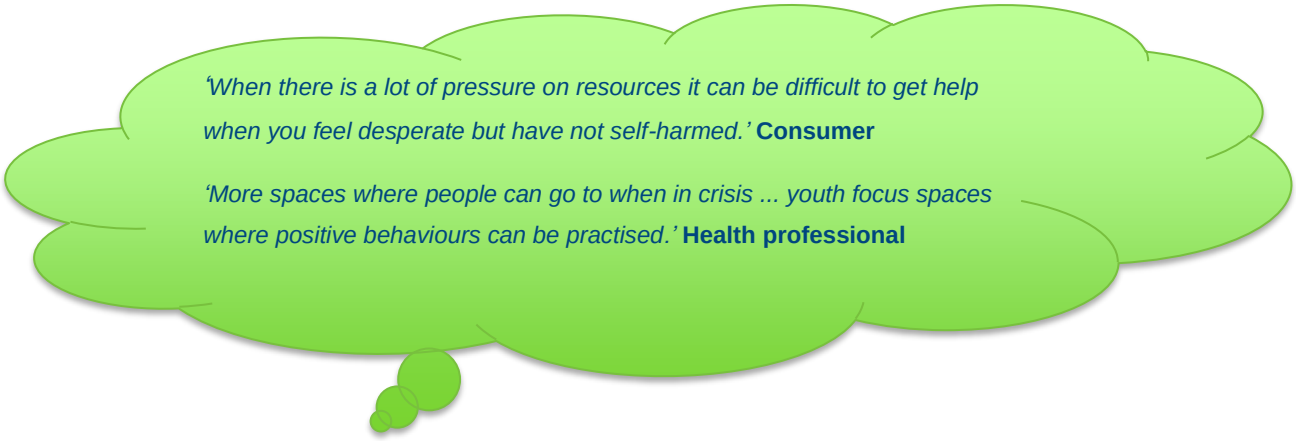
3. Better communication between primary/secondary care and health consumers is needed

'Need to build links between secondary/primary and education services rather than isolate the support services. This requires negotiation around the sharing of information.' **Health professional**

'… since the age of 13 I have worked with over 25 different counsellors, social workers, psychologists, psychiatrists and nurses. This has affected my willingness to open up and ability to trust in new relationships and has severely impacted in the way I have been able to talk about my illness and the way I feel about myself.' **Consumer**

This was a very strong theme that emerged from all the health professionals interviewed and consumer feedback.

4. More resources are needed



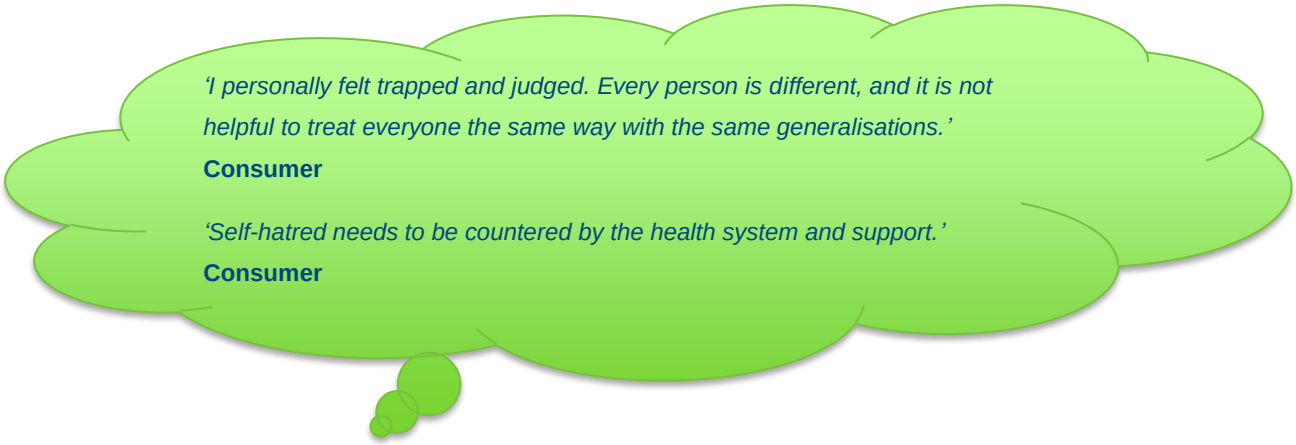
Resources are needed for:

- well-trained staff
- appropriate youth-friendly support for young people
- a place where youth can go to get support before they reach crisis.

5. Generalisations and assumptions are made by health practitioners, and further and ongoing education is required.

Health practitioners need to better empathise with young people admitted/presenting due to self-harm injuries. This requires education around self-harm and patient advocacy.

6. Better evaluation of services, particularly by young people/consumers, is needed



This highlights the importance of co-design projects for the future, including asking consumers if they trust their support networks and feel like they have some control over decisions being made for them and their whānau, and what improvements could be made.

7. There is too much change and instability in services provided

'Patients should be asked how they are genuinely finding the services.'

Consumer

This theme was interwoven through other comments related to lack of resources and generalisations and assumptions. Health practitioners identified underfunding, high acuity levels of people presenting, a backlog of people waiting to be referred onto services, and an under-resourced mental health system as being of real concern.

Consumers talked about the difficulty in transitioning from child to adult services, lack of communication, and having to tell their story multiple times.

8. Cost and timeliness of access to support services are barriers.

Cost is a significant barrier to timely follow-up post-presentation/admission to ED for some. However, cost may not be the only barrier. Provision of service by youth-friendly staff and adequate funding to provide timely access to doctors' appointments may significantly reduce barriers to access.

Improve

Improvement using common themes

Collating common themes and asking consumers and health practitioners to identify measures for improving services has been an invaluable part of the project.

Given that the purpose of this project was to identify areas for quality improvement, the team, in collaboration with health professionals and using feedback/narratives from consumers, looked at the common themes and identified two key areas of focus as a starting point:

1. Communication gaps
2. Education

Sustainable, long-term effective changes will require a system-level approach and ongoing cross-sectoral engagement and collaboration in order to identify future quality improvement co-design projects that will address current issues to improve mental health and wellbeing and reduce presentations and admissions to hospital.

The following activities and improvement ideas, based on the two broad themes of communication gaps and education, are currently being implemented by CPHO and will be evaluated to gauge their effectiveness.

1. Communication gaps

This is a system-wide issue which has been raised at various forums, is ongoing, and is currently being addressed. However, it remains a work in progress. The table below identifies actions and activities that are currently being implemented by CPHO.

Activities and improvement ideas to address communication gaps	Rationale
Activity: Ascertain if CPHO health professionals access HealthOne (information sharing platform) for patients with mental health concerns, action feedback received and provide additional support/education.	Provides a baseline measure from which any improvements can be measured against, which may include: • identifying communication gaps • providing opportunity for education and discussion with other clinicians/services.
Activity: Continue to audit receipt of discharge information from secondary care and feed this back to CDHB and other appropriate parties.	Provides audit trail and evidence for action and can be measured.
Action: Raise awareness of crisis plans and availability of acute plans that can be completed with consumers and shared on HealthOne. Identify youth-friendly resources available that support young people to have a strategy plan for periods of crisis.	Raises awareness of documentation/support available. Improves documentation and enables sharing of patient information and may improve communication between services.
Action: Continue to work with practices to source up-to-date data and use this to audit patient care.	Will identify trends/issues and opportunities to provide additional or alternative services and can be measured at a later stage.

2. Education

Practitioners need to be advocates for their patients. To do this, practitioners need to intentionally develop an understanding of, and interventions for, self-harm that are grounded in definitions and models from a culturally relevant context.

Activities and actions currently being implemented by CPHO

Upskilling health professionals includes:

- providing links to educational sites on self-harm on the CPHO website and sharing these with practices (eg, HealthPathways, HealthInfo, WerryWorkforce, Mental Health Advocacy and Peer Support Service, Leading Lights, Sparklers, AEIOU educational material)
- discussion with the Canterbury Suicide Prevention Coordinator on how the knowledge gained from the co-design project can be incorporated into future educational forums. Involving consumers in the development of resources about self-harm and ensuring that an equity lens is used as part of the planning and implementation and evaluation is vital
- further discussion with the Medical Director of the Youth Health Clinic on how and where to share learnings from the project.

Potential improvements for CPHO to action

Whilst the team have identified education and communication gaps as the primary areas to focus on, there were other related activities that were implemented as part of the co-design project with several of the youth practices which proved to be beneficial. We have therefore included these as part of an ongoing plan of potential improvements for CPHO to consider. These will be presented for further discussion and endorsement to the CPHO Clinical Governance Group, a clinical advisory committee which reports to the CPHO Board of Trustees, in May–June 2019.

Whilst these potential improvements may not have an immediate impact on consumer/health professionals' experience of self-harm, there will hopefully be a flow-on effect that will have a positive impact in the future.

Potential improvements include the following.

- A joint care coordination and social worker service has been piloted at one practice using data received quarterly for those who have presented to ED more than four times a quarter. People are then contacted by the care coordinator and social worker, and offered ongoing input and support, if required. This service has resulted in a decrease in presentation and admissions to hospital.

  This model could easily be adapted, with the possibility of obtaining more frequent data than each quarter, to include those who self-harm and could be extended out to other CPHO general practices with the support of CPHO.
- All CPHO practices should identify and improve processes of tracking people who have self-harmed by accessing the current electronic daily record sent from the hospital and contacting patients as soon as possible after the admission/presentation to offer support. Currently two youth practices are already using this electronic data to implement this.
- Process mapping for people accessing mental health services for self-harm under 18 years of age would also be a valuable exercise to identify any gaps or where there could be improvement in current service provision. This is a work in progress.

Measure

The CPHO co-design team has gained a greater depth of understanding of the reasons for self-harm hospital admissions and presentations. Whilst the focus of the project has been on hospital admissions, we have discovered that this is just the tip of the iceberg and more specific focus on addressing the high number of presentations to ED for self-harm is required. At this stage, the measurement section of the co-design project has not been completed, as actions and activities are still being implemented as a result of the themes identified.

There has not been sufficient time, to date, to fully implement and evaluate all improvement ideas; however, we believe that the aims of the co-design project have been met.

CPHO remains committed to continuing to provide youth-appropriate mental and physical health services that support both consumers and their families and are grounded in the core principles of co-design. This project is the beginning point of future quality improvement projects to address the needs of CPHO's enrolled population.

Working as a co-design team

As the co-design process evolved, it became clear that the project scope needed to be narrowed to ensure that the workload and goals remained manageable and achievable. The co-design project has raised some interesting ethical questions which also resulted in reflection and revision of initial plans. It has been challenging reconciling how to engage with consumers while ensuring their safety remains the main priority. There is a level of risk in asking consumers to re-visit a traumatic period in their life, as this could trigger past emotional experience, and it would be

unethical to do so without ensuring the consumers would be supported after revisiting such trauma.

Consumers are integral to the co-design process, and the team have worked hard to engage with them in collaboration with health professionals to capture meaningful and informative patient experiences. However, the engagement process posed some challenges, and given that the consumer voice is vital to the co-design process, questions were raised by the team members as to whether we could continue with the project. The events of 15 March 2019 also had an impact on our intention to continue to gain consumer input and feedback on themes that emerged and measurement of improvement strategies. We would like to acknowledge the support, mentoring and advice that we have received from the Health Quality & Safety Commission to guide us through this process.

Health professionals were identified as key experts to consult with, as they work closely with young people who engage in self-harming behaviour. Their insight into the experiences of young people has been invaluable. Engaging with health professionals also provided the additional opportunity to forge stronger relationships and cross-sector collaboration.

The team was fortunate that funding was provided by CPHO to support a post-graduate BA Honours (Psychology) summer student, with an interest in youth mental health and wellbeing, to join the team between November 2018 and January 2019 to assist with the literature review and interviews. This was appreciated, as the team was small and the workload was much greater than initially anticipated.

Being involved in the co-design project has been a great experience and has identified several opportunities for ongoing quality improvement for CPHO and its member practices.

The project team

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