Suicide Mortality
Review Committee

‘Nuggets of gold’: Insights from voices of lived experience

‘He maramara kōura’: He tirohanga mai i ngā reo o te hunga whai wheako

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Acknowledgements | He mihi

The Suicide Mortality Review Committee would like to acknowledge whānau, family and friends who are bereaved by suicide; the experiences that those with lived experience shared in this work, as gathered by Gareth Edwards; and the work of the mortality review committee secretariat.

Nuggets of gold Zoë Hickerson[1]

When I'm flying on my own
How can I be syncopated
When my story isn't corroborated
No wonder
I have a face of thunder
Some things are secretly squirrelled away
Don't make me pay
With my nuggets of gold
What am I going to say when I give you my life
Wait I want another chance to make it right
If it changes everything, I will give it a go
I can easily say no
I can give you my last dime
If you tell me your favourite nursery rhyme
The monster puffs indignantly and increases in size
Who is going to be his prize
On the job working in the dark
He usually hits the mark
As your lungs obliterate
Who can we liberate
When we are flying without wings
He is the one who sings
It's how he gains his voice
It's his choice
Who and where he picks a lost soul
He does it surreptitiously
With a swipe of his finger
He doesn't linger
On a sophisticated computer generated from hell
I guess we all sell
Our own nuggets of gold
When we're down and out of luck
I can give you my last dime
If it's me this time.

Members of the Suicide Mortality Review Committee | Ngā Mema o te Komiti Arotake Mate Whakamomori

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Support when reading this report on suicide | Ngā tautoko mō te pānui i te pūrongo mō te mate whakamomori

If any issues in this report are personal for you and you want to talk to someone, please contact any of the agencies and services below.

Need to Talk? **1737** call or text (mental health, depression and anxiety counselling)

Lifeline: **0800 543 354**

Suicide Crisis Helpline: **0508 828 865** | **0508 TAUTOKO**, 12 noon to 12 midnight (for people in distress, or people who are concerned about the wellbeing of someone else)

Kidsline (for children up to 14 years): **0800 543 754 (0800 KIDSLINE)**, 4–6 pm weekdays

Youthline: **0800 376 633 | free text 234; email talk@youthline.co.nz**

Supporting Families: supportingfamilies.org.nz (support for whānau bereaved by suicide)

Skylight: www.skylight.org.nz (for those facing loss, trauma and grief)

Mental Health Foundation: www.mentalhealth.org.nz offers a list of resources (including videos) (www.mentalhealth.org.nz/get-help/a-z/resource/52/suicide-bereavement) and the bereavement handbook, with updated support information, which you can download (www.mentalhealth.org.nz/assets/Suicide/Bereavement-Handbook-Online-Sept.pdf)

Le Va: www.leva.co.nz

LifeKeepers National Suicide Prevention Training Programme (Le Va): www.lifekeepers.nz

Waka Hourua: teaumaori.com/support/waka-hourua

Aunty Dee: www.auntydee.co.nz offers a free online tool for anyone who needs some help working through a problem or problems; a systematic approach to decision-making that is based on structured problem-solving.

You can also talk to your general practitioner (GP) or another local health professional, friends, family, whānau or someone else you trust.

Guidance for reporting on suicide | He aratohu mō te pūrongo i te mate whakamomori

The Suicide Mortality Review Committee provides useful guidance for journalists and others in the media on reporting on suicide. We recommend reviewing this guidance before reporting any data and discussion in this report: www.hqsc.govt.nz/our-programmes/mrc/sumrc/publications-and-resources/publication/3612/.

Language used to talk about suicide | Te reo e whakamahia ana ki te kōrero mō te mate whakamomori

It is important that we understand the language used to talk about suicide. This shared understanding helps us make better decisions together and reduce the potential for misunderstanding.

Please consider the terms below when discussing suicide, whether you are collecting and analysing data or discussing prevention or interventions.[2]

Glossary

Term	Meaning
Deliberate self-harm	A deliberate act of self-inflicted injury without the intent to die; however, some people who self-harm are at increased risk of suicide
Lived experience	A person who has experienced mental distress and recovery
Suicidal behaviour	The range of behaviours related to suicide and self-harm, including acute self-harming behaviours not aimed at causing death and suicide attempts. Some commentators consider that deliberate risk-taking behaviours are also suicidal behaviours
Suicidal contagion	Where suicidal thinking, verbalisations and behaviours spread through a community; where suicide contagion occurs, a suicide cluster can also occur
Suicide	The deliberate and conscious act by a person to end their life
Suicide attempt	A range of actions where a person makes an attempt at suicide but does not die
Suicide cluster	An event in a community where multiple deaths are linked by geospatial and/or psychosocial connections. If psychosocial connections are not obvious, links in space and time must be evident for the deaths to be classified as a cluster
Suicide ideation	When a person has thoughts about ending their life
Suicide rate	A measure of how often a suicide occurs relative to the number of people in the population. Rates, rather than numbers, are more meaningful when comparing suicide data over time and between different populations

Preferred terms

Preferred term	Not desirable	Reason for rejecting non-desirable term
Died by suicide	Committed suicide	Alludes to suicide being a criminal act
Non-fatal or suicidal self-directed violence	Suicide gesture, manipulative act, suicide threat	Gives a value judgement with a negative impression of the person's intent; usually used to describe an episode of non-fatal, self-directed violence
People living with thoughts of suicide	Suicidal	Contributes to stigma of suicide; preferred term focuses on the person instead of the potential actions
Suicide	Completed suicide, successful suicide	Implies achieving a desired outcome
Suicide attempt; suicidal self-directed violence; non-fatal attempt	Failed attempt	Gives a negative impression of the person's action, implying an unsuccessful effort aimed at achieving death
	Non-fatal suicide	Portrays a contradiction; 'suicide' indicates a death, while 'non-fatal' indicates that no death occurred
Suicidal thoughts and suicidal behaviour	Suicidality	Intends to refer simultaneously to suicidal thoughts and suicidal behaviour; yet these two phenomena are vastly different in occurrence, associated factors, consequences and interventions so should be addressed separately

Executive summary | Whakarāpopototanga matua

This report summarises the outcomes of a scoping project exploring the possibility of gathering and sharing 'nuggets of gold' – that is, stories from those with lived experience of suicide attempt.

The 'nuggets of gold' project came about after members of the Suicide Mortality Review Committee identified a gap in knowledge in Aotearoa New Zealand relating to lived experience of suicide and what tools or techniques helped when people had or acted on thoughts of self-harm or suicide.

The original and primary aim of the project was to define questions for a survey that would identify tools for staying well. However, during the interview process it quickly emerged that how to ask those questions was more important than what the questions should be. The process was modified accordingly.

For this reason, interviews asked the 15 participants with lived experience how best to gather and share stories of what works from a lived experience perspective. The scoping project documented the participants' comments on the process of gathering and sharing lived experience stories and this report summarises those comments.

From the interviewees' comments, the following key themes emerged.

- Any research must engage those with lived experience from the very beginning of conceptualising an idea, involve them in co-defining before co-designing, and have lived experience leadership.
- Methodology must be appropriate for participants.
- Lived experience voices offer unique perspectives needed to inform policy.
- Those with lived experience are a diverse group, and any research with them must take account of their diversity.
- Those with lived experience have a desire to be heard, and for their voices to be captured and used to change the system.

Another purpose of the work, and this report, is to demonstrate the value and importance of hearing the voices of those with lived experience. Policy makers, clinicians, health and social sector professionals and media need to listen to and absorb those voices, then respond differently based on what they hear.

By listening and responding well, all of us will be able to more constructively include those with lived experience in the co-defining and co-designing stages of service and policy development.

Background | Kōrero whakamārama

How we review death by suicide

The Suicide Mortality Review Committee (the SuMRC) has the responsibility of carrying out reviews on the life course of those who have died by suicide in Aotearoa New Zealand.[3] However, the information we get from reviews of those who have died tells us little about protective factors and what works to keep people alive. The SuMRC realises that the important information to support the changes needed to prevent suicide will come from those who are living.

Traditionally the analysis of suicide and suicide attempts has involved applying the psychological autopsy approach to officially collected data and coronial findings. This approach provides sociodemographic data, methods and contacts with agencies. However, it focuses on the deficits of individuals and its quality is reduced because:

- the data is second-hand
- agencies can be biased in their recall or documentation
- those collecting data give a distorted view of informants.[4]

In general, part of suicide prevention work is to analyse risk and protective factors relating to the individual. The system then uses this analysis to create population-based interventions to increase access to services and raise community awareness. These interventions tend to operate in an individualistic framework, promoting a focus on personal behaviours, individual resilience and risk factors.[5] The result may be to place an unfair burden on the individual and distract from the system-level responsibility for addressing the wider determinants of mental health.

In Aotearoa New Zealand, a researcher noted that, as of early 2019, input from current users of services had not featured in any Ministry of Health documents.[6]

Why the voice of lived experience is important

To make progress with suicide prevention, a way to turn the focus back on the system is to gain the views (voices) of the individuals exposed to this system – individuals with lived experience.

Much of the work to date on suicide prevention has focused on clinical and academic opinions about what works or is needed for consumers. However, health and social sectors around the world, including in Aotearoa New Zealand, are slowly but increasingly realising the value of encouraging and supporting the voice of consumers across the wider health sector.

Listening to those with experience of suicide attempt and service use can provide unique perspectives and strategies for supporting ongoing mental health wellness and recovery. Such strategies have included, for example, art therapy, targeted cultural services, and appropriate investigation and diagnosis of physical disease when someone presents with depression or suicidal ideation.[7]

Only the voices of lived experience can share the complexity of factors that lead individuals to choose suicide and of the tools that prevent them from doing so. Work with them needs to include narrative-based research into their lives, teasing out the historical and contextual factors that influence them towards ending their life; barriers that prevent them from communicating and being heard; and particularly determining their own unique pathways to recovery.[8]

The following are some of the reasons why it is important for those specifically with lived experience of suicide attempt to be more involved in suicide prevention work and co-design of improved systems and practices.

- The limitations of the 'scientific/medical' model of suicidology and intervention are becoming evident given that it is failing to achieve systemic or sustained results for suicide prevention globally.
- By involving those with lived experience, suicide prevention is 'catching up' to other health and disability communities that actively engage 'consumers' as key informants.
- Attempt survivors are seen as effective change agents who can speak to those who are having and/or acting on suicidal thoughts and feelings.[9]

It is important not to normalise suicide or make it socially acceptable, and to avoid enabling the media to present it in a way that makes suicide seem more common than it is. However, sharing stories of those with lived experience can bring balance. These examples of how people have gone on to live show that thoughts of distress and suicide may be more common but do not have to lead to suicide itself.

By hearing from the voices of those with lived experience, and acting on them, we can be better informed about the systemic drivers of suicide, and the impact of the social determinants of health on lives and outcomes and supportive factors enabling a good life.[10]

> *... people who are deemed vulnerable can, and should, be involved in the research and policy formation that affects them.*[11]

How the project came about

In 2018 Changing Minds[12] conducted an online survey with its community and its findings formed the basis of its submission to the recent Government Inquiry into Mental Health and Addiction. The results showed that those with lived experience in Aotearoa New Zealand want to be included in reviews relating to suicide prevention. The SuMRC believes that sharing stories of lived experience may decrease stress and isolation, and help in reducing self-harm and suicide attempts.

The SuMRC recognises the need to fill the gap in Aotearoa New Zealand research on lived experience of suicide and what helped when people had or acted on thoughts of self-harm or suicide. We need to learn what works for survivors and contribute to improving mortality review processes through involving key informants or lived experience in reviewing findings. These voices provide context and a way of developing a process where lived experience can easily influence policy work on suicide prevention.

The original intention of the work with those with lived experience was to ask individuals in Aotearoa New Zealand to help the SuMRC develop questions to find out what tools and techniques individuals had used – and do use – to stay alive and well. From this information, the SuMRC thought it would be useful to develop a public resource that provides relatable techniques as tested by those who used them to survive. Identifying what works would also allow suicide mortality review processes to look for evidence of the presence or absence of these tools and techniques.

However, these individuals challenged the assumption that a 'survey' would be appropriate and that questions could ever begin to capture 'what works' for them. Although they understood and appreciated the intent of the work, they largely dismissed this concept of engaging with them and procuring the information on what helped them, as an inappropriate method for them.

The process of challenging the assumptions made shows how valuable it is to engage with consumers as early as possible. It is critical that policy, practice and strategy developers engage those with lived experience as co-designers in the concept phase. By listening to the voices of lived experience before doing the work, the SuMRC will gain a further way to again review the methodology of this important kaupapa.

The SuMRC discussed whether a national survey would be an appropriate way to gather the stories. To scope this idea, Taimi Allen, the SuMRC member with lived experience, initiated and guided the 'nuggets of gold' project. The aim was to prepare the ground for continuing the work to capture the voice of lived experience through a co-define and co-design process with a diverse group of individuals.

How we conducted the project

We conducted 15 semi-structured interviews with a range of lived experience leaders. From an analysis of the notes taken, we identified key themes.

The interviewer discussed with the participants:

- the value of the idea of gathering and sharing 'nuggets of gold' stories
- the best ways to gather those stories, including how to invite people to contribute and in what format, such as through a survey, interviews or groups/hui
- the best ways to share the stories, including how to make them discoverable and what format to use, such as a website, book, social media and/or information resource.

The interviewer also invited participants to offer a nugget of gold if they chose.

In this report, we use participants' quotes in their entirety, as these present in detail the voice of lived experience that has been largely unheard before. We hope that presenting the direct voice of participants will bring a new and useful perspective to practitioners, researchers and policy makers.

Ethics and care of participants

The SuMRC recognises the need for an ethical process around providing information, gaining consent and ensuring support when working with those with lived experience.

Given the limited focus of this brief scoping project, Changing Minds approached only those people with personal lived experience of suicide attempts. It chose these individuals because they are aware of the risks and triggers associated with talking about this topic and are professionally supported and supervised. All participants self-identified as having lived experience and many talked of their own experiences with suicide personally and professionally. Many also have good networks with their peers so are well informed about their perspectives.

To ensure safety, a co-design process is critical. For example, the participants noted it was important to allow future story-sharers to use a pen name, choose not to be photographed and withdraw their story at a later date if they wished.

The participants

The 15 participants with lived experience included: three who have registered PhDs in this area; government and health service employees; cultural leaders; and people who have run regional and national lived experience projects. Eight were female and seven male, in the age range of 24 to 58 years. Three participants identified as LGBTQIA+.[13] The ethnicities of the participants were Māori, Pacific peoples, Asian, East European, British and Pākehā/European.

This group of participants represents a relatively small and hand-selected sample of those with lived experience. Nevertheless, their experiences and thoughts provide a valuable insight into the needs of survivors of suicide attempts and capture lived experience voices more appropriately to inform the next phase of the SuMRC's work. Three participants wished to remain anonymous. Participants who gave their full consent to be named for this report are:

- **Becky Ali** – student, University of Auckland
- **Delia Middleton** – field officer, Age Concern
- **Ksenia Kala** – accounts and finance officer, Changing Minds
- **Ivan Yeo** – deputy director, Asian Family Services
- **Maringikura Mary Campbell** – long-term conditions advisor, Heath Navigator
- **Mariameno Kapa-Kingi** – Fusion member, Taitokerau ki Muriwhenua
- **Paul Whatuira** – Internal Strength
- **Shaun McNeil** – board trustee, Balance Aotearoa

- **Tom Lamb** – educator, No Worries Project
- **Tracey Cannon** – consumer advisor, Waitematā District Health Board
- **Kieran Moorhead** – mental health policy analyst
- **Zoë Hickerson** – author and poet.

Interviewer and author of the insights

In developing this scoping project, the SuMRC identified a researcher and writer with lived experience, Gareth Edwards. Professionally Gareth started life as an academic with a BSc (Hons) in psychology and an MSc in applied artificial intelligence. He was mid-way through his PhD when he was sectioned under the Mental Health (Compulsory Assessment and Treatment) Act 1992. His personal journey includes childhood trauma, substance abuse, homelessness, compulsory hospitalisation, seclusion, forced treatment and a bipolar disorder diagnosis.

Gareth works to create a platform for people who bring together personal and professional experiences of mental health and addiction. He has led a range of innovative projects and recovery-oriented services.

Insights | Ngā tirohanga

Summary of key findings from the lived experience perspective

Hearing from voices of lived experience is needed

Lived experience stories can actively inform research, education and policy in mental health and suicide prevention. Projects like this require lived experience leadership, including clear Māori leadership, and a commitment to a co-define/co-design process if it is to meet the needs and aspirations of key audiences.

Most participants liked the idea of gathering and sharing stories. One called it a 'no brainer'; another summed it up as 'simply tools for living with and through suicidality'. Importantly most people felt the purpose of the project should be a campaign or initiative to offer people direct support. Participants talked about the power of video for sharing stories, featuring the stories in a campaign that included a website, social media and podcasts, and publishing them as a book.

These ideas are significantly different from the original proposal with its research focus. However, several people talked about the potential for these stories to inform research, education and policy in mental health and suicide prevention. One Māori participant felt informing policy change should be the primary purpose.

Participants perceived the value of gathering and sharing 'nuggets of gold' stories. They appreciated the SuMRC's proposal for research on tools for support, and for voices to be heard; many saw such voices as a need and a gap in the current response to suicide prevention in Aotearoa New Zealand. Participants were enthusiastic about capturing lived experience 'nuggets'.

What makes a good process

The methodology for gathering stories must favour individual or small-group interviews rather than an online survey to capture the context of the 'nuggets'. Storytelling itself is valuable to the storyteller: the main purpose of gathering and sharing stories is to directly support people experiencing self-harm, suicide and crises. When gathering stories from those with lived experience, we must give people options around how to engage and share. We must also recognise that people need to know who is going to use their stories and why.

It is vital to capture diversity in the voices of lived experience. This means we must clearly acknowledge that people with lived experience are a diverse group and, as such, will benefit in different ways from the nuggets. Further, we must respond to that reality by ensuring the nuggets reflect this diversity and are relevant specifically to Māori, Pacific and Asian communities, and men.

Everyone felt the project had to 'get it right' for Māori through partnership. Four people suggested it should be Māori-led. An important part of getting it right for Māori is recognising a need for more expansive storytelling that goes beyond a focus on suicide alone to look at a 'whole reality'. Also important is to recognise there may be some 'healthy cynicism' that this is the 'subject of interest today' and that Māori stories on this topic have already been shared and, some may feel, ignored. In terms of engagement and audience, two people talked about the importance of cultural context in Pacific and Asian communities, where taboo and prejudice can be powerful dynamics that need to be understood and addressed. One person also emphasised the need to 'get it right' for men, who are 'about 75%' of the issue.

The need for more expansive story-sharing may also relate to the nature of the topic. Inviting people to share a personal 'nugget of gold' revealed how important context is when considering 'what works'. Several people felt they would need more time to think further about this and might need to write it out. Those who did offer a nugget of gold expressed a need to contextualise it within their broader story and one person asked for a second interview to work through their story.

Importantly, no one felt stories should be gathered through a survey and most expressed a preference for face-to-face interviews.

Some also felt people should be able to choose how they shared stories, with options like participating in groups or hui or contributing in writing, such as through email. Two ideas for how to gather stories were to have someone travel the

country to carry out this task or to see if it was possible to resource the members of Rākau Roroa/Tall Trees, a nationwide trained and supported network, to do so. The gentleness and openness with which participants addressed this issue reflects a sensitivity and depth that most people expressed about our stories, especially around suicide.

One person gave a useful account of the journey that a project like this may go on. They had just met someone who had recently attempted suicide and, in reflecting on the experience, felt that we 'seem to be designed to live not die, so now I have to figure out how to live'. The participant felt that a story like this couldn't be collected in this kind of project.

In terms of approaching people to participate, the main ideas were to invite them through social media, mental health newsletters, and posters in general practices and district health board services. Two participants suggested more general public advertising through posters in libraries, free newspapers and online platforms such as Neighbourly.

We must also consider the best places to share the stories to achieve the widest reach. Options include, for example, websites, social media and physical locations throughout the health system.

What makes a good 'nugget'

The concept of 'nuggets of gold' refers to things of value to those with lived experience that have helped them survive and thrive. These nuggets may be tools or techniques but anecdotally we know individuals have their own nuggets that work for them. We are interested in finding out if making those nuggets available on a public platform would be a useful addition to current resources for those seeking help and support.

Talking through people's stories also led some people to distinguish perceived 'acceptable' nuggets (for example, cognitive behavioural therapy (CBT), mindfulness and spending time in nature) from other valuable ones that may be perceived as 'ridiculous or highly inappropriate' ones (for example, watching science fiction movies, reading 'dark' poetry and thinking about people who have been maimed by suicide attempts). Each of these nuggets made most sense within a more in-depth story.

Findings in detail

This section presents unedited transcripts from interviews that Gareth Edwards carried out with the 15 participants individually. Their words and phrasing contain nuances that demonstrate the importance of face-to-face interviews.

The concept of 'nuggets of gold'

One Māori participant used 'nuggets of gold' interchangeably with 'nuggets of pounamu' (greenstone) so finding the right name may involve a journey. One person disliked the concept and name 'nuggets of gold' because:

> *I know they are dug from the depths and are precious, but they are also mined from stolen land at great cost to the environment and accessible usually only to the rich.*

The name aside, inviting people to offer a nugget of gold drew out diverse responses. As noted in the previous section, some people felt the need for more time to reflect and one person had a second interview to talk it through. Even those who came to the interview with a nugget prepared talked about the interesting personal journey they had been on in preparing for the interview.

Understandably asking people to share personal wisdom from some of their most distressing and challenging times can be a profound question.

One participant reflected positively on their experience of participating in other research exploring suicide but noted it may be different for others:

> *I found the process of answering her questions and talking through my recovery, that in itself was helpful, to participate, to reflect back and think 'oh yeah look how far I've come and all the different tools I've used and people I've met along the way'. I guess for some people it could be re-traumatising, but for me I found it quite therapeutic almost.*

Though this person found it a positive experience, they still talked about it being therapeutic rather than simply sharing information. It is reasonable to expect others will have similar therapeutic journeys that could potentially be traumatising.

Another person simply laughed and said they couldn't offer a nugget of gold because:

> *I still don't know what it is, even for myself.*

The person went on to talk about something that came up in several other interviews – a disconnect from what they felt they 'should' say:

> *Sometimes it's so personal. I can do a lot of things for myself but that is because of my own learning, but, you know the typical one would be hold on to hope and talk to someone. But I know even for myself I don't like to talk to people, I can't, I literally can't, for me I always withdraw.*

This person went on to raise another important feature others spoke about as well. That is, they noted the idea that it is an ongoing journey to discover 'what works' and, again said with an almost apologetic self-consciousness, that it's not what they think it should be:

> *It's still a learning process, because it evolves and changes all the time. I don't even have one for myself, I'm still learning, and sometimes it works now and next time it won't.*
>
> *The only thing I can say is it's not a linear process, it's like peeling the onion, you just keep peeling to deeper levels, and sometimes I don't even feel like doing it, I'm so over it, so the only thing I can say that works for is, I can't even tell people it's because of the love for myself, or this or that, it's none of that.*

At this point the participant's cat joined the video call and the person laughed:

> *The cat is my therapy! My cats help me a lot. How do you tell people 'when I feel upset I just need to go home and cuddle with my cat, and my cat will come purring and that's enough for me'.*

As this person recounted their experiences, the idea emerged that finding 'nuggets of gold' is ongoing learning and depends on context:

> *I have made two attempts on my life and they were entirely different in terms of the lead-up to them, in terms of what I tried to do and in terms of the response to it.*
>
> *The first time in terms of nuggets of gold that helped me get through were less clear because there was so much going on. Because I was hospitalised, because I was on medication, because I had a key nurse, because I had a psychologist, because I had a psychiatrist, because I got ECT [electroconvulsive therapy] – it was so multi-factorial.*
>
> *You know people say, 'so, what made the difference?' And it's very hard to say because how do you separate out one thing from another. I think being connected to other people who have a similar experience, it has undoubtedly helped.*
>
> *In terms of the second experience and the fact that my recovery from that was much more self-driven and self-directed I think having resources that you can tap into when you are able to do that are at whole different levels.*
>
> *I'm very mindful of my first appointment with a community nurse after my second suicide attempt. I'd been saying just before I'd been discharged that I didn't even have the concentration to read a newspaper and this nurse brought me huge manual about cognitive behavioural therapy and I thought – 'I've just said I can't even read a newspaper, how do you expect me to read and learn from a huge manual like this?'*
>
> *So, it's that thing about having resources at a whole lot of different levels, so if you can only feel like you can read one page or the home page then you would get something out of that and then stepping that up as your concentrating comes back and as your recovery improves.*

This need for context cannot be overestimated. Even people who had spent some time preparing for the interview still needed to give some background as to what was going on for them to make sense of any nugget of gold. Again this came with a sense of 'here's what I should say':

> *I did write some stuff down about my own experience and I'm trying to work out where the nuggets of gold is!*
>
> *So, this is the things that were going on leading up to feeling suicidal and attempting suicide, so it's probably stuff you're really familiar with and heard before. It's the three things I've experienced and also from there research we know is the kind of things that lead people to want to take their lives.*
>
> *Hopelessness, and for me that was being able to see a future with me in it, being able to see a future that you want, or you think is worth living for.*
>
> *And then it's coupled with feelings of shame, guilt and unworthiness so for me there was*

feeling like the future that I want is not one I'm allowed to have or that people want me to have, and I'm unworthy to have it and I felt that really strongly.

And the third one is actually having the ability to enact the act itself, of doing it, which is probably the one I didn't obviously do it.

I think those are the three core aspects of suicidality and what leads to the act.

And I think the antithesis of that and what protects from that is connections, is the opposite of wanting to take your life, connections to whānau and family, relationships and a purpose greater than yourself, could be literally something like looking after a pet or a grander purpose.

In exploring this reflection further in the conversation, it felt like a nugget emerged when we focused a little more on the actual things that were useful. For example, although the person first mentioned 'connections and relationships', it was a specific aspect of these connections and relationships that felt like the nuanced gold:

Definitely relationships. So, being able to be honest with your relationships. And understanding and positively feeling love, and what that feels like. And what authentic relationships are.

Because you spend a lot of checking assumptions and reality checking that comes from attempting suicide and people are like 'no, no, we don't want that' and you're like 'ok'. And then checking your own beliefs and assumptions, about what you think other people are thinking and feeling about you. Because then you develop authentic relationships after that.

I wish I'd had that before the event, before it came to that.

This sense of 'digging for gold' kept occurring and usually came after someone had said what they thought was the right answer:

I only have highly inappropriate and unacceptable ones like thinking about people who have attempted suicide and been left maimed. There was the cold reality wakeup call of my sister's suicide and seeing her kids crying. But it's not evidence based so it may not be acceptable. I do have appropriate ones too like going outside in nature, tramping, mindfulness, meditation etc.

After a long pause, the person commented:

But then poetry is a huge help. Some of it is dark, but it resonates. Hearing attempt survivors' stories was important, feeling understood and not alone.

You just come to accept that you might feel like you want to kill yourself for the rest of your life at times and actually that's ok, you know, we don't need to panic about that and be judgemental about or pathologise that.

You can actually live with suicidality.

And it takes that tension and compulsion away from it, rather than constantly fighting it which is exhausting and draining and shitty, just like 'yeah, ok'.

This idea of acceptance was common among people's personal experiences. One participant talked about trying to find ways to convey the ordinariness of suicide and the challenges around it:

When you do feel suicidal it's really important if you voice that feeling that people don't freak about it because it's actually a feeling that probably 80% of the population have felt, so in some sense it's a normal feeling when you're feeling detached or disconnected and anxious. So, it's important not to be afraid of crazy thoughts that you have, because that was one of the things for me, was that I had these thoughts in my head and I was so anxious about my thoughts, they used to travel round and round. So, it's the whole thing of, actually we all have crazy thoughts from time to time it's just that when your reactions are depressed you put more into and attach more to those thoughts.

This person also felt it was important to start normalising this idea from a young age:

One of the things we don't teach people, especially our children, is we don't teach people that life is bloody difficult, it's actually normal. Life is difficult, it's really difficult and when you understand that concept you can kind of cope with life a bit better because it's normal. Difficulties in life is normal.

The need for this attitude was echoed in another person's story of attempting suicide as a child. For this person, it was hard to recall 'what worked' at that time beyond remembering meetings with teachers and parents. Their struggle to remember poignantly underlined that not everyone can distil a 'nugget of gold' from their experiences.

Another person's path to uncovering their nugget of gold started with strategies that might be expected:

> *To share a nugget of gold, in terms of crisis I found calling a friend or partner and they can listen to my story was a very effective step. The only problem is when you're feeling suicidal you don't feel like talking to someone or you actually don't feel like you have a friend or a partner or anyone to call.*

Similar to the person who cuddles their cat, this person almost instantly reframed this common call to 'talk about it' as a challenge in itself.

The next nugget this person shared started in a reasonably straightforward way before it took an unexpected turn:

> *The second-best thing that works for me really well, particularly at a time when I'm really suicidal, is instead of thinking of the reasons why you're suicidal, normally it's the past or whatever happened to you in the past, thinking about the future helps me a lot.*
>
> *Switching my attention from thinking about the past to thinking about the future and planning my future. So, after talking to a friend I take a note pad and start planning my week or journalling or doing whatever makes me feel like I have a future and I have control over my future. I actual have a power to change it and make it what I want. So, thinking about the future or getting into sci-fi and thinking about how exciting the future can get kind of takes me away from that negative space.*

Again, it was almost a throw-away comment that led to the context that made sense of the nugget. In this case, the nugget is seemingly 'watch sci-fi [science fiction] to get your thinking future-focused' but the story adds important flavour:

> *Funny enough a couple of years ago I had a major suicidal episode and after that I randomly made a new friend who were really into sci-fi and somehow, I feel like part of my recovery was getting into sci-fi movies.*
>
> *I started watching* Star Trek *and things like that, because when you watch* Star Trek *and things like that, when you see the world they are portraying you think, 'wow – I definitely want to be part of this world'.*
>
> *And when I realise I might be able to see it with my own eyes I feel like, 'wow – life is worth living'! Like I have to stay on this earth just to see something like that, just to be able to witness space travel. It would suck so much to die before something like that happens!*
>
> *So, when I watch sci-fi it gives me ideas about what kind of exciting future I might be able to witness. It's ridiculous but it works pretty well.*
>
> *Or if you watch like – it's another ridiculous idea but it works pretty well – like watching a keynote speech by Apple once a year because they always talk about all the incredible technology that's about to come or they're about to implement and you think, 'wow – humanity has gone so far and in a couple of months we'll about to see advancements like this and that, and I as a simple person, as user, can use these advanced technologies and make my life easier'.*
>
> *So, when I think about the future and future technologies and I think, 'well, I don't want miss out on that'.*

Again, notice the self-consciousness of 'it's ridiculous' when this person reveals something that 'works pretty well' to help them when they're suicidal.

Earlier in this person's story, they talked about a sequence of 'usual things' like talking to someone and journalling, and then doing something unexpected like watching sci-fi. This idea of doing the normal things people do and then something else was also apparent in this person's story about coming to creative writing late in life:

> *My nuggets of gold are mindfulness, and there's lots of apps and stuff on YouTube, CBT from counselling, deep breathing and my creative writing. I'd never written a creative thing in my life and I woke up one morning wanting to write something and it hasn't stopped.*

> *So, if I wake up feeling really low and my thoughts are not very good, I try my deep breathing, then I try my CBT and then I do my creative writing because if those two things [deep breathing and CBT] don't work, then I've got to try something else.*

So it is clear that nuggets of gold are incredibly personal and have to be set in the context of an individual's story.

A comparison of two people's experiences underscores the uniqueness of each individual's experience. One person went back to the day of their suicide attempt to set the scene:

> *I remember being disappointed I wasn't dead and feeling guilty and embarrassed to still be here.*

Local mental health crisis staff were called and they suggested an admission to hospital but this person:

> *... didn't want a clinical environment that was just going to medicate me to my eyeballs and remove my shoelaces. Everything I'd heard about that place told me I didn't want to go there.*

The person went on to talk about how important it was for them to be able to make that decision to stay at home and expressed gratitude for family and friends:

> *I am really lucky I had people around me who knew me and all I felt from them was love and support. They didn't treat me like a freak, they acted like they would with anyone who was ill, sitting with me on the couch, cooking me meals.*

Talking more generally, this person expressed an opinion that the last thing people needed when they are suicidal is to be hospitalised and become part of the mental health system. However, in exploring this further they did talk about how daily visits from a community nurse were important to them and then perhaps another nugget emerged.

This male participant, in the moment of talking about these visits, reflected on how profoundly important and reassuring it was to have a slightly older male checking in with him. Again, it felt like the storytelling revealed unexpected things that helped.

By comparison, another person tells their story about their journey through mental health services and discovering peer support:

> *I was pleased to hear about mental health support at GP [general practitioner] and Primary Care level [referring to the recent budget announcement] and I thought, 'wow', because if I was to ask for something it would have to be that.*
>
> *Because if I felt let down by anyone along the way, it was definitely at GP level.*
>
> *For me that was the first place of disclosure and diagnosis and then it was straight to the PHQ9 questionnaire[14] and prescribing medication and then not much more from there.*
>
> *I remember seeing one locum GP and at that stage I was at risk of suicide and he picked up on that and I remember in the evening he actually picked up the phone to call to see how I was and that was just incredible! I remember thinking that was quite significant and thinking, 'oh my goodness, someone does actually care' because you've got it in your head that no one does care. So, for a GP to do that, to make an outbound call was actually significant.*
>
> *Because the support just isn't there at that level, you know you feel like you've got the 15-minute appointment and, depending on how good your relationship with your GP is, I felt like I was just a number and things weren't followed up and I wasn't pointed in the right direction.*
>
> *So, to introduce it at that level I just thought, 'hallelujah, that's fantastic!' Otherwise you're left to navigate on your own. Because when you're vulnerable, and I know for me I was at the point of considering suicide and then went on to attempt suicide, because the support wasn't there. No one had sort of intervened proactively.*
>
> *I guess it's a bit more a peer support model, that two-way relationship so you're not just left on your own and, 'ok, if you need help when you're vulnerable or at risk, pick up the phone and call someone' but actually when you're distressed you're probably not going to do that. It's an ideal thing to do, but when you're actually there in the depths of despair, reaching out is really difficult, you kind of need support coming to you.*
>
> *It was only when I was hospitalised that I heard about peer support. It always feels like you have to be at the bottom getting in an ambulance to then start to realise what is available to stop you from getting there in the first place.*

So, it's coming back to having things at GP level and you've got all these interventions being offered to you rather than being at the bottom getting into an ambulance and having to figure out how to get well. It's kind of a bit back to front.

Within this journey, the actual nugget feels like 'discovering peer support' but again it is the story that hints at what works.

To conclude this section, the researcher offers a short tale of his experience of nuggets of gold as one of the participants related it to him. The central idea in his own book *The Procrastinator's Guide to Killing Yourself* is that putting off the act of killing yourself can help take the pressure off the strong desire to kill yourself. Maybe the nugget is that 'delaying killing yourself can be more useful than denying the pain of wanting to'.

One participant related an experience of having just met someone who had recently attempted suicide. The person had 'put it off' for some time because they had:

Heard something on the radio that didn't say 'don't try to kill yourself', rather the message was 'just put it off'. They couldn't remember anything more about where/what they'd heard on the radio but said the best thing about that was that it didn't deny the 'pain', just gave the option to put off killing yourself as long as you felt able.

The person was reflecting on their suicide attempt and was coming to a realisation that:

We seem to be designed to live not die, so now I guess I just have to figure out how to live... not just exist (and figure out what to do about the pain I'm in).

The participant felt that a story like this couldn't be collected in this kind of project. Part of the reason was they would not have wanted to ask for the name and location of the person who had attempted suicide, but perhaps more significantly:

The moments were between us, were spontaneous and I consider them sacred.

This observation is problematic in that the half-remembered 'nugget' was part of this person's journey but perhaps it wasn't enough in nugget form?

But it does speak of the sanctity of our stories.

Most participants liked the idea of gathering and sharing stories

Twelve of the fifteen participants were enthusiastic about the project. For example:

I like the idea – it's simply tools for living with and through suicidality.

My first thought is that it's good to learn from what keeps people here, alive, as opposed to focusing on the converse – what causes people to die, what causes death, it's a really useful reframing I think , it's like a no-brainer when you think about it, why not, why wouldn't you, what keeps you alive, what keeps you with us, it's a really important key thing, yeah I think it's great.

Let's hope we get so many nuggets we can melt them into a bar!

People also spoke about how important connecting with stories was for their personal journey and how they would like to be able to share something useful for others:

I think it's great to talk to people with lived experience. I certainly know when I was unwell it was really helpful to read other people's stories about their recovery and the strategies they used and then that gives you some ideas and 'oh I might try that, or I might try this'. So, it's really valuable to be learning from others who have their own journey. I really like the idea, because I personally can relate. Part of my lived experience is dealing with suicidal thoughts and it's something I'm most passionate about. I always thought of something like that for myself. I kind of have my own strategies in place and I think that's what helped me, having those strategies in place, and I'm happy to share what I find worked for me and I'm interested in how that might help others.

As this perspective came from most of a reasonably diverse group, it felt like an endorsement of the idea of gathering sharing lived experience stories, with a particular focus on what helped people when experiencing self-harm and suicide and the crises around them.

What is the rationale?

Two participants raised important questions about why this approach was selected.

One person asked:

> *Who says we need [another] resource of 'stories of what helped'? How have all the countless resources we already have helped so far?*

Another participant's question echoed this view:

> *Where is the evidence that storytelling works? I assume there is some and I'm sure there'll be someone out there who's done the research, but it would be good to know.*

These seem reasonable questions. We may need to provide either evidence or at least a compelling context to show why we are taking a storytelling approach.

One person did speak to the tension between 'evidence' and lived experience perspectives:

> *It's very difficult to argue with people's lived experience. I've had a few stand-up fights with psychiatrists about evidence base and RCT [randomised controlled trial][15] and you know – this is the shit that happens in my life and this is how I got through it.*
>
> *That's pretty in-contradictable evidence! It's very difficult to challenge that kind of stuff because it's so real. The push-back we might get is that it's emotional, yeah of course it's emotional, this is emotional stuff we're talking about. I can't believe that psychiatrists trying to discredit things by saying there's too much emotion or feelings wrapped up in it, for goodness sake the whole business is about the impact of what they would define as mental illness and how that impacts people's emotional make-up and wellbeing.*

This view was echoed in another person's perspective that the value of storytelling was self-evident:

> *Testimony has worked since Bob was on the mountain giving the 10 commandments! It's something that people have a listening for inherently, people have a listening for stories, it's part of who we are.*

Another participant felt the focus would be better placed on making use of existing resources and supporting communities:

> *Don't know 'more' is needed, maybe people need to know what's out there already... guess it never hurts to have 'more' but if there is money to 'collect' then I'd be giving that to communities to figure out how to do that for themselves – and having people expert in co-design methodology to help guide groups/communities through the process.*

Significantly a Māori participant noted:

> *There's been quite lot of collecting the stories and so there is a level of cynicism, you know 'what's the subject of interest today?" I actually think we've done a lot of [storytelling] already, but what has happened is that it's probably been ignored.*

This observation underscores the need to be clear about why this project wants to gather and share stories. Getting the rationale right is especially important for making it work for Māori, as the next section discusses.

Making it work for Māori, Pacific and Asian communities

All of the participants felt the project had to be useful for Māori communities. People spoke about the Māori suicide statistics and the need to 'get it right' in terms of working with Māori organisations and leaders. As some participants spoke about both Māori and Pacific communities in their responses, their comments about both are presented here together to honour the ways they expressed their views.

Three people spoke about leadership and delivery by Māori and Pacific peoples:

> *Māori need to find these answers for themselves, so the best thing you can do is encourage and put money into that, and make sure that instead of having one Māori in a group that you've actually got a lot of well-trained, experienced people with experience of distress and also a very solid understanding of the Māori world, te ao Māori.*
>
> *I particularly think the time for partnering with Māori (and Pacifika) and being culturally responsive is well and truly – maybe redirect this money/project to Māori/Pacifika to figure out what would be useful given the suicide stats?*
>
> *To be able to attract those groups, you need to work with those groups. They need to be part of the administration of the project. Because I notice the best way to deliver something for Māori is to include Māori in the project, make them a part of the project administration.*

One of these three people went on to identify the issue is around establishing trust and clarity of purpose to help with accessing stories:

> *There's a lot of mistrust from Pacific Island and Māori people around Western or European services, and there's good reason for that; in the past Pacific and Māori haven't been getting the same sort of treatment as non-Pacific and Māori, so it's really getting Pacific people going and asking for stories, and someone that is trusted in the community.*
>
> *And what it will be is people asking, 'well what are you going to do with these stories?' So, there's a really clear process around what you're going to do with these stories: are you going to publish them, how are you going to protect them and protect their experience and stories? And it's getting the right people in, make sure you have a team of people who are trusted by the Pacific community who are able to get the stories.*

One Māori participant working with Māori communities expressed a firm position:

> *It has to work and be framed up and understood from a Māori – I don't want to say perceptive or point of view or anything like that, because it just gets diluted, it has to absolutely work for Māori and whether it works for anybody else then kai pai.*
>
> *I'm not going to say if it works for Māori then it works for everyone else, I don't want to talk like that, I just want it to work for Māori and if it happens to work for anyone else then that's ok.*

In exploring the reasons for this position, the participant went on to say:

> *It's a real intrinsic understanding. What I'm going to bring is mauri ora and it trumps everything else, and you can hear my emphatic position on this because a non-Māori perspective in any regards cannot trump anything else and why I say that is because it is fundamentally different. The lived reality for Māori is not the same as for non-Māori, it's absolutely not, it is so fundamentally different, and I want to bring that into this discussion.*

When asked how a project like this one could be useful, the participant then said:

> *That it is dominated by Māori-minded analysts, a pedagogy, even reo [Māori language]. In reality it is as many of the minds, hearts of this are Māori thinking, functioning, speaking, analysing people. It's dominant in that regard. That would be at least a starter. And the governance of that would be reflected in the same way, in the committee or whatever the setup is.*

This need reflected the multifaceted context in which suicide is understood in a Māori worldview and in Māori communities. It also reflects the need to:

> *Discuss the whole reality, the born, the living and the dying of it all from a Māori reality, because you're going to come across all of those things that splice with this thing, that spliced with suicide, spliced with aspiration, spliced with optimism, spliced with radicalism, spliced with Iwi, so the preparation then for anyone who comes from anywhere, be ready for the whole story to understand this death by suicide.*
>
> *That's bigger than a big thing, and the nuggets in that, well it's going to take a while, like any nugget I guess chipping away at the coal until you get that piece of gold, panning for a few years to get that gold.*

In continuing to explore how lived experience and understanding suicide are 'fundamentally different' for Māori, when asked if the idea of distilling a nugget of gold could work the participant spoke to different worldviews:

> *Not quite in that same way really, because the whole 'I exist therefore I am', that idea, that model is not a Māori idea, the reason 'I belong therefore I am' – so right there that's just a whole different, so what are the nuggets of pounamu?*
>
> *Those things can be then captured in all kinds of different ways, and we might have already gone past our own nuggets, and there's already enough in our research in the last while that already can refine and state 'these are the things that make life better' and whether it's death by suicide or death by a whole lens of trauma, death by inter-generational trauma, death by racism, you see – that's a whole different way of understanding of the living and the dying for Māori.*
>
> *It's absolutely got to be from that inside understanding that we would retell our story of whatever those nuggets are.*

Another example of how worldviews can differ came from a Pacific participant reflecting on the cultural context for understanding these experiences:

> *There're still many Pacific people who see mental un-wellness as a curse, that that person has been cursed. They've still got some of those unhealthy and unhelpful fundamentalist Christian kind of stuff around people being unwell, that they've got demons, which is really unhelpful for someone who is having crazy thoughts anyway and is really depressed.*

Being aware of how that perspective could be shaping an individual's experience of suicide, self-harm and crisis is crucial in contextualising what might work for that person and why. For example, the Pacific participant above offered an example of how they supported someone in their community:

> *There's something about being around somebody, putting a team around somebody. I had a friend whose son was suicidal, and I said, 'make sure that every night someone sleeps next to him'. And this kid actually came out of the depression quite quickly.*
>
> *Every night someone slept next to him, there's something that happens at a wairua level, on a higher level that we can't even understand, but having someone there, 24/7, when they're at that really acute stage is vital.*

One participant from the Asian community also spoke to the continued stigma in their community and the need to explore effective ways of dealing with it:

> *Try not to use the words 'mental health', because mental health, mental illness, mental distress is very stigmatised, so we might say 'care for the heart of the community' and not mental health.*
>
> *So, it's communicated but not directly communicated.*
>
> *So, use some other words to communicate, so it could be sharing a story about how a person has come to change through some struggle, some change that might be emotional rather than focus on suicide. You can incorporate suicide inside the story. People in the Asian community don't seem to want to talk about suicide.*

When asked for a personal nugget of gold from a Māori perspective, another person gave a response that showed how specific the answer needs to be to an individual's context:

> *I can name some critical things right now that help us live as Māori and die as Māori and they are whakapapa, it is about whanaungatanga, it is about language, it is about whenua,*[16] *and what does that mean in detail? Well the only way you get the privilege of that is living inside it. I don't know where any of this fit into taking it into gold nuggets idea.*

When asked if it felt like the project needed a rethink in terms of making it work for Māori, the participant said it did. They also echoed the earlier comment about self-determination and leadership:

> *What I end up with is that any and all of this to be working for whānau in an Iwi has to come from the Iwi. The essence of it has to come from inside that moment, in the marae. From those moments of that kind of tragedy or at the other end, this whare is full of people want to design a plan of how we keep people alive.*
>
> *It's in those spaces that any of our life restoration ideas will come from.*

While this section has given a range of individual perspectives, it also contains a consensus opinion in support of partnering with Māori and the need to 'get it right' for Māori communities. Furthermore, it highlights the need for more cultural leadership and co-define/co-design to ensure the project operates effectively. For example, how should storytelling about suicide occur with Pacific communities that may feel it is taboo or with Asian communities that may not want to talk about it in those terms, if at all?

Making it work for men

One participant noted the importance of engaging men given they are over-represented in the suicide statistics:

> *As the subject is suicide, we've got to think about how to get men involved because we're about 75% of it, so how do you target men in terms of participation and audience?*

This participant went on to reference the Choose Life suicide prevention campaign in Scotland.[17] The campaign addressed this issue by having a presence in bars and at sports events. It placed

advertisements on beer mats and in the urinals and arranged for sports teams to wear t-shirts that displayed campaign slogans.

Inviting people to participate

Eleven participants gave ideas for inviting people to share their stories, including through social media, mental health newsletters and posters in district health board services and general practices. Five participants also mentioned asking mental health services to invite service users directly as an option. However, they still felt it should be an invitation to the general public, as did five of the other participants who discussed this issue:

> *This unpublicised approach is ok but is limited to the networks and it needs to get stories from people outside of those networks.*

One participant felt a more 'proactive reaching out' approach may be better:

> *It's better for people in good spaces to reach in rather than expecting hurting people to reach out, us actually going to people and being referred, almost word of mouth, or going to people who we feel would offer a really good perspective, as opposed to putting a mass call out through communities or media, like 'if you've ever experience this give us a call'.*

> *I feel it's better for us to be more proactive just because of the nature of what we're asking of people, and want to get some really good robust information about what people have been through, so we might know who are some people we can go and talk to just because we've worked in this area and we know lots of people's stories and we can get some people who we think will offer some really good perspectives, that would be a good way to first approach it.*

Another participant felt it was important to avoid paying for stories:

> *It is sensitive stuff that we're asking you to share, but our motivation should be to fill the gap and really help learning from the point of view of people who have survived attempts or who live with suicidal thoughts on a regular basis, so hopefully you would motivate people from an altruistic point of view that they're doing some good and some good is coming from their experience rather than have to think about necessarily incentivising and saying we'll pay $50 for every participant because that could become unmanageable.*

This view was echoed in another participant's motivation for taking part in other research on suicide:

> *Knowing that what you've got to share may go on to help others and for me that was the drawcard from the outset – what have I learnt along the way that perhaps could help others with their recovery?*

One participant also noted that obtaining ethics approval for a previous study they were involved in had taken 18 months so it was important to allow time for this if such approval was required:

> *If it's worth doing it's worth doing properly, don't rush for a deadline.*

Notably that project required both national and multi-site ethics processes because district health boards were involved in recruitment.

Another participant felt it was important for the project not to become overly focused on Auckland or Wellington. Instead it should gain a balance of perspectives from across Aotearoa New Zealand.

Gathering stories

No participant suggested a survey as a method of gathering stories even though that was listed in the document given to them beforehand and was likewise mentioned as an option in the questions. Twelve participants gave an opinion on how best to gather stories.

Ten participants expressed a preference for face-to-face individual interviews. They based this choice on both their personal preference and their professional experience. For example:

> *I think face-to-face as you get a better connection and rapport and are less likely to misunderstand and be misunderstood.*

> *I personally think it's best to talk to people about suicide in person, if that's possible, because I think it's a very difficult thing to talk about and open up to. So, I think people will be more inclined to talk about it in person and when they can see the person they are talking to, where they connect with the interviewer as well. I personally think it's best to interview people in person. That's something I've seen in my work*

and projects, people often prefer to share their experiences in person.

One-to-one conversations, face-to-face if possible and make it as informal as possible. Best to start slowly as there's still a lot of prejudice and self-stigma and people don't want to talk about it.

In person as it's an intensely personal thing and you can't replace being in a room with someone, and it needs to feel like a safe place to share this kind of thing.

The idea is to create a safe environment when someone is extremely vulnerable and know they won't be rejected, so the key is creating that place where being vulnerable is all right. A group setting might be too confronting and might be triggering so talking one-to-one with someone you know and trust.

People acknowledged that a face-to-face approach was costly. One person felt:

I really like the idea of someone travelling and talking about stories would be really good.

Another also thought having a travelling interviewer was one possible approach. They wondered if the Rākau Roroa national network of story-sharers could be resourced to carry it out.

Two people had a personal preference for a group setting:

I'm a group person and I'm quite happy to share in that kind of forum, but I know for some people that doesn't suit them, so it's nice to have options, some people want more privacy and don't operate well in a group. And it's quite nice to have that sense of connection, face-to-face, when you're talking about this sort of subject.

I believe interviews, one-to-one is a better choice, however groups are good as well. Of course, it might be difficult for some people to share in a group. However, if you hear other people sharing you get to open more as well. I'm actually pro both ways, I like the idea of interviews and I like the idea of groups. Personally, actually I think I might be more open and engaged in a group. Of course, it would have to be a small group where the interviewer is sensitive and empathic, and I know that everyone else in the group are just like me and have lived experience of suicide and suicidal thoughts. I personally would be comfortable in a group, if I see other people opening up, I might be more inclined to share mine.

Three people (who did not identify as Māori) referenced the importance of hui, possibly on marae. They supported having an approach rooted in Māori protocol with time for customs like speeches of greetings, introductions and sayings or proverbs.

Seven people also noted it would be best to offer people options that included face-to-face interviews, groups, written submissions via email and telephone or videoconference but did not go into further detail. One person also felt it was important to allow story-sharers to use a pen name, choose not to be photographed and withdraw their story at a later date if they wished.

Another point worth noting is that when invited to share a personal nugget of gold, people had either prepared one before (often talking about notes they'd made) or felt they needed to think some more and maybe write out their ideas first. One person had a second interview to talk it through after some time to reflect. These responses suggest that careful consideration is needed when offering options and people may need time to work out how they might feel most supported in sharing a story.

On the subject of questions to ask in gathering stories, participants spoke about the need for an open approach. One person offered a simple starting place:

Have an open free-flow narrative structure with some key elements. What keeps you safe, what works for you, understanding what others can do for you and how to step in. And people's stories might emphasise different settings, like family, community, employment.

I'd just ask, 'please tell me your story in a way that makes sense to you'.

One person referenced the 2018 film *Māui's Hook* about five whānau who have lost a family member to suicide. They felt it is a good example of Māori storytelling because:

... it doesn't seem like a transactional approach, taking information from someone, you're actually engaging and understanding and doing it really sensitively.

It's pūrākau and Māori storytelling and how people make meaning from experiences, a kaupapa Māori approach using stories as a frame of reference and a really interesting way to decolonise the suicide space.

These comments underscore a preference for a qualitative approach to story gathering that allows people to share in ways that they feel comfortable with and that allow them to express themselves safely.

One reason for sharing stories: to support people

Most participants saw the main purpose for gathering and sharing stories was to directly support people experiencing self-harm and suicide and the crises around them. Ideas included a website, social media, podcasts, apps, books and a television documentary.

It is important to note these ideas are different to the original proposal, which had expected outcomes of: a report with a summary for community networks; a brief version for government agencies and suicide prevention coordinators; and a peer publication. Participants saw merit in achieving these outcomes (see the next section) but did not see them as the primary goal.

Most spoke about the stories forming part of a national campaign or initiative to connect with people with lived experience who, through their stories, could offer ideas that others found useful:

Certainly, suicide could do with a little bit more of a... if you like, a positive branding. One thing about that campaigning approaching is that we were telling people to Choose Life so it was an introduction to a positive conversation. When you're feeling crap, this is how you can choose life, or these are some concepts you can hold on to. So, if that's informed from the nuggets of gold about how people like us have gone through this stuff then I think that's got incredible potential.

It's a solid way of feeding back some of the things from people who have been in that situation and collating that and packaging that that can be used to help other people of informing, I would hope, other ways of supporting people.

It needs to be its own entity with a name, and it's known as this place people can be linked in with a single point of access, and it became known as this repository of all this information of a whole lot of things that all of these people who had lived through it found helpful.

One person noted that making the sharing as personal and accessible as possible was important when considering how people may be feeling when they access stories:

I think it's important for those people involved to make it as personal as possible, because it is personal, and when you're in that sort of headspace, sometimes if you can actually see somebody that seems real, that could really be something that could make a difference. So, it's finding a form that's not just a huge written tome, like a huge PDF, it's got to be alive and it's got to show the people at the centre of everything, of the medium, of the story, of the way it's told.

One participant had close ties with the national depression campaign. They spoke of good uptake of the stories section is the website, especially after it added general public stories to those of campaign champion Sir John Kirwan:

When you see a photograph of the farmer and the person in the shop and the person driving the bus, ordinary people who all share this experience, I think it helps to normalise it and for people like us who experience it helps us to feel like we're not alone and there are people who have positive stories and have got through things.

This person went on to add that having a website is a valuable part of the help-seeking journey as a more accessible alternative to the helplines on offer:

It's a lot easier, it's huge step to phone somebody, it's a lot less intrusive to go on a website and have a look at something.

Another person felt the depression campaign was one of the significant differences setting Aotearoa New Zealand apart internationally in leading the public conversation about depression and suicide. Four people also felt a documentary would be a powerful way to share stories on suicide.

One person also thought the proposed initiative or campaign could bring more positive stories into mainstream media:

> *Through media – though they lead with negative stories 'if it bleeds it leads' so how to get more positive stories of survival and recovery. Media tends to focus on the deaths and how many we've lost but it doesn't talk about how many thousands of people that are saved every year, so it would be about how to get those more positive stories of survival and recovery into media. I wonder if there's opportunities in media to reflect those stories.*

The youngest participant spoke to the power of video and how connecting with the right story in the right context can support people's help-seeking journey online:

> *From my personal perspective I think the best way to share the stories is in a way that a lot of people can access them and see them. I have personally gone online a lot to hear other people's stories and that helped me, and the first place I went to was YouTube.*
>
> *I would like to be able to find those videos on YouTube because when I want to learn about a person, I'm going to learn from looking at them, hearing them narrate their story, and seeing their face helped me as well, helps me to relate to that person more, better than text.*
>
> *When I was researching that information, reading was not good enough, I felt when I read, I don't connect to the story that much, but when I see a video of someone sharing the story, that was really impactful.*
>
> *So, I think recording a video and sharing it on YouTube will probably be the most successful way for youth and maybe other people too. I would like to hear a video like that on YouTube then read more on a website. I'd be happy to find a video where someone is sharing an experience and then there could be on the website the strategies coping. So, on the video, hearing the person sharing their story then on the website the strategies and suggestions of how to cope with your own issues.*

A counterbalancing view from one of the older participants was that physical books and libraries are important 'for people like me who struggle to work an electric toothbrush!' It is not simply a matter of age, however: the second-youngest participant also saw the value in having a high-quality 'coffee-table' book like *The Roaring Silence* and another spoke about the quality and presentation of the book *Us*, which tells the stories of rape and sexual abuse survivors.

Sharing stories in culturally effective ways was another concern. For example, one participant spoke about the self-stigma in Asian communities that might make direct story-sharing challenging:

> *Try not to use the words 'mental health', because mental health, mental illness, mental distress is very stigmatised, so we might say 'care for the heart of the community' and not mental health. So, it's communicated but not directly communicated.*
>
> *So, use some other words to communicate, so it could be sharing a story about how a person has come to change through some struggle, some change that might be emotional rather than focus on suicide. You can incorporate suicide inside the story. People in the Asian community don't seem to want to talk about suicide.*

Some people thought it was important to have these lived experience stories as it would be different from what they and others received from mental health services:

> *People who hear from people who have that experience immediately get more legitimacy from saying, 'oh yeah, they understand' and that's not necessarily something you'd get from the mental health services.*
>
> *It's really important, there's no focus on service users after treatment.*
>
> *Clinicians have their place, but I certainly got a lot of value from reading about other people's experiences and practically how they became well or recovered.*
>
> *The reason I want to participate in this project is because I have personally used mental health services and I haven't found them extremely useful. I have found them useful to some extent, I was happy to see there people they can help, but I feel they can do a bit better and I'm hoping that a project like this can make a difference.*

However, it was also important for an initiative or campaign to be accessible from mental health services, campaigns and primary care:

> *... people thought of it around suicide awareness and suicide prevention, so people were fed through to it from other NGOs [non-governmental organisations] and providers, in that way it's quite special and it is important, and the nature of the material is significant.*

> *There's so much information out there, especially on this topic, so how do you get it out there? Can you tag on to all the websites and helplines that are already out there?*

> *I was quite proactive in terms of wanting to go looking for answers, but it's a minefield, it's really quite difficult, because you know there's lots of support and information out there, but where to go exactly is quite challenging. Because when you're unwell it's really difficult to navigate the sources of support or the sources of information, really difficult. And if you're not sort of alongside somebody, like a GP who is particularly proactive and pointing you in the right direction, it's even more difficult.*

A second reason for sharing stories: beyond research

The original research proposal gained support from four participants because they saw it as addressing a gap in Aotearoa New Zealand suicide prevention. For example, one person commented:

> *It's almost like the research community and the suicide prevention community are only now waking up to the value and the benefit of experience and research and information for people who have survived suicide attempts and deal with suicidal thoughts.*

> *I think it's a really worthwhile thing to be doing and I'm really supportive of the concept. I think when you look at the information and research that we've got in Aotearoa New Zealand I think there's definitely a gap with regards to the lived experience of people who have had suicidal thoughts and actions and got through them or people who live with suicidal thoughts all the time. So, I think it's a really good thing to be doing and I think it's really useful information.*

However, people were keen for the project to produce more than 'research that sits on a shelf'. Several people asked where this idea fits with recent responses such as the Mental Health and Addiction Inquiry Panel findings and announcement of the Wellbeing Budget. One participant felt it should be included in the Suicide Prevention Strategy and Action Plan.[18] Another felt influencing policy was the main purpose, especially for Māori:

> *Part of my reaction is healthy cynicism about what that will mean, because I'm willing to contribute until I sense it's going to mean nothing but just another collection of stories. So, I'm listening for the tell-tale signs of that kind of behaviour. It is the way we check quality around when people are asking us (Māori) for things, and our willingness, because we're really keen for people to know what it is but not so often does that track through to it meaning anything. For real understanding and policy change and resource that follows, it doesn't.*

Three people spoke about how 'nuggets of gold' could be useful to those who offer support, such as family, friends, colleagues, employers and mental health staff. As one person commented:

> *My family members didn't have a clue what to say to me so to deal with their feelings of inadequacy they cut me off all together and that just compounded the feelings of both isolation and that actually I wasn't of very much value to them so there is definitely something to be said for giving some real basic tools to members of the public and making them feel more comfortable about having conversations and that they don't need to be experts and they won't make somebody make an attempt on their lives.*

> *We are talking about different communities, are we talking about lay people, school environment, are we talking about you know government agencies, or frontline staff? Something for all these different settings – they will all need it the way they need it.*

Reflecting on the role of communities more generally, a second person went further to talk about how a campaign could help in a broader sense:

> *I read an article that zero suicide is not government responsibility, it's everyone's responsibility and that's what I believe as well. People always believe that that person needs to*

be being looked after by the state but it's not just state care, actually it is the people surrounding them can show up at the time.

I think lay people sometime underestimate the power they have because state can provide health care, but it is people that help them stand up and be strong again, so I wish to see people stop thinking government have the answer. Government have some answers, but you need a whole community to make the change, and that community does not need to do it alone, but how do we create that kind of acceptance and environments where people feel they can belong?

One participant who delivers suicide prevention workshops in Aotearoa New Zealand reflected that the biggest request is always 'personal information on what got me through it and how did it feel, so I think there's real value in the voice of lived experience in suicide and suicide work'. This person had been involved in developing training materials overseas that included videos of people telling their stories and thought this could be one way of using these stories.

Conclusion | Whakakapi

Most participants agreed that capturing nuggets of 'what works' directly from those with lived experience is needed, while noting such a project must consider key issues around leadership and cultural fit. Many supported using stories in a campaign as a way of offering direct support to people in crisis and living through and with self-harm and suicidality. Such a campaign could also help those who offer support such as whānau, families, friends, colleagues, employers and people in the community. Participants supported the purpose of gathering stories for research as long as the results play a role in shaping policy and practice in the mental health and addiction sector, rather than becoming results that just 'sit on a shelf'.

Understandably, being asked to share personal wisdom from some of their most distressing and challenging times can be a profound experience for people. Therefore, participants considered that it was essential to approach them through face-to-face interviews, individually or in a small group, in a safe and supportive environment. An unintended consequence of sharing self-disclosed stories of suicidal thoughts and survival may be to improve the mental health and physical wellbeing of the participant.[19]

Participants supported the proposal to explore in co-define/co-design the idea of video-recording face-to-face interviews and sharing them via YouTube, podcasts and social media as well as having a website to provide further information and signposting or access to support if desired. The same working idea should be explored in the context of making videos part of resources for the education of health and allied health professionals and training for those supporting people who experience self-harm and suicidal thoughts or behaviours. Participants were also interested in the publication of a high-quality book (like *The Roaring Silence* – see the Appendix).

In terms of questions to ask in gathering stories, participants offered two ideas: an open free-flow narrative structure with some key elements, such as what keeps you safe, what works for you, understanding what others can do for you and how to step in; and starting with, 'tell me your story in a way that makes sense to you'. Most interviewees felt face-to-face interviewing was the best method, while acknowledging this was a costly approach. One person suggested the network created by the Rākau Roroa/Tall Trees initiative at Changing Minds could have a role. This national network has a storytelling focus and could be resourced and trained to gather stories. The original idea for the project – to conduct a survey, which leads to a research report and peer publication – has been shown to be of limited value.

Framing and naming this work appropriately is important. As not all participants thought the working title of 'nuggets of gold' is suitable (they are mined from stolen land at great cost to the environment and accessible usually only to the rich), a new name could be considered in the co-design process for further work. One Māori participant used the term 'nuggets of pounamu'.

For a project like this to be effective, it must be led by those it is intended for. Therefore, there is a need for clear Māori leadership. Also needed is a commitment to a co-design process to meet the needs and aspirations of key audiences, including Pacific and Asian communities, LGBTQIA+, youth, older adults, rural communities and people living in the unique situation of Christchurch and wider Canterbury.

Next steps | Ngā mahi whai ake

The SuMRC will continue to progress this work with those with lived experience in the following ways.

1. It will further investigate an appropriate format for questioning – capturing stories directly from the people themselves, and in-person, questions online, how to elicit the contextual and nuanced information that gets to the heart of what helped, and helps, individuals to survive and thrive; noting that one size does not fit all.
2. It will ensure the work is inclusive and takes account of diversity. Analyses of people's experiences of mental distress and recovery will be led by those who have lived experience and those for whom the output is intended. Individuals with lived experience must be involved in co-defining/co-designing the initiative. Because of the inequity of suicide deaths for Māori, it will have authentic Māori leadership. Likewise, due to the inequitable burden, Pacific, Asian and LGBTQIA+ voices will be at the table.
3. It will craft nuggets of gold of lived experience to gain tools and techniques that may be of value to others – including those in distress, their whānau, families, friends, communities and colleagues, and health professionals.

Appendix: Examples of lived experience stories | Āpitihanga: Ngā tauira o ngā kōrero a te hunga whai wheako

Participants mentioned the following examples as lived experience stories they had found useful in their journeys.

The Roaring Silence: A compendium of interviews, essays, poetry, art and prose about suicide

Linda Blincko, Amelia Harris and Julia West (eds)

A book about suicide awareness that contains contributions from 79 artists, writers, poets and a few professionals from all generations and backgrounds, and from throughout Aotearoa New Zealand. They together communicate the message that life is both dark and bright and that none of us is immune from times of shadow. In its diversity and creativity, this book is enlightening and empowering, challenging and reassuring and a great read all round.

http://www.depotpress.co.nz/2017/02/27/the-roaring-silence-book-launch/

Live Through This: Life on the other side of suicide

Dese'Rae L Stage

A collection of portraits and true stories of suicide attempt survivors. Its mission is to change public attitudes about suicide for the better; to reduce prejudice and discrimination against attempt survivors; to provide comfort to those experiencing suicidality by letting them know they're not alone and tomorrow is possible; to give insight to those who have trouble understanding suicidality, and catharsis to those who have lost a loved one; and to be used as a teaching tool for clinicians in training, or anyone else who might benefit from a deeper understanding of first-person experiences with suicide.

https://livethroughthis.org

The Butterfly Diaries

Raewyn Alexander, Henrietta Bollinger, Owen Bullock and Phoebe Wright

Four true stories of recovery from being suicidal as told by four creative writers. *The Butterfly Diaries* gives voice to the stories of those who have been there and made it out alive. Sean, Jane, Mary and Brad have all been suicidal, survived their own suicide attempts and found their way to a place where they are glad to be living their lives. They share how they strengthened their wings and learned to fly.

National depression initiative

These websites have personal story pages on anxiety, depression and related topics:

https://depression.org.nz/is-it-depression-anxiety/stories/

https://thelowdown.co.nz/videos

Rākau Roroa

Rākau Roroa trains and supports a growing network of people who want to use their personal lived experience of mental distress and recovery to inspire others. By the end of the training, Rākau Roroa will enable people to tell their own story and champion positive mental health messages in their communities.

https://changingminds.org.nz/rakauroroa/

No Feeling Is Final

Graham Panther and Honor Eastly

Award-winning podcast memoir series from ABC Usually when we talk about suicide, we say those four magic words: 'just ask for help'. But Honor Eastly knows it's not that simple. At times heartbreaking and desperate – but also darkly funny and charming – No Feeling Is Final is a story of difference, identity and why we should stay alive.

https://www.abc.net.au/radio/programs/no-feeling-is-final/

Headlands: New Stories of Anxiety

Naomi Arnold (ed)

Headlands tells the real, messy story behind the statistics – what anxiety feels like, what causes it, what helps and what doesn't. These accounts are sometimes raw and confronting, but they all seek to share experiences, remove stigma, offer help or simply shine a light on what anxiety is. It is not a book of solutions nor is it a self-help guide. Instead, it has been put together for all individuals and whānau affected by anxiety. It's also for those who are still suffering in silence, in the hope they will see themselves reflected in these pages and understand they are not alone.

http://vup.victoria.ac.nz/headlands-new-stories-of-anxiety/

Us: Book of stories

Megan Bowers-Vette

The Us project shares the portraits and stories of 50 men and women from Aotearoa New Zealand and Australia who have experienced sexual assault. Anonymity sends a signal that there is still something to be ashamed about. It is normal, understandable and totally acceptable to feel guilt and shame about what has happened, but Megan wanted to connect with people who had worked through those feelings and were ready to show up and stand in their truth. Megan spent 12 months photographing and interviewing experiencers and has published the full transcripts from all 50 participants.

The procrastinator's guide to killing yourself: Living when life feels unliveable

Gareth Edwards

This short book expands on a blog of the same name and is written for people who were thinking about killing themselves. It draws on Gareth's personal experiences of wanting to kill himself in his mid-20s. The main idea is that rather than fight himself about wanting to kill himself, he accepted it and allowed himself to go ahead... later. This is a technique also often used in addiction: don't fight the urge to drink or use, just delay it.

https://gareth-edwards.com/tpgtky/

Endnotes | Tuhipoka

1 Participant Zoë Hickerson offered this poem to us the day after her interview for the work that underpins this report. https://www.zjhick.com

2 Crosby AE, Ortega L, Melanson C. 2011. *Self-Directed Violence Surveillance: Uniform definitions and recommended data elements.* Atlanta, Georgia: Centers for Disease Control and Prevention; and the Clinical Advisory Service Aotearoa: www.casa.org.nz.

3 www.hqsc.govt.nz/our-programmes/mrc/sumrc

4 Hawton K. 2001. Studying survivors of nearly lethal suicide attempts: an important strategy in suicide research. *Suicide and Life-Threatening Behavior* 32(1 Suppl): 76–84.

5 Fitzpatrick SJ. 2018. Reshaping the ethics of suicide prevention: responsibility, inequality and action on the social determinants of suicide. *Public Health Ethics* 11(2): 179–90.

6 Ali B. 2019. What works? Individuals' experiences and knowledge of suicide prevention interventions in Aotearoa/New Zealand. PhD thesis, University of Auckland, Auckland.

7 *Ibid*.

8 SANE Australia. 2015. *Lessons for Life: The experiences of people who attempt suicide: A qualitative research report.* Armidale, NSW: University of New England.

9 Vega E. 2014. *The Lived Experience in Context – why now?* Washington, DC: Suicide Attempt Survivors Task Force, National Action Alliance for Suicide Prevention.

10 World Health Organization. 2014. *Preventing Suicide: A global imperative*. Geneva: World Health Organization. URL: http://www.who.int/mental_health/suicide-prevention/world_report_2014/en/ (accessed 12 December 2019).

11 Ali 2019, *op. cit*.

12 Changing Minds is an advocacy group for those with lived experience of mental health and addiction challenges in Aotearoa New Zealand. See: https://changingminds.org.nz/

13 Lesbian, gay, bisexual, trans, queer, intersex, asexual and other sexualities.

14 A self-administered patient questionnaire; it is one of the tools used to screen for the presence and severity of depression and to monitor response to treatment; it is not intended to provide a diagnosis.

15 A randomised controlled trial is a prospective, comparative, quantitative study performed under controlled conditions with random allocation of interventions to comparison groups; it is the most rigorous and robust research method of determining whether a cause–effect relation exists between an intervention and an outcome.

16 Whakapapa = cultural genealogy, ancestral lineage, related kinship structures; whanaungatanga = networks and relationships; whenua = land.

17 www.chooselife.net/Home/index.aspx

18 www.health.govt.nz/our-work/mental-health-and-addictions/suicide-prevention-new-zealand/suicide-prevention-strategy-and-action-plan

19 Pennebaker J, Smyth J. 2016. *Opening Up by Writing It Down: How expressive writing improves health and eases emotional pain* (3rd edn). New York: Guildford Press.

newzealand.govt.nz

Health Quality & Safety Commission New Zealand
Kupu Taurangi Hauora o Aotearoa