Te Roopu Rangatira:

Our holders of knowledge

The Haemophilia Foundation of New Zealand's report into the how well the Foundation are meeting the needs of our older members.

Haemophilia Foundation
of New Zealand Inc.
HFNZ

The research project is entitled *Te Roopu Rangatira: Our holders of knowledge*.

In this research context, **Roopu** relates to a collection of individuals, older people with bleeding disorders, coming together for a purpose or cause.

Rangatira meaning leaders, people with chiefly attributes, holders of knowledge, and acknowledges lived experiences.

Ranga also refers to the weaving together of this knowledge.

Therefore, the research weaves together the korero and lived experiences of this respected group of people: *Te Roopu Rangatira: Our holders of knowledge*.

The Foundation wishes to acknowledge Sarah Elliott as the lead researcher for this project. In 2015/16 Sarah undertook a research project as part of her requirements for a Master of Social Work degree, exploring the unique issues and challenges for older men with haemophilia. In addition, Sarah is familiar with the workings of the Foundation, having previously worked as an Outreach Worker, so was well placed to lead this research project.

The Foundation thanks Sarah for all her work on this important project.

Contents

Executive Summary

This survey, *Te Roopu Rangatira: Our holders of knowledge,* sought to determine how well HFNZ is meeting the needs of members aged 55 and over. Sarah Elliott, social worker and former HFNZ outreach worker, led the survey, overseen by the HFNZ CEO and supported by the Communications Manager.

The findings of *Te Roopu Rangatira: Our holders of knowledge* were informed by a written survey, a focus group, and four individual interviews. Forty-one people completed the written survey, and their responses guided the subsequent four-person focus group and four individual interviews. In total, 208 surveys were distributed to members in the 55 plus age group. Of the 41 responses, 21 were women and 20 men, 34 were Pākēha, four Māori, and three of other ethnicities.

The survey found that 48% of respondents think that HFNZ is effective in meeting their needs, while 29% believe that HFNZ is ineffective. Furthermore, 88% think that HFNZ could change or improve their services. Of the services HFNZ provide, 36% said that outreach support was the most valuable; 18% selected Bloodline, Pānui, and other information; 14% selected conferences and workshops; 14% selected socialising and social events; and 9% highlighted footwear vouchers.

Regarding information specific to their needs, respondents were most interested in new treatments, pain management, remaining active, exercise, and weight management.

The most common theme for specific services was more contact with their outreach workers. Concerns were expressed about staff turnover and the need for rapport building. Forty-five percent of respondents thought their outreach worker was supportive, while 20% felt they were unsupportive. The most common response (35%) was that they felt moderately supported.

Participants noted a lack of connection and most had not seen an outreach worker for many years, or may have a quick catch-up once a year that did not focus on getting into the details of their specific needs and issues. There was a lot of discussion about the recruitment of outreach workers and the types of people participants thought best suited to an outreach role, including those outreach workers from outside the bleeding disorder community who need to spend time upskilling especially related to the impact of bleeding disorders on older people. They suggested outreach workers need regular training/hui where they meet with a group of active parents and an older member to share their experiences and gain insight.

The focus group broadly focused on access to services and supports, outreach support, social supports, and HFNZ support. The key them that ran through this group was concern about their own physical health. This is particularly interesting given the sessions and questions were developed to focus on services and supports.

Most people found that the medical system could be tricky to navigate, including knowing which specialists to follow up with. There was a clear concern about medical professionals' lack of bleeding disorder knowledge. Participants felt they were sometimes lost in the hospital system, and found the medical system slow in meeting their needs. They found it hard to access the equipment they need and were often waiting very long periods. They discussed the possibility of HFNZ funding some of this equipment, which is essential for mobility and quality of life. There was significant feedback about whether outreach workers were able to help advocate and support them to get the equipment they need, and at hospital appointments, as well as having knowledge of what resources are available to members.

The importance of social connection with others with bleeding disorders was another key theme for everyone. The participants were very clear that face-to-face time together was essential and should be a main role for HFNZ and outreach workers. Camps, workshops, meetings, and social events should provide a space for discussions, support, and sharing. This was more important than the education sessions for many.

When talking about HFNZ specifically, participants felt that HFNZ was no longer visible, that they have “wound down” and they were not sure what HFNZ actually does, as they do not see a lot anymore. There were not many suggestions about what changes HFNZ may need to undergo to better support their older members, although did suggest HFNZ need fresh people on the Board with new ideas, passion, and enthusiasm.

Background

In 2020, the Haemophilia Foundation of NZ (HFNZ) undertook a survey of its members to understand how members viewed the Foundation's performance focussed on what it offers to them, and to what extent they are satisfied with what the Foundation offers. Of the 182 respondents, 39% were in the 51 to 70-year-old age group.

Results from this survey included age-related comments, relating to specific support and events just for seniors. Examples of comments from the survey related to the older age group respondents included:

"Too elderly to travel"

"At my age in life I feel much less need to connect to HFNZ than when I was a child/youth…"

"Any events just for seniors?"

"As a 73-year-old I have become less interested. In fact I have only attended regional and local events in the past"

Because of the findings from that survey, HFNZ sought further information from its older age members in what the Foundation can do to provide the support and care needed.

Purpose

The purpose of undertaking this research project was to ensure HFNZ is meeting the needs and the support that is required by their older members, this included:

- Assessing what services older members use both within HFNZ, wider supports and through the health system
- Determining how older members are accessing these services
- Determining how effective HFNZ services are in addressing their needs.

The research project looked to establish an accurate view of HFNZ services currently used by older members, the level of activity and potential contribution to successful outcomes for them using these services. This was to enable HFNZ to consider what further services and care are required, if any, to address older member's needs.

Process

The research project scope included:

1. The challenges faced by HFNZ older members
2. The current HFNZ services accessed by them
3. What services are working well
4. Identifying opportunities for improvement to services.

The research project objectives were:

1. Identify the issues and challenges faced by older members
2. Identify level of engagement of services and supports used by older members
3. Identify improvements needed to services and care to support older members

Methodology

Mixed methodology was used in order to allow integration of both qualitative and quantitative data, using a two-phase design consisting of a national survey and then follow up focus groups and interviews. Triangulating the results of phases allows for comprehensive examination of participants experiences from multiple angles, to unpack the complexity, to cross check each source of data against the other to reinforce or reveal any gaps and add greater validity to the research.

A national anonymous standardised self-report survey was sent out to all people over the age of 55 years with a bleeding disorder in Aotearoa who are identified on the HFNZ database. Participants had the opportunity to complete the survey in hardcopy or via survey monkey online.

Surveys are known to be useful because they allow participants to complete them when and where convenient to them, and when anonymous are likely to generate honest answers. Therefore, this is an appropriate way to collect significant amounts of data, from a wide range of people who live large distances from one another, in a short timeframe.

The survey was analysed using quantitative analysis including graphs and statistics, and qualitative analysis for open-ended questions.

Participants could indicate on the survey if they were interested in being a part of a focus group or interview via a tick box. Focus groups and interviews took place via zoom or telephone. Focus group and interview questions were based on the findings from the survey and this method allowed for discussion on opinions, perceptions, and experiences.

The benefits associated with this approach are that they are useful at generating discussion; they are more flexible and can obtain a broad range of information.

Comparative and thematic analysis was used to interpret data, by extracting key themes and ideas and later be transcribed and coding applied.

Ethical considerations and consent

The aims and objectives of the research were clearly explained, especially in relation to highlighting why the participant views are important and how their information could be used to inform practice and service changes.

The implications of informed consent, voluntary consent, and confidentiality were clearly outlined in the survey participant information sheet at the top of the survey.

Participants were informed that the focus group or interviews they participated in were audio/video recorded for data collection and data analysis purposes only. Each participant provided informed consent to participate. Participants were informed that their participation was voluntary and that they could withdraw from the focus group or interview at any time. Focus group edict was outlined at the beginning regarding respect and privacy for other members.

All data remained anonymous. No names were attached to any of the data collected. Focus group recordings and notes; word files and draft written material were stored in the password protected laptop in the office of the researcher and be destroyed after a period of five years.

As HFNZ were initiating and contributing to the research and process, and participants were made aware of this. As questionnaires were completely anonymous this did not pose a large issue, and the focus groups and interviews were be run by the lead researcher (and HFNZ were only given access to the non-identifiable comments and themes).

Social work research usually focuses on promoting social justice and improving outcomes for vulnerable populations within society. The conduct of the researcher adhered to the guidelines of professional codes of ethics that underpin social work practice (ANZASW, 2019) through engagement with participants, respecting the stories and information shared, and the way information has been reproduced in the report. These guiding codes include the following values;

- Rangatiratanga
- Manaakitanga
- Whanaungatanga
- Aroha
- Kotahitanga
- Mātātoa
- Wairuatanga

The research project has also gone through full Eastern Institute of Technology ethics approval.

Dissemination

Participants had the opportunity to share their knowledge and experience, to inform future supports, services, practices and approaches to support other older people with bleeding disorders in Aotearoa, New Zealand. A copy of the research summary was made available to all participants involved in the research. Research findings may be published in academic social work journals and/or academic conferences by the lead researcher (in discussion with HFNZ regarding property rights / ownership).

Survey analysis

In total 151 surveys were emailed out and 57 were posted (with return envelope). Reminder emails were given after two weeks and again at three weeks. In total 41 people responded to the survey (out of 208) between the 21 March and 25 April 2022.

Below is the analysis of each of the questions that were within the survey.

Question One: Which age group do you fall within?

Participants selected from one of six drop down categories:

Age Bracket	Responses	Female	Male
Aged 55-59	15	9	6
Aged 60-69	18	8	10
Aged 70-79	7	3	4
Aged 80-89	1	1	0
Aged 90-99	0	0	0
Aged 100+	0	0	0

Question Two: What is your ethnicity?

Participants selected from 9 drop down options with an ‘other’ category also included. The vast majority (34) participants identified as New Zealand European, with the next highest category being Māori (4).

Ethnicity	Responses	Female	Male
New Zealand European	34	17	17
Māori	4	2	2
Chinese	1	1	0
Indian	1	0	1
Scottish	1	1	0

Question Three: What is your gender?

Participants were asked to select from four different options; *Female, Male, Non-binary* or *prefer not to say.* The responses were very evenly distributed between male and female.

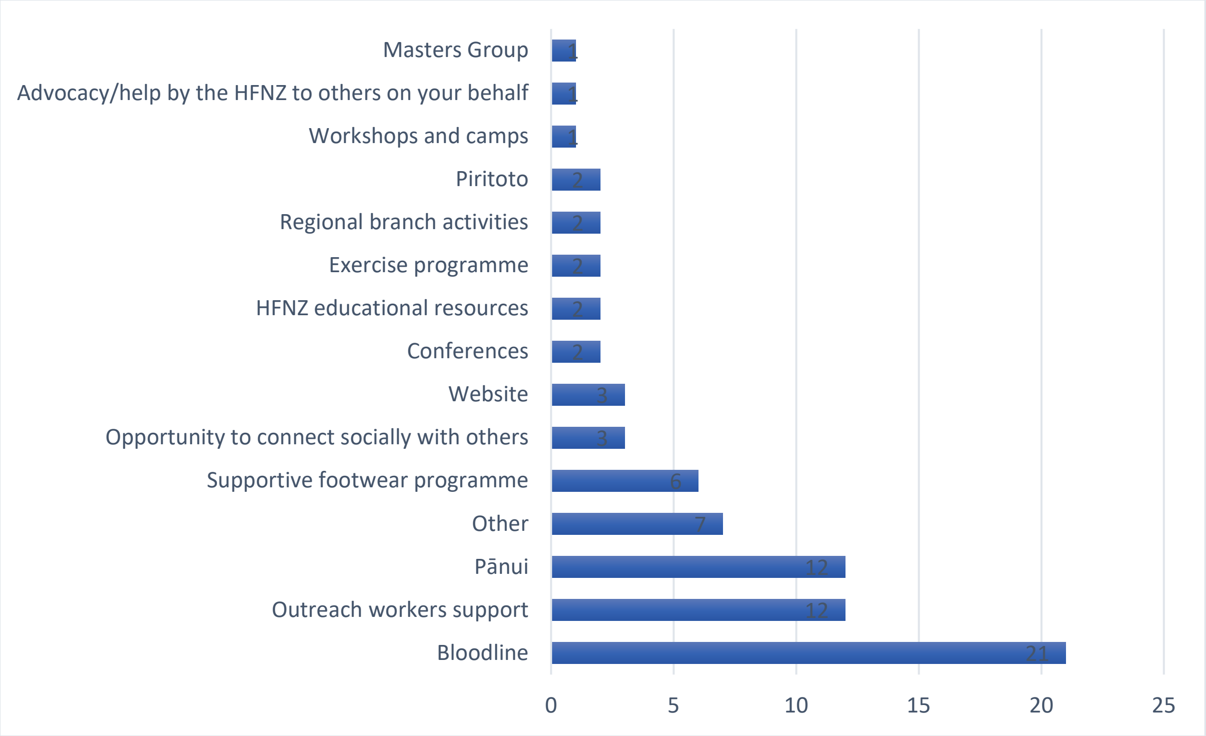
Ethnicity	Responses
Female	21
Male	20

Question Four: Which HFNZ services have you used in the last year?

The participants were given a drop-down menu for this question and 33 participants selected one or more options, with 77 individual responses. Eight participants didn’t answer the question.

The service which was used the most by the members was the Bloodline magazine (21), was nearly double that of the next most used services, Outreach worker support and Pānui (both 12). None of the participants selected defensive driving program

There were several responses listed under the *other* option, where some mentioned medical support (from other services), two participants indicated they used no services and one participant indicating direct HFNZ emails.



Question Five: Which of these services do you find the most important/valuable?

This was an open-ended question where participants could write short answers. Twenty-two participants responded to this question. The key themes in feedback were:

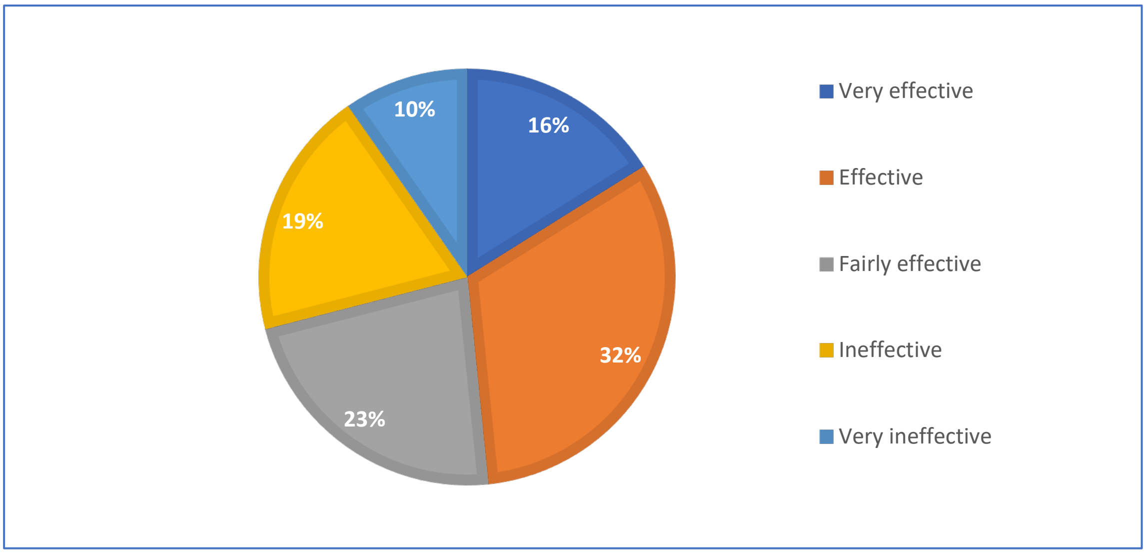
- Outreach worker support (8)
- Bloodline/ Pānui / info (4)
- Conference / workshops (3)
- Socialising / social events (3)
- Footwear (2)

All services are important. Several participants responded saying that none of the services provided by HFNZ was valuable to them, with the main two reasons being that they have not needed support (2), and that none were useful (1).

One participant indicated that outreach was important but that they hadn't heard from anyone in quite some time and another highlighted the importance of camps, which were postponed due to Covid. Two people mentioned their medical teams.

Question Six: How effective is HFNZ in meeting your needs?

Thirty-one participants responded to this question and the most popular response was that HFNZ is 'Effective' in meeting their needs – 32% or respondents selected this option.



Question Seven: Do you think that HFNZ could change or improve their services?

Thirty-two participants responded to this question.

Options	**Reponses**	**Percentage**
Yes	6	19%
Maybe	22	69%
No	4	12%

Question Eight: Please list any specific services, events or activities you would like to see HFNZ provide

Fifteen responses were provided to this question. The most common response from participants was that they wanted more contact with their outreach workers, with specific comments about change in staff and rapport building. Three of the responses were question marks or N/A and one person talked about the need for designated physio in all regions.

- More contact with outreach workers (4)
- More medical information (3)
- More workshops and camps (2)
- Social events / active masters group (2)

Question Nine: What information/education materials would you like in relation to getting older with a bleeding disorder?

Participants were asked to select all answers that applied from a multi-choice list. Thirty-one participants responded to this question. There were 129 options selected.

Information regarding new treatments and Pain management rated the highest receiving 15 votes each, followed closely by the need for information on remaining active, exercise and weight management. One person provided an alternative in the *other suggestions* option; stating *'Medical issues to look out for'.*

Option	**Reponses**
New treatments	15
Pain management	15
Remaining active	14
Exercise	13
Weight management	13
Safety at home when getting older	11
Working with a GP	11
Nutrition	9
Travel	8
Caring for mental health	7
Accessing aged care services	6
Vein care	3
Accessing NDIS	1
Financial management	1

Question Ten: How supportive is your HFNZ Outreach worker?

Thirty-one responses were provided to this multi-choice question. The most common selection was that participants felt '*Moderately supported'*, by their outreach worker, which 35% of the participants selected.

Of the six participants that selected *unsupportive* or *very unsupportive*, four were female. Of the seven participants that selected *very supportive,* 6 identified as male.

Options	**Responses**	**Percentage**
Very supportive	7	22.5%
Considerably supportive	7	22.5%
Moderately supportive	11	35%
Unsupportive	3	10%
Very unsupportive	3	10%

Question Eleven: How involved are you with groups, clubs or teams (e.g. spiritual, cultural, volunteer, sport, hobbies or educational)?

Thirty-five responses were provided to this multi-choice question. Of these responses the majority, 13 participants selected that they were ‘*Not at all involved*’, with groups, clubs or teams.

Options	**Responses**	**Percentage**
Very involved	4	12%
Considerably involved	8	23%
Moderately involved	5	14%
Slightly involved	5	14%
Not at all involved	13	37%

Question Twelve: Please list these, and comment if you think any are specifically beneficial to people with bleeding disorders?

Sixteen responses were provided to this question. Car clubs, golf, and swimming received were the most common.

Activity	**Number of participants**
Car club	3
Golf	2
Swimming	2
Yachting	1
Club Sport	1
Gym	1
Trotting club	1
Retirees club	1
Race walker	1
Researching genealogy	1
Rugby	1
Church	1
Bridge Club	1
Weaving	1

Question Thirteen - How supported do you feel by family and friends to meet your emotional needs?

Thirty-two responses were provided to this multi-choice question. Of those participants who responded, 94% felt moderately supported or more by their family and friends to meet their emotional needs.

Options	Responses	Percentage
Not at all Supported	1	3%
Slightly supported	1	3%
Moderately Supported	10	31%
Considerably supported	7	22%
Very supported	13	41%

Question Fourteen: What could HFNZ do to help your support network better understand your needs?

Eleven responses were provided to this question:

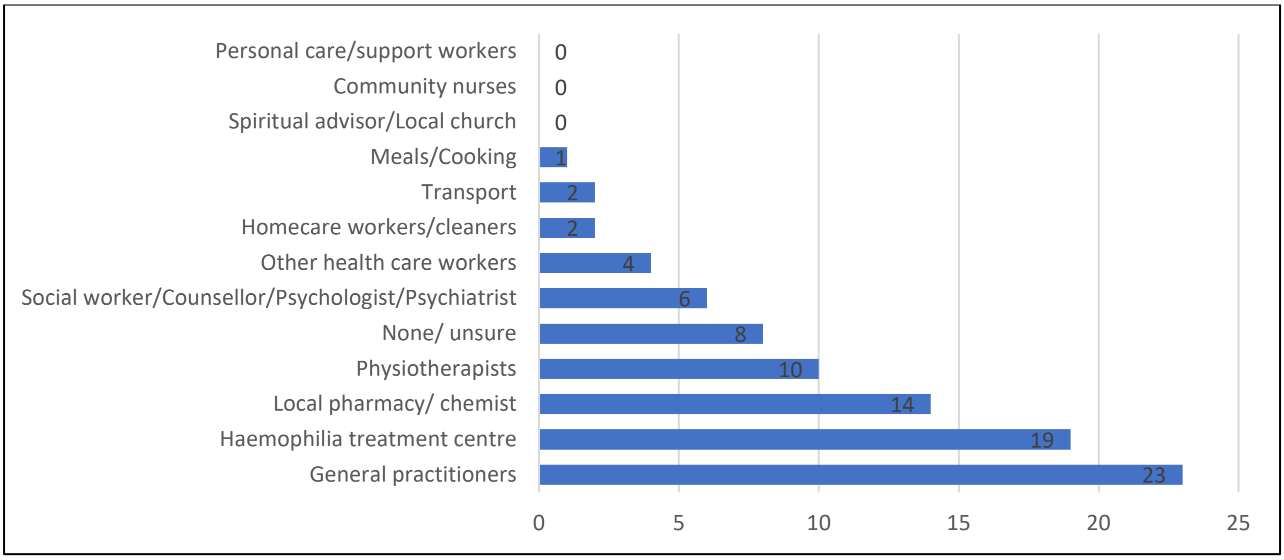
- Four people talked about ensuring there is up-to-date education and information for family, friends and employers
- Two people indicated a need for support people to have access to outreach workers
- Three participants replied with not sure or nothing
- One person said to continue as they are

Question Fifteen: What services do you access for support?

Thirty-four participants responded to this multi-choice question. Participants were asked to select as many choices as they wanted from the list of 12 options, in total 89 selections were made.

The support service selected the most times by participants was *General practitioners* with 23 responses, which equates to 67% of the respondents, followed by the HTC.

Spiritual advisor/Local church, community nurses, personal care/support workers were not selected by anyone.



Question Sixteen: To what degree does having a bleeding disorder affect your mobility?

Thirty-three participants responded to this multi-choice question. Thirty-six percent of the respondents (12 people) selected not at all. One person selected that they were severely affected, (male participant, aged 70-79).

Options	Reponses	Percentage
Not at all	12	37%
Slightly	7	21%
Moderately	6	18%
Considerably	7	21%
Severely	1	3%

Question Seventeen: To what degree do you experience pain as a result of your bleeding disorder?

Thirty-three participants responded to this multi-choice question.

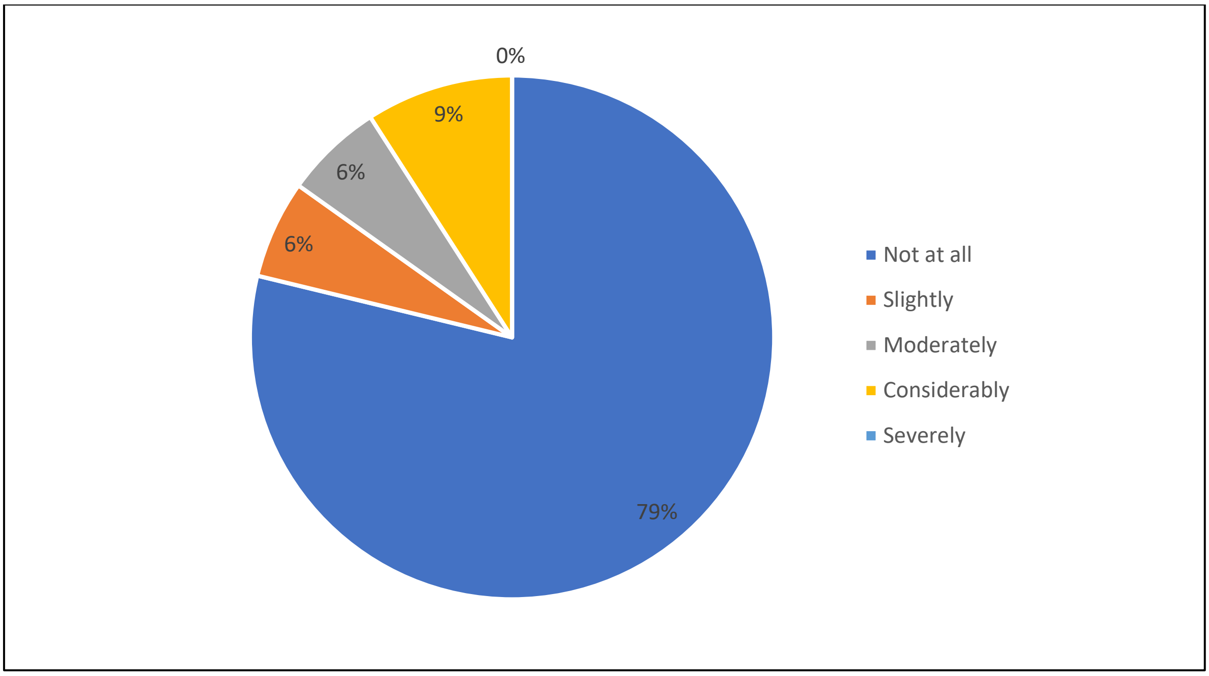
The most common selection was *'slightly'* with 10 participants selecting this response. Two participants selected severely, they are both male and 55-59 years old.

Options	Reponses	Percentage
Not at all	9	27%
Slightly	10	31%
Moderately	5	15%
Considerably	7	21%
Severely	2	6%

Question Eighteen: To what degree do you experience transport difficulties to access services or supports?

Thirty-three participants responded to this multi-choice question.

An overwhelming majority, 26 respondents (79%), selected the *not at all* option and no one selected *severely.* Three participants selected considerably.



Question Nineteen: If you experience transport difficulties please list any details that might be impacting on your ability to get to and from services?

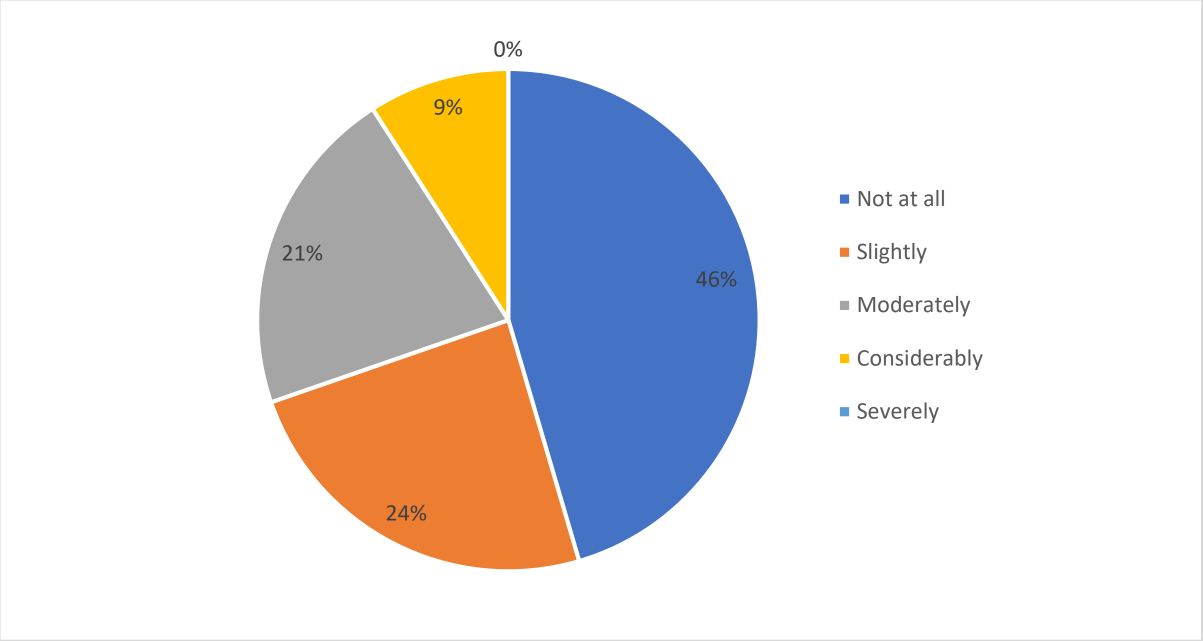
Three responses were provided to this question, and one wrote not applicable, the responses are as follows:

- Bus drivers not pulling the bus in close to the footpath
- Difficulty getting into and out of the car as a passenger and driver
- Ambulance or shuttle service

Question Twenty: To what degree does your bleeding disorder impact on you financially?

Thirty-three participants responded to this multi-choice question.

Fifteen of the respondents (46%) selected that a bleeding disorder does '*not at all' impact* on them financially and no one selected '*severely'.* Three participants selected considerably all of them fall within the 55-59 age bracket.



Question Twenty-One: Please list any other key factors that limit your ability to engage with support services.

Thirteen responses were provided to this. Three wrote none/not applicable/all okay, the responses are as follows:

- Lack of knowledge about support services and what they can offer (3)
- Mobility (3)
- Pain (2)
- Medical issues (2)
- Finding a suitable parking spot
- Need to work full time
- No support

Question Twenty-Two - Would you like to participate in a focus group to discuss your opinions?

Twelve participants initially indicated they would like to participate in the focus groups.

Focus group and interview qualitative analysis

This thematic analysis incorporates the content from a focus group (of four participants) and four individual interviews; all gathered using either online video conferencing or phone interviews between 03 and 19 June 2022.

All participants had contributed to the initial survey and advised that they wanted to participate in the focus groups. They were able to participate in whatever format they preferred or was most convenient to them.

The focus group had four people, two females, and two males. Two were in the 60-69 age range, one in the 55-59 age range, and one in the70-79 age range. The session was 85 minutes.

The four individual interviews consisted of three males, and one female. The age ranges were the same as the focus group, two were in the 60-69 age range, one in the 55-59 age range, and one in the70-79 age range. The individual interviews took approximately 30 minutes each.

Both formats included the same questions, which were established using the feedback gained in the initial survey. They were all deliberately posed as open questions which allowed for discussion and sharing of other important or relevant factors or areas as they arose. The key questions broadly focussed on:

- Access to services and supports
- Outreach support
- Social Supports
- HFNZ support

One key theme featured throughout the focus groups was the participants concerns and issues around their own physical health. This was brought up repeatedly, and threaded throughout the broad discussion areas. This is particularly interesting given the sessions and questions were developed to focus on services and supports.

All participants indicated that as they get older with a bleeding disorder life gets a lot harder for them and there is a lot more for them to consider:

> *"A number of us have quite a lot of disabilities and it seems to bite as you get older and older"*
>
> *"I was hoping life would get easier as we got older…but it's actually a bloody sight harder"*
>
> *"As we get older, more things come up".*

Below are some of the key themes that emerged from the interviews and discussions:

Access to services and supports (health)

Most people found that the medical system could be tricky to navigate in terms of knowing which specialists to follow up with, and a clear concern was of medical professionals bleeding disorder knowledge (for example physiotherapists and occupational therapists). Participants found that often it was left up to them to weigh up decisions about their needed surgeries, support and medical care as other people did not understand the complexities they live with "no one knows how to properly assess our needs."

Participants also felt they were sometimes lost in the hospital system, and they found the medical system slow in meeting their needs and that everything has to be hard fought for. They found it hard to access the equipment they need and were often waiting very long periods.

"The chances of getting into the health service are slim to nil"

"I needed a walker. It's impossible to try and get"

"I've been looking for a suitable chair…. impossible to find".

It is important to note that this on the most part was in relation to the wider medical system (not the Haemophilia Treatment Centre). Medical professionals from the Haemophilia Treatment Centre were spoken about in high regard.

Discussion about deteriorating bodies and the need for specialist equipment to support their specific health and mobility needs was also a key theme in the focus group and two individual interviews. They stated that, not only is hard to get the needed equipment but some of the participants in the focus group identified that standard issue equipment was not always suitable for their bodies or "totally inappropriate" causing further pain, bruising and bleeds. They noted that standard issues equipment they receive is often inadequate and harmful to them, as it did not take into consideration their bleeding disorder.

There was much discussion throughout the focus group and interviews about the possibility of HFNZ funding some of this equipment, which is essential for mobility and quality of life of some older people with bleeding disorders. Some suggested if not funding or only partial funding, then perhaps HFNZ could play a role in sourcing / helping to advocate for grants or external funding around mobility equipment such as mobility scooters, walkers, and wheelchairs – which are hard to find, access, fund, and often not suitable for their needs. It was agreed this funding should be open and easy to access.

"Could the foundation be a bit of a hub where grants could be found for mobility aids?"

"Keep our men active and alive… I'm surprised that you have to buy your own scooters… I think it's a must for the Foundation to apply… We run camps and get hot air balloons and helicopters and really expensive things… surely, we need that money to go to our 30 or so older people who need to be able to move… I would re-direct funds to mobility aids"

"I would hate to see someone cooped up in a one-bedroom flat and not going out because they don't have the equipment they need".

Some discussion was also had about the importance of trying to maintain a healthy body weight to prevent further joint damage, as two participants agreed, "With lack of mobility weight is an issue too."

While it will be reiterated in the outreach workers element of this thematic analysis, there was significant feedback on how useful it would be if outreach workers were also health ambassadors. Their role should include helping to advocate and supporting members to get the equipment they need, providing advocacy for members at hospital appointments, having in depth knowledge of what is available for members to access across the board, and being able to share that knowledge in a way that is specific to each individual need.

Outreach workers

When discussing outreach workers most of the participants (7/9) talked about lack of connection and support. Most of them had not seen an outreach worker for many years or may have a quick catch-up once a year that did not focus on getting into the details of their specific needs and issues.

"I haven't seen an outreach worker for a couple of years cause the staff are turning over so much"

"Only one or two over the years have bothered to come and see me"

"An experienced outreach worker should be able to see needs for the members"

"I would love to know who to contact if there was an issue".

Two participants had experienced the other extreme where an outreach worker may be contacting them too much and this felt like more a of a tick the box exercise; "they are constantly trying to get hold of us … some have interfered with privacy by asking too many questions"

There was a lot of discussion in the focus group, and one interview, about the recruitment of outreach workers and the types of people participants thought best suited to an outreach role. Participants thought it might be best to recruit outreach workers who are already connected to HFNZ, like family members of someone with bleeding disorder. They talked about their favoured experiences with outreach workers who had been previously involved with the foundation *"there has been some bloody good ones"*. People who already had connection to bleeding disorders were likely to have some historical knowledge as well as empathy. They believed it was also likely that they would stick around in the positions longer. Participants did not think that outreach workers needed to be social workers, they just wanted people who acted as a 'hub of information', 'navigators', 'admin' and 'connectors' and most importantly, people who had a lot of aroha and empathy. They believed many were using the role as a steppingstone in their career. "For a long time, they have been employing the wrong people".

One participant said there has been so many changes and that members had not been informed or they themselves may have applied.

They thought perhaps outreach workers from outside the bleeding disorder community needed to spend more time upskilling in terms of the impact of bleeding disorders on older people and that the candidate needed a very good understanding of the role and community before offering a job.

"They walk through the door seeing us bent and battered people and think oh my god what have I walked into here"

"They don't have the knowledge, experience, or tools in their tool kit to make a significance difference"

Two participants in interviews talked about how a nurse's skills and knowledge would be useful in this outreach role as well.

Participants also suggested that outreach workers need regular training/hui where they meet with a group of active parents and an older member to share their experiences and gain insight into what members need and what their expectations are.

Everyone agreed that the main role of an outreach worker should be doing everything possible to connect people with bleeding disorders to other people with bleeding disorders.

"The measure for attendance is wrong … we have to aim to get everybody there. That is what outreach should be for"

"Social activities are really great, but we [members/branches] had to do a lot to contact and keep communicating with people and encouraging them to come. I thought that is what OR should do"

"Outreach doesn't bring people together".

Participants thought the main role for outreach in meeting their specific needs would be:

- Helping to advocate and support them to get the equipment they needed for their mobility issues.
- Encouraging people to attend camps and workshops. Outreach should aim to get everyone to these events. Helping them to overcome and challenges or barriers. Encouraging and making sure people felt supported to attend.
- Advocacy for members at hospital appointments and education.
- More information for members on their very specific issues and needs.
- Knowing what is available for older members to access and clearly telling them about what is available.

There was also comment from two participants that it is difficult to see what outreach can actually do to 'help' them, especially if they do not fully understand the impacts and have the relationships. "I find it difficult to see what they can do in lots of ways".

Three participants talked about key outreach workers who made a big difference in their lives in terms of support and connecting them to others when they first connected to the foundation; "outreach got me involved in HFNZ".

Social support

Throughout all the conversations, the importance of social connection with others with bleeding disorders was a key theme for everyone. The participants were very clear that face-to-face time together was essential and should be a main role for HFNZ and outreach workers. These camps, workshops, meetings, and social events should provide a space for discussions, support, and sharing. This was more important than the education sessions for many.

Participants talked about the need to connect with people who were similar to them (same bleeding disorder, same gender, and same age). They need to share with people with similar experiences. This was an agreed point by others.

> *"Talking to someone else who has a particular bleed is quite valuable"*
>
> *"Talking to people with similar experience is valuable"*
>
> *"Good to know others are having as much trouble as we are".*

When the camps and workshops are so diverse it is hard for them to connect with those people with similar experiences. There were some suggestions made that during larger workshops/camps, where there is a variety of bleeding disorder, age, genders etc., there is a considerable and dedicated time for these specific groups with common experiences to spend time together.

A few participants mentioned that having a central location for all camps would not only be an economical decision but for older people with bleeding disorders (one plane ride for all), but also that going to the same place for events would add some familiarity and helps manage stress and mobility:

> "Travelling hard for some older people"
>
> "We need a base – wellington would be easiest and best – a neutral spot – no one needing two flights - not all travelling really far – know who organising and can be the same familiar place".

There were discussions about using Facebook to connect, however everyone had differing thoughts and views on how useful this would be and how it would be best achieved.

Some participants really missed the social aspect, and with adult camps every second year, if they missed one it might be four years before they saw another person with a similar bleeding disorder.

Three people who lived further from the centres commented that it is hard to get to social events in the local branch depending on where you are based/live. These people are often the ones who need the most support, so work needs to be done to get them to national events "the people who are isolated who don't get to anything need the most assistance (financial and encouragement)".

However, one said that it makes sense to focus on the local get-togethers, as it would be cheaper, easier, and more time effective for people. Two people mentioned that they individually would call around and get people together but were not allowed contact details of members, therefore it relied on outreach doing this well.

HFNZ

Like the questionnaire, there were not many specific suggestions about changes HFNZ may need to undergo to better support their older members when asked specifically. It seems that the main reason for this was that participants felt that HFNZ was no longer visible, that they have *"wound down"* and participants were not sure what HFNZ actually does, as they do not see a lot anymore.

> *"Think the foundation has wound down a lot"*

"HFNZ is absent without leave the last 3 or 4 years"

"We don't see a lot to be able to change things"

"HFNZ has lost its purpose for the people in translation somewhere along the way".

There were questions about the role that HFNZ now plays in national haemophilia care. There was a belief that perhaps the clinicians have *"regained control of the haemophilia agenda"*, yet this was still a very important space to have a strong HFNZ voice as were any other advocacy.

"Pushing issues forward like we did for Hepatitis C"

"I'm not sure where we are at for advocacy"

"I wonder how much input HFNZ now have into the group controlling haemophilia treatment now…I would like to see haemophilia with a fairly strong and loud voice into that group".

Bleeding disorder medication was also mentioned by a few. One participant talked about getting access to new medication being life changing, one wanting to know what advances and trials were happening and if/when they might get access *"getting a long-lasting blood product … would be a miracle"*.

A few people mentioned the idea of HFNZ being more of a 'hub' – a place with bleeding disorder information, but also a place older members can go to be linked up with other supports and services information. This may include events for senior citizens, how to access activities for older people, how to access needed equipment, how to access specific WINZ subsidies, and a list of medical people in the regions who are familiar with bleeding disorders such as general practitioners and physiotherapists. All HFNZ benefits should also be clearly displayed so they know what they can access; a single place to get all of the information they need as they age.

Some small but relevant points that were brought up briefly by numerous people in discussions and which relate to HFNZ were:

- Many people are appreciative of the supportive footwear vouchers. This group often need specialty footwear due to a lifetime of bleeds. Members need to know that they can access these as some thought they were for the younger ones.
- The gym is very useful and greatly appreciated for some, although some are unable to get to the gym due to mobility issues. One participant indicated funding of other things such as Pilates and Thai chi would be useful.
- One person mentioned having an older member on the council, but consideration would be needed around mobility and fatigue.
- HFNZ need fresh people in council with new ideas and passion and enthusiasm
- Someone thought that counselling might be an area HFNZ need to look at more closely in terms of supporting members to access this.
- There was some discussion about participants' shaky joints bleeding more, and needing specific needles for their eyesight and older veins, which are sometimes hard to access.

Combined research analysis

The analysis below pulled together key information from the quantitative analysis from the national survey, and from the thematic analysis of the focus group and interviews. You can refer to both of these in detail in the prior sections. It also includes a summary of research impressions/final considerations.

The overall objectives for this research were to:

1. Identify the issues and challenges faced by older members
2. Identify level of engagement of services and supports used by older members
3. Identify improvements needed to services and care to support older members.

These headings are used below to present the key findings of the combined quantitative and qualitative data gathered.

Identify the issues and challenges faced by older members

Medical issues

While medical issues were not a focus of the survey, some answers in the survey and a lot of the focus group and interview discussions did sway to issues and concerns with medical, physical health and mobility. This is particularly interesting given the sessions and questions were developed to focus on services and supports.

All of the focus group participants and the majority of the interview participants indicated that as they get older with a bleeding disorder life gets a lot harder for them and there is a lot more for them to consider.

The survey highlighted that the two top areas participants wanted more information about was also related to medical issues, with ‘new treatments’ and ‘pain management’ both selected by 15 participants.

When asked at the end of the survey if there were any other challenges individuals wanted to highlight, medical issues were spoken about in more detail by two participants (the third equal most prevalent answer).

There was also significant discussion in the focus group and interviews highlighting the challenges in navigating the medical system. Participants expressed concern that many medical professionals (outside of the Haemophilia Treatment Centre) lack bleeding disorder knowledge. Participants found that it was frequently left up to them to weigh up decisions about their needed surgeries, support and medical care as other people did not understand the complexities they live with. Additionally, participants also felt they were sometimes lost in the hospital system and that everything had to be hard-fought.

Access to medical equipment

Access to medical equipment was also a significant topic of discussion in terms of issues and challenges in the qualitative analysis. Participants expressed that they have found it hard to access the equipment they need and were often subjected to very long wait periods. They highlighted that not only is hard to get the needed equipment but that standard issue equipment was not always suitable for their bodies, causing further pain, bruising and bleeds.

Mobility, pain, and remaining active

In the written survey, when asked to what degree their bleeding disorder impacts their mobility, 63% of participants said that their mobility was impacted in some way. Additionally, 73% of people said they experienced some pain in relation to their bleeding disorder.

When asked at the end of the survey if there were any other challenges that they wanted to highlight which limit their ability to engage with services, mobility and pain were both discussed in more detail (the second and third-equal most prevalent answer).

Some focus group and interview discussions were also had about the importance of trying to maintain a healthy body weight to prevent further joint damage, this was reinforced by the survey where ‘remaining active’ (14 people), ‘exercise’ (13 people) and ‘weight management’ (13 people) were the most prevalent areas where participants wanted more information (after pain and new treatments).

Outreach

When discussing outreach workers support, a key challenge or issue that arose from most of the focus group and interview participants (7/9) was the lack of connection and support they felt they received from their HFNZ Outreach Workers. Most of them shared that they had not seen an outreach worker for many years or may have a quick catch-up once a year that did not focus on understanding the details of their specific needs and issues.

It is important to note the challenges that arose around outreach workers in the qualitative findings. However, this needs to be balanced with the questionnaire responses where participants were asked how supported they felt by their HFNZ outreach workers, 14 indicated they felt very or considerably supported, 11 indicated they were moderately supported and 6 indicated they were unsupported or very unsupported.

Identify level of engagement of services and supports used by older members

HFNZ services used

The written survey asked participants which HFNZ services they had used in the last year:
The service which was used the most by the members was the Bloodline magazine (21), which was nearly double that of the next most used services, Outreach worker support and Pānui (both 12). None of the participants selected defensive driving program.

Participants were asked which services they found to be the most valuable and the key themes in feedback were: Outreach worker support (8), Bloodline & Pānui (4), Conference & workshops (3), social events (3), footwear (2), and two indicated all services are important.

In the qualitative analysis, many people mentioned their appreciation for and the usefulness of the supportive footwear vouchers and the gym membership. Camps and workshops were also discussed at length as being a crucial HFNZ function.

Other services used

In the written survey participants were asked what services they access for support, the support service selected the most times by participants was General practitioners (23), followed by the HTC. HTC was also spoken about in the majority of interviews and focus group as being a very supportive service.

Spiritual advisor/Local church, community nurses, personal care/support workers were not selected by anyone.

External support (groups, clubs or teams)

There was high engagement with external support. The survey asked participants to indicate how involved they are with groups, clubs or teams (e.g. spiritual, cultural, volunteer, sport, hobbies or educational). Twelve participants said they were ‘very’ or ‘considerably’ involved, 10 said they were moderately or slightly involved, and 13 said they were not involved at all.

When looking at the types of groups people were involved with that they thought were most beneficial to people with bleeding disorders people responded car clubs, golf, and swimming.

Emotional support

The participants were also well engaged with a variety of emotional support. The survey asked participants how supported they felt by family and friend to meet their emotional needs, of those participants who responded 94% felt moderately supported or more by their family and friends to meet their emotional needs.

Transport services

The written survey asked participants to what degree they experienced transport difficulties to access services and supports. An overwhelming majority (79%) selected the *not at all* option and no one selected ‘severely’.

In terms of transport for camps/workshops, the focus group mentioned that having a central location for all camps would not only be a sensible economical decision (one plane ride for all), but also that going to the same place for events would add some familiarity and help to manage stress and mobility. Three people who lived further from the centres commented that it is hard to get to social events in the local branch depending on where you are based/live.

Limitations for engagement with support services

Participants were asked to list key factors that limit their ability to engage with support services the following key themes emerged: Lack of knowledge about support services and what they can offer (3), mobility (3), pain (2) and medical issues (2).

Identify improvements needed to services and care to support older members

HFNZ

The written survey asked participants how effective HFNZ was in meeting their needs, the most popular response was that HFNZ is in the upper-mid range and is ‘Effective’ in meeting their needs (32%), followed by ‘fairly effective’ (23%).

The survey asked if they thought HFNZ could change to meet their needs better, and 69% said maybe, followed by 19% saying yes, and 12% saying no. The survey then asked participants to list any specific services, events or activities they would like to see HFNZ provide, and only 15 responses were provided to this question. The most common response from participants was that they wanted more contact with their outreach workers, with specific comments about change in staff and rapport building. There were three responses asking for more medical information, two asked for more workshops and camps and two asked for more social-events.

The survey asked participants to outline what HFNZ could do to help their support network better support them. Four people talked about ensuring there is up-to-date education and information for family, friends, and employers, two people indicated a need for support people to have access to outreach workers as well.

Like the written survey, there were not many specific suggestions from participants in the focus groups and interviews about changes HFNZ may need to undergo to better support their older members when asked specifically. It seems the main reason for this was that participants felt that HFNZ was no longer visible, that they have “wound down”, and participants were not sure what HFNZ actually does as they do not see a lot anymore.

A few people mentioned the idea of HFNZ being more of a ‘hub’ – a place with bleeding disorder information, but also a place older members can go to be linked up with information on other supports and services regarding ageing.

Medication

Bleeding disorder medication was mentioned by a few in terms of improvements they want to see made. One participant talked about getting access to new medication being life changing, and some wanting to know what advances and trials were happening and if/when they might get access “getting a long-lasting blood product…would be a miracle”. ‘New treatments’ was also top equal (15 people) in the survey for an area participants wanted more information about.

In the focus group, there were some questions and concerns about the (lack-of) role that HFNZ now have in the national haemophilia care groups and their role in advocacy in terms of treatments and medications.

Outreach

In terms improvements, there was a lot of discussion in the focus group, and one interview, about the recruitment of outreach workers, and the types of people participants thought best suited to an outreach role. Participants thought it might be best to recruit outreach workers who are already connected to HFNZ through family members or someone with bleeding disorder, as they were likely to have some historical knowledge as well as greater empathy. They believed it was also likely that they would stick around in the positions longer.

Participants did not think that outreach workers needed to be social workers, they just wanted people who acted as a ‘hub of information, ‘navigators’, ‘admin’ and ‘connectors’ and most importantly, people who had a lot of aroha. They thought the main role for an outreach worker for older people with bleeding disorders should be to advocate and support them to get needed mobility equipment, advocate at medical appointments, encourage people to attend camps (and help people overcome any obstacles), and to know about and help people to access entitlements.

They thought that outreach workers from outside the bleeding disorder community might need specific training to understand the true impact of bleeding disorders on older people.

Social connection

Throughout the survey and all the conversations, the importance of social connection with others with bleeding disorders was a key theme for everyone. The participants were very clear that face-to-face time together was essential and should be a main role for HFNZ and outreach workers. These camps, workshops, meetings, and social events should provide a space for discussions, support, and sharing. This was more important than the education sessions for many. Participants talked about the need to connect with people who were similar to them: same bleeding disorder, same gender, and same age. They need to share with people with similar experiences.

Some participants really missed the social aspect, and with adult camps every second year, if they missed one it might be four years before they saw another person with a similar bleeding disorder.

In the survey, ‘conferences/workshops’ were chosen by three participants as one of their most valuable HFNZ services, and ‘social events’ were also chosen by three.

Interestingly these face-to-face camps/workshops were much more highly valued by participants than online, Facebook, or masters group events/communications.

Researcher impressions and key areas for consideration

The key impressions the researcher came away with following both the quantitative and qualitative research were:

- Participants are concerned about mobility as they age and access to appropriate medical equipment is a key issue. HFNZ to consider funding or helping to support members to access equipment
- Face-to-face social engagement within the cohort is hugely important especially when it allows for shared experiences with those facing the same challenges as them. It should be a priority to get as many members connected face-to-face to local and national events as possible. People need to be contacted to discuss these events and help provided to overcome any barriers to attend them
- More information and support is required regarding keeping physically active (exercise, keeping mobile and weight management)
- More support and advocacy is required from outreach to help members navigate the health system and access appropriate advice, medications, equipment and supports
- Review recruitment and retention of outreach workers
- HFNZ needs to increase their visibility to members and also ensure members know what entitlements and services are available to them
- Bloodline, Panui, Outreach, face to face interactions and footwear vouchers were the most used and valued supports from HFNZ
- Emotional networks (family & friend), and external networks (clubs, hobbies, groups) were areas where participants felt very supported and did not have further needs.

It was both a privilege and a pleasure to be involved in this research. The feedback and information provided (particularly as part the focus group and individual interviews) was delivered by an engaged and passionate cohort with a genuine intent to help provide feedback that would grow the service and ensure that future generations, as well as their peers, got the best support possible.