Appendix 1

Getting Older Community Survey findings

The **Getting Older Community Survey** was a questionnaire for people with bleeding disorders in Australia who are getting older and their partners, family and carers. It was available in print and online.

The survey was one of several consultation tools used for the Haemophilia Foundation Australia **Getting Older needs assessment**. It built on the initial Getting Older project needs assessment consultation, which was primarily conducted through interviews and community forums, to strengthen the evidence base.

The survey was intended to reach the wider bleeding disorders community nationally to:

- Collect a wider sample of information on needs identified in the initial community and health professional consultation, including work/retirement, finances, aspirations for the future, support and social connectedness
- Identify specific needs and preferences around information and education, computer use and online and social media platforms.

It complemented the health impact and quality of life data HFA was collecting during 2019 in the **PROBE (Patient Reported Outcomes Burdens and Experiences) study**.

Ethics approval for the survey was obtained from the Bellberry Human Research Ethics Committee on 30 October 2019.

RECRUITMENT

The survey was distributed during November and December 2019.

- The print survey was posted nationally to community members on Haemophilia Foundation Australia and state/territory Foundation mailing lists. In some states, parents of young affected children with no family history of bleeding disorders were excluded from the mailout.
- The online and print surveys were promoted via Haemophilia Foundation Australia and local foundation email newsletters and social media platforms, including Facebook, Instagram and Twitter.

RESPONDENTS

There were **169 respondents**:

- 157 (93%) completed the survey
- 12 (7%) partially completed the survey

Respondents who only completed the demographic questions were excluded.

How did they respond to the survey?

- 89 (53%) returned the online survey
  - 74 were older people with a bleeding disorder
  - 15 were partners/family/friends/carers
- 80 (47%) returned the print survey
  - 59 were older people with a bleeding disorder
  - 21 were partners/family/friends/carers

Table 1: Respondents

	Older people with bleeding disorders	Partners/family	Total
Total (N=)	**133**	**36**	**169**
Male	87 (65%)	7 (19%)	94 (56%)
Female	45 (34%)	29 (81%)	74 (43%)
No gender given	1 (1%)	-	1 (1%)
Age groups			
25-34 years	7 (5%)	2 (5%)	9 (5%)
35-44 years	13 (10%)	5 (14%)	18 (11%)
45-54 years	25 (19%)	6 (17%)	31 (18%)
55-64 years	32 (24%)	13 (36%)	45 (27%)
65-74 years	38 (29%)	8 (22%)	46 (27%)
75 years +	18 (13%)	2 (5%)	20 (12%)
Where they live			
Capital city	60 (45%)	18 (50%)	78 (46%)
Rural/urban fringe	18 (13.5%)	2 (6%)	20 (12%)
Regional/rural/remote	37 (28%)	12 (33%)	49 (29%)
No answer	18 (13.5%)	4 (11%)	22 (13%)
What state/territory they live in			
ACT	2 (2%)	4 (11%)	6 (4%)
NT	1 (1%)	0 (0%)	1 (1%)
NSW	23 (17%)	8 (22%)	31 (18%)
QLD	25 (19%)	4 (11%)	29 (17%)
SA	18 (13.5%)	5 (14%)	23 (14%)
TAS	4 (3%)	0 (0%)	4 (2%)
VIC	28 (21%)	11 (31%)	39 (23%)
WA	14 (10%)	0 (0%)	14 (8%)
No answer	18 (13.5%)	4 (11%)	22 (13%)

PEOPLE WITH BLEEDING DISORDERS (PWBD)

Who were they?

Of the survey respondents, 133 completed the survey as a person who has a bleeding disorder or carries the gene and is getting older.

The question asking them to identify their situation highlights the multiple roles that people play when there is an inherited bleeding disorder in their family: while they themselves have a bleeding disorder or carry the gene, they may also be the parent, child, grandchild, sibling or occasionally the partner of someone with a bleeding disorder.

Figure 1: **Please tick all the statements that apply to your situation**

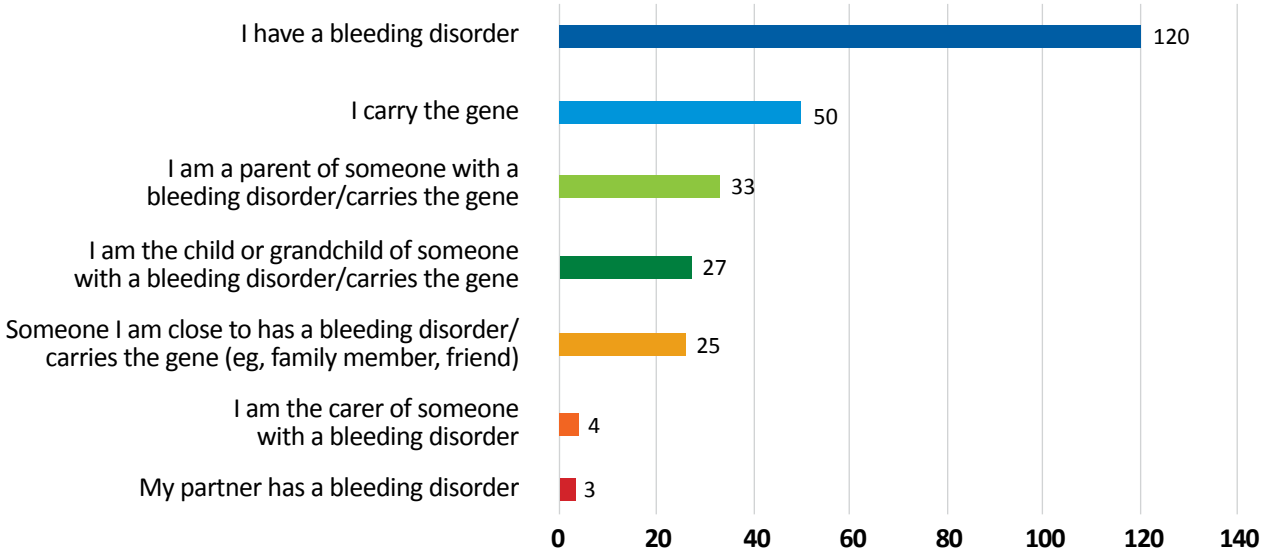


Table 2 shows the bleeding disorder of survey respondents who identified as older people with bleeding disorders. Some respondents indicated that they had more than one bleeding disorder.

Table 2:

Bleeding disorder	Response
Haemophilia	104
Von Willebrand disease	19
Rare clotting factor deficiency (factor I, II, V, V+VIII, VII, X, XI, XIII)	15
Inherited platelet function disorder	4
Acquired haemophilia	3

GETTING OLDER COMMUNITY SURVEY FINDINGS

Aspirations

By far the most commonly expressed aspiration for the future was to maintain their quality of life, be healthy and remain independent. This involved maintaining their mobility, reducing stiffness and pain, and being able to participate in family life, travel, pursue their interests and to 'be useful'.

> *'To remain fit, healthy and well. Travel. Support my children in caring for their future children, who may have haemophilia. Volunteer work.'*
>
> *'Maintaining my quality of life as I am noticing my health is getting more challenging year by year.'*
>
> *'To continue to be active and find a way to reduce stiffness and pain.'*

Being able to travel was high on their priority list and was associated with visiting family and friends as well as having adventures and enjoying themselves.

> *'To be well enough to enjoy time with family and friends and be able to travel overseas to where close family members now live.'*
>
> *'To travel with my husband and not have to worry about my bleeding disorder.'*
>
> *'Remaining active and continuing to be able to explore the world.'*

Another high priority was being able to follow their interests, whether they were related to sports, or other activities like gardening, art, writing, singing in choirs or helping their family.

> *'Be as healthy as I can be so that I can participate and be involved with my husband and wider family and friends and be able to continue to paint.'*
>
> *'Comfortable and safe accommodation, travel, engaging in enjoyable pursuits, being active and fit, quality family time, reading for fun.'*
>
> *'I would like to be able to be more active with the grand kids, to be able to garden, shop, gym and bike ride with a minimum of pain being generated.'*

For some, the vision of the future involved retirement or reducing work, while remaining comfortable financially. Others were more focused on staying involved in the community and continuing to work or contributing as a volunteer.

> *'To be able to choose how much I work after 60. Then to live an active and enjoyable retirement in good physical condition.'*
>
> *'Golf, travel, spend time with family and stay involved with the industry that I worked in (a few hours each week).'*
>
> *'To get out more. Be more social. Try to contribute more to the community. Experience new things. Enjoy life.'*

Concerns about achieving this

Health concerns were perceived as the greatest barrier to achieving their aspirations. Respondents spoke of joint deterioration and mobility issues, arthritis and pain, slow recovery after surgery and cancer.

> *'Intense deterioration of joint functions and daily level of pain.'*
>
> *'Recovery from operations/accidents take a LONG time. I rather hope to avoid them!'*
>
> *'The impact my bleeding disorder may have on treatment of medical issues including operations and removal of skin cancers.'*
>
> *'My mobility issues will hinder my life and life plans will not eventuate.'*

They were worried by the implications of their health care issues for aspects of their life, such as working, their interests and their ability to live independently.

'As I get older, the harder it will be to do the simplest things. Already difficult, concern is not being able to adapt like I have always in the past.'

'Physical and haematomas when doing physical work.'

'Ongoing loss of function that will prevent me doing the things I currently enjoy.'

'Restricted mobility combined with the possibility of some major medical issue that would necessitate confinement in an aged care facility.'

Finances were another concern, both being able to afford their health care costs and having the financial security to be able to stop work and afford to live comfortably.

'Cost and availability of ancillary health care - eg physio. Degenerative disorders. No adequate carer.'

'I don't have much super due to an intermittent part time work history. I worry that I won't have enough $. That my partner & kids will place high care demands on me. And vice versa.'

'Finances - medical expenses are costly. Location as driving to access services is more difficult as I get older. Services are not easily available where I live.'

Some described their frustration at having their health problems dismissed by health care providers, for example, when doctors perceived their complications as a common problem of ageing, or in other cases because they had a mild condition such as von Willebrand disease.

'Medical staff dismissing symptoms due to ageism. Eg "What did you expect, you're fifty now." Rather than explore the reason why I have painful joints.'

'Some agencies do not consider Von Willebrands disease to be of any concern. They may need help to understand the problems that we face.'

For some younger people with bleeding disorders, getting older caused concerns about raising their children.

Some older people were anticipating a shorter lifespan and grieving in advance for the loss of time with their partner and family.

'In terms of bleeding, concerned I may not be able to carry as many children as I would like, Concerned arthritis may prevent me from playing with my children as much as I'd like.'

'Not being able to see my grandchildren grow and prosper. The thought of not being with my wife.'

Current concerns

When asked about their greatest concerns at present, the most prominent were worries about the complications of their bleeding disorder and the challenges of living with multiple health issues as they aged. This included:

- skin problems, bruising and internal bleeding
- arthritis and need for further joint replacements
- need for factor replacement with surgery and medical procedures to manage the problems of ageing, such as cancer
- not being able to self-infuse
- increasing problems with mild conditions such as von Willebrand disease
- travel to the HTC, particularly if they lived in country areas.

'Access to DDAVP for removal of skin cancers and the added complication when having tests. E.g. colonoscopies.'

'Fragile skin and bruising easily.'

'Facing the prospects of getting total care following a total knee replacement. Prospect of long waiting list as public patient for same.'

'The need for joint replacement surgery (i.e. total knee replacements and ankle fusions) which despite the chronic pain I've been avoiding.'

'Not being able to continue to self-infuse as I get older and then having to go to a nursing home where they can't do it either.'

'As I age I was led to believe that von Willebrands would not be such an issue. I have NOT found this so. My body says otherwise!!!!'

'Von Willebrands seems to impact more now. I didn't know I had it till I was 40 but did realise something wasn't right.'

Pain, mobility and balance problems were also often mentioned. They were concerned about their increasing inability to manage their pain and the lack of medications that could help. Pain and mobility problems went hand-in-hand and were described as a 'breakdown' of their body with a serious impact on their independence.

'Mobility loss and loss of independence, rely on more full-time care from my wife.'

'Pain related to bleeds - a serious inability to control pain, now that codeine is unavailable over counter. And most GPs have no clue what REAL PAIN is.'

'Tripping over and losing balance. I do go to a fitness class focusing on balance.'

'Deteriorating joints makes exercise difficult so I am gaining weight which I am concerned with.'

The impact of their ageing on their relationships was another area of serious concern. For younger people with bleeding disorders, this could relate to supporting their partner and children, or even starting a family when they were uncertain of their ability to support them into the future. Older people were concerned about being able to support other members of their family who were ageing. This time in their life could also remind them of the premature loss of other family members with bleeding disorders, who did not survive complications when they were older.

'Bringing up my children as well as possible and keeping my relationship with my partner intact.'

'Starting a family. Wanting healthy children and to stay healthy myself.'

'The health of my ageing mother and mother in-law.'

'I lost my mother 2 years ago. Mum was a bleeder and had a major operation. When I talked to doctors about her bleeding disorder, it fell on deaf years!!! Because of their ignorance mother passed away.'

For some, financial security was the major concern: being able to buy their own home or remain in it, paying bills, financial stability into the future.

'Having to stop work before I am financially secure enough to do so.'

Future plans

Both people with bleeding disorders and partners/family were asked about the plans for getting older that the person with the bleeding disorder had made, in particular, financial, accommodation, legal and medical plans. In both groups, the highest proportion of planning had been financial. For people with bleeding disorders, there was a focus on owning their own home. Partners and family were more likely to comment on being careful with spending rather than formal financial plans. Planning around their future accommodation, which may involve modifying their current housing or moving to a smaller residence or to residential care, was also common. It was less common in both groups to comment on having formal medical or legal documents, such as a will, a power of attorney or an advance care plan. A considerable number in both groups said they had no plans. For some, this was a reflection of their personal situation and lack of financial security or family. Others commented on the psychological impact of making these types of plans.

GETTING OLDER COMMUNITY SURVEY FINDINGS

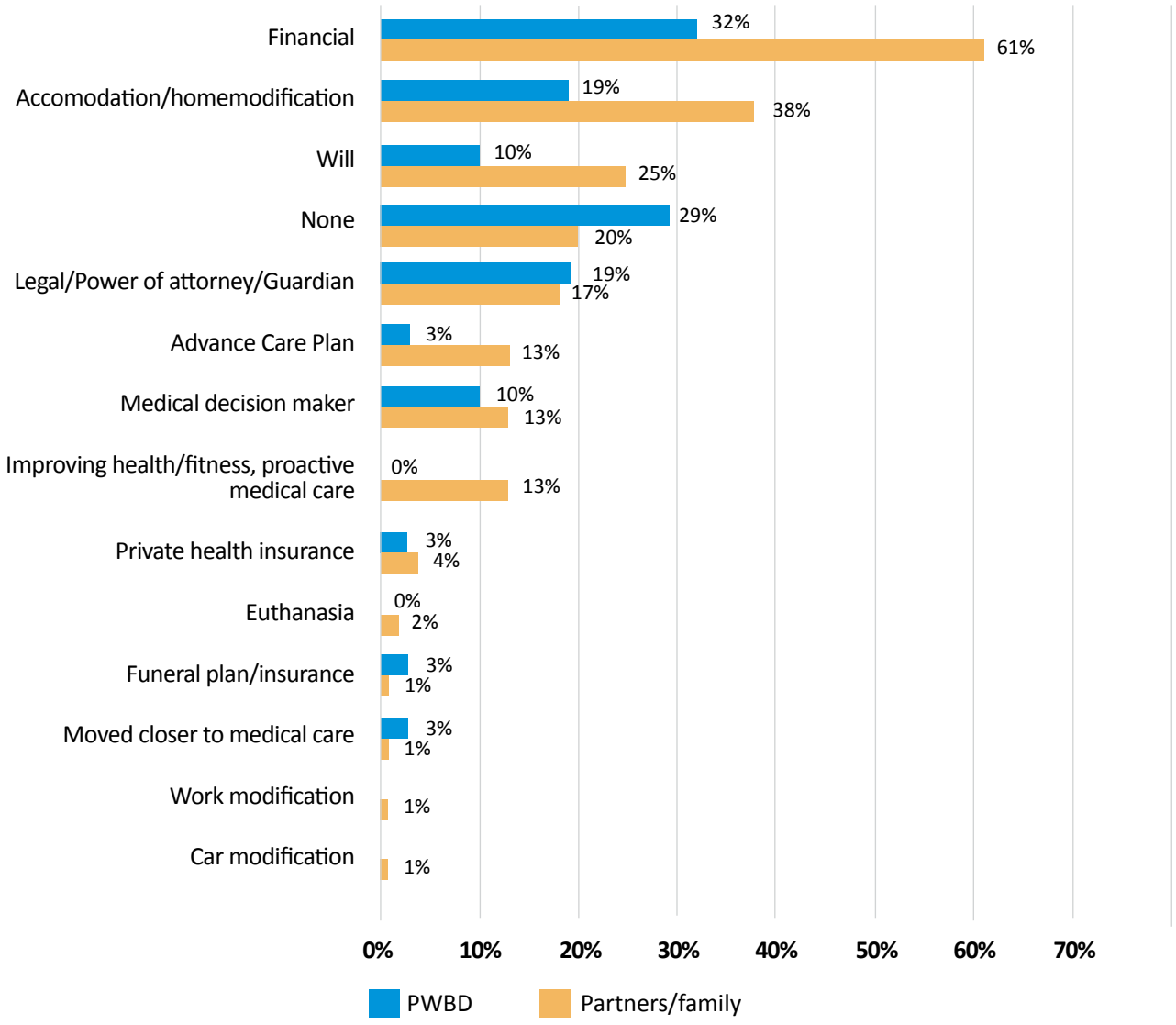
'None. Neither own my own home. No superannuation. NO legal arrangements, no wills no dependents, no partner.'

'None. Too stressful and neither of us are psychologically equipped to do so.'

For some people with bleeding disorders, planning for the future also involved improving their health and fitness and being proactive in their medical care.

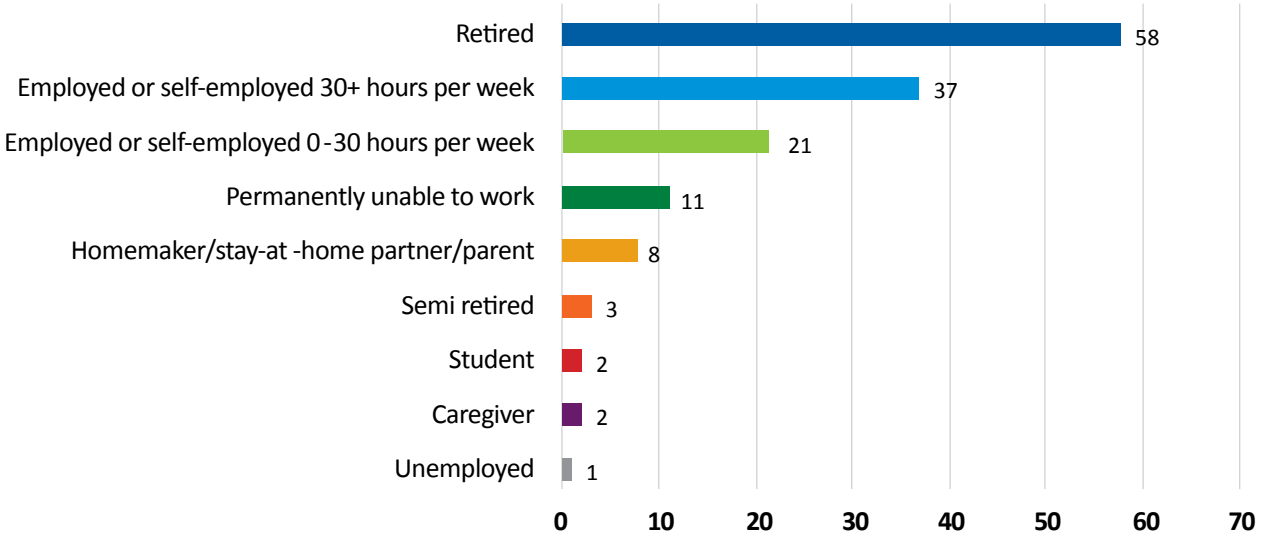
Partners or family were more likely to comment that there were plans for increased family support in the future.

Figure 2: **What plans for getting older have you put in place (with the person with a bleeding disorder?)**



Impact on working life

Figure 3: PWBD Please select the best description of your current work or study situation



The largest group were working (61/133 or 46%): most more than 30 hours per week (37/133 or 28%), while a smaller number were working less than 30 hours a week or described themselves as 'semi-retired' (24/133 or 18%). A similar number described themselves as retired (58/133 or 44). There was also a number who were permanently unable to work (11/133 or 8%). Some were homemakers (8/133 or 6%) and there was a small number of individuals who described themselves as students, caregivers or unemployed (5/133 or 4%).

The greater majority thought that their health had impacted on their work or study life (91/131 or 70%). This included:

- Disruption to study or work with time off and hospitalisation for bleeds
- Early retirement due to joint damage or HIV infection
- Difficulties with travel to work with mobility problems
- The negative impact of hepatitis C symptoms and treatment.

Some commented on the strategies they used to manage this, such as using up their leave or having modified duties, and some attended work in spite of their bleeding episode.

'Over the years, essentially my younger years when treatment of bleeds was non-existent or restricted my work and study life was impacted with days I couldn't attend.'

'Bleeds often stopped me going to school. I had to go to work when I had bleeds because work didn't know.'

'It has affected my education, however now that I manage it, it has minimal effects on my work life.'

'Sometimes especially if I have needed a tooth extraction and it causes issues and I can't go to work.'

'Numerous joint bleeds over many decades (mainly ankles and knees) and the associated impact these have had in terms of reduced mobility and chronic pain.'

'I have worked from the age of 16 years to 66 years continuously. I mainly took sick leave and went to work many times with nose bleeds, heavy periods etc and raised two kids, adopted children along the way.'

'For 25 years I was on crutches 20% of my working time.'

'Days off work due to bleeds. Modified duties due to pain.'

'I was forced to retire at the age of 54 because of complications from HIV acquired from C.S.L factor VII treatment.'

'Hep C treatment (2012-13) had a negative impact.'

A large group wished to stay longer in the workforce (54/128 or 42%), while for one-third this was not applicable as they were retired or permanently unable to work (33/128 or 32%).

Barriers

The greatest barriers they perceived were complications relating to their bleeding disorder: having a major bleed at work, arthritis, fatigue, and mobility and agility problems, the unpredictability of their bleeding episodes and the time taken to recover. Some commented that the impact of this increased as they grew older, for example, managing pain. Women were facing concerns about heavy menstrual bleeding associated with menopause.

'Fear of getting a major bleed or having to take time off work.'

'That I could get an accident at work and people wouldn't understand the urgency of internal bleeding if I was rendered unconscious.'

'General mobility and health. Additional time required to recover from bleeding episodes.'

'Arthritis may stop me from doing my work.'

'Range of movement, joint pain and bruising/pain from bumps etc.'

'The inability to control when, where and how often I become ill. The inability of doctors to recognise fatigue caused by the bleeding disorder as opposed to getting older.'

'Being physically and mentally being able to work enough hours to earn a decent income over time while managing daily life.'

'In my profession it is very physical. Knowing and feeling pain due to my duties not only affects my performance but mental health.'

'Age-related health problems where my bleeding disorder may complicate treatment. E.g. not being able to take anti-inflammatory medication.'

'That my womanly bleeding and hormone issues do not impact on my ability to perform.'

The impact of mobility problems on travel to work was also identified as a barrier.

'Staying mobile enough to be able to catch public transport to work and move around for work.'

Several commented that employers had a low tolerance for absentia and unreliability and that this had impacted on their work.

'Employers will no longer tolerate absences due to bleeding treatment.'

Others had fewer concerns at present because they were able to manage their bleeding episodes, particularly if their treatment protocol was preventing bleeds successfully.

'None, I am healthy and on prophylactic treatment.'

'I am comfortable staying in the workforce as the interruptions are not yet too intrusive.'

What would help?

When asked what would help them stay in the workforce, they had a range of suggestions:

- Improved treatment to reduce the number of bleeding episodes, or that could be taken orally
- Better pain management, which would improve mobility
- Modified work activities or change the type of job to reduce the number of bleeds
- Flexible working arrangements to accommodate bleeding episodes
- Retraining for more suitable work
- More understanding of bleeding disorders in the workplace
- Disability-friendly workplaces
- Government-funded support, including support from the NDIS.

'Reduction in the work activities which are a risk of me sustaining a bleed.'

'I have a desk job and use my mind so there is no work threat to me. I am happy to continue as long as I am interested and well.'

'Programs for them [employers] to understand how better to deal with it. Many times they think you are faking it.'

'Lots of things. Flexibility of work hours, having an understanding/supportive employer, career advice, support to retrain if required, pain management, physio, counselling, psychosocial support, you name it.'

'I am currently seeking NDIS support to manage my life better. But, my applications have been twice denied.'

A smaller proportion said they wished to reduce their working hours or retire early (26/82 or 32%). Suggestions on what would help included:

- Slightly shorter working day
- Financial sustainability
- Being able to work part-time
- Fewer personal demands outside the workplace.

Finances

The largest group of people with bleeding disorders who were getting older received their main source of income from their employment, either in wages/salaries or business income. A substantial number received government benefits, such as the age or disability support pension, carer payment or other government income support. More than a third were self-funded retirees, whose income came from superannuation or other investments. 12 (10%) were supported by their partner and 3 (2%) said they were supported by family or friends.

Table 3: PWBD
What are your main sources of income? Please select all that apply.

Answer Choices	Responses	
Wages/salaries	38%	49
Business income	8%	10
Superannuation	34%	44
Returns on investment, savings, rental, annuity (excluding superannuation)	22%	29
Age pension	26%	34
Disability support pension	15%	19
Carer payment	5%	6
Other government income support	2%	3
Partner supports me	9%	12
Family/friends support me	2%	3
	Answered	**130**
	Skipped	3

Superannuation and insurance

Table 4: PWBD
Have you had any of the following? Tick all that apply

Answer Choices	Responses	
Superannuation	91%	96
Life Insurance	37%	39
Income protection insurance	23%	24
Disability insurance	10%	10
	Answered	**105**
	Skipped	28

The great majority of people with bleeding disorders (96/105 or 91%) had superannuation. One third (40/119 or 34%) said they had problems getting insurance or superannuation. They mentioned income protection, disability and life insurance most commonly, with comments that they had been refused or that there were exclusions or much higher and unaffordable premiums. Many also described difficulty obtaining travel insurance. Some said they had not tried to get insurance.

'Yes, I have been refused life insurance, disability insurance as well as travel insurance.'

'I can't get income protection due to liver/Hep C prior history. I can't increase my base insurance cover for the same reason.'

'Difficult to get life insurance, so only have limited through my super.'

'Applied for TPD [Total and Permanent Disability Insurance] as a fit and healthy 55-year-old. Premiums were outrageously high and anything I was every likely to need to claim for was explicitly excluded from the cover. They did not 'get' that being an asymptomatic carrier did not increase the risk of me needing to make a TPD claim.'

'No problems obtaining superannuation or life insurance but I have had some difficulty purchasing affordable travel insurance.'

Housing

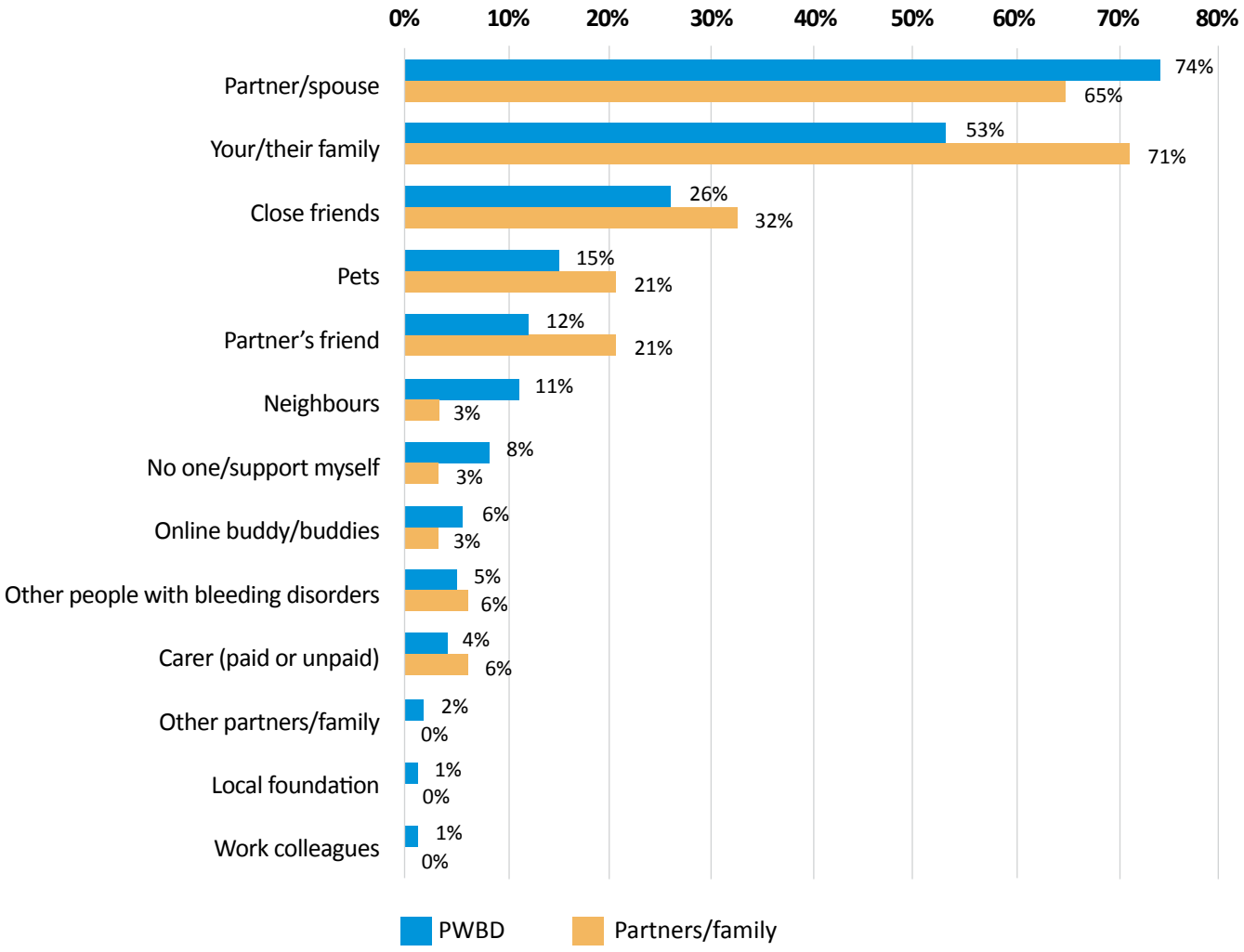
Their housing reflected the high priority put on home ownership in this group. The low level of public housing or itinerant lifestyle may reflect the survey distribution strategy as print surveys were posted to home addresses and they would have needed internet access to do the online survey.

Table 5: PWBD
Which one best describes where you currently live?

Answer Choices	Responses	
An independent house/unit/ villa/ apartment that I / We own	65%	85
An independent house/unit/ villa/ apartment that is mortgaged	17%	22
An independent house/unit/ villa/ apartment that I / We rent	11%	14
A retirement village/ over-50s lifestyle village	3%	4
Public or community housing	2%	2
A room or granny flat in someone else's house/property	2%	2
A residential aged care home	1%	1
Caravan (permanent home)	1%	1
Currently travelling/ caravan/mobile home	0%	0
	Answered	**131**
	Skipped	2

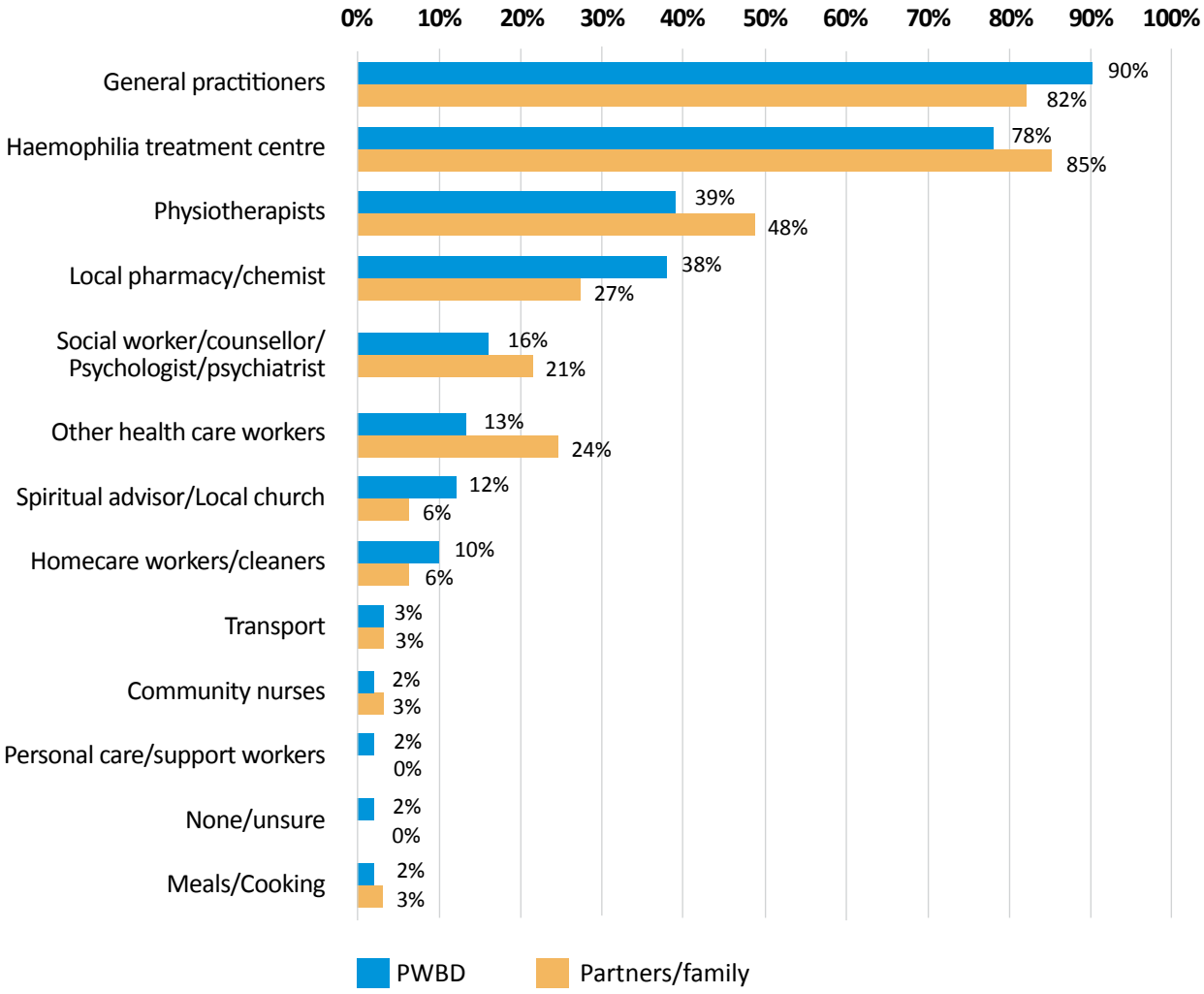
Support

Figure 4: **Who supports you [person with bleeding disorder] in your daily life? Tick all that apply**



Both the person with the bleeding disorder and their partner and family were asked who supported the person getting older in their daily life. In most cases partners and family were identified as key sources of support. For some, close friends, neighbours and pets were also important. Few identified online buddies or paid or unpaid carers as providing support. A small number commented that no one provided support; some because they felt they were self-sufficient and did not need support, but others were conscious of not having support and being isolated.

Figure 5: What services do you access that support you [person with bleeding disorder]? Tick those that apply to you



Both people with bleeding disorders and partners and family were also asked about the services that support the person who is getting older. For both groups, general practitioners and Haemophilia Treatment Centres (HTCs) were high on the list, but people with bleeding disorders identified general practitioners more often than HTCs (114/126 or 90% compared to 98/126 or 78%). Physiotherapy was the next most common service accessed, followed by the local pharmacy. Approximately one-fifth accessed support from a psychosocial service, such as a social worker or counsellor, but only a small number identified a spiritual advisor or local church as a source of support. For people with bleeding disorders, other health care workers could include complementary medicine such as acupuncture, chiropractic, or naturopathy. Only a very small number accessed community support services such as personal care or support workers or community nurses.

When asked about other services or supports that

would help, suggestions included:

- Specialised sports physiology, pilates, yoga for strength training
- Training and support for local physiotherapists around managing someone with a bleeding disorder
- Transport to medical appointments
- HTCs to have more flexible hours and provide more outer suburban and regional clinics and referrals to local services
- Access to a nurse to assist with infusions
- Assistance with setting up aged care or NDIS
- Home help: cleaner, gardener, handyman for home maintenance
- Local peer support for individuals and families
- Financial support, particularly as out-of-pocket costs for these services can be expensive
- A cure or access to longer acting treatments.

Some commented that it was difficult to think of suggestions when they didn't know what could be available.

Achieving aspirations for the future

People with bleeding disorders were asked if there was anything else that would help them achieve their aspirations for the future. Health-related suggestions were the most common:

- A cure or improved treatment that is longer-lasting or non-intravenous
- A cure or rejuvenation for joints that were damaged or arthritis
- Holistic care
- Physiotherapy to maintain movement, balance and regular exercise
- Being pain free.

'Non-intravenous treatment. My veins are not good and limit the amount of treatment I can administer. Ie, I cannot apply proactive treatment only reactive.'

'A cure for slowly deteriorating joints (the one that are not fused or replaced).'

'Often a chronic illness such a bleeding disorder needs holistic care. Our current hospital and referral system is such that each specialisation acts as a silo rather than working together. This is fine if a person is treated for a one-off issue. But becomes a problem when an illness creates a myriad of issues that need examination.'

Another common response related to assistance with accessing services, such as home care, physiotherapy and the NDIS.

'Perhaps a social worker who deals with bleeding disorders in particular and who could give advice when needed. I feel a bit lost sometimes.'

'NDIS including haemophilia as this is directly associated with mobility and disability.'

'Knowing how to access in-home care that could assist with self-treatment.'

Other suggestions included:

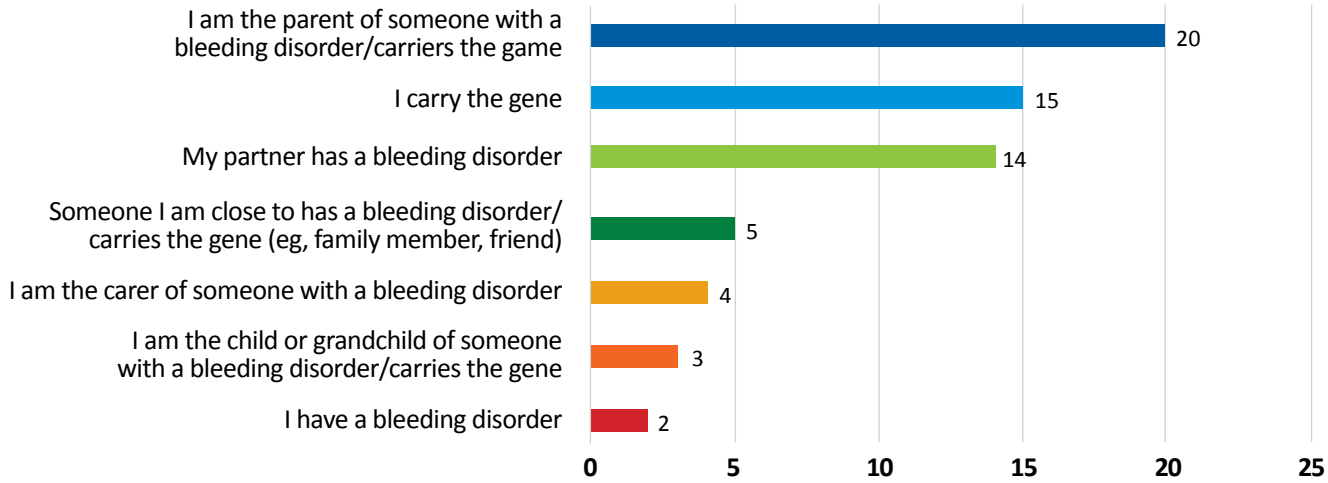
- A study of women with haemophilia
- Reviving old friendships, including with university teachers and classmates
- Regular art group sessions
- Cheaper travel insurance for people with bleeding disorders
- Staying well enough to continue working
- Reducing time in volunteer activities so as to have more personal time.

PARTNERS AND FAMILY

Who were they?

36 people responded to the survey as partners, family or carers. Some also had a bleeding disorder or carried the gene themselves.

Figure 6: Partners/family Please tick all the statements that apply to your situation



Nearly all (35/36 - 97%) were partners or family of a person with haemophilia who was getting older. In 3 cases the person who was getting older had a rare clotting factor deficiency and in 1 case the person had VWD.

Just over half of the partners or family lived with the person with the bleeding disorder (19/36 or 53%). The others did not live with the person with the bleeding disorder (15/36 or 42%) or did not answer (2/36).

Aspirations for the person with a bleeding disorder

Most commonly partners and family were hoping that the person with a bleeding disorder would be able to maintain their independence and be able to participate in and contribute to the community. To do this involved good health, freedom from pain, increased mobility and being able to travel.

> *'That it [haemophilia] can be managed. That he will get older with me!'*

They spoke of the hope for the reduction in haemophilia symptoms associated with new and innovative treatments, such as gene therapy and treatments that are longer lasting or could in future be taken orally. Access to appropriate treatment and care was mentioned several times: in some cases, being able to have treatment at home; in others, to have access to specialist medical services in country areas so as to reduce travel and other financial costs. The treatment should be targeted individually to address joint and dental issues, to avoid joint replacements in the future, reduce preventable bleeds and pain.

'He has very difficult veins to have regular factor for preventable bleeds, to be active at all. Its frustrating/confusing to know how to "push" exercise, to keep him as active as possible without intensifying his pain, or worse, cause another bleed. He's had enough of pain. Nothing is easy.'

'My partner has lost four months of income this year alone due to a recurrent joint bleed which caused him significant distress. Our hope is to avoid joint replacements and improve or halt the progression of his haemophiliac arthritis.'

Living well into the future involved work choices and opportunities to engage with the community, to express themselves and help others.

'Remaining in good health, enjoying interesting activities.'

'I want them to have the opportunity to use their brilliant mind to tutor others and write.'

Concerns about achieving this

Health issues were mentioned most often in their concerns for the future. The impact of increasing joint problems such as arthritis, pain and the necessity for joint replacements was very worrying: they noted that it interfered with the person's ability to work into the future and their career opportunities and could result in them 'ending up on a pension with little hope of "more"'. Those experiencing the impact of early ageing on their partner were concerned about their job satisfaction in the future. Those who were older could see implications for themselves when their partner could no longer be as independent.

'So many health problems through life created significant issues already.'

'My partner has not undertaken a career he aspired to due to the physical limitations of his disease and I worry about his job security and job satisfaction for the future.'

'To stay "ahead of the game" with my health. How am I going to cope when his mobility decreases? And that my own ability is naturally deteriorating as well.'

If the person with the bleeding disorder was no longer able to work as much, this could have financial consequences, particularly if the person was the main income earner. Partners and family commented that they would need adequate finances to cover the care that would be needed, but that with emerging health issues, out-of-pocket costs for treatment and travel to the city to receive care the future costs were unknown.

They also worried about the ability of services to provide adequate and appropriate care into the future, especially in their local area.

'If they ever had to live in an aged care facility, I worry about staff training and the access to treatment and care.'

'More specialist dr/teams to treat illness. Doesn't exist in the local area which doesn't give me hope it will happen in the future.'

Current concerns

Of most immediate concern were the impact of the person's pain and mobility problems. The need for more effective pain management was described as 'urgent' and several partners and parents noted that the person's pain was increasing as they grew older. The person's ongoing loss of mobility led to worry about the long-term outcomes related to this. If the partner had problems with their own health, this was further complicated by trying to support the person with the bleeding disorder and manage their appointments.

> *'The bleeding can be controlled but the pain can't. Going to hospital to support pain relief can be difficult as drs don't respond to support patients who may use level of pain relief daily to sustain some type of normal life.'*
>
> *'Continuing loss of joint mobility and concerns for what the future looks like with loss of mobility.'*
>
> *'My own health is a bit "out of whack" at the moment (unbalanced blood tests) and I am having to struggle between my appointments and his and other family members. How am I physically going to cope when his mobility decreases and "caring role" gets more intense.'*

Health issues could be across several areas.

> *'Joint care, pain management, dental health and psychological care are needed urgently now. We're barely coping now and expect it to worsen.'*

Some were concerned about the negative impact of the person with the bleeding disorder's behaviour in relation to their health in the past.

> *'Not constructively tackling his haemophilia-related health issues and poor decision/non-compliance on treatments from the past, (including his poor care of his teeth!).'*

Others had experienced problems accessing appropriate treatment or care, particularly in regional areas, or had had to travel for several hours to the Haemophilia Treatment Centre for care.

> *'Having people experienced in bleeding disorders at our ED.'*
>
> *'No regular monitoring and services for issues affecting older people with bleeding disorders.'*

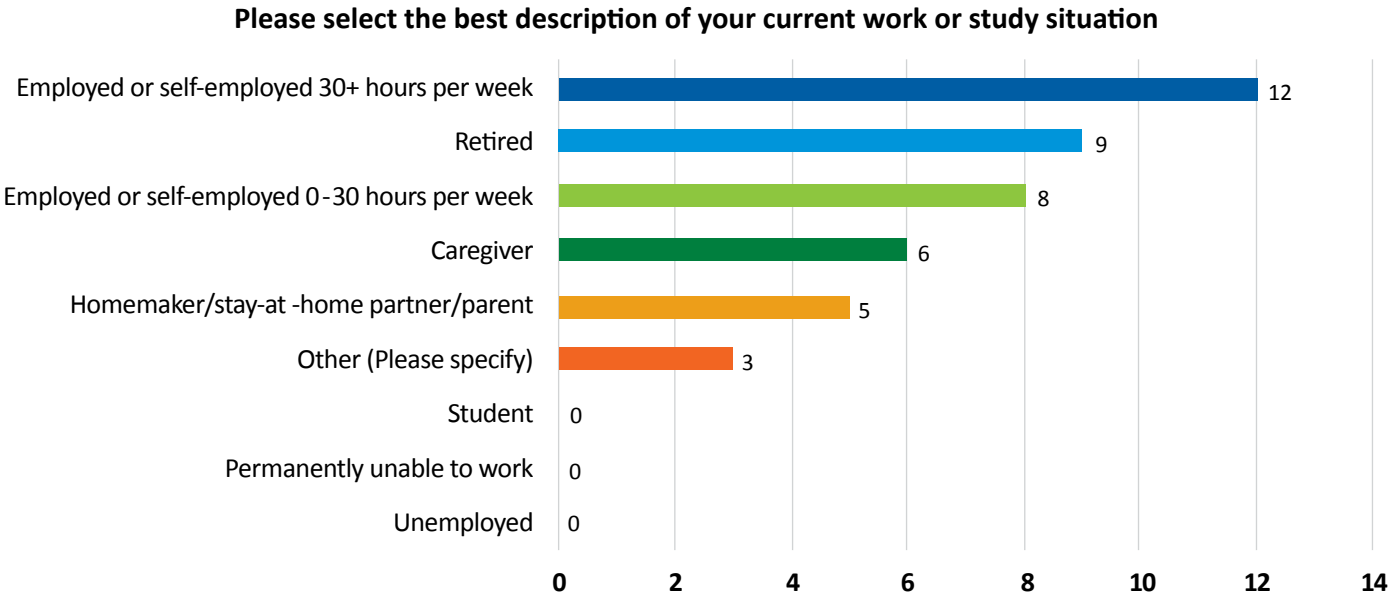
Several issues related to work were also prominent:

> *'That the physical requirements of the job will be too hard and taxing on the body.'*
>
> *'That I could get a job to provide for the family.'*
>
> *'Concern about how long he can work and medical care in future. Nursing home will not cater for him so needs to be at home.'*

Financial worries were also raised regularly: financial stability and having enough money to support the family; what would happen if the government stopped their financial assistance payments; the *'limited government budget (or willingness to find), to make living comfortably in old age a realistic/achievable goal.'*

Impact on working life

Figure 7: Partners/family



More than half of partners or family (20/36 or 55%) were currently employed, with one third currently employed more than 30 hours per week. One quarter (9/36 or 25%) were retired. A smaller number identified themselves as direct caregivers (6/36 or 17%) or homemakers (5/36 or 14%). None were unemployed, students or permanently unable to work, although one was on Workcover.

Most (24/32 or 75%) did not think the person with a bleeding disorder's health had impacted on them stopping work or working part-time before they wanted to. However, the person's health could impact on a partner's leave and one commented:

> *'Have taken a number of days carer's leave to assist my partner getting to appointments after bleeding episodes where he is unable to drive himself or is in pain and has trouble absorbing information and making treatment decisions.'*

Others (7/32 or 22%) thought the person with a bleeding disorder's health had impacted on their working hours. One explained the dilemma she faced and the decisions she had to make about where her 'true responsibilities' lay:

> *'Going to work was a burden to the whole family because of my lack of supporting them. Family life is "very full on" and life itself is so unpredictable. It was just wrong, cruel, heart-breaking and even unsafe at times. Especially in the past years I was the only capable carer in the family. Going to work at times was an escape for me and help to pay our house payments. The pros were outweighed by my true responsibilities. He means more to me than money (priceless) and his health and pressures need much more help.'*

Around one third (11/34 or 32%) wanted to return to work or stay longer in the workforce, while the larger proportion did not want to (13/34 or 38%). For 10/34 or 29%, the question was not applicable, presumably because they were retired or homemakers.

When asked about returning to work or staying in the workforce, several described their concerns:

- Their partner's care needs in the future, including mobility issues
- The supporting care for haemophilia is expensive: special needs aids, allied health care, medications, dental and psychological care
- Concerns about how to manage financially between casual jobs
- Being constantly tired and not being able to pursue any personal interests outside of work and carer duties
- The unpredictability of care needs for someone with haemophilia
- Loss in currency of skills if they had become self-employed to manage the person's care.

'I'm always tired and don't have any activities outside work and carer duties.'

'You can go days or weeks without a problem but you just never know when you will need time away from work.'

There were a few suggestions on how to help with this:

- Resolution of the person with bleeding disorder's pain and mobility issues
- More understanding in the workplace
- Support with home help and a carer/volunteer to take the person to appointments and for companionship during the day
- A couple of partners and parents noted that they had become self-employed to have the flexibility they needed.

'We became full-time farmers and being self-employed helps a lot with this situation. Before this, it was very hard to be employed full-time and be there for my son at the same time.'

Some (8/29 or 28%) said they wished to reduce their working hours or retire early. Greater financial support was the most common response when asked what would help with this.

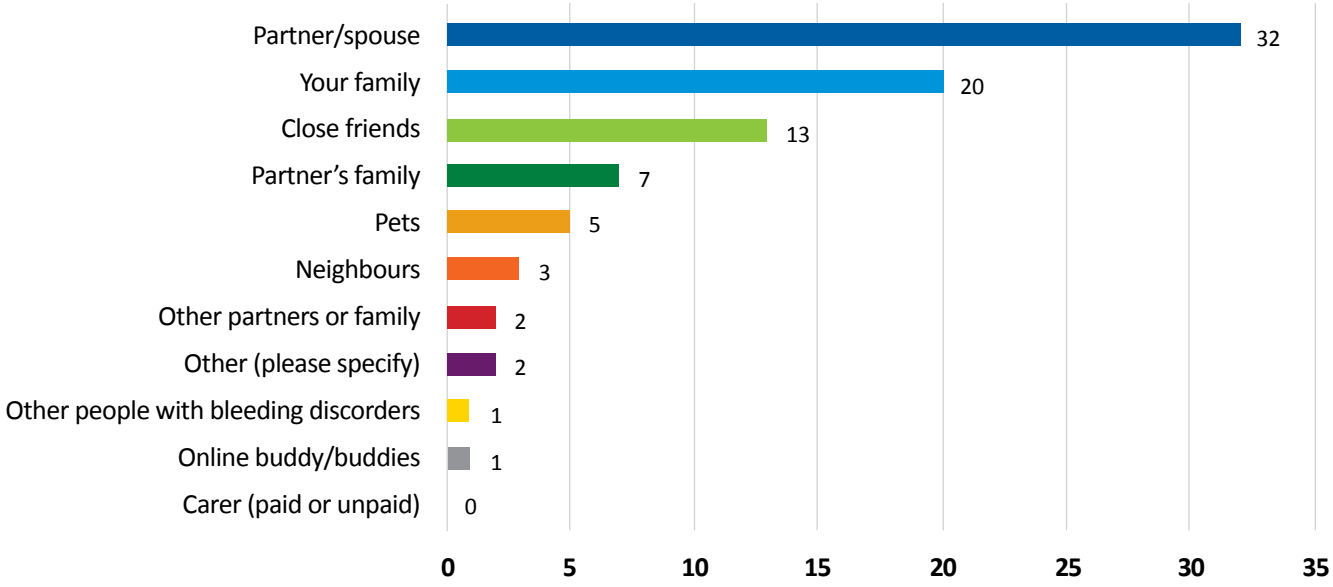
Finances

Most partners or family described their main source of income as coming from their employment (25/35 or 71%). Some were self-funded retirees (7/35 or 20%).
A small number received government benefits, such as the aged pension or carer payment (5/35 or 14%) and 2 were supported by their partner (6%).

They were also asked to describe the person with a bleeding disorder's main source of income. More than half had their primary source of income from employment (19/36 or 53%). A substantial number were supported by their partner or family (10/36 or 28%). Some received government benefits, such as the aged or disability support pension, National Disability Insurance Scheme (NDIS) or carer payment (7/36 or 19%). A small number were funded by their superannuation or investments, including a total and permanent disability payment (5/36 or 14%).

Support

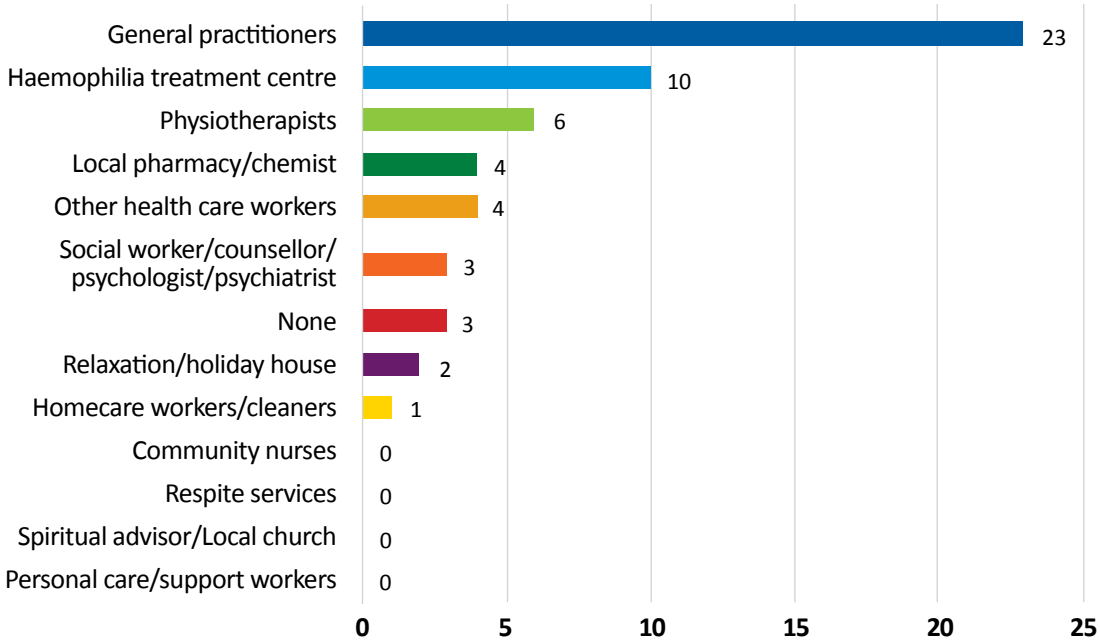
Figure 8: Partners/family **Who supports you in your daily life? Tick all that apply**



The large majority of partners or family had support in their daily life from their partner (32/36 or 89%). Close friends and family were also strongly represented.

Figure 9: Partners/family

What services do you access that support you? Tick those that apply to you



Only 29 out of 36 partners or family identified support services that they accessed. At this point, none had accessed community nurses, respite services and personal care or support workers and none identified spiritual advisors or a local church as a support. Interestingly, 2 identified 'relaxation places' or holidays and beach houses as support services. A small number said they did not access support services (3/29 or 10%), one because they were in a country area and there was no support available.

What would help them?

There were only a few suggestions about other supports or services that could help them, including:

- Someone to talk to
- Support with garden and home duties
- Better private health extras insurance and rebates
- Transport services to the HTC
- More support to country patients from the HTC.

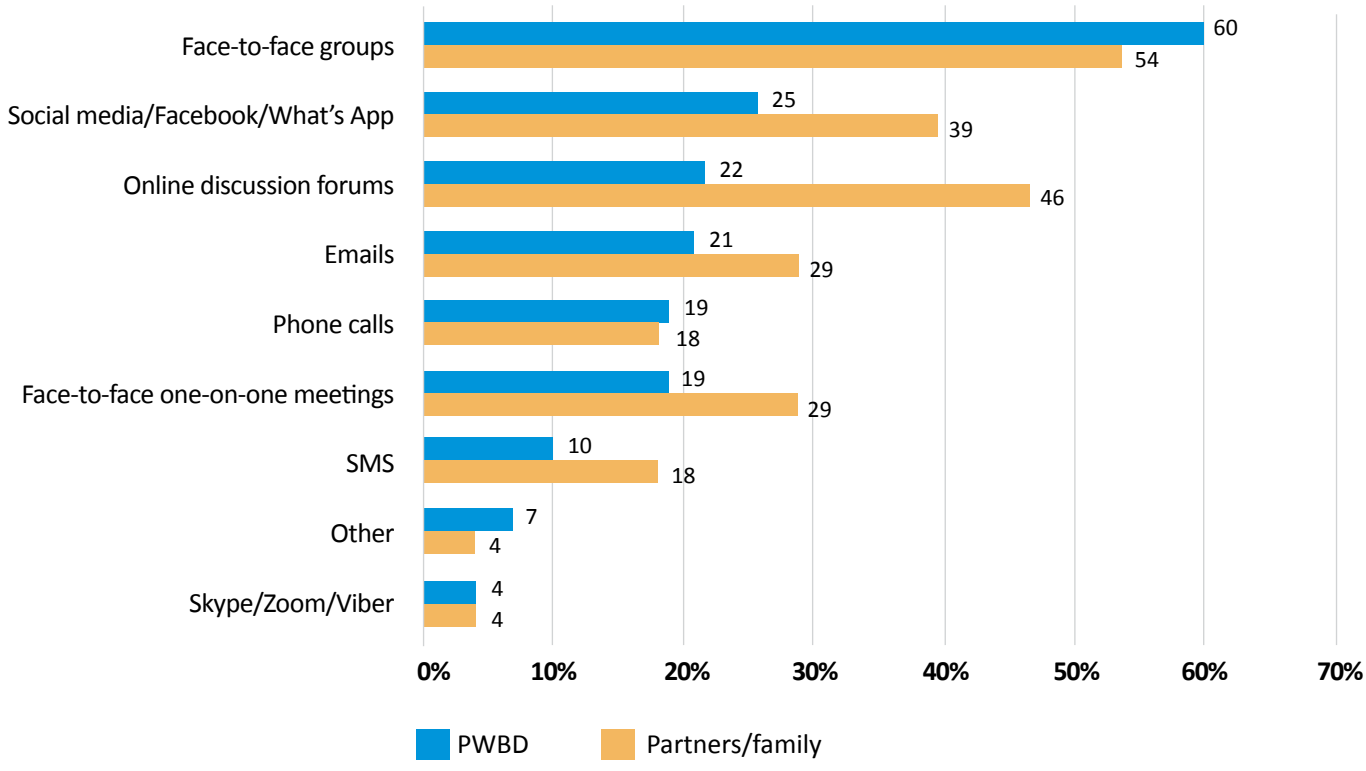
A small number (3/12) said they didn't know what else would help.

Peer support

Both people with bleeding disorders and partners and family were asked about how they would prefer to meet other people in the bleeding disorders community.

Figure 10:

What opportunities would you like to use to meet other people in the bleeding disorder community? (You can choose multiple answers)



GETTING OLDER COMMUNITY SURVEY FINDINGS

By far the most popular in both groups was to meet in face-to-face groups. Around 20-25% of people with bleeding disorders were equally interested in remote and online options, including social media platforms, online discussion forums and email. Partners and family were more likely to be interested in these options than older people with bleeding disorders. Around one fifth of both groups were interested in telephone calls. One-on-one face-to-face meetings were more popular with partners and family than people with bleeding disorders. There was very little interest in change to VoIP (Voice over Internet Protocol) technology such as Skype, Zoom or Viber. Other suggestions for meeting included conferences and dedicated clinic times at the HTC.

'My experience is that other than brief shared discussions about medical issues the true value of meeting other haemophiliacs is not having to explain yourself. The networking and making new friends who are kindred spirits has been invaluable. Went to a haem retreat a few years ago, was awesome and was fortunate that one of the guys picked me up. Otherwise would have missed so much that came after with new connections.'

Some commented about the impact of distance and that having a bleeding disorder was very isolating, particularly if you don't know anyone else affected.

'Happy to meet in social activities, but distance is often a problem, plus when we have booked into events, recently they have been cancelled due to lack of numbers.'

'Any connection would be good as it can be very isolating.'

'I have never met anyone in Australia who has my bleeding disorder. Hence, my only contact is with people overseas over social media.'

'I don't know anybody with a bleeding disorder.'

A smaller group of older people with bleeding disorders (12/102 or 12%) commented that they were not interested in meeting other people with bleeding disorders. This was for various reasons: they didn't feel they needed support; or they preferred to connect with people who shared their interests rather than their health condition; or they preferred to discuss their condition with their family rather than others.

'Face-to-face groups occasionally. But it depends on the individuals who attend & whether you like them and feel a bond with them.'

'I have mild haemophilia. Discussing this with my wife and health practitioner is sufficient at the moment.'

'I don't feel the need to meet others with haemophilia, other than to discuss how the HTC can improve its services.'

'None, I don't like to discuss my condition with anyone other than family. And I do not feel I require any additional support as I am comfortable with my condition.'

'I choose friends/associates for their attributes, not because we share some medical condition.'

One partner/family member commented: 'I don't participate in these. Reading reports or stories is nice.'

Connecting online or via social media

When asked about their interest in connecting with other people online or through social media, most in both groups (49/66 people with bleeding disorders and 8/12 partners/family) commented that they were not interested or that they prefer face-to-face and it was not something they do. Reasons given included:

- Not active on social media, 'too old for that'
- Not interested in digital connections or computers
- Concerns about privacy/security
- Can be defamatory and 'stories snowball away from the truth'
- No internet connection.

> *'Personally, it would be an issue, as need to be able to talk to person face to face. Social media would be too much of a barrier as far as not making true connection. That said, I am sure others may find it useful.'*
>
> *'Social media is a very lean and isolating forum to discuss sensitive topics.'*
>
> *'I find using a computer difficult because of my eyesight and choose NOT to be on Facebook etc.'*
>
> *'Probably best suited to the young (ish) people (ie, older people use internet/social media less).'*

A smaller group (13/66 people with bleeding disorders and 2/12 partners/family) thought that it would be valuable to have this option available. Most said they were already active in social media groups, such as Facebook, and found it helpful.

> *'I have a Facebook account and communicate with a few groups of common interest.'*
>
> *'A group page would be good.'*
>
> *'I like that you can take a little time to think about your answer rather than being rushed in real time.'*
>
> *'It would be nice to hear other people with the disorders' outlook on life.'*
>
> *'It helps to know that other people experience similar effects and how they deal with it.'*
>
> *'I do that now as it's good to stay in touch.'*

Some were aware that the small size of the group could make it difficult to maintain momentum in an online peer support group. This was particularly the case for those with HIV, where the numbers of those with bleeding disorders who have survived is very small now.

A partner/family member commented:

> *'N/A there would be only a small number with both HIV that have survived this long'*

A man with haemophilia and HIV noted the peer support tended to be through individual connection after face-to-face peer support events, such as the men's retreat, which is a regular Foundation event in some states:

> *'We started a facebook grp (secret) for guys living with haemophilia and HIV but there is very little participation. I'm not sure why. I can only put it down to the guys being busy with work and young families. Also, some of them work with computers so probably don't want to be looking at a computer when they come home. I have made some strong connections with the guys who go to the men's retreat. But it tends to be individual contact by sms/email. I really value those connections I now have after many years of being rather isolated.'*

Table 6: Peer support meetings

Suggested topics for peer support meetings	
People with bleeding disorders	**Partners/family**
• Impact of haemophilia/bleeding disorder on the body as you grow older • Pain management • New treatments and/or cures • Wellbeing, health and fitness, travel • Lifestyle issues as you grow older • Tips/strategies that have worked for you • Relationships • Common issues for mild haemophilia • Women's issues • Improving services at the HTC • Working with your GP, local hospital or services • Sharing life experiences, achievements, what makes life enjoyable and rewarding • Group lunches in regional areas	• Impact of bleeding disorder as they age, what to expect for the future • New treatments • Sharing experiences, support when things are not going well, dealing with partner with a bleeding disorder • Coping financially when your partner has a disability • Helping with the person with a bleeding disorder's health • Wellbeing
What could you share that would help others?	
People with bleeding disorders	**Partners/family**
• Personal experience of living with a bleeding disorder • Lessons learned, including financial strategies for potentially stopping work early • Strategies to avoid injury, reduce impact of bleeding disorder – particularly for young people • Positive approach to life • Challenges for people with mild disorders and their carers • Strategies for self-advocacy	• Personal experience • Survival tips • Listening skills • Partners/family to the headers on this column
How would you like to do it?	
People with bleeding disorders	**Partners/family**
• Face to face in small groups or casual get togethers • Group discussion online • Social media discussion • Email, sms, telephone • Workshop or Zoom • Write personal story	• Group • Social media • Conference • Meeting • Newsletter

Online communications

Table 7: PWBD and Partners/family

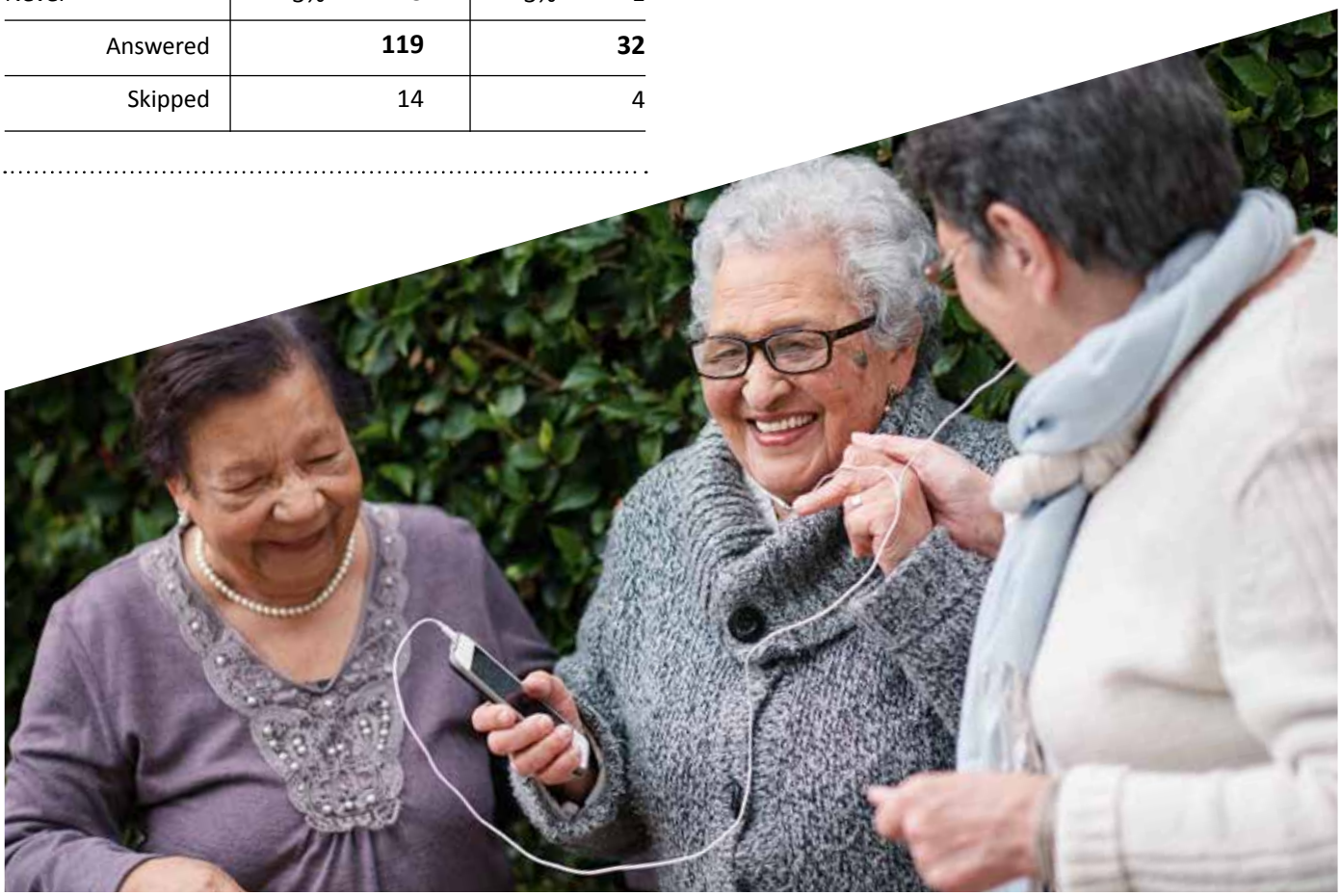
In your day-to-day life how often do you use a computer/tablet/iPad?

Answer Choices	Responses			
	People with bleeding disorders		Partners/ family	
Daily	86%	102	88%	28
Several times weekly	7%	8	3%	1
Once weekly	2%	2	3%	1
Once in a fortnight	1%	1	0%	0
Once in a month	1%	1	0%	0
Rarely	3%	3	3%	1
Never	3%	3	3%	1
Answered		**119**		**32**
Skipped		14		4

The vast majority of both older people with bleeding disorders and their partners and family said they used a computer or a mobile device like a tablet or iPad daily.

They used it for a wide range of activities:

- Work
- Contact with family and friends
- News, information and education
- Entertainment, watching television shows or movies, music
- Games and betting
- Organising holidays
- Keeping records
- Cooking
- Grocery shopping
- Banking.



Information and education

Figure 11: What information/education materials would you like in relation to getting older with a bleeding disorder? Tick all that apply

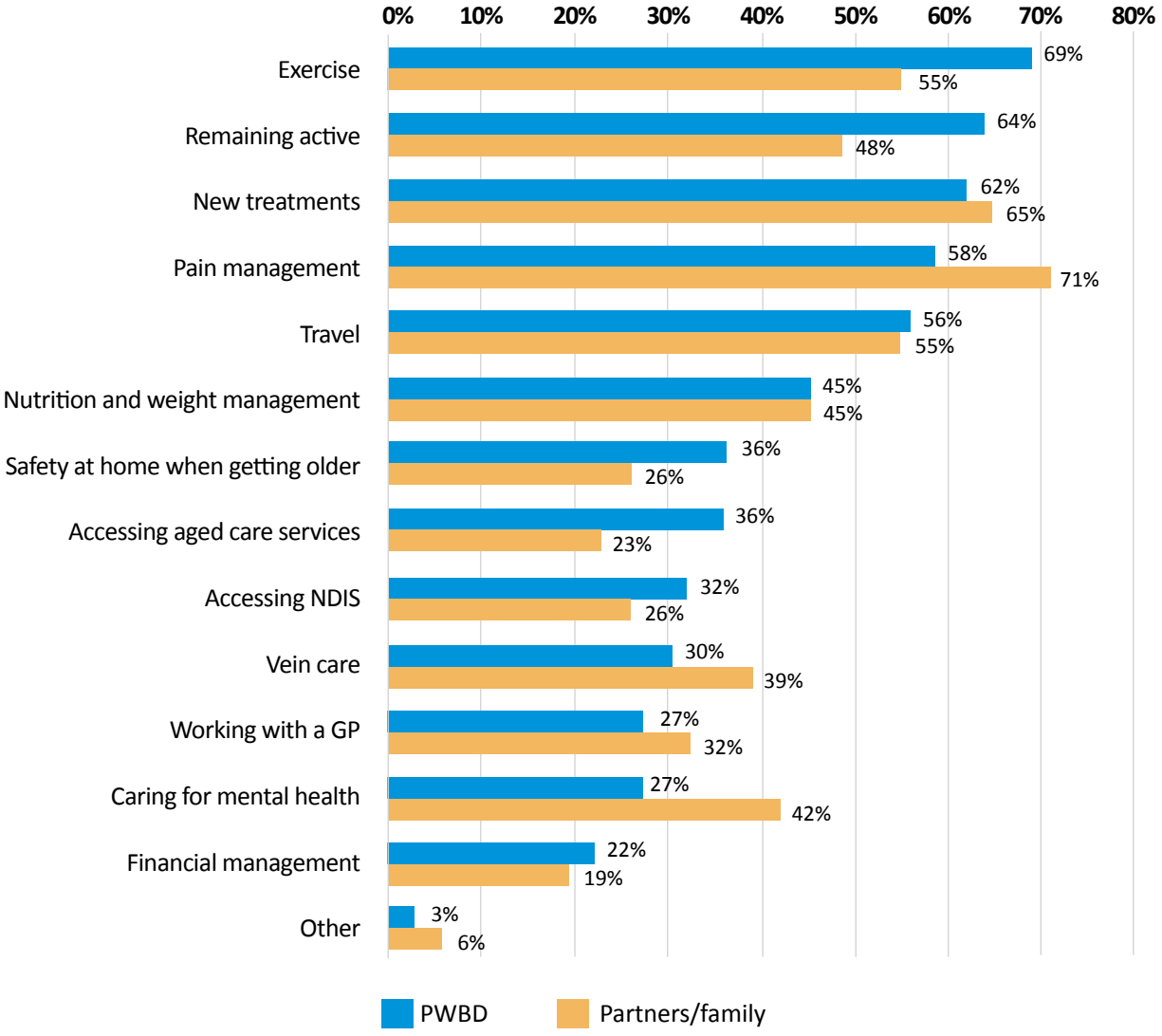
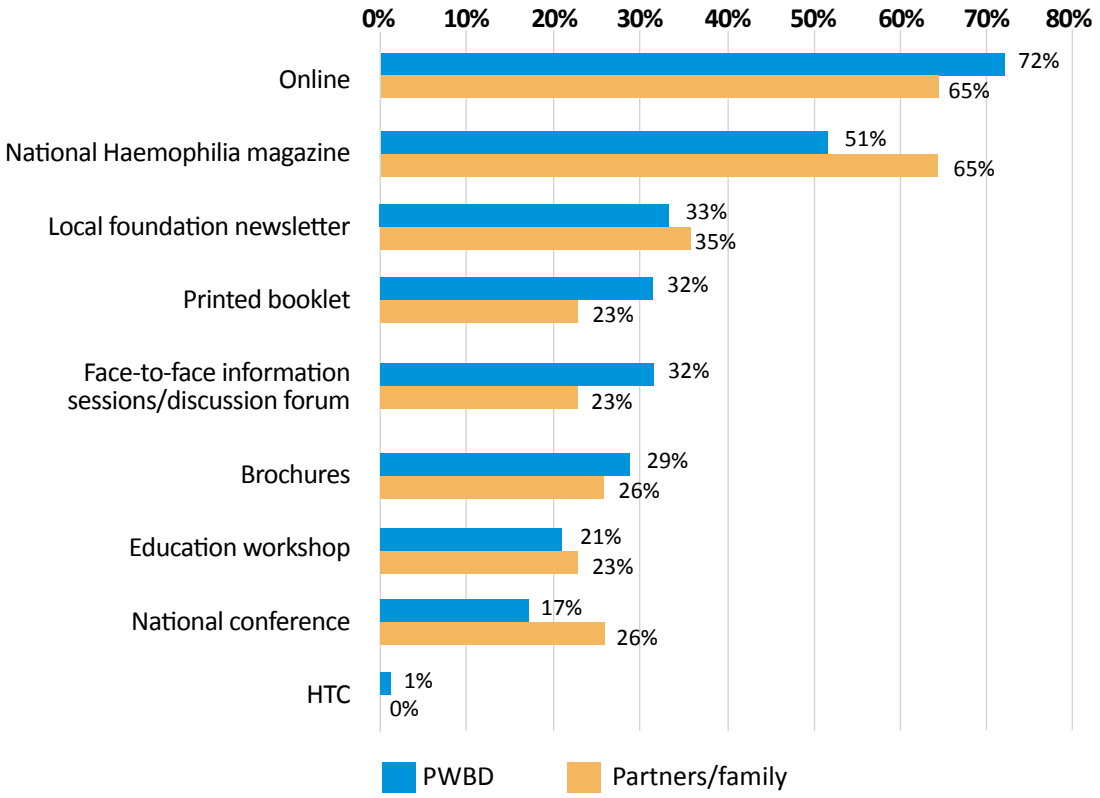


Figure 12: How would you prefer to get this information? Tick all that apply



Most preferred to get their information online, although around one third of older people with bleeding disorders and one quarter of partners and family preferred printed booklets. There was also a marked preference to receive this information from Australian haemophilia foundations, in the Haemophilia Foundation Australia journal, *National Haemophilia*, or the local foundation newsletter.

Limitations

As HFA did not have ethics approval to use HTC mailing lists for distribution of the Getting Older Community Survey, promotion and distribution was limited to community networks. As a result, this limited the extent of the bleeding disorders community HFA was able to reach with the consultation.

HFA identified a number of barriers for people with bleeding disorders to participate, including frailty, disability, physical and mental capacity, literacy and limited English language skills, along with lack of engagement with haemophilia foundations and their communication networks. HFA had taken this into account with the Community Survey, encouraging partners, family and carers to complete the survey if the older person was unable to undertake the survey or not engaged. Anecdotal reports suggested that partners and family prioritised supporting the older person with a bleeding disorder to complete the survey, rather than completing it themselves.

Local foundations drew the survey to the attention of some families with perceived barriers and they were also invited to use interpreting and TTY services or to contact the Project Officer for help with completing the survey, but this would probably only occur if they were highly motivated. HFA also used popular social media channels such as Facebook and Instagram to promote the survey to supporters who may then encourage relevant older people to participate, but this was limited by the reach of the social media posts and how engaged supporters were with the cause.

The timeframe for the Community Survey was also relatively short and limited the ability of foundations and supporters to reach out to people who were less engaged or might need more support to complete the survey.