

5. Summary findings



The findings from the consultation for the HFA Getting Older needs assessment are summarised below.

5.1 Interviews

43 interviews were conducted with participants from the Australian Capital Territory, New South Wales, Queensland, South Australia, Victoria and Western Australia.

Table 4: Interview participant profile

Number	Role
16	Older men and women with bleeding disorders , consisting of:
13	Men with haemophilia
1	Woman with haemophilia
2	Women with VWD
6	Partners and family members Including women who carry the gene
15	Haemophilia Treatment Centre health professionals , consisting of
1	Haematologist
6	Nurses
2	Physiotherapists
6	Psychosocial workers
6	Other stakeholders: local and national Foundation staff, other organisations with a common interest in chronic health conditions, and a peer support worker.

5.2 Getting Older Community Survey

Detailed results are available in Appendix 1.

There were **169 respondents** to the **Getting Older Community Survey**

- **89 (53%)** returned the online survey
- **80 (47%)** returned the print survey

All states and territories were represented in the responses.

Table 5: Getting Older Community Survey respondents - Demographic profile

	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%)

Table 6 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 6: Survey respondents who identified as older people with bleeding disorders by bleeding disorder

Bleeding disorder	Respondents
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

5.3 State/territory Foundation Consultation

In the needs assessment consultation, all state and territory Haemophilia Foundations and a community representative from South Australia, where there is currently no Foundation, provided responses about priorities, barriers and what would help in relation to their older community members with bleeding disorders.

5.4 Results

Qualitative responses to the interviews, the community survey and the consultation with the state and territory Haemophilia Foundations were analysed by theme.

Tables 7 to 11 provide a summary of responses from the perspectives of the different participant groups. Only older people with bleeding disorders and their partners and family were asked about the aspirations and goals of the older person with a bleeding disorder.

5.4.1 ABOUT THE OLDER PERSON WITH A BLEEDING DISORDER

Table 7: Aspirations and goals of the older person with a bleeding disorder

Older people with bleeding disorders responses	Partner/family responses
<ul style="list-style-type: none"> • Good health and quality of life • Retaining mobility and independence • Able to pursue personal interests • Travel • Spending time with friends and family • Retiring; or continuing to work, but reduced hours • Contributing to society 	<ul style="list-style-type: none"> • Good health and quality of life • Access to appropriate treatment and care • Travel • Financial security • Staying active and independent • Using their talents and skills • Enjoying their interests

Table 8: Challenges and concerns for the older person with a bleeding disorder

Older people with bleeding disorders responses	Partner/family responses
<ul style="list-style-type: none"> • Losing independence • Mobility, joint and dexterity problems, pain • Increased problems with mild disorders, VWD • Difficulties with treatment – infusing into a vein, remembering to infuse, accessing nurse to infuse • Developing dementia in the future • Impact of bleeding disorder on working • Health care providers outside HTC who don't liaise with HTC re bleeding disorder; don't understand bleeding disorders • Nursing homes unable to provide adequate care • Financial security into the future • No future planning • Depression and anxiety • Inability to support others • Isolation if do not have a partner 	<ul style="list-style-type: none"> • Pain • Joint, mobility, dexterity problems • Waiting lists for joint replacements • Impact of bleeding disorder on working • Transport to HTC • Financial security into the future because of limited working history and problems with sustaining work • Losing independence • Lack of expertise with bleeding disorders in the aged care sector • Appropriate housing for mobility problems • What would happen if partner becomes unwell • Out-of-pocket care costs • No long-term planning

Table 8: Challenges and concerns for the older person with a bleeding disorder (cont.)

Health care professional responses	Foundation responses
<ul style="list-style-type: none"> • Variable needs according to severity of disorder • Early ageing in severe disorders, inhibitors • Joint, mobility, dexterity problems • Difficulties with self-infusion • Pain, distinguishing source of pain, appropriate pain management, dependence on opioids, cannabis • Weight management • Ongoing management of cirrhosis in hepatitis C, HCV status of those with mild disorders • Managing the health conditions of ageing with a bleeding disorder • Appropriate care from other health care providers, being believed by them • Timely access to treatment • People with mild disorders: increasing complications but lack of knowledge, engagement with HTC • Managing health and treatment with memory loss • Fear of nursing homes • Managing work, needing to retrain • Inability to access NDIS if under 65 years through ineligibility or difficulty in completing applications • Grief and trauma from history of bleeding episodes, HIV, hepatitis C • Financial problems • Isolation for some: women, rare bleeding disorders, single/widowed people • Very stoic and resilient, but may not ask for help when they need it 	<ul style="list-style-type: none"> • Complexities of ageing-related conditions with a bleeding disorder • Maintaining physical wellbeing, activity • Early ageing • Inability to infuse when frail • Adequate and informed care from aged care services • Recognition of complications in women and appropriate care in the community • Ongoing impact of HIV and hepatitis C • Anxiety, depression • Social isolation • Stoicism and self-reliance means sometimes do not engage about needs • Employment and financial problems from a lifetime of complications • Transport to appointments • Regional/rural access • Challenges of engaging with geographically distant community

Table 9: What will help the older person with a bleeding disorder

Older people with bleeding disorders responses	Partner/family responses
<ul style="list-style-type: none"> • Help to remain mobile, active, independent • Assistance with infusions • New treatments for fewer infusions, subcutaneous injection, better health outcomes • Better pain relief • Transport services • Work: reducing work, supportive employer, disability-friendly workplace, education for employers • Education for health care providers outside the HTC • Acknowledgement of person’s own expertise about their health, resilience • Opportunity to pursue personal interests • Independent living aids • Support: family, friends, neighbours, local Council/aged care services, peer support • Counselling • Easier access to or eligibility for NDIS or aged care for those under 65 years of age 	<ul style="list-style-type: none"> • New treatments, prophylaxis • Assistance with infusions • HTC liaison to provide care locally • Transport services • Assistance to be able to exercise, stay active • Assistance to continue working • Education for health care providers in the community, aged care services • Education on getting older with a bleeding disorder for person with bleeding disorder • Information on support services available • Home help and care services • Support: family, friends, neighbours, bleeding disorders community, pets • Future planning • Sharing their strengths: optimism, resilience, individual skills

Table 9: What will help the older person with a bleeding disorder (cont.)

Health professional responses	Foundation responses
<ul style="list-style-type: none"> • Good co-ordinated comprehensive care for the range of their needs • Comprehensive care delivery options to reduce travel • Vein care and infusion education • Access to new treatments: extended half-life, subcutaneous; higher uptake of prophylaxis • Pain management, education about pain • Good liaison and communication with other health care providers • Working with a consistent GP • Education for other care providers • Patient education about ageing with a bleeding disorder and need for compliance • Staying active, mobile • Exercise programs, falls and balance classes, corrective footwear • Independent living aids • Flexible, supportive workplace • Assistance with retraining • Home help and care services • Access to limited NDIS services for those under 65 years and currently ineligible • Transport services • Information, guidance around aged care services • Support, counselling, trauma-based practice • Validating their experiences: traumatic bleeding episodes in childhood; impact of HIV, hepatitis C • Encouragement to develop friendships, personal interests • Peer support 	<ul style="list-style-type: none"> • Encourage closer relationship between person, GP and HTC • Options for remote care, eg telehealth • Collaboration between Foundation and HTC in developing innovative services • Information and education for aged care facilities, including individual needs • Targeted programs for affected community engagement, connection and support, both through peer support and with the wider community • Individualised outreach • Education resources about getting older with a bleeding disorder and future planning • Online and print communications and education materials • More research into complications in older women

5.4.2 ABOUT PARTNERS AND CARERS

Table 10: Challenges and concerns of partners/carers

Older people with bleeding disorders responses	Partner/family responses
<ul style="list-style-type: none"> Physical challenges of caring Depression, anxiety Understanding ageing with a bleeding disorder Time to take care of their own health and needs 	<ul style="list-style-type: none"> Physical decline Managing the person's care and their own needs Having adequate income Managing maintenance tasks Transport, driving Isolation
Health professional responses	Foundation responses
<ul style="list-style-type: none"> Burden of care – physical, co-ordinating services, taking person to appointments, emotional/psychological Understanding issues of ageing with a bleeding disorder, services available 	<ul style="list-style-type: none"> Burden of care Transport Lack of information about ageing with a bleeding disorder and services available

Table 11: What will help partners/family

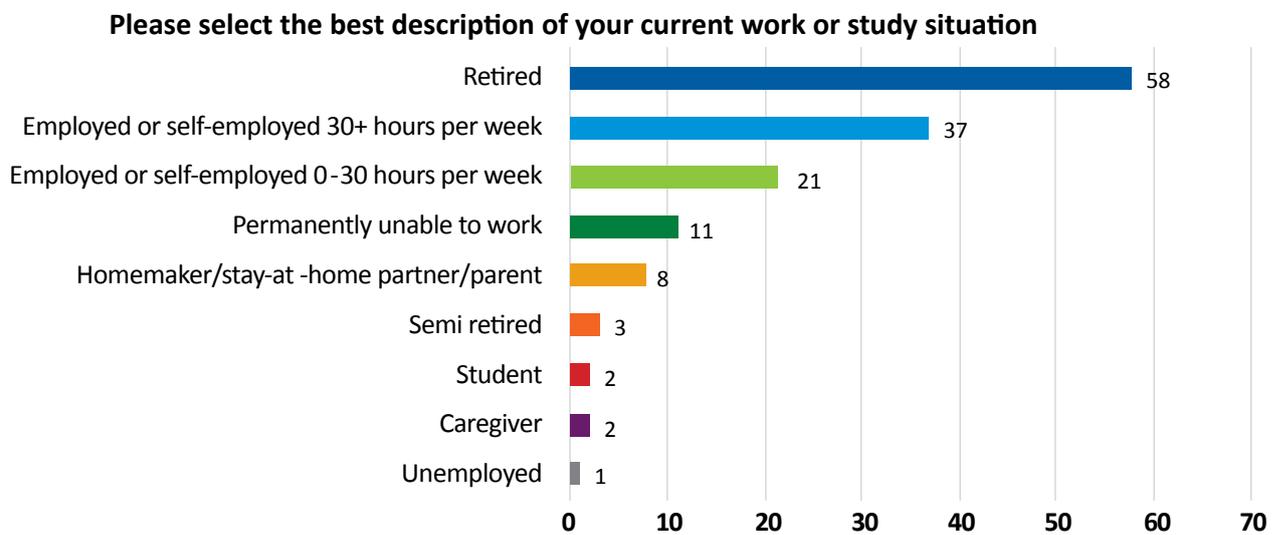
Older people with bleeding disorders responses	Partner/family responses
<ul style="list-style-type: none"> Home help services Home care services for the person with the bleeding disorder Education about ageing with a bleeding disorder Support 	<ul style="list-style-type: none"> Transport services Home help services Support Someone to talk to, peer support Reducing challenges that cause stress and anxiety
Health professional responses	Foundation responses
<ul style="list-style-type: none"> Education about ageing with a bleeding disorder Information about services available Assistance to access services Someone to talk to, peer support Respite 	<ul style="list-style-type: none"> Support for carer Information about ageing with a bleeding disorder Information about services available

5.5 Other Getting Older Survey results

Detailed results are available in Appendix 1.

5.5.1 WORKING

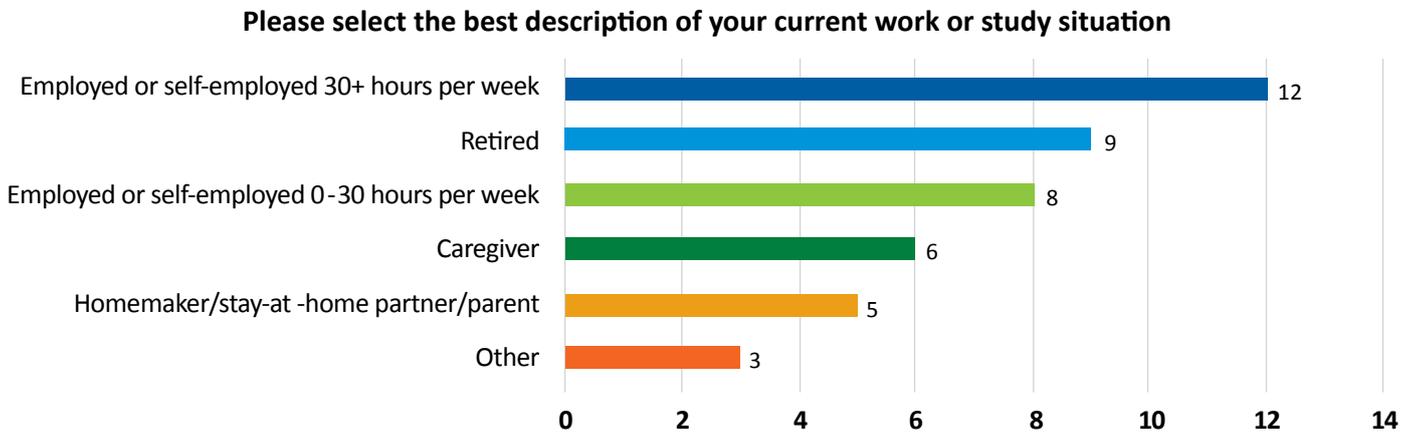
Figure 2: Work or study situation of older people with bleeding disorders



- The greater majority of older people with bleeding disorders (70% or 91/131) thought that their health had impacted on their work or study life.
- A large group (42% or 54/128) wished to stay longer in the workforce
- 32% (33/128) said staying in the workforce was not applicable as they were retired or permanently unable to work.

5.5.2 PARTNERS/FAMILY

Figure 3: Work or study situation of partners/family



- Most partners or family (75% or 24/32) 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.
- 22% (7/32) thought the person with a bleeding disorder's health had impacted on their working hours.
- 32% (11/34) wanted to return to work or stay longer in the workforce
- 38% (13/34) did not want to return to work or stay longer in the workforce.

5.5.3 FINANCES

Table 12: Income - Responses from older people with bleeding disorders

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

Table 13: Superannuation and insurance - Responses from older people with bleeding disorders

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

- 34% (40/119) of older people with bleeding disorders said they had problems getting insurance or superannuation.

Table 14: Current housing – Responses from older people with bleeding disorder

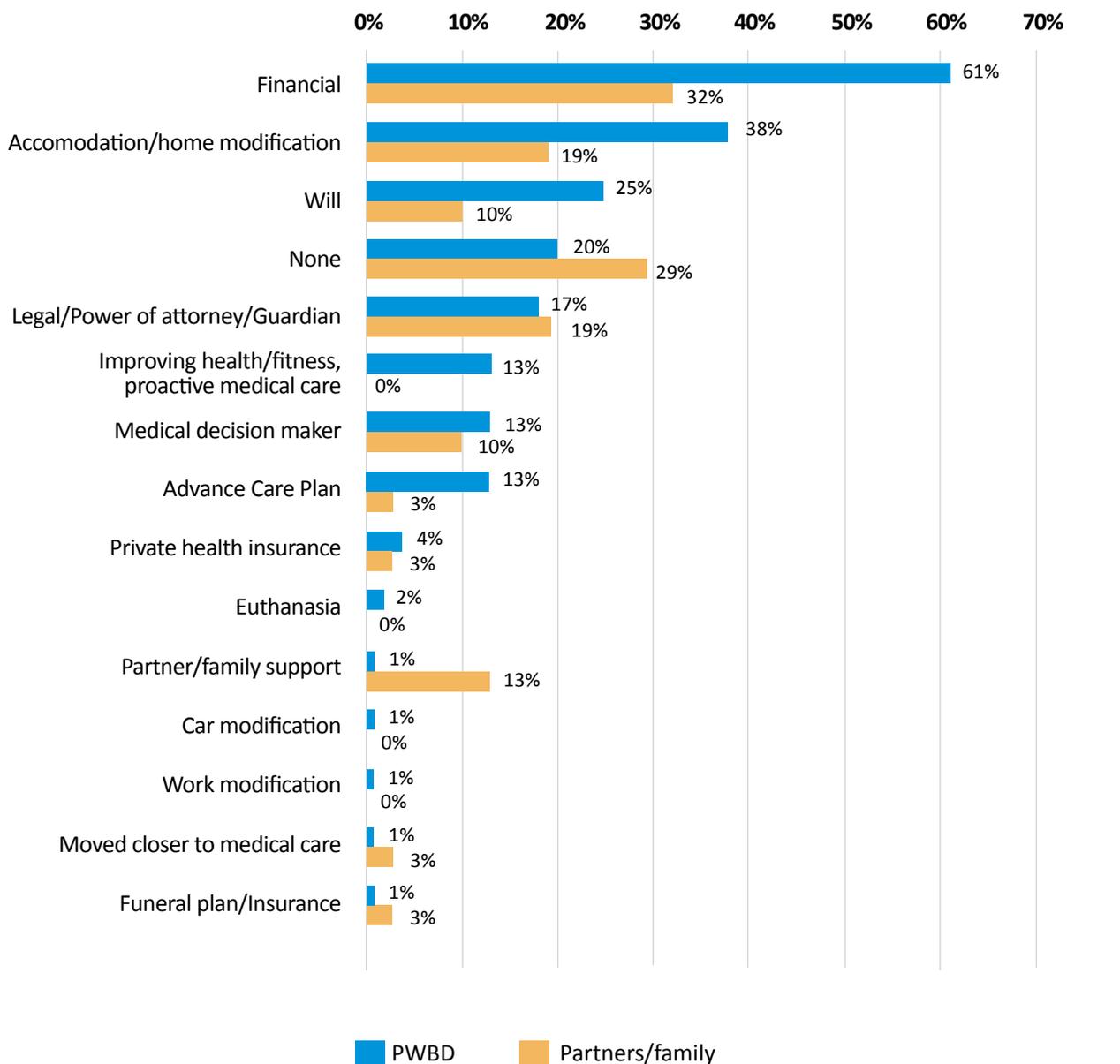
Which one best describes where you currently live?

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

5.5.4 FUTURE PLANNING

Figure 4: Future plans for the older person with a bleeding disorder (PWBD) – responses from PWBD and their partners/family

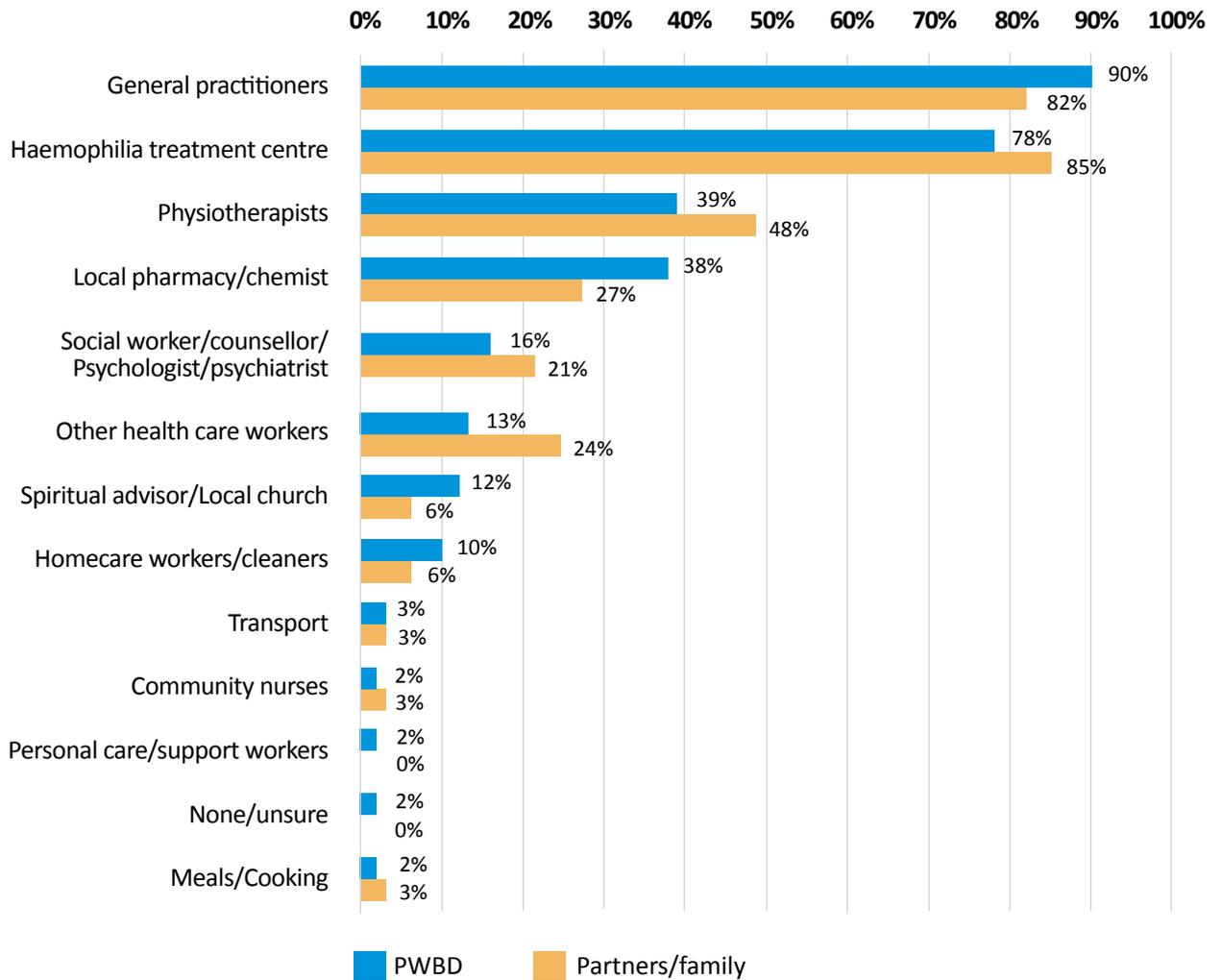
What plans for getting older have you put in place (with the person with a bleeding disorder?)



5.5.5 SUPPORT

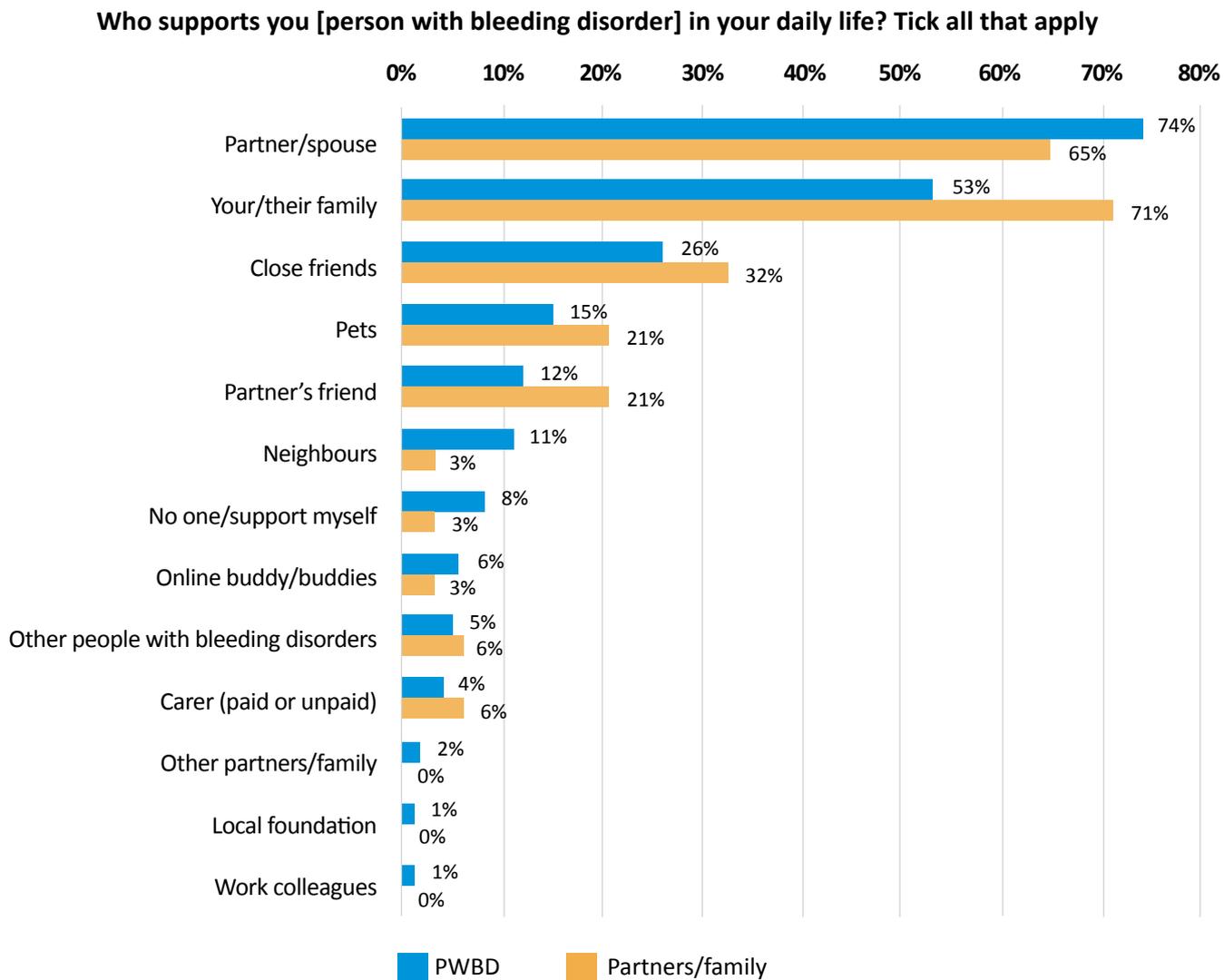
Figure 5: Support services used by the older person with a bleeding disorder (PWBD) – responses from PWBD and their partners/family

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



For older people with bleeding disorders, the ‘other health care worker’ support services they accessed (figure 5) could also include complementary medicine such as acupuncture, chiropractic or naturopathy.

Figure 6: Support in daily life for the older person with a bleeding disorder (PWBD) – responses from PWBD and their partners/family

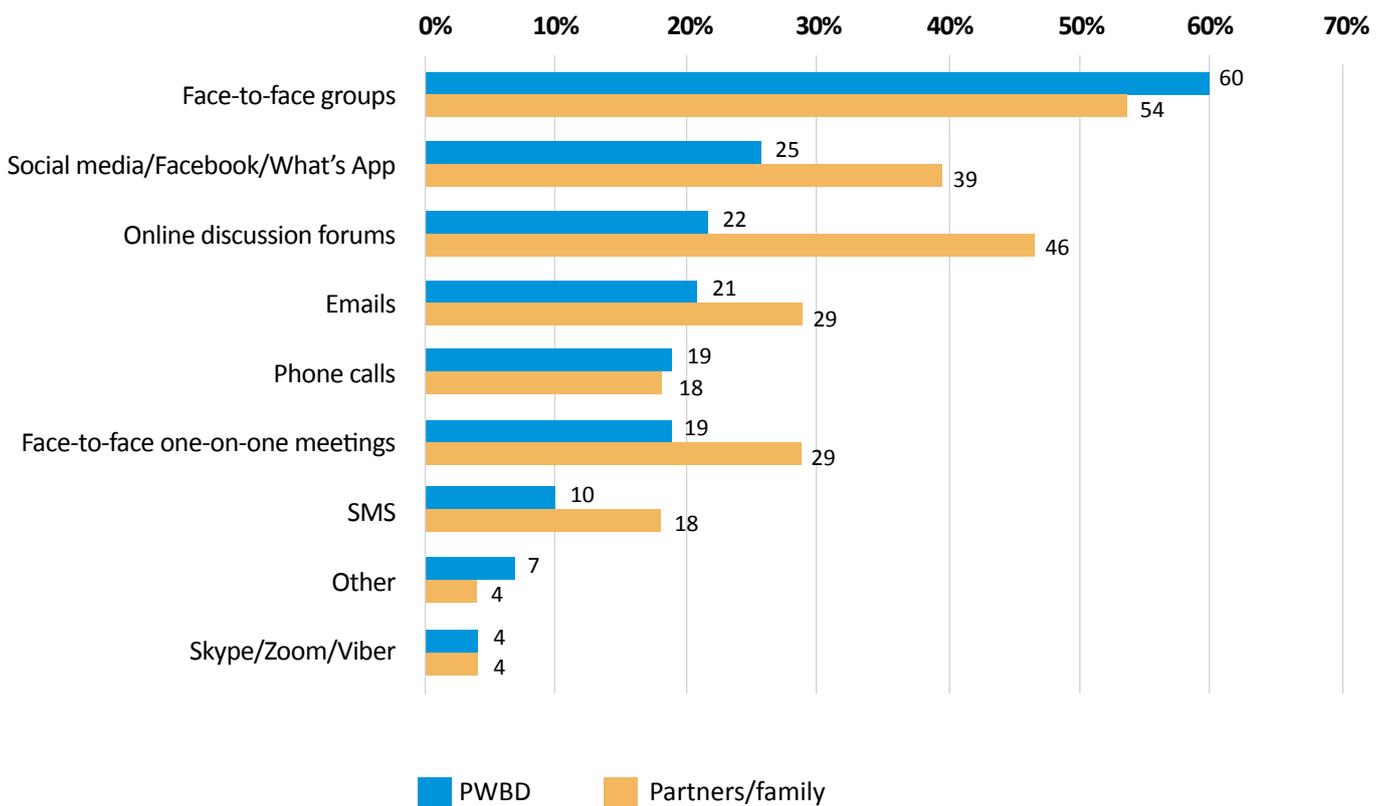


As can be seen in figure 6, a small number commented that no one provided them with support in their daily life; some because they felt they were self-sufficient and did not need support, but others were conscious of not having support and being isolated.

5.5.6 PEER SUPPORT

Figure 7: Peer support preferences – responses from older people with a bleeding disorder (PWBD) and their partners/family

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



When asked about their interest in connecting with other people online or through social media:

- Most in both groups (74% or 49/66 people with bleeding disorders and 67% or 8/12 partners/family) commented that they were not interested or that they prefer face-to-face and it was not something they do.
- A smaller group (20% or 13/66 people with bleeding disorders and 17% or 2/12 partners/family) thought that it would be valuable to have this option available.

5.5.7 ONLINE COMMUNICATIONS

- 86% (102/119) of older people with bleeding disorders said they used a computer/tablet/iPad daily
- 88% (28/32) of partners and family said they used a computer/tablet/iPad daily

Table 15: Accessing online information: responses from older people with bleeding disorders and partners/family
How do you access online information? Please choose the answers that apply to you

Answer Choices	Responses			
	People with bleeding disorders		Partners/family	
I use my computer at home	79%	90	87%	26
I use my computer at work	26%	30	43%	13
I use my mobile phone to access online information	61%	69	73%	22
I use my tablet/iPad	41%	47	33%	10
I use computers at the local library	3%	3	0%	0
I use computer at the communal area of the place where I live	2%	2	7%	2
Someone else helps me	4%	4	3%	1
Someone else gets online information for me	3%	3	3%	1
I don't use computers or mobile devices	2%	2	0%	0
Other	3%	3	3%	1
Answered		114		30

Figure 8: Information topics – responses from older people with a bleeding disorder (PWBD) and their partners/family

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

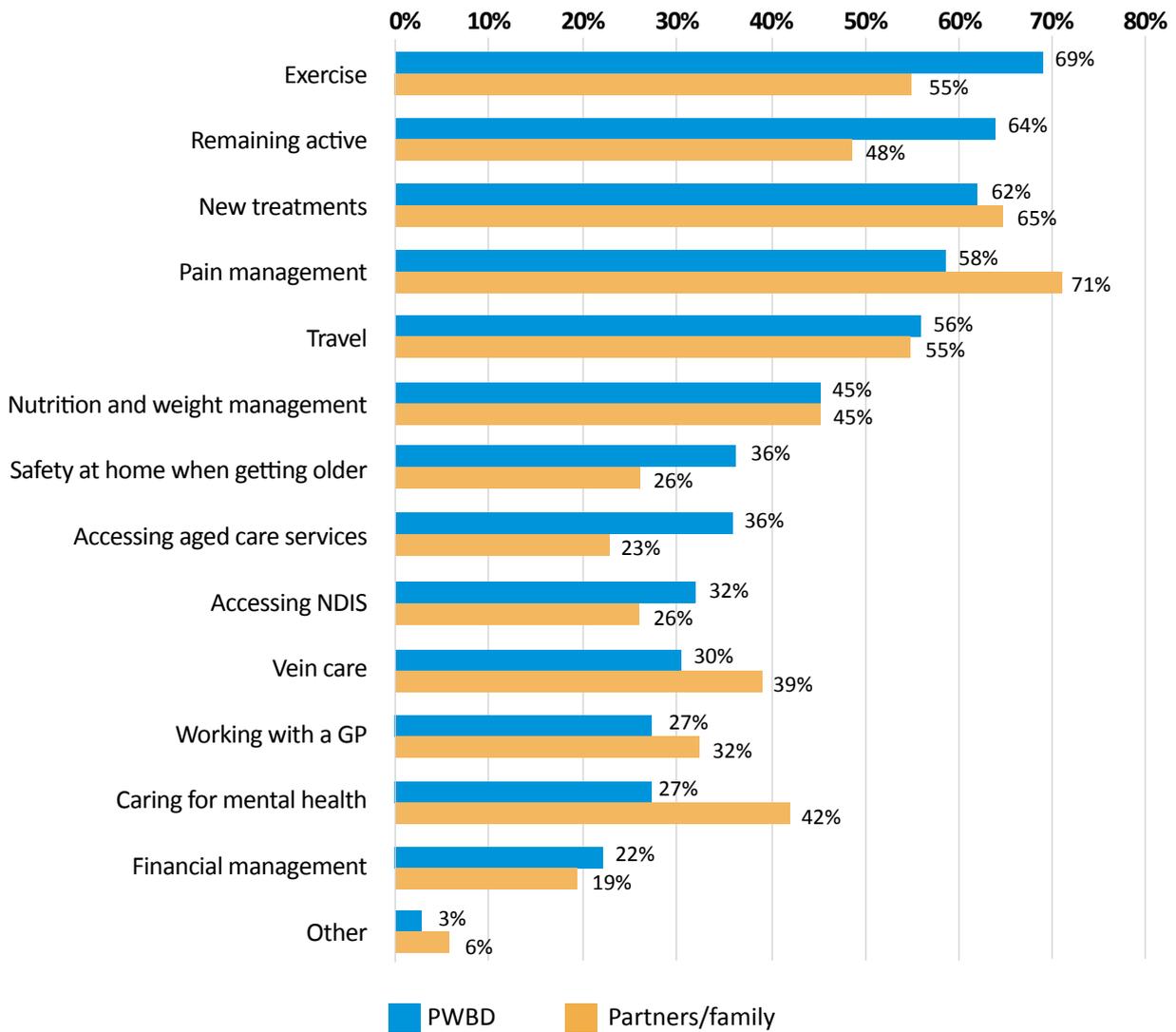
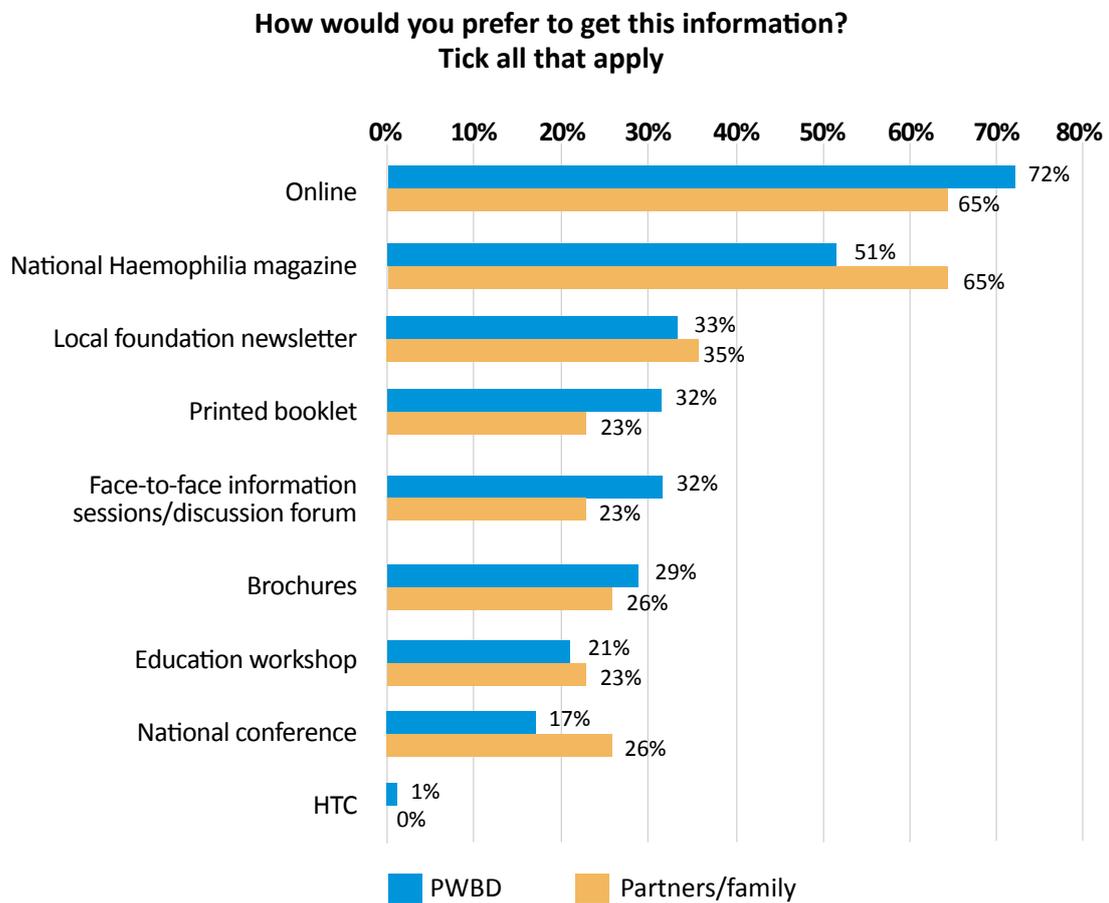


Figure 9: Information preferences – responses from older people with a bleeding disorder (PWBD) and their partners/family



5.6 PROBE Australia Study results

Detailed results are available in Appendix 2.

Age-related data was sourced from the PROBE Australia Study in February 2020. There were **337 respondents** from Australia aged 19 years or over:

- **328** returned the **online** questionnaire
- **9** returned the **print** questionnaire

Table 16: PROBE Australia respondents by gender and age

	People with haemophilia/ carry the gene	People without a bleeding disorder (controls)	Total
Total (N=)	196	141	337
Male	104	73	177
Female	92	68	160
Age groups			
19-44 years	80	40	120
45-64 years	74	65	139
65 years +	42	36	78

Women who reported their haemophilia severity as mild, moderate or severe have been aggregated as 'factor level below normal' and have been described as 'women with haemophilia', even if they described themselves as a 'carrier'.

Table 17: Respondents by haemophilia diagnosis, gender and severity

	Men and women with haemophilia (PWH) All had factor levels in the range for a clinical diagnosis of haemophilia (<40%)		
	Male	Female	Total
Total (N=)	91	27	118
By diagnosis			
Haemophilia A (FVIII)	75	10	85
Haemophilia B (FIX)	16	-	16
'Carrier' – haemophilia (type not specified)	-	17	17
By severity			
Severe (<1%)	39	-	39
Moderate (1-5%)	15	-	15
Mild (5-40%)	37	-	37
Factor level below normal (<40%)	-	27	27

Table 18: Other respondents affected by haemophilia by gender and severity

	Male	Female	Total
Total (N=)	<17	65	<83
Normal	<5	36	<41
I do not know - carrier	-	16	16
Did not report	12	13	25

Table 19: Respondents ≥ 45 yrs by gender and severity

	Men with haemophilia ≥ 45 yrs MWH By severity			Men without a bleeding disorder ≥ 45 yrs MNBD	Women with haemophilia ≥ 45 yrs WWH	Women without a bleeding disorder ≥ 45 yrs WWH
	Mild	Severe/ moderate	Total	Total	Factor level below normal	Total
Total N =	29	28	57	49	21	52

Table 20: Respondents ≥ 45 yrs by age, gender and haemophilia diagnosis

	Men with haemophilia MWH		Men without a bleeding disorder MNBD		Women with haemophilia WWH		Women without a bleeding disorder MNBD	
	45-64 yrs	≥ 65 yrs	45-64 yrs	≥ 65 yrs	45-64 yrs	≥ 65 yrs	45-64 yrs	≥ 65 yrs
Total N =	30	27	32	17	15	6	32	19

Table 21: Treatment regimen

	Men with haemophilia ≥ 45 yrs MWH By severity		Women with haemophilia ≥ 45 yrs WWH
	Mild	Severe/ moderate	Factor level below normal
Total N =	29	28	21
Prophylaxis	2	12	0
Periodic prophylaxis	2	1	4
On demand	23	13	13
No treatment	2	2	4

Table 22: Prophylaxis treatment frequency

	Men with haemophilia ≥ 45 yrs MWH
Total N =	14
3 times per week	5
2 times per week	4
Once per week	3
Once per 4 weeks	1
Not reported	1

5.6.1 TARGET JOINTS

Table 23 shows the experience of target joints in men and women with haemophilia 45 years and over.

- Men with severe and moderate haemophilia were the most affected by target joints.
- A smaller proportion of men with mild haemophilia had also been affected by target joints and joint damage resulting from bleeds.
- Very few women with haemophilia reported target joints or joint damage from bleeds.
- There may have been some under-reporting from men with mild haemophilia and women due to lack of knowledge about joint bleeds.

Table 23: Target joints

	Men with haemophilia ≥ 45 yrs MWH By severity			Women with haemophilia ≥ 45 yrs WWH
	Mild	Severe/moderate	Total	Factor level below normal
Total N =	29	28	57	21
Currently have target joints	6	15	21	2
Do not have target joints	16	10	26	15
Don't know if have a target joint	7	2	9	3
Not reported	-	1	1	1
Chronic pain related to target joint				
Chronic pain due to target joint	5	14	19	2
Developing a target joint 3+ spontaneous bleeds into a joint in the last 6 months				
Yes	2	11	13	1
No	26	15	41	19
I don't know	1	1	2	1
Not reported	-	1	1	-

Table 24: Target joints – range of motion

	Men with haemophilia ≥ 45 yrs MWH By severity									Women with haemophilia ≥ 45 yrs WWH		
	Mild			Severe/moderate			Total			Factor level below normal		
Total N =	29			28			57			21		
	Yes	No	Not reported	Yes	No	Not reported	Yes	No	Not reported	Yes	No	Not reported
Joint range of motion reduced due to haemophilia	15	14	-	26	1	1	41	15	1	3	17	1

5.6.2 PHYSICAL FUNCTIONING AND PAIN

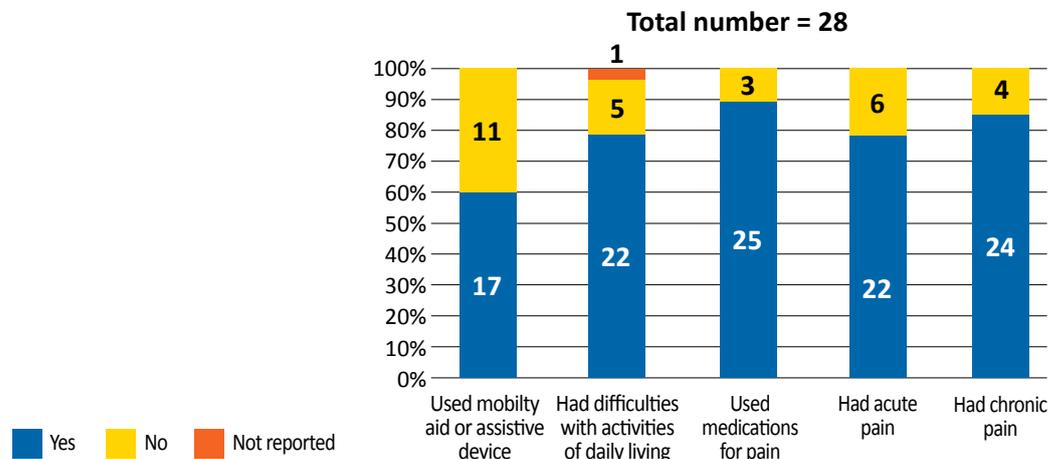
- Men and women with haemophilia were more likely to say they experienced pain and issues relating to mobility and activities of daily life than people of the same age without a bleeding disorder
- The difference between the two groups was particularly apparent in relation to areas involving mobility and physical functioning.
- This comparison is demonstrated in every age bracket – see Appendix 3 for age group breakdowns.

Differences are even more apparent when analysed by gender and haemophilia severity in the 45 years and over age group.

5.6.3 MEN WITH SEVERE AND MODERATE HAEMOPHILIA

- A very high proportion of men with severe and moderate haemophilia aged 45 years and over experienced problems with pain and physical functioning:
 - 79% (22/28) had experienced acute pain, 86% (24/28) had experienced chronic pain, 89% (25/28) had used medication for pain
 - 79% (22/28) had problems with activities of daily living in the last 12 months and 61% (17/28) had needed a mobility aid or assistive device.

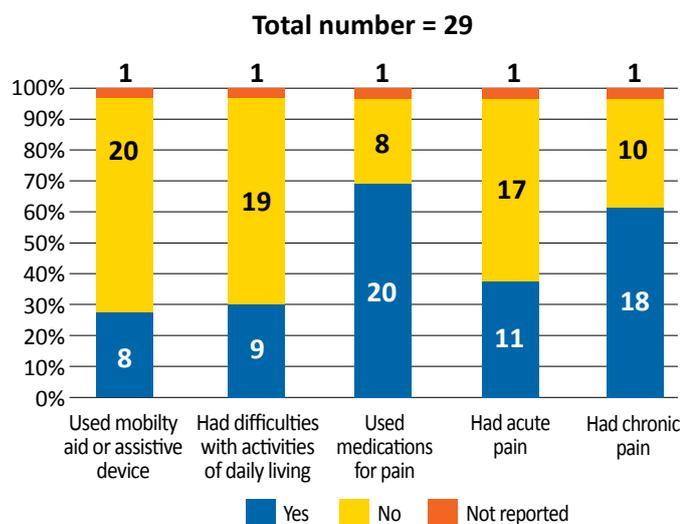
Figure 10: Physical functioning and pain in the last 12 months - men with moderate and severe haemophilia 45 years and over



5.6.4 MEN WITH MILD HAEMOPHILIA

- A substantial proportion of men with mild haemophilia aged 45 years and over reported pain and difficulties with mobility and activities of daily living, although this was a smaller proportion than men with moderate and severe haemophilia.
- 62% (18/29) of men with mild haemophilia reported chronic pain and 69% (20/29) reported using medication for pain
- 28% (8/29) reported problems with mobility and 31% (9/29) with activities of daily living.
- This is markedly higher than the equivalent age bracket of men without a bleeding disorder.

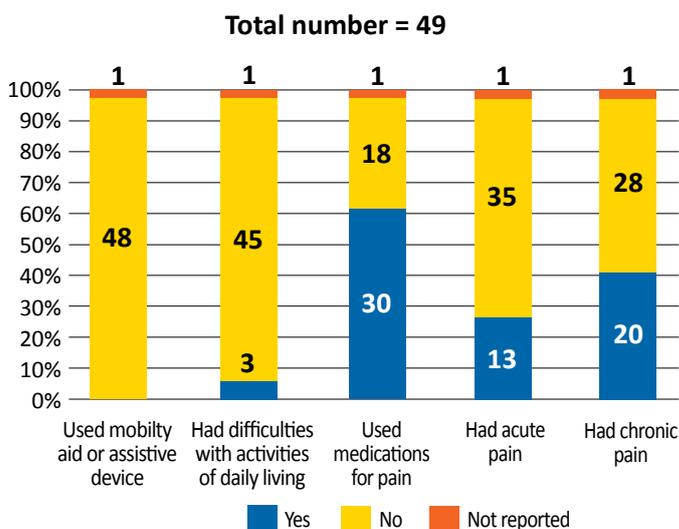
Figure 11: Physical functioning and pain in the last 12 months - men with mild haemophilia 45 years and over



5.6.5 MEN WITHOUT A BLEEDING DISORDER

- Men without a bleeding disorder aged 45 years and over were much less likely to report pain and problems with mobility and activities of daily living.
- 41% (20/49) of men without a bleeding disorder reported chronic pain and 61% (30/49) reported using medication for pain.
- None reported problems with mobility and 6% (3/49) reported problems with activities of daily living.

Figure 12: Physical functioning and pain in the last 12 months - men without a bleeding disorder 45 years and over



5.6.6 WOMEN WITH HAEMOPHILIA AND WOMEN WITHOUT A BLEEDING DISORDER

- Women with haemophilia 45 years and over also reported substantial problems with mobility, activities of daily living and pain, similar to men with mild haemophilia.
- Differences: the men with mild haemophilia were more likely to report have used a mobility aid (28% or 8/29) compared to the women with haemophilia (14% or 3/21); and the women with haemophilia reported experiencing acute pain (57% or 12/21) more often than men with mild haemophilia (38% or 11/29)
- Women with haemophilia (figure 13) also had similar experiences to the women without a bleeding disorder in the equivalent age bracket (figure 14)
- Difference between the two groups of women: 57% (12/21) of women with haemophilia reported acute pain compared to 29% (15/52) of women without a bleeding disorder.

Figure 13: Physical functioning and pain in the last 12 months - women with haemophilia 45 years and over

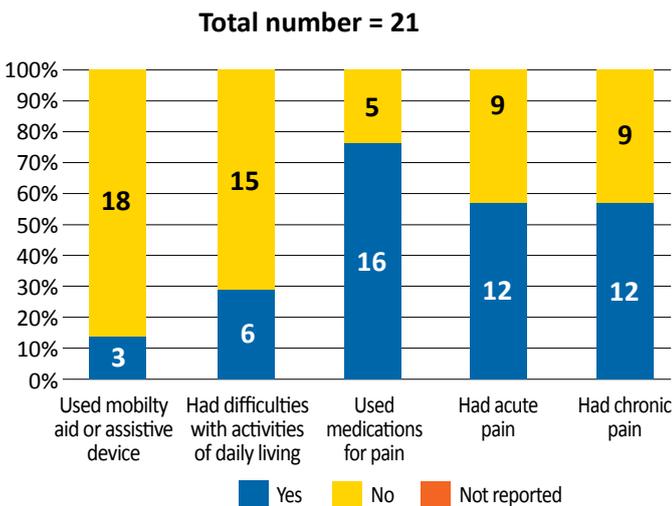
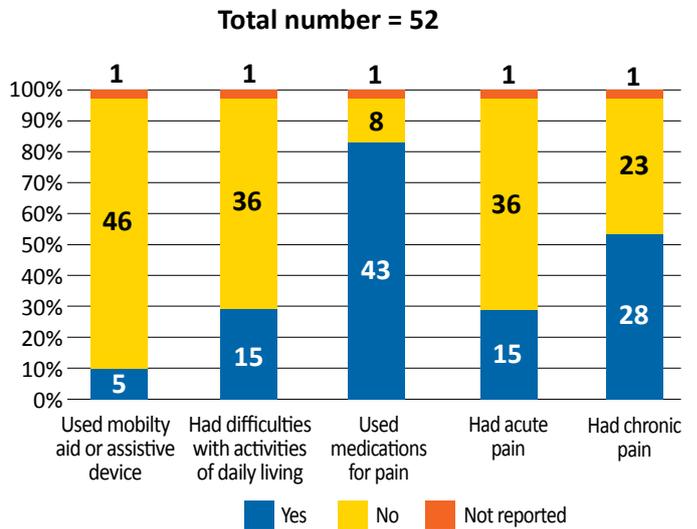


Figure 14: Physical functioning and pain in the last 12 months - women without a bleeding disorder 45 years and over



5.6.7 OTHER HEALTH PROBLEMS

All PROBE study participants were asked whether they had other specific health problems in the last 12 months, many of which are health conditions related to ageing.

The proportion who experienced some ageing-related health conditions such as stroke, diabetes and kidney disease was similar between the people with haemophilia and people with no bleeding disorder aged 45 years and over.

Marked differences between people with haemophilia and people with no bleeding disorder aged 45 years and over were:

Heart disease and hypertension

- Substantially more men with haemophilia reported heart disease and hypertension. For example, 29% (11/57) of men with haemophilia reported angina/ chest pain compared to 2% (1/49) of men without a bleeding disorder; and 49% (28/57) of men with haemophilia reported high blood pressure in comparison to 35% (17/49) of the men without a bleeding disorder.

- Fewer of the women with haemophilia (19% or 4/21) reported high blood pressure than the women without a bleeding disorder, where it was reported by 35% (18/52); this was also less than the 49% (28/57) of the men with haemophilia who reported high blood pressure.
- Only small numbers of women with or without a bleeding disorder reported heart conditions.

Mental health issues

- Men with moderate and severe haemophilia reported mental health issues more often, including anxiety (32% or 9/28) and depression (14% or 5/28). In comparison 17% (5/29) of men with mild haemophilia and 14% (7/49) of men without a bleeding disorder reported anxiety and 10% (3/10) and 10% (5/49) respectively reported depression.
- Only small numbers of women with or without bleeding disorders reported depression or anxiety.

Gum disease/bleeding gums

- 21% (6/29) of men with mild haemophilia said they had gum disease or bleeding gums compared to 7% (2/28) of men with moderate and severe haemophilia and 6% (3/49) of men without a bleeding disorder.
- 33% (7/21) of women with haemophilia reported gum disease or bleeding gums compared to 8% (4/52) of women without a bleeding disorder.

Arthritis

- Men and women with haemophilia were much more likely to report arthritis than men and women without a bleeding disorder.
- 58% (33/57) of the men with haemophilia 45 years and over reported arthritis: 85% (24/28) of the men with moderate and severe haemophilia and 31% (9/29) of men with mild haemophilia. This contrasted to 18% (9/49) of the men without a bleeding disorder
- 52% (11/21) of the women with haemophilia reported arthritis compared to 29% (15/52) of women without a bleeding disorder.

5.6.8 HEPATITIS C

The PROBE Australia Study results for people aged 45 years and over demonstrate the high level of exposure to HCV among people with haemophilia in Australia through their treatment products. The results also highlight that a high proportion have now had treatment and been cured, although there remains a small number who have had unsuccessful treatment. The results are also a reminder that some do not know their current HCV status.

5.6.8.1 Diagnosis

- 69% (20/29) of men with mild haemophilia and 93% (26/28) of men with moderate and severe haemophilia had ever been diagnosed with HCV.
- 14% (3/21) of the women with haemophilia and 1/20 of the women who carried the gene and had a normal factor level had also been diagnosed with HCV.
- In comparison, only 1 of the 101 men and women without a bleeding disorder aged 45 years or over had ever been diagnosed with HCV: a male, who had cleared the virus spontaneously.

5.6.8.2 Current HCV status

- 96% (48/50) men and women with haemophilia had successfully cleared HCV, either spontaneously or through treatment.
- 1 man with moderate/severe haemophilia had unsuccessful treatment.
- 1 woman with a normal factor level did not know her current HCV status.

5.6.9 WORK

From the age of 45 years onwards, men and women with haemophilia were more likely to be working part-time or retired than their counterparts without a bleeding disorder.

Men with haemophilia

- 23% (7/30) of the men with haemophilia aged 45-64 and 22% (6/27) of those aged 65 and over were working part-time, compared to 9% (3/32) of the men without a bleeding disorder aged 45-64 and 12% (2/17) of those aged 65 and over.
- 10% (3/30) of the men with haemophilia aged 45-64 and 67% (18/27) of those aged 65 and over were retired compared to none of the men without a bleeding disorder aged 45-64 and 53% (9/17) of those aged 65 and over.
- 2/30 of men aged 45-64 with haemophilia (2/30) were on long-term sick or disability leave.
- 70% (21/30) of men with haemophilia in the 45-64 year age group and 44% (12/27) in the over 65 age group had made education or career decisions due to their health. This is compared to 19% (6/32) of the men aged 45-64 and none of the men aged 65 years and over without a bleeding disorder.

Women with haemophilia

- 53% (8/15) of women with haemophilia aged 45-64 years were working part-time compared to 18% (6/33) of women who did not have a bleeding disorder.
- 100% (6/6) of women with haemophilia aged 65 years and over were retired compared to 74% (14/19) of the women of the same age who did not have bleeding disorder; 3/19 of the latter group were still working.