Appendix 2

PROBE Australia study findings

Age-related data from the **PROBE (Patient Reported Outcomes Burdens and Experiences) Australia study** was analysed to inform the needs assessment.

The PROBE study is a multi-national validated community questionnaire to understand the impact of haemophilia and treatment on quality of life including number of bleeds, pain, mobility, activities of daily living and related surgical interventions, including the EQ-5D measure.

Haemophilia Foundation Australia leads the PROBE study in Australia. The Participant Information Sheet, questionnaire and dataset have been customized for Australia by the international PROBE lead investigators, although the questions are common to all participating countries. Participation in Australia is fully anonymized. The questionnaire was available online and in print and reply-paid envelopes were provided in the print questionnaire pack.

In Australia PROBE study participants are:

- Adults (men and women) with a clinical diagnosis of haemophilia
- Adult females (women) who describe themselves as haemophilia 'carriers'
- Adults (men and women) who do not have a bleeding disorder (controls/comparative group)

The lead investigators from the international PROBE group obtained ethics approval from McMaster University, Hamilton, Canada, which houses the study database. Ethics approval in Australia was provided by Monash University Human Research Ethics Committee. Monash University has been involved pro bono in ethics oversight for the Australian testing and implementation of this study.

RECRUITMENT

HFA commenced the Australian 'real-world' data collection phase in May 2019.

- Print questionnaire packs were distributed via state/territory Foundations. A small number were posted to selected individuals who were known to prefer print, and sometimes on request.
- The online questionnaire was promoted via Haemophilia Foundation Australia and state/territory foundation newsletters, e-news and social media platforms, including Facebook, Instagram and Twitter.
- The study was also promoted at community events, such as camps and the national bleeding disorders conference in October 2019.

RESULTS

From January 2020 de-identified Australian results were provided to HFA by the international PROBE team via a secure online dashboard, with regular data updates. The age-related data in the Getting Older needs assessment was sourced from the February 2020 update. As this data was sourced for a community needs assessment rather than for research purposes, it was analysed for general trends and comment rather than statistical significance.

PROBE
Patient Reported Outcomes Burdens and Experiences Study

PROBE AUSTRALIA STUDY FINDINGS

1. RESPONDENT DEMOGRAPHICS

In February 2020 there were **337 respondents from Australia aged 19 years or over**:

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

Respondents who did not complete the diagnosis, gender or age questions or answered the questions on behalf of their child were excluded.

Table 1: 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

There was only a very small number of women who completed the PROBE questionnaire who described their severity as moderate or severe. For privacy reasons HFA does not report individual diagnostic categories under 5. For analysis by severity in this report all women who reported their 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 also described themselves as a 'carrier'.

'Carriers'

Until recently in Australia women who had factor levels in the mild range were often described as 'symptomatic carriers', but are now defined as having mild haemophilia.[96] Included in Table 2 are 17 women who reported factor levels in the range for a clinical diagnosis of haemophilia (factor levels under 40%) but described themselves as 'carriers' in the PROBE questionnaire. Nearly all were in the range for mild haemophilia.

As indicated in table 3, there was also a substantial number of women who described themselves as 'carriers' and did not know what their factor level was (17% or 16/92). This could have implications for their care: if their factor levels are below normal they may require treatment to prevent prolonged bleeding after medical and dental procedures and surgery, but if they do not know their factor level, they may not know to request liaison with their Haemophilia Treatment Centre for preventive treatment.

Table 2: 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

Men with haemophilia with normal factor levels

In table 3 a very small number of men with haemophilia reported normal factor levels. This may be because they had had gene therapy and their factor levels were now in the normal range.

Table 3 : 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

PROBE AUSTRALIA STUDY FINDINGS

Analysis by age, gender and severity

In some areas relating to physical health and treatment in the older respondents, data was analysed further by age, gender and haemophilia severity. Those who did not know or report their severity were excluded. Numbers were too small to divide further by age, so the analysis was limited to men and women aged 45 years and over.

Table 4 shows the numbers of respondents in this analysis.

Table 4: 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
	Mild	Severe/moderate	Total	Total	Factor level below normal
Total N =	29	28	57	49	21

Table 5 shows the number of respondents aged 45-64 and 65 years and over when analysed by gender and haemophilia diagnosis but not further defined by haemophilia severity. This breakdown was used for employment.

Table 5: 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

2. TREATMENT

Tables 6 and 7 demonstrate the range of treatment regimens in men and women with haemophilia who were aged 45 years and over. Most of the men with haemophilia on prophylaxis were treating frequently, 2-3 times weekly (9/13). Only 2 men with mild haemophilia reported being on prophylaxis. None of the women were on prophylaxis.

Table 6: 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 7: 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

PROBE AUSTRALIA STUDY FINDINGS

Treatment products

In table 8 men and women with haemophilia aged over 45 years described their treatment regimen. Most men with moderate and severe haemophilia (19/28) were being treated with standard half-life factor concentrate, with smaller numbers having extended half-life (EHL) factor concentrate (5/28) or subcutaneous products such as emicizumab (3/28). Men with mild conditions and women reported treatment with standard half-life clotting factor concentrate and DDAVP. Some men with mild haemophilia (6/29) and women (7/21) said they did not need treatment; a small number of men with moderate/severe haemophilia (2/28) also said they did not need treatment.

Table 8: Treatment product

	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**
Factor VIII/IX concentrate (standard half-life)	19	19	8
Factor VIII/IX concentrate (extended half-life)	-	5	-
Subcutaneous injections	-	3	-
Desmopressin (DDAVP)	2	-	5
Antifibrinolytics (ie, tranexamic acid or aminocaproic acid)	5	2	8
Whole blood transfusions	-	1	1
Fresh frozen plasma	1	-	-
Cryoprecipitate	2	-	-
No treatment needed	6	2	7
Other	-	1	-

Table 6 showed that the men with mild haemophilia and women with low factor levels were much more likely to have treatment on demand rather than prophylaxis. As a result, as can be seen in table 9, most of these two groups (23/29 men with mild haemophilia and 11/21 women) reported visiting the HTC or Emergency Department (ER) for their treatment, rather than treating at home. A small number of men with moderate or severe haemophilia (4/28) also reported visiting their HTC for treatment. While they would be able to access expertise in treating bleeding disorders at their HTC, this would also mean travel to the HTC which may be at a distance for some. The questionnaire did not ask whether the Emergency Department was located in the same hospital as their HTC. If they had sought treatment locally at the Emergency Department of a hospital which was not where their HTC was located, while this may have reduced their need to travel, but they may have had the disadvantage of the hospital having limited or no expertise in bleeding disorders.

Table 9: Where treatment was received

	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**
Home	5	22	3
Haemophilia Treatment Centre	20	4	8
Emergency room	3	-	3
No treatment	-	-	4
Not reported	1	2	3

3. JOINTS, PHYSICAL FUNCTIONING AND PAIN

Target joints

When three or more bleeds have occurred in a particular joint without an apparent cause (spontaneous) within 6 months, the joint is known as a 'target joint'.[1] Some people with haemophilia find that one or more particular joints become 'target joints' and have ongoing recurrent bleeding.[2]

Men with severe and moderate haemophilia were the most affected by target joints. In table 10 approximately half of men 45 years and older with severe and moderate haemophilia reported current target joints (54% or 15/28) and chronic pain (50% or 14/28) resulting from target joints; 39% (11/28) reported recent bleeds that fit the definition of a target joint. In table 11 nearly all (93% or 26/28) respondents in that category noted that their range of motion in at least one joint had been reduced due to haemophilia.

While the proportion was lower, a considerable number of men with mild haemophilia had also been affected by target joints and joint damage resulting from bleeds. In table 10 around one-fifth said they had current target joints (21% or 6/29) and 17% (5/29) reported chronic pain resulting from target joints. More than half (52% or 15/29) in table 11 described joints with reduced range of

motion as a result of haemophilic bleeds. Table 10 notes approximately a quarter (24% or 7/29) who responded that they didn't know if they had a target joint, which suggests the need for further review or education to assess whether they had target joints.

In contrast, in table 10 very few women 45 years and over with haemophilia reported target joints (2/21) or joint damage from bleeds (3/21). As with men with mild haemophilia, there may also be some under-reporting due to lack of knowledge about joint bleeds.

Table 10: 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 11: 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

Figures 1-8 - Physical functioning and pain problems in the last 12 months, by age group and overall

Men and women with haemophilia – PWH compared to **Men and women without a bleeding disorder – NBD**

Figures 1 to 8 show that both overall and in every age group, 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.

Interestingly, figures 7 and 8 show a similar finding for both people with haemophilia and those without a bleeding disorder: in both groups the proportion experiencing acute pain and using medication for pain was noticeably lower in those aged 65 years and over compared to other age brackets.

Respondent numbers and the relative percentages are shown in figures 1-8 below.

Figure 1: Physical functioning and pain in the last 12 months -men and women with haemophilia (PWH), aged 19 years and over

Total number = 118

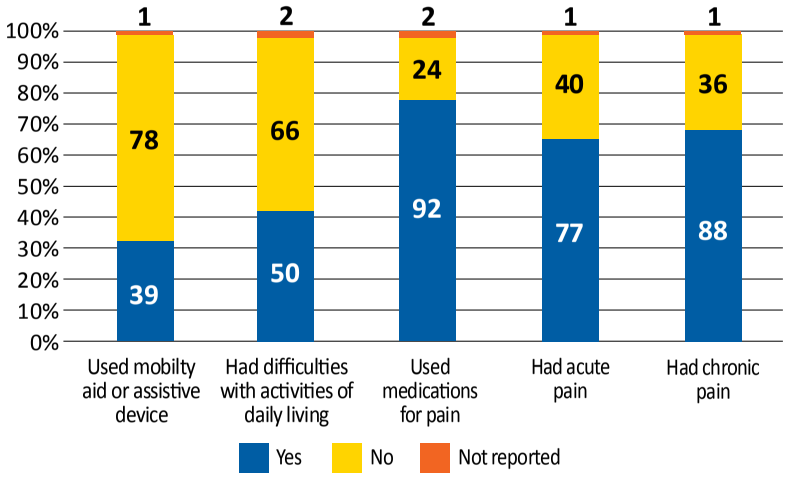


Figure 2: Physical functioning and pain in the last 12 months -men and women without a bleeding disorder (NBD), aged 19 years and over

Total number = 141

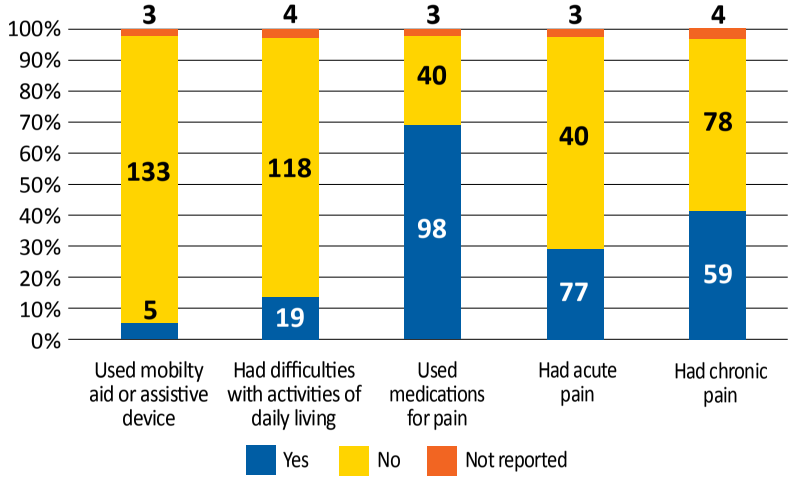


Figure 3: Physical functioning and pain in the last 12 months - men and women with haemophilia (PWH), aged 19 - 44 years

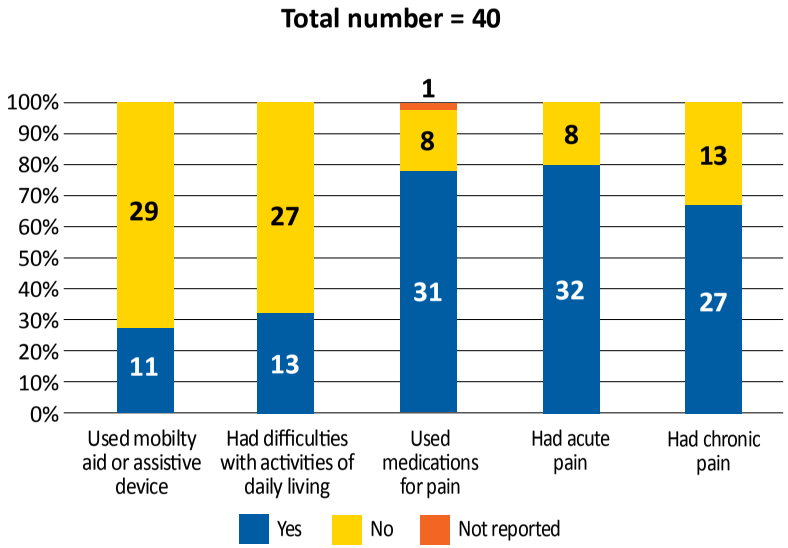


Figure 4: Physical functioning and pain in the last 12 months - men and women without a bleeding disorder (NBD), aged 19 - 44 years

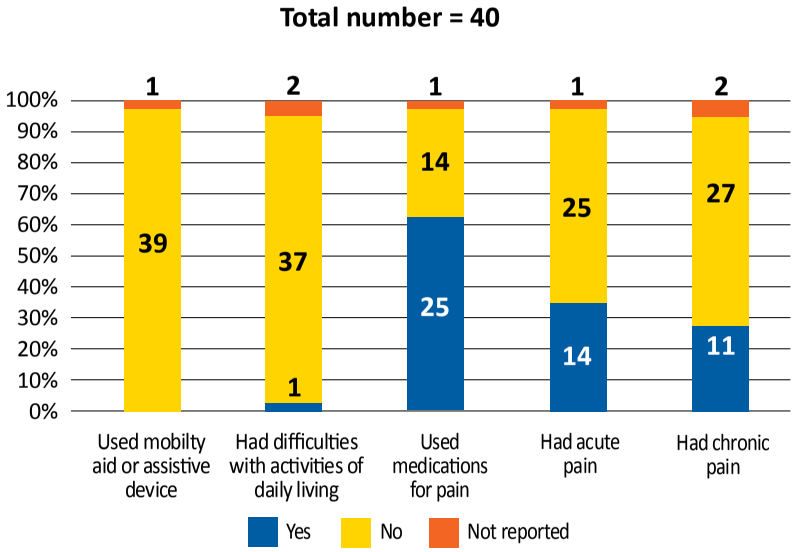


Figure 5: Physical functioning and pain in the last 12 months - men and women with haemophilia (PWH), aged 45 - 64 years

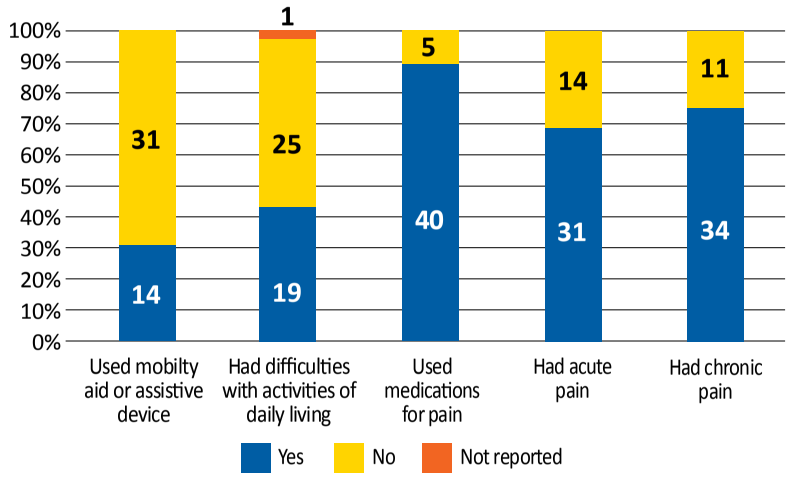


Figure 6: Physical functioning and pain in the last 12 months - men and women without a bleeding disorder (NBD), aged 45 - 64 years

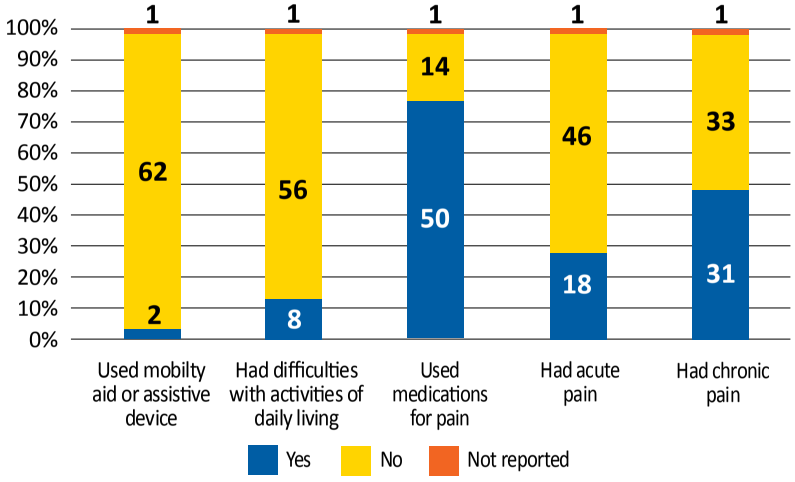


Figure 7: Physical functioning and pain in the last 12 months - men and women with haemophilia (PWH), aged 65 years and over

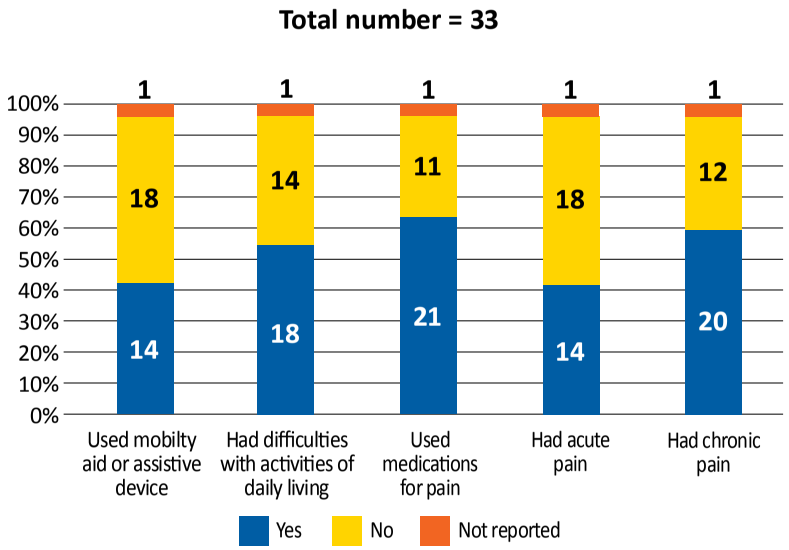
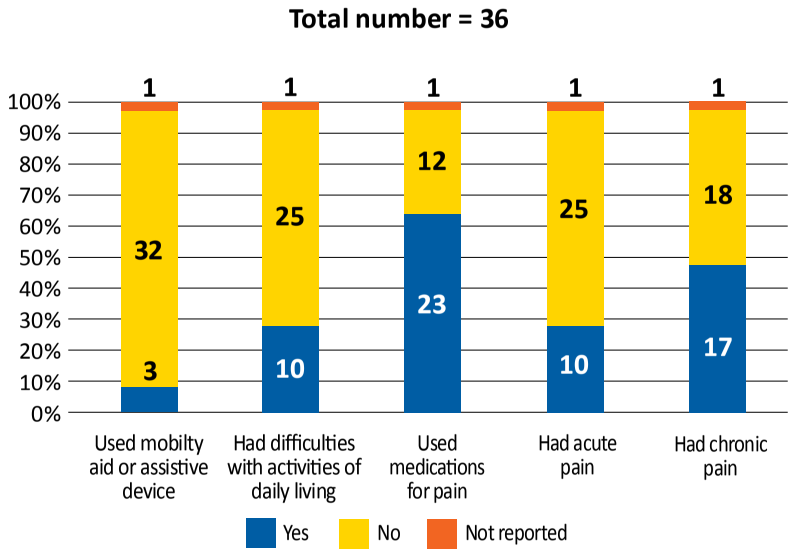


Figure 8: Physical functioning and pain in the last 12 months - men and women without a bleeding disorder (NBD), aged 65 years and over



Figures 9-12: Physical functioning and pain problems in the last 12 months in men aged 45 years and over

Men with haemophilia compared by **severity** and compared to **men without a bleeding disorder**

The PROBE questionnaire asked participants about problems they had experienced in physical functioning and pain in the last 12 months. Figures 9 and 10 show the overall differences in these areas between men with haemophilia and men without a bleeding disorder aged 45 years and over.

When analysed by age, gender and haemophilia severity, the specific differences in pain and physical functioning between men with haemophilia and men without a bleeding disorder become more apparent.

Figure 11 shows that there was a very high proportion of men with severe and moderate haemophilia who had experienced problems with pain and physical functioning in the previous 12 months: 79% (22/28) had experienced acute pain, 86% (24/28) had experienced chronic pain, 90% (25/28) had used medication for pain; 81% (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.

Mild haemophilia

While men with mild haemophilia in figure 12 had reported pain and difficulties with mobility and activities of daily living less often than men with moderate and severe haemophilia, a substantial number did experience problems in these areas.

The comparison of men with mild haemophilia in figure 12 with men who do not have a bleeding disorder in figure 10 highlights particular problems: of the men with mild haemophilia, 64% (18/29) reported chronic pain and 71% (20/29) reported using medication for pain; 29% (8/29) reported problems with mobility and 32% (9/29) with activities of daily living. This is markedly higher than the equivalent age bracket without a bleeding disorder. In the group without a bleeding disorder 42% (20/49) 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 9: Physical functioning and pain in the last 12 months - men with haemophilia 45 years and over

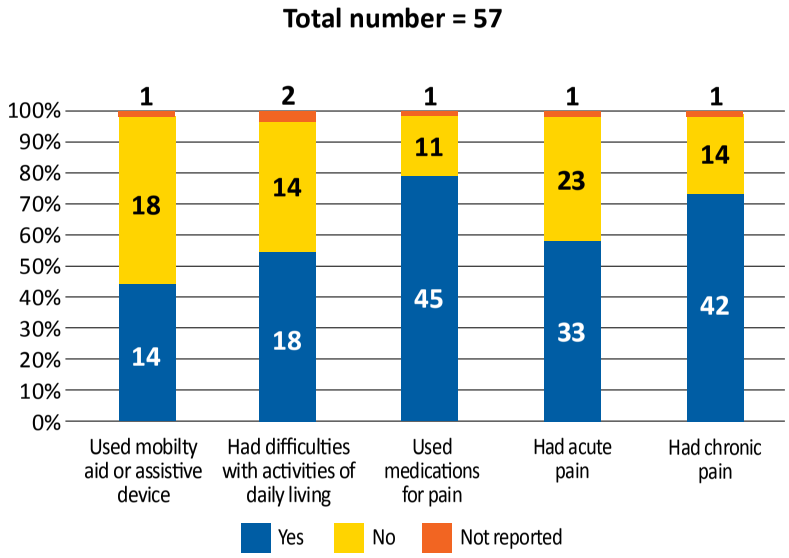


Figure 10: Physical functioning and pain in the last 12 months - men without a bleeding disorder 45 years and over

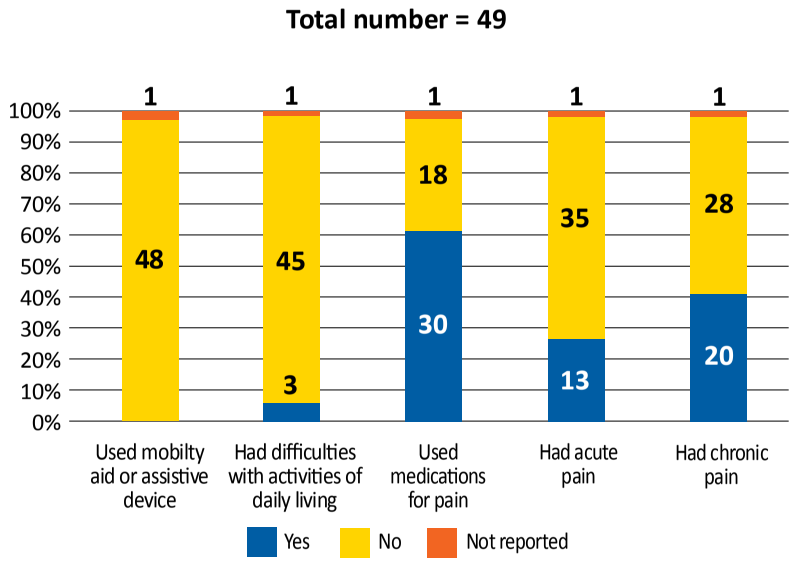


Figure 11: Physical functioning and pain in the last 12 months - men with moderate and severe haemophilia 45 years and over

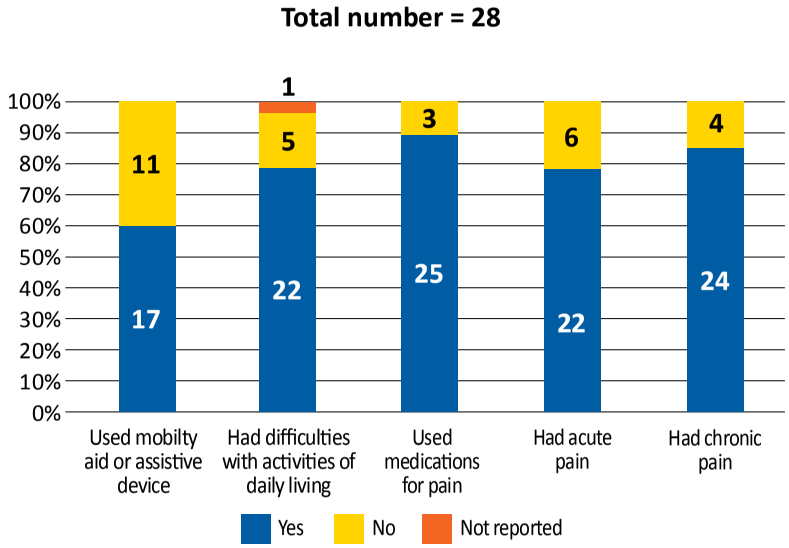
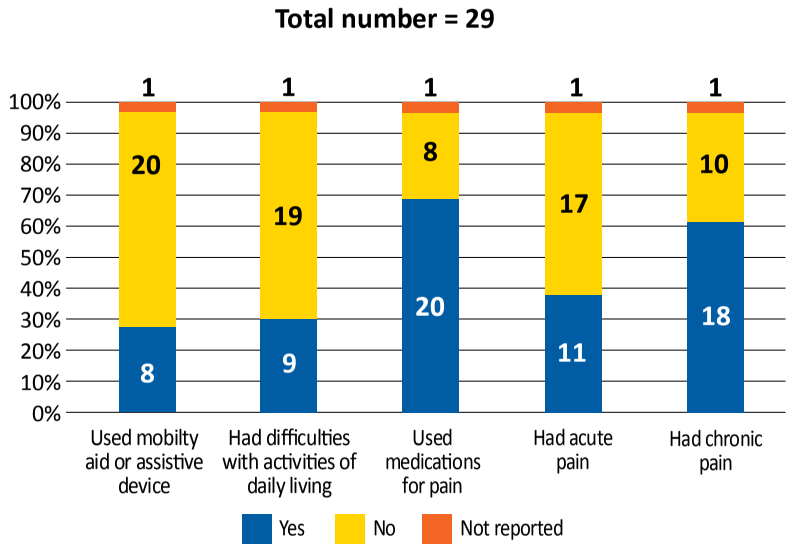


Figure 12: Physical functioning and pain in the last 12 months - men with mild haemophilia 45 years and over



Figures 13-14: Physical functioning and pain problems in the last 12 months in women aged 45 years and over

Women with haemophilia compared to **women without a bleeding disorder**

Figure 13 shows that when analysed by age, gender and severity, women with haemophilia 45 years and over also reported substantial problems with mobility, activities of daily living and pain.

Interestingly, the experience of the women with haemophilia (figure 13) was similar in most of these areas to the women without a bleeding disorder in the equivalent age bracket (figure 14). The one area where a marked difference between the two groups of women can be seen is in the experience of acute pain, which was reported by 57% (12/21) of women with haemophilia and 29% (15/52) of women without a bleeding disorder.

However, the experience of the women with mild haemophilia (figure 13) was also similar to the men with mild haemophilia (figure 12) across most areas relating to pain and physical functionality. Marked differences: the men with mild haemophilia were more likely to report having used a mobility aid (29% or 8/29) compared to the women (14% or 3/21), while the women with haemophilia reported experiencing acute pain (57% or 12/21) more often than men with mild haemophilia (39% or 11/29).

When analysed by gender and haemophilia severity numbers were relatively small and it is difficult to draw strong conclusions. They were also not asked to explain what their acute pain related to. Larger studies of women with haemophilia would be valuable to better understand their experience of pain and physical functionality.

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

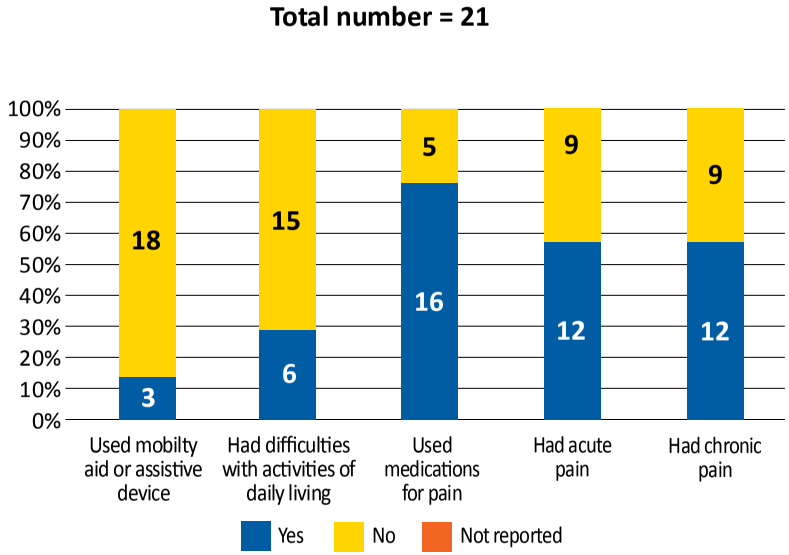
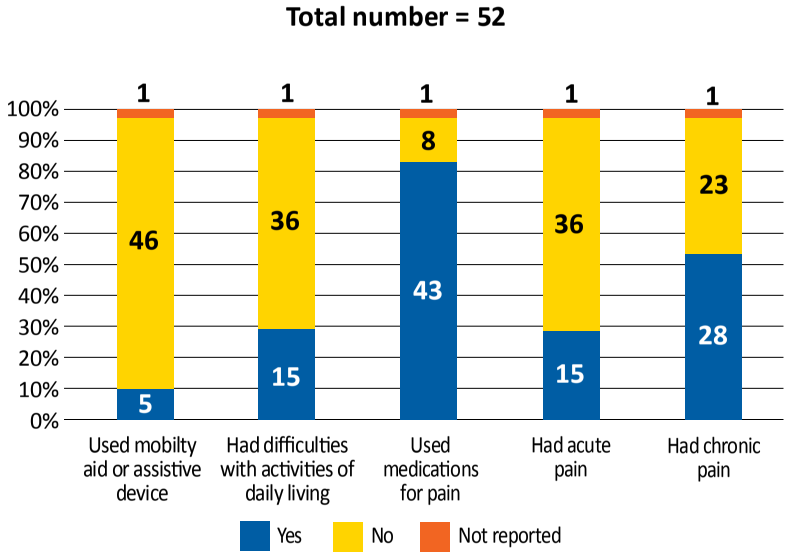


Figure 14: Physical functioning and pain in the last 12 months - women without a bleeding disorder 45 years and over



4. OTHER HEALTH PROBLEMS

Table 12: Other health problems in the last 12 months – men aged 45 years and over

	Men with haemophilia ≥ 45 yrs MWH By severity			Men without a bleeding disorder ≥ 45 yrs - MNBD
	Mild	Severe/moderate	Total	Total
Total N =	**29**	**28**	**57**	**49**
Hepatitis B	1 (3%)	1 (4%)	2 (4%)	0 (0%)
Stroke/Brain haemorrhage	0 (0%)	1 (4%)	1 (2%)	0 (0%)
High blood pressure	14 (48%)	14 (50%)	28 (49%)	17 (35%)
Angina/Chest pain	6 (21%)	5 (18%)	11 (29%)	1 (2%)
Heart attack	0 (0%)	2 (7%)	2 (4%)	0 (0%)
Heart failure or enlarged heart	1 (3%)	3 (11%)	4 (7%)	0 (0%)
Asthma	3 (10%)	2 (7%)	5 (9%)	6 (12%)
Liver cancer	0 (0%)	1 (4%)	1 (2%)	0 (0%)
Cancer (Other than liver)	5 (17%)	3 (11%)	8 (14%)	2 (4%)
Diabetes	5 (17%)	1 (4%)	6 (11%)	4 (8%)
Seizure disorder	1 (3%)	1 (4%)	2 (4%)	0 (0%)
Arthritis	9 (31%)	24 (85%)	33 (58%)	9 (18%)
Gingivitis or gum disease (bleeding gums)	6 (21%)	2 (7%)	8 (14%)	3 (6%)
HIV/AIDS	0 (0%)	5 (18%)	5 (9%)	0 (0%)
Renal/Kidney disease	1 (3%)	0 (0%)	1 (2%)	1 (2%)
Anxiety disorder	5 (17%)	9 (32%)	14 (25%)	7 (14%)
Clinically diagnosed depression	3 (10%)	5 (18%)	8 (14%)	5 (10%)

All respondents were asked whether they had other specific health problems in the last 12 months, many of which are related to ageing. Table 12 shows the responses from men with haemophilia, compared by severity and in total, and compared to men without a bleeding disorder.

As would be expected, 58% (33/57) of the men with haemophilia 45 years and over reported arthritis, and this proportion was very high in the men with moderate and severe haemophilia (85% or 24/28). However, 31% (9/29) of men with mild haemophilia also reported arthritis, in contrast to 18% (9/49) of the men without a bleeding disorder, raising the question of unrecognised haemophilic arthropathy. The impact of bloodborne viruses was also apparent, with small numbers of men with haemophilia reporting hepatitis B and HIV infection and liver cancer, which may be related to hepatitis C infection.

While the experience of some ageing-related health conditions was similar between the two groups, for example,

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stroke, diabetes and kidney disease, there were other health conditions where there were noticeable differences.

Compared to men without a bleeding disorder, 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 bleed 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.

Men with moderate and severe haemophilia also reported mental health issues more often, including anxiety (32% or 9/28) and depression (14% or 5/28). This compared to men with mild haemophilia and men without a bleeding disorder, both of whom reported mental health issues in similar proportions: 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

Men with mild haemophilia were also more likely to say they had gum disease or bleeding gums (21% or 6/29) than either men with moderate and severe haemophilia (7% or 2/28) or men without a bleeding disorder (6% or 3/49). This suggests that it may be valuable for men with mild haemophilia to have increased education around dental hygiene with a bleeding disorder and regular review by a dentist, and perhaps a review of their bleeding issues.

There was also a higher proportion of men with haemophilia who reported cancer other than liver cancer (14% or 8/57) compared to men without a bleeding disorder (4% or 2/49), although numbers were small and this may be just related to the specific group of questionnaire respondents.

Table 13: Other health problems in the last 12 months – women aged 45 years and over

	Women with haemophilia ≥ 45 yrs WWH	Women without a bleeding disorder ≥ 45 yrs - WNBD (controls)
	Total	Total
Total N =	**21**	**52**
Hepatitis B	0 (0%)	0 (0%)
Stroke / Brain haemorrhage	0 (0%)	0 (0%)
High blood pressure	4 (19%)	18 (35%)
Angina / Chest pain	2 (10%)	1 (2%)
Heart attack	1 (5%)	0 (0%)
Heart failure or enlarged heart	0 (0%)	1 (2%)
Asthma	3 (14%)	8 (15%)
Liver cancer	0 (0%)	0 (0%)
Cancer (Other than liver)	2 (10%)	4 (8%)
Diabetes	1 (5%)	2 (4%)
Seizure disorder	0 (0%)	0 (0%)
Arthritis	11 (52%)	15 (29%)
Gingivitis or gum disease (bleeding gums)	7 (33%)	4 (8%)
HIV / AIDS	0 (0%)	0 (0%)
Renal / Kidney disease	0 (0%)	1 (2%)
Anxiety disorder	3 (14%)	4 (8%)
Clinically diagnosed depression	3 (14%)	3 (6%)

Table 13 shows the responses of women with haemophilia compared to women without a bleeding disorder aged 45 years and over in relation to other health problems they had experienced in the last 12 months.

Most of the health conditions associated with ageing were only reported in low numbers by the women who have haemophilia, or in similar numbers to women without a bleeding disorder. High blood pressure was a problem for a considerable number of both groups of women, although fewer of the women with haemophilia (19% or 4/21) reported this 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.

Of note is arthritis, which was reported by 52% (11/21) of the women who have haemophilia and 29% (15/52) of women without a bleeding disorder. This raises the question of unrecognised haemophilic arthropathy, particularly as so few women reported target joints, and suggests that there needs to be further investigation into this area.

Gum disease or bleeding gums was another area of concern for a higher proportion of women with haemophilia (33% or 7/21) compared to women without a bleeding disorder (8% or 4/52). As with men with mild haemophilia, it may be an area where education and dental review to prevent gum disease and a review of bleeding issues would be valuable for these women.

5. HEPATITIS C

The high level of exposure to HCV among people with haemophilia in Australia through their treatment products is reflected in the number who reported ever being diagnosed with HCV (table 14). More than two-thirds (20/29) of men with mild haemophilia and nearly all men with moderate and severe haemophilia (26/28) had been diagnosed with HCV. Some women had also been affected: 3/21 of the women with haemophilia and 1/20 of the women who carried the gene and had a normal factor level.

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 (data not shown in a table): a male, who had cleared the virus spontaneously.

Table 14: Hepatitis C diagnosis

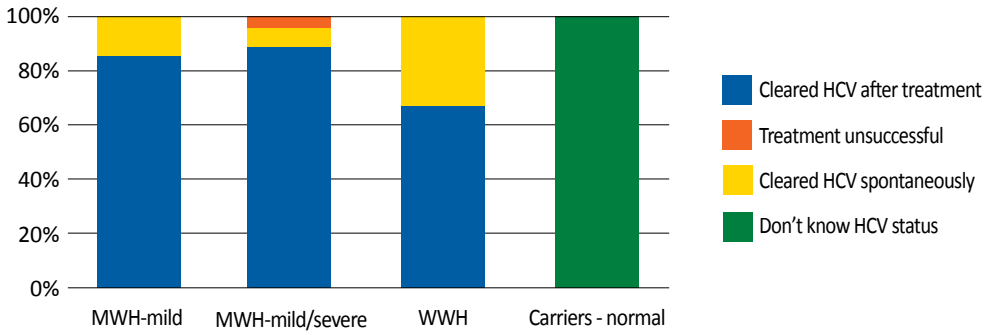
	Men with haemophilia ≥ 45 yrs MWH By severity		Women with haemophilia ≥ 45 yrs WWH By severity	
	Mild	Severe/moderate	Normal	Factor level lower than normal
Total N =	**29**	**28**	**20**	**21**
Ever diagnosed with HCV	20	26	1	3

Table 15 describes the current HCV status of people with haemophilia and carriers with normal factor levels aged 45 years and over. Nearly all of the men and women with haemophilia or carriers in this age group who had been diagnosed with hepatitis C now reported that they had cleared the virus, either after treatment or spontaneously. However, there remained 1 man with severe haemophilia who had unsuccessful treatment and 1 woman with normal factor levels who did not know her current HCV status.

Table 15: Current HCV status of those diagnosed with HCV

	Men with haemophilia ≥ 45 yrs MWH By severity		Women with haemophilia and carriers ≥ 45 yrs WWH By severity		TOTAL
	Mild	Severe/moderate	Normal	Factor level lower than normal	
Total N =	**20**	**26**	**1**	**3**	**50**
Cleared HCV after treatment	17	23	0	2	42
Cleared HCV spontaneously	3	2	0	1	6
Treatment unsuccessful	0	1	0	0	1
Don't know HCV status	0	0	1	0	1

Figure 15: Current HCV status of men with haemophilia (MWH), women with haemophilia (WWH) and carriers with normal factor levels aged 45 years and over.



6. EMPLOYMENT

Table 17 and figure 16 highlight the very noticeable effect having haemophilia had on the employment of men with haemophilia.

Only 50% (15/30) of the men with haemophilia in the 45-64 year age group were employed full-time, in comparison to 81% (26/32) of the men without a bleeding disorder of the same age. From the age of 45 years onwards, the men with haemophilia were more likely to be working part-time or retired than their counterparts without a bleeding disorder: 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.

A small number of younger men with haemophilia (2/30) were also on long-term sick or disability leave.

Table 17: Employment status - men aged 45 years and over

	Men with haemophilia MWH		Men without a bleeding disorder MNBD	
	45-64 yrs	≥ 65 yrs	45-64 yrs	≥ 65 yrs
Total N =	**30**	**27**	**32**	**17**
Working full-time	15	2	26	5
Working part-time	7	6	3	2
Stay at home parent/caregiver	0	0	1	0
On long-term sick or disability leave	2	0	0	0
Retired	3	18	0	9
Unemployed	1	0	0	0
Student	2	0	1	1

Figure 16: Employment status of men with haemophilia (MWH) and men without a bleeding disorder (MNBD) aged 45 years and over, by age

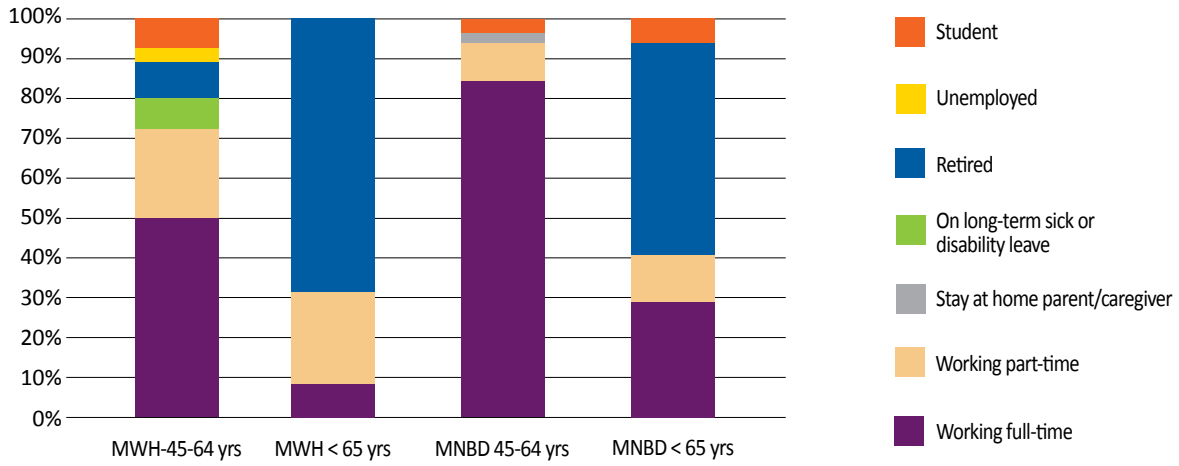


Table 18 shows the different employment patterns for both women with haemophilia and women without a bleeding disorder aged 45 years and over.

Numbers of women with haemophilia by age bracket were small, but some trends were noticeable. A higher proportion of the younger women with haemophilia were working (93% or 14/15) than younger women who did not have a bleeding disorder (76% or 25/33), but it was more common for women with haemophila to be working part-time (53% or 8/15) than women who did not have a bleeding disorder (18% or 6/33).

In the older groups, this trend was reversed: all (100%) of the women 65 years and over affected by haemophilia (6/6) 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.

Table 18: Employment status - women aged 45 years and over

	Women with haemophilia WWH		Women without a bleeding disorder MNBD	
	45-64 yrs	≥ 65 yrs	45-64 yrs	≥ 65 yrs
Total N =	**15**	**6**	**33**	**19**
Working full-time	6	0	19	1
Working part-time	8	0	6	2
Stay at home parent/caregiver	1	0	2	0
Retired	0	6	3	14
Unemployed	0	0	2	0
Other	0	0	1	1

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Table 19 shows some of the employment decisions based on health reported by men aged 45 years and over.

Their health was an important factor in employment decisions for some of the men with haemophilia 45 years and over. For some of the younger men (13% or 4/30), this involved working part-time; for some of the older men (22% or 6/27), it led to retiring early.

Most noticeable was the number with haemophilia who had made education or career decisions due to their health. Interestingly it was the younger men who were more likely to report this: 70% (21/30) in the 45-64 year age group compared to 44% (12/27) in the over 65 age group. This may relate to increased vocational education at HTCs over recent decades as part of comprehensive care.

In contrast, only 1/32 in the younger men without a bleeding disorder was working part-time due to his health, and 1/17 of the older age bracket had retired early due to his health. Only 19% (6/32) of the younger men without a bleeding disorder had made an education or career decision relating to their health, and none of the men 65 years and over.

Table 19: Impact of health on employment decisions - men aged 45 years and over

	Men with haemophilia MWH		Men without a bleeding disorder MNBD	
	45-64 yrs	≥ 65 yrs	45-64 yrs	≥ 65 yrs
Total N =	**30**	**27**	**32**	**17**
Retirement due to health	1	6	0	1
Unemployed due to health	1	0	0	0
Work part-time due to health	4	1	1	0
Education/career decision due to health	21	12	6	0

Table 20 provides a comparison of the employment decisions based on health by women aged 45 years and over.

Once again numbers were small, but similar patterns were noticeable in women with haemophilia 45 years and over: for some younger women (20% or 3/15), their health was the reason they worked part-time, and for some older women (33% or 2/6) the reason they retired early. In approximately half of all the women with haemophilia (53% or 8/15 aged 45-64 and 50% or 3/6 aged 65 and over), their health had affected their decision-making related to their education or career.

Some women without a bleeding disorder also made similar decisions, but the proportion was much lower. A small number of younger women (6% or 2/33), worked part-time due to their health, and a small number of older women (11% or 2/19) retired early because of health reasons. In 21% (7/33) of all the younger women without a bleeding disorder and 1/19 of the older age bracket, their health had affected their decision-making related to their education or career.

Table 20: Impact of health on employment decisions - women aged 45 years and over

	Women with haemophilia MWH		Women without a bleeding disorder MNBD	
	45-64 yrs	≥ 65 yrs	45-64 yrs	≥ 65 yrs
Total N =	**15**	**6**	**33**	**19**
Retirement due to health	1	2	0	2
Unemployed due to health	0	0	0	0
Work part-time due to health	3	0	2	0
Education/career decision due to health	8	3	7	1

In table 21 the impact of haemophilia can also be seen in the work or study days missed due to health: the average number of days was more than 5 times higher in the younger group of men with haemophilia (52 days) than the younger men without a bleeding disorder (9 days). This age group was more likely to be working full-time. Older men with haemophilia also missed a much higher average number of days (19 days) than men without a bleeding disorder (4 days).

For men with haemophilia, these days missed would include both days managing bleeds or other health problems and days required to attend clinic appointments for haemophilia and their other complications.

Table 21: Average work/study days missed due to health in the last 12 months - men aged 45 years and over

	Men with haemophilia MWH		Men without a bleeding disorder MNBD	
	45-64 yrs	≥ 65 yrs	45-64 yrs	≥ 65 yrs
Total N =	**30**	**27**	**32**	**17**
Days missed	52	19	9	4

Table 22 highlights the different patterns in average number of days missed due to health between age groups in women. In the 45-64 year age group of women the difference between those with haemophilia (10 days) and those without a bleeding disorder (7 days) was not as pronounced. This increased substantially in the over 65 year age group to 68 days for women with haemophilia compared to 2 days in women without a bleeding disorder. This older group of women with haemophilia had all now retired and the high number of days missed in the previous 12 months could possibly have been the catalyst for retirement.

Table 22: Average work/study days missed due to health in the last 12 months - women aged 45 years and over

	Women with haemophilia MWH		Women without a bleeding disorder MNBD	
	45-64 yrs	≥ 65 yrs	45-64 yrs	≥ 65 yrs
Total N =	**15**	**6**	**33**	**19**
Days missed	10	68	7	2

LIMITATIONS

As the PROBE questionnaire could not be distributed through HTCs due to ethics approval constraints, it was restricted to distribution through community networks. As a result, it is likely to be reflective of men and women affected by haemophilia who are more engaged in haemophilia foundation communications and activities and the extended family and friendship networks of people with bleeding disorders who are engaged with haemophilia foundations.

This means that the wider population of people with bleeding disorders, particularly people with mild haemophilia who have had few bleeding episodes over their lifetime and less reason to connect to a haemophilia foundation, may not have been as likely to contribute to this study.

The study also required individuals to initiate completing the questionnaire and to complete it themselves, either online or in print. Having to complete a survey is likely to have skewed participation towards more active and motivated community members; and to have skewed participation away from those who were more disabled or elderly and frail and who lacked accessibility tools to help them. It is also likely to have skewed participation away from those with mental health issues such as clinical depression or dementia, who may have lacked the drive, ability to concentrate or mental capacity to undertake the questionnaire.

The distribution strategy for print surveys may also have impacted on the level of participation among older community members. State and territory Foundations targeted mailing the print surveys to community members known to prefer print and otherwise posted them out on request. There was a noticeable difference in PROBE print survey response rates from the Getting Older Community Survey: the Getting Older print survey was mailed out to broadly relevant community members on Foundation mailing lists and had 59 print responses from people with bleeding disorders in a short timeframe, in comparison to the 16 print responses for the PROBE study over 8 months. This may have biased the PROBE survey results towards those who were more active online.

This was the first implementation of the PROBE Australia study and it is an unlinked and completely anonymised questionnaire. At this stage the PROBE Australia study does not provide questionnaire respondents with an opportunity to link their study data and provide longitudinal data for individual comparison.

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