Getting older with a bleeding disorder

Needs assessment report

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Contents

Ak	brevia	tions	i
Ex	ecutive	summary	1
Re	comme	endations	4
1.	Introd	uction	9
	1.1	Why a needs assessment?	9
	1.2	Getting Older Project	9
	1.3	Approach	9
	1.4	Advisory Group	10
	1.5	Data collection	10
2.	About	bleeding disorders	11
	2.1	Types of bleeding disorders	11
	2.2	Age distribution of people with bleeding disorders in Australia	12
	2.3	Treatment	15
	2.4	Comprehensive care	16
3.	Literat	ure review	17
	3.1	A journey into unchartered territory	17
	3.2	Defining 'older person'	17
	3.3	A patient-centred approach	18
	3.4	Older people with bleeding disorders population	19
	3.5	Treatment	21
	3.6	Age-related health impacts	25
	3.7	Women	31
	3.8	Sexuality	32
	3.9	Mental Health	32
	3.10	Comprehensive care	33
	3.11	Social connection	34
	3.12	Carers	34
	3.13	Finances	34

4.	Metho	dology	35
	4.1	Scoping phase	35
	4.2	National consultation	35
	4.3	Interviews	35
	4.4	Community forums	36
	4.5	Getting Older Community Survey	36
	4.6	PROBE Australia study	37
	4.7	Privacy	37
	4.8	Limitations	38
5.	Summ	ary findings	39
••••••	5.1	Interviews	39
	5.2	Getting Older Community Survey	40
•••••	5.3	State/territory Foundation Consultation	41
	5.4	Results	41
••••••	5.5	Other Getting Older Survey results	47
	5.6	PROBE Australia Study results	57
6.	Discus	sion	66
	6.1	Ageing and getting older	66
		Ageing and getting older	
	6.2	Aspirations and goals	67
	6.2 6.3	Aspirations and goals When stoicism isn't enough	67 70
	6.2 6.3 6.4	Aspirations and goals When stoicism isn't enough Living with multiple health conditions	67 70 70
·····	6.26.36.46.5	Aspirations and goals When stoicism isn't enough Living with multiple health conditions Mild conditions	67 70 70 71
·····	 6.2 6.3 6.4 6.5 6.6 	Aspirations and goals When stoicism isn't enough Living with multiple health conditions Mild conditions The rarer bleeding disorders	67 70 70 71 71
·····	 6.2 6.3 6.4 6.5 6.6 6.7 	Aspirations and goals When stoicism isn't enough Living with multiple health conditions Mild conditions The rarer bleeding disorders Costs of delayed or inadequate treatment	67 70 70 71 71 71
·····	 6.2 6.3 6.4 6.5 6.6 6.7 6.8 	Aspirations and goals When stoicism isn't enough Living with multiple health conditions Mild conditions The rarer bleeding disorders Costs of delayed or inadequate treatment Physical functioning and quality of life	67 70 70 71 71 71 72 74
	 6.2 6.3 6.4 6.5 6.6 6.7 6.8 6.9 	Aspirations and goals When stoicism isn't enough Living with multiple health conditions Mild conditions The rarer bleeding disorders Costs of delayed or inadequate treatment Physical functioning and quality of life Pain	67 70 70 71 71 72 74 83
	 6.2 6.3 6.4 6.5 6.6 6.7 6.8 6.9 6.10 	Aspirations and goals When stoicism isn't enough Living with multiple health conditions Mild conditions The rarer bleeding disorders Costs of delayed or inadequate treatment Physical functioning and quality of life Pain Veins and skin	67 70 70 71 71 72 74 83 85
	 6.2 6.3 6.4 6.5 6.6 6.7 6.8 6.9 6.10 6.11 	Aspirations and goals When stoicism isn't enough Living with multiple health conditions Mild conditions The rarer bleeding disorders Costs of delayed or inadequate treatment Physical functioning and quality of life Pain Veins and skin Bleeding gums and dentistry	67 70 70 71 71 71 72 74 83 85 86
	 6.2 6.3 6.4 6.5 6.6 6.7 6.8 6.9 6.10 6.11 6.12 	Aspirations and goals When stoicism isn't enough Living with multiple health conditions Mild conditions The rarer bleeding disorders Costs of delayed or inadequate treatment Physical functioning and quality of life Pain Veins and skin Bleeding gums and dentistry Bloodborne viruses	67 70 70 71 71 71 72 74 83 85 86 87
	 6.2 6.3 6.4 6.5 6.6 6.7 6.8 6.9 6.10 6.11 6.12 6.13 	Aspirations and goals When stoicism isn't enough Living with multiple health conditions Mild conditions The rarer bleeding disorders Costs of delayed or inadequate treatment Physical functioning and quality of life Pain Veins and skin Bleeding gums and dentistry Bloodborne viruses Health conditions of ageing	67 70 70 71 71 71 72 74 83 85 86 87 92
	 6.2 6.3 6.4 6.5 6.6 6.7 6.8 6.9 6.10 6.11 6.12 6.13 6.14 	Aspirations and goals When stoicism isn't enough Living with multiple health conditions Mild conditions The rarer bleeding disorders Costs of delayed or inadequate treatment Physical functioning and quality of life Pain Veins and skin Bleeding gums and dentistry Bloodborne viruses Health conditions of ageing Women	67 70 70 71 71 71 72 74 83 85 86 87 92 95

6.16 Clinical treatment and care services	97		
6.17 Aged care	102		
6.18 Early ageing and disability services	104		
6.19 Mental health	105		
6.20 Carers	111		
6.21 Working	112		
6.22 Finances	116		
6.23 Travel	119		
6.24 Future planning	119		
6.25 Information and education	120		
6.26 Hard-to-reach populations	122		
7. The way forward	123		
8. References	124		
Appendix 1 – Getting Older Community Survey findings	129		
ppendix 2 – PROBE Australia Study findings 15			

Abbreviations

Australian Bleeding Disorders Registry (ABDR):

a registry for patients in Australia with bleeding disorders. It is used on a daily basis by clinicians in all Australian Haemophilia Treatment Centres to assist in managing the treatment of people with bleeding disorders and to gain a better understanding of the incidence and prevalence of bleeding disorders. This information will also be used to understand demand for, and to facilitate ordering of, treatment products.

Australian Haemophilia Centre Directors'

Organisation (AHCDO): the national medical body for haemophilia in Australia. Membership consists of the medical directors of Haemophilia Treatment Centres and other clinicians actively involved in the treatment of people with bleeding disorders.

Haemophilia Treatment Centre (HTC):

A designated medical centre staffed by a multidisciplinary team of health professionals who specialise in bleeding disorders.

Haemophilia Foundation Australia (HFA): the

peak body representing people with bleeding disorders and their partners, family and carers in Australia.



MyABDR: A secure smartphone app and website for people with bleeding disorders. It is used to record bleeds and treatments at home and to manage the person's treatment product inventory. MyABDR links directly to the ABDR.

National Blood Authority (NBA): a statutory agency within the Australian Government Health portfolio that manages and coordinates arrangements for the supply of blood and blood products and services on behalf of the Australian Government and state and territory governments.

PROBE (Patient Reported Outcomes Burdens and Experiences) Study: a long-term independent international study aiming to investigate and directly probe patient perspectives on outcomes they deem relevant to their life and care. The current questionnaire collects patient self-reported outcomes, burdens and experiences in living with haemophilia. The PROBE Australia Study is the Australian implementation led by Haemophilia Foundation Australia.

Executive summary

Improvements to treatment and care over recent decades have created a new phenomenon: for the first time there is a generation of people with bleeding disorders who are living into their senior years. Newer and emerging therapies give hope that they will also be able to enjoy a better quality of life.

While this is a welcome change, it is challenging. This new older generation is entering into unknown territory: encountering the issues of ageing faced by the general population, and the first group to experience the impact of ageing on their bleeding disorder.

'Early ageing' is also a problem in this community. Many relatively young people with bleeding disorders experience complications usually associated with growing older: joint and muscle damage, arthritis, pain and mobility problems. This impacts on many aspects of their life and many have difficulty meeting the eligibility criteria to access support services.

Haemophilia Foundation Australia (HFA) consulted with the bleeding disorders community, specialist health professionals and other relevant organisations to understand the needs of older people with bleeding disorders into the future. This **Getting Older needs assessment** report brings together the findings from that consultation.

ASPIRATIONS AND GOALS

Understanding the aspirations and goals of older people with bleeding disorders is essential to achieving the HFA vision of 'active, independent and fulfilling lives for people in our bleeding disorders community'.

When older people with bleeding disorders were asked about their aspirations for the future, most said they wanted to maintain their quality of life, be healthy and remain independent. This involved improving their



mobility, reducing stiffness and pain, and being able to participate in family life and enjoy friendships, travel, pursue their interests and to contribute in a useful way to society.

ISSUES AND CONCERNS

Health concerns were perceived as the greatest barrier to achieving these aspirations.

There was a culture of stoicism and 'getting on with it' in this older generation, developed in childhood to overcome the outcomes of treatment shortages and the pain and disability they experienced over their lifetime. Many had also acquired hepatitis C and some also HIV from their treatment products during the early days of the epidemics and lived with the consequences. As they entered their senior years, they were concerned they were reaching a tipping point, where the health conditions of ageing combined with the complications of their bleeding disorder could be too difficult for them to manage, even with their usual determination and positive approach.

A significant worry was losing their independence. Joint and muscle damage, arthritis and pain resulting from bleeding episodes over their lifetime had a big impact on their mobility and dexterity, their ability to undertake activities of daily living and their quality of life. This could limit their working life, make it difficult to travel and prevent the social interactions and activity – catching up with family, friends, peers - so necessary to their resilience. Memory loss, increasing frailty and injuries related to falls were identified as particular challenges. They worried about who would have the expertise and the vigilance to manage their bleeding disorder if they developed dementia and moved to a residential aged care facility. They did not know what aged care services were available or how to access them.

In bleeding disorders these multiple complications become increasingly complex when combined with issues of ageing and can also challenge treatment and care. Infusing treatment into veins was increasingly difficult and prophylaxis (preventive) treatment to reduce bleeding episodes, infused multiple times weekly, was unattractive. Compounding health conditions created a domino effect: mobility and weight problems could lead to a fall, joint problems could make rehabilitation challenging, leading to an ongoing spiral of physical decline.

Accessing care was also becoming more difficult. Some had moved to outer suburban and regional areas to save money. With stiff legs and increasing fatigue and frailty, travel to the HTC for appointments and programs, such as physiotherapy, could be a problem. They were overloaded with appointments to manage all their health conditions. Nearly all had a general practitioner (GP) for their general health care, but the continuity of care with GPs was variable. HTCs were concerned that they were missing regular preventive health checks.

Younger people with the 'early ageing' complications of a bleeding disorder could slip through the eligibility cracks of the National Disability Insurance Scheme and other government safety net support programs.

Most people with bleeding disorders have mild conditions, and usually do not need regular treatment for bleeding episodes. Many are not well-connected to HTCs. HTCs were now seeing their older patients with mild conditions more often, with joint problems and needing preventive treatment for surgery and medical and dental procedures. Bleeding disorders are rare and not well understood by many health care professionals outside the HTC. Men and women with mild and rarer bleeding disorders reported that some health care professionals in the community did not take their bleeding disorder seriously. This resulted in unnecessary bleeding episodes and other health complications.

There has been little research into the impact of ageing on mild haemophilia, VWD, the rarer bleeding disorders and on women with bleeding disorders: this area will need further investigation. The PROBE (Patient Reported Outcomes Burdens and Experiences) Australia Study, for example, highlighted questions around arthritis, physical functioning and bleeding problems in older people with mild haemophilia, when this has traditionally been associated with severe haemophilia.

Mental health is key to maintaining resilience. Older people with a bleeding disorder and their partner and family could be affected by traumatic experiences with their bleeding disorder, or from HIV and hepatitis C, and the lifetime impact of the complications. Professional psychosocial care for both was vital, along with strategies to enable the older person to pursue personal interests, social connection and peer support.

Living with a bleeding disorder had a cumulative impact on increasing health care costs and reducing income over a lifetime. Most older people with bleeding disorders had acquired hepatitis C, compounding their health and financial issues, and becoming vulnerable in their senior years. Although the 2004 Senate Inquiry into Hepatitis C and the Blood Supply recommended case management and financial support for their health care costs, this was never implemented.

WHAT WILL HELP

For older people with bleeding disorders, solutions will need to address their goals of living the healthiest life possible, maintaining or improving quality of life, prolonging independence and contributing to society.

The Australian Productivity Commission *Shifting the dial* report pointed to the benefits of making the patient the centre of care for achieving better health outcomes and developing a more efficient and cost-effective health system. It also underlined that integrated care could improve workforce participation in people with chronic health conditions.

Achieving integrated care for older people with bleeding disorders will involve strengthening and expanding the comprehensive care provided by HTCs. This would enable HTCs to better co-ordinate the range of services and programs required to support the older person with a bleeding disorder and build a closer relationship with GPs. It would allow innovations to make access to HTC services and programs and other specialist services easier for older people with bleeding disorders or support liaison with local health and community services. It would support work to help younger people with bleeding disorders with 'early ageing' access disability support services and programs. However, this level of comprehensive care would require adequate resourcing for all HTCs.

Treatment with newer and emerging therapies could mean fewer intravenous infusions or subcutaneous injections and decrease the treatment burden for older people with bleeding disorders and their carers.

Access to robust data will be needed to support further research into ageing with a bleeding disorder and to evaluate related health and quality of life outcomes. This will require investment to develop and promote existing databases, including the Australian Bleeding Disorders Registry (ABDR), along with the patient recording tool MyABDR, and the PROBE Australia study. Ways of combining the data from the two databases could also be investigated.

Although vigorous exploration of government financial safety net options may assist some older people with bleeding disorders financially, they will have out-ofpocket health and welfare costs not covered by existing programs. Most have been affected by hepatitis C. If the Senate Inquiry recommendations to extend financial assistance and case management to this group are implemented, it would make a considerable difference to managing their care and quality of life into the future. Both professional psychosocial care and peer support are integral to the mental wellbeing and resilience of older people with bleeding disorders. It will be important to explore options enabling them to connect with other people with bleeding disorders or with shared interests, both face-to-face and in the digital space, and how they can contribute their skills and experience to the community. Support for partners, family and carers is also critical.

Achieving the best possible health and quality of life will involve education about the patient journey: the issues the person with a bleeding disorders will encounter as they grow older, and how these can be best managed. This will need to be targeted at people with bleeding disorders, the people who provide their care and other relevant settings such as the workplace.

An important way to support a patient-centred approach will be to centralise information about getting older with a bleeding disorder in an information hub on the HFA website. This will be an effective way to co-ordinate information for older people with bleeding disorders, their partners and family and their health and care services in the community. Producing targeted information online and in print will also be an effective strategy to reach older community members. Foundation newsletters were very popular as trusted sources of information and continue to be a valuable way to communicate with the community.

Recommendations



LANGUAGE AROUND GETTING OLDER

 That careful consideration be given to the use of the words 'ageing' and 'old' when discussing getting older with a bleeding disorder or the disability in younger people related to the complications of their bleeding disorder.

PATIENT-CENTRED CARE

 That there is a patient-centred approach to treatment and care for older people with bleeding disorders. This involves holistic and integrated care that takes the complexities of their bleeding disorder complications, their aspirations and quality of life, and their experience of service provision into account.

INTEGRATING CARE

 That the role of the Haemophilia Treatment Centre (HTC) in providing comprehensive care and co-ordinating the range of services and programs to support older people with bleeding disorders is strengthened and resourced adequately in all HTCs to undertake this work statewide. This involves resourcing to provide the essential elements of a comprehensive care team:

- A medical director who is a haematologist
- A nurse co-ordinator specialising in bleeding disorders
- Musculoskeletal experts, including physiotherapy, orthopaedics and rheumatology
- A psychosocial expert, preferably a social worker or psychologist
- Specialist medical laboratory services.

It also involves expanding access to the following specialities:

- Pain management
- Geriatric services
- Occupational therapy
- Dietitians
- Podiatry
- Dentistry
- Gynaecology for women
- Vocational counselling.
- 4. That general practitioners should be involved by the comprehensive care team as key partners in primary care and preventive medicine.
- 5. That older people with bleeding disorders be provided with options to access appropriate treatment and care services and programs in relation to their complications with bleeding disorders. This may involve:
 - Some evening or weekend clinics or outer suburban or regional outreach from the HTC
 - The use of telehealth where appropriate and practicable
 - HTC liaison with local GPs and other local health care services
 - Investigation of all suitable transport and parking options available and support to access this.

- 6. That the role of the HTC, comprehensive care and the ABDR and the benefits of connection and ongoing management be promoted in particular to:
 - Men and women with mild bleeding disorders.
 - General practitioners (GPs) and other clinicians in the community who provide primary care to people with bleeding disorders.
- 7. That there be ongoing work to evaluate the older person with a bleeding disorder's experience of health service provision. This should cover both their and their caregivers' perspective on the breakdowns and improvements that occur in their care pathways.

ABDR AND MYABDR

- That HFA, the Australian Haemophilia Centre Directors' Organisation (AHCDO) and the National Blood Authority (NBA) collaborate to ensure:
 - There is ongoing development of the ABDR system and the MyABDR website and app to maintain a robust national clinical management system and database.
 - Proactive use of the ABDR and MyABDR is promoted to HTCs and to HTC patients.
 - Effective use of data by stakeholders for treatment and policy decision-making.

NEW AND EMERGING THERAPIES

9. That new and emerging therapies that require less frequent infusions, can be administered subcutaneously rather than intravenously, and will encourage uptake of prophylaxis to prevent bleeds be given strong consideration in older people with haemophilia, where clinically appropriate.

VEIN CARE AND INFUSIONS

- 10. That HTCs are resourced adequately:
 - to provide vein care and infusion education to older people with bleeding disorders and their carers
 - to investigate individual options for skilled nurses to provide infusions in the home.

DENTISTRY

- 11. That the following areas are explored:
 - Promoting preventive dentistry
 - Accessing appropriate local dentists who will treat patients with bleeding disorders and liaise with HTCs on their management
 - Accessing specialist dentists in the capital city or the dental service co-located at the same hospital as the HTC
 - Transport options to assist with visits to specialist dentists
 - Financial support to pay costs of private dentistry.

INDEPENDENT LIVING

- That older people with bleeding disorders be supported to continue living independently for as long as possible. This includes through:
 - Treatments and programs to support being active and to maintain mobility and physical functioning
 - Access to mobility aids and equipment, medical devices and other independent living aids
 - Information about and access to home
 modifications to enable independent living
 - Education about and opportunities to share strategies to work around problems with physical functioning and mobility
 - Inclusion of an occupational therapist in the comprehensive care team to facilitate and perform reviews, undertake education and support older people with bleeding disorders to apply for relevant aids and equipment, home modifications or other funding required.

INSURANCE

 That barriers to various types of insurance and superannuation are explored and relevant advocacy is considered.

AGED CARE SERVICES

- 14. That older people with bleeding disorders and their partners, family and carers are provided with:
 - Information about and assistance to access aged care services
 - Case management and advocacy to access appropriate aged care services in a timely way, to explore government financial safety net options and to manage the transition to residential aged care if appropriate.

'EARLY AGEING' AND THE NDIS

- 15. That people with bleeding disorders with complex co-morbidities under the age threshold for aged care services are provided with:
 - Assistance from members of the comprehensive care team, including psychosocial workers and occupational therapists, with completing National Disability Insurance Scheme (NDIS) applications to ensure eligibility criteria are addressed.
 - Assistance with an appeal or review where they have been rejected initially or the approved package seems inadequate.
 - Support and advocacy around employment.
- 16. That HFA explores the potential for modifications to the NDIS or other government income support schemes to enable people with chronic health conditions to continue working.
- 17. That there is adequate resourcing of all HTCs to assist with NDIS applications.

HIV AND HEPATITIS C

- 18. That the traumatic experience of being exposed to HIV and hepatitis C and the ongoing impact on the life of affected people with bleeding disorders is acknowledged by Australian governments, even if they have been cured of hepatitis C.
- 19. That Australian governments implement the recommendations of the 2004 Senate Inquiry into Hepatitis C and the Blood Supply, so that:
 - Case management is extended to people with bleeding disorders affected by hepatitis C to ensure their physical and psychosocial health and financial needs are being met, and that advocacy on behalf of individuals takes place when required
 - Financial assistance is provided for costs with health and community care not covered through existing services.
- 20. That HFA continues to work with HIV and hepatitis organisations on discrimination.
- 21. That HFA continues to work with HTCs, hepatitis clinics and organisations and general practitioners to ensure there is health promotion and clinical follow-up for people with bleeding disorders exposed to hepatitis C. In particular, this relates to:
 - Liaison between hepatitis specialists and HTCs for management of people with bleeding disorders who have advanced liver disease
 - Ongoing monitoring for people with cirrhosis
 - Reaching men with mild conditions and women with bleeding disorders or who carry the gene for haemophilia to encourage testing for their current HCV status and to seek treatment if they have hepatitis C.

MENTAL HEALTH AND PEER SUPPORT

22. That psychological care by both health professionals and haemophilia foundations takes into account the traumatic experiences and the impact of a bleeding disorder over a lifetime, including the impact of HIV and hepatitis C, both for the older person with a bleeding disorder and their partner or family.

- 23. That haemophilia foundations and HTCs explore peer support activities to enable older people with bleeding disorders to connect with other older people with bleeding disorders or other people with shared interests, both face-to-face and in the digital space.
- 24. That haemophilia foundations consider ways to enable older people with bleeding disorders to contribute their skills and experience to the community.
- 25. That psychosocial and peer support should be extended to partners, family and carers of older people with bleeding disorders.

INFORMATION AND EDUCATION

26. That HFA collaborates with HTCs, specialist health professional groups and other experts on information and education about the special issues of growing older with a bleeding disorder for older people with bleeding disorders, their partners, family and carers, the health and community services who provide their care and their employers.

Information provision

- A **Getting Older Information Hub** to be established on the HFA website to centralise access to this information and education.
- Education materials to be high-quality, evidencebased and appropriate to the target audience.
- Education materials to be provided online; some also to be provided in print, where appropriate to the target audience.
- Community education materials to be developed and tested with the target audience.

Community education

HFA to develop or source education materials for the older person with a bleeding disorder and their partner/ family/carers that focus on the patient journey, the issues that may come up and how to self-manage for the best possible health and quality of life outcomes, including:

- Understanding how getting older affects a person with a bleeding disorder
- Working effectively with the HTC and other health services for good health outcomes
- Self-advocacy in the health care setting
- Preventing and managing health conditions and complications associated with ageing, including preventive health checks, weight management and exercise
- Pain management
- Staying active and involved, building resilience, self-care
- Recreation and travel
- Aids and strategies to assist with independent living
- Support and services available and how to access them
- Financial and future planning.

This information also to be published in *National Haemophilia* and state/territory haemophilia foundation newsletters.

Special issues for older women with bleeding disorders continue to be incorporated into the HFA The Female Factors education resources.

Education to young people with bleeding disorders to highlight the benefits of adherence to treatment and care and self-management strategies to prevent joint and muscle complications in the future.

Health care and community worker education

Education on special issues in ageing with a bleeding disorder for health care and community workers to be targeted to the particular specialities and settings providing treatment and care to older people with bleeding disorders. For this education to be effective, it would need to be led by key leaders in bleeding disorders in the relevant discipline and may involve a range of different strategies, including:

- Best practice clinical guidelines and fact sheets
- Integration in undergraduate and postgraduate education
- Relevant professional development, including for special interest groups
- Journal articles and conference presentations and posters
- Education materials for the point of care, for example, for an HTC to provide to a surgeon, a general practitioner or a community physiotherapist.

In addition,

- Educational resources about bleeding disorders in older people also to include mild conditions, VWD and the rarer bleeding disorders.
- These resources to acknowledge the experience of the older person with their bleeding disorder and to encourage a collaborative relationship between the health care provider and the patient.

Specialist health professionals at HTCs to be resourced adequately to undertake the development and delivery of these education resources.

Employers

HFA to collaborate with specialist health professionals and employer groups to develop education materials for employers.

Other information portals

27. That HFA explores how best to disseminate these education resources through HealthDirect and other relevant government and aged-care related information portals.

FURTHER RESEARCH

- 28. That there be further research:
 - To understand the impact of ageing in men and women with mild haemophilia, VWD and the rarer bleeding disorders, including health and quality of life outcomes and education and support needs.
 - To investigate arthritis and problems with physical functioning and mobility in men and women with mild haemophilia.
 - To investigate the occurrence of heart disease and hypertension in men with haemophilia.
- 29. That HFA undertakes further consultation around needs relating to getting older in harder-to-reach and more vulnerable populations. This might include people experiencing housing insecurity or literacy problems, or where cultural, language and connection issues are a barrier, for example, in some people of culturally and linguistically diverse (CALD) backgrounds, some Aboriginal and Torres Strait Islander people, and some people experiencing mental health and other serious health issues.
- 30. That HFA continues to develop and promote the PROBE Australia study and supports investigation into the potential to use the PROBE Australia study to link with the ABDR to collect data on health-related quality of life.

1. Introduction

1.1 Why a needs assessment?

Improvements to treatment and care over recent decades have created a new phenomenon: for the first time there is a generation of people with bleeding disorders who are living into their senior years.

This is a welcome change, but it brings its own challenges. Although this generation of people with bleeding disorders has a longer life expectancy than ever before, they are also at the forefront of navigating issues associated with getting older with a bleeding disorder. They are entering into unknown territory: encountering the issues of ageing experienced by the general population, while also being the first group to experience the impact of ageing on their bleeding disorder.

At the same time there continues to be a problem with 'early ageing' in this community. Many relatively young people with bleeding disorders experience complications usually associated with growing older, particularly joint and muscle damage, arthritis, pain and mobility problems. This has implications for many aspects of their life, but also may create difficulties for accessing services as they will not fit the standard criteria for 'ageing' and may not fit the eligibility criteria for disability services.

1.2 Getting Older Project

Understanding the needs of older people with bleeding disorders and how best to address them is a priority for Haemophilia Foundation Australia.

Haemophilia Foundation Australia (HFA) is the national peak body for the bleeding disorders community in Australia. The Foundation provides national representation and advocacy, information and education, and support for those affected by a bleeding disorder in Australia. It promotes research and supports initiatives in health care to promote high quality treatment and care, and better health outcomes for people affected by haemophilia, von Willebrand disease and other related bleeding disorders. With its vision of 'active, independent and fulfilling lives for people in our bleeding disorders community', a key objective for HFA is to enable people with bleeding disorders to overcome isolation and develop resilience and strategies for self-management as they grow older. This also involves support for the affected community: partners, family, friends and carers.

HFA commenced the **Getting Older Project** in February2019. A major part of the Project was a needs assessment.

HFA needed to understand the key issues for older community members, including those experiencing the issues of early ageing.

- What are their aspirations and goals?
- What are their concerns about growing older?
- What planning is required for them to 'future proof' for getting older?
- What resources already exist that could be used to support an ageing community?
- What are the implications of their needs with growing older for their treatment and care and the comprehensive care provided through Haemophilia Treatment Centres?
- What would be required to support access to existing mainstream and local services?
- What information do individuals and their carers need to manage the issues of ageing?
- Are there ways of providing support for older community members apart from traditional face-toface activities, such as digital support and information?

1.3 Approach

The HFA *Getting Older needs assessment* aims to understand community needs across a range of domains in people's lives. In line with best practice for a



HFA established an Advisory Group to provide information and guidance for the project. The Group included representatives with relevant expertise from:

Bleeding disorders community

- Older people with bleeding disorders
- · Partner of an older person with a bleeding disorder
- Haemophilia Foundation Australia

Health professionals

- Australian Haemophilia Centre Director's Organisation (AHCDO)
- Australia/New Zealand Haemophilia Psychosocial Group
- Australian and New Zealand Physiotherapy Haemophilia Group
- Australian Haemophilia Nurses' Group

Other organisations with a common interest

- National Ageing Research Institute (NARI)
- Living Positive Victoria
- Gerontology/Physiotherapy research (Monash University, Melbourne)

1.5 Data collection

Scoping and data collection for the needs assessment has included:

- Information, review and advice from the Advisory Group
- Interviews with community members and relevant health professionals
- Community forums in Queensland and the Australian Capital Territory
- Consultation meetings with other relevant agencies
- Consultation with state/territory Foundations on key issues and priorities
- The HFA Getting Older Community Survey
- Age-related data from the 2019-20 PROBE (Patient Reported Outcomes Burdens and Experiences) Australia Study.

community needs assessment¹, HFA has used a systematic process involving:

- Scoping activities to gather input from the community and other stakeholders about the project design, frameworks, approaches and tasks
- Development of a data collection plan
- Collection and analysis of data to determine priorities and make decisions about addressing current and future needs.

The HFA needs assessment uses an 'evidence-informed' approach: a multipronged approach, which recognises that lived experience, expertise relating to practice and evidence from current research each play a role in ensuring a full range of issues are identified and explored.¹

As expressed in its vision, HFA is committed to a strengthbased approach with the bleeding disorders community. This is a positive approach, focused on working towards the goals of people with bleeding disorders and their partners, family and carers. A strength-based approach acknowledges the strengths and capacities of individuals, often arising from the adversity and difficulties they experience over their lifetime, and builds on these attributes to encourage resilience, to support people in self-management and to enable them to seek their own solutions. It identifies the resources individuals have both within themselves and around them to deal with problems and difficulties and what they themselves have to share with their community.²

An important element of this for the needs assessment has been to collect data and report on community 'assets', for example, on the services and supports people have available to them in their life, as well as the traditional financial and housing assets.¹

The needs assessment also identifies areas where there are gaps or further development is needed to enable older people with bleeding disorders to achieve their goals.

2. About bleeding disorders

Inherited bleeding disorders are genetic conditions and occur in families.

2.1 Types of bleeding disorders

2.1.1 HAEMOPHILIA

Haemophilia is caused by a mutation or alteration in the gene making factor VIII (8) or IX (9).

- Haemophilia A is the most common form of haemophilia and is due to reduced levels of clotting factor VIII.
- Haemophilia B is due to reduced levels of clotting factor IX.

The reduced levels of clotting factor produce bleeding episodes, or 'bleeds', largely internally into joints, muscles or organs. These bleeding episodes may have no obvious cause or may occur as a result of trauma or injury, including medical procedures and surgery and menstruation and childbirth in women.

If internal bleeding is not managed quickly with treatment to increase clotting, it will result in pain and swelling. It can be life-threatening, particularly when bleeding is into organs. Over time, repeated bleeding into joints and muscles will cause joint and tissue destruction which leads to permanent damage such as arthritis, chronic pain and joint damage requiring surgery.

• Severe haemophilia: people with severe haemophilia bleed frequently into their muscles and joints, sometimes once or twice a week and often from no apparent cause. They use replacement factor therapy often throughout their life. Severe haemophilia is rare in females.

- Moderate haemophilia: People with moderate haemophilia bleed less frequently. They may have bleeding problems after minor injuries, such as sporting injuries, as well as after medical and dental procedures, surgery or major injury.
- Mild haemophilia: People with mild haemophilia usually only have serious bleeding episodes as a result of surgery, dental extractions or injury. If females have haemophilia, they are most likely to have mild haemophilia. Females may also have significant bleeding problems with menstruation or after childbirth.

2.1.2 VON WILLEBRAND DISEASE (VWD)

VWD is the most common inherited bleeding disorder and occurs in women and men equally. It is caused by reduced levels of a blood clotting protein called von Willebrand factor or where the protein does not work properly. Like haemophilia, it results from a genetic alteration.

In VWD bleeding usually involves the mucous membranes, the delicate tissues that line body passages such as the nose, mouth, uterus, vagina, stomach and intestines. Nose and gum bleeds and easy bruising are common. Some women experience heavy and prolonged menstrual bleeding and postpartum haemorrhage after childbirth. There can be excessive bleeding after injury, surgery, or medical and dental procedures. In severe VWD, there can also be bleeding into joints and muscles. VWD can often be undiagnosed. Although more recently people with VWD have been encouraged to go to a Haemophilia Treatment Centre for treatment, it has usually been managed by other health professionals in the community, such as general practitioners.

- Severe VWD: People with severe VWD may have frequent bleeding episodes, and sometimes joint and muscle bleeds. Severe VWD is rare.
- Mild VWD: Most people with VWD have a mild form and do not need treatment unless they have surgery, medical or dental procedures or an injury; or may also have bleeding problems with menstruation or childbirth if they are female.

2.1.3 OTHER RARE BLEEDING DISORDERS

Apart from haemophilia and VWD, there are also other rare bleeding disorders.

Rare clotting factor deficiencies are caused when the body does not produce enough of a specific certain clotting factor, or when the factor does not work properly. They include factor I (1), II (2), V (5), VII (7), X (10), XI (11), or XIII (13) deficiencies and combined factor V (5) and factor VIII (8) deficiency.

In **platelet function disorders**, the platelet plug does not form properly, leading to a tendency to bleed for longer than normal or bruise easily. Since platelets have many roles in blood clotting, platelet function disorders can range from mild to severe. Examples include Glanzmann thrombasthenia and Bernard-Soulier syndrome.

These bleeding disorders are very uncommon.^{3,4}

2.1.4 ACQUIRED HAEMOPHILIA AND VWD

In very rare cases a person can develop a different type of haemophilia or VWD over their lifetime, usually as an adult, which is not genetic or inherited. It is known as an acquired bleeding disorder.

Acquired haemophilia can occur when a person's immune system produces antibodies that mistakenly target their own factor VIII. It is very rare but can sometimes occur in older people and young women who are in the later stages of pregnancy or have recently given birth. The bleeding pattern is different to inherited haemophilia and it is usually curable with treatment.

Acquired von Willebrand disease can also occur but is extremely rare. 4,5

Acquired bleeding disorders are not inherited or passed on to children. Men and women are equally likely to be affected by an acquired bleeding disorder.

2.2 Age distribution of people with bleeding disorders in Australia

Data for this section was sourced from the Australian Bleeding Disorders Registry (ABDR). The data was released to HFA by the National Blood Authority (NBA) following an HFA request to the ABDR Steering Committee for approval.

By June 2019 there were more than 6300 people diagnosed with bleeding disorders in Australia. Bleeding disorders are rare, but some occur more commonly than others and some are diagnosed more often than others.

Table 1 shows the age distribution in haemophilia, VWD, factor XI deficiency and platelet disorders, which was collated from the June 2019 data from the Australian Bleeding Disorders Registry (ABDR). These were the more commonly diagnosed bleeding disorders.

Mild disorders are likely to be under-represented in the ABDR as many people may not be diagnosed until they have a major bleeding episode or may be managed by a general practitioner or a clinician that is not associated with an HTC and their data not contributed to the ABDR. VWD, for example, is the most common bleeding disorder but if they have mild symptoms, many people may not be aware they have the disorder.⁴ Table 2 shows that, although VWD is more prevalent in the population than haemophilia, fewer people with VWD have been diagnosed and their diagnosis recorded in the ABDR than those with haemophilia. Mild bleeding disorders may be challenging to diagnose, especially if there is no recognised family history.⁶ Consultation for the HFA women's project found that some women with mild disorders had experienced years of misdiagnosis or lack of diagnosis before their bleeding disorder was identified.

Many bleeding disorders are very rare. This is demonstrated in table 2: the numbers of these other rare bleeding disorders were too small to aggregate by age group and have been collated in total by gender.

	0-19 yrs	20-34 yrs	35-49 yrs	50-64 yrs	65-79 yrs	80-94 yrs	95 yrs plus	TOTAL
Haemophilia - Female	79	118	167	83	53	7	-	507
Haemophilia - Male	704	557	494	353	245	62	8	2423
Haemophilia - total	783	675	661	436	298	69	8	2930
VWD - Female	165	400	392	247	165	36	<5	1408
VWD - Male	222	204	149	131	81	25	<5	813
VWD - total	387	604	541	378	246	61	<5	2221
Factor XI deficiency - Female	21	47	61	26	30	13	<5	199
Factor XI deficiency - Male	21	22	18	14	16	7	<5	99
Factor XI deficiency - total	42	69	79	40	46	20	<5	298
Inherited platelet disorders - female	35	47	48	34	29	7	-	200
Inherited platelet disorders - male	29	41	20	22	10	<5	-	123
Inherited platelet disorders - total	64	88	68	56	39	8	-	323

Table 1: Age distribution of haemophilia, VWD, factor XI deficiency and inherited platelet disorders in Australia 2019

Table 2: Other bleeding disorders in Australia 2019

	Female	Male	Total
Other inherited bleeding disorders			1
Factor V deficiency	9	9	18
Factor VII deficiency	44	43	87
Factor X deficiency	9	9	18
Factor XII deficiency	9	6	15
Factor XIII deficiency	11	17	28
Fibrinogen disorders	70	43	113
Other bleeding disorders	130	63	193
Acquired bleeding disorders			
Acquired haemophilia	33	46	79
Acquired VWD	14	18	32

2.2.1 VWD SEVERITY

VWD diagnostic categories are currently being revised internationally and the ABDR data reflects this changing picture of how severity in VWD is understood. However, table 3 shows at a broad level the smaller proportion of males and females in Australia diagnosed as having the severe form in comparison to the larger numbers with other milder forms of VWD. While the severe form is likely to be diagnosed in childhood due to the frequency of bleeding episodes, mild forms may not be diagnosed until the person is an adult and it is thought that a large proportion in Australia remain undiagnosed.

	Mild	Moderate	Not applicable	Severe	Unknown	Total
VWD - female	813	148	320	72	55	1408
VWD - male	376	112	221	71	33	813
VWD - total	1189	260	541	143	88	2221

Table 3: VWD in Australia 2019 by gender and severity

2.2.2 HAEMOPHILIA SEVERITY AND SURVIVAL

Figure 1 shows the age distribution of haemophilia by severity. This analysis highlights the very low numbers of people with moderate or severe haemophilia who have survived into their senior years and what a new phenomenon this is; and that the larger proportion have mild haemophilia. In June 2019 there were, for example, only 69 men with moderate or severe haemophilia listed in the ABDR nationally who were 65 years or over.



Figure 1: Age distribution of haemophilia in Australia 2019: males with haemophilia (MWH) by severityand females affected by haemophilia (FWH)*

* Females affected by haemophilia (FWH) includes females with factor levels below normal and females classified in the ABDR as haemophilia 'carriers'.

The complications causing lower survival rates in people with moderate and severe bleeding disorders, including both haemophilia and VWD, are discussed in the literature review, under **Older people with bleeding disorders population** (section 3.4).

2.3 Treatment

Treatment for bleeding disorders may be **preventive** ('prophylaxis') or 'on demand', to treat bleeds as they occur.

There is a variety of treatment products used to treat bleeding disorders.

Clotting factor concentrates are infused (injected) into a vein. The intention of treating with a clotting factor concentrate is to replace the specific clotting factor that is missing or does not work properly to help blood to clot and prevent or control bleeding episodes.

Plasma-derived factor concentrate is manufactured from pooled donations of human plasma, the pale yellow fluid part in blood. In the past people with bleeding disorders acquired bloodborne viruses from plasma-derived products, but with improved safety measures the infection risk is now considered to be extremely low.

Recombinant factor concentrate is a clotting factor made by genetic engineering, containing little or no human product. There have been no reports that viruses have been transmitted by recombinant products.

In some rare bleeding disorders a clotting factor concentrate specific to the factor deficiency may not yet have been developed or be suitable. In this case **fresh frozen plasma** may be used. This is prepared from human plasma donations and contains the range of proteins or factors required to help blood to clot. It is stored frozen and thawed for treatment, when it is infused into a vein.

Platelet transfusion may be required for more severe inherited platelet function disorders and on occasion for other bleeding disorders. To avoid reactions to platelets, the transfusions are often matched to the individual. This requires specialised testing which can take some weeks.

Desmopressin (DDAVP) is a synthetic hormone that boosts levels of factor VIII and von Willebrand factor. It may be injected under the skin or infused into a vein.

Tranexamic acid is an antifibrinolytic agent that slows blood clots from breaking down after they have been formed. While it does not prevent bleeds, it can help to control bleeding from skin and the mucous membranes and is often used to treat mouth or nosebleeds, gut bleeding, bleeding after dental work and heavy menstrual bleeding. Most commonly it is taken as tablets, syrup or in a mouthwash and it can be used as an addition to a clotting factor concentrate.

Women may also be prescribed hormonal contraceptives such as the oral contraceptive pill or the Mirena intrauterine device to manage heavy menstrual bleeding.^{4,8,9,10}

2.4 Comprehensive care

International best practice for treatment and care of a person with a bleeding disorder is through co-ordinated delivery of **comprehensive care**. This is provided by a multidisciplinary team with specialised expertise in bleeding disorders, who address the wide-ranging physical and psychosocial needs of the person with a bleeding disorder and their family:

- a haematologist
- a nurse co-ordinator
- a psychosocial expert, preferably a social worker or psychologist
- musculoskeletal experts including a physiotherapist and orthopaedics or rheumatology specialists
- and access to a specialised laboratory.

To provide integrated care to their patients, the team will also co-ordinate their care with other relevant specialities, which should include at least pain management, a geneticist, infectious diseases, immunology and hepatology, gynaecology and obstetrics, dentistry and vocational counselling.¹¹

In Australia comprehensive care is provided by specialist **Haemophilia Treatment Centres (HTCs)**. There is at least one HTC in each Australian state or territory. These are usually located in tertiary public hospitals and provide a collaborative and educational role statewide, with outreach services to isolated patients and the capacity to undertake research.⁴ An important tool in comprehensive care is the **Australian Bleeding Disorders Registry (ABDR)**. This system is used by HTCs for the clinical care of their patients. The ABDR collects data on people with bleeding disorders, their bleeding episodes and related problems, treatments and care. Statistical data from the system can be used to better understand the impact of the bleeding disorder, outcomes of various treatments and for treatment product supply and planning. People with a bleeding disorder and parents of a child with a bleeding disorder can contribute data about their bleeds and home treatments through the **MyABDR** app and website. MyABDR links directly to the ABDR system.⁴

National groups of the specialist health professionals at HTCs have been established to promote clinical excellence and research in each discipline:

- Australian Haemophilia Centre Directors' Organisation (AHCDO)
- Australian Haemophilia Nurses Group (AHNG)
- Australia/New Zealand Haemophilia Psychosocial Group (ANZHPG)
- Australian And New Zealand Physiotherapy Haemophilia Group (ANZPHG).

3. Literature review



3.1 A journey into unchartered territory

Growing older with a bleeding disorder is a relatively new development. Ongoing improvements in treatment and care since the advent of factor replacement therapy with clotting factor concentrate in the 1960s and 1970s and a comprehensive care approach to health care services have seen more people with bleeding disorders reaching older age than ever before. New and emerging therapies give hope that this increased lifespan can also be accompanied by improved quality of life.¹²⁻¹⁹

The road to increased life expectancy for people with bleeding disorders has had its backward steps: tragically over the last 40 years in Australia and worldwide there have been large numbers of premature deaths in this population related to the HIV and hepatitis C epidemics. Many people with bleeding disorders in Australia acquired HIV or hepatitis C infection from infected plasmaderived clotting factor concentrates before 1993, by which time blood supply screening and viral inactivation manufacturing processes had been introduced. Ironically it was the life-saving new clotting factor concentrates that also brought with them the blood-borne viruses that would have such an impact on recent generations of people with bleeding disorders. The fact that there is a current generation that is living on into senior years is also a reflection of the recent advances in HIV and hepatitis C treatment and care.¹⁹⁻²³

Over the last decade there has been a growing body of literature that has focused on the emerging and anticipated medical, psychosocial and lifestyle challenges associated with ageing with a bleeding disorder. Many highlight the lack of evidence-based data and the limited experience in managing age-related concerns, due to the small population of individuals who have a bleeding disorder and have survived into old age to date.^{17,18,23-27} One author described growing older with a bleeding disorder as a 'journey into unchartered territory'.²⁸

3.2 Defining 'older person'

When is a person 'ageing' or an 'older person'? The World Health Organization (WHO) notes that most developed countries use the chronological age of 65 years as the definition of an 'elderly' or 'old' person, and that this is often associated with the age when a person becomes eligible for a government pension.²⁹ The Australian Government My Aged Care portal defines an 'older Australian' as being eligible for funded aged care services at 65 years or older or 50 years or older for Aboriginal or Torres Strait Islander people.³⁰ The current age at which a person is eligible for an Age Pension in Australia is 66 years; this will increase to 67 years by 1 July 2023.³¹

However, WHO points out that 'ageing' and 'older person' are only loosely associated with a person's years: the physiological and social changes experienced by an individual as they age are very variable, and one person at 70 years may be very active and still working while another is unwell and frail. Most noticeable is the change in the older person's goals, priorities and what motivates them. To deal with losses in close relationships and functionality, older adults may have fewer goals and use creative strategies to find different ways to achieve their daily tasks.³² Interestingly, the Australian Government also requires a person to have a diagnosed medical condition or functional or mobility problems to be eligible for aged care services³⁰, on the assumption that some people will be well enough to remain active and independent without assistance.

3.3 A patient-centred approach

Making the patient the centre of care was a key recommendation of the Australian Productivity Commission for achieving better health outcomes for Australians and for developing a more efficient and costeffective health system. In the 2017 review, *Shifting the dial*, the Productivity Commission identified a number of factors to improve care and the quality of health for Australians using this approach, including:

- more integrated and seamless care
- a better understanding of patient experiences and patient-reported treatment and care outcomes
- improved patient health literacy.

The Commission noted that achieving a higher level of integrated care would have broad-based benefits. It would 'lead to substantial improvements in the health of Australians, particularly those who are the most dependent on health services. This would bring welfare gains for the individuals concerned, savings for the health system and gains for the economy more broadly.' ³³

3.3.1 INTEGRATING CARE AND QUALITY OF LIFE

Bleeding disorders affect many aspects of life, both for the person with the bleeding disorder and those who are close to them. Understanding how growing older may impact on treatment and care needs is complex and needs to take account of how this relates to the person's quality of life. WHO identifies six broad domains of quality of life: physical health, psychological, level of independence, social relations, environment (including finances, leisure, opportunities to learn new skills), and personal beliefs.³⁴

With its aim of addressing the wide-ranging physical and psychosocial health needs of people with bleeding disorders and their partners and families, the comprehensive care approach provides multidisciplinary treatment and care, co-ordinates the provision of care, including other medical specialities that need to be accessed, and provides education to the Haemophilia Treatment Centre patients, their partners and families.⁸ As a result most of the review articles about ageing with a bleeding disorder produced by clinicians at Haemophilia Treatment Centres explored quality of life issues for older people with bleeding disorders and raised questions about the changes to HTC treatment and services that would be required to address their needs in an integrated way. This is discussed below under **3.6 Age-related health impacts**.

3.3.2 HEALTH LITERACY AND SELF-MANAGEMENT

The Productivity Commission also highlighted the importance of health literacy in improving health: enabling 'prevention, better self-management of chronic conditions, patient collaboration with clinicians, a greater capacity for informed choice and effective advocacy'.³⁵ The Australian Commission on Safety and Quality in Health Care has defined health literacy as 'health literacy is about how people understand information about health and health care, and how they apply that information to their lives, use it to make decisions and act on it'.³⁶

While the Productivity Commission considered ways for health care providers to improve the health literacy of their patients, there is also a body of literature which underlines that some individuals seek information about their health condition as a way of taking control of their health. Being able to access that information independently of their health care provider is an important self-management strategy for them.^{37,38} Information in plain language, that can be understood by the target population, was one aspect of accessible information identified by the Productivity Commission. The Commission also noted that the health literacy programs would need to be provided in environments accessed regularly by the patient target group.³⁵

3.3.3 MEASURING QUALITY OF LIFE OUTCOMES

Having a bleeding disorder impacts on the range of quality of life domains. Tools to measure this need to address this in a way that is meaningful to the person with a bleeding disorder.

The PROBE (Patient Reported Outcomes Burdens and Experiences) study has been developed specifically to measure quality of life domains that are common to men and women with bleeding disorders globally. PROBE is a multinational independent project which has established a patient-led research network to develop standardised questionnaires to gather patient-reported outcomes. Haemophilia Foundation Australia joined the PROBE study in 2014 and was involved in the initial validation phases to ensure the study was appropriate to Australians with bleeding disorders.

The current PROBE questionnaire investigates health problems and health-related quality of life in men and women with haemophilia. It is comprised of four major sections (demographic data, general health problems, haemophilia-related health problems and health-related quality of life using EQ-5D-5L and EQ-VAS). Questions are intended to help understand the impact of haemophilia and treatment on quality of life including the number of bleeds, pain, mobility, activities of daily living and related surgical interventions. It also asks about the impact on education and employment. The study has been validated internationally.^{39,40}

Australia was the first country to implement the realworld PROBE study, commencing in May 2019, and HFA has used age-related data sourced from the real-world implementation for this needs assessment (see **4.6 PROBE Australia study** and **5.6 PROBE Australia study results**). The PROBE Australia data has shown a strong association between ageing and physical functioning, mobility problems and pain as well as lifetime impacts on working and education. An abstract from the PROBE investigators demonstrating the association between aging and health status in people with haemophilia using current PROBE study results, including Australian data, has been accepted for the International Society on Thrombosis and Haemostasis ISTH 2020 Virtual Congress in July 2020.⁴¹

3.4 Older people with bleeding disorders population

3.4.1 INCREASING LIFE EXPECTANCY

Several studies have documented the dramatic increase in life expectancy in haemophilia in high income countries over the twentieth century. Until the introduction of fresh frozen plasma in the 1950s, treatment for bleeding episodes was largely to manage symptoms using the management principles of the time, e.g. through rest, ice, compression and immobilisation. As a result most people with haemophilia did not survive beyond adolescence. Clotting factor concentrates became available in the 1960s and by the 1970s plasma-derived concentrates were being manufactured in enough quantities to make home therapy a reality.¹⁶ A US study noted that, as a result, life expectancy for haemophilia had increased to nearly 68 years of age in the decade 1971 to 1980.⁴²

3.4.1.1 Impact of HIV and hepatitis C

This progress was reversed sharply during the 1980s and 1990s, when the full impact of the HIV and hepatitis C epidemics on the bleeding disorders population became clear. Plasma-derived clotting factor concentrates were produced from the plasma donations of many individuals and the risk of infection was very high, particularly for people with severe haemophilia who treated often. In a government inquiry in Australia, the Australian Red Cross Blood Service (ARCBS) explained that each batch of concentrate was fractionated from the pooled donations of up to 10,000 donors and that one donation with HIV or hepatitis C virus (HCV) could infect the entire batch. They also acknowledged that a high proportion of Australians with haemophilia had been exposed to hepatitis B through blood products.⁴³ In Australia the hepatitis B vaccine was introduced in 1983⁴⁴ and blood screening and viral inactivation manufacturing processes to prevent the transmission of HIV and HCV had been introduced by the early 1990s.⁴³ However, by this time a large proportion of people with bleeding disorders had already been exposed. The same US study noted that life expectancy for haemophilia declined from 68 to only 49 years of age in the decade 1981 to 1990, largely as a result of mortality from AIDS.⁴² After highly active antiretroviral therapy (HAART) for HIV infection was introduced in 1996, Canadian, UK and German studies showed that HIV-related mortality rates in the haemophilia population dropped substantially. However, they also described the increasing impact of hepatitis C infection and noted that after 1998 the leading causes of death were haemorrhage from a bleeding episode and liver disease.^{13,16,45,46}

There is limited published data on the prevalence of HIV and HCV infection among people with bleeding disorders in Australia. A 1993 survey of Haemophilia Treatment Centre (HTC) patients with haemophilia A in three Australian states found an overall prevalence of 23% with HIV infection, and up to 45% in some Haemophilia Treatment Centres. The prevalence of HCV exposure was higher – 74% overall.²¹ Those with HIV were likely to be co-infected with HCV.^{47,48} A more recent study of HCV infection in one Australian Haemophilia Treatment Centre found that exposure rates were very high for their patients with severe haemophilia (92%-94%) and type 3 (severe) VWD (83%), and also substantial for their patients with mild haemophilia (52%-61%) and type 1 (usually mild) VWD (16%).²² By 2007 HTCs were reporting that more than half of their patients who had HIV had died, some of them from liver disease as they were co-infected with HCV.48

The last several years have seen some remarkable advances in treatment for HIV and hepatitis C. With the availability of highly effective antiretroviral therapy (ART), HIV infection is now described as a 'chronic manageable condition'.⁴⁹ In March 2016 new direct acting antiviral (DAA) treatments for hepatitis C were made available for all Australians. They have very high cure rates and few if any side-effects and there has been a high uptake by people with bleeding disorders.^{50,51}

3.4.1.2 A new older generation

Over the last 10 years leading haemophilia clinicians have started to describe a new generation of people with severe as well as mild bleeding disorders who are living into old age.^{18,24,25,28}

As well as more effective treatment for bloodborne viruses and access to co-ordinated comprehensive care through Haemophilia Treatment Centres, they have also pointed to more widespread use of prophylaxis to prevent bleeding episodes among people with severe haemophilia.^{14,19} In previous decades there had been concern about the difference in lifespan between people with severe and mild haemophilia. For example, a UK study of people with haemophilia who did not have HIV from 1977 to 1999 found that those with severe haemophilia had a life expectancy of 63 years, compared to 75 years for people with mild haemophilia and 78 years for the general population.¹³ A recent study, which also used data from national registries such as the Australian Bleeding Disorders Registry, found that overall there was still a 'survival disadvantage' for people with haemophilia even in well-resourced countries. It proposed that this indicated even for wealthier countries, that 'the quality of haemophilia care is still insufficient to close the life expectancy gap for patients with the disease.⁵²

While the improvement in survival rates among older people has been a cause for celebration, it has also led to a focus on the challenges of living into older age with the complications of bleeding and what else can be done to prevent bleeds, reduce the impact of complications and improve quality of life.^{24,53}

3.5 Treatment

3.5.1 HAEMOPHILIA

3.5.1.1 Factor replacement therapy

Factor replacement therapy using clotting factor concentrates has been a standard treatment for haemophilia in Australia since it became available in the 1970s.^{8,9,43}

During the 1980s there were major shortages of factor VIII concentrates in Australia. As a result, leading haematologists noted that Australians with severe haemophilia A were being treated with much less factor VIII than in Haemophilia Centres in the UK, the USA and West Germany.⁵⁴ At this time, Australia had a policy of self-sufficiency in blood and blood products. In spite of the efforts of Australian blood services to source enough plasma donations and the Commonwealth Serum Laboratories (CSL) to increase factor VIII yield, factor VIII concentrate production did not reach the levels required for recommended treatment standards until 1995.⁴³

3.5.1.2 Recombinant product

Recombinant factor product was made available for children and previously untreated adults with haemophilia in Australia from 1994 to prevent further transmission of bloodborne agents and to overcome shortages of plasmaderived factor products. In 2004 recombinant factor was made available for all Australians with haemophilia regardless of age in response to a theoretical risk of variant Creutzfeldt Jacob disease (vCJD). Most Australians with haemophilia now use recombinant factor products for factor replacement therapy.

A small number continue to use plasma-based clotting factor concentrates.^{4,43,55}

3.5.1.3 Prophylaxis

The aim of **prophylaxis** (prophylactic factor replacement therapy) is to keep factor levels high enough to prevent bleeding and joint destruction, with the goal of therapy described as being 'to preserve normal musculoskeletal function'.⁸

Since 1995 prophylaxis treatment to prevent bleeding has been available for children and younger people in Australia, and more recently for older adults as well.^{56,57} With the standard half-life products currently available in Australia, prophylaxis with clotting factor concentrates usually involves infusions two to three times weekly, but the treatment plan is individualised to the patient. Individualisation is 'based on age, venous access, bleeding phenotype, pharmacokinetics, activity, and availability of clotting factor concentrate.'⁸ Extended half-life products could reduce the number of infusions by one or two or more weekly. These are widely in use globally, but not yet funded for all in Australia. They are discussed below under **Newer and emerging therapies (section 3.5.1.6).**

The benefits of prophylaxis in preventing bleeds and the resulting damage to joints have been established through extensive study internationally, but the long-term outcomes for health and quality of life over the lifetime continue to be examined and debated, particularly as the impact of joint disease takes at least 5 years to be seen. Prophylaxis protocols and doses vary from country to country.^{9,58} There has also been ongoing discussion about the value of 'tertiary prophylaxis', or prophylaxis which is started when the person with haemophilia has existing joint disease, usually as an adult, as compared to 'on demand' treatment.⁸ For older adults with moderate and severe haemophilia in Australia, this would be the only relevant type of prophylaxis as they were adults when prophylaxis became available and would already have developed joint disease.

A 2018 international review of long-term outcomes compared prophylaxis to on demand treatment of haemophilia A. It found that sustained prophylaxis produced better control of bleeds, joint outcomes, health-related quality of life and attendance at school and work than on demand treatment for both children and adults. However, it also pointed to the need for more improvement, even for those having consistent prophylaxis: the protocol used and how long the person had maintained prophylaxis had a significant impact on results. There were also issues with the development of inhibitors, the burden of regular treatment infusion over many years and the challenges of adhering to treatment.⁵⁸

Prophylaxis in Australia

To understand current practice with prophylaxis in Australia, leading Australian haematologists recently reviewed national ABDR data on prophylaxis in people with moderate and severe haemophilia A and B. They found that prophylaxis rates in people with severe haemophilia were comparable with other developed countries, but were concerned that the current rates of prophylaxis in adults were too low to achieve the potential benefits with preventing bleeds and further joint deterioration, particularly those aged 60 years and over. The percentage having prophylaxis declined substantially from the age of 40 years, increased again in the 50-59 age group and declined again after the age of 60 years to less than half of those with haemophilia A and around a third of those with haemophilia B. The authors suggested the reasons for this 'may reflect the interplay of multiple factors, including patient acceptance (compounded by entrenched beliefs about their own therapy), physician preference, challenges around intravenous access and impact of other comorbidities'. They noted that people with haemophilia A who were over 60 also used far more factor than their expected dose. This was perhaps due to the need for surgical cover in this age group, or because this group found it difficult to distinguish between arthritic pain and pain caused by an acute bleed, or because their prescribed dose was too low to adequately prevent bleeds.59

3.5.1.4 Inhibitors

One of the challenges of factor replacement therapy is the development of inhibitors, or antibodies to clotting factor treatments, that make the treatment much less effective. The lifetime risk of developing an inhibitor in people with severe haemophilia is about 20-30%, while for people with moderate or mild haemophilia it is about 5-10%.

In recent years several treatment options for inhibitors have become available and many people are successful at overcoming inhibitors, while others have ongoing problems. The continuing bleeding is severe and results in significant disability. It can be life-threatening. People with inhibitors experience constant pain and increasing disability over time.⁸

3.5.1.5 Other products

The Australian clinical guidelines also describe a number of other products for treating bleeding problems in haemophilia. This includes desmopressin (DDAVP), which is often used to treat people with mild or moderate haemophilia A, tranexamic acid, and hormonal contraceptives for women to manage heavy menstrual bleeding.⁸

3.5.1.6 Newer and emerging therapies

Over the last several years a range of innovative new products have become available to treat haemophilia.

Extended half-life (EHL) clotting factor concentrates have been developed for factor VIII and factor IX and are described as having substantial advantages when used for prophylaxis. They have enabled clinicians to refocus on eliminating bleeding episodes in people with haemophilia entirely, with a much-increased rate of zero bleeds, especially for haemophilia B. The extended halflife reduced the frequency of infusions from 2-4 times weekly to 1-2 times weekly for people with haemophilia A and from 1-2 times weekly to once every 10-14 days for people with haemophilia B. This was associated with improved quality of life and reduced absenteeism from school and work. However, the development of inhibitors continues to be a problem. Follow-up data from some factor VIII studies has also suggested that EHL treatments may improve musculoskeletal outcomes, even when there is existing joint damage. If this data is confirmed in other larger studies, it could offer new possibilities with tertiary prophylaxis for older people.^{60,61}

Non-clotting factor concentrates, for example, emicizumab, fitusiran and concizumab, are another new class of product. These treatments are not based on factor replacement, but target other aspects of the blood clotting process, so they do not produce inhibitors and are effective for people who have inhibitors. They are injected under the skin, rather than into a vein, and have a long half-life, so that they can be given once every 1-4 weeks for prophylaxis. This is a major advance for ease of administration and adherence. Safety continues to be monitored, as a small number of thrombotic complications have been reported in some of these products.⁶⁰

The recent advances in **gene therapy** for haemophilia A and B have led to great excitement internationally. Clinical trials using the adeno-associated virus (AAV) vector in small numbers of patients reported successful sustained results with few side-effects: reducing the patients' factor severity level from severe to mild, and even normal in some cases, and having few, if any, bleeding episodes over a 12-month period. While this has raised the question of whether gene therapy is a 'cure' for haemophilia, at present the conclusion with these therapies is that they are reducing the rate of bleeding to an equivalent of mild haemophilia rather than preventing bleeds altogether.

Some new studies are investigating ways to extend the groups who are suitable for gene therapy as a considerable number of people have been excluded; for example, whether the treatment can be modified so that it is effective in people with pre-existing immunity to AAV. These clinical trials are now being extended to larger groups and other new trials are starting. However, to monitor the effects of gene therapy in the longer term, the trials will need to follow participants for several years – on average 5 years.⁶²⁻⁶⁷

In Australia

At the time of publication EHL and non-clotting factor concentrate treatments were not publicly funded in Australia except for a limited early access program. Some people were using them following participation in clinical trials or through compassionate access schemes. There were several gene therapy clinical trials taking place nationally.

3.5.2 VON WILLEBRAND DISEASE (VWD)

There have been far fewer new developments in treatment for von Willebrand disease (VWD).

The Australian clinical management guidelines describe the intention of treatment for VWD as to restore the factor that is missing or does not work properly, in this case von Willebrand factor and sometimes factor VIII. Some people with von Willebrand disease require treatment with clotting factor VIII concentrates containing von Willebrand factor, which need to be injected intravenously. Others can be treated primarily with desmopressin (DDAVP).⁶⁸

Treatment for VWD needs to be tailored to the individual and involves careful and complex testing of their VWD Type and response to treatment and reassessment over their lifetime. In Type 1, which is the most common Type, factor levels can increase with age but there is some question about whether this changes the bleeding pattern and therefore the need for treatment in older people.⁶⁹ DDAVP is not effective for all Types of VWD and some people do not respond well to it; there are also added risks of side effects with some health conditions associated with ageing and it is not recommended for people with existing heart or cerebrovascular disease.^{68,69}

People with severe VWD (eg, Type 3) may require factor replacement therapy regularly for prophylaxis or to treat bleeds on demand. Most people with VWD usually have mild symptoms, and may need only to treat with factor replacement therapy when they have a substantial injury or as cover in preparation for surgery or medical and dental procedures. For women, factor levels and bleeding issues with pregnancy, childbirth and menstruation need to be taken into account. As with haemophilia, hormonal contraceptives may be used to manage heavy menstrual bleeding.

Von Willebrand factor (VWF) recombinant clotting factor concentrates are not yet available in Australia and people with VWD who require clotting factor concentrate are treated with plasma-derived factor VIII concentrate that contains VWF.

Other additional treatments such as tranexamic acid and fibrin glue are recommended for mouth, nose and uterine bleeding, minor wounds and after dental procedures. The guidelines also note that occasionally some people may benefit from a platelet transfusion containing VWF.⁶⁸

3.5.3 OTHER RARE BLEEDING DISORDERS

There is a diverse range of rare bleeding disorders other than haemophilia and VWD, including rare clotting factor deficiencies and inherited platelet function disorders. These disorders have symptoms which can vary widely from mild to severe, vary from one disorder to another, and from one affected person to another. They are very rare and affect small numbers of people in comparison to haemophilia and VWD.

Leading clinical experts have noted that this diversity along with the small numbers has delayed the development of new and effective treatments. Many rely on single-factor plasma-derived concentrates for factor replacement therapy and in some cases a specific factor concentrate is not available, for example, factor V deficiency where fresh frozen plasma is used. Treatment is usually on demand and preventive for surgery, although some may have prophylaxis if they have a severe disorder and a suitable treatment is available. Inherited platelet function disorders are often treated with platelet transfusion, or with desmopressin if the disorder is mild.

Women are at risk of gynaecological bleeding complications, with heavy menstrual bleeding, miscarriage and post-partum haemorrhage common across many rare disorders.^{70,71}

A recent review of treatment notes that the development of new classes of treatment for haemophilia has had an important role in treatment for rare bleeding disorders. A number of early studies are pursuing the same focus on reducing the number of infusions and gene therapy is being explored in factor VII deficiency.⁷⁰

3.6 Age-related health impacts

Over the last decade there have been a number of publications from leading haemophilia clinicians that have described the complications related to ageing with a bleeding disorder.^{17,18,24-28,53}

More recently an editorial by a group of UK haematologists took a different look at these complications related to ageing, describing them in terms of a 'third age', or the period after retirement, and a 'fourth age' of partial or full dependency. Reviewing the issues of their current patients, they produced the list below:⁴³

Third age: retirement

Cardiovascular disease Renal disease Hypertension, obesity, diabetes Increasing tendency to falls Decreasing visual acuity Dementia Malignancy HIV and HCV coinfections Mobility Arthropathy

Bone health

Loss of social network

Fourth age: dependency

As in third age but worse Seeking care/support outside the home or hospital This list highlights both the bleeding disorder-specific complications, and the other age-related health conditions also seen in the general population including cancer, cardiovascular disease, hypertension, renal disease, vision problems, dementia, and issues with balance and falls.

Leading haematologists internationally point out that there is still much to learn about the impact of ageing on bleeding disorders and of bleeding disorders on agerelated health conditions. This is a new population and gathering this evidence will take time: the numbers of older people with bleeding disorders are still relatively low, but increasing as the next generation ages as well. Moreover, most of the literature has focused on haemophilia and there is still much to be explored in ageing with VWD or a rare bleeding disorder.

However, it is well recognized in this group that managing the complications of ageing with a bleeding disorder will be complex, both medically and in its impact on quality of life. The authors underlined the importance of specialist haemophilia treatment centres in co-ordinating care between the various health care providers in the community, but also were concerned about the need to work with general practitioners to ensure regular screening relating to ageing is carried out.^{17,18,24-28,53}

3.6.1 VEINS

Standard factor replacement therapy is administered through an infusion into a vein and vein care becomes increasingly problematic as a person grows older. Haematologists note that there are a number of difficulties for the person who is ageing: fragile or hidden veins, collapsed veins due to hydration, problems with dexterity in the hands, vision problems are some of these. As a result, a person may have to have multiple attempts to infuse, which could increase their anxiety and lead to avoidance or delay of treatment; some may switch back to on demand treatment from prophylaxis. All of this could have negative impacts on their health.⁵³

3.6.2 JOINTS AND MUSCLES

For older people with bleeding disorders, some health and wellbeing problems are the direct result of having lived for many years with a bleeding disorder before prophylaxis and adequate supplies of treatment product were available. Joint and muscle damage and the resulting pain and disability are an example of this and are the most common complication experienced by older people with haemophilia.^{17,18,24-28} A recent review of VWD pointed out that arthropathy can also be seen in people with severe VWD as a result of joint bleeds.⁷²

Joint arthropathy (joint disease) is caused by repeated bleeds into a joint over time. Many people with moderate and severe haemophilia develop a pattern of bleeding into the same joint, typically a large load-bearing joint such as the ankle, knee or elbow.⁷³ When three or more bleeds have occurred in a particular joint within 6 months, the joint is known as a 'target joint'.⁸ Older people with haemophilia often have several joints with arthropathy that have a limited range of motion with pain or stiffness and may also have muscle weakness and contractures, resulting in reduced daily activity. This may in turn increase the potential for the person to become overweight or obese, which can then put extra strain on their already damaged joints.^{17,27} Over the years bony changes such as osteoporosis can also be caused and exacerbated by repeated bleeds and by the person's inactivity.⁷³

3.6.1.1 Mobility, independence and quality of life

Studies on the impact of target joints have confirmed that they can have a very negative influence on the quality of life of a person with haemophilia.⁷⁴ By the time they reach their senior years many people with haemophilia are experiencing a life in which limited mobility, reduced joint function and chronic pain is beginning to dominate their lives.²⁵

Two Italian studies have compared men with severe haemophilia aged 65 years and over to controls from the general population of the same age. They found that nearly all the men with severe haemophilia had joint arthropathy and had a bloodborne virus such as HIV, hepatitis C or hepatitis B. Two thirds of them reported moderate pain or discomfort compared to one guarter of men without haemophilia. They were much less physically active and more likely to have difficulty with transport, shopping, dressing and using the bathroom than the men without haemophilia. They had a similar cognitive status to men without haemophilia, but experienced depression more commonly. The second study confirmed these results, and also found that the men with haemophilia were more likely to be worried about the impact of their health on their future.^{75,76}

Lifelong joint problems directly influence the person with haemophilia's independence and ability to manage their activities of daily living. This adds another layer of difficulty to their ability to manage their bleeding disorder and attend medical appointments, both at their haemophilia treatment centre and in the general community, and impacts on their overall health and wellbeing.⁷⁶ As age increases, these joint problems become more apparent and pronounced.⁷⁷

3.6.1.2 Joint replacement and surgery

Because their joint and muscle damage occurred at a young age and the associated pain and disability is considerable, older people with haemophilia will often have had orthopaedic surgery, particularly if they have severe haemophilia or inhibitors. This commonly involves hip, knee and sometimes elbow replacements, ankle fusions, and a range of other procedures to manage arthropathy in the bones and joints. Joint replacement surgery is usually delayed for as long as possible due to the limited lifespan of the prothesis (replacement joint), but if the person with a bleeding disorder had a joint replacement at a relatively young age, they are likely to need a revision operation to replace the prosthesis in another 10-20 years.^{17,27,78,79}

3.6.3 FALLS AND BALANCE

As people with bleeding disorders age, they have a potential cascade of risk factors that could lead to balance problems and falls, and then serious injury as a result. Impaired mobility is a risk for overweight or obesity which can put additional strain on already damaged, painful joints. They have a higher risk of osteoporosis, which tends to progress with increasing age, and the low bone density is usually associated with increased fracture risk. They also can experience gait problems from arthropathy in their ankles and knees and muscle weakness around these joints with impaired proprioception (awareness of body position and movement), which put them at a higher risk of losing their balance and then falling.^{80,81,82}

An Australian study which compared men with haemophilia to an age-matched group of healthy men found a much higher rate of balance problems in the men with haemophilia, with more than 50% of them reporting falls in the last 12 months, mostly while walking.⁸³ To improve balance and mobility, studies have suggested that individualized exercise programs of balance, strengthening and walking exercises would be valuable for men with haemophilia.⁸⁴ One study suggested that exercises that targeted hip strength and retraining ankle movement would be particularly helpful.⁷⁷

3.6.4 EXERCISE

There have been many studies to show that exercise has benefits for people with haemophilia. A Cochrane review noted that most studies showed that exercise 'produced improvement in one or more of the measured outcomes including pain, range of motion, strength and walking tolerance'.⁸⁵ This was confirmed in another systematic review. Strength training, for example, has been shown to improve joint stability and decrease pain and disability. Combined with weight loss, it can reduce the impact on joints and lead to fewer bleeds. Several studies highlighted the benefits of hydrotherapy, e.g., exercise in a swimming pool, to provide resistance training for a person with haemophilia without putting extra load on joints.⁸⁶ Exercise has also been shown to be effective in reducing the age-related impact of arthropathy in older people with haemophilia.⁸⁷ Clinical management guidelines for older people with haemophilia also point out the value of physical activity in reducing the risk of cardiovascular disease, diabetes and some cancers, as well as improving mental health and mood.²⁵

With existing joint and mobility problems, access to appropriate exercise is important. A large study of participation in sports and physical activity among people with VWD found that those with severe forms of VWD were also likely to have developed joint disease, which limited their ability to take part in the range of sports and physical activities.⁸⁸ Pain is also an issue which may prevent people with bleeding disorders from participating in exercise.²⁵ Recent work in arthritis has shown that, in contrast to people's fear that exercise will increase their pain with arthritis, the opposite is true: that with an individualized exercise program and education, pain and quality of life can be improved.⁸⁹ Haemophilia physiotherapists have encouraged their patients to participate in these programs.

3.6.5 PAIN

Pain is a very significant problem among older people with bleeding disorders. The Hemophilia Experiences, Results and Opportunities (HERO) study, which surveyed adult males with moderate and severe haemophilia from 10 countries, found that 31% those aged 40 years and over reported that pain had interfered with their daily life 'extremely' or 'quite a lot' in the last 4 weeks. Pain was associated with a higher frequency of bleeding episodes annually and impacted on mobility, quality of life and employment.⁹¹ Common sources of pain are the acute pain with a bleed and the chronic pain from arthropathy and inflammation in joints. Pain affects quality of life and mental health and can lead to dependence on alcohol, opioids and other substances used to alleviate pain, such as cannabis.^{25,81}

There are a number of complexities in pain with a bleeding disorder. Australian clinical management guidelines note that the cause of the pain needs to be assessed for effective management – for example, while pain from a bleed may be alleviated by replacement factor therapy and an anti-inflammatory medication, this medication will have no impact on pain from arthropathy.⁸ A US study highlighted the difficulty for both doctors and patients in determining whether pain was from a bleed or arthritis from symptoms alone and the need for other objective forms of assessment, such as musculoskeletal ultrasound.⁹² In bleeding disorders there also needs to be caution with commonly used pain medications including aspirin and non-steroidal anti-inflammatory drugs (NSAIDS) such as ibuprofen as they can increase bleeding.⁸

An Australian study of people with haemophilia who had joint replacements over 23 years found the surgery was very valuable in relieving pain.⁷⁹ The value of medicinal cannabis in treating pain, however, is still debated. Although the law in Australia has been changed to allow medicinal cannabis to be prescribed through Special Access and Authorised Prescriber Schemes, medical professional groups have been cautious about support for it, while their patients describe benefits from its use that do not always align with the findings from the clinical trials. Many Australians using cannabis medicinally continue to obtain it illicitly through dealers, by growing it themselves or online rather than through prescription.⁹³

An important aspect of pain management is understanding how and why pain occurs. The work of the NOI (Neuro Orthopaedic Institute) group to explain how to reconceptualise chronic pain has been very popular as a pain management approach in Australia and has figured regularly in recent Australian haemophilia conferences. This approach is supported by research demonstrating that it can reduce pain and disability and that activitybased pain treatments have better outcomes.⁹⁴

3.6.6 EARLY AGEING

Early ageing is also a major problem in this population. The Australian clinical management guidelines note that arthropathy from haemophilia can develop any time from the second decade of life, and sometimes earlier.⁸ Very early joint damage could occur, for example, if the person has had inhibitors, making treatment less effective. A European study noted that the impact of target joints on health-related quality of life in people with haemophilia started being noticeable in the 25-34 year age group but was very marked in the 45+ age group.⁸⁰ In Australia people with haemophilia who are currently in their mid-30s and older have lived through periods where prophylaxis was not available and their access to treatment products was prone to shortages. As a result, many now live with significant arthropathy, mobility issues, pain and other complications due to joint and muscle damage from repeated bleeds in their earlier years. A substantial number have also been affected by added complications associated with bloodborne viruses such as hepatitis C and HIV, acquired through their treatment before 1993.

3.6.7 OTHER AGE-RELATED HEALTH PROBLEMS

As people with bleeding disorders grow older, they experience the same age-related health conditions as the general community. With so few people with bleeding disorders living on into old age in previous generations, information on the impact of these health conditions on people with bleeding disorders as they age is still being collected.¹⁷ These complications are an extra challenge to clinical management and require some vigilance. The Australian guidelines highlight the importance of managing age-related health conditions appropriately: they may accentuate problems associated with the bleeding disorder and reduce quality of life even further.⁸

3.6.7.1 Heart disease and hypertension

In the community it is commonly thought that having a bleeding disorder protects against heart disease because of lower clotting levels, but there is much discussion and uncertainty in the literature about this.^{8,17,24,78} Authors noted that people with bleeding disorders had the same risk factors as the general population, such as hypertension, kidney disease and reduced physical activity. They may also be at increased risk of heart disease if they have HIV.^{24,78} Some more recent European studies compared people with and without haemophilia in older age groups and found similar or lower rates of heart disease and hypertension in older people with haemophilia. This may be reflective of the particular group they studied and highlights the need for more studies of older people with haemophilia to understand the range of experience.^{95,96}

Several haematologists concluded that even if the rates of particular forms of heart disease, such as coronary artery disease, were lower in people with bleeding disorders than the general population, they certainly did occur and occurrence may be increasing because there are more people with bleeding disorders living on into senior years. Managing anticoagulant treatments such as aspirin and surgery when the person has a bleeding tendency creates further complications. They stressed that for good outcomes, there needs to be tight co-operation between the haemophilia and cardiology specialists.^{17,24,27,78}

Some health conditions of ageing may be compounded by having a bleeding disorder. Lack of activity can result in a person becoming overweight. People with haemophilia are at increased risk of obesity as a result of decreased joint mobility and function and associated chronic pain. There is also a higher risk of developing diabetes in older people who are overweight.^{8,24}

3.6.7.2 Bloodborne viruses

The added complications of having a bloodborne virus such as hepatitis C or HIV also create another level of complexity. The risk of developing cancer seems to be similar for people with bleeding disorders as for the general community and for everyone increases with age. However, people with long-term hepatitis C infection are at a higher risk of developing liver cirrhosis and liver cancer and this risk increases with older age.⁹⁷ HIV infection increases the risk of other specific cancers and at a younger age.⁴⁹ HIV and hepatitis C can also increase the risk of gum disease⁸, which compounds the dental problems for older people with bleeding disorders in Australia. Even in the general population the Australian national health plan notes that periodontal (gum disease) increases with age and is the reason for dental extraction for 16.5% of people aged 45-64 and 20% of people over 65.⁹⁸

As with heart disease, treating health problems like cancer and dental disease in people with bleeding disorders requires good co-ordination between the haemophilia and oncology, surgical or dental specialists. In particular, there needs to be care with managing factor replacement during surgical or medical procedures, including biopsies, and monitoring the side-effects of drugs and chemotherapy.^{8,17,24,27,78}

3.6.8 WIDER IMPACTS OF HIV AND HEPATITIS C

The HIV and hepatitis C epidemics had an enormous impact on the bleeding disorders community and across many aspects of their lives.

HFA's 2007 hepatitis C needs assessment, 'A double whammy', revealed the depth of this experience. A large proportion were exposed through their treatment products, particularly to hepatitis C, and a significant number died, often at a young age. Multiple members of the same family could be affected. Discrimination in the community meant that there was a silence about this for people with bleeding disorders and their partners and families: many did not disclose their viral status, sometimes even within their own family, and were often careful of disclosing or proactively hid their haemophilia, as this was associated with HIV. HIV and hepatitis C symptoms and side-effects from treatment impacted not only on their quality of life and relationships, but their ability to work and earn an income, and many retired early or took lower paying or part-time work. Some were forced to sell their house and move their family into rental accommodation; single people became more vulnerable and isolated.²⁰

These bloodborne viruses also had a major impact on their self-management. Acquiring such a serious health condition from their treatment meant that many lost confidence in the safety of their treatments and some became suspicious of the health system generally.²⁰ HFA's 2009 follow-up report, Getting it right, noted that many experienced overload with health conditions and would prioritise what was affecting them immediately, sometimes to the detriment of their long-term health, for example, by not monitoring liver disease.⁹⁹ The 2019 National Association of People with HIV Australia (NAPWHA) report HIV and ageing in Australia describes some of the issues for people living with HIV as they grow older, including the complexities of managing multiple health conditions with particular problems such as developing physical frailty, unsteadiness when walking, and problems with managing an increasing number of medications (polypharmacy) from an earlier age than the general population.¹⁰⁰ These problems are already issues for many people with bleeding disorders as they age and are added to when they also have HIV or hepatitis C.

In more recent years advances in treatment safety and in HIV and hepatitis C treatments have had a number of positive effects for the bleeding disorders community in Australia. Most people with haemophilia now use recombinant products, which are synthetic and not at risk of infection by human diseases. With HIV a 'chronic manageable health condition' and curative hepatitis C treatments, many affected community members have been able to move beyond survival. Some have chosen to disclose their HIV status very publicly as a gesture of support to other affected community members.¹⁰¹ When they were cured of their hepatitis C, some wrote personal stories about their treatment experience and how they felt afterwards to encourage others to have treatment. They were excited by the relief from the crippling fatigue of hepatitis C, using words such as 'exhilarating'.¹⁰²

The understated comment of one young man with haemophilia highlighted just how much impact this had on their quality of life:

Having had the new treatment and being cured has also had a big impact on my quality of life and improved the quality of my leisure and personal time. I have noticed over the last few months that I have a lot more energy. I used to go to work and then go home and feel really tired, now I get home and tinker about in the shed or whatever for a couple of hours if I feel like it.¹⁰³

Although the treatments may have cleared the virus, the Australian hepatitis C clinical management guidelines note that people with cirrhosis will need to have ongoing monitoring for liver health complications such as hepatocellular carcinoma. Treatment may also be unsuccessful or unsuitable for some people with very advanced liver disease. Data on the long-term effects of the new treatments on liver health is currently being gathered.⁵¹

3.6.9 AGEING WITH MILD HAEMOPHILIA

Although the larger proportion of people with haemophilia have mild haemophilia, there are few publications that directly address ageing with mild haemophilia. A recent literature review of mild haemophilia found that the clinical issues of living with mild haemophilia had not been clearly delineated in haemophilia research studies, and as a result the impact of mild haemophilia is not well understood or addressed. It commented that further study will be very valuable, particularly as the new types of treatment for haemophilia could mean that in the future people with severe haemophilia live with sustained factor levels in the mild haemophilia range.¹⁰⁴

A 2018 European article on clinical management of mild haemophilia noted that people with mild haemophilia have a good life expectancy and those with mild haemophilia are likely to predominate in the 60 years and over age group. The guidelines described several concerns with the risk of bleeding complications in this group: older people with mild haemophilia would have had few bleeding episodes in
their lifetime, often diagnosed in adulthood, and may not understand the need to raise their bleeding disorder with other health professionals to prevent bleeding episodes with surgery or medical or dental procedures. Although they may experience less arthropathy than people with severe haemophilia, using NSAIDs to manage the joint problems that occur with ageing may also increase bleeding problems. Discussion between their haemophilia and other specialists will be very important to work out the balance between medication for their various health conditions and the likelihood of it increasing bleeding, and the need to manage health issues such as hypertension to decrease the very serious risk of intracranial haemorrhage. The authors suggested that clinics via telephone may be useful for some in this group.⁶

3.6.10 AGEING WITH VWD AND RARE BLEEDING DISORDERS

As with mild haemophilia, there is little research on ageing with a bleeding disorder that is specific to VWD or other rare bleeding disorders.

In 2011 leading European haematologists pointed out that the population of elderly people with VWD was growing due to improved medical care, and that an evidence-base on ageing with VWD needed to be developed to support clinical management guidelines. They highlighted several clinical questions. One was whether bleeding symptoms would change with age: on the one hand von Willebrand factor levels can increase with age, but studies have also shown an ageing-related increase in some symptoms such as gastrointestinal bleeding. Treatment needs may change: treatment with desmopressin may no longer be suitable for older people because of its side-effects and is not recommended for people over 70 years of age; in fact, prophylaxis may be required more often due to increased bleeding with cancer, medications or surgery. They also noted a need for research to establish whether having VWD protected against cardiovascular disease.¹⁰⁵

This was reinforced in a more recent review, with a call for more clinical trials in the older patient with VWD and

that these consider common issues of ageing such as healing rates and management of pressure ulcers. It also recommended that these older patients be encouraged to participate in national bleeding disorder registries to help understand the ageing-related complexities of VWD.¹⁰⁶

3.7 Women

The HFA women's project consultation found that many women had been treated for their bleeding disorder in the community, for example, by a general practitioner (GP) rather than a Haemophilia Treatment Centre. However, most doctors have not received training about managing bleeding disorders. As a result, many women had experienced problems with diagnosis and referral, with late diagnosis common, and had bleeding problems with surgery, medical and dental procedures, with menstruation and after childbirth. Many women also spoke about their difficulties in being 'taken seriously' by health professionals, as some of their non-haemophilia health professionals (eg, general practitioners, surgeons, dentists) didn't know that women can have bleeding disorders.⁷ This is similar to the experience of women with bleeding disorders in other developed countries such as Canada.¹⁰⁷

In Australia women with factor levels in the mild severity range were formerly described as 'symptomatic carriers' and have only recently been redefined as having 'mild haemophilia', when international definitions changed in 2014.¹⁰⁸ This shift in thinking about females with haemophilia has resulted in new questions about this population, for example, whether women develop arthropathy from joint bleeds as they age. A recent study of Swedish haemophilia carriers found that those with low factor levels had a significantly higher level of joint problems and earlier diagnosis with their first joint problem than women with normal factor levels, but did not publish age-specific results.¹⁰⁹ There remains much work to do to understand the impact of ageing on women with bleeding disorders and if and how this differs to men.

3.8 Sexuality

Several clinical reviews noted that older people with bleeding disorders may experience sexual dysfunction related to pain, problems with their joints and range of movement and concerns about causing bleeding. Medications and ageing-related health conditions can also contribute to this, along with concerns about transmitting bloodborne viruses.^{18,25,27} Haematologists from the Netherlands pointed out that satisfactory sexual expression and intimacy are essential to wellbeing for many people and should not be abandoned simply because a person is older. They recommended that the HTC team should raise this proactively, as their patients will usually be too shy to bring up the subject, and consider the range of options for managing any problems.²⁷

3.9 Mental Health

3.9.1 VULNERABILITY

Canadian research examining patient perspectives of ageing with a bleeding disorder found that many older people with bleeding disorders reported physical limitations, pain and mental exhaustion to be a major concern in their everyday lives. *'I am just tired of fighting,'* said one study participant. The participants were worried about their loss of independence. They were anxious about not being able to take care of themselves in the future because of their physical problems and whether other carers would have the expertise to provide their care safely. The researchers underlined the importance of recognizing depression in this population.²⁸ These findings are consistent with other reviews and studies, which raised concerns about quality of life and mental health in older people with bleeding disorders.^{18,25,27}

Some reviews noted that people with bleeding disorders are likely to experience the same rate of dementia as in the general population.^{18,25} A small number of

older people with bleeding disorders who also have HIV may develop a condition known as HIV-associated neurocognitive disorder (HAND) which can affect thinking and concentration.^{18,97} The incidence of dementia may nevertheless be a concern for older people with bleeding disorders, as it is estimated that nearly one in ten Australians over 65 years has dementia.¹¹⁰

3.9.2 STOICISM AND RESILIENCE

It is interesting to note that an international study of health-related quality of life in people with haemophilia found that, while their physical quality of life was significantly lower than people in the general population, their mental, emotional and social scores were similar to the general population and higher than other people with chronic health conditions. The authors speculated that this might be because they had been able to adapt to their health condition over their lifetime.⁸⁰ In contrast, the *Don't go it alone* study, a large study of life satisfaction in older Australians, found that health status was the second most important factor in life satisfaction and that those who perceived that they were in poor health displayed much lower levels of life satisfaction than those who described their health as excellent.¹¹¹

The HFA *Double Whammy* report identified a culture of stoicism among Australians with bleeding disorders. Growing up they had been encouraged to *'carry on like anybody normal'* and not to complain about their bleeding disorder. They often dealt with health issues by downplaying them or making jokes about them. *'You learn to live with haemophilia. You're born with it, you grow up with it,'* commented one community member.²⁰

An Australian study on the hepatitis C treatment experience described the self-management strategies of a participant with haemophilia as 'resilient coping': he drew on his past experience of living with haemophilia to deal with his hepatitis C treatment and took an optimistic approach to its challenges. '*With haemophilia... you tend to be a bit onwards and upwards in your approach to things,*' he explained. The authors noted that optimism and determination are acknowledged as assisting with resilient coping.¹¹² It is important to note that in the Canadian research on older patient perspectives, many had not allowed their bleeding disorder to limit them, remaining physically active, working and travelling widely. However, for some their pain and physical limitations had exhausted them, and it was at this point that they were unable to keep up their positive approach.²⁸

3.9.3 GRIEF AND LOSS

Grief and loss may occur in many ways for an older person with a bleeding disorder. They may have had to retire from work or lost their job; they may no longer be able to play sport or be physically active; they may be losing their independence.

A very significant impact is on relationships. In the HFA *Double Whammy* report, community members spoke about their ongoing sadness at having lost family and friends to HIV and hepatitis C. They may have chosen not to have children because of their bloodborne virus, or sometimes because of their haemophilia, and some described their difficulties in having a relationship as they felt they had very little to offer a partner.²⁰ UK haematologists drew attention to the narrowing social circle of the person with a bleeding disorder at this point in their life. If they then lost their spouse, family or friends, they would need extra support, both to manage their emotional health and often also to deal with the loss of their carer network.⁵³

3.10 Comprehensive care

The value of comprehensive care for people with bleeding disorders and their families has been well established.^{11,113} The literature highlights the ongoing importance of comprehensive care as people with bleeding disorders grow older, to manage both their bleeding disorder and the complications of other age-related health conditions in collaboration with their other health care providers.^{8,17,18,25,27}

Older people with bleeding disorders have expressed concern about their future care if they are frail and unable to advocate for themselves effectively in community care facilities where they are totally dependent.²⁸ The Australian haemophilia nurse and psychosocial worker groups recognised the need to educate nurses and personal care attendants in residential care facilities about bleeding disorders and in 2018 published an information booklet and fact sheet targeted at care staff that can be used in conjunction with individual education from the HTC.^{114,115}

Managing their ageing-related health conditions will also require older people with bleeding disorders to have treatment and care in the community, for example, with a GP. A 2016 Australian study considered how often local men with haemophilia attended a GP to undertake their preventive health checks associated with ageing. Around 90% of the men had a GP and two-thirds had seen their GP in the last 6 months, with two-thirds seeing the same GP for over 2 years. However, although they often knew about the preventive health checks for their age group, this did not necessarily mean that they undertook the recommended health check and only one-third actively visited their GP for a health check. The study highlighted the need for stronger integration between HTC and community-based services and proposed that HTCs take opportunities to educate their patients about working with their GP to access health checks appropriate to their age.¹¹⁶

With its multidisciplinary team and regular communication with older people with bleeding disorders, the HTC is also a good environment to trial innovative programs around ageing with a bleeding disorder. One example was a 2017 Italian project, which combined a physiotherapistled exercise-based rehabilitation program with an occupational therapy program on skills and strategies to overcome problems with activities of daily life for older people with haemophilia.¹¹⁷

3.11 Social connection

The effect of social relationships and peer support on physical and mental health and wellbeing has been explored widely.

The *Don't go it alone* study found that the highest factor in the life satisfaction of older Australians was their social wellbeing, and that life satisfaction was reduced in people who often or occasionally experienced lack of companionship and loneliness.¹¹¹

Peer-based support is recognised as a way for people with chronic health conditions to decrease loneliness and feelings of difference, while improving their competence in self-management and acceptance of their health condition.^{118,119} Peer support groups can also be effective in improving self-care and complementing health care in people with haemophilia including those living in remote and regional areas.¹²⁰ Australian state and territory Haemophilia Foundations provide a range of peer support activities, but also acknowledge the importance of strategies to engage the bleeding disorders community in the activities. Their more successful strategies included having a focus to activities, such as a popular topic or invited speaker for a meeting, personal invitations to attend the meeting and making it a good social experience.¹²¹

Some new Australian studies are also considering the potential for peer activities using digital technology to provide support and education, particularly for those who have limited mobility or are geographically isolated. This includes interventions, such as 'befriending', where volunteers keep regular contact with individuals: this may be face-to-face, by telephone or using VOIP technology such as Skype.¹²²

3.12 Carers

While there have been a number of studies that have investigated the impact of caring for a child with haemophilia on parents, there has been little work on the needs of partners and family of older people with bleeding disorders. Carers are an important part of the support network for older people with bleeding disorders and research to understand their experience and what could help them will be essential for the health and wellbeing of the bleeding disorders community into the future.

3.13 Finances

Financial security plays an important role in supporting the wellbeing of many Australians. The consultation for the HFA hepatitis C needs assessment highlighted that establishing yourself early financially was a key aspect of future planning for young men with severe haemophilia in earlier generations – that they *'only had so many years to work and try to get a good financial background happening'*.⁹⁹

For many Australians, financial security involves owning your own home. A 2019 report on home ownership and rental from the Australian Institute of Health and Welfare commented, *'home ownership continues to be a widely held aspiration in Australia, providing owners with security of housing tenure and long–term social and economic benefits'.* The report noted that 67% of Australians were home-owners:

- 32% without a mortgage
- 35% with a mortgage.¹²³

An important finding of the *Don't go it alone* study of life satisfaction in older Australians was that it was the perceived financial situation that made the most difference to older people: if they were comfortable with their current financial situation, this was associated with greater life satisfaction.¹¹¹

4. Methodology

The HFA Getting Older needs assessment was a 12 month project to identify, understand and respond to the range of needs Australian people with bleeding disorders may have as they grow older, and help find appropriate solutions for them and their partner, family or carers.

Both qualitative and quantitative data was collected relating to:

- Lived experience and preferences of older people with bleeding disorders and their partners, family or carers
- Professional expertise of expert health professionals, researchers and other relevant agencies.

4.1 Scoping phase

As an initial scoping phase, HFA conducted some preliminary interviews and discussions with a sample of the range of stakeholders and members of the Advisory Group. A set of open-ended questions for interviews was tested and refined. HFA also developed a table of emerging issues, constructed from the data arising from interviews, and this formed the basis of further consultation with Haemophilia Treatment Centre health professionals and discussion with the HFA Getting Older Project Advisory Group.

4.2 National consultation

The scoping phase was followed by more in-depth national consultation, consisting of:

- Interviews with affected community members, partners and family members
- Interviews with health professionals, Foundation staff, and other organisations with a common interest

- Community forums
- The HFA Getting Older Community Survey
- Age-related data from the PROBE Australia study
- Further information and comment from the HFA Getting Older Project Advisory Group
- Responses from state and territory Haemophilia
 Foundations about priorities for their older community members and their partners/family.

4.3 Interviews

The HFA Getting Older Project Officer conducted face-toface and telephone interviews nationally with:

- older people with bleeding disorders
- partners and family members
- Haemophilia Treatment Centre health professionals
- National and state/territory Foundation staff, other organisations with a common interest in chronic health conditions, and a peer support worker.

Interviews were conducted during March 2019 to January 2020 with participants from the Australian Capital Territory, New South Wales, Queensland, South Australia, Victoria and Western Australia.

The interviews used interview question schedules developed during the scoping phase and tailored for each group.

- Questions for community members covered aspirations and plans for getting older, current and future concerns, personal and external supports, any HIV- or hepatitis C-specific issues, what would help both individual and their partner/family and how they could help others.
- Questions for health professionals, Foundations and other organisations asked at what age a person with a bleeding disorder might be said to be 'ageing' and what emerging issues they were seeing in relation to getting older.

Interviews were transcribed and analysed by theme.

4.4 Community forums

Bleeding disorder community forums were conducted in the Australian Capital Territory (ACT) and Queensland (QLD) in June and July 2019. Older people with bleeding disorders and their partners and family were invited to take part, with forum discussion activities over a casual meal. The forums were conducted by the HFA Getting Older Project Officer and supported by the local haemophilia social worker or counsellor and the local Haemophilia Foundation. Questions were based on a simplified version of the community member interview schedule.

The forums were well-attended:

- 10 community members participated in the ACT
- 18 community members participated in QLD.

Discussions from the forums were recorded, transcribed and analysed by theme.

4.5 Getting Older Community Survey

The **HFA Getting Older Community Survey** was an anonymous 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, using the SurveyMonkey platform.

The survey was developed specifically as a consultation tool for the HFA Getting Older needs assessment. It had been noted that most of the interviews and community forums were conducted with community members who were well-connected to HFA or their local Foundation. This survey was intended to reach a broader range of bleeding disorders community members nationally to collect a wider sample of information and strengthen the evidence base. Questions covered:

- Work/retirement, finances, aspirations and planning for the future, support and social connectedness
- Needs and preferences around information and education, peer support, computer use and online and social media platforms.

Ethics approval was received through the Bellberry Human Research Ethics Committee on 30 October 2019.

HFA did not have ethics approval to recruit participants through Haemophilia Treatment Centres and so community networks were used to distribute the survey. The intention was to reach those who are in outer suburban and regional and rural areas, those with other bleeding disorders as well as haemophilia, and those less engaged as well as those who are the most active in the local haemophilia foundations. Information on TTY and interpreting services and an invitation to contact the Getting Older Project Officer to discuss help with completing the survey were provided in the participant information sheet to encourage independent completion of the survey.

The survey was mailed to community members on HFA and local Foundation mailing lists with a covering letter from the HFA President and in some cases from the local Foundation President. The online version was promoted through HFA and local Foundation e-news, newsletters and social media and on the HFA website to reach those who are active online and may not participate regularly in face-to-face foundation activities.

Partners, families and friends were also targeted with the survey. Bleeding disorders occur in families and HFA experience is that some members of a family or a partner or friend may be more connected to a haemophilia foundation than the person with the bleeding disorder and will pass on communications to them, provide peer education to them and advocate for them. Survey promotion aimed to use a 'snowball sampling' technique, using this group to reach those who are less connected and also encouraging them to complete the survey themselves.

Surveys were distributed and responses collected during November and December 2019.

4.6 **PROBE** Australia study

Age-related data from the **PROBE (Patient Reported Outcomes Burdens and Experiences) Australia study** were also analysed to inform the needs assessment. This 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. In Australia participation is fully anonymized. It is available online and in print.

HFA leads the PROBE study in Australia and commenced implementation of the 'real-world' data collection phase in May 2019. As with the community survey, the PROBE questionnaire was promoted and distributed through HFA and local Foundation communication networks. Only a small number of print copies were distributed, usually on request. It was also promoted at community events, such as camps and the national bleeding disorders conference in October 2019.

From January 2020 de-identified Australia 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 were sourced from the February 2020 update.

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.

4.7 Privacy

As the consultation for the Getting Older needs assessment asked sensitive questions about individuals' personal health information, relationships and financial status, privacy considerations were very high for HFA. Moreover, apart from discrimination related to their haemophilia, many in the bleeding disorders community in this age group have experienced a traumatic level of discrimination relating to the HIV and hepatitis C epidemics and are extremely private and careful about their personal health information. An important part of the information provided to community members before participating covered how their privacy would be protected.

Interviewees were consented for participation and their consent forms, interview recordings and transcripts stored in password-protected and locked storage on the secure HFA server or at the HFA office. Data from the interviews was de-identified before analysis.

Both the Getting Older Community Survey and the PROBE Australia study were developed to enable respondents to participate anonymously. Survey questions did not ask for identifying information. Print surveys were returned in uncoded reply paid envelopes and stored in locked storage at the HFA office. The Community Survey and PROBE study both used completely anonymized survey platforms, where not even the IP address was collected. We were unaware of any identifying information in the survey responses, but as a precaution any data that could potentially be identifying was de-identified before analysis.

4.8 Limitations

As HFA did not have ethics approval to use HTC mailing lists for distribution of the Getting Older Community Survey and the PROBE study, 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. 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.

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
 Good health and quality of life Retaining mobility and independence Able to pursue personal interests 	 Good health and quality of life Access to appropriate treatment and care Travel
• Travel	Financial security
 Spending time with friends and family 	 Staying active and independent
Retiring; or continuing to work, but reduced hours	Using their talents and skills
Contributing to society	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	
Losing independence	• Pain	
 Mobility, joint and dexterity problems, pain 	Joint, mobility, dexterity problems	
 Increased problems with mild disorders, VWD 	Waiting lists for joint replacements	
 Difficulties with treatment – infusing into a vein, 	Impact of bleeding disorder on working	
remembering to infuse, accessing nurse to infuse	Transport to HTC	
 Developing dementia in the future 	Financial security into the future because of limited	
 Impact of bleeding disorder on working 	working history and problems with sustaining work	
Health care providers outside HTC who don't liaise	Losing independence	
with HTC re bleeding disorder; don't understand	Lack of expertise with bleeding disorders in the	
bleeding disorders	aged care sector	
 Nursing homes unable to provide adequate care 	Appropriate housing for mobility problems	
Financial security into the future	What would happen if partner becomes unwell	
No future planning	Out-of-pocket care costs	
Depression and anxiety	 No long-term planning 	
Inability to support others		
 Isolation if do not have a partner 		

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

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Older people with bleeding disorders responses	Partner/family responses
Help to remain mobile, active, independent	New treatments, prophylaxis
Assistance with infusions	Assistance with infusions
 New treatments for fewer infusions, subcutaneous injection, better health outcomes 	 HTC liaison to provide care locally Transport services
Better pain relief	 Assistance to be able to exercise, stay active
Transport services	Assistance to continue working
• Work: reducing work, supportive employer, disability- friendly workplace, education for employers	 Education for health care providers in the community, aged care services
Education for health care providers outside the HTC	• Education on getting older with a bleeding disorder for
Acknowledgement of person's own expertise about	person with bleeding disorder
their health, resilience	Information on support services available
Opportunity to pursue personal interests	Home help and care services
Independent living aids	• Support: family, friends, neighbours, bleeding disorders
Support: family, friends, neighbours, local Council/aged	community, pets
care services, peer support	Future planning
Counselling	Sharing their strengths: optimism, resilience,
 Easer access to or eligibility for NDIS or aged care for those under 65 years of age 	individual skills

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

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Health professional responses	Foundation responses		
 Good co-ordinated comprehensive care for the range of their needs 	 Encourage closer relationship between person, GP and HTC 		
Comprehensive care delivery options to reduce travel	Options for remote care, eg telehealth		
Vein care and infusion education	Collaboration between Foundation and HTC		
 Access to new treatments: extended half-life, subcutaneous; higher uptake of prophylaxis 	in developing innovative servicesInformation and education for aged care facilities,		
Pain management, education about pain	including individual needs		
 Good liaison and communication with other health care providers 	 Targeted programs for affected community engagement, connection and support, both through 		
Working with a consistent GP	peer support and with the wider community		
Education for other care providers	Individualised outreach		
 Patient education about ageing with a bleeding disorder and need for compliance 	 Education resources about getting older with a bleeding disorder and future planning 		
Staying active, mobile	Online and print communications and education		
• Exercise programs, falls and balance classes, corrective footwear	 More research into complications in older women 		
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			

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

5.4.2 ABOUT PARTNERS AND CARERS

Table 10: Challenges and concerns of partners/carers

Older people with bleeding disorders responses	Partner/family responses	
 Physical challenges of caring Depression, anxiety Understanding ageing with a bleeding disorder Time to take care of their own health and needs 	 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	
 Burden of care – physical, co-ordinating services, taking person to appointments, emotional/psychological Understanding issues of ageing with a bleeding disorder, services available 	 Burden of care Transport Lack of information about ageing with a bleeding disorder and services available 	

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Table 11: What will help partners/family

Older people with bleeding disorders responses	Partner/family responses
 Home help services Home care services for the person with the bleeding disorder Education about ageing with a bleeding disorder Support 	 Transport services Home help services Support Someone to talk to, peer support Reducing challenges that cause stress and anxiety
Health professional responses	Foundation responses
 Education about ageing with a bleeding disorder Information about services available Assistance to access services Someone to talk to, peer support Respite 	 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

Please select the best description of your current work or study situation



- 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

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

What are your main sources of income? Please select all that apply.

Answer Choices	Respo	nses
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

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

Have you had any of the following? Tick all that apply

• 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	Response	S
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.





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

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/familyHow do you access online information? Please choose the answers that apply to you

Answer Choices	Responses				
	Peopl bleeding	e with disorders	Partner	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

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How would you prefer to get this information?



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
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	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'.

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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	

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

	Male	Female	Total
Total (N=)	<17	65	<83
Normal	<5	36	<41
l 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	Total Factor level below normal	
Total N =	29	28	57	49	21	52

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

	Men v haemo MW	with philia /H	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
		1				1		

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Table 21: Treatment regimen

	Men with h ≥ 45 yrs By sev	aemophilia 5 MWH verity	Women with haemophilia ≥ 45 yrs WWH	
	Mild	Severe/ moderate	Factor level below normal	Total
Total N =	29	28	21	3 time
Prophylaxis	2	12	0	2 time
Periodic prophylaxis	2	1	4	Once p
On demand	23	13	13	Once p
No treatment	2	2	4	Not re

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 join	t			
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	I	
Yes	2	11	13	1
No	26	15	41	19
I don't know	1	1	2	1
Not reported	-	1	1	-
			1	

		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	

Table 24: Target joints – range of motion

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



Total number = 28

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Not reported

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.



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.



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 of 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

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Total number = 21



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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.

6. Discussion

6.1 Ageing and getting older

The language around getting older can make a considerable difference to how people with bleeding disorders perceive themselves.

At the beginning of the consultation for this needs assessment, HFA asked older community members about how to engage their peers in consultation about 'ageing'. Older people with bleeding disorders commented that they did not identify with the term 'ageing' and thought it was negative and discriminatory and put them in an 'old person' box where they did not belong. A social worker noted:

'We talked at camp recently and it was really interesting. "No one is ageing. We are all getting older." The word "ageing" is not a good word. They talk about others; "I am not getting old". That is how we are wired, because if you are seen as older or frail, you are seen as broken in our society. Our whole community is wired as young and beautiful – that is what we must aspire to.'

After some discussion, HFA changed the terminology for the needs assessment, so that the 'Ageing Project' became the 'Getting Older Project'.

6.1.1 'EARLY AGEING'

During the scoping for the needs assessment, 'early ageing' was identified as an issue for many people with bleeding disorders. However, younger people with bleeding disorders thought this term was problematic: that their physical issues were more related to disability than being an older person.

One younger man with haemophilia outlined the dilemma facing younger people with joint and muscle damage from their bleeding disorder. He could see that explaining this damage by comparing it to the kind of joint damage you might see with ageing helped others to understand it. At the same time, he pointed out how this muddied the understanding of the issues specific to younger people with haemophilia and the complications arising from it.

"Ageing" is a word, like that we have an "ageing population". The word "ageing" misses the mark. It feels mainstream. Everyone ages eventually. I don't think we feel mainstream. I think we feel like we are a very unique group with very unique needs and experiences... One thing that I can say is that the results of haemophilia, joint deterioration and bleeds into the joints, can look like early ageing. So the younger person with haemophilia effectively has the mobility of an older person.'

This dilemma around the language of ageing and being 'old' was also acknowledged by a physiotherapist:

'We've got an 18-year-old with joint damage that we would expect to see in the general community in an 80-year-old. So they are not ageing but their joints are [like] old joints, they are deteriorating because of bleeding.'

WHAT WILL HELP?

It would be valuable to give careful consideration to the use of the words 'ageing' and 'old' when discussing getting older with a bleeding disorder and the disability in younger people related to the complications of their bleeding disorder.

6.1.2 HOW OLD IS AN 'OLDER PERSON'?

When is a person with a bleeding disorder 'ageing' or an 'older person'? The needs assessment consultation highlighted that this can vary widely between individuals.
Haemophilia Foundation and peer support workers and the health professionals at Haemophilia Treatment Centres were asked at interview at what age a person with a bleeding disorder is 'ageing'. Their answers were consistent: while they noted that the Australian Government My Aged Care portal generally defines 'an older Australian' as 65 years or older³⁰, 'ageing' can be both younger or older for a person with a bleeding disorder. With health challenges such as joint and muscle damage and bloodborne viruses, like HIV or hepatitis C, they could see 'early ageing' occurring for some people from their 40s onwards, and in people with inhibitors, where their treatment is not effective, even as young as their late teens. However, other people with bleeding disorders were functioning well, and were active and independent into their 70s and 80s, particularly people with mild disorders.

Foundations and health professionals also consistently associated 'early ageing' with inadequate treatment during the childhood years. They pointed out that the generation aged over 40 years had grown up not having prophylaxis factor replacement therapy or with insufficient clotting factor treatment to stop bleeds and this had resulted in significant joint and muscle damage, particularly for people with severe haemophilia.

6.1.3 WHAT DEFINES 'AGEING'?

This definition of 'ageing' was related to physical and mental functioning rather than a chronological age. One psychosocial worker explained,

'For me the ageing process starts when people are starting to need support from others, or they feel that they can't manage to do things that they have always done in their life. That may be the physical things or cognitive things.'

For physiotherapists, 'ageing' was closely related to the physical impact of joint damage. It could start 20 years earlier or more in the person with haemophilia than in the general community. Another psychosocial worker commented that people with haemophilia had created phrases such as 'the haemophilia shuffle', which they used to explain how they could identify the disability associated with early ageing in themselves and others.

The workers also associated 'ageing' with a state of mind. They noted that some elderly people with bleeding disorders could be engaging meaningfully with their world, had a strong social network, were proactive in managing their health care and treatment needs and were thriving. Others were 'not looking after themselves' and were not following up their regular health checks. Some might be struggling with grief and loss. As one nurse commented,

'Some of the older fellows have planned for their future, thinking that their partner is going to be looking after them and then their partner is suddenly gone. No one wants to plan for that. Preparing different options to what they had in mind is sad as well.'

6.2 Aspirations and goals

HFA's vision is for 'active, independent and fulfilling lives for people in our bleeding disorders community' – but what does this look like for older people with bleeding disorders? Understanding the aspirations and goals of older people with bleeding disorders is an important first step in achieving this.

WHO's *World report on ageing and health* points out that a person's goals, priorities and what motivates them change as they grow older. Some changes may be a way of dealing with the loss of physical functioning and social roles they held previously as well as the loss of close personal relationships and social networks. WHO also notes that other changes reflect an 'ongoing psychological development in older age': for some this involves moving away from materialistic to more spiritual perspectives, but for many this is related to developing new roles and viewpoints and a period in their life where they have a better sense of wellbeing.³²

In both the interviews and the Getting Older Community Survey, older people with bleeding disorders were asked about their aspirations and goals as they grew older. Their partners and families were also asked what aspirations they had for the person with a bleeding disorder, and their responses often related to a future they would share together.

Most pictured themselves as actively involved in their life and their future. For many this involved participating in and contributing to the community or their family in some way. In psychological literature, this optimism and use of social networks is associated with 'resilient coping'.¹¹² For others, however, there was a sense of being alone, which made maintaining optimism and resilience more challenging.

6.2.1 GOOD HEALTH AND INDEPENDENCE

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.'

'As I get older I hope to have a comfortable life. Still having quality of life. As I said I am young at heart.'

'I hope to maintain a good standard of health, improve my health and to be worthwhile in society.'

For partners and family, to remain healthy was important to sharing a future together.

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

For some individuals, the lack of a partner reduced their goals for the future.

'I will be probably be a bit of a unique case. I do live alone. I don't have a partner. So my only hope when I get older is to continue to enjoy good health.'

6.2.2 TRAVEL

Being well enough 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.'

'When I grow older, I want to be fit enough to do a few trips and active enough to go on outings and be with our family.'

6.2.3 PURSUING PERSONAL INTERESTS

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. This reflected a change in their priorities, from paid or domestic work, to being able to give more time to their recreational interests. '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.'

'Have more time for reading and for my artwork. I would like to spend less time on my domestic tasks. That's the hope for the future.'

For some, the vision of the future involved retirement or reducing work, while remaining comfortable financially. For others, while they were hoping to stop or reduce work, they saw their social role evolving and wanted to stay involved in the community and continue to work or contribute as a volunteer.

'In general, I hope for things like financial security. Being able work long into older age. Staggered hours.'

'To be able to choose how much I work after 60. Then to live an active and enjoyable retirement in good physical condition.'

'To get out more. Be more social. Try to contribute more to the community. Experience new things. Enjoy life.'

'Golf, travel, spend time with family and stay involved with the industry that I worked in (a few hours each week).

'The word retire doesn't mean anything to me. I rather not retire and just keep doing things that are worthwhile, whatever that may be.'

Partners were sometimes more prepared to acknowledge the value of what older people with bleeding disorders could contribute.

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

6.2.4 RELATIONSHIPS WITH FAMILY AND FRIENDS

Looking to their future, some people reflected on the importance of family and friends to provide a network of support and comfort into their old age. Many who were parents to adult children saw a role for themselves helping with care for their grandchildren.

'Enjoyment of my grandchildren. The relationships that I do have with people. They will be comforting and reassuring in my lucky years, however few they may be or how many.'

'And for me it's a sense of family. I think the Royal Commission into Aged Care really show how bad it can be! For me it is important to think how will I live in my old age, how will I have supports around me and the social networks and family around me. So you don't lose that.'

'I would like to be able to be more active with the grandkids, to be able to garden, shop, gym and bike ride with a minimum of pain being generated.'

6.2.5 TAKING LIFE AS IT COMES

Some were more philosophical about letting life unfold rather than worrying about or planning for their future.

'I just get up every day and do what I've got to do and get on with life. I don't think about getting older. I am 58 years old now. I don't worry about it. If it happens it happens.'

6.2.6 BARRIERS TO ACHIEVING ASPIRATIONS

Health concerns were perceived as the greatest barrier to achieving the aspirations of people with bleeding disorders who are getting older.

6.3 When stoicism isn't enough

HFA's consultation for the Double Whammy hepatitis C needs assessment highlighted a culture of stoicism among people with bleeding disorders. This was prominent in the generations who had grown up before prophylaxis treatment and recombinant factor products were readily available.²⁰ Several of the health professionals from Haemophilia Treatment Centres commented on the older generation's resilience and determination to overcome challenges. As one psychosocial worker said,

'The haemophilia community have been so resilient and stoic; they continue that one into their ageing as well. So they manage and push through a lot of things when other people need extra help.'

For this older generation, there was a sense of a tipping point where the health conditions of ageing combined with their bleeding disorder could prove too much of a challenge for them to manage, even with their usual determination and positive approach. Some voiced their concern about this in the interviews, for example saying,

'I always had to deal with issues all my life, but I deal with them. If I lose that ability, I feel that's the place I am not really happy about to go to.'

There was some similarity between their comments and a Canadian research study on the perspectives of older people with bleeding disorders, where their pain and physical limitations had exhausted their ability to stay positive.²⁸

6.4 Living with multiple health conditions

When asked about their greatest concerns at present, the most prominent worries for older people with bleeding disorders were the complications of their bleeding disorder and the challenges of living with multiple health issues as they aged. This could impact on many aspects of their life.

Some were unsure how much their health issues were related to their bleeding disorder and how much to ageing. Others were only too conscious of the impact of the diseases of ageing, when they were already struggling with the joint and pain problems from their bleeding disorder.

'It's still murky to know what it is, depending on how your body is.'

'I am hoping to slow the decline in my health. The last four years have seen me declining a lot, having several more medical conditions I haven't had before.'

'At times it's hard. The only thing that stops me from doing things is my physical being – that being hip replacements and lately I have a heart condition. I am finding with this heart condition, it's more doing shopping. I am finding it little bit more difficult.'

'I have learned that things change as you get older and they are worsened by the effects of having a bleeding disorder.'

Health professionals recognized the burden of the increasing number of health conditions as their patients aged. One haematologist commented,

'Lot of patients have got complex multi-system disorders. This has an impact on their quality of life, which is compounded by the bleeding disorder, which needs regular treatment.' Health professionals also considered that having multiple health conditions had an impact on ageing and the associated needs. As a psychosocial worker noted,

'The issue really is around what other comorbidities they have as well, haemophilia and a heart condition and an inhibitor and something else going on. For me that's where I see differences. Comorbidities impact on your health and take a greater toll on your ability to manage. Comorbidities push the ageing needs.'

6.5 Mild conditions

There has been little research on the impact of ageing on mild conditions such as mild haemophilia and VWD. However, health professionals at the HTCs reported that they were seeing their patients with mild conditions much more often as they aged. These patients were presenting to the HTC with complications such as coronary artery disease and needing liaison and advice about anticoagulant treatments or requiring preventive treatment to cover for surgery and medical procedures – or dealing with prolonged bleeding if the health care provider outside the HTC had not commenced preventive treatment in liaison with the HTC before administering treatment or undertaking an invasive procedure. Some older people with mild haemophilia were also presenting with joint problems.

Most people with bleeding disorders in Australia have mild conditions and data from the Australian Bleeding Disorders Registry highlights that people with mild conditions are currently the largest proportion of those surviving into old age. They are likely to experience fewer bleeding episodes in their lifetime and have less contact with an HTC. Some receive treatment for their bleeding disorder in the community instead, from general practitioners and private haematologists.⁴ As a result they may have had fewer opportunities for HTC review and education. Some are also not diagnosed until later in life and may already have had a number of unrecognised bleeding episodes. There is much still to be understood about the effect of ageing on VWD, including whether the rising factor levels with Type 1 decrease bleeding episodes as the person ages.⁶⁹ The clinicians in the HFA Getting Older Project Advisory Group noted that they would expect to see similar issues in VWD as in haemophilia in relation to ageing, with the exception of joint problems in mild forms of VWD. People with VWD who responded to the Getting Older Community Survey commented that they were experiencing more problems with their bleeding disorder as they grew older:

'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.'

This lack of engagement with the HTC in mild haemophilia and VWD raises a significant concern about the impact it may have on the health and wellbeing of older people with mild disorders at a point when they will require more medical and surgical interventions and care for their joint problems. It also highlights the potential for breakdown in the communication flow between the HTC and medical and surgical health care providers in the community.

6.6 The rarer bleeding disorders

A small number of older people with rare clotting factor deficiencies, inherited platelet disorders and acquired haemophilia responded to the Getting Older Community Survey. Their responses were consistent with other older people with bleeding disorders, although they focused more on the health issues specific to their bleeding disorder. Those with rare clotting factor deficiencies and acquired haemophilia noted their goals of improving health, fitness and pain management, but were less likely to comment on joint and mobility problems than older people with haemophilia who responded to the survey. Those with inherited platelet function disorders also pointed to the impact of anaemia on their working life.

However, their comments also highlighted the clinical management issues related to having a rarer bleeding disorder. For example, several highlighted difficulties with having their bleeding disorder taken seriously by the health professionals who provided their other care outside of the HTC.

There is increasing recognition of the rarer bleeding disorders at an international level and this may support more research into the area and the development of evidence-based education materials. Addressing the knowledge base of the wider group of health professionals who provide their care will be important for the health and wellbeing of older people with rarer bleeding disorders into the future.



WHAT WILL HELP?

Connection with an HTC

Encouraging people with mild bleeding disorders to connect to an HTC is an important way to ensure they have access to best practice treatment and care and the latest information about bleeding disorders as they grow older. This may also involve engaging with their general practitioner or other clinicians in the community to ensure the person has a referral to the HTC and that ongoing comprehensive care can take place. This will also assist with integrating their care for their complications and preventing unnecessary bleeding episodes.

Further research

Further research to understand the impact of ageing in mild conditions, VWD and the rarer bleeding disorders will be valuable to support specialised treatment, care and support into the future.

One aspect of connecting to an HTC is the use of the **ABDR** to collect clinical data. This would be an effective way to aggregate evidence about the impact of ageing on people with mild disorders, VWD and the rarer bleeding disorders and to study the outcomes of particular treatments and care programs. Encouraging all people with bleeding disorders to participate in the ABDR will be imperative to improving knowledge, treatment and care.

The **PROBE study** has been another effective way of gathering evidence about the impact of haemophilia and the related health-outcomes, from the perspective of the person with haemophilia. Promoting the PROBE Australia study to people with haemophilia will increase the evidence base about people with mild haemophilia in comparison to those with moderate and severe haemophilia. There has also been discussion at an international level about extending PROBE to other bleeding disorders, such as VWD, and Australia's proactive support for this work will be required for us to enable a similar collection of data in VWD and other rare bleeding disorders.

Community surveys targeted at people with mild haemophilia, VWD and/or other rare bleeding disorders could also be another tool for collecting information about the impact of ageing on people with these health conditions and the health and quality of life outcomes that they report.

Education

It will be important to include evidence-based information about ageing with these conditions in both education for the community and for health professionals.

6.7 Costs of delayed or inadequate treatment

6.7.1 PROPHYLAXIS AND ADHERENCE

The aim of prophylaxis is to keep factor levels high enough to prevent bleeding episodes, and treatment regimens are individualised to achieve this.⁸ When the individual does not adhere strictly to their treatment regimen, their factor trough levels will drop and this is associated with experiencing more bleeds, further joint deterioration, pain and other complications.¹²⁴

In the Australian prophylaxis study, leading Australian haematologists had expressed their concern about the low uptake of prophylaxis in adults, particularly those aged 60 years and over.⁵⁹ In the interviews nurses commented that some older people with haemophilia were 'not keen on prophylaxis': they had difficulty organising themselves to manage the 2-4 infusions required per week with prophylaxis on standard half-life products and worried about injecting themselves: 'organising to do prophylaxis on the whole is difficult, and again there is the anxiety, pain that comes with an infusion.' Prophylaxis with standard products could add to their stress levels and sense of being overwhelmed by their health conditions. However, if they were not adherent to their regimen or preferred on-demand treatment, this could leave them open to more health problems and complications.

6.7.2 TIMELY TREATMENT

Nurses and psychosocial workers were particularly concerned about health complications for older people who were less engaged with the HTC: people with mild or rare disorders, who have fewer bleeding episodes and require specialised treatment for their bleeding disorder less often, or others who for various personal reasons did not connect as often with the HTC. This could mean that they did not realise they needed to organize preventive treatment to cover surgery or did not contact the hospital for treatment until a bleeding episode was well advanced, and as a result of the delayed treatment, bleeding complications could be worse.

'Those that are less engaged, those that care less, or those that have problems less tend to have larger problems when they occur. They don't call the HTC, they don't call their doctor, they don't call the Emergency Department.'

'The lack of timeliness in treatments amplifies the problems they are presenting with. That bothers me.'

Partners also expressed their concern about the cumulative impact on older person with a bleeding disorder if they did not take care of all aspects of their health:

'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!)'

WHAT WILL HELP?

Education and support

HTC health professionals highlighted the need to educate people with bleeding disorders about the importance of adhering to treatment, attending their regular reviews and seeking treatment early.

Education strategies would need to be innovative to reach the various target groups and could perhaps demonstrate the health problems that are caused by missed or delayed treatment and the value of recording treatments and bleeds.

Nurses also suggested 'value-adding' to clinical reviews, for example, with referrals to general practitioners (GPs) or other mainstream services in relation to their patients' specific issues.

Target groups include:

- People with mild conditions and rare clotting factor deficiencies who do not usually engage with the HTC regularly
- Young people on prophylaxis to prevent future joint and muscle complications
- People with severe disorders who for various reasons do not connect regularly with the HTC.

The promise of new treatments

Both community members and health professionals commented on the potential of newer and emerging treatments to solve some of the treatment issues for older people with haemophilia. In particular, they mentioned extended half-life (EHL) factor products, treatment products that are injected subcutaneously rather than infused into a vein, and gene therapy. These products are administered less often and studies indicate they may be more effective than standard half-life factor products.^{60,61} In the case of gene therapy, a single course of treatment could mean that the person has very few or no breakthrough bleeding episodes.

- Treating less often would assist the older person to adhere to their treatment regimen more easily and make prophylaxis more attractive or workable
- It would also make infusion by a partner or carer or an external provider such as a GP or a community nurse more viable
- Subcutaneous treatments would be particularly beneficial for:
 - o older people with dexterity or vein issues who have difficulty infusing into a vein
 - where the older person has dementia and may require a carer to administer the treatment and may potentially be distressed by an infusion
 - and where nurses with expertise in infusions are not easily available, for example, in a residential aged care facility or a home environment.

'Having to treat less could help. Getting the half-life products might reduce having to treat from every 3 or 4 days, but with the subcutaneous product I could treat once a month. Accessing veins will become an issue the older you get, also with my elbow getting worse – and I think about getting dementia or something like that.'

'I am keen to see the long acting factor coming. That will be life changing.' Nurses noted the value of these products for encouraging the uptake of prophylaxis in older people with haemophilia:

'There is the benefit of being on prophylaxis, which with standard product is good, but the benefit of being on an EHL and also being on prophylaxis is even better.'

'The impact of EHLs on patients particularly on haemophilia B patients has been 99% positive. This is the best thing that has happened to them and they have never had a bleed again. Prophylaxis treatment is tedious for patients.'

'The impact of prophylaxis is encouraging. Even people who were never brought up with prophylaxis are encouraged to do prophylaxis or continue to do prophylaxis. Ok their joints are bad, but even EHLs are much better than taking 4 to 5 injections per week.'

'Subcutaneous injections do make much difference to life – two-weekly, monthly injections, not into veins.'

6.8 Physical functioning and quality of life

6.8.1 LOSS OF INDEPENDENCE

Both community members and health professionals described the loss of independence that could come with ageing and the increasing complexity of health conditions as a major challenge for the older person with a bleeding disorder. This was heightened because so many had worked very hard over their lifetime to maintain their independence in spite of the disability from joint and muscle damage. Memory loss, increasing frailty and injuries relating to falls were identified as particular challenges. 'The thought of me losing my independence is not something that I look forward to.'

'I have a number of disabilities that I have to cope with every day. I walk funny, I do all that stuff, but it doesn't bother me. I parked my car and walked into this office and I am very happy. If I lose that ability, I don't know whether I will be so happy.'

'I am worried that my arthritis will restrict what I could do independently. So, I could go to a nursing home younger than I would like to go.'

A psychosocial worker highlighted that this loss of independence could prevent the social interaction and activity so necessary to resilience:

'They can't take part in the community activities other people may have. For example, one was bound to his house as he couldn't get in and out of his car, because his joints didn't move. So, he was trapped with a lot of pain and the physical side of it as he could not get out.'

6.8.3 JOINTS AND MUSCLES

Joint and muscle damage related to bleeding episodes over a lifetime was often raised as an issue. It was recognised by all as a very important factor in the quality of life and physical functioning of many older people with bleeding disorders, particularly those with haemophilia.

A nurse explained:

'When it comes to pain management and declining mobility, we start to see them much earlier on than in the general population. Haemarthrosis is the issue. Rather than seeing normal arthritic changes, we are seeing degradation due to multiple bleeds within their joints.' By the time they reached their senior years, some people with severe disorders had developed a number of target joints prone to bleeds, which caused pain and stiffness and restricted their movement. This could also impact on their mood, and memory loss could compound their problems.

'I've had haemophilia arthropathy since I was 9 years old. It started in my ankles and moved to my elbows. As I got older, it became more severe and more extensive. It restricts my movement, my dexterity, my range of movement and how long I can do things.'

'I have target regions in certain joints. My left elbow, my right ankle. Over the years they have become worse, in terms of repeated bleeding especially in joints in my 20s and 30s. Now I am left with accelerated arthritis and limited movement. It's really painful and that can change moods and the ability to work. Because pain is really tiring.'

'My joints have been a bit of a problem when getting older. I've had a knee and hip replacement and both my ankles are fused. I have problems with memory, misplacing the odd thing, can't remember people's names. I struggle with depression a bit, mood swings.'

In some cases, they had joint replacements or ankle fusions, which decreased the pain and sometimes improved their mobility. Others were concerned about the prospect of joint surgery, avoiding it because of the long waiting list and substantial recovery time. An Australian study noted that people with haemophilia often had joint replacements at a younger age than the general population.⁷⁹ If they had already had joint replacement surgery, some were now concerned about their options for the future. 'I started to lose my joint movements in my late teens. Because I had the operations they are better now. I do 4 to 5 kilometres every day now, with my dog. I feel I am in a better stage now, but there is bit of arthritis there.'

'I had my left knee replaced 27 years ago. That's been the best thing that ever happened to me, healthwise.'

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

'I have two prosthetic knees. I worry that if one of them wears out my options are limited. I think the state of knowledge at the moment is that you either have to fuse or amputate below or above the knee.'

6.8.4 ARTHRITIS AND ARTHROPATHY

In the needs assessment consultation older people with bleeding disorders often described their arthropathy related to haemophilia as 'arthritis', but health professionals distinguished between the two conditions. Using the clinical definition of haemophilic arthropathy, the health professionals explained that the arthropathy resulted from repeated bleeding into a joint and noted that they were more likely to see it in older people with severe conditions who had grown up without prophylaxis, particularly men with haemophilia from the age of 35-45 years. This could also occur in younger men with haemophilia with inhibitors, which makes treatment less effective, and those with severe conditions who had not adhered to their prophylaxis regimen. They had noticed increasing numbers of older males with mild haemophilia who were starting to display arthropathy, but would not expect to see it in women with bleeding disorders, or only in a few, as they do not appear to have joint bleeds as often. They would, however, expect to see the same arthritis that you would see in the general population in both men with mild haemophilia and women.

In the interviews women commented that while they knew women were different in relation to the level of

arthritis, they were unclear why this was: 'It's different for women. I don't know how different it is. I never understood.'

Although it was a relatively small study, the PROBE Australia questionnaire showed some interesting results in relation to 'arthritis' in men and women with mild haemophilia (See Appendix 2). As would be expected, more than half (54% or 15/28) of the men with severe and moderate haemophilia 45 years and over reported target joints, as compared to around one-fifth (21% or 6/29) of the men with mild haemophilia and a small number (2/21) of women with haemophilia in the same age bracket. However, when asked about 'arthritis', men with mild haemophilia and women with haemophilia both reported this approximately twice as often as men and women without a bleeding disorder in the same age bracket. This raises the question of unrecognised haemophilic arthropathy and joint bleeds, especially as so few women reported target joints, and suggests that further investigation in this area may be valuable.

6.8.5 MUSCLES

Muscle contractures, weakness and other muscle damage were also a feature of living with a bleeding disorder for many older people.

This damage might have begun during their childhood:

'There are ongoing issues caused by previous damage due to haemophilia and Perthes disease [hip disease] that I had when I was eight: pain, restriction in joints and muscles caused through bleeding etc. I have had a hip replacement, but this has highlighted other physical issues.'

'When I start talking about my childhood, the pain, oh my God, the pain we went through you couldn't even imagine. When you bled into joints you would be immobilised for months. It was just like being paralysed, no muscle power to do anything. You had to build up your muscles and get back on your feet and it took forever. This happened over and over. The simple act to get back on your feet and take a step - so many people take it for granted, that you can jump out of bed and play around. When you got back on your feet, it felt very good.'

Nurses commented that they also saw older people with VWD with muscle damage from bleeds, for example, compartment syndrome, particularly those with severe forms such as Type 3 VWD.

People with mild haemophilia could also be at risk of muscle damage from inadequate treatment and care in other health settings where they underestimated the bleeding complications for someone with a mild disorder. One older man with mild haemophilia described the outcome of a bleed in his hip after hip replacement surgery:

'Post-surgery I had a major bleed in the muscle, and that muscle was damaged. I was not given any factor VIII. None. I was in emergency ward for two nights and no treatment whatever. When I came back home after surgery, I was given a packet of factor VIII and a packet of syringes. I had no idea how to administer it. I had never needed to. While I was in emergency, my wife brought both of those into the hospital and gave it to them and I never saw it. Now I have got a permanent limp.'

6.8.6 MOBILITY AND PHYSICAL FUNCTIONING

For older people with bleeding disorders, a major concern was the increasing impact of joint and muscle damage on their mobility and physical functioning. This could interfere with all aspects of their life: their ability to undertake activities of daily living, to work, to socialise, to travel, and to achieve their aspirations in life. They were worried about what this would mean for their future:

'As I get older, the harder it will be to do the simplest things. Already difficult, [my] 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.'

'My mobility issues will hinder my life and life plans will not eventuate.'

The PROBE Australia study compared physical functioning in men and women with haemophilia to people without a bleeding disorder. For this needs assessment the results were collated by age group: 19-44 years, 45-64 years, and 65 years and over (see **Section 5.6 Probe Australia Study results**).

In every age bracket men and women with haemophilia were much more likely to say they had used a mobility aid or assistive device or had difficulties with activities of daily living than people without a bleeding disorder. The proportions increased in each age bracket: from around one-sixth of those aged 19-44 years; to around one quarter of those aged 45-64 years; to nearly half of those aged 65 years and over.

In comparison, men and women without a bleeding disorder reported low numbers with problems in physical functioning. This ranged from none using mobility aids and one experiencing difficulties in activities of daily living in those aged 19-44 years to small numbers using mobility aids and just over a quarter reporting problems with activities of daily living in those aged 65 years and over.

The differences became more marked when analysed by age, gender and severity. More than three-quarters of men with moderate or severe haemophilia aged 45 years and over had problems with activities of daily living and more than half had needed a mobility aid or assistive device.

6.8.7 MILD HAEMOPHILIA IN MEN AND WOMEN

There has been little research into the issues around physical functioning for men and women with mild haemophilia. The PROBE Australia study results suggest that having a bleeding disorder may impact on mobility and activities of daily living for some people of both sexes in this group. Although men with mild haemophilia aged 45 years and over reported difficulties with physical functioning less often than men with moderate and severe haemophilia, a substantial number did experience problems in this area. More than a guarter of the men with mild haemophilia reported problems with mobility and approximately a third with activities of daily living, which is markedly higher than the equivalent age bracket of men without a bleeding disorder, none of whom reported problems with mobility and only a small number reporting problems with activities of daily living.

Women with haemophilia aged 45 years and over reported fewer mobility problems than men with mild haemophilia but a similar proportion reported difficulties with activities of daily living.

This suggests the need for further research in this area.

6.8.8 THE DOMINO EFFECT

Having a bleeding disorder and multiple joint and physical functioning problems could have a domino effect and exacerbate health complications. The experience of people with severe bleeding disorders aged 35 years and over who had acquired bloodborne viruses such as HIV and hepatitis C from their treatment was commonly given by community members and health professionals as an example. The interviews and the Getting Older community survey provided a picture of what this meant in daily life.

Some identified the impact of 'early ageing':

'For me complications are occurring earlier simply because of the number of medical conditions I have which can all be traced back to haemophilia. I don't know they are specific to haemophilia, but they have made worse because of haemophilia. I think we get the onset of arthritis earlier. So we face restrictions when we are younger, and then we worry about how bad our restrictions will be in the future. Some 70-year-olds may not have the lack of movement as we do. We have knee replacements earlier.'

6.8.9 SELF-CARE AND DEPENDENCE

Both health professionals and people with bleeding disorders noted that the domino effect of bleeds and joint and muscle damage could lead to dependence in a very confronting way.

A psychosocial worker gave an example of the complexity:

'Men have problems as they age and get damaged joints - the complications of having target joints of shoulders and elbows and knees and hips and ankles. That's so complicated, when so many bits of them are grumbly. They can't manage normally the way they have managed in the past when they have a bleed. They have a bad elbow and they can't manage the crutches or weight bearing on one leg. How do you do an infusion when one arm is not working? That's tricky for our patients when they are getting older.'

For the older person with a bleeding disorder, this could impact on the basics of self-care.

'Just restriction in movement. No being able to wash - I use a loofah now. I am a lot more careful not to fall in the shower now. Around 50 I started to think about it more. I am expecting my joints to get worse and worse. That's when I will have to make changes to my life. I am going to lose my lifestyle and certain level of independence.' A relatively young man with severe haemophilia noted:

'It's difficult to shave, I can't reach my top button. Brushing teeth, cutting up pieces of food, tying up shoelaces are a problem. I buy slip on shoes. My partner dries and dresses me.'

One nurse commented on the effect on their dignity:

'Joint and muscle issues can mean some people can't wipe their bottom and [it's very difficult] if they are reliant on their partners and if they have no one.'

6.8.10 WEIGHT MANAGEMENT

Recognised as an issue for people with bleeding disorders, community education about weight management has been a priority and a feature of bleeding disorder conferences in Australia over the last several years. People with bleeding disorders who are overweight or obese join the general community in being at higher risk of heart disease and stroke, diabetes, musculoskeletal problems and cancer.¹²⁵ In the interviews physiotherapists and nurses commented that education about weight management was important for older people because being overweight would also put more pressure on their joints and decrease their mobility. The physiotherapists noted that exercise was an important aspect of controlling weight: 'we need to keep them active, keep them moving. Because once they sit down, it's the "slippery slope" and it gets worse and worse.'

For the older people interviewed, weight management could be a challenging issue. While they recognised the importance of not being overweight and some commented that they wanted to lose weight, they also struggled with the impact of joint problems on being active and the consequences for their weight. This was an area where they felt they needed ongoing support. 'Deteriorating joints makes exercise difficult, so I am gaining weight which I am concerned with.'

6.8.11 BALANCE AND FALLS

Losing their balance and falling was a common fear for older people with bleeding disorders.

'I had a fall three years ago. So I am not even allowed to look at a ladder. My life has been dominated by health issues so that's what I focus on mainly. I can't see past it.'

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

The cascade of risk factors for balance problems and falls in older people with bleeding disorders with the potential for serious injury is well-recognised in the literature. Joint damage and muscle contractures and weakness in ankles, knees and elbows can lead to less activity and weight gain, as well as osteoporosis, and combined with gait problems make older people with bleeding disorders very vulnerable to falls.⁸⁰⁻⁸⁴

The older people interviewed were aware of the increased need for strategies to prevent falls. As one man with severe haemophilia explained,

'Your bleeding disorder makes it more challenging with your movement and stability. It's getting out of bed in the morning. I use a crutch and I only have been doing that about the last two years. I go to bed at night with crutch beside the bed. So, when I do get up, I feel more comfortable hopping down to the bathroom. Once I have been down there, I leave it down there until night-time.' Physiotherapists spoke about the difficulties of rehabilitation and the ongoing spiral of physical decline after a fall.

'They have poor balance because of their joints. Whereas somebody else without elbow issues will use their arms to push themselves up if they are getting older, when [older people with haemophilia] use their arms, because they've got the issues with terrible arthritis with their elbows, they can't rely on their arms as much. And if they have surgery, they are going to struggle a bit more with the frame. Post-surgery a fracture may happen, and they are going to be in a wheelchair for a short time. With that they can deteriorate further. If you put someone in a wheelchair, they are not going to use their muscles at all.'

While older people with mild haemophilia had joint damage less often, they were also less likely to be on prophylaxis treatment to keep their factor levels high enough to prevent bleeding complications, and health professionals noted that a fall for them could be catastrophic:

'If a patient with mild haemophilia is having any issues with balance, and they fall straight ahead, that has a massive implication if they have a head bleed. Not only that they are going to break their head, but they are going to have massive bleed with it.'



In the consultation older people with bleeding disorders were asked what would help them achieve their aspirations for the future. Most commonly they gave health-related suggestions that would enable them to stay active, mobile and independent.

Treatment approaches

Older people with bleeding disorders identified a number of treatment approaches that could assist with this:

- A cure or improved treatment that is longerlasting or non-intravenous
- A cure or 'rejuvenation' for joints that were damaged or arthritic
- Holistic and integrated care to take the complexities of their complications into account.

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

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

'My ankles have progressively got worse in the past 20 years. I am managing - I had a steroid injection this year and that really improved my quality of life. I am trying to walk more and keep moving as much as I can.'

'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.'

Programs and services to assist with physical functioning

Both community members and health professionals noted that programs and services to assist with mobility, exercise, balance and falls and pain management would be valuable for physical functioning and quality of life.

Specialised and individualised programs developed and monitored by haemophilia physiotherapists were a high priority and were provided through the HTC as part of comprehensive care. Standard programs, such as falls and balance classes in the community, had their place. However, HTC physiotherapists underlined the need to ensure that the program suited the individual and that their patients were able to undertake the exercises and movements correctly so that the exercise program did not aggravate their problems.

'I am really not a fan of online therapies. Every patient's bleeding disorder affects them in a different way; every patient has different issues. And there is really isn't a one size fits all.'

HTC physiotherapists sometimes also provided exercises in online videos, but noted that uptake was very individual: '*people do them or don't do them*'.

Accessing programs and services in the community

Physiotherapy is an essential requirement for comprehensive care in a Haemophilia Treatment Centre and older people with bleeding disorders could access physiotherapy at their HTC hospital. Some older people with bleeding disorders said it was important to have the option to access physiotherapy programs and services in the community, closer to where they lived, and where they could park closer to the venue. This included therapies targeted at older people with mobility and balance problems and arthritis, for example:

- Hydrotherapy and aqua aerobics
- Massage
- Falls and balance programs
- Specialised sports physiology and pilates, yoga and T'ai chi for people with arthritis
- Weight management education and support.

'Access to aqua aerobics sessions, physio, massage - all those things I find myself accessing to keep moving and to keep as flexible and strong as possible. Anything that helps me to get on the floor and participate in those sessions is very valuable.' 'I think access to therapies to keep strong and mobile. I am talking about my local community support centres, so I don't have to go to the hospital to access my aqua-physio. Having access to parking spaces would help, so we don't have to walk too far.'

'I identified a gym that has a hydrotherapy pool. It has a good infrastructure - good steam rooms and things like that. That would help aches and pains. That's really important to me. I am really conscious that if things don't go well, and I have more injuries or more bleeds, my health could deteriorate.'

Some state and territory Foundations noted a problem with affordability with these programs when delivered outside the HTC and that subsidised access would also be important.

HTC physiotherapists had already been working with physiotherapists in the community and had found this worked well for some of their older patients.

During the consultation, the HTC physiotherapy and the rehabilitation experts had several suggestions to support this approach:

- Identifying a local physiotherapist who would accept and most benefit the person with a bleeding disorder in a reasonable timeframe
- The HTC physiotherapist may prepare an individualised program for the patient and liaise with the local physiotherapist to implement and monitor the program, including ongoing questions and concerns
- Or the HTC physiotherapist may refer to the local physiotherapist to assess the person for a program
- Supporting education resources on physiotherapy for an older person with a bleeding disorder would be provided to the local physiotherapist and could perhaps be available on the HFA website
- Older people with bleeding disorders may be able to access some government funding or support for physiotherapy sessions through community health and nursing home funding programs, including through My Aged Care.

For equitable access nationally, this approach would require adequate resourcing for specialised haemophilia physiotherapy in all state and territory HTCs.

Home modification and independent living aids

Another area that was raised by both community members and HTC health professionals were the strategies, aids and modifications that would enable older people with bleeding disorders to remain active and independent for as long as possible.

This included:

- Mobility aids, such as motorised scooters and wheelchairs
- Equipment such as shower chairs
- Medical devices such as arm supports and braces for elbows, modified footwear and orthotics, artificial limbs and other prostheses
- Home modifications, including ramps, rails throughout the house and disability-accessible bathrooms
- Independent living aids, for example, reaching aids to pick objects up from the floor
- Strategies developed to work around problems with physical functioning.

'So, these are the things I think would help in long run. For example, my stiff elbows mean I am having more trouble doing shaving, doing my teeth, doing my buttons up, wearing a tie. Each of these problems requires a unique solution such as a longhandled toothbrush, dressing more casually - I don't wear ties anymore.'

HTCs noted that referral to an occupational therapist for review was essential and needed to be integrated into comprehensive care.

While some older people saw their future as downsizing or moving to residential care, others saw more value in remaining in their current home. 'We have already modified the house so it's agedcare friendly and completely accessible. We have two bathrooms that have disabled access. Almost every entrance that it has is wheelchair friendly. I have done a lot of work to it. It may be easier to stay where we are than to move.'

'I don't want to go to a nursing home. I would prefer to stay in my home, and still do whatever I can for myself. We own our home. Since my knees went crook, we have recently put concrete ramps outside and also have done the flooring. We had carpet but put floating boards down to make it easier to clean.'

Some also found it helpful to reduce their home maintenance tasks.

'Fortunately, I planned years ago, so that my garden is almost maintenance free and there is minimal work to be done. I don't have any lawn at all so that I don't have worries about that. Life is a bit easier.'

HTCs also identified that funding for and access to specialised aids and equipment in a timely way needed to be addressed. This was an area where occupational therapists could assist and was an important reason for occupational therapists to be integrated into HTC comprehensive care teams.

'The funding model is an issue. For equipment they have to use another funding model, for example the State-wide Equipment Program. They might need to self-fund.'

'It is very difficult for men [with severe haemophilia]. They need scooters and something more permanent. Not all scooters fit all people. It is very difficult to have funding to provide that, you need support to access it.'

Physical functioning in mild haemophilia and women

Although men with mild haemophilia and women with low factor VIII or IX levels are the larger proportion of older people with haemophilia, little is known about the effect of their haemophilia on their joints and muscles and their physical functioning. The results of the PROBE Australia highlight the unexpectedly high proportion of 'arthritis' and difficulties with activities of daily living in both the men and women and problems with mobility in the men.

It would be valuable to have some larger clinical studies to look more closely at this area.

Physical functioning in VWD and rare bleeding disorders

There has also been little research into the impact of having a bleeding disorder on physical functioning in people with VWD and other rare bleeding disorders. Further study of this area will help to understand the issues for these groups.

6.9 Pain

Pain was often mentioned by both community members and health professionals as a significant issue for older people with bleeding disorders.

6.9.1 COMPARATIVE EXPERIENCES

Data from the PROBE Australia study suggests that the experience of pain in people with haemophilia may vary according to age, gender and severity (see **Section 5.6**, **Probe Australia Study results**).

People in the younger group aged 19-44 years were slightly more likely to experience acute pain rather than chronic pain, with more than half reporting acute pain and less than half reporting chronic pain. In the older age groups these proportions switched, with more than half reporting chronic pain. Interestingly, in the group aged 65 years and over, the proportion reporting acute pain dropped to a third. When the pain experiences of people with haemophilia aged 45 years and over are further analysed by gender and severity, there are clear differences between the groups. The highest proportions were in men with moderate and severe haemophilia, where more than three-quarters reported acute and chronic pain. Men with mild haemophilia were less likely to experience pain than those with moderate and severe haemophilia, but nevertheless, more than a third reported acute pain, and nearly two-thirds reported chronic pain. The pain experience of women with low factor levels seemed to follow a different pattern, with more than half reporting both acute and chronic pain. The interviews did not reveal more information about the acute pain experience of women, and this will need further investigation to understand it better.

It might be expected that many people in the general community experience pain as they grow older but the PROBE Australia data highlighted the very much higher proportion of those with haemophilia who were affected by pain in comparison to the those without a bleeding disorder. This occurred in every age bracket. It was particularly remarkable in the 19-44 year age group, where for example, around a half of younger people with haemophilia reported chronic pain in comparison to about a quarter of younger people without a bleeding disorder when compared by gender. This may be related to some of the issues associated with early ageing.

6.9.2 THE INTENSITY OF PAIN

Understanding the intensity of this experience is important.

One man with severe haemophilia who was active in peer support observed that community members with bleeding disorders managed pain very individually.

'As you grow older medications are very individualised, how you cope with the pain is very individualised. I think after a lot of discussions over the years I have realised that a lot of people deal with their pain in different ways.' For some the experience of pain was intermittent. An older man who was interviewed commented:

'There are pinch points in my life where you go through bit of pain to perform your tasks. Coming here today was not easy.'

For many, the impact of pain was an immediate concern. Several Getting Older survey respondents described the need for more effective pain management as 'urgent' and partners and parents noted that the person's pain was increasing as they grew older.

'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.'

The national approach to reducing codeine use and dependence on other opioids was a cause of frustration for some older people with bleeding disorders, who had not found other ways of managing pain. A partner noted:

'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.'

6.9.1.1 Pain management approaches

For the person with a bleeding disorder, medication options for managing pain were limited as they were not able to take some NSAIDs, such as ibuprofen, because these medications increased their bleeding tendency.

Cannabis is known to be used for pain management by some people with bleeding disorders. The value of cannabis in reducing pain was viewed quite differently by the various participants in the consultation. Some individuals with bleeding disorders spoke highly of its benefits in pain relief; some with HIV also used it for stimulating appetite. On the other hand, health professionals were concerned about its impact on decreasing their patients' motivation and ability to organise themselves. Parents of middle-aged children who were frail and dependent, particularly if they had HIV and had cognitive changes, were concerned about their vulnerability to trafficking. Changes to legislation in 2016 have meant that medicinal cannabis is available for chronic pain in some states and territories under the Special Access and Authorised Prescriber schemes.¹²⁶ A large 2019 Australian study found that most cannabis users surveyed had continued to obtain marijuana from illicit sources rather than accessing medicinal cannabis through an authorised medical practitioner⁹³, and this was also the case with participants in the HFA consultation. The ongoing study of medicinal cannabis will be important to this debate and to finding effective pain management approaches.

Health professionals were very conscious of the need to determine the cause of the pain to manage it more effectively. Being able to assess whether the pain was related to haemarthrosis or a bleed using diagnostic tools such as Point-of-Care Ultrasound was crucial to the type of treatment required - would they treat the bleed with factor or the arthritic pain with an appropriate antiinflammatory or neuropathic medication? In some cases, physiotherapists noted that exercise may be beneficial, but would need to be carefully monitored not to aggravate the problem. A physiotherapist remarked that their patients' stoic approach to pain could in this case be a disadvantage:

'And they just brush it off as haemophilia not knowing that it could be something else and engaging with their teams. It is very difficult for a person who has haemophilia to tell whether or not the pain in their knee is due to a bleed or due to rheumatological inflammation - their haemarthrosis flaring up. It's very difficult to get the message across that they don't need to accept this and there is help.'



WHAT WILL HELP?

Specialised pain management is clearly a high priority and will need to be a significant aspect of comprehensive care into the future.

Several Haemophilia Treatment Centres spoke of the value of liaising with specialist pain management services and rheumatologists to reduce pain and find alternative and more effective pain management strategies. This could then become a pain management plan to be implemented with the support of the person's general practitioner.

Education for older people with bleeding disorders about pain was a common recommendation to assist with self-management:

- Understanding the experience of pain
- Differentiating arthritic pain from pain related to a bleed
- Strategies for managing pain, including specialist pain management services and alternative medication options to opioids
- Benefits of exercise for pain.

Physiotherapists also noted the benefits of having access to Point-of-Care Ultrasound for diagnosing the cause of the pain, both at the HTC and at local health care services.

6.10 Veins and skin

As they aged, people with bleeding disorders were very aware of the complications of increasingly fragile skin, loss of dexterity and having a bleeding disorder.

Both men and women, particularly those with moderate and severe bleeding disorders, were concerned about the difficulty of infusing their replacement factor product into a vein and the damage to their veins with scar tissue, both from many years of infusion and from unskilled venipuncture from some health care professionals. 'I can find myself getting a bit shakier now which can make intravenous injections little bit harder. I am lucky, I have got good veins. I have issues with the veins in my right arm, but I use the other arm but I can inject right-handed or left-handed.'

'I can't use the other arm. I can't straighten this arm.'

'I still give injections myself and the veins are getting very tired - there is lot of scar tissue. I have been injecting myself since I was age 13. That's 40 years. I try and rotate the veins, but especially with the little bit of weight on, it is little bit more difficult too. When I was in the hospital my vein was damaged due to all the blood tests.'

Some found accessing veins psychologically daunting. Partners took an increasing role in undertaking the infusions for them.

'I just put it in the same vein. It's frustrating if you miss it twice - you feel like throwing it away.'

'Each time you go to different location for vein access, it's like starting over psychologically.'

'I have [plasma-derived factor VIII] three times a week. My husband does it for me. I tried to do it myself but no.'

Health care professionals in some states commented on the difficulty of accessing community nurses with appropriate skills to help with infusions at home and wondered about the possibility of using schemes such as hospital-in-the home programs to provide assistance with infusions. 'When people who are on prophylaxis treatment can no longer infuse into their arms - if they have elbow issues and they can't access themselves adequately - we don't have any means in the community where they can have somebody go into their house and help them. No community nurse would do that, and then they are required to come to the hospital and with some severe physical ailments, it's really taxing to have to come into the hospital. Hospital resources could be used in these areas.'

Nurses also commented that skin integrity required extra care as their patients grew older. Some people with bleeding disorders had noticed increased bruising and were concerned by it.



WHAT WILL HELP?

Newer and emerging treatments that could reduce the frequency of infusions or be injected subcutaneously rather than into a vein were viewed by all as a positive solution to vein problems in older people with bleeding disorders.

This is discussed in Section 6.7 under The promise of new treatments.

Other suggestions from HTC haemophilia teams and older people with bleeding disorders included:

- Education on vein care targeted at older people with bleeding disorders
- Teaching partners or carers to infuse
- Access to a skilled infusion nurse to assist with infusions in the home or residential aged care facility.

Venipuncture to provide infusions is a specialised area of nursing. Access to skilled infusion nursing in the community will be variable across Australia, and it will be important to explore the options available in each individual situation. 'Last night we talked about it [wife learning to do infusions]. She is reluctant but she thinks she probably could if she had to. If I was in residential care for example, she would be an advocate or learn how to do it herself. That is the possible solution to that residential care worry.'

'Vein health issues increase as they are getting older and it may well be to do with venous elasticity. They have been on treatment for so long, their veins are running out of places to puncture. Or they may be using veins over and over again and all of a sudden the vein gives up and then they may have no other alternative because they have never used another vein. We offer them education - to come in for training. It's not like you don't know what you are doing, it's more like a refreshing thing - do you warm up your arm, etc. Some of them might have a phobia accessing there. It also depends how they were trained when they were younger, for example with rotating veins. It's like reprogramming.'

6.11 Bleeding gums and dentistry

There was some discussion about dentistry in the consultation with community and health professionals. All agreed that dentistry for a person with a bleeding disorder could be fraught because of the potential for bleeding episodes. It could also be difficult to access a dentist, for financial reasons and because only certain dentists would agree to work with a person with a bleeding disorder due to the potential complications. Going to the dentist could also be a source of anxiety because of the pain and bleeding.

HTCs highlighted that preventive dentistry was very important.

Gum bleeds may be a symptom of a bleeding disorder or may also indicate periodontal or gum disease, often due to inadequate teeth cleaning and sometimes exacerbated by HIV and hepatitis C.^{8,95} Some older people interviewed commented that they were having difficulty brushing their teeth because of problems with their elbows. It is interesting to note that in the PROBE Australia data, people with severe haemophilia only reported gingivitis/ gum disease or bleeding gums at the same proportion as people without a bleeding disorder. However, men with mild haemophilia and women with low factor levels were more than three times more likely to report bleeding gums or gum disease. This suggests a need for increased education around dental hygiene with a bleeding disorder and a regular review by a dentist, and perhaps a review of their bleeding issues.

Access to a local dentist was becoming more of a priority as they grew older and travel was proving difficult. One woman with a severe disorder expressed her frustration with a drastic solution:

'I want all my teeth out. I have been going to the dentist in [capital city] since I was a kid. I have had enough of going down there. I have had 50 odd years of going back and forth. I would rather just stay home.'



WHAT WILL HELP?

Increasing access to dentistry for older people with bleeding disorders was seen by all as important, but finding ways to achieve this remains an ongoing issue. A number of areas will need to be explored:

- Accessing appropriate local dentists who will treat patients with bleeding disorders and liaise with HTCs on their management
- Accessing specialist dentists in the capital city or the dental service co-located at the same hospital as the HTC
- Transport options to assist with visits to specialist dentists
- Financial support to pay costs of private dentistry.

HTCs noted that it was often difficult to know what dentists were available locally, and that it may work better to ask older people with bleeding disorders to source a local dentist and then for the HTC to liaise with the dentist. Promoting preventive dentistry was also a priority.

6.12 Bloodborne viruses

People with bleeding disorders commented that it was hard to separate the impact of a bloodborne virus such as HIV or hepatitis C from that of haemophilia as they grew older, but they were very aware that it led to earlier ageing.

'I have had HIV for 35 years. HIV is well suppressed, well managed. Certainly it is still there, but it is undetectable. But due to that antiviral treatment, I am aging faster than most people. For example, people have been asking me to produce my senior's card or my pension card from my early 50s.'

Psychosocial workers noted the dramatic impact of bloodborne viruses on their clients' health and their relationship with their treatment and the health system generally.

'Those who have been infected with HIV and hep C have special needs depending on how these diseases have impacted them, not just emotionally and psychologically, but then also the trust they have in the treatment services, considering that more than likely these individuals were infected years ago by unscreened blood.'

State and territory Haemophilia Foundations and psychosocial workers described the impact on some community members' life expectations and personal relationships.

'You have to recognise that the group with HIV are different cohort. One has spoken to me about "not being able to dream or plan for future" because three quarters of his community of friends died within six months, when they first had HIV. So all his life from his 20s, he was told not to expect much -"You probably have two years".' 'HIV and hep C infection has affected their personal life due to stigma. Their sexual life is also badly affected and they refuse to be in relationships or have pretty much withdrawn from their friendship circle.'

6.12.1 HIV

Although it was recognised that HIV infection was now well-managed with treatment, both people with bleeding disorders and health professionals spoke about the accelerated effects on pain, mobility, complications such as osteoporosis, heart disease or cognitive impairment, and overall fragility when growing older was combined with HIV and a bleeding disorder.

Psychosocial workers commented that those with complex needs were well-serviced by a range of agencies specialising in HIV and providing case-management.

Some people with bleeding disorders had acquired HIV during childhood and were now in their middle years. While some felt they were managing reasonably well, others were particularly unwell and frail. When they had not established a long-term relationship and their parents were their primary carers, their parents were growing anxious about their care into the future – who would advocate for them and protect them when their parents were gone?

As they grew older and needed surgery and other medical and dental procedures for ageing-related problems, they experienced discrimination from health care professionals in the wider community:

'I understand where their fear is based. But it doesn't seem to be based on current practices. How if someone HIV positive is well treated the risk of infection is probably none. My GP is normally fine. [Discrimination is] normal from my dental surgeon, general surgeon, a neurosurgeon, people who might be operating on me. You can see it in the way they look at you, in the way they respond to administering a procedure.'

6.12.2 HEPATITIS C

The legacy of hepatitis C infection

Many had lived with hepatitis C infection in the past, although nearly all had successful treatment and were now cured. Some commented on hepatitis C symptoms they had experienced in the past, such as fatigue, or side-effects from interferon-based treatments, but often brushed over the enormous impact both had on their working and personal lives, with brief comments such as *'Hep C treatment (2012-13) had a negative impact'* or *'forced to retire early'.*

A stoic approach to hepatitis C was common. Some explained that hepatitis C was yet another medical issue that they had tried to take in their stride:

'It's funny getting older with hep C. It didn't affect me. I live quite happily. It happened years ago. That's 30 odd years. It didn't cause me any problems. I get the occasional liver scan. Slight anomalies, the next one will be clear. I didn't know I had it until the 1990s, by which stage I was married and had children. And suddenly they say you know you have hep C. That kind of hit me with a ton of bricks – when, where? But you get your head around it and go on.'

Some were grateful for successful hepatitis C treatment and the potential improvement to their health and lifespan:

'There are the added medical issues [of living with hep C] – the extra layer of appointments and medical management. Getting rid of hep C was a load off psychologically - one less thing to worry about. Also, my risk of liver cancer has dropped dramatically, which was a really happy thing. I have an ultrasound every six months for monitoring, surveillance for cancer. So, there is a layer of worry there about the risk of cancer. But that's what we live with I suppose. I am lucky to be here. And the treatment for hep C came along in time for me. So, it's not so bad having an ultrasound every six months, when you are cured.'

However, those who cared for them - their partners and family and the HTC health professionals - were concerned about the health complications that some older people with bleeding disorders affected by hepatitis C were now experiencing. Several commented on their ongoing issues with liver damage and cirrhosis. Nurses noted that, while some of their patients had 'picked up their lives' after curative treatment for hepatitis C, others were having liver transplants and they anticipated that some of their patients would go on to develop liver cancer.

A psychosocial worker described the impact of living a large part of their life with hepatitis C infection and then having curative treatment:

'Of course, all that trauma is still there. Most have been treated for hep C and doing well. But 20 to 30 years of their optimal life have been affected. They were not feeling great and only realised after they had [successful] treatment. The early treatments had severe side-effects and caused psychiatric disturbances, for example, one had severe depression and his marriage nearly broke down.'

In some cases, the psychological impact was substantial. The legacy of these experiences continues into the present.

'My mind was going crazy in the years [19]84 -85. All these people I used to go into [the HTC] with, all passing away. I thought I am next. So, I have been fortunate in that regard. Anyway, with the tablets two years ago I cleared hep C. But I went through issues coping mentally and it's hard.' 'I think the issue now is that for the people who have liver damage, it's causing issues. Other things - a few people have started talking about the investigation happening in the UK around blood borne viruses [in the past] and that is impacting on their state of mind.'

The consultation for the needs assessment around the impacts of hepatitis C on older people with bleeding disorders underlined its negative impact on their working life and ability to earn an income during what would otherwise have been the most productive years of their life. As a result, some now had limited or no superannuation and their financial security in their senior years was becoming problematic. This is discussed in more detail under **Section 6.21, Working** below.

For some, the inability to sustain a career was having an increasing effect on their psychological wellbeing as they came closer to their senior years.

'I struggle with depression a bit. I am in a bad patch at the moment. Sometimes you have issues with your feeling of self-worth when you are not working any more. [15 years ago] I was pretty sick with hep C and had hep C treatment which worked. But my health at that time wasn't good. I did part-time and was working less and less and struggling for it. In the end I found that it's too much of an ask from the employer, arriving at work late and not going to work. I thought I had been letting my employer down.'

Foundations described their concern that the effect of a lifetime of complications with hepatitis C was being overlooked because many of their community members had a stoic approach of *'just getting on with it.'*

'If they have had successful treatment for hep C, I hear a lot of the older people with bleeding disorders say they just want to get on with their lives. But there's no doubt, when you look at the evidence and hear their stories, that hep C has had a huge impact on their work and income and their quality of life over the years. And now that they are getting older and having more complications, it's all starting to unravel for some people. They don't have much in the way of savings or superannuation, they have multiple chronic health problems, they have often moved away from the city to save money, and now they are really struggling. But they are stoic and uncomplaining and don't want to talk about it or ask for help. It just seems really unfair to leave them in this kind of position after all that happened because they try to make the best of things. You look at what can be done, in the services for HIV, for example, and think that's the sort of help they need.'

'Individuals have specific needs, such as anxiety and depression. More than 75% contracted hep C at one point. Some have liver cancer now. There are specific socio-economic factors that are related to hep C - the financial burden from unemployment and because they missed out on education. This needs to be addressed.'

Unlike the situation with HIV, there has been no government financial assistance for people with bleeding disorders who acquired hepatitis C from their clotting factor treatment products in Australia. The 2004 Senate Inquiry into Hepatitis C and the Blood Supply recommended that those who acquired hepatitis C through the blood supply should be offered financial assistance for out-of-pocket health care costs and case management for their treatment, care and welfare issues¹²⁷, but, in spite of repeated requests from Haemophilia Foundation Australia, this was never implemented. The needs assessment highlighted that these issues remain – in fact, are increasing for some – and still need to be addressed.

Ongoing medical concerns

The results from the PROBE Australia study highlight the high level of exposure to HCV among people with haemophilia in Australia through their treatment products. More than two-thirds of the men with mild haemophilia and nearly all the men with moderate and severe haemophilia aged 45 years and over had been diagnosed with HCV. Some women had also been affected, including small numbers of the women with haemophilia and one of the women who carried the gene and had a normal factor level.

In comparison, only one of the more than a hundred 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.

HTCs have reported high rates of treatment and cure among their patients. Nearly all of the men and women with haemophilia or carriers in the PROBE study who had been diagnosed with hepatitis C now reported that they had cleared the virus, either after treatment or spontaneously. However, there remained one man with severe haemophilia who had unsuccessful treatment, a reminder that there is still a small number of people who have not been able to clear the virus. It is also notable that there was one woman with normal factor levels who had been diagnosed with HCV but did not know her current HCV status. The PROBE study reflects results from the more engaged in the community; there would possibly be many more in this situation in the wider community. This raises another concern: HTCs were convinced that there were more older people with mild conditions and carriers who had not yet been diagnosed. This highlights that those who are not engaged with HTCs might not have had a review of their HCV status and be missing the opportunity to have treatment and be cured.

Haemophilia foundations and HTCs also expressed concern about the number of people with cirrhosis who were not being followed up with ongoing liver health monitoring. Many assumed that because they had been cured, their cirrhosis was no longer a liver health risk, when they actually needed to be monitored regularly for serious complications such as liver cancer. To some extent this may also be an accidental by-product of the relief of one less co-morbidity to manage as you grow older, and demonstrates the need for continued health promotion messages as well as liaison with hepatitis clinics.

'I have been cured of hep C. Now it's not an issue. It is an issue with the long-term consequences, as you may get carcinoma or you might get liver damage. Because it is cured I don't worry about it. Once it is cleared, it's one thing you tick off and you worry about everything else.'

Another issue with managing advanced liver disease in an older person with a bleeding disorder was that it could have implications for bleeding complications and interactions with their medications. A haematologist noted that it would be important for other health services managing their liver disease to liaise with the HTC to alert the HTC and seek their advice.



WHAT WILL HELP

Acknowledgement

It will be important for the bleeding disorders community in Australia to have the traumatic experience of being exposed to HIV and hepatitis C and the ongoing impact on their life acknowledged formally, even if they have been cured of hepatitis C.

This acknowledgement will also need to be included in psychological care. Psychosocial workers considered that a trauma-based clinical practice approach may be appropriate. Understanding the experience of the bleeding disorders community in this framework may also be helpful for all of the health and community services who provide their care and support.

'Probably by validating their experiences. This person has been generous: he doesn't rage against [his experience with bloodborne viruses]. I think validating that it has occurred, not dismissing or diminishing their experience, but also being really aware how much damage physically their body has been through too. Having an awareness around such trauma – medically-induced trauma - and managing trauma at psychological level with trauma-informed practice. There is a group – the Blue Knot Foundation - they do trauma-informed care to manage, for example, childhood abuse.'

Further work

The needs assessment consultation clarified that there are several areas where further work needs to take place:

- Case management extended to people with bleeding disorders affected by hepatitis C, as is the case with those with HIV, to ensure their physical and psychosocial health and financial needs are being met, and that advocacy on behalf of individuals takes place when required
- Financial assistance for out-of-pocket costs with health and community care
- Continuing to work with HIV and hepatitis organisations on discrimination
- Health promotion and clinical follow-up for people with bleeding disorders exposed to hepatitis C.
 In particular, this relates to:
 - o Ongoing monitoring for people with cirrhosis
 - Liaison between hepatitis specialists and HTCs for management of people with bleeding disorders who have advanced liver disease
 - Reaching men with mild conditions and women with bleeding disorders or who carry the gene for haemophilia to encourage testing for their current HCV status and to seek treatment if they have hepatitis C.

'There needs to be a concerted education campaign for health professionals to educate them about the low risks of HIV infection when the patient is well suppressed.'

6.13 Health conditions of ageing

Nurses in the HTCs commented that their older patients, both male and female, were experiencing many of the health conditions that occur in the general population as people age:

'What we are starting to see is more of natural ageing processes such as arthrosclerosis or cardiopulmonary ageing-related issues - people needing heart bypasses or stents or pacemakers. We are seeing other degenerative diseases and other problems such as gastrointestinal problems or cancer.'

6.13.1 WORKING WITH OTHER HEALTH CARE PROVIDERS

Haematologists and nurses explained that these conditions would be managed by the appropriate specialist for the condition in a public or private health care setting, or in an ongoing treatment plan by a general practitioner. However, for the person with a bleeding disorder there were the added complications of needing to prevent bleeding episodes. This might require balancing anticoagulants with factor levels, preventive cover for surgery and medical and dental procedures, and other management of bleeding complications and would need careful liaison with the HTC. A haematologist commented that other health care services may sometimes overlook contacting the HTC for management advice when older people with bleeding disorders consulted with them about health conditions unrelated to their bleeding disorder. This could have significant implications for their health if bleeding complications and interactions with their bleeding disorder treatments were not taken into consideration.

For the older person with a bleeding disorder, there was not only an issue about preventing unnecessary bleeding, but also a need for their other health care providers to have a good understanding of the other complications with their bleeding disorder. Some described their frustration at having their health problems dismissed by health care providers in the general health care setting, for example, when doctors perceived their complications as a common problem of ageing. This often occurred when they had a mild condition such as von Willebrand disease or a rare bleeding disorder, such as an inherited platelet function disorder, and their bleeding disorder was unfamiliar to their health care provider.

'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.'

6.9.1.2 Heart disease and hypertension

In the PROBE Australia study all participants were asked if they had other specific health problems in the last 12 months, many of which were related to ageing. When the results for those aged 45 years and over were analysed, these produced some interesting results.

While the experience of some ageing-related health conditions was similar between the older people with haemophilia and those without a bleeding disorder, for example, stroke, diabetes and kidney disease, there were other health conditions where there were noticeable differences. Substantial numbers of men with haemophilia reported heart disease - for example, around one-fifth reported angina/chest pain compared to only one man without a bleeding disorder; and approximately half reported high blood pressure in comparison to the just over a third of the men without a bleeding disorder. There has been ongoing debate about heart disease and hypertension in men with haemophilia and these results underline the need for more research in this area to understand the underlying factors at work.

6.9.1.3 Dementia

Dementia was a common concern. Older people with bleeding disorders were worried about the impact developing dementia would have on their ability to manage themselves and their treatment, 'not getting treatment on time' and having to go into residential care. In a nursing home, 'if I had a bleed how anyone is going to know. Because I am not able to tell them.' They were uncertain that they would be able to identify when they were developing dementia and needing extra care. If their partner was still at home, they worried about the extra burden on them.

Health professionals commented that with increasing numbers of people with bleeding disorders living on into older age, they were starting to see more of their patients develop dementia. This could impact on treatment management issues: forgetting instructions and appointments, making treatment management 'tricky', having problems with balance and walking. Although some of their patients were placed in nursing homes, most relied on relatives or partners as carers and health professionals were concerned about the extra burden on family, but they were also concerned about patients who were single and did not have anyone to advocate or care for them.



WHAT WILL HELP

Special issues for older people with bleeding disorders

The research to understand how having a bleeding disorder impacts on the health conditions of ageing is necessarily in an early stage, as this is the first generation where larger numbers of people with bleeding disorders are surviving into old age. It will be very important to prioritise specific research into this area, particularly in areas such as heart disease and hypertension where some studies show higher rates of prevalence in older people with bleeding disorders in comparison to the general population.

Australia is fortunate to have a strong database as a tool for research in the Australian Bleeding Disorders Registry (ABDR), the system used by HTCs for the

clinical management of their patients with bleeding disorders. Aggregated data from the ABDR will be an essential element in research to understand ageing with a bleeding disorder. It will be crucial to maintain ongoing development of a robust national database by supporting:

- the collection of clinical data into the ABDR system
- the contribution of information about bleeds and home treatment from people with bleeding disorders and their carers through MyABDR
- The development of the ABDR to provide meaningful data reports
- The ability of researchers to access relevant and de-identified information in an appropriate and timely way.

Education and support

Both community members and HTCs identified the need for education and support around the special issues in health conditions of ageing for a person with a bleeding disorder. They thought this should be developed for different target groups:

- The older person with a bleeding disorder
- Their partner, family or carers
- Health care workers who provide their care outside the HTC.

Community education

Older people with bleeding disorders thought it would be useful to have education materials about growing older with a bleeding disorder, explaining what to expect and how they affect a person. The resources could be developed in such a way that they were not just for the person with the condition, but could also be suitable for partners and carers.

HTC health professionals and state/territory Foundations saw the value in educating not only about the medical conditions, but also about how to self-manage for the best health outcomes. This could include:

- Understanding how getting older affects a person with a bleeding disorder
- Preparing for medical, surgical or dental procedures
- The value of attending a regular review at the HTC
- Falls prevention, pain management
- Preventing and managing health conditions associated with ageing such as heart disease, diabetes, hypertension, dementia, gum disease, obesity, cancer, osteoporosis
- Staying active, healthy eating and exercise habits
- Self-advocacy in the health setting
- Building resilience, participation, respite, self-care.

Some also suggested promoting apps that work as reminders about exercise or as mental activities to prevent cognitive decline.

Health care worker education

Education for health care providers in the community about bleeding disorders and issues of ageing would have a significant role in supporting integrated care and reducing unnecessary bleeding episodes and other complications in older people with bleeding disorders.

The strategies that would provide the most effective education for health care workers would need to be targeted to the particular specialities providing treatment and care and may involve:

- Best practice clinical guidelines
- Education at the undergraduate and postgraduate level
- Integrating information about bleeding disorders in relevant professional development courses
- Journal articles and conference presentations and abstracts
- Education materials developed specifically for particular procedures or services that could be supplied to support liaison between the HTC and the care provider, eg surgery, dentistry, podiatry, physiotherapy, residential care, dementia care, general practice

 Professional development sessions for particular interest groups, for example, general practitioners who have patients with bleeding disorders.

Older people with bleeding disorders thought it was important that education for health care workers outside the HTC recognises the experience of the person with a bleeding disorder and their knowledge of their own body.

'If a doctor gives me a diagnosis - I know my body better than the medicos sometimes. I have been in the hospital system for an awfully long time. You listen to what they say because they are medical people. If it sounds right, that sounds right. If it doesn't sound right, if it doesn't make sense to me, I will question the medical profession.'

Dementia

The consultation highlighted that the cognitive and physical decline associated with dementia complicated treatment and care, including managing infusions. Replacement factor therapy involving fewer infusions or subcutaneous rather than intravenous injections was suggested as one way of decreasing the difficulty of treatment.

Case management to support both the person and their partner and family or carers would be valuable for managing the transition period while they progress to high care and various primary care and community services are called in to play a role, and for appropriate management in high care facilities such as residential aged care, where education for care providers and advocacy may be required.

6.14 Women

Women with bleeding disorders also experienced female-specific problems as they grew older, particularly gynaecological problems such as heavy menstrual bleeding in the lead-up to menopause. Because bleeding disorders are rare and haemophilia has traditionally been associated with males, the health professionals providing their care could sometimes be unaware of the special needs of women with bleeding disorders. A nurse explained:

'We do see some women who have polycystic ovarian syndrome or other kinds of gynaecological issues. Their bleeding disorder does have an effect upon that and complicate those matters. The complications sometimes come when the medical professional they go to see does not have a full or in-depth understanding of their bleeding disorder and does not engage with their Haemophilia Treatment Centre haematologist.'

Psychosocial workers pointed out that some women had the feeling that their bleeding problems were not recognised or anyone else's problem and the isolation that this could cause.

'I think older females are isolated in their bleeding. They are not very connected and feel it is their burden to carry.'

'Women's issues: being believed is important. For some women it is definitely a major thing. We are used to it [bleeding in females], women menstruate - so I think there is a historical bias against women.'

Women with bleeding disorders who were interviewed highlighted how often they had to advocate for themselves in the health care setting as they grew older and were concerned about how they would manage this as they grew frailer. Some had been diagnosed late in life and were still coming to grips with their bleeding disorder. Their primary care often came from a general practitioner, rather than the HTC.

'The radiology team are like, let's do the biopsy now. Then I have to say I have a bleeding disorder, I can't have the biopsy now... okay...then the nurse [from the HTC] calls and plans. My concern with getting older is the invisibility that you get. Older women are really invisible. Older people in general are so dismissed.'

'I think there is general stuff with being older. I have one ovary sleeping, I am on high blood pressure medications and I am on the pill too. I am on a painkiller. I am on a cocktail of things. GPs generally forget that you have a bleeding disorder and need information about classes of drugs. Everyone has to advocate for themselves as they get older.'

An older man with a bleeding disorder described his deep grief and feelings of powerlessness when surgical staff would not listen to his concerns about his mother's bleeding problems:

'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 ears!!! Because of their ignorance mother passed away.'



Education

Older women saw education about women with bleeding disorders for the wider medical community as a high priority. As with education related to growing older with a bleeding disorder (see above), this would need to be targeted to the medical specialty providing care. Raising awareness among health care professionals about bleeding disorders in females would play a significant role in improving treatment and care for older women and preventing unnecessary bleeding episodes.

Educating older women to recognise and manage bleeding complications will also be essential to ongoing community education through the HFA Female Factors project. This project involves the development of high quality evidence-based resources that women can also use as an education and self-advocacy tool with their health care providers in the community.

Comprehensive care and the ABDR

It may also be valuable for women to develop a relationship with their local HTC as well as their GP or the medical specialist who currently manages their bleeding disorder. This would enable co-ordinated and best practice care to manage the complications of their bleeding disorder as they age and increase the understanding of the complications that women may experience. Some HTCs in Australia and internationally have established women's clinics to achieve this. Collecting clinical data about women with bleeding disorders into the ABDR will also be important to develop an understanding of an area where there has been little research to date.

6.15 Transport

For older people with bleeding disorders and their partners, issues of ageing that impacted on their ability to drive or use public transport were a major barrier to access to specialized treatment and care and participation in the workforce. They were battling fatigue and finding the traffic too challenging to travel to attend reviews at the HTC or other specialist appointments. However, specialist healthcare services were often not available in rural or regional areas. If their partner was the driver, they were concerned about what would happen when their partner could no longer drive. 'Transport issues may affect us. Most of the time my partner drives me to treatment. It will be interesting to see whether the local hospital can help without going to the HTC. I have a general hospital 10 minutes away from here.'

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

'I use a mobility scooter these days. It's in the back of my car. If I lose the ability to drive, I am going to be relying on other people to take me places.'

Health professionals noted that some of their patients had moved to outer suburban or regional areas for financial reasons as they grew older or retired from work, which made access to the HTC more difficult. They also commented on the problems their older patients experienced with public transport, including volunteer driving services:

'But due to stiffness, their legs can't fit inside the [volunteer's] vehicle and they can't use public transport, or they don't know how to use public transport.'

WHAT WILL HELP?

The consultation identified options to assist older people with bleeding disorders who have transport problems that are discussed further under **Section** 6.16. Clinical treatment and care services:

6.16, Clinical treatment and care services:

- Innovations in comprehensive care to enable care to be managed locally
- Investigation of suitable options for parking and support to access it
- Information and support to access disabilityappropriate transport.

'If there is some kind of organisation that you could call and drive you to the appointment. Public transport is difficult due to transferring to bus to train etc.'

6.16 Clinical treatment and care services

6.16.1 COMPREHENSIVE CARE

With the range and increasing complexity of issues faced by their older patients with bleeding disorders, the multidisciplinary HTC team was described as having an essential role in co-ordinating their care across the various care pathways. The consultation highlighted that as well as the standard individualised treatment plan and care for their patients' bleeding disorder, this role may also involve liaison with other health care professionals in both public and private health care settings to manage interventions related to their bleeding disorder complications or health conditions unrelated to their bleeding disorder. This could involve liaison around treatment to prevent bleeding with surgery or medical and dental procedures, or balancing factor treatment with anticoagulants for health conditions such as heart disease or stroke. There may be cautions for some of their existing bleeding disorder treatments that need to be taken into account. Advanced liver disease related to hepatitis C also needed careful management. For women, it may also involve liaison with women's health specialists for gynaecological problems. Specialist physiotherapy and psychosocial services continue to be central to the individualised and holistic management required, and could well be in higher demand as musculoskeletal complications and support needs increase. The HTC also needed to work closely with their general practitioner around primary and preventive care and with aged care services as their dependency increased. HTC health professionals identified key partners in comprehensive care at this stage of life as pain management, rheumatology, orthopaedic, geriatric, occupational therapy, dietitian, podiatry and dentistry services, and general practice.

The HTCs were also seen as having a crucial role in providing expert education about bleeding disorders to the health care professionals in the wider community who dealt with their patients' other health conditions as they aged.

6.16.2 ABDR/MYABDR

HTCs currently use the ABDR system as a tool to manage the clinical care of their patients and to assist with co-ordinating comprehensive care services. Their patients contribute to the system by recording bleeding episodes and home treatments with the MyABDR app and website and can upload photos of bleeds. MyABDR also operates as a tool to manage the inventory of their treatment stock at home.

With so much communication about bleeding episodes, treatment and care now taking place remotely, for example, through discussion between the HTC and the person with a bleeding disorder on the telephone and via email, MyABDR has become a vital source of accurate information for managing treatment and care and alerting HTCs to the possibility of bleeding complications.

Uptake and usage of MyABDR has been variable between the states and territories and anecdotal feedback suggests that this may be related to local cultural attitudes to treatment recording. However, health professionals in states with higher usage rates noted that their older patients were more likely to be compliant with using MyABDR, as they were used to recording treatments and could see the value of being able to track batches after their experiences with bloodborne viruses.

Aggregated and de-identified data from the ABDR will assist greatly with understanding the impact of ageing with a bleeding disorder and the outcomes of different treatments. Increasing MyABDR usage nationally to provide robust clinical data remains an objective for all partners involved: HFA, AHCDO, the NBA and Australian governments.

6.16.3 HEALTH-RELATED QUALITY OF LIFE

With new treatments coming to market and innovations in comprehensive care programs, evaluating their impact on quality of life will be important to understanding benefits for older people with bleeding disorders. The PROBE study has been validated internationally as a tool to investigate health-related quality of life in people with haemophilia and the Australian PROBE study implementation has provided very valuable quality of life data for the Getting Older needs assessment. Canada uses an equivalent system to Australia for collecting clinical data on HTC patients with bleeding disorders, the Canadian Bleeding Disorders Registry (CBDR), and also provides MyCBDR, a patient recording tool that is linked directly to the CBDR. In Canada a number of innovations with PROBE are currently being trialled to increase uptake and improve specificity, including an app version and an option for participants to link their PROBE questionnaire to their MyCBDR record. These trials are currently being monitored to assess whether these innovations may also be an effective way for Australia to collect data on quality of life outcomes for haemophilia patients at HTCs. Patient recording systems also work differently in Canada to Australia and assessing these innovations will also involve investigating their feasibility in the Australian situation.

6.16.4 NEW CHALLENGES

Health professionals at the HTCs identified several new challenges:

- Mild bleeding disorders: They were seeing many more people with mild disorders who were experiencing complications of their bleeding disorder, but may not recognise the complications and seek care in a timely way. Patient education was important for this group, and also encouragement to attend a regular review at the HTC when this was something they had not had to do in the past.
- New treatments meant that their older patients with severe haemophilia were having few bleeding episodes. As a result, these patients needed less face-to-face contact, which could weaken their close relationship with the HTC team and make them less inclined to come for an assessment when needed.
- Integrating new care programs: with so many disruptions to their life with increasing health problems and medical appointments, and difficulties in travel due to ageing, their older patients were

reluctant to visit the HTC to participate in new care programs or reviews, which would involve regular faceto-face visits. However, there still needed to be careful monitoring as their patients could be desensitised to issues such as pain after a lifetime of complications. Online programs could be helpful when taken up, but might not provide adequate monitoring.

- Co-ordinating care in regional and rural areas: while there were now a number of medical resources in regional areas, including haematologists, there may not be the ancillary services needed, such as physiotherapy, laboratory services, dentistry, professional psychosocial care, etc. It could be a challenge for HTCs to integrate or use these medical services well, as they often had other local priorities.
- Financial costs to their patients for services provided privately, such as dentistry, podiatry.



Innovation in HTC services

Options to provide easier access to comprehensive care were discussed by many.

HTC nurses commented that older people with bleeding disorders wanted to live life as normally as possible, but their increasing complications meant that for good care, they needed to attend more appointments with a range of services. Community members, health professionals and Haemophilia Foundations all noted the difficulties of travel to appointments for both the person and their partner.

Suggestions considered ways to expand the reach of HTCs and included:

- Use of telehealth
- Evening or weekend clinics
- Liaising with haematologists in regional services
- Liaising with local hospitals to manage some aspects of treatment and care

 Commencing or further developing outer suburban and regional outreach with the full primary HTC team of haematologist, nurse, physiotherapist and psychosocial worker.

Some states and territories have supported the use of telehealth to deliver comprehensive care at a distance for some years. A telehealth consultation with the HTC can also be provided during an appointment with the person's local GP. The recent COVID-19 crisis meant that many appointments at HTCs around the country were converted to video calls, where patients had the technology, or telephone calls, where they did not. This highlighted the number of patients who did not have suitable video technology available to them and the difficulties of managing consultations about bleeding disorders without visuals. Health professionals noted that they were still asking people with acute bleeding episodes to visit the HTC. Communication issues raised by the HTC experience with the COVID-19 crisis has provided valuable insights for exploring telehealth services into the future. HTCs will also need to define when it is important to attend a consultation or review face-to-face with the HTC team.

Given the difficulty with travel to the HTC for older people with bleeding disorders, patients would also need to see the value in attending the HTC clinical consultation, whether this was face-to-face or via telehealth. This may be assisted by ensuring that a face-to-face review is co-ordinated with the multidisciplinary team, or by including some of the other 'value-added' strategies discussed earlier, such as referrals to general practitioners or other providers for their patients' specific issues.

The nurses also commented that while local health care services could provide support and liaison, they were less likely to be proactive in initiating best practice multidisciplinary programs to manage bleeding disorders and this role would still need to be taken by the HTC. There would also need to be more work to identify the gaps in service provision in regional and rural areas and to find ways to coordinate comprehensive care for HTC patients, when suitable services are not available locally.

Co-ordinating care

Health professionals underlined that ensuring continuity and consistency in care was critical to the health and wellbeing of the older person with a bleeding disorder, particularly as their care needs became more complex with ageing and they became more vulnerable and dependent.

They noted that the HTC would need to play a strong role to co-ordinate the range of services and programs to support people with bleeding disorders with complexities of growing older, but, with the comprehensive care model, had the approach to make it possible to achieve best practice treatment and care.

'We work collaboratively and it's a very multidisciplinary team. We meet regularly and we discuss patients and we collaborate with others.'

The development of best practice will rely on a national approach to comprehensive care so that access to specialities is expanded to accommodate the needs of the older person with a bleeding disorder. Australian haemophilia clinical management guidelines identify the essential members of a comprehensive care team as:

- A medical director who is a haematologist
- A nurse co-ordinator specialising in bleeding disorders
- Musculoskeletal experts, including physiotherapy, orthopaedics and rheumatology
- A psychosocial expert, preferably a social worker or psychologist
- Specialist medical laboratory services.⁸

The needs assessment consultation also identified other key specialities to include in comprehensive care for the older person with a bleeding disorder:

- pain management
- geriatric services
- occupational therapy
- dietitians
- podiatry
- dentistry
- gynaecology for women
- vocational counselling.

General practitioners were also identified as key partners in primary care.

This may involve strengthening the resourcing for comprehensive care, to ensure older people with bleeding disorders have access to key specialities as required.

Nurses highlighted that providing effective co-ordination of a range of different clinical services required good communication:

'You need seamless communication between the care teams: data co-ordination and a centralised system where each of the clinicians is able to access and see the patient records.'

There will also need to be ongoing work to evaluate the older person with a bleeding disorder's experience of health service provision. This should cover both their and their caregivers' perspective on the breakdowns and improvements that occur in their care pathways.

ABDR and MyABDR

The ABDR and MyABDR have a significant role in reliable and accurate HTC and patient communication. They can also support research into new areas such as ageing with a bleeding disorder and issues for older people with mild conditions and women with low factor levels. It will be important to promote and support the use of the ABDR and MyABDR nationally to ensure it is integrated into everyday practice and is able to collect comprehensive clinical data.

Health-related quality of life outcomes

For older people with bleeding disorders, quality of life is a very significant aspect of health and wellbeing. Evaluating the impact of particular health interventions, including new treatments or health programs, will need to include the effect on their health-related quality of life. While the ABDR will provide some data on quality of life, other tools will also be required to collect meaningful data. The PROBE Australia study has been able to deliver valuable information on health-related quality of life for this needs assessment. One approach would be to explore the potential to use the PROBE Australia study to link with the ABDR to collect data on healthrelated quality of life, for example, using the model trialled in Canada. This will involve investigating the feasibility of undertaking this with the ABDR system and the acceptability to patients using the ABDR, HTCs and governments.

Patient education

The consultation underlined the many areas that HTCs would need to cover in patient education into the future. They would also need to develop strategies to engage their older patients in working with their HTC and other partners in comprehensive care and developing knowledge and skills for self-management.

Resourcing HTCs adequately to undertake this work and provide innovative and multidisciplinary education programs and resources will be crucial to achieving this.

Education for health care workers

If education for health care workers around managing older patients with bleeding disorders is

to be effective, it will need to be led by those often described as 'key leaders', health professionals in relevant disciplines with recognised expertise. Members of the HTC multidisciplinary team are well-positioned to take on this role and already have established national groups to develop best practice around the disciplines of haematology medicine, nursing, psychosocial work and physiotherapy.

Developing appropriate education resources and programs will be time-consuming and will likely involve collaborations with other organisations, such as HFA, aged care services and relevant bodies among their health professional peers. Nurses commented, for example, that they had already developed education resources for residential care facilities on managing people with bleeding disorders: these resources were the result of a collaboration with the psychosocial workers, were reviewed by residential aged care nurses and were published by HFA. As with patient education, resourcing members of the HTC multidisciplinary team adequately will be required to ensure they have the capacity to undertake this work.

6.16.5 PRIMARY CARE: PARTNERSHIP WITH GENERAL PRACTITIONERS

General practitioners (GPs) were seen as providing a central role for people with bleeding disorders as they grew older, undertaking their age-related health checks, implementing their pain management plans, making decisions such as their safety to drive, and even infusing their treatment at times. They would see the person with a bleeding disorder for their hypertension or diabetes and make a referral to a specialist. They may be responsible for setting up a primary care management plan.

Nearly all people with bleeding disorders who completed the Getting Older survey said they accessed the services of a GP, more than those who accessed the services of an HTC. This is consistent with the findings in the 2016 Queensland Haemophilia Centre study, where around 90% of the men reported having a GP. However, as the study pointed out, having a GP was not necessarily an indication of undertaking preventive health checks, with only one-third in the study actively visiting their GP for a health check.¹¹⁶ With the overload many older people with bleeding disorders experience in relation to the complications related to their bleeding disorder and the health conditions of ageing and the number of medical appointments, it would be easy for preventive health checks to be sidelined or forgotten. Older people with bleeding disorders would need a clear message that these health checks could prevent further serious health conditions. However, there would also need to be other strategies to ensure that preventive health checks are more likely to occur.

Building a relationship with a GP so that preventive health consultations become routine was a critical factor raised by the HTCs. The interviews and the survey underlined that the person's trust in their relationship with their GP was very individual and often appeared to be related to their GP's interest in understanding their bleeding disorder. Several described having a good relationship with their GP and felt confident that the GP understood their bleeding disorder. Others were not confident that their GP understood their issues. A haematologist also commented on the issues relating to lack of continuity:

'A patient's life needs to have a focus point or home base. Usually it's the treating Haemophilia Centre or in many cases their general practitioner. But not all of them have GPs. There is also a problem with the way GPs rotate and there are different doctors each week.'

HTCs perceived this lack of continuity as a dilemma: the HTC was considering whether the GP could take a co-ordinating role with their patient's primary care as they grew older, but also were concerned that there would need to be very close liaison with the HTC for management of their bleeding disorder treatment and complications. This would be difficult if there was not a strong relationship with a specific GP.



WHAT WILL HELP?

HTC nurses highlighted the importance for HTCs of developing relationships with GPs who would be prepared to work with their older patients and understand their bleeding disorder and of involving the GP as part of the treating team. It would be important for there to be continuity with a particular GP, so that the GP knew their patient and their individual needs. This may involve recruiting GPs who were available at short notice and would bulk bill, for those patients with financial issues.

Suggestions included:

- Linking with GPs through GP organisations
- Providing workshops for interested GPs.

HTCs were committed to including patient education about preventive health checks in their regular reviews.

Education resources for both older people with bleeding disorders and GPs on relevant health checks and managing the health conditions of ageing with a bleeding disorder would also be valuable. It would also be important to have the associated health promotion messages reiterated in haemophilia foundation newsletters and education materials.

6.17 Aged care

6.17.1 RESIDENTIAL AGED CARE FACILITIES

While many older people with bleeding disorders recognised that they might need to move to a residential aged care facility in the future, most were deeply concerned about the level of care and expertise that would be available to them in these facilities. Would their treatment be stored properly? Who would have the venipuncture expertise to undertake their infusions? Or the expertise to follow their treatment plan? Would they know or notice if the person was having a bleed? What if the person fell out of bed? How long would it take them to respond? What would be the access to specialist treatment and care? They were particularly worried because they knew they would be frail or have dementia and be unable to advocate for themselves, and if they had a partner, they might be in a similar position.

Partners sometimes assumed that it would be better not to go into care:

'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.'

Nurses noted that the decision to go into residential care may have its own inevitable progress and the process may sometimes be put in motion by the person's partner or GP if the person could no longer be managed at home. They had already developed educational materials for aged care facilities and had liaised closely with facilities in the past, but acknowledged that managing people who needed residential care could have its challenges.



Given the great concern many older people with bleeding disorders and their partners and family have about entering residential aged care facilities, it may be valuable to develop education materials to explain what they can expect, services available, how the relationship with the HTC will work, and how they can best self-manage and advocate for themselves in the facilities.

Existing education materials for nurses, personal care assistants and other staff are currently available on the HFA website and could be promoted to both the facilities and the community. They may also need to be updated around new and emerging therapies when these become widely available in Australia.
These education materials are part of the education HTCs provide to residential aged care facilities when their patients enter the facility and are aimed at supporting integrated care and responsiveness to the special issues of living with a bleeding disorder into old age.

Newer therapies involving less frequent infusions and/or subcutaneous injections may also reduce the treatment burden for older people with bleeding disorders and be more manageable in a residential care facility.

6.17.2 AGED CARE SERVICES AND SUPPORT

In the Getting Older community survey older people with bleeding disorders were asked about the support services they currently access.

The largest number of services accessed were related to their health care: GPs, the HTC, physiotherapists, psychosocial services, and other health care workers, which could include complementary medicine such as acupuncture, chiropractic, or naturopathy. A substantial number (38%) also identified their local pharmacy. As with other health care workers in the community who provide their care, complementary therapists and community pharmacists may also provide therapies and medications that involve risks for a person with a bleeding disorder and it will be important to ensure they have access to information about this to prevent unnecessary bleeding and other complications.

A smaller number (12%) said they accessed a spiritual advisor or local church for support.

Of the survey respondents, 10% accessed homecare workers or cleaners. Only a very small number accessed community support services such as personal care or support workers, community nurses, or services such as meals or cooking. With their high care needs, this is a surprisingly low use of aged care support services. The survey respondents gave a couple of reasons for this:

- They didn't know what was available
- Out-of-pocket costs for these services can be expensive.

The consultation also highlighted that many older community members found the number and complexity of their health conditions to be overwhelming and were struggling to organise themselves. This suggests that they would have difficulty initiating access to support services.

A psychosocial worker noted that My Aged Care was intended to provide information about resources available and some guidance to accessing them, but 'it will be overwhelming if you don't know the process, which most people don't.'



Assistance with access to aged care services

When asked about services or supports that would help, suggestions from older people with bleeding disorders included:

- Home help such as cleaners, gardeners, a handyman for home maintenance
- Assistance with setting up and accessing aged care services
- Information about the services available
- Financial assistance with out-of-pocket costs for these services.

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

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

Psychosocial workers thought that it would be helpful to provide guidance to older people with bleeding disorders about aged care services in the community and what services they could access. Community members interviewed noted that their support needs had changed over time and they needed to increase their package and funding to accommodate this. Case management to manage their ongoing needs may also be important, along with investigation of options for funding if they are not able to afford the out-of-pocket costs for the services required.

It will also be important to provide older people with bleeding disorders and their partners and family with self-directed access to information about accessing aged care services and what services are available. This could include:

- Information about aged care services on the Getting Older Information Hub on the HFA website
- Articles in foundation newsletters.

Education for complementary therapists and pharmacists

The need to educate health care workers in the community about special issues if they care for an older person with a bleeding disorder has already been identified. It will be important to also include education and information for complementary therapists and community pharmacists to complete the loop of the care pathway.

6.18 Early ageing and disability services

6.18.1 NATIONAL DISABILITY INSURANCE SCHEME (NDIS)

A major problem for the people with bleeding disorders under 65 years who experienced ageing-related issues was that they were not yet eligible for aged care services, but could also fall through the cracks of the National Disability Insurance Scheme (NDIS). A psychosocial worker commented:

'One of the other issues is the grey area with the NDIS. You can see benefit in the NDIS but the younger guys needing support do not qualify because they don't meet the criteria for the NDIS. I think with some small NDIS support they might thrive and have a better quality of life – also for their partners.'

While younger people with bleeding disorders born in Australia might have disability problems due to lack of access to prophylaxis treatment when they were young or having inhibitors, which make their treatment less effective, HTC health professionals commented that more recent migrants might also have joint and muscle problems if they had not had access to regular prophylaxis in their country of birth.

The psychosocial workers noted that while a few of their clients had accessed the Scheme, others were deemed to be not impaired enough by NDIS assessors, which meant that they could not access disability services. There was consensus among the health professionals at the HTCs that NDIS assessors often did not have enough expertise or understanding of bleeding disorders to make appropriate assessments. Nevertheless, the NDIS application needed to be reflective of the eligibility criteria and presented in the format and language required to have a better chance of being successful. There was a role for members of the comprehensive care team at the HTC who had experience with the NDIS, such as the psychosocial worker, to assist applicants with their application. An occupational therapist and physiotherapist could provide functional assessments to support their application.

The inability to access care services when aged under 65 years might also explain the low access to support services by older people with bleeding disorders in the Getting Older community survey: a large proportion of 'older' people with bleeding disorders are actually under 65 years. In the case of the survey, only 56/133 or 42% of survey respondents who identified themselves as 'people with bleeding disorders who are getting older' were aged 65 years or over – 57/133 or 43% were aged 45-64 years and a small number were even younger.



WHAT WILL HELP?

The consultation highlighted a number of areas to address with the NDIS:

- Assistance with completing NDIS applications to ensure eligibility criteria are addressed.
- Involvement of members of the comprehensive care team with experience in NDIS applications, including psychosocial workers and occupational therapists, to support people with bleeding disorders to make their NDIS applications. This could entail HTC support with reports and advocacy for services and modifications for those with higher needs.
- Assisting applicants with an appeal or review where they have been rejected initially or the approved package seems inadequate.
- Advocacy around modifications to the NDIS so that it supports applicants to continue working.
- Adequate resourcing of all HTCs to assist with NDIS applications.

It may also be relevant to have some discussion with clinical experts on the value of considering early ageing in people with bleeding disorders more definitively. This could consider whether there would be benefit in a policy shift to recognise early ageing in bleeding disorders as a reason for earlier access to aged care services, similar to the current proposal by HIV organisations. Some participants in the consultation drew attention to the advocacy work of HIV organisations to lower the aged care threshold for people who have had long-term HIV infection and live with complex co-morbidities and suggested that this might also be relevant to people with bleeding disorders who live with similar health issues.

Further investigation into sources of financial assistance for equipment and support services when people with bleeding disorders cannot access the NDIS is also required.

'Well, here is a radical idea. Maybe people with haemophilia need access to services earlier than at the retirement age. Maybe support those who are financially challenged. Some sort of dollar-to-dollar support to get things done. Orthotics, podiatry etc is expensive.'

6.19 Mental health

A number of mental health issues were raised during the consultation.

6.19.1 DEPRESSION AND ANXIETY

In the PROBE Australia study, men with moderate or severe haemophilia who were 45 years and over were twice as likely to report clinically diagnosed anxiety and depression as men with mild haemophilia and men without a bleeding disorder in the same age bracket. The interviews highlighted several different causes. Many spoke of the traumatic years of the HIV and hepatitis C epidemics, the loss of friends and family and the pain of discrimination in their everyday life, of feeling 'like a leper' and for example, as a teenager being banned from a girlfriend's house when her father found out he had haemophilia. A less well-recognised source of trauma was their experience of pain and immobilisation when hospitalised with bleeds as a child, and the deaths of their fellow paediatric patients if they were hospitalised in an oncology ward.

'I had depression. They say I have something called PTSD. Some of my earliest memories are of kids dying in the hospital ward. Those children would normally have things like leukemia. So, I made friends and they died within a few weeks. I was in the hospital regularly as a child. And then I thought I was fairly tough.'

Another source of trauma that was identified was having a very severe bleeding episode, which could be difficult for people with mild disorders for whom this was not a common experience. A psychosocial worker commented:

'Some of the mild patients have very traumatic memories. There is one who had a traumatic experience with blood in his mouth, a horrible bleed. Every time he needs an operation, he becomes super anxious. To the outsider he looks like an anxious man, but he is not and it's because of his strong memories. He may need a psychiatrist for his PTSD.'

For some there were issues related to grief and loss. This was sometimes related to their increasing problems with mobility and pain and loss of independence, and not being able to undertake the activities that formerly gave them pleasure. Some had lost people close to them and were greatly saddened: their partner, family members or friends.

6.19.2 PERSONAL INTERESTS

Psychosocial workers were concerned about the inertia and lack of motivation that could accompany depression and spoke of the need to keep older people psychologically active with activities that they enjoyed, such as fishing, reading and gardening. It was interesting to note that some of the people interviewed who described themselves as having a positive approach to life had personal interests and hobbies – 'plenty to keep me busy' – including music and art, reading, fishing, walking the dog, going to films or eating out with friends.

Psychosocial workers also pointed out the importance for older people with bleeding disorders of feeling like they were doing something useful or constructive.

'The ones I know are loving the Men's Shed and creating things. One group I know of actually built aids for disabled. I know others who have projects like restoring furniture. Because men love to be doing stuff. Sitting and having coffee makes them depressed about how creaky and old they are.'

6.19.3 PERSONAL STRENGTH AND RESILIENCE

Although some interviewees spoke about their depression, many prided themselves on their personal strength and resilience. They often attributed this to their experiences of managing their bleeding disorder over their lifetime and the personal strategies they had learned to overcome challenges.

'I feel like I can navigate myself around the system because of my health issues all my life rather than somebody who has had a reasonably normal life.'

'A combination of strength, stoic nature and all of that. I am fiercely independent as guys tend to be. I think it's better to have a strict perspective on it.'

'Resilience is my strength. It's a marathon and you've got to have resilience.'

It is interesting to note the fragility of this resilience, particularly if the person felt isolated or vulnerable. This was demonstrated during the consultation, when some community members in remote areas were reluctant to participate in consultation because they found thinking about getting older too confronting.

6.19.4 SOCIAL CONNECTION

An important aspect of their resilience was social connection and being able to call on personal networks. In the *Don't go it alone* study, older Australians who often or occasionally experienced lack of companionship and loneliness also recorded lower life satisfaction.¹⁰⁸ In both the interviews and the Getting Older survey, older people with bleeding disorders spoke about spending time with their grandchildren and extended family. Psychosocial workers described individuals who were confident and content with their life as they grew older – for example, an elderly woman living in a retirement village, with relatives close by, and a strong social network of friends *'thriving quite well and not overly strained as a result of her bleeding disorder'.*

The consultation identified some challenges to social connection as people with bleeding disorders reached their senior years: loss of their partner, inability to participate in social or community activities, losing connection with their workplace and work friends. Many relied on strong relationships with their partner and a single man pointed out the difficulties of needing increased personal connection as he grew older:

'I believe it is unique to having a chronic condition and also being a single male. You have lived your life with it [haemophilia] and unless you have had this support throughout (i.e. a stable marriage, supportive friends etc.) you begin to crave it later in life as you see yourself as vulnerable and needy.'

Psychosocial workers highlighted the importance of friendships in the senior years, whether the person had a partner or not.

'It is really important for men [with a bleeding disorder] to make sure that they have good male friendships. They don't often have them outside of their partner. When their partner goes, they might find themselves suddenly, totally alone, but if you have got few good male mates, then you have a real lifeline into life.'

6.19.5 SUPPORT

In the Getting Older survey, 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.

Peer support

Face-to-face peer support activities are a major feature of state/territory Haemophilia Foundation work with their community. Activities may be aimed at the bleeding disorders community generally, such as family or community camps, or targeted at specific groups, such as men and women's groups, grandparent groups, men's retreats, youth camps and inter-generational activities such as men and boys activities, where an older relative may attend with a boy with a bleeding disorder.

Access to the range of peer support activities has been variable between states and territories, depending on the level of peer support development, size and geographical distribution of the community and resourcing. This has been discussed at a national level and as a result, some Foundations have offered places in activities such as camps to nearby states and territories. Some Foundations also described encouraging older community members to take on volunteer roles, for example, in fundraising activities.

The value of peer support

For the majority of older people with bleeding disorders who participated in the consultation, there was great value in connecting and sharing experiences with other older people with bleeding disorders. They found having a rare health condition very isolating, particularly if they did not know anyone else with a bleeding disorder.

'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.'

'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.'

For older people with bleeding disorders, it was an opportunity to share not only what they had experienced, but what they had learned and tips and strategies that had been successful for them in managing their bleeding disorder. They thought it was important to celebrate their achievements and what made life enjoyable and rewarding for them.

'It's always better to sit around a table and chat. We have a men's breakfast [in my local haemophilia foundation] and discuss how we manage with certain circumstances. That is something that is practical and relevant to me. People going through the same thing as you is reassuring - you can work it out when you are sitting down together and have a laugh about it.'

A psychosocial worker explained how the proactive approach of some community members supported others to have the confidence to follow in their footsteps: 'What I have noticed with the older guys if they are connected is that if one person does something and it works well, then they will talk about it and support each other. They need someone to make that first move. It's bit like mentoring - or gaining the confidence to deal with the services with the support that you get.'

In the community survey a smaller number of older people with bleeding disorders (12 of 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.

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

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

The definition of a 'peer' is very relevant to the motivation for social connection: is it someone who also has a bleeding disorder or someone who shares your interests? Engaging older people with bleeding disorders in social activities with their 'peers' will need to take both definitions into account.

Ways to connect

When asked about how they would prefer to meet other people in the bleeding disorders community, by far the most popular choice for older people with bleeding disorders was in face-to-face groups, with 60% giving this as their preference. 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. About one-fifth were interested in peer support via telephone. For some distance was an issue and frailty and mobility problems would also make travel to face-to-face events problematic. Some state and territory Foundations undertake routine regional visits with social events to connect to community members and provide them with an opportunity to meet each other as well as Foundation leaders.

The community survey also asked about their interest in connecting with other people online or through social media. In response most older people with bleeding disorders 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.'

A smaller group were already active in social media groups and thought it would be helpful to have online options available for peer support. They also liked the opportunity to communicate with each other in their own time. While some community members thought that it would be helpful for HFA to provide a national Facebook group, for example, others commented that they would not like a haemophilia foundation to moderate or 'be in the room' and thought that it would be better to have independent peer support groups. '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.'

Although most older people in the consultation were not interested in online technologies for peer support, the COVID-19 crisis has exposed many older people in the community to VoIP (Voice over Internet Protocol) platforms such as Zoom and Skype to connect socially to their family and friends. As a result of this experience, their attitudes to using this type of technology for peer support may have shifted. In the disability and aged care sector there are also a number of innovative projects using digital technology for older people, for example using simple interfaces for a Skype product that are appropriate to older people and those with cognitive decline. Digital options for peer support may provide a way for older people with bleeding disorders to connect with each other, when they are unable to meet face-to-face for distance, mobility or other reasons.

Australian haemophilia foundations have described the challenges of maintaining engagement with their peer support groups and the need to use strategies such as personal invitations, meals and interesting guest speakers or activities to attract participants.¹¹⁸ With the small size of the affected community, some survey respondents were aware that it could be difficult to maintain momentum in an online peer support group. However, it was clear that meeting each other face-to-face at some point to establish a friendly relationship was key to continuing the connection online or by telephone.

'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.' Peer support for older people with bleeding disorders, whether provided face-to-face or online, will need to address strategies to engage them. In the digital space this will involve, for example, understanding how to create an attractive social event online and how to schedule it nationally across multiple timezones. Providing peer support on digital platforms is a new and evolving area and there is still much to be learned about how to provide peer support for older people, particularly those with dexterity and mobility problems.

WHAT WILL HELP?

Psychosocial care

The frequency of depression, anxiety and phobias in older people with bleeding disorders highlights the need for professional psychosocial care. This also involves resourcing for psychosocial workers in the HTC comprehensive care team to identify problems and provide support and referral. Post-Traumatic Stress Disorder has been identified in people with bleeding disorders and HIV and/or hepatitis C and may also be an important factor in the mental health issues of older people with bleeding disorders generally. It will be important to explore this further and to consider whether trauma-informed practice may be an appropriate approach for some people in this group.

Personal interests, social connection and peer support

Investing in strategies to encourage personal interests and facilitate social connection for older people with bleeding disorders will be an important way of keeping these individuals active and supporting their quality of life. It will also be a means to encourage their resilience, while providing less confronting avenues for them to ask for help.

Peer support activities with the bleeding disorders community are an opportunity for older people with bleeding disorders to meet, share experiences and strategies for self-management, support each other to ask for help or changes in their treatment and care and develop friendships. Foundations may also consider ways to enable older people to contribute their skills and experience to the community.

As one partner commented,

'I think he could share his general optimism and positive attitude, his resilience.'

Other community services and activities that bring together older people with shared interests may also have much to offer, for example, Men's Shed, Rotary and Probus, University of the Third Age, special interest groups, and innovative interventions such as 'befriending', where volunteers keep regular contact with individuals.

It will be important for Foundations to continue to look for opportunities to bring older people with bleeding disorders together face-to-face so that they can get to know each other and establish relationships that they can continue outside these forums.

Continuing to investigate and trial digital peer support options may identify workable solutions for the bleeding disorders community, which may supplement face-to-face events and provide opportunities for those who cannot attend faceto-face events to connect with their peers. This will involve looking at what has worked for other similar organisations and how to engage community members on digital platforms and maintain engagement. Resourcing may be an issue and it may be helpful to collaborate with other organisations or use existing community resources, such as peer support training through organisations such as the Chronic Illness Alliance.

6.20 Carers

The physical and emotional burden for partners and family as carers was a common concern. Older people with bleeding disorders explained that the outcomes of their bleeding disorder complications often fell on their partner, if they had one:

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

They often worried that their partner may not have the physical strength to manage carer duties such as lifting, or that they would need to take the brunt of domestic tasks. Their partner's health may also be deteriorating; and their partner could be emotionally affected by the person's health problems, and several commented that their partner had experienced depression in relation to issues such as their HIV diagnosis or life-threatening health episodes.

Partners commented that they worried about the future with the person's ongoing loss of mobility and multiple health problems.

'Continuing loss of joint mobility and concerns for what the future looks like with loss of mobility.'

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

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.

'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 [my] "caring role" gets more intense?'

Some people with bleeding disorders were aware that their partner needed their own time to care for themselves. Health professionals commented that partners often found the carer role stressful and exhausting as they grew older and that it was important to provide them with opportunities to take time out from caring and to talk with others on their own about their experiences.

The partner/carer role could be a dilemma for both people with bleeding disorders and their partners. Partners felt guilty at wanting to have time and space for themselves while also wanting to demonstrate their love for the person with the bleeding disorder. Some people with bleeding disorders felt that their relationship would become unequal if their partner was also their carer and not necessarily a role that their partner wanted. They were keen to maintain their independence and to take their share of responsibilities within their relationship.



WHAT WILL HELP?

When asked what supports or services could help them, partners and family who responded to the survey said:

- Someone to talk to
- Support with garden and home duties
- Transport services to the HTC
- More support to country patients visiting the HTC.

Some older people with bleeding disorders acknowledged the need of their partner to have time to care for themselves.

Health professionals also suggested:

- Access to information about getting older with a bleeding disorder and services available
- Acknowledgement of their role and the difficulties they face, including the emotional toll and lack of control over their own life in their caring role
- Finding ways to include the partner or carer, even if the older person with the bleeding disorder doesn't want to engage
- Respite.

It is interesting to note that around 29-46% of partners and family who completed the Getting Older survey said they would like to use social media, online discussion forums, email, and faceto-face one-on-one meetings for peer support. This was a much higher proportion than older people with bleeding disorders. It will be important to take the needs of carers into consideration with digital options for peer support.

6.21 Working

6.21.1 OLDER PEOPLE WITH BLEEDING DISORDERS

While the desire to contribute to society was a common aspiration, having a bleeding disorder had a noticeable impact on the working life of many older people who participated in the interviews and surveys.

The PROBE Australia study showed that 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. More than half (54% or 69/128) of older people with bleeding disorders who completed the Getting Older survey were retired or permanently unable to work. The greater majority of them (70% or 91/131) thought that their health had impacted on their work or study life in various ways. 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.

This is consistent with the results of the PROBE Australia study, where 70% (21/30) of men with haemophilia aged 45-65 years and 44% (12/27) of men with haemophilia aged 65 years and over had made education or career decisions due to their health. In contrast, only 19% (6/32) of 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.

The interviews underlined the impact of HIV and hepatitis C on employment, and some spoke of the symptoms of extreme fatigue and physical and mental side-effects of hepatitis C treatment that meant they struggled to keep working. They also pointed to the difficulty of separating symptoms such as hepatitis C-related fatigue from the experience of ageing with a bleeding disorder, although those who had curative treatment recently noticed they now felt better overall.

Some of the participants in the Getting Older survey commented on the strategies they used to manage the impact of their health on their work, such as using up their leave or having modified duties, and some attended work in spite of their bleeding episodes.

'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.'

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

Many of those who completed the survey (42% or 54/128) wanted to stay longer in the workforce. When asked about barriers to staying in the workforce, they largely described 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.

'Arthritis may stop me from doing my work.'

'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.'

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

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

Partners were concerned about the impact on their career:

'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.'

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.'

Psychosocial workers commented that employment was a big issue for the older bleeding disorders community, and that it was important for people to be respected and to be able to maintain a connection with their workmates – to be given the 'disability tag' could mean they were diminished by the workplace.

The Productivity Commission noted that improved health and more integrated care could enable Australians to have more days that can be used in productive activities, such as employment, home activities and leisure, rather than being lost to ill health and time spent on attending appointments. It argued that this would improve their capacity to work, leading to higher workforce participation and increased personal income. This would also contribute to a gain in GDP.¹²⁸

6.21.2 PARTNERS AND CARERS

Most of the partners and family who completed the Getting Older survey did not think they had stopped work or worked part-time before they wanted to because of the health demands of the person with a bleeding disorder. However, the person's health could affect 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.'

Around a third wanted to return to work or stay longer in the workforce, but several described their concerns about this:

- 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 selfemployed 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.'



Older people with bleeding disorders

Older people with bleeding disorders who participated in the Getting Older survey had a range of suggestions to help them stay in the workforce:

- Improved treatment to reduce the number of bleeding episodes, or that did not need to be injected
- 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.'

'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.'

A psychosocial worker commented:

'I think employment is a huge issue in the community. Retraining to find suitable work is also an issue. Managing their work life is an issue. Some employers are good - if you've got a flexible workplace, it's really good.'

Vocational counselling is considered an integral element of comprehensive care in an HTC and it will be important to continue to introduce it at an early age so that appropriate career decisions can be made and to continue it throughout a person's working life. It would also be helpful to provide vocational counselling and mentoring through both the HTC and haemophilia foundations, to provide professional guidance, peer support and supported opportunities to gain workplace skills.

The Productivity Commission has highlighted the role of a patient-centred care approach and integrated care in improving workforce participation for people with chronic health conditions.^{33,35,128} Support to implement the innovations to comprehensive care proposed in **Section 6.16 Clinical treatment and care services** would assist to achieve this, as well as the shorter waiting times for appointments raised by the Productivity Commission.

Around one-third of older survey respondents said they wished to reduce their working hours or retire early. Suggestions on what would help included:

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

'What I hope to be able to do is to scale down from full-time work in about 10 years, when I turn 60. I hope I can concentrate on things like getting access to aqua therapy sessions to support my joints and to keep my weight down and things like that; get my orthopaedic needs addressed. I would like between now and when I am 60 to look at a 4-day working week if I can negotiate it and make it financially viable.'

Partners and carers

Partners and family who completed the survey agreed that resolving the person with a bleeding disorder's pain and mobility issues and having more understanding in the workplace would also help the partner or family member to stay in the workforce. Other suggestions included:

- 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 selfemployed 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.'

Support and advocacy

Working and feeling productive and useful are key aspects of many older people with bleeding disorders' quality of life. Resourcing the psychosocial workers in the HTC team to support them to negotiate the options available to them will be a major factor in maintaining this community's wellbeing into the future.

It would be difficult for a rare health area such as bleeding disorders to achieve change in the workforce on its own and it would be useful for HFA to consult with other community agencies in the chronic illness area who are investigating ways to support their community members to remain in the workforce and seek collaborations, where appropriate. At the time of publication, the workforce adjustments to the COVID-19 epidemic were foreshadowing a shift in thinking regarding flexible working arrangements. Workplaces had accommodated working from home to assist with 'social distancing'. It would be valuable to consult further with the older bleeding disorders community about the impact of working from home and whether this was able to provide them with the benefits they hoped. Once again, due to the small numbers, collaborations with other community agencies on this issue would be helpful to gain a broader national perspective.

Education for workplaces

Education materials on managing a person with a bleeding disorder targeted at workplaces may also be valuable.

6.22 Finances

Both community members and health professionals drew attention to the financial costs of living with a chronic health condition. Finances were a concern for the future, 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 \$.'

Among partners, 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.' As was noted in the HFA hepatitis C needs assessment, with an uncertain working life, many older people with bleeding disorders had looked to establish their financial security early in their working life.⁹⁹ The Getting Older survey highlighted the importance of owning their own home to participants, with 65% of the older people with bleeding disorders owning their own home outright and 17% with a mortgage.

As a sample of the wider community of older people with bleeding disorders, the Getting Older survey showed a more financially independent community than expected. Most received their main source of income from their employment, either in wages/salaries or business income. The next largest group received government benefits, such as the age or disability support pension. More than a third were self-funded retirees, whose income came from superannuation or other investments. A smaller number were supported by their partner or by family or friends.

6.22.1 SUPERANNUATION AND INSURANCE

Nearly all older people with bleeding disorders who completed the Getting Older survey had superannuation, although they did not indicate whether the amount of their superannuation would be adequate for a comfortable retirement. They also commented that their bleeding disorder and for some their bloodborne viruses meant that getting income protection, disability and life insurance could be problematic, 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. This could have significant implications for their financial situation in the future if they were forced to retire early due to disability from their health conditions.

'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.'

A partner described the impact of an interrupted working life on their superannuation and financial security:

'There have been always financial issues as he hasn't worked for a long time. He was on casual work and on disability support, I was working casual and on a carer's pension. We have always kept ourselves out of debt but it's not like we have got much in reserve. We are just living as we go. Things like super, he doesn't have. My super has been at a minimum as I was working part-time for a long time. And he hasn't got life insurance.'

With a fragile financial situation going into their senior years, this could make access to the services where there would be out-of-pocket costs much less available to older people with bleeding disorders because of the affordability issues. This would include many of the services proposed in this needs assessment, including home and community care services, community nursing, disability aids and equipment, and health services outside their HTC, including local services, such as physiotherapy, podiatry and dentistry, which would be accessed through the private system.

While private health insurance may assist with some of the out-of-pocket health care costs, HFA community consultation for the Private Health Insurance Inquiry in 2017 indicated that affordability and value-for-money issues made private health insurance unattractive to many people with bleeding disorders in Australia. Many community members said they used the private health system for some aspect of their health care – as a private patient in a public hospital, or to manage health issues not related to their bleeding disorder, or for extras such as optometry, hearing aids, dentistry, or physiotherapy. They were very concerned that the premiums for private health insurance were becoming unaffordable, even for those on middle incomes, while the benefits were decreasing sharply. Others commented that although they had private health insurance they were unsure of its value to them, as benefits were poor and they were largely required to use the public health system because of their bleeding disorder.¹²⁹ These concerns are likely to increase as people with bleeding disorders grow older, particularly if their financial situation becomes more precarious and they have to wind back their expenditure. However, this would mean they would be less likely to access the services that would improve their health and wellbeing as they grow older.

6.22.2 FINANCIAL PLANNING

The *Don't go it alone* study pointed out that if older Australians were satisfied with their perceived current financial situation, they often experienced higher life satisfaction.¹¹¹ It was interesting to see that older people with bleeding disorders who participated in the consultation were aware that they may need to make uncomfortable decisions in the future to manage their finances and had not yet sought financial planning to deal with this. People who completed the survey were more likely to comment on being careful with spending rather than formal financial plans.

'Probably a financial plan...I need to receive financial planning advice as my savings and superannuation are very limited. I am awaiting the opportunity to discuss this issue with a professional as I live day to day.'

'Having been through aged care process with her [wife's] mother and my mother, we are aware if I need residential care, it is expensive. So we need financial flexibility to afford that. That means planning ahead. That I think is fairly probable for me.'



WHAT WILL HELP?

The consultation highlighted the cumulative impact of living with a bleeding disorder on reducing income over a lifetime and increasing health care costs.

The greater majority of older people with bleeding disorders had acquired hepatitis C before the 1990s, which compounded their health and financial issues. In spite of the recommendation of the Australian Senate Committee that they should receive access to financial support for the costs that flow on from these health complications, this support has not been received. This financial support would make a considerable difference to alleviating some of their concerns about managing their care and home environment into the future.

Participants in the needs assessment consultation raised a variety of specific concerns around financial security as they grow older, depending on their individual situation. A range of options would be required to address their concerns, including:

- Information about financial planning and the services available promoted widely in foundation activities, for example, on the Getting Older Information Hub on the HFA website, in foundation newsletters and peer support activities and at education events such as the national bleeding disorders conference.
- Exploration of government financial safety net options and vigorous advocacy through HTCs and foundations to access all options under existing programs, including the NDIS and MyAgedCare.
- Support and advocacy from HTCs and foundations to enable older people with bleeding disorders and their partners to access existing programs providing assistance for disability aids and equipment, travel to medical appointments and community nursing. There is wide state and regional variation in how these programs are implemented and the options available would need to be investigated individually.

- Increased resourcing to HTCs and foundations to enable them to undertake this investigation and advocacy on behalf of their patients/community members and their partners and family.
- Government financial assistance with out-of-pocket health and welfare costs not covered by existing government programs. Where an older person has private health insurance and this could provide some assistance with defraying costs, the government financial assistance could cover the gap fees. However, as outlined in this section, the needs assessment highlighted the financial problems for some older people with bleeding disorders and their concerns about private health insurance, making it less likely they would have private health insurance as they reached their senior years.
- Government financial assistance to support people with chronic health conditions and disabilities to remain in the workforce, who are currently excluded from the NDIS and other disability financial support.
- Exploration of barriers to various types of insurance and superannuation and consideration to relevant advocacy.

6.23 Travel

The desire to travel, see the world and meet up with family and friends interstate and overseas was a commonly held aspiration. Underneath this aspiration lay an acknowledgement of the complexities of travel for a person with a bleeding disorder.

'Actually, there is clash between what you hope for yourself. I hope to travel around the world. But actually, it's not simple. I did it when I was young and didn't even think that I might need treatment. I went all over the place and didn't even consider that I should have a plan.'

Although travelling internationally could offer a considerable challenge to an older person with limited mobility and who needed to take treatment product with them, this did not appear to deter them from their plans. Most of the concern about travel was the difficulty of obtaining travel insurance, either because companies would not insure them or had high premiums for pre-existing health conditions like haemophilia.



WHAT WILL HELP?

Education resources about travel targeted at older people with bleeding disorders may assist them to plan and travel more safely and comfortably. With the aftermath of COVID-19, this will need to take into account travel restrictions for older people and special considerations around safety and infection control, for example, on cruise ships, which are often an appealing option for older people with mobility problems.

Advocacy around lower costs for travel insurance for people with bleeding disorders may also be advantageous.

6.24 Future planning

When asked about planning for the future, older people with bleeding disorders and their partners would commonly discuss planning around their future accommodation, which may involve modifying their current housing or moving to a smaller residence or to residential care. Partners or family were more likely to comment that there were plans for increased family support in the future.

'I am expecting my joints to get worse and worse. That's when I have to make changes to my life. I am going to lose my lifestyle and a certain level of independence. First option is to move into a retirement village and get help to do bits and pieces. I never contemplated it before now I have start putting things in place.'

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

Psychosocial workers were concerned about the lack of planning around end-of-life care. One commented, 'practical things are also required to help improve quality of life, such as planning with making a will, an advance care directive, having control over medical decision- making with a Medical Power of Attorney.' Survey results highlighted this problem: only a quarter or less had prepared formal medical or legal documents, such as a will, a power of attorney or an advance care plan.

A considerable number 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. These are important issues which would need to be addressed through psychosocial support, such as counselling.

'The issue for me is I don't have any plans. I live on a day to day basis, I don't have a plan for when I get older. Why do I want to retire from work? Do I have enough money to retire?' '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.'



WHAT WILL HELP?

Planning for the future is an important aspect of health and wellbeing. Given the psychological issues identified in the consultation, a considerable number of older people and their partners will require psychosocial support to deal with the issues confronting them with future planning. A case management approach may be beneficial.

Promoting education materials about future planning could also support community members. This could include:

- House modification, downsizing, residential care
- Powers of attorney
- Advance care planning
- Making a will.

6.25 Information and education

The consultation identified a range of areas on growing older with a bleeding disorder where education materials would benefit the health and wellbeing of people with bleeding disorders and their partners and family.

This included education resources targeted at:

- Older people with bleeding disorders
- Their partners, family and carers
- Health care and community workers who provide their care in the community
- Workplaces.

Topics for education materials included:

- Special issues related to growing older with a bleeding disorder in men and women, including what to expect with health conditions of ageing
- Self-management for best health outcomes
- Understanding pain
- Aged care services.

Getting older survey respondents also ranked their interest in particular topics and the results are summarised in order of popularity for older people with bleeding disorders below:

- Exercise and remaining active
- New treatments
- Pain management
- Travel
- Nutrition and weight management
- Safety at home when getting older
- Accessing aged care services and the NDIS
- Vein care
- Working with a GP
- Caring for mental health
- Financial management.

More than 85% of both older people with bleeding disorders and their partners and family who completed the Getting Older survey said they used a computer or a mobile device like a tablet or iPad daily. Most used their computer at home or their mobile phone to access online information, with older people more likely to say they used their tablet or iPad than partners or family. This may be a reflection of their manual dexterity.

When asked about how they would prefer to get information or education materials about getting older with a bleeding disorder, most preferred to get their information online. However, around one third of older people with bleeding disorders and one quarter of partners and family preferred printed materials. 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.



WHAT WILL HELP?

How to provide education materials

Developing a **Getting Older Information Hub** on the HFA website will be a valuable way to centralise access to information for both the bleeding disorders community and for the health care and community workers who provide their care. It would also support independent research by both groups.

The Getting Older survey underlined that the HFA website is trusted and well-respected in the community as a source of information on bleeding disorders. The website has an information partnership with the Australian Government health information portal, HealthDirect, and provides high-quality, evidence-based health information in plain language, most of which has been focus-tested with the target groups.

To reach the wider bleeding disorders community, it will be crucial to promote the Information Hub in the environments where people with bleeding disorders receive their treatment and care, for example, in HTCs and through the general practitioners and other clinicians who provide their care outside the HTC. Promotion will also involve investigating ways to rank the Information Hub higher in search engines and other online promotion strategies so that people undertaking independent online research are directed to it.

It will also be important to provide information in local foundation newsletters and the HFA journal, *National Haemophilia*.

Consideration will need to be given to what information to provide in print format, including brochures and booklets, to meet the range of needs in the community, and where it may be valuable to provide information both online and in print.

Approach

Ensuring that the information is presented in an accessible way for the target group will be essential if it is to be effective as an education resource.

The objectives of the education resources will be to improve:

- The health literacy of the older person with a bleeding disorder and their partner and family
- The understanding of care providers on how best to provide care to them.

A key aspect of creating a meaningful framework for the education materials will be to focus on the patient journey as they grow older, the issues they encounter, and how these can be managed for the best possible health and quality of life.

The education materials will also need to be tested with the target group to ensure that the language, concepts and format are accessible and meet their information needs.

Development

To develop relevant and effective education resources will involve collaborations between the community, HTCs and other organisations and individuals with expertise and experience in the area. In some cases, it may be more appropriate for HFA to lead development, for example, with consumer resources, while health professionals may need to lead the development for resources related to their specific discipline. These collaborations may also assist with sourcing education resources or strategies that could be adapted for the bleeding disorders community.

6.26 Hard-to-reach populations

The needs assessment identified that there needed to be further research to understand the special issues with ageing for some populations with bleeding disorders who were difficult to reach through the consultation. This included the people with mild disorders who were not connected to HTCs or haemophilia foundations and some particularly vulnerable people where there may have been barriers to participation in the consultation in the timeframes. This would include some people experiencing housing insecurity and not contactable via post, phone or email. Literacy problems, and/or cultural, language and connection issues may have been a barrier, for example, in some people of culturally and linguistically diverse (CALD) backgrounds or some Aboriginal and Torres Strait Islander people, or some people with mental health or other serious health issues.

As for the wider population with bleeding disorders, the experience of growing older will also be a new phenomenon in the more vulnerable groups and numbers are likely to be small. Early ageing is also likely to be a significant issue.



WHAT WILL HELP?

There are several opportunities to build further consultation around ageing onto existing and proposed work to connect to these groups.

HFA will be conducting a wider community awareness campaign around VWD in 2021 when the new national diagnostic and clinical management guidelines are released. Through this campaign, HFA, state/territory foundations and HTCs aim to connect to people with VWD not previously known to them. Many are likely to have a mild form as those with severe disorders are usually connected to an HTC early in life. Further consultation around the impact of getting older and their associated education and support needs could take place during the process of connecting with older people with VWD, either formally, for example, as questions in a membership survey, or informally as part of the welcome to the foundation or HTC services.

A variety of strategies will be required to consult further with the more vulnerable groups. HTCs and state/territory foundations have existing outreach with Aboriginal and Torres Strait Islander people and services and have been building connections and peer support for individual people of CALD backgrounds and their families. It will be important to link any further consultation to this existing work. Bleeding disorders occur in families and it may also be valuable to use 'snowballing' techniques through families that are already connected to communicate and consult with others who may be affected.

Discrimination is a common issue for people with bleeding disorders and this may make disclosure and connection more difficult, particularly in vulnerable groups. Because bleeding disorders are genetic and inherited, disclosure of a bleeding disorder in an individual can have implications for their entire family. It will be valuable to discuss strategies for overcoming this with international colleagues: this is a recognised issue and some will already have addressed this locally when undertaking consultation. It may also be helpful to consider the strategies adopted by other Australian agencies who consult with vulnerable populations around health conditions, which may be associated with social stigma.

7. The way forward

A common goal of all community and health professional stakeholders consulted was to enable older people with bleeding disorders to maintain the healthiest life possible.

The intention was to assist them to maintain or even improve their quality of life and to remain independent for as long as they could.

Another important objective was to support the aspiration of many older people to contribute and be productive members of society.

Systemic barriers

In 2017 the Australian Productivity Commission identified factors and influences that may affect Australia's future economic performance and priorities to enhance national welfare. The Shifting the Dial report points to chronic ill health problems and systemic barriers in the health system that impact on the health of Australians.³³ The Getting Older needs assessment confirms that many older people with a bleeding disorder are also deeply affected by comorbidities with other chronic health conditions. Some experienced poorly integrated health services, lack of case management, concerns about access to care, treatment and referral, particularly in the community and regional areas, inadequate or inconsistent funding models across jurisdictions, the tyranny of distance where living in rural and regional locations or marginalisation by disability or mobility issues. There is potential to address and prevent some of these complications now and introduce prevention strategies at an earlier stage of the lives of others as they grow older.

Reporting health outcomes

The bleeding disorders treatment environment is fast moving with innovative therapies including gene therapy on the horizon that can improve health outcomes. The outcomes of these treatments should be measured using patientoriented outcome measurement tools already validated and available and the data should be reported and built upon. An important step will be to explore whether the PROBE Australia data can be combined with ABDR data to generate a more comprehensive dataset and subsequently incorporated into clinical guidelines.

Achieving bleeding disorder community goals and aspirations

For older people with bleeding disorders, HFA's vision of 'active, independent and fulfilling lives for people in our bleeding disorders community' has been translated to goals of living the healthiest life possible, maintaining or improving quality of life, prolonging independence and contributing to society.

A range of factors will be involved in achieving this:

- Innovations in comprehensive care to provide easier access to targeted services and programs and coordinated care with relevant medical specialties
- Treatment plans, including access to newer and emerging therapies, to improve quality of life and reduce the burden of treatment
- Further research to better understand specific issues of ageing, including in mild conditions, in the rarer bleeding disorders, and in women
- Targeted patient education to assist with their understanding of growing older with a bleeding disorder and effective self-management
- Education about growing older with a bleeding disorder for health care professionals and carers
- Continuing to address the complications of bloodborne viruses, such as HIV and hepatitis C, including the need for financial support
- Support for an active approach to life: exercise, travel, personal interests
- Support to continue working, where appropriate, and other ways of contributing their skills and experience
- Assistance with future planning
- Building on the resilience and existing support networks of older people with bleeding disorders
- Addressing the needs of their partners and carers
- Increased information about and access to community support and home care services
- Advocacy around financial issues
- Developing social connection and peer support for both the person and their partner/carer
- Investigating digital solutions for community information and communication needs related to getting older.

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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.



Let's talk about getting older

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

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	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:









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

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-inhand 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.

'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





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

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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	Respon	ises
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?

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 selfemployed 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 selfemployed 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



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





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)



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-toface 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	 Personal experience Survival tips Listening skills Partners/family to the headers on this column 	

- Challenges for people with mild disorders and their carers
- Strategies for self-advocacy

	How would you like to do it?							
	People with bleeding disorders	Partners/family						
•	Face to face in small groups or casual get togethers	• Group						
•	Group discussion online	Social media						
•	Social media discussion	Conference						
•	Email, sms, telephone	Meeting						
•	Workshop or Zoom	Newsletter						
•	Write personal story							

Online communications

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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 bleeding	e with 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





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.

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.



Patlent Reported Outcomes Burdens and Experiences Study

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.

	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

Table 1: Respondents by gender and age

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

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	vrs bv	gender	and	severitv
	neoponacinto		<i>j</i> ·• ~ <i>j</i>	Benaci	4114	sevency

	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 v haemo MW	with philia /H	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.

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Table 6: Treatment regimen

	Men with haer MWH	nophilia ≥45 yrs 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

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 had ≥ 45 yrs I By seve	emophilia MWH rity	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 haem M\ By se	nophilia ≥ 45 yrs WH verity	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

Table 10: Target joints		Men with haemophili ≥ 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 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	1						

Yes	2	11	13	1
No	26	15	41	19
l 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		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

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 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 was particularly apparent in relation to areas involving mobility and physical functioning.

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

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





- %08 - %02 - %09 - %05 40% -30% -20% -10% -

%0

100% 80% 100% · %06 80% 20% .%09 50% 40% 30%

20% -

10%

%0



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, 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.

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, 62% (18/29) 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 without a bleeding disorder. In the group without a bleeding disorder 41% (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 10: Physical functioning and pain in the last 12 months men without a bleeding disorder 45 years and over







PROBE AUSTRALIA STUDY FINDINGS

Not reported

No

Yes

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

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

Fotal number = 21



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 (28% 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 (38% 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.





4. OTHER HEALTH PROBLEMS

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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	T	Total 57		Total		
Total N =		29		28				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,

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.



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

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:

Table 14: Hepatitis C diagnosis

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.

	Men with h ≥ 45 yr: By se	aemophilia s MWH verity	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 h ≥ 45 yr By se	aemophilia s MWH verity	Women with and carriers a By se	TOTAL		
	Mild Severe/moderate		Normal	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.

	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

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



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

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	s 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.

	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

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

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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