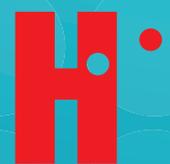


BEYOND PROPHYLAXIS PROJECT

*understanding and addressing the unmet needs
of young people with bleeding disorders*

NEEDS ASSESSMENT REPORT

JULY 2012



HAEMOPHILIA FOUNDATION AUSTRALIA

This report was researched and written by Haemophilia Foundation Australia

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- Former HFA Youth Committee members
- Parents who participated in consultation
- State and Territory Haemophilia Foundations
- Haemophilia health professionals at State and Territory Haemophilia Centres
- Burnet Institute Centre for Population Health, Family Planning Victoria, the Australian Research Centre in Sex, Health and Society and the Australian Centre for the Moving Image

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EXECUTIVE SUMMARY

Improvements to treatment and care for young Australians with bleeding disorders have changed the experience of living with a bleeding disorder and there is little information about the impact of this on young people. Haemophilia health professionals and community organisations have reported poor decision-making among young people about their lifestyle and life choices, with significant impacts on their health and wellbeing. They have also reported difficulties engaging young people in their own treatment and care, community activities and peer education.

Beyond Prophylaxis project

The Haemophilia Foundation Australia (HFA) *Beyond Prophylaxis* project addresses the lack of information and understanding about the unmet needs of young Australians with bleeding disorders and the lack of resources to respond to their needs. It aims to involve young people in developing an accessible and attractive web-based communication tool for peer engagement, education and support. The intention of the project is to work towards equipping young people to manage the reality of the limitations of living with a bleeding disorder positively and with the least harm to themselves.

Living a 'normal' life

More effective treatment and care for young Australians with bleeding disorders has created a new generation which has expectations of living a 'normal' life. However, this has meant that young people now have fewer opportunities to connect with their peers or older members of the community through Haemophilia Centre visits or clinics. This means young people also have fewer opportunities to talk with others about both managing the problems related to bleeding disorders that they nevertheless do experience, and the long-term impact of bleeding complications. For young people at all levels of severity, experiencing the reality of living with a bleeding disorder and the complications that can result can be isolating and confronting when they have been educated to expect a 'normal' life.

Disengagement and non-compliance

Consultation with the community, parents and health professionals has highlighted that as teenagers, many young people also disengage from the bleeding disorders community and do not comply with their treatment and care regimes for a range of reasons:

- Peer pressure and wanting to be 'normal' or needing to look 'cool'
- Pressures of study
- 'Don't care' attitude
- Maturity issues and stages of development
- That most people with haemophilia are male, at this age they feel "*invulnerable*", and "*boys don't talk*".

Perspectives of young people

In contrast, consultation with young people indicated that they experience a range of problems due to their bleeding disorder at this age, including:

- Understanding their medication and how to manage it
- Managing pain
- Missing out on school, sport, travel or work due to bleeding problems or appointments
- Feeling different and alone
- Discrimination, bullying and stigma
- Issues in managing their relationships with health professionals
- Negotiating health care services and understanding what is available
- A need for health services to be more flexible to accommodate their needs.

Young people also commented that it is important to get to know their body as it develops during puberty and learn how their bleeding disorder affects them individually.

One spoke of a *“hating my haemo”* phase and that, while he was now resigned to living with his bleeding disorder, he still wished he did not have it. Younger people in the 13-15 year age group described particular difficulties in learning the skills to:

- Manage their treatment, including self-injection
- Explain their health condition or health needs to others, for example, to friends and other school students, friends’ parents, teachers, and health professionals who do not specialise in bleeding disorders.

Risk-taking and experiencing life

Haemophilia Foundations and health professionals had particular concerns about young people discontinuing treatment, making uninformed decisions and taking risks related to career choice, sports and other physical activities because of the permanent musculo-skeletal damage or injury that could result. They noted that disabilities acquired through haemophilia or injury could cause young people to drop out of participation in sports, school, work, or with their peers, and could lead to them becoming disempowered and isolated. They were aware of problems with depression, anxiety and self-esteem among young people with bleeding disorders.

Young people, on the other hand, wanted the opportunity to explore their independence and have the opportunity to make mistakes and learn from them.

Environments for connection

Young people, community members and health professionals saw the Beyond Prophylaxis project as an opportunity to take positive steps towards creating spaces where young people could connect, share experiences and learn from each other, inform themselves about bleeding disorders, develop life skills and have some fun together.

They agreed there should be a mix of options for contact and connection:

- Web-based and social media-based communication tools
- Face-to-face meetings, such as national youth camps, weekends or “catch-ups”
- Using the telephone and Skype to connect
- Other information resources, including print-based.

Peer education and mentoring

It was important to young people to have opportunities to share stories and learn from each other’s experiences; for example, to have video and story blogs on a web site and their own examples of ‘how to’. Young people also agreed that it was important to develop a group of older young people who could take on the role of peer educators and mentors, with the potential for being community leaders in the future.

Engaging the disengaged

Engagement with young people with bleeding disorders in the consultation was difficult and highlighted the need for face-to-face connection and other strategies to build trust and confidence in HFA’s work in this area. All groups consulted referred to young people with bleeding disorders who are isolated and difficult to engage, often because they prefer not to identify with having a bleeding disorder or with the bleeding disorders community or do not find the community activities attractive. They noted that isolation from peers with bleeding disorders and community could contribute to the sense of being alone and decrease opportunities for learning effective ways to manage their bleeding disorder from peers, community mentors or health professionals. Further investigation into engaging with this group and understanding their needs would be valuable.

Preparing adolescents for independence

Health professionals also noted the need to prepare pre-teens for the skills they will need to become independent in the future, before they start to disengage from their Haemophilia Centre during their early teenage years. This work will need more exploration to enable it to be scoped.

Proposed web site

The project’s web-based communication tool could provide a more attractive forum for young people to discuss their needs and experiences and explore sensitive issues anonymously and honestly. It could provide evidence-based information on priority issues such as health, lifestyle and life skills for working, relationships and socialising in the language of the young people accessing it and create a space for peer education and connection. Ensuring that this is developed appropriately and any forums moderated carefully would involve the work of a skilled professional.

RECOMMENDATIONS

Target group

1. Target the project at young people affected by bleeding disorders in the 13–30 year age group.

Engagement and further consultation with young people

2. Investigate further how to engage isolated and disengaged young people with bleeding disorders, in particular those in the 13-16 year age range. This may include further consultation with the Youth Working Group (YWG), parents and other bleeding disorders groups, and also with other services for young people with disabilities or chronic health conditions.
3. Explore further the “*hating my haemo*” phase with young people with bleeding disorders through the YWG and discussion forums in the web-based communication tool.
4. Work to engage with young people with bleeding disorders should include a face-to-face component to build connection and trust.

Web site design and content

5. Develop a web-based communication tool. The design to include:
 - Sections where young people can share experiences and personal stories
 - Accurate information in the language of young people
 - Information for girls with bleeding disorders and siblings
 - An area restricted to young people affected by bleeding disorders which can include moderated forums on sensitive topics
 - The moderation of the discussion forums to be undertaken by a skilled professional such as the Youth Project Officer
 - Polls, surveys and other tools to promote engagement and maintain an understanding of current priorities and interests among young people affected by bleeding disorders.
6. Focus the information and activities in the web-based communication tool on priority issues, using creative ways to engage young people, including challenges, humour, videos, personal stories and peer education.

Web site promotion

7. Undertake a targeted promotion of the web-based communication tool to reach both well-connected young people with bleeding disorders and those who are disengaged.

Peer education and mentoring

8. Further develop the role of young people with bleeding disorders as peer educators and mentors:
 - 8.1 Identify potential mentors and include them in the development of the project.
 - 8.2 Explore the possibilities of their role in the ongoing sustainability of the project, including training needs.

Ongoing strategy for connection and education

9. Develop an ongoing communication, education and engagement strategy for young people affected by bleeding disorders that includes a range of options for contact, including online and social media technology such as facebook, telephone or Voice Over IP (VoIP) technology such as Skype, and face-to-face meetings, such as national youth camps, weekends or *"catch-ups"*.

Education of adolescents, community and other stakeholders

10. Provide feedback and education to the community, health professionals and government on priority issues for young people so that these can be addressed in future planning.
11. Explore opportunities and the resources available or required to educate parents, schools and the wider community on bleeding disorders to increase understanding and reduce stigma, discrimination, harmful peer pressure and bullying.
12. Investigate further work to prepare pre-teens with bleeding disorders for the skills they will need in the future to become independent.

INTRODUCTION

Improvements to treatment and care for young Australians with bleeding disorders have changed the experience of living with a bleeding disorder and there is little information about the impact of this on young people. Haemophilia health professionals and community organisations have reported poor decision-making among young people about their lifestyle and life choices, with significant impacts on their health and wellbeing.

The *Beyond Prophylaxis* project addresses the lack of information and understanding about the unmet needs of young Australians with bleeding disorders and the lack of resources to respond to their needs. It aims to involve young people in developing an accessible and attractive tool for peer engagement and support. The intention of the project is to work towards equipping young people to manage the reality of the limitations of living with a bleeding disorder positively and with the least harm to themselves.

The project consists of:

- A needs assessment to investigate the unmet needs of young Australians with bleeding disorders
- Involving young people affected by bleeding disorders in developing a web-based tool to connect, share experiences and obtain information about relevant life and lifestyle choices, including work, travel, sport, recreation, relationships and socialising
- Working with young people to develop a sustainable strategy to enable them and others to improve their life skills and make positive and informed choices about their lifestyle now and in the future.

The project will assist in building the youth leadership capacity of Haemophilia Foundation Australia (HFA) and increase the sustainability of HFA's work with its younger members into the future.

The *Beyond Prophylaxis* project started in April 2011 and a Youth Project Officer was employed to lead the project in August 2011. The project has a large component of community development and this process is incremental. Through the needs assessment activities and the development of the web-based communication tool, the project aims to:

- Engage young people with bleeding disorders in communicating about the issues they experience living with a bleeding disorder
- Increase the understanding of the young people themselves, Haemophilia Foundations, health professionals, and parents about the life and lifestyle issues that young people encounter
- Build connections between the young people, and also with the haemophilia organisations who represent them and provide their education and support
- Develop an effective on-going strategy to enable young people to make decisions that can have better outcomes for their future, while building the youth leadership capacity of HFA.

The plan was for the Youth Project Officer to recruit a Youth Working Group (YWG) of young people affected by bleeding disorders and work with them on the consultation for the needs assessment and on the development of an accessible and attractive web-based tool as a communication platform. The YWG will have an active role in deciding what the communication tool will look like and what information it will provide. With the Youth Project Officer, the YWG will also develop a strategy to sustain the work of the project into the future and promote youth leadership in the bleeding disorders community. The aim of the project is to encourage and motivate young people with bleeding disorders to participate in the development of treatment and care services and to create an environment for peer support. It is anticipated that some YWG members may take on youth leadership roles themselves.

BACKGROUND

"There needs to be more support of teenage males in particular who may say they are coping but in fact may not be." – Parent

"As a mild haemophiliac, my contact with the bleeding disorders community is small to non-existent. When I was a teenager I was quite ignorant about haemophilia. It is crucial to inform teenagers with bleeding issues about them. I have only ever met one other haemophiliac in my life - my brother!" – Community member

"I believe that the real benefit of using social media will be for the teen/youth section of our community, in terms of both being able to better engage that group in the bleeding disorder community and secondly (and probably more importantly) providing a support network via a medium that they will be comfortable using. As a parent of a 14 year old boy with haemophilia I see social media as about the only way he will engage (willingly) in the bleeding disorder community. He is beyond/not interested in many of the other activities that our Foundation does, with the exception of the camps." – Parent

Sources: HFA National Member Survey 2010; HFA Social Media Community Consultation 2011

Recent improvements to treatment and care of young Australians with bleeding disorders have created a new generation which has expectations of living a 'normal' life. Ironically, the benefits of effective treatment and the resulting normalisation of their bleeding disorder have also brought some unforeseen disadvantages. Young people now have fewer opportunities to connect with their peers through Haemophilia Centre visits or clinics and to talk with others about managing the bleeding disorder-related problems that they nevertheless do experience. They also have less opportunity for intergenerational contact and to see the long-term impact on joints, mobility and pain of having repeated bleeds. Some have a severe bleeding disorder or may have inhibitors, meaning that their treatment is less effective, and can live with considerable disability and pain. For young people at all levels of severity, experiencing the reality of living with a bleeding disorder and the complications that can result, when they have been educated to expect a 'normal' life, can be isolating and confronting.

Haemophilia Foundations struggle to engage young people in current and future planning for treatment and care services and in peer education and support. While there has been a core of young people who have been interested and involved in HFA programs, there has been difficulty engaging with the wider community of young people with bleeding disorders. When new participants attend a youth program development camp, they are excited to meet each other and keen to stay in touch, but finding effective ways to sustain this contact and extend it to others has so far had limited success.

A preference not to identify with having a bleeding disorder or with the bleeding disorders community may also have a negative impact on transition from paediatric to adult treatment services, and there are anecdotal reports of treatment non-compliance and adjustment issues for youth transitioning from children's hospitals to adult treatment settings. When young people do not attend regular clinical reviews and Haemophilia Centre health professionals do not have the opportunity to see young people at appropriate times, this can result in inappropriate treatment product use, suboptimal dosing and/or inadequate clinical oversight and follow up.

HFA has been aware for some time of the concerns of State and Territory Foundations, health professionals and parents regarding young people's lifestyle choices, but had little evidence-based information about this. There is little information about the impact of bleeding disorders on young people in Australia. Haemophilia health professionals and community organisations have reported a lack of decision making skills among young people about their lifestyle and life choices, with significant impact on their health and wellbeing. Health professionals described a lack of understanding by young people of how having a bleeding disorder will affect their way of life such as recreation and sport, travel, career, relationships, or having children until they are confronted with injury, rejection, failure or other complications. This can have significant physical, social and psychological impacts on their lives.

Haemophilia health professionals and Haemophilia Foundations have reported a range of medical and psychosocial problems in this group, including problems due to lack of connection and isolation and problems related to lack of knowledge about bleeding disorders or how to apply this information to themselves. They noted that this can result in an inability to make good and well-informed decisions about their lifestyle and life choices. There has been little research in this area and as yet the needs of this group are not properly understood. However, the increasing impact of poor decision-making on young people with bleeding disorders and the physical and psychological harm that results has made the need for action in this area a priority.

LITERATURE REVIEW: THE REALITY OF LIVING WITH A BLEEDING DISORDER

Studies of young people with bleeding disorders have identified a number of crises that occur as they mature, particularly during adolescence and teenage years, during the transition from paediatric to adult haemophilia treatment settings and as they become more independent and take on adult activities and responsibilities¹. During this time young people with bleeding disorders are experiencing normal but nevertheless dramatic and simultaneous physical, psychological, social and sexual changes, which are compounded by the challenges of living with a bleeding disorder².

Some issues identified include:

- Decreasing compliance with treatment. A worldwide study showed that adherence to treatment decreased from 90% in the 0-12 age group to 54% in the 13-18 age group and 36% in the 19-28 age group. Reasons cited most frequently were: inability to understand potential benefits, denial, poor venous access, lack of parental/family commitment, interference with lifestyle, teenage rebellion and lack of time.

¹ Breakey, VR, Blanchette, VS, Bolton-Maggs, PHB. Towards comprehensive care in transition for young people with haemophilia. *Haemophilia* 2010;16:848-857.

Geerts, E, Van de Viel, H, Tamminga, R. A pilot study on the effects of transition of paediatric to adult health care in patients with haemophilia and in their parents: patient and parent worries, parental illness-related distress and health-related Quality of Life. *Haemophilia* 2008;14:1007-1013.

² Petrini, P, Seuser, A. Haemophilia care in adolescents – compliance and lifestyle issues. *Haemophilia* 2009;15(Suppl 1): 15-19.

This can result in bleeding episodes which would have been prevented with prophylaxis and the potential for developing arthritis and joint problems later in life, which has been of concern to clinicians³.

- Unrealistic expectations of their ability to participate in sport without extra equipment, limits on types of activities and physical training to manage joint and movement deficits and prevent injury⁴. Australian children have been encouraged by haemophilia physiotherapists to increase muscle strength and fitness and participate in sport⁵. However, there have been increasing concerns both in Australia and internationally about the sub-clinical musculo-skeletal deficits among children, e.g. tender points in joints, shortening of muscles, development of target joints⁶. There is ongoing research in this area.
- The psychosocial challenges of restrictions to physical activities to young people's participation in sport, employment and managing their sexuality and relationships. International research highlights that issues relating to sexuality and sexual activity in youth are often neglected by paediatric doctors, with the result that both male and female patients can be concerned by common symptoms of bleeding and need advice on suitable ways to manage bleeding, pain and the social aspects of their relationships. Young women may also need advice on how to manage symptoms of menorrhagia at school or at work as well as in their relationships⁷.

Communication issues

During adolescence and teenage years, the development of a sense of identity and maturing cognitive abilities mean that a young person undergoes a massive transformation in a relatively short timeframe. Developing an understanding of who they are is a complex and challenging process that takes place alongside the development of language and communication skills. It is a period of life associated with struggle, crisis and conflict and where a young person does not necessarily have the language or ability to communicate the issues they are dealing with⁸.

For a young person with a bleeding disorder, identity also involves their bleeding disorder and being able to explain it to others. If they are not connecting with peers with bleeding disorders or older members of the bleeding disorders community, they have few opportunities to explore this with others who have had similar experiences, to discuss what this means for them or learn effective ways to talk about it.

³ Geraghty, S, Dunkley, T, Harrington, C, et al. Practice patterns in haemophilia A therapy – global progress towards optimal care *Haemophilia* 2006;12:75-81.

⁴ Petrini, P, Seuser, A. Haemophilia care in adolescents – compliance and lifestyle issues. *Haemophilia* 2009;15(Suppl 1): 15-19.

⁵ Broderick, CR, Herbert, RD, Latimer, J, Curtin JA. Fitness and quality of life in children with haemophilia. *Haemophilia*. 2010 Jan;16(1):118-23.

⁶ Seuser, A, Kusch, E. Multicenter study of orthopaedic outcome of the lower extremities in 249 children with haemophilia. *Haemophilia* 2006;12: abstract 18FP538.

⁷ Breakey, VR, Blanchette, VS, Bolton-Maggs, PHB. Towards comprehensive care in transition for young people with haemophilia. *Haemophilia* 2010;16:848-857.

⁸ Peterson, C. *Looking forward through the lifespan: developmental psychology*. 3rd ed. Sydney: Prentice Hall, 1996.

Recently there have been a number of initiatives to develop internet-based educational and social programs for adolescents with haemophilia to overcome this lack of connection.

A Canadian study investigated the preferences of young people with haemophilia aged 12-18 years to develop a web site to meet their educational needs and help them with self-management skills. The study found that the young people would like a web site with less text but nevertheless detailed information, videos about others' experiences, social networking through chat, forums and blogs, mentoring from older peers close to them in age and quizzes. The young people thought the web site would also be a useful educational tool for parents, friends, teachers and others⁹. A program for adolescents with haemophilia and other bleeding disorders in the United Kingdom is developing a restricted access online social network, with games and other features. Web site users can work through a modular training scheme and become "experts" in managing bleeding disorders, and through this may qualify as advisers for younger members using the site¹⁰.

THE AUSTRALIAN EXPERIENCE

There are more than 4300 people in Australia with inherited bleeding disorders. Australian young people with bleeding disorders include:

- Boys and young men with haemophilia
- A very small number of girls and young women with haemophilia
- Girls and young women who carry the haemophilia gene, with or without symptoms of a bleeding disorder
- Boys and girls and young men and women with von Willebrand disorder
- A small number of boys and girls and young men and women with other rare inherited bleeding disorders¹¹.

Bleeding disorder symptoms can range from severe, with bleeds into joints and muscles for no apparent reason, to mild, where bleeding episodes will only occur after injury or surgery or other invasive medical procedures.

⁹ Sterling, L, Nyhof-Young, J, Blanchette, VS et al. Exploring internet needs and use among adolescents with haemophilia: a website development project. *Haemophilia* 2012;18:216-221.

¹⁰ Khair, K, Holland, M, Carrington, S. Social networking for adolescents with severe haemophilia. *Haemophilia* 2012;18:e290-e296.

¹¹ National Blood Authority. *Australian Bleeding Disorders Registry Annual Report 2009-2010*. Canberra: NBA, 2010.

Australian haemophilia health care professionals and Haemophilia Foundations have reported that most young people will describe themselves as “fine” and will say that they don’t need any assistance. They are naturally more interested in engaging with their own peer groups than in creating a new one with other young people with bleeding disorders. However, their behaviour and experiences highlight a number of concerning medical and psychosocial issues:

- Periods where young people do not comply with treatment, especially in the 14-18 year age-group – they feel they do not need or want to have their treatment and do not consider the consequences
- Substantial numbers not attending regular haemophilia multidisciplinary review consultations at the Haemophilia Centre
- Lack of understanding of how having a bleeding disorder will affect their life and lifestyle choices such as recreation and sport, travel, career, relationships, or having children until they are confronted with injury, rejection, failure or other complications. This can have significant physical, social and psychological impacts
- Lack of knowledge about their bleeding disorder, e.g. genetic inheritance, target joints, prevention of long-term problems such as arthritis and joint damage
- Risk-taking with the result of injury complicated by their bleeding-disorder, especially under the influence of alcohol
- Lack of preparation for a new workplace (e.g. supportive shoes, adapted working environment) with the result that they are unable to continue working and feel that they are not suitable for the workforce
- Bullying and discrimination at school due to their bleeding symptoms, particularly among girls.

Many of these issues relate to the young person’s knowledge, insight, self-management and decision-making. They are complicated by the young people’s isolation from others in similar situations and by the normal behaviour of a young person who is maturing and becoming independent. These issues can have a major impact on a young person at an important time in their development.

Further investigation is required to understand how these issues relate specifically to young people with bleeding disorders, the complications they experience and to develop an effective strategy to enable young people to make decisions that can have better outcomes for their future.

METHODOLOGY

SCOPING THE NEEDS ASSESSMENT

A literature review was conducted to gain an overview of current local and international perspectives on the issues for young people with bleeding disorders. The perspectives of other Australian agencies with programs involving young people and social media were also sought and the Youth Project Officer met with the Burnet Institute Centre for Population Health, Family Planning Victoria, the Australian Research Centre in Sex, Health and Society and the Australian Centre for the Moving Image to discuss their current youth research and resources.

PHASE ONE CONSULTATION

An initial round of consultation with the HFA Youth Committee (who are young people affected by bleeding disorders), the community and health professionals was conducted during August and September 2011. The aim was to identify the main issues affecting young people with bleeding disorders and the types of information or resources that would be helpful to them. Preliminary results could then be provided to HFA Council (representatives of State/Territory Haemophilia Foundations) and the haemophilia health professional groups at their annual meetings in October 2011 to stimulate further discussion and recommendations.

Promotion and recruitment

Between April and July 2011 the needs assessment consultation was promoted widely to the community and to haemophilia health professionals. State and Territory Haemophilia Foundations were requested to consider options for promoting the project consultation and to bring it to the attention of young people they thought may be interested. The project was integrated into the biennial Australian and New Zealand Haemophilia Conference program, providing an opportunity to promote the needs assessment widely in the lead up to the Conference. The needs assessment was also advertised in *National Haemophilia*, HFA's quarterly journal, which is circulated to both community members and health professionals.

The project and needs assessment were discussed with the HFA Youth Committee and members were keen to be involved and promote the project. An article about the project was published in the June issue of *Youth News*, with a call for young people who were interested to identify themselves to HFA or to their State/Territory Foundation as a way of beginning the conversation about their potential involvement and engaging them with the project. If they demonstrated interest, they would be sent the consultation questions.

Data collection

Phase one consultation included concurrent discussions with the HFA Youth Committee, State and Territory Haemophilia Foundations and haemophilia health professionals on a similar set of questions, using various methods including teleconferences, electronic communications and face-to-face meetings.

All groups were asked:

- Their definition of the age range for 'youth'
- The main issues for young people with bleeding disorders
- Useful information and resources for this group

Haemophilia Foundations and health professionals were asked to describe:

- Concerns held for this group of young people.

The Youth Committee was also asked to comment on:

- The issues and help needed when they were younger
- What would help them now
- Preferred communication methods over the internet.

Haemophilia health professionals including nurses, physiotherapists and social workers and counsellors were recruited to participate in the consultation through their national groups. The groups included 23 nurses, 17 physiotherapists and 11 social workers and counsellors.

Seven Haemophilia Foundations were approached. Consultation questions were emailed, with follow up phone calls for Foundations who were slow to respond.

The eight members of the Youth Committee were consulted via email, following a discussion of consultation preferences at the regular Youth Committee teleconference.

PHASE TWO CONSULTATION

Need for further consultation with young people and parents

Only two members of the Youth Committee responded to the consultation questions, in spite of considerable follow-up, demonstrating the difficulties of engaging young people with bleeding disorders.

As a result a broader strategy was undertaken in a second phase of consultation. This included recruiting a Youth Working Group (YWG) to form part of the consultation process as well as to drive the development of the communication tool. This group would consist of young people affected by bleeding disorders aged between 13 and 30 years who showed interest in contributing to the project.

This phase also included consultation with parents of young people with bleeding disorders. In the initial consultation phase health professionals noted that it would be valuable to obtain the perspective of parents. Consultation with parents could also give insights into the issues of those young people who are reluctant to identify with the bleeding disorders community and are difficult to engage with the project.

Promotion and recruitment

From October to December 2011 the consultation with young people and parents was advertised in national and state Haemophilia Foundation newsletters, on the HFA Facebook page, and flyers were distributed to Haemophilia Centres for distribution to young patients and their parents. Local Haemophilia Foundations were encouraged to identify appropriate young people or parents and approach them about participating.

Face-to-face contact approaches were also used to recruit young people. The youth social activities at the Australian and New Zealand Haemophilia Conference in October 2011 provided an opportunity for the Youth Project Officer to engage and build rapport with young people and encourage them to join the national YWG. An interstate visit for a youth event was another occasion for face-to-face recruitment.

Young people in the 13-15 year age group were particularly slow to respond. In order to recruit young people in this age group paediatric health professionals were contacted and asked to target this age group specifically.

Data collection

Consultation with the YWG and parents took place between December 2011 and April 2012.

Most YWG members indicated that email would be their preference for consultation. They were emailed 2-3 questions weekly. In comparison, many YWG members aged 13-15 were contacted via phone as this was their preferred method and answered all of the questions in one phone call. All YWG members were asked the same series of questions, covering areas such as:

- Issues for young people with bleeding disorders
- Current needs and needs when younger
- Useful information and resources
- Preferences relating to information format, for example, personal stories
- Technologies used to access information on bleeding disorders
- Communication preferences now and into the future
- Web site style and format preferences
- Youth leadership in the bleeding disorders community.

Parents were all asked the same set of questions via telephone or email, depending on their preference. Questions were similar to those for the Haemophilia Foundations and the health professionals, with a greater emphasis on whether issues change at different stages of their child's development and the types of communication technologies used by their child.

See Appendix One for the complete set of consultation questions.

RESULTS

Qualitative methodologies were used to analyse the consultation responses. Data from the consultation responses was collated and summarised by topic. Responses relating to the main issues for young people were analysed for themes. All data was compared within and between the groups.

RESPONDENTS			
GROUP	RECRUITED	PARTICIPATED	SUB-GROUP PARTICIPANTS
YOUTH COMMITTEE	8	2	--
HAEMOPHILIA FOUNDATIONS	7	7	--
HAEMOPHILIA HEALTH PROFESSIONALS	54 Consisting of: 23 nurses 17 physiotherapists 11 social workers	16	7 nurses 6 physiotherapists 3 social workers; 8 adult setting 7 paediatric setting 1 combined adult/ paediatric setting
PARENTS	9	9	--
YOUTH WORKING GROUP	34	27	8 13-15 year olds 19 16-27 year olds

Youth Working Group (YWG)

By April 2012, 34 young people had been recruited to the YWG with ages ranging from 13 to 27 years. All states and territories were represented, except Northern Territory. Most participants were relatively well-connected to their State or Territory Haemophilia Foundation, but those aged 13-15 needed encouragement from their health care professionals to join the group. Of the 34 young people recruited, 27 answered the consultation questions.

Prior to the national Haemophilia Conference, there had been little response from young people to the requests to participate in the consultation. Of the YWG, 13 attended the national Haemophilia Conference and responded to requests to join the YWG after meeting the Youth Project Officer face-to-face at the Conference youth social events. Some were hesitant and asked for more information about what would be required of them before agreeing. Two members of the YWG agreed to join after meeting the Youth Project Officer at a visit for a youth-based activity in their state. Of the 10 young people aged 13-15 who were recruited, one responded to the promotional material in a newsletter, one was recruited by a Foundation and the other 8 were recruited through health care professionals.

Responses from the 13-15 year old YWG members were also analysed separately and compared to older YWG members. This analysis was undertaken for a number of reasons:

- This age group was much more difficult to engage in the consultation
- Their consultation preferences were different: most preferred telephone contact and did not offer an email address
- Their language and communication skills were markedly less well developed than older YWG members.

SUMMARY OF RESPONSES ACROSS ALL GROUPS

Perceived age range of youth	Most common start and end years for age range: 13-30 years
Concerns/Issues	<ul style="list-style-type: none"> ○ Suitable employment options/preparation ○ Independence when entering the adult health system/taking responsibility/self-management ○ Disengagement from health care professionals ○ Poor compliance with treatment ○ Fitting treatment in with school/university ○ Disclosure to friends/employers/schools ○ Mental health (depression, anxiety, self-esteem, body image) ○ Risk taking behaviour (physical activity; alcohol and drug use) ○ Planning for travel ○ Informed decision-making ○ Learning what haemophilia is and what it means ○ 'Fitting in' with peers
Resources that would be useful	<ul style="list-style-type: none"> ○ Web-based ○ Handouts/leaflets ○ Easily accessible ○ Fun and interactive ○ Career counselling ○ Role modelling ○ Group-based learning that is practical and hands on

SUMMARY OF GROUP RESPONSES – ISSUES/CONCERNS - THEMES

YOUTH COMMITTEE	HAEMOPHILIA FOUNDATIONS	HEALTH PROFESSIONALS	PARENTS	YOUTH WORKING GROUP
Preparing for independence Sport and exercise Personal relationships Working Peer education and mentoring Self-management Support Travel Discrimination Experiencing life Hepatitis C Hope for the future Negotiating health care services "Hating my haemo" phase	Preparing for independence Sport and exercise Personal relationships Negotiating health care services Mental health Risk taking (physical activity; drugs and alcohol) Disclosure Working Non-compliance and trying to fit in Disengagement and isolation Peer education and mentoring Self-management Informed decision making Support Travel Discrimination Accessibility of health care resources Understanding your condition School Acceptance of condition	Preparing for independence Sport and exercise Personal relationships Negotiating health care services Mental health Risk taking (physical activity; drugs and alcohol) Disclosure Working Non-compliance and trying to fit in Disengagement and isolation Girls with bleeding disorders Peer education and mentoring Informed decision making Self-management Support Travel Understanding your condition School Reproduction	Preparing for independence Sport and exercise Personal relationships Risk taking Mental Health Working Disengagement and isolation Peer education and mentoring Self-management Non-compliance and trying to fit in Informed decision making Discrimination Experiencing life Hope for the future Accessibility of health care resources School Accepting your condition Understanding your condition	<p>16-27 year olds:</p> Preparing for independence Sport and exercise Personal relationships Negotiating health care services Mental health Disclosure Working Disengagement and isolation Girls with bleeding disorders Peer education and mentoring Informed decision making Travel Discrimination Hope for the future Knowing your own body Accessibility of health care resources Siblings Understanding your condition School Experiencing life Non-compliance and trying to fit in Self-management Reproduction
				<p>13-15 year olds:</p> Sports and exercise Mental Health Disclosure Self-management Informed decision making Discrimination Accessibility of health care resources Understanding your condition School Stuff you can't do

SUMMARY OF GROUP RESPONSES - USEFUL INFORMATION TOPICS

YOUTH COMMITTEE	HAEMOPHILIA FOUNDATIONS	HEALTH PROFESSIONALS	PARENTS	YOUTH WORKING GROUP
<p>Understanding your condition Sport and exercise Employment Travel Discrimination Experiencing life Support Hepatitis C Personal relationships</p>	<p>Travel Employment Understanding your condition Negotiating health care services Sport and exercise Genetics</p>	<p>Employment Genetics Personal relationships Reproduction Basic life skills Mental health Risk taking Negotiating health care services Sport and exercise</p>	<p>Information for schools Sport and exercise Employment Research Understanding your condition</p>	<p>16-27 year olds: Navigating services Sexual relationships Self-management Deciding whether or not to have children Disclosure Moving out of home Sport and exercise Mental health Employment Girls with bleeding disorders Travel Discrimination Finding a cure Siblings Alcohol Transitioning to adult services Emerging treatment options Peer pressure Lack of knowledge in community Inhibitors Tattoos Puberty and adolescence</p> <p>13-15 year olds: How to tell people Self-injection Communication with doctors Why I have haemophilia How to treat different muscles</p>

SUMMARY OF GROUP RESPONSES - RESOURCE FORMATS

YOUTH COMMITTEE	HAEMOPHILIA FOUNDATIONS	HEALTH PROFESSIONALS	PARENTS	YOUTH WORKING GROUP
<p>Talking to peers Personal stories</p>	<p>Online: Social networking Peer education/role modelling Phone apps Group activities Booklets DVDs</p>	<p>Group activities Hands-on learning Online: forum, chat, social networking, videos Computer-based – Interactive games Group chat before appointments Phone apps Mentor National youth camp Handouts/leaflets Youth-focused folder</p>	<p>Mentor Online: chat Network with people same age Career counsellor Interactive educational info Self-infusion clinics Information sessions at schools</p>	<p>16-27 year olds: Telephone Organised gatherings Mentor Face to face contact Training kit/video demonstration Pamphlet/booklet Newsletters Discuss with parents Online: Social networking, email, forums, video blogs A central hub for young people to speak DVD Programs/workshops</p> <p>13-15 year olds: Online: Web site, Twitter, video call, chat, forum, email Video session An app Talking to someone Picture books More info for parents Videos Pamphlet Text messages</p>

SUMMARY OF GROUP RESPONSES - COMMUNICATION PREFERENCES

YOUTH COMMITTEE	HAEMOPHILIA FOUNDATIONS	HEALTH PROFESSIONALS	PARENTS	YOUTH WORKING GROUP
<p>Online: Social networking Phone Text messages Face-to-face</p>	<p>Online: social networking</p>	<p>N/A Health professionals were not asked this question</p>	<p>Online: social networking, VoIP (Skype), chat, Twitter, photos, videos instant messaging Face-to-face Text messages</p>	<p>16-27 year olds: Online: Video and blogs, forums, social networking, VoIP (Skype), email, Twitter, photos Telephone Face-to-face Text messages Newsletters Word of mouth Organised gatherings Mailed to the individual</p> <p>13-15 year olds: Online: Twitter, VoIP (Skype), chat, forums, email Face-to-face Text messages</p>

SUMMARY OF YOUTH WORKING GROUP (YWG) RESPONSES

MAIN ISSUES - TOPICS

16-27 year olds:

Transitioning - from hospitals but also transitioning into adulthood: for example, learning to be independent, knowing your own body, leaving home, sexual partners, planning for the future (having kids)

13-15 year olds:

Not mentioned

16-27 year olds:

Life issues - peer pressure (how to say no to your mates), disclosure (who/how to tell), balancing haemophilia with work, lifestyle, sport, other health issues and relationships. Getting information and advice from health professionals on information such as risky sports, tattoos and mental health. Poor knowledge in the wider community affecting relationships

13-15 year olds:

Disclosure, sport, stuff I can't do, discrimination

16-27 year olds:

Medical issues - Pain control, psychological issues, self-infusion, conflict and confidence/trust issues with health care professionals, what to do when you are too embarrassed to present with a bleed and managing medications and treatment

13-15 year olds:

Learning to self-inject, injuries, it can get in the way of sport and sometimes school (school isn't that bad but sport can be disappointing), amount of equipment, getting sore if not treated at the right time

16-27 year olds:

Psychological – Isolation from the bleeding disorders community, lack of engagement and feeling socially embarrassed

13-15 year olds:

The idea of self-injecting, bullying, the idea of bleeds happening and excluding you from things, stigma of having a disease

16-27 year olds:

Other issues - Unequal health and community resources from state to state, disengagement from the bleeding disorder community, more communication needed from HFA and state Foundations, more youth activities, more information for siblings, a gap in terms of information, support and networking options for females, treatment options for people living in remote areas, government funding for greater research

13-15 year olds:

Not enough awareness by public, not enough information

HOW TO BUILD A STRONG YOUTH PRESENCE

16-27 year olds:

- Online: Social media, email
- Awareness of new tool
- Staying abreast of what young people like
- Word of mouth in community
- Workshops
- Open days
- Attractive resources for young people
- Ask HTC to promote new website
- *National Haemophilia* magazine
- Send info to doctors' association
- Camps, catch-ups

13-15 year olds:

- Online: social networking, website, email
- Newspaper
- Advertise through a game
- Newsletters
- Competition
- Get together
- Awareness
- Ask the nurses to talk about it
- Useful resources

LIKED ABOUT WEBSITES

16-27 year olds:

- Social networking – the ability to share
- Clean cut
- Simple
- Easy navigation
- Useful information
- Precise search filter
- Humour
- Large range of topics
- Information is displayed in sections
- Advertising is off to the side
- Secure personal information
- Help function
- Alerted to any new information
- Tags
- Aesthetically pleasing
- Entertainment
- Free information

13-15 year olds:

- Social networking – brings people together/ games/talk/lots of different stuff to do
- Nice design
- Lots of pictures
- Easy to find information
- Search function
- Having videos
- Up-to-date information

DISLIKED ABOUT WEBSITES

16-27 year olds:

- Poor structure
- Bad colours
- Too busy
- Out-dated design
- Boring and corporate looking
- Poorly designed
- No photos or images
- Hard to navigate
- Search function gives non-specific results
- Too much information is overwhelming
- Need to scroll down to read more text
- Buffering; pages take a long time to load
- Pages that freeze often
- Need to download the latest flash player
- Unnecessary sound
- Bullying
- Pop up ads
- Viruses

13-15 year olds:

- Confusing and overwhelming sites
- Too complicated to use
- Boring content
- Lack of purpose
- Too much information that drags on
- Over-sharing (posting too much personal/ useless information)

COMPARISON OF GROUP RESPONSES - ISSUES/CONCERNS

COMMON TO ALL GROUPS	MENTIONED BY YWG/ YOUTH COMMITTEE BUT NOT FOUNDATIONS, HEALTH PROFESSIONALS OR PARENTS	MENTIONED BY FOUNDATIONS, PARENTS AND HEALTH PROFESSIONALS BUT NOT YWG/YOUTH COMMITTEE	MENTIONED BY 13-15 YEAR OLDS ONLY
<p>Sport and exercise</p> <p>Personal relationships</p> <p>Self-management</p> <p>Mentioned by everyone except 13-15 year olds:</p> <p>Preparing for independence</p> <p>Personal relationships</p> <p>Working</p> <p>Peer education and mentoring</p>	<p>Hepatitis C</p> <p>“Hating my haemo” phase</p> <p>Siblings</p> <p>Knowing your own body</p> <p>Increased government funding for research</p>	<p>Risk taking (physical activity; drugs and alcohol)</p> <p>Non-compliance and trying to fit in</p> <p>Understanding your condition</p> <p>Accepting your condition</p> <p>Returning only when have problems- after years of disengagement, when it is too late to fix problems</p>	<p>Stuff I can't do</p>

RESPONSES - DEFINITION OF 'YOUTH'

Age range of 'youth'

Responses to the question to define the age range of 'youth' showed a diversity of opinion across all groups, with older and more experienced respondents often giving a larger age range and linking it to maturity levels and stages of development.

Whereas a younger Youth Committee member thought the age range of youth was 12 to 18 years, an older youth mentor on the Youth Committee extended the age range to 13 to 25 years, noting *"it seems to be the age range that you start to make more of your own decisions and when you have matured enough to know what's right for you."*

Generations and prophylaxis

One Foundation pointed out that generations in the haemophilia community have been defined by access to treatment and the impact of this on their lifestyle. The younger generations are those under 30 years who have had access to prophylaxis and recombinant treatment products for most of their lifetime, in comparison to the *"older generation"* who are over 30 years of age and are more likely to have had human plasma-based *"on demand"* treatment until relatively recently.

Life stages – independence and responsibility

For many parents, Foundations and health professionals, 'youth' covered a number of life stages, with independence and the development of responsibility as key elements.

Taking control of their own health care was seen as an important indicator of maturity. One Foundation defined 'youth' as aged from 15- 30 years as *"this covers children in high school beginning to manage the shift in care and responsibility of health from parent to themselves"*. Similarly a physiotherapist described 'youth' as 15-24 years: *"this is when they start forming independent ideas about their bleeding disorder and the management, rather than just having it managed by a parent and go from not taking any responsibility for their haemophilia to somehow 'getting it'."*

Starting high school and the physiological changes of maturing were other common markers for the entering the 'youth' age bracket. A parent also pointed out that there were at least three stages of development in these age brackets: *"tween early teenagers 12-14 years; teenagers 15-18 yrs; teen - youth 16-22 years"*.

Delayed maturity

As haemophilia occurs predominantly in males, several health professionals thought that the age group should be extended into the 20s and even up to 30 years as *“boys mature a lot later than girls and their brain development is still happening in the early 20s.”* A nurse pointed out that those aged 15-24 years were the most disengaged – *“boys take a while to grow up.”* The social workers all extended the ‘youth’ age group to 30 years:

- *“People around this age are still finding their identity and integrating a diagnosis of a bleeding disorder into their lives, establishing a career, investing in a house, finding a life partner and being comfortable with their sexual lives.”*
- *“Young men mature later and around their late 20s are beginning to take full responsibility for themselves and their decision making and consequences.”*

Youth mentors

Some parents, health professionals and Foundations described two separate life stages and roles for ‘youth’ within the 12-30 age group. One Foundation felt that there was a ‘youth’ group of 14-22 years and an older ‘youth mentor’ group of 23-28 years. A social worker also commented *“older guys act as a mentor/role model/teacher/educator on ethical issues and treatment etc”*. A parent commented that anyone over 24 years had reached the next phase of ‘mentor’; that teenagers were *“going to see people older than 24 as ‘old’”*.

RESPONSES - MAIN ISSUES AND CONCERNS - THEMES

Self-management

For many YWG members, self-management was important, but complicated, and involved new skills and detailed knowledge. The desire to take control of their treatment was a common theme among those who were mid-teens or older. This included:

- Self-injecting
- Managing pain
- Understanding their medication; what the right dosage is; when to take it and how often; remembering to take it; how to keep it at the right temperature; the right combinations of medications
- How to obtain their factor medication
- Learning procedures in adult Haemophilia Centres
- Knowing who to go to for help
- Understanding what services are available.

A key issue for the younger Youth Committee member was the effort involved in managing his own health: always needing to keep up-to-date with his prophylaxis infusions, to be aware of his sporting events in advance and plan his treatment around them, knowing *“when you shouldn’t do something”*.

In the 13-15 age group these concerns were particularly marked. Nearly all of them spoke about their problems with learning to self-inject, the amount of equipment required, *“getting sore if not treated at the right time”*.

Parents, Foundations and health professionals thought that skills in self-management were crucial. One Foundation felt this related to *“attempts to live a normal, active lifestyle while on recombinant prophylaxis”*. For Foundations, these skills included gaining control over their treatment and care:

- Self-infusion
- Self-ordering for home delivery
- Understanding why and when something needs changing
- Compliance with their treatment regime and attending appointments
- Being confident and proactive in their health care
- Booking appointments at their Haemophilia Centre
- Managing transition; negotiating adult health services.

Health professionals had several more specific skills to add:

- Understanding the diagnosis and their disorder
- Intravenous access
- Bleed management if not having prophylaxis
- Treating bleeds in a timely way
- Understanding the importance of rest and rehabilitation as well as factor treatment.

For parents, who had previously been responsible for their child's management, self-management from adolescence onwards was a process of learning and maturity. Self-infusion was the first step, followed by learning about their condition and asking the health professionals questions. Parents thought that taking responsibility for remembering to take their prophylaxis, storing their product properly and keeping records about their treatment were steps to be learned in the mid-teens, in preparation for leaving home and being independent.

Understanding your condition

Education was a critical element and one Foundation noted, *"A good knowledge of anatomy and physiology is important so that these 'youth' can manage, discuss and cope with symptoms accurately and in sync with healthcare professionals."*

Several YWG members spoke about the importance of gaining a clear understanding of their condition and how to manage it and the language to discuss it, particularly in their early to mid-teens: *"I was never told what RICE was (I still don't know)".* YWG members in their early teens had little language to articulate their questions: *"what in your body has made you have haemophilia... helpful to have a book what haemophilia is and how it all works in basic language".* An older YWG member reflected that when he was younger he had so little contact with others with haemophilia, that a major issue was *"not knowing what is normal for haemophiliacs my age".*

Non-compliance and trying to 'fit in'

Both Foundations and health professionals expressed concerns about non-compliance. Some thought there was an element of complacency; that this generation had grown up with factor replacement and they and their peers had less bleeding and joint problems. As a result they were not as aware of the long-term consequences of not maintaining general and specific fitness or correct treatment of joint and muscle bleeds as earlier generations.

Others thought there were issues related to peer or family pressure and wanting to be 'normal' that could potentially compromise their health care or lead them to be coerced into activities to fit in:

- Being embarrassed by their haemophilia
- Pressures of study in late secondary school
- Needing to 'look cool'
- 'Don't care' attitude
- Wanting to be the same and not stand out.

As a result of these issues young people may:

- Pretend they don't have haemophilia
- Not comply with treatment, exercise and rehabilitation regimes
- Not attend appointments or health reviews
- Not listen to their body and continue with activities beyond a safe point.

Health professionals were concerned that non-compliance during this life stage could cause irreversible damage:

"In my experience the boys often stop adherence to disciplined prescription of all or many forms of treatment around this time, and although often do get back on track after months or more likely years, there is a huge amount of permanent damage that can be done at this time. Again, the evidence shows that very few, even possibly just one or two untreated bleeds (again, untreated meaning not just factor replacement alone) can set up a process of arthritic changes, which once established will continue to progress."

For parents, issues about non-compliance were sometimes related to maturity: "[my son] is still not mature enough to handle the mundane aspects of his condition, i.e. proper storage of medicine (he left the last batch out of the fridge)." This was clearly frustrating for parents, but they identified it as a life stage, most noticeable at mid-teens: "Not wanting to keep a diary or any admin/stocktake/keep track of bleeds, written or electronic, not interested".

Similarly, several parents connected behaviours or attitudes such as "the feeling of invulnerability" or "not wanting to accept the boundaries of his condition" to a developmental stage as a teenager.

Parents also observed that their child's desire to be seen as 'normal' was to avoid feelings of isolation and overreactions from other children and their parents: "Treatment can make them weird – they don't want to be different." From their observations, being 'different' could also lead to bullying, both at school and in sport.

Interestingly, a number of YWG members spoke about being “embarrassed” – “feeling socially embarrassed about having haemophilia” or “what to do when you have bleeds you’re embarrassed to present”. Feelings of “being different in others’ eyes” or “being isolated from friends” were also common. Some mentioned needing to explain to others why they couldn’t participate, and “learning when to say no to your peers when you cannot partake in a sport or activity because of its dangers or a bleed you may have”.

These situations could place pressures on the young people to conform or barriers to taking what parents, Foundations and health professionals considered to be ‘appropriate’ action on their health. In addition, some YWG members noted that understanding the limitations of their bleeding disorder was something they had to learn “by trial and error” and that they had to get to know their own body as they were growing up. Surrounded by peers who did not have a bleeding disorder, they were not sure what to expect of their own body as they went through the immense body changes of puberty and that “not having as healthy a body as a person without haemophilia can sometimes be an issue with life’s everyday challenges”. ‘Normality’ measures with menstrual bleeding were particularly difficult for girls: “some people have a reaction of ‘she’s over-reacting, periods aren’t that bad. She clearly doesn’t have as high a pain threshold as me/my girlfriend/sister/etc’”.

Negotiating health care services

Being able to manage appointments and clinic visits around school, university and working was raised by several health professionals as an issue that needed addressing. Youth Committee members highlighted the difficulties this posed for them and one commented that more flexible health care from the hospitals and consolidation of appointments would be very helpful to him currently.

Transitioning from paediatric to adult health services and taking responsibility for managing relationships with health professionals were major issues for many in the YWG:

- Being able to self-diagnose or communicate medical problems effectively: “Children’s hospitals are used to diagnosing the problem for you, whereas adult hospitals ask you what’s wrong most of the time”
- Lack of trust in emergency staff or other health professionals with a limited knowledge of bleeding disorders
- Knowing how to advocate for themselves to achieve the best outcome
- Experiencing confusion at adult Haemophilia Centres due to regular changes of staff and procedures
- Being too embarrassed to present or ask questions about bleeds relating to sensitive issues such as sex.

Informed decision-making

"I just hope they have access to the right information to make informed decisions."

While Foundations saw the importance of education for informed decision-making, health professionals were concerned about access to up-to-date and accurate information. Some sources of information were seen to be potentially problematic:

- Parents: information could be outdated, relating to when their child was first diagnosed, or at times incorrect and incomplete
- Social networking: web sites sometimes provided wrong information.

In contrast, YWG members were frustrated by the lack of accurate information specifically targeted at people with bleeding disorders in their age group and on topics that they felt were very relevant to them, especially on lifestyle topics such as tattooing and alcohol.

Preparing for and establishing independence

Independence was a common theme among all groups. Responses pointed to two stages:

- Preparing for independence
- Establishing their independence.

One Youth Committee member pointed out that when younger his mother took responsibility for his treatments and he had had little awareness of his treatment responsibilities: *"When you're young you don't keep up to date with needles as it was mum's job."*

Many YWG members highlighted the need for education on how to self-infuse in the early teens to give young people time to become *"confident and competent at it"*. Independence for them involved transitioning to adult services and, for some, wanting to be independent of the hospitals and treatment centres.

Some health professionals thought that work with young people needed to start much younger, for example, at 10 years of age, to prepare young people for becoming independent and managing their own lives, self-treatment and health care. They commented that some mothers had been *"doing everything"* and that some young people were transitioning to adult services and an expectation that they could manage independently without the skills and knowledge required. They thought it was important for the preparation work to begin before young people began to disengage from health services and community in their early teens.

Establishing their independence from their family was another stage: *"moving out of home, and learning to make their own decisions, and taking responsibility for those decisions; gaining confidence and a sense of when to trust their own judgement and when to ask for help, and knowing who to ask for help."* Health professionals saw this as a process of taking over from their parents and finding their own boundaries and some commented that it might also require *"getting mother to 'let go'"*. Interestingly, paediatric health professionals also suggested getting the perspectives of parents on this, noting that although 18 year olds attended the adult service, they were often still living in the family home and parents would still need to take them to the emergency unit if they had a health crisis.

For YWG members, learning to live independently in the world could be daunting, especially if they did not know many others with bleeding disorders: *“Explanation of the unknown – I feel like no one has really experienced being a 26 + year old and had to think through their options regarding having a family and what life looks like with controlled haemophilia.”*

Parents were conscious of the steps that needed to be taken in the future to secure independence, both for their children and for themselves. This included:

- Learning to self-infuse so they could travel without their parents
- Getting pain management under control, for example, with target joints, so that they could join the workforce
- Parents reminding them occasionally of their bleeding disorder if they are ignoring it completely
- Mothers *“letting go”* of treatment: *“It has been easy for him, and I might say me as well, for me to take control and keep him treated ... I think even I will have a hard time letting go.”*

Risk-taking

Risk-taking behaviour was a common theme among Foundations and health professionals. This included risk-taking in sports and other physical activities, and drugs and alcohol.

Some felt this stemmed from young people’s denial of their health condition or their vulnerability and a desire to challenge themselves:

- *“The ‘it’ll never happen to me’ attitude in terms of joint care or more likely, the consequences of lack of joint care”*
- *“Being ‘bullet proof’”*
- *“Denial and not bothered attitude – not wanting to be mollycoddled.”*

Others thought the risk taking behaviours and choices were related to *“adolescent impulsiveness”*, a normal stage of development, but were very concerned about the harmful consequences considering the particular vulnerability of young people with bleeding disorders: *“If injury occurs seek treatment early, minimise risk taking. Wear your safety equipment.”*

One social worker spoke of the need for them to be able to take calculated risks; a balancing act that was part of being empowered to handle their condition.

Experiencing life

In contrast to the Foundations and health professionals, the younger Youth Committee member was adamant that haemophilia should not be a reason to hold young people back from both the positive and negative aspects of life: *“I am against parents not allowing their children to experience life to the fullest as it could hurt you. The only way we learn in life is through our own choices and mistakes.”*

Taking risks was seen as a normal part of exploring life and one YWG member expressed his concern that having a bleeding disorder limited this: *"Spontaneous and random bleeds for small trauma can bring you down, make you go out less - take less risks."*

Some parents had consciously not tried to stop their children from doing things because of their bleeding disorder (*"within reason"*): they wanted their children to grow up with a *"normal life"*. One parent felt that openness to the challenges of life was an important factor in her son accepting his condition and developing *"a courageous attitude that he can overcome obstacles."*

Travel

Travel was a challenging area for some groups.

For one Youth Committee member, travel highlighted the limitations of living with a bleeding disorder. He had been unable to travel to *"rough"* or remote locations as he was unable to keep his factor VIII treatment cold.

Some Foundations and health professionals thought that young people needed to be challenged on their expectations about this and learn preparatory skills early: *"Many youth travel. [A key issue is] knowing how to plan factor supplies (or even that they HAVE to plan!), and manage their treatment 'on the go'."*

Few YWG members commented on travel. Those who did were older and were aware that there could be issues with travelling overseas or travel insurance.

Sport and exercise

Sport and exercise were issues common to all groups. Physiotherapists in particular thought it was important that young people received *"good advice in regards to bleed management, 'at risk' activities and likely prognosis of musculoskeletal conditions with particular sports/activities"* so that they could make informed decisions about activities such as contact sports, running, skateboarding etc.

The physiotherapists noted that in the teenage years, sport for boys became more aggressive and their physical size and bulk increased as well, making impact more of a problem. They also identified that there was a lifestyle change for those who had left school, with enforced exercise at school and little or none at university or work *"and the general depletion of muscle tone and stability necessary for joint protection."* It is interesting that the Youth Committee member commented that he had cut down on sport due to work commitments.

Some of the health professionals expressed concern about young people who took on a 'sick role' or who caused themselves long-term disability through high risk sports or activities. Disabilities acquired through haemophilia or injury could cause them to drop out of participation in sports, school, work, or with their peers, and could lead them to become disempowered and isolated.

Parents found that sport raised a number of concerns:

- Bullying by team-mates: *“as he had to take his factor with him on trips he became an easy target”*
- The *“pushback”* from children when parents said no to inappropriate sports
- Sport-related and *“rough house play”* injuries.

Several parents remarked that sport was a *“beloved”* activity for their son, and sport rated highly for comment among YWG members:

- Knowing what sports you can and can't play
- Getting accurate information about this early in life
- Being disappointed about missing out on sporting activities
- Learning how to manage your prophylaxis routine to work in with sporting activities
- How to tell others why you can't play certain sports.

School

Managing issues at school was alluded to by all groups. One Foundation thought knowing how to handle issues at school was an essential skill. Respondents mentioned issues such as:

- Accessing health care appointments around study
- Interruptions to study related to bleeds and other health problems
- Organising treatment and exercise into the school/study routine was not seen as a priority
- The disappointment of not being able to attend school camps/play school sports
- Disclosure to teachers and friends
- Discrimination.

Parents and YWG members saw education of other students, other parents and teachers as a key aspect:

- To debunk myths, *“that I won't die if I get cut etc”*
- So that safety, the need to attend to bleeds quickly, and haemophilia-related psychological issues were taken seriously
- To help with understanding their situation: *“missing a lot of school – kids ask questions about odd circumstances”*.

Working

All groups agreed that working and career options were key issues, and their responses outlined some of the complexities.

One Youth Committee member reiterated the problems of going for job interviews with needle marks on his arms. Other YWG members worried about restrictions relating to employment and being treated differently, not only because of what they were unable to do, but also because of the fears of employers. They also worried about missing work due to bleeds and needing medical certificates when they didn't need to see a doctor to manage their bleed. One highlighted the importance of ongoing access to expertise and facilities to help maintain fitness, joints and movement especially when they were starting work.

Health professionals voiced a great deal of concern about realistic career choices and preparation for the workplace. Their experience was that some young people had difficulties with the limitations to their work and the time off needed to manage bleeds and other health issues and hospital appointments. Career planning was an important step to ensure they made appropriate choices to manage long-term musculoskeletal issues and to prevent too many problems at the beginning of their working life, leading them to become *"very disempowered early in life or take on a sick role"*. Some choices would not be an option, for example, joining the armed forces, and awareness of this from an earlier age would help them to handle this and try different things and avoid frustration.

Parents were very conscious of the need for career counselling; that their children had *"big ideas"* but there would be challenges: aspirations to join the police or armed forces were unlikely to be successful; they were unsure about working in remote areas; and that there would be difficulties obtaining the high marks required for entry to some university courses when they had lost time at school due to bleeds.

Support

The difficulty of managing the range of issues that might occur when growing up with a bleeding disorder was a common thread throughout the responses and there were a number of responses that highlighted the importance of having strong support. One Youth Committee member described this as having a good network of friends, family, doctors and nurses which *"helps with any tough situations"*.

A parent and a YWG member also pointed to the need for professional and specialised support from a social worker or counsellor to deal with times of psychological crisis. However, some YWG members thought this would not be an easy process and were unsure how a counsellor would be able to reach a young person: *"it's hard for a young person to take in information from someone if they don't want to hear it."*

Social workers and nurses noted their concerns for those who did not have a lot of family support and the impact of lower socio-economic status, particularly in large capital cities where the cost of living and distances could make life *"tough"*. They felt it was important to get young people together, either electronically or in person, to know that they were not alone with their bleeding disorder.

Peer education and mentoring

For the Youth Committee and YWG members, talking with other young affected people about living with a bleeding disorder was a very important source of support and education. Most wanted to connect with someone of a similar age with the same kind of bleeding disorder or affected status, for example, a sibling: *“someone just to talk to about it and compare notes, and also prevent the feeling of being so different”.*

One Youth Committee member had a role as a youth mentor and, although he described himself as fairly independent and self-sufficient when younger, thought that mentoring from and interaction with others who were a little older would have helped him when he was younger. This thought was echoed by other older members of the YWG:

“For me talking to older haemophiliacs was by far the best way to find out more information and learn more about what was to come. Reading pamphlets or booklets can make haemophilia seem like the worst thing in the world when in reality it just makes you a stronger person. A personal experience was when I met a sports teacher (a likely career path for me) who had haemophilia. Seeing him just coming in for his treatment laughing and happy really made me realise that haemophilia doesn’t run your life, you do, and chatting to him made me feel a lot better.”

One Foundation had identified an age group of 23 years and older who sometimes took on a mentoring role and that parents would be happy for their teenage children to take part in camps and outings with someone who had been mentoring them for a couple of years. A social worker also noted that *“older guys”* performed a mentoring/role model/education role in relation to ethical issues and treatment. A parent thought this role could be two-way: *“[my son] could be a Big Brother to someone but also have a Big Brother?”*

Personal relationships

One social worker thought a significant issue for young people was to learn how to fulfil their needs in intimate relationships and maybe find a steady partner, move in with them or marry. Many from all groups agreed that personal relationships were an important issue. Like other areas of life, having a bleeding disorder complicated this: health professionals considered that having a good understanding of the genetics of bleeding disorders was necessary if contemplating unprotected sex or pregnancy. This involved not only young men with bleeding disorders and their partners, but also their sisters and other young women who may carry the gene.

Reproduction

Young women in the YWG who carry the gene highlighted that they would need more information as they entered their childbearing years. Genetic testing and the implications of carrying the gene for their children were as yet unexplored areas for some. One commented that her parents had not had the information to explain it to her and she had put off learning about it until it was something she needed to deal with in the near future. Sometimes they felt there was little information available: *“Even now, as I’m looking to the future, there is little information for women who have used the pill (and/or other medications) to control gynaecological bleeding on what to do when you want to come off the pill to get pregnant.”*

It is interesting to note that none of the males in the YWG spoke about genetic inheritance. One, however, was aware of the need to educate young women about the experience of living with haemophilia in today's world: *"For me personally, making prospective mothers of children with haemophilia aware that it shouldn't be something to abort over"*.

Disclosure

For all groups, relationships with girlfriends or partners, along with others in their life – friends/"mates", teachers, colleagues, employers, others in the workplace – raised the question of disclosure and what, when and how to disclose; and how much to tell: *"how much is too much?"*

This was a fraught question. A common experience was that people overreacted. YWG members feared rejection or not being offered employment. In those aged 18 or under, most were very eager to learn skills in how to tell people about their bleeding disorder, *"what to say to people that you can't do this because of haemophilia"*.

Discrimination

Stigma and discrimination was mentioned by both Youth Committee members. The younger member talked of the difficulties relating to having needle marks on his arms due to treatment infusions: *"I have had many job interviews with the HR staring at my arms and a couple of people at school telling people I was a junkie."*

A parent related a very serious episode of bullying from school students and sports team mates when her son was in junior secondary school. This related to both his haemophilia, *"as they knew he couldn't fight back"*, and because he was perceived to be *"good"*, excelled at school work and did not have trouble with teachers. He has since moved to a different school where the students know about his haemophilia and have respect for what he has achieved.

For both parents and YWG members, the reactions of others could be a problem. A 13-15 year old described *"the stigma of having a disease"* and said *"people make such a big deal about it or overreact"*. Several parents felt that normalising haemophilia in the community was very important *"so that other kids and parents weren't confused or freaked out"*. One parent noted *"people jump to the conclusion that abuse is involved"*.

Disengagement and isolation

A common theme among Foundations, parents and health professionals was the difficulty in engaging young people around health care relating to their bleeding disorder and in community activities, even those focused on getting a group of young people together. They noted a number of specific issues:

- Priority can go to study, particularly in late secondary years
- Denial of their condition
- Lack of opportunity to connect with peers with haemophilia at hospital clinics due to home therapy
- Difficult to interest this age group in bleeding disorder community activities
- Need to engage more frequently than two-yearly camps to sustain interest
- *"Boys don't talk"*.

Health professionals felt it was important to talk in an honest, non-patronising way to this age group in order to engage them in their health care.

Isolation was a related issue: isolation from their peers with bleeding disorders, from the bleeding disorders community and its supportive role, and social isolation generally from feeling alone or dropping out of school or work due to health problems.

Mental health

YWG members, parents, Foundations and health care professionals also referred to mental health issues as a major concern: depression, anxiety and self-esteem problems. They identified several related issues:

- Coping with having haemophilia in general
- The *"grinding"* routine of prophylaxis
- Feeling alone and different
- Pain and difficulties managing bleeds
- Having a permanent condition *"with no apparent relief on the horizon"*
- Restrictions now and in the future
- Change
- Identity/fitting in/belonging
- Having a label of 'disability'
- Lack of family support.

One Foundation felt that it was a priority to improve young people's skills in this area to develop *"confident, strong young men with strong psychological and joint health."*

Some parents and YWG members thought that the challenges of living with a bleeding disorder could develop resilience: *"Now he wants to be seen as just like any other kid. He has had a tough time in his earlier years but it has built an inner strength and appreciation of life, more so than any average child."*

"Hating my Haemo" phase

In spite of strong support of family, friends and hospital staff, one Youth Committee member still experienced what he called a *"hating my Haemo phase"* in his teenage years. He commented that even though he had learned to live with it, to this day he wished he didn't have haemophilia. Meeting *"some awesome people along with way"* was an important element in helping him through this phase.

"Stuff you can't do"

It was very common for YWG members to speak of things they were not able to do, *"missing out"* on sport, school or camps, not being able to play contact sports, having to *"be careful"*, having difficulty self-injecting, including being able to inject with one hand, or not knowing how to tell people about their haemophilia.

In the 13-15 year old group, this sense of restriction and lack of skill was particularly marked. Haemophilia was an *"inconvenience"*, it took *"time and effort"*, and *"the amount of equipment"* was daunting. They lacked the knowledge and the language to explain themselves and felt they needed help, for example, *"someone who takes blood to tell doctors whether or not our veins are big enough"*. At a stage when they were expected to start learning self-management skills, they experienced barriers to even conceptualising impact of their health condition and how to treat it, struggling with *"the idea of bleeds happening and excluding you from things"* and *"learning to inject myself, would like to know if others have trouble with the idea"*.

The younger YWG members were very aware of the consequences of their lack of skills:

- *"People make such a big deal about it or overreact"*
- *"People teasing me"*
- *"Injections – if you miss your vein you have to go to hospital"*.

Hope for the future

With all the challenges of growing up with a bleeding disorder, one Foundation commented: *"This is also an age where young men are questioning their sense of self and may need support and positive role models to see an optimistic dynamic future for themselves with haemophilia."*

Significantly, when one Youth Committee member was asked what would help him now, his reply focused on knowing there was hope and a bright future for young people with bleeding disorders: *"less injections a week, a tablet you can take, ultimately a cure."* This was also reflected in some YWG members' comments that they would like easily accessible information about research into treatments for bleeding disorders and that government funding for research was a major issue for young people.

Some parents felt this also related to an approach to life: *“living his life positively. Focusing on what he can do, not on what he can’t do.”*

Girls with bleeding disorders

Although one health professional pointed out it was important to remember to include information for girls with bleeding disorders, groups other than the YWG made few other comments about affected girls except to note that they should be encouraged to understand genetics and inheritance and gain information and seek counselling if they were considering pregnancy or unsafe sex.

This lack of attention was pointed out by a young woman with a bleeding disorder in the YWG. She acknowledged that it was understandable that boys and men received the bulk of the attention as they form the majority of the population with bleeding disorders, but felt that *“information directed at women is primarily related to how to support your son/father/brother/etc with haemophilia”. This left a “huge gap in terms of information, support and networking options for girls and women with bleeding disorders”.*

Hepatitis C

Blood borne viruses were only mentioned by one Youth Committee member, who felt that hepatitis C was a significant issue and government financial assistance would be helpful.

Accessibility of health care resources

The impact of difficulties accessing specialist health care services was very clear in responses from parents and YWG members. One parent noted that the establishment of a comprehensive care clinic, with access to a haematologist, nurse, social worker and physiotherapist, had been *“hugely beneficial”* for her son and that the availability of a social worker some years earlier would have helped to manage the bullying and problems at school her son had experienced. Both parents and YWG members in smaller states spoke about their problems with Emergency Departments and of feeling isolated and *“cut off”*.

Talking to people

Although the Foundations, parents and health professionals assumed that young people would prefer online forms of communication, it was important to note that YWG members wanted to be able to *“talk to”* other young affected people in a range of different ways:

- Interactive online formats, using video and blogs, email, forums, social networking
- By telephone and VoIP technology, such as Skype
- Face-to-face in organised camps and weekends and less formal *“catch-ups”*.

One member thought that if face-to-face contact was organised and an interactive web site also existed, the young people who participated and contributed would find other ways to stay in contact: *“as long as there is a way to communicate, we probably will!”*

DISCUSSION

Engagement and isolation

Both the recruitment processes and the comments of Haemophilia Foundations and health professionals pointed out the difficulties of engaging and maintaining engagement with young people with bleeding disorders. In spite of a multi-faceted approach to young people inviting them to join the project, give their opinions and design a response that works for them there was little response until they had face-to-face contact with the project leader. Some continued to show reservations at this point and only agreed to participate when they were sure about what was being asked of them.

The YWG responses showed that the young people did consider the project to be important and to be addressing issues that were relevant to them. It is possible that they needed to develop confidence in the project process and that it would indeed be relevant to their needs. Addressing this required considerable work on the part of the Youth Project Officer to build connection and trust.

Most of the YWG participants have been relatively well-connected to their State or Territory Haemophilia Foundations. All of the groups consulted referred to *“other young people”* who are isolated and difficult to engage, often because they prefer not to identify with having a bleeding disorder or with the bleeding disorders community or do not find community activities attractive. They noted that isolation from peers with bleeding disorders and community could contribute to the sense of being alone and decrease opportunities for learning effective ways to manage their bleeding disorder from peers, community mentors or health professionals. They had concerns that this had already demonstrated the potential to lead to psychological harm, with the occurrence of depression, anxiety and mental health issues among young people with bleeding disorders, and physical harm, when young people made poor decisions about treatment and care or physical activities, leading to permanent musculoskeletal damage or injury.

It is unclear whether this disengagement from the bleeding disorders community is because these *“other young people”* do not have bleeding disorder related problems and it is not an issue for them or for other reasons related to not coping well with their bleeding disorder. With the potential for harm associated with isolation and lack of knowledge about managing bleeding disorders, it is important to gain a better understanding of how to engage with these isolated and difficult to reach young people and what their current and future needs are. Given that the bleeding disorders community is small and many young people met each other when they were children at community camps or activities and paediatric service activities, it is likely that the YWG may be able to provide ideas and pathways to address connection with this group. However, engaging with this group is also likely to pose further challenges and would require considerable development work by a skilled professional such as the Youth Project Officer.

Communication options

Web-based and social networking communication options were popular suggestions from all groups. Many young people with bleeding disorders are clearly active facebook users and commonly use email and internet for contact – email was the preferred tool for consultation for YWG members over the age of 15. Nationally they are geographically widely separated from their peers with bleeding disorders and all groups were conscious of the benefits of internet and social media-based technologies to bring them together.

However, face-to-face contact has proven to be an important element in the recruitment of young people to the project and in establishing relationships of connection and trust. Interestingly, it has also figured prominently as an alternative preference for young people to engage with each other, both in suggestions from young people and health professionals, for example, national youth camps or “*outings*”. One Youth Committee member also commented that he did not use internet-based technologies to communicate with his peers.

It would also be valuable to investigate the use of telephone and Voice Over IP (VoIP) technology such as Skype. Most of the YWG members aged 13-15 asked to be consulted by telephone rather than email and telephone and Skype rated highly on the preferred communication options of those aged 16 and under. It may be that this age group is encouraged to use the telephone rather than email by their parents, or that their verbal communication skills are more advanced than their written skills, or that they prefer the social nature of verbal communication and may use webcam to add to the sense of connection – some noted that Skype is popular in their peer group. Skype was also mentioned as a potential means of communication among older YWG members who used it to connect with friends and relatives overseas.

It is clear that a mix of web-based, social networking, face-to-face and telephone-based options will be important in any sustainable strategy to engage with young people with bleeding disorders. Increased synergy may also be created if local Foundations integrate opportunities for young people to meet more regularly in their social activities; but as was highlighted by YWG members, this needs to be a multi-layered approach, and will be more successful if it works alongside ongoing engagement of young people on the HFA youth web site and national activities.

Website preferences

YWG responses showed a preference for a web site that allowed them to interact with each other and share. They were not interested in a “*boring*” corporate style, but thought an attractive web site would be simple, with easy navigation, not too much information or text, and lots of images. Humour and entertainment were important features. However, they did not see the point of web sites or information without a purpose. Their focus was more on high quality “*useful*” information on a large range of topics, with “*how-to*” videos and other educational materials created by peers, so that they could learn from each other.

Education

The educational model proposed by YWG members is that of a dynamic education program, where web site content creation is shared between HFA and young people and there is a strong peer education component. While it would require guidance and moderation from a skilled professional, and review at times by experts, this is a standard process for developing HFA education materials. The advantage of this model is that it would allow for the creation of a large amount of content on relevant topics in a shorter length of time and not as much of the content would need to be drafted by an educator. Moreover, as some blogs, videos and images would be created by young people on topics that interest them, the content, approach, language and style is more likely to be relevant and acceptable to young people. Polls and surveys and question and answer forums on the web site would increase the interactivity and also indicate which topics are priorities.

Both parents and YWG members highlighted the need for education to other groups, such as schools, the wider community and parents themselves. While information on the web site could perform this function in some circumstances, it will be important to consider other opportunities for this education, for example, by updating and promoting education kits for schools, targeting education materials and newsletter articles to parents and incorporating it into awareness-raising activities during Haemophilia Awareness Week.

Promotion

Engaging YWG members in discussion about promoting the web site resulted in a very productive response on potential strategies and demonstrated the value of involving a group of young people who are familiar with the way their own community operates in strategic planning for the project.

YWG members pointed out that it was the regularity of updates about the web site, what young people were getting out of it and new postings that would encourage young people to remain connected and promote the web site to others. Most recommended online and more instant methods, such as updates on facebook, by sms, or email alerts generated by new postings on the web site. However, the YWG members were aware that those not currently engaged with their local Haemophilia Foundation will be harder to reach, and that it will be important to use a multi-pronged approach for promotion to this group, using existing activities and networks. Ideas included promoting it in Foundation newsletters, to parents who could *"mention it"* to their children, at annual community camps and through Haemophilia Centres. They were also conscious of the need to use psychological 'hooks' for young people, such as creating a sense that others are already involved and they are *"the ones missing out"* or that being involved does not require too much of them.

Work on promotion of the web site to non-engaged groups is likely to be ongoing and complex and the involvement of the YWG will be a significant factor in developing appropriate strategies.

“Hating my haemo” phase

In spite of active recruitment with both paediatric haemophilia centres and State and Territory Haemophilia Foundations, engaging with those in the 13-15 year age group proved to be very slow and required targeted efforts. Many of the health professionals talked of young people starting to disengage from haemophilia health services and community at around the age of 13-14 years and there being a life stage when many do not want to acknowledge their bleeding disorder. Even with a strong personal support network, a Youth Committee member described a *“hating my haemo”* phase of his life during his teenage years. While this phase has been observed, the experience of the young person who is living through it is not well understood, nor is how to respond to it effectively.

The second phase of consultation specifically targeted the 13-15 age group. YWG members were also asked about their experiences when they were younger and parents were consulted about their child’s experiences some years earlier to elicit some information with the benefit of hindsight. This consultation produced some valuable insights for further work in this area.

In this age group there appears to be a collision between the young people’s developmental stage and what is being expected of them. They are starting to take on responsibility for self-management, which involves the need to master self-injection, managing treatment product, understanding their health condition and being able to communicate about it. At the same time, they are in a process of rapid development physically, cognitively and emotionally and struggle with the skills required to achieve self-management. Those in the 13-15 age group appeared to be daunted by the effort involved and the significant consequences of not being successful: they may experience injuries, have to go to hospital for treatment, and others may overreact or bully them when they try to explain their health condition. It may be easier for both the young person and their parents if their mother retains the responsibility for their treatment, which can add further problems later when self-management becomes a necessity, for example, going to school camp, travelling apart from parents or moving out of home.

More work needs to be done to understand how to engage with this group and understand their experiences and needs. This may require further consultation with bleeding disorders groups and also with other services for young people with disabilities or chronic health conditions.

Discussion of sensitive issues

There were a number of issues discussed by Foundations and health professionals but not raised by YWG members. This included risk-taking with illicit drugs and compliance with treatment and care. YWG members also discussed a number of issues not raised by Foundations and health professionals, including discrimination and bullying, dealing with their embarrassment at presenting with bleeds at hospital and how to manage relationships with health professionals when they were not convinced of their expertise or had conflict, and the need for more flexible health services.

On some aspects of life YWG members had very different perspectives to Foundations and health professionals. Taking risks and drinking alcohol, for example, were seen by YWG members as social norms and a positive part of their life experience, whereas Foundations and health professionals saw them as potentially damaging.

All of these issues are sensitive topics where the different perspectives of young people and their family and carers need to be explored and taken into account. The varied perspectives already highlighted in the consultation point to the difficulties of growing into adulthood and independence with a health condition associated with physical vulnerabilities. Young people wanted the opportunity to be informed but also to make their own decisions, and be allowed to make mistakes and learn from them. On the other hand, health professionals were concerned at the permanent harm that might result.

Although the YWG members chose email as their preference for consultation, this is also an identifiable means of communication, and may limit their openness in responding. It would be valuable to establish a non-identifiable space in the communication tool restricted to affected young people to discuss these sensitive issues further, where young people can be anonymous and honest, but where inaccurate information or harmful approaches are not promoted as peer education. Limiting the internet forum to young people with bleeding disorders via a membership login would also enable credible data to be collected, as comments from spammers or unaffected members of the public would not occur and be included. This forum would require careful moderation by a skilled professional, such as the Youth Project Officer.

Resilience

One YWG member made a telling remark that educational material *“can make haemophilia seem like the worst thing in the world”*. Although all groups were conscious of the difficulties of living with a bleeding disorder, they also identified a need for a positive and strength-based approach, which developed skills and confidence and focused on what the young people could do rather than what they couldn't. Some parents and young people felt that young people's experiences of overcoming health problems, pain and other obstacles developed inner strength and resilience. It will be important to explore this further when developing educational materials.

Girls with bleeding disorders

There are very few girls with haemophilia. However, girls can be affected by haemophilia by carrying the gene, and can sometimes have bleeding symptoms. Both females and males are affected by von Willebrand disorder equally. Girls can also be affected by bleeding disorders in the role of a sibling. The needs of girls with bleeding disorders were rarely raised in the consultation by Foundations and health professionals but was a high priority for the young women in the YWG, who pointed out how little information was available. This area needs more attention.

The experience of siblings was also raised by the YWG as an area requiring more attention.

Preparing adolescents for independence

While the project has focussed on young people with bleeding disorders from teenage years onwards, health professionals pointed out it would be a valuable strategy to prepare adolescents in the 10-12 year age group for the independence required of them in the future as a 'youth' and the issues that result. This would be particularly helpful as many disengage from health services and support when they enter their teenage years and are harder to reach.

Undertaking further work in this area raises a number of questions, such as who would provide the preparation and what it would consist of: would it be education that is integrated into paediatric centre work and supported by Haemophilia Foundations? Or primarily driven by parents? How would this preparation be carried out? How would this preparation relate to their stage of development and physical and intellectual maturity? More investigation would be required to scope this work further.

Mentors

In the consultation parents, Foundations, health professionals and Youth Committee members were asked to identify what they thought the age range of a 'youth' with a bleeding disorder was and why. The aim of this question was to define a target group for the project and understand the age range of the target audience for the planned web site and resources. This proved to be a valuable exercise on two counts. It pointed out that maturity could be delayed in this group and that older people would need to be included in the target group. It also indicated the existence of a second group of 'youth mentors', who while they are still relatively young adults, are more responsible and well-informed and can provide peer education, leadership and support to younger people with bleeding disorders.

When asked about information and resources that would help them, all YWG members mentioned mentors except for 13-15 year olds. This age group said they "*wanted to talk to someone*" but did not identify who that person would be. Reflecting back on their teenage years, several older YWG members said they had been unaware of the existence of mentors but thought talking to someone a little older about how to manage their current issues and what lay ahead of them would have helped them at the time. Stories and responses from older and more articulate young people could provide this younger age group with both experiences of others to learn from and the language to explain themselves or express their concerns.

It will be valuable to identify potential mentors and include them in the development of the project and to explore the possibilities of their role in the ongoing sustainability of the project, including training needs.

Response rates

Less than one-third of the health professionals approached responded to the consultation questions. However, given the heavy clinical responsibilities and low allocation of funded hours for haemophilia that many haemophilia health professionals experience, this is a relatively high response rate. This demonstrates that work to address the needs of young people is a high priority area for health professionals and that they support HFA's efforts to develop strong evidence-based youth programs to enable young people with bleeding disorders to lead an independent and fulfilled life.

APPENDIX ONE

CONSULTATION QUESTIONS

Questions for the Youth Committee:

1. What do you think is the age range of “youth” with bleeding disorders? Why do you think this?
2. What do you see as the 5 main issues for you and other young people affected by bleeding disorders?
3. Are these issues different if you are younger?
4. What information/resources would be useful to you and others your age?
5. What would have helped you deal with your bleeding disorder when you were younger?
6. What would help you now?
7. What do you think is the best way for young people to communicate with each other over the internet?

Questions for State and Territory Haemophilia Foundations:

1. What do you think is the age range of “youth” with bleeding disorders? Why do you think this?
2. What do you see as the main issues for this age group?
3. What information/resources would be useful for this age group?
4. Given your experience, what are your main concerns about this age group?
5. Who else do you recommend I should consult with in your State or Territory?

Questions for haemophilia social workers and physiotherapists:

1. What do you think is the age range of “youth” with bleeding disorders? Why do you think this?
2. What do you see as the main issues for this age group?
3. What information/resources would be useful for this age group?
4. What are your personal/professional concerns about this age group?

Questions for haemophilia nurses:

1. What do you think is the age range of “youth” with bleeding disorders? Why do you think this?
2. What do you see as the 5 key challenges for this age group?
3. What information/resources would be useful for this age group?
4. Given your experience, what are your main concerns about this age group?

Questions for the Youth Working Group:

1. What do you see as the 5 main issues for you and other young people affected by bleeding disorders?
2. What information/resources would be useful to you and others your age for your bleeding disorder?
3. How do you currently access HFA's website? E.g. iphone, laptop, home computer
4. What would have helped you deal with your bleeding disorder or carrying the gene when you were younger? And how should that information have been presented to you e.g. pamphlet, booklet, internet, talking to someone?
5. What would help you deal with your bleeding disorder or being a carrier right now? And how should this information be presented to you e.g. pamphlet, booklet, internet, talking to someone?
6. Apart from Facebook, what do you think is the best way for young people to communicate with each other over the internet? E.g. Videos, forums, photos, video diaries.
7. How do you think this group of people should continue communicating with each other into the future? Please keep privacy issues/laws in mind.
8. How do you suggest we build a strong youth presence in the bleeding disorder community? E.g. how do we get as many young people using the new tool as we possibly can? Including those who are currently not connected with anyone.
9. Do you want to continue to receive updates/stories about other young people with bleeding disorders? If so, in what format e.g. enews, videos, printed newsletter?
10. List 3 websites you like and tell me what you like about them.
11. List 3 websites you don't like and tell me why you don't like them.

Questions for parents:

1. What do you think is the age range of "youth" with bleeding disorders? Why do you think this?
2. What do you see as the 5 main issues for your son/daughter:
 - a) A few years ago?
 - b) Now?
 - c) In 5 years' time?
3. What information/resources would be useful for your son/daughter right now?
4. What information/resources would have been useful a few years ago?
5. How do you see your son/daughter communicating with their friends? E.g. phone, Facebook, face to face?



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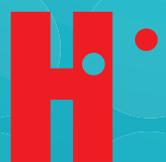
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