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Dear Sir/Madam

Australian Non-Admitted Care Classification Development

Thank you for the opportunity to comment on the development of the Australian Non-Admitted Care Classification

The submission from Haemophilia Foundation Australia follows.

Yours sincerely

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HAEMOPHILIA FOUNDATION AUSTRALIA

HAEMOPHILIA FOUNDATION AUSTRALIA SUBMISSION

Australian Non-Admitted Care Classification Development

April 2018

Comments

People with haemophilia, von Willebrand disorder and other related bleeding disorders have chronic health conditions that require admitted and non-admitted hospital services over their lifetime. Many of these patients will also often experience complications and many develop co-morbidities that require input across a range of health services. Many of these services need to be provided by tertiary hospital services because of the specialisation required.

Haemophilia Foundation Australia does not have hospital funding expertise, and we do not intend to respond to each of the questions in the current consultation, however we do wish to describe the importance of interventions provided to bleeding disorders patients who are not admitted, but whose treatment is prescribed and monitored regularly and where life and limb saving interventions may be required at any time. We urge careful consideration of the range and extent of some of the necessary activities undertaken by health professionals in tertiary settings. We note that funding gaps can have a significant negative outcome for the health and quality of life of patients and lead to reduced cost effectiveness for government payers.

People with bleeding disorders require ongoing use of replacement clotting factor treatments. Whilst these treatment products are provided free to patients, their costs are shared across jurisdictions under the National Blood Agreement. In 2016, 15% of the $504m spent by governments on plasma derived and recombinant products was for factor VIII and factor IX alone.[1] Although clotting factor replacement therapy represents the highest cost component of best practice treatment, it is the activities provided by specialist Haemophilia Treatment Centres which have a profound impact on the cost effectiveness of the overall treatment and care and for high quality health outcomes for patients.

The essential elements of the national framework for haemophilia care are described in the Guidelines for the Management of Haemophilia in Australia (2016) as the supply of clotting factor products, information systems and data, stakeholder partnership and collaboration, appropriate patient care, efficient use of clotting factors, knowledge development and practice improvement. These elements are largely driven by the services provided from tertiary hospitals. While many of the patients treated receive home therapy and do not attend the hospital physically, except for annual reviews or bleeding complications, they would likely be interacting with treating health professionals, or are being monitored through the recording of their bleeds and clotting factor use on the patient app MyABDR on an ongoing basis.

Consultation with our community members and with haemophilia health professionals has also highlighted that where services are integrated and access is provided seamlessly, this leads to the best use of resources, so they are efficient and cost-effective for governments and of greatest benefit to the patient.

Our comments below highlight the importance of admitted and non admitted hospital services in the management of bleeding disorders, and more importantly identifies the importance of appropriately remunerating the activities provided.

Comprehensive care

International and national guidelines indicate that treatment and care for people with bleeding disorders is best managed though a model of comprehensive care which is provided by specialist Haemophilia Treatment Centres. These are currently located in major public hospitals around Australia and most provide statewide services because of the level of expertise they have. They provide treatment and care to a person with a bleeding disorder over their lifetime and support and education for their partner and family. For many patients this treatment is provided at a childrens' hospital in a capital city until age 16 or 18, and for the rest of their life through an adult hospital in the capital city.

This model of care requires a multidisciplinary team of health care professionals with expertise in bleeding disorders: haematologists, nurses, physiotherapists, social workers and counsellors and laboratory scientists, along with access to other relevant specialties, such as genetic services, pain management, dentistry, rheumatology and orthopaedic services, gynaecology and obstetrics and other counselling services. Treatment and care may be provided as inpatient or non-admitted services. It may involve case

management; or referral to other services, which may be community based, or in the public or private health systems. It may involve delivery of the service in a regional setting, or a community setting, such as a physiotherapy group education session or education session to a school around managing a child with haemophilia. The provision of this necessary level of input is time consuming and requires consultation, liaison and coordination, and the admitted and non admitted hospital services provided by Haemophilia Treatment Centre health professionals should be remunerated appropriately to ensure ongoing availability and sustainability.

Because haemophilia and related bleeding disorders are rare, with low global prevalence, there is a considerable expertise concentrated in established Haemophilia Treatment Centres, including those in Australia. A relatively small international community of specialist health professionals collaborates within and across disciplines, and with the World Federation of Hemophilia and within international professional bodies and associations. This level of expertise is not available outside the Haemophilia Treatment Centre setting, and has led to evidence based treatment guidelines and practice experience that benefits the health outcomes of patients.

Australian Bleeding Disorders Registry (ABDR)[2]

The ABDR is an important tool for co-ordinating treatment and care and evaluating its effectiveness. The ABDR is a registry for patients in Australia with bleeding disorders. The current fourth generation system was launched by the National Blood Authority (NBA)in 2012 and is managed in collaboration with the Australian Haemophilia Centre Directors' Organisation (AHCDO), Haemophilia Foundation Australia and all Australian governments.

The ABDR is used by the NBA for clotting factor supply management and planning. However it is also used on a daily basis by clinicians in all Australian Haemophilia Treatment Centres (HTCs) to assist in managing the treatment of people with bleeding disorders and to gain a better understanding of the incidence and prevalence of bleeding disorders. People with bleeding disorders and parents/caregivers contribute data about home treatments and bleeds through the secure app and website MyABDR, which links directly to the ABDR. HTCs work closely with their patients on MyABDR, educate them on how to use it and use the data to review patients' treatment plans with them and discuss any issues with bleeding episodes or compliance between their annual reviews.

The data from the ABDR is proving to be a critical evidence base for assessing the impact of comprehensive care as well as treatment regimens. It collects data from all members of the comprehensive care team as well as the patient. It is an opportunity to measure, for example, the effect of a range of treatments from a new type of replacement factor therapy to a physiotherapy intervention. A current study is investigating compliance with treatment and associated factors.

Health care co-ordination

Co-ordination of health services is essential to the person's health and wellbeing, but as the systems are fragmented, services can be split across different systems and communication between services can be difficult, this can require careful management to occur. A person with a chronic health condition such as a bleeding disorder and other co-morbidities will often have difficulty negotiating the health system and the various services they require. Without assistance, they find this very stressful, which impacts negatively on their health, and may find themselves having unnecessary or prolonged bleeding episodes or other complications.

When health care professionals are constrained by classification systems so that they are limited in providing services in the way or setting required, or in providing referrals, this can prevent appropriate care from occurring or make it difficult for patients to access care in a timely or efficient way.

In contrast, a health care classification system that offers seamless access to integrated services can provide benefits to both the patient and the health service.

In bleeding disorders, Haemophilia Treatment Centres are essential to provide oversight to their patients' treatment and care. Patients often do not come to the hospital either as an inpatient or outpatient except for their annual review. However, in the meantime they are receiving home factor replacement therapy prescribed and managed by their HTC. The management of these patients should not be considered trivial:

it includes the best use of expensive clotting factor products, encouraging compliance with treatment and recording in MyABDR, reporting health care outcomes and intervening if it appears that the patient has a bleeding problem that has not been resolved through treatment. It also includes appropriate and timely referrals to other health services and individual liaison to prevent bleeding complications, for example, with surgeons, dentists or obstetricians. It also includes patient education and support that may be provided in the community, over the telephone or via email or VoIP and other digital communication networks.

For the patient this can make the difference to access to care or education when they need it and working towards a good quality of life with as few bleeding episodes as possible. For the health service provider, there is the satisfaction of achieving a good health outcome for their patients while reducing the costs involved in inefficient use of clotting factor products or bleeding complications. If the classifications of non-admitted care can support the delivery of integrated care between health settings and the delivery of health care outside the hospital through regional or community settings and digital technologies as is now the case in bleeding disorders management, it will be of great benefit to all.

Background

Haemophilia Foundation Australia

Haemophilia Foundation Australia (HFA) is a not for profit organisation which represents people with haemophilia, von Willebrand disorder and other rare bleeding disorders in Australia. It is the national peak organization for bleeding disorders. It provides advocacy, education and support to the bleeding disorders commmunity and works to promote Australian based research.

Treatment and care for bleeding disorders in Australia

In Australia most people with bleeding disorders use recombinant or plasma derived clotting factor treatment products to treat their bleeding disorder. The financial cost of all clotting factor products is shared by Australian governments under the National Blood Agreement. Treatment and care for people with bleeding disorders is best managed though a model of comprehensive care which is provided by specialist Haemophilia Treatment Centres. These are currently located in major public hospitals around Australia and provide statewide services.

Comprehensive care
The aim of comprehensive care is to promote physical and psychosocial health and quality of life while decreasing morbidity and mortality. People with bleeding disorders and their families have wide ranging needs. The co-ordinated delivery of comprehensive care by a multi-disciplinary team of health care professionals with expertise in bleeding disorders is an effective way of providing treatment and care over the patient's lifetime, while managing the use of health resources. Comprehensive care in a Haemophilia Treatment Centre involves:

- Haematologists
- Haemophilia nurse
- Musculoskeletal experts, including physiotherapists
- Laboratory specialists
- Psychosocial experts, such as social workers or psychologists.

The complications of people's bleeding disorders, their co-morbidities and the issues that occur as they age result in a need for a wide variety of health, social and support services. This includes identifying resources and strategies to deal with risks of having further children with bleeding disorders, the risks of everyday living, and issues relating to growth and development over a lifetime. [10,11] Many of these services have to be obtained through referral outside the Haemophilia Treatment Centre, and sometimes outside the public hospital system.

The long-term relationship between patients and their families and the comprehensive care team promotes timely and effective management of a bleeding disorder and its complications, compliance with treatment and wellbeing.[3]

As they are statewide services, most of the Haemophilia Treatment Services provide outreach clinics to regional areas and, in some cases, telehealth services.

Australian Bleeding Disorders Registry[1]

The Australian Bleeding Disorders Registry (ABDR) is a registry for patients in Australia with bleeding disorders. It is used on a daily basis by clinicians in all Australian Haemophilia Treatment Centres (HTCs) to assist in managing the treatment of people with bleeding disorders and to gain a better understanding of the incidence and prevalence of bleeding disorders. Statistical data from this information is also used to understand demand for, and to facilitate ordering of, clotting factor product.

MyABDR is a secure app for mobile devices and website for people with bleeding disorders and parents/caregivers to record home treatments and bleeds and manage the inventory of their factor replacement therapy stock at home. MyABDR links directly to the ABDR.

Patients with bleeding disorders may only have reviews annually. The communication between them and their comprehensive care team through MyABDR is an important tool in keeping accurate records of treatment use, bleeding episodes and the need for treatment compliance, adjustment to the treatment plan and rehabilitation. It also becomes a discussion tool for issues such as risks associated with activities of daily life, for example, bleeds with repetitive movements at work and an opportunity for patient education to prevent bleeding episodes.

The ABDR also provides an important evidence base to study trends and patterns in treatment and care and ways to improve patient outcomes.

Bleeding disorders

There are around 5900 people diagnosed with bleeding disorders in Australia. Approximately 3000 have haemophilia, with those diagnosed being largely male[1].

Haemophilia is a lifelong inherited condition and occurs in families. In one third of cases it is a spontaneous mutation, appearing in families with no previous history of the disorder. Haemophilia is found in all races and socio-economic groups.

Haemophilia occurs when there are reduced levels of blood clotting factors VIII (eight) or IX (nine) in a person's blood or the clotting factors do not work properly. It is incurable and can be life threatening if not treated appropriately. Bleeding is internal, into muscles, joints and organs. Bleeding may occur as a result of injury, or as a result of surgery or invasive procedures; in severe haemophilia bleeding can occur spontaneously, from no obvious cause, up to several times a week.

The two main forms of treatment for haemophilia are 'on demand' or 'prophylaxis'.

- **'On demand' treatment:** treatment when a bleeding episode occurs or to prevent bleeding, for example, with surgery or other invasive procedures
- **Prophylaxis:** preventive treatment for moderate or severe haemophilia, involving regular factor replacement therapy infusions, up to four times weekly. Spontaneous bleeding can largely be prevented through prophylaxis treatment, but bleeding episodes may still occur due to injury.

Women and girls with haemophilia and symptomatic women who carry the altered gene causing haemophilia frequently experience menorrhagia and bleeding complications with childbirth. They may also experience other gynecological problems associated with their bleeding disorder. These are usually treated with hormonal medications but may require surgery.[3,4]

Impact of haemophilia complications

Bleeding episodes in infants and children can result in frequent emergency admissions until the bleeding is controlled. Small children may also have a port surgically inserted in their chest used to administer clotting factor treatment directly into a central vein. They may also experience infections in the port in their chest, requiring a visit to the hospital.

Care at a paediatric level requires:

- Liaison between the local medical centre and the Haemophilia Treatment Centre for emergency admissions
- Considerable education of the parent and child by the Haemophilia Treatment Centre, with a focus on management and prevention, for effective use of factor replacement therapy
- Introduction to physiotherapy and rehabilitation to increase muscle and prevent joint damage
- Social work liaison and counselling for both parents and sometimes extended family to manage distress and complexity of needs, sometimes provided in the community
- The Haemophilia Treatment Centre team may also need to provide emergency management plans and education for childcare centres, schools and sporting clubs.

Both parents of children and adults with or thought to have bleeding disorders may also require genetic testing and counselling for clinical diagnosis and to manage the risks of having future children with bleeding disorders.

Episodes of bleeding over the long term can cause permanent damage to joints and muscles, resulting in:

- Arthropathy, joint deformity, muscle atrophy and contractures
- Pain
- Disability and reduced mobility
- Decreased quality of life.

The likelihood of bleeds and the resulting joint and muscle damage is increased if the person has an inhibitor, a complication of treatment that reduces the effectiveness of treatments. A person who experiences repeated bleeding over their lifetime may start to experience these problems within the first 10 or 20 years of their life.[3,4]

Today in Australia, children and young people who have been treated all their lives with the required replacement clotting factor are less likely to have the problems of older adults. However, many adults live with significant joint damage caused by inadequate clotting factor therapy in the past.

Women may have continual problems with very heavy menstrual bleeding and the resulting anaemia. If they carry the gene or have a bleeding disorder, they will need to have monitoring during their pregnancy and liaison between their obstetrics and Haemophilia Treatment Centre teams for a safe birth for both mother and child.

Adults with bleeding disorders may also require:

- Aids such as artificial limbs, crutches, wheelchairs, modified vehicles and home, work or school environments, orthotics and bracing
- Regular and specialized physiotherapy and education to improve muscle strength and balance and prevent falls
- Prescribed strengthening exercise such as swimming or gym work
- Other specialist services, such as podiatry, dentistry, rheumatology, pain management
- Considerable support to manage the activities of daily life
- Hospitalization at times for serious bleeds or complications such as joint infections
- Surgical interventions including athroscopy, joint replacements, ankle fusion, soft tissue release
- Referral to gynaecology to manage abnormal uterine bleeding. [4,5,6]

Haemophilia Treatment Centres also provide:

- Education to patients and parents about using MyABDR
- Information and education at community-based events such as community camps or information nights. This is an important way of keeping the community up-to-date with the latest treatment and care issues and techniques such as self-infusion
- Advice and documentation to enable their patients to travel with a bleeding disorder, including self-management, prevention of injury and travel insurance.

Von Willebrand disorder (VWD) is another inherited bleeding disorder caused when there is not enough of the von Willebrand clotting factor in a person's blood, or it doesn't work properly. It is thought that many Australians with VWD are undiagnosed as it is more common in a mild form, and most people do not need treatment unless they have invasive medical or dental procedures, surgery or an injury. However, some people have severe VWD with frequent bleeding episodes and joint and muscle bleeds. Women and girls with VWD may experience menorrhagia, affecting their ability to work, and bleeding problems after childbirth. Some people with VWD can only be treated with clotting factor VIII concentrates made from human plasma, while others can be treated with synthetic hormones.[3]

Blood borne virus co-morbidities

Some adults with haemophilia or von Willebrand disorder may also have been living with blood borne viruses, including HIV and hepatitis C, for more than 20 years due to treatment with infected blood clotting products before safe blood screening tests and viral inactivation procedures were introduced. For many, their co-morbidities have increased the complexity of their health problems and need for health and support services. Many of those who have both a bleeding disorder and hepatitis C reported that it impacted on their ability to work and earn an income from the age of 35 onwards.

Most of those with hepatitis C have now been treated successfully, but those who have not may be accessing treatment through a general practitioner or local health service and need liaison with their Haemophilia Treatment Centre.

HFA's national hepatitis C needs assessment found that many experience overload with health problems and services, and need assistance to negotiate the health and social services system. Given affected community members' ill-health and disability, this assistance is required to help them understand and find the services that are available to them, support them in completing the applications and assessments, and advocate for them to receive the services they require when they do not fit the "one-size-fits-all" criteria, which is often the case.[5,6,7,8]

Ageing

Haemophilia is categorized according to levels of severity, eg mild, moderate and severe, and people with other bleeding disorders can experience a range of severity in their bleeding disorder. The degree of disability as the person ages is specific to the individual. However, early ageing occurs for many people with haemophilia, particularly if the person has inhibitors or where clotting factor treatment was rationed in early life due to plasma supply shortages.

Improved treatment, treatment safety and quality of care in Australia has meant that people with bleeding disorders are now living longer and for the first time there is a generation experiencing the age-related medical problems also encountered in the general population. This includes diseases such as:

- Heart disease
- Cancer
- Renal disease
- Osteoporosis and degenerative or osteoarthritis.

Testing and treatment for all of these health conditions may be complicated by bleeding problems, for example, with the need for factor replacement with surgery or invasive diagnostic procedures, or with haemodialysis, or managing side-effects such as thrombocytopenia from chemotherapy.[7]

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