Australian Framework for

Management of Bleeding Disorders

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Introduction

Close collaboration between stakeholders can provide the environment to optimise patient care. Providing care for haemophilia and other bleeding disorders is complex, difficult and expensive.

An 'Australian Framework for Management of Bleeding Disorders' is in development to highlight the various inputs necessary for appropriate patient care and effective use of clotting factor products.

Supply of clotting factor products

- A sufficient supply of safe and effective clotting factor products is critical to appropriate treatment outcomes.
- As clotting factor products are expensive for governments, coordinated national supply planning and management with appropriate expertise and governance ensures greatest efficiency. The National Blood Authority acts on behalf of all Australian governments to provide a safe, secure, adequate and affordable supply through national tendering and supply management.
- Close liaison with all patient, clinical, funder and industry stakeholders is important in order to obtain best value for money, particularly in a tight fiscal environment.

Comprehensive care

- Comprehensive care is central to the effective treatment and care of people with bleeding disorders (patients).
 - Health care needs of patients are best met in accordance with nationally accepted protocols and guidelines through a range of specialist multidisciplinary treatment services and care.
 - Haemophilia treatment centres (HTCs) have been developed and are recognised by governments, to deliver the full range of services needed to optimise a patient's health and quality of life.

Stakeholder partnership and collaboration

- Recognition of all stakeholders in the bleeding disorders community is important: health professionals from all disciplines supporting comprehensive care; patients and patient organisations; health funders, administrators and policy makers; and industry partners.
- Although competing interests of stakeholders are inevitable, it is paramount to recognise patients and their families and carers as the focal point of the collaborative framework of care.
- Funders and policy makers have a responsibility to collaborate with other stakeholders to seek the most effective use of publicly funded healthcare resources.

Information and data systems

- Data assists accurate diagnosis, safety of treatment and analysis of effectiveness. The rarity and complexity of bleeding disorders requires a sophisticated data tool incorporating clinical, research and realtime patient management capabilities.
- The Australian Bleeding Disorders Registry is a pivotal clinical registry for patients and clinicians in Australia. MyABDR facilitates data integrity by allowing patients to record information directly about their condition and use of clotting factor products.
- The information in the ABDR is also important in clotting factor supply planning and management.

Appropriate patient care

Effective use of clotting factor products

Quality healthcare outcomes

Knowledge development and practice improvement

- Nationally agreed treatment protocols and guidelines optimise effective therapy and minimise inappropriate treatment.
- Education and training is also important to maintain expertise and to inform the medical and broader community.
- Research to improve patient care and outcomes is most effectively harnessed through collaboration between HTCs and can be facilitated by the support of a national clinical registry.
- National safety and quality standards for health care in Australia apply to the use of blood products including clotting factor products.

Historical and future development

A number of significant past milestones support the strength of the Australian framework for management of bleeding disorders today:

- Recognition by all governments in 1998 of the benefit of providing comprehensive care through dedicated Haemophilia Treatment Centres
- The establishment, and ongoing operation and resourcing of:
 - state and territory haemophilia foundations and Haemophilia Foundation Australia
 - Australian Haemophilia Centre Directors' Organisation Australian Haemophilia Nurses Group

- Australian and New Zealand Physiotherapy Haemophilia Group
- Australia/New Zealand Haemophilia Social Workers' and Counsellors' Group
- ABDR Data Managers' Group
- Implementation of the National Blood Agreement between all Australian governments in 2003 to enable national policy setting, supply planning and management, and improvement programs for blood products including clotting factors, including establishment of the National Blood Authority to act on behalf of all governments to provide a safe, secure, adequate and affordable supply of clotting factor products
- The decision to provide funding for full access to recombinant Factor VIII and Factor IX products in 2004
- The national redevelopment stages of the Australian Bleeding Disorders Registry in 2008 and 2012, and development of MyABDR in 2014
- The development of national Factor VIII and Factor IX guidelines in 2006, and the commissioning of a project to develop updated national haemophilia care guidelines in 2013

The optimal management of bleeding disorders will not remain static. The framework described above will be developed and used over time as a means of identifying current and future challenges and opportunities. This will facilitate the development of forward strategies for national priority setting, collaboration and improvement.

Conclusion

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Describing the Australian Framework for Management of Bleeding Disorders as outlined above can be used as a vehicle to consider the elements required to provide effective treatment and care for patients within the arrangements and approaches applying in Australia.

The framework will be developed and used as a tool to facilitate examination and improvement of what is already in place, and to develop future strategies and measures, in a manner which recognises and balances all stakeholder interests.

Collaboration between stakeholders with different and competing interests may at times be challenging but is essential to optimise the care and outcomes for people with bleeding disorders.

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