

7. The way forward



Achieving bleeding disorder community goals and aspirations

A common goal of all community and health professional stakeholders consulted was to enable older people with bleeding disorders to maintain the healthiest life possible. The intention was to assist them to maintain or even improve their quality of life and to remain independent for as long as they could.

Another important objective was to support the aspiration of many older people to contribute and be productive members of society.

Systemic barriers

In 2017 the Australian Productivity Commission identified factors and influences that may affect Australia's future economic performance and priorities to enhance national welfare. The *Shifting the Dial* report points to chronic ill health problems and systemic barriers in the health system that impact on the health of Australians.³³ The Getting Older needs assessment confirms that many older people with a bleeding disorder are also deeply affected by comorbidities with other chronic health conditions. Some experienced poorly integrated health services, lack of case management, concerns about access to care, treatment and referral, particularly in the community and regional areas, inadequate or inconsistent funding models across jurisdictions, the tyranny of distance where living in rural and regional locations or marginalisation by disability or mobility issues.

There is potential to address and prevent some of these complications now and introduce prevention strategies at an earlier stage of the lives of others as they grow older.

Reporting health outcomes

The bleeding disorders treatment environment is fast moving with innovative therapies including gene therapy on the horizon that can improve health outcomes. The outcomes of these treatments should be measured using patient-oriented outcome measurement tools already validated and available and the data should be reported and built upon. An important step will be to explore whether the PROBE Australia data can be combined with ABDR data to generate a more comprehensive dataset and subsequently incorporated into clinical guidelines.

A range of factors will be involved in achieving this:

- Innovations in comprehensive care to provide easier access to targeted services and programs and co-ordinated care with relevant medical specialties
- Treatment plans, including access to newer and emerging therapies, to improve quality of life and reduce the burden of treatment
- Further research to better understand specific issues of ageing, including in mild conditions, in the rarer bleeding disorders, and in women
- Targeted patient education to assist with their understanding of growing older with a bleeding disorder and effective self-management
- Education about growing older with a bleeding disorder for health care professionals and carers
- Continuing to address the complications of bloodborne viruses, such as HIV and hepatitis C, including the need for financial support
- Support for an active approach to life: exercise, travel, personal interests
- Support to continue working, where appropriate, and other ways of contributing their skills and experience
- Assistance with future planning
- Building on the resilience and existing support networks of older people with bleeding disorders
- Addressing the needs of their partners and carers
- Increased information about and access to community support and home care services
- Advocacy around financial issues
- Developing social connection and peer support for both the person and their partner/carer
- Investigating digital solutions for community information and communication needs related to getting older.