



# Getting older with a bleeding disorder

## Needs assessment report

May 2020



HAEMOPHILIA FOUNDATION AUSTRALIA

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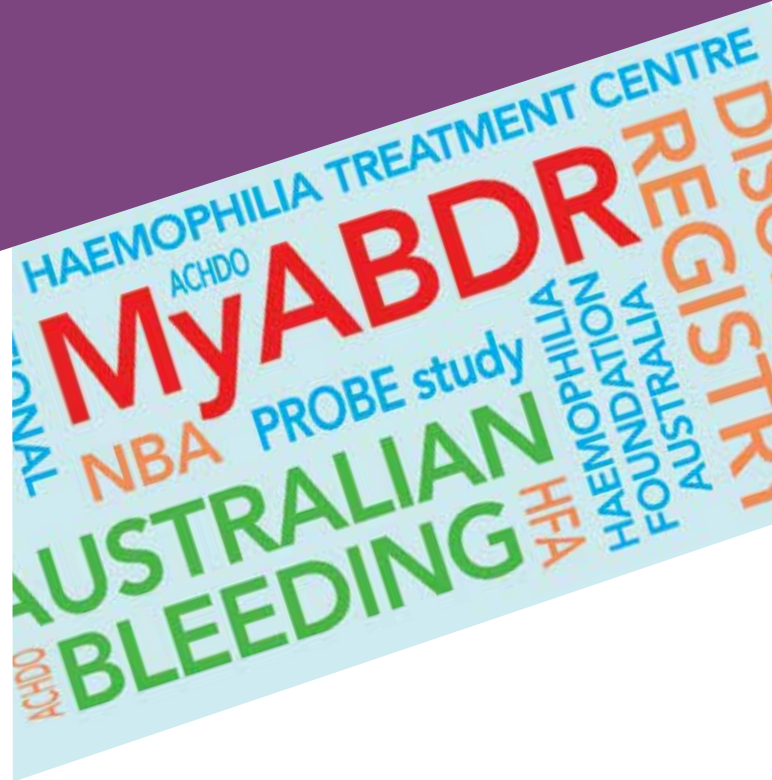
# Abbreviations

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

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

**Haemophilia Treatment Centre (HTC):** A designated medical centre staffed by a multidisciplinary team of health professionals who specialise in bleeding disorders.

**Haemophilia Foundation Australia (HFA):** the peak body representing people with bleeding disorders and their partners, family and carers in Australia.



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

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

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