

Data Managers Group (DMG) – The powerhouse behind Australian Bleeding Disorders Registry (ABDR)

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Introduction and Objectives:

The National Blood Authority (NBA) - an Australian government agency, funds the employment of Data Managers (DMs) through the Australian Haemophilia Centre Directors Organisation (AHCDO).

DMs are now situated in the Haemophilia Treatment Centres (HTCs) in each state and territory in Australia to ensure high quality and consistent data in ABDR.

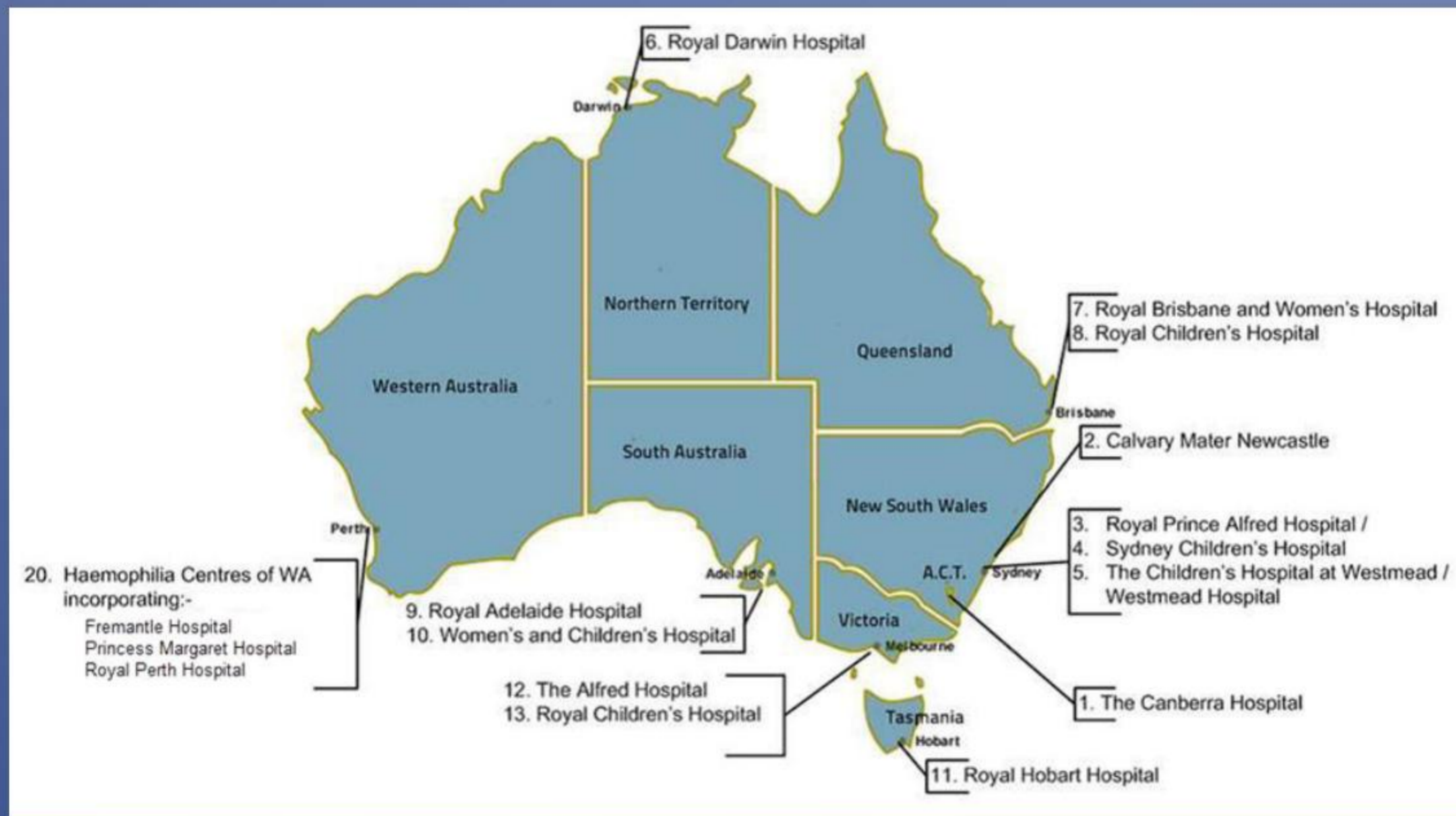
Results:

Members of DMG attend biennial Haemophilia Foundation of Australia conferences and biennial World Haemophilia Congresses.

As new DMs have been appointed, mentoring has been undertaken by more experienced DMs to ensure a smooth transition to the role and uniformity in collected data.

DMG representatives participate in the NBA User Reference Group which provides ongoing input into the updating of ABDR.

HTC Sites around Australia



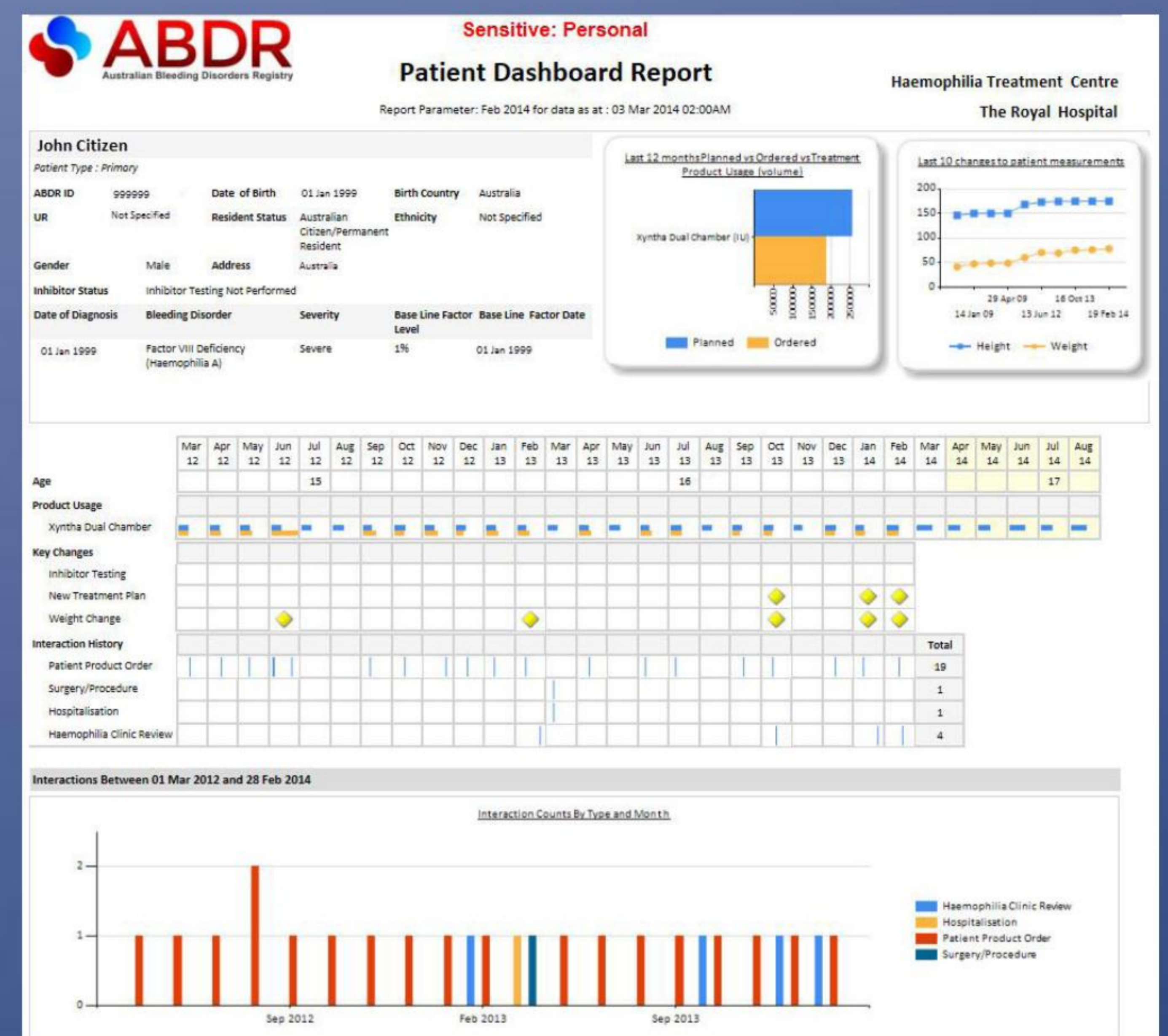
Materials and Methods:

The DMG was formed to provide support for individuals working in the same role around Australia. Position descriptions (PDs) have been developed over time for this pivotal role.

The DMG is supported by AHCDO in conducting regular telephone conferences and attendance at a yearly face to face meeting. The goals of the group include:

- fostering a team spirit among the ABDR DMs
- continuously improving the quality of the data submitted to the ABDR
- actively participating in the reporting and analysis of the ABDR data to assist in enhancing the efficiency of the ABDR, leading to improved outcomes for registered patients.

An example of a report generated utilising data from ABDR



Data shown in image is test data and does not represent any individual or specific clinical condition

Conclusion:

As the personnel responsible for the quality of information included within the ABDR, DMs are mindful of the importance of accuracy of information to ensure best outcomes for people with bleeding disorders.

References:

- <http://www.blood.gov.au/abdr>
- <http://www.ahcdo.org.au>
- <https://www.haemophilia.org.au>



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