

Data Managers - Pivotal role in documentation of care for people with bleeding disorders in the Australian Bleeding Disorders Registry (ABDR) database

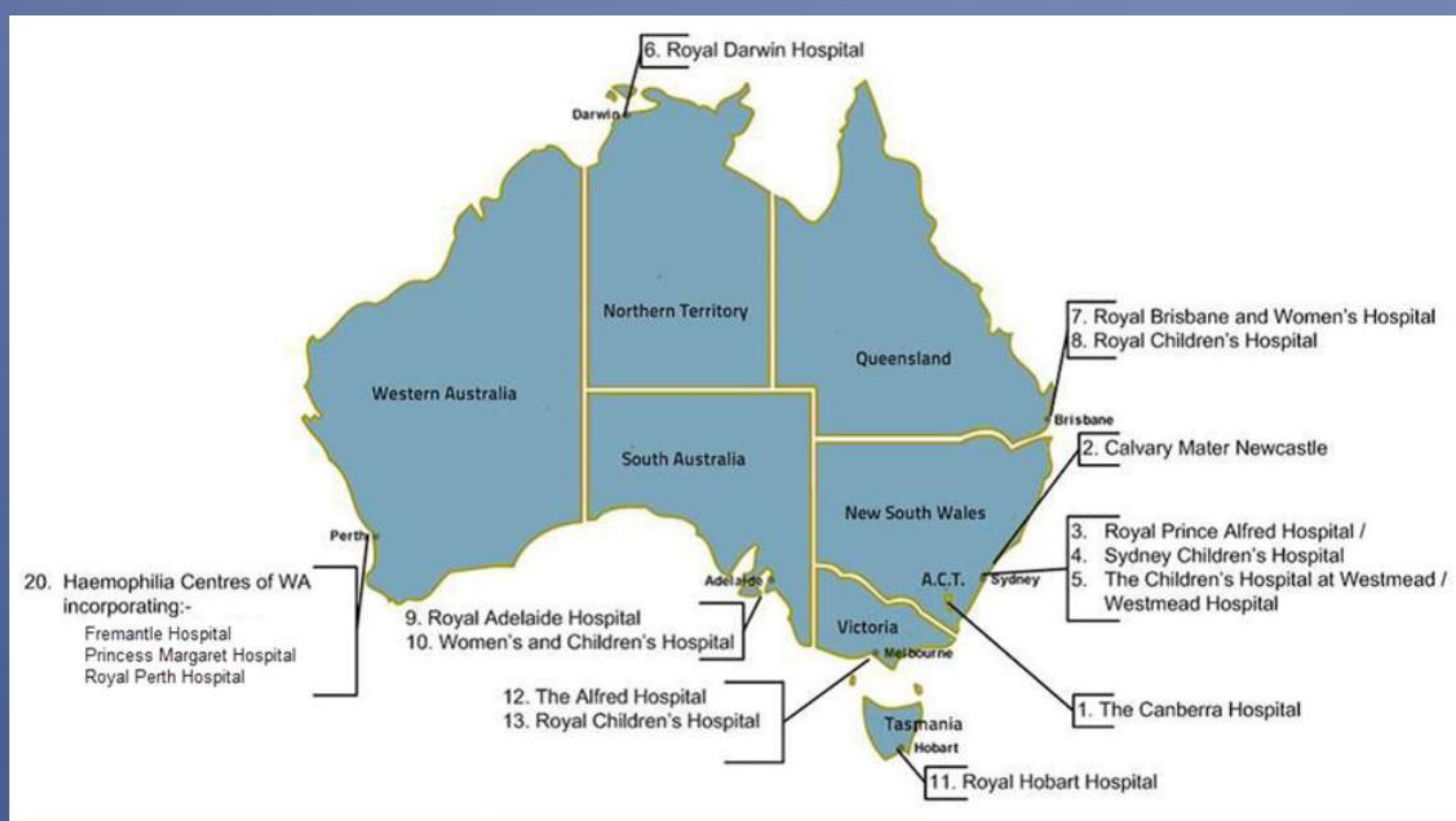
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Introduction and Objectives:

In 2008 the ABDR was launched, funded by National Blood Authority (NBA) - an Australian government agency.

To ensure the success of the ABDR, NBA through the Australian Haemophilia Centre Directors Organisation (AHCDO) has provided ongoing funding to employ Data Managers (DMs) at each of the Haemophilia Treatment Centres (HTCs) in each state and territory around Australia.

HTC Sites around Australia



Materials and Methods:

The DMs' role has evolved over time to be responsible for ensuring that the information contained within the database is accurate, meaningful and able to be used for clinical reference, auditing and with scope for research.

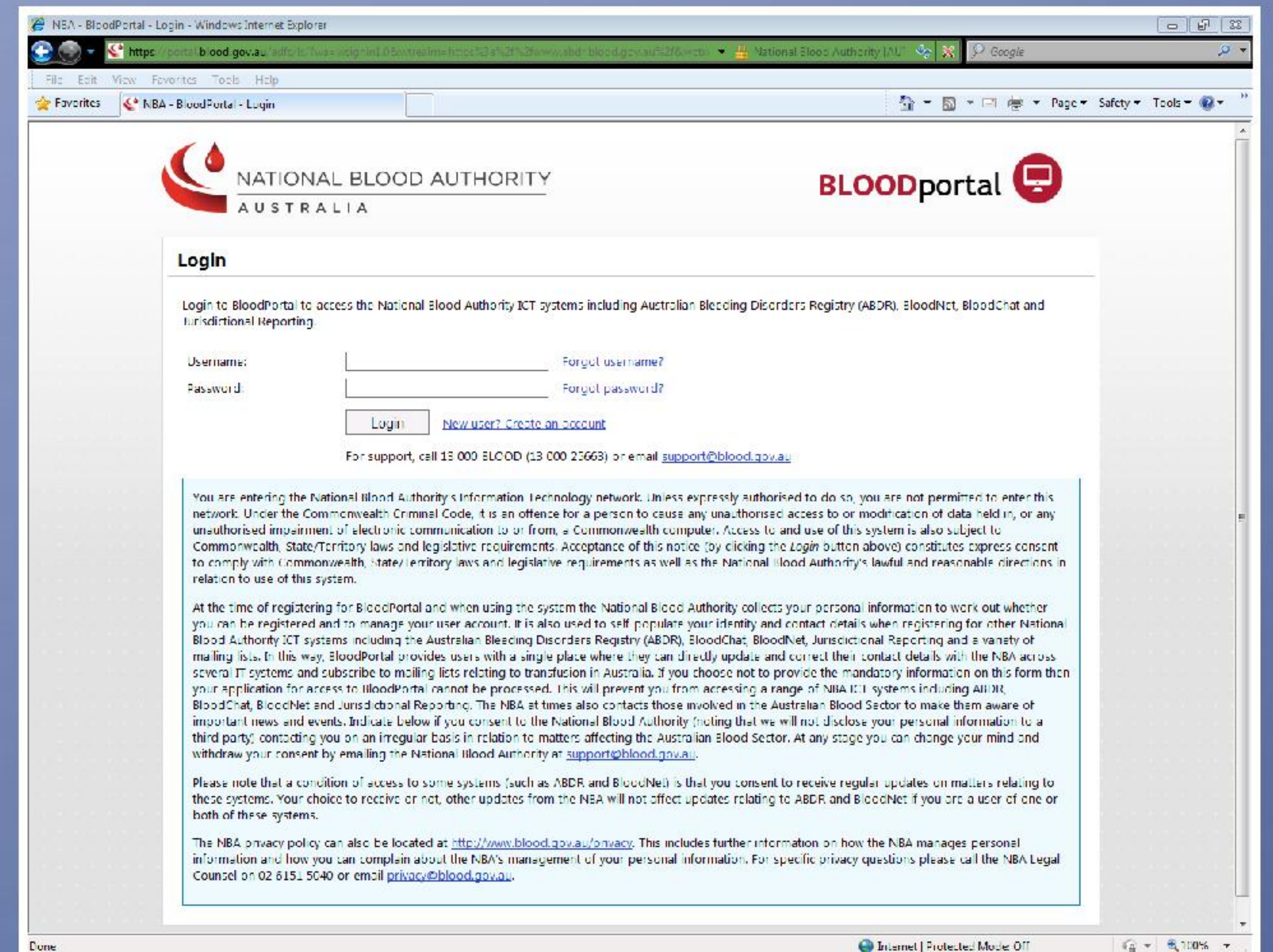
Previously each HTC collated their individual state's information in a variety of database systems. Patient demographic and product usage information was then collated nationally on a six monthly basis. Most of these databases were maintained by the haemophilia treatment team on an ad hoc basis rather than by dedicated DMs.

The ABDR was designed to include demographic information, diagnosis, pathology and genetic investigations, product usage and bleeding episodes.

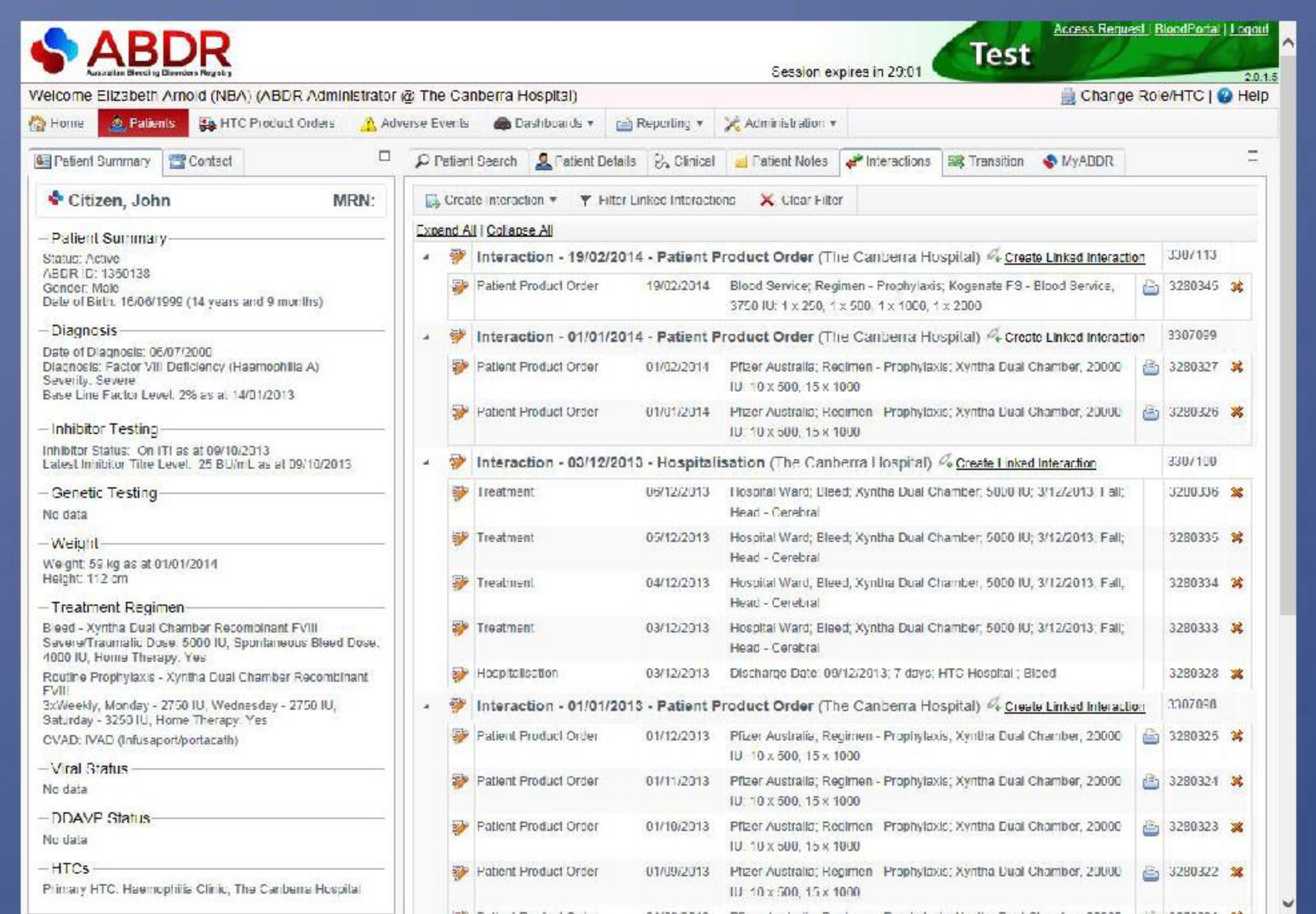
Results:

Over the ensuing six years, ABDR has been adapted and refined - with Version 4 now in use. The information contained within the ABDR is highly confidential, with limited and stringent access controls.

Screen shot of Login for ABDR



An example of a patient's history of interactions within ABDR



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

Conclusion:

The great advantage of a national system is that information can be shared between HTCs as people with bleeding disorders (PWBD) move around the country for work, study or leisure pursuits.

This means that where ever PWBD are situated - all information pertaining to that person, including treatment plans can be easily accessible and implemented - leading to optimal care as the outcome.

References:

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



Acknowledgements: DMs would like to thank members of the NBA, HFA, EC AHCDO & Dr Megan Sarson - Project Officer AHCDO for their ongoing support and guidance

P-M-080 Medical - Data Base & Registries