

MyABDR: an online personally controlled clinical tool for recording treatments and bleeds

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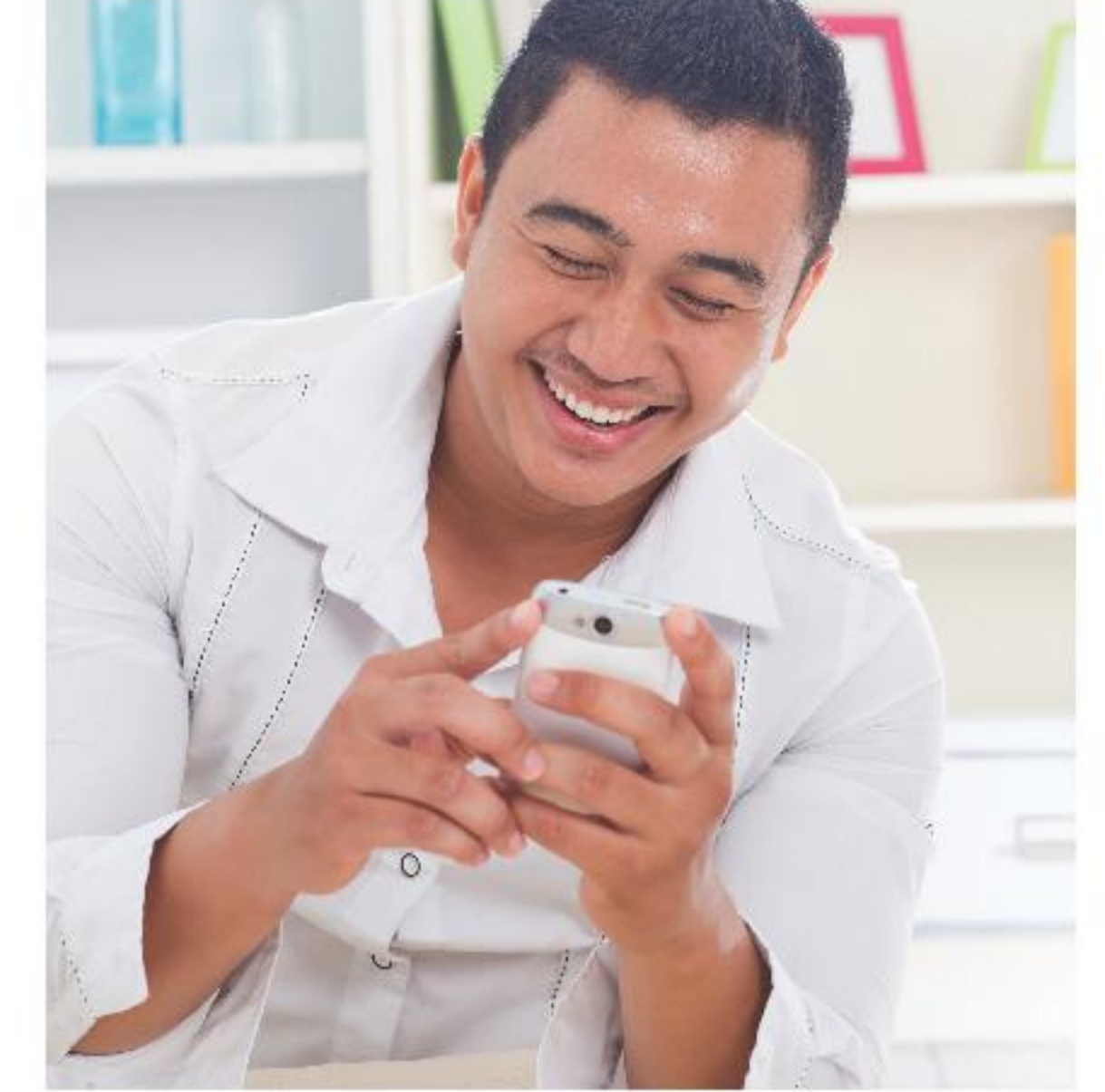
INTRODUCTION AND OBJECTIVES

With widespread home therapy and individualised treatment plans for people with bleeding disorders (PWBD), using online technology to communicate between PWBD and their haemophilia treatment centre (HTC) has become integral to best practice clinical care in Australia. The MyABDR project aims to address this by developing a secure app for smartphones and web site for PWBD to:

- » Record home treatments and bleed details
- » Manage their inventory of treatment product
- » Share this information with their HTC.

Australian Bleeding Disorders Registry (ABDR) - the national system used by HTCs for the clinical care of their patients:

- » Data recorded in MyABDR (app or web site) is stored in the ABDR
- » Summarised de-identified ABDR data can be used to understand bleeding disorders, treatment use and related health outcomes and for governments to plan for treatment product purchase and supply.



METHODS: COLLABORATION, CONSULTATION AND GOVERNANCE

MyABDR is the result of collaboration between:

- » **Haemophilia Foundation Australia (HFA)** - representing PWBD in Australia
- » **The Australian Haemophilia Centre Directors' Organisation (AHCDO)** - the national medical body for haemophilia in Australia
- » **The National Blood Authority (NBA)** - the Australian Government agency responsible for the delivery of a blood supply system. The NBA developed and maintains the ABDR, including the support of all ABDR users.

Development involved staged consultation with:

- » PWBD and parents/caregivers (Survey n=81; Focus group n=8; Home testing group n=24)
- » Specialist haemophilia health professionals (haematologists, haemophilia nurses, physiotherapists, social workers and data managers).

ABDR Steering Committee: oversees the governance of the ABDR and MyABDR. Membership includes representatives of AHCDO, the NBA, HFA and Australian governments.



RESULTS

AN INTEGRATED AND HOLISTIC SYSTEM

This collaboration has enabled communication across a range of systems that manage treatment product and supply. The MyABDR patient-controlled record integrates fully with the ABDR clinical record at the HTC, so that the MyABDR user can see:

- » Their own MyABDR treatment records
- » Summary of their ABDR treatment records from their HTC
- » Other information, such as their treatment plan, weight and contact details.

The MyABDR inventory:

- » Allows the user to add product, report use and monitor remaining product
- » Draws on product data from suppliers via NBA systems e.g. pre-filling product details using batch numbers
- » Shows notifications about expiring, expired or recalled products.

Strict security protocols ensure identifiable data is kept private.

SELF-MANAGEMENT AND PATIENT EDUCATION

Consultation with PWBD and health professionals raised education issues around self-management. MyABDR acts as a shared clinical tool for PWBD and HTCs and provides online guidance to the PWBD on treatment plans and communication with their HTC:

- » Access to their treatment plan
- » Shared plain language definitions
- » Online prompts and education messages.



These features support the user's confidence to take control of recording their treatment and bleeds, and can be reinforced by HTCs through individual patient education.

FEEDBACK AND UPTAKE

Uptake has been rapid. The MyABDR app went live on 28 February 2014. 1468 PWBD received treatment product in Australia in 2012/13. Within 6 weeks 145 patients had registered to use MyABDR and are actively recording treatments.

User feedback collected during the rollout is being used to enhance MyABDR. New features will include optimisation for iPads and tablets and the ability to upload photos to the memos/notes sections.

What did the focus group say?

"Less paper!! Yay!! I don't need to carry a book around with details of treatments."
 "I love the inventory details on the home screen."

CONCLUSION

The collaboration to develop MyABDR has provided an opportunity to engage PWBD and health professionals in tailoring a shared online clinical tool integrated with existing information systems for best practice clinical care.

REFERENCES

MyABDR information page - www.blood.gov.au/myabdr
 MyABDR section, Haemophilia Foundation Australia web site - www.haemophilia.org.au/myabdr

