PROJECT TITLE:

Getting important information to Rh (D) Negative women from CALD communities- a pilot project

PURPOSE OF DOCUMENT: Final Report 2009-2011

PROJECT DESCRIPTION:

Background

The Victorian Quality Council (VQC) was established in 2001 and identified consumer, carer and community collaboration as a key tenet of effective health care improvement. It therefore aims to strengthen the consumer role in quality and safety improvement of health care through enhancing consumer leadership capacity across Victoria.

A research project commissioned in 2006 confirmed the need for consumer leadership programmes, networks and guidelines to ensure effective consumer participation and leadership. As a result, a pilot Consumer Leadership Development Programme (CLDP) was commissioned for implementation and evaluation in 2008. Sixteen consumer leaders were recruited and as part of the CLDP were required to conduct a project that allows them to take up a leadership role.

This CALD project was a collaboration between the Consumer Leader undertaking the CLDP and the Blood Matters program. The project was informed by the leader's areas of interest which are:

- Providing effective health care for cultural and linguistically diverse (CALD) people.
- Bridging any gaps between the public administration and delivery of health care in hospitals.

This project was undertaken as part of the existing work within the Blood Matters program along with three health services in Victoria. The Blood Matters program is a joint initiative of the Department of Human Services Victoria and the Australian Red Cross Blood Service. It aims to improve the safe and appropriate use of blood and blood products, such as Rh (D) immunoglobulin and provides education and resources to help clinicians and patients.

There are ethnic variations in the frequency of Rh D negative individuals with approximately 17 per cent of women in Australia being negative for the Rh D antigen. In East Asians and African populations, the frequency of Rh D-negative status is less than one per cent.

Project rationale and scope

An important part of the Blood Matters program is to ensure consumers are informed of the risks and benefits of blood and blood products they may receive. This pilot focused on CALD pregnant women and Rh (D) immunoglobulin. Informing CALD consumers should take into account their language and cultural needs. The pilot project aims to establish how best to translate and make information accessible to **Vietnamese**, **Chinese and Sudanese women** who are required to receive Rh (D) immunoglobulin as part of their antenatal care at **The Women's Hospital**, **Sunshine Hospital and Sandringham Hospital in Victoria**. These CALD groups were chosen as each of the three participating hospitals, highlighted them as reasonably large CALD groups for their health services.

Aim

To identify how best to get important information to Rh (D) negative CALD consumers. The findings of this pilot project are to inform subsequent Blood Matters initiatives for other blood and blood product information dissemination.

Objectives

- 1. Identify appropriate content information for dissemination to the consumer group.
- 2. Establish how best to translate and make information accessible (format of material and dissemination of material).
- 3. Identify how to sustain informed consent for blood and blood product transfusions through feedback from involved consumers and staff.
- 4. Identify the role of the Consumer Leader in the project process.



Project method

The existing brochure 'You & your baby: Important information for Rh (D) Negative women' produced by CSL Biotherapies and Australian Red Cross Blood Service was translated by accredited translators, and printed in three languages so that it can be read and discussed with the women and their families. Midwives disseminated the written information during their appointment with the women, and at that time provided the women with a request for consent to be contacted to obtain feedback on the usefulness of the information provided.

The planned intervention is two-step process.

- 1. Written information is to be disseminated to CALD, Rh (D) negative antenatal women.
- 2. Feedback will be sought on the effectiveness of the intervention.

Hard copy brochures in three languages were made available at each site: Vietnamese, Arabic (for use with Sudanese women) and Chinese.

English language brochures are available on site for midwives, so they knew what information the women were getting.

The brochure was to be distributed to Rh (D) negative women by midwives over a six week period. (This was extended to 3-4 months as no use of the brochures was captured in the initial time frame).

Sunshine Hospital devised labels and information that could be placed on the Victorian maternity record (this was utilised at two of the health services, the midwifery nursing care plan was utilised elsewhere). Workbooks for each maternity antenatal area were developed to maintain records of the information being presented to the CALD groups. Examples of these processes are contained in Appendix 1 of this report.

Project Team

- Blood Matters program secretariat,
- · Consumer Leadership project participant,
- Transfusion Nurse Consultant's from Sunshine, Sandringham and The Women's Hospital.

Results

The uptake of brochures was minimal at each site during the project course, despite increasing the time available at each antenatal area. Commencement was delayed for a period of time at The Women's Hospital, as there was no Transfusion Nurse Consultant to lead the project. As The Women's Hospital is a major provider of maternity care for Victoria, it would be a valuable participant and hence commencement of the project was delayed until that position was filled.

Sandringham: There was no uptake of the brochure from any of the three CALD groups in the time frame allocated.

Sunshine: A total of five patients received one of the translated brochures, (two Vietnamese and three Arabic).

The Women's Hospital (WH): Fifteen Arabic O Rh D negative women were identified in the time frame and eleven brochures were distributed.

Feedback was gained directly from midwives via survey (Appendix 2).

Sunshine Hospital midwives reported, they felt that it was extremely helpful to have these brochures although identified that:

The vast majority of Vietnamese women were second generation Australian, so spoke and read



English. The two women that preferred the brochure in Vietnamese were fairly recent arrivals who could speak English, but were more comfortable reading Vietnamese than English.

The Arabic brochures were given to two Sudanese women and one Somalian woman. Both of the Sudanese women had limited English, spoke Arabic and required an interpreter to be present. One of these women could read Arabic the other could not, but her partner could. The Somalian woman had some English but preferred Arabic. She also required an interpreter and while she was unable to read Arabic, her sister could, so chose the Arabic brochure over the English version.

It is unknown from the data collected at WH, if the women, who spoke Arabic, were Sudanese. This was the original CALD group targeted by this site.

The use of focus groups to interview patients directly following the distribution of the brochure was part of the original project plan. As the uptake was small; it was felt that focus groups would be resource intensive and minimal value adding.

OUTCOME:

Despite the uptake of the resources being minimal, the project was able to achieve the development and translation of brochures for three CALD groups of women who required anti-D. Given the timeframe and uptake, no alternative methods of dissemination were explored. The consumer leadership representative and each health service participant gained, and were able to share valuable project management experience about the project, through regular meetings to discuss managing different aspects of the project and development of support materials.

The only opportunity to seek the effectiveness of the intervention was feedback from the midwives, as focus groups were not used. This does limit the knowledge of whether this was an effective intervention for the women who received the material, as they were not directly questioned.

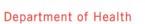
The midwives reported that some of the participants chose the language in their native tongue rather than English, despite being able to read written English, thus demonstrating their preference was to receive information this way. Informing patients about blood and blood products prior to administration needs to be patient focused. Information needs to be in a style that is easily understood and outlines the process, along with the risks and benefits associated with the product, whether written or verbal. The project team felt this was achieved by being able to provide written information in the language of their choice for the anti-D product. During this project there were no reports of any woman refusing to give consent for anti-D following the provision of information.

The brochure 'You and Your Baby: Important Information for Rh (D) Negative Women' has been translated into the three languages as outlined and these are now available as electronic tools on the Blood Matters website for health services with maternity services to access.



BLOOD SERVICE



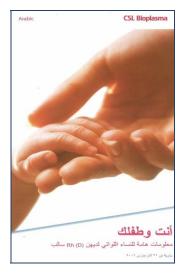


Appendix 1

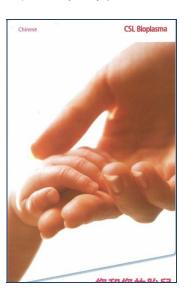
Getting important information to Rh (D) Negative women from cultural and linguistically diverse communities – a pilot project.

This pilot project aims to provide knowledge about how better to achieve the dissemination of blood product information to cultural and linguistically diverse (CALD) consumers, an area of particular challenge. The pilot will be conducted at three health services with significant CALD patient populations, namely the Royal Women's Hospital, Bayside and Western Health.

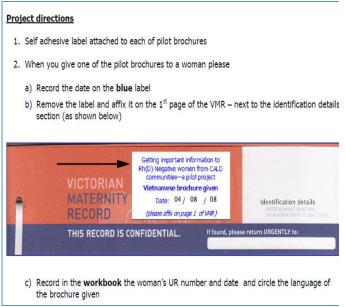
The information brochure You and Your Baby: Important Information for Rh (D) Negative Women has been translated into 3 languages Arabic, Vietnamese and Mandarin Chinese (currently only produced in English).







The pilot project will commence August 23rd 2010 and will run for approx 8 weeks.



Brochure given (circle)	Brochure given (circle)
Vietnamese Arabic Mandarin	Vietnamese Arabic Mandarin
UR number:	UR number:
Date: / /	Date: / /
Brochure given (circle)	Brochure given (circle)
Vietnamese Arabic Mandarin	Vietnamese Arabic Mandarin
UR number:	UR number:
Date: / /	Date: / /









At the completion of the pilot Clinicians will be asked to provide feedback via a short survey.

More information: CNC Ext / Pager /



BLOOD SERVICE



Appendix 2

Getting important information to Rh(D) Negative women from CALD communities—a pilot project

This document is an **invitation** to midwives and colleagues, to provide feedback on the "Getting important information to Rh(D) Negative women from cultural and linguistically diverse communities".

Project summary:

- The CSL brochure 'You and your baby' was translated into Arabic, Vietnamese and Chinese.
- It was available for Sudanese, Vietnamese and Chinese speaking Rh(D) Negative pregnant women at three pilot hospitals: Sunshine Hospital, Royal Women's Hospital and Sandringham hospital.
- Feedback is being sought on this approach to making information available on prophylactic anti-D immunoglobulin treatment.
- This feedback will inform subsequent initiatives to make information available on blood and blood products to CALD individuals receiving health care in Victoria.

SURVEY

	ease complete the below short form and return to [insert name of TN, contact details] by [TN to sert where they are to leave, send them].
1.	Name of hospital: Midwife: Yes/No. Other
2.	Did the brochure help to discuss the following elements of the prophylactic anti-D treatment?:
	• Risks Yes/No
	Comments:
	Benefits Yes/No
	Comments:
	 Improve the women's understanding of the prophylactic anti-D treatment they may receive (as best you can tell)? Yes/No. If you answered Yes, please comment on how it may have improved their understanding?
3.	Did you have good access to the written information, so that you could use it and give it to the women? Yes/No
	If you had difficulty getting access to the written information, please state the nature of the problem:
4.	Is there any other format you think the material could be provided in? (non-written formats, revised written brochure)





- 5. What proportion of patients do you think take written information?

 25% 50% 75% 100% (approximately) [pls circle the appropriate answer]
- 6. Other comments?
- 7. Would you like to have a short discussion with the Transfusion Nurse at your site, to let us know about the pilot project? Yes/No. If yes, pls write your name and phone number.

Thank you for your participation on the project and for your feedback to us.



BLOOD SERVICE

