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Ms Maria Burgess
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Dear Ms Burgess

Re: Blood Transfusion Patient Information Brochure and A4 Poster

The Health Care Consumers' Association (HCCA) welcomes the opportunity to comment on the A4 poster and tri-fold pamphlet designed to inform patients about the blood transfusion process. Our comments are informed by consultation with our consumer membership and have been ordered to directly answer the questions provided.

1. *Is the information contained in these brochures easy to read/understand?*

a. Readability

Consumers raised several issues with the readability of the information in both the tri-fold pamphlet and the A4 poster. It is vital the information included in these documents is clear and concise to ensure strong consumer understanding of the blood transfusion process. There are grammatical errors that require editing and some formatting issues that need addressing in order to improve consistency and readability. We suggest using shorter sentences to improve clarity, allowing for the documents to be more precise.

Consumers have suggested the information would be more engaging and personal if it were written in the first person. In addition, pictures and diagrams would aid the explanation of the different blood products and the transfusion procedure itself. The consumers raised issues with the volume of text on both the pamphlet and the poster, warning an overload of information may be detrimental to gaining a full understanding of the procedure.

b. Headings

Some of the headings in both the poster and the pamphlet are very long and often do not follow a logical sequence, making the information segmented and confusing. For example, the poster begins with two headings, 'How do I receive a blood transfusion' and 'Before the transfusion', which HCCA suggests should be formed into a single heading. The third heading of the poster, 'How is the transfusion done?' is the same as the first heading, 'How do I receive a blood transfusion?'. The 'Further Information' heading in the pamphlet is repeated.

HCCA suggests that the heading for the A4 poster should read 'ACT Health Directorate Blood Transfusion Information'.

c. Relevance of Information

Consumers did not understand the need to specifically mention Jehovah's Witnesses in the tri-fold pamphlet. They suggested a more general approach, acknowledging that there are a number of religious/cultural factors which may induce anxiety about blood transfusions. Staff will need to give appropriate assurances to consumers and their families.

d. Medical Jargon

Consumers identified medical jargon in both the tri-fold pamphlet and the A4 poster that may be difficult for readers to understand. The poster discusses a 'unit' of blood product. It is not clear to the reader what a unit is or how many units may be needed during a transfusion. Consumers also identified 'CNC' as an unnecessary acronym which should be printed in full in both the poster and the pamphlet.

2. *Is the information contained in these brochures appropriate for everyone?*

Consumers were concerned the information in both the tri-fold pamphlet and the A4 poster would not be appropriate for a wide consumer readership.

a. Children under the Age of Consent

This information was not appropriate for children under the age of consent. The information is too advanced for young children to understand and is not clear regarding who is able to give consent on behalf of a minor. Also, if there are different risks involved for children receiving a blood transfusion these must be highlighted. There may need to be a separate brochure tailored for younger consumers. The Australian Red Cross Blood Service has developed some resources for the parents of children, young children and older children receiving blood transfusions, which can be found at www.mytransfusion.com.au/node/children-receiving-blood.

b. Visually Impaired Consumers

Consumers suggested audio or screen-reader friendly copies of this information be made available for people who are blind. In addition, the colour scheme of the poster and brochure should be in line with the guidelines provided by Vision Australia to increase visibility. These guidelines are available online at www.visionaustralia.org.au/info.aspx?page=628. The final copy of both the tri-fold pamphlet and the A4 poster should have large font to assist visually impaired consumers.

c. Consumers from Non-English Speaking Backgrounds

The ACT Health Directorate has recognised Cantonese, Mandarin, Bosnian, Croatian, Serbian, Spanish and Vietnamese as the main language groups, other than English, within the ACT Community. In order to increase accessibility for consumers from CALD backgrounds, it would be advisable to reproduce the pamphlet and poster in some or all of these languages. While interpreter services are available for CALD consumers, they are not always available on demand, thus necessitating linguistically diverse consumer information. HCCA acknowledges that small print runs for informational materials can be expensive. As such, these linguistically diverse patient information resources could be provided electronically and printed by staff as required. Any approaches in this area should be developed in connection to the Health Directorates own policies on culturally sensitive/appropriate care.

d. Consumers Who Cannot Give Consent

Consumers also recognised a need to ensure there are proper processes in place for consumers who are unable to understand the procedure or are not in a condition to give consent.

3. *After reading the information contained in the brochures would you have a good understanding of the why you would need a blood transfusion and the benefits of having a blood transfusion?*

Consumers stated they did not understand the benefits of having a blood transfusion. Both the pamphlet and the poster clearly address the circumstances in which a transfusion could be administered. However, neither document explains why a transfusion may be necessary. Consumers would like to know how a transfusion would assist them, for example to supplement a blood product deficiency.

4. *After reading the information contained in the brochures would you have a good understanding of the risks involved in having a transfusion?*

Consumers identified several issues about the clarity of information regarding the risks of having a transfusion. Consumers suggested that the more likely risks should be emphasised and fully explained to ensure that fully informed consent can be obtained. Similarly, consumers did not understand what the 'unique risks' for directed

donations would be, or which 'other blood-borne viruses' are a risk as identified in the pamphlet.

There is no mention of the longer term after effects of having a blood transfusion. The consumers were concerned they would not know how they would feel after they left the hospital. HCCA acknowledges that hardcopy patient resources are only one source of patient information, and that clinicians will also provide information and answer questions to ensure consumers understand why they need a transfusion, the risks involved in the procedure, and the possible side-effects. The provision of this information is vital for truly informed consent to be provided.

The Calman Chart and the Residual Risk Data chart may be utilised more effectively if they were combined. It is important for the reader to see the risk level on the Calman Chart next to the potential infectious agent. Also, there was a concern the Residual Risk Data may be out of date. The Australian Red Cross Blood Service has compiled a more recent example of a risk chart which can be found at www.mytransfusion.com.au/node/transfusion-risks.

5. After reading the information brochures would you feel comfortable and understand the importance of alerting the nursing staff in the event of the symptoms listed?

Consumers were unsure why there was a risk of the symptoms listed, or what underlying issues these symptoms indicated. Including this information would emphasise the importance of informing staff of any side effects of the transfusion. In addition, consumers asserted the need for information regarding the escalation of treatment, or other action, if patients displayed any of the symptoms listed.

Additional Sources

Comprehensive, consumer centred transfusion information can be found at www.mytransfusion.com.au, while more technical information can be found at www.transfusion.com.au.

If you would like to discuss any part of this feedback, please do not hesitate to contact me by phone on 02 6230 7800 or at darlenecox@hcca.org.au.

Yours sincerely



Darlene Cox
Executive Director
Health Care Consumers' Association