

Final Report on Survey Findings

***Blood Matters Breakthrough Collaboration
Consumer Study***

for the Department of Human Services, Victoria

July 2003

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Health Issues Centre

Health Issues Centre Inc. is an independent not-for-profit organisation incorporated under the Associations Incorporation Act 1981. The Centre has a strong reputation for its research capacity and its analysis of the health system with an emphasis on research from the perspective of health consumers. A particular strength of Health Issues Centre is partnership approach to the development of recommendations for reform in dialogue with health practitioners, consumers and government. The Centre's staff have a strong overview of health policy generally and a particular interest in documenting consumers' experiences and expectations of health care and examining the information needs of consumers.

Acknowledgments

We acknowledge the cooperation and effort of the Transfusion Nurses in eight metropolitan and rural health services that administered the surveys to their patients in the midst of a busy environment and with short timeframes. We thank members of the Blood Matters Reference Group for their useful comments on the survey tool. Lastly we would certainly like to thank the 70 patients who took the time to complete the questionnaires.

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INTRODUCTION

Health Issues Centre was commissioned by the Office of the Chief Clinical Advisor of the Department of Human Services in Victoria (DHS) to undertake a study of consumers' experiences and expectations of blood transfusions in the elective and emergency setting, particularly in relation to the information provided to them. 'Consumers' in this context includes patients, carers and family members.

This follows participation by a range of health services during 2002-03 in the Blood Matters Breakthrough Collaborative, and the study findings will feed into the ongoing work of the Collaborative.

This final report describes the findings from the analysis of all of the responses to a scoping survey of patients attending metropolitan health services and requiring blood transfusions. The survey was intended to be just the first stage of a two-stage project, where the second stage was to comprise in-depth qualitative focus groups or face-to-face interviews. An interim report was produced after the initial round of survey responses was received.

Unfortunately, for a range of reasons it has proved impossible to recruit volunteers to participate in focus groups as planned, or even in face-face interviews in their own homes. More survey responses were sought as one alternative to collecting more data, and analysis of this larger data set comprises the main element of this final report. A discussion section has been enlarged in scope, and comparisons made with other research into consumer experiences of information provision. Lastly, a set of recommendations has been developed.

SURVEY METHODOLOGY

The survey of patients had three aims:

- to understand and then document the experiences and expectations of a broad cross-section of consumers who have used or are waiting to use blood transfusion services;
- to assist Health Issues Centre in developing a range of questions for the focus groups.
- to provide Health Issues Centre with a list of consumers to recruit for the focus groups.

The survey tool was developed by Health Issues Centre based on a set of questions provided through DHS and the existing Blood Matters Breakthrough Collaboration Reference Group. A draft tool was reviewed by key members of the Reference Group and refined. As the timelines were very short, and the survey's purpose was limited to identifying themes, it was agreed not to pilot the tool.

It was distributed by DHS to 16 Blood Transfusion Nurses across Victoria. They were provided with a set of instructions on gaining patient consent and administering the questionnaire, the survey tool, a consent form and a list to record volunteers for the focus groups. These are all attached as appendices.

A convenience sample was utilised in this study, given the short timelines and time constraints on Transfusion Nurses. It is not therefore seen as necessarily representative of the entire population of blood transfusion recipients across the state during the study period. The survey was designed as a scoping tool to identify key themes and to enable suitable questions to be developed for the more in-depth focus groups.

A short update (clarifying some of the potential issues in implementing the survey) was distributed about ten days after the survey package was distributed to health services. All of these documents gave the Health Issues Centre phone number and encouraged clarification inquiries from nurses. One transfusion nurse rang Health Issues Centre to make use of this.

CONSTRAINTS

There were significant constraints on the methodology of this study. The timelines in the Project Brief were very tight and allowed a relatively short time to collect data during the survey phase. Transfusion Nurses, who were asked to administer the survey tool, are very busy and work in a high-pressure environment. Thus DHS has been very keen to keep the load on the nurses from this exercise to a minimum. Therefore they have required that all communication with the nurses be directed through them.

In studies with similar short timelines, HIC would normally have attempted to have a great deal of communication with the staff that were going to undertake this survey with patients. This would have been aimed at: ensuring that staff were very clear about the method; providing support and encouragement; and seeing that deadlines and targets were met, especially in regard to recruiting volunteers for the focus groups. This was not possible in this case and to some extent the numbers of responding health services and completed responses reflects this.

There were also some unexpected concerns by transfusion units about the necessary ethics clearance. DHS had seen this as a quality improvement exercise and had not foreseen ethics clearance as being required. However, five services wished to gain official confirmation of this from their local committees before proceeding. No responses were received most of these services.

FINDINGS

Demographics of respondents

A total of seventy responses were received. The characteristics of the survey responses are as follows:

Gender:

Male	34
Female	36

Patient's age:

Age	11-20	21-30	31-40	41-50	51-60	61-70	71-80	81+	N/k	Total
No.	1	1	2	9	10	21	19	6	1	70

Languages spoken at home:

English	55
English/Italian	4
English/German	1
Greek	2
Polish	2
Vietnamese	2
Arabic	1
Italian	1
Maltese	1
Unknown	1
Total responses	70

Carer present

Sixteen patients were interviewed with a family member/carer present.

Health service used:

Eight hospitals provided survey responses. Of these, five were from metropolitan health services and three from large regional/rural health services.

Overall sample characteristics:

Participants were predominantly older people. The majority were over 61 years of age with 30% between 61-70 years of age and 27% between 71-80 years of age. Less than six percent were younger than 40.

There is an almost equal balance between males and females. Just fewer than 80% reported English as the language spoken at home; eight other languages were listed among the remaining 20%.

Most participants (70%) had already had a transfusion and 7-% of this group in turn reported that the transfusion was anticipated. Thus only 20% of respondents overall had received an emergency transfusion.

Analysis of responses

Information received

Twenty-nine (41%) patients stated that they did not receive any information (verbal or written) before their blood transfusion. These included patients responding by themselves and responses coming from both patients and their carers.

All of the remaining 59% who were given information received verbal information.

Opportunity to ask questions

Nearly one quarter of those 41 patients that received information reported that they did not get sufficient opportunity to ask enough questions before their transfusion. If we add in those other patients that had had transfusions and received no information, a total of 19 (38%) out of the 50 who had transfusions did not get such an opportunity to ask questions.

Written information

All patients received verbal information in this group but only 10 patients (20%) reported receiving any written information. However, as is described later, they all found the information mix as useful or highly useful.

Further, other respondents reported that written information would have been useful to them so that they could have taken it home, read it in their own time, and had more time to process the details.

Differences between health services in information provision

Numbers of responses to information provision by treating health service					
N=70	Received some information	Received Verbal information	Could ask questions	Received written information	Overall rating of information provided
Regional Service 1 n=5	3	3	3	-	Highly useful=2 Bit/little useful=1 Unhelpful = 1 NR= 1
Regional 2 n=30	17	16	14	8	Highly useful=4 Useful=13 Bit/little useful=2 NR=11
Regional 3 n=6	4	4	4	-	Useful=3 Bit/little useful=3
Metro 4 n=5	2	2	2	-	Highly useful=2 Useful=1 Unhelpful=2
Metro 5 n=2	2	1	1	1	Highly useful=1 NR=1
Metro 6 n=6	5	5	4	1	Highly useful=1 Useful=1 NR=4
Metro 7 n=2	1	1	1	-	Bit/little useful=1 Unhelpful=1
Metro 8 n=14	7	7	3	-	Useful=4 Bit/little useful=2 NR=8

Although these comparisons should be interpreted cautiously because of methodology, there would appear to be some differences between services in the level of information provision and satisfaction. In particular, written information was only provided by three services.

Topic of information provided

The topic of information provided appeared to be varied. Some patients and carers remembered receiving information regarding the medical reasons for needing a transfusion; some others about the risks and benefits involved and a few their likelihood of needing a transfusion.

A number of respondents also made additional comments:

"You only get information if you ask"

"The nurse asked if I had any questions but then she went away"

"I looked up more information on the Internet".

Alternatives to blood transfusion

Only seven participants (17%) reported that the alternatives to transfusion had been discussed with them.

Reasons for blood transfusion

Only a few respondents did not know why they were receiving a transfusion. Almost all of the remainder understood they had a specific medical condition that required them to undergo a blood transfusion. The range of medical conditions included:

- Anaemia
- Low haemoglobin levels
- Blood loss/bleeding
- Thalassaemia major
- Cancer or cancer treatment (chemotherapy)
- Bone marrow failure

Benefits

All respondents except two had some understanding of the benefits, many in general terms, some in specifics. For example:

"Makes me feel better, gets rid of the tiredness";
"Made me feel like lots of energy, could walk to China";
"Replaces blood loss";
"Need it to have chemotherapy".

More philosophically, one participant answered
"It's a good alternative to dying".

One person did not answer and one stated they did not know the benefits but trusted the doctors.

Risks

Unclear of risks	14
Have some sense of risks	55
There are no risks	1
Total	70

Approximately 20% of respondents stated that they did not know, or were unclear about, the risks involved in undergoing a blood transfusion. Several participants reported that hospital staff had not discussed the risks with them.

Of the 14 respondents who were unclear about the risks associated with a blood transfusion, six had not received any prior information. However, eight respondents had received information and were still unclear about the risks involved.

Three-quarters had a sense of at least some of the risks involved. Most commonly respondents noted the risk of receiving contaminated blood, resulting in infection/disease, or the risk of receiving the wrong blood type. They noted specific risks about:

- HIV/AIDS
- Hepatitis C
- Iron overload
- Wrong blood/contaminated blood
- Blood clotting
- Viral infection
- Herpes
- Receiving blood too quickly

Several participants reported gaining some of their information from elsewhere (not hospital staff), while two commented that the information they received from the hospital had differed from information reported in the media.

Degree of satisfaction with information provided

Comparison of value to patients of information provided levels between patients receiving written information and those receiving verbal only (n=34)				
	Highly useful	Useful	Less useful	Total
Both written and verbal	5	5	0	10
Verbal only	4	14	6	24
Total	9	19	6	34

One further respondent answered "the decision was made for me" and did not provide a rating.

Over 80% found the overall information provision useful or highly useful. Further, it would appear that those patients receiving both written and verbal information were much more satisfied on average than other respondents were. This group rated overall information provision as either highly useful (5) or useful (5). The remaining patients gave much more mixed ratings.

A total of 14 respondents stated their blood transfusion was not anticipated and eight of them did not receive any information before the procedure. However six had received some and four of these had found information overall highly useful or useful. It is difficult to interpret this too much as the context is unknown, but this may suggest that it is possible to provide satisfactory information to patients receiving emergency transfusions.

Main information sought

The main items of information the majority of participants felt was important to receive before a blood transfusion can be grouped as follows:

Risks and benefits

- Risk information about the safety of the products and procedure
- Potential risk of catching other diseases, and potential side effects, eg the possibility of iron build-up for patients receiving regular transfusion.
- Benefits – what it would do for the patient, its impact on any complications associated with their existing condition.

Reasons for the procedure

- Why the transfusion was needed
- Whether it was essential or were there alternatives to blood transfusion
- What exactly was wrong with patient's blood?

Details of the procedure

- What would happen during the transfusion process itself
- How long it would take
- Whether it would hurt
- What would happen afterwards
- How patient would feel.

Blood products

- How the blood was screened and how effective it was in detecting contaminated blood
- Reasons why patients couldn't use blood donated by a family member.

Other

- How this would fit with patient's religious beliefs.

Consent

Whilst four patients thought it was unnecessary to seek their consent, as they trusted their doctors to make the right decision, the remainder had a range of suggestions about this process. These included:

Communication with staff

- Having more time/access to discuss with doctor and nurse
- More communication with staff, staff being available to answer questions after handing out information
- Use of interpreters
- Inclusion of family members in discussions where appropriate
- Attitude of staff – whether they are caring and willing to listen to the patients concerns
- Obtaining advocates' consent where applicable

Content of information

- Giving information on risks and benefits (including evidence), and on the reasons for the procedure
- Clearer understanding of the risks and benefits
- More information about the procedure – side effects, time taken
- Why patient needs this procedure
- Explanation before surgery that patient might need transfusion as a consequence of the operation
- Why is it not possible to use blood donated by a family member
- Information on how the blood has been screened

Dissemination of information

- Allowing enough time to process information
- Explaining in easy terms
- Providing written information as well as verbal explanation
- Having information to take home so have more time to process and think about the details

DISCUSSION

The findings presented in this report need to be considered cautiously, given the design and number of people surveyed. The original design intended the survey tool and convenience sampling approach to be a scoping methodology to identify themes and areas of interest for the second stage. This was to involve more in-depth interviews. If the difficulties in recruiting patients for the second stage had been foreseen and the survey seen as the primary data collection tool, it would have been designed differently and included more questions.

Hence the findings should not be treated as necessarily representative of all patients receiving blood transfusions in Victoria, but merely as potentially indicative.

However, despite this, a number of consistent themes have been identified in this analysis, suggesting they are indeed important. The themes to emerge are as follows.

Patients not receiving information before transfusion

A surprising number of patients (41%) reported they did not receive any information prior to having a blood transfusion. Even given the possibility that some patients may have forgotten, the figure stands out as a surprisingly high proportion of participants in the study.

Emergency transfusions did not explain this low rate either – in fact most of those receiving such transfusions did receive information and rated it as useful.

Such an overall low rate of information provision (or perceived lack of information provision) does not meet NHMRC Clinical Practice Guidelines which state that a patient should be given a clear explanation of the potential risks and benefits of blood component therapy in his or her situation (NHMRC, 2001).

Nor, we would suggest, is it meeting the expectations of consumers receiving blood transfusions. Providing information pre and post procedures helps to prepare patients, to relieve their anxiety, to help them understand what to expect in their treatment, and to foster an understanding of post-operative care (Clarke, 2002; Hibbard et al, 1996, Meredith et al, 1996; Sahay et al, 2000). Patients also prefer information about possible side effects of their treatment (Fieler et al, 1996).

This finding raises three important key questions.

Consent

First, it creates some considerable doubts about the rigor and legitimacy of the informed consent each of these patients would have given. How informed was their consent if it was not based on a reasonable understanding of the benefits, risks and alternatives?

This is of course not an isolated issue. There is considerable evidence of a range of common issues in patients giving informed consent, including: patients signing consent forms without having any comprehension of what it is they are consenting to; nurses incorrectly assuming that treating doctors have explained a recommended medical procedure or treatment to a patient or relatives before obtaining the patient's consent; consents being obtained from people of non-English-speaking backgrounds without the assistance of qualified health interpreters; patients consenting to a procedure, knowing what the procedure involves, but having no knowledge of associated risks or potential adverse side effects of the procedure in question; and procedures performed without consent being obtained from the patient at all (Johnson, 1999).

However, just because this is a common practice does not mean that it is not a serious issue. It is one of the basic rights consumers assume when using a health service and is enshrined in many patient charters.

Shared decision-making

Second, a lack of information deprives patients of any opportunity to share in decision-making about their treatment. Most patients' want to know about their condition so they can be involved in making informed decisions about their treatment and care (Spink et al, 2000). Further, there is considerable evidence to support the positive impacts of shared decision-making on patient health status (England & Evans 1992; Fallowfield et al, 1990).

Barriers for patients in asking for information

Third, it signals there are considerable barriers for many patients in asking for information about their treatment. It may be appropriate for health services to reflect on whether their own culture and processes encourage and allow for patients to seek such information. On the other hand, it suggests some need for consumers to be better educated about their rights, and for the general availability of easy-to-use tools to guide them in discussing their treatment with providers.

Verbal information and dialogue

Almost all patients who indicated they received information reported that got verbal information. However, nearly 40% reported that they did not get enough opportunity to ask questions before their transfusion.

Other studies conducted by Health Issues Centre and others have shown that patients value verbal information and dialogue most highly of all forms of information. A recent report on a project at the Austin & Repatriation Medical Centre with patients undergoing surgery for colorectal cancer showed that what patients saw as essential was prompt, face-to-face, verbal communication with clinicians, with the opportunity to discuss their treatment and to ask questions. Verbal communication was valued both by itself and particularly in conjunction with good quality written information (Romios & Naksook 2003). Similar findings have been made elsewhere (eg, Aabakken et al, 1997).

Written information

Less than one-sixth of patients participating in this study received written information, and these were mainly patients at one health service. However, interestingly, there appeared to be a strong link between receiving written information and high levels of satisfaction with information provision overall.

There is considerable evidence that patients and their carers want more written information. A few patients are typically reluctant to receive any information and prefer to trust their doctor. A few more are generally very anxious about hearing the full details about their condition and treatment, and how they will cope with the full picture (Romios and Naksook, 2003). However, more typically the majority of patients want the full picture and it has been found that written material can be sufficiently well-designed to convey detailed information, including potentially alarming facts, without increasing patients' anxieties (Aabakken et al, 1997).

This finding signals a significant gap in practice. Health services could take reasonably immediate actions to address this. Clearly, increasing the understanding of patients about the risks and benefits of blood transfusion is one of the goals of the Breakthrough Collaborative, and this will be facilitated with the recent availability via DHS of the *Blood: Who Needs it?* brochures in multiple community languages. However, it will be valuable to evaluate patients' experiences of these brochures once they are being systematically utilised to ensure that they are meeting all their needs.

Information gaps

The findings show how many people are not receiving adequate information.

Alternatives: Clearly little information was provided on the alternatives to blood transfusion. This is not in accordance with NHMRC Guidelines.

Benefits: Most patients were able to list at least one benefit of transfusion from the information proffered. Although the questions were not framed to provide a rigorous assessment of their understanding of the benefits, responses in this study were often very general (eg "makes me feel better"). It may be worth investigating further whether patients are adequately informed on this aspect.

Risks: This is perhaps the most significant information gap, with one-fifth of patients stating they were unclear about the risks of their transfusion. Half of these stated they had had received information about the procedure, but this had obviously not been sufficient. Further, the risks identified by patients covered some, but by no means all, of the common risks.

It would be valuable to develop a standard of the basic level of understanding of benefits, risks and alternatives that are appropriate for patients to understand prior to signing the consent forms and receiving a blood transfusion. Subsequently it would then be necessary to undertake some evaluations of patients' understanding to see whether such verbal and written information being communicated was achieving this standard.

The responses also showed consumer preferences for the types of information required. These fell into the unsurprising categories of: benefits and risks, especially about the safety of the blood products; reasons for needing the procedure and reassurance; alternatives; and details about the procedure. One respondent wanted to know how this fitted with their religious beliefs. The responses provide a checklist against which providers can assess the information they are utilising to ensure it is comprehensive enough. The information sought covers a wide range of topics, especially when linked to the variety of medical conditions for which may blood transfusion may be required. This suggests that information may have to be packaged into several forms so that it can all be covered without making the material too lengthy or bulky.

RECOMMENDATIONS

Based on the findings of the study, Health Issues Centre makes the following recommendations.

1. All health services should ensure that patients receive verbal and written information before receiving blood component therapy (except where this is not feasible, such as certain emergency situations).
2. All health services should review their informed consent processes in relation to blood component therapy, as some appear to be inadequate.
3. All health services should review processes to investigate ways in which medical and nursing staff could be more available to discuss the blood transfusion with clients and answer questions. This should occur on more than one occasion so that patients and carers have the opportunity to absorb the information provided and ask further questions once they have considered the issue in detail.
4. The Department of Human Services considers developing some simple tools for assisting consumers to be better informed and to enable them to ask questions more effectively of their treating health practitioners.
5. The Department of Human Services and/or the Blood Matters Collaborative should ensure that written information is based on existing standards, policy and evidence on quality and effective information exchange, for example as set out in the Department of Human Services guidelines (eg. Currie et al, 2000).
6. The Department of Human Services and/or the Blood Matters Collaborative should investigate further the actual needs of patients and carers for information provision prior to and after the procedure, including the acceptability of current information, and develop uniform processes for its provision.
7. The Department of Human Services and/or the Blood Matters Collaborative should review the cultural acceptability of the translated versions of the NHMRC 'Blood: Who needs it?' consumer brochure.
8. The Department of Human Services and/or the Blood Matters Collaborative develop and disseminate a standard of the basic level of understanding of benefits, risks and alternatives that are appropriate for most patients to understand prior to signing the consent forms and having the procedure.
9. The Department of Human Services and/or the Blood Matters Collaborative subsequently evaluate patients' understanding to see whether the verbal and written information being provided is achieving this standard.

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APPENDIX 1

BLOOD MATTERS BREAKTHROUGH COLLABORATION

QUESTIONNAIRE FOR PATIENTS ON BLOOD TRANSFUSION

Hospital Unit / staff member Survey response #

Patient or carer interviewed? (please circle) Patient's age Gender M / F

What languages do you speak at home?

1. Have you had a blood transfusion yet? Yes / No

2. Was it anticipated? Yes (eg elective surgery, haematology patient, etc)

No (eg emergency, acute blood loss, trauma, ICU, ED)

3. Did you receive any information (verbal or written) before your transfusion? Yes No

IF NO GO TO Q9

4. Did you receive verbal information? Yes No

5. Did you have the opportunity to ask enough questions before your transfusion? Yes No

6. Did you get written information as well? Yes No

7. What information did you get?

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8. Were the alternatives to blood transfusion discussed with you before transfusion? Yes No

9. What were the reasons you required a blood transfusion?

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10. What do you understand are the benefits of blood transfusion?

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11. What do you understand are the risks of blood transfusion?

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12. How useful was all the verbal and written information given to you in helping you to understand your treatment and make decisions about it with your doctor and nurse?

Highly useful	useful	A bit useful	Of little use	unhelpful
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13. What are **three** main items of information that you feel that all patients should receive before transfusion?

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i......
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ii......
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iii.....
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14. What should the doctor/nurse do to help patients understand their treatment enough so you can comfortably give your consent for treatment?

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.....

15. Would you be willing to come to a 2-hour discussion with other patients or carers to talk about this in more detail? These discussion groups will help transfusion staff all around Victoria to understand patients' needs better to provide a better service for future patients.

Yes No

16. Has interviewer recorded your name, address and phone number on a separate sheet?

Yes No

Thank you for your time and comments

APPENDIX 2

BLOOD MATTERS BREAKTHROUGH COLLABORATION

INTERVIEW CONSENT FORM

I,..... of
(PLEASE PRINT)

.....
(ADDRESS)

has been asked to participate in an interview being conducted by

I,..... of
(PLEASE PRINT TRANSFUSION STAFF MEMBER NAME)

.....
(HEALTH SERVICE)

as part of the following project:

***Blood Matters Breakthrough Collaboration,
conducted by the Health Issues Centre on behalf of the Department of Human Services and
participating health services.***

I give my consent by signing this form on the understanding that the interview will be carried out in a manner conforming with the principles set out by the National Statement on Ethical Conduct in Research Involving Humans, and further that:

1. I understand the general purposes, methods, demands and benefits and possible risks, inconveniences and discomforts of the study as outlined in the 'Participant Information Sheet' that has been given to me.
2. Although I understand that the purpose of this research project is to improve the quality of care, it has also been explained that my involvement may not be of any personal benefit to me.
3. I understand that my participation in the research study is voluntary and that I am free to withdraw at any time and to continue receiving appropriate treatment for my condition, as will be the case if I do not volunteer to enter the study.
4. I have been given the opportunity to have a member of my family or a friend present while the project was explained.
5. I have been given the opportunity to ask questions in relation to the research study, and I have received all the information and explanations I have requested.
6. I understand that the confidentiality of my contribution will be safeguarded save where required by law, and that my identity will not be revealed in any projects or publications arising from this research.

Signature (Participant): Date:.....

Investigator / Transfusion nurse): I,
(PLEASE PRINT)
have fully explained the aims, risks and procedures of the above named study to the person named herein.

Signature: Date:

For further information please contact Tony McBride, Health Issues Centre on 9479 5827

APPENDIX 3

BLOOD MATTERS BREAKTHROUGH COLLABORATION

VOLUNTEERS FOR DISCUSSION GROUPS

Hospital

Unit / staff member

Phone NUMBER

Volunteer name	address	Phone numbers	Comments , if necessary
1.			
2.			
3.			
4.			
5.			
6.			
7.			

APPENDIX 4

Possible further themes and questions to explore in future studies

This study intended to explore a range of further questions but was unable to identify and recruit sufficient patients willing to participate. However, should a follow-up study be envisaged, the following questions appear worthwhile to build on the basic picture captured by this survey.

- What are patients' general expectations about provision of information on health care or treatment (eg level, timing, detail, written or verbal)?
- What are patients' general expectations specifically about provision of information for blood transfusion?
- Were their information expectations met and to what degree and in what way?
- Was blood transfusion information contained within material on their specific condition, but was overlooked?
- Would patients prefer blood transfusion information separately or as part of their information about their treatment?
- Did patients ask for more information? If not, why not?
- Did the information answer the questions patients most wanted to know about? In what way?
- What was nature of verbal information received? What made it satisfactory? In retrospect, should patient have receive more verbal information and of what type?
- Do consumers want written information?
- What content would such patients have preferred in written form?
- What is the link between gaining written information and patient satisfaction with information provision and overall care?
- What extra information, over and above that which they received, did patients expect or desire? What was missing?
- What information exactly did they want about the risks of transfusion?
- How did people give consent if they hadn't had risk information?
- Did they in retrospect fell sufficiently informed to give their consent?
- Exactly what information did they require to give informed consent?
- What are people's expectations about receiving information about alternatives?