A SURVEY OF PATIENT'S PERCEPTIONS OF BLOOD TRANSFUSION

Survey Data collected by:

Angela Wright	NZBS Canterbury
Christopher Corkery	NSBS Waikato
Fiona King	NZBS Capital & Coast
Jacqueline Raynes	Counties-Manukau DHB
Liz Thrift	NZBS MidCentral
Louise Bobbitt	Waitemata DHB
Rachel Donegan	NZBS Auckland
Suzi Rishworth	NZBS Otago

Report prepared by:
Christopher Corkery
Richard Charlewood

June 2013

INTRODUCTION

The Code of Health and Disability Services Consumers Rights (1996)[1]. sets out requirements for health professionals providing services to patients. This includes the right to effective communication and the right to be fully informed. New Zealand Blood Service (NZBS) has developed a Policy on Informed Consent for Transfusion based on the Code of Health and Disability Services Consumers Rights Code. This policy outlines the key elements of providing informed consent for transfusion and identifies who is responsible for them. NZBS provides a range of patient information leaflets to support the process of gaining informed consent. These are freely available to all hospitals and healthcare organisations throughout New Zealand.

The NZBS policy on consent identifies several elements to the informed consent process. These include provision of information about the appropriate use of blood, the expected benefits, possible alternatives and the risks and unwanted side effects. Hospitals and institutions must also have a system in place that documents how recipients are offered information and consent to the transfusion.

The subject of patient consent has long been discussed in health circles. As early as 1955 Szasz and Hollender proposed three models of patient-doctor relationships[2]. These include the "active-passive model", "guidance-cooperative model" and the "mutual-participation" model. The first two models have a distinctive paternalistic theme, at the time probably an accepted behaviour in hospitals. Since the 1970s, the "mutual-participation" model has increasingly gained ground reflecting the public attitude that patients expect to be involved in decision making about their treatment[3–6].

There were 159,587 fresh components transfused in New Zealand in 2010[7]. Blood transfusions are a frequent medical intervention undertaken in hospitals. With such a common procedure, obtaining informed consent from patients should be routine, straight forward and well-practiced. However clinical audits conducted by NZBS in hospitals suggests otherwise, with many hospitals having no documented evidence of consent from many patients. This issue is not peculiar to New Zealand. In 1999 an audit of hospitals in London showed that 17% of patients who received a blood transfusion were completely unaware of the fact[8].

There is limited research about how patients view blood transfusions but Lee and colleagues noted that patients have a different perspective of blood transfusion to that of the doctor[9]. The doctor looks at the appropriateness of blood transfusions whereas the patient wants to know about infection risks and their comfort during the procedure. To our knowledge no survey has been done in New Zealand that has attempted to obtain patients' perceptions of blood transfusions.

AIM

The primary aim of the audit was to survey recipients who had recently received red cells or Anti-D (RhD Immunoglobulin, CSL, Melbourne). The patients were asked:

- whether they recall receiving red cells or Anti-D
- about any concerns they had about receiving red cells or Anti-D
- about their level of satisfaction concerning the information they received.

The survey specifically did not test patient's memory or recall of facts about blood transfusions, rather whether they were satisfied "at the time" with the information given to them.

Red cells were selected for auditing as they are the commonest blood component transfused. Anti-D was also selected as concerns about the comprehensibility of the

information leaflet provided with Anti-D had been raised by some Lead Maternity Carers (LMCs).

A secondary aim was to compare each red cell recipient's list of anaemia-related symptoms, if any, before and after the transfusion. Indications for red cell transfusions are contained in guidelines developed by the National Health and Medical Research Council and the Australian and New Zealand Society Blood Transfusion[10]. The guidelines identify that the decision to transfuse should not be made solely on the basis of a haemoglobin value but should also take into account the patient's clinical state particularly with respect to symptoms consistent with anaemia. In this audit we assumed that the benefit identified by the patient following the transfusion would correlate positively with the haemoglobin value.

METHOD

Patients who received either red cells or Anti-D were asked to take part in the survey. Patients were chosen randomly by the Transfusion Nurse Specialist (TNS) in each hospital. A verbal consent was obtained from the patient before the survey took place. The TNS then discussed the audit questionnaire with the patient. The first part of the questionnaire referred to the information that the patient obtained prior to receiving the product. The second part referred to the symptoms the patient had before and after the transfusion of red cells. All patients were approached within five days of receiving red cells or Anti-D.

Patients that received red cells in the emergency departments, intensive care units, high dependency units, operating theatres, delivery suites or paediatric wards were excluded. Red cell recipients where haemoglobin values were unavailable were also excluded. All patients were over the age of 16 and were able to give consent. All patients had to have an adequate command of the English language to answer the questions. Each patient was included once only in the survey.

An adapted version of the *Satisfaction with Information about Medicines Scale (SIMS)* was used for the survey[11].

Similar pro forma questionnaires were used for red cell recipients and for Anti-D recipients (see Appendices 3 and 4).

A pilot of five episodes was collected from each site and evaluated. The process of asking questions as well as the questionnaire was reviewed. No changes were made following the pilot and the survey continued. The initial goal was to obtain 50 episodes of red cell recipients and 50 Anti D recipients from each of the participating hospitals.

The data was collated in a PostgreSQL database (PostgreSQL Global Development Group) with restricted access, located on a secure NZBS webserver. Only the TNS interviewing the patient had access to that patient's identifying data. This was recorded so that the TNS could follow up on any queries by the reviewing Transfusion Medicine Specialist. No identifying data was entered into the database. Multi-region ethics committee approval, as well as permission from the DHBs involved, was obtained prior to commencement.

RESULTS

Demographics

Data was collected from 547 patients over a 23 week period beginning on the 23rd November 2011 and ending on the 30th April 2012. Several sites were unable to collect fifty episodes from each population due to patient mix and TNS staffing issues. Five patients refused to take part in the survey.

Tables 1, 2, and 3 and Figure 1 show episodes by site, clinical grouping, ethnic group and age. There were slightly more female red cell recipients (55%) than male recipients whereas all Anti-D recipients were women. The largest ethnic group that took part in the survey were those who described themselves as either New Zealand European or European, making up 78% of the participants. The next largest group were Maori at just under 9%. Figure 1 shows that the age of the red cell recipients is similar to recipients in previous audits.

Table 1: *Episode numbers by site*

DHB	Red Cells	Anti-D
Auckland	50	50
Canterbury	50	35
Capital and Coast	50	23
Counties Manukau	37	1
MidCentral	50	19
Southern	50	5
Waikato	50	50
Waitemata	19	8
Total	**356**	**191**

Table 2: *Clinical grouping of recipients.*

Group	Red Cells	Anti-D
antenatal		33
postnatal		157
routine prophylaxis		1
with RhD+ platelets		0
medical	166	
obstetric	14	
post-op	107	
regular	69	
Total	**356**	**191**

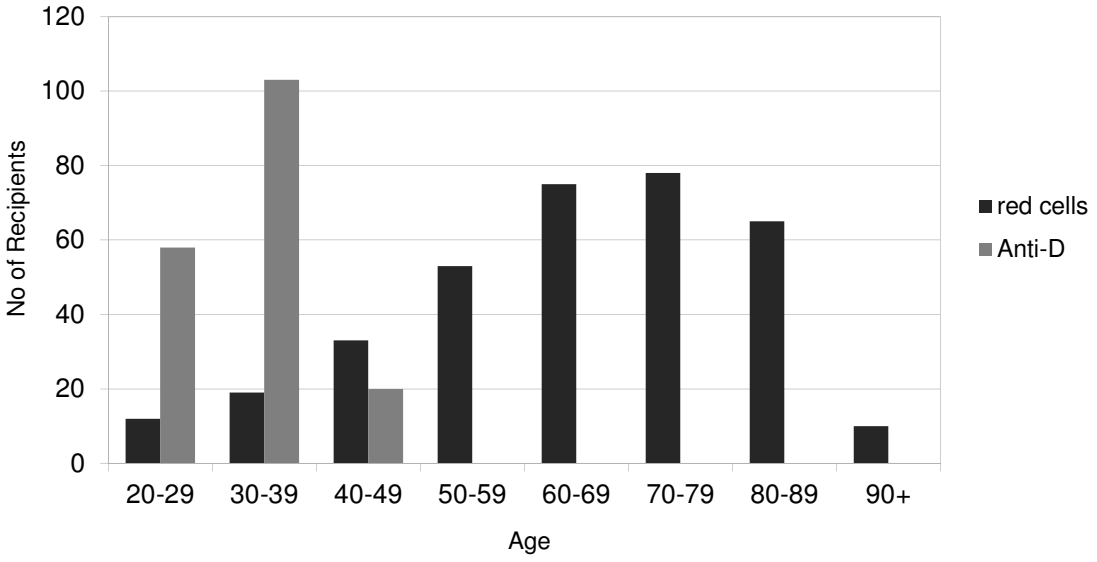

Figure 1: *Age of recipients*

Participation in decision making

All patients who received red cells were aware that they had received a blood transfusion. All the recipients of Anti-D were aware that they had received Anti-D but three patients were unaware that the product was derived from human plasma. All patients who received Anti-D felt part of the decision making process whereas only 87% (311) of the red cell recipients did. This is statistically significant ($p<0.00001$).

For red cell recipients, 45 (13%) patients felt they weren't included in the decision making, and 16 of these "non-involved" patients made further comments that suggested that clinicians simply informed them that they needed blood and that there was no choice involved. One patient, a typical example, reported:

> *"I recall that I was told that I needed blood. I overheard the discussion occurring with the doctors but not with me and they came and told me that I needed the blood. Someone should just sit and talk with the patient and written information would be good."*

Table 3: *Ethnic group of participant and participation in the decision making process*

Ethnicity	**Red Cells**	**Anti-D**	**Felt included in decision making**	
			Red cells*	**Anti-D**
NZ European	225	157	86%	100%
Maori	43	6	91%	100%
Other European	35	15	81%	100%
Samoan	19	0	89%	-
Cook Islands	8	0	100%	-
Chinese	5	0	100%	-
African	4	1	75%	100%
Other Pacifika	3	1	33%	100%
Indian	3	8	100%	100%
Other Asian	3	1	100%	100%
Not Stated	3	2	100%	100%
Tongan	2	0	100%	-
SE Asian	2	0	100%	-
Niuean	1	0	0%	-
Middle Eastern	1	0	100%	-
Latin American	0	1	-	100%
Other	1	0	100%	-
Totals	**358**	**192**	**87%**	**100%**

* $p=0.1585$ (no significant variation in feeling included compared with ethnicity)

Receiving information

All Anti-D recipients obtained information about the product with the majority (83%) receiving both written (NZBS leaflet) and verbal information. A slightly smaller proportion (78% of those who received the leaflet) admitted actually reading the NZBS leaflet.

Ninety five per cent of the red cell recipients stated that they had received information but a significantly smaller proportion (35%) received written information. 100 (28%) red cell recipients received the NZBS leaflet but only 53 (53%) of those who received the leaflet recalled actually reading the leaflet supplied. Some reasons provided that the patients did not read the leaflet were that the writing was too small, the patient was overwhelmed with

information, a next of kin went through the information, or the patient didn't want to know more.

Concerns before consenting

Prior to the transfusion, 15% of red cell recipients and 7% of Anti-D recipients reported concerns about receiving a blood product. Table 4 depicts these concerns with the majority regarding the risk of contracting viral infections as uppermost. Table 5 shows the number of patients who felt that they were informed of the risks of a blood product. A slightly higher percentage of red cell recipients (69%) felt informed of the risks, compared with 65% of Anti-D recipients. Patients also referred to previous negative personal experiences of transfusions to themselves or relatives. These included previous allergic reactions and the death of a family member post transfusion.

Table 4: *Concerns prior to information*

Concerns	Red Cells	Anti-D
HIV	18 (26%)	1 (25%)
Other viral	21 (31%)	2 (50%)
vCJD	6 (9%)	0 (0%)
Wrong blood	7 (10%)	0 (0%)
Squeamish	5 (7%)	0 (0%)
Reaction	9 (13%)	0 (0%)
Spiritual	2 (3%)	1 (25%)

Table 5: *Felt they were informed of risks*

	Red Cells	Anti-D
Yes	247 (69%)	125 (65%)
No	53 (15%)	49 (26%)
Can't recall	56 (16%)	17 (9%)

Impact of provision of information and consent process

Patients were asked if they had concerns before and after consenting. 15% of red cell recipients and 7% of Anti-D recipients had concerns prior to the consent process. Following receipt of information, this dropped to 7% and 0% respectively (p=0.00002).

Patients had significantly less concerns following the receipt of written information (with or without verbal explanation), compared with "verbal only" information (p=0.03).

13 (4%) red cell recipients had no concerns prior to receiving information for consenting but this process appears to have heightened concerns as they had new concerns following consenting. These showed a similar ethnicity and clinical groupings compared with the rest of red cell recipients but showed a much higher percentage of "verbal only" information (83% compared with the rest of red cell recipients, 61%).

Table 6: *Comparison of concerns pre & post consent by information type received with numbers and percentages of all recipients*

Red cells:

Type of information	Concerns pre-consent	Concerns post-consent	Number of respondents
Verbal only	8% (28)	5% (18)	60% (214)
Written only	1% (2)	0% (0)	1% (5)
Both	6% (21)	2% (6)	33% (119)
Can't recall	0% (0)	0% (1)	3% (12)
None	0% (1)	0% (0)	2% (6)
Total	15% (52)	7% (25)	100% (356)

Anti-D:

Type of information	Concerns pre-consent	Concerns post-consent	Number of respondents
Verbal only	1% (1)	0% (0)	14% (27)
Written only	0% (0)	0% (0)	3% (5)
Both	6% (12)	0% (0)	83% (159)
Total	13	0	191

Quality of information received

Patients were asked to grade five aspects of the information they received using an adapted version of the SIMS tool. Their responses are summarised below (Table 7).

Both Anti-D and red cell recipients generally felt they had received the right amount of information as to why a transfusion was needed (90% and 87% respectively) but 7% said they received either no information or too little.

When asked what the product was meant to do for them, both Anti-D and red cell recipients graded this similarly (84% and 87% respectively) as "about right", with 9% they received either no information or too little.

Less than two-thirds of all respondents (60%) graded the information received about the risks of a blood product as "about right". Almost 30% of the patients felt that they either had "no information offered" or it was "too little". Patients who had received the NZBS leaflet and read it, were less likely to feel they had not received enough information ($p<0.05$). There was a marked difference between red cell recipients that had read the leaflet (8% felt they had not received enough info vs 30% who had not read the leaflet) compared with Anti-D recipients (26% felt they had not received enough info vs 36% who had not read the leaflet).

Table 7: *Grading of info received*

		None offered		None required		Can't recall		About Right		Too little		Too much	
Why the product was needed	RBC	16	(4%)	5	(1%)	4	(1%)	309	(87%)	18	(5%)	4	(1%)
	Anti-D	3	(2%)	12	(6%)	0	(0%)	172	(90%)	3	(2%)	1	(1%)
What the product was meant to do	RBC	23	(6%)	6	(2%)	7	(2%)	299	(84%)	15	(4%)	6	(2%)
	Anti-D	6	(3%)	8	(4%)	0	(0%)	167	(87%)	9	(5%)	1	(1%)
Possible side effects or risks	RBC	78	(22%)	10	(3%)	17	(5%)	230	(65%)	14	(4%)	7	(2%)
	Anti-D	63	(33%)	13	(7%)	10	(5%)	95	(50%)	9	(5%)	1	(1%)
Possible alternatives to the product	RBC	254	(71%)	28	(8%)	12	(3%)	49	(14%)	12	(3%)	1	(1%)
	Anti-D	77	(40%)	23	(12%)	3	(2%)	81	(42%)	7	(4%)	0	(0%)
Action to take for side effects or concerns	RBC	111	(31%)	13	(4%)	11	(3%)	201	(56%)	16	(4%)	4	(1%)
	Anti-D	68	(36%)	18	(9%)	3	(2%)	89	(47%)	12	(6%)	1	(1%)

A noticeable difference was seen between the red cell and Anti-D recipients regarding information on possible alternatives. Only 14% of the red cell group stated that they thought they had received an appropriate amount of information compared with 42% for Anti-D recipients. 71% of red cell recipients received no information at all on alternatives compared with 40% for Anti-D. This is despite a number of alternatives existing for red cell transfusion and very few for Anti-D.

When patients were asked if they were given information as to what action to take if they had any concerns or side effects, 53% of the total respondents graded this as “about right” however 38% stated they either had no information offered or it was too little.

Red cell transfusion and impact on anaemia-related symptoms

The second part of the audit looked at symptoms in relation to haemoglobin levels in red cell recipients.

18% of patients did not report any symptoms prior to receiving a red cell transfusion (Table 8). This group of patients had a mean haemoglobin (Hb) level of 84g/L ranging from 60g/L to 136g/L. Some of these pre-transfusion haemoglobins are likely to be pre-operative samples, i.e. not reflecting the patient’s degree of anaemia at the time of transfusion.

Both groups of patients, symptomatic and asymptomatic were given an average of two red cell units. There was no statistical difference in post-transfusion haemoglobins although there was a trend towards lower pre-transfusion haemoglobins in the symptomatic group.

85% (304) patients had post-transfusion haemoglobin values. Of these, 40% (121) had a post-transfusion haemoglobin over 100 g/L.

Table 8: *Haemoglobin values of symptomatic vs asymptomatic red cell recipients*

Patient group	Symptoms	Pre transfusion Hb Mean (range)	Post transfusion Hb Mean (range)	Average units transfused
Medical	Symptomatic	81 (28 - 112)	99 (64 - 151)	1.9
	Asymptomatic	84 (67 - 109)	101 (73 - 124)	1.9
Obstetric	Symptomatic	75 (60 - 91)	90 (76 - 105)	1.9
	Asymptomatic	81 (81 - 81)	87 (87 - 87)	1.0
Post-op	Symptomatic	80 (54 - 108)	100 (72 - 122)	1.8
	Asymptomatic	84 (60 - 136)	97 (76 - 119)	2.2
Regular	Symptomatic	82 (48 - 101)	96 (73 - 118)	1.9
	Asymptomatic	83 (65 - 93)	93 (71 - 108)	1.9

86% of the symptomatic patients stated their symptoms improved following the red cell transfusion. Table 9 denotes the number of patients with changes to their specified symptoms. Of the 292 symptomatic patients, 14% (42) showed no improvement in symptoms after transfusion. This sub-group also had a mean Hb of 80 g/L and a post-transfusion Hb of 98 g/L. Obstetric patients appeared to be over-represented in this subgroup with 21% of obstetric patients not showing an improvement compared with 11% in other groups, although this did not reach statistical significance.

Table 9: *Symptom change after transfusion of red cells*

	Dizzy	SOB	Headache	Tired	Angina
Better	116 (88%)	107 (81%)	48 (76%)	213 (79%)	22 (76%)
No change	14 (11%)	24 (18%)	13 (21%)	56 (21%)	5 (17%)
Worse	2 (2%)	1 (1%)	2 (3%)	0 (0%)	2 (7%)
Ave units	1.9	1.9	1.9	1.8	2.3

Patients' general comments

Patients were also given the opportunity to make comments during the survey. These are included in appendices 2 and 3. These were then reviewed and the comments and separated into comments that were positive, negative or neutral as depicted in Table 10.

Positive comments were those comments that were interpreted as stating something that was positive about the procedure, staff or the patient's feelings. Examples include;

"I liked the pictures in the leaflet",
"Good information from the midwife and GP"
"I felt very safe that they kept coming back to check on me".

Negative comments were any criticism of the procedure, staff or the patient's feelings. Examples include:

"Writing on leaflet was too small so couldn't read it"
"I would have appreciated the leaflet"
"I really didn't understand the procedure. I thought that they would take out the old blood and give me the new".
Patient was unaware that Anti-D is a blood derived product and asked where it came from.

Neutral comments were any comments that could not be clearly interpreted as either negative or positive.

The majority of comments of red cell and Anti-D recipients were positive or neutral (86% and 62% respectively). The increased frequency of negative comments in Anti-D recipients was statistically significant ($p<0.00001$).

Table 10: *Comments from Anti-D and Red Cell recipients*

	Red Cells	Anti-D
Positive	79 (42%)	23 (27%)
Neutral	82 (44%)	29 (35%)
Negative	26 (14%)	32 (38%)
Total Comments	187	84

LIMITATIONS

The sample size was chosen based on what was practically achievable from past experience of audits, rather than based on statistical power. However as the aim was to look at a large group of recipients rather than comparing individual District Health Boards, we believe the results are clinically useful.

The exclusion of red cell recipients in emergency departments, intensive care units, high dependency units, operating theatres, delivery suites, paediatric wards as well as red cell

recipients where haemoglobin values were unavailable does limit the study to patients transfused in a less urgent situation. Additionally, patients with limited English were excluded as the interviewers could only speak English. This may have introduced a bias, if so this is likely to be towards consent appearing to have been better performed than happens in urgent situations.

DISCUSSION

To our knowledge there have been no multi-centre audits aimed at exploring New Zealand patients' views of blood transfusion. As the survey was undertaken in eight main centres where the majority of red cell transfusions and Anti-D are administered in New Zealand, we believe the results are likely to be generalisable to what occurs nationally.

To date there are few surveys that explore the patient's experience of blood transfusion. Weiss and colleagues interviewed 21 patients and found that patients would benefit with more information about transfusion before, during and after the transfusion[12]. They also stated that providing information leaflets on its own is insufficient and that patients benefit from interacting with clinical staff. Davis et al investigated both patients' and clinicians' perspective of patient involvement with the aim of improving transfusion safety. Both clinicians and patients were positive with attempts to actively include the patient in the decision making[13].

A previous Canadian study showed that patients had difficulty in recalling specific details of information given to them about blood transfusions[14]. For this reason we decided not to test patient's recall of information given to them, but rather to find out if patients were satisfied with the information provided at the time of consent.

It was reassuring to find that all recipients were aware that they had received either red cells or Anti-D. This compares well to a 1999 audit of hospitals in London that showed that as many as 17% of transfusion recipients were completely unaware of the fact[8].

It was encouraging to see that almost 90% of red cell recipients and all Anti-D recipients felt part of the decision making process. Nevertheless (13%) of red cell recipients felt there was no choice involved. The difference between these two groups may reflect differences in the circumstances and preparedness of the two groups. This is particularly as pregnant women may well have been counselled about Anti-D beforehand. Differences in communication styles between LMCs and medical staff may also be playing a role.

It was also encouraging to see that ethnic minorities do not appear to be feeling marginalised in the decision making process, recognising that the numbers involved in this audit are small. A concern has been raised though regarding the number of patients with limited English. These patients were excluded in the audit design due to the interview having to be conducted in English.

All the recipients of Anti-D stated that they were involved in the decision making process. However 38% of comments from Anti-D recipients were negative suggesting that some patients are receiving poor quality information in the consenting process. This correlates with 26% who felt they were not informed of risks although it contrasts with the 0% that had concerns after consenting. Given that the risk of serious side-effects from Anti-D is very small indeed, having an excellent safety track record, this may reflect an issue of expectations of the consenting process rather than significant omissions.

While clinicians have to raise issues with patients that they themselves deem to be important, they must also be sensitive to issues that patients find equally important. Generally patients were satisfied with the information provided regarding why the product was needed and how it would help them, but patients were less satisfied with explanations

about risks associated with administration of blood products and alternatives to it. A significant minority (38%) of Anti-D recipients felt that discussion about the risks of Anti-D was inadequate with 18% of all respondents stating that there was no discussion at all. This may reflect the LMC's awareness of Anti-D's excellent safety record but nevertheless leaves the recipient's concern unaddressed.

Alternatives to red cells and Anti-D appeared to be poorly covered in consenting with only 14% of the red cell recipients and 42% of Anti-D recipients believing they had received an appropriate amount information. 71% of red cell recipients and 40% of Anti-D recipients received no information at all on alternatives. There are very limited alternatives to Anti-D, namely a choice between two subtly different products or choosing no product at all. Nevertheless, the implications of not receiving Anti-D would be worth discussing. For red cells, a variety of alternatives may be available, ranging from more conservative transfusion triggers to haematinics and erythropoietin to cell salvage, autologous donation and acute normovolaemic haemodilution. Providing the alternatives, or lack of them, not only offers patients both choice and empowerment but also helps contextualise the treatment approach finally chosen.

As in other studies, patients' concerns about the risk of infection lingered with our respondents[13]. Fifteen percent of red cell recipients and 7% of Anti-D recipients had concerns before they received their product but this reduced significantly after the consenting, presumably following discussion with their doctor or midwife. It is interesting to note though that providing information can raise anxieties itself, with 4% of red cell recipients having concerns following consenting that they did not have beforehand, with 77% of these having received only verbal information. Those patients that received written as well as verbal explanations had significantly less concerns post transfusion suggesting that written information was useful for patients. This is consistent with the comments offered by the patients themselves and from other studies[15].

Several patients stated that they *"went with the flow as I was too ill to read the leaflets".* Here was an opportunity for information to be repeated following the transfusion. This may provide answers for the patient that at the time they weren't in a position to question but could still be of concern to them post transfusion.

In the second part of the audit, the majority of respondents reported that they had symptoms prior to the red cell transfusion with 86% of this group stating that they had relief from these symptoms. However 18% stated that they had no symptoms prior to the transfusion. One patient was quoted as saying *"I feel fine before having the blood so why bother having it".* Both symptomatic and asymptomatic groups of patients had similar pre and post haemoglobin levels and were transfused similar numbers of red cell units. This result may suggest that some patients were given inappropriate transfusions as the clinical indication for red cells is to alleviate symptoms of anaemia.

If a patient doesn't have any of these symptoms then it is questionable that a transfusion was appropriate, however there may be explanations for this. Firstly, some patients are transfusion dependent patients requiring regular transfusions depending upon haemoglobin value rather than wait till they have symptoms. However this group showed the lowest proportion of patients not showing an improvement. Secondly, the symptoms of anaemia are non-specific. It was interesting to see that the obstetric group had the highest proportion of patients not responding to transfusion. These women may exhibit many of the symptoms of anaemia, particularly after a difficult and physically demanding childbirth. However, there physiological need for haemoglobin is likely to be relatively low, being otherwise generally fit and healthy. For both groups, the lack of response may reflect a lack of communication between the doctor and the patient about the exact reasons why a transfusion may be needed, what benefits can be expected and whether the patient agrees that a transfusion is indicated.

This first ever multi-centre survey in New Zealand suggests that most patients are generally happy with the information provided about why they needed the blood product and what it was meant to achieve. However it suggests that patients still need information about risks and side-effects, what to do about them should they occur, and what the alternatives to receiving a blood product are. This audit has shown that providing accompanying written information is better than verbal information alone and it shouldn't replace interacting with patients.

RECOMMENDATIONS

- As concerns about risks of transfusion continue to linger with patients, and as patients appear more reassured after receiving written information, using the information leaflets provided by NZBS should be encouraged and these should be reviewed regularly to ensure the information on risks remains current.
- NZBS is encouraged to provide translated information leaflets in languages that are spoken within New Zealand in large communities that may have limited understanding of written English.
- Leaflets should be available at all sites where consenting takes place and those consenting recipients should be aware of the leaflets.
- There is some evidence that the consent process is less recipient-focussed than it arguably should be. Health care providers are encouraged to look at what barriers are present that prevent clinicians adequately involving patients in the consenting process.
- Specific education for health care providers is encouraged, concentrating on appropriate methods to obtain consent and where to source relevant information.
- Effective informed consent requires spending time with the recipient to discuss risks, benefits and, where available, alternatives. Currently, within public hospitals, consent for blood components is typically conducted by junior doctors. Benefits might arise from credentialing specific nurses to perform this function which, if adopted, should be incorporated into DHB policy on informed consent.

REFERENCES

1. The Health and Disability Commissioner. *Code of Health and Disability Services Consumers' Rights*. Auckland, New Zealand

2. Szasz T, Hollender M. A contribution to the philosophy of medicine; the basic models of the doctor-patient relationship. *Archives of Internal Medicine*. 1956;97(5):585–592.

3. Tsai DF-C. How should doctors approach patients? A Confucian reflection on personhood. *Journal of Medical Ethics*. 2001;27(1):44–50.

4. Howell C a, Forsythe JLR. Patient consent for blood transfusion--recommendations from SaBTO. *Transfusion medicine*. 2011;21(6):359–62.

5. Courtney MJ. Information about surgery: What does the public want to know? *ANZ Journal of Surgery*. 2001;71(1):24–26.

6. Newton-Howes P, Bedford N, Dobbs B, Frizelle F. Informed consent: what do patients want to know? *New Zealand Medical Journal*. 1998;11(111):340–342.

7. Badami K, Dagger J, Dinesh D, Ghosh S. *National Haemovigilance Programme Annual Report 2010*. Wellington, New Zealand; 2011:1–54.

8. Regan F, Hewitt P, Vincent B, Nolan A. Do they know they have been transfused? *Vox Sanguinis*. 1999;76(4):248–249.

9. Lee DH, Mehta MD, James PD. Transfusion complications. *Transfusion*. 2003;43:772–778.

10. National Health Medical and Research Council, Australasian Society of Blood Transfusion. *Clinical Practice Guidelines on the Use of Blood Components (red blood cells, platelets, fresh frozen plasma, cryoprecipitate)*. Canberra, Australia; 2001:1–101.

11. Horne R, Hankins M, Jenkins R. The Satisfaction with Information about Medicines Scale (SIMS): a new measurement tool for audit and research. *Quality In Health Care*. 2001;10(3):135–40.

12. Weiss-Adams K, Tolich D. Blood Transfusion: The Patient's Experience. *American Journal of Nursing*. 2011;111(9):24–30.

13. Davis R, Murphy MF, Sud A, et al. Patient involvement in blood transfusion safety: patients' and healthcare professionals' perspective. *Transfusion Medicine*. 2012;22(4):251–6.

14. Chan T, Eckert K, Venesoen P, Leslie K, Chin-Yee I. Consenting to blood: what do patients remember? *Transfusion Medicine*. 2005;15(6):461–6.

15. Court EL, Robinson JA, Hocken DB. Informed consent and patient understanding of blood transfusion. *Transfusion Medicine*. 2011;21(3):183–9.

APPENDIX 1: RED CELL RECIPIENT RESPONSES BY DHB:

DHB	Auckland	Canterbury	Capital & Coast	Counties Manukau	MidCentral	Southern	Waikato	Waitemata
Average age (years)	64	66	64	61	59	70	57	68
Female (%)	54	50	68	51	46	54	52	78
Average units received	1.9	2.0	2.0	1.7	2.0	2.0	1.8	1.3
Ave pre-transfusion Hb (g/L)	79	80	84	89	80	81	79	81
Ave post-transfusion Hb (g/L)	96	102	102	98	95	100	94	97
Felt part of decision making process (%)	88	100	98	94	86	82	90	21
Received written & verbal information (%)	38	22	22	27	68	30	20	47
Received only written information (%)	2	0	2	2	2	2	0	0
Received only verbal information (%)	54	68	74	70	20	64	76	52
Received no information (%)	6	0	0	0	2	0	4	0
Can't recall what information received (%)	0	10	2	0	8	4	0	0
Received NZBS leaflet (%)	22	18	20	10	68	32	18	36
Can't recall if received NZBS leaflet (%)	12	24	22	16	8	6	2	15
Not informed of risks (%)	38	10	4	2	12	22	12	15
Had concerns pre-transfusion (%)	12	10	6	13	22	20	18	15
Had concerns post-transfusion (%)	2	2	8	13	8	8	8	10
Sufficient information on why transfusion needed (%)	88	94	90	94	86	84	82	84
Insufficient information on why transfusion needed (%)	12	4	6	2	6	16	16	15
Sufficient information on aim of transfusion (%)	84	94	88	89	86	88	80	63
Insufficient information on aim of transfusion (%)	16	4	4	8	6	8	18	36
Sufficient information on risks (%)	46	48	72	83	74	66	76	78
Insufficient information on risks (%)	54	38	14	13	18	24	20	15
Sufficient information on action to take for side effects or concerns (%)	32	34	78	59	64	80	60	47
Insufficient information on action to take for side effects or concerns (%)	68	48	12	40	28	14	36	47
Sufficient info on alternatives (%)	10	20	10	16	16	12	18	5
Insufficient info on 'alternatives (%)	90	60	70	72	68	82	76	84
Symptoms of anaemia (%)	88	88	88	83	74	62	92	78

APPENDIX 2: ANTI-D RECIPIENT RESPONSES BY DHB:

DHB	Auckland	Canterbury	Capital & Coast	Counties Manukau	MidCentral	Southern	Waikato	Waitemata
Average age (years)	35	31	32	30	26	31	30	32
Female (%)	100	100	100	100	100	100	100	100
Antenatal post-exposure indication (%)	18	8	21	0	21	20	20	12
Postnatal indication (%)	80	91	78	100	78	80	80	87
Routine antenatal Anti-D prophylaxis (%)	2	0	0	0	0	0	0	0
Standard 625 IU dose received (%)	86	94	86	100	100	100	96	100
Part of decision making process (%)	100	100	100	100	100	100	100	100
Received written & verbal information (%)	74	94	91	100	84	60	86	62
Received only written information (%)	4	0	0	0	5	20	2	0
Received only verbal information (%)	22	5	8	0	10	20	12	37
Received no information (%)	0	0	0	0	0	0	0	0
Can't recall what information received (%)	0	0	0	0	0	0	0	0
Received NZBS leaflet (%)	76	94	91	100	89	80	88	62
Can't recall if received NZBS leaflet (%)	2	0	0	0	0	0	0	12
Not informed of risks (%)	40	0	8	0	42	40	32	12
Had concerns prior to receiving Anti-D (%)	2	8	8	0	5	40	8	0
Had concerns after receiving Anti-D (%)	0	0	0	0	0	0	0	0
Sufficient information on why transfusion needed (%)	94	85	95	100	84	100	90	87
Insufficient information on why transfusion needed (%)	6	0	4	0	10	0	0	0
Sufficient information on aim of transfusion (%)	94	82	91	100	84	100	84	87
Insufficient information on aim of transfusion (%)	6	2	8	0	10	0	12	12
Sufficient information on risks (%)	26	71	52	100	63	100	44	75
Insufficient information on risks (%)	72	2	30	0	36	0	38	25
Sufficient information on action to take for side effects or concerns(%)	22	48	69	100	57	100	46	75
Insufficient information on action to take for side effects or concerns concerns(%)	76	5	21	0	42	0	50	25
Sufficient information on alternatives (%)	62	48	43	0	15	60	34	0
Insufficient information on 'alternatives (%)	36	2	43	100	78	40	60	87

APPENDIX 3: RED CELLS QUESTIONNAIRE:

Patient's Perceptions of Blood Transfusion Survey:

This is a routine survey to assist in improving information given to patients receiving blood transfusions. Please be assured there are **no** concerns around your treatment or the recent transfusions you have received.

This survey aims to 1) determine if you were satisfied with the information provided on blood transfusion and 2) consider the symptoms you experienced before and after the transfusion and compare these symptoms with your laboratory results.

Your answers are confidential and will not be shared with hospital staff and your participation in this survey will not identify you in any way.

Please note: This survey is not a test of your knowledge but a review of whether you believe you received adequate information. You may withdraw from the survey at any time and any information previously provided will be destroyed.

Demographics

My record number		Database audit number	
Patient's initials		NHI number	
Date of birth:		Gender	
Group	medical ⩤ obstetric ⩤ post-op ⩤ regular transfusions ⩤		

Data from records (not patient)

Ethnicity	
Date red cells	
Time red cells	
Number of RBC units transfused	
Pre transfusion Haemoglobin (g/L)	
Post transfusion Haemoglobin (g/L)	

1. Are you aware that you received a blood transfusion? Yes □ No □
   (If no, discontinue survey but answer any questions the patient may have)
2. Were you part of the decision making about receiving a blood transfusion? Yes □ No □
3. If you received information can you recall whether it was:
   a) written □
   b) verbal □
   c) both written and verbal □
   d) can't recall □
4. If received written information, did you receive this leaflet (show NZBS leaflet)?
   Yes □ No □ Can't recall □.
5. Did you read the information before your transfusion? Yes □ No □ N/A □ Can't recall □
6. Were you told about any risks of a blood transfusion? Yes □ No □ Can't recall □

7. Did you have any concerns about the blood prior to having received the transfusion?
   Yes □ No □

8. If Yes, what were your concerns?
   HIV risk □ other viral risk □ vCJD risk □
   wrong blood □ squeamish □ reaction □
   spiritual/cultural □ Other □ _____

   Comments:_____
   __

9. Did you have any concerns about the red cells after receiving the blood transfusion?
   Yes □ No □.

10. If Yes, what were your concerns?
    HIV risk □ other viral risk □ vCJD risk □
    wrong blood □ squeamish □ reaction □
    spiritual/cultural □ Other □ _____

    Comments:_____

Please indicate how you rated the information you received concerning the following aspects about the transfusion:	None required	None offered	Too little	About right	Too much
11. Why you needed a transfusion?					
12. What the transfusion was meant to do?					
13. What the possible side effects or risks of the transfusion?					
14. What possible alternatives to a transfusion?					
15. What you should do if you had any side effects or concerns?					

16. This second part of the questionnaire is about the symptoms you had before the transfusion. **From the list below please indicate which of the symptoms, if any, you had before and whether the symptoms improved, worsened or remained the same after the transfusion. If you felt you didn't have any symptoms then say "No symptoms".**

	No symptoms	Worse	No Change	Better
Dizzy or Lightheaded				
Breathless or Shortness of Breath				
Headache				
Tired or lethargic				
Angina				
No Symptoms				

17. Lastly, do you have any comments that you wish to add?

APPENDIX 4: ANTI-D QUESTIONNAIRE:

Patient's Perceptions of Anti-D Survey:

This is a routine survey to assist in improving information given to patients receiving Anti-D. Please be assured there are **no** concerns around your treatment or the recent Anti-D you have received.

This survey aims to determine if you were satisfied with the information provided on Anti-D.

Your answers are confidential and will not be shared with hospital staff and your participation in this survey will not identify you in any way.

Please note: This survey is not a test of your knowledge but a review of whether you believe you received adequate information. You may withdraw from the survey at any time and any information previously provided will be destroyed.

Demographics

My record number		Database audit number	
Patient's initials		NHI number	
Date of birth:		Gender	
Group	Antenatal □ Postnatal □ Routine Prophylaxis □		

Product data (from records)

Ethnicity	
Date Anti-D given	
Time Anti-D given	
Anti-D dose received	

1. Are you aware that you received Anti-D recently? Yes □ No □
   (If no, discontinue survey but answer any questions the patient may have)
2. Were you part of the decision making about receiving Anti-D? Yes □ No □
3. If you received information can you recall whether it was:
   a) written □
   b) verbal □
   c) both written and verbal □
   d) can't recall □
4. If received written information, did you receive this leaflet (show NZBS leaflet)
   Yes □ No □ Can't recall □.
5. Did you read the information before receiving Anti-D? Yes □ No □ N/A □ Can't recall □
6. Were you told about any risks of Anti-D? Yes □ No □ Can't recall □
7. Did you have any concerns about the Anti-D prior to having received it? Yes □ No □

8. If Yes, what were your concerns?

HIV risk	□	other viral risk	□	vCJD risk	□
wrong product	□	squeamish	□	reaction	□
spiritual/cultural	□	Other	□	_____	

Comments:_____

9. Did you have any concerns about the Anti-D after receiving the product? Yes □ No □.

10. If Yes, what were your concerns?

HIV risk	□	other viral risk	□	vCJD risk	□
wrong product	□	squeamish	□	reaction	□
spiritual/cultural	□	Other	□	_____	

Comments:_____

Please indicate how you rated the information you received concerning the following aspects about the Anti-D:	None required	None offered	Too little	About right	Too much
11. Why you needed Anti-D?					
12. What the Anti-D was meant to do?					
13. What the possible side effects or risks of the Anti-D were?					
14. What possible alternatives to Anti-D were available?					
15. What you should do if you had any side effects or concerns?					

16. Lastly, do you have any comments that you wish to add?

_____

_____