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BLOOD DONORS AND BLOOD COLLECTION

TRANSFUSION

Donor and non-donor perspectives on receiving information from routine genomic testing of donor blood

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Abstract

Background: Genomic testing is already used by blood collection agencies (BCAs) to identify rare blood types and ensure the best possible matching of blood. With ongoing technological developments, broader applications, such as the identification of genetic markers relevant to blood donor health, will become feasible. However, the perspectives of blood donors (and potential blood donors) on routine genomic testing of donor blood are under-researched.

Study Design and Methods: Eight online Focus Groups were conducted: four with donors and four with non-donors. Participants were presented with three hypothetical scenarios about the current and possible future applications of genomic testing: Performing rare blood type testing; identifying donors with genetic markers associated with iron metabolism; and identifying donors with genetic markers associated with bowel cancer.

Results: Testing to identify rare blood types was perceived to be an appropriate application for the BCA to undertake, while identifying markers associated with iron metabolism and cancer genetic markers were only partially supported. Participants raised concerns about the boundaries of acceptable testing and the implications of testing for privacy, data security, and health insurance. Perspectives of donors and non-donors on all scenarios were similar.

Discussion: The principles of who benefits from genomic testing and the perceived role of BCAs were key in shaping participants' perspectives. Participants generally agreed that testing should be directly related to blood donation or be of benefit to the recipient or donor. Findings indicate that consent and communication are key to the acceptability of current and expanded genomic testing.

KEYWORDS

donors, ethics, genomics

1 | INTRODUCTION

Blood collection agencies (BCAs), including Australian Red Cross Lifeblood (Lifeblood), conduct genotyping on selected donors to solve complex serological problems, identify novel blood group antigens, or clarify rare variants, such as RhD variants.[1] Recently blood group genotyping platforms have been used to extend typing capability and have been integrated into red cell reference centers.[2] While limitations of DNA-based arrays, including high cost, have prevented BCAs from genotyping all blood donors, recent development of a universal blood donor genotyping platform enables genotyping of more donors at a lower cost, identifying more rare donors, and enabling better matching of donor blood to recipients.[3,4]

Researchers are also interested in identifying genetic markers of importance to blood donor health, such as those related to iron metabolism.[5] These studies aim to predict which donors are susceptible to adverse events or to becoming anemic from donating. This can lead to the development of individualized donation intervals to help maintain healthy donors and reduce costs associated with deferrals.[6,7] While Lifeblood does not currently use genomic technologies to inform blood donor selection, it is likely that future strategies may be informed by investigating links between genetic markers and donor health. However, little is known about how current and potential donors view their blood being tested for genomic markers, their reaction to information and donor management strategies based on these results, or their views on receiving more extensive genetic health information through blood donation.

Studies report that most blood donors are positively oriented towards participating in genetic research or use of their blood samples for biobanking,[8,9] however, scholars have questioned whether the use of donated blood for genetic research is the mission of BCAs, as donors donate to help the community directly, while research is intended to benefit future rather than current communities.[10,11] To our knowledge, research has not addressed donor perspectives on their donated blood being genotyped and the receipt of health information through blood donation. This situation differs from genotyping conducted through biobanking in which donors have explicitly consented to participate. In Australia and other countries, blood donors do not provide separate consent for genotyping, and it is unclear whether they are aware of this testing, or of the kind of information that could be provided to them through this testing. As BCAs move toward precision-medicine it is vital to include the donor and public perspectives to ensure continuation of donation.

Given this, the aim of this research was to explore the perspectives of current donors and non-donors on (a) current and potential future genomic testing of donor blood, (b) perspectives on the appropriateness of each test and why, and (c) whether participants perceived they had consented to this testing.

2 | STUDY DESIGN AND METHODS

Given the lack of research on this topic we used a qualitative approach, conducting focus groups with donors and non-donors. To guide discussion, scenarios based upon current and possible future genomic testing of donated blood by a BCA were used.[12] The use of scenarios can encourage participants to raise self-identified issues and allow them to bring their own behaviors, opinions, and beliefs into the discussion, while also allowing for different opinions to be voiced.[13,14] Details of the three scenarios are included in Table 1. The scenarios were always introduced in this order to start discussions about current testing before moving on to possible future testing. As we were interested in how the topics of interest were discussed, and the co-construction of meaning, as well as what was discussed, we took a constructivist approach to the focus group design and analysis.[15,16]

2.1 | Participants

Current blood and/or plasma donors (donated at least once in the past 12 months) were eligible to participate if they had not participated in research at Lifeblood in the past 3 months and had not opted out of research or communications. Non-donors (those who had not donated in Australia) could participate if they were eligible to donate blood in Australia.

2.2 | Recruitment

Demographic and donation history information were extracted from Lifeblood's donor database to facilitate the recruitment of donors with diversity in: donation experience, gender, age, location, and ethnicity. Ninety donors were contacted by telephone and invited to participate. Forty-eight were reached, and 28 donors agreed to participate (response rate of 31.1%). Donor participants did not differ significantly from invited-non-participants in age, gender, or donation experience.

Eligible non-donors were recruited through a social research company (Stable Research). Potential participants completed a screening survey to assess their eligibility to donate blood and to facilitate the recruitment of

TABLE 1 The three scenarios used to guide the focus groups

Scenario	A donor is informed…
1	They have a rare blood type and they may be contacted to donate for a specific recipient
2	Testing has revealed a genetic marker that indicates reduced ability to replace iron stores and the donor is advised to donate blood a maximum of twice a year or donate plasma
3	Testing has revealed a genetic marker implicated in bowel cancer and the donor is advised to contact their doctor

participants with diversity in gender, age, location, and ethnicity.

This study was approved by Lifeblood's Human Research Ethics Committee. All participants were sent the participant information sheet prior to the focus group session, and all consented to participate. A digital gift voucher (worth $80AUD or equivalent) was offered as reimbursement to all participants.

3 | FOCUS GROUPS

Eight focus groups (4 with donors and 4 with non-donors) were held online using Microsoft Teams.[17] Separate focus groups were held for donors and non-donors because we expected donors to have greater knowledge of blood donation procedures and of Lifeblood than non-donors and anticipated that discussions would be facilitated through participants sharing similar levels of background knowledge.[18] Each focus group was attended by 5–8 participants, a facilitator, a research assistant, and at least one transfusion medical specialist. Participants were generally diverse in age, location, and gender (see Table 2). Compared to population data, our sample over-represented Asian Australians, under-represented European Australians, and under-represented other ethnicities.

The focus groups started with an ice-breaker activity, followed by an introduction to the topic by the facilitator and a brief definition of genomics. Each of the scenarios was then shown on the screen and read out by the facilitator, followed by discussion prompts.

3.1 | Data analysis

Focus groups were recorded and transcribed verbatim. Transcripts were checked against the audio and video to add participant names and non-verbal cues, including agreement or disagreement with a speaker. The first two transcripts were coded by three researchers (RT, KJ, and AT) for topics identified from the literature (deductive coding) and new topics (inductive coding). The researchers then met to agree on a list of draft codes and descriptions. These were then shared with other team members for feedback. Following agreement on a final coding framework, the remaining transcripts were coded in the qualitative data management software NVivo (QSR International). Higher level themes were then constructed by the first author, an experienced qualitative researcher, through examining the codes and identifying the central organizing concept underpinning each theme.[19] Themes were then reviewed and agreed upon by the broader project team.

TABLE 2 Demographic characteristics of donor and non-donor participants

	Donors	Non-donors
No. of participants	24	25
Gender		
Male	14	10
Female	10	15
Age		
18–24	2	2
25–34	11	8
35–44	7	5
45–54	3	2
55–64	1	5
65+	0	3
State of residence		
QLD	2	2
SA	1	3
VIC	9	8
NSW	9	6
NT	1	0
ACT	1	2
WA	1	4
TAS	0	0
Ethnicity		
European	11	17
Asian	7	7
Afrikaner	1	
Unavailable	5	1

4 | RESULTS

In the results section, the focus groups from which example quotations are drawn are indicated in brackets,

TABLE 3 Acceptability of testing of donor blood

Code	Benefits recipients	Benefits donor	Related to blood donation	Sustainability of blood supply	Better quality donations	Preventative health
Rare blood type testing	✓	✓	✓			
Iron metabolism		✓		✓	✓	
Disease predisposition		✓	×	×	×	✓

Note: A tick indicates that participants felt this test was related to the code topic listed in the top row, while a blank box indicated that this topic was not discussed in relation to that test and a cross indicates that the test was not believed to be related to the code topic.

followed by whether they were a donor or a non-donor. As no differences in the views of participants based on gender, age, and ethnicity were identified, these characteristics are not discussed in the following sections.

4.1 | Rare blood type

Both donors and non-donors thought that rare blood type testing of donor blood was an appropriate activity for BCAs to undertake because they thought that this testing would benefit recipients with illnesses who needed to receive blood products (see Table 3). This type of testing was also considered appropriate because it aligns with the purpose of blood donation, although some expressed concerns about the security of this information and how it could be used in the future:

> The sort of people who are receiving these donations are critically unwell - if doing some screening like this can improve their probability of recovery, or quality of life even minutely, then I think there's definitely a benefit there. (FG6, non-donor)

> There are some buzzwords going around at the moment that might tie into, like, an anti-vax sentiment, but...that to me is still - ... blood-donation focused, so it probably will not be as alarm bells ringing for some people perhaps. (FG3, donor)

Participants, particularly donors, identified a number of additional benefits for the donor from rare blood type testing. Donors with rare blood types were perceived to have more value, as were their donations, while knowledge of their rare blood type was perceived to be important if they needed to receive blood, and an added benefit of donation:

> Overall, I think the more you learn about yourself, the more you can be prepared for anything that may go down the track...The fact that I know that if this is a rare type, therefore I can be aware of what happens in the future. I can be prepared for something in case something does happen. (FG2, donor)

Most participants agreed that genotyping to identify rare blood types fell within the scope of routine testing consented to by donors because the purpose was related to improving health outcomes for recipients. However, one non-donor thought that donors should be given the choice to opt in or out of contact from the BCA, including results of rare blood type testing. Despite general endorsement of the testing, participants questioned whether the donor consent was informed, as they were unaware that rare blood type testing was currently conducted by Lifeblood (see Table 4).

> I feel it would make sense to just assume that you are doing some form of testing and that by us signing the donation slip every time, we are giving you guys permission to do what you are trusted to do. (FG1, donor)

> To be honest, I wasn't aware that it was done, but I've got no problem with it. (FG3, donor)

4.2 | Iron metabolism

In discussing this scenario, both donor and non-donor participants identified benefits for donor health, and thus, for the sustainability of the blood supply. The identified benefits were that donors could use this information to adapt donation behavior (e.g., donate less frequently) to avoid iron deficiency and could undertake preventative measures such as seeking medical advice. Some participants suggested that BCAs have an ethical responsibility to inform donors of any conditions that have a negative impact on their ability to continue to donate blood safely and that providing this information to donors would strengthen donor-BCA relations.

TABLE 4 Perspectives on consent for genomic testing

Code	Part of routine consent	Informed consent	Opt-in preferred	Opt-in only
Rare blood type	✓	×		
Iron metabolism	✓	×	✓	
Disease predisposition	×	×	✓	✓

Note: A tick indicates that participants felt this the code listed in the top row was discussed in the positive for that test, while a blank box indicates this topic was not discussed in relation to that test and cross indicates that the code was discussed as negative for that test.

Participants thought that donors receiving this advice would be less likely to become iron deficient and be deferred, and thereby more likely to continue donating, with a positive impact on the blood supply. In discussions, participants raised the idea that this advice would result in better quality donations because donors would not donate with low iron levels.

> If it's something that's going to impact on how often you should donate, then I guess my expectation would be that that would be routinely done, so that if someone is risking their health by donating too often, that that's picked up. (FG7, non-donor)

> looking to how much blood we need every year, I think you guys are responsible for taking care of – like provide blood for people, so any necessary tests that will improve this process, I do not think anyone will mind doing that. (FG4, donor)

Through discussions, participants began to consider the boundaries of acceptable testing as they related to the core activities of a BCA and to the agreement between a BCA and donor. While both donor and non-donor participants raised similar concerns, donors tended to provide more concrete examples of the impact of iron testing based on their donation experiences and donor identities. For example, one donor questioned the extent to which donor health is the responsibility of the BCA versus the donor, while donors and non-donors queried whether Lifeblood has the expertise to provide this kind of information and advice, with discussions about verifying this information with their doctor. Despite some diverse opinions about whether this testing was within the scope of a BCA, most considered it to be acceptable because of the benefits identified:

> As long as the tests are limited to things that are for protecting the safety of the donor and the recipient, and I guess the quality of the blood as well. And nothing else. Then I would be happy with that. (FG1, donor)

> I do not want to be banned from this thing that does give me self-esteem or positive feelings...maybe I could go to my doctor and make sure that everything's still okay, or whatever. Yeah, how far it's your job to protect me, and how far that's my prerogative is, I guess, what you are here to work out a little bit. But I do not want you overstepping that, for sure. (FG2, donor)

Both donor and non-donor participants were divided about donors' consent for this testing. Some believed that routine consent included testing of blood for anything that could cause a donor harm, while others thought donors should be given the choice to opt in or out of this testing. Those who preferred separate consent raised this as an opportunity for BCAs to inform donors about the scope of routine testing and to avoid surprising them with feedback they did not expect or did not want to receive through donating blood.

> In this case it affects the health of the person that's giving blood, that if they keep giving blood every three months their iron levels will be too low...if it affects their own health, then it should not be an opt out thing, it's just a standard thing...so, it's a responsibility of the Red Cross to test for these things in the future. (FG6, non-donor)

> I feel like this has to be an opt-in sort of situation...and you need to be upfront with information and say, "we're testing for these specific things and nothing else", and then we can expect a letter in the mail. We know what we are sort of dealing with. (FG3, donor)

4.3 | Predisposition to bowel cancer

Discussion of this scenario provoked mixed responses, with participants divided as to whether testing for disease predisposition was appropriate for a BCA. Perspectives of donors and non-donors on this scenario were similar. Those who thought the testing was appropriate viewed this as beneficial in maximizing donation testing and applying available technology as part of a continuum of information that BCAs could obtain from donated blood, adding to preventative health:

> I see this as a bit of an educational kind of opportunity. In that you are getting to know what your blood types are like is the first one we go through. And then you are finding out a little bit more of what's the blood actually saying to you guys...I do not have a problem with those tests being taken and that information coming to hand. (FG1, donor)

> Because it would get on my radar as a part of my health maintenance. It's no longer just altruistic. It's also care of me. (FG2, donor)

Others doubted its appropriateness, as the testing would not directly benefit donors, recipients, or the quality of donated blood. Participants also raised concerns about the boundaries of testing for disease predispositions, the ethical implications, blood donor privacy, data security, and health insurance. Concerns were raised that testing blood donors for disease predisposition could confuse donors and the public about the role of a BCA, whether a BCA is a place where you donate blood or receive a health check, and about the consequences for donors of receiving potentially negative health information through blood donation:

> It's a slippery slope, because you'll end up, when the technology becomes good enough, you might end up having a slightly increased risk of 40 diseases or something. What are you going to do with that information? Are you going to investigate all of them? (FG1, donor)

> If you are testing for predispositions or other things...then you are going across that boundary and I think you are going a little bit further than I would assume that you are going to go...are you a blood testing area or are you donation area? (FG5, non-donor)

Most participants thought that testing donor blood for markers related to disease predisposition was acceptable only if the donor was given a choice to opt into this testing. They emphasized how upsetting it would be to receive such information without knowing the BCA was conducting this testing and the right of the donor to opt out of receiving this kind of information. An alternative suggested in one group was that the testing could be conducted without additional consent for research purposes only, with the results not given to donors. Despite concerns expressed by some, many participants did perceive benefits for themselves from receiving this information and indicated that, if given the choice, they would opt to receive it:

> If this kind of testing does not...impact directly on someone's ability to donate blood or the quality of the donation for the recipient, then I definitely think it has to be opt in.... Whereas the other types of testing that we have already talked about, I feel like they have a clear impact on someone's ability to donate, and the quality of the donation that's received. So, I feel like you probably do not get a choice about that. (FG6, non-donor)

> I think it's the sort of thing that people should consent to when they give blood rather than having it sprung on them. I personally would want to know, like I mentioned before, as much information as I could, and if I got a bit of free genetic testing then all the better for my time. But I think a lot of people might actually choose to not know about those sort of things. (FG5, non-donor)

5 | DISCUSSION

As whole-genome sequencing becomes more cost-effective, BCAs are likely to genotype higher proportions of donor panels with potential benefits for precision medicine, and changes to donor management and recruitment.[3] This paper presents findings from focus group discussions with donors and non-donors about receiving health-related information through routine genomic testing of their blood.

Both donors and non-donors considered the purpose and benefits of genomic testing from the perspective of the donor role, with donors identifying specific benefits or concerns based on their donation experiences. However, participants also questioned how genomic testing related to the perceived core purpose of a BCA: collecting blood needed for the treatment of patients. While participants generally agreed that the core purpose included testing directly related to donor and recipient safety and improving the quality and use of donor blood, differing views were expressed about whether certain tests, which some perceived to have benefits, fell within the core purpose and existing consent. Findings suggest that the core purpose conceptualized by participants was informed by ideas about the role of a BCA in the Australian healthcare system and of voluntary donors within this system, as well as by ideas about who should benefit from blood

donation.[20] Overall, findings for donors and non-donors were similar, particularly in discussions about future testing, possibly because those scenarios required all participants to consider a theoretical situation. The similarities in donor and non-donor perspectives may also reflect a consistency across the Australian population in views about the role of the national blood collection agency (Lifeblood) within the Australian healthcare system.

Consistent with this, our participants raised concerns when no direct benefits of genomic testing for either donors or recipients were identified, and potential harms to donors were raised. Concerns about data security of personal genomic data and about who will have access to data, as raised by our participants, have been noted in international and Australian studies both within and outside of the blood donation context.[4,12,21] Other concerns related to the potential for donors to receive unexpected, potentially negative, health information through blood donation.[4]

Participants also questioned whether the BCA would be operating outside of the boundaries of their current accepted role in undertaking extended genomic testing through routine testing of donor blood, and the implications of this for healthy donors. Drawing on these findings, we suggest that genomic health information cannot simply be considered to be either beneficial or harmful but that the context in which this information is given is important. To avoid the risk of losing donor trust, BCAs need to invest resources to understand diverse donor perspectives on what they think they are consenting to and to engage with current and potential donors to explain the potential harms and benefits of genomic testing and the provision of information to donors.

Bidirectional communication and informed consent seem to be key to the acceptability of expanded genomic testing.[22] In a recent Dutch focus group study, Luken and colleagues[4] identified concerns donors would not be willing to consent to genotyping. Our findings suggest that introducing genomic testing may require separate consent and communications for different tests, as participants perceived each test to relate differently to existing consent and to the core purpose of the BCA. Communication with donors should aim to explain how the testing, and test results relate to the core purpose of blood collection, be communicated clearly so people can form an opinion, and include how the information will be managed by the BCA. As the implications of testing for donors may not be clear at the time of consent, consent could be thought of as an ongoing process of engagement, collaborative learning, and communication.[23]

Our data is limited by the hypothetical nature of the future testing scenarios that we employed. Cognisant of the problems with affective forecasting,[24] we cannot be sure that our findings reflect how donors would respond if faced with these situations in reality. Further, we cannot determine whether our findings would generalize to other types of genomic testing beyond the specific examples that we used. It is of note, however, that participants drew on higher order principles (e.g., testing that benefits the donor or the recipient) when reflecting on the scenarios rather than the specifics of the test suggested (e.g., for bowel cancer). This suggests that our findings could generalize to different tests that fall within the (differing) boundaries of appropriateness constructed by participants. A further limitation of our work is that the consequences of the violation of these boundaries were not explored. It may have been useful to explore whether the introduction of the types of testing outlined in our future scenarios, which may represent a violation of trust for some people, would affect participants' willingness to become or remain a donor.[25] Our findings are also limited by our sample size and the demographics of those who agreed to participate in the study.

6 | CONCLUSION

This paper presents the first insights into donor and non- donors' perspectives on receiving health information through routine genomic testing of donated blood. Findings clearly demonstrate that responses to this type of testing are yoked to the core principles of relations between BCAs and blood donors, while the principle of who benefits is key to acceptability. As routine testing evolves and can provide more information back to donors about their health, clear communication and the active use of dynamic consent will be important. We suggest that donors are considered partners in this journey, accepting that some donors may opt out of such testing.

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CONFLICT OF INTEREST

The authors have disclosed no conflicts of interest.

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