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SHORT COMMUNICATION

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Designing and testing an ethnic-ancestry question for Australian blood donors: Acceptability, feasibility, and understanding

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Abstract

Objectives: We aimed to evaluate the acceptability, feasibility, and understanding of a donor ethnic-ancestry question with Australian blood donors.

Background: Ethnic-ancestry assists blood collection agencies to meet the demand for rare blood-types. However, there is no standard ethnicity question used by health/blood services around the world and we do not know how blood donors in Australia will respond to being asked for this information.

Methods/Materials: A survey and ethnic-ancestry question was administered to a sample of donors ($n = 506$) to evaluate their views on being asked for their ethnic-ancestry, test a comprehensive ethnic-ancestry list, and determine the level of information required by donors.

Results: Donors reported being very comfortable providing their ethnic-ancestry and the majority of donors found an ethnic-ancestry option they were happy with (91.3%). Overall donors reported a high level of understanding of why ethnic-ancestry was important to blood donation. However, when provided more information on why ethnic-ancestry is required, donors reported increased understanding.

Conclusion: The findings from this study demonstrated that it is acceptable and feasible to introduce a comprehensive ethnic-ancestry question for Australian blood donors. We also found that a greater understanding is achieved when a more comprehensive explanation for inclusion of the question is provided.

KEYWORDS
blood donors, ethnicity, ethnic-ancestry

1 | INTRODUCTION

Information on donor ethnicity is critically important in assisting blood collection agencies (BCA) to adequately meet the demand for rare blood-types. Between 2017 and 2020, Australian Red Cross Lifeblood (Lifeblood) experienced a 50% increase in demand for phenotyped red blood cell units, most commonly required for patients needing chronic transfusion support.[1] Increased migration has resulted in more minority groups requiring blood types that are not present in the majority populations of their new countries[2]—for example, the phenotype Fy(a-b-) found among those with West African ancestry. A survey of 42 BCAs worldwide revealed that many do not record blood donors' ethnicities, either because they are not legally allowed, or because the data has not yet been of interest.[2] Although Lifeblood routinely

collects information on donors' country of birth, this information is not sufficient for identifying which donations to perform extended phenotyping on to locate rare blood-types. While the majority of Lifeblood's donors were born in Australia and people from sub-Saharan Africa, Melanesia/Polynesia, or East/South-East Asia are underrepresented in the donor panel,[3] country of birth is not a reliable indication of donors' ethnic-ancestry. For instance, in the 2016 Australian census, a fifth of people born in Australia (21%) had at least one parent born abroad and over 300 ancestries were separately identified.[4] For these reasons, Lifeblood identified the need to introduce an ethnic-ancestry question for donors.

The Australian Privacy Principles guidelines (APP) classify racial or ethnic origin as sensitive information.[5] In an Australian context, these sensitivities are layered in a history of colonisation and racial government policies that have shaped people's experiences and understanding of race and ethnicity.[6,7] Accordingly, the APP requires that for organisations to legally collect this information, the data must be reasonably necessary for one or more of their functions or activities and that the individual is adequately informed before consenting to the collection.[5] Consequently, prior to commencing routine collection of donor ethnic-ancestry, it is important to ensure that donors understand why it is required and are comfortable providing it.

As well as meeting our legal obligations, adequately explaining to donors why BCAs need this information may result in them being more comfortable about providing the information and therefore increased uptake. In their study exploring the perceptions of general practitioners and patients in Ireland, Roura et al.[8] concluded that the implementation of an ethnicity question requires a strong rationale that makes sense to patients to ensure greater buy-in. Similarly, in the study by Alfridi and Murji[9] exploring the quality and limits of ethnicity data collected by higher education and health services in England, participants suggested that low disclosure rates were, in part, due to a lack of confidence in what the data was being used for.[9] Two studies[10,11] in the USA tested whether giving patients information explaining the rationale for the collection of ethnicity data made them more comfortable providing it. Patients were asked how concerned/comfortable they were towards providing their ethnicity before and after being given information.[10,11] In both studies, information explaining the rationale for the data collection increased patients' comfort level, and in one of the studies the increase was higher among those from ethnic-minority backgrounds.[10,11] While these findings provide valuable insight on the collection of ethnicity data, we have been unable to locate research that evaluates the use and acceptability of an ethnicity question with blood donors.

There is no standard ethnicity question used by health services in Australia or BCAs around the world. Race and ethnicity are complex social constructions[12] resulting in vast differences in the way governments and services have categorised them. For BCAs the need for this data is to help locate specific blood-types found more frequently in certain groups. Unlike race, ethnicity takes into account ancestral homelands[13] and can provide more specific information needed when looking for blood groups and phenotypes which have developed through a combination of environmental factors, migration/isolation of human populations, and in response to contact with infectious diseases that are often regionally specific.[14,15] However, there is no uniform list of ethnicities and due to the subjective, relational, and created nature of ethnic groups, they number in the thousands and can be categorised in different ways.[12,13,16] Research has shown that the options people are presented with to classify themselves can make a difference to their uptake and quality of responses. In Alfridi and Murji,[9] fewer than half of respondents were satisfied with the ethnic categories used by their organisation when collecting this information. Respondents wanted more granularity in the categories and the findings suggested more detailed data can increase the quality of information collected.[9] Burton et al.[17] suggest that it is not only important to focus on what is relevant to those collecting the data, but to ensure it is relevant to the respondent and to consider the impact of acceptability, phrasing, position, and mode. Consequently, while a much smaller list of ethnic categories would be adequate to meet the current needs of a BCA, we decided to develop a more comprehensive list.

Therefore, the aim of our study was to determine donor acceptability of a request to provide their ethnic-ancestry, to test the effect of providing different levels of information on donors' understanding of why the information is needed, and to test whether a comprehensive list of ethnicities was feasible and granular for donors to complete. Given the findings in previous research that people with ethnic-minority ancestry may be less comfortable providing the information, we hypothesised that there will be differences in donors' understanding and acceptability of the ancestry question for Australian donors who reported a European ancestry compared to those with non-European ancestries.

2 | METHOD

2.1 | Procedure

The study was approved by the Lifeblood Human Research Ethics Committee. An online survey was emailed to eligible donors ($n = 3000$; 16.9% response rate) in July 2019. Donors were considered eligible to participate if they had made at least one successful donation in the previous 12 months, had not been contacted for research in the last 6 months, and had a valid email address. To diversify the sample, at least 2000 of the eligible donors had recorded a country of birth other than Australia. Eligible donors were randomised to receive one of two question preambles (a short preamble and a long preamble) about why we were asking for ethnicity using simple randomisation performed in Microsoft-Excel-2016.

2.2 | Ethnicity question and preambles

A list of ethnicities for donors to choose from was created in consultation with Lifeblood's Red Cell Reference Team, to ensure that the information provided would assist in meeting current and future

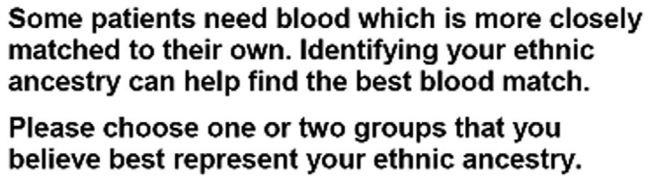

FIGURE 1 Short preamble

transfusion demands. The list was also informed by the recommendations in the literature to provide more granularity and relevance to respondents to ensure greater acceptability and uptake.[9,17] Consequently, we developed a comprehensive ethnic-ancestry list containing 53 choices—including 10 that allowed for a written response (Appendix S1). It was presented to donors via seven regional dropdown lists with headings matching those presented in Appendix S1. Donors were asked to select up to two options that they believed *'best represented their ethnic-ancestry'* or alternatively to select the *'prefer not to say'* option. Donors who selected *'prefer not to say'* were asked to provide the reason why they chose this option. To determine how much information is required for donors to understand why Lifeblood is asking for their ethnic-ancestry, two different question preambles were tested, one that was short with less detail (Figure 1) and a longer version with additional detail on why ancestry information was needed (Figure 2). The two preambles were developed with representatives from Lifeblood's legal and marketing teams to ensure they met their respective requirements.

2.3 | Measures

After participants answered the ethnic-ancestry question, they completed a survey to determine their understanding of why they were being asked to provide their ethnicity, their satisfaction with the options provided, and how easy it was to find an option they were happy with. Donors were asked to indicate *'yes'*, *'maybe'*, or *'no'*, as to whether they understood why information on donors' ethnicity was important to Lifeblood. Donors were asked to indicate *'yes'* or *'no'* to whether they were able to find an option they were happy with. Those who responded *'yes'* to being happy with their choice were asked to rate how easy it was to find the option they were happy with using an 11-point scale (0 = 'very difficult' to 10 = 'very easy'). Those who responded 'no', indicating they were not able to find an option they were happy with, were asked why and were provided with three options: *'I do not know my ethnic-ancestry'*, *'I had to select an "Other" option and write in my ethnic-ancestry'*, and *'something else'*. Donors were allowed to multiselect options and those who selected *'something else'* were provided with an optional textbox to provide details. Lastly, donors were asked to indicate how comfortable they were about providing their ethnic-ancestry information to Lifeblood on an 11-point scale (0 = 'very uncomfortable' to 10 = 'very comfortable').

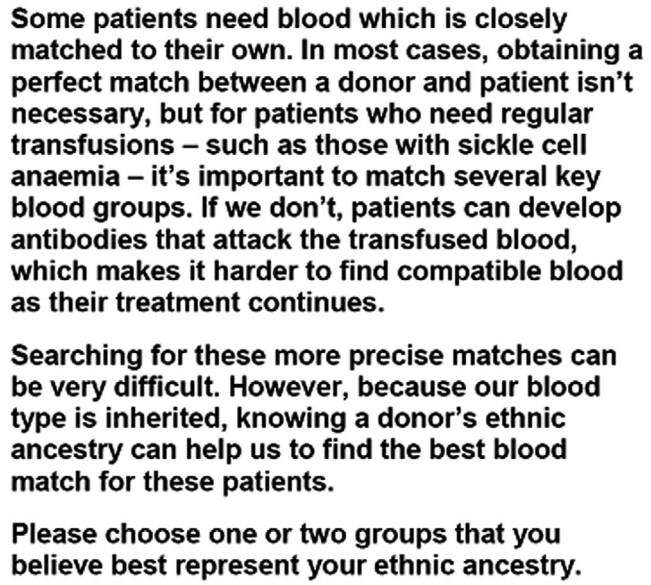

FIGURE 2 Long preamble

2.4 | Analysis methodology

Free text responses were compiled and analysed using inductive thematic analysis in Microsoft-Excel-2016. Coding schemes identifying key categories were revised and expanded, resulting in key themes.

Statistical analyses were performed using statistical software IBM SPSS (IBM SPSS Statistics 23.0; IBM Corporation). Survey responses were described by totals (percentages) for categorical variables, and medians/interquartile ranges Med(IQR) for non-parametric ordinal data. Univariate differences between preambles one and two, and European and non-European ethnic-ancestry were examined using chi-square goodness of fit tests for frequency data, and Mann Whitney U tests for non-parametric ordinal data. European was defined as anyone who selected a European-ancestry as either their first or second choice. Statistical significance was defined at $p \leq 0.05$.

3 | RESULTS

The sample consisted of 506 donors, with 266 receiving the short-preamble and 240 receiving the long preamble. Overall, 68% of donors reported a European ethnic-ancestry for their first selection, with British/Irish the most common response (52.3% short-preamble and 51.2% long-preamble). The majority of donors reported only one ethnic-ancestry for both preambles (79.7% and 80.4%). No notable differences were observed for ethnic-ancestry selection between the short and long preambles. A minority of donors selected *'prefer not to say'*—short-preamble: 6(2.3%) and long-preamble: 5(2.1%). Of these, nine participants provided a written response when asked why they chose *'prefer not to say'* and these responses were grouped into three themes: believing that ethnicity was not relevant to blood donation (all from those who received the short-preamble), being unsure of their

ethnic-ancestry, or confusion between ethnicity and nationality (i.e., looking for their country of birth). An overview of donor response is available in Appendix S3.

3.1 | Finding an ethnic-ancestry option they are happy with

A majority of donors indicated that they found an ethnic-ancestry option they were happy with (91.3%). When asked to indicate how easy it was to find an ethnic-ancestry the were happy with, respondents reported a median score of 8.[8–10]

Only 43 donors (8.4%) reported that they did not find an acceptable ethnic-ancestry option. Of these, 11 reported their reason was having to select *'other'* and write in their ethnic-ancestry, five reported not knowing their ethnic-ancestry, and 30 reported it was *'something else'* with 28 providing a qualitative response. The most common theme from the small number of the qualitative responses was confusion between one's nationality and one's ethnic-ancestry. For example, a small number of donors requested a non-Indigenous Australian or New Zealander ethnic-ancestry. Participants also used the qualitative response to request certain ethnicities to be added to the list. Sinhalese, Tamil, Lebanese, and Hispanic/Portuguese/Latin American received the most mentions and were also the most commonly entered into the write-in *'other'* options when participants answered the ancestry question.

3.2 | Donors' perceptions of providing ethnic-ancestry information

Overall, 74.3% of participants responded *'yes'* to understanding why donors' ethnic-ancestry was important to Lifeblood, while 11.0% responded no, and 14.7% responded maybe. Further, we investigated differences for those who responded yes or no to the question. Looking at differences between the preambles, 83.6% of those who received the short-preamble reported understanding compared to 91.1% who received the long-preamble; $\chi^2 = 5.302$, $p = 0.021$. Additionally, donors with European ancestries reported higher levels of understanding (92.9%) than those with non-European ancestries (74.8%); $\chi^2 = 25.53$, $p < 0.0001$. Lastly, we investigated differences between ethnic-ancestry for the preamble version they were provided; donors with European ancestries who received the short-preamble (90.6%) were more likely to report that they understand than those with non-European ancestries (68.9%; $\chi^2 = 16.08$, $p < 0.0001$). Similarly, donors with European ancestries who received the long-preamble reported higher levels of understanding (95.3%) than those with non-European ancestries (82.0%; $\chi^2 = 8.96$, $p = 0.003$).

Overall, donors reported being very comfortable providing their ethnic-ancestry to Lifeblood (10 [9, 10]), with no notable differences between those who received different preambles. Those reporting European ancestries reported slightly higher median scores (10 [9, 10]) than those reporting non-European ancestries (10 [8–10]; $U = 21200.5$, $p < 0.0001$).

4 | DISCUSSION

To our knowledge, this study is the first to evaluate the use and acceptability of an ethnicity question with blood donors. Our results indicate that overall, donors in Australia are very comfortable providing their ethnic-ancestry to Lifeblood. They demonstrate that while a majority of donors understand why the information is needed regardless of the explanation provided, greater understanding is achieved when a more comprehensive explanation is provided. The findings also confirm that it is feasible to introduce a comprehensive ethnic-ancestry list and that donors find it easy to locate their ancestry within the list and are happy with their choice. Importantly, the findings reveal differences in both comfort and understanding between Australian donors with European and non-European ethnic-ancestries.

Although a majority of donors with non-European ancestry were comfortable providing their ethnic information regardless of the preamble version, they nonetheless had lower comfort levels than those with only European ancestries. This is consistent with the studies by Baker et al.,[10,11] which found that ethnic-minority patients were less comfortable than other patients having their ethnicity recorded. While the difference in our study was minimal, it is nonetheless significant and should be considered when BCAs ask donors for this information. As there were limited qualitative responses in our study, we cannot be certain why comfort was lower among those with non-European ancestry. Baker et al.[10,11] suggest that ethnic-minorities in the USA may have lower comfort providing their ethnic information due to historic and current discrimination; it is plausible that the same could be true for minorities in Australia. Similarly, previous research exploring ethnic-minority blood donation in Australia has shown that for some communities, real and/or perceived experiences of discrimination in their everyday lives can impact their views on blood donation.[18] Increasing the diversity of the donor panel is important to help BCAs identify rare blood types and provide the best match for patients to prevent alloimmunization.[1,3] Therefore, it is important that BCAs address any concerns that ethnic-minority donors may have through relevant, easy to understand information about the collection of ethnicity data. Additional qualitative research with ethnic-minority communities to co-design appropriate messaging and educational materials on the need for ethnic ancestry information may assist in raising comfort and understanding.

The number of participants in our study who selected *'prefer not to say'* was very low, and willingness to provide ethnicity details was high. Nevertheless, our findings can provide lessons that may help improve the uptake further. While only a small number of donors provided a reason for not disclosing their ancestry, the qualitative responses revealed that some participants selected *'prefer not to say'* due to confusion between nationality, country of birth, and ethnicity. Therefore, we recommend that donors are provided with information explaining what ethnic-ancestry is and why it is more useful than country of birth or nationality. The wider literature also suggests that privacy concerns and hesitance about what race/ethnicity data will be used for can impact disclosure.[9–11] While we cannot know from our limited data whether this was a factor in our study, we recommend

that BCAs provide donors with privacy assurances and a detailed understanding what the information will be used for.

A majority of participants indicating that they were able to find an option they were happy with when presented with the comprehensive list of ethnic-ancestries. While only a small number were not happy with their choice because they could not find their specific ancestry and had to use a write-in *'other'* option rather, we have recommended expanding the list to include the ancestries that received the highest write-in responses and which were raised the most frequently within the qualitative responses. This final list of ethnic-ancestries (Appendix S2) will be introduced by Lifeblood.

Although this study provides a critical first insight into donors' acceptability of providing their ethnicity, there were several important limitations. First, donors self-selected to participate in the survey and therefore our data may over-represent those who were strongly motivated by the research topic or who understood the email written in English. Second, a response rate of 16% was obtained for this survey. Although this is on the lower end of response rates, is not unusual for Australian blood donation surveys (27% vs. 10.3%).[19,20] Future studies should consider different survey recruitment methodologies to increase response rates. Third, we were unable to link the survey to the donor records and were unable to determine demographics of those who completed the survey; therefore, we were unable to determine the response rate based on country of birth. Future surveys should include the ability to link through to donation records.

Overall, our results have demonstrated the acceptability of Australian blood donors to provide their ethnicity to Lifeblood to target rare blood-types. A comprehensive list of ethnicities, as well as detailed information, can create greater and willingness to provide the information and understanding about why this information is needed. Lifeblood is progressing towards a full launch of the question with all donors being encouraged to provide their ethnic-ancestry.

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AUTHOR CONTRIBUTION

Luke Gahan: Conceptualization, Methology, Investigation, Formal Analysis, Writing – Original draft, Writing – review and editing, Project administation. Carley Gemelli: Formal Analysis, Writing – Original draft, Writing – review and editing. Sarah Kruse: Formal Analysis, Writing – review and editing. Tanya Davison: Conceptualization, Funding Acquisition, Supervision, Writing – review and editing.

CONFLICT OF INTEREST

The authors have no competing interests.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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