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**TITLE: Donor understandings of blood and the body in relation to more frequent donation**

**RUNNING HEADER: Donor understandings of blood and the body**

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## **Donor understandings of blood and the body in relation to more frequent donation**

### **ABSTRACT**

**Background and objectives:** The INTERVAL trial aimed to find the optimum frequency of blood donation to enhance blood supplies and maintain donor health. This not only requires biological knowledge, but also an appreciation of donor perspectives, and how their experiences and beliefs might be central if any changes are ever to be made. To address this, trial participants were interviewed about their ideas of blood and the body in relation to their experiences of increased donation frequency.

**Materials and methods:** Thirty in depth face-to-face interviews conducted with blood donors participating in the trial.

**Results:** Three key themes emerged: ideas about how blood and iron reserves are replenished, and what people did to facilitate this; beliefs about physiological differences relating to age and gender; and practical issues that affected the experience of donation. Overall, participants interviewed welcomed more frequent donation, despite a range of pragmatic concerns.

**Conclusion:** Despite some practical obstacles, increased donation frequency aligned with participant's ideas about bodily replenishment, the value of donation, and their identity as enduring blood donors. They therefore supported the idea of increasing frequency of donation, independently of the biomedical evidence from the trial itself.

**Key words:** blood donation, iron deficiency, donor experience, donor understandings

## INTRODUCTION

Significant amounts of iron are lost from the body through blood donation, while the capacity to store and replace it from food is limited(1). The greatest risk of increased frequency of blood donation is consequently iron deficiency and a fall in haemoglobin (Hb) levels(1). Limits on frequency of donation exists primary to protect donor health, however, there is no internationally agreed optimum interval between donations, and blood donation services in different countries have adopted different policies. The current frequency implemented by NHS Blood and Transplant (NHSBT) in England and Wales is 16 weeks for women and 12 weeks for men(2). The INTERVAL trial aimed to establish the impact of different donation intervals on blood supply and donor health over two years through comparing standard UK practice with shorter donation intervals used in other countries(2). These trial objectives fit with the broader aims of NHSBT, which seeks to provide a safe, cost-effective and sustainable blood supply while modernizing its service to improve its effectiveness and efficiency and meeting the changing demands for blood from the NHS(3).

A central concern of NHSBT is to maintain active donor numbers and blood group efficiently while retaining donor good will(4). However, it is unclear whether the views and experiences of blood donors would align with any future changes made by the blood service in light of the trial results. To address the concern that increased frequency may negatively affect the willingness to donate, this qualitative study was conducted to investigate the experiences of donors participating in the INTERVAL trial. As well as the more obvious practical consequences, we were interested in how ideas about blood and iron depletion might influence their views on increased donation frequency. Thus, although already committed donors, the aim of this study was to investigate whether there might be new retention issues arising if the blood service were to adopt a widespread policy of increased donation frequency.

Medical literature in relation to frequency of donation has tended to focus on impacts on blood donor health and service practicalities (1,5–7) without foregrounding donor perspectives and experiences. Social science approaches have engaged with blood donation in two broad areas. More sociologically framed work has often centred on gift-giving, notions of altruism, and organizational aspects of the blood service (e.g. 7–9). In doing so, much of this literature has sought to link donor views with the perceptions they hold about membership of wider society, and, in UK studies, the role of the National Health Service(12). From a different perspective, relevant anthropological literature has tended to focus on the symbolic nature of blood, its different values and meanings, and how these relate to ideas about the body more generally (10–11; see also 13–15). In combination, this work could be said to focus on the ideas that people hold, with a view to understanding how these might motivate blood donation.

In line with our aim to explore how more frequent donations might relate to the views they hold about blood, we take an approach that draws on these two themes, but highlights the dynamic relationship between beliefs and the experiences of donation. Thus, rather than compare prior ideas about blood and the body with those held

having participated in the trial, with the assumption that new beliefs and ideas would arise from participating, and following theorists such as Reckwitz and Warde(18,19), we take the view that being part of INTERVAL served to reinforce some ideas that already existed, and by implication relegated others. In this instance, the symbolic ideas about blood, and non-expert ideas about its role in the body, are intimately shaped by the on-going experiences the donors had.

Our focus is therefore on how ideas about being a donor, and the rich symbolism associated with blood, not only influences the practice of donating, but how the experiences of donating – in this instance more frequently whilst participants in the INTERVAL trial - reinforce or alter such beliefs. What is key to this approach is that there is never a simple causal relationship between the ideas people hold and their experiences of donating; instead, practices and beliefs mutually shape each other in parallel (20). Informed by this approach, our study was consequently not solely concerned with the practical impacts of donating more frequently or how donors felt about these challenges, but the extent to which their experiences and understandings mutually inform each other, and subsequently the ideas they held about blood and their body.

Given our focus is on the productive role beliefs play for regular donors, here we resist the potentially oppositional language that refers to ‘lay misunderstandings’ or ‘public misconceptions’ that sometimes accompanies studies investigating donor knowledge, attitudes and beliefs (e.g. 11-12). Instead, recognizing that our particular participants are committed donors, and hence are already a vital resource for NHSBT, we focus on the extent to which their ideas are drawn on, and either re-affirmed or revised, through their practice of donation.

## **MATERIALS AND METHODS**

Qualitative studies have much to offer transfusion medicine because they are able to address questions that are hard to investigate through quantitative methods(23,24). A major advantage of the approach is that it does not pursue a priori assumptions; it is guided by what people themselves think is important, allowing specific matters to be contextualized within wider accounts of everyday life(25–27). Given this, rather than drawing on direct, closed questions, our face-to-face interviews allowed participants’ experiences of participating in the trial and ideas about blood, to emerge via broader accounts of donation. Specific issues were then explored further using more focused prompts in the context of what had already been said. This approach was therefore the most appropriate to investigate ways in which donors’ practical experiences and their more general beliefs might relate to each other.

### *Selection and recruitment of participants*

The INTERVAL trial was a large parallel group, pragmatic randomized trial. Full details of its design, recruitment and findings have been published (28–30). Participants were 18 years or older, satisfied standard criteria for donation and were required to give blood at one of the 25 permanent donor centres across England for two years, having

been randomized to particular donation frequencies (every 12, 10, or 8 weeks for men and 16, 14, or 12 weeks for women).

Participants at four of the locations (Cambridge, Oxford, Edgware and Tooting) who had joined within the last 22 months and had donated more frequently than NHSBT's current policy were invited to take part in this interview study. Fifteen participants were recruited from the two large city centres (Edgware and Tooting) and 15 from the two smaller city sites (Cambridge and Oxford). A maximum-variation purposive sampling strategy according to age, gender and location was adopted. Because the ethnicity of trial participants was 91% White British(29), reflecting the general population of donors in the UK, sampling could not also take ethnicity into account for such a small cohort. In contrast to seeking statistical representativeness, or an approach designed to establish the saturation of themes from the volume of interviews conducted, a maximum variation strategy is used to elicit the breadth of views within a small sample(31). This both allows for findings that might suggest general or common views, as well as illustrative outlier cases that might be indicative of some unforeseen factor. Written consent was obtained from all interviewees.

### *Interviews*

Interviews were held either at the donor centers or in university offices in central London to suit those who worked full time, part time or were retired. Interviews were semi-structured, comprising open questions about motivation to donate and participate in the trial, donation experiences and activities undertaken both before and after donation, and prompts to elicit lay understandings of blood, iron levels, and how the body worked. Interviews were audio-recorded with verbatim transcriptions subsequently imported and coded in NVivo 10, a qualitative data management system. Initial codes were derived from the interview topic guide (deductive coding), but were augmented and revised during analysis (inductive coding)(24). Coding was initially undertaken by RL and then shared with SC, who blind coded a sample. Inter-rater reliability was assessed to identify those particular codes where there was too much divergence. In such instances, codes were revised and reapplied. Agreed codes were finally organised into hierarchies, collapsing those that proved to be too similar. This approach means it is inappropriate to ascribe percentages to findings, because to do so would be to imply quantitative proportions that would not be defensible(23). Further, the extent to which the higher level themes discussed below were identified as significant was derived not simply from their frequency across the participant cohort, but additionally how foregrounded they were within individual interviews.

## **RESULTS**

Interviews lasted between 40-145 minutes. The characteristics of participants are indicative of the general NHSBT donor population, See Table 1.

[TABLE 1 ABOUT HERE]

From the coding of individual accounts, three main themes emerged. We are not claiming that these themes arose simply by virtue of participation in the INTERVAL trial and increased donation frequency, or that they are necessarily unique to this group of donors. Rather, the experiences of donating more frequently, and then being asked to reflect upon this, foregrounded these particular ideas, potentially above others. In this way, as argued in our introduction, the practice of giving blood more frequently not only served to make certain ideas more meaningful, but consolidate them further.

#### *Preparing and replenishing the body*

For many participants, having a 'healthy lifestyle' by eating a balanced diet and being physically active, was believed to enable them to donate regularly without health repercussions. Nearly all, however, said they avoided doing strenuous physical activity following donation:

'I wouldn't [undertake exercise after donating] because I did that once and felt like I was going to pass out halfway through my run, so I had to stop and then get a taxi home' (interviewee 9, transcript page 6)

Through these experiences, ideas about the role of blood, and effect of having less blood than usual, were established. Similarly, donors had views regarding the amount of time they thought the body took to replace blood lost through donation, ranging between a week and a month.

Many, however, described things that they did to facilitate this natural process, preparing their bodies in advance or helping replenishment afterwards, often by focusing on the food and drink they consumed. Depending on the time of day, some made sure they had a 'good', 'proper' or 'more substantial' meal beforehand. Others talked about having particular, 'more filling', foods afterwards. Underlying these strategies was the general idea of providing energy as well as nutrition content to help the body recover quickly. Drinking water either before or after donating was also understood to be important. A small number of participants also talked about avoiding alcohol afterwards, having had first-hand experience of its enhanced effect after donation. Using his knowledge of how his body was impacted by donation to his advantage, one participant even recalled how he used to go out drinking with his teammates after donating precisely because of these consequences.

A number talked about having been 'shocked' to discover they had low iron levels previously, when they were tested just before donating. This had drawn their attention to asymptomatic fluctuations of iron levels. In general however, interviewees were aware that giving blood might influence their iron levels and prevent them from donating. Some interviewees consequently took iron tablets or actively included 'leafy vegetables' or meat (such as liver) into their diets in order to compensate for the loss of iron;

'I want to make sure I'm topped up [my iron levels] beforehand, and then having given it, you know that you've lost a bit so you need to top up to replenish what you lost' (14, p15)

In contrast to this general idea that giving blood might deplete their body in terms of energy, liquid or nutrients such as iron, people also talked about how giving blood might actually be beneficial to their body. Approximately half described donation as removing 'old' blood, and encouraging the body to produce 'new' blood to replace it. Donation was, in this way, thought to encourage the body's capacity to replenish its supply:

'As far as I'm concerned it's keeping the blood-manufacturing part of your body functioning properly.' (7, p21)

In relation to this, participants often talked about giving blood as energizing; 'I have always found that I have more energy... I sort of get a bit more get-up-and-go in the few days after giving blood' (13, p13). These feelings reinforced the idea that the body was working to produce new blood, and that 'new' blood had different qualities:

'I've got one new pint of blood in my body, makes me feel like I am fitter and healthier... So I think I've given [blood] more than seven times, so I've completely regenerated my blood supply, and I know it isn't quite like that but that's how it feels mentally I think' (9, p13).

Overall, interviewees described how giving blood had an impact on their body – sometimes positive, and sometimes negative. Usually, the same interviewee would describe a range of effects, such that donation was never viewed as solely good or solely bad. Increased frequency of donation was therefore not viewed as particularly problematic because there were always bodily benefits as well as potential risks.

#### *Perceptions of different bodies: issues of size, age and gender*

For the majority of those interviewed, giving blood was thought to be easier for some people than others. Those with bigger bodies were thought of as having more blood, and consequently the standard volume of blood taken by NHSBT was deemed less significant than for a smaller person. As one participant noted, in reference to their larger build;

'There's certainly less of an impact... even when I've been thinner... because I'm still a larger volume, just from the fact that I'm taller and wider than somebody smaller, therefore the percentage effect is going to be less anyway just on a physiological point of view' (27, p5)

A few of the participants also talked about whether their blood would still be 'good enough' as they got older. For example, one person felt that she could now fill a blood bag faster than in the past, something she put down to having 'thinner blood' which 'flowed more speedily' (22, p13).



Two thirds of those interviewed felt there were clear gender distinctions that were relevant. Although women were felt to be more familiar with blood and 'less likely to faint' because they routinely had to deal with their own blood, it was believed that men's bodies could 'regenerate' more quickly (13, p27). It was also felt that women found it more difficult to replenish their blood because of menstruation. A few women who had experienced heavy periods in the past talked about not wanting to donate because they would not have sufficient blood reserves. Most also thought blood loss during menses was different to loss through donation, either because it was lost over a longer time frame, or because it was thought of as being 'dirty' blood - in contrast to the 'clean' blood extracted during donation. For one older female participant, blood donation was a way to allow her body to bleed as it had in the past, something which she believed kept her looking younger; 'every month, women's bodies, they lose the blood and they produce it, refresh it, and [donation] is a kind of refreshment' (18, p4).

While blood donation was seen to impact on different bodies differently, the potential benefits to the body of donation meant that increased frequency was not, in itself, regarded as categorically harmful. Participants accepted that men might be able to donate more frequently than women – at least prior to menopause. Some also felt that larger people would be able to donate more regularly than smaller people. But the experience of donating more while participating in the INTERVAL trial was not merely drawn on as evidence that donating more often was possible, but it was used as a way to valorize the potential of the body to produce and replace blood within certain biological limitations.

#### *Practical issues*

Although a range of practical issues were raised in relation to donating more frequently while participating in the trial, participants remained enthusiastic about having the opportunity to donate more frequently. Although the majority had donated for many years at various NHSBT centres they all had to donate in the large, new, or reconditioned, static centres located in urban areas as part of the INTERVAL arrangements. For many, this was a new experience, and sometimes involved travelling long distances. Nonetheless, the majority were impressed with these large donation centres, seeing them as better organized, more 'streamlined', 'spacious', and generally 'nicer' than the mobile units or set-up clinics they previously attended. Some were also grateful for the longer opening hours, which enabled them to fit donation around other commitments. Thus, although one participant felt such static centres prevented donation feeling like a 'community event', (7, p23) most preferred the more modern venues;

'It feels... a bit more proper, like that's where you should be giving blood rather than lying in the middle of a hotel function room' (9, p21).

Transport to and from these centres, as well as parking, were however key issues. Whilst a couple of donors raised the idea of have such costs reimbursed, most saw this as a dimension of their altruism. Nevertheless, long and complicated journeys

remained an issue, with many calculating whether 'the inconvenience was outweighing the feel-good factor' (17, p11).

On a different matter in relation to practical aspects, a number talked about the positive relationships they forged with staff, describing them as always being 'professional', 'kind' and 'interested' - while not being 'too personal' (18, p20). Such comments suggest these relationships were an important dimension to the donation experience. Some consequently liked the increased frequency of donation when participating in the trial because this meant that they recognized, and were recognized by, staff;

'...you build up a little bit of a rapport with people, which I find quite nice...coming every ten weeks now, when I'm here I see the same people on a fairly regular basis...' (14, p10)

A number of participants reported experiencing issues with donating blood over the years, such as blood not clotting afterwards, bruising from mis-inserted needles, or fainting. These were seen as unusual events, and were not associated with increasing donation frequency. Participants were always at pains to emphasize that they trusted staff and NHSBT systems.

Overall, whilst some pragmatic difficulties did inevitably arise, donating more frequently was not thought about in terms of increasing their risk of adverse events. Instead it was associated with establishing a stronger relations with donation staff, and becoming even more familiar with the donation venues and procedures.

## **DISCUSSION**

At a time when services in the UK and across Europe are having to respond to both changes in the use of blood and the re-organization of healthcare more broadly, the possibility of taking blood more frequently from current donors is a promising development. Establishing evidence for, and potentially personalizing, safe intervals for donation relies on better understanding of how donation impacts on iron stores and Hb levels, and the extent to which biological factors, together with environmental variables, may predict individual differences. However, such findings will have limited practical use if increased donation frequency is not acceptable to donors themselves.

Many of the previous social and cultural studies on blood donation have focused on ideas that people hold with a view to understanding how these might influence motivation(5-16). However, to consider the changing practice of increased frequency of donation, we take an approach that emphasizes how beliefs and the experiences of actual practices mutually inform each other(19). In other words, beliefs are produced and reinforced by practice, rather than simply a psychological dimension prior to it. Informed by this approach, the paper has presented some of the common beliefs about blood and how it is produced in the body that are drawn on to make sense of donation, and were foregrounded in light of donating more frequently while

participating in a trial. We have shown how some of the apparently pragmatic aspects of giving blood, many of which can readily be predicted - for example, relating to transport and timing, they should not be separated from the less tangible social dimensions.

Of these, two key complementary areas were noted that are likely to influence the acceptability of a general policy to increase and tailor frequency: understandings of blood and iron, and differences associated with body size, age and gender. Donors possess their own ideas about how blood is replenished, and frequently their own strategies to adjust their behavior accordingly. All those interviewed described how their body's capacity to restore blood volume and iron levels over time was a natural ability that underpinned their capacity to be altruistic, and their capacity to donate more frequently. Some also felt that giving blood was biologically beneficial. Interviewees felt, however, that this capacity was not uniform; ideas around the body's ability to donate and the 'quality' of blood were related to different physical factors – such as body size, gender and age. Even though many of these ideas are not biomedically accurate, as Goldman et al have pointed out(25), they form an important aspect of how donors frame their actions and construct identities as loyal donors. In combination, the accounts we describe reveal not only the extent to which general ideas about blood shaped people's experiences of donation, but equally how those experiences are then drawn on to legitimate and confirm beliefs.

Contrary to any assumption that donors may be unreceptive to increased donation frequency, our findings suggest that increasing the frequency of donation – certainly for existing NHSBT donors who are already committed - would not be problematic or undesirable. A broader interpretation of the findings suggests that the central and related themes of replenishment and rejuvenation are drawn on by many to convey their particular role and the 'work' they undertake to be able to donate. In other words, describing the body's physiological potential in this way not only frames their understanding of how frequently they can donate, but also articulates a sense of the personal contribution they are able to make. Accordingly, donors did not present their ideas as ones that necessarily contradicted what staff and medical experts might advise, but rather as ways to convey their own sense of agency.

This study can therefore inform blood donation management, especially in the context of new policies to increase donation efficiency and effectiveness. Because donor retention remains an ongoing concern, our findings are important for considering the role and function of donor views. Our findings demonstrate that amongst some donors at least, increasing frequency actually aligns with what they already think about the role of blood and its replenishment, and hence might not necessarily lead to donor attrition. Rather than simply regarding such views as ill-informed or unscientific, these ideas are not only reinforced but give meaning to donation and help foster an enduring donor identity. Given this, donor views need to be acknowledged as an important form of sense-making, and potentially a resource to be worked with. We consequently argue a blood service needs to recognize the extent to which these views are an integral part of the very practice of blood donation, and hence should be worked with, rather than against.

### *Limitations*

A key feature of this study is that the interviewees were participants in a large trial, and were recruited because they were regular donors. They therefore are unlikely to be representative of all donors, or the potential blood donor pool. Given a purposive sampling strategy was adopted to capture the breadth of views according to age and gender, the study does not claim any statistical representativeness. However, the limited range of ethnic variation amongst the donor population meant that experiences and understandings from other groups are not included. Finally, since this qualitative study and the main INTERVAL trial was primarily concerned with increasing blood donation for those who already committed donors, questions concerning the extent to which the views and ideas reported here are representative of the wider donor population, and indeed non-donors, will clearly require further research.

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Competing interests: The authors have no competing interests.

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## FIGURES AND TABLES

Table 1: Participant characteristics

| <b>Participant characteristics</b> | <b><i>n</i></b> |
|------------------------------------|-----------------|
| <b><i>Large city sites</i></b>     | <b>2</b>        |
| Total participants across sites    | 15              |
| <i>Age</i>                         |                 |
| 20-39                              | 3               |
| 40-59                              | 9               |
| 60-79                              | 3               |
| <i>Sex</i>                         |                 |
| Male                               | 7               |
| Female                             | 8               |

|  |          |
|--|----------|
| <i>Ethnicity</i>                       |          |
| White British                          | 12       |
| Other White                            | 2        |
| Black British                          | 1        |
| <i>Usual donating centre</i>           |          |
| INTERVAL donation centre               | 4        |
| Other donation centre                  | 11       |
| <b><i>Small city sites</i></b>         |          |
| <b>Total participants across sites</b> | <b>2</b> |
| <i>Age</i>                             |          |
| 20-39                                  | 3        |
| 40-59                                  | 7        |
| 60-79                                  | 5        |
| <i>Sex</i>                             |          |
| Male                                   | 8        |
| Female                                 | 7        |
| <i>Ethnicity</i>                       |          |
| White British                          | 14       |
| White Other                            | 1        |
| <i>Usual donating centre</i>           |          |
| INTERVAL donation centre               | 6        |
| Other donation centre                  | 9        |