

Appendix 1

Haemochromatosis: Donor Questionnaire

Thank you for agreeing to participate in this study by Australian Red Cross Lifeblood. This study is a survey that will take approximately 20 minutes. The questions will ask about your high iron condition and your experience donating at Lifeblood. Your participation is greatly appreciated and will help us to improve the donation experience for our high iron donors.

The questionnaire is voluntary, and you are under no obligation to participate. The information you provide will only be known to the research team and where we use any data related to you it will remain anonymous and cannot be linked back to you.

Please answer all questions unless you are asked to skip questions because they do not apply to you. If you have any queries, please feel free to contact the study team via email donorresearch@redcrossblood.org.au

If you are ready to begin, please continue to the survey.

BLOCK: Haemochromatosis Knowledge

1. Why were you investigated for haemochromatosis? (Select all that apply)

- High iron
- Abnormal liver function tests
- Family member was diagnosed (genetics)
- Incidental finding resulting from other investigations
- Symptoms e.g. stiff joints, fatigue, lethargy, weight loss, skin pigmentation,
- Diabetes Mellitus (Type 2),
- Cardiac symptoms

2. How old were you when you were diagnosed?

3. How much do you know about haemochromatosis.

I am not at all knowledgeable 1 2 3 4 5 6 7 I am very knowledgeable

4. How important do you think it is to reduce your body's iron by regular venesection for the benefit of your own health

Not at all important 1 2 3 4 5 6 7 Very important

5. How important is it to you to donate blood for the benefit of others?

Not at all important 1 2 3 4 5 6 7 Very important

6. Where do you access information about haemochromatosis (Select all that apply)

- Internet search
- Support groups
- Social media communities
- My doctor
- I don't access information

- Other, please provide more detail
7. Are you a member of Haemochromatosis Australia?
 - Yes
 - No
 8. Do you use a digital application to track/ manage your iron
 - Yes
 - No (Select to Q11)
 9. If Yes, which digital application do you use?
 - My Iron Manager App
 - Other, please specify

BLOCK: Compliance

10. Many people find a way of managing their HHC that suits them. This might differ from what their doctor has prescribed. How often do you do any of the following? (The word donate below refers to venesection treatment for your iron overload)

	Always	Often	Sometimes	Rarely	Never
I donate only when I think I need to	1	2	3	4	5
I avoid donating if I can	1	2	3	4	5
I forget to donate	1	2	3	4	5
I alter my donation frequency	1	2	3	4	5
I stop donating for a while	1	2	3	4	5
I donate exactly as prescribed	1	2	3	4	5
I miss donations	1	2	3	4	5
I donate more than instructed	1	2	3	4	5
I donate less than instructed	1	2	3	4	5

11. If applicable, please indicate reason(s) below why you might miss a Lifeblood venesection appointment? (select all that apply)
 - I never miss a venesection appointment
 - I had a bad experience while donating
 - I went somewhere else to donate
 - The distance I must travel makes it hard to attend
 - I don't like needles
 - It is hard to get an appointment
 - Other, please explain

BLOCK: Donating at Lifeblood

12. Before you started donating at Lifeblood, did you attend another health / pathology service to have a venesection performed?
 - Yes
 - No [Skip to Q17]
13. Where else have you had a venesection performed? [Select all that apply]
 - Private hospital
 - Public hospital
 - Pathology Provider
 - GP/Specialist office
 - Other, please explain

14. When was the last time you attended this health / pathology service?

- Month/ year

15. Do you plan to attend this health / pathology service in the future?

- Yes/ No/ Unsure

16. Why did you choose to attend Lifeblood to have your venesection performed? [Select all that apply]

- GP / Specialist recommended it
- I was a volunteer donor prior to my HHC diagnosis
- The donor centre is conveniently located to me
- It is free
- My blood is used
- Other, please explain

17. How strongly do you identify as a blood donor

Not at all	1	2	3	4	5	6	7	Very much
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18. How strongly do you identify as a patient

Not at all	1	2	3	4	5	6	7	Very much
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19. To the best of your knowledge, did your GP/ Specialist have any issues sending through your referral to Lifeblood?

- Yes
- No [Skip to Q21]
- Unsure [Skip to Q21]

20. To the best of your knowledge, what issue(s) did your GP/ Specialist have? (Select all that apply)

- They had not heard of the High Ferritin App
- The High Ferritin app was unavailable
- They had difficulty completing the referral form located through the app
- They submitted incomplete or incorrect paperwork
- Other, please explain

21. Have you ever had any questions about hemochromatosis and donating at Lifeblood that a Lifeblood employee was not able to help you with?

- Yes
- No [Skip to Q23]

22. If yes, what were the questions?

BLOCK: Enablers and barriers to donating at Lifeblood

23. What are the benefits that you see in having your treatment performed in Lifeblood? [select all that apply]

- Easy access to the donor centre
- My blood will be used to help others, if possible
- Snacks provided after donation
- Phlebotomy skills of the staff
- Customer service in centre
- Ease of managing your condition

- Donation rewards I receive, e.g., badges, incentives
- Being able to donate with friends and family
- Blood pressure check
- Refreshments

24. What are the barriers that you experience to, or difficulties you see in, donating at Lifeblood?
[select all that apply]

- Not being able to manage my own appointments
- Customer service in centre
- Pain from donating
- Being seen as different to other donors
- Phlebotomy skills
- Waiting time
- Location of the donor centre
- Time taken to donate
- Difficult veins
- Opening hours of the centre
- Having my donation postponed due to a medical condition
- Cost associated with getting to the donor centre
- Repeated questioning

25. Have you ever had your donation postponed by Lifeblood?

- Yes
- No [Skip to Q32]

26. How was this experience for you

- Positive [Skip to Q28]
- Negative

27. Why was this a negative experience?

28. When your donation was postponed, did you understand the reason why?

- Yes
- No

29. When your donation was postponed, did you understand when you were allowed to return?

- Yes
- No

30. What, if anything, could Lifeblood have done to improve this experience?

BLOCK: Knowledge of Blood Usage

31. Is your blood used by Lifeblood?

- Yes
- No [Skip to Q35]
- Unsure [Skip to Q36]

32. What is your blood used for? (Select all that apply)

- Provided to recipients needing blood transfusions

- My plasma is removed and used for recipients
- To make different components (e.g. vaccines)
- For research
- I'm not sure [Skip to Q38]
- Other, please explain

33. How did you find out your blood was being used? (select all that apply)

- A Lifeblood staff member told me
- I received a SMS from Lifeblood
- I received an email from Lifeblood
- My doctor told me
- Other, please specify

34. Does knowing your blood is being used encourage you to attend your appointments [Skip to Q43]

- Yes
- No
- Unsure

35. How did you find out your blood wasn't being used? (select all that apply) [Skip to Q43]

- A Lifeblood staff member told me
- My doctor told me
- Other, please specify

36. Would you like to know if your blood is being used?

- Yes [Skip to Q38]
- No
- Unsure [Skip to Q39]

37. Why do you not want to know why your blood is being used? [Skip to Q39]

38. Would you like to know how your blood is used?

- Yes
- No
- Unsure

BLOCK: Communication from Lifeblood

39. How do you usually make your appointments?

- In centre after my last donation
- On the phone with the call centre
- Walk in on the day
- Other, please explain

40. Could Lifeblood improve this process for you?

- Yes [How]
- No

41. I think that the amount of communication I receive from Lifeblood is:

Too Little	1	2	3	4	5	6	7	Too much
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42. What additional communication would you like to receive from Lifeblood?

- SMS with where blood has been sent
- Donor Newsletter
- Appointment reminders
- Other, please explain
- No additional communications are needed

43. Please indicated your agreement with the following statements

I encourage my relatives, friends, and co-workers to donate blood at Lifeblood

Strongly disagree	1	2	3	4	5	6	7	Strongly agree
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I discuss the positive aspects of giving blood at Lifeblood among my relatives, friends, and co-workers

Strongly disagree	1	2	3	4	5	6	7	Strongly agree
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I recommend giving blood at Lifeblood to my relatives, friends, and co-workers

Strongly disagree	1	2	3	4	5	6	7	Strongly agree
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BLOCK: Knowledge about plasma

Lifeblood is considering inviting therapeutic donors whose iron levels have been lowered to a safe level (donors in maintenance phase) to donate plasma in-between their whole blood donations

44. How much do you know about donating plasma?

I am not at all knowledgeable 1 2 3 4 5 6 7 I am very knowledgeable

45. How interested would you be interested in donating plasma?

Not at all	1	2	3	4	5	6	7	Very much
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46. If you are interested in donating plasma why are you? (For example the ability to use your plasma to help more patients)

47. If you are not interested in donating plasma why not? (For example I'm concerned about my vein health?)

BLOCK: Survey close

We've reached the end of the survey.

Is there anything else you would like to tell us?

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Would you be interested in being contacted again by the research team about other research opportunities?

- Yes
- No

Would you like to receive a copy of the study findings?

- Yes
- No

THANK YOU FOR YOUR TIME