## Supplementary File S1. Patient survey questionnaire

## Screening questions

S1. Do you have chronic kidney disease? [single code]

1. Yes [CONTINUE]
2. No [TERMINATE]

S2. What other conditions do you have, or have you experienced? Please select all that apply [multicode]

1. Type 2 diabetes, or high blood sugar
2. A heart attack, or chest pain (angina), or chronic heart failure
3. A stroke
4. High blood pressure
5. High potassium level
6. Rheumatoid arthritis
7. Cancer or cancer-induced anemia
8. None of the above
9. Other

S3. Do you know what stage your chronic kidney disease is at? [single code]

1. Normal kidney function (stage 1)
2. Mild kidney disease (stage 2)
3. Moderate kidney disease (stage 3)
4. Severe kidney disease (stage 4)
5. Severe kidney disease/failure and receiving dialysis (stage 5)
6. I don’t know the stage of my kidney disease

## Questionnaire

**Section 1: Knowledge: what do patients know about anemia with CKD?**

In this section, we’d like to know a little more about your kidney disease and what you understand about anemia linked to, or in the context of, your kidney disease.
(Whenever we talk about “anemia” in the survey, we mean anemia linked to, or in the context of, your kidney disease only.)

1. **Which of the following statements about anemia do you think are correct? Please select all correct answers. [multicode, do not show [F]/[T], this is for reference and data processing only]**
2. Anemia is caused by low hemoglobin levels [T]
3. Anemia is caused by irregular heart rhythm [F]
4. Anemia is caused by low blood sugar [F]
5. Anemia has little to no impact on health [F]
6. Anemia is something a patient can easily live with, without treatment [F]
7. Anemia can be treated [T]
8. People living with kidney disease are at high risk of anemia [T]
9. Anemia might be caused by something other than kidney disease [T]
10. **Has your doctor ever told you that you have anemia? [single code]**
11. Yes
12. No
13. I can’t remember or am unsure [treat as ‘No’ response]
14. **If you’ve had a blood test in thepast year, do you know what your hemoglobin level is? [single code, numerical box if code a selected]**
15. Yes (please write in your approximate hemoglobin level in gm/dL if you know it, eg, XX.X gm/dL)
16. No
17. I have not had a blood test in the past year
18. **Which of the following do you think are symptoms of anemia? Please select all that apply. [multicode]**
19. Weakness
20. Fatigue, or feeling tired
21. Headaches
22. Problems with concentration
23. Paleness
24. Dizziness
25. Difficulty breathing or shortness of breath
26. Chest pain
27. None of the above
28. **When were you told you had anemia? [single code, only ask if A at 2]**
29. In the past 6 months
30. Between 6 months and 1 year ago
31. Between 1–2 years ago
32. Between 2–3 years ago
33. Between 3–4 years ago
34. Over 4 years ago
35. I can’t remember or am unsure

**Section 2: Quality of life and symptoms: What do patients attribute to anemia?**

In this section, we’d like to know how you think your kidney disease and/or your anemia impacts your life.

1. **Below are a few things which people who have a chronic condition, such as kidney disease, have mentioned that they feel. Please tell us how much these apply to you on a scale of 1 to 5, with 1 being ‘not at all’ and 5 ‘very much’ [5 pt scale, not at all, a little bit, somewhat, quite a bit, very much, ask if A at 2; split into two screens, first screen a–g, second screen h–n]**
2. I have a lack of energy
3. I have nausea
4. Because of my physical condition, I have trouble meeting the needs of my family
5. I have pain
6. I am bothered by side effects of treatment
7. I feel ill
8. I am forced to spend time in bed
9. I am able to work (include work at home)
10. My work (include work at home) is fulfilling
11. I am able to enjoy life
12. I have accepted my illness
13. I am sleeping well
14. I am enjoying the things I usually do for fun
15. I am content with the quality of my life right now
16. **Which of these feelings would you say is made worse by your anemia? [multicode, ask if A at 2; split into two screens, first screen a–g, second screen h–n]**
17. [Statement list from question 6]
18. None of the above
19. Don’t know
20. **Below are a few things which people who have a chronic condition, such as kidney disease, have mentioned in relation to their emotions. Please tell us how much these apply to you on a scale of 1 to 5, with 1 being ‘not at all’ and 5 ‘very much’ [5 pt scale, not at all, a little bit, somewhat, quite a bit, very much, ask if A at 2; split into two screens, first screen a–f, second screen g–m]**
21. I feel sad and/or depressed
22. I am satisfied with how I am coping with my illness
23. I am losing hope in the fight against my illness
24. I feel nervous
25. I worry about dying
26. I worry that my condition will get worse
27. I feel close to my friends
28. I get emotional support from my family
29. I get support from my friends
30. My family has accepted my illness
31. I am satisfied with family communication about my illness
32. I feel close to my partner (or the person who is my main support)
33. I am satisfied with my sex life [include prefer not to answer box]
34. **Which of these feelings would you say is made worse by your anemia? [multicode, ask if A at 2; split into two screens, first screen a–f, second screen g–m]**
35. [Statement list from question 8]
36. None of the above

**Section 3: Information and trust: Where do patients seek trusted information?**

In this section, we’d like to know how you find out more about kidney disease and/or anemia in the context of your kidney disease.

1. **Where have you looked for information about anemia, or received information about anemia from? Please select all that apply [multicode grid, statements, first column ‘looked for’, second column ‘received’]**
2. My family doctor
3. A nephrologist
4. A hematologist
5. A cardiologist
6. A pharmacist
7. Another specialist
8. A nurse or clinic staff
9. Other patients
10. Friends or family
11. Online (e.g. using Baidu)
12. On social media
13. From patient support groups
14. None of the above
15. Other
16. **And how much do you trust the information you get from these sources? From 1 being ‘not at all’ to 5 being ‘completely’? [5pt scale, show statements selected at 10, and add don’t know/unsure]**
17. **Do you get conflicting information from doctors and healthcare providers? i.e. do doctors or healthcare providers tell you different things about anemia? [single code]**
18. I find the anemia information I am given by my doctor/health care providers is consistent
19. Different doctors/healthcare providers tell me different conflicting things [cannot be selected alongside code A]
20. I don’t get any information on anemia [exclusive]
21. I am not sure
22. **How does this information on anemia you get from doctors/healthcare providers compare to advice from patient support groups? [single code, do not show if code C is selected at Q12]**
23. The information I get from doctors/healthcare providers is consistent with the information I get from patient support groups
24. The information I get from doctors/healthcare providers conflicts with the information I get from patient support groups
25. I am not sure
26. I don’t get any information from patient support groups
27. **Would you like more information and support about managing conditions like anemia? [single code]**
28. Yes
29. No
30. I am not sure

**Section 4: Patient–doctor relationships: how are patients discussing CKD or anemia with their HCPs?**

In this section, we’d like to know how your doctor talks to you about your kidney disease and/or anemia in the context of your kidney disease.

1. **Are you currently on treatment for kidney disease? [single code]**
2. Yes – I am on treatment for kidney disease, but not anemia
3. Yes – I am on treatment for kidney disease and anemia
4. No
5. **When did you start your treatment for anemia? [single code, ask if B at 15]**
6. In the past 6 months
7. Between 6 months and 1 year ago
8. Between 1**–**2 years ago
9. Between 2**–**3 years ago
10. Between 3**–**4 years ago
11. Over 4 years ago
12. I can’t remember or am unsure
13. **Has the doctor who diagnosed you with anemia told you about the relationship between your anemia and your kidney disease? [single code, only ask if A at 2]**
14. Yes
15. No
16. I can’t remember or am unsure
17. **Which of the following issues about anemia has your doctor discussed with you? [multicode]**
18. The symptoms of anemia like weakness, headaches or feeling tired
19. The impact anemia could have on your daily life or activities
20. A risk of heart disease (including stroke)[[1]](#footnote-2)
21. A higher risk of needing to go into hospital1
22. Problems with memory, language, thinking and judgment1
23. The severity and impact of anemia if left untreated1
24. None of the above
25. I can’t remember, or I am not sure
26. **After your discussions with your doctors about anemia, no matter how small, how do you feel? [single code per statement, more/same as before/less, only if A at 2]**
27. Confident about the management of my anemia [More, Less, No change]
28. Knowledgeable about my anemia [More, Less, No change]
29. Scared of my anemia [More, Less, No change]
30. Able to ask questions that are worrying me [More, Less, No change]
31. Comforted [More, Less, No change]
32. In control of me anemia [More, Less, No change]
33. **Does your doctor take your blood to test hemoglobin levels (anemia) during your regular check-ups? [single code]**
34. Yes, always
35. Yes, sometimes
36. No
37. I’m not sure – it is not mentioned when my blood test is being done
38. **Does your doctor ask about your anemia symptoms during your regular check-ups? [single code, only ask if A at 2]**
39. Yes, always
40. Yes, sometimes
41. No
42. **Do you know about the different treatments which are available for managing anemia, and if so, how did you find out? [single code]**
43. Yes, my doctor informed me about different treatments options for anemia
44. Yes, I asked the doctor about treatment options for anemia
45. Yes, I found out myself about anemia treatments
46. No, but I would like to know
47. No, but I don’t feel I need to know about anemia treatments
48. **How is your doctor currently managing your anemia? Please tick all that apply [multicode, only ask if A at 2]**
49. With oral medication
50. With injections
51. With blood transfusions
52. With iron supplements
53. Gives advice on my diet
54. No treatment that I know of [exclusive]
55. Other (specify)
56. **Would you say you know about the side effects of different treatments for anemia? [single code]**
57. Yes, I feel confident I know about various treatment side effects
58. No, I don’t feel confident I know about treatment side effects
59. **On a scale from 1 to 5, how well do you think your anemia is managed, with 1 being ’very badly managed’, 3 being ‘neither badly nor well managed’, and 5 being ‘very well managed’? [5pt scale, only ask if A at 2]**

**Section 5: Motivations and barriers to seeking support: What motivators lie behind patients’ behavior?**

In this section, we’d like to know more about what would encourage you to find out more about anemia.

1. **What prevents you from seeking help to find out more about your anemia? Please select all that apply [multicode, only ask if A at 2]**
2. My doctor is monitoring it and will tell me if it gets worse
3. I don’t feel my life is being affected by anemia
4. I don’t feel it is a priority in the overall treatment of my kidney disease
5. I don’t feel confident enough to talk about it with my doctor
6. I don’t think I can afford treatment
7. I don’t want to ask because I’m scared of finding out that I have anemia
8. I don’t know who I should talk to
9. I am afraid of the side effects of anemia treatments
10. I am happy to manage my anemia through diet and supplements
11. I want to avoid taking medication
12. My doctor doesn’t think it is necessary
13. I don’t feel prevented from finding out more information
14. Other
15. **What would encourage you to seek more information, or greater support, about anemia in the context of your kidney disease? Please rate the answers below [rating scale from 1 ‘this would not encourage me to seek help’ to ‘this would definitely encourage me to seek help’ and middle point ‘it may encourage me to seek help’]**
16. My symptoms getting worse
17. My everyday activities or daily life being impacted
18. Worrying about my future health
19. A friend or patient encouraging me to ask
20. Feeling I am in a better financial position to afford treatment

## Demographic Questions

**D1. What is your gender? [single code]**

1. Male

2. Female

3. Other

**D2. What is your age? [single code – drop-down list]**

[drop down list – 18–99]

**D3. In what region do you live?**

1. South

2. East

3. North

4. Northeast

5. Central

6. Southwest

7. Northwest

**Supplementary Table 1 Hemoglobin Levels**

|  |  |  |
| --- | --- | --- |
| **Hemoglobin level, g/dL,a *n* (%)** | **By genderb** | **By anemia statusc** |
| **Male(*n* = 73)** | **Female(*n* = 52)** | **Anemia cohort (*n* = 65)** | **Non-anemia cohort (*n* = 54)** |
| 8.0–8.9 | 3 (4.1) | 4 (7.7) | 7 (10.8) | 0 (0.0) |
| 9.0–9.8 | 5 (6.8) | 2 (3.8) | 6 (9.2) | 0 (0.0) |
| 10.0–10.9 | 10 (13.7) | 8 (15.4) | 16 (24.6) | 2 (3.7) |
| 11.0 | 7 (9.6) | 2 (3.8) | 3 (4.6) | 6 (11.1) |
| 12.0–12.8 | 17 (23.3) | 10 (19.2) | 15 (23.1) | 12 (22.2) |
| 13.0–13.8 | 4 (5.5) | 4 (7.7) | 3 (4.6) | 5 (9.3) |
| 14.0 | 4 (5.5) | 6 (11.5) | 1 (1.5) | 9 (16.7) |
| 15.0–15.6 | 10 (13.7) | 7 (13.5) | 9 (13.8) | 8 (14.8) |
| 16.0–16.5 | 6 (8.2) | 5 (9.6) | 5 (7.7) | 4 (7.4) |
| 18.0 | 3 (4.1) | 2 (3.8) | 0 (0.0) | 5 (9.3) |
| 19.0 | 2 (2.7) | 1 (1.9) | 0 (0.0) | 2 (3.7) |
| 20.0 | 2 (2.7) | 1 (1.9) | 0 (0.0) | 1 (1.9) |

aLevels/intervals shown are based on actual levels reported; for example, no patient reported a level of 17 g/dL. bPatients in the overall cohort of 456 patients with known hemoglobin levels. cPatients in the anemia and non-anemia cohorts who knew their hemoglobin levels.

1. Webster et al. Chronic Kidney Disease. Lancet 2017; 389: 1238–52 [↑](#footnote-ref-2)