

Understanding patient perspectives of the impact of anaemia in chronic kidney disease: A United States patient survey

Abstract

Background Anaemia, a common complication of chronic kidney disease (CKD), is associated with reduced health-related quality of life and physical functioning. This study investigated the knowledge, perceptions and awareness of anaemia in patients with CKD in the United States.

Methods Between 29 August and 17 September 2018, an online survey was administered to consenting patients in the United States aged ≥ 18 years with self-reported CKD, with or without anaemia; patients with cancer were excluded. The survey comprised 27 questions, exploring anaemia knowledge, health-related quality of life, anaemia management, practitioner–patient relationships, and the information sources patients used.

Results Of 446 patients with CKD, 255 (57.2%) were diagnosed with anaemia and 191 (42.8%) reported not being diagnosed with anaemia, or were unsure/could not remember (non-anaemia cohort). In patients with anaemia, 71.0% were aware of the relationship between CKD and anaemia versus 52.9% of those in the non-anaemia cohort. In the anaemia cohort, 46.3% of patients were aware of their haemoglobin level, compared with 27.2% of patients in the non-anaemia cohort. Symptoms most commonly reported as being made worse by anaemia included lack of energy (82.4%), feeling ill (31.4%), and the ability to enjoy life (30.2%). Despite 67.4% of

patients with anaemia in CKD believing that their condition was well or very well managed, only 50% reported being informed about different treatments without having to prompt their healthcare professional, and 43.9% were seeking more information and support about managing their condition.

Conclusions In the United States, patients with anaemia and CKD perceived that anaemia had a negative impact on their physical health and emotional wellbeing. Our findings emphasize the lack of disease awareness regarding anaemia in patients with CKD, suggesting that patients would benefit from further education regarding its management, and available treatment options.

Keywords: anaemia, chronic kidney disease, survey, patient perspectives, United States

What is already known about this topic?

Anaemia is a common complication of CKD and is associated with reduced HRQoL and physical functioning. Anaemia in CKD is associated with increased risk of hospitalisations, cardiovascular disease, cognitive impairment and mortality, and appropriate anaemia management can improve patient outcomes.

What does this article add?

This study found that there are varying levels of knowledge regarding the causes and symptoms of anaemia CKD. Patients with anaemia reported being impacted both physically and emotionally and were actively seeking more information about managing their condition from a variety of sources. In addition to the negative impact of anaemia in CKD on HRQoL, this highlights that patients would benefit from further

education, and that a patient-centered approach to treatment and care has the potential to improve patient outcomes.

1. Introduction

The prevalence of CKD in the United States (US) is increasing.¹ This increase may be attributed to increases in risk exposure, particularly type 2 diabetes (the leading factor associated with CKD in the US), hypertension, obesity and an ageing population.^{1,2} Anaemia is a common complication of CKD; of the approximate 37 million patients with CKD in the US,³ nearly 5 million have anaemia.⁴ Anaemia in CKD is associated with increased risk of hospitalisations, cardiovascular disease, cognitive impairment and mortality.⁵ Appropriate anaemia management can improve patient outcomes, as demonstrated in the Trial to Reduce Cardiovascular Events with Aranesp Therapy (TREAT) study; fatigue scores improved for patients receiving treatment targeted to a higher haemoglobin level compared with the control group receiving treatment targeted to a lower haemoglobin level.⁶ There is also a need for renal centres to standardise and individualise anaemia management in patients with CKD.⁷

While anaemia is common in patients with CKD, patients may be unaware of the association between CKD and anaemia.⁸ Furthermore, symptoms specific to anaemia may be difficult to discern from those of progressive CKD due to their similarities,⁹ contributing to confounding patient perceptions, clinician diagnosis, and treatment decisions, as well as the communication between patients and healthcare providers (HCPs). Many patients with CKD and anaemia experience reduced health-related quality of life (HRQoL) and physical functioning compared with those without anaemia.¹⁰ However, the precise contribution of anaemia in CKD to reduced HRQoL is difficult to ascertain; it is likely due to a combination of comorbidities, CKD progression and anaemia.⁶

Although treatments exist for anaemia in CKD, evidence suggests that the condition is underrecognised and undertreated^{4,11} compared with guideline recommendations.¹² Insight into patients' perceptions of disease, experiences and needs is important to improve recognition of this condition as well as to optimise treatment plans and to provide the best possible support at every stage of CKD.

Previous studies have identified a lack of awareness and knowledge of disease symptoms in patients with CKD.^{8,13} In a US study, only 19% of patients were aware of the relationship between proteinuria and poor kidney function, and only 22% understood that CKD may be asymptomatic.¹³ This lack of knowledge may be influenced by suboptimal communication between patients and HCPs; one-third of patients take a passive role in communicating with their physician, with 28% stating that they did not understand physicians' explanations of topics related to their CKD.⁸ Understanding patients' experiences or impact of the illness and treatments on HRQoL is increasingly recognised as key in the US, with organisations such as the National Kidney Foundation and American Kidney Fund launching specific patient platforms for patient engagement and research.^{14,15} In addition, there is an increasing emphasis on patient-centred care and shared decision making, with researchers seeking patients' voices through patient advisory boards, leading to improvements in study design, communication materials and new patient-centred end points.¹⁶ This highlights the importance of involving patients in their care through education and support.

This study aimed to understand the experience of patients with self-reported CKD with or without anaemia in the US, in terms of their knowledge of anaemia,

treatments received, and HRQoL. Sources of information used by patients to learn about their condition and their relationships with HCPs were also evaluated.

2. Materials and Methods

2.1. Survey design and participants

A quantitative, custom-made, online survey was developed following insights gained from interviews with three clinicians regarding the treatment and management of patients with anaemia in CKD. The survey was developed in collaboration with Portland Communications, London, UK, and was completed between 29 August and 17 September 2018 by 500 consenting patient volunteers from the US aged ≥ 18 years with self-reported CKD (any stage, on dialysis or not), with or without anaemia (the latter acted as a neutral control group); patients with cancer were excluded. Assessment of the knowledge and awareness of anaemia in the CKD population as a whole, regardless of anaemia status, was carried out. It was assumed that patients who had self-reported their CKD would provide an accurate insight into their self-awareness of the condition. A proprietary network, developed by the research firm Opinion Health Ltd, London, UK, was used to identify and recruit patients for this study. Recruitment sources included an online community, patient associations, online support groups and patient–patient referrals. Portland Communications worked with Opinion Health to carry out recruitment, fieldwork and data processing. Recruitment was not subject to quotas for CKD disease stages.

The research was carried out in accordance with the European Pharmaceutical Market Research Association Code of Conduct, the European Medicines Agency good pharmacovigilance practice guidelines, and General Data Protection Regulation guidance. All patients provided informed consent to take part in the study and were financially compensated for their time (incentive fee of \$5 USD per participant, in accordance with AstraZeneca’s guidelines on fair market value

compensation). Ethics Committee approval was not sought as this survey was conducted as a market research study.

2.2. Data collection

A survey was developed *de novo* in collaboration with Portland Communications, London, UK for the present study, and was made accessible to participants via an online platform. The final survey included 27 questions and aimed to gain insight into patient demographics; knowledge of anaemia, its management, and its impact on symptoms and HRQoL; effects on the healthcare practitioner–patient relationship; and information sources for the condition. A full list of the questions is provided in the Supplemental Material.

All information on disease status, including CKD stage, presence of anemia, and treatments received was self-reported by patients, and responses were not validated clinically. Self-reported disease is a common approach in patient selection for surveys, unless linked to some other data source (e.g., payer claims). Data collected from the survey were aggregated and anonymised to protect patient confidentiality.

2.3. Data analysis

Data collected from the survey were analysed in three separate cohorts: the overall cohort comprised all eligible patients who completed the survey; the anaemia cohort included patients who reported being diagnosed with anaemia by their HCP; and the non-anaemia cohort included both patients who reported not having been diagnosed with anaemia and those who were unsure or could not remember. Only patients in the anaemia cohort were surveyed on their perceptions of disease impact, awareness of the relationship between anaemia and CKD, and satisfaction of care.

The findings are reported descriptively as figures, which include n (%) of patients for each response. No formal hypotheses were tested, and no inferential statistics were performed.

3. Results

3.1. Study cohort selection

Of 500 volunteers with CKD who completed the survey, 54 patients reported having cancer or cancer-induced anaemia and were excluded from the overall cohort.

3.2. Demographics

In the overall cohort (N = 446), 69% of respondents were female, and the mean age was 52.2 years, with 58% of patients aged 51 years and over (Table 1). The most common comorbidities in the overall cohort were hypertension (67.3%), type 2 diabetes mellitus (29.6%), and hyperkalaemia (20.2%). In the overall cohort, the majority of patients had stage 3–5 CKD (67.7%); 22.6% had stage 5 CKD and were receiving dialysis (Table 1).

Of the overall cohort, 57.2% (n = 255/446) reported being diagnosed with anaemia by their doctor, 34.1% (n = 152/446) reported that they did not have anaemia, and 8.7% (n = 39/446) could not remember or were unsure whether they had been diagnosed with anaemia (Table 1).

3.3. Anaemia disease knowledge

In the overall cohort, 63.2% of patients were aware of the association between CKD and the risk of anaemia; a greater proportion of patients in the anaemia cohort (71.0%) were aware of this risk compared with the non-anaemia cohort (52.9%). A small proportion of patients in both cohorts had misconceptions about the causes of anaemia, such as low blood sugar and irregular heart rhythm, which were included as negative controls (Figure 1A).

Fatigue or feeling tired, weakness and dizziness, were identified by most patients in the overall cohort as anaemia-associated symptoms, with a slightly higher proportion of patients in the anaemia cohort identifying these symptoms (Figure 1B).

Of the overall cohort, only 38.1% of patients knew their haemoglobin level, compared with 46.3% of patients in the anaemia cohort and 27.2% of patients in the non-anaemia cohort. Some patients in both cohorts reported not having had a blood test in the last year (Table 2).

3.4. Disease Impact on HRQoL

Patients with anaemia in CKD indicated that the condition worsened their physical wellbeing (Figure 2A), affecting symptoms broadly divided into the following categories: fatigue, general malaise and feelings (including feeling ill, pain and being bothered by side effects), and daily activities. Lack of energy was most frequently identified as being aggravated by anaemia in CKD (82.4%; Figure 2B).

Patients with anaemia in CKD also reported an emotional impact caused by their condition (Figure 3A). Approximately half of the patients in this group indicated that anaemia increased their concern that their condition will worsen (Figure 3B).

3.5. Disease awareness and management

Overall, 27.8% of patients reported receiving treatment for both anaemia and CKD. In the anaemia cohort, 42.7% of patients reported receiving treatment for both anaemia and CKD. While 52.4% of patients in the non-anaemia cohort reported receiving treatment for CKD only, 7.9% reported also receiving treatment for anaemia (Table 1).

Approximately two-thirds of patients with CKD reported always having their haemoglobin levels assessed during regular check-ups, with the proportion in the anaemia cohort higher than in the non-anaemia cohort (Table 3). Of those with anaemia, almost half reported always being asked about symptoms during regular check-ups, and approximately two-thirds were made aware of the relationship between anaemia and CKD by the doctor who diagnosed them with anaemia (Table 3).

Patients in the anaemia cohort reported discussing immediate symptoms and risks of anaemia (e.g., weakness, headaches or feeling tired [66.7%], and impact of anaemia on daily life or activities [45.9%]) with their HCPs. Serious long-term risks, such as needing to go into hospital (25.5%) and risk of heart disease (22.4%), were discussed less frequently.

Half the patients in the anaemia cohort were informed by their HCP about treatment options for anaemia versus 14% in the non-anaemia cohort. In the anaemia and non-anaemia cohorts, 21% and 36% of patients, respectively, wanted to learn about treatment options for anaemia (Figure 4A). The majority (58.8%) of patients with anaemia in CKD felt confident that they understood the side effects associated with treatment for anaemia, compared with 29.3% of patients in the non-anaemia cohort.

Patients with anaemia in CKD most commonly reported receiving treatment with iron supplements (54.5%) and dietary advice on managing their anaemia (33.3%) (Figure 4B).

3.6. Patient perceptions on anaemia in CKD care

Most patients with anaemia in CKD felt that their anaemia was either “well managed” (24.7%) or “very well managed” (42.7%; Figure 5A). In addition, 48.2% of patients with anaemia felt that conversations with doctors made them feel more knowledgeable about anaemia (Figure 5B).

3.7. Disease information sources

Common sources to look for information about anaemia were HCPs, online sources and social media (Figure 6A). Approximately half of patients in the anaemia and non-anaemia cohorts looked to online sources to learn about anaemia. HCPs, particularly specialists, were the most trusted source of information on anaemia by both cohorts (Figure 6B). However, 9.9% of patients with anaemia in CKD indicated that the information received from HCPs and patient support groups was conflicting (Table 4).

Of the patients with anaemia, 44.7% relied on their doctor to monitor their anaemia and tell them if the condition had worsened (Figure 7). Patients with anaemia felt that the worsening of their symptoms and daily life being affected would encourage them to seek more information or support about anaemia in the context of their CKD (Figure 8).

Overall, 38.1% of all patients with CKD and 43.9% of those who had anaemia in CKD confirmed that they would like to receive more information and support about managing conditions like anaemia.

4. Discussion

This study evaluated the experience and awareness of patients with anaemia and self-reported CKD in the US, examining how they perceive the consequences and treatment of anaemia.

The study findings highlight the challenges faced by patients with CKD and anaemia in terms of disease awareness and its impact on HRQoL. Many patients were unaware of the association between CKD and anaemia, the diverse symptoms of anaemia, and the different treatment options available. This lack of awareness may be attributable to the variability in anaemia management amongst HCPs and support groups. This emphasises a need for improved patient education through a patient-centred approach and consistent messaging across HCPs and other trusted sources, to ensure that patients have all the necessary knowledge required to successfully manage their condition.

Despite the Kidney Disease: Improving Global Outcomes (KDIGO) guidelines recommending that all patients with anaemia in CKD should have their haemoglobin (Hb) levels assessed regularly,^{12,17} in this study, only 50.3% of patients indicated that their Hb levels were always assessed during regular check-ups. However, some patients may have been unaware of what is being assessed when blood samples are taken. This may also suggest that haemoglobin assessments are not routinely performed, such as in CKD patients not on dialysis. These findings highlight an opportunity for enhanced physician–patient communication regarding anaemia management, given that patient knowledge of their Hb levels has been suggested to be associated with HRQoL.¹⁸ In addition, studies have found associations between

higher haemoglobin levels and improved HRQoL in non-dialysis-dependent CKD patients.¹⁹

Patients with CKD and anaemia perceived that anaemia had a negative effect on their physical symptoms and emotional wellbeing. Physical symptoms of CKD become more apparent as the condition progresses, including fatigue, sleep disturbance, feeling a lack of control, and depressive symptoms, similar to symptoms associated with anaemia.^{9,20} Thus, patients with anaemia could have been conflating CKD and anaemia symptoms when surveyed. However, a number of patients reported aspects of their physical and emotional wellbeing as being made worse by their anaemia, including lack of energy and feelings of depression, suggesting an additional impact of anaemia on HRQoL and the patients' awareness of this.

Previous studies have shown a detrimental impact of anaemia in CKD on HRQoL.^{6,10} A review noted the adverse impact of anaemia on energy/vitality and physical functioning in patients with CKD, supporting the findings from the present study.²¹ Evidence also suggests that increasing haemoglobin levels can improve energy-related HRQoL scores;⁶ therefore, more routine measurement of haemoglobin levels than is currently reported in this study and that are recommended by KDIGO guidelines¹⁷ are essential in order to improve patients' HRQoL. These improvements include increased physical activity, lower rates of CKD progression and greater survival rates.¹⁹

Treatment options were discussed by HCPs for half of patients with CKD and anaemia, and approximately 20% of patients were seeking more information, indicating an opportunity for further patient education to ensure all patients receive information about their treatment options. Nearly half of patients in the anaemia

cohort (43%) confirmed that they would like to receive more information and support about managing their condition. Online information and HCPs were the most popular sources for information about anaemia. However, regardless of anaemia status, patients with CKD trusted their HCPs to a greater extent than all other information sources. The use of online sources may be reflective of the younger patient demographic for this survey (mean age 52.2 years), compared with the US CKD population as a whole [38% are aged 65 years or older ³].²²

These findings suggest that there is an opportunity for increased dialogue between patients and HCPs, regarding the association between CKD and anaemia, its symptoms, treatment options and the effects of treatment on patients. Such dialogue may enable patients to have better control over the management of their condition, allowing them to seek monitoring and guidance on treatment or alternative treatment options. Patients may also benefit from having a better understanding of the value of assessing their haemoglobin levels, and take proactive measures in managing their anaemia in CKD. This approach is important in CKD management since slowing its progression, and hence improving HRQoL, must include patient involvement. In addition, our findings suggest that there is a need for more trustworthy and consistent information to be readily available online to support patients in addition to discussions with HCPs, as some patients received conflicting information from HCPs and patient support groups. A recent systematic review reported that self-management support interventions (resulting in increased patient knowledge) were most frequently associated with statistically significant improvements in chronic disease management.²³ Therefore, improved patient knowledge through more reliable information sources (such as awareness campaigns and patient advocacy groups) has the potential to improve HRQoL.

However, the challenge now will be how to provide this improved education to patients in a meaningful and engaging, and coherent manner.

The study had several limitations. Due to the survey methodology, all information collected, such as CKD status, stage and information discussed with HCPs, was self-reported by patients and not confirmed by medical records. Thus, patients who reported that they had not discussed anaemia symptoms or treatment options may have failed to recollect such discussions. Some patients with CKD in the non-anaemia cohort reported receiving anaemia treatment. This indicates an opportunity for HCPs to provide patients with more information and clarification regarding treatments. Furthermore, patients who responded to the online survey may be more engaged with, and knowledgeable about, their care than the general patient population, in addition to being better informed than those unfamiliar with technology and the internet. In addition, the demographics of the study are skewed towards advanced CKD. Therefore, this cohort may not be entirely representative of the CKD and anaemia population as a whole, and may not provide a comprehensive picture of anaemia treatment in the US. Finally, this was a cross-sectional study that used an unvalidated *de-novo* questionnaire in a limited sample size and did not include a longitudinal follow-up. As such, this is an area for further scientific development in the future.

5. Conclusion

These study findings emphasise gaps in the knowledge of disease awareness in patients with CKD and anaemia, adding to the scarcity of patient-specific knowledge and experiences of patients with CKD and anaemia. It also reiterates the challenges faced by these patients, highlighting an opportunity for further patient education from HCPs and other trusted sources in the management of anaemia, the importance of anaemia monitoring, the symptoms of anaemia, and available treatment options. This may aid the transition to a more patient-centred approach to treatment with potential to improve clinical care and patient-specific outcomes.

Supplemental Material

Survey Questionnaire

Screening questions

Questionnaire

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

Section 2: Quality of life and symptoms: what do patients attribute to anaemia?

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

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

Section 5: Motivations and barriers to seeking support: What motivators lie behind patients' behaviour?

Demographic Questions

References

1. Bowe B, Xie Y, Li T, et al. Changes in the US burden of chronic kidney disease from 2002 to 2016: An analysis of the global burden of disease study. *JAMA Netw Open*. 2018;1:e184412.
2. Jha V, Garcia-Garcia G, Iseki K, et al. Chronic kidney disease: global dimension and perspectives. *Lancet*. 2013;382:260-272.
3. Centers for Disease Control and Prevention. Chronic Kidney Disease in the United States, 2019, https://www.cdc.gov/kidneydisease/pdf/2019_National-Chronic-Kidney-Disease-Fact-Sheet.pdf.
4. Stauffer ME, Fan T. Prevalence of anemia in chronic kidney disease in the United States. *PLoS One*. 2014;9:e84943.
5. Babitt JL, Lin HY. Mechanisms of anemia in CKD. *J Am Soc Nephrol*. 2012;23:1631-1634.
6. Finkelstein FO, Finkelstein SH. The impact of anemia treatment on health-related quality of life in patients with chronic kidney disease in the contemporary era. *Adv Chronic Kidney Dis*. 2019;26:250-252.
7. Padhi S, Glen J, Pordes BA, Thomas ME, Guideline Development Group. Management of anaemia in chronic kidney disease: summary of updated NICE guidance. *BMJ*. 2015;350:h2258.
8. Lederer S, Fischer MJ, Gordon HS, Wadhwa A, Popli S, Gordon EJ. Barriers to effective communication between veterans with chronic kidney disease and their healthcare providers. *Clin Kidney J*. 2015;8:766-771.
9. Romagnani P, Remuzzi G, Glassock R, et al. Chronic kidney disease. *Nat Rev Dis Primers*. 2017;3:17088.

10. Eriksson D, Goldsmith D, Teitsson S, Jackson J, van Nooten F. Cross-sectional survey in CKD patients across Europe describing the association between quality of life and anaemia. *BMC Nephrol*. 2016;17:97.
11. Rasu RS, Manley HJ, Crawford T, Balkrishnan R. Undertreatment of anemia in patients with chronic kidney disease in the United States: analysis of national outpatient survey data. *Clin Ther*. 2007;29:1524-1534.
12. Kidney Disease: Improving Global Outcomes. Work Group Membership. *Kidney Int Suppl* (2011). 2012;2:281.
13. Wright JA, Wallston KA, Elasy TA, Ikizler TA, Cavanaugh KL. Development and results of a kidney disease knowledge survey given to patients with CKD. *American journal of kidney diseases : the official journal of the National Kidney Foundation*. 2011;57:387-395.
14. National Kidney Foundation. NKF to Develop First-Ever Patient Registry for Chronic Kidney Disease, 2019, <https://www.kidney.org/news/nkf-to-develop-first-ever-patient-registry-chronic-kidney-disease>.
15. American Kidney Fund. American Kidney Fund Completes Pilot Program with Patients Using Cricket Health Online Platform to Enhance Kidney Care Management, 2017, <https://www.kidneyfund.org/news/news-releases/akf-completes-pilot-program-with-cricket-health.html>.
16. Anderson A, Bengner J, Getz K. Using Patient Advisory Boards to Solicit Input Into Clinical Trial Design and Execution. *Clin Ther*. 2019;41:1408-1413.
17. KDIGO. KDIGO Clinical practice guideline for anemia in chronic kidney disease. *Kidney Int Suppl*. 2012;2:380-335.
18. Kallich J, McDermott A, Xu X, Fayers P, Cella D. The relationship between patient knowledge of hemoglobin levels and health-related quality of life. *Qual Life Res*. 2006;15:57-68.

19. Hoshino J, Muenz D, Zee J, et al. Associations of hemoglobin levels with health-related quality of life, physical activity, and clinical outcomes in persons with stage 3-5 nondialysis CKD. *Journal of renal nutrition : the official journal of the Council on Renal Nutrition of the National Kidney Foundation*. 2020;S1051-2276:30414-30415.
20. Stavroula G, Fotoula B. Psychological Aspects in Chronic Renal Failure. *Health Sci J*. 2014;8:205-214.
21. Anand S, Johansen KL, Kurella Tamura M. Aging and chronic kidney disease: the impact on physical function and cognition. *J Gerontol A Biol Sci Med Sci*. 2014;69:315-322.
22. DOPPS. US-DOPPS Practice Monitor, 2019, <https://www.dopps.org/dpm/DPMSlideBrowser.aspx>.
23. Reynolds R, Dennis S, Hasan I, et al. A systematic review of chronic disease management interventions in primary care. *BMC Fam Pract*. 2018;19:11.

Table 1. Patient baseline characteristics

	Overall, N = 446	Anaemia cohort, † n = 255	Non-anaemia cohort, n = 191
Male, n (%)‡	135 (30.3)	84 (32.9)	51 (26.7)
Female, n (%)	309 (69.3)	171 (67.1)	138 (72.3)
Age, years, n (%)			
18–35	86 (19.3)	60 (23.5)	26 (13.6)
36–50	103 (23.1)	66 (25.9)	37 (19.4)
51–65	172 (38.6)	86 (33.7)	86 (45.0)
≥65	85 (19.1)	43 (16.9)	42 (22.0)
US region			
Northeast	113 (25.3)	64 (25.1)	49 (25.7)
Midwest	124 (27.8)	64 (25.1)	60 (31.4)
South	133 (29.8)	79 (31.0)	54 (28.3)
West	76 (17.0)	48 (18.8)	28 (14.7)
Comorbidities, n (%)			
T2D/high blood glucose	132 (29.6)	80 (31.4)	52 (27.2)
MI/angina/CHF	63 (14.1)	42 (16.5)	21 (11.0)
Stroke	34 (7.6)	18 (7.1)	16 (8.4)
Hypertension	300 (67.3)	168 (65.9)	132 (69.1)
Hyperkalaemia	90 (20.2)	61 (23.9)	29 (15.2)
Rheumatoid arthritis	33 (7.4)	16 (6.3)	17 (8.9)
None of the above	67 (15.0)	45 (17.6)	22 (11.5)
Other	90 (20.2)	48 (18.0)	42 (22.0)
CKD stage§			
1	31 (7.0)	15 (5.9)	16 (8.4)
2	77 (17.3)	47 (18.4)	30 (15.7)
3	132 (29.6)	60 (23.5)	72 (37.7)
4	69 (15.5)	44 (17.3)	25 (13.1)

5 (receiving dialysis)	101 (22.6)	74 (29.0)	27 (14.1)
Don't know	36 (8.1)	15 (5.9)	21 (11.0)
Diagnosis of anaemia‡			
Yes	255 (57.2)	255 (100.0)	0 (0.0)
No	152 (34.1)	0 (0.0)	152 (79.6)
Can't remember/unsure	39 (8.7)	0 (0.0)	39 (20.4)
Time since diagnosis of anaemia			
≤6 months	–	44 (17.3)	–
6 months–1 year	–	35 (13.7)	–
1–2 years	–	57 (22.4)	–
2–3 years	–	36 (14.1)	–
3–4 years	–	16 (6.3)	–
≥4 years	–	59 (23.1)	–
Can't remember or unsure	–	8 (3.1)	–
Treatment for CKD§			
Yes, for CKD but not for anaemia	213 (47.8)	113 (44.3)	100 (52.4)
Yes, for both CKD and anaemia	124 (27.8)	109 (42.7)	15 (7.9)
No	109 (24.4)	33 (12.9)	76 (39.8)

† Anaemia was diagnosed by a doctor.

‡One patient reported 'other' as their gender.

§Patients self-reported their CKD stage in response to the question 'Do you know what stage your chronic kidney disease is at?'

|| Includes pharmacologic treatments and dietary advice.

Abbreviations: CHF, chronic heart failure; CKD, chronic kidney disease; MI, myocardial infarction; T2D, type 2 diabetes mellitus.

Table 2. Knowledge of haemoglobin levels

n (%)	Overall (N = 446)	Anaemia cohort (n = 255)	Non-anaemia cohort (n = 191)
If you've had a blood test in the past year, do you know what your haemoglobin level is?			
Yes	170 (38.1)	118 (46.3)	52 (27.2)
No	242 (54.3)	126 (49.4)	116 (60.7)
I have not had a blood test in the past year	34 (7.6)	11 (4.3)	23 (12.0)

Table 3. Monitoring for anaemia and associated symptoms during regular check-ups

n (%)	Overall (N = 446)	Anaemia cohort (n = 255)	Non-anaemia cohort (n = 191)
Does your doctor take your blood to test haemoglobin levels (anaemia) during your regular check-ups?			
Yes, always	289 (64.8)	193 (75.7)	96 (50.3)
Yes, sometimes	82 (18.4)	40 (15.7)	42 (22.0)
No	34 (7.6)	12 (4.7)	22 (11.5)
I'm not sure – it's not mentioned when my blood test is being done	41 (9.2)	10 (3.9)	31 (16.2)
Does your doctor ask about your anaemia symptoms during your regular check-ups?			
Yes, always	NC	122 (47.8)	NC
Yes, sometimes	NC	71 (27.8)	NC
No	NC	62 (24.3)	NC
Has the doctor who diagnosed you with anaemia told you about the relationship between your anaemia and your kidney disease?			
Yes	NC	168 (65.9)	NC
No	NC	56 (22.0)	NC
Can't remember/unsure	NC	31 (12.2)	NC

Abbreviation: NC, not calculated.

Table 4. Consistency in information received from HCPs and patient support groups

n (%)	Overall (N = 446)	Anaemia cohort (n = 255)	Non-anaemia cohort (n = 191)
Information from HCPs			
Consistent information	225 (50.4)	166 (65.1)	59 (30.9)
Conflicting information	72 (16.1)	47 (18.4)	25 (13.1)
No information given by HCPs	93 (20.9)	22 (8.6)	71 (37.2)
Not sure	56 (12.6)	20 (7.8)	36 (18.8)
Information from HCPs and patient support groups			
	(N = 353)	(n = 233)	(n = 120)
Consistent information	127 (36.0)	90 (38.6)	37 (30.8)
Conflicting information	34 (9.6)	23 (9.9)	11 (9.2)
No information given by HCPs	144 (40.8)	96 (41.2)	48 (40.0)
Not sure	48 (13.6)	24 (10.3)	24 (20.0)

Abbreviation: HCP, healthcare provider.

Figure 1. Beliefs about (A) causes of anaemia, and (B) symptoms associated with anaemia

Figure 2. (A) Perception of chronic disease impact on HRQoL (anaemia cohort, n = 255): (B) worsening of physical symptoms attributed to anaemia by these patients

Figure 3. (A) Perception of chronic disease impact on HRQoL (anaemia cohort, n = 255): (B) worsening of emotional symptoms attributed to anaemia in CKD by these patients

Figure 4. (A) Knowledge of treatment options for anaemia and how this was acquired, and (B) anaemia treatments reported by patients

Figure 5. For the anaemia cohort (n = 255): (A) Patient perceptions of how well their anaemia was being managed, and (B) impact of discussing anaemia in CKD with HCPs

Figure 6. (A) Sources used by patients to look for information about anaemia, and (B) trust in the information received from these sources

Figure 7. Factors that prevented patients with anaemia in CKD from seeking more information about anaemia (anaemia cohort, n = 255)

Figure 8. Factors that would encourage patients to seek more information or greater support about anaemia in CKD (anaemia cohort, n = 255)