



European PREM survey of anaemia associated with chronic kidney disease

Results

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Contributors to this document

Nephrologists:

Corinne ISNARD BAGNIS, Pitié Salpêtrière Hospital, Paris, France

Hans FURULAND, Uppsala University Hospital, Uppsala, Sweden

Sapna SHAH, Kings College Hospital, London, UK

Patient Advocates:

Daniel GALLEGO-ZURRO, European Kidney Patient Federation (EKPF), Madrid, Spain

Laurie CUTHBERT, Kidney Care UK, London, UK



Policy Advocates:

Raymond C VANHOLDER, European Kidney Health Alliance (EKHA), Brussels, Belgium



Background and objectives



Background and objectives

Disease Background

- Anaemia is a frequent complication in chronic kidney disease (CKD) and is associated with an array of clinical and humanistic impacts. The mechanisms of anaemia associated with CKD (aCKD) are complex however several treatment options exist. There is limited evidence regarding the experience and opinions of patients with aCKD about the care and management of their disease*.

Primary Objective

- This study aimed to find out how patients with aCKD in Europe feel about the care and treatment they receive.
- Results from this study will help to establish a European dataset of patient experience that can lead to service improvements by enabling patients to have the opportunity to share what matters most to them.

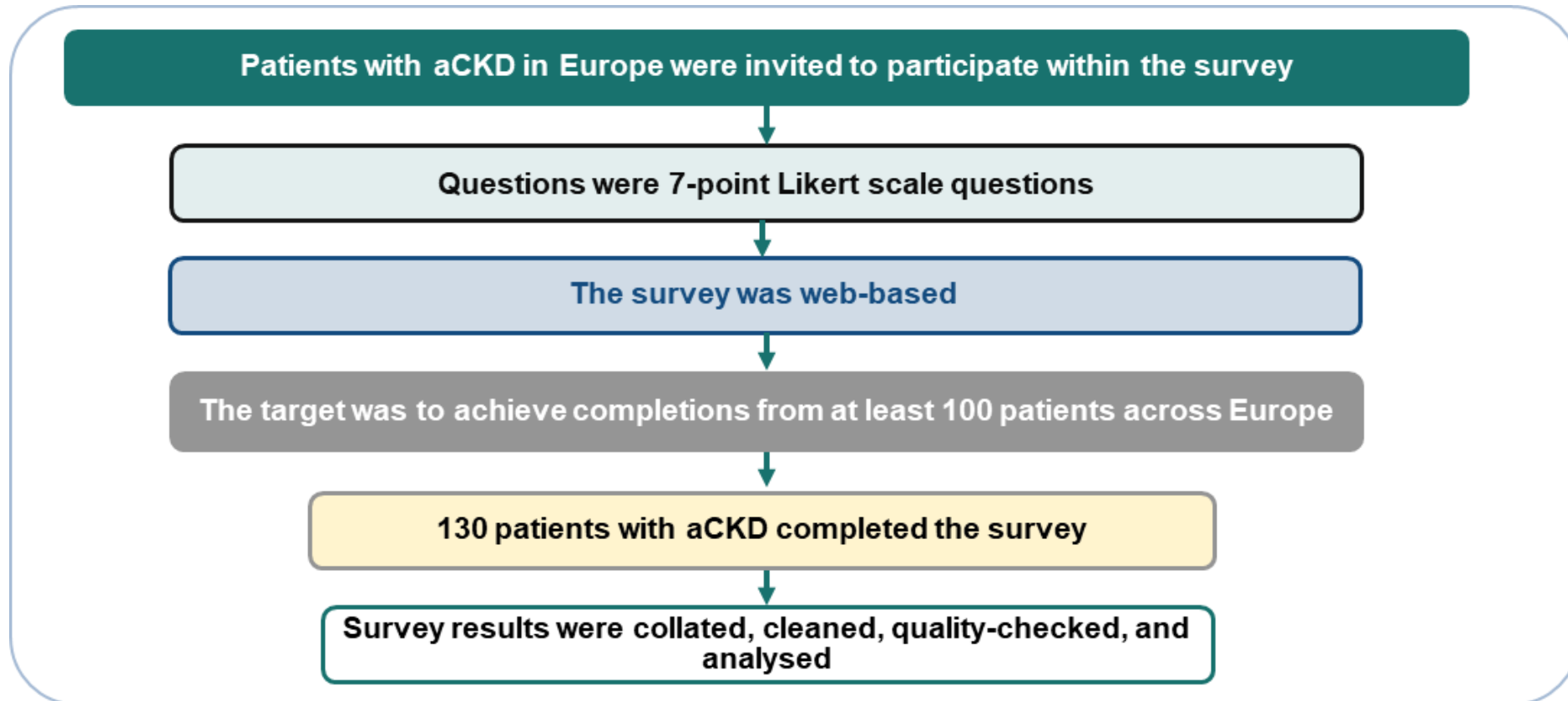


Methodology



Methodology

A quantitative survey was designed and launched for completion. The survey encompassed 14 questions that were asked as 7-point Likert scales, where respondents answered these questions from 1 (strongly disagree) to 7 (strongly agree). These were accompanied by a small number of open-ended questions. This PREM survey was broadly similar in format, and the types of questions asked, to the established UK Kidney PREM.

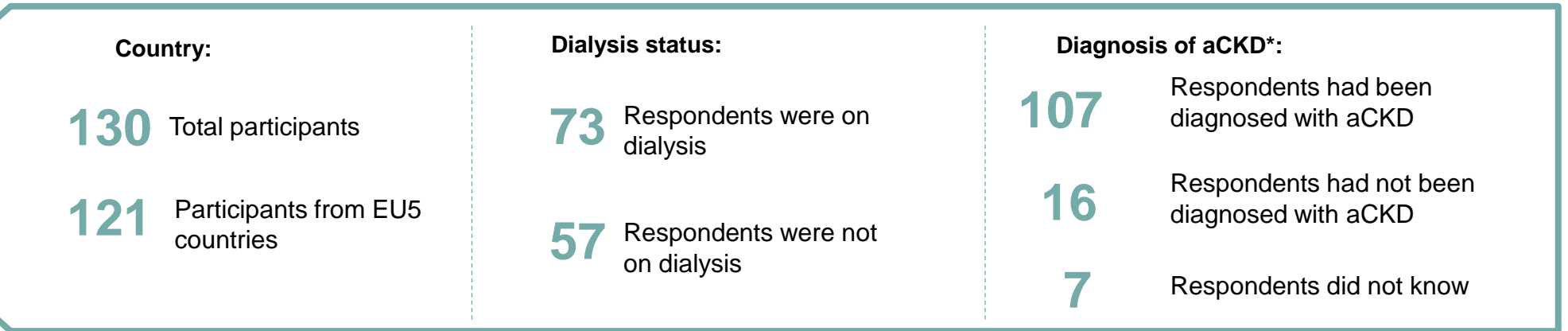




Respondent demographics



Respondent demographics



Country	France	Germany	Italy	UK	Spain	Other
Respondents	4	41	2	55	19	9

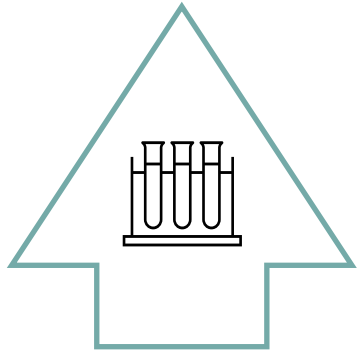
* Self-reported diagnosis of aCKD



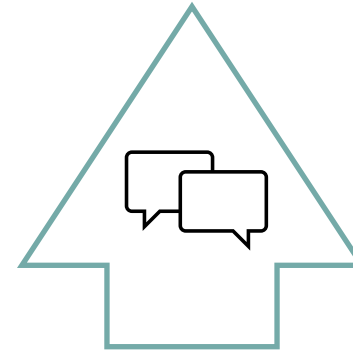
Executive summary of survey results



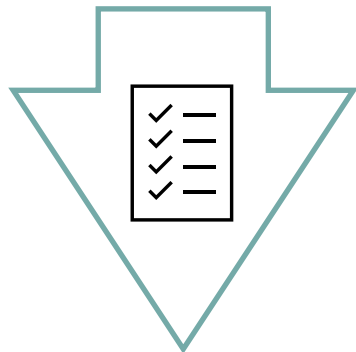
Executive summary of survey results: Key data points



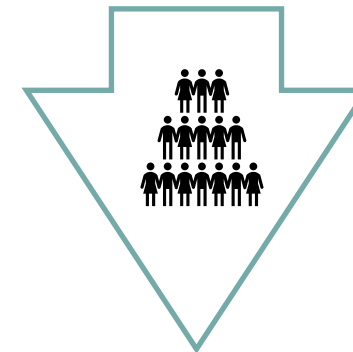
The highest scores were recorded for questions regarding the understanding of the reasons for performing blood tests on patients **6.1** and of the results of these tests **5.7**.



High scores for questions regarding the communication of the renal team with patients, including the time they take to answer their questions **5.6** and how clearly things are explained **5.6**.

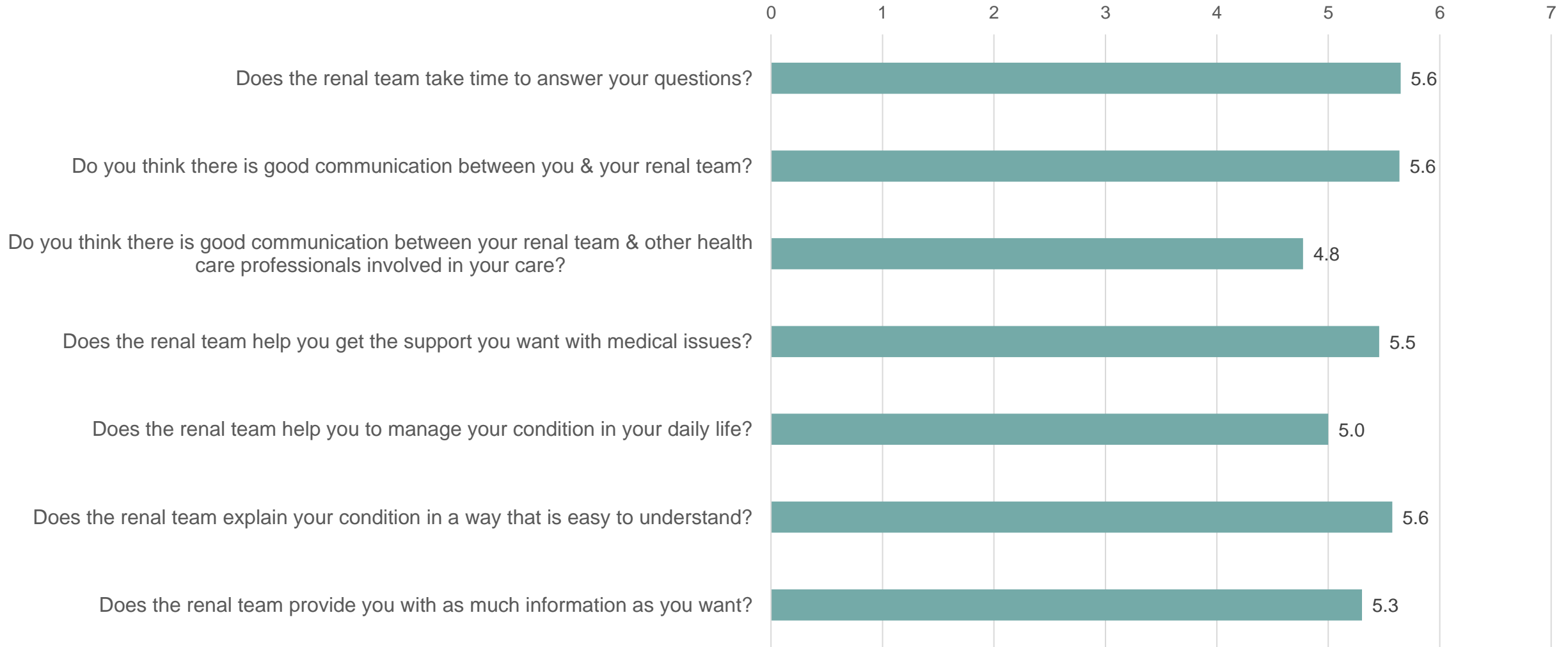


The lowest score was reported for the question inquiring about the communication of the renal team with the patients regarding their life goals **3.9**.



Patients also consider that communication between the renal team and other healthcare professionals involved in their care could improve **4.8**

Executive summary of survey results: General results



Executive summary of survey results: General results (continued)



Executive summary: Limitations and future considerations

Limitations

Sample size

Limited sample size with significant results only achieved for 3 countries, making it hard to draw conclusions that consider all the major 5 European countries

Selection bias

The online distribution and completion method may have favoured certain demographics (e.g. more educated and empowered patients)

Drop-outs

Only 130/160 patients who completed the screening questions went on to complete the rest of the survey and it's unclear why (e.g. question complexity, lack of incentive)

Considerations for future surveys

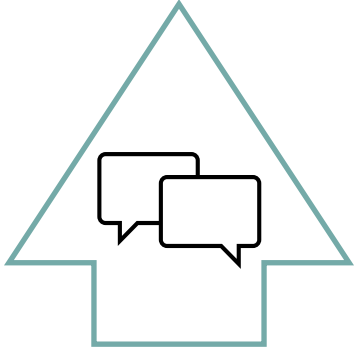
- **Provide respondent incentives to drive completion**
- **Apply country quotas (keeping the survey open until these are met)**
- **Release a paper version in parallel to the online version**



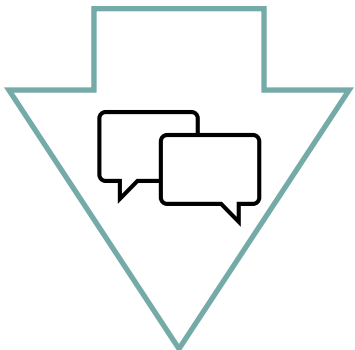
Summary of survey results by key topics



Summary – communication

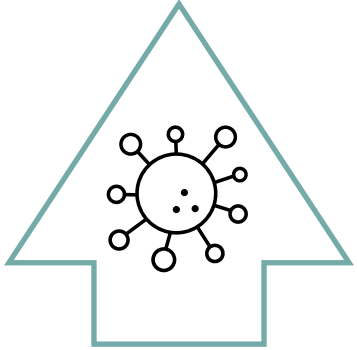


- Overall, respondents believe that communication between patients with aCKD and renal healthcare teams is good, and that HCPs take enough time to answer any questions they might have.
- Despite small differences, this opinion is consistent across countries and for patients with and without dialysis.
- Respondents also believe that HCPs provide patients with an appropriate amount of information.

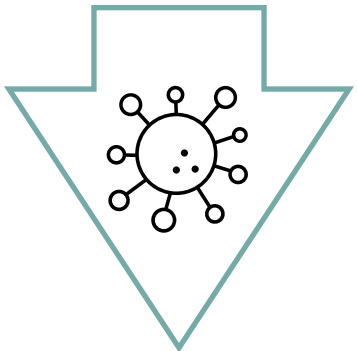


- HCPs could tailor the amount of information provided to each patient to better accommodate to their specific wants and needs.
- Respondents considered that the communication the renal team treating them, and other healthcare professionals involved in their care could be improved, *especially noted in the UK.*

Summary – support with medical condition

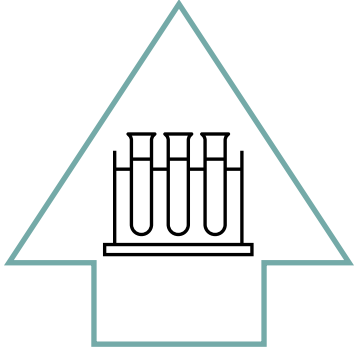


- Participants feel the renal team helps them get the support they need with medical issues associated with their disease.
- Participants believe that aspects associated with their condition are well communicated by the renal team in simple clear ways that allow them to understand, despite not being experts in the disease.



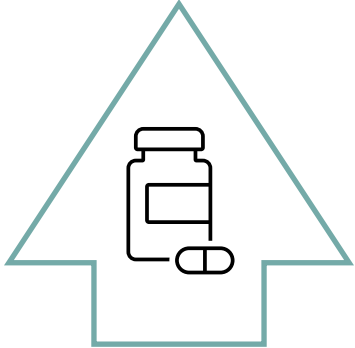
- Nevertheless, complicated medical terms could be better explained in ways that are even easier to understand by people with different expertise levels, *especially noted in Spain*.

Summary – blood tests



- Most participants feel they understand why blood tests are required and understand the results of these tests.

Summary – involvement in treatment

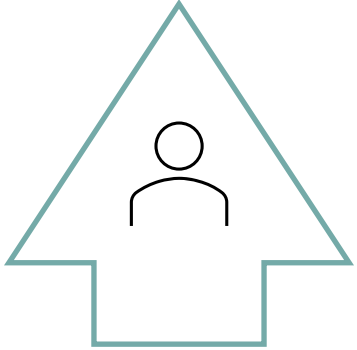


- Patients note that HCPs discuss their treatments and their disease with them.
- Respondents feel that their renal team enables them to participate in decisions about their care.

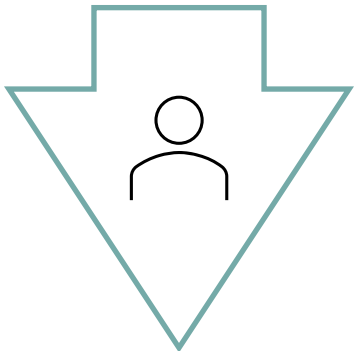


- Despite HCPs discussing treatments with them, aCKD patients *could* be involved in decision-making regarding their treatment options and their care more often.
- Patients could be encouraged by HCPs to participate in discussions regarding their own treatment and care more.

Summary – QoL and personal treatment



- Most patients believe that the renal healthcare team cares about them as a person and not just as a patient, which provides a strong basis for trust in the disease management process and could encourage more personalised therapy approaches.



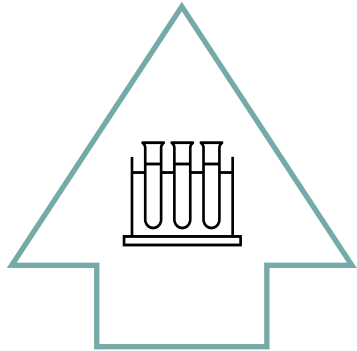
- The management of aCKD in a patient's daily life (not just treatment in the hospital setting) could be encouraged, so that the patient's overall QoL improves.
- To achieve this better, HCPs could learn more about patients personally, including their life goals.



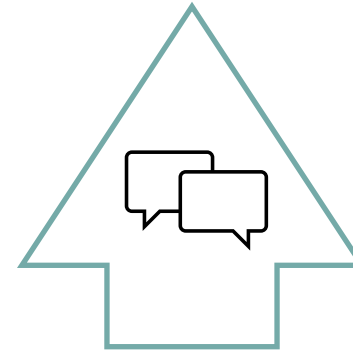
Executive summary of survey results by country



Executive summary of survey results: UK (n=55)



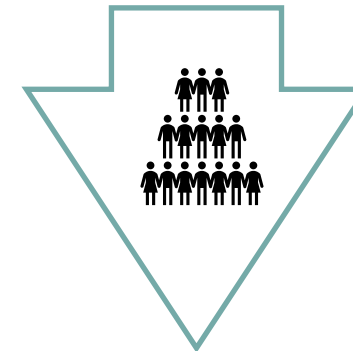
In the UK, the highest scores were recorded for questions regarding the understanding of the reasons for performing blood tests on patients **6.1** and of the results of these tests **5.5**.



High scores for questions regarding the communication of the renal team with patients, including the time they take to answer their questions **5.5**, if there is good communication with the renal team **5.6** and how clearly things are explained **5.6**.



The lowest score was reported for the question inquiring about the communication of the renal team with the patients regarding their life goals **3.7**.



Patients also consider that the renal team could encourage patients to take a more active role in their own care and participate in decisions more **4.9**.

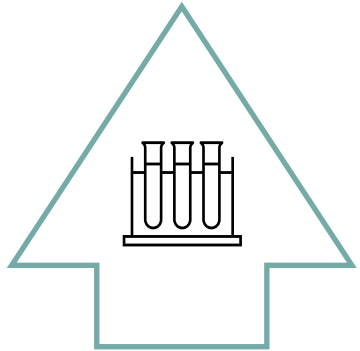
Executive summary of survey results: UK (n=55) (1/2)



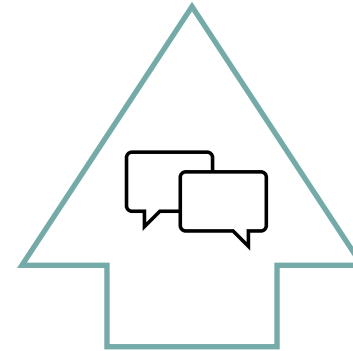
Executive summary of survey results: UK (n=55) (2/2)



Executive summary of survey results: Germany (n=41)



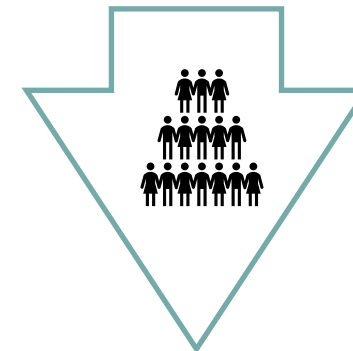
Once more, the highest scores were recorded for questions regarding the understanding of the reasons for performing blood tests on patients **6.4** and of the results of these tests **5.9**.



High scores for questions regarding the communication of the renal team with patients, including the time they take to answer their questions **5.9**, if there is good communication with the renal team **5.8** and if the renal team talks to patients about their treatment **5.8**.

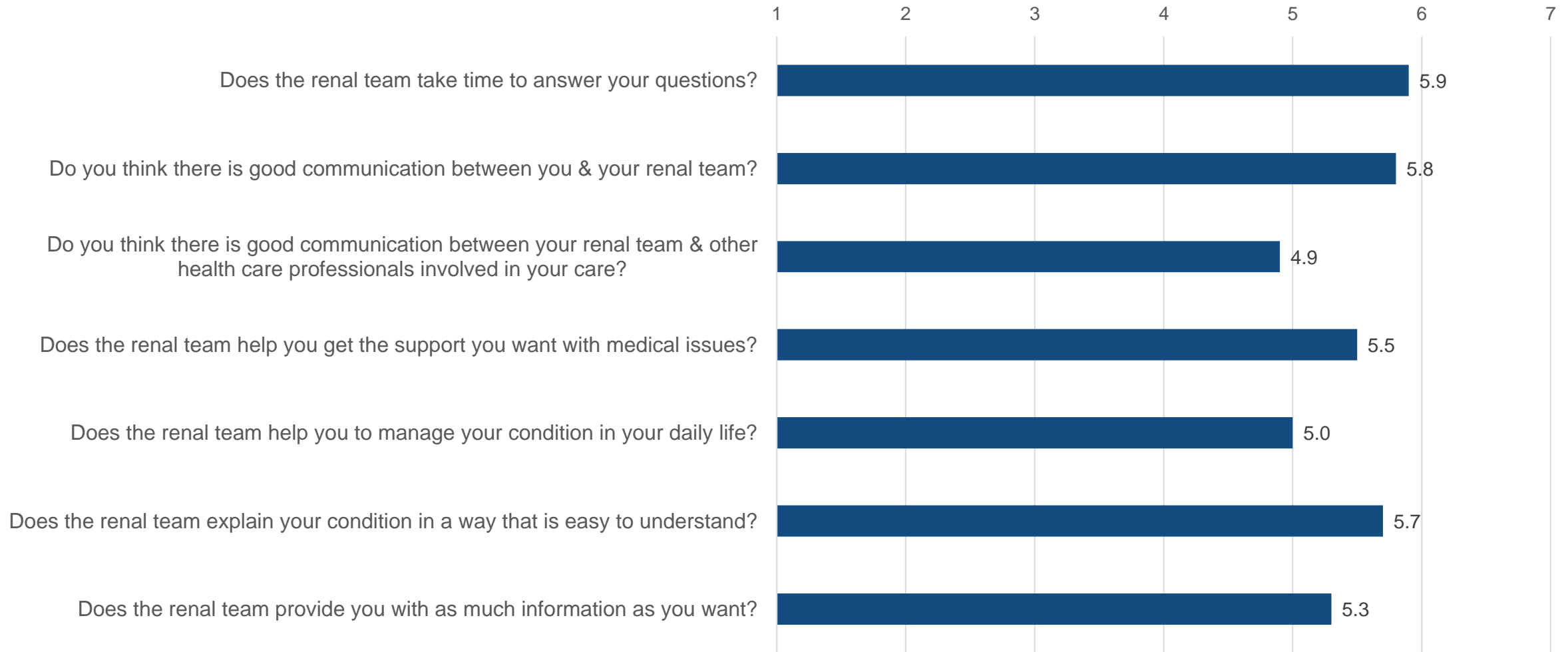


The lowest score was reported for the question inquiring about the communication of the renal team with the patients regarding their life goals once again **3.6**.

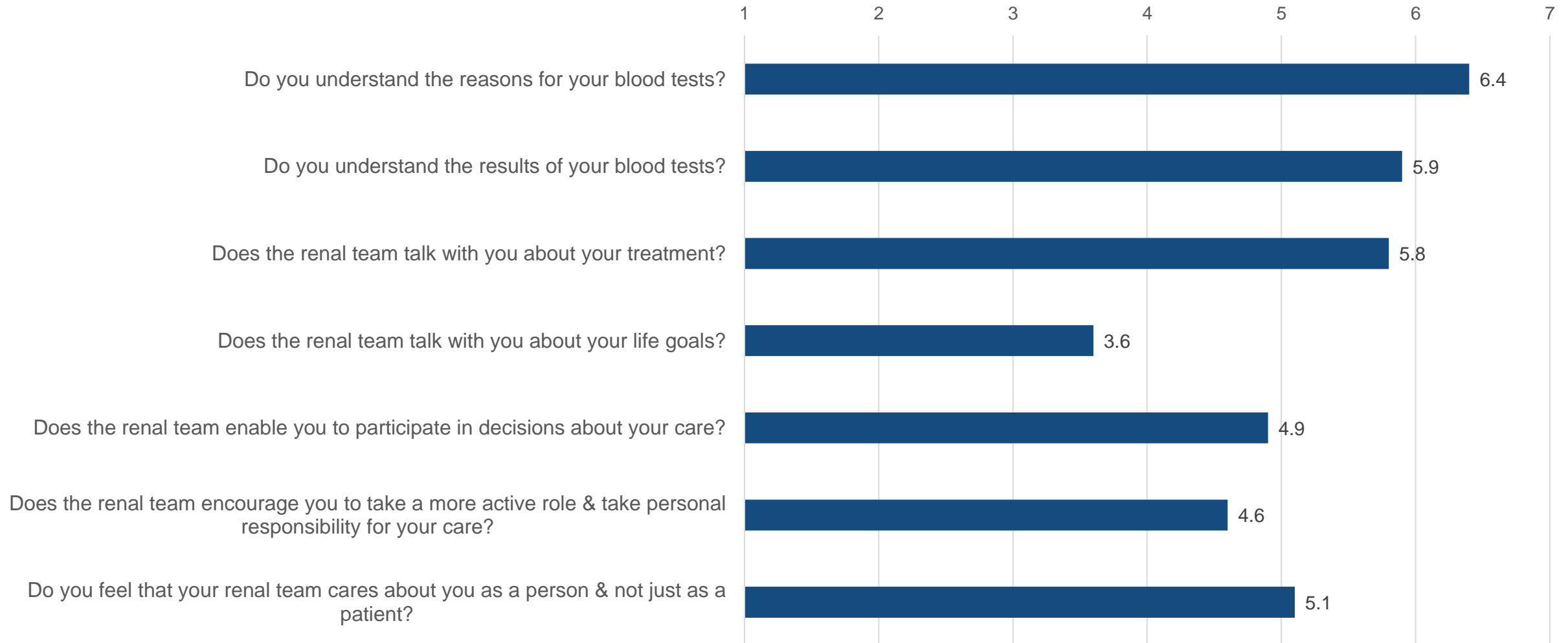


Patients also consider that the renal team could enable **4.9** and encourage **4.6** patients to take a more active role in their own care and participate in decisions.

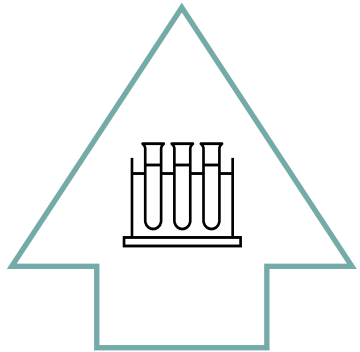
Executive summary of survey results: Germany (n=41) (1/2)



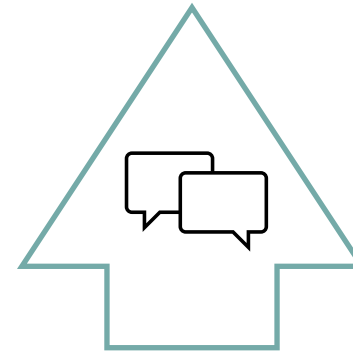
Executive summary of survey results: Germany (n=41) (2/2)



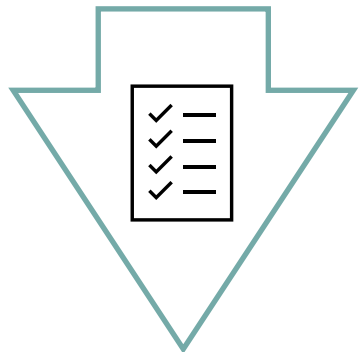
Executive summary of survey results: Spain (n=19)



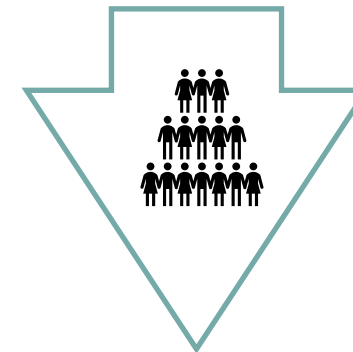
Again, the highest scores were recorded for questions regarding the understanding of the reasons for performing blood tests on patients **6.1** and of the results of these tests **5.6**



High scores for questions regarding the communication of the renal team with patients, including the time they take to answer their questions **5.8** and if there is good communication with the renal team **5.8**

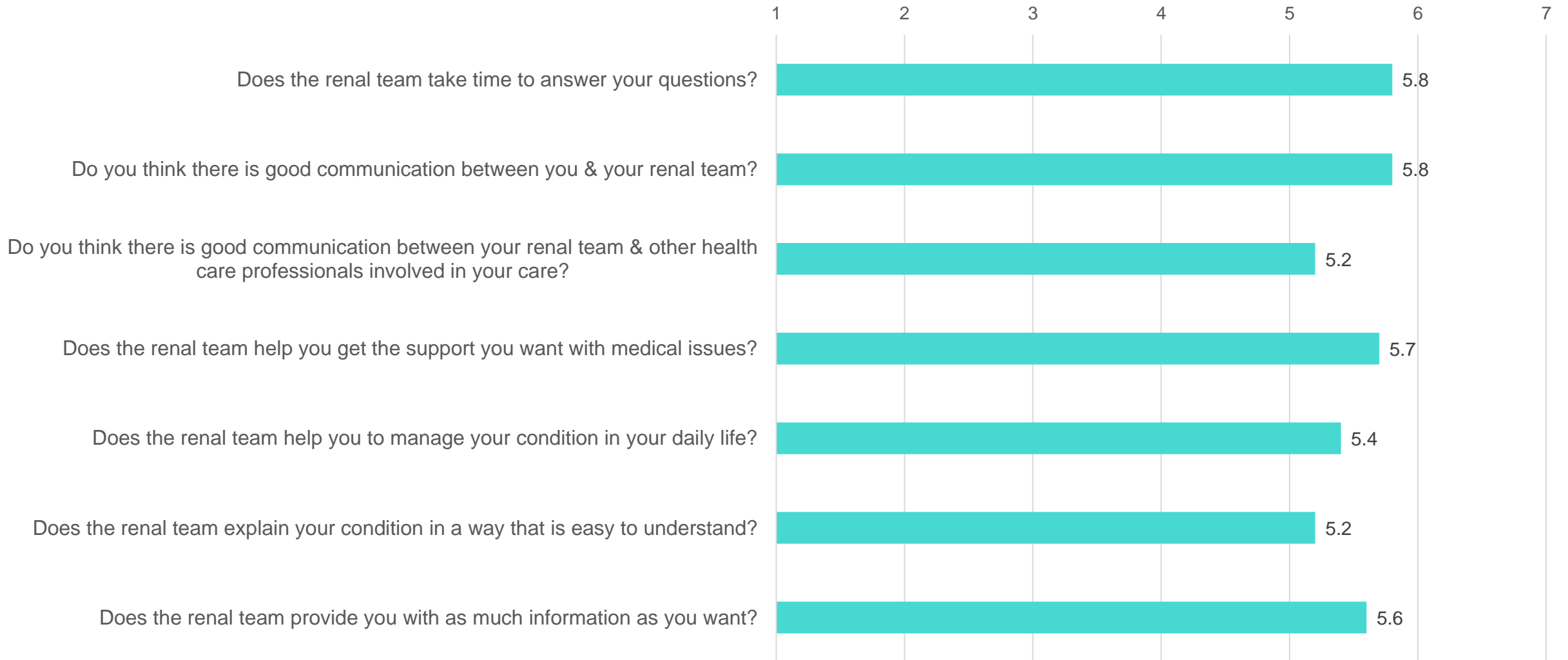


Once again, the lowest score was reported for the question inquiring about the communication of the renal team with the patients regarding their life goals **4.4**

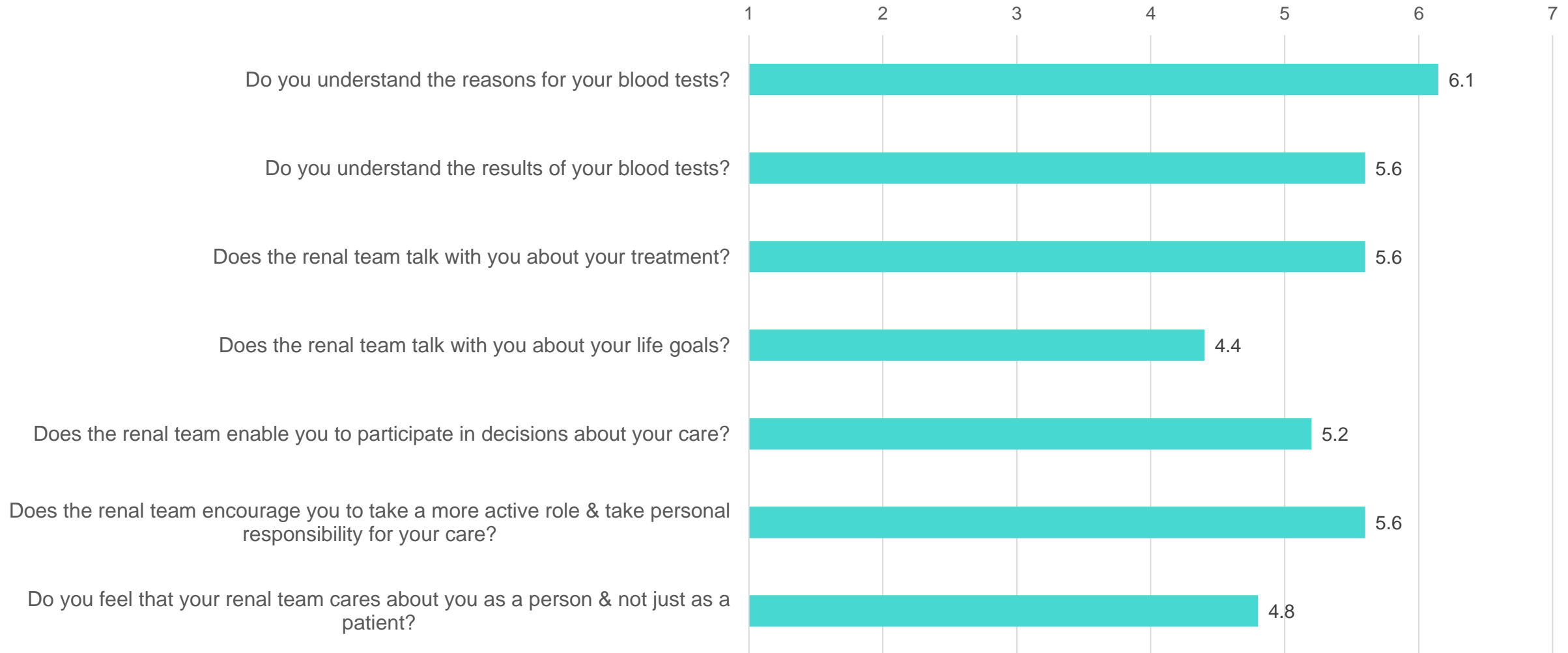


The second lowest rating was for the question exploring to what extent the renal team cares about patients as a person & not just as a patient **4.8**

Executive summary of survey results: Spain (n=19) (1/2)



Executive summary of survey results: Spain (n=19) (2/2)





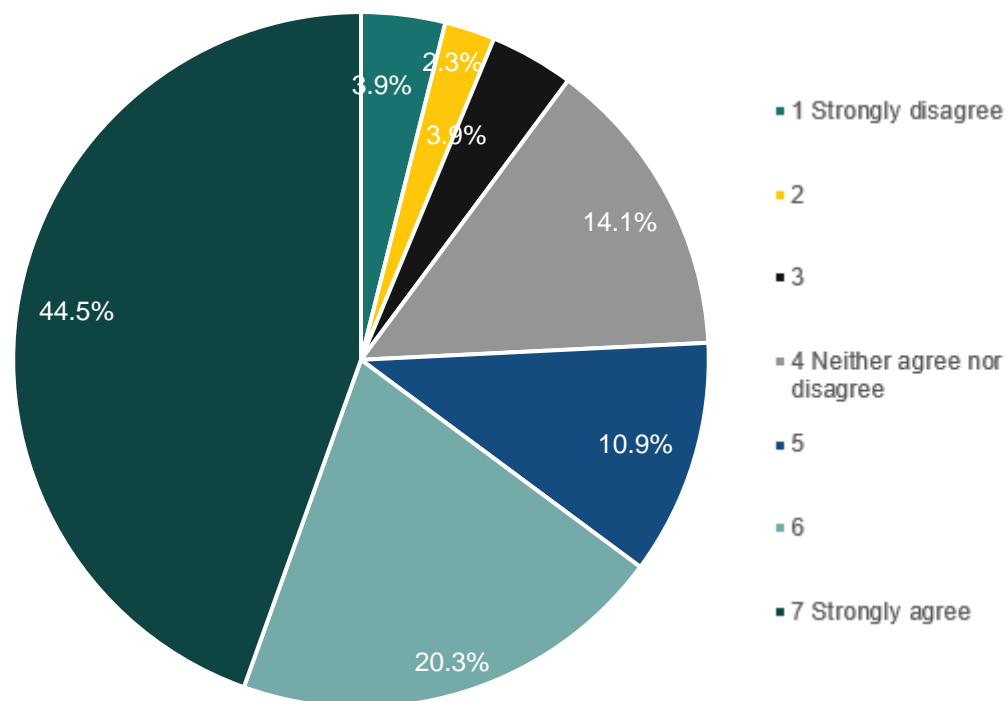
Detailed analysis of survey results



Communication

Overall, patients consider that members of the renal team take enough time to answer their questions (5.6 average score, n=128).

Percentage of participants selecting each answer option for this question



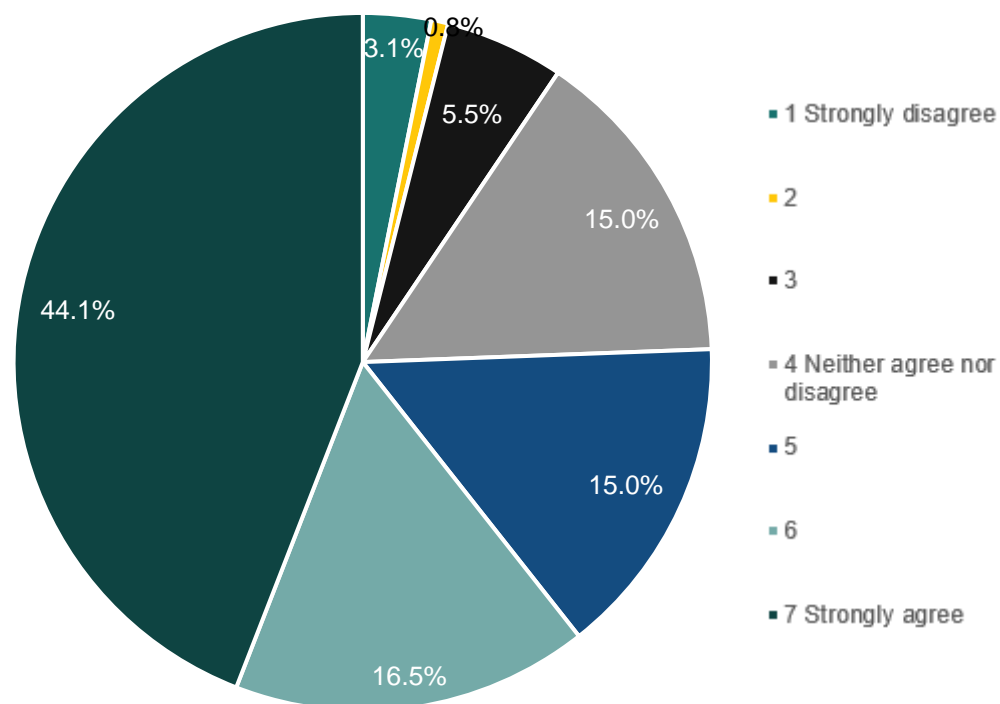
- Only 13 participants answered 1-3 to this question, while 97 respondents answered 5-7
- Answers were very similar for different countries, especially the countries with higher participation numbers; UK (5.5), Germany (5.9) and Spain (5.8).
- Answers were also similar for patients on dialysis (5.6) when compared to patients without dialysis (5.7).

It is very important that patients can get their doubts resolved, as this will help to calm them down in difficult situations and will improve their trust in the management process and in HCPs.

Communication

Patients also consider that this communication between patients and their renal team is good
(5.6 average score, n=127)

Percentage of participants selecting each answer option for this question



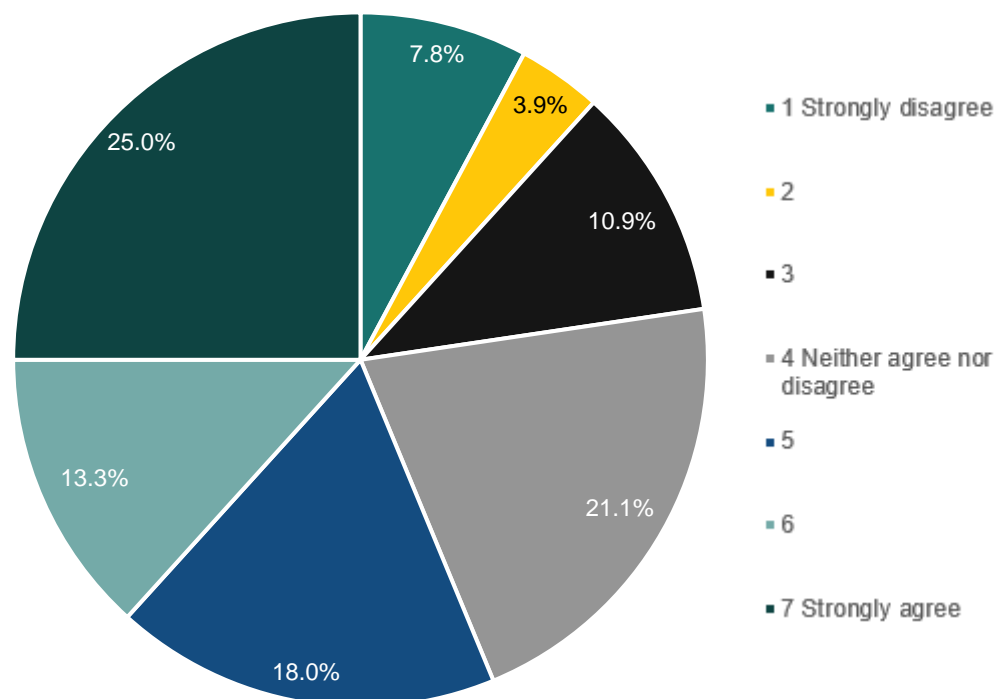
- Only 12 participants answered 1-3 to this question, while 96 respondents answered 5-7.
- Again, answers were very similar for different countries, especially the countries with higher participation numbers, although slightly higher for Germany (5.8) and Spain (5.8) than for the UK (5.6).
- The mean rating was slightly lower for patients on dialysis (5.5) when compared to patients without dialysis (5.9).

It is key that patients can easily contact and communicate with HCPs and that time is taken for this communication to be as good as possible.

Communication

Respondents consider that communication between the renal team treating them, and other healthcare professionals involved in their care could be improved, with an average score of **4.8** overall (n=128)

Percentage of participants selecting each answer option for this question



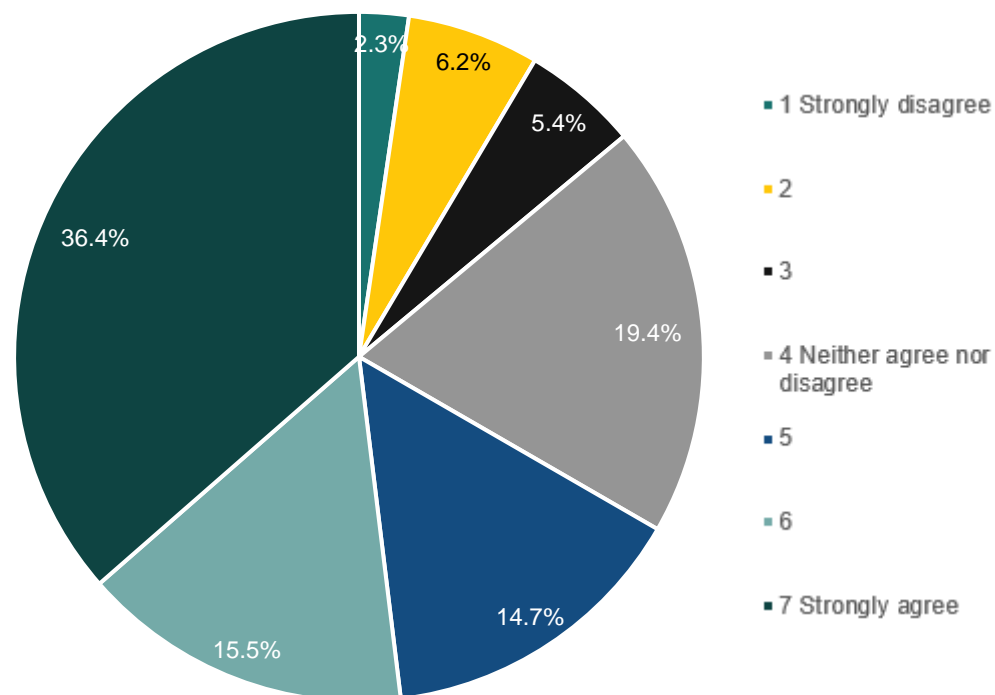
- 29 participants answered 1-3 to this question, while 72 respondents answered 5-7.
- The mean score for this question was especially low for respondents from the UK (**4.5**), which shows this could be an area of improvement in the treatment of patients with aCKD in this country.
- Mean scores were similar in Spain (**5.2**) and in Germany (**4.9**).
- The mean rating was the same for patients on dialysis and patients without dialysis (**4.8**).

This is a good opportunity to improve communication between teams in hospitals to improve patients' care.

Communication

Despite a slightly lower rating than for other questions, most participants consider that the renal team looking after them provides them with as much information as they want (average score of **5.3**, n= 129)

Percentage of participants selecting each answer option for this question



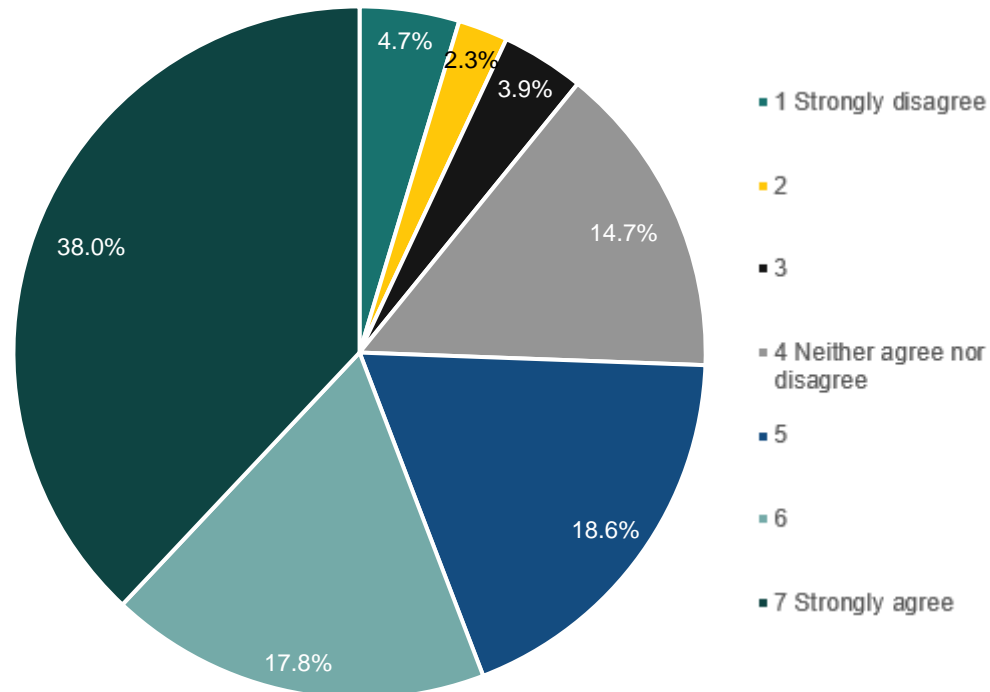
- Only 18 participants answered 1-3 to this question, while 86 respondents answered 5-7.
- The mean score for this question was very similar for all countries, with a slightly higher rating in Spain (**5.6**) than in Germany (**5.3**) and the UK (**5.3**).
- The mean rating was lower for patients on dialysis (**5.1**) than for patients not receiving dialysis (**5.5**).

Different patients will want to receive different amount and detail of information regarding their condition and treatment. It is important to understand this as soon as possible to tailor communications for each individual patient.

Support with medical condition

Most participants feel like the renal team helps them get the support they want with medical issues associated with their disease, with an average score of **5.5** (n=129).

Percentage of participants selecting each answer option for this question



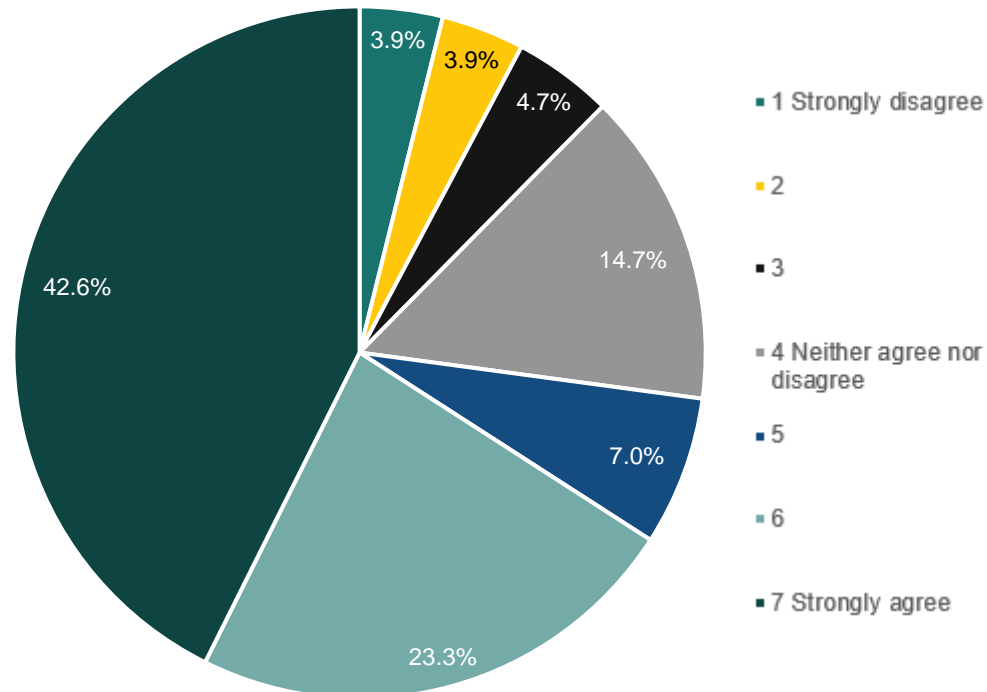
- Only 14 participants answered 1-3 to this question, while 96 respondents answered 5-7.
- Once again, answers were very similar for different countries, especially the countries with higher participation numbers; UK (**5.4**), Germany (**5.5**) and Spain (**5.7**).
- Answers were also similar for patients on dialysis (**5.5**) when compared to patients without dialysis (**5.4**).

As medical experts, it is important that patients can trust HCPs to support them and take correct decisions regarding their condition.

Support with medical condition

Participants feel that, when the renal team is communicating to them regarding their condition, things are explained in a way that is easy to understand (5.6 average score, n=129)

Percentage of participants selecting each answer option for this question



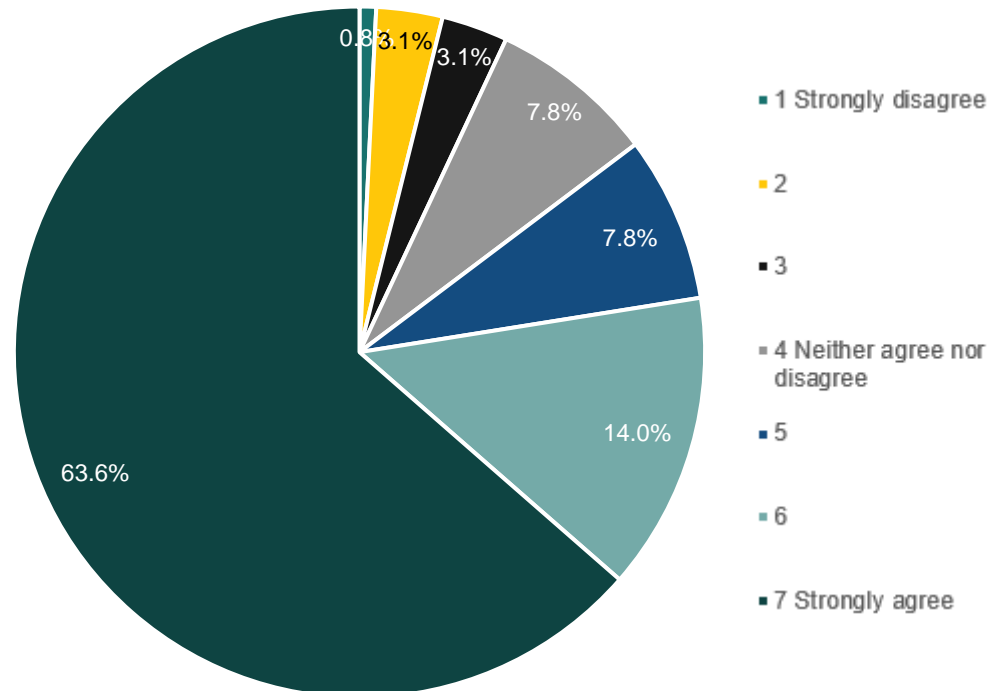
- Only 16 participants answered 1-3 to this question, while 94 respondents answered 5-7.
- Once again, answers were very similar for different countries, although with a slightly lower rating for Spain (5.2) than for the UK (5.6) and Germany (5.7).
- Answers were also similar for patients on dialysis (5.5) when compared to patients without dialysis (5.6).

This is key (especially in the earlier stages of the disease when patients have just been diagnosed) as patients will not be experts in the field and will need things explained in simple terms so that they can understand their own disease.

Blood tests

Participants understand well the reasons behind blood tests performed during the management of aCKD
(6.1 average score, n=129)

Percentage of participants selecting each answer option for this question



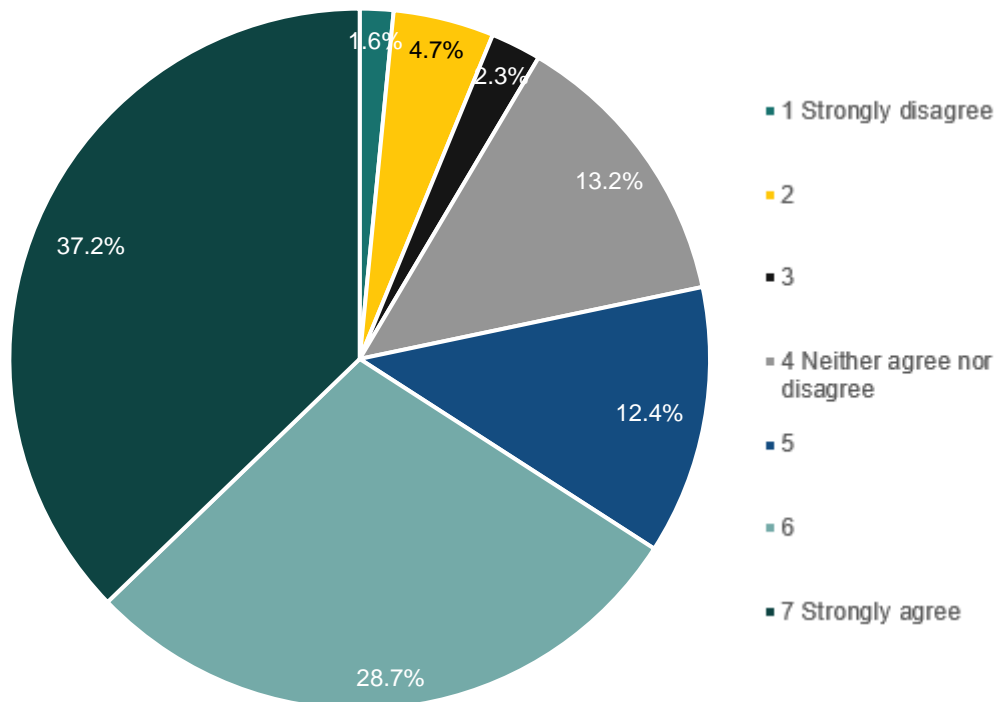
- Only 9 participants answered 1-3 to this question, with most (110) respondents answered 5-7 and almost two thirds answering 7.
- Ratings of this question were slightly higher in Germany (6.4) than in the UK (6.1) and in Spain (6.1).
- Answers were very similar for patients on dialysis (6.1) when compared to patients without dialysis (6.2).

It is important that patients understand why blood tests are needed to encourage them and reduce the reluctance to take them, especially for patients with needle phobia.

Blood tests

Participants also believe that they understand well the results of their blood tests, with an average score of **5.7** (n=129)

Percentage of participants selecting each answer option for this question



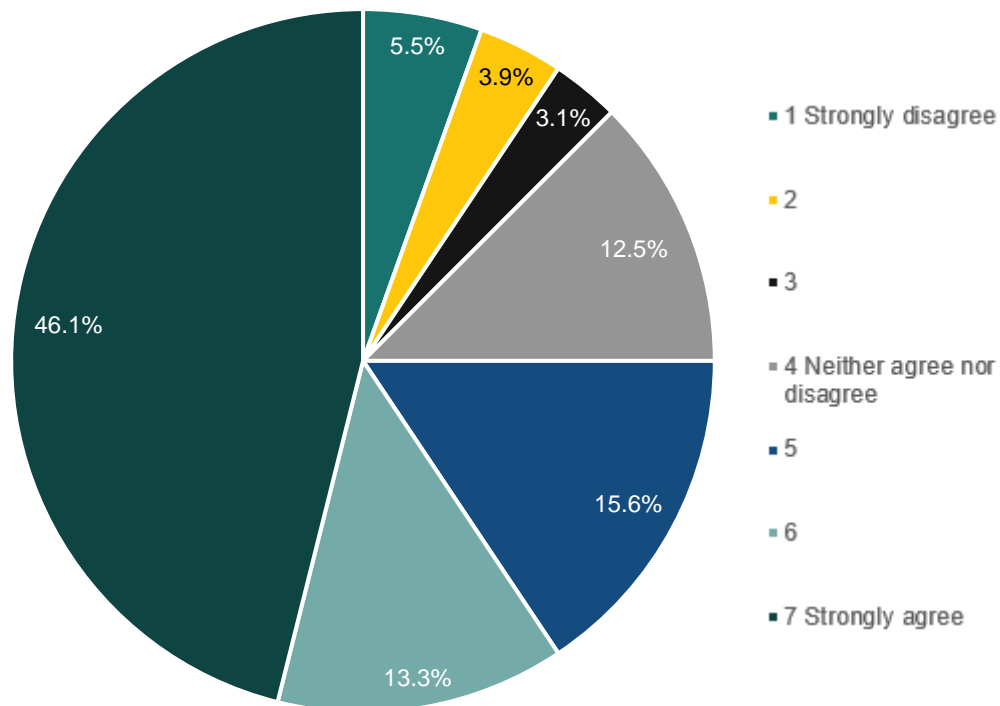
- Only 11 participants answered 1-3 to this question, compared to 101 respondents answering 5-7.
- Ratings of this question were especially high in Germany (**5.9**) and were very similar in the UK (**5.5**) and in Spain (**5.6**).
- Answers were very similar for patients on dialysis (**5.6**) when compared to patients without dialysis (**5.7**).

Once again, it is important that medical terms are explained in a simple and clear way to make patients feel involved in the management of their disease and encourage them through the process.

Involvement in treatment

Respondents expressed that the renal healthcare team talks to patients about their treatment as well as their disease (5.5 average score, n=128)

Percentage of participants selecting each answer option for this question



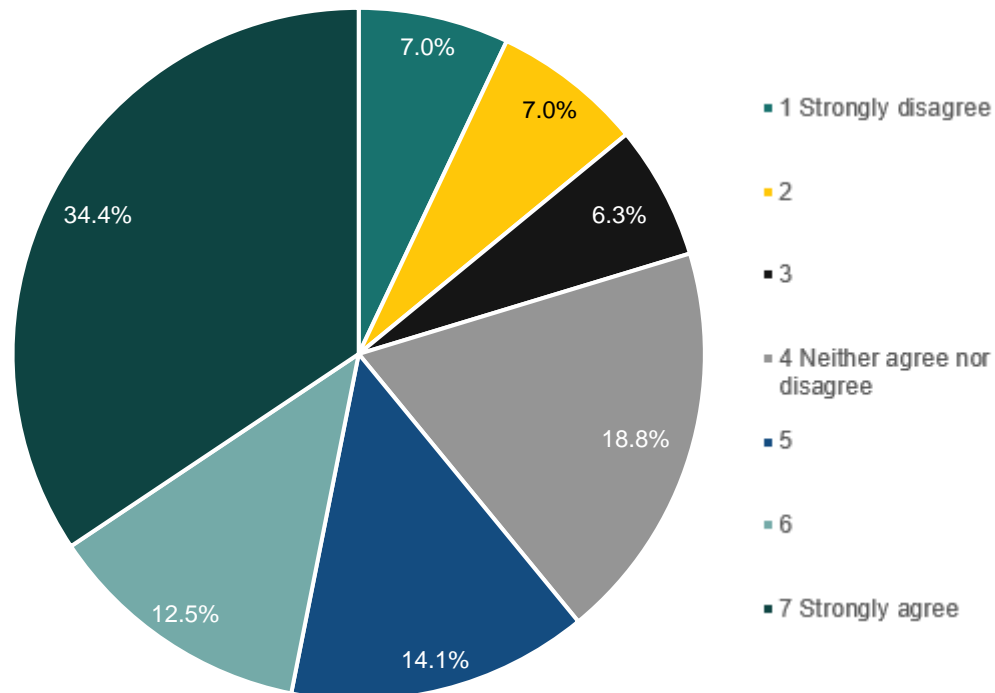
- 16 participants answered 1-3 to this question, compared to 96 respondents answering 5-7. Almost half of respondents (n=59) answered 7.
- Responses to this question were slightly higher for German (5.8) and Spanish (5.6) patients, than for patients from the UK (5.3).
- Answers were very similar for patients on dialysis (5.5) when compared to patients without dialysis (5.6).

Explaining the therapy before and during treatment (including benefits, expected side effects...) will help manage expectations and increment patients' trust in the process.

Involvement in treatment

Respondents expressed that the renal team enables them to participate in decisions about their care fairly often (although this could be improved), with them giving an average rating of **5** (n=128)

Percentage of participants selecting each answer option for this question



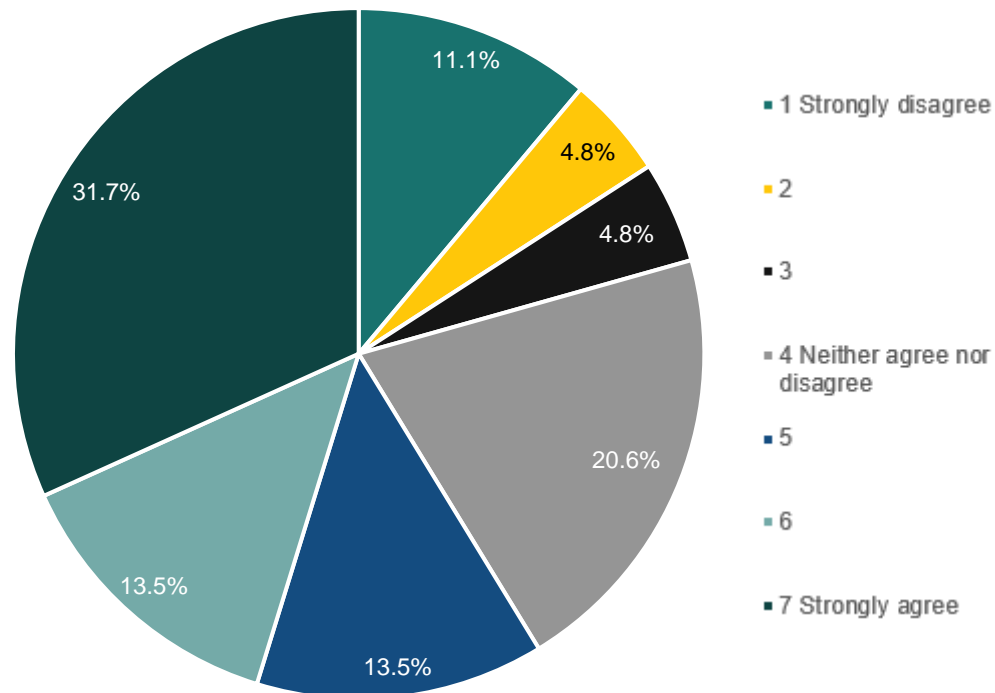
- 26 participants answered 1-3 to this question, and 78 respondents answering 5-7. Only one third of respondents (n=44) answered 7.
- Responses to this question very similar for respondents from Germany (**4.9**), UK (**5.2**) and Spain (**5.2**).
- Ratings were especially low for patients on dialysis (**4.8**) when compared to patients without dialysis (**5.3**).

Involving patients in the decision-making process will make them feel more involved and can help to identify a more appropriate treatment, although the scientific criteria should be prioritised over personal preference.

Involvement in treatment

The renal team somehow encourages patients to take a more active role and take personal responsibility for their own care (4.9 average score, n=128)

Percentage of participants selecting each answer option for this question



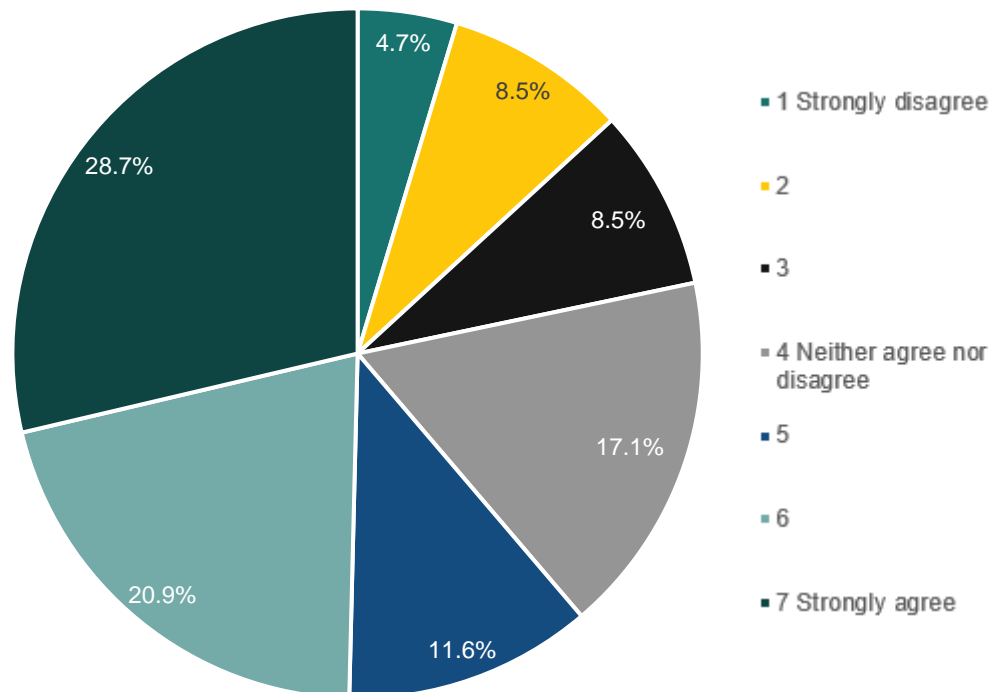
- 26 participants answered 1-3 to this question, and 74 respondents answering 5-7.
- Patients in Spain feel like they are more encouraged to take action for their own care (5.6).
- Responses to this very similar for respondents from Germany (4.6) and UK (4.9).
- Ratings were especially low for patients on dialysis (4.5) when compared to patients without dialysis (5.4).

HCPs could encourage patients to take a more active role in their own disease management, as they can provide valuable insight into their condition and help to choose the appropriate treatment.

QoL and personal treatment

Respondents feel like the renal team does help them to manage their condition in their daily life (outside of the hospital setting), although this aspect could still be improved (5 average rating, n=129)

Percentage of participants selecting each answer option for this question



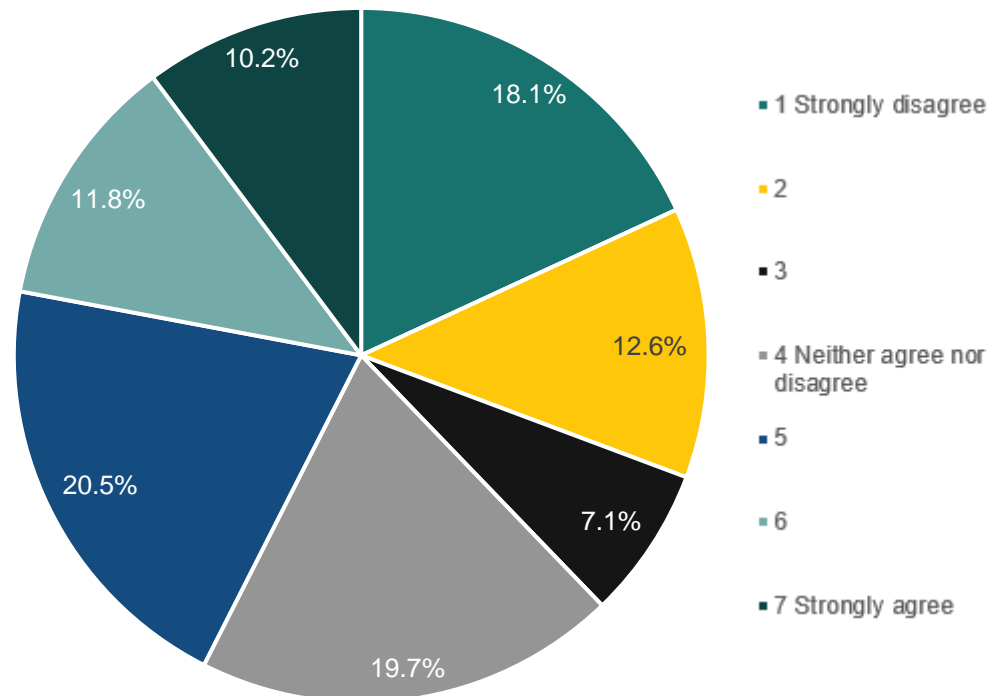
- 28 participants answered 1-3 to this question, and 79 respondents answering 5-7.
- Patients in Spain feel like HCPs help them to manage their condition in their daily life more (5.4).
- Responses to this very similar for respondents from Germany (5.0) and UK (4.9).
- Answers were similar for patients on dialysis (4.9) when compared to patients without dialysis (5.1).

It is important for patients to not only recover clinically, but also being able to continue with their normal life as much as possible maintaining a good HRQoL.

QoL and personal treatment

Respondents reported that the renal team does not talk with them about their life goals very often
(3.9 average score, n=127)

Percentage of participants selecting each answer option for this question



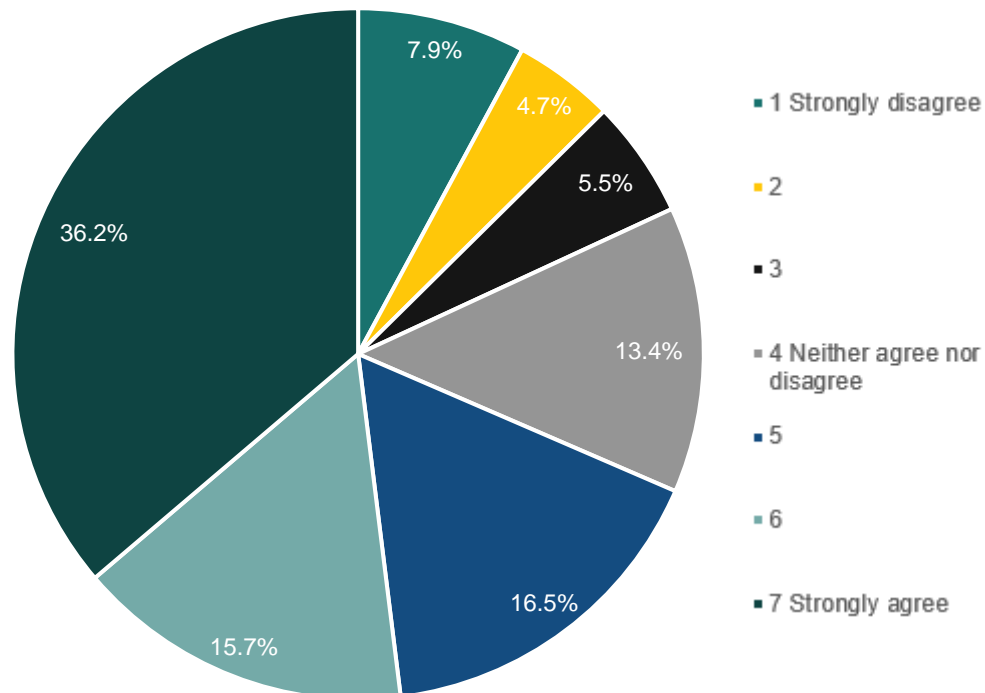
- 48 participants answered 1-3 to this question, with only 54 respondents answering 5-7.
- Patients in Spain feel like HCPs talk to patients about their life goals more (4.4) than in the other main countries of the analysis; Germany (3.6) and UK (3.7)
- Ratings were especially low for patients on dialysis (3.7) when compared to patients without dialysis (4.2).

Although not as crucial as the medical benefits of the treatment, it would be beneficial for HCPs to be informed of this, to increase patients' satisfaction with the care given and to choose treatments that would suit best each patient outside of the hospital setting too.

QoL and personal treatment

Overall, most participants believe that the renal healthcare team cares about them as a person and not just as a patient, with an average score of **5.2**

Percentage of participants selecting each answer option for this question



- 23 participants answered 1-3 to this question, and 87 respondents answered 5-7.
- Responses to this question were slightly lower for Spanish (**4.8**) patients, than for patients from the UK (**5.3**) and Germany (**5.1**).
- Answers were similar for patients on dialysis (**5.1**) when compared to patients without dialysis (**5.3**).

It is important that patients feel cared by HCPs, and a more personal interest from doctors towards patients can help them understand patients better and could improve the care provided to patients with aCKD.



Dynamo Alliance members



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Nephrologists:

Antonello PANI, University of Cagliari and Division of Nephrology and Dialysis, G. Brotzu Hospital, Cagliari, Italy

Christian ROSENBERGER, Charité University Hospital, Berlin, Germany

Christoph WANNER, University Hospital Würzburg, Würzburg, Germany

Corinne ISNARD BAGNIS, Pitié Salpêtrière Hospital, Paris, France

Hans FURULAND, Uppsala University Hospital, Uppsala, Sweden

Harald SEEGER, Universitätsspital Zürich, Zürich, Switzerland

Indrani DASGUPTA, Heartlands Hospital, Birmingham, UK

José Emilio SANCHEZ-ALVAREZ, Hospital Universitario de Cabueles, Asturias, Spain

José Maria PORTOLÉS-PEREZ, Hospital Universitario Puerta de Hierro Majadahonda, Madrid, Spain

Loreto GESUALDO, Nephrology Unit, Department of Emergency and Transplant Organs, University Aldo Moro of Bari, Bari, Italy

Matteo FLORIS, Division of Nephrology and Dialysis, G. Brotzu Hospital, Cagliari, Italy

Pablo URENA-TORRES, AURA Nord, Saint Ouen, France

Roberto MINUTOLO, Nephrology division, Department of Advanced Medical and Surgical Sciences, University of Campania Luigi Vanvitelli, Naples, Italy

Samira BELL, Ninewells Hospital, Dundee, UK

Sapna SHAH, Kings College Hospital, London, UK

Thilo KRÜGER, DaVita Geilenkirchen and Düsseldorf, Germany

Patient Advocates:

Daniel GALLEGRO-ZURRO, European Kidney Patient Federation (EKPF), Madrid, Spain

Laurie CUTHBERT, Kidney Care UK, London, UK

Policy Advocates:

Raymond C VANHOLDER, European Kidney Health Alliance (EKHA), Brussels, Belgium



Appendix: survey questions English-French-German-Italian-Spanish



Questions – English (1/2)

Description	We would like to know how you, as a patient living with CKD, feel about the care and treatment you receive for anaemia of CKD. We hope these findings will lead to quality of care and service improvements as we build a better understanding of what matters most to patients in Europe.
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Topic area	Question #	Text	Answer options
Screening questions	S1	Are you on dialysis?	Yes / No
	S2	Have you ever been diagnosed with anemia of chronic kidney disease (not enough red blood cells due to your renal disease)?	Yes / No / I don't know
	S3	In which country do you live?	United Kingdom / Spain / Germany / France / Italy / Other
Instructions		Using a scale of 1-7, where 1 signifies you strongly disagree and 7 signifies you strongly agree, please indicate how much you agree with the following statements:	
Access to renal team	Q1	Your renal team takes time to answer your questions	1 – Strongly disagree 2 3 4 – Neither agree or disagree 5 6 7 – Strongly agree
Communication	Q2	There is good communication between you and your renal team	
	Q3	There is good communication between your renal team and other healthcare professionals involved in your care	
Support	Q4	The renal team help you get the support you want with medical issues	
	Q5	The renal team help you to manage your condition in your daily life	
Patient information	Q6	The renal team explain your condition in a way that is easy to understand	
	Q7	The renal team provide you with as much information as you want	

Questions – English (2/2)

Topic area	Question #	Text	Answer options
Patient information about tests	Q8	You understand the reasons for your blood tests	1 – Strongly disagree 2 3 4 – Neither agree or disagree 5 6 7 – Strongly agree
	Q9	You understand the results of your blood tests	
Sharing decisions about your care	Q10	The renal team talk with you about your treatment	
	Q11	The renal team talk with you about your life goals	
	Q12	The renal team enable you to participate in decisions about your care	
	Q13	The renal team encourage you to take a more active role and take personal responsibility for your care	
How the renal teams treat you	Q14	You feel that your renal team cares about you as a person and not only as a patient	

Questions – French (1/2)

Description	Nous aimerions savoir ce que vous pensez, en tant que patient vivant avec une maladie rénale chronique, des soins et des traitements que vous recevez pour l'anémie due à une maladie rénale chronique. Nous espérons que ces résultats permettront d'améliorer la qualité des soins et des services et que nous comprendrons mieux ce qui compte le plus pour les patients en Europe.
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Topic area	Question #	Text	Answer options
Question de filtrage	S1	Êtes-vous en dialyse ?	Oui / Non
	S2	Avez-vous déjà été diagnostiqué avec une anémie (insuffisance de globules rouges) associée à votre maladie rénale?	Oui / Non / Je ne sais pas
	S3	Dans quel pays vivez-vous ?	France / Royaume-Uni / Espagne / Italie / Allemagne / Autres
Instructions		Sur une échelle de 1 à 7, où 1 signifie que vous n'êtes pas du tout d'accord et 7 que vous êtes tout à fait d'accord, veuillez indiquer dans quelle mesure vous êtes d'accord avec les affirmations suivantes:	
Accès à l'équipe rénale	Q1	Votre équipe de néphrologie prend le temps de répondre à vos questions.	1 – Pas du tout d'accord 2 3 4 – Ni d'accord ni en désaccord 5 6 7 – Tout à fait d'accord
Communication	Q2	Il y a une bonne communication entre vous et votre équipe de néphrologie.	
	Q3	Il existe une bonne communication entre votre équipe de néphrologie et les autres professionnels de santé impliqués dans vos soins.	
Soutien	Q4	L'équipe de néphrologie vous aide à obtenir le soutien que vous souhaitez pour vos problèmes médicaux.	
	Q5	L'équipe de néphrologie vous aide à gérer votre maladie dans votre vie quotidienne.	
Information des patients	Q6	L'équipe de néphrologie explique votre état de santé d'une manière facile] à comprendre.	
	Q7	L'équipe de néphrologie vous fournit autant d'informations que vous le souhaitez.	

Questions – French (2/2)

Topic area	Question #	Text	Answer options
Information du patient sur les tests	Q8	Vous comprenez les raisons de vos analyses de sang.	1 – Pas du tout d'accord 2 3 4 – Ni d'accord ni en désaccord 5 6 7 – Tout à fait d'accord
	Q9	Vous comprenez les résultats de vos analyses de sang.	
Partage des décisions concernant vos soins	Q10	L'équipe de néphrologie discute avec vous de votre traitement.	
	Q11	L'équipe de néphrologie discute avec vous de vos objectifs de vie.	
	Q12	L'équipe de néphrologie vous permet de participer aux décisions concernant vos soins.	
	Q13	L'équipe de néphrologie vous encourage à jouer un rôle plus actif et à assumer la responsabilité de vos soins.	
Comment l'équipe rénale vous traite-t-elle?	Q14	Vous sentez que votre équipe de néphrologie se soucie de vous en tant que personne et pas seulement en tant que patient.	

Questions – German (1/2)

Wir würden gerne wissen, wie Sie als Patient mit einer chronischen Nierenerkrankung über die Betreuung und Behandlung Ihrer Anämie bei chronischer Nierenerkrankung denken. Wir hoffen, dass diese Ergebnisse zu einer Verbesserung der Qualität der Versorgung und der Dienstleistungen führen werden, da wir besser verstehen werden, was für die Patienten in Europa am wichtigsten ist.

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Topic area	Question #	Text	Answer options
Frage zum Screening	S1	Sind Sie dialysepflichtig?	Ja / Nein
	S2	Wurde bei Ihnen bereits eine durch chronisches Nierenversagen ausgelöste Anämie (eine Blutarmut) diagnostiziert?	Ja / Nein / Ich weiß es nicht
	S3	In welchem Land leben Sie?	Deutschland / Vereinigtes Königreich / Spanien / Italien / Frankreich / Andere
Anweisungen		Bitte geben Sie auf einer Skala von 1 bis 7 an, wie sehr Sie den folgenden Aussagen zustimmen, wobei 1 bedeutet, dass Sie überhaupt nicht zustimmen, und 7, dass Sie voll und ganz zustimmen:	
Zugang zum nephrologischen Team	Q1	Ihr nephrologisches Team (Nierenärzte und/oder Schwestern) nimmt sich Zeit, um Ihre Fragen zu beantworten	1 – Stimmt überhaupt nicht zu 2 3 4 – Weder zustimmen noch nicht zustimmen 5 6 7 – Eindeutig zustimmen
Kommunikation	Q2	Es gibt eine gute Kommunikation zwischen Ihnen und Ihrem nephrologischen Team	
	Q3	Es besteht eine gute Kommunikation zwischen Ihrem nephrologischen Team und anderen an Ihrer Behandlung beteiligten medizinischen Fachkräften	
Unterstützung	Q4	Das nephrologische Team hilft Ihnen, die gewünschte Unterstützung in medizinischen Fragen zu erhalten	
	Q5	Das nephrologische Team hilft Ihnen dabei, Ihre Krankheit im Alltag zu bewältigen	
Informationen für Patienten	Q6	Das nephrologische Team erklärt Ihnen Ihren Zustand auf leicht verständliche Weise	
	Q7	Das nephrologische Team versorgt Sie mit so vielen Informationen, wie Sie möchten	

Questions – German (2/2)

Topic area	Question #	Text	Answer options
Patienteninformationen über Tests	Q8	Sie verstehen die Gründe für Ihre Blutuntersuchungen	1 – Stimmt überhaupt nicht zu 2 3 4 – Weder zustimmen noch nicht zustimmen 5 6 7 – Eindeutig zustimmen
	Q9	Sie verstehen die Ergebnisse Ihrer Bluttests	
Gemeinsame Entscheidungen über Ihre Versorgung	Q10	Das nephrologische Team spricht mit Ihnen über Ihre Behandlung	
	Q11	Das nephrologische Team spricht mit Ihnen über Ihre Lebensziele	
	Q12	Das nephrologische Team ermöglicht es Ihnen, an Entscheidungen über Ihre Versorgung mitzuwirken	
	Q13	Das nephrologische Team ermutigt Sie, eine aktivere Rolle zu übernehmen und selbst Verantwortung für Ihre Pflege zu übernehmen	
Wie Sie das nephrologische Team behandelt	Q14	Sie haben das Gefühl, dass Ihr nephrologisches Team sich um Sie als Person und nicht nur als Patient kümmert	

Questions – Italian (1/2)

Description		Vorremmo sapere cosa ne pensa lei, in quanto paziente affetto da malattia renale cronica, dell'assistenza e del trattamento che riceve per l'anemia da malattia renale cronica. Ci auguriamo che questi risultati portino a un miglioramento della qualità delle cure e dei servizi, grazie ad una migliore comprensione di ciò che conta di più per i pazienti in Europa.	
Topic area	Question #	Text	Answer options
Domanda di screening	S1	Al momento lei è sottoposta a trattamento dialitico?	Sì / No
	S2	Le è mai stata diagnosticata un'anemia (riduzione dei globuli rossi) dovuta alla malattia renale cronica?	Sì / No / Non lo so
	S3	In quale paese vive?	Italia / Regno Unito / Spagna / Germania / Francia / Altro
Istruzioni		Utilizzando una scala da 1 a 7, dove 1 significa che siete fortemente in disaccordo e 7 significa che siete fortemente d'accordo, vi preghiamo di indicare quanto siete d'accordo con le seguenti affermazioni:	
Accesso al team renale	Q1	I componenti del team renale (medici e infermieri) trovano il tempo per rispondere alle vostre domande	1 – Fortemente in disaccordo 2 3 4 – Non sono né d'accordo né in disaccordo 5 6 7 – Fortemente d'accordo
Comunicazione	Q2	La comunicazione tra voi e il vostro e i componenti del team renale è buona	
	Q3	La comunicazione tra i componenti del team renale e gli altri operatori sanitari coinvolti nella cura del paziente è buona	
Supporto	Q4	I componenti del team renale vi aiutano a ottenere il supporto che desiderate per le questioni mediche.	
	Q5	I componenti del team renale la aiutano nella gestione della vostra condizione nella vita quotidiana	
Informazioni per i pazienti	Q6	I componenti del team renale le spiegano le sue condizioni cliniche in maniera comprensibile	
	Q7	I componenti del team renale le forniscono tutte le informazioni che desidera	

Questions – Italian (2/2)

Topic area	Question #	Text	Answer options
Informazioni al paziente sui test	Q8	Comprende le motivazioni per la quale vengono richiesti le analisi del sangue	1 – Fortemente in disaccordo 2 3 4 – Non sono né d'accordo né in disaccordo 5 6 7 – Fortemente d'accordo
	Q9	Comprende i risultati relativi alle analisi del sangue	
Condivisione delle decisioni sulle cure	Q10	I componenti del team renale parlano con lei del vostro trattamento	
	Q11	I componenti del team renale parlano con lei dei suoi obiettivi di vita	
	Q12	I componenti del team renale le consentono di partecipare alle decisioni relative alla sua assistenza	
	Q13	I componenti del team renale la incoraggiano ad assumere un ruolo più attivo e ad assumere la responsabilità personale della sua cura.	
Come vi trattano i team renali	Q14	Ha la sensazione che i componenti del suo team renale si preoccupino di lei come persona e non solo come paziente.	

Questions – Spanish (1/2)

Description	Nos gustaría saber qué opina usted, como paciente que padece enfermedad renal crónica, sobre la atención y el tratamiento que recibe para la anemia asociada a la enfermedad renal crónica. Esperamos que estos resultados permitan mejorar la calidad de la asistencia y de los servicios a medida que comprendemos mejor qué es lo que más importa a los pacientes en Europa.
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Topic area	Question #	Text	Answer options
Pregunta de selección	S1	¿Está usted en diálisis?	Sí / No
	S2	¿Le han diagnosticado anemia asociada a ERC (insuficiencia de glóbulos rojos asociada a enfermedad renal crónica)?	Sí / No / No se
	S3	¿En qué país vive?	España / Reino Unido / Italia / Alemania / Francia / Otros
Instrucciones		Utilizando una escala del 1 al 7, donde 1 significa que está totalmente en desacuerdo y 7 que está totalmente de acuerdo, indique en qué medida está de acuerdo con las siguientes afirmaciones:	
Acceso al equipo de Nefrología	Q1	Su equipo de nefrología dedica tiempo a responder a sus preguntas	1 – Totalmente en desacuerdo 2 3 4 – Ni de acuerdo ni en desacuerdo 5 6 7 – Totalmente de acuerdo
Comunicación	Q2	Existe una buena comunicación entre usted y su equipo de nefrología	
	Q3	Existe una buena comunicación entre el equipo de nefrología y los demás profesionales sanitarios implicados en su tratamiento.	
Apoyo	Q4	El equipo de nefrología le ayuda a obtener el apoyo que desea en cuestiones médicas	
	Q5	El equipo de nefrología le ayuda a gestionar su enfermedad en su vida diaria	
Información al paciente	Q6	El equipo de nefrología le explica su enfermedad de forma fácil de entender.	
	Q7	El equipo de nefrología le facilita toda la información que desea	

Questions – Spanish (2/2)

Topic area	Question #	Text	Answer options
Información al paciente sobre las pruebas	Q8	Entiende usted las razones por las que se realizan sus análisis de sangre	1 – Totalmente en desacuerdo 2 3 4 – Ni de acuerdo ni en desacuerdo 5 6 7 – Totalmente de acuerdo
	Q9	Entiende usted los resultados de sus análisis de sangre	
Compartir las decisiones sobre sus cuidados	Q10	El equipo de nefrología habla con usted sobre su tratamiento	
	Q11	El equipo de nefrología habla con usted sobre tus objetivos de vida	
	Q12	El equipo de nefrología le permite participar en las decisiones sobre sus cuidados	
	Q13	El equipo de nefrología le anima a asumir un papel más activo y a responsabilizarse personalmente de sus cuidados.	
Cómo le tratan los equipo de nefrología	Q14	Siente que su equipo de nefrología se preocupa por usted como persona y no sólo como paciente.	



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