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astellas

BEYOND CKD

Unveiling the hidden truth of anaemia

CONTENTS

GLOSSARY

Throughout this report there may be a number of terms such as abbreviations or acronyms that may be unfamiliar. They are explained and listed below for your reference.

ANAEMIA
Medical condition where the percentage of red blood cells circulating in the blood is reduced

CKD
Chronic kidney disease: a common condition characterised by a gradual loss of kidney function over time

Hb
Haemoglobin

PAG
Patient Advocacy Group

CV
Cardiovascular

FOREWORD

"Chronic kidney disease (CKD) is a growing global health concern,[1] yet anaemia of CKD has received limited focused research to date, resulting in little innovation in this area.

Nephrologists tend to consider anaemia as a part of CKD; a part that is easily treated for the majority of patients. However, patients often view their anaemia as a separate disease, and as the findings from this survey attest, the condition is causing them more concern than nephrologists may be aware of.

The research outlined in this report reveals insights from both patients and nephrologists about their experiences of managing anaemia of CKD and the challenges they face. Research of this nature is integral to help us better understand the reality of the condition and help inform future patient care.

With more than half of the patients surveyed (57%) reporting that their life was dominated by their disease, it is clear that gaps in the management of anaemia of CKD remain. The findings also indicate nephrologists are aware of high rates of undiagnosed anaemia among their CKD patients. This could be partly explained by late referrals which is something that requires further investigation. Furthermore, there is an opportunity to better educate patients about their condition and its complications at the time of their CKD diagnosis, giving them the tools to prompt discussions around anaemia to ensure earlier diagnosis.

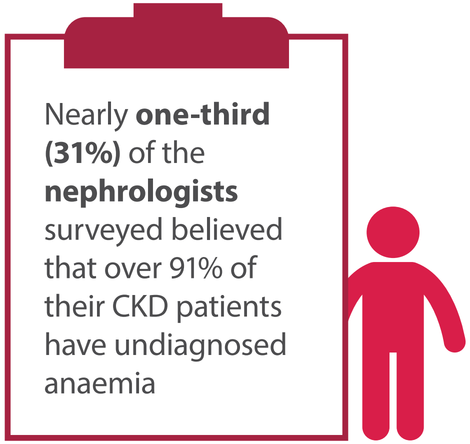
These are important learnings not just for nephrologists but for the wider community of healthcare professionals and patient organisations. By applying these insights to the daily practice and management of anaemia of CKD, and improving dialogue between patients and their physicians, there is the potential to drive real change in terms of patient outcomes and quality of life."

Professor José Portolés Pérez
Nephrologist
Puerta de Hierro de Majadahonda University Hospital, Spain

This foreword includes opinions and perspectives of Professor José Portolés Pérez.

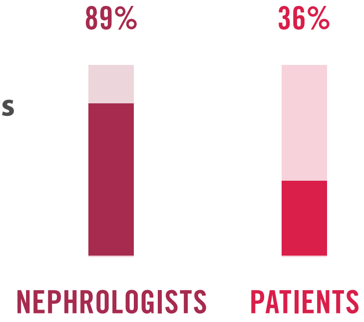
KEY FINDINGS FROM THE SURVEY

UNDIAGNOSED ANAEMIA OF CKD



Nearly **one-third (31%)** of the **nephrologists** surveyed believed that over 91% of their CKD patients have undiagnosed anaemia

89% of nephrologists vs 36% of patients surveyed were aware that untreated anaemia can lead to long-term health implications



GETTING A DIAGNOSIS OF ANAEMIA OF CKD

48%	**of patients** surveyed reported feeling the diagnosis process was frustrating
28%	**of nephrologists** surveyed recognised the logistical impact the diagnosis process had for patients
69%	**of nephrologists** stated that they immediately started treatment for their patients following a diagnosis
89%	**of nephrologists** reported providing information around treatment options to their patients
45%	**of patients** reported that their nephrologist provided them with information about treatment options

THE BURDEN OF LIVING WITH ANAEMIA OF CKD

57%

of patients surveyed said their life was dominated by their disease

On average, **patients reported missing more than 8 days of work** per month due to their symptoms

66%

of patients had a caregiver to help with day-to-day tasks

MANAGEMENT OF ANAEMIA OF CKD

The patients surveyed appeared to be much more concerned about their anaemia than the nephrologists surveyed **(62% of patients vs 45% of nephrologists)**

The nephrologists surveyed estimated that almost a third **(32%) of their patients had Hb levels outside target range** (10–12 g/dL)

Only **9%** of nephrologists surveyed thought that their **patients always followed the medication schedule provided** to them

HOPE FOR THE FUTURE MANAGEMENT OF ANAEMIA OF CKD

TOP THREE HOPES IDENTIFIED BY THE PATIENTS SURVEYED:

Better **treatment options (27%)**

Better understanding of the **impact of anaemia (25%)**

Earlier diagnosis of CKD **(23%)**

TOP THREE HOPES IDENTIFIED BY THE NEPHROLOGISTS SURVEYED:

Earlier diagnosis of CKD **(57%)**

Better **treatment options (49%)**

Quicker **referral time (29%)**

WHAT DO THESE FINDINGS MEAN FOR THE FUTURE OF ANAEMIA OF CKD?

NEPHROLOGISTS:

> “It is never wrong to highlight where there is an unmet need for patients. These findings are important for identifying where there are gaps in management of care from a patient’s perspective.”
>
> - Jonathan Barratt, Nephrologist, UK

KEY INSIGHTS FROM NEPHROLOGISTS ON THE EXPERT PANEL:

- The findings are clear—nephrologists are underestimating how much anaemia of CKD is affecting patients and their families. We need to acknowledge this and take it into consideration when re-designing our services
- We need to increase awareness of anaemia of CKD and the importance of early diagnosis and treatment. This opportunity is not specific to nephrologists; it is an important learning for the wider community of healthcare professionals, so that patients with low haemoglobin levels are referred to nephrologists as early as possible
- We are not providing patients with enough information about anaemia and it is clear this is something that patients desire
- We need to address the communication skills of nephrologists when discussing concerns with patients
- We need to continue to work extremely closely with patient organisations and our professional organisations to encourage patient engagement in conversations around CKD and anaemia

PROFESSOR JOSÉ PORTOLÉS PÉREZ
Nephrologist, Spain

PROFESSOR JONATHAN BARRATT
Nephrologist, UK

WHAT DO THESE FINDINGS MEAN FOR THE FUTURE OF ANAEMIA OF CKD?

PATIENT ADVOCACY GROUPS (PAGS):

> "The impact anaemia of CKD has on quality of life highlighted by these results is huge and is crucial to understanding the social environment of patients and their families."
>
> - Daniel Gallego
>   PAG Representative, Spain

KEY INSIGHTS FROM THE PAG REPRESENTATIVE ON THE EXPERT PANEL:

- Ensure patients are referred and diagnosed quickly
- Once a patient is diagnosed with CKD, they need to be given information about anaemia and other symptoms related to CKD straight away
- A lot of patients will go online before they go to the doctor. It is therefore crucial that patients are looking at reliable resources
- Run focus groups—it can be useful for patients to help them learn about the reality of the disease and to know that they are not alone
- Always remember that nephrologists live the disease from the outside and patients live it from the inside

DANIEL GALLEGO
PAG Representative,
Spain

WHAT DO THESE FINDINGS MEAN FOR THE FUTURE OF ANAEMIA OF CKD?

RENAL NURSES:

> "These findings highlight the need to bring to attention the differences between what patients with anaemia of CKD are feeling and what doctors might think they are feeling. It's important to understand which aspects of a patient's condition are impacting their quality of life and what might be causing them anxiety."
>
> - Jennifer Ann Williams
>   Renal Nurse, UK

KEY INSIGHTS FROM THE RENAL NURSES ON THE EXPERT PANEL:

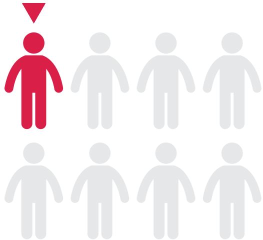
- While nephrologists may be focused on the clinical parameters, we need to remember that patients are often focused on symptoms that are impacting their day-to-day functioning
- It will be useful for patients to be presented with a list of symptoms that are associated with anaemia of CKD at diagnosis—but remember every patient is different, and therefore the style and amount of information will change per patient
- Patients want more information about their condition—we need to highlight and direct them to patient organisations, charity groups and clinics for additional and credible information
- The value of a multidisciplinary team in renal care needs to be highlighted in regions that don't currently have a specialty renal team
- Encourage patients to spend time with other patients outside the treatment room; patients often have a unique bond with other patients
- We also can't forget about the family and friends of patients, to ensure they are supported and understand the condition

EDITA NORUISIENE
Renal Nurse,
Europe

JENNIFER ANN WILLIAMS
Renal Nurse,
UK

WHAT IS CHRONIC KIDNEY DISEASE?

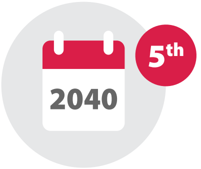
Chronic kidney disease (CKD) is a highly prevalent disease affecting approximately **1** in **10** people **worldwide**.[2]



Prevalence rates are higher in **Europe, East Asia (including Japan)** and the Middle East where **1 in 8 people** are living with the condition.[2]

CKD is a rapidly growing problem with both prevalence and incidence rates almost **doubling since 1990**.[1]

The condition is projected to be the **fifth most common cause of premature death by 2040**.[3]



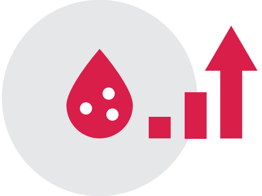
CKD is defined as a progressive loss of kidney function over time.[4] People with **diabetes** and **high blood pressure** are most susceptible to develop CKD, causing up to **two-thirds** of all cases.[4]

The condition is characterised by **five stages of disease**[5] with patients at stage 5 (advanced CKD) having only **10–15% kidney function** remaining.[5] When a patient's kidney function becomes severely impaired they may require dialysis or a kidney transplant.[6]

ANAEMIA OF CKD

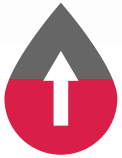
Anaemia is a serious complication of CKD that affects approximately **1 in 5 people** with the condition.[7]

Anaemia of CKD **increases** in **frequency** and **severity** as CKD progresses.[8]



Despite the high burden of anaemia of CKD[9] many patients are not receiving any treatment[10] putting them at risk of serious complications.[11,12]

Anaemia of CKD **accelerates the progression** of CKD.[11]



x2

as well as **doubling the risk** of death compared with CKD patients without anaemia.[13]

ABOUT THIS REPORT

Between January and February 2020, market research company Research Partnership carried out a survey on behalf of Astellas Europe Limited to explore patient and nephrologist perceptions of CKD and anaemia of CKD.

The survey looked to uncover the experiences both patients and nephrologists have during the diagnosis and management of the condition.

METHODOLOGY

Patients and nephrologists were recruited via online panels and were eligible if they were:

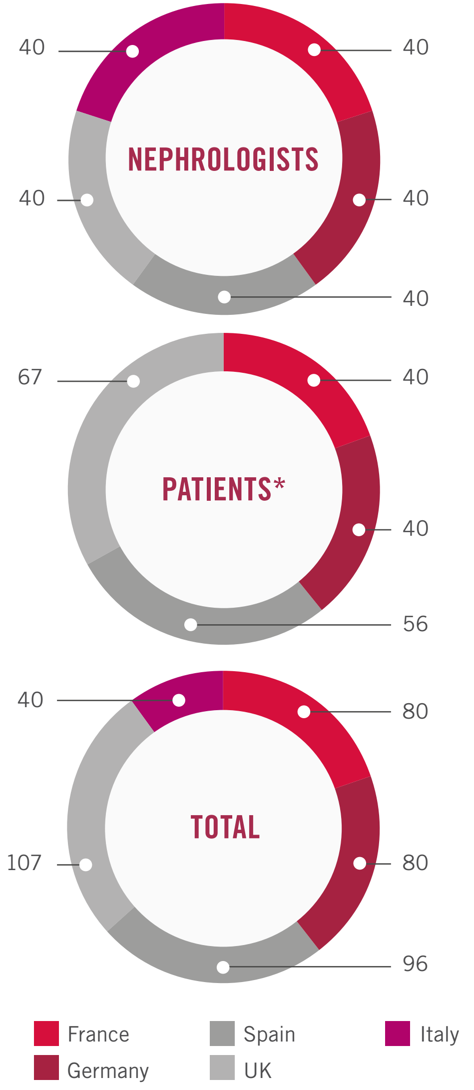
A **patient** diagnosed with anaemia of CKD

A **nephrologist** practicing for at least 2 years who sees a minimum of eight patients on treatment for anaemia of CKD from stages 3+**

Participants took part in a **25-minute online quantitative survey**.

PARTICIPANTS

403 participants were surveyed from five European markets:

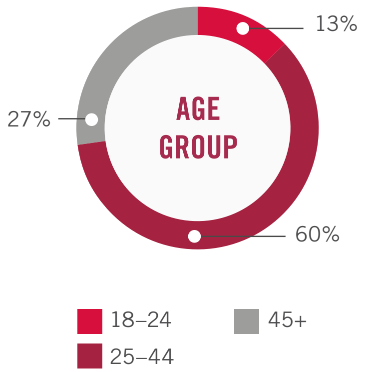


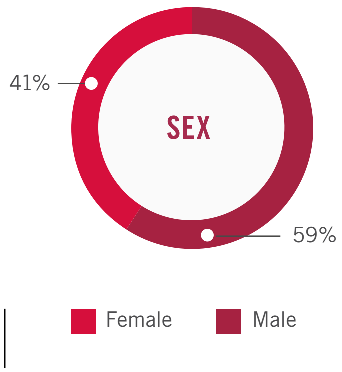
*For compliance reasons, patients were not recruited in Italy

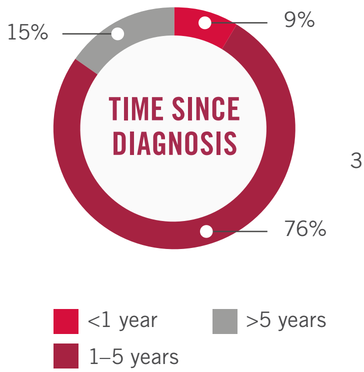
**CKD stage: stage 1=kidney damage, normal function; stage 2=kidney damage, mild loss of function; stage 3=moderate to severe loss of kidney function; stage 4= severe loss of kidney function; stage 5=kidney failure, need treatment to live

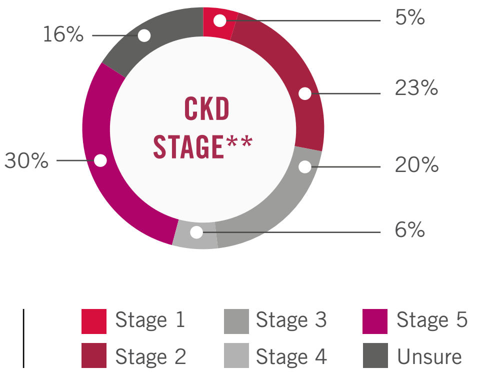
PATIENT DEMOGRAPHICS

The patients who took part in the survey came from **every stage of the CKD patient journey** and **the majority had been diagnosed with CKD several years ago**.





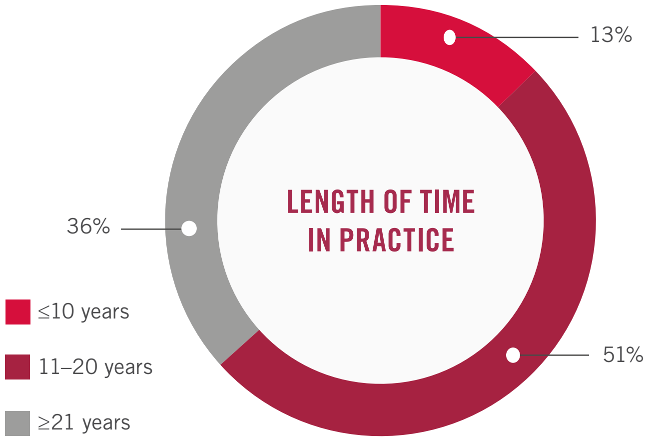


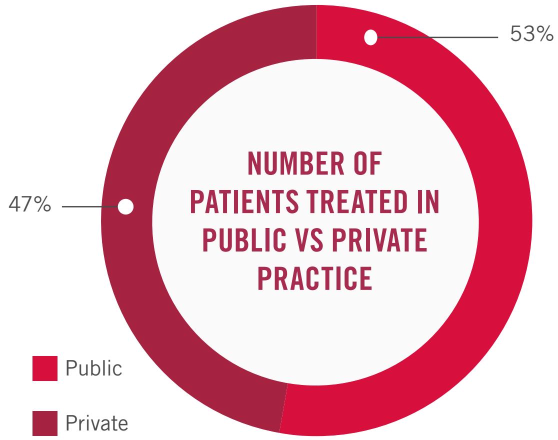


***CKD stage: stage 1=kidney damage, normal function; stage 2=kidney damage, mild loss of function; stage 3=moderate to severe loss of kidney function; stage 4= severe loss of kidney function; stage 5=kidney failure, need treatment to live*

NEPHROLOGIST DEMOGRAPHICS

The nephrologists who took part in the survey were experienced, with **87% having spent more than 10 years working as nephrologists**. On average, they actively managed **182 CKD patients** and **113 patients with anaemia of CKD** each month, and spent **87% of their time treating patients**.





MEET THE EXPERT PANEL

An external Expert Panel were convened by Astellas to provide their perspective on the survey results. The Expert Panel included nephrologists, nurses and a patient advocacy group (PAG) representative. The Expert Panel assisted Astellas in interpreting the results and providing their perspectives on how the results related to everyday practice and management of anaemia of CKD. All members of the Expert Panel received honoraria from Astellas for their services.

DANIEL GALLEGO
PAG Representative, Spain
President of National Federation of Associations for the Fight Against Kidney Diseases (ALCER)

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PROFESSOR JONATHAN BARRATT
Nephrologist, UK
University of Leicester and Leicester General Hospital

DIAGNOSIS

GETTING A DIAGNOSIS:

CKD is a progressive loss of kidney function over time, characterised by five stages of disease:[4,5]

STAGE 1
kidney damage, normal function

STAGE 2
kidney damage, mild loss of function

STAGE 3
moderate to severe loss of kidney function

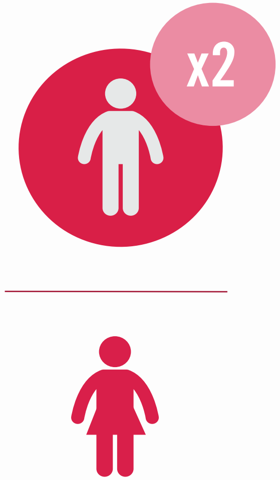
STAGE 4
severe loss of kidney function

STAGE 5
kidney failure, need treatment to live

Over **half (59%)** of the patients surveyed received their CKD diagnosis before they were subsequently diagnosed with anaemia, which is a serious complication of CKD that affects approximately **one in five people** worldwide with the condition.[7]

> "Early diagnosis is so important; if you feel something is not right in your body you should go to your doctor at the earliest convenience; sooner rather than later is always better in diagnosis."
>
> \- Daniel Gallego
> PAG Representative, Spain

Just over a quarter of patients (26%) reported that they received their anaemia diagnosis at the same time as their CKD diagnosis. **Men were more than twice as likely (33%) than women (15%)** to report having their **anaemia and CKD diagnosed at the same time**.



This increased to 28% of the patients receiving their anaemia diagnosis within one year of their CKD diagnosis.

Of the patients surveyed, 8% reported that it was three years or more before they received their anaemia diagnosis, with this increasing to 13% for patients in Spain and France.

IMPLICATIONS OF UNDIAGNOSED ANAEMIA

From nephrologist reports, it was apparent that many of their patients with CKD are living with undiagnosed anaemia.

Nearly one-third (31%) of nephrologists surveyed believed that more than 91% of their patients living with CKD had undiagnosed anaemia, with more nephrologists in **Italy (43%)** and **Spain (45%)** believing this was the case than those in **Germany (13%)**.

Interestingly, nephrologists working in private practices (50%) were more likely to report undiagnosed anaemia in their patients than those working in public practices (30%).

The high prevalence of undiagnosed anaemia of CKD patients reported by nephrologists was thought to have been for one of **two reasons**:

- late referral of patients to nephrologists
- the similarities between CKD and anaemia symptoms resulting in anaemia going unnoticed in CKD patients

The nephrologists within the Expert Panel, agreed that late referrals could explain this high level of undiagnosed patients, but they also highlighted that even if the patient is referred at an appropriate time, the referrals don't always include the relevant information about a patient's anaemia. They were surprised that a patient would be undiagnosed once in renal care.

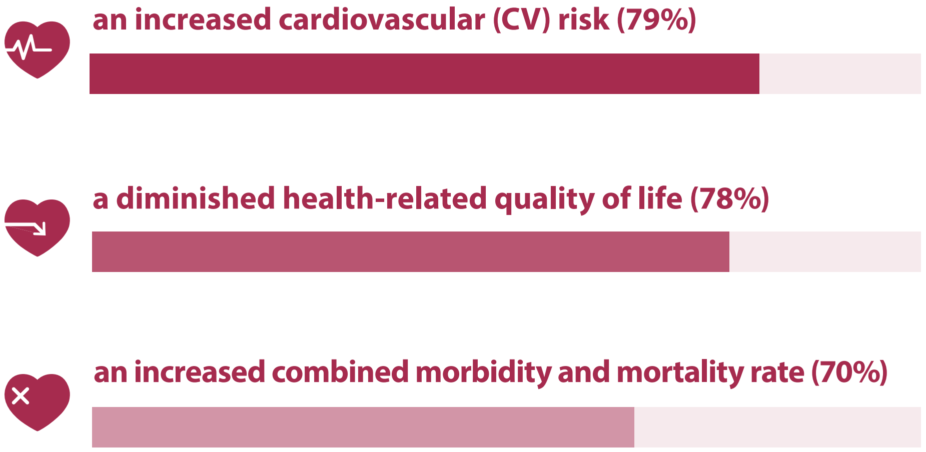
These results suggest that many patients with anaemia of CKD are not receiving treatment for their anaemia, which is consistent with current literature.[10]

> "I am surprised by the high rates of undiagnosed anaemia reported by nephrologists. While nephrologists may often be aware of a patient's anaemia, it is not always prioritised in the discussions that they have with their patients."
>
> - José Portolés Pérez
> Nephrologist, Spain

CLINICAL RISKS ASSOCIATED WITH UNTREATED ANAEMIA

The level of undiagnosed patients is concerning considering the majority of nephrologists surveyed (89%) acknowledged the **long-term impact** untreated anaemia has on patients health.

The top three clinical risks nephrologists worried most about were:



an increased cardiovascular (CV) risk (79%)

a diminished health-related quality of life (78%)

an increased combined morbidity and mortality rate (70%)

TOP CLINICAL RISKS IDENTIFIED BY THE NEPHROLOGISTS SURVEYED

Increased CV risk was ranked as the highest concern by nephrologists in **Italy (93%)**, **Spain (83%)** and **France (88%)**.

Nephrologists in the **UK (93%)** were most concerned by a diminished health-related quality of life in their patients.

Nephrologists in Germany demonstrated similar levels of concern across: increased CV risk 60%; increased combined morbidity and mortality rate 75% and diminished health-related quality of life 70%.

These findings suggest that the nephrologists surveyed in Germany are more concerned about the **overall care for their patients**.

CLINICAL RISKS ASSOCIATED WITH UNTREATED ANAEMIA

Discrepancies in reports of top clinical risks were also seen when findings were considered by the number of years a nephrologist had spent in practice.

<15 YEARS

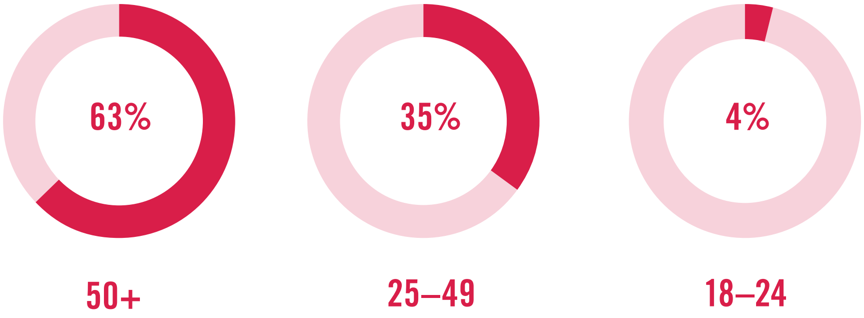
Nephrologists surveyed with less than 15 years of experience were more likely to report concerns over diminished health-related quality of life (75%) and morbidity and mortality (75%).

16+ YEARS

While those with 16 or more years in practice, reported increased CV risk as their top concern (82%).

Interestingly, the patients surveyed appeared much less aware of the risks associated with untreated anaemia, with **only one in three (36%) aware of the long-term implications of their anaemia of CKD remaining untreated**.

Patients over the age of 50 (63%) claimed to be much more educated about the risks of untreated anaemia than those **aged 25–49 (35%)** and those **aged 18–24 (4%)**.



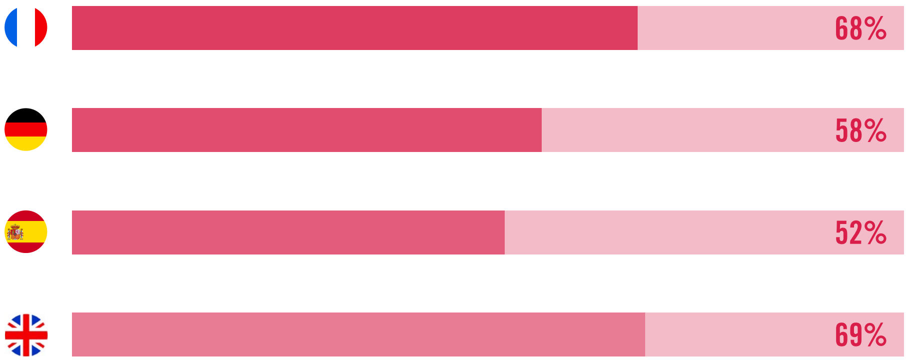
These findings demonstrate the importance of highlighting the clinical risks of untreated anaemia of CKD to patients, but also the need for anaemia to become more of a priority for nephrologists when managing the care of CKD patients.

AWARENESS AT DIAGNOSIS

A relatively high level of awareness around CKD was reported by the patient population with nearly two-thirds (62%) reporting to have been **informed about CKD** as a condition before receiving their diagnosis. An equal number of patients (62%) reported being **aware of anaemia as a complication of CKD** before receiving their anaemia diagnosis.

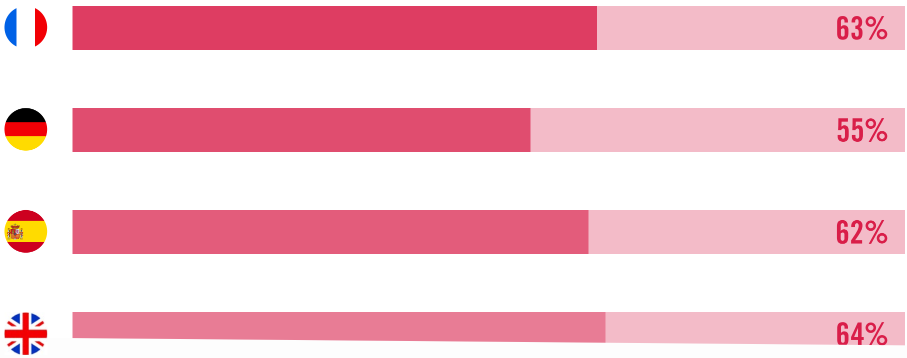
PATIENTS AWARENESS

OF CKD AT DIAGNOSIS



PATIENTS AWARENESS

OF ANAEMIA AS A COMPLICATION OF CKD



In speaking with the Expert Panel it was not surprising to Jennifer and Jonathan, that patients within the UK were very aware of CKD and anaemia as a complication. They both expressed the amount of work that has been done over recent years with patient and professional organisations to raise awareness.

From a Spanish perspective, both José and Daniel were surprised that only 52% of patients were aware of CKD; but it was unexplainable as to why patients reported being more aware of anaemia as a complication (62%).

Interestingly, nephrologists across Europe appeared to underestimate patients levels of awareness, with only 26% reporting patient awareness of CKD at their diagnosis and 22% reporting patient awareness of anaemia as a complication of CKD.

SYMPTOMS OF CKD AND ANAEMIA OF CKD

Early stages of CKD are often symptomless, however as CKD advances and kidney function becomes progressively worse symptoms start to develop.[14]
A person with advanced CKD is likely to develop oedema.[14] This happens when the kidneys cannot expel extra fluid and often occurs in the legs, feet, ankles and less often in the hands or face.[14]

OTHER SYMPTOMS COMMON IN ADVANCED CKD CAN INCLUDE:[14]

- **Chest pain**
- **Feeling tired**
- **Headaches**
- **Increased/ decreased urination**
- **Shortness of breath**
- **Trouble sleeping**

PATIENTS THAT HAVE ANAEMIA OF CKD ARE LIKELY TO EXPERIENCE SUPPLEMENTARY SYMPTOMS, SUCH AS:[15]

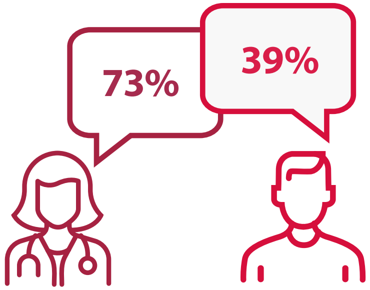
- **Rapid heartbeat**
- **Shortness of breath**
- **Feeling dizzy**
- **Headaches**
- **Poor appetite**
- **Fatigue**
- **Feeling depressed**
- **Trouble thinking clearly**

> “By increasing patients’ understanding of their symptoms it will help to better manage their expectations around treatment. Patient education is key in order to better understand which symptoms are causally related to anaemia and which symptoms cannot be corrected by anaemia treatments.”
>
> - Jonathan Barratt
> Nephrologist, UK

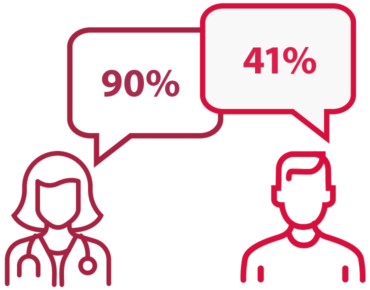
SYMPTOMS OF CKD AND ANAEMIA OF CKD

Within the survey, both patients and nephrologists identified **tiredness as the most common symptom** present at:

CKD DIAGNOSIS



ANAEMIA DIAGNOSIS



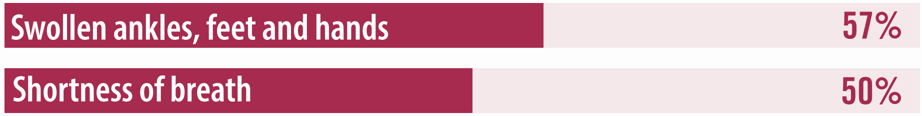
However, beyond this, there appeared to be confusion between patients and nephrologists on which symptoms were connected to CKD and which linked to their anaemia.

> “It is surprising that patients associated an increased need to urinate with anaemia. This perhaps suggests that patients don’t have the information and knowledge relating to anaemia symptoms to allow them to distinguish them from symptoms of CKD. Symptoms of anaemia need to be considered in context with other symptoms experienced by renal patients.”
>
> - José Portolés Pérez
> Nephrologist, Spain

Further reported CKD symptoms:

PATIENTS

NEPHROLOGISTS

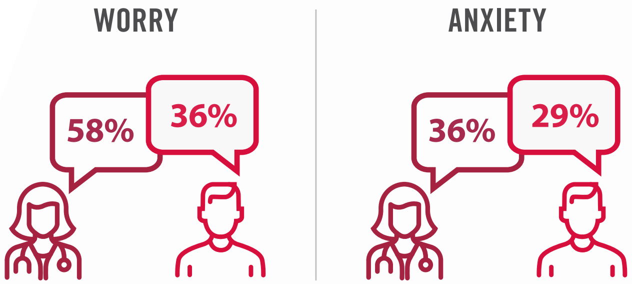


Swollen ankles, feet and hands were chosen as the second most common symptom of anaemia reported by a third of patients (33%), which is a symptom more commonly associated with CKD in the literature.[14] This suggests patients may be struggling to distinguish the symptoms between the two conditions.

EMOTIONAL IMPACT

Both patients (80%) and nephrologists (76%) agreed that being diagnosed with anaemia of CKD had an **emotionally negative impact**.

MOST COMMON FEELINGS EXPERIENCED AT DIAGNOSIS:



Interestingly, patients aged 18–24 years (15%) were half as likely to report feelings of anxiety at diagnosis than patients aged 25 years or over (30%).

> “Embarrassment is a feeling experienced by patients that can often be underestimated. The aesthetic symptoms of anaemia, such as weight loss and change in skin colour, can make patients feel embarrassed and judged by others. While these aesthetic symptoms are not seen as crucial to the nephrologist, they are important to a lot of patients as our society is concerned with appearances and the impressions we give to others.”
>
> - Daniel Gallego
> PAG Representative, Spain

SIGNIFICANT DISCONNECT IN PATIENT AND NEPHROLOGIST REPORTS OF EMOTIONS AT DIAGNOSIS WERE ALSO OBSERVED ACROSS COUNTRIES:

🇩🇪 Nephrologists over-reported the level of **worry** their patients experienced at diagnosis, compared with patient reports (78% vs 23%, respectively)

🇪🇸 Nephrologists significantly overestimated how **accepting** patients were (35% vs 4%, respectively)

🇫🇷 Nephrologists overestimated how **informed** patients felt at diagnosis (38% vs 13%, respectively)

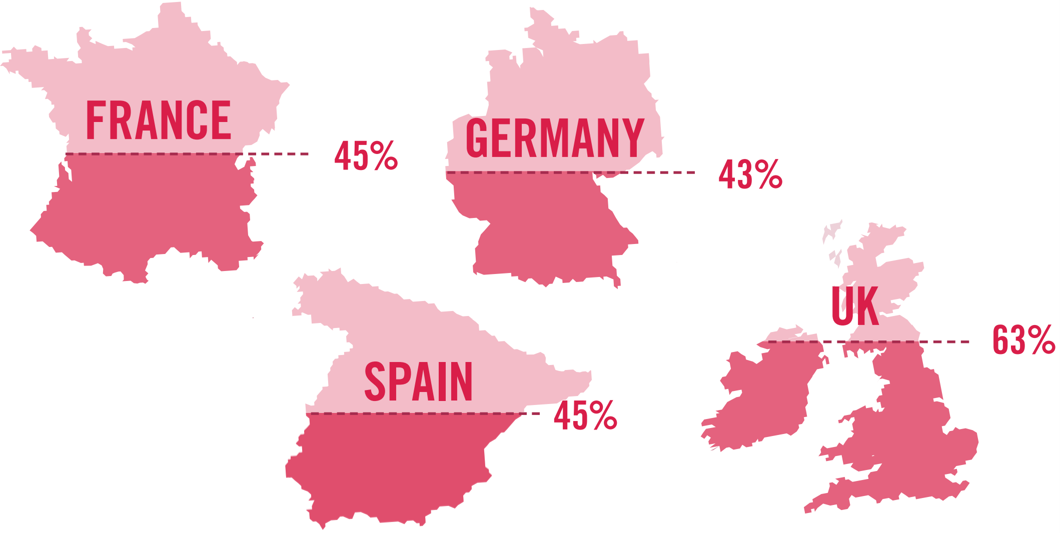
🇬🇧 Nephrologists underestimated patients feeling **embarrassed** about their diagnosis (0% vs 21%)

DIAGNOSIS PROCESS

A significant disconnect was observed in the amount of time the patients and nephrologists surveyed felt the diagnosis process took.

One in two patients surveyed thought that the diagnosis of their anaemia of CKD took a long time, while only one in five nephrologists surveyed reported this to be the case.

PATIENTS REPORTED THAT THEIR DIAGNOSIS PROCESS TOOK A LONG TIME:



Expert Panel members from the UK thought delays reported by the surveyed patients would most likely to have been determined by the capacity of the healthcare system.

> **“The way that the system is set up means that chronic patients can sometimes be de-prioritised.”**
>
> **- Jonathan Barratt**
> **Nephrologist, UK**

> **“The diagnosis process can differ between clinics across the UK; clinics without a team of specialist renal nurses would be more likely to experience delays.”**
>
> **- Jennifer Ann Williams**
> **Renal Nurse, UK**

Across the four European countries, almost half of the patients surveyed (48%) reported finding the **diagnosis process frustrating**, however, nephrologists (28%) appeared to underestimate patients frustration during the diagnosis process.

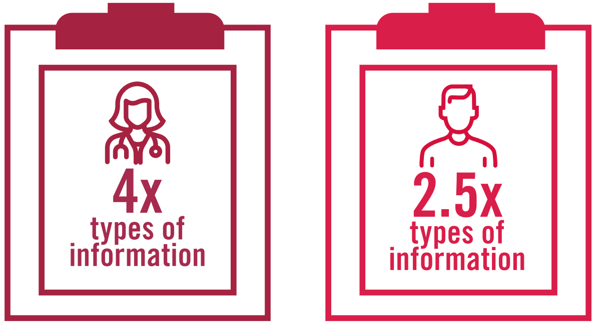
Nephrologists were also significantly more likely to report the **diagnosis process as straightforward** (63%) compared with patients (39%).

These levels of disconnect in patients and nephrologists reported attitudes towards the diagnosis process suggests the diagnosis experience was perceived differently by patients and nephrologists. It also highlights a potential to improve the patient diagnosis experience.

INFORMATION AT DIAGNOSIS

There was a clear disconnect in terms of the information the surveyed nephrologists reported providing to patients at diagnosis and the information that the surveyed patients reported they received.

On average, nephrologists reported providing **4 types or sources of information** to patients at diagnosis, while patients recorded only receiving an average of **2.5**.



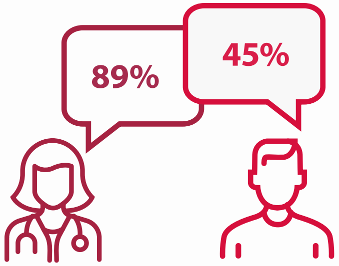
The majority of nephrologists reported having **general discussions around anaemia of CKD** with their patients at diagnosis (85%); while less than a third of patients reported this to be the case (31%). At a country level, it appeared nephrologists in Italy were least likely to report having these discussions (65%).

> "I wish I'd been given information about anaemia and other symptoms related to CKD when I first received my CKD diagnosis."
>
> - Daniel Gallego
>   PAG Representative, Spain

> "Nephrologists don't want to overwhelm patients with information in their consultations; appointment time constraints also limit them as to how much information they are able to provide. It is important the patient has the support of a multidisciplinary team so they can talk to other professionals if they have questions following their appointments."
>
> - Jennifer Ann Williams
>   Renal Nurse, UK

INFORMATION AT DIAGNOSIS

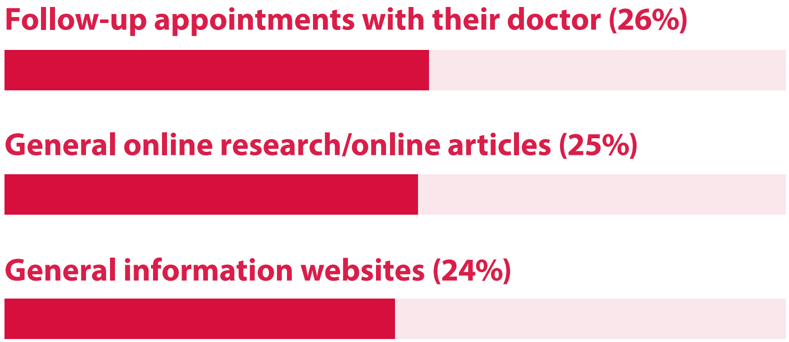
A disconnect can also be seen in **discussions around potential treatment options** as reported by the patients and nephrologists surveyed. The majority of the nephrologists surveyed (89%) reported providing information around treatment options to their patients while less than half (45%) of patients surveyed reported receiving this information.



Nephrologists surveyed in Germany (48%) appeared to be most likely to support patients with brochures about anaemia of CKD, while only 18% of nephrologists in Italy reported to provide these materials to their patients.

This lack of information provided by nephrologists, leaves 94% of patients **looking for more information about their condition**.

On average, patients reported turning to three additional sources of information, the top three being:



Follow-up appointments with their doctor (26%)

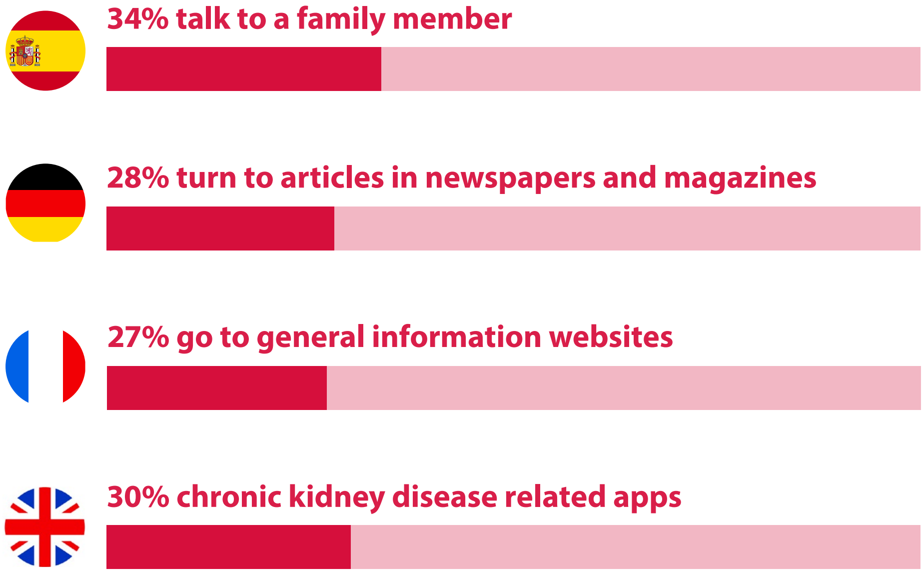
General online research/online articles (25%)

General information websites (24%)

> “When educating patients about their condition the important thing is to explain their illness and treatment to them according to their individual conditions and needs. In addition, it is important to check that they have understood the explanations provided to them.”
>
> \- Edita Noruisiene
> Renal Nurse, Europe

INFORMATION AT DIAGNOSIS:

WHERE PATIENTS IN DIFFERENT COUNTRIES IMMEDIATELY TURN TO FOR MORE INFORMATION:



34% talk to a family member

28% turn to articles in newspapers and magazines

27% go to general information websites

30% chronic kidney disease related apps

Whilst patients reported they were going elsewhere for further information, only 13% of nephrologists saw the need for more education around the impact of anaemia on patients' lives. This highlights a need to increase awareness within nephrologists around patients' interest in their condition and **encourage more information to be provided to patients during consultations**.

> "It's important for patients to have a reliable contact to communicate with if they want more information. The danger is when patients go online and read the wrong information from the internet."
>
> - Jennifer Ann Williams
> Renal Nurse, UK

> "Often patients don't have a direct contact to turn to for more information about their condition or to answer their questions, therefore patients often search for support online. I'm concerned that if their questions remain unanswered it could evolve into an emotional burden for them."
>
> - Edita Noruisiene
> Renal Nurse, Europe

BURDEN AND IMPACT OF DISEASE

Anaemia of CKD can have a significant negative impact on a patient's quality of life.[12]

People with anaemia of CKD often have more challenges with the below compared with patients without anaemia:[12]

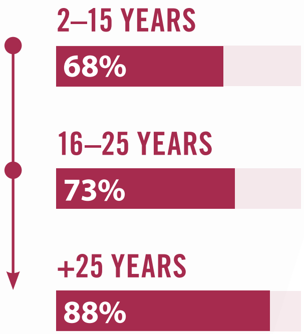
- INCREASED PAIN AND DISCOMFORT
- GREATER ANXIETY AND DEPRESSION
- MOBILITY
- SELF-CARE
- DAY-TO-DAY LIVING

57% of the patients surveyed reported that **their life was dominated** by their anaemia of CKD.

It appeared that the nephrologists surveyed were aware of the impact the condition can have on the lives of patients.
Nearly three-quarters (74%) of nephrologists surveyed reported that anaemia of CKD had a high impact on their patients' everyday lives.

> "It's to be expected that healthcare professionals and patients perceive the impact of the condition differently; nephrologists live the disease from the outside and patients live it from the inside."
>
> -Daniel Gallego
> PAG Representative, Spain

The nephrologists surveyed who had been practising for more than 25 years were more likely to recognise the impact anaemia of CKD has on the daily lives of patients than nephrologists who had been practising for less time:



Differences were also seen between nephrologists surveyed in private versus public practice:

Despite relatively high numbers of surveyed nephrologists recognising the impact of the condition, more than half of the patients surveyed (56%) believed their **physician did not fully appreciate the impact anaemia had on their everyday life**.

WHAT PATIENTS MISSED OUT ON

It was found that, on average, the patients surveyed **missed more than 8 days per month of work** due to their anaemia of CKD.

There were some age and country discrepancies:

PATIENTS AGE:

18–24
10 DAYS
PER MONTH

25–49
7 DAYS
PER MONTH

50+
10 DAYS
PER MONTH

COUNTRY:


10 DAYS
PER MONTH

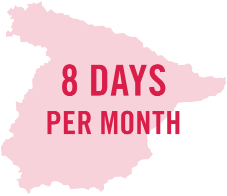
FRANCE


10 DAYS
PER MONTH

GERMANY


5 DAYS
PER MONTH

UK


8 DAYS
PER MONTH

SPAIN

Nearly **half of the patients surveyed (44%) reported that they had to stop work indefinitely**; this was notably higher in France (68%).

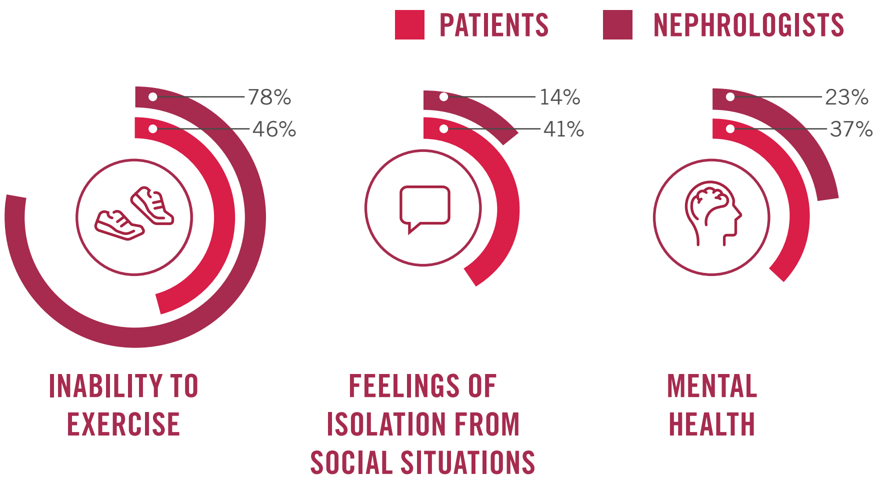
It appeared that the nephrologists surveyed significantly underestimated the number of patients whose anaemia of CKD stopped them from working indefinitely. Less than a quarter (24%) recognised this as an effect of the condition for their patients.

> "Nephrologists often forget about anaemia of CKD and the impact it has on a patient's quality of life. While not a priority in the eyes of the nephrologist, factors such as an inability to work and exercise are really important to a patient."
>
> - Daniel Gallego
> PAG Representative, Spain

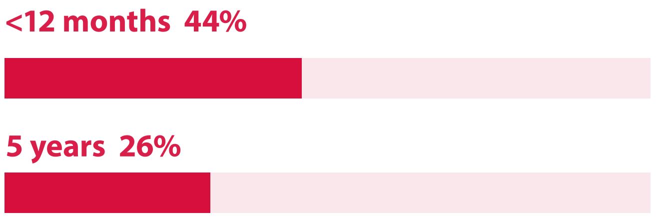
> "A patient's ability to work will depend on what stage their CKD is at and whether they are on dialysis; it is very hard for a patient on dialysis to manage a full-time job."
>
> - Edita Noruisiene
> Renal Nurse, Europe

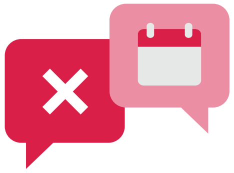
WHAT PATIENTS MISSED OUT ON

When looking at what patients missed out on because of their anaemia of CKD, there appeared to be differences between the patients and nephrologists surveyed:



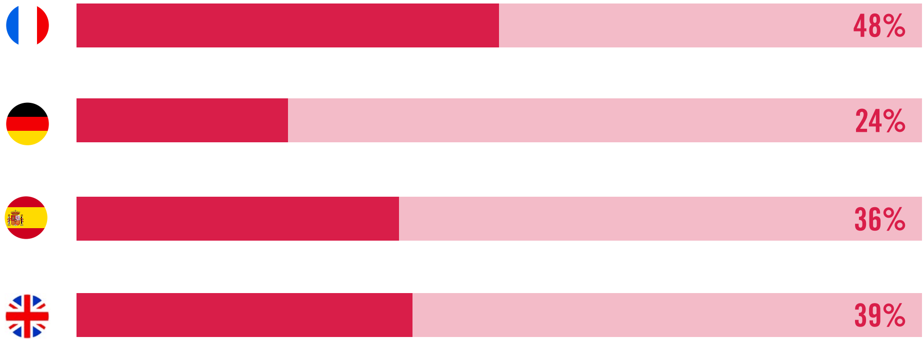
Patients surveyed who had been diagnosed in the last year were more likely to experience **feelings of social isolation** than those diagnosed 5 years ago. This suggests that the longer patients live with their condition, the better they are able to adapt to social situations.



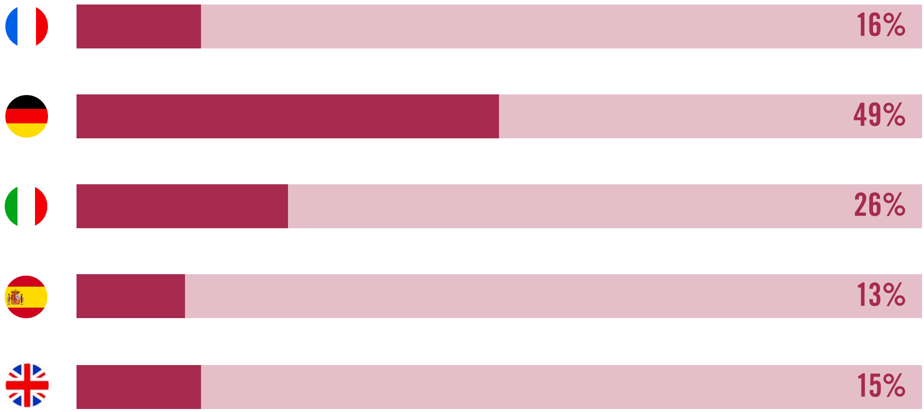


When comparing reports of patient mental health across countries, there were also differences:

PATIENT REPORTS OF ANAEMIA OF CKD AFFECTING THEIR MENTAL HEALTH



NEPHROLOGIST REPORTS OF ANAEMIA OF CKD AFFECTING PATIENTS MENTAL HEALTH



PATIENTS AND THEIR CAREGIVERS

Of the patients surveyed, two-thirds (66%) had a caregiver, of which 90% were their partner or spouse.

Interestingly, over 80% of patients in the UK had a caregiver, which was significantly more than Spain (48%) and France (60%).

In speaking with the Expert Panel, Daniel and José believed that the Spanish figure was so low as patients wouldn't recognise their family member/loved one as a caregiver and therefore didn't report this.

The main ways in which patients reported their caregivers providing support were:

67% HELPING AROUND THE HOUSE

51% TAKING MEDICATION

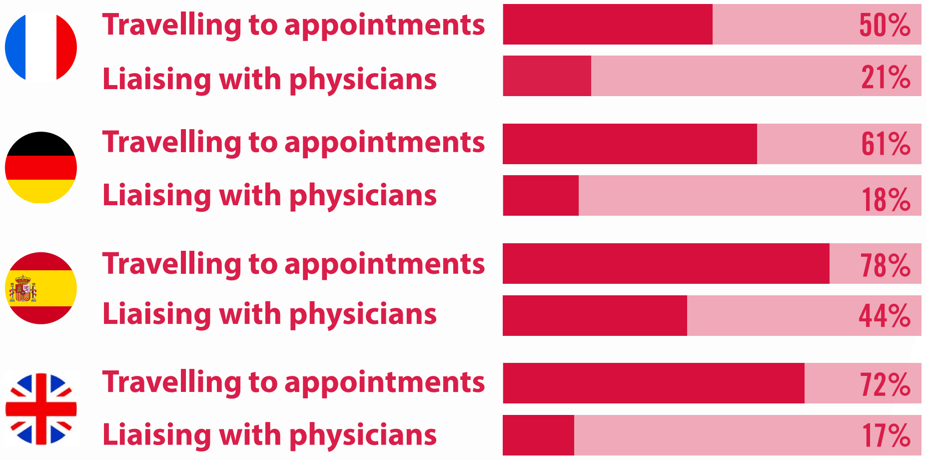
45% TRAVELLING TO APPOINTMENTS

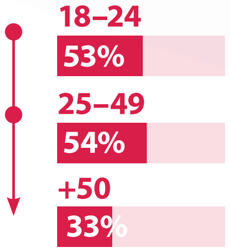
23% LIAISING WITH HEALTHCARE PROFESSIONALS

10% RESEARCHING INFORMATION

Across all countries, while the patients surveyed reported their partners/caregivers helping them travel to appointments, very few reported that their partner or caregiver was involved in helping them to liaise with physicians.

> “It is common for patients to come to appointments with two or more family members to help them take on board the information that the doctor gives them. It is therefore surprising that a low proportion of patients reported liaising with physicians as a way that their caregiver helps them.”
>
> \- Jennifer Ann Williams
> Renal Nurse, UK



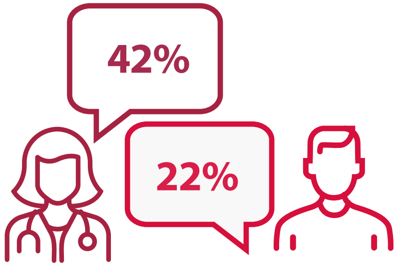


Patients surveyed who were over the age of 50 were more reliant on their caregiver for all tasks. Interestingly, those aged 18–49 were more reliant on their caregivers for help with taking their medication than those patients aged 50 years or older.

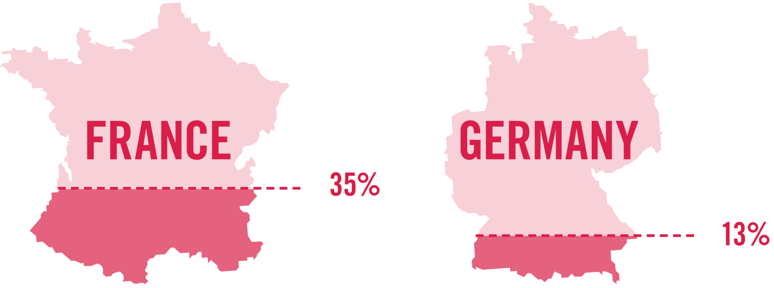
PATIENTS AND THEIR CAREGIVERS

Half of the patients (54%) and nephrologists (52%) surveyed believed that anaemia of CKD had an impact on **logistical and psychological aspects of the lives of those around the patient**.

Nephrologists surveyed were twice as likely to believe that patients' partners felt anxious and depressed than patients reported.



Patients surveyed in France were more likely to report that their partners felt anxious or depressed (35%) than those in the other countries; only 13% of patients in Germany believed their partners were affected in this way.

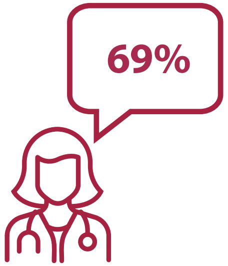


When looking at the impact on the lives of carers in relation to gender, more males (27%) believed that their partners felt anxious or depressed than females (16%).

> "When a patient's partner or family member comes with them to appointments, we can see when they are worried or anxious. It is when a patient comes to appointments alone that we lack insight into how their partners or family are feeling. These are perhaps conversations that need to be had between the patient and a professional within the wider multidisciplinary team."
>
> - Jonathan Barratt
> Nephrologist, UK

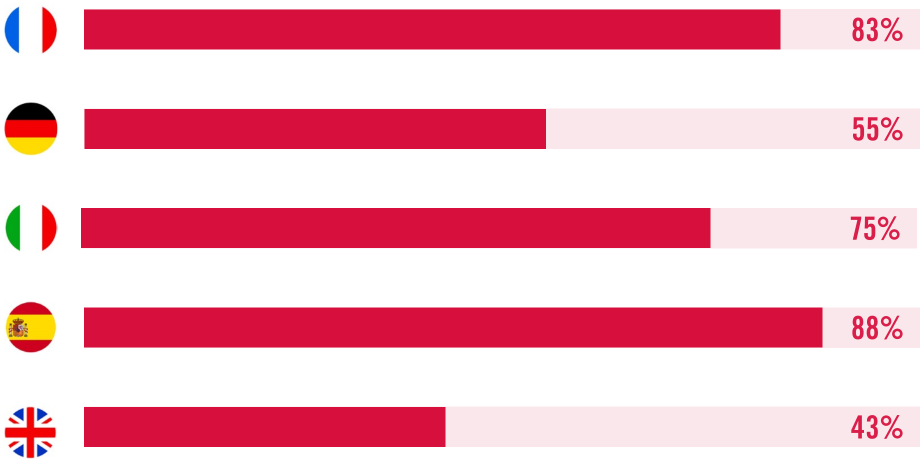
MANAGEMENT OF CARE

TIME TAKEN TO TREAT



Over two-thirds of nephrologists (69%) surveyed believed that their patients' treatment for their anaemia of CKD typically started immediately following their diagnosis.

Nephrologists surveyed in Spain and France were most likely to start initiating treatment straight away, while in the UK nephrologists were significantly less likely to report that treatments started at the time of a patient's diagnosis.



However, when surveyed patients were asked when they were initiated onto treatment:

55% reported that their treatment started immediately following their diagnosis

29% reported that it took up to 3 months

16% stated that it took more than 3 months before they were prescribed treatment

Patients surveyed who were over the age of 50 were much more likely to report starting their treatment immediately after receiving their diagnosis (83%) compared with patients aged 18–24 (46%) and 25–49 (51%).

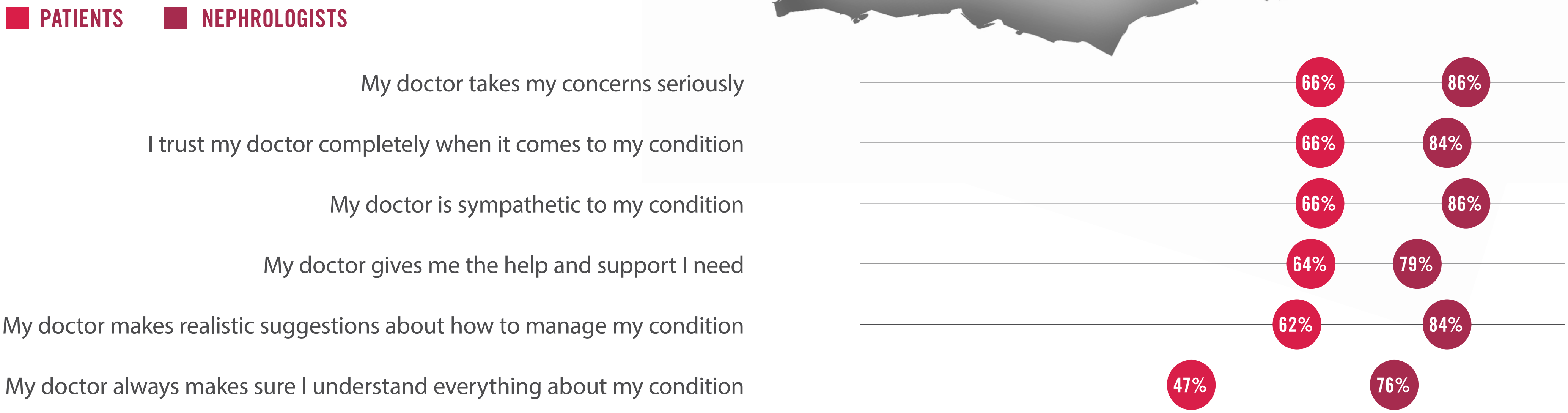
NEPHROLOGIST–PATIENT RELATIONSHIPS

There was a large disconnect in attitudes towards the patient–nephrologist relationship when comparing the responses of the patients and nephrologists surveyed. Generally, the nephrologists surveyed appeared to have a more positive perception of the patient–nephrologist relationship, whereas surveyed patients perceived a lack of support and trust from their physician. Patients surveyed in Germany were most likely to perceive a lack of sympathy from their doctor with only half of the patients surveyed reporting that their doctor was sympathetic towards their condition.

> “Nephrologists are not always good at translating their awareness and knowledge of the disease to the patient. This could explain why patients might perceive that their nephrologist doesn’t take their concerns seriously.”
>
> - José Portolés Pérez
> Nephrologist, Spain

> “If a nephrologist doesn’t properly explain the patient’s condition to them, this can sometimes lead to a poor patient–nephrologist relationship. If patients aren’t provided with sufficient information at diagnosis this can cause them concern later on. This situation can also cause a lack of patient adherence to treatment if they don’t fully understand the importance of it.”
>
> - Edita Noruisiene
> Renal Nurse, Europe

PERCEPTION OF NEPHROLOGIST–PATIENT RELATIONSHIP

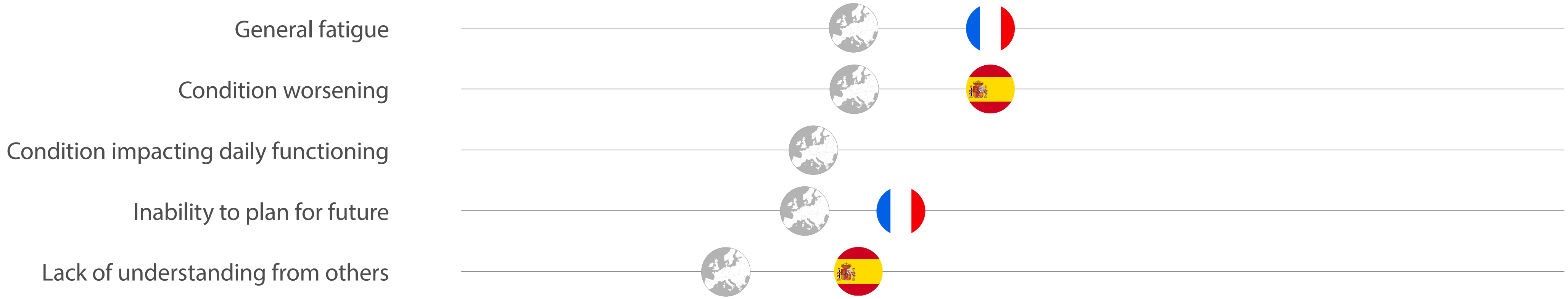


PATIENT CONCERNS

The surveyed patients reported being much more concerned about their anaemia than the surveyed nephrologists thought they were (62% vs 45%, respectively).

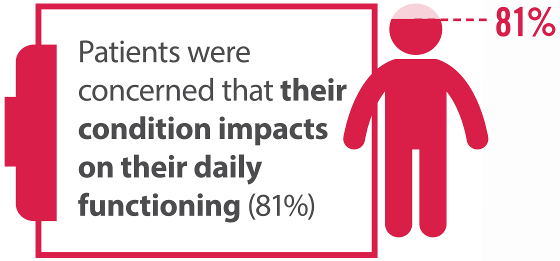
Patients reported being most concerned by their general fatigue (35%) and their condition worsening (35%). Patients in Spain (48%) reported especially high levels of concern that their condition would worsen, while patients in France were most concerned by their general fatigue (48%).

Other concerns reported by patients included their condition impacting their daily functioning (32%) and an inability to plan for the future (31%), which was reported most highly by patients in France (40%). A lack of understanding from others appeared to concern almost a quarter of all patients (24%), with higher levels of patients in Spain (36%).



When nephrologists were asked what factors relating to anaemia of CKD caused their patients most concern or worry, their top answers were:

Patients were concerned that **their condition would worsen** (81%)



Patients were concerned that **their condition impacts on their daily functioning** (81%)

> It's interesting that despite patients reporting a lack of concern from their doctors, nephrologists recognised similar worries and concerns as those identified by patients and, in fact, reported them to higher levels than patients themselves.

TIME ASSIGNED TO PATIENT CONSULTATIONS

Interestingly, while surveyed patients reported **negative feelings towards their relationship with their physician**, they also reported that the time assigned to their consultation appointments was sufficient. Forty percent of patients reported the time they spent with their physician was 'about right' and 50% reported too much time was spent during consultation. Similarly, 59% of nephrologists felt time assigned to consultations was about right.

Patients surveyed in France (60%) were most likely to be satisfied with the amount of time they spent with their physician

Less than a quarter (24%) of patients surveyed in the UK felt time spent during consultations was about right

Understandably, patients surveyed who were on dialysis were more likely to rate the time spent with physicians as too much (72%)

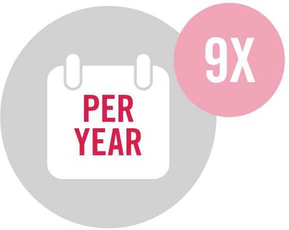
> **"If a nephrologist doesn't properly explain the patient's condition to them, this can sometimes lead to a poor patient–nephrologist relationship. If patients aren't provided with sufficient information at diagnosis this can cause them concern later on. This situation can also cause a lack of patient adherence to treatment if they don't fully understand the importance of it."**
>
> **- José Portolés Pérez**
> **Nephrologist, Spain**

Out of the patients surveyed who felt that they needed more time with their doctor, they prioritised **wanting to learn more about the condition (37%)**.

Nephrologists surveyed who believed that more time with their patients would be beneficial also reported wanting patients to be **able to learn more about the condition (35%)** but prioritised wanting to spend more time on **patient support (43%)**.

MANAGING HAEMOGLOBIN LEVELS

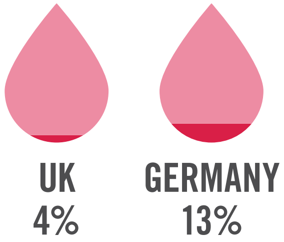
On average, nephrologists surveyed stated that they tested their patients' haemoglobin (Hb) levels **9 times a year**. The majority of nephrologists surveyed (81%) believed that their patients noticed their symptoms worsening when their Hb levels were low.



However, nearly a quarter (23%) of surveyed patients were not aware of the concept of Hb levels, with **the majority of the patients (92%) reporting to not know their current Hb level**. This suggests that while patients may be able to recognise when their symptoms are worsening, they are unable to attribute this to fluctuations in their Hb levels as nephrologists believe.

Despite regular monitoring of their patients, surveyed nephrologists estimated that almost a third (32%) of their patients had **Hb levels outside target range (10–12 g/dL)**.

Patients surveyed in the UK (4%) were least likely to be aware of their current Hb level, while patients in Germany (13%) reported higher levels of awareness.



> **“Patients engagement with their Hb test results is crucial to help them better manage their CKD. These test results are unique and specific to a patient and are important for them to be able to monitor their condition.”**
>
> **- Daniel Gallego**
> **PAG Representative, Spain**

There was mixed feedback from the Expert Panel on whether it is necessary for patients to know about their Hb levels. The consensus was that if patients have a greater understanding of their condition and its complications in the earlier stages it can help them to proactively manage their condition long term.

TREATMENT COMPLIANCE

The nephrologists surveyed reported that almost half of their patients (47%) were **not fully compliant with their anaemia of CKD treatment**.

Only 9% of nephrologists surveyed believed their patients always followed the medication schedule provided to them. Furthermore, over half of the patients surveyed (59%) reported having missed a dose of their treatment.

REASONS PATIENTS WERE MISSING A TREATMENT DOSE

48%

of patients reported side effects

41%

of patients reported being unable to get to appointments due to feeling unwell

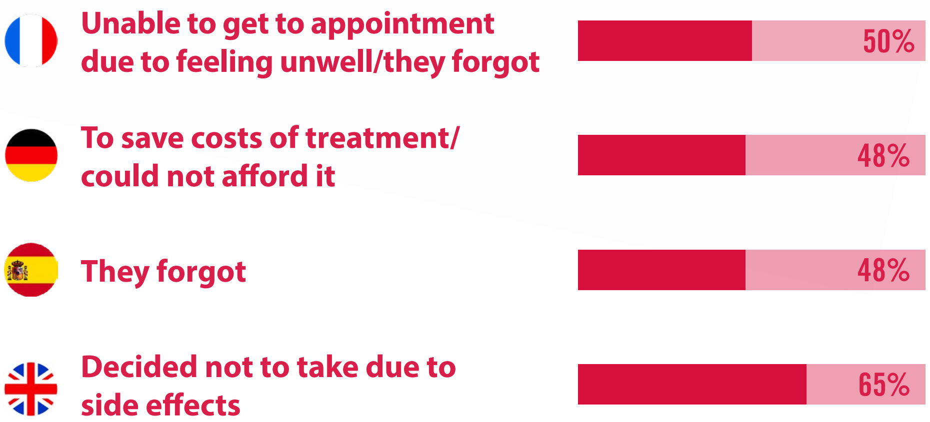
41%

of patients reported being unable to afford treatment or wanting to save on treatment costs

> “All patients will sometimes miss a treatment dose; life sometimes gets in the way and that is normal.”
>
> - Jonathan Barratt
> Nephrologist, UK

While surveyed patients under the age of 50 were most likely to report missing a dose due to the side effects, those aged 50+ were more likely to forget. Interestingly, these findings were not consistent across markets:

COUNTRY DIFFERENCES IN PATIENTS—MOST COMMON REASON FOR MISSING A TREATMENT DOSE



FUTURE MANAGEMENT OF ANAEMIA OF CKD

Nephrologists and patients were asked about their hopes for the future management of anaemia of CKD.

A quarter of surveyed patients reported wanting **to better understand the impact anaemia has on their health and their life**, yet only 13% of nephrologists ranked this as a desired improvement. This finding demonstrated a disconnect between the surveyed nephrologists and patients in their desires for more education on the impact of anaemia.

A further disconnect was observed between the patients and nephrologists surveyed in the **hope for a greater understanding from family and friends** about how it feels to have anaemia of CKD. While nearly a quarter (22%) of patients surveyed reported this as a desired improvement for the future, only 3% of surveyed nephrologists reported this as an improvement they hoped for moving forward.

> **"I believe there is opportunity to increase awareness of the importance of early diagnosis; this opportunity is not specific to nephrologists. It is an important learning for the wider community of healthcare professionals so that patients with low Hb levels are referred to nephrologists as early as possible."**
>
> **- José Portolés Pérez**
> **Nephrologist, Spain**

Overall, the main improvement desired by the patients surveyed for the future management of anaemia of CKD was **better treatment options** (27%).

Better treatment options were also ranked as a high priority by the nephrologists surveyed (49%).

The nephrologists surveyed (57%), however, reported **earlier diagnosis of CKD** as their number one desired improvement for the future of the condition.

IMPROVING FUTURE TREATMENTS

When asked specifically about improving treatment options for anaemia of CKD, the surveyed nephrologists appeared divided in what they thought were the most important aspects to improve. Improving **patient quality of life (47%)**, demonstrating a **long-term safety profile of treatments (45%)** and **convenient routes for administration (41%)** were ranked as the top three most important treatment improvements desired.

TOP 5 TREATMENT IMPROVEMENTS FOR CKD AMAEMIA BY NEPHROLOGISTS

Significantly improves patients' quality of life	47%
Demonstrates a long-term safety profile	45%
Convenient route for administration	41%
An effective treatment in presence of inflammation	38%
Reduces Hb levels variability and maintains within recommended target	35%

> "Patients look for concrete improvement from their treatments. They just want to feel better; that is the most important thing for them."
>
> - Edita Noruisiene
> Renal Nurse, Europe

When looking at a country level there appeared to be significant differences in the surveyed nephrologists' top priorities for the future management of anaemia of CKD.

68% of nephrologists in the UK were most concerned with **improving patients' overall quality of life**

48% of nephrologists in France ranked demonstrating a **long-term safety profile of treatments** as their top choice

55% of nephrologists in Spain ranked the **long-term safety profile of treatments** as a high priority

53% of nephrologists in Italy were most concerned with **reducing variability in Hb levels** in patients and **maintaining them within the recommended target**

When asking patients about their treatment desires, **improved efficacy** was ranked highest (24%). Patients surveyed in Spain (38%) were most likely to report improved efficacy compared with patients in Germany (15%).

WHAT DO THESE FINDINGS TELL US?

It is clear from the range of patient and nephrologist responses that there are a number of aspects across a patient journey whereby improvements for the future are desirable.

The surveyed nephrologists' desire for **earlier diagnosis** of anaemia of CKD is in line with their reported concerns of the clinical risks linked to the condition if it remains untreated. These consistent findings identify the opportunity for earlier diagnosis as fundamental in the eyes of nephrologists and the health of their patients.

In speaking with the Expert Panel, it was apparent that this improvement needs to be addressed by a wider multidisciplinary team of healthcare professionals so that patients with anaemia of CKD are referred to nephrologists as early as possible and with the correct information.

The patients surveyed desired **better communication** with their doctor and wanted **more information around their condition**. The need for increased communication between patients and nephrologists was recognised across the Expert Panel.

The impact anaemia of CKD has on the **quality of life of both patients and their loved ones** was a key theme identified by both the patients and nephrologists surveyed throughout these findings. While the nephrologists surveyed recognised the impact anaemia of CKD can have on the daily lives of patients, it was apparent that patients are often more affected by the burden of the disease than the nephrologists perceived.

When speaking to the Expert Panel, greater acknowledgement of the detrimental effects anaemia of CKD can have on patients quality of life was a learning that was identified by all members.

> **"As nephrologists, we tend to devote far less time to discussing anaemia in patient consultations than discussing CKD; it is clear from these findings that patients would like more information about their anaemia."**
>
> **- José Portolés Pérez**
> **Nephrologist, Spain**

> **"Often, acknowledgement of the condition from the healthcare professional and the way that the patient is feeling is as important to the patient as the treatment."**
>
> **- Jonathan Barratt**
> **Nephrologist, UK**

THE ASTELLAS COMMITMENT IN NEPHROLOGY

At Astellas, *Changing tomorrow* is the ethos that guides everything we do. We are working to turn innovative science into value for patients. Our research is focused predominantly in areas of high unmet need in under-served, serious diseases, and our work in nephrology is living proof of this.

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