The realities of living with CKD:

People with T2D and CKD speak up

Results from a pan-European survey by the European Kidney Patients Federation (EKPF) in collaboration with Bayer AG



Report sponsored by

About this report

This report has been developed by the European Kidney Patients Federation (EKPF) in collaboration with Bayer AG to shine a light on the key unmet needs in people with type 2 diabetes (T2D) who are diagnosed with chronic kidney disease (CKD).

We wanted to gain the perspective of people living with these conditions on a wide range of topics, from their CKD diagnosis to their relationship with their doctor, to the impact that CKD has had on their life. With that in mind, we commissioned a survey of 500 patients with CKD and T2D across five countries to better understand how they are affected. Our goal is to unlock insights that will help to inform stakeholders involved in the management of CKD associated with T2D.

Acknowledgements

The EKPF would like to acknowledge and thank all parties involved in the dissemination of this survey. We would also like to especially recognise all survey participants, patients and healthcare professionals who have offered their time to bring this vital report to life.

This research was made possible with support from Bayer AG.

Methodology

The results of this report are based on a 24-question online survey fielded among 500 respondents with CKD and T2D across five European countries: UK (n = 100), France (n = 100), Germany (n = 100), Italy (n = 100) and Spain (n = 100).

The survey was fielded by TRUE Global Intelligence in partnership with Vitreous World, and fieldwork ran from 20th July – 19th August 2022. Results are reported at the 95% confidence level with a margin of error of +/- 4.4%.

Where results are presented according to stage of CKD, the following definitions apply:



Screening Criteria:

Respondents were screened for age (18 and over) and had to have a diagnosis of both CKD and T2D.

Stage of CKD:

Overall, 44% of respondents have mild stage CKD, 31% have moderate stage CKD and 13% have severe stage CKD. 10% of respondents don't know which stage they are at.

Respondent stage of CKD per country

	Total	UK	France	Germany	Italy	Spain
Stage 1 (a normal eGFR above 90ml/min, but other tests have detected signs of kidney damage)	17%	12%	19%	9%	23%	24%
Stage 2 (a slightly reduced eGFR of 60 to 89ml/min, with other signs of kidney damage)	27%	33%	22%	33%	21%	28%
Stage 3a (an eGFR of 45 to 59ml/min)	19%	15%	15%	19%	25%	23%
Stage 3b (an eGFR of 30 to 44ml/min)	12%	14%	9%	17%	14%	8%
Stage 4 (an eGFR of 15 to 29ml/min)	8%	7%	3%	14%	4%	12%
Stage 5 (an eGFR below 15ml/min, meaning the kidneys have lost almost all of their function)	5%	7%	7%	3%	5%	5%
Not sure / I do not know	10%	12%	25%	5%	8%	-

Foreword

Chronic kidney disease (CKD) associated with type 2 diabetes (T2D) is a complex and devastating condition that takes a significant toll on both patients and healthcare systems around the world. Despite its prevalence, the far-reaching effects of CKD in T2D have been underrecognized globally.

The findings presented in this report provide the first comprehensive look at the patient experience, from diagnosis to dialysis, across Europe. Besides the direct health implications associated with CKD, the data shared here also shines a light on the psycho-social realities for patients which can affect all aspects of their lives. The realities of living with CKD and T2D have long been overlooked, and we are pleased to be able to add to the body of knowledge in this area.

Some of the data shared in this report may be surprising to stakeholders who already work in this field. For example, we found that T2D patients, despite being at risk of developing CKD, knew very little about the condition before their diagnosis. We also found that a significant proportion of patients experienced symptoms for more than a year before their diagnosis. As a result, it is likely that patients are experiencing kidney damage and loss of kidney function that may have been delayed with earlier intervention and better management.

The findings outlined in this report highlight the need for stakeholders to work better together to prioritise T2D patients' kidney health through regular testing, early referral and comprehensive treatment that targets the multiple causes of kidney damage, therefore improving patients' quality of life. The EKPF is committed to improving the quality of care received by CKD patients with T2D. This report provides a new perspective on the challenges faced by patients and a new opportunity to act.



Daniel Gallego Zurro

President of the European Kidney Patients' Federation

CKD associated with T2D can drastically affect the lives of patients and their loved ones, having an impact on personal well-being and many socio-economic factors. It is therefore paramount to get a better grasp of the barriers faced by people living with CKD and T2D. It is our hope that the present work will help foster an enhanced understanding of how patients can be better supported.

As this report demonstrates, CKD and T2D impacts all aspects of life including work, finances, relationships, and intimacy. Still, devastating consequences of living with CKD and T2D can be avoided with comprehensive and multidisciplinary support and education, regular testing, timely intervention, and access to treatment options.

By partnering with the EKPF on this report, we endeavour to enhance the dialogue with key stakeholders to address a variety of issues facing both patients and healthcare professionals. Together, we strive to ensure that all who are involved in the care and management of people with T2D and CKD are well-informed about chronic kidney disease and the associated cardiovascular risk. We are dedicated to making a meaningful difference to the lives of patients.



Dr Richard Nkulikiyinka

Head of Cardiology, Nephrology & Pulmonology within Clinical Development & Operations, Bayer Pharmaceuticals

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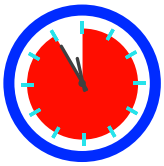
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Executive summary and key recommendations

While early stages of CKD are often symptom-free, timely detection and treatment of chronic kidney disease (CKD) in people with type 2 diabetes (T2D) is critical for their long-term health and survival. Regular kidney health screening of people with T2D using both a urine albumin-to-creatinine ratio (UACR) and estimated glomerular filtration rate (eGFR) test is therefore essential and will help alleviate the huge burden of healthcare system expenditures on advanced CKD.

Despite the fact that regular tests to check the health of the kidneys in people with T2D is recommended by international guidelines,[1,2,3] and widely available tests make early detection of CKD possible, our new survey of people living with T2D and CKD reveals it isn't happening enough, or soon enough, for many people, potentially putting their long-term health and quality of life at risk.

Our survey of 500 people with T2D and CKD across five European countries (France, Germany, Italy, Spain, UK) yielded the following results:



There are likely to be significant delays to CKD diagnosis – with potentially dire consequences

Nine out of 10 (91%) of those surveyed said they were experiencing symptoms for more than two months before diagnosis, while 38% were experiencing symptoms for more than six months, and 20% for more than a year. Considering that CKD is usually symptom-free in the early stages, these results suggest that many people had 'silent' undiagnosed CKD, possibly for many months or years. Left unchecked, and, thus, untreated, CKD is more likely to progress to an advanced stage, resulting in loss of kidney function and increasing cardiovascular risk, eventually leading to end-stage kidney disease (ESKD)[4] which means patients require dialysis or a kidney transplant to stay alive.[5] One study showed that compared with participants with stage 3 CKD, the odds of falling into poverty were 78% higher for those on dialysis.[6] Early diagnosis is essential.



Awareness of CKD among people with T2D before their diagnosis is low – worryingly so

Despite the known link between T2D and CKD, the survey revealed that over half of respondents (54%) knew nothing about CKD prior to their diagnosis, with only 11% saying they knew a lot about CKD. Awareness of CKD and its associated risks is a key first step toward effective management and disease control.



CKD has a profound negative impact on many people's lives – including mental health

In total, 88% of people in the survey said that their life has changed in some way since they were diagnosed with CKD, with impact on work, finances, relationships and intimacy commonly cited. One of the most unsettling insights from the survey was the emotional impact of CKD. Around seven out of 10 (69%) of respondents said they experience anxiety around managing their CKD, and 57% said they have experienced depression since their diagnosis. In total, 65% agreed that living with CKD has had a negative impact on their mental health. These are worrying numbers, and it is highly likely that many mental health issues go undetected.

Call to action: It's time to act

The survey results paint a picture of a condition that is having a widespread impact on millions of lives all over the world but is still going under the radar in terms of the urgency of response. We believe there are considerable opportunities to increase early identification and management of CKD in people with T2D to slow CKD progression, improve outcomes, and improve quality of life of people living with CKD and T2D.

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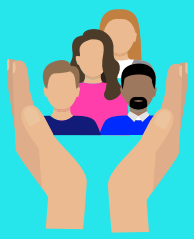
Assessment

CKD in people with T2D is a silent disease, meaning that early signs of kidney damage are not always visible. As per international guidelines, all people with T2D should be tested at least annually, using both a UACR and eGFR test.[1,2,3] Monitoring these patients with a combination of both tests not only reveals the level of kidney damage incurred, but also the risk of cardiovascular complications. The multidisciplinary care team need to work together to prioritise kidney health of people with T2D through frequent testing, timely referral and comprehensive treatments that target the multiple drivers of CKD.



Communication

By achieving the goal of regular and timely testing, the dialogue between a patient and their doctor is opened earlier. An open dialogue focused on awareness of CKD and its associated risks in those with T2D is the first step toward effective management and disease control. Whilst it is crucial that doctors strive to educate all people with T2D about CKD, patients must feel empowered and prepared to both receive and understand this information at the right time. We must eliminate the disconnect and encourage the implementation of processes to enhance both knowledge sharing and receiving amongst physicians and patients alike.



Togetherness

Living with CKD can take a huge toll on a person's mental health and, worryingly, these issues often go undetected. It is crucial we observe a patient's emotional state to help the process of accepting the disease to avoid emotional disorders that interfere with treatments. All stakeholders involved are responsible for ensuring ongoing and available mechanisms are in place to check-up on a patient's mental health, helping them to manage their condition day-to-day. Together, we can improve people's quality of life and optimise approaches to collaborative care.

Introduction: CKD and T2D – a growing global health burden

Chronic kidney disease (CKD) is a common and life-threatening condition that is widely underrecognized. CKD is one of the most frequent complications arising from diabetes[7,8] and is an independent risk factor of cardiovascular disease. The condition can significantly shorten the life expectancy of people living with T2D by 16 years, relative to the general population living without either disease.[9]

Around two out of every five people living with T2D will develop CKD in their lifetime.[4,10,11] Considering there are approximately 462 million individuals currently living with T2D worldwide[12] – which is around 6% of the world's population – the potential scale of CKD in people with T2D becomes clear. T2D is the leading cause of CKD, with an estimated 190 million people with T2D affected by the condition worldwide.[13,14] But many of them are not aware.

What is CKD?

CKD develops over a long period of time, as following kidney damage, the kidney function can gradually decline and as a result, the kidneys cannot filter blood as well as they should. There is a gradual loss of kidney function over a period of months to years and eventually the kidneys may stop working altogether, requiring dialysis or a kidney transplant.

It is estimated that around 700 million people worldwide have CKD.[15]

CKD is very common in people with T2D. This is because over time, high blood sugar from T2D can damage the kidneys.

Health impact

The impact of CKD on people's lives can be devastating, particularly if undiagnosed and, thus, untreated. CKD is associated with a significantly increased risk of cardiovascular disease (CVD), including myocardial infarction, ischemic stroke/transient ischemic attacks, and all-cause mortality, when compared with the risk in people with T2D without CKD.[16] In fact, people with CKD and T2D are at least three times more likely to die from a cardiovascular-related cause than those with T2D alone.[17] Many people with CKD and T2D progress to loss of kidney function, eventually leading to ESKD[4] and potentially needing dialysis or a kidney transplant to stay alive.[5]

Economic impact

CKD represents a significant economic burden. CKD-related costs in Europe are estimated at 1.3% of total healthcare costs.[18] Significantly, the financial cost of caring for someone with CKD increases exponentially with CKD stage progression[19] – therefore, the huge cost associated with treating advanced CKD offers a compelling economic advantage for improving the early detection of T2D-associated CKD. Indeed, the economic impact could be mitigated by early and comprehensive therapeutic approaches.[20]

Psycho-social impact

Evidence from various chronic disease studies indicates that psychosocial factors including depression, anxiety and social isolation have a significant impact on quality of life, biological factors and disease progression. Targeted psychosocial interventions have been shown to improve quality of life, treatment compliance, physical functioning and reduce the risk of cardiovascular disease.[21] However, despite the increasing social and economic burden of CKD, not enough is being done to understand and address our understanding of the impact of psychosocial factors on the progression of disease and management of those with CKD.

Early detection of CKD in people with T2D is critical

Early detection of CKD in people with T2D is critical to halting its progression and improving outcomes.[22,23] Early detection can also prevent emotional disorders, as it allows more time for a patient to digest their diagnosis, readying them for the receipt of information and the potential upcoming lifestyle changes required.

Therapies exist that can slow the progression of CKD in people with T2D, which means early detection and intervention of CKD through screening tests is vital to prevent further kidney damage and delay kidney function decline.

Early detection will likely prevent CKD progression, cardiovascular complications, ESKD and premature death, in addition to improving quality of life.[24]

The good news is that therapies exist that can slow the progression of CKD in people with T2D, which means early detection and intervention for CKD through screening tests is vital

CKD is often 'silent' in early stages – but effective tests exist

The main challenge with early detection of CKD is that it usually progresses silently and often unpredictably, with many symptoms not appearing until the disease is well-advanced.[25,26] This means that doctors cannot rely on people self-reporting with symptoms – making early diagnosis and treatment more challenging and further progression of the disease more likely.

There are two main tests widely available to proactively screen, diagnose and monitor kidney disease and determine the level of kidney damage, as well as how well the kidneys are functioning.



The UACR test tracks how much albumin, a protein commonly found in the blood, is leaking into the urine and is a sensitive measure of early kidney damage.[27]



The eGFR test estimates the kidney filtration rate and thus informs about how well the kidneys are functioning by measuring creatinine, a waste product eliminated via the kidneys.[27]

Ideally, these tests should be used together, allowing for early and more comprehensive detection of CKD.[22,27] The major internationally acknowledged guidelines developed by the most prominent primary care and endocrinology societies all advocate yearly screening for CKD in people with T2D via testing UACR and eGFR.[1,2,3]

Chapter 1:
The path to diagnosis

Summary

In this section, we present survey results focused on the journey to diagnosis, revealing that it often takes much longer than necessary for many people, potentially putting their long-term health and quality of life at risk. The results also reveal the impact that the news of a CKD diagnosis can have on people with T2D.

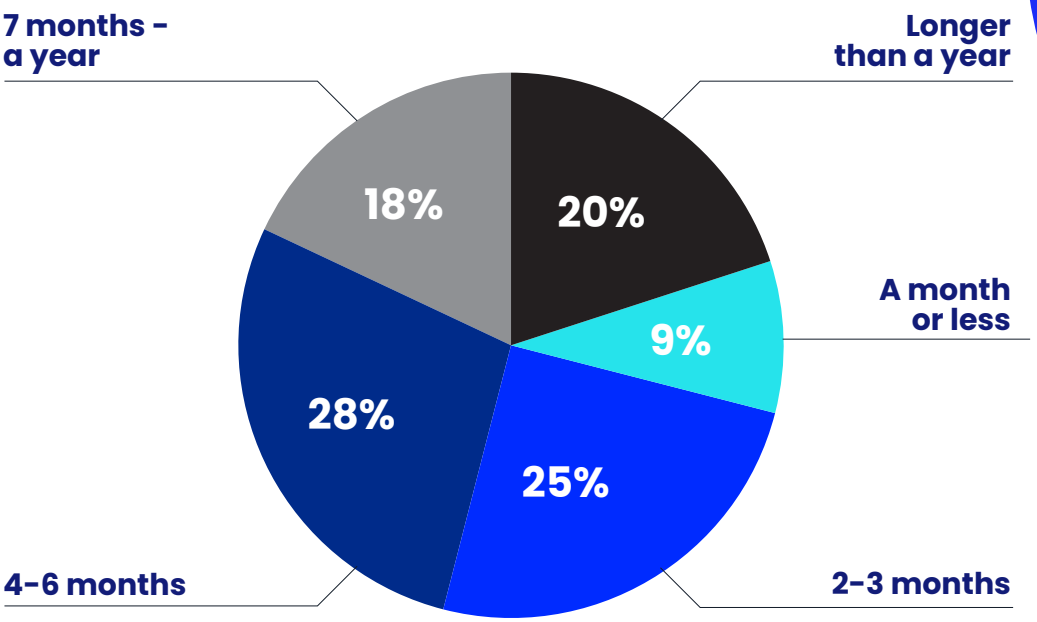
CKD detection may be unnecessarily delayed in many people with T2D

Despite compelling evidence on the benefit of early, regular screening of CKD in people with T2D and major internationally acknowledged guidelines advocating it, our research suggests that it isn't currently happening.[1]

Our survey revealed that many people experienced symptoms of CKD for months before their diagnosis. In total, 91% of respondents said they were experiencing symptoms for more than two months (See Fig 1), while 38% were experiencing symptoms for more than six months, and 20% for more than a year. This suggests that, if people with T2D were more aware of their risk of CKD, they could also play a key part in early diagnosis, promptly discussing the arising symptoms with their healthcare professionals.

This is worrying because CKD usually progresses silently in the early stages, with most symptoms not appearing until the disease is well-advanced.[25,26] The results suggest that many people had 'silent' undiagnosed CKD, possibly for many months or even years.

Fig 1: Time spent experiencing symptoms prior to diagnosis



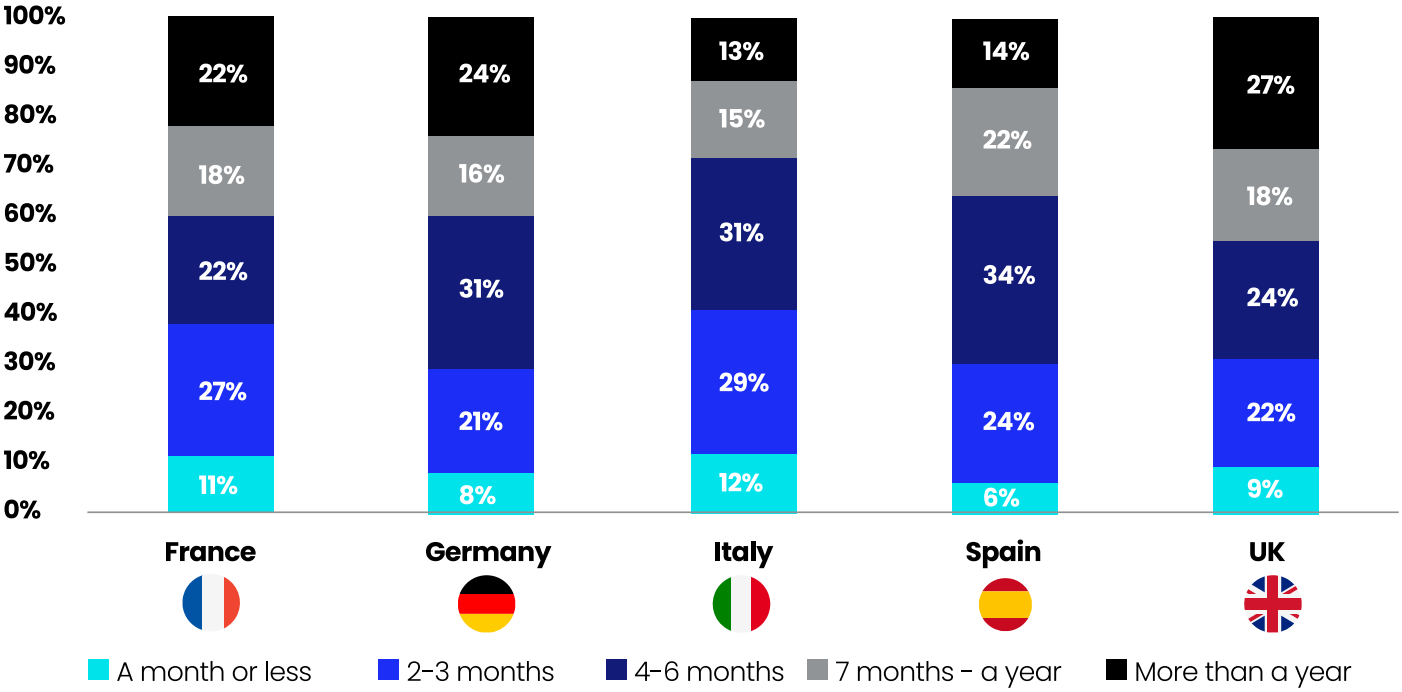
It is somewhat troubling that so many people with type 2 diabetes are not screened for chronic kidney disease for months or even years before the disease becomes apparent. We must detect it earlier, when we can really make a difference. We have the tools at our disposal to do so.



– Professor Christoph Wanner, Nephrologist,
Professor of Medicine and Head of the Division of Nephrology in the Department of Medicine at the University Hospital of Würzburg, Germany

The country results for time spent experiencing symptoms of CKD before diagnosis (Fig 2) reveal that in both Germany and the UK, around one in four people experienced symptoms for more than a year before diagnosis (24% and 27% respectively). In the UK, nearly half (45%) of people experienced symptoms for more than six months before diagnosis.

Fig 2: Time spent experiencing symptoms prior to diagnosis: country comparison



These results suggest that despite guideline recommendations to screen for CKD in people with T2D, many patients remain undiagnosed and undertreated.

This is supported by wider research. In a study assessing undiagnosed CKD in people with T2D in Germany and France, undiagnosed CKD was extremely high (94% and 74%, respectively), and was greater in those aged over 65 and in females.[28] One US study by the US Renal Data System looked at testing trends during one year in two populations of people with T2D and without diagnosed CKD. During that year, less than half in both the Medicare (42%) and Optum Clinformatics (49%) populations had undergone any testing.[29]

An analysis in Germany of 116,747 people with T2D showed that only 49.1% of them were annually screened for CKD using both a UACR and eGFR test.[30] A US study assessing CKD screening of people with T2D and / or hypertension revealed that only 28.7% of people with T2D and 41.4% of those with both comorbidities were tested for CKD over a six-year period.[31]

The conclusion from our survey and other supporting research is that there are considerable opportunities to increase early identification and proactive management of CKD to slow progression and improve outcomes.

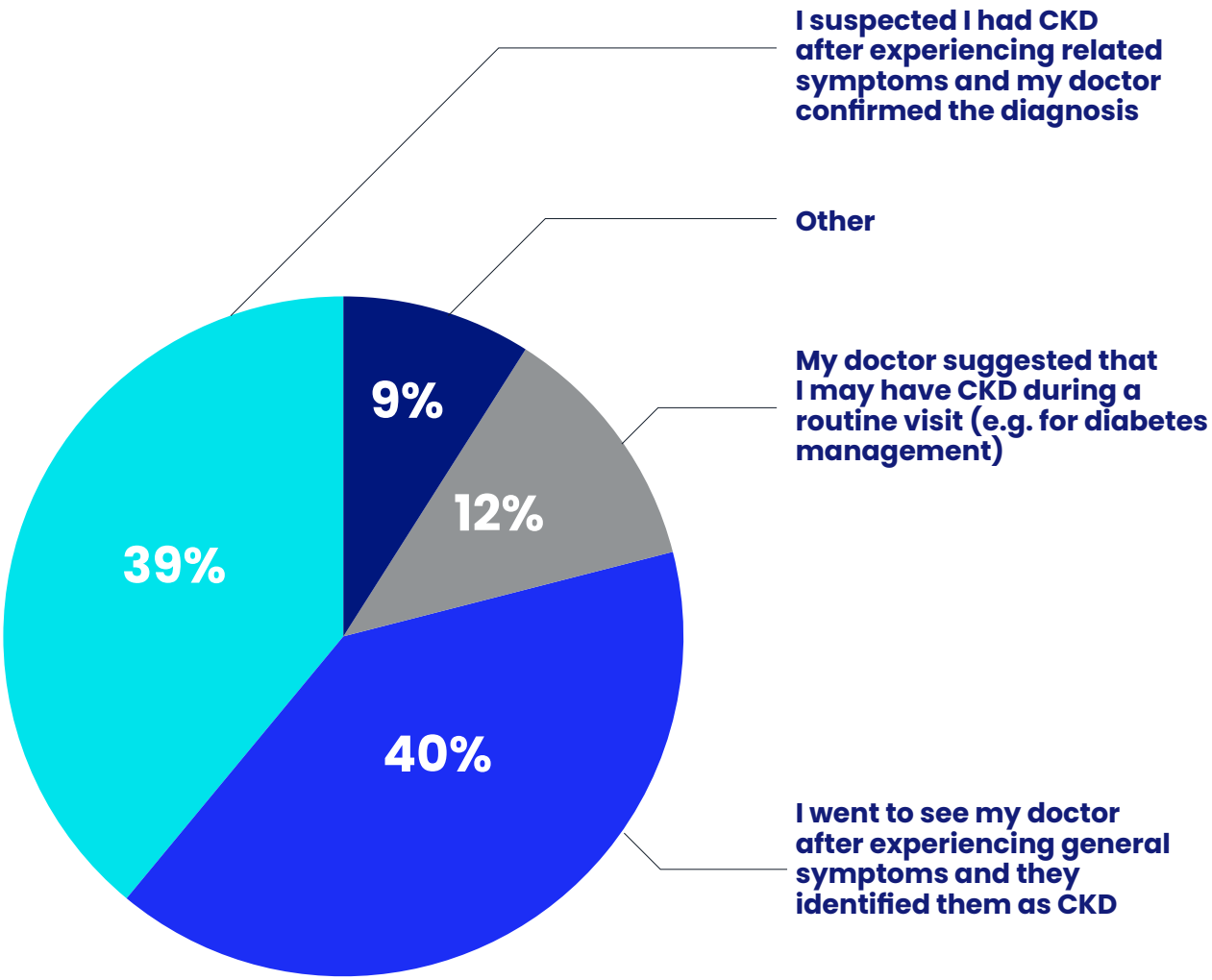
There are considerable opportunities to increase early identification and proactive management of CKD to slow progression and improve outcomes.

Understanding the process of CKD diagnosis

When asked about how the process of their CKD diagnosis occurred, survey respondents were given options and asked to select the most accurate to their own situation (see Fig 3). It is noticeable that over half of them (52%) either went to see their doctor after experiencing general symptoms (e.g. fatigue, shortness of breath), later diagnosed as CKD (40%), or suspected CKD themselves after experiencing symptoms, which was then confirmed (12%).

Either way, it reaffirms that the majority of people in the survey appear to have already been symptomatic by the time they were diagnosed. A further 39% were diagnosed during a routine visit for their T2D management.

Fig 3: How did the process of CKD diagnosis occcur?



Anxious, scared, stressed, depressed – the impact of diagnosis

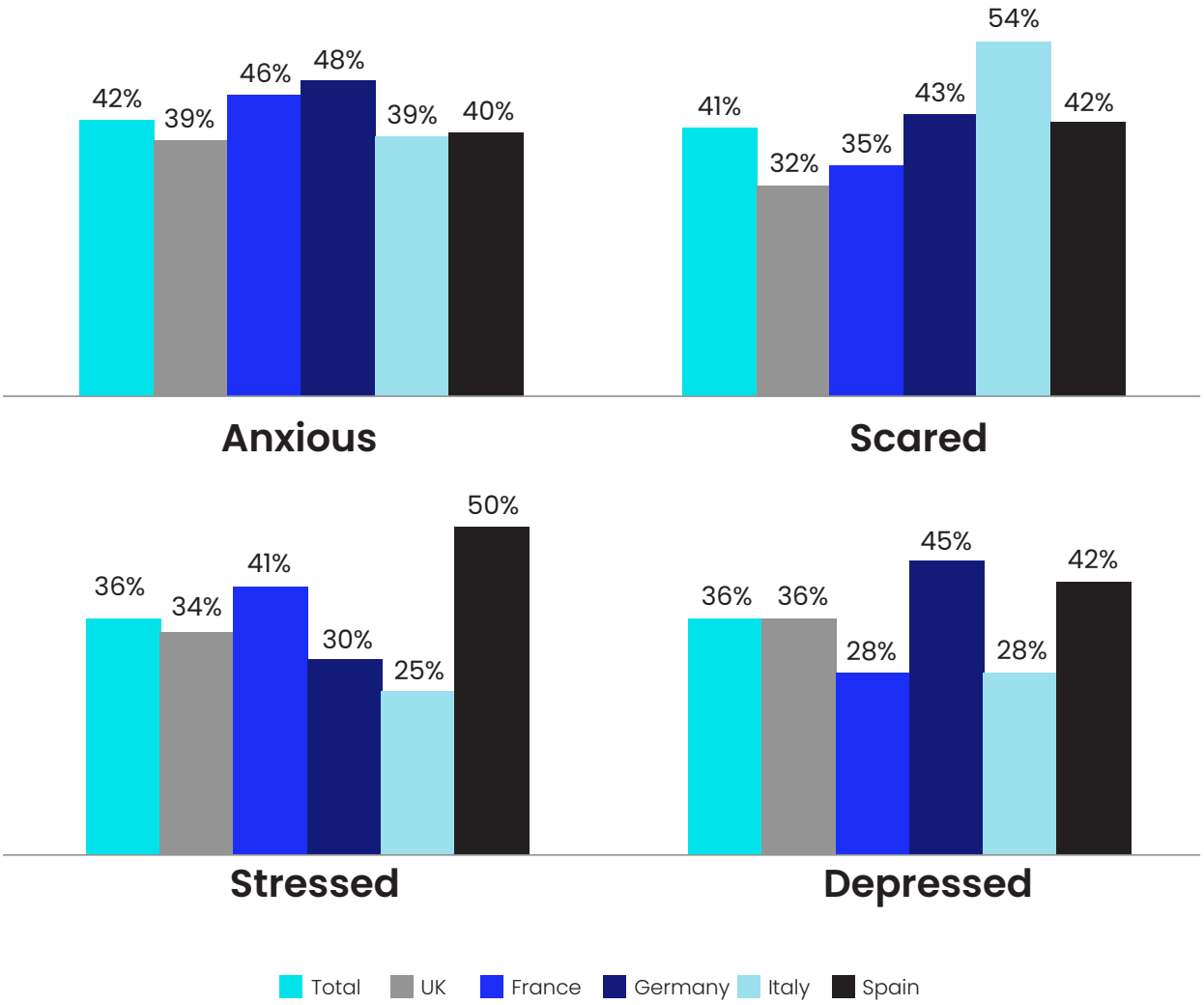


A diagnosis of a life-threatening chronic disease such as CKD can have a major impact on an individual's life that can cause a great deal of stress and create a range of feelings and worries. This will likely only be exacerbated when already living with another chronic condition, in this case T2D.

Our research revealed that receiving a CKD diagnosis left more than one in every three people feeling anxious (42%), scared (41%), stressed (36%) or depressed (36%).

The results revealed some interesting differences between countries (see Fig 4). Respondents in Italy were considerably more likely than those in other countries to feel scared, while people in Spain were by far the most likely to say it made them feel stressed. Although Germans were most likely to report feeling anxious after diagnosis (48%), they were also significantly more likely to report they felt ambivalent (26%) or relieved (17%) than respondents in any other country, potentially hinting at some cultural differences in attitudes to health. These findings indicate the necessity to ensure ongoing and available mechanisms are in place to check-up on a patient's mental health, helping them to accept their diagnosis, manage their condition day-to-day and address emotional disorders that can interfere with treatment.

Fig 4: How did you feel after receiving your CKD diagnosis?



Chapter 2:
Patient knowledge and care

Summary

In this section, we present results from the survey around patient knowledge of CKD and review satisfaction levels around doctor relationships. The research suggests that many people with T2D are not aware of the connection with CKD or what symptoms to look out for.

People with T2D lacked knowledge of CKD prior to diagnosis

Awareness of a disease is the first step toward effective management and disease control. However, the majority of people in the survey (54%) knew nothing about CKD prior to their diagnosis:

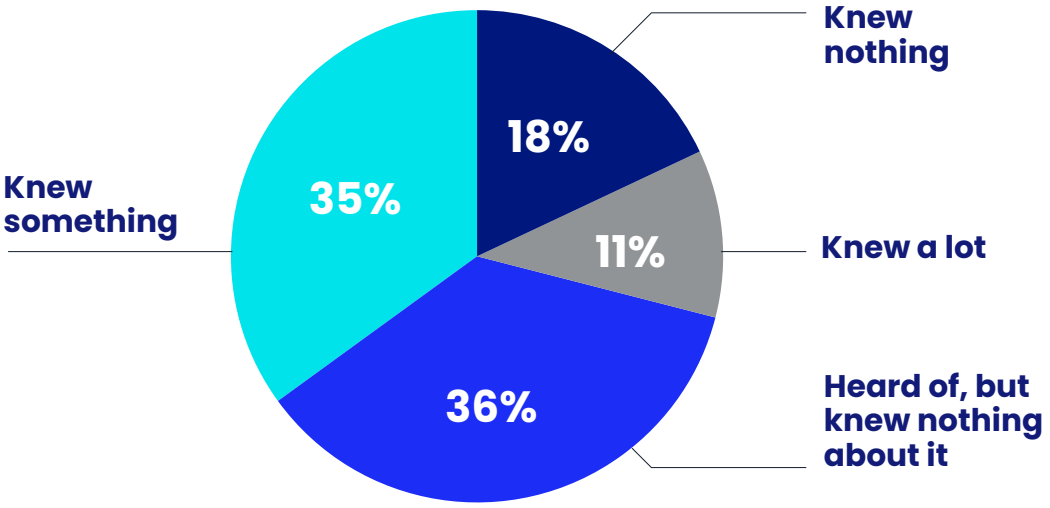
18%
Said they knew nothing

36%
Had heard of it, but knew nothing about it (see Fig 5)



Only a small minority (11%) said they knew a lot about CKD prior to their diagnosis.

Fig 5: Prior to diagnosis, did you know about chronic kidney disease?



Knowledge may help people to be more proactive with their own care, both asking their doctor for screening as well as spotting the signs and symptoms of CKD.

However, CKD progresses silently and oftentimes unpredictably, with many symptoms not appearing until the disease is well-advanced.[25,26] By this time, it may be too late to prevent irreversible organ damage. That is why proactive screening is so essential.

The types of symptoms people may experience at a more advanced stage of disease include the need to urinate more often, leg swelling, tiredness in the day, nausea, muscle cramps, joint pain and confusion, difficulty concentrating, and memory problems.[5,32]

Most people with T2D and CKD have a good relationship with their doctor

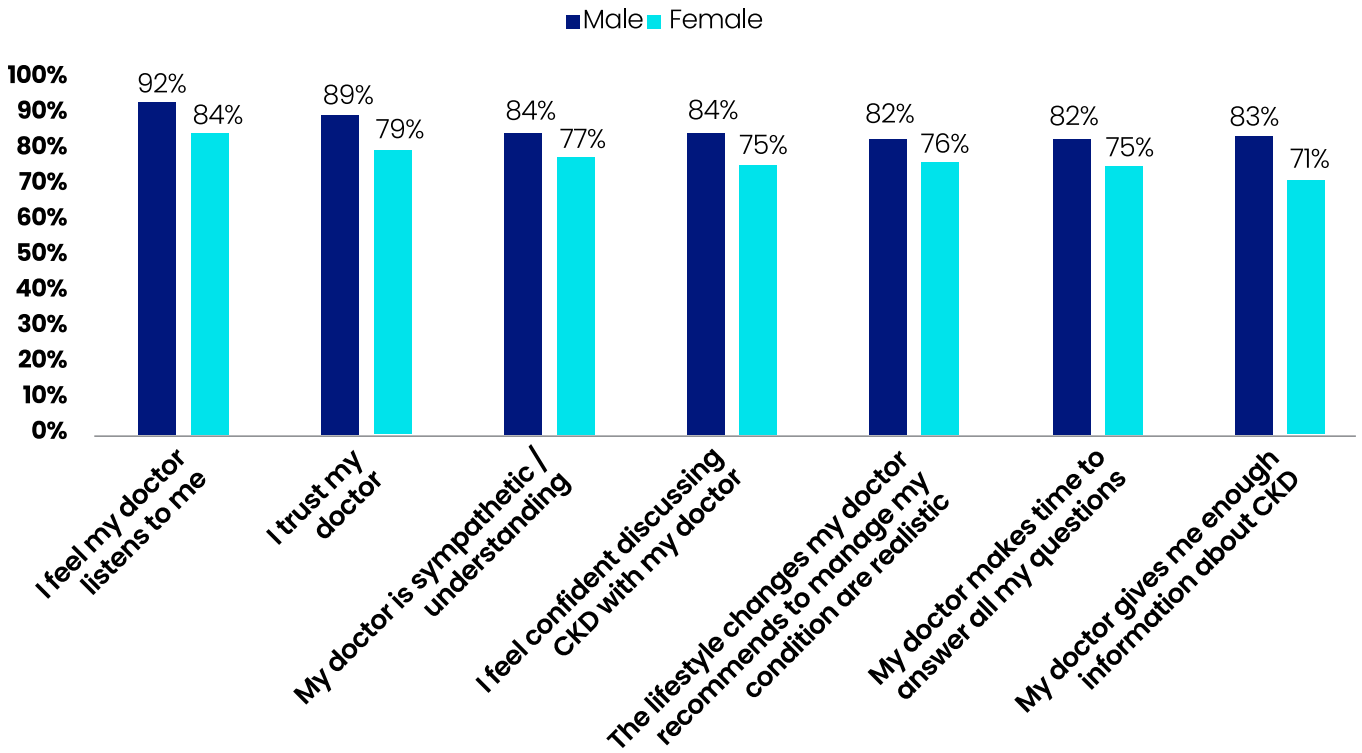
The good news is that once diagnosed with CKD, people are generally satisfied with the care they receive and have a good relationship with their doctor. 79% of people in the survey said they were very satisfied or satisfied with the level of care they were receiving from their primary care practitioner (PCP). Only a very small minority (5%) said they were very unsatisfied or unsatisfied with their level of care, although this number did increase to 11% in the UK.

When asked to agree or disagree with a series of statements – including "I feel my doctor listens to me" and "I trust my doctor", the majority of respondents agreed with them.

Of some potential concern is the difference in responses between men and women (see Fig 6). Significantly more men agreed with several of the statements, including "I feel my doctor listens to me" (92% vs 84%), "I trust my doctor" (89% vs 79%), "I feel confident discussing CKD with my doctor" (84% vs 75%) and "My doctor gives me enough information about CKD" (83% vs 71%).



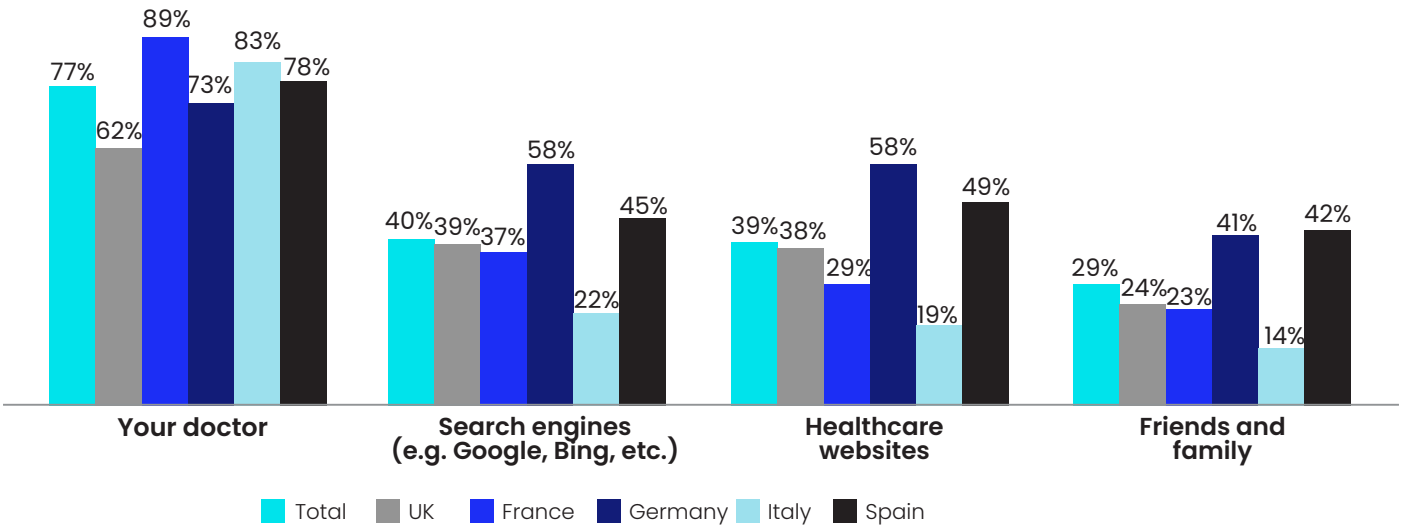
Fig 6: To what extent do you agree, or disagree, with the following statements as they pertain to the relationship you have with your PCP in the management of your CKD?



Doctors are the primary source of information on CKD for people across all countries, with 77% of respondents saying they use their doctor to answer questions they have about CKD. This is significantly higher than the number who said they use other options such as search engines (40%), healthcare websites (39%), friends and family (29%), and online forums (22%).

Looking at the country differences (Fig 7), it is interesting to note that those in Germany and Spain were much more likely to turn to other sources of information beyond their doctor.

Fig 7: Which of the following do you use to answer questions you have about CKD?



The type of doctor people use as a source of information/advice is somewhat country dependent, too (see Fig 8), with significant differences on which healthcare professionals people consult within each country. This is likely due to difference in national healthcare pathways and access, for example the involvement by auxiliary health professionals such as diabetes specialty nurses in certain countries.

Fig 8: Which of the following HCPs do you get advice on CKD from?



	Diabetologist	Nephrologist	GP	Nurse
Total	53%	53%	50%	24%
	33%	44%	49%	32%
	42%	43%	68%	14%
	80%	61%	36%	34%
	61%	61%	56%	3%
	49%	58%	43%	36%

Chapter 3:
Impact of CKD on life

Summary

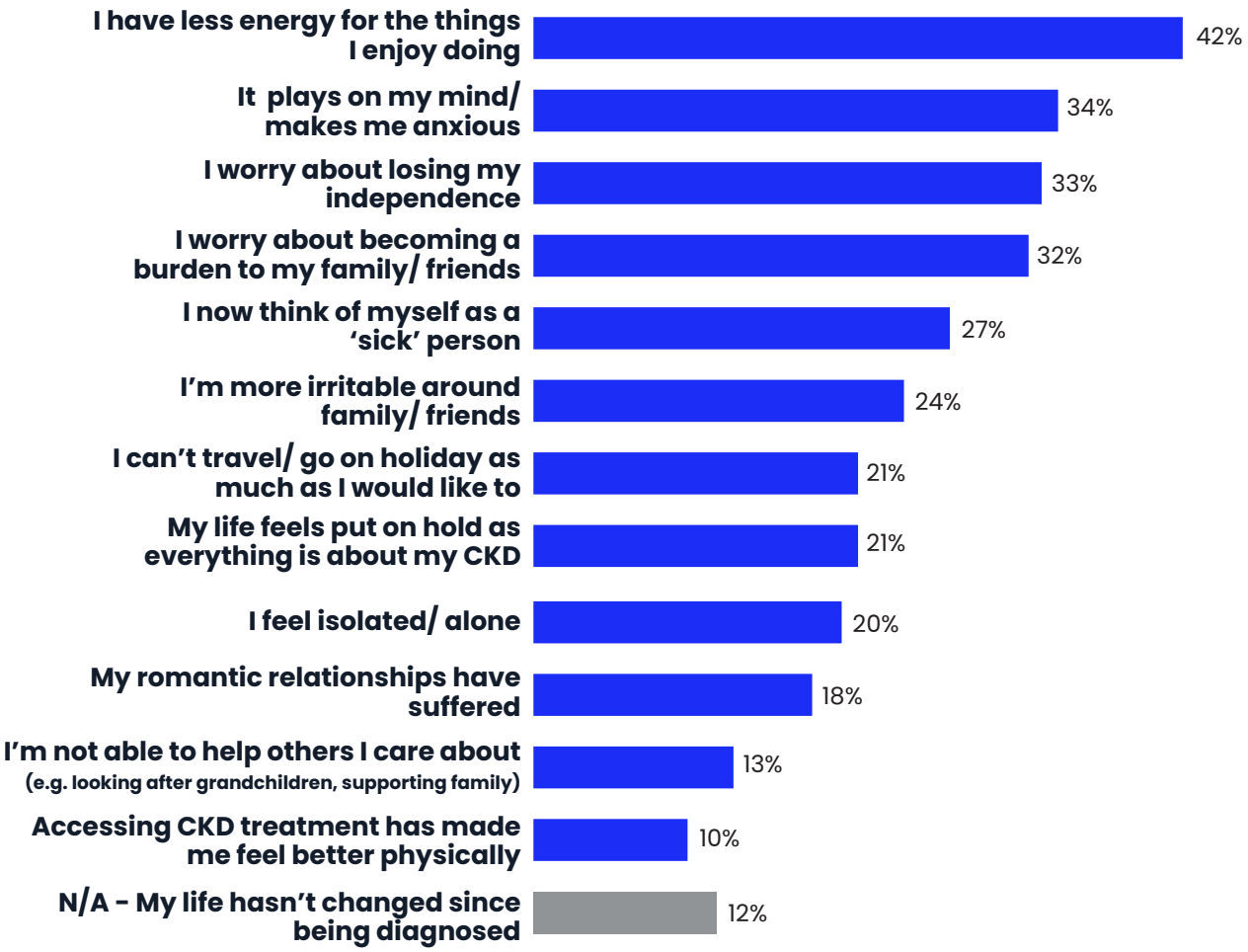
In this section, we present results from the survey around the impact of CKD on people's lives, revealing the often-untold story of CKD and T2D – one of debilitating symptoms, depression, anxiety, and deep concerns around work, finances and personal relationships.

CKD: A life-changing impact

A diagnosis of CKD can drastically affect the lives of those affected and their loved ones. It can have a profound and wide-ranging impact on an individual's personal life, including social, economic, and physical effects.[33]

In total, 88% of people in the survey said that their life has changed in some way since they were diagnosed with CKD. Given a range of statements to agree or disagree with to indicate how their life has changed (see Fig 9), nearly three out of four respondents (73%) agreed with at least two statements, and over half (57%) agreed with at least three, suggesting the impact of a CKD diagnosis has been quite profound for many people.

Fig 9: How have you found your life has changed since you were diagnosed with CKD?



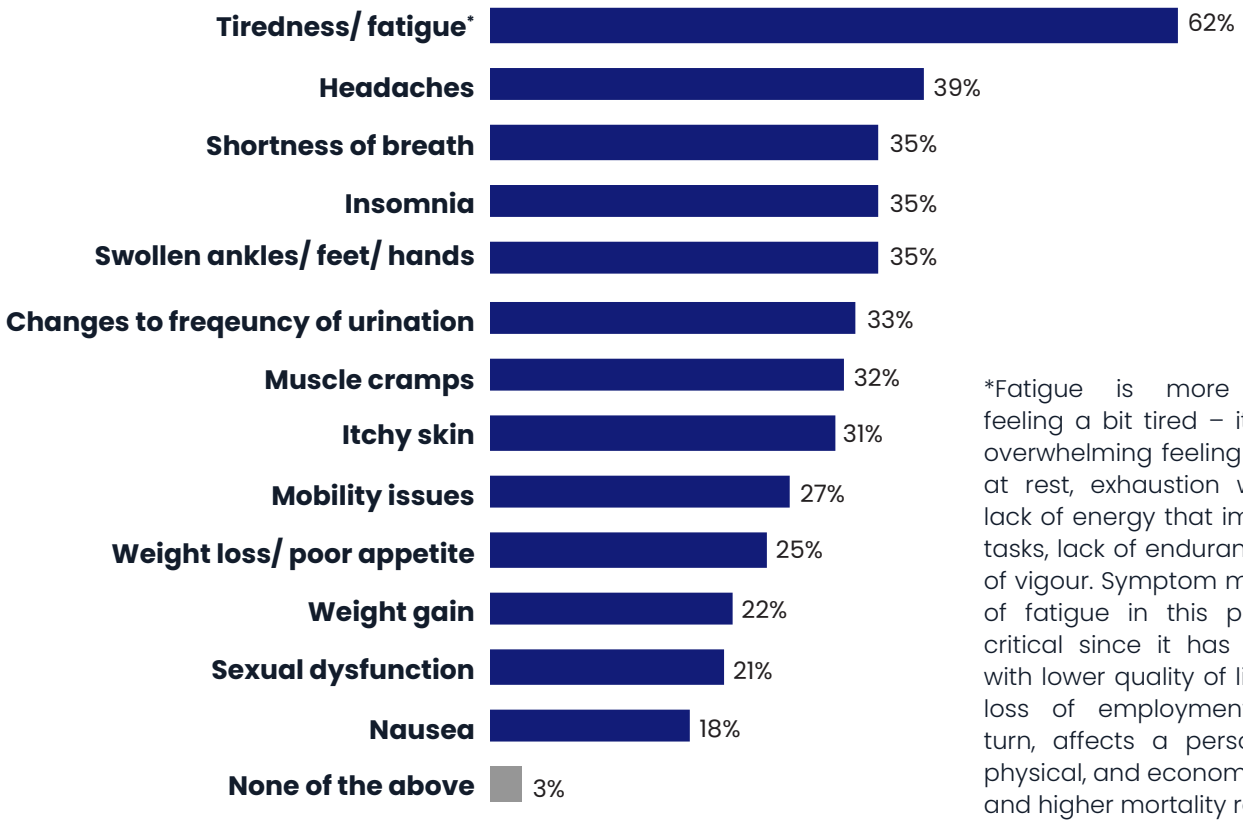
The most commonly selected life impact was having less energy for things that they enjoy doing, with 42% of all respondents selecting this option. Other key concerns include feeling anxious (34%), losing independence (33%) and becoming a burden to friends/family (32%).

That 'having less energy' was the most commonly selected impact on life is not surprising. Fatigue is among the most common and most distressing symptoms for people with kidney disease, and the prevalence increases with advancing CKD stages.[34]

Respondents were asked directly about the symptoms of CKD they experience, and nearly two thirds (62%) reported they felt tiredness/fatigue (see Fig 10). In people with severe CKD (stage 4 and 5), this number rose to 75%.



Fig 10: Do you experience any of the following CKD symptoms?



*Fatigue is more than just feeling a bit tired – it can be an overwhelming feeling of tiredness at rest, exhaustion with activity, lack of energy that impedes daily tasks, lack of endurance, or a loss of vigour. Symptom management of fatigue in this population is critical since it has been linked with lower quality of life, including loss of employment which, in turn, affects a person's mental, physical, and economic wellbeing, and higher mortality rates.[35]

Fatigue is such a common symptom that we see, but effective treatment is complicated because we do not fully understand the causes of fatigue in CKD. But it's very important that we acknowledge to people that we understand just how challenging living with fatigue can be, and that we try the various options to help mitigate it.



– Professor Peter Rossing, Diabetologist,
Head of Complications Research at Steno Diabetes Center Copenhagen, Denmark

Fatigue is not the only debilitating symptom.
Around a third of respondents in the survey experienced:



Headaches
39%



Insomnia
35%



Swollen ankles/ hands/feet
35%



Shortness of breath
35%



Changes to frequency of urination
33%

As would be expected, many of these numbers increased in those with more advanced CKD, with people significantly more likely to experience shortness of breath, swollen ankles/feet/hands, mobility issues and weight loss/poor appetite.

Those with severe CKD said they were also more likely to experience multiple symptoms - 55% said they experienced five or more of the symptoms listed, which reflects the significant impact of the disease once it progresses.

More than half of those with severe CKD (55%) said they experienced five or more symptoms, reflecting the significant impact of the disease once it progresses.

Lifestyle changes are essential but difficult

Fatigue is also a complicating factor when it comes to people trying to change their lifestyle following a diagnosis of CKD. When someone is diagnosed with CKD, it is likely their doctor will ask them to implement some lifestyle changes, such as stopping smoking if a smoker, doing regular exercise, losing weight if overweight or obese and eating a healthy, balanced diet.

The survey suggests that many individuals find this difficult. Almost half (48%) said they find losing weight difficult, while many said they found other lifestyle changes difficult, including exercising (41%) changing their diet (36%) and quitting smoking (29%). These lifestyle changes were more challenging for people than adhering to their medical treatment plan, with 25% and 24% saying attending appointments and taking prescribed medication were difficult, respectively.

Lack of energy – likely caused by fatigue – is the biggest barrier in making healthy lifestyle changes. Almost half of those with CKD (45%) said that it is hard to make the lifestyle changes their doctor recommends as they don't have the energy to exercise as much.

Lack of energy – likely caused by fatigue – is the biggest barrier in making healthy lifestyle changes. Almost half of those with CKD (45%) said that it is hard to make the lifestyle changes their doctor recommends as they don't have the energy to exercise as much.

There were some interesting differences between male and female respondents:



More women (46%) found it difficult to exercise as much as their doctor recommends to them than men (37%)



More men (36%) found it harder to quit smoking than women (24%)

Meanwhile, a key reason that many found it difficult to adhere to their medical treatment plan, both of medicines (37%) and hospitals/clinics (34%), was because the costs are too high. Those with severe (47%) and moderate (44%) stage CKD were more likely than those with mild stage CKD (28%) to find it difficult to adhere to medical treatment because the cost is too high.

Changing diet is difficult but achievable

On a positive note, while 36% said changing their diet was difficult, more than half of respondents (57%) said that they now eat more healthily in general, with a similar number (56%) saying they now control how much salt is in their diet due to their CKD.

This is encouraging, and very important. While healthy kidneys can balance salts and minerals in the blood, in people with CKD, the kidneys can't filter the blood the way they should. This means that eating the right types of food is very important to help the kidneys maintain a healthy balance of salts and minerals in the body. If foods high in sodium (salt), potassium, and phosphorus are avoided, it may help to prevent or delay some health problems from CKD.[36]

In the survey, 30% of respondents said they now limit the amount of potassium in their diet, while 43% control the amount of fluid they drink and 32% have reduced the amount of alcohol they drink. These steps all help to reduce pressure on the kidneys.

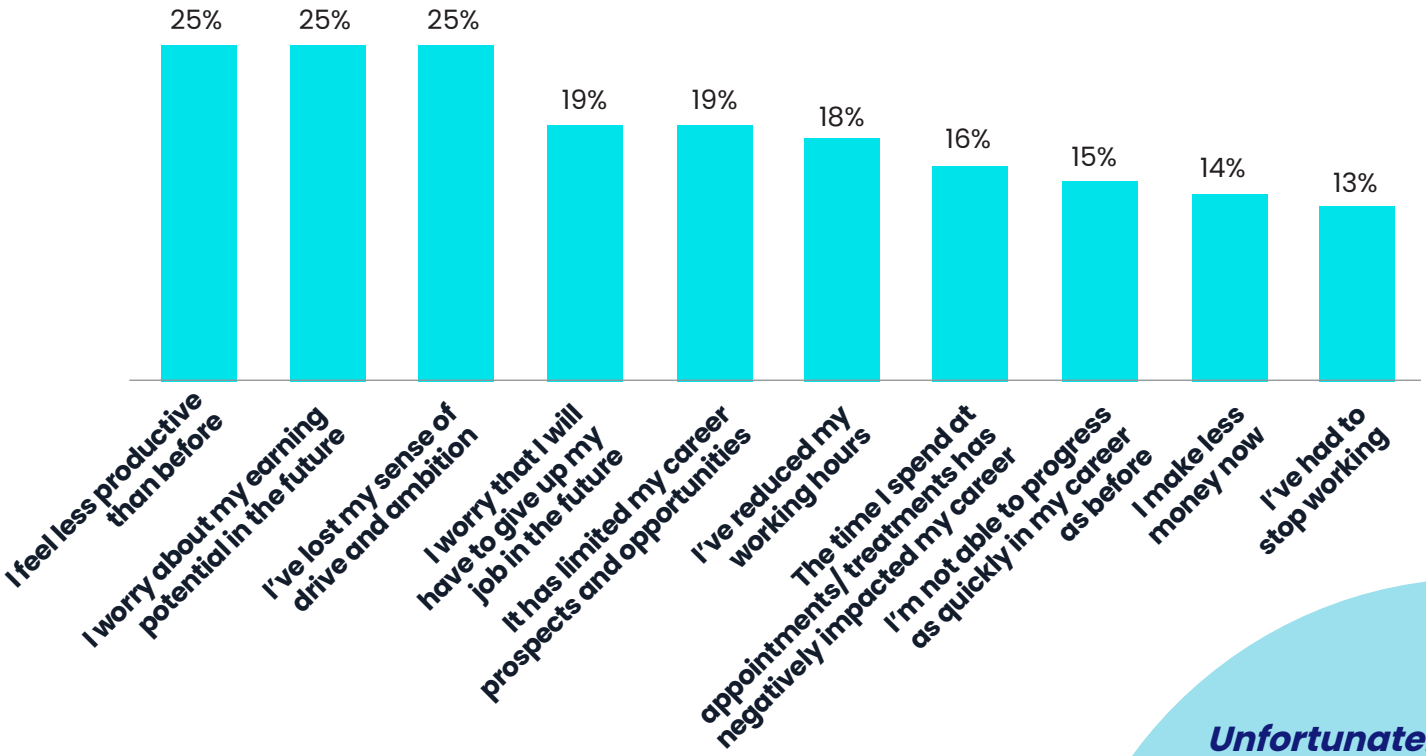
Only 19% said they exercise more than they did before, although with the high levels of fatigue reported, this is perhaps not surprising. Nonetheless, regular exercise has been shown to improve physical and walking capacity for people with non-dialysis CKD,[37] and even just 12 weeks of aerobic and strength-based exercise reduces symptoms and levels of fatigue,[38] so it should be encouraged where appropriate and feasible.

Impact on career and finances can be substantial

CKD can place a financial burden on individuals and on their carers through lost working days and morbidity.

Over three in four (77%) survey respondents said that CKD has had some kind of impact on their working life and career, with one in four (25%) saying they are less productive, worry about their future earning potential and have lost their sense of drive and ambition (see Fig 11).

Fig 11: What impact has CKD had on your working life and career?



Around one in five (19%) said they were worried they will need to give up their job in the future. It is true that many who progress to severe stages of disease and dialysis face a potential loss of employment.[39] In the survey, 31% of respondents with severe CKD said they have had to stop working, compared with 10% of those with mild CKD.

Unfortunately, the overall financial burden worsens with disease severity, too. One study showed that compared with participants with stage 3 CKD, the odds of falling into poverty were 51% higher for those with stage 4, 66% higher for those with stage 5, and 78% higher for those on dialysis.[6]

The financial impact can be quite significant. In the survey, among those who say that they now make less money since their CKD diagnosis, 43% have seen their annual income decrease between €5,900 (£5,000) and €17,700 (£15,000). When you consider that the average wage, for example in the UK, is £38,131 (€44,995, using the same exchange rate used in the survey), the scale of the impact is clear.



Unfortunately, the overall financial burden worsens with disease severity, too. One study showed that compared with participants with stage 3 CKD, the odds of falling into poverty were 51% higher for those with stage 4, 66% higher for those with stage 5, and 78% higher for those on dialysis.[6]

The unseen and devastating emotional impact of CKD

Any chronic illness can have an emotional impact and affect mental health, but CKD is characterised by a gradual loss of kidney function over time. It gives people a lot more to think about, particularly in terms of worrying about the future, which can lead to feelings of anxiety, anger, worry, and stress.

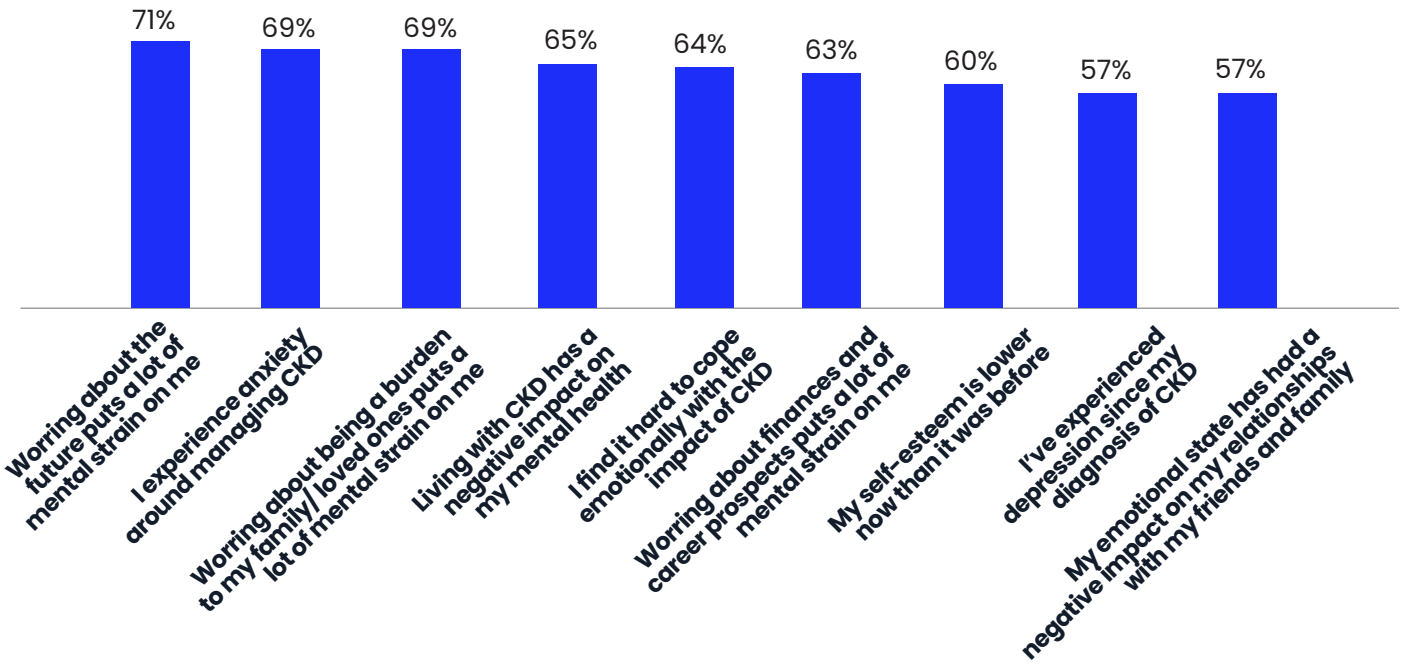


Almost everyone who was surveyed (96%) had some concern about the future because of their CKD.

The most common concerns about the future included having an overall poorer quality of life (40%), a fear of their symptoms – and overall health – getting worse (39%), feeling like a burden to their loved ones (37%), concern about their life being cut short (36%), and losing their independence (35%). The COVID-19 pandemic also made 69% of people feel less optimistic about the future.

Respondents were also asked if they agreed with a series of statements related to the emotional impact that CKD has had on them. It is telling that every statement received agreement from at least half of all respondents (see Fig 12).

Fig 12: What emotional impact has CKD had on you?



Depression, anxiety and other mental health issues are common among people living with kidney disease.

It is a significant concern because, as well as the impact on quality of life, the presence of psychiatric disorders such as depression or anxiety has been shown to be associated with a higher likelihood of adverse clinical outcomes in people with CKD.[40]

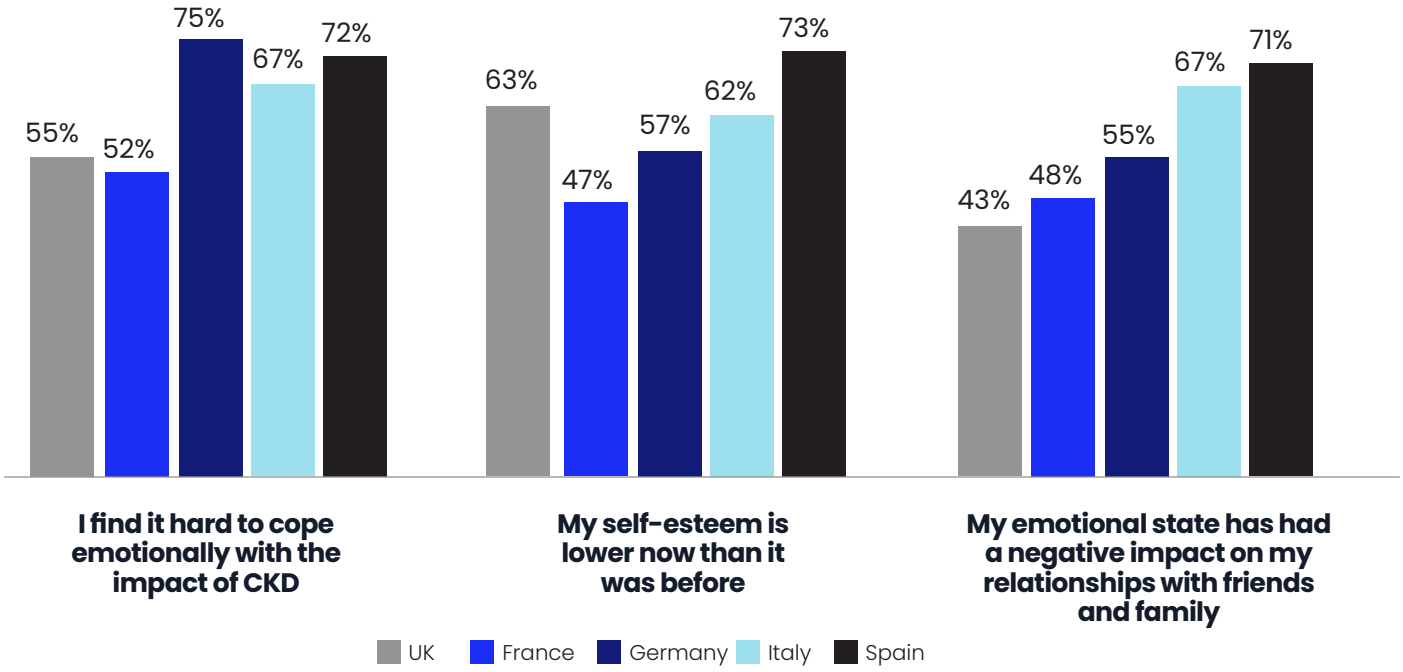
In the survey, 69% of respondents said they experience anxiety around managing their CKD, and 57% said they have experienced depression since their diagnosis. In total, 65% agreed that living with CKD has had a negative impact on their mental health. These are worrying numbers.

More than seven in ten (71%) said that worrying about the future puts a lot of mental strain on them and a similar number (69%) said the worry about being a burden to their family or loved ones causes mental strain. Nearly two-thirds (64%) said they find it hard to cope emotionally with the impact of CKD.

69% of respondents said they experience anxiety around managing their CKD, and 57% said they have experienced depression since their diagnosis.

The results revealed some interesting country differences. In general, more German and Spanish respondents agreed with the statements on emotional impact than those in France and the UK, with Italy somewhere in between. The three statements in Fig 13 in particular revealed some significant differences between the countries.

Fig 13: What emotional impact has CKD had on you?





This timely report reminds us of the many problems and issues for coping experienced by people living with CKD. Being aware of the range of problems that can so significantly impact on people's lives is important for our clinical practice. The experiences of the patients who kindly responded to this survey bring such challenges to life – for example how common symptoms, such as fatigue, can be difficult to live with and can interfere with important plans and social interactions especially when symptoms flare up. As healthcare professionals, being better aware of the challenges facing our patients with long term problems can directly influence our caring role.

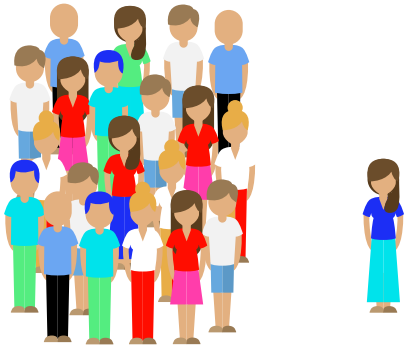
– Professor Richard Hobbs, PCP,
Nuffield Professor of Primary Care at the University of Oxford, UK, and Head of the Nuffield Department of Primary Care Health Sciences

Impact on relationships and social life

As well as having a significant impact on quality of life and mental health, social relationships are important determinants of health-related outcomes for people with chronic conditions.[41] Individuals who are more socially integrated have a lower risk of premature death from heart diseases, are less depressed and have better immune responses.[42] In older adults with CKD, social isolation and poor mobility has been shown to contribute to comorbidities, hospitalisations and mortality.[43]

The survey paints a picture of the devastating social impact that CKD can have, draining confidence and self-belief, and damaging treasured relationships.

As well as having a significant impact on quality of life and mental health, social relationships are important determinants of health-related outcomes for people with chronic conditions.



Over half of all respondents (58%) said they don't feel as close to certain loved ones as they used to due to CKD, and half (50%) even said they have lost friends because they cannot participate in certain leisure activities anymore.

Understandably, this leads to some frustration. Six in ten respondents said that they get frustrated with people close to them as they don't fully understand the experience of CKD, while 51% said their family and friends no longer open up to them about their own problems because they think they won't be able to handle it.

These responses suggest that a diagnosis of CKD makes many people feel like outsiders and at the edges of society. Social isolation, accentuated by the COVID-19 pandemic and the need to physically shield, increases the risk of depression and other comorbidities, often resulting in higher health costs and a higher risk of premature death. Still, the findings demonstrate that there is clearly a will to participate. Nearly three-quarters of respondents (73%) said that socialising makes them feel 'normal' and less like a patient.

Impact on intimacy

Although previously an understudied topic, CKD can also affect sexual relationships. While some couples become closer after a diagnosis of a chronic condition like CKD, others are affected by worries about how they'll both cope. Impact on body image and self-esteem can significantly affect relationships.

A low sex drive (libido) is very common in people with kidney disease. It is often due to a combination of factors including hormone imbalances (common in both men and women), medications, tiredness, anxiety, and low self-esteem.[44]

In the survey, around seven out of ten respondents (73%) said that CKD affects their romantic/intimate life in some way (see Fig 14), including body image/self-esteem issues (41%) and reduced sex drive (40%). Interestingly, those in the early stages of CKD (1 + 2) are most likely to experience reduced sex drive (48%) than those in moderate (33%) or severe (36%) stages.

Men are also more likely than women to experience reduced sex drive:



Men

45%

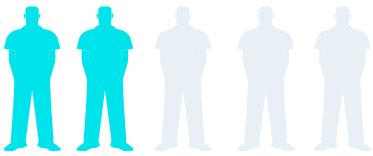


Women

34%

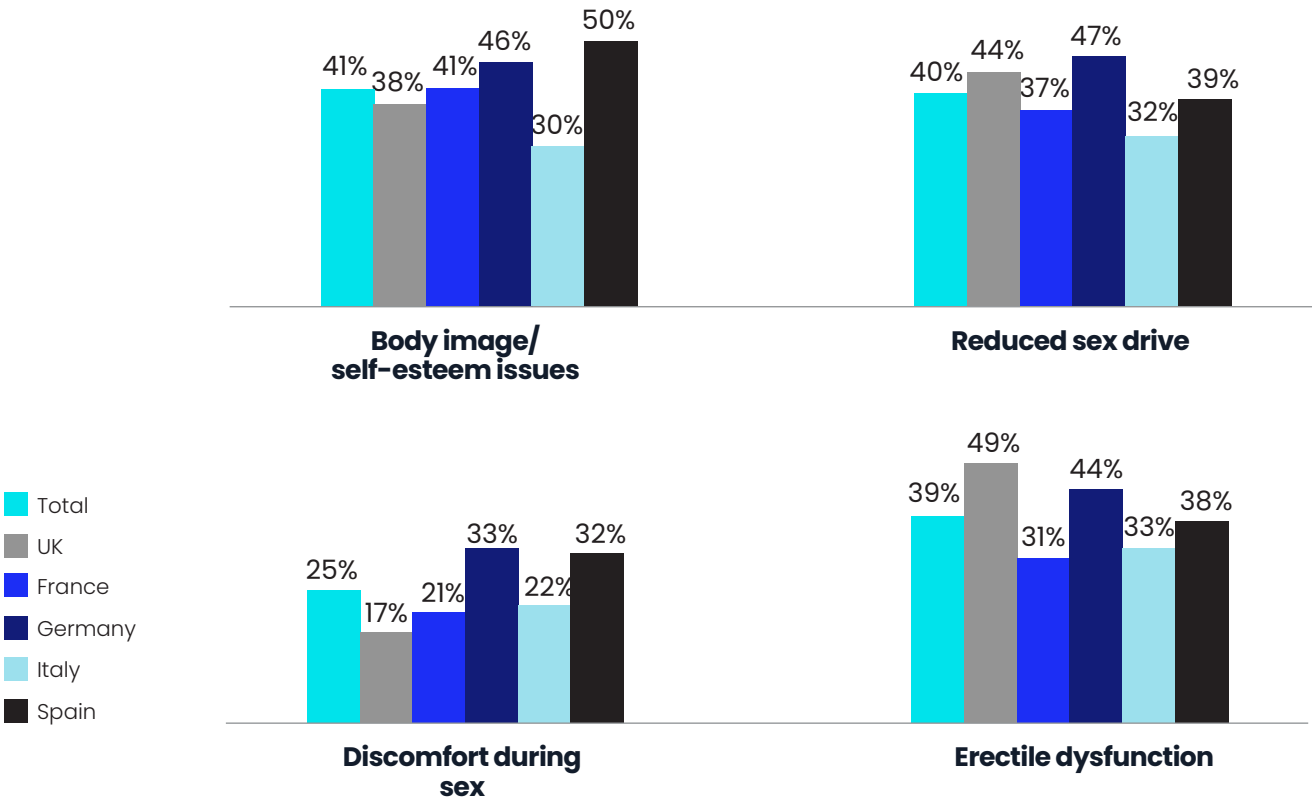
Around two out of every five men in the survey (39%) said they have experienced erectile dysfunction since their diagnosis. Male sexual dysfunction is very common in CKD, although historically this has been under-reported and under-recognised.[45]

Fig 14: Have you experienced any of the following issues related to your romantic/ intimate life, since having been diagnosed with CKD?



2 out of 5 men

Experienced erectile dysfunction



Chapter 4: COVID 19

Summary

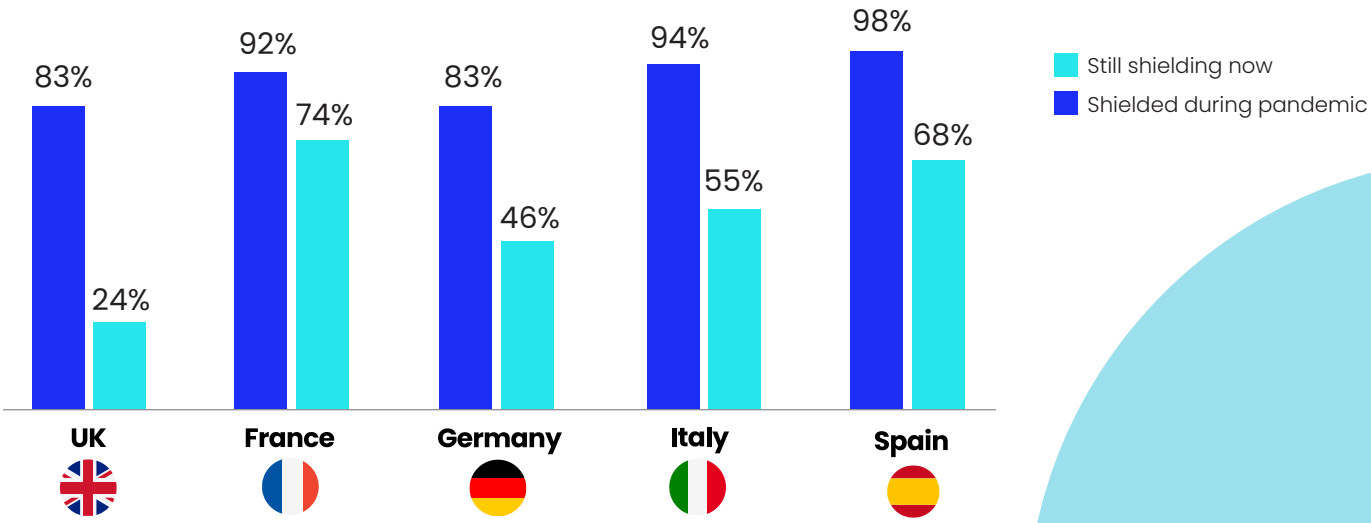
In this section, we present results from the survey around the impact of COVID-19 on people's care, including the unfortunate impact it had on many doctor-patient relationships.

The COVID-19 pandemic was extremely challenging for anyone with a chronic condition like T2D and/or CKD. Firstly of course, because people with T2D and/or CKD are more vulnerable to developing a severe illness with COVID-19. But also, because those who would normally be in regular contact with healthcare professionals, were now isolated, receiving care remotely.

The majority of respondents in the survey (90%) shielded (i.e., remained at home) during the pandemic – and around half (53%) were still shielding at the time the survey was fielded.

In total, 72% of respondents said they still feel at risk from COVID-19. Interestingly, the country with the highest number of people saying they still felt at risk was in the UK (84%) and the lowest in France (62%), potentially reflecting the respective shielding status of the participants in the survey.

Fig 15: Have you been shielding during the pandemic?



Nearly everyone with severe stage CKD (97%) shielded during the pandemic – more than those with mild (88%) and moderate (90%) stage CKD.

Isolation has been an ongoing challenge for those people shielding long-term during COVID-19. The pandemic intensified loneliness for many, but in particular among many older adults with chronic conditions who are at high risk for severe illness.[46]

One of the unfortunate impacts of being isolated from healthcare professionals is the risk of the doctor-patient relationship suffering, and that appears to be supported by the survey findings. Approximately two-thirds (66%) of people in the survey said their relationship with their doctor had suffered due to the pandemic.

On the positive side, 59% agreed that the rise in telemedicine did at least make it easier to speak to their doctor, and 65% appreciated the increase in online social events, which they were able to join.

Approximately two-thirds (66%) of respondents said their relationship with their doctor has suffered due to the pandemic.

Chapter 5: Conclusion

The evidence presented in this report reveals the perspective of people living with CKD and T2D on a wide range of topics, identifying three core areas where patients are affected. The first of these is an avoidable delayed diagnosis, with many people's CKD not being identified until symptoms have developed. As per international guidelines, regular and comprehensive monitoring of people with T2D with a combination of a UACR and eGFR test can reveal both the kidney damage incurred and whether kidney function is impaired.[1,2,3] If UACR is increased, this also indicates an increased risk of cardiovascular complications. To achieve the best possible outcomes, the multidisciplinary care team need to collaborate to prioritise kidney health of people with T2D through frequent testing, timely referral and comprehensive treatments that can delay the progression of CKD.

This report has also uncovered a limited awareness of CKD among people with T2D prior to their diagnosis, despite the known connection and importance of proactive management. It is crucial to strive for an open dialogue between patient and physician, encouraging awareness of CKD and its associated risks in those with T2D. Patients should feel empowered and prepared to both receive and understand this information at the right time. We advocate for the implementation of processes to enhance better conversations amongst healthcare providers and patients.

Beyond the physical implications of CKD, we have seen that this condition can take a significant toll on people's lives, with mental health being a particular concern. To aid the process of accepting the disease and avoid mental health disorders that interfere with treatment adherence, it is key a patient's emotional state is observed. We encourage all stakeholders involved to ensure ongoing and available mechanisms are in place to check-up on a patient's mental wellbeing, helping them to proactively manage their condition.

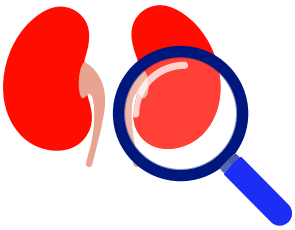
Whilst the realities of living with CKD and T2D have been widely underrecognized in the past, the body of evidence presented in this report provides a new perspective on the challenges faced by patients and a new opportunity to act. Through education, supportive measures and stakeholder cooperation, we can improve the lives of patients and optimise approaches to care.

Chapter 6:
Country summaries



France

In France, it is estimated that 4–5% of the general population has T2D and that almost 40% of those with end-stage renal failure have diabetes.[47]



The path to diagnosis

In total, 89% of respondents in France were experiencing symptoms for more than a month before they were diagnosed with CKD (compared to 91% across all countries). 40% said they were experiencing symptoms for more than six months before diagnosis, and 22% for more than a year (compared to 38% and 20% across all countries).

Other research in France supports the lack of CKD diagnosis in people with T2D. A study including a cohort of 3,532 people with T2D with stage 3 CKD in France, revealed that undiagnosed CKD was extremely high, at 94%.[28] The most common emotional responses to diagnosis in France were feeling anxious (46%), stressed (41%) and scared (35%).

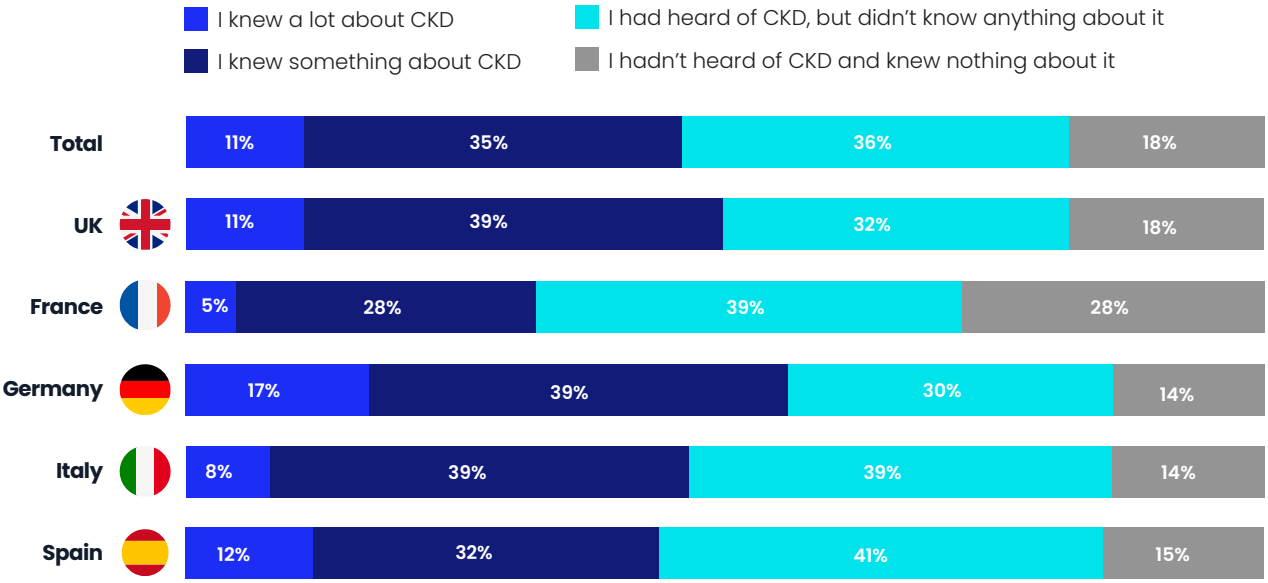


Patient knowledge and care

Knowledge

People in France were significantly more likely than other European countries to say they hadn't heard of CKD and knew nothing about it (28% vs 18% overall). In total, 67% said they knew nothing about CKD prior to their diagnosis – 28% said they knew something about it, and 39% had heard of it, but knew nothing about it (see Fig 16). Only 5% said they knew a lot about CKD prior to their diagnosis – the least of any country in the survey.

Fig 16: Prior to diagnosis, did you know about chronic kidney disease?



HCP relationships

French respondents appeared to have the strongest bond with their doctor, particularly at the primary care level – they were significantly more likely than other countries to get information on CKD from their doctor, 89% vs 77% overall.

It was also noticeable that in France, significantly more people turn to their PCPs for advice on CKD, compared to other countries – 68% vs 50% overall. Conversely, they are significantly less likely than those in other European countries to turn to diabetologists (42% vs 53%) or nephrologists (43% vs 53%).

French respondents were most likely to be satisfied with the care they receive from their PCP – 88% vs 79% overall. While two-thirds of overall survey respondents said their relationship with their doctor has suffered during the pandemic (66%), those in France were least likely to agree (46%)

Support and disease management

When asked which factors would most improve their day-to-day lives, the most popular options among French respondents were more financial support (34% vs 32% overall), more frequent appointments with their doctor / care team (33% vs 31%) and more information about CKD, their prognosis and their treatment plan (31%, the same as the overall average). While 29% said that their day-to-day lives would most be improved by more emotional/psychological support, this was the lowest percentage of respondents in all countries (vs 34% overall).



Impact of CKD on life

Symptoms

While tiredness/fatigue is the main symptom in all countries, a higher proportion of people in France and the UK reported the symptom (69% vs 62% overall). More than one third of French respondents (37%) suffer from five or more symptoms in total.

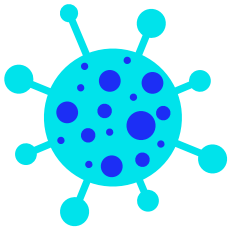
Mental health

Respondents in France were significantly less likely than those in other countries to say their self-esteem is lower now than before they had CKD (47% vs 60% overall), and less likely to have experienced depression since their diagnosis (37% vs 57% overall). Interestingly, another study of a French cohort concluded that cognitive avoidance seemed common in many people with advanced CKD.[48]

However, people in France were the most likely of any country to worry about having an overall poorer quality of life in the future (48% vs 40%).

Relationships

Generally, French respondents were less likely to have felt the impact of CKD on their social lives than other countries. Fewer said that they don't feel as close to certain loved ones now as they used to, compared to other countries (42% vs 58% overall). Similarly, while 46% say they can't see their friends/family as often as they would like to, this is significantly less than the overall figure of 56%.



COVID-19

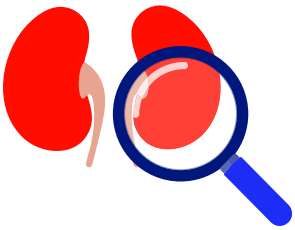
French respondents were the most likely in Europe to still be shielding at the time the survey was fielded – and significantly more than average (74% vs 53%).

Interestingly, only six in ten said they still feel at risk from COVID-19 – the lowest among all European countries (vs 72% overall). This may correlate to the high numbers shielding and feeling protected. Similarly, those in France were the least likely to say that the pandemic has made them feel less optimistic about the future (54% vs 69% overall).

Germany

In Germany, it is estimated that up to 10% of people have been diagnosed with T2D and approximately 40% of individuals with T2D have comorbid CKD.[30]

Findings of note from the survey show Germans were the most knowledgeable about CKD before their diagnosis and the most likely to research the disease but found it hardest to cope emotionally with the impact of CKD, and were the most impacted in terms of their career and finances.



The path to diagnosis

In total, 92% of respondents in Germany were experiencing symptoms for more than a month before they were diagnosed with CKD (compared to 91% across all countries). Meanwhile, 40% said they were experiencing symptoms for more than six months before diagnosis, and 24% for more than a year (compared to 38% and 20% across all countries).

Other research in Germany supports the lack of CKD diagnosis in people with T2D. A study including a cohort of 6,935 people with T2D with stage 3 CKD in Germany revealed that undiagnosed CKD was very high, at 74%.[28]

The most common emotional responses to diagnosis in Germany were feeling anxious (48%), depressed (45%), and scared (43%). Of note, significantly more respondents in Germany felt ambivalent (26%) or relieved (17%) after their diagnosis than in any other country (compared to 12% and 8% overall, respectively).

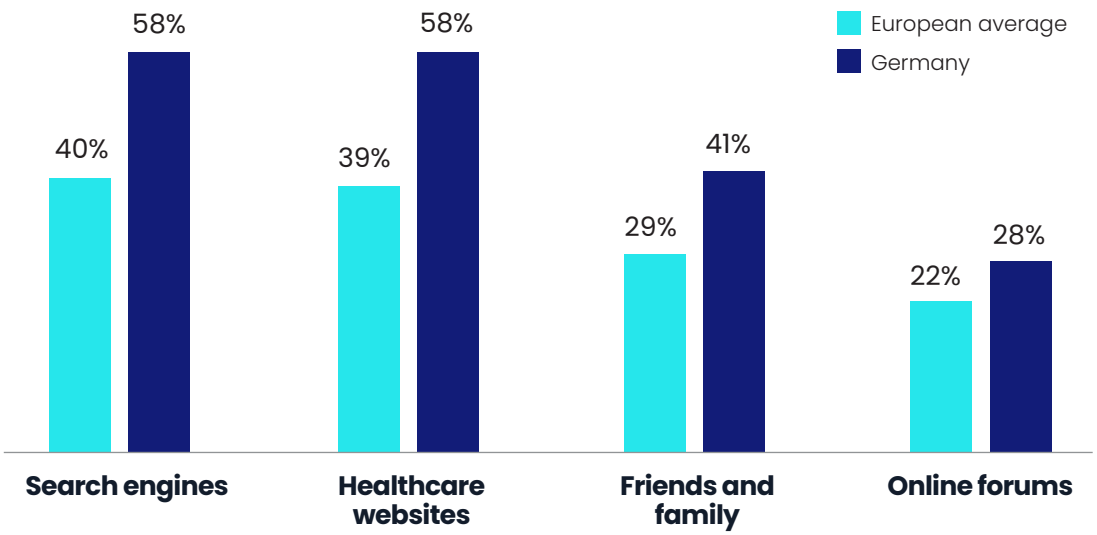


Patient knowledge and care

Knowledge

More Germans knew something of CKD before their diagnosis than in any other country. In total, 17% said they knew 'a lot' about it – compared to 11% overall– and 39% knew 'something'. Germans were significantly more likely to gather information on CKD from alternative sources to their doctor – including search engines (58% vs 40%), healthcare websites (58% vs 39%) and friends and family (41% vs 29%) (see Fig 17). This mirrors other research that shows two out of five internet users in Germany search for health information before their doctor's appointment, and around half of internet users after their appointment.[49]

Fig 17: Which of the following do you use to answer questions you have about CKD? (Average vs Germany)



HCP relationships

Overall, the relationship between people in Germany and their doctors seems positive. For example, 85% of Germans said they were satisfied with the care they receive from their PCPs (vs 79% overall), and 36% said they were very satisfied, which is higher than any other country. German respondents felt that their doctor listens to them (94%) and that they trust their doctor (86%).

They also appear to turn to different types of healthcare professional for advice on CKD. A lower percentage of Germans go to their PCP for advice compared to other countries (36% vs 50% overall), but significantly more seek advice from their diabetologist (80% vs 53%), their nurse (34% vs 24%) or their pharmacist (18% vs 10%).

Support and disease management

German respondents said that their day-to-day lives would most be improved by more public awareness of T2D and CKD (highest in Europe at 46% vs 33% overall), more information about CKD, their prognosis and treatment plan from doctors/care teams (37% vs 31%), and longer appointments with doctors/care teams (highest in Europe at 36% vs 25% overall).



Impact of CKD on life

Symptoms

The most commonly reported symptom was tiredness/fatigue, experienced by 58% of German respondents. They were significantly more likely than those in other countries to report shortness of breath (54%) and insomnia (51%). Respondents in Germany and the UK were most likely to specify multiple symptoms they experience as a result of their CKD, with almost half from both countries experiencing five or more symptoms (48% UK, 46% Germany).

Mental health

Germans were most likely to say they find it hard to cope emotionally with the impact of CKD (75% vs 64% overall) and the most likely to worry about becoming a burden to loved ones (43% vs 32%).

Work

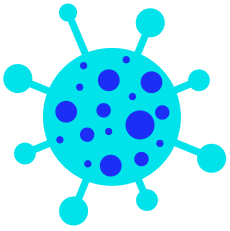
The career impact for people in Germany appears to be particularly significant and they are the most likely to say CKD has limited their career opportunities (31% vs 19%). In fact, almost nine in ten German respondents (89%) have experienced some impact on their working lives – the highest in Europe (vs 77% overall).

More German respondents were likely to worry about earning potential (36% vs 25%) than those in other countries. 22% said they had to stop working since diagnosis, the highest among all countries (vs 13% overall).

Relationships

The pronounced career and financial impact among German respondents may have a knock-on effect with the impact on social relationships. Nearly three-quarters (72%) said that they don't have as much disposable income for social events/occasions now (vs 64% overall), are more likely to fear feeling isolated and alone (30% vs 21%) and fear not being able to maintain friendships (22% vs 13%) than those in other countries.

They were also more likely than those in other countries to say they can't see their loved ones as often as they would like to (72% vs 56%).



COVID-19

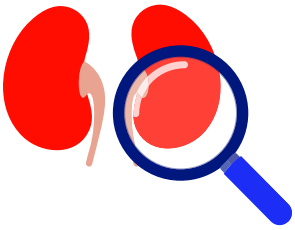
Whilst the majority shielded during the pandemic (83%), only 46% were still shielding at the time the survey was fielded – the second lowest proportion after the UK. Around seven in ten Germans (69%) said they still feel at risk from COVID-19.

German respondents particularly appreciated the rise in telemedicine during the pandemic as it made speaking to their doctor easier – 73% agreed, the highest of all countries (compared to 59% overall).

Italy

More than 3.2 million people in Italy suffer from T2D, which equates to over 5% of the total population[50]

Findings of note from the survey show fewer Italians experienced CKD symptoms for six months or more before diagnosis compared to other countries and were the least likely to turn to different sources of information other than their doctor. When thinking about the future, Italians were most likely of all to worry about losing their independence due to CKD.



The path to diagnosis

In total, 88% of respondents in Italy were experiencing symptoms for more than a month before they were diagnosed with CKD (compared to 91% across all countries).

But fewer Italians experienced symptoms for a longer period compared to other countries. A total of 28% of respondents in Italy said they were experiencing symptoms for more than six months before diagnosis, and 13% for more than a year (compared to 38% and 20% across all countries respectively).

The most common emotional responses to diagnosis in Italy were feeling scared (54%), anxious (39%) and depressed (28%). Significantly more people in Italy felt scared (54%) than in any other country (compared to 41% overall).



Patient knowledge and care

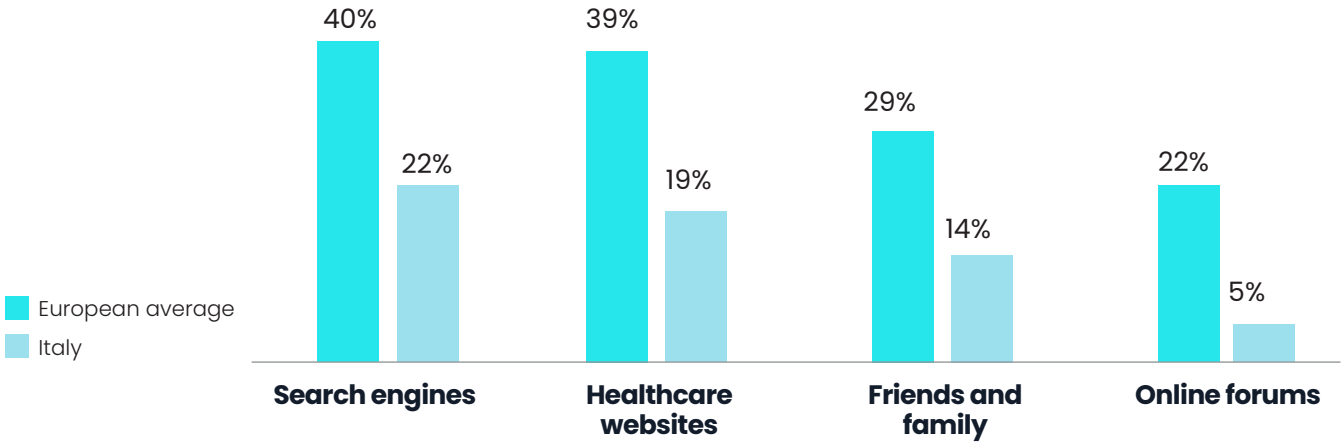
Knowledge

Similar to the European average (54%), just over half of respondents in Italy (53%) knew nothing about CKD prior to their diagnosis – 14% said they knew nothing, and 39% had heard of it, but knew nothing about it. Only 8% said they knew a lot about CKD prior to their diagnosis.

HCP relationships

Italians were the least likely to turn to different sources of information other than their doctor (see Fig 18). While 83% said they would turn to their doctor to answer any questions about CKD, people in Italy were the least likely to consult search engines (22% vs 40% overall), healthcare websites (19% vs 39%), friends and family (14% vs 29%) and online forums (5% vs 22%).

Fig 18: Which of the following do you use to answer questions you have about CKD? (Average vs Italy)



However, slightly fewer Italian respondents were satisfied with the care they receive from their PCPs compared to the overall average (71% vs 79% overall). Italians were more likely than the average to turn to diabetologists (61% vs 53%) and nephrologists (61% vs 53%) for advice on their CKD.

Support and disease management

35% of people in Italy said that their day-to-day lives would most be improved by more emotional/psychological support, similar to the European average (34%). The next most popular options for Italian patients were more public awareness of T2D and CKD (32% vs 33%) and more financial support (28% vs 32%). However, significantly fewer people in Italy said that more support at home (7% vs 20%) or the ability to work part-time/ flexibly (10% vs 19%) would improve their day-to-day lives – both of which were the lowest of all countries.



Impact of CKD on life

Symptoms

The most commonly reported symptom was tiredness/fatigue, with 54% of Italian respondents experiencing this. The next most common symptoms experienced were swollen ankles/hands/feet (37%) and insomnia (35%). Italians were significantly less likely than those in other countries to experience shortness of breath (14% vs 35% overall) and weight loss/poor appetite (11% vs 25% overall).

Mental health

Generally, respondents in Germany, Spain and Italy were slightly more likely to feel the emotional impact of CKD than those in the UK and France.

Italians were significantly more likely to agree that their emotional state has had a negative impact on their relationships with friends and family (67% vs 57%).

Looking to the future, Italian respondents are most likely of all to worry about losing their independence due to CKD (46% vs 35% overall).

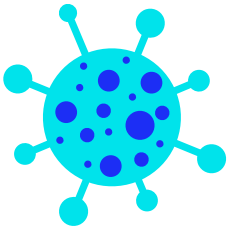
Work

Although 74% of Italian respondents have experienced an impact on their working lives, and more than in any other country feel CKD has affected their career progression (61% vs 52% overall), they are less likely than those in other countries to worry about their earning potential in the future (16% vs 25% overall).

Relationships

People in Italy were significantly more likely than average to agree that they don't feel as close to certain loved ones as they used to (66% vs 58%).

On the plus side, Italians were less likely to feel that CKD has affected their romantic/ intimate life – 61% compared with 73% overall. They were also far less likely to worry about not being able to maintain friendships (4% vs 13% overall).



COVID-19

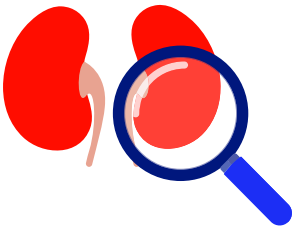
Similar to the overall average (72%), around seven in ten (73%) say they still feel at risk from COVID-19.

More Italian respondents said that the pandemic has made them less optimistic about the future than most countries (76% vs 69% overall).

Spain

Diabetes prevalence in Spain has reached 14.8%, or one in seven adults, the second highest rate in Europe.[51] Approximately 28% of individuals with T2D have some degree of CKD.[52]

Findings of note from the survey show people in Spain were among the least likely to turn to their PCP for advice, with more turning to their nephrologist or diabetologist. They were the most in need of more emotional/psychological support, and the most likely to appreciate more support to help them manage their condition, both at work and at home.



The path to diagnosis

In total, 94% of respondents in Spain were experiencing symptoms for more than a month before they were diagnosed with CKD (compared to 91% across all countries).

A total of 36% of people in Spain said they were experiencing symptoms for more than six months before diagnosis, and 14% for more than a year (compared to 38% and 20% across all countries respectively).

The most common emotional responses to diagnosis in Spain were feeling stressed (50%), scared (42%) and depressed (42%). Significantly more Spanish respondents felt stressed (50%) than in any other country (compared to 36% overall).



Patient knowledge and care

Knowledge

Similar to the European average (54%), just over half of respondents in Spain (56%) knew nothing about CKD prior to their diagnosis – 15% said they knew nothing, and 41% had heard of it, but knew nothing about it. Only 12% said they knew a lot about CKD prior to their diagnosis.

Those in Spain were significantly more likely to gather information on CKD from alternative sources to their doctor than most countries – including healthcare websites (49% vs 39% overall), friends and family (42% vs 29%), online forums (34% vs 22%) and specialist charities/ organisations (24% vs 14%).

HCP relationships

Generally, Spanish respondents seem happy with the relationship with their doctor. In total, 84% said they were satisfied with the care they receive from their PCPs (vs 79% overall), while 92% said their doctor listens to them and 90% said that they trust their doctor.

Many Spanish respondents get advice on CKD from healthcare professionals other than their PCP. Those in Spain were among the least likely to turn to their PCP for advice (43% vs 50% overall), with more turning to their nephrologist (58%) or diabetologist (49%). They were also the most likely of all countries to turn to their nurse for advice (36% vs 24% overall).

Support and disease management

People in Spain were the most likely among all countries to say that their day-to-day lives would most be improved by more emotional/psychological support (42% vs 34% overall). They were also the most likely to cite more frequent appointments with their doctors/care teams (38% vs 31%), more financial support (38% vs 32%) and the ability to work from home more frequently (32% vs 22%) as aspects that would improve their day-to-day lives.



Impact of CKD on life

Symptoms

Tiredness/fatigue was the most commonly reported symptom, with 60% of respondents experiencing this. The next most common symptoms experienced were headaches (51%) and shortness of breath (33%), with significantly more experiencing headaches vs those in other countries (51% vs 39% overall).

Lifestyle changes

Respondents in Spain were the most likely out of all countries to find certain lifestyle changes difficult, including changing their diet (43% vs 36% overall) and quitting smoking (39% vs 29% overall, second only to Germany at 40%). They were also the most likely to find adhering to elements of their treatment plan difficult, including attending appointments (36% vs 25%) and taking prescribed medications (36% vs 24%). Interestingly, other research has found treatment adherence in Spain to be among the lowest in Europe.[53]

Mental health

Respondents in Spain were among the most likely to feel that their lives had changed in multiple ways since their diagnosis – almost half (48%) identified at least four. A third (33%) said they now think of themselves as a 'sick' person, and the same proportion said they are more irritable around family and friends – both higher than any other country.

Alongside those in Germany and Italy, people in Spain were generally more likely to find it hard to cope with the emotional impact of CKD (72% vs 64%), and to have noticed their emotional state having a negative impact on their relationships with friends and family (71% - the highest among all countries – vs 57%).

Those in Spain were also more likely than those in any other country to report lower self-esteem after diagnosis (73% vs 60% overall).

Work

Almost nine in ten (86%) of Spanish respondents said they have experienced an impact on their working lives (vs 77% overall), while they were also most likely to worry about having to give up their jobs in the future (30% vs 19% across all countries).

Relationships

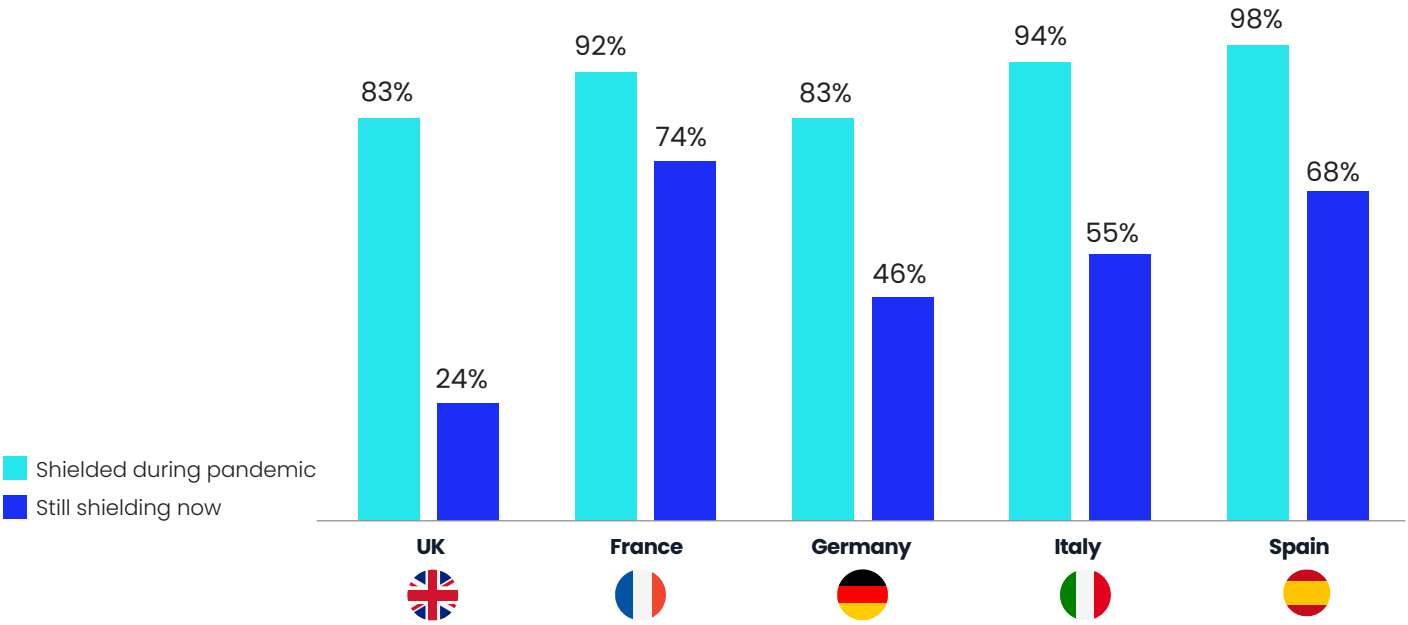
The impact on relationships appears to be quite profound for many people in Spain. They were more likely to worry about relying on support at home from loved ones than other countries (31% vs 20% overall) and were most likely to say that they don't feel as close to certain loved ones now as they used to (69% vs 58% overall). Significantly more people than from any other country said that friends/family don't open up to them anymore about their problems because they think they can't handle it.

COVID-19

Similar to the overall average (70%), around seven in ten Spanish respondents (74%) said they still feel at risk from COVID-19.

Almost all respondents in Spain shielded during the pandemic (98%) – the most from any country (see Fig 19) – and two thirds (68%) were still shielding at the time of survey fielding, more than any country, except France.

Fig 19: Have you been shielding during the pandemic?



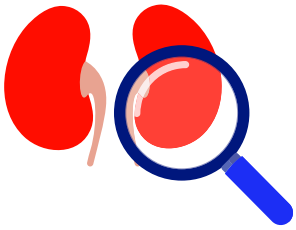
Along with those in Germany (73%), people in Spain (72%) were most likely to agree that the rise in telemedicine during the pandemic made speaking to their doctor easier (vs 59%). Seven in ten (73%) also said they appreciated the increase in activities and events taking place online – the highest of all countries (65% overall).

They were also the most likely of all country respondents to appreciate more support to help them manage their condition, both at work (27%), and at home (29%).

United Kingdom

In total, over 4 million people in the UK are living with T2D – or around 7% of the total UK population,[54] with approximately 1.6 million of those believed to be living with concomitant CKD.[55]

Findings of note from the survey show more people in the UK were experiencing symptoms before diagnosis for more than a year, they were the least likely to be satisfied with their doctor, and the most likely to have experienced depression.



The path to diagnosis

In total, 91% of respondents in the UK were experiencing symptoms for more than a month before they were diagnosed with CKD (the same figure as overall across all countries).

A total of 45% of people in the UK said they were experiencing symptoms for more than six months before diagnosis, and 27% for more than a year (compared to 38% and 20% across all countries respectively). More UK respondents said they were experiencing symptoms for more than a year than in any other country.

The most common emotional responses to diagnosis in the UK were feeling anxious (39%), depressed (36%) and stressed (34%).



Patient knowledge and care

Knowledge

Similar to the European average (54%), half of UK respondents (50%) knew nothing about CKD prior to their diagnosis – 18% said they knew nothing, and 32% had heard of it, but knew nothing about it. Only 11% said they knew a lot about CKD prior to their diagnosis.

HCP relationships

People in the UK were the least likely to be satisfied with their doctor out of all countries. Although two-thirds (67%) said they were happy with their care, this is significantly lower than the average (79%). One in ten said they were unsatisfied (11%), which is significantly higher than all other countries. Around three-quarters (77%) said their relationship with their doctor has suffered during the pandemic compared with 66% overall – the most from any country.

British respondents were the least likely to turn to their doctor to answer questions about CKD (62% vs 77%), and among the least likely to seek advice from a diabetologist (33% vs 53% overall) or nephrologist (44% vs 53%). However, they were among the most likely to seek advice from a nurse (32% vs 24%).



Impact of CKD on life

Symptoms

The most common symptom was tiredness/fatigue, with 69% of British respondents reporting this – the highest of any country, along with France. The next most common symptoms experienced were itchy skin (48%) and changes to frequency of urination (42%), with significantly more experiencing itchy skin (48% vs 31% overall) and weight gain (33% vs 22%) than those in other countries.

Mental health

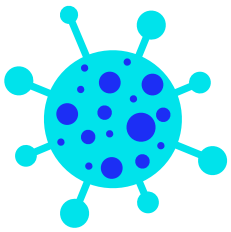
Respondents in the UK were the most likely to have experienced depression of all countries (67% vs 57% overall), but the least likely to have noticed their emotional state having a negative impact on their relationships with friends and family (43% vs 57%).

Work

Respondents in the UK were least likely to have seen an impact of CKD on their working lives, with 66% agreeing it had, compared to 77% overall and 89% in Germany. However, they were the most likely to have reduced their working hours (24% vs 18%).

Relationships

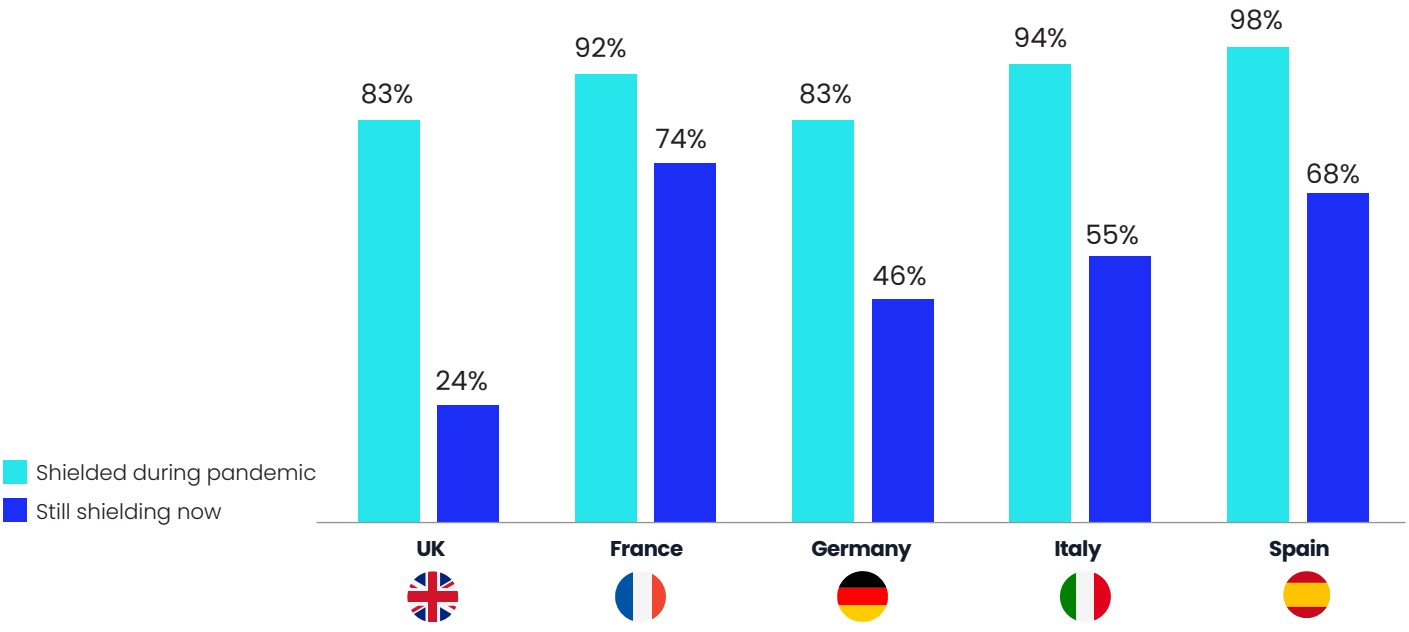
British men were the most likely to have suffered from erectile dysfunction due to CKD (49% vs 39%) and were among the most likely to have experienced a reduced sex drive (44% vs 40%).



COVID-19

Whilst the majority shielded during the pandemic (83%), UK respondents were significantly less likely than people in other countries to still be shielding at the time the survey fielded (see Fig 20). Only 24% were still shielding, compared with 53% overall, and 74% in France. Conversely, those in the UK were among the most likely to say they still felt at risk from COVID-19, with 84% agreeing with this vs 70% overall, the highest among all countries.

Fig 20: Have you been shielding during the pandemic?



Those in the UK were also most likely of all countries to say that more stringent COVID-19 regulations – such as mask-wearing – would improve their quality of life (29% vs 20% overall), and among the least likely in Europe to say the rise in telemedicine has made it easier to speak with their doctors (47% vs 59%).

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