EKPF
EUROPEAN KIDNEY PATIENTS' FEDERATION
CEAPIR

evoke incisive health
www.evokeincisivehealth.com



Improving Chronic Kidney Disease-associated Pruritus (CKD-aP) patients' quality of life

EKPF
EUROPEAN KIDNEY PATIENTS' FEDERATION
CEAPIR



Improving Chronic Kidney Disease-associated Pruritus (CKD-aP) patients' quality of life

Table of Contents

4 **Executive summary**

6 **Introduction**

8 **Chronic Kidney Disease-associated Pruritus**

12 **The patient's voice: survey results on CKD-aP patients quality of life**

16 **Policy recommendations**

28 **Conclusion**

30 **About EKPF**

32 **References**

34 **Appendix – Survey analysis**

Background information

Respondents' experience of pruritus

Location of pruritus on patients' bodies

Repercussion of pruritus on patients' quality of life

Treatment of pruritus and success of the treatment

Communication with and information provided by healthcare professionals

Involvement of patients in their care

Executive summary

Chronic kidney Disease is a long-term progressive disease, characterised by alterations in kidney function or structure, that persist over more than 3 months and has implications for health.[1] The condition affects more than 10% of the general population worldwide, with up to 100 million people thought to be suffer from it in Europe, and 300 million in risk to develop it.[2, 3] Kidney diseases are a leading cause of death worldwide and CKD is associated with high human and financial burden.[2, 4] Chronic Kidney Disease-associated Pruritus (CKD-aP) – a medical term used to describe the systemic and unpleasant itch – is a common symptom experienced by many CKD patients, particularly those in more advanced disease stages, where dialysis is required.[5]

Gaining a comprehensive understanding of the experience of kidney disease patients, particularly the profound influence of pruritus on their quality of life and well-being, is pivotal in comprehending this debilitating disease. With this goal in mind, patient surveys were conducted by national members of the European Kidney Patients Federation (EKPF) in France, Germany, Italy, Portugal, and Spain, between 2021 and 2022. They focused on assessing the prevalence, symptoms, treatment, and, notably, the effect on Health-Related Quality of Life in CKD-aP patients.

“Patient surveys were conducted by national members of the European Kidney Patients Federation (EKPF). They focused on assessing the prevalence, symptoms, treatment, and, notably, the effect of CKD-aP on patients’ quality of life.

To deliberate and draw conclusions from the surveys, the CKD-aP Patient Steering Group was formed – a panel of experts comprising representatives from the organisations overseeing the surveys. The group reviewed the survey results, revealing that more than two-thirds of respondents reported experiencing pruritus, significantly affecting



their daily lives, sleep, social interactions, and overall well-being, as well as their mood and mental health. Additionally, the CKD-aP Patient Steering Group identified a low level of patient reporting, often due to lack of awareness, understanding, or previous follow-up regarding the condition. From these findings, the group extracted key themes and formulated policy recommendations aimed at providing support to the CKD-aP patient community:

Recommendation 1 – Raise awareness on the impact of Chronic Kidney Disease associated Pruritus on the Health Related Quality of Life and collaborate with European and National Patient Associations to implement awareness campaigns

Recommendation 2 – Strengthen healthcare professionals understanding and knowledge about Chronic Kidney Disease-associated Pruritus, including its frequency, impact on patients' daily life, and treatment options, through education and the setting up of ambassadors in clinical centres to ensure strong communication flows with patients

Recommendation 3 – Raise policymakers and regulators awareness of Chronic Kidney Disease-associated Pruritus, its effects and impacts in the daily lives of patients and the treatments available

Recommendation 4 – Foster research to improve the knowledge of root causes of CKD-associated pruritus to have a better understanding of its impact on patients

Recommendation 5 – Generate more data on patient experiences around pruritus, specifically on its impact, especially on the mental well-being of patients, on how they perceive treatments, and how they would like to be involved in their care

Recommendation 6 – Advancing patient care implementing a comprehensive approach to Chronic Kidney Disease-associated Pruritus



Introduction

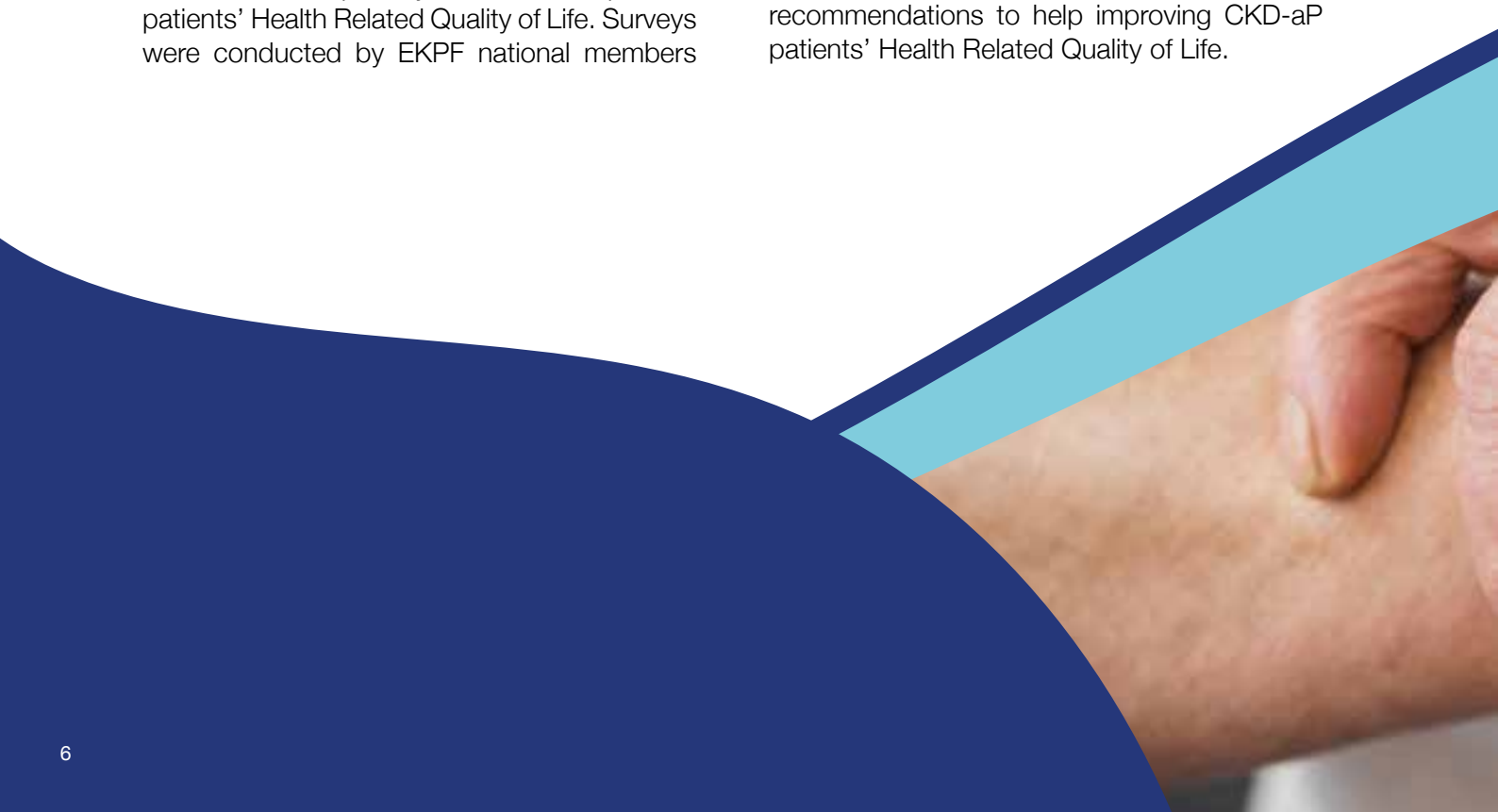
Background

Chronic Kidney Disease-associated Pruritus (CKD-aP) is a common, troubling and in some cases debilitating problem for patients with CKD and end-stage renal disease.[6]

CKD-aP is more than just itch, it is a chronic and systemic itch impacting patients' wellbeing and Health Related Quality of Life. Being a chronic condition, it never disappears, and some patients feel the itch constantly.

Following the publication of the 'Living with chronic kidney associated pruritus' White Paper, a number of the European Kidney Patients Federation (EKPF) members organised patient surveys at a national level to better understand CKD-aP prevalence, symptoms, treatment and especially, the disease impact on patients' Health Related Quality of Life. Surveys were conducted by EKPF national members in France, Germany, Italy, Portugal and Spain between 2021 and 2022. The objective of the surveys was to better understand of the experience of CKD patients, and especially the impact of pruritus on their quality of life and wellbeing.

Representatives of EKPF national members joined forces to draw conclusions from their surveys under the umbrella of the CKD-aP Patient Steering Group. The Patient Steering Group was set up to support a national surveys analysis, in order to identify and inform key recommendations to help improving CKD-aP patients' Health Related Quality of Life.



Methodology

This report is the result of a combination of desk research, analysis of survey responses provided by kidney disease patients from five European countries, and the outcome of the discussions of the CKD-aP Patient Steering Group.

The findings of the survey responses were analysed and are presented in this report. In order to analyse responses key themes were identified and where possible, final outcomes were compared. It is important to note that there were variations in the questionnaires disseminated in the five countries, with different questions and themes explored. Additionally, the way questions were asked and framed differed to some extent, reflecting nuances unique to each country. These variations were taken into consideration during the survey analysis process.

The report reflects discussions of the CKD-aP Patient Steering Group, presented as a set of policy recommendations, including concrete asks to raise awareness of CKD-aP and seek policy changes at European and national level.

"Representatives of EKPF national members joined forces to draw conclusions from their surveys under the umbrella of the CKD-aP Patient Steering Group. The Patient Steering Group was set up to support a national surveys analysis, in order to identify and inform key recommendations to help improving CKD-aP patients' quality of life.



Chronic Kidney Disease-associated Pruritus

Chronic Kidney Disease (CKD) is a serious long-term progressive disease defined as *"abnormalities of kidney structure or function, present for more than 3 months, with implications for health"*. [1] The disease is characterised by a gradual loss of kidney function and an increased risk of morbidity and mortality. Worldwide, 10% of the general population is affected by CKD. The World Health Organisation (WHO) ranked kidney diseases as one of the ten leading causes of death worldwide and projections estimate it might rise to become the fifth cause of worldwide death by 2040.[2, 4, 7, 8] In Europe, up to 100 million people suffer from CKD, and 300 million are at risk, with both numbers thought to continue increasing given the aging population.[2, 3] Although finding data on the aggregated cost of CKD is extremely difficult, estimates show overall costs for CKD in European healthcare systems to be around €140 billion, putting them at the same level, likely even higher, than the costs for diabetes or cancer.[2]

Chronic Kidney Disease-associated Pruritus (CKD-aP) – a medical term used to describe the systemic and unpleasant itch that occurs in CKD patients- is a common symptom experienced by many CKD patients, particularly those in more advanced disease stages where dialysis is required.[5]

Symptoms

Chronic pruritus is defined as an unpleasant sensation of the skin that leads to a desire





to scratch and persists for 6 or more weeks. This is an extremely distressing and debilitating symptom, comparable to chronic pain. CKD is one of the diseases most frequently associated with this symptom.[9, 10] The multifactorial pathogenesis of Chronic Kidney Disease associated Pruritus (CKD-aP), formerly known as uremic pruritus, is still not fully understood, with different explanations being considered possible.[11-13] These include: dermatological factors, such as dysfunctions in the skin barrier; systemic factors, such as dysfunction of the immune system and the proinflammatory state associated with chronic kidney disease; neurological factors, including uraemic neuropathy and dysregulation of the endogenous opioid system; toxin accumulation; and consequences of the type of renal replacement therapy undergone by the patient.[12, 14] The severity of the pruritus, as well as the itching frequency and timing, differs among patients, and can range from mild to severe, significantly impacting patient's quality of life.[15] Patients report diverse itching patterns, frequently including large areas of the skin in discontinuous and symmetrical manner.[14] The most common locations are the face, chest, and limbs, but for some patients it can be generalised.[14] In some cases, pruritus can be associated with xerosis (dry skin) and/or a diverse set of secondary skin lesions, namely crusts, papules, impetigo, prurigonodualris, erosions and ulcerations.[14]

Furthermore, CKD-aP has been linked to adverse medical outcomes. Several studies have associated CKD-aP with increased mortality. Findings from the Dialysis Outcomes and Practice Patterns Study (DOPPS) I and II show that patients with moderate to severe pruritus exhibit higher increased mortality when compared to patients without pruritus.[16] Results from two other Japanese studies, including the Japanese Dialysis Outcomes and Practice Patterns Study (JDOPPS) also report that in patients undergoing haemodialysis, pruritus was associated with increased mortality risk even after adjusting for other clinical risk factors.[17, 18] The increased mortality is hypothesized to be associated with poor sleep quality and other impacts CKD-aP has on quality of life.[16, 19] Higher levels of pruritus severity in CKD-aP patients undergoing haemodialysis have also been associated with increased rates of medication use, including intravenous antibiotics, erythropoiesis-stimulating agents, and iron, increased number of missed HD sessions and increased healthcare utilization.[5, 20]

Prevalence

The prevalence of CKD-aP is hard to define as it is often underreported by patients and underdiagnosed or not fully understood by healthcare professionals. Estimates ranging from 20% to 90% have been reported, with

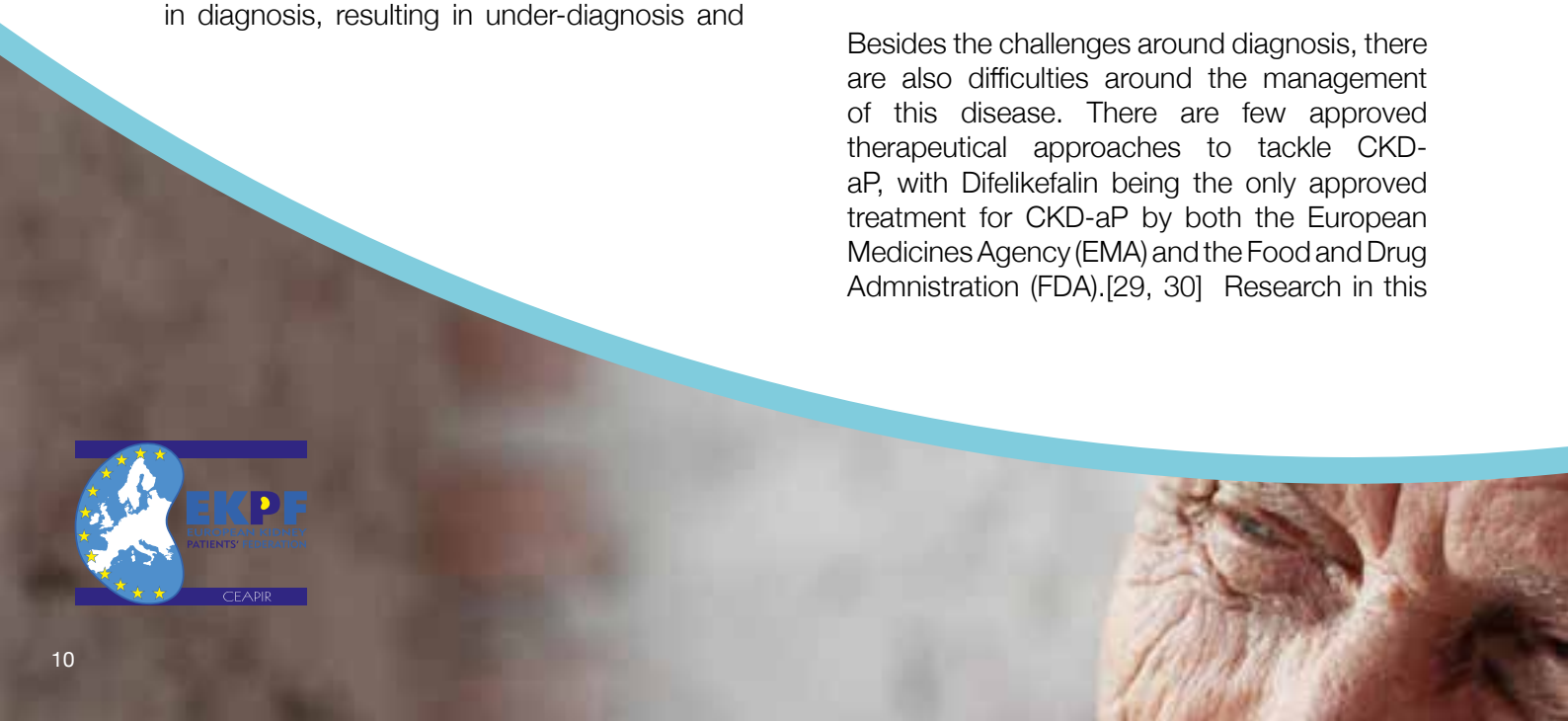
values varying between studies, from country to country, and even within countries between different centres.[15] Evidence shows that the prevalence increases with the decreasing in kidney function. In pre-dialysis stages, studies report up to 24% prevalence, and this number increases to 40%-55% in dialysis patients.[14] In a recent publication from Sukul et al., where data from the DOPPS prospective cohort of adult chronic in-centre haemodialysis patients from 21 countries is used, 51% of the patients reported having moderate to severe CKD-aP. This group presented no striking differences in clinical risk factors (i.e. demographic data and comorbidities).[21] Some dialysis patients also report heightened intensity during the dialysis session or immediately after. Throughout time, with the improvement of dialysis treatment, the incidence of CKD-aP is thought to be decreasing. Other triggering factors that have been described include temperature extremes (both cold and heat), showering, physical activity and stress.[14] One of the reasons that explains the difficulties in estimating prevalence lies with the challenging diagnosis of this disease.[15]

Diagnosis – Underreported and underdiagnosis of CKD-aP

The absence of specific clinical features, the diverse secondary skin lesions it can be associated with and the lack of diagnosis and management guidelines leads to difficulties in diagnosis, resulting in under-diagnosis and poor patient management.[15, 22] This has been reported in several studies, including literature reviews.[23-26] In a large international comparative study, an underestimation of CKD-aP was identified in nearly 70% of the facilities.[27] This has been associated on one hand to a general unawareness of CKD-aP among healthcare professionals but also among patients that don't always report it as a symptom.[27] In a study conducted by Burton et al., 75% of the nephrologists interviewed (coming from France, Germany, Italy, Spain, UK and Australia) agreed that CKD-aP is under-diagnosed in haemodialysis patients. The nephrologists highlighted the lack of diagnostic guidelines and absence of standardised pruritus intensity scales to consistently diagnose and classify CKD-aP severity as main barriers to proper screening.[26] In a Spanish study, 35% of the patients (including patients with severe and moderate pruritus) claimed never having reported their itching symptoms to a healthcare professional, mainly because they felt they would be ignored (26%), feared there was no solution (23%), did not think it was related to CKD (20%), or lacked the opportunity to do so (9%).[28] When reporting itching symptoms, patients more frequently do it to nephrologists, followed by nurses or other dialysis staff members, dermatologists and primary care doctors, as reported by another large study, using with data from several countries.[27]

Disease management and treatment

Besides the challenges around diagnosis, there are also difficulties around the management of this disease. There are few approved therapeutical approaches to tackle CKD-aP, with Difelikefalin being the only approved treatment for CKD-aP by both the European Medicines Agency (EMA) and the Food and Drug Admnistration (FDA).[29, 30] Research in this



area is challenging, with most studies having small samples and a lack of standardised measurements and designs between different studies.[11, 28, 31] Patients experiencing CKD-aP face clear unmet medical needs, with studies reporting high numbers of untreated patients or, when under treatment, still reporting symptoms and being unsatisfied. Despite an overall lack of evidence to support it, one of the most common first-line off-label treatment approaches worldwide is antihistamines.[14, 31] Several other interventions are available, aimed at addressing the diverse mechanisms underlying the pathogenesis of CKD-aP.[14] Gabapentinoids (gabapentin and pregabalin), are an off-label example of a drug class that has shown good results in reducing itchiness. These are analogues to a neurotransmitter aimed at addressing the possible neuropathic component of the disorder. [14, 32] Nevertheless, there are still limitations on the understanding of the treatment.[32, 33] Other treatments directed at addressing the dysregulation of the immune system, such as oral montelukast, turmeric and zinc sulfate, have also showed an itch score reduction, although the studies that support this are small and more evidence is needed.[32]

Quality of life

Although further research is needed focusing on the impact of CKD-aP, studies have reported it to be associated with poor quality of life, depression, anxiety, sleep disturbance, and increased mortality. [15, 16, 19, 22, 24] In a study done on patients with CKD, patients with pruritus reported significantly lower health status than patients without pruritus. Patients frequently report experiencing difficulties sleeping which has been associated with increased mortality.[27, 34] Impacts in mental health are also common, with patients reporting feelings of frustration, depression, shame, anguish, and irritability and impacts on social, professional and even sexual life, although further studies are needed on this.[28, 31]

"Patients experiencing CKD-aP face clear unmet medical needs, with studies reporting high numbers of untreated patients or, when under treatment, still reporting symptoms and being unsatisfied



The patient's voice: survey results on CKD-aP patients quality of life

Better understanding the patients' perspective is key. The objective of the surveys, rolled out by members of the European Kidney Patients Federation (EKPF) in France, Germany, Italy, Portugal, and Spain between 2021 and 2022, was to gather information about the reality of kidney disease patients suffering from CKD-aP, and especially the impact of pruritus on their quality of life and wellbeing.

The surveys focused on patients' experience of pruritus, asked where it was present on their bodies, and about the repercussions of the condition on patients' quality of life, whether it was affecting their sleep, mental health, physical and social activities. The surveys also explored patients' experience of treatments against pruritus. Finally, some of the country surveys questioned patients' experience of the communication with and information provided by healthcare professionals and patients' interest in being involved in decisions related to their care.

In total, 3,803 European kidney disease patients responded to the surveys. The number of respondents varied between countries; between 1,896 in Italy (close to half of the total number of respondents) and 43 in Portugal (Table 1).



Despite individual country surveys being structured differently, with different questions and themes explored, we were able to identify trends in all countries.

Over two thirds of respondents declared that they suffer from pruritus. The level of severity varies from patient to patient, but most respondents noted facing moderate or severe case of pruritus, mostly in their legs, backs, and arms (see Appendix – Respondents' experience of pruritus).

The high impact that pruritus has on patients' daily lives is evident from the different surveys, as the condition tends to be **present for most of the day and night** (see Appendix - Repercussion of pruritus on patients' quality of life). Pruritus impacts patients' quality of sleep, as it not only makes it difficult to fall asleep, but also wakes patients up in the middle of the night. It also impacts their **mood and mental health**, as it makes patients irritable, frustrated, stressed, ashamed and impacts their concentration, which also leads to a high level of impact in their **physical and social activities**, such as physical performance, relationships, work and studies (see Appendix - Repercussion of pruritus on patients' quality of life).



"Over two thirds of respondents declared that they suffer from pruritus

When it appears, pruritus seems to stay, adding to the patient's burden and distress. The majority of survey respondents shared they suffered from pruritus for more than a year (see Appendix – Respondents' experience of pruritus).

The surveys undertaken, also showed how patient's wellbeing and perception of pruritus impacted their communications with healthcare professionals and their treatment. Only **a third of respondents reported having discussed the issue of pruritus to their healthcare professionals** (see Appendix - Communication with and information provided by healthcare professionals). This happens for a number of reasons: lack of patient awareness, previous reporting that was not followed up by their healthcare provider or understanding of the difficulty to the condition. However, responses showed patients are willing to receive more information on associated physical issues (e.g., pain, itching), adequate psychological support, medications side effects and possible physical

Table 1 – Respondents' profile

Country	Number of respondents	Gender	Age
France	857	■ 40% - women ■ 60% - men	■ Middle age 62 years ■ 55%: 18 < 65 years
Germany	569	■ 56% - women ■ 43% - men	■ 21% - Under 45 ■ 22% - 46-55 ■ 34% - 56-65 ■ 23% - Above 66
Italy	1,896	■ 36% - women ■ 64% - men	■ N/A
Spain	438	■ 32% - women ■ 68% - men	■ N/A
Portugal	43	■ 37% - women ■ 63% - men	■ 8% - 20-29 ■ 5% - 30-39 ■ 30% - 40-49 ■ 24% - 50-59 ■ 11% - 60-69 ■ 19% - 70-79 ■ 3% - 80-89

activities (see Appendix - Communication with and information provided by healthcare professionals).

In countries where questions on treatment were asked, **only a third of respondents mentioned following a treatment against pruritus**. The **types of treatments used by patients against the itching varied**, with a preference for **external treatments**. Respondents allocated mixed level of success



to treatments against pruritus (see Appendix - Treatment of the pruritus and success of the treatment). Even though, as depicted by the surveys, pruritus has an undeniable impact on all aspects of patients' lives not many respondents reported following a treatment to help alleviate its impact.

The insights garnered from the surveys offer a profound understanding of the challenges faced by kidney disease patients afflicted with CKD-aP, particularly the significant repercussions of pruritus on their overall quality of life and well-being. These findings underscore the imperative for concerted efforts in several key areas. First, there is a pressing need to channel resources towards comprehensive research aimed at uncovering the root causes of pruritus, enabling a more targeted and effective approach to treatment and patient care. Additionally, it is crucial to bolster data generation, ensuring a robust foundation for evidence-based interventions. Furthermore, adopting a multidisciplinary approach to treatment and patient support is essential, including integrating expertise from various medical disciplines to provide holistic care and address the multifaceted impacts of pruritus on patients' lives. Lastly, there is a clear call to action to heighten awareness among patients and healthcare professionals, as well as regulators and policy makers, highlighting the gravity of pruritus as a debilitating aspect of kidney disease. By collectively addressing these imperatives, we can significantly enhance the quality of life for those affected by CKD-aP.

Obtaining a clear understanding of CKD-aP and its impact on patients is paramount. Organising a harmonised pan-European patient survey on patients' quality of life and well-being, with the support of patient organisations and medical societies, would be instrumental in achieving this goal. Such an initiative would not only enhance our comprehension of the condition's prevalence but also provide a comprehensive picture of its effects on patients' quality of life and overall well-being. This collaborative effort would serve as a pivotal step towards a more comprehensive understanding of CKD-aP and pave the way for more targeted and effective approaches to treatment, ultimately improving the lives of those affected by this condition.

Policy recommendations

To guarantee that the results from the patient survey conducted in each geography would be properly analysed and reflected upon, the Chronic Kidney Disease-associated Pruritus Patient Steering Group met for the first time in June 2023. During this meeting, patient responses were discussed, and key themes were identified and used to prepare an initial set of policy recommendations. Afterwards, further research was conducted to enhance and support this set of policy recommendations, ultimately resulting in six comprehensive recommendations that can be found below. These target several aspects of the condition and put forward concrete asks to raise awareness and ask for policy changes at European and national level. These recommendations were contextualised with the other elements presented in this report and a second meeting was held in September 2023, where the Chronic Kidney Disease-associated Pruritus Patient Steering Group discussed the entire structure of the report and agreed on a final version.

Recommendation 1 – Raise awareness on the impact of Chronic Kidney Disease associated Pruritus on the Health Related Quality of Life and collaborate with European and National Patient Associations to implement awareness campaigns

While further research is needed to fully understand the impact of CKD-aP, existing studies already unveil a concerning picture. Many patients suffering from pruritus report significant difficulties in sleeping and adverse effects on their mental health.[27, 28, 35]

Given the often-hidden nature of CKD-aP, a united effort by international, European, and national patient associations on a dedicated and specific date, like for instance on World Kidney Day, would be instrumental in bringing attention to this disease. Provided the disease is often





underreported by patients and underdiagnosed by healthcare professionals, the collaborative efforts of international, European, and national patient associations on a dedicated and specific date would hold significant weight in amplifying awareness regarding this condition. This emphasis would be particularly directed towards comprehending its substantial effects on the day-to-day lives, overall quality of life, and general well-being of affected individuals.

To bolster this collective endeavour, there is potential to develop a patient mentoring programme, orchestrated by patient associations with the endorsement of medical professionals. This initiative would play a pivotal role in assisting patients in their coping strategies and emotional adjustments. An example of a similar initiative that has been successful is the project organised by Bundesverband Niere e.V, where volunteer patients are extensively trained to become “patient companions”. In this role, the volunteer patients are able to support fellow patients coping with the illness, provide relevant and updated information, and assist with matters related to work, pension, rehabilitation, household support and social benefits.

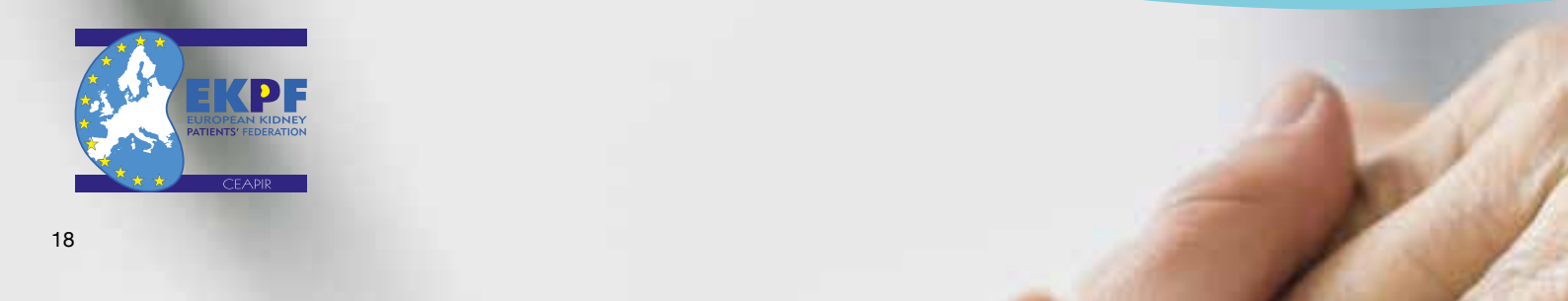
Additionally, European and national patient organisations could organise a pan-European campaign centered on CKD-aP with a focal point on its ramifications for patients’ daily lives, quality of life, and general well-being. Part of the campaign could even include patient testimonials, to reinforce the burden patients experience and sensitise the public to the still many unmet needs around CKD-aP. These coordinated actions would collectively contribute to heightening awareness surrounding CKD-aP, ultimately leading to a positive impact on patient care, daily routines, and overall well-being. This report, along with the surveys analysed and presented throughout it, can serve as a tool to support and strengthen these campaigns. It not only provides relevant data that can highlight the need for urgent action, but also guides such action through the provided policy recommendations.



"A standardised tool for measuring patient-reported experiences should be developed. Such a tool, co-created by patient organisations and medical societies,would hold the potential to transform how we understand and address the unique challenges faced by patients coping with CKD-aP.

Recommendation 2 – Strengthen healthcare professionals understanding and knowledge about Chronic Kidney Disease-associated Pruritus, including its frequency, impact on patients' daily life, and treatment options, through education and the setting up of ambassadors in clinical centres to ensure strong communication flows with patients

There are many challenges surrounding CKD-aP, one of them being its underdiagnosis and underreporting. Several studies have highlighted there is still a high level of unawareness of this condition, even nephrologists are believed to often underestimate the occurrence and impact that CKD-aP can have in the patient's life, often failing to accompany and properly manage this condition.



[36] The crux of the issue often lies within the realm of patient-healthcare communication. Numerous studies have identified this communication as inefficient, with patients frequently hesitating to report itching to any healthcare professional. [27, 28] This reluctance is driven by their fear of being disregarded or overlooked, their inability to link the symptom to CKD, their perception that there are no viable solutions, or the absence of a suitable treatment.[28]

By prioritising the improvement of healthcare professionals' understanding and knowledge about CKD-aP there would be an upgrading of patient-healthcare communication. More aware healthcare professionals could actively monitor the surge and development of CKD-aP, providing support and solutions to minimise the burden of the condition. This approach involves educating healthcare providers about the prevalence, underlying mechanisms, and impact of pruritus, and the need to improve its underreporting. Effectively achieving this requires a multi-pronged approach. First, cooperating with medical societies can be pivotal in disseminating updated information, leveraging platforms such as conventions and newsletters to provide healthcare professionals with comprehensive insights into the condition. Medical societies can facilitate continuous education and knowledge-sharing on this topic, raising awareness of its importance among professionals. They can also play a key role to raise awareness among healthcare professionals about the importance to include systematic pruritus screening in their consultations with CKD patients. In addition, in collaboration with medical societies, patient organisations and national health systems, can take proactive measures to train healthcare professionals and prepare 'Pruritus Ambassadors.'

These ambassadors would serve as crucial points of contact between healthcare professionals and patients within medical centres. Their role would involve ensuring that patients are equipped with updated, high-quality, and balanced information regarding CKD-aP. By being well-informed about the latest advancements in treatments, research findings, and strategies to manage pruritus, the ambassadors could effectively bridge the communication gap between healthcare providers



and patients and ensure clinical guidelines are implemented once they become available. This approach would not only empower patients to openly discuss their concerns but also foster a collaborative environment where personalised and holistic care plans can be developed. Identifying the most effective ambassador for this initiative is crucial. Nurses, with their close and sustained patient interactions, offer a unique perspective and can serve as effective ambassadors to relay information and provide ongoing support. Considering their integral roles in patient care, nurses are well-suited for this task. Physicians, particularly nephrologists with their specialised knowledge of kidney-related conditions, are also well-positioned to take on this role. Their expertise enables them to provide accurate and detailed information to both colleagues and patients. Given the differences between healthcare systems in different countries, namely in terms of available resources, the role of Pruritus Ambassador should remain flexible and accessible to other healthcare professionals interested and available to rake on this role.

To strengthen this effort, a network of ambassadors could be established at both national and EU levels facilitated by the support of patient associations and medical societies. This network would serve as a platform for sharing knowledge, best practices, and resources among ambassadors, enabling them to stay updated with the latest developments in CKD-aP. Additionally, it would elevate the conversation on this critical issue at the EU level, driving collective efforts towards better care and support for patients.

Recommendation 3 – Raise policymakers and regulators awareness of Chronic Kidney Disease-associated Pruritus, its effects and impacts in the daily lives of patients and the treatments available

The current clinical model often falls short in identifying and adequately treating patients



> **To address this challenge, it is imperative for national health systems to proactively establish specialised multidisciplinary teams attuned to the distinct needs of CKD-aP patients.**

dealing with severe CKD-aP.[27] Patient surveys have highlighted a significant portion of CKD-aP sufferers who remain untreated, and even those undergoing treatment often express dissatisfaction and continued symptom prevalence.

It is imperative to increase awareness about pruritus and how patients' quality of life can be improved. This will facilitate the adoption of effective therapies, presenting a substantial opportunity to enhance the health, quality of life and well-being of CKD-aP patients. One pivotal approach involves the development and implementation of standardised treatment guidelines that would encompass routine pruritus monitoring and the proactive collection of data on itch prevalence and severity within patient registries. This structured framework could be developed by nephrologists through a revision of the existing evidence and serve as a powerful tool in improving patient outcomes and quality of life.[27] Moreover, the development, dissemination and adoption of these guidelines could be facilitated by medical societies.

Raising policy awareness on CKD-aP is of paramount importance to address the existing



gaps in diagnosis and treatment. It is crucial for policymakers to grasp the full extent of CKD-aP's societal and economic burden in order to allocate resources effectively. For instance, a targeted scientific campaign could quantify the economic impact of CKD-aP, demonstrating how investments in treatment can yield substantial returns in terms of improved patient well-being and reduced healthcare costs. Moreover, engaging CKD-aP patients through follow-up surveys would offer a direct line to understanding their unique challenges. By gathering data on how CKD-aP affects their daily lives, including employment and caregiving responsibilities, policymakers would gain a first-hand perspective on the tangible difficulties faced by patients. This data would serve as an insightful tool in policy discussions, illustrating the urgent need for tailored interventions and support for CKD-aP patients.

Furthermore, it is paramount to underscore the profound impact of CKD-aP on patients' overall well-being and mental health. The European Mental Health Strategy provides an opportune platform to emphasise the comprehensive needs of CKD-aP patients. This strategy encompasses a wide range of policies and efforts aimed at promoting mental well-being across various sectors, including capacity-building and prevention and early intervention, elements crucial for optimising CKD-aP patient care.

"By prioritising the improvement of healthcare professionals' understanding and knowledge about CKD-aP there would be an upgrading of patient-healthcare communication.

Elevating policy awareness for CKD-aP is a strategic imperative to drive meaningful change. Through targeted campaigns, patient-centric data collection, and integration with complementary initiatives, it would be possible to effect positive transformation in the lives of those affected by CKD-aP. These initiatives collectively reinforce the urgent need for policy interventions, ensuring a more inclusive and empathetic healthcare landscape for CKD-aP patients.



EKPF
EUROPEAN KIDNEY PATIENTS' FEDERATION
CEAPIR

Recommendation 4 – Foster research to improve the knowledge of root causes of CKD-associated pruritus to have a better understanding of its impact on patients

Scientists believe CKD-aP is a multifactorial disorder but the current understanding of this condition remains very limited, namely with regards to root causes, underlying mechanisms, and effective treatment modalities.[11, 12] This is also because the onset of symptoms varies amongst patients, and their intensity can range from mild to severe.[27] A deeper understanding of the intricate pathways of CKD-aP will be crucial to prevent, manage and treat the complex physiological, biochemical, and neurological factors that might contribute to its onset and persistence of this condition.

Conducting a coordinated and harmonised pan-European patient survey on the quality of life and well-being of patients, in partnership with patient organisations and medical societies, is crucial in attaining this objective. This endeavor would not only deepen the understanding of the condition's prevalence but also offer a complete overview of its impact on patients' quality of life and general well-being. This joint undertaking would mark a significant stride towards a more thorough comprehension of CKD-aP and lay the foundation for more precise and efficient treatment strategies, ultimately enhancing the well-being of individuals grappling with this condition.

Moreover, research can also provide further clarity on the impact of the disease in the patient's life. Such research can also support the development of interventions and materials that can alleviate the burden the disease might have on the quality of life and well-being of both the patient and their immediate circle.

Collaboration lies at the heart of this transformative journey. Industry stakeholders, medical societies, universities, and research centres must join forces to propel impactful research initiatives forward. Establishing grants dedicated to nurturing researchers in their pursuit of comprehensive studies on CKD-aP can yield far-reaching benefits.

To this extent, it would be critical to prioritise resources at European level. Advocating for



specific research grants on CKD-aP within the Horizon Europe health cluster can serve as a catalyst for progressing knowledge on this disease. Therefore, it is imperative to emphasise the necessity for a timely conversation surrounding CKD-aP research ahead of the formulation of the next work programme of Horizon Europe. This foresight would be key for strategic planning and ensure that the research agenda aligns with the evolving needs of patients and the broader healthcare landscape. Moreover, it is worth noting the significant potential that the Innovative Health Initiative (IHI) holds for advancing treatment research in this domain as well as the opportunities provided by the EU 4 Health programme in the field of improving patients' quality of life. This collaborative effort, involving stakeholders from various sectors within the framework of specific European projects, is paramount to driving meaningful progress towards comprehending and ultimately mitigating the impact of this complex condition on patients' lives. Through strategic partnerships and targeted advocacy, we can pave the way for transformative breakthroughs in the field of CKD-aP research and treatment.

Recommendation 5 – Generate more data on patient experiences around pruritus, specifically on its impact, especially on the mental well-being of patients, on how they perceive treatments, and how they would like to be involved in their care

There is a clear need to have more data on the prevalence of the Chronic Kidney Disease-associated Pruritus, as well as the impact on patients' quality of life.[16, 28, 35]

The lack of understanding regarding CKD-aP has far-reaching consequences. It diminishes healthcare professionals' proficiency in comprehending the condition, thereby impeding their ability to offer the highest standards of

care and provide comprehensive information to patients. Furthermore, it hinders patients' own understanding of the condition, including the importance of reporting it to their healthcare provider. This knowledge gap directly impacts the available treatment options and the extent to which patients can actively participate in their own care.

However, assessing pruritus intensity objectively is challenging. Since it is a subjective feeling, the assessment of pruritus in CKD patients is solely based on their reports. Thus, the only way to assess CKD-aP presence, intensity, course and response to treatment of patients with pruritus remains Patient Reported Outcomes (PROs).

While various measurement tools for assessing pruritus exist, none have attained the status of a definitive standard, and many of the existing methodologies are primarily tailored for clinical research rather than everyday application in clinical practice. It is therefore imperative for patients and their healthcare providers to integrate these tools into routine clinical practice, thus providing a more comprehensive understanding of this often underreported condition.[22] The routine implementation of validated PROs, coupled with the integration of patient reported experience and the introduction of novel itching detection tools, holds the potential to offer durable insights into the persistence and severity of CKD-aP over time. This approach can ultimately serve as a litmus test for the effectiveness of newly targeted treatments and yield deeper insights into their impact on patients' quality of life.[22]

"Patient surveys have highlighted a significant portion of pruritus sufferers who remain untreated, and even those undergoing treatment often express dissatisfaction and continued symptom prevalence



In this sense, a concerted effort involving medical societies, patient organisations, and competent health authorities at European, national, and regional levels is necessary. By pooling expertise and resources, stakeholders should work towards establishing a comprehensive and standardised data collection platform for patients affected by CKD-aP. This unified registry would serve as an invaluable resource, capturing a multifaceted view of the condition, including its diverse array of symptoms, evolving treatment modalities, and the trajectory of the ailment.

For this to happen, a standardised tool for measuring patient-reported experiences should be developed. Such a tool, co-created by patient organisations and medical societies, would hold the potential to transform how we understand and address the unique challenges faced by patients coping with CKD-aP. By providing a structured framework for patients to articulate their experiences, preferences, and needs, this tool would not only enhance the precision of care but also foster a deeper sense of empowerment and agency among those navigating the complexities of CKD-aP. Through these concerted efforts, it would not only be possible to refine the delivery of targeted treatments but also to foster a more compassionate and patient-centric approach to managing CKD-aP. By prioritising the voices and experiences of patients, meaningful progress would be made towards improving the overall quality of life of those coping with this often-underestimated condition.[22]

Recommendation 6 – Advancing patient care implementing a comprehensive approach to Chronic Kidney Disease-associated Pruritus

CKD-aP varies from patient to patient. The diversity of symptoms allied with the lack of awareness of healthcare professionals makes the diagnosis of pruritus challenging and might result in patients seeking health from different types of healthcare professionals.[27]

To address this challenge, it is imperative for national healthcare systems to proactively establish specialised multidisciplinary teams attuned to the distinct needs of CKD-aP patients. These teams should be composed of a diverse array of experts, including nephrologists for their specialised kidney care expertise, dermatologists with a focus on skin conditions, dedicated nursing professionals providing critical day-to-day support, and primary care physicians who serve as central



"Raising policy awareness on CKD-aP is of paramount importance to address the existing gaps in diagnosis and treatment. It is crucial for policymakers to grasp the full extent of CKDaP's societal and economic burden in order to allocate resources effectively

coordinators of holistic care. Moreover, the integration of professionals from psychological and social work disciplines is paramount. Their specialised training equips them to identify patients grappling with severe pruritus symptoms, allowing for a more nuanced and compassionate approach to care. This collaborative approach not only ensures comprehensive monitoring but also enables a timely and effective treatment response, ultimately enhancing patients' quality of life and overall well-being.

In addition, patient associations at the national level stand as crucial partners in this endeavour. Drawing on their wealth of experience and advocacy efforts, these associations can play an instrumental role in navigating potential hurdles and ensuring the seamless integration of this comprehensive approach within hospital settings. Their unique position allows them to act as a bridge between patients, healthcare providers, and policymakers, facilitating communication and understanding of what it means to be a CKD-aP patient. By harnessing the collective knowledge and resources of patient associations, health systems can elevate the efficacy and longevity of these specialised care teams. This collaborative synergy fosters an environment where patients receive the highest standard of care, ultimately leading to better outcomes and enhanced patient satisfaction.

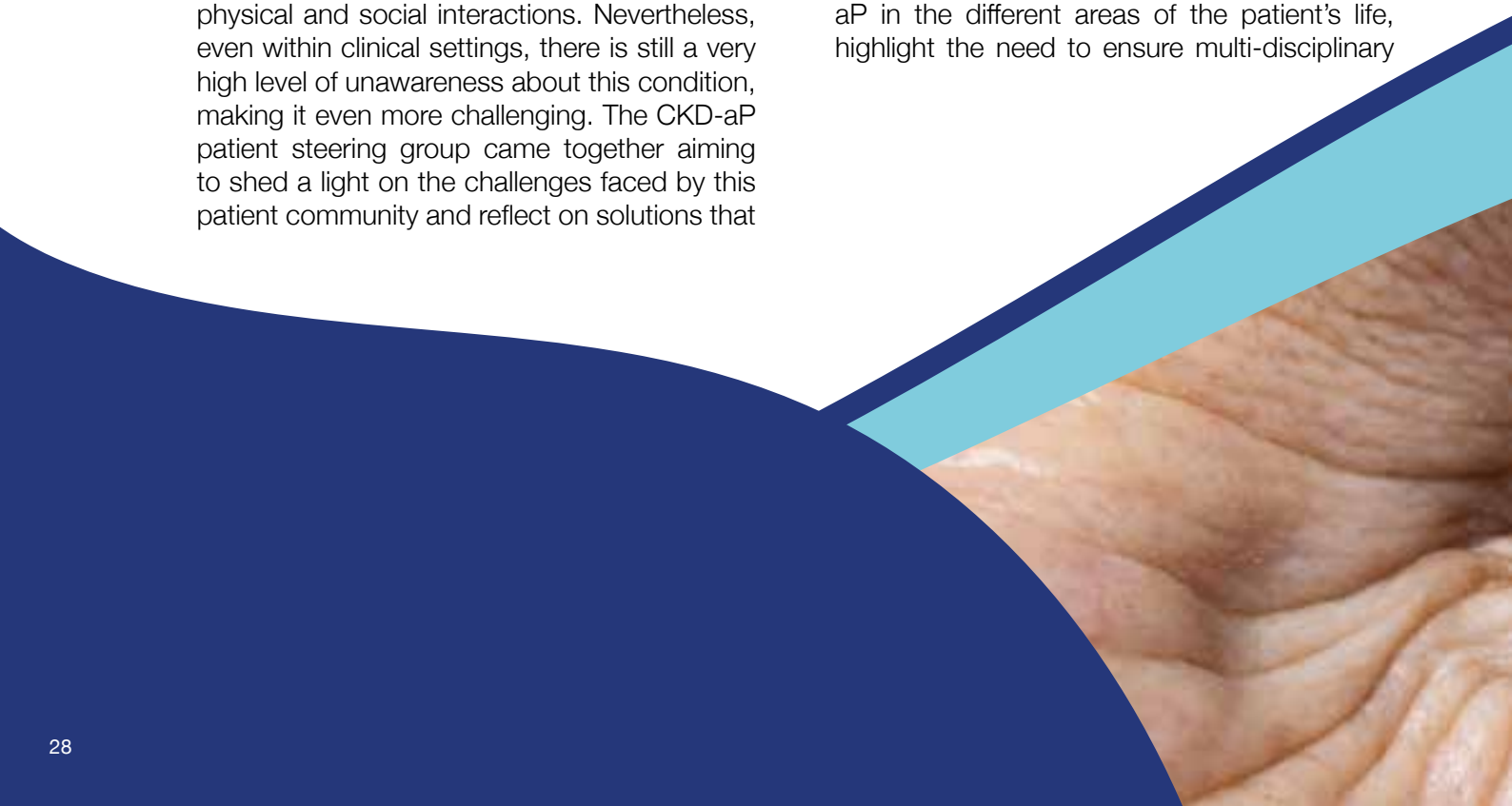


Conclusion

The COVID-19 pandemic has revealed the European Union's ability to unite and take swift, impactful action in the face of health crises. Through collective efforts and shared commitment, we witnessed the EU's capacity to make a tangible difference in the lives of European citizens. As we emerge from the pandemic's shadow, we find ourselves at a crucial moment, with reminded awareness that, by collectively addressing health challenges we can drive fast and impactful change across several countries. This newfound awareness can now be applied to other health topics, extending beyond infectious diseases, and focusing on other burdensome issues, namely within the realm of non-communicable conditions and their extremely high human and financial cost.

Chronic Kidney Disease-associated Pruritus is a burdensome condition that brings many challenges to the life of patients, both physically and psychologically. As evidenced by the results of the patient surveys, across the included countries – France, Germany, Italy, Spain and Portugal – patients report disruptions in their sleep, mood, mental health, and their physical and social interactions. Nevertheless, even within clinical settings, there is still a very high level of unawareness about this condition, making it even more challenging. The CKD-aP patient steering group came together aiming to shed a light on the challenges faced by this patient community and reflect on solutions that can be taken at a European level to ignite change that can be translated into better management and ultimately, improved quality of life. Through reflection on the insights collected from the patient surveys and thoughtful discussion on what it means to live with and provide care to these patients, the CKD-aP developed a set of comprehensive recommendations. These recommendations should be viewed as interconnected, forming a mosaic of care that has the potential to transform the quality of life for CKD-aP patients.

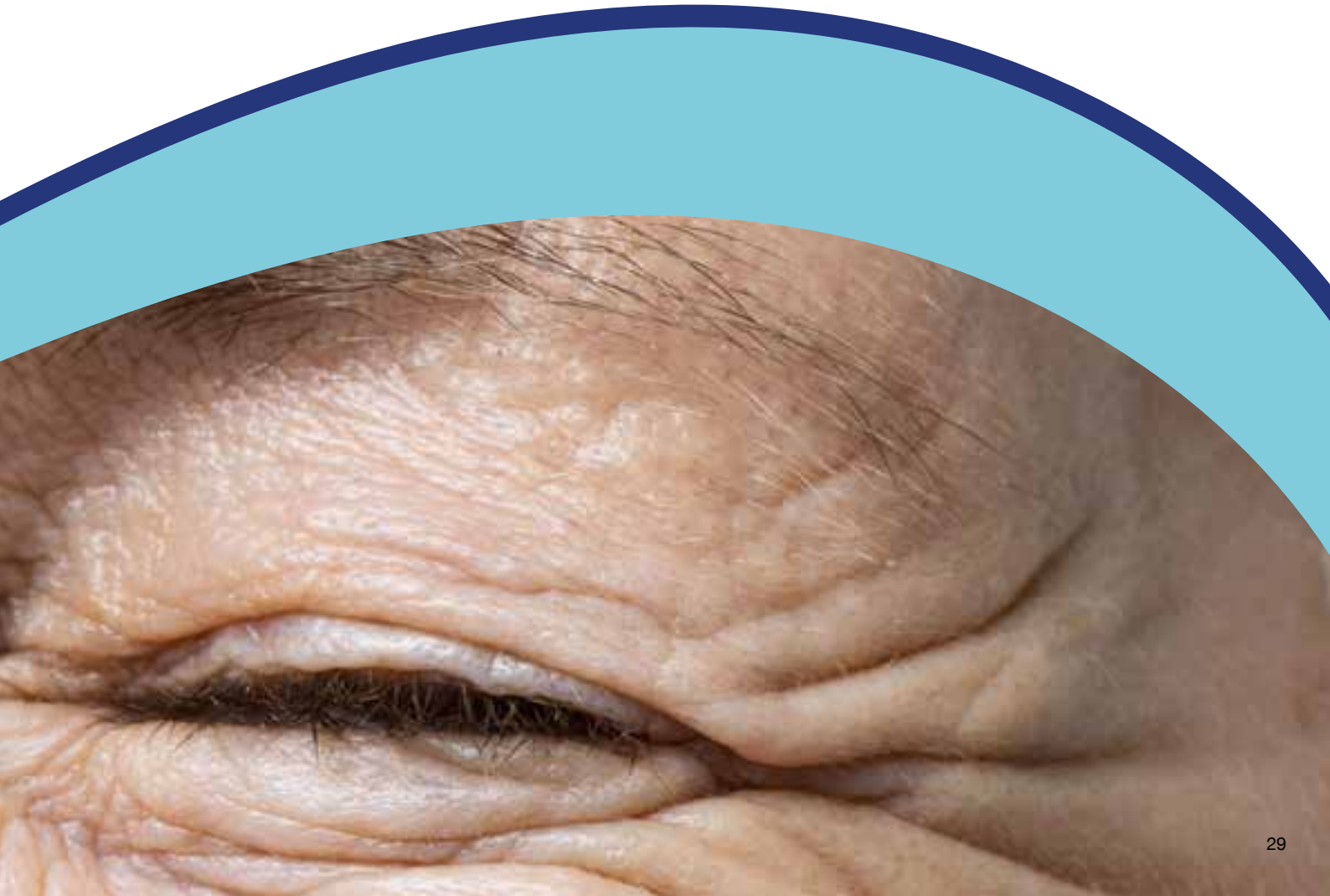
If on one hand, there is a need to foster awareness among healthcare professionals, caregivers and even patients themselves on the root causes, impact, and options available to tackle CKD-aP, on the other hand there is also a need to foster research that can deepen our knowledge on each one of these aspects. A robust understanding of this condition is essential to improve patient outcomes, and facilitating access to comprehensive data is crucial for the development of more effective interventions and therapies that can dramatically enhance patients' lives. Moreover, the far-reaching consequences of CKD-aP in the different areas of the patient's life, highlight the need to ensure multi-disciplinary



approaches to care, incorporating different types of professionals that can ensure holistic approaches to patient care. To drive true change at EU level the support of regulators and policy makers is crucial, thus, increasing the awareness and fostering political debate around this topic can be extremely impactful.

The CKD-aP community yearns for recognition, support, and, most importantly, solutions to meet their unmet medical needs. The time to act is now. The European healthcare policy landscape is evolving and the increase in attention and political discourse around health issues brought by the COVID-19 pandemic needs to be seized. New and pioneering policy frameworks, such as the European Mental Health Strategy, the European Health Data Space and the General Pharmaceutical Legislation, are being developed and reshaped and bring opportunities to improve the well-being of European citizens. The CKD-aP Patient Steering Group's recommendations stand as clear guide to drive change and tackle the still many unmet needs faced by those living with this condition.

"The CKD-aP patient steering group came together aiming to shed a light on the challenges faced by this patient community and reflect on solutions that can be taken at a European level to ignite change that can be translated into better management and ultimately, improved quality of life



About EKPF

The European Kidney Patients Federation (EKPF) is a non-profit organisation that serves as an umbrella entity, uniting national associations across various European countries.

With a collective reach that spans over 75 million individuals living with kidney health conditions in Europe, EKPF is dedicated to advancing the well-being and rights of kidney patients throughout the continent.

Our mission at EKPF is rooted in a commitment to enhance several critical aspects of kidney health: Voice, Choice, Involvement, Safety, Autonomy, Quality of life, Innovation, and research. In line with our mission, EKPF's objectives, as outlined in our statutes, encompass a broad spectrum of goals, from raising awareness of End Stage Kidney Disease (ESKD) and promoting disease prevention to establishing early detection standards and improving the treatment and living conditions of ESRD patients and their families. Additionally, EKPF seeks to foster cooperation and information exchange with organizations and institutions involved in renal diseases and to increase organ donation and transplantation rates. Through these initiatives and collaborations, the European Kidney Patients Federation remains steadfast in its dedication to advocating for the rights and well-being of kidney patients across Europe, working tirelessly to create a brighter and healthier future for all those affected by kidney health conditions.



This White Paper has been created with the expert collaboration of:

Country	Representative	Patient Group
France	Cécile Vandevivère – Director General	France Rein
Italy	Maria Elisabetta De Ferrari – HCP Francesco Moretti – Patient	ANED
Spain	Juan Carlos Julián – Director General	ALCER
Portugal	Marta Campos – Coordinator	APIR
UK	George Lankester – Policy Manager	Kidney Research UK
Germany	Angela Monecke – Manager	Bundesverband Niere e.V



References

1. Hector Alvarado Verduzco, S.S., *CKD-Associated Pruritus: New Insights Into Diagnosis, Pathogenesis, and Management*. Kidney International Reports, 2020. 5: p. 1387–1402.
2. Fishbane, S., et al., *Randomized Controlled Trial of Difelikefalin for Chronic Pruritus in Hemodialysis Patients*. Kidney Int Rep, 2020. 5(5): p. 600-610.
3. Kremer, A.E., et al., *Receptors, cells and circuits involved in pruritus of systemic disorders*. Biochim Biophys Acta, 2014. **1842**(7): p. 869-92.
4. Molina, P., et al., *Etiopathogenesis of chronic kidney disease-associated pruritus: putting the pieces of the puzzle together*. Nefrologia (Engl Ed), 2023. **43**(1): p. 48-62.
5. Agarwal, P., et al., *Chronic Kidney Disease-Associated Pruritus*. Toxins (Basel), 2021. 13(8).
6. Manenti, L. and E. Leuci, *Do you feel itchy? A guide towards diagnosis and measurement of chronic kidney disease-associated pruritus in dialysis patients*. Clin Kidney J, 2021. 14(Suppl 3): p. i8-i15.



EKPF
EUROPEAN KIDNEY PATIENTS' FEDERATION
CEAPIR

7. Weisbord, S.D., et al., *Renal provider recognition of symptoms in patients on maintenance hemodialysis*. Clin J Am Soc Nephrol, 2007. 2(5): p. 960-7.

8. Santos-Alonso, C., et al., *Pruritus in dialysis patients. Review and new perspectives*. Nefrologia (Engl Ed), 2021.

9. Santoro, A., et al., *Il prurito in dialisi, visto dalla prospettiva dei pazienti*. Giornale Italiano di Nefrologia, 2022. **39(4)**: p. 13-22.

10. Rayner, H.C., et al., *International Comparisons of Prevalence, Awareness, and Treatment of Pruritus in People on Hemodialysis*. Clin J Am Soc Nephrol, 2017. **12**(12): p. 2000-2007.

11. Reyes, V., *Pruritus Associated to Chronic Kidney Disease (CKD-aP) has a Negative Impact in the Quality of Life of Hemodialysis Patients in Spain: A Survey*.

12. Esteve-Simo, V., et al., *Chronic Kidney Disease-Associated Pruritus and Quality of Life: Learning from Our Patients*. J Clin Med, 2023. **12**(13).

13. Hercz, D., S.H. Jiang, and A.C. Webster, *Interventions for itch in people with advanced chronic kidney disease*. Cochrane Database Syst Rev, 2020. **12**(12): p. CD011393.

14. Pisoni, R.L., et al., *Pruritus in haemodialysis patients: International results from the Dialysis Outcomes and Practice Patterns Study (DOPPS)*. Nephrol Dial Transplant, 2006. **21**(12): p. 3495-505.

15. Orasan, O.H., et al., *Hemodialysis Patients with Pruritus and Insomnia Have Increased Risk of Death*. Blood Purif, 2020. **49**(4): p. 419-425.

16. de Sequera, P., et al., *Impacto del prurito asociado a la enfermedad renal crónica (Pa-ERC) en la calidad de vida de los pacientes en hemodiálisis en España*. Nefrología, 2023.

17. e.V, B.N., *Lebensqualität und chronische Nierenerkrankung, in Der:die nierenpatient*. 2023.









Appendix – Survey analysis

Background information

This section captures the results of the surveys rolled out by members of the European Kidney Patients Federation (EKPF) in France, Germany, Italy, Spain and Portugal between 2021 and 2022. They gathered information about the reality of kidney disease patients suffering from CKD-aP, and especially the impact of pruritus on their quality of life and wellbeing.

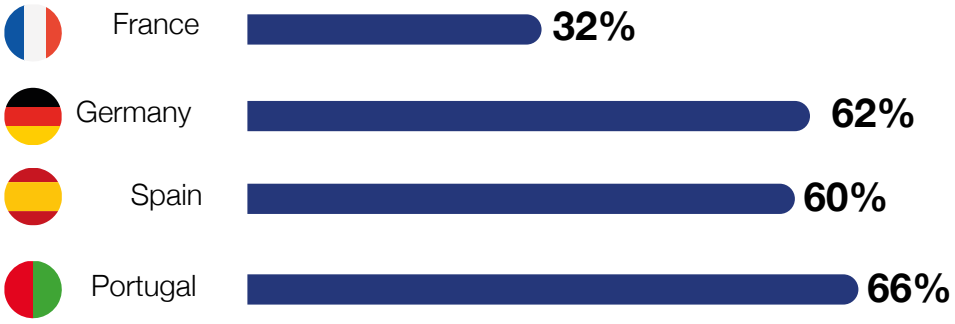
In total, 3,803 European kidney disease patients responded to the surveys. The number of respondents varied between countries; between 1,896 in Italy (close to half of the total number of respondents) and 43 in Portugal.

Respondents' experience of pruritus

Severity of the condition

When asked about the itching, in most countries over two third of respondents declared suffering from pruritus: **66%** in Portugal, **62%** in Germany and **60%** in Spain. The percentage of people stating suffering from itching was however lower in France, where it was of **32%**.

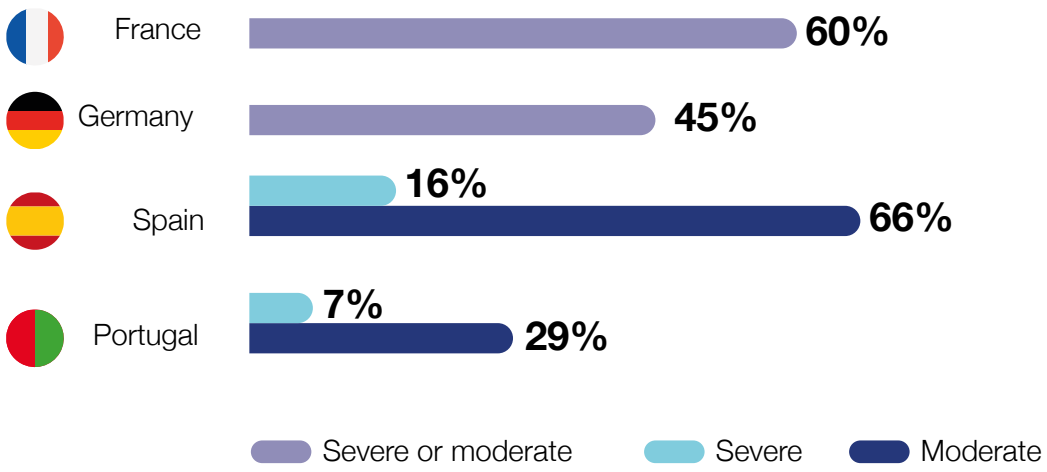
Graph 1 – Percentage of respondents declaring suffering from pruritus



Most respondents explained facing moderate or severe cases of pruritus. In Spain, **82%** of respondents declared having moderate (**66%**) or severe (**16%**) states of the condition. France, **60%** shared their itching was moderate or severe. In case of home dialysis respondents, **74%** (peritoneal dialysis) and **60%** (haemodialysis) of French respondents declared that the itching was one of their most bothersome symptoms. In Germany, **45%** of respondents described their itching was moderate or severe. In Portugal, **36%** responded that their itching was moderate (**29%**) or severe (**7%**). In Portugal, a larger percentage of respondents stated having a mild state of the condition (**42%**).



Graph 2 – Severity of the pruritus



Length of time living with and progression of the condition

In some countries, respondents were asked about the length of time they lived with the condition, about when it started and about its progression.

- **90%** of Portuguese respondents mentioning suffering from pruritus for more than a year up to since ten years ago.
- **42%** of Italian respondents explaining suffering from pruritus for more than a year.



Link to dialysis

- **80%** of Italian respondents linked the start of pruritus with dialysis. **10%** of Italian respondents explained pruritus only occurred during a dialysis session.
- Only a small percentage of Spanish respondents explained pruritus only occurred after a dialysis session (**16%**) or during a session (**13%**).
- **10%** of Italian respondents explained pruritus only occurred during a dialysis session.

Frequency of the condition

The vast majority of respondents, who were asked about when the itching is taking place, declared suffering from pruritus most day.

- **94%** of Portuguese and **73%** of German respondents stated that the itching was present for up to six hours per day.
- In Spain, **60%** of respondents with pruritus explained experiencing it every day, both during the day and the night.
- In Italy, however, respondents explained that pruritus lasted a few days before disappearing (**53%**) or was almost always present (**36%**). Only **10%** of Italian respondents mentioned that the pruritus was always present.

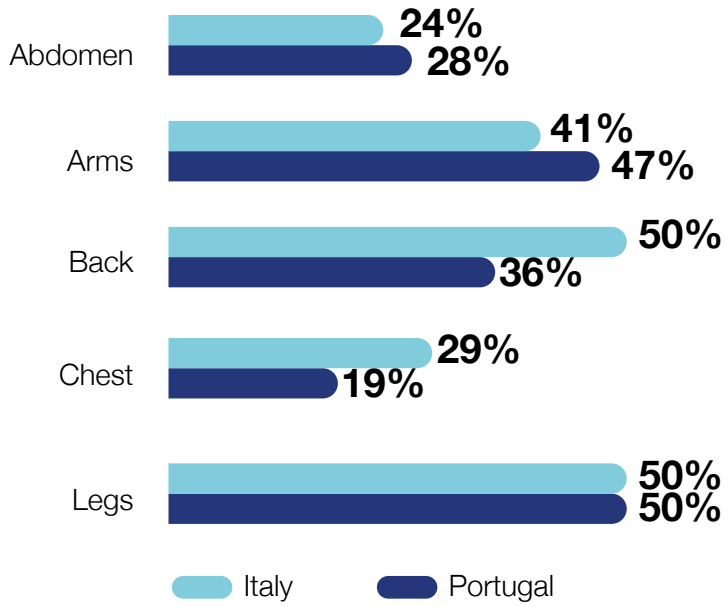
The pruritus seems to be equally present during the day and the night with **30%** of Spanish and **20%** of Italian respondents reporting its presence during the day; and **29%** of Spanish and **18%** of Italian respondents reporting it at night.



Location of pruritus on patients' bodies

When asked about which part of their bodies was the most affected by pruritus, respondents mentioned their legs (**50%** Italian respondents and **50%** Portuguese respondents), their back (**50%** Italian respondents and **36%** Portuguese respondents) and their arms (**41%** Italian respondents and **47%** Portuguese respondents). Their chest (**29%** Italian respondents and **19%** Portuguese respondents) and abdomen (**24%** Italian respondents and **28%** Portuguese respondents) were less frequently mentioned.

Graph 3 – Location of the itching on respondents' bodies



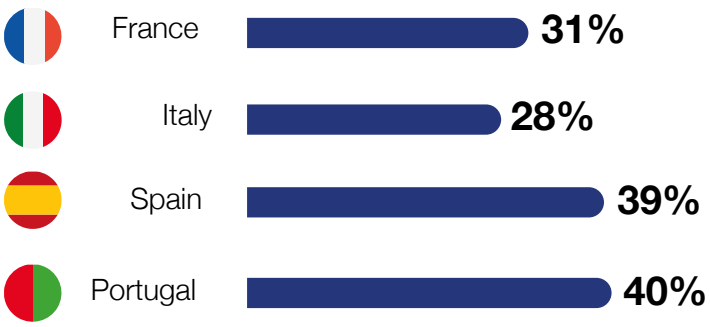
Repercussion of pruritus on patients' quality of life

A worsened quality of sleep

The impact of pruritus on patients' quality of sleep is not negligeable.

- In Portugal, **40%** of respondents explained that the itching affected their sleep
- In Spain, **39%** mentioned to have difficulties falling asleep because of the itching, and **38%** explained waking up at night because of the itching.
- In France, **31%** stated to have bad or very bad quality of sleep.
- In Italy, **28%** affirmed that the itching made them nervous and doesn't let them sleep

Graph 4 – Percentage of respondents stating pruritus was impacting their sleep



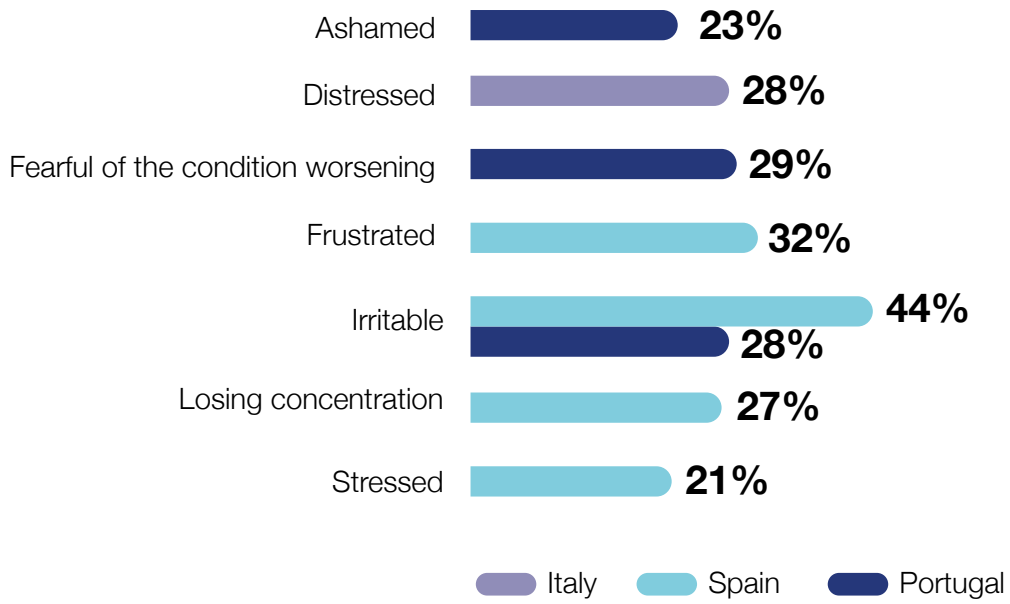
Impact on mood and mental health

Pruritus seems to have a significant impact on patients' mood and mental health.

- In Spain, **44%** of respondents mentioned that pruritus made them irritable, **32%** frustrated, **27%** lose concentration and **21%** become stressed.
- In Portugal, the stronger emotions reported by patients were fear that the itching would get worst (**29%**), irritability (**28%**) and shame (**23%**).
- In Italy, nearly a third of respondents reported distress (**28%**).



Graph 5 – Impact of pruritus on the mood and mental health of respondents



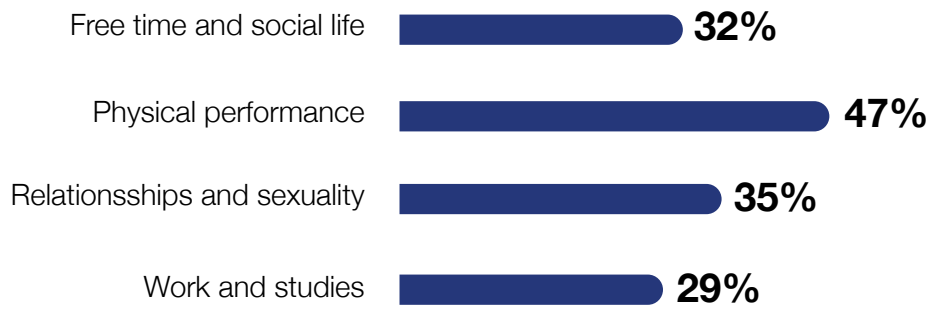


Impact on physical and social activities

Pruritus is impacting the physical and social activities of patients.

In Germany, patients reported that the itching affected their physical performance (**47%**), their relationships and sexuality (**35%**), their free time and social life (**32%**) and their work and studies (**29%**).

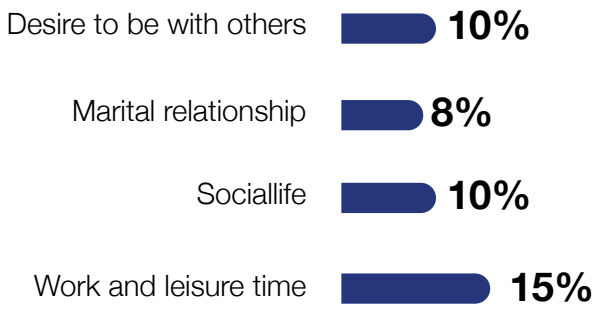
Graph 6 – Impact of pruritus on the physical and social activities of German respondents



In Portugal, respondents explained that pruritus disturbed their work and leisure time (**15%**), their social life (**10%**), their desire to be with others **(8%**) and their marital relationship (**8%**).



Graph 7 – Impact of pruritus on the physical and social activities of Portuguese respondents



In Italy, respondents stated that the itching limited them in their interactions with people as they often bad to scratch (**10%**).

Nevertheless, the negative impact of pruritus on patients' quality of life was not experienced to the same extend in all countries with **65%** of German respondents stating being satisfied with their quality of life and **60%** of Italian respondents mentioning that pruritus is just an inconvenience, which they could easily overcome.

Treatment of pruritus and success of the treatment

Treatment against the pruritus

In the countries where the question of treatment was asked, only a third of respondents mentioned following a treatment against pruritus. Indeed, in Germany, Spain and Portugal approximately **60%** of respondents were not treated for pruritus. In Germany, a having prescription against the itching was reported in only **24%** of cases. In Italy, **32%** of respondents reported having been prescribed by a healthcare professional a treatment with some level of effectiveness.

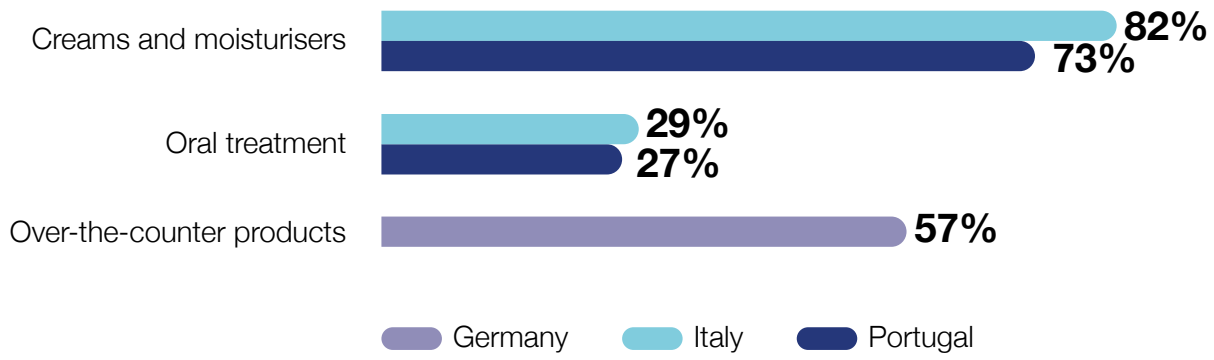


Type of treatment

The types of treatments used by patients against the itching varied, with a preference for external treatments.

- In Italy, patients reported using emollient and moisturising creams (**68%**), oral antihistamines (**29%**) and creams containing cortisone (**14%**).
- In Portugal, the majority of patients (**73%**) stated using external treatments (e.g., cream, lotion) in comparison to oral treatments (e.g., tablets, capsules, syrup) (**27%**).
- In Germany, over half of respondents explained using over-the-counter products from the drugstore or pharmacy (**57%**).

Graph 8 – Types of treatments used by respondents against pruritus



Success of the treatment

Respondents allocated mixed level of success to treatments against pruritus.

- In Germany, even if **91%** of patients affected by pruritus declared being more or less satisfied with the success of their treatment, **70%** reported only partial success.
- In Spain, **47%** of respondents using a treatment against pruritus were dissatisfied with it.
- In Portugal, respondents described the evolution of the itching after the treatment as better or much better (**54%**) or worst or the same (**46%**).
- In Italy, **22%** of respondents mentioned that the prescribed medications they used didn't relieve them from the pruritus.

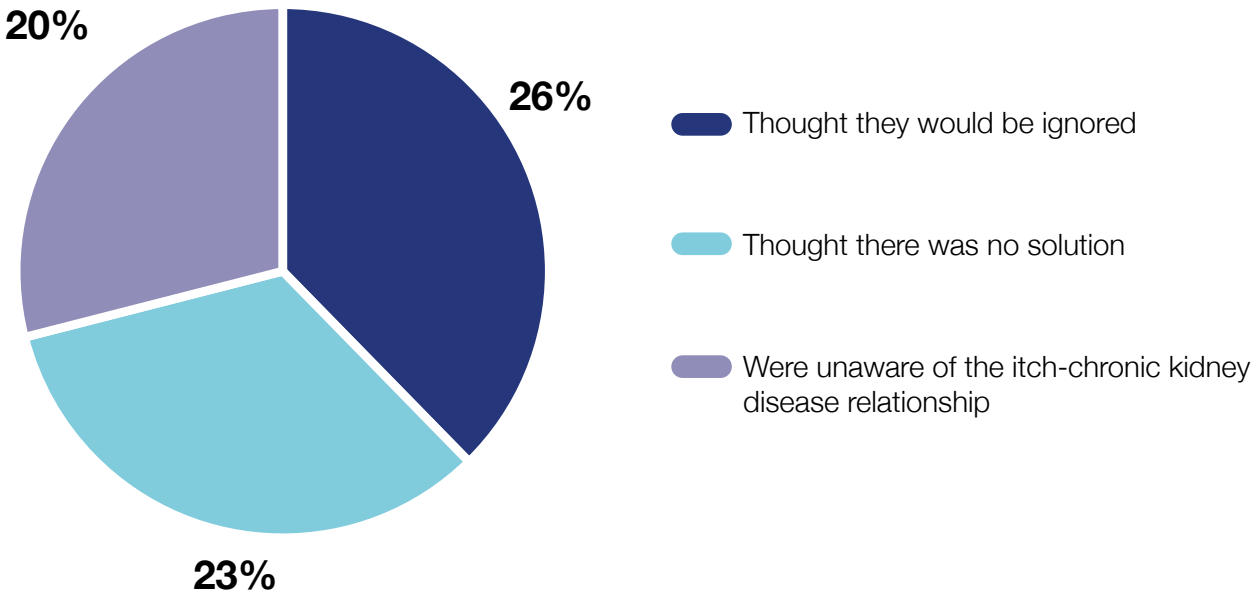
Communication with and information provided by healthcare professionals

Discussing pruritus with healthcare professionals

Only a third of respondents reported having discussed the issue of pruritus to their healthcare professionals.

In Spain, **35%** of respondents stated not to communicate issues associated with pruritus to their doctor or nurse. When asked why they would not talk to their healthcare professional about pruritus, Spanish respondents explained that: they thought they would be ignored (**26%**), there was no solution (**23%**), or they were unaware of the itch-chronic kidney disease relationship (**20%**).

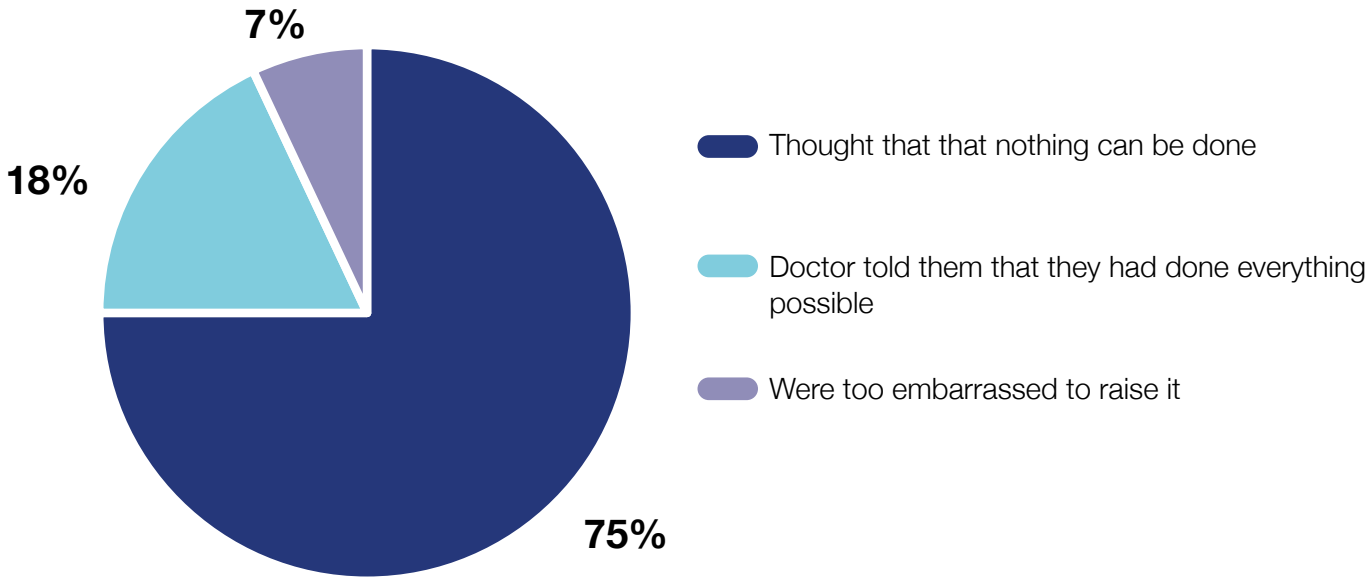
Graph 9 – Reasons given by respondents who did not raise pruritus to their HCPs in Spain





In Italy, **66%** of respondents mentioned that they had an initial conversation about pruritus with their nephrologist but would not continue raising pruritus to their doctor. They explained that they understood that the itching is caused by dialysis and that nothing can be done (**75%**), that their doctor told them that they had done everything possible in light of current medical knowledge (**18%**), or that they were too embarrassed (**7%**). When asked if they talked to their dialysis nurse about pruritus, Italian respondents stated that it was not the case (**47%**), that they mentioned it and the nurse gave them some useful advice to follow at home (**28%**), or that they only told the nurse when the itching becomes unbearable (**26%**).

Graph 10 – Reasons given by respondents who did not raise pruritus to their HCPs in Italy



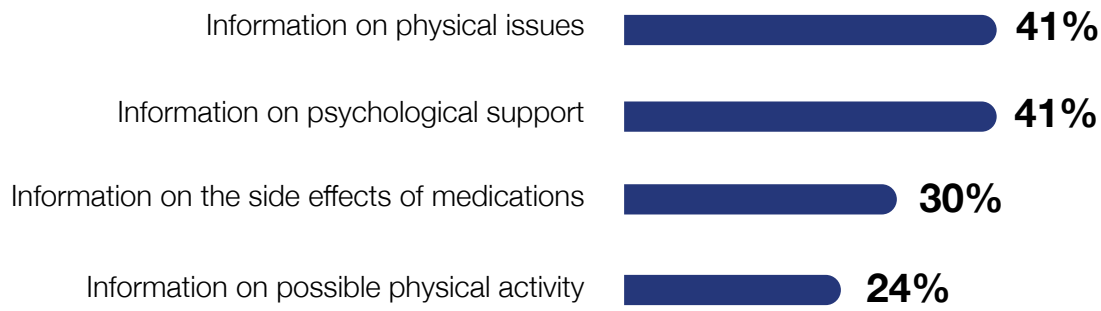


Information from healthcare professionals

In Italy, when asked if they received answers that made them aware of the nature of pruritus, **71%** of respondents felt that they received enough information, **27%** did not feel that they received satisfactory answers and were unsure about the cause of pruritus.

In Germany, patients asked for information going further than the underlying nephrological disease, as for instance, focusing on physical issues (e.g., pain, itching) (**41%**), psychological support (**41%**), the side effects of medications (**30%**) and information about physical activity (**24%**).

Graph 11 – Type of information asked by respondents in Germany



Involvement of patients in their care

The connection between patient involvement in the medical decision-making process was directly related to their satisfaction with nephrological care and in their quality of life.

In Germany, a section of the survey focused on patients' wishes to be involved in their care. **86%** responded that they would like to be involved in decisions about their care. **50%** felt that they were currently taken into account in decisions, whereas **37%** felt that they were partially involved in their medical treatment.

Interesting to note is that, in Germany, patients who were the most involved in discussions and decisions about their care were found to be far more satisfied with the care provided at dialysis centres (**87%**), in comparison to those who were dissatisfied with the exchange of information with healthcare professionals (**55%**).





EKPF
EUROPEAN KIDNEY PATIENTS' FEDERATION
CEAPIR

evoke incisive health
www.evokeincisivehealth.com

CSL Vifor