

Scientific Briefing & Policy Recommendations

KIDNEY CANCER: CLOSING THE GAP TO BETTER OUTCOMES IN EUROPE



IKCC
International Kidney
Cancer Coalition



European
Association
of Urology

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KEY SUMMARY

Kidney cancer has a high mortality and is frequently severe - around 1/3 of patients are diagnosed with an advanced form, for which curative options are limited. Due to populations growing and aging, we are expecting to see 71% more cases in Europe by 2050. Because of this, despite improvements in treatment, current projections indicate nearly twice as many deaths from kidney cancer in 2050, compared to 2022*. The Europe Beating Cancer Plan, the EU Research Mission on Cancer, and several other policies offer critical frameworks to address these challenges, yet substantial evidence gaps across prevention, detection, and treatment hinder their effectiveness and kidney cancer receives disproportionately low research funding relative to its disease burden.¹

Overview of global research funding on kidney cancer:

- **40 M\$ per year** for research on kidney cancer (during 2016-2020 period)
- Only **1% of global funding** for cancer research on kidney cancer (while incidence of kidney cancer represents 2.1% of global cancer cases and 3.3% in Europe)
- **16th cancer site for funding** out of 20

REDUCING AVOIDABLE CASES

Almost half of all kidney cancers could be prevented if smoking were eliminated and healthy body weight maintained. Yet the biological mechanisms by which smoking, obesity, and hypertension drive kidney cancer remain understudied, hindering targeted prevention strategies. Emerging evidence on environmental threats also suggests that specific PFAS, particularly PFOA, are associated with increased RCC risk. Investigation into these must underpin EU policy.

CLOSING THE DIAGNOSTIC GAP

The majority of kidney cancer cases are still detected incidentally, not systematically. No validated biomarkers exist despite promising candidates. Evidence on screening programmes is strikingly insufficient, meaning that policymakers lack data on cost-effectiveness and optimal modalities. Much more policy at-

ention is needed to assess how screening and diagnostic pathway interventions could better identify at-risk patient groups to improve outcomes.

OPTIMISING CARE

Researchers have made significant advances in the identification of genetic and environmental drivers that affect the course of kidney cancer and drive tumour growth. Turning these discoveries into better treatments requires sustained investment. This includes identifying which patients suitable for active surveillance, which would benefit from adjuvant therapy after surgery, and which treatments or combinations work best for individual patients.

ELIMINATING INEQUALITIES

Critical gaps in understanding persist for rare subtypes (20-25% of cases) and other less common but clinically challenging scenarios that fall outside standard care pathways. Regional and socio-economic disparities in access to primary prevention, secondary prevention, innovative treatments, and multidisciplinary care teams, lead to preventable mortality differences.

THE PATH FORWARD

Coordinated EU investment is essential to reduce avoidable deaths and improve the quality of life for patients living with kidney cancer. Substantial, earmarked research investment within Horizon Europe, a focus on kidney cancer within strengthened cancer data infrastructure, and systematic monitoring of disparities are urgently needed.

This briefing presents the current state of kidney cancer in Europe, drawing on global comparisons where relevant. It covers epidemiology, risk factors, diagnosis, treatment, and patient impact, and provides concrete policy recommendations to close evidence gaps, reduce preventable deaths, and ensure equitable access to care across all Member States.

* There is also a funding gap between kidney cancer and other cancers with a similar incidence. For example, between 2007 and 2020 the average melanoma research grants were €11 million/year compared to €2 million/year for kidney cancer - a difference of more than 5-fold. (IKCC roundtable paper)

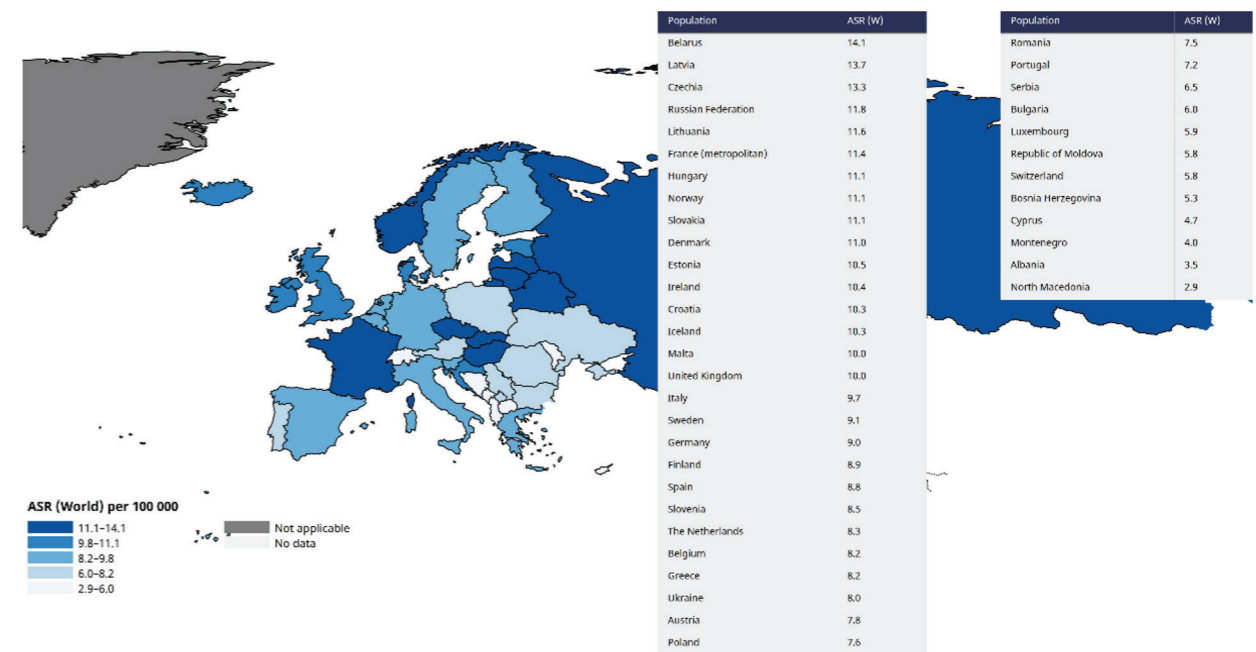
1. KEY FIGURES: INCIDENCE AND MORTALITY

Kidney cancer is the 5th and 10th most commonly diagnosed cancer in men and women at European level, respectively, with approximately 145,789 new cases and 52,370 deaths in Europe recorded in 2022². Europe is the continent with the largest number of kidney cancer cases and deaths, just after Asia. Men represent 63% of cases.

PROJECTIONS

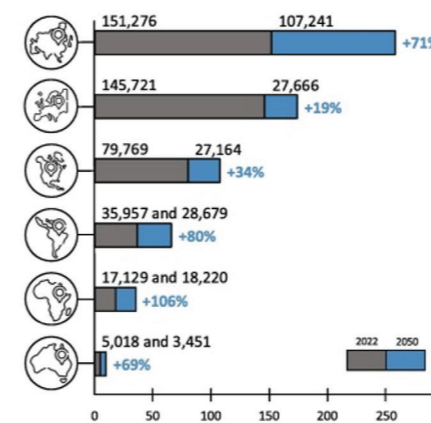
Due to populations growing and aging, we are expecting to see 71% more cases in Europe by 2050. Because of this, despite improvements in treatment, **current estimated predict to see nearly twice as many deaths from kidney cancer in 2050, compared to 2022².**

Age-Standardized Rate (World) per 100 000, Incidence, Both sexes, in 2022
Kidney



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Cancer TODAY | IARC
https://gco.iarc.who.int/today
Data version: Globocan 2022 (version 1.1) - 08.02.2024
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Source: Cancer Tomorrow - IARC, https://gco.iarc.who.int/today
Data version: Globocan 2022 (version 1.1) - 01.03.2025

These projections are based on current trends, and may be higher if nothing is done to address the modifiable risk factors that contribute to the disease. For example, obesity rates are predicted to continue to rise³ which could directly impact rates of RCC. Tobacco use remains at extremely high levels throughout the WHO European Region, with adult smoking prevalence still among the highest in the world, meaning a large proportion of the population remains exposed to this major preventable cancer risk that also contributes to kidney cancer and other cancers.⁴

PREVALENCE

There are currently 473,212 people alive today in Europe who were diagnosed with kidney cancer in the past 5 years. Europe is the continent with the highest numbers of kidney cancer survivors.

The most common type of kidney cancer in adults is **renal cell carcinoma (RCC) which represents over 90%** of cancers arising from kidney tissue. Other rarer kidney tumours include urothelial carcinoma of the renal pelvis and several rare histological subtypes⁵. **RCC occurs roughly twice as often in males as in females.** Rates are highest among people older than 75, but an increasing number of young adults are also being diagnosed with kidney cancer. Wilms tumour (Nephroblastoma) is the most common type of kidney cancer in children. Hereditary kidney cancer syndromes account for around 5% of kidney cancers and usually affect younger patients.

Kidney cancer is generally asymptomatic in early stages. If RCC does cause symptoms it is usually a sign that the disease is already at an advanced stage. The symptoms of advanced RCC include blood in the urine (haematuria), flank pain on one side, a mass on the side or lower back, fatigue, anaemia (low red blood cell counts), weight loss, and persisting fever not caused by an infection. Other findings secondary to a renal tumour are a non-reducing varicocele (enlarged veins around the testicle in men). However, these symptoms can also be caused by other diseases, such as lung or bladder conditions.

Increased use of imaging techniques, such as ultrasound and CT scans, has increased the detection of early-stage disease. This includes detecting small renal masses incidentally during scans that are looking for something else. This increase of imaging data has naturally led to treatment of small renal masses without the evidence that supports the necessity of such treatments. In particular, whether older patients (with potential co-morbidities) actually benefit from intervention at this stage of disease remains unclear. Evidence for the management of small renal masses is of low quality, and intervention in the case of asymptomatic, isolated small renal masses may be unnecessary. Strategies to safely apply active surveillance in order to prevent overtreatment with unnecessary morbidity for the patients and costs for the society are needed.

MORTALITY

In Europe, overall mortality rates have stabilised or decreased since the early 1990s. Apart from the role of reduced tobacco smoking in men, the cause of these mortality trends remains only partially explained. The explanation for international variations in incidence and mortality of kidney cancer is probably a combination of genetic susceptibility and regional populations, lifestyle, and environmental factors coupled with availability of healthcare resources for imaging (see SCREENING), variations in early detection and treatment of tumours at lower stage (smaller tumours), variable treatment options, skilled healthcare professionals and inaccurate RCC data in countries where investment is needed in cancer reporting². Mortality for metastatic cancer has improved since the introduction of targeted therapies in 2005 and immunotherapy in 2015.⁶

KIDNEY CANCER IMPOSES A SIGNIFICANT BURDEN ON PATIENTS, FAMILIES AND HEALTHCARE SYSTEMS.

Health-related quality of life (HRQOL) deteriorates with increasing tumour burden and the spread of cancer cells to another part of the body, along with the impact of treatment-related side effects. The financial/economic burden on healthcare systems is expected to increase dramatically throughout Europe over the coming years because diagnosis and management often involves high-cost drugs, and/or medical treatment combined with surgery, implying hospitalisation and regular follow-up. Preliminary findings suggest that at least 20% of people with RCC have metastatic disease (mRCC) at first diagnosis. Up to 30% of people undergoing potentially curative surgery develop metastases during follow-up⁷. Much more research is needed to confirm these numbers.

The cost for medical treatment for high risk and advanced disease is high due to the very high cost of systemic treatments, which has further increased with the use of immune checkpoint inhibitors. These high-cost treatments are common as front-line treatments, and after the primary treatment to reduce the risk of cancer coming back. They are also used if other treatments stop working. The cost of managing side effects is also significant. Approximately 85% of RCC patients with bone metastases experience skeletal related events which results in an increase in cost associated with hospital visits.

2. RISK FACTORS AND PRIMARY PREVENTION

2.1 ESTABLISHED RISK FACTORS

We do not yet fully understand why the incidence of kidney cancer is increasing, but it is likely due to many factors. Several modifiable risk factors play a major role and require urgent attention. Risk increases with age, but substantial variation exists across populations, highlighting the importance of prevention strategies targeting environmental and lifestyle determinants.



Cigarette smoking, obesity and hypertension are the most well-known risk factors for RCC⁶. 43% of all kidney cancers could be prevented if smoking were eliminated and healthy body weight maintained⁸. All three of these major risk factors are modifiable and can be prevented or reduced, yet they are increasing in prevalence in the population.

- **Tobacco use:** 1 in 4 cases of RCC is caused by cigarette smoking (25%). Smoking increases the risk of RCC by 54% in male and 22% in female former and current smokers. Studies have shown that **stopping smoking after RCC diagnosis led to a 55% lower risk of disease progression**, including tumour recurrence, metastasis, or death⁹.
- **Obesity: Obesity causes about 20% of RCC.** Obesity is now recognised by the European Association for the Study of Obesity (EASO) as a chronic, relapsing, progressive disease and is a well-established risk factor for renal cell carcinoma (RCC). A 35 kg/m² **higher BMI is associated with a 70% higher risk of kidney cancer**. 1 in 8 people in the world are living with obesity¹⁰. Obesity prevalence is projected to rise significantly across Europe over the next decade. It is **not only a significant risk factor for RCC directly, but it is also a risk factor for other conditions that worsen the course of RCC** such as cardiovascular events.

A growing evidence base is showing that obesity plays a role in the initiation, progression, and aggressiveness of RCC through multiple biological pathways. Excess adipose tissue (fat) drives metabolic dysregulation, chronic inflammation, insulin resistance, hypoxia, and altered adipokine signalling, which can create a tumour-promoting microenvironment.¹¹

There is some evidence to suggest that although obesity increases the risk of developing renal cell carcinoma, patients with a higher BMI often have better survival outcomes after diagnosis than those with lower BMI¹². More research is needed into this “obesity paradox”.

It is still unknown how novel medications for obesity will impact the incidence of RCC in the future.

- **Hypertension:** Uncontrolled elevated systolic (≥ 160 mm Hg) and diastolic (≥ 100 mm Hg) blood pressure is associated with a two- or threefold increased risk of RCC.
- **Metabolic Syndrome** (high body mass index, elevated blood pressure, elevated blood sugar, high triglycerides and low HDL cholesterol) increases the risk of RCC it by 60%, as well as the risk of developing RCC risk factors such as heart disease and diabetes.
- **Kidney disease and long-term dialysis** increase the risk of acquired cystic kidney disease⁶, a risk factor for RCC.
- **Inherited genetic predisposition:** This is likely underestimated at 5-8% of cases. Genetic screening is recommended for all patients aged 46 or younger and for those with medical or family features suggesting an inherited condition. First-degree relatives of kidney cancer patients face 2-4 times higher risk, with greater risk elevation in women. Hereditary syndromes affecting RCC often manifest outside the kidney - for example, if a patient has a first-degree relative with brain tumours, it could be suggestive of Von Hippel-Lindau syndrome which increases the risk of RCC.
- **Environmental exposure to carcinogens:** Exposure to many substances is a recognised as a risk factor for RCC. Among these agents are per- and polyfluoroalkyl substances (PFAS), a class of highly persistent synthetic compounds often referred to as “forever chemicals” due to their resistance to environmental degradation. The conclusions of an IARC conducted a study suggest that PFAS is a carcinogen.
 - o Perfluorooctanoic acid (PFOA) was classified as Group 1 (carcinogenic to humans)
 - o Perfluorooctanesulfonic acid (PFOS) classified as Group 2B (possibly carcinogenic to humans)¹³.

The effect on RCC specifically remains unknown.

2.2 RISK FACTORS WITH CONFLICTING OR LIMITED EVIDENCE

A number of other factors are associated with higher risk of RCC but data from the literature are still inconclusive¹¹.

- **Kidney stones:** There is some evidence of a significant increased risk of RCC in males with prior kidney stones⁷.
- **Viral hepatitis C infection**
- **Occupational carcinogenic exposures:** Petroleum products, asbestos, heavy metals, arsenic in drinking water has been reported to be high in low- and middle-income countries, the effects have not been studied.
- **Pain killers:** A recent meta-analysis suggested that acetaminophen and non-aspirin nonsteroidal anti-inflammatory drugs (NSAIDs) are associated with an increased risk of developing kidney cancer.
- **Meat intake and intake of related mutagens (agents that cause genetic mutations)** are suspected risk factors. Recent data support an association between red and processed meat consumption and risk of RCC only in women.
- **Sodium intake:** Sodium intake could increase the RCC risk, particularly if fluid consumption is low.

2.3 PRIMARY PREVENTION: INITIATIVES AT EUROPEAN LEVEL

It has been estimated that up to half of the overall burden of all cancers can be prevented. The 5th edition of European Code against Cancer sets 14 recommendations that European citizens can apply to help to reduce their cancer risk. These **recommendations include quitting smoking and avoiding exposure to other people's tobacco smoke**, managing **overweight and obesity**, being **physically active**, **avoiding alcoholic drinks**, adopting a **healthy diet and lifestyle** by avoiding or **reducing carcinogenic exposures** such as air pollution and possible PFOA/PFAS, and **participating in vaccination programmes** or organised **screening programmes** for bowel cancer, breast cancer and cervical cancer. For the first time, the Code is not only focused to change at an individual level but also targets policymakers¹⁴.

Avoiding smoking and maintaining normal blood pressure and normal weight can reduce the risk of developing kidney cancer and there is emerging research suggesting that **limiting the consumption of ultra-processed food** could reduce incidence and mortality¹⁵. The 2021 Europe's Beating Cancer Plan (EBCP) acknowledges the need for prevention, setting several ambitious aims in this field. Additionally, the EU Safe Hearts Plan includes several benefits for kidney cancer prevention that mitigate the impact of "commercial determinants of health", as recognised in

the UN Political Declaration on prevention and control of Non-Communicable Diseases.¹⁶

SMOKING REDUCTION

The 5th edition of the European Code Against Cancer identifies exposure to other people's tobacco smoke as the second recommendation to reduce cancer prevalence. The Code, alongside the Council's Recommendation on smoke-free environment, identifies new tobacco products, such as vapes and e-cigarettes as equally harmful. One of the objectives of the prevention pillar of the EBCP is "a tobacco-free generation, ensuring that less than 5% of the population uses tobacco by 2040"¹⁷. **This EU goal will not be achieved without strict tobacco control measures.** Further measures promoted for consideration have included recommending all EU countries raise the minimum age for tobacco sales to 21¹⁸.

Although some work has been done on this front, the Council, encouraged by the Commission, published the Recommendation on stronger measures on smoke-free environments. The Safe Hearts Plan commits to reaching the same target and includes provision for the review of the Tobacco legislation in 2026. Additionally, the Commission's proposal on the new Multi-Annual Financial Framework for the EU includes a plan for a tobacco excise duty own resource (TEDOR). This plan envisages member state specific minimum tax rates for tobacco and tobacco related products, with dual benefits of increased revenue, and public health gains.



HYPERTENSION REDUCTION

The Safe Hearts Plan commits to **70% of people with hypertension being diagnosed and controlled by 2035**, with appropriate national targets being incorporated into national cardiovascular health plans by 2027. If properly and fully implemented, **this will reduce a significant risk factor for RCC.**

* Likely due to an increased use of imaging for these populations

HEALTHY WEIGHT MANAGEMENT PROMOTION

The Safe Hearts Plan includes a target that 80% of people with obesity by 2035 will have it diagnosed and controlled, which will also have a significant positive impact on RCC prevalence. Focusing on prevention and **empowering consumers through information on food processing** in the EU, a food processing assessment system should be developed to empower consumers with transparent, science-based digital information on food processing, with the aim to ultimately encourage shifts towards healthier diets. As it stands, the EU's attempts at food labelling requirements have fallen short of hopes of many stakeholders. The European Commission will also promote work towards the introduction of **levies and taxes on 'ultra-processed' foods**, high fat, sugar and salt foods and drinks.



EVIDENCE GAPS AND FUTURE RESEARCH – PRIMARY PREVENTION

Substantial research **gaps remain in understanding how lifestyle factors interact with genetics and social determinants to influence kidney cancer risk.** Improved characterisation of these interactions is essential to identify high-risk population groups and to design effective, targeted prevention strategies.

Policy support is needed to enable the integration of environmental monitoring, population biobanking, and genomic analyses into cancer surveillance infrastructures. The EU-funded DISCERN project is beginning to address these gaps by adopting an exposome-based approach that integrates molecular, lifestyle, environment and behavioural data. It underscores the need for strengthened epidemiological research and expanded surveillance to better capture geographical inequalities in RCC incidence, exposure patterns, and outcomes across Europe¹⁹.

Emerging evidence suggests associations between specific dietary patterns, occupational exposures, and RCC risk, however

there is limited high-quality prospective data⁶. What is available points to a likely causal link between PFOA and kidney cancer, but more studies in larger cohorts measuring chemical concentrations are needed to confirm it²⁰.

For many established RCC risk factors, the underlying biological mechanisms remain insufficiently characterised. There is a need to clarify how smoking, obesity, and hypertension biologically drive RCC development and progression. The "obesity paradox" and the link between BMI and RCC onset and progression needs further study¹¹. Strengthening population-level monitoring and integrating molecular and exposure data will be critical to improving RCC prevention and reducing avoidable disease burden.

It is currently unclear on how medications such as GLP1 agonists could impact kidney cancer incidence.

3. SCREENING & DIAGNOSIS

3.1 DIAGNOSTIC TOOLS & SCREENING IMAGING

RCC often presents without early symptoms, leading to late diagnosis.²¹ The majority of RCC cases are still detected incidentally during scans performed for unrelated symptoms or other medical reasons, due to the generally increased use of cross-sectional imaging. Scans most commonly used for diagnosis and staging include contrast-enhanced CT of the abdomen and chest. Magnetic resonance imaging (MRI) is an important alternative to reduce radiation exposure and aid the identification of the tumour type and staging, as well as for patients with contrast allergy, who are pregnant, or who are on active surveillance. Imaging alone often struggles to tell whether a tumour is benign or malignant, so smaller renal masses often require a renal biopsy.



Advances in imaging are underway and these are crucial to reduce biopsies²². These will be particularly valuable in vulnerable populations, such as elderly people where doctors are finding more small kidney masses on routine scans that may not need immediate treatment. Nuclear medicine imaging studies are being explored for this purpose. Specialised PET imaging has shown promise for detecting clear cell RCC²³. While this technology is likely to be commercially promoted to clinicians and patients as a novel diagnostic tool, it is important to maintain a balanced perspective on both its value and limitations. Further validation in diverse clinical settings is needed before widespread adoption.

Researchers are also using AI to build better tools to diagnose and treat RCC, such as using AI to analyse CT and MRI scans to predict whether a kidney mass is cancerous and what type it might be. Early studies show this could work, but much larger

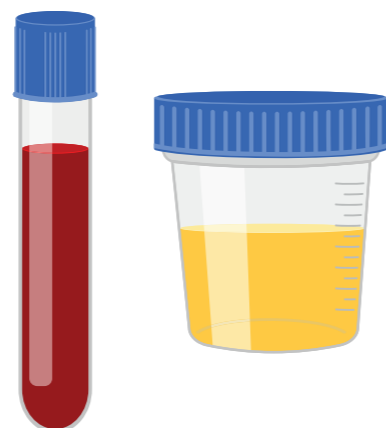
studies are needed to prove these tools truly help patients before doctors can rely on them routinely. EU-funded projects such as COMFORT²⁴ are a first step to making this a clinical reality.

SCREENING

In the EU, organised, population-based screening is well established for breast, cervical and colorectal cancers, and is expanding in a risk-based way to lung and prostate cancer, guided by strong evidence, quality assurance systems and EU-level policy coordination. By contrast, currently there is no standard rule in screening tests recommended for kidney cancer. Screening programmes are most efficient and cost-effective when they target high-risk populations and/or combining detection of RCC with other routine health screenings⁶. Today, there is no evidence to support primary screening in the general population, which should be addressed.

Screening is only advised for patients with hereditary conditions or patients on long-term renal replacement therapy (either dialysis or transplant), who all have a higher risk of RCC. The development of new technologies for cancer screening, improvement in the selection of candidates for cancer screening and better understanding of the biological basis of carcinogenesis (development of cancerous cells) will allow for improvements in cancer screening over time.

While blood tests can detect some atypical findings associated with kidney cancer, and urine tests can detect blood in the urine (a common sign of more advanced kidney cancer), no clinically validated urinary or serum biomarkers have been identified yet. The success and continued funding of EU-funded projects such as CARE1²⁵ continue to be essential in this pursuit.



EVIDENCE GAPS & FUTURE RESEARCH – SCREENING & DIAGNOSIS

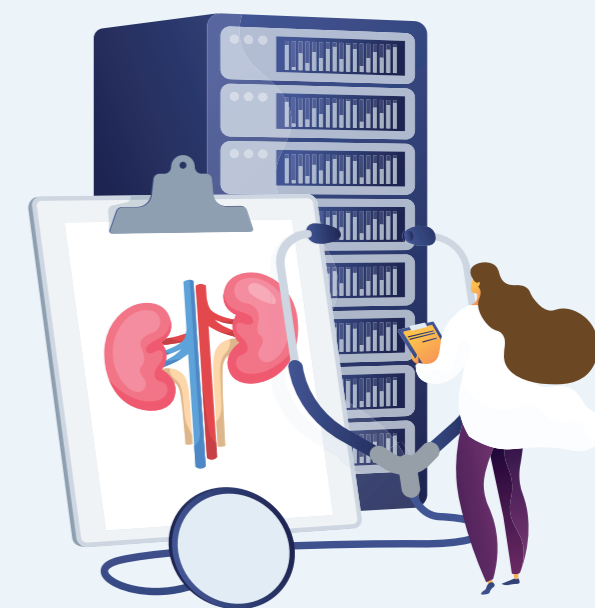
Major research gaps persist in prognostic tools. Although some genetic and molecular signatures have shown promise⁶, **more high-quality research is required to validate promising biomarkers** such as Kidney-Injury Molecule-1 (KIM-1), Aquaporin-1, and perilipin-2, and glycosaminoglykan-scores to enable their use for early detection and prognosis of kidney cancers. **Establishing and connecting registries and databases** to collect clinical and molecular data will support research and improve RCC screening and management.

Despite a growing interest from both patients and clinicians in RCC screening programmes, there is a relative lack of **studies reporting the efficacy, cost-effectiveness, and optimal modality for RCC screening.**

Evidence from recent feasibility work (most notably the Yorkshire Kidney Screening Trial, the only dedicated RCC screening study to date) suggests **adding abdominal imaging to existing lung cancer screening programmes could be an efficient way to screen for kidney cancer.**

As these already use low-dose CT, it could be a practical way to identify kidney cancers earlier, with early results showing that incidental kidney tumours can be detected at a more treatable stage^{26,27}.

Emerging studies on specialised PET scans and AI computer programs show promise for identifying kidney masses but large and well conducted studies are currently lacking.



4. PROGNOSIS

4.1 HOW ARE KIDNEY CANCER TUMOURS CLASSIFIED?

TYPE

The many types of RCC are grouped into broader categories by the 2022 World Health Organization (WHO) classification of the urinary system and male genital organs²⁸. These are:

- Clear cell renal tumours
- Papillary renal tumours
- Oncocytic and chromophobe renal tumours
- Collecting duct tumours
- Molecularly defined renal carcinomas
- Other renal tumours

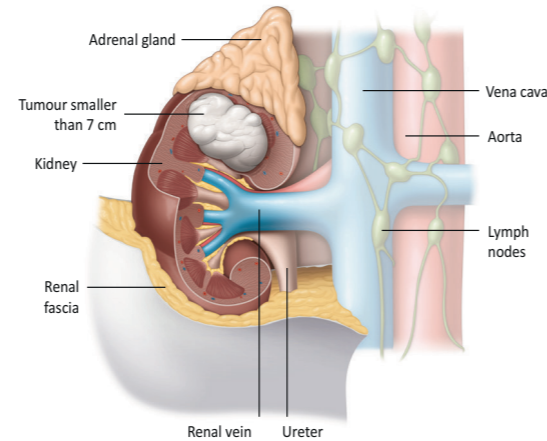
The three most common RCC types with genetic and histological differences are clear cell RCC (approx. 75%), papillary RCC (approx. 10%) and chromophobe RCC (approx. 5%).²⁹ The remaining 5-10% include unclassified tumours and rare entities such as collecting duct carcinoma (Bellini duct), renal medullary carcinoma and translocation RCC.

About 5% of RCCs develop sarcomatoid changes (sarcomatoid RCC). This is a transformation that can happen in different RCC subtypes, where the cancer cells start to look and act more like a fast-growing soft-tissue cancer (sarcoma). An aggressive clinical course and poor prognosis is associated with sarcomatoid RCCs, as well as certain subtypes such as collecting duct carcinoma and renal medullary carcinoma.

STAGE

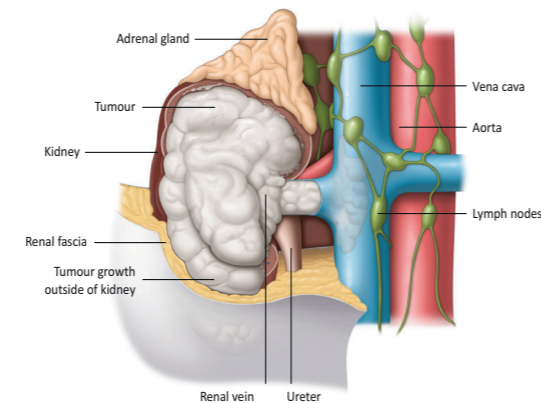
Kidney tumours are classified according to the stage (as defined by TNM, UICC version 8, 2016), the subtype, and the aggressiveness of the tumour. The pathologist determines the subtype of the tumour and whether it is an aggressive form (by assessing it using the ISUP/WHO grade I, II, III or IV). The following terms are used to indicate how advanced the kidney cancer is:

- **Localised:** The cancer is limited to the kidney and has not spread. It may be a stage T1 or T2 tumour, depending on the size (up to 7 cm or more than 7 cm).



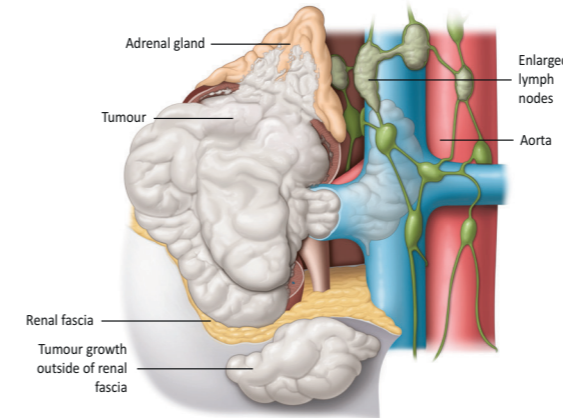
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- **Locally-advanced:** The cancer has invaded structures within the kidney or has grown out of the kidney into the surrounding tissue and invaded veins, the adrenal gland and nearby lymph nodes. It may be a stage T3 or T4 tumour (depending on local extent) and/or N1 (if regional lymph nodes are involved).



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- **Metastatic:** The cancer has spread either to distant lymph nodes or other organs such as the lungs, or less frequently bones or brain or other sites. Metastatic disease can rarely be cured. Instead, the treatment will try to slow the growth of the tumour and the metastases.



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4.2 ASSESSING THE RISK OF A KIDNEY CANCER

Doctors estimate how kidney cancer is likely to behave by looking at several features:

- How big the main tumour is and how far it has grown
- The type of cancer cells it contains and how aggressive they look
- Whether the cancer has spread into blood vessels or nearby lymph nodes
- Whether it has spread to other parts of the body (and if so, how many areas and where they are)

When the disease has spread to other parts of the body, other risk factors apply such as low red blood cell count, high neutrophil count, short time from diagnosis to treatment initiation, high calcium levels in the blood, low performance status, and high platelet count.

The classification of these factors combined with age, family history, general health status, and routine blood test results are used to assess how the cancer is likely to behave. This allows clinicians to develop a treatment plan and to determine a patient's prognosis. For patients who might have a hereditary kidney cancer, genetic risk assessment and testing are crucial for improving patient care, guiding surveillance, and offering tailored treatments³⁰.

Prognosis varies widely based on the stage of cancer at diagnosis. If caught early, a significant proportion of localised kidney cancer patients can be cured, however advanced or metastatic RCC

is a highly heterogeneous disease and in many patients can be linked to poor outcomes³¹.

Several systems that combine prognostic factors have been developed and validated. For clear cell RCC, potential prognostic biomarkers have been identified but are not yet validated for routine clinical use. Attention is needed to bring existing promising serum/urine RCC biomarkers into clinical care. The 3 main subtypes of RCC (clear cell, papillary and chromophobe) have distinct characteristics and treatment responses. There are emerging imaging techniques that show promise for identifying RCC in a non-invasive way, but these are not yet in routine clinical use. Rarer subtypes require further research to understand the biology, clinical outcomes, and potential treatments. **Meaningful advances are unlikely to be achieved without coordinated and collaborative research efforts.**

EVIDENCE GAPS & FUTURE RESEARCH - PROGNOSIS

There is a clear **need for the identification of novel biomarkers** to improve how we assess how RCC will develop. Incorporating molecular profiling data could enable us to better predict which patients are at higher risk for disease recurrence, which could lead to personalised screening schedules and follow-up care tailored to each patient's individual risk level.

The 3 main subtypes of RCC (clear cell, papillary and chromophobe) cannot yet be differentiated with certainty using scans. Research into these, as well as rarer RCCs is much needed.

Future studies should explore whether scanning frequency can be safely reduced, especially for low-risk patients. This could lower healthcare costs and reduce patients' radiation exposure while maintaining the same quality of care.

5. TREATMENT

The most important factors for selecting treatment are the stage, the subtype and the aggressiveness of the disease. The various RCC subtypes have different clinical courses and responses to treatment. Other important things to consider are individual life expectancy, general health status and the preference of the individual patient. Individual recommendations may depend on the country and the healthcare system.

For early-stage tumours, surgery is the main approach, with options for less invasive treatments for some cases. For metastatic kidney cancer, treatment has significantly changed in recent years. Radiotherapy and other local therapies support local control and symptom management within multidisciplinary care. Systemic therapies such as immunotherapy and targeted drugs are now available to control the disease and improve survival. In advanced cases, surgery may be combined with additional therapies in selected cases.

We are moving towards treatment choices that are increasingly personalised based on tumour characteristics and patient health. Some initiatives and networks are emerging in Europe for a better diagnostic and treatment of rare renal cancers, such as the Carare network in France.

5.1 CURRENT TREATMENT OPTIONS

Each procedure has its own advantages and disadvantages. Because this decision is complex, the best approach is when a multidisciplinary team (urologists, oncologists, radiologists, nurses, radiation oncologists, etc.) discuss the case together and recommend the safest and most effective plan.³² The final treatment decision should be the result of shared decision-making (SDM) between the person with kidney cancer and the healthcare team, however much more research into how this should be done is needed.

LOCALISED KIDNEY CANCER (EARLY STAGE)

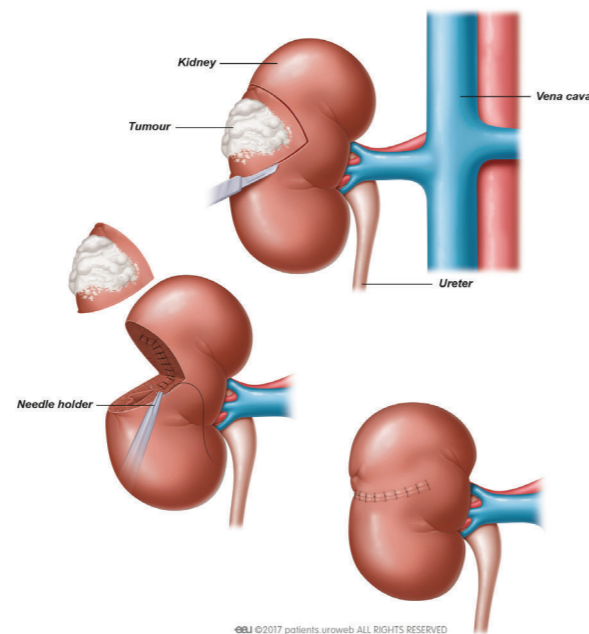
Surgery is the main treatment, aiming to remove the tumour. This can be:

- **Partial nephrectomy** (removing only the tumour and leaving the healthy tissue), which is preferred in order to preserve kidney function when possible.
- **Radical nephrectomy** (removal of the entire kidney), which is used when partial surgery is not possible.

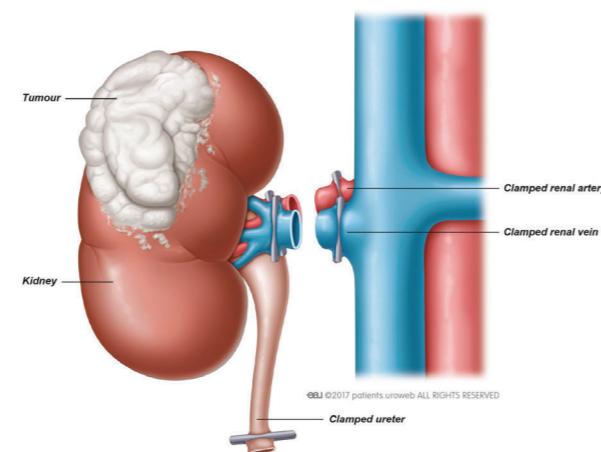
Ablative therapies (destroying the tumour cells) such as cryoablation (by freezing) or radiofrequency ablation (by heating).

Stereotactic body Radiotherapy (SBRT) may be an option for patients who aren't ideal candidates for surgery or other treatments. It delivers precisely targeted, high-dose radiation³³ to the tumour while sparing surrounding healthy kidney tissue.

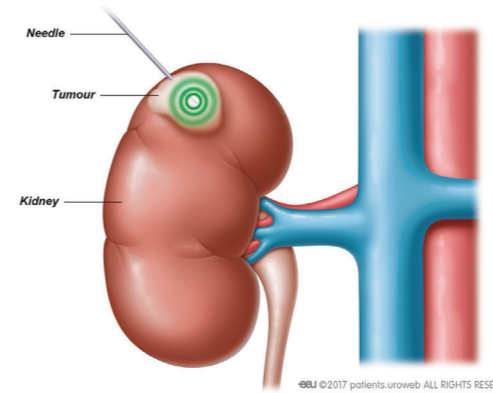
Active surveillance means keeping an eye on disease progression at specific intervals. It may be considered for small tumours, elderly patients, or patients with other health issues.



Partial nephrectomy



Radical nephrectomy



Ablative therapies

LOCALLY ADVANCED KIDNEY CANCER

Surgery remains important and may also involve the removal of lymph nodes if necessary. In some cases, the tumour may extend into major veins, requiring specialised surgical approaches.

Adjuvant therapy (treatment after surgery) with an immune checkpoint inhibitor called pembrolizumab may be offered to reduce the risk of recurrence in patients at increased risk of recurrence.

ADVANCED OR METASTATIC KIDNEY CANCER (SPREAD)

To treat clear cell RCC (the most common type) when the cancer has spread to other parts of the body, treatment usually focuses on whole-body treatments that travel through the bloodstream. These include:

- **Immune checkpoint inhibitors**, which help the immune system attack cancer. They can be used in combination with another checkpoint inhibitor, or with targeted therapies. They are used the first line setting for advanced disease, or sometimes on their own in later lines of treatment. They can result in long-lasting disease control, but only for some patients.
- **Targeted therapies** (tyrosine kinase inhibitors like sunitinib, pazopanib, axitinib, sorafenib, cabozantinib, lenvatinib) that block cancer growth signals.

Sometimes, **cytoreductive nephrectomy** (removal of the kidney tumour even when cancer has spread) may be considered to reduce tumour burden or in selected cases where patients are expected to derive clinical benefit from subsequent systemic therapy.

Radiation treatment can also be used to precisely target and destroy the tumour using SBRT (see Localised Kidney Cancer >

SBRT). It can be used to precisely target and destroy all visible areas where the cancer has spread when there a small number of spots, as well as to relieve symptoms.

SPECIAL SITUATIONS

Tumors with sarcomatoid features which are associated with a more aggressive clinical behavior may benefit more from **immune checkpoint inhibitors**.

Around 10% of kidney cancer that has spread will spread to the brain (brain metastases) and 30-40% of patients with RCC that has spread will experience bone metastases. However, modern radiotherapy techniques, particularly SBRT, offer important advantages for patient quality of life. Radiotherapy is an important tool, not only as a palliative treatment, but also for bone or brain metastasis, RCC that has spread to several places, as well as for bone treatments with Denosumab and bisphosphonates. Today, for patients with cancer that has spread to both the brain and other parts of the body but is still relatively confined, highly focused ablative radiotherapy (stereotactic radiotherapy), is increasingly used as it can achieve long-lasting tumour control for some patients.³⁴

5.2 FOLLOW-UP

Monitoring patients after kidney cancer surgery is important to catch any complications or adverse events or changes in kidney function, but how it should be done remains unclear. Current guidelines use a risk-based approach, recommending that low-risk patients receive baseline imaging within 3-12 months after surgery, then yearly scans for 3 years.⁶ Patients at higher risk are recommended for more frequent monitoring, with scans every 3-6 months initially.

That said, in reality many healthcare facilities (studies suggest up to 80%) perform imaging more frequently than guidelines recommend. Yet, there is emerging evidence that more frequent scanning does not improve outcomes. Patients show similar rates of disease recurrence regardless of scan frequency, and survival does not appear to improve.³⁵

Importantly, monitoring must consider kidney function, as surgery and systemic therapies can impact long-term renal health. There is a bidirectional relationship between kidney function and cancer: Impaired renal function can influence treatment options and outcomes, while kidney cancer and its treatment can contribute to chronic kidney disease.

EVIDENCE GAPS & FUTURE RESEARCH - TREATMENT

Clear evidence gaps remain across the RCC care pathway. These include **developing more effective systemic therapies, particularly for rare and difficult-to-treat RCC subtypes** and strengthening approaches that **improve patients' quality of life** throughout treatment³⁶.

Further research is needed to clarify when kidney surgery, radiotherapy, or thermal ablation should be used for patients with metastatic kidney cancer now that modern immunotherapy and targeted treatments are available. Evidence is still evolving, and ongoing studies aim to determine which patients benefit most, how to select them, and how different focal therapies should be timed alongside drug treatments. **Understanding the impact of different therapies on survival and quality of life is essential to guide future standards of care.**

Advances in **molecular research have identified key genetic drivers of kidney cancer**, particularly clear-cell RCC. An improved understanding of the biology of kidney cancer is increasingly enabling the development of new targeted and immune-based therapies. Researchers are also working to develop novel liquid or tissue-based biomarkers that can **predict treatment response and support more personalised care**. While these tools are not yet ready for routine clinical use, sustained investment in biomarkers development and validation studies is essential to translate these discoveries into more effective, tailored treatment strategies for patients⁶ which will also reduce the cost of overtreatment.

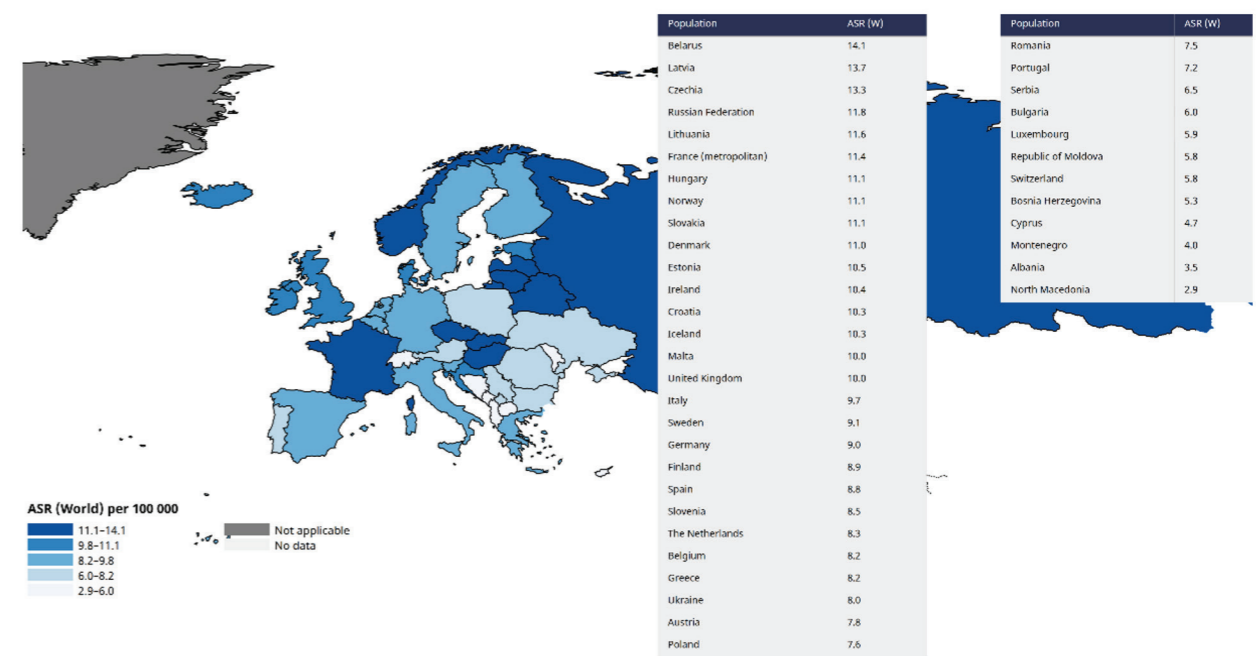
Promising early studies into **rare kidney cancers** (non-clear cell kidney cancers representing 20-25% of RCCs³⁷) suggest some targeted and immunotherapy combinations may help, but **no clear standard of care yet exists. Major investment is needed** in dedicated clinical trials, better molecular understanding, and new treatment strategies to ensure these patients, who often have fewer options, receive effective, evidence-based care⁶.

Immune checkpoint inhibitors (ICIs) have transformed the treatment landscape of renal cell carcinoma, especially clear-cell RC. Despite the growing number of effective therapies, **important questions remain on how to optimise treatments, which is starting to be explored via the Horizon Europe CAREI project.**²⁵ Research priorities include determining the best combinations and sequences of ICIs with other systemic therapies. Additionally, **studies are needed to assess the long-term safety, efficacy, and impact on quality of life of ICIs.**

Active surveillance has been studied as a management option, particularly for small renal masses and patients with comorbidities or limited life expectancy. However, **research is needed to determine standardised surveillance strategies that balance effective cancer control with minimizing unnecessary costs and radiation exposure.**



Age-Standardized Rate (World) per 100 000, Incidence, Both sexes, in 2022
Kidney



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International Agency
for Research on Cancer
World Health
Organization

5.3 COST AND AVAILABILITY

The cost and availability of treatments are highly variable in different healthcare systems. Treatment for RCC is resource intensive. Radical treatments require substantial follow-up as they might also require dialysis. Non-radical treatments also require additional resources for regular follow-up clinical appointments and rely heavily on the availability of suitable imaging and biopsy procedures.

INEQUALITIES

Across the EU, substantial inequalities remain in access to cancer treatment. Research is urgently needed to quantify disparities in access across EU Member States and its impact on kidney cancer outcomes. This should include access to advanced radiotherapy including mapping stereotactic body radiotherapy (SBRT) availability, workforce distribution, and equipment capabilities and age.

Cancer mortality varies up to 1.6-fold between EU countries, with Central and Eastern European Member States consistently experiencing higher mortality due to later diagnoses, higher exposure to risk factors, and more limited access to high-quality care.³⁸ These disparities mirror wider socioeconomic inequalities. Patients with lower education or income face significantly higher cancer mortality and are less likely to access timely screening, diagnostic path-

ways, and innovative treatments. Even countries with a long-established tradition of equitable welfare and social justice policies witness increases in cancer inequalities between sexes³⁹.

As RCC is most often detected during other scans, early detection still depends heavily on equitable access to primary care, imaging, and specialist referral. Variation in reimbursement and availability of cancer medicines, workforce shortages in oncology and radiology, and uneven adoption of best-practice clinical pathways further reinforce unequal outcomes between patients in different EU countries.

VALUE-BASED HEALTH CARE (VBHC)

VBHC, which ties patient outcomes and impact to cost, has been proposed as a fundamentally new strategy for how urological healthcare should be delivered, measured, and remunerated. It encourages a more holistic approach to patient care, including multidisciplinary teams and a heavier focus on outcomes that matter to patients.

For RCC, implementing VBHC requires measuring outcomes that matter most to patients throughout the complete care cycle, including survival rates, preservation of renal function, quality of life during treatment and recovery, and long-term functional

status. As there is substantial variation in treatment pathways and follow-up protocols for RCC across healthcare systems, systematically tracking these patient-centred outcomes alongside costs, health systems can identify opportunities to reduce variation and inequalities in care.

The cost of RCC to different health systems has been difficult to quantify, leading to a lack of data. Several studies have evaluated the implementation of value-based healthcare in urology, and while in its infancy, the available literature suggests promising early results on this shift.

POLICY EFFORTS

Europe's Beating Cancer Plan (EBCP) is a crucial milestone to begin to address these inequalities. Through flagship initiatives such as the EU Network of Comprehensive Cancer Centres (EU-NetCCC), the EBCP is essential to support harmonising cancer care standards, improve access to multidisciplinary expertise, and strengthen quality assurance across Member States. These initiatives will have a Europe-wide effect, but particular attention should be paid to ensuring actions benefit countries and regions with limited specialist capacity.

The EU HTA Regulation also has the potential to reduce inequalities in access to innovative RCC treatments by streamlining clinical assessments across Member States. A single EU-level evaluation should help shorten delays, particularly in countries that historically face slower access to new cancer medicines. For RCC patients, this could mean more timely availability of immunotherapies and targeted treatments that significantly influence survival. However, the extent to which inequalities narrow will depend on implementation and follow-up, and how consistently Member States use the Joint Clinical Assessments.

EVIDENCE GAPS – COST & AVAILABILITY

The impact of **differences in regional funding and timely access** to quality care/new treatments on patient outcomes needs to be evaluated in order to eliminate the disparities in kidney cancer care in the different countries.

Standardised, EU-wide outcome **registries linking patient-centered RCC outcomes to comprehensive cost data are essential** to support VBHC implementation and enable health systems to identify and address inequalities in care delivery.

6. LIVING WITH KIDNEY CANCER

6.1 PATIENT UNDERSTANDING AND CHOICE

WHO projections predict a 19% increase of new cases of RCC in Europe by 2050², however the number of kidney cancer survivors also continues to grow. As more people are living with kidney cancer, patients, general practitioners, caregivers and the broader public need to be well informed about the needs of kidney cancer survivors in order to improve their quality of life.

The number of kidney cancer patients that do not know their subtype doubled between 2022 and 2025 (from 5% to 10%). This lack of knowledge or awareness can affect future decisions on prognosis and treatment options⁴⁰.

Shared decision making is a process which ensures patients are supported to make decisions about their care and treatment which are right for them. It is a collaborative process and starts with a conversation between the patient receiving care and the healthcare professional delivering it. They work in partnership to make the best possible decisions, bringing together the clinician's expertise, treatment options, evidence, risks and benefits, and the patient's individual preferences, personal circumstances, goals, values and beliefs.

Shared decision-making must be a core pillar in treatment options, including active surveillance. This cannot happen without knowledge and awareness. **For the first time in 2025, the majority of patients (55%) said they were as involved in their treatment plans as they wanted to be**³⁹. The EAU Patient Office and IKCC have been long advocating for shared-decision making, which has three main benefits:

1. Reduces regret
2. Improves adherence
3. Empowers patients



The European Code of Cancer Practice is a patient-centred charter that sets out what every person affected by cancer in Europe should expect and be entitled to across the whole cancer care pathway. The Code emphasises shared decision-making as one of the ten core rights that every cancer patient in Europe should expect to be upheld.¹⁷

6.2 PATIENT IMPACT

On top of the physical impacts of a diagnosis, **patients are also reporting issues with their emotional wellbeing**. According to an IKCC survey³⁹, 85% of patients globally have experienced an impact on their emotional wellbeing as a result of kidney cancer or a growth. The majority of concerns were disease-related anxiety (50%) and fear of recurrence (49%), followed by depression, fear of dying and general anxiety. For those with no symptoms, the most common emotional effect is fear of recurrence. Psychosocial issues for kidney cancer patients also include stress related to financial issues, difficulty in daily living, work and school, concerns about body image or changes in physical appearance, and changes in relationships with loved ones, friends or co-workers.

Health-related quality of life (HRQOL) issues associated with tumour burden such as anorexia, fatigue, pain, anaemia, hypercalcaemia (elevated calcium levels in the blood), venous thromboembolism (combination of a deep vein thrombus (blood clot) and pulmonary embolism (blockage in a lung artery by blood clots that travel through the bloodstream)) and psychological concerns, along with the impact of treatment-related side effects, require further study.

Undergoing treatment for kidney cancer is intense and will affect everyday life, work and social life. Patients need to obtain balanced and fair information on the advantages as well as the adverse side-effects of their management plans. After surgery or other local and systemic treatments, they will probably feel tired or sick and may need help to resume normal everyday activities. Radiotherapy is an outpatient treatment that is generally well tolerated, with limited impact on daily life, though some patients may need logistical support. As new treatment approaches such as immunotherapy become an important part of care, **patients should receive clear information about their specific and sometimes long-lasting side effects.**

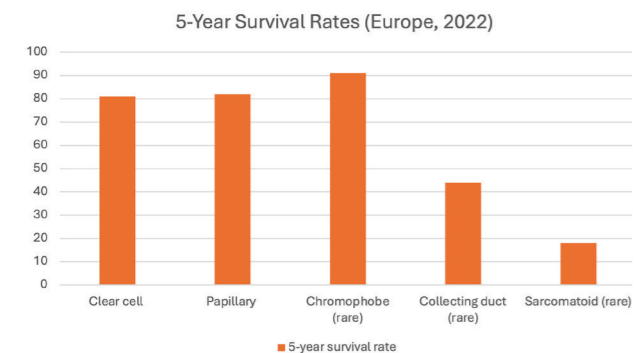
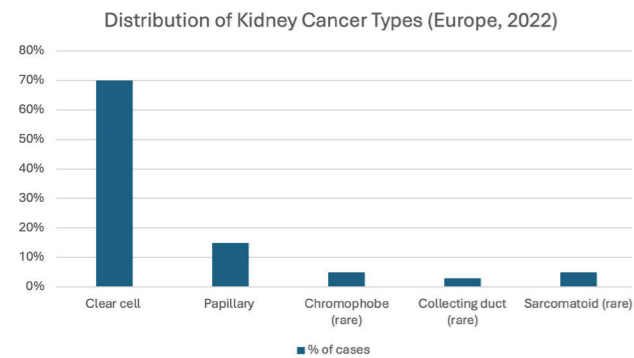
Follow-up is important to check general health, monitor kidney function, to manage any side effects from treatment, to watch

for a return of the kidney cancer, and to watch for other types of cancers.

6.3 SURVIVORSHIP

In 2022, 35.5% of all people around the world still living with kidney cancer 5-years after diagnosis were in Europe. There are currently 473,212 people alive today in Europe who were diagnosed with kidney cancer in the past 5 years. Europe is the continent with the highest numbers of kidney cancer survivors, and the number of survivors continues to grow.

The overall survival rate 5-years post diagnosis ranges from 40% to 75% in Europe. It depends on the type of kidney cancer and patient characteristics².



Survivorship for kidney cancer patients extends far beyond treatment, with many continuing to **experience long-term impact on renal function, as well as emotional, and social impacts**. Many patients experience lasting treatment-related effects such as neuropathy, gastrointestinal issues, or kidney function changes. Fear of recurrence and anxiety often remain significant for many years after diagnosis and treatment. **As survival rates improve, more patients are living longer with the consequences of their disease and treatment**, highlighting the need for structured survivorship care. This includes regular follow-up for physical health, support for managing long-term side effects, mental

health services, and practical assistance to help patients resume daily activities, work, and social life. Survivorship programs that address these holistic needs should be increasingly recognised as essential to improve quality of life and overall outcomes for kidney cancer patients.

6.4 PATIENT SUPPORT

People diagnosed with kidney cancer may be anxious about their prognosis, and **oncology nurses play an important role** in supporting patients with kidney cancer. They often serve as the patient's first line of communication (primary contact person) and help coordinate the many aspects of care throughout all the phases of the treatment (care coordination) and during the follow up (survivorship). They play a key role in helping patients to understand treatments, but also how lifestyle may impact prognosis.

An IKCC survey indicated that 59% of patients fully comprehend the importance of proper nutrition, while 37% acknowledge it to some extent. Nutritional deficiency is associated with higher mortality in people undergoing surgery for RCC and adapting dietary habits can assist in managing the side effects associated with both the disease and its treatments. **Support for patients to understand how to lead a healthy lifestyle** – and understanding how food and nutrition impact the body, during and after treatment (diet and regular physical activity) – is crucial.

Treatment of kidney cancer frequently also has negative impacts on physical and psychosocial functioning. As such, **psychologists play an important role** in providing support of the patient and his/her family. Survivorship information and assessment of supportive care needs for patients with kidney cancer and their families are also crucial.

6.5 THE ROLE OF PATIENT ORGANISATIONS

Patient organisations play a crucial role in supporting people affected by kidney cancer and their caregivers. Groups such as the International Kidney Cancer Coalition (IKCC) or umbrella organisations like Cancer Patient Europe (CPE), together with their national member organisations, **offer reliable information and practical resources** for patients and carers that help them understand the diagnosis, make informed treatment decisions, and manage the impact of the disease in everyday life. They also guide patients on where and how to seek support and help them stay on track with their treatment.

Beyond treatment decisions, **these organisations are especially important in addressing longer-term needs**. These include nutrition, rehabilitation, managing side effects that can appear after treatment, and supporting the return to work and daily activities

once the acute treatment phase is over. They also provide emotional and peer support, helping patients navigate the complex conversations that follow a cancer diagnosis, and make information on participation in clinical trials if available, or through tools such as the IKCC initiative “My treatment, My Choice”⁴¹ which offers decision-support tools in patient-friendly language.

Patient organisations are increasingly active in European-funded projects, where they promote patient voices within research programs, such as via Horizon Europe. They play an important role in EU health policy advocacy by representing patient perspectives in consultations, expert groups, and stakeholder dialogues, and by bringing real-world evidence and lived experience into policymaking. They support the development of equitable, patient-centred health policies across Member States and act as intermediaries between patients, policymakers, clinicians, researchers, regulators, and industry within the EU health ecosystem.

6.6 PATIENTS, HTA AND ACCESS TO INNOVATION

The EU HTA Regulation was first implemented for cancer treatments and Advanced Therapy Medicinal Products (ATMPs), covering new therapies for cancers such as kidney cancer. By introducing Joint Clinical Assessments (JCAs), it aims to reduce duplication of clinical assessments across EU Member States and **support more consistent evidence appraisal**, a necessary first step to **narrowing differences in access to innovative treatments** across Europe.

For kidney cancer, where outcomes can depend on timely access to immunotherapies, targeted therapies, and combination regimens, more aligned clinical assessment processes can help address one driver of unequal access; variable and resource-intensive national evidence reviews that contribute to delays and fragmentation. However, equitable **access will still depend on how consistently Member States build on JCAs in national processes**, and on transparent, predictable implementation.

Patients and patient organisations have a key role in helping HTA better reflect real-world needs and lived experience. In the JCA process, patients play a key role in assessments, ensuring that the evaluation reflects outcomes that matter in daily life (e.g., symptom burden, fatigue, mental wellbeing, ability to work, and treatment convenience), and that evidence gaps affecting rare subtypes or under-represented populations are visible to decision-makers. Patient perspectives also help contextualise benefit–risk trade-offs, particularly where clinical evidence is uncertain or not fully representative of clinical practice.

EVIDENCE GAPS & FUTURE RESEARCH – LIVING WITH KIDNEY CANCER

Multiple studies have demonstrated that shared-decision making contributes positively to patient outcomes, including improved adherence, compliance, and engagement and may reduce healthcare costs by decreasing the frequency of emergency care visits. Despite these advantages, **shared decision-making** is not yet standard practice across Europe. Further investigation into where targeted investments are most needed to enhance patient involvement in their own care decisions are crucial (e.g. improving consultation time, bettering patient comprehension, improving decision support tools, compensating for cultural contexts, etc.).

All psychosocial issues frequently reported by patients require specific investigation in order to combat their consequences and improve the lives of people diagnosed with RCC.

Further investment in interventional research on the **intersection of kidney cancer and nutrition is needed**, including areas such as food and drug interactions, management of symptoms and side effects, and maintaining a balanced diet following diagnosis.

7. FUTURE RESEARCH

We have identified the following priorities for further EU research to meet the needs of kidney cancer patients.

LESS COMMON KIDNEY CANCERS

Non-clear cell kidney cancers represent 20-25%. For these less common subtypes, much more research is required to understand the biology, clinical outcomes and potential treatments. Promising early studies suggest some targeted and immunotherapy combinations may help, but no clear standard of care yet exists.

RISK FACTORS AND CAUSES

Understanding who are the high-risk populations for RCC (genetics, lifestyle, and social determinants) is key to our ability to develop effective screening, to reduce socio-economic inequalities in outcomes, and to develop personalised treatments. Studies suggest links between RCC and diet, occupational exposures, and chemicals like PFOA, but larger cohort studies are needed to confirm these associations.

For hereditary RCC, research is needed to improve how we monitor patients and understand risk and to establish evidence-based management strategies that account for the distinct clinical characteristics and increased cancer risk in these populations.^{29,42}

There are significant gaps in understanding of RCC's metabolic and inflammatory drivers. Current research is exploring how obesity, hypertension, and smoking biologically influence RCC onset and progression, but these pathways need further study as it will likely inform both prevention and personalised management.

SHARED DECISION-MAKING

Shared decision-making is inconsistently applied, with few well-tested decision aids and limited strong evidence on what works best. More research is needed to develop and validate shared decision-making tools, personalise information to each patient, and test whether these tools truly improve patients' decisions in real life. We also need to better understand patient preferences and evaluate how shared decision-making impacts treatment adherence, quality of life, and patient satisfaction across diverse populations.⁴³

BIOMARKERS

Biomarkers show promise for the entire RCC pathway. Currently, RCC is mostly diagnosed incidentally through scans for other

diseases - RCC biomarkers such as KIM-1, Aquaporin-1, and perilipin-2 have emerged as promising tools for early RCC detection and prognosis and ongoing validation efforts aim to bring these biomarkers closer to clinical use, potentially improving early diagnosis and risk stratification. Research is needed to identify predictive and prognostic biomarkers of different types, including tissue-based molecular and spatial markers, circulating biomarkers, and imaging-based biomarkers, to guide treatment selection, monitor response, and refine personalised therapeutic strategies.

SCREENING STRATEGIES

Research is urgently needed to determine the most effective and cost-effective ways to screen for RCC and the optimal frequency of screening in at-risk populations. Feasibility studies have suggested that incorporating abdominal CT scans into lung cancer screening programs may enable earlier RCC detection and largely have a low impact on patients, but further research on effectiveness is required.

THE ROLE OF SURGERY IN MANAGEMENT OF RCC

Further research is needed to clarify when kidney surgery is the most effective for patients with metastatic kidney cancer, now that modern immunotherapy and targeted treatments are also available. Research priorities include determining if and when surgery should be used to remove remaining tumour, after patients have achieved good disease control with systemic therapy. For less advanced cases, active surveillance has been studied as a management option, particularly for small renal masses and patients with comorbidities or limited life expectancy. However, research is needed to determine standardised surveillance strategies that balance effective cancer control with minimising unnecessary costs and radiation exposure.

EQUITABLE ACCESS TO DIAGNOSIS

As most kidney cancer is detected incidentally during scans for other diseases, regional and socioeconomic disparities in access to healthcare directly impact when kidney cancer is detected in different sub-populations. Addressing these inequalities first requires measuring the impact of socio-economic status of outcomes both in Member States and between them, with an initial emphasis on primary prevention and diagnosis.

EQUITABLE ACCESS TO CARE

Multidisciplinary care is a core principle of high-quality kidney cancer care across health systems. Research into the cost barriers

is needed to inform policies to address inequitable access, including to effective and evidence-based local and systemic treatment options. While SBRT shows promising results, longer follow-up data and randomised controlled trials comparing SBRT directly with surgery are needed and access to it examined.

PERSONALISED MEDICINE

Advances in molecular profiling are enabling personalised treatment and better recurrence prediction. Research is defining optimal combinations of surgery, targeted therapies, and immunotherapies. Multidisciplinary decision-making that incorporates patient preferences and tumor characteristics is essential. Investment in validating these approaches will establish evidence-based standards that improve outcomes while using resources efficiently.

IMAGING AND RENAL TUMOUR BIOPSY

Advances in imaging, including specialised PET and AI-based CT/MRI analysis, offer opportunities to better characterise small renal masses and reduce unnecessary biopsies, particularly in elderly or frail patients. Future research should generate robust evidence of their clinical utility, cost-effectiveness, and limitations across diverse healthcare settings. Refining renal tumour biopsy criteria and understanding how regional differences in access to imaging and expertise affect outcomes remain important priorities to reduce disparities in kidney cancer care.

RADIOTHERAPY

Despite radiotherapy's growing role in kidney cancer treatment, we urgently need randomised trials comparing SBRT with surgery and ablation for primary tumours. Research must also focus on defining optimal patient selection for oligometastatic treatment, clarifying radiotherapy combinations (radiotherapy with immunotherapy or other new agents) and timing, and investigations into quality-of-life and cost-effectiveness outcomes. Addressing these gaps will help personalise treatment and improve patient care.

EVIDENCE-BASED FOLLOW-UP STRATEGIES

Current follow-up protocols after kidney cancer treatment lack solid evidence. Guidelines vary widely in surveillance intensity, yet we don't know whether more frequent monitoring actually impacts survival. Research is needed to identify which patients benefit from active surveillance, determine optimal imaging intervals, and prove that structured follow-up translates into better outcomes.

ARTIFICIAL INTELLIGENCE

The role of artificial intelligence may expand beyond imaging to

encompass diagnosis, prognosis prediction, and treatment response assessment. Rigorous validation studies are essential to determine which AI applications meaningfully improve patient outcomes and can be reliably implemented across diverse European healthcare settings.

QUALITY INDICATORS AND CARE STANDARDS

Addressing the lack of shared quality indicators for RCC care across EU Member States is essential to enable meaningful comparison of outcomes, identify areas for improvement, and reduce unwarranted variation in care delivery. Research should define meaningful, measurable and patient-centred indicators spanning the complete care pathway from diagnosis through survivorship⁴⁴.

DIRECT AND INDIRECT COSTS OF KIDNEY CANCER

While direct healthcare costs rise sharply with advanced disease and new therapies, solid evidence is still lacking⁴⁵. Indirect and societal costs, including productivity loss, informal care, and long-term financial impact, are not quantified enough. Dedicated research on both direct and indirect costs is needed to support sustainable reimbursement, value-based decisions, and equitable resource allocation across Europe.

8. CALLS TO ACTION

RECOMMENDATIONS TO THE EU ON IMPROVING AND SAVING LIVES OF PATIENTS WITH KIDNEY CANCER

1. PUSH FOR EFFECTIVE, LONG-TERM IMPLEMENTATION OF EUROPE'S BEATING CANCER PLAN

- Ensure implementation **focuses on tangible reductions in inequalities** in diagnosis and treatment to reduce RCC mortality and improve equal access to care.
- Establish **measurable indicators to track progress**: Stage at diagnosis, time-to-diagnosis, time-to-treatment, access to biomarker testing, etc.
- Ensure that kidney patients have **access to high quality, comprehensive, multi-disciplinary care** through the standards and patient pathways on genito-urinary cancers defined as part of the Comprehensive Cancer Centres and networks.
- Support maintenance of Europe's Beating Cancer Plan in the next **EU budget 2028-34**, with a possibility for refresh of the Plan to reflect developments in science and practice.
 - Provide for a 2 billion EUR European Cancer Fund in the next EU budget to achieve this.

2. STRENGTHEN DIGITAL CANCER INFRASTRUCTURES

- Ensure that the **European Health Data Space does not add undue burden to academic researchers** to enable non-partisan cross-border research.
 - Strong digital infrastructures are essential to validate RCC biomarkers, assess screening approaches.
- **Support open research and cancer registries** on RCC subtypes across borders.
- **Focus on clear rules for AI tools in the AI Act** that are proportional to their risk/reward for public health and minimise overlapping legislation that endangers the continuation of organisations without large regulatory teams from harnessing secondary health data.
- Within the framework of reducing time to market for products under the MDR and IVDR, **strengthen post-market surveillance for medical devices** focusing on long-term follow-up to advance research into screening strategies and surgical timing for RCC patients, including comparative effectiveness and open science registries.

3. INCREASE KIDNEY CANCER RESEARCH FUNDING TO REFLECT ITS DISEASE BURDEN^{*,47}

- Increase funding at EU level (including a **dedicated, earmarked health budget** in the multi-annual financial framework and Horizon Europe) and at member state level, **ensuring kidney cancer receives investment proportional to its incidence and burden**.
- **Establish a European Cancer Institute** or similar as part of the next EU budget to help improve the long-term effectiveness of EU supported cancer research.
- Include high-potential **RCC biomarker innovations in the Health Biotech Investment Pilot** under the Biotech Act.



* Only 1% of global funding for cancer research is spent on kidney cancer, while the incidence is 2.1% of cancer cases worldwide and 3.3% in Europe.

4. ADDRESS KEY SOCIAL, ECONOMIC AND ENVIRONMENTAL DETERMINANTS OF KIDNEY CANCER AND THE IMPACT OF ECONOMIC FACTORS

- **Systematically monitor disparities across regions and population groups**, as is done for other cancers through the Cancer Inequalities Registry⁴⁸.
- Recognise that a **competitive EU economy rests upon healthy populations**.
 - o **Agree an ambitious revision of the EU tobacco legislation** to include all tobacco products that are risk factors for kidney cancer.
 - o **Prioritise the initiatives on processed foods**, and levies for highly processed foods and foods high in salt, sugar and fats as part of the Safe Hearts Plan. This includes the need for mandatory front-of-pack nutrition labelling for food products.
 - o Strengthen research and environmental regulations to **reduce population exposure to emerging contaminants linked to kidney cancer** such as PFAS.
- Include **cancer-related indicators in European Semester** reporting to monitor and address structural drivers of cancer inequalities, including prevention, early diagnosis, access to treatment, workforce capacity, and survivorship support, and to inform targeted country-specific recommendations where gaps persist.

5. PRIORITISE EQUITABLE AND AFFORDABLE ACCESS TO TREATMENT AND CARE

- Ensure **effective and well-resourced application of the EU HTA Regulation**, with meaningful involvement of clinical experts and patients.
- Ensure the **EU Medical Devices and In Vitro Diagnostic Regulations promote increased availability instead of withdrawal of lifesaving RCC devices** by clarifying clinical evidence requirements and strengthening scientific coordination through a central body.
- Ensure **equitable access to advanced radiotherapy technologies** across all EU Member States.

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