



KIDNEY HEALTH

FOR EVERYONE
EVERYWHERE



Advocacy
TOOLKIT

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1. Introduction

About the WKD Toolkit

The World Kidney Day Advocacy Toolkit offers guidance and support to the efforts of champions and colleagues advocating for kidney disease.

World Kidney Day (WKD) is a joint initiative of the **International Society of Nephrology (ISN)**¹ and the **International Federation of Kidney Foundations (IFKF)**². Both organizations and their affiliates are advocating for overcoming the burden of kidney disease and for improving access to kidney health by accelerating policy change and the development of new policies at the level of the United Nations (UN) and the World Health Organization (WHO), in order to tackle unmet needs of kidney disease patients³. Now, we offer you a resource to structure how you can advocate effectively for kidney health in your country and region.

The Toolkit provides evidence on the global burden of kidney disease, outlines the international political environment which anchors policy making for kidney diseases, outlines steps you can take to strengthen your capacity for advocacy and to structure your advocacy including the generation of evidence, formulation of advocacy messages and asks, the identification of advocacy targets and the forming of partnerships to advance your advocacy asks as well as other strategies, tools and resources to successfully apply your advocacy asks. For ideas on how to create awareness about the importance of kidney disease prevention and treatment to encourage behavioural change in your local or regional community, please read our [World Kidney Day General Campaign Toolkit](#).

This Toolkit provides a starting point and ideas for how to create and implement your own advocacy strategy but we recommend that you adapt the suggested methods and materials to fit your case at local or regional level.

If you need any more information regarding the implementation of the Toolkit, please feel free to contact us at info@worldkidneyday.org

¹ <https://www.theisn.org/about-isn/about-isn>

² <https://ifkf.org/about-ifkf.html>

³ <http://www.who.int/bulletin/volumes/96/6/17-206441/en/>

About Kidney Disease

Chronic Kidney Disease (CKD) affects approximately 10% of the world's adult population: it is within the top 20 causes of death worldwide, and its impact on patients and their families can be devastating.⁴ Acute kidney injury (AKI), an important driver of CKD, affects over 13 million people worldwide and 85% of these cases are found in low- and middle-income countries. The cost of treating CKD and its complications is unaffordable for governments and individuals in many parts of the world. Annual costs of dialysis and kidney transplantation alone range between USD 35,000-USD 100,000 per patient.⁵

Despite the significant human and economic costs of kidney disease, it is true that little has been done to recognize the illness as a priority non-communicable disease (NCD) in terms of international health policy-making and as contributing factor to other NCDs such as diabetes and cardiovascular diseases.⁶ While in 2010, 2.6 million people with end-stage kidney disease (ESKD) or 'kidney failure' received dialysis or transplantation worldwide, this number is projected to increase to 5.4 million by 2030.⁶ If policy inaction is not reversed now, CKD will be the 5th leading cause of Years of Life Lost in 2040.⁷

Kidney Health for Everyone Everywhere - World Kidney Day 2019

World Kidney Day is a global campaign aimed at raising awareness about preventive behaviours, awareness about risk factors, and awareness about people living with a kidney disease. World Kidney Day is celebrated every second Thursday in March.⁸

In 2019, World Kidney Day, under the motto of "Kidney Health for Everyone Everywhere", emphasises the widespread disparities and inequities in kidney health across the world. Many are faced with cumbersome and at times insurmountable barriers to available, accessible, adequate and quality kidney care. WKD 2019, therefore, calls for universal health coverage (UHC) for prevention and early treatment of kidney disease as sustainable options to reduce costs and consequences of kidney diseases for individuals and countries.

⁴ <https://www.worldkidneyday.org/wp-content/uploads/2015/05/KI-final-article.pdf>

⁵ https://www.theisn.org/images/ISN_advocacy/UN_High_Level_Meeting_on_NCDs_2018_-_Toolkit/ISN_priorities_briefing_paper_UN_HLM_NCDs_2018.pdf

⁶ http://apps.who.int/gb/ebwha/pdf_files/WHA66/A66_R10-en.pdf?ua=1

⁷ [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(18\)31694-5/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(18)31694-5/fulltext)

⁸ <https://www.worldkidneyday.org/about/world-kidney-day/>



The ultimate goal of a UHC policy is to promote population health by ensuring universal, sustainable and equitable access to essential healthcare of high quality, protecting people from health impoverishment and improving equity in health across socioeconomic groups.

To read more about the 2019 WKD campaign priorities, please visit: <https://www.worldkidneyday.org/2019-campaign/2019-wkd-theme/>.

2. Global Advocacy on Kidney Disease: Towards the 2030 Agenda

On international level, policy making has come a long way since the year 2000 in terms of recognizing NCDs as a health epidemic which affects all countries, all genders and all ages. NCDs kill 41 million people each year, equivalent to 71% of all deaths globally. Each year, 15 million people die from an NCD between the ages of 30 and 69 years; over 85% of these "premature" deaths occur in low- and middle-income countries.⁹

The latest culmination of international policy making on NCDs is the political declaration of the third UN High-level Meeting on NCDs which took place in September 2018. While it recognized "that action to realize the commitments made for the prevention and control of non-communicable diseases is inadequate and that the level of progress and investment to date is insufficient to meet "target 3.4 of the Sustainable



SDG 3: Ensure healthy lives and promote wellbeing for all at all ages

3.4 by 2030 reduce by one-third pre-mature mortality from non-communicable diseases (NCDs) through prevention and treatment, and promote mental health and wellbeing

⁹ <http://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases>

Development Goals”, it gave no new or improved drive to reduce the number of death and healthy life years lost to kidney disease.

Besides the lack to address kidney disease as a major cause of death and driver of related NCDs, the political declaration increased the likelihood of little action being taken for all NCDs in the next years with the next HLM on NCDs now only due in 2025.

Now is the moment to recognize kidney disease as a key NCD, so that targeted action on kidney disease becomes integral to the global, regional and national NCD policy response.

→The WKD Campaign Toolkit stresses the need to recognize kidney disease as an important NCD and to put pressure on your national policy makers to reduce the significant burden from NCDs such as kidney disease on global health.

 The Advocacy Timeline of UN and WHO Conferences and Committee meetings in 2019 (Appendix) provides you with a roadmap for advocacy opportunities. Furthermore, the meetings and conferences ordinarily follow national preparation, consolidation and/or consultation processes which open up more opportunities for advocacy in your specific environment. In attending those meeting, you will be able to meet with policy makers, present them with your evidence based policy asks and facilitate policy change. In case you are not able to attend, you can engage in live tweeting and supporting the cause through your social media webpages. Furthermore, you can contact your local, regional and national authorities ahead of time asking them to attend the meetings and to represent your community and speak up on behalf of people living with or at risk of kidney disease.

3. How to create and structure your advocacy actions

In this section, you will find the steps for actions to take on a national level in order to advocate effectively for better kidney health and care.

Here are some recommendations:

Generate the evidence for your advocacy messages

- Identify local/regional/national progress and policy gaps on kidney disease and kidney care through accessing data from patient organisations and professional organizations specializing in kidney disease
- Gather more evidence through research of local sources (e.g. reports, local surveys, interviews, unpublished academic papers)

 Find more useful sources to gather evidence in 'Links' section of the Annex.

Develop your advocacy asks and messages

- Based on your evidence gathered develop concrete asks to improve kidney health in your country
- Identify what the most pressing issue(s) are based on your specific environment and formulate clear ask for policies to be made and/or adapted.
- Take into account that kidney health has many policy dimensions including: Access to medicines (e.g. ACE inhibitors and statins) and technologies (e.g. dialysis and transplantation), Financing for kidney disease detection and treatment, Availability of kidney care interventions, Training of workforce in kidney care, Set up of information systems such as registries (e.g. for AKI, CKD, dialysis or transplantation), formulation of regional and national kidney health guidelines and strategies and/or NCD strategies integrating kidney care, local/ regional and national capacity for Research and Development of kidney disease related health products including drugs, diagnostic tools and interventions for renal replacement therapy

 In the Annex you will find general ideas for advocacy messages in line with the WKD 2019 theme "Kidney Health for Everyone Everywhere"

Identify key advocacy targets and stakeholders

- Depending on the most pressing policy issues that you have identified, map out who can help you to address the policy gap and achieve policy change.
- Typically, key advocacy targets and stakeholders will include policy makers such as Heads of Governments, Minister of Health, Deputy Ministers of Health and policy officers, Finance Ministers etc but can also include regulatory bodies such as medical safety and approval agency. Other stakeholders can include ministry officials, government advisors and experts, leading media and press outlets and journalists.

Identify advocacy opportunities

- Keep up-to-date with political developments in the area of kidney disease and non-communicable disease. This can happen through signing up to newsletters of kidney organizations and (or) NCD networks or attending events, conferences and webinars. In addition, you can follow/like policy makers on social media for their latest announcements.
- Applying your advocacy asks in response to political processes can give you a leg up in your advocacy work as policy makers will be receptive to evidence-based policy asks in order to inform their policy work.

 You will find a timeline of international policy meetings in 2019 in the Annex.

Join forces in advocacy partnerships, networks and alliances

- Identify key local/regional/national players on kidney disease and NCDs, register as members and engage in the exchange of best practises.
- Create strong coalitions with patients, nephrologists, researchers from the medical community, local communities and other organisations.

 Find links to national nephrology societies, national kidney foundations and national NCD alliances in the Annex.

Take action

- Address your asks and queries on policy evolution to key advocacy targets and stakeholders
- Engage through communicating directly (letter, email or even telephone) with the relevant stakeholders or indirectly through your informal and formal networks

 Find a template letter to your local/regional/ national policy maker(s) in the Annex.

- **Use social media:** policy makers and other stakeholders rely increasingly on social media for the promotion of their policies and to communicate their next steps regarding the progression of health issues. You can use platforms like Facebook, Instagram and Twitter to spread your advocacy asks by posting in a friendly tone and engage users with relevant hashtags, such as #WorldKidneyDay2019. Make sure you connect (follow and like) with other relevant organizations, so as to support and promote each other's work.

 Find ready-made social media posts and hashtags relevant to kidney health in the Annex.

4. Annex

Advocacy Timeline of UN and WHO Conferences and Committee meetings in 2019



Messages and asks

- 🔊 Call for an integrated approach to prevention and treatment of NCDs including kidney disease and other relevant NCDs which are currently excluded from the SDG 3.4 definition and the scope of the political declaration of the UN HLM 2018
- 🔊 Call for an increased investment in NCDs, including kidney disease
- 🔊 Ask to adopt policies that encourage healthy lifestyles (access to clean water, exercise, healthy diet, tobacco control). Many types of kidney diseases can be prevented, delayed and / or kept under control when appropriate prevention measures are in place.
- 🔊 Ask to make screening for kidney diseases a primary healthcare intervention including access to identification tools (e.g. urine and blood tests). Screening of high-risk individuals and early diagnosis and treatment is cost effective to prevent or delay end-stage kidney diseases.
- 🔊 Promote policies that ensure kidney patients receive basic health services they need (e.g. blood pressure and cholesterol control, essential medications) to delay disease progression without suffering financial hardship.
- 🔊 Call for transparent policies governing equitable and sustainable access to advanced health care services (e.g. dialysis and transplantation) and better financial protection (e.g. subsidies) as more resources become available. Breaking down socioeconomic barriers and expanding access to comprehensive services in order to meet the needs of the population is essential to guarantee equitable kidney care and increase quality.

Template letter

[insert the logo of all organizations supporting this letter]

To: [Insert name and title. Ideally, the letter will be sent to 1. the Prime Minister or equivalent 2. the Minister of Health; 3. the Minister of Finance; 4. the ambassador to the United Nations in New York; 5. other policymakers (senators, deputies, Members of Parliament)]

Subject: [COUNTRY]'s commitments towards better kidney care and health

[Insert date]

Dear Honorable [NAME],

Kidney disease is the eleventh cause of death on a global scale and the number of people receiving dialysis is expected to rise up to 5,4 million by 2030. Yet, kidney disease is not given the attention needed at a policy level: case in point the WHO Global Action Plan 2013-2020 for non-communicable diseases (NCDs) where it is only briefly mentioned in Appendix 1. According to the Institute for Health Metrics and Evaluation (IHME), if kidney disease is not given the attention needed, it will become the 5th leading cause of Years per Life Lost in 2040. Therefore, we believe that it is more imminent than ever to raise awareness for better kidney health and care.

Moreover, chronic kidney disease (CKD) is closely linked to other major NCDs, particularly cancer, diabetes and cardiovascular disease, and should be recognized as both a considerable cause and consequence of these diseases. There is evidence suggesting that the coexistence of diabetes and CKD increases the risk of cardiovascular diseases whereas overall mortality rates are tripled for diabetes patients suffering as well from kidney disease. Hence, kidney disease needs to be included in our national NCD policy as one of the main NCDs to be dealt with in the imminent future.

[continues on next page]

An integrated national NCD strategy should focus on prevention, early detection and management of early stages of all relevant NCDs. Failing to do so translates into kidney disease not being given the attention needed by patients and even worse by the medical staff. For example, secondary prevention is often suboptimal for patients with insufficient kidney function. Studies have shown that they do not receive the necessary interventions and, in most of the cases, leave the hospital with fewer medications than recommended by international guidelines. As a result, these people are at risk of higher mortality e.g. from cardiovascular disease.

Besides the need for an integrated NCD strategy which includes kidney disease, [COUNTRY] needs to increase investment and national budgetary allocations to support local, regional and transnational research into NCDs including kidney disease. Secondly, new public health strategies need to be introduced in order to promote a healthy lifestyle that will eventually lead to the reduction of other NCDs, such as diabetes, obesity and hypertension. Finally, better educating the nephrology workforce, as well as the public in particular those who are at an increased risk, will eventually contribute to better awareness of kidney disease.

The [NAME OF ORGANIZATION] strongly believes, for the reasons stated above, that kidney disease should not be considered a 'neglected' NCD and should be included explicitly in the national and global health policy discussions (e.g. for the next WHO Global Action Plan for NCDs). The latest UN High Level meeting on NCDs created momentum. Hence we believe that now is the time to exercise your influence on the discussions about the national and global health policy agenda to promote and support the inclusion of kidney disease as a separate NCD.

Yours sincerely,

[NAME]

Social Media posts and hashtags



Kidney care should be provided as part of #UniversalHealthCoverage. The comprehensiveness of covered interventions will differ among countries based on political, economic and cultural factors. **#WorldKidneyDay #noonesizefitsall**



Kidney health equality is improved by understanding what is feasible and important for a country or region as regards kidney disease. **#WorldKidneyDay #KnowledgeIsPower**



Basic infrastructure for services must be strengthened at the primary care level for early detection and management of **#AKI and #CKD** across all countries. **#WorldKidneyDay**



All countries should ensure access to kidney disease identification tools (e.g. urine and blood tests) and basic health services (e.g. blood pressure and cholesterol control, essential medications). **#WorldKidneyDay**



Kidney care should emphasize prevention including promotion of healthy lifestyles to reduce adverse consequences of kidney disease at the population level **#WorldKidneyDay**



Kidney transplantation should be encouraged through increased awareness among the public and political leaders across countries. **#WorldKidneyDay**



Cost-effective prevention and delay of end stage kidney disease should be done by screening high-risk individuals for early diagnosis and treatment. **#WorldKidneyDay**



Kidney health equity depends on transparent policies governing equitable and sustainable access to dialysis and transplantation and better financial protection according to country's financial solvency. **#WorldKidneyDay**



Equitable and quality kidney care requires breaking down socioeconomic barriers and expanding access to comprehensive services in order to meet the needs of the population. **#WorldKidneyDay**

Useful links

Evidence of the burden of disease:

- [Institute for Health Metrics and Evaluation : https://vizhub.healthdata.org/gbd-compare/](https://vizhub.healthdata.org/gbd-compare/)

Kidney health policy progress per country/region:

- [ISN Global Kidney Health Atlas: https://www.theisn.org/images/ISN_advocacy/GKHAtlas_Linked_Compressed1.pdf](https://www.theisn.org/images/ISN_advocacy/GKHAtlas_Linked_Compressed1.pdf)

Partnerships:

ISN affiliated societies:

- <https://www.theisn.org/about-isn/partners-affiliates-and-supporters/affiliated-societies>
- <https://www.worldkidneyday.org/about/endorsing-organisations/isn-affiliated-societies/>

IFKF partners:

- <https://ifkf.org/partners-links/recommended-links.html>
- <https://www.worldkidneyday.org/about/endorsing-organisations/ifkf-members/>

National and Regional NCDs alliances:

- <https://ncdalliance.org/what-we-do/capacity-development/list-of-national-regional-ncd-alliances>

Position Papers: Global Advocacy for Kidney Health

- <https://www.theisn.org/advocacy#publications>

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