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1. Introduction

About the WKD Advocacy toolkit

The World Kidney Day Advocacy Toolkit offers guidance and support to the efforts of kidney health champions, healthcare professionals, such as nephrologists, primary care physicians, nurses and care-takers, patients and their families, 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 patients.³

With this Toolkit, we aim to offer you a resource for 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 health, and outlines steps you can take to strengthen your capacity for advocacy and to structure your advocacy.

We will address issues such as 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 strategy. For specific ideas on how to create awareness about the importance of kidney disease prevention and treatment to encourage behavioral change in your local or regional community, please read our World Kidney Day General Campaign Toolkit.

This WKD Advocacy 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 WKD Advocacy Toolkit, please feel free to contact us at info@worldkidneyday.org

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

850 million people worldwide are now estimated to have some sort of kidney disease! Kidney disease is the 11th leading cause of death globally and a rapidly growing health burden which poses a significant health care challenge for governments, particularly in low- and middle-income countries.⁵

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.⁶ 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 unfordable 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.⁷ Kidney disease is a key contributor to the global NCD burden as both a cause and consequence of other major NCDs notably cardiovascular disease and diabetes.

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. If policy inaction is not reversed now, CKD will be the 5th leading cause of Years of Life Lost in 2040.8

Kidney Health for Everyone Everywhere – from Prevention to Detection and Equitable Access to Care

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

In 2020, World Kidney Day aims to raise awareness of the increasing burden of kidney diseases worldwide and to strive for kidney health for everyone, everywhere. Specifically, the 2020 campaign highlights the importance of **preventive interventions to avert the onset and progression of kidney disease**. In 2020, World Kidney Day calls on everyone to advocate for concrete measures in every country to promote

and advance kidney disease prevention, including:

- Renewed focus on primary care, awareness raising and education including patient empowerment and cross-specialty training
- Integration of CKD prevention into national NCD programs for comprehensive and integrated services, which are essential in improving the early detection and tracking of CKD at country level
- Whole-of-government, whole-of-society, health in all policies, multi sectoral collaboration to promote prevention of kidney disease

⁴https://www.theisn.org/images/ISN_advocacy/UN_High_Level_Meeting_on_NCDs_2018 - Toolkit/ISN_priorities_briefing_paper_UN_HLM_NCDs_2018.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 https://www.worldkidneyday.org/wp-content/uploads/2015/05/KI-final-article.pdf

⁷https://www.theisn.org/images/ISN advocacy/UN High Level Meeting on NCDs 2018 - Toolkit/ISN priorities briefing paper UN HLM NCDs 2018.pdf

⁸ https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(18)31694-5/fulltext

For more information about prevention see Figure 1.

WHAT IS PREVENTION?

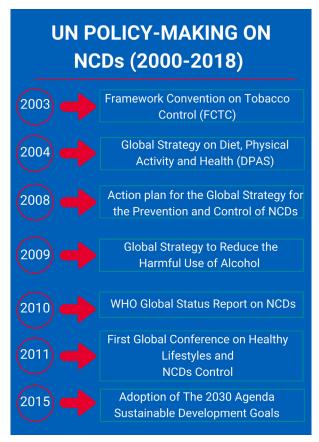
The term "prevention" refers to the following three definitions:

- (1) <u>Primary Prevention</u>, implies intervening before health effects occur in an effort to prevent the onset of kidney disease before the disease process begins
- (2) Secondary Prevention suggests preventive measures that lead to early diagnosis and prompt treatment of kidney disease to prevent more severe problems developing
- (<u>3) Tertiary Prevention</u> indicates managing kidney disease after it is well established in order to control disease progression and the emergence of more severe complications.

Figure 1: 'What is Prevention'.

To read more about the 2020 WKD campaign priorities, please visit: https://www.worldkidneyday.org/2020-campaign/2020-wkd-theme/

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



At the 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 – Figure 2. 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. In 2015, world leaders adopted the 2030 Agenda and the 17 Sustainable Development Goals (SDGs) – Figure 3. SDG 3 in particular aims to ensure healthy lives and promote well beings for all ages by 2030 and mentioned specifically NCDs as a key priority for action (SDG 3.4) – Figure 4.

Figure 2: United Nations Policy-Making on NCDs 2000-2018



Figure 3: Agenda 2030 Sustainable Development Goals (Source: https://sustainabledevelopment.un.org)

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

The Political Declaration on the Prevention and Control of NCDs

The latest culmination of international policy making on NCDs is the Political Declaration on the Prevention and Control of Non-communicable diseases (NCDs) which took place in September 2018.

The Political Declaration 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 Development Goals".

Although failing to directly mention kidney disease, the Declaration does recognize the need to scale up the efforts of Member States to appropriately tackle the devastating consequences of NCDs worldwide by 2023 and reinstates their commitment to:

SDG 3: ENSURE HEALTHY LIVES AND PROMOTE WELLBEING FOR ALL AT ALL AGES

Target 3.4 : By 2030, By 2030, reduce by one third premature mortality from non-communicable diseases through prevention and treatment and promote mental health and well being

Figure 4: Sustainable Development Goal 3: Target 3.4 on the reduction of NCDs by 2030

- Implement a set of cost-effective, affordable and evidence-based interventions and good practices for the prevention and control of NCDs
- Invest in research in NCDs
- Strengthen health systems and reorient them towards the achievement of universal health coverage (UHC) and high-quality, integrated and people-centered primary and specialized health services
- Commit to mobilize and allocate adequate, predictable and sustained resources for national responses to prevent and control non-communicable diseases.¹⁰

The Political Declaration on the High Level Meeting on Universal Health Coverage (UHC)

In September 2019, world leaders unanimously endorsed the Political Declaration of the High Level Meeting on Universal Health Coverage: https://undocs.org/en/A/RES/74/2.

The Declaration represents a landmark for global health and development as for the first time in history world leaders committed to making UHC a reality in their countries by 2024 in four major areas, namely:

- Mechanisms to ensure no one suffers financial hardship because they have had to pay for healthcare out
 of their own pockets;
- High-impact health interventions to combat diseases, including NCDs;
- Health workforce and infrastructure;
- Governance capacity.

¹⁰ https://www.un.org/en/ga/search/view_doc.asp?symbol=A/RES/73/2.

WHAT IS UNIVERSAL HEALTH COVERAGE?

Universal health coverage (UHC) means that all people have access to the health services they need, when and where they need them, without financial hardship. It includes the full range of essential health services, from health promotion to prevention, treatment, rehabilitation, and palliative care*.

*https://www.who.int/health-topics/universal-health-coverage#tab=tab_1

nttps://www.wno.int/nediti-topics/oniversal-nediti-coverage#tab=tat

Now is the moment to ensure that world leaders uphold their global

commitments to tackle

Although the Political Declaration does not

mention kidney disease explicitly, it commits to

strengthen efforts to

UHC.11

address NCDs as part of

Figure 5: What is Universal Health Coverage?

NCDs and achieve UHC. Specifically, targeted action on kidney disease should become integral to the global, regional and national NCD policy response and UHC advancement.

- → The WKD Campaign Toolkit aims to help you advocate for the need to recognize kidney disease as an important NCD which should be fully integrated in national NCD and UHC plans.
- The Advocacy Timeline of UN and WHO Conferences and Committee meetings in 2020 (Appendix 1) provides you with a road map 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 meetings, 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 profiles. 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.

https://www.who.int/news-room/detail/23-09-2019-who-welcomes-landmark-un-declaration-on-universal-health-coverage

3. How to create and structure your advocacy actions

In this section, you will find the steps for actions needed to be taken on a national level to advocate 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 organizations 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 the '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 in 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: Prevention & Detection (e.g. social & health determinants, primary, secondary, tertiary prevention measures); 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 and asks in line with the WKD
 2020 theme.

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 agencies. Other stakeholders can include ministry officials, government advisors and experts, leading media and press outlets and journalists.

- Keep up-to-date with political developments in the area of kidney disease and NCDs. This can happen through signing up to newsletters of kidney health organizations and (or) NCD networks or attending events, conferences and webinars. In addition, you can follow 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 2020 in the Annex.

Join forces in advocacy partnerships, networks and alliances

- Identify key local/regional/national players as regards kidney disease and NCDs, register as member 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 #WorldKidneyDay, #BeatNCDs, #KidneyHealthForAll, #HealthforAll. Make sure you connect ("follow and like") with other relevant organizations, so as to support and promote each other's work.
- Find ready-made tweets and hashtags relevant to kidney health in the Annex.

4. Annex

Advocacy Timeline of UN and WHO Conferences and Committee meetings in 2020

ADVOCACY TIMELINE 2020 UNITED NATIONS AND WORLD HEALTH ORGANISATION CONFERENCES AND REGIONAL MEETINGS			
3-8 February 146th session of the WHO Executive Board Geneva, Switzerland	8-11 Febrary Global NCDA Forum Sharja, UAE		
12 March World Kidney Day	17-21 May 73rd World Health Assembly Geneva, Switzerland		
15-17 June The Circulatory Health Summit Washington, USA	WHO Regional Committee Africa		
7-11 September WHO Regional Committee South East Asia Thailand (tbc)	Lomé, Togo 14-17 September		
15-18 September United Nations General Assembly	WHO Regional Committee Europe Tel Aviv, Israel		
New York, USA 21-22 November	5- 9 October WHO Regional Committee Western Pacific Kobe, Japan		
G20 Riyadh Summit Riyadh, Saudi Arabia	kobe, Japan		

Messages and asks

Prevention & detection

- 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.
- Call for primary care interventions which address the growing burden of multiple comorbidities.

Health services advancement

- 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.
- 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.

Universal Health Coverage

Call for full integration of kidney disease in national UHC plans by providing sustainable access to effective and affordable prevention, early detection and access to medicines to treat risk factors for kidney disease and delay kidney disease progression

Funding

Call for an increased investment in NCDs, including kidney disease.

People's centered approach to care

Call for empowerment of individuals, families and communities by promoting a people-centered rather than disease-centered approach to care delivinterland music management ery.

Template letter¹

[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],

850 million people are affected by some sort of kidney disease globally. 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 fully given the attention needed at a policy level. According to the Institute for Health Metrics and Evaluation (IHME), if kidney disease is not urgently tackled, it will become the 5th leading cause of Years of Life Lost in 2040. In our country, [Insert national data on burden] . Therefore, we believe that it is more imminent than ever to ensure better kidney health and care.

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 fully integrated in our national Non-Communcable Disease (NCD) policy as one of the main NCDs to be dealt with in the imminent future. An integrated national NCD strategy should focus on prevention, early detection and management of early stages of all NCDs including kidney disease.

Besides the need for an integrated NCD strategy which includes kidney disease, [COUNTRY] needs to increase investment and national budgetary allocations to support an appropriate implementation of Universal Health Coverage (UHC) and health systems which fully strive for a people-centred, integrated and multisectoral approach to healthcare which leaves no-one behind or out-of-pocket.

With the adoption of the 2018 Political Declaration on the Prevention and Control on NCDs and the 2019 Political Declaration on UHC, our government committed to truly advance NCDs control and management by 2023 and to ensure the implementation of UHC in our country by 2024. The time to uphold to these commitments is now and we thus call on you as a matter of urgency to implement the following measures:

x # [....]

[List according to your advocacy asks and messages (as developed according to p.8 of this Toolkit)] Yours sincerely,

[NAME]

¹ To be adapted according to national needs, priorities and circumstances

Social Media posts and hashtags

Kidney Health for Everyone Everywhere – from Prevention to Detection and Equitable Access to Care

- Kidney care should be provided as part of #UniversalHealthCoverage. The comprehensiveness of covered interventions differs among countries based on political, economic and cultural factors. #WorldKidneyDay #noonesizefitsall #KidneyHealthforAll #BeatNCDs #UHC
- Kidney health equality is improved by understanding what is feasible and important for a country or region as regards kidney disease. #WorldKidneyDay #KnowledgeIsPower #KidneyHealthforAll #BeatNCDs #UHC
- 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 #KidneyHealthforAll #BeatNCDs #UHC
- 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 #KidneyHealthforAll #BeatNCDs #UHC
- Kidney care should emphasize prevention including promotion of healthy lifestyles to reduce adverse consequences of kidney disease at the population level #WorldKidneyDay #KidneyHealthforAll #BeatNCDs #UHC
- Kidney transplantation should be encouraged through increased awareness among the public and political leaders across countries. #WorldKidneyDay #KidneyHealthforAll #BeatNCDs #UHC
- Cost-effective prevention and delay of end stage kidney disease should be done by screening high-risk individuals for early diagnosis and treatment. #WorldKidneyDay #KidneyHealthforAll #BeatNCDs #UHC
- Kidney health equity depends on transparent policies governing equitable and sustainable access to dialysis and transplantation and better financial protection according to a country's financial solvency. #WorldKidneyDay #KidneyHealthforAll #BeatNCDs #UHC
- 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 #KidneyHealthforAll #BeatNCDs #UHC

Download the WKD 2020 Social media visuals here:



Useful Links

Evidence:

Evidence of burden of disease

firstitute for Health Metrics and Evaluation: https://vizhub.healthdata.org/qbd-compare/

Kidney health policy progress per country/region

SISN Global Kidney Health Atlas: https://www.theisn.org/images/ISN_advocacy/GKHAtlas_Linked Compressed1.pdf

Partnerships:

ISN affiliated societies:

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

UN/WHO legislation:

Political Declaration of the High Level Meeting on Universal Health Coverage:

https://undocs.org/en/A/RES/74/2.

Political Declaration on the Prevention and Control of Non-communicable diseases (NCDs) which took place in September 2018:

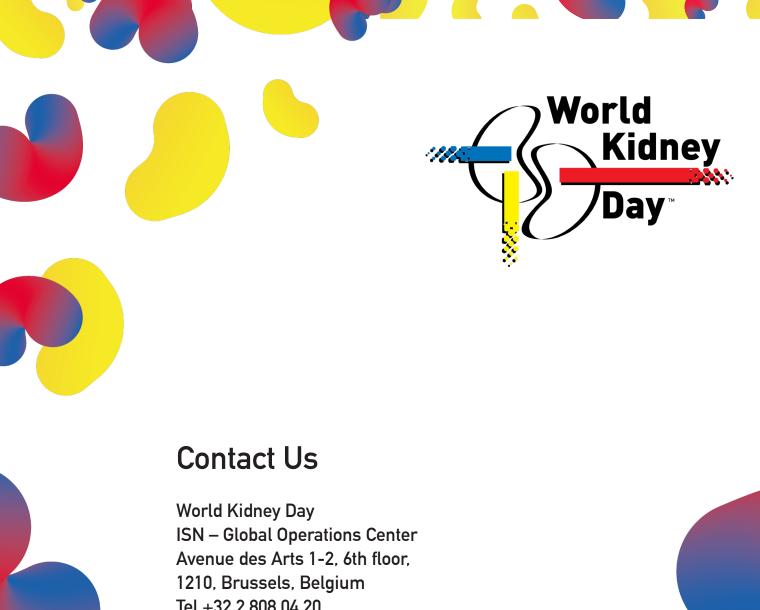
https://www.un.org/en/ga/search/view_doc.asp?symbol=A/RES/73/2

WHO HEARTS Technical Package:

https://www.who.int/cardiovascular_diseases/hearts/en/

WHO Time to Deliver Report:

Attps://www.who.int/ncds/management/time-to-deliver/en/



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