



ISN

**CLOSINGTHEGAPS**  
CKD INITIATIVE

# **ISN Global Kidney Health Summit: designing the roadmap for chronic kidney disease: care, research and policy**

## Summary report

JULY 26-28, 2016 VANCOUVER, CANADA



Advancing Nephrology Around the World

# Sponsors

Support for the Summit was made possible through unrestricted grants from various organizations in addition to the International Society of Nephrology.

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# Intention and outcomes of the Summit

The global nephrology community recognizes the need for a cohesive plan to address the problem of Chronic Kidney Disease (CKD). The International Society of Nephrology (ISN) therefore organized a Summit that was held in Vancouver, Canada in July 2016. The purpose of the meeting was to identify and prioritize key activities for the next five to 10 years in the domains of clinical care, research, and policy; to identify potential partners within and outside the nephrology community; and to create an action plan and performance framework. Intended users of the action plan

include clinicians, patients, scientists, industry, governments, and advocacy organizations.

Participants met for two and a half days to develop the plan, based on 10 themes and four key areas (Table 1). Delegates participated in two working groups, each of which addressed a single theme. Pre-work for the meeting consisted in identifying key issues, supporting literature searches, and facilitating discussion. Using an iterative process, each group produced a prioritized list of key issues, goals, and activities.

**TABLE 1 Key areas and themes**

Key areas	Theme
IMPROVE THE IDENTIFICATION OF CKD AND REDUCE RISK FACTORS FOR CKD	1. Strengthen CKD surveillance
	2. Tackle major risk factors for CKD
	3. Reduce AKI - a special risk factor for CKD
IMPROVE THE UNDERSTANDING OF CAUSES AND CONSEQUENCES OF CKD	4. Enhance the understanding of the genetic causes of CKD
	5. Establish better diagnostic methods in CKD
	6. Improve the understanding of the natural course of CKD
IMPROVE OUTCOMES WITH CURRENT KNOWLEDGE	7. Evaluate and implement established treatment options in patients with CKD
	8. Improve the management of symptoms and complications of CKD
DEVELOP AND TEST NEW THERAPEUTIC STRATEGIES	9. Develop novel therapeutic interventions to slow CKD progression and reduce CKD complications
	10. Increase the quantity and quality of clinical trials in CKD

All groups were asked to develop a set of potential deliverables to inform the performance framework, demonstrate progress, and hold stakeholders to account. Progress will be reported regularly according to the framework (Table 2 shows a condensed version), and will leverage the parameters identified in the ISN Global Kidney Health Atlas (GKHA), which describes CKD-relevant access to care, health infrastructure, national and regional policies, and

research capacity. A manuscript was prepared for The Lancet based on the summit outputs, Global Kidney Health 2017 and beyond: A roadmap for closing gaps in care, research, and policy, and submitted for publication prior to the World Congress of Nephrology in 2017. In addition, seven individual Working Group (WG) manuscripts have been drafted and will be submitted as a set to Kidney International (KI) Supplements to complement The Lancet paper.

# Special Summit presentations and outputs

ISN GKHA Co-chairs Professor David **Johnson** and Dr. Aminu **Bello** presented the preliminary ISN GKHA survey results, which cover six domains: health financing, service delivery and safety, health workforce, access to essential medications and technology, health information systems and statistics, and governance and policies. This supports the World Health Organization's (WHO) push toward Universal Health Coverage and the United Nations' Sustainable Development Goal 3: Health.

Their team has drafted an overarching concept and main findings paper, which has been submitted to a high-impact journal, and detailed papers on each domain highlighting data from around the world, with interpretations and implications for the community. A paper detailing the study protocol will be published in KI Supplements along with the individual WG Summit papers.

Dr. Valerie **Luyckx** gave a presentation on Sustainable Development Goals (SDGs) and kidney disease. The SDGs are important potential levers for reducing the global burden of CKD and its complications. Dr. Luyckx emphasized aligning health care activities with SDGs relevant to improving child and maternal health, ensuring access to education, clean water, essential medications and vaccines, focusing on preventing and reducing infections, and improving access to care and health infrastructure, especially in the context of risk factors for CKD (Theme 2). A detailed manuscript is in preparation.

## Summit findings

The main findings in each theme are summarized below and divided into three sections: current status, knowledge gaps, and action steps. Detailed information will be available in the published manuscripts.



**Health in the SDG Era**  
World Health Organization  
[WWW.WHO.INT/UHC](http://WWW.WHO.INT/UHC)  
Sustainable development Goals  
[WWW.WHO.INT/SDGS](http://WWW.WHO.INT/SDGS)

# CKD current status: what we know

- CKD affects as much as 10-15% of the population worldwide, and is due to multiple causes
- CKD is associated with impaired quality of life and strongly reduced life expectancy
- CKD is associated with enhanced rates, altered manifestations, and adverse outcomes of all types of Cardiovascular Disease (CVD)
- CKD reflects the most serious complications of many different diseases, including diabetes, hypertension, and systemic immune disorders
- The etiology of CKD remains uncertain in a large proportion of affected individuals; knowledge of the etiology of CKD is important for targeting specific therapies
- The mechanisms causing progressive kidney failure and associated systemic complications, including CVD, remain incompletely understood, resulting in a lack of targeted therapies
- Nephrology lags behind other medical disciplines with respect to the conduct of clinical trials
- CKD and Acute Kidney Injury (AKI) should be considered as related manifestations of renal impairment with mutual predisposition, functional and structural overlap, and potentiating adverse consequences
- The costs of treating CKD-associated complications (including kidney failure) provide a strong challenge for health care budgets that cannot be met in many parts of the world
- Successful prevention and treatment of CKD is strongly linked to progress on the SDGs.

# Knowledge gaps: what we don't know

## Surveillance, risk factors, and causes

- Data about the burden of illness (incidence, prevalence, progression rates) of CKD is lacking, so poor information is available for decision-making
- Hotspots for Chronic Kidney Disease of unknown origin (CKDu) is an important and growing worldwide problem
- There is limited understanding about the relationship of known risk factors to incidence, prevalence, and progression in different regions:
  - Kidney stones and CKD
  - Infections
- The importance of maternal health and fetal risk factors is poorly defined in all regions of the world
- The genetic causes of CKD vary in different locations and knowledge remains limited.

## Diagnosis, prognosis, and treatment

- Variability in pathophysiology and prognosis among similar diseases remains unexplained
- Diagnostic facilities and methods lack standardization and vary around the world
- Symptoms such as pruritus, restless legs, etc., are common, multifactorial, and incompletely understood; treatments for these conditions are needed
- The relative contribution of traditional and non-traditional risk factors to CVD in CKD populations remains unknown:
  - Effective treatment strategies for CVD in CKD are impacted by this lack of understanding
- Affordable and sustainable methods to reduce the clinical and economic burden of monitoring abnormalities in CKD, especially in low-and-middle-income countries (LMIC), are a key priority
- Better treatments to reduce the risk of progression from CKD to kidney failure are needed
- Few effective research consortia exist between academia, industry and biotechnology companies, philanthropy and funding bodies, policy makers, and government.

## Clinical trials

- Endpoints for clinical trials are debated, limiting the conduct of many trials
- Exploration into disease-specific markers of kidney damage as endpoints continues
- Safety endpoints have received insufficient attention in clinical trial design
- A culture of, and capacity for, clinical trials is lacking in the international community relative to other disciplines.

# Action steps: what we can do



## Strengthen CKD surveillance

- Engage stakeholders, making sure the rationale for monitoring programs is clear and tailored appropriately to different settings
- Standardization of laboratory testing and availability of reliable point-of-care testing should be available globally
- Include measures of CKD in large chronic disease studies
- Establish registries of chronic dialysis and transplantation in all countries, especially LMIC, and promote minimum data sets for each
- Develop and test screening strategies to appropriately measure efficiency.

## Tackle major risk factors

- Enhance CKD surveillance systems to facilitate the discovery of novel risk factors
- Include CKD measures in all large communicable and non-communicable disease surveys
- Improve and coordinate regional and international efforts to address CKDu, including all stakeholders: researchers, clinicians, and policy makers
- Promote activities to prevent obesity, diabetes, and hypertension
- Use electronic infrastructure existing in many jurisdictions to maximize surveillance education, safety, and research activities
- Focus on unique risk factors prevalence in LMIC, and systematically address them: known and emerging nephrotoxins (including traditional remedies), kidney stones in susceptible populations
- Improve efforts in prevention, timely identification, and the appropriate management of infections, which are linked to AKI or CKD or both in all countries
- Promote strategies to improve maternal and fetal health by reducing risk factors and improving socioeconomic factors.

## Control AKI: a special risk factor for CKD

- Target patients with CKD who are at risk of AKI for preventive activities.

## Identify the genetic causes of CKD

- Increase awareness about the importance of genetics for understanding and treating CKD
- Increase the diversity of genotyped populations beyond those of European ancestry
- Promote a better understanding of genes through environment interactions that are relevant to the causes and consequences of CKD.



## Establish better diagnostic methods

- Enhance renal-biopsy-based CKD diagnosis
- Enhance non-invasive imaging analyses of the kidney in CKD
- Facilitate the identification, validation, and implementation of CKD diagnostic and prognostic biomarkers
- Enhance the clinical assessment of CKD renal (dys)function and underlying pathomechanisms
- Improve the monitoring of kidney disease progression among patients with CKD
- Improve CVD-risk prediction in CKD patients.





## Manage symptoms and complications of CKD

- Develop a better understanding of symptoms associated with CKD and their impact on patient quality of life, employability, and functional status
- Promote basic and clinical research into understanding the pathophysiology of the key symptoms to better target therapeutic efforts
- Promote the availability of affordable point-of-care measurement devices and treatments for hormonal, hematological, and biochemical abnormalities
- Develop an integrated research program to better understand vascular and cardiac diseases occurring in the context of CKD populations
- Improve the understanding of global variation in CVD associated with CKD
- Develop new therapeutic approaches to reduce CVD-risk in CKD patients.

## Develop novel interventions

- Interrogate human samples using state-of-the-art omics approaches, merged with detailed patient phenotyping and existing biomarkers to identify and qualify new therapeutic targets
- Enhance participation in cross-disciplinary research on pathophysiological mechanisms relevant for CKD and other diseases
- Leverage research networks for CKD and segmented disease populations to facilitate data acquisition and trial recruitment
- Facilitate and formalize interaction and exchange of ideas between academic researchers and drug/device/diagnostic manufacturers
- Improve access to effective but costly drugs/biologics/devices, especially in LMIC
- Target aid support from Organisation for Economic Co-operation and Development (OECD) countries to LMIC to prevent/treat CKD
- Encourage industry/biotechnology/government investment in the development of new therapies for CKD.

## Increase the quantity and quality of clinical trials

- Promote trials in areas of unmet needs and orphan diseases, including outcome development
- Engage activated patient groups, payers, and other stakeholders, aiming to substantially increase the number of clinical trials in CKD
- Promote models for early conditional approval of new therapies to encourage investment
- Increase the number of people with CKD who are included in CV, diabetes, and oncology trials, reflecting the prevalence of CKD in such patient populations
- Develop a regular stand-alone meeting to review ongoing and planned clinical trials with CKD patients on a global scale
- Develop and refine appropriate endpoints for CKD trials and promote their uptake and dissemination
- Develop innovative trial designs to enhance the feasibility and success of CKD trials
- Implement priority setting exercises for interventions to be tested in clinical trials globally and by region
- Develop networks of kidney clinical trialists including community physicians and other specialties, etc.

# Summary and conclusions

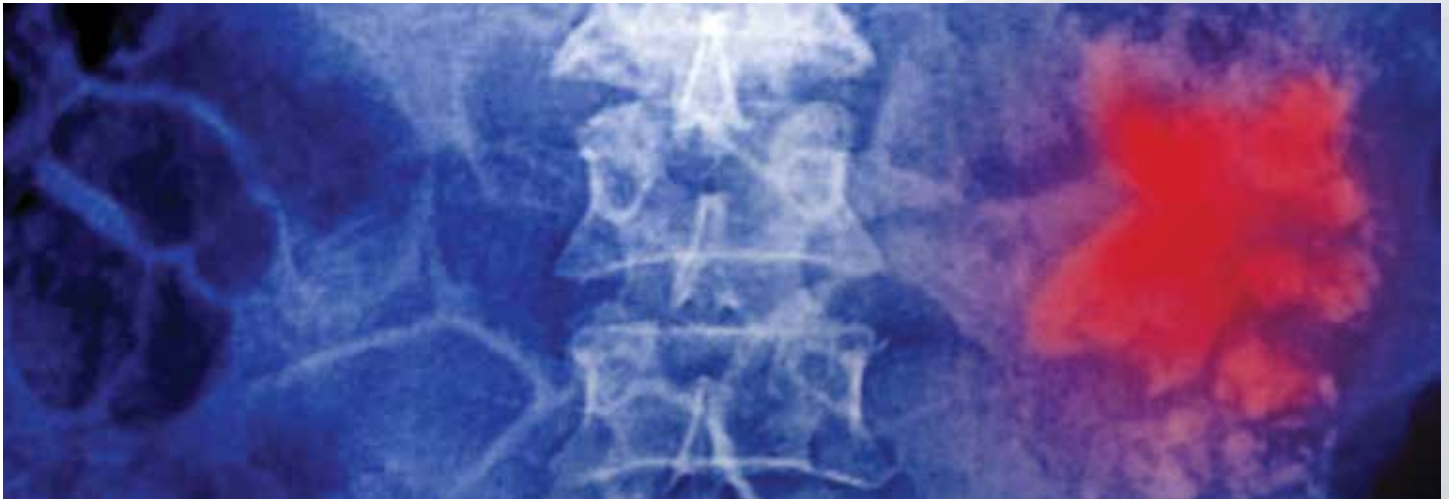


The ISN Global Kidney Health Summit was successful, unique and the first meeting of its kind in the international nephrology community, developing a roadmap to guide activities over the next five to 10 years. We developed a high-level performance measurement framework based on the key areas and specific Working Group action plans, to ensure accountability of the work planned. We are optimistic that this tracking of events, activities, and desired outcomes will galvanize the nephrology community to close the identified gaps - to reduce the global burden of kidney disease around the world (see Table 2 for condensed version).

## Key messages

- A global collaborative effort of all stakeholders is required to execute a multifaceted action plan to combat the growing burden of CKD and its complications
- More work is needed to define the etiology and pathophysiology of CKD at the individual patient level, and at the population level in regions where CKD is endemic
- A concerted effort is required to increase the number, size, and quality of clinical trials investigating how to reduce the burden of CKD and its complications
- Existing data and biomaterial sources need to be better utilized by promoting collaborative efforts and reducing administrative hurdles
- The existing clinical and research workforce is inadequate to address the global burden of CKD, especially in LMIC.





**TABLE 2 Condensed performance framework**

Key areas	Activities	Measurable outputs	Data sources
IMPROVE THE IDENTIFICATION OF CKD AND REDUCE RISK FACTORS FOR CKD	Support of novel collaborative translational and clinical research	Increase in: a) number of countries with written policies on CKD identification and care, b) number of countries with capacity to diagnose CKD (kidney biopsies/laboratory), c) uptake and knowledge of position statements as outputs of workshops, consensus conferences, and task forces, d) uptake of international CKD-relevant guidelines in high-income countries (HIC) and LMIC	WHO, ISN, national research groups  Patient organizations, industry
IMPROVE THE UNDERSTANDING OF CAUSES AND CONSEQUENCES OF CKD	Position statements to aid in awareness, advocacy, and collaboration		Documents in public domain
	Workshops of multiple stakeholders to address complex problems	Proportion of: a) high-risk populations receiving simple urine and blood tests to detect CKD, b) patients with End-Stage Renal Disease (ESRD) who report their symptom burden as 'mild' or 'very mild', c) medical schools with AKI and CKD modules within curriculum	ISN Global Kidney Health Atlas (GKHA)
IMPROVE OUTCOMES WITH CURRENT KNOWLEDGE	Consensus conferences to develop unified messaging		National and regional documents
		Number of clinical trials: a) focusing on CKD or ESRD patients, b) including CKD as an important subgroup, c) reporting important outcomes in the CKD subgroup, d) including patients with stage 3 or 4 CKD, e) conducted in LMIC	International, regional and national societies
DEVELOP AND TEST NEW THERAPEUTIC STRATEGIES	Specific time-limited task forces to address barriers for collaboration and progress across jurisdictions		Study registries, clinicaltrials.gov, other publications
	Develop inventories to objectively measure current state and progress	Number of: a) people with access to essential CKD care, basic CKD-relevant medication, b) new agents available for CKD or symptoms treatment, c) formal agreements with funding partners, d) knowledge translation tools developed and events held, e) international collaborative consortiums conducting CKD-relevant research, f) tools and strategies developed to enhance access to ethical dialysis or living donor transplantation	
	Surveys to establish current state and perspectives and to use as update tools	ISN Global Kidney Policy Forums held: number, participants, and locations	
	Develop, update, and implement guidelines	30% of CKD patients worldwide involved in a clinical trial by 2030	
		Creation of administrative data platform for kidney research developed in collaboration with international groups	
		Median survival among patients with ESRD in HIC and LMIC	
		Total funding for CKD-relevant research	



## Participants

Participants of the ISN Global Kidney Health Summit included more than 85 individuals with diverse expertise and professional background from around the globe: clinicians, basic scientists, clinical researchers, epidemiologists, methodologists, and industry scientists.

## Summit co-chairs

Adeera **Levin** MD  
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