Seeing kidney disease patients struggling against movable barriers to dialysis and transplantation is heart-breaking.

Nicki Scholes-Robertson
Patient
The ISN Global Kidney Policy Forum series aims to formulate actionable policy recommendations on kidney care.

### Thinking global, acting locally

The Global Kidney Policy Forum presents an international viewpoint on key health issues related to prevention of kidney disease and delivery of best-practice kidney care specific to a region. The Forum aims at continued promotion and reinvigoration of the ISN’s 12 Recommendations to Global Kidney Health, which offer practical, benchmarkable and actionable guidance to improve kidney care.

Building on the first Policy Forum, which took place in Mexico City in 2017, participants in the 2019 Forum in Melbourne addressed equitable access to kidney care, including the prevention, detection and management in Australia, New Zealand, and South East Asian and Pacific Island countries.

The program:

- highlighted lessons learned since Mexico;
- outlined the regional burden of kidney disease;
- reviewed the quality and acceptability of kidney care from the perspectives of patients, healthcare providers and ministries of health;
- discussed estimates of the economic and financial burden of non-communicable diseases (NCDs) and kidney diseases;
- and illustrated the intricate nature of NCD co-morbidities and their shared risk factors, which are often exacerbated by social inequalities and scarce resources.

In the interactive Q&A sessions, the speakers and participants identified prevention, integrated and people-centered health care services, and community-based advocacy as vital strategies to improve kidney health in the region.

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1) The Oceania & South East Asia (OSEA) region as defined by ISN includes: Australia, Brunei, Cambodia, East Timor, Fiji, Indonesia, Laos, Malaysia, Myanmar, New Zealand, Pacific Islands, Papua New Guinea, Philippines, Singapore, Thailand, Vietnam.
At a glance: ISN Policy Forum
Melbourne, Australia,
held on April 12th, 2019

Participants included
Policymakers and healthcare authorities, nephrologists, patient representatives, international health organizations, private sector, researchers, scientists and clinicians, advocacy representatives

More than 180 participants
15 speakers
3 representatives from Ministries of Health in South Asia and Oceania

ISN’s
12 Recommendations to
Global Kidney Health
381 signatories
81 nations

This publication showcases the Policy Forum series, providing highlights and main conclusions. Readers are encouraged to use the brochure in local contexts for their own advocacy purposes. For example, readers may want to use the 12 recommendations as a “scorecard” to assess gaps in kidney care, which require policy-related solutions; or, make local policy makers aware of potentially transferable best practices presented in this brochure.
Facts: burden of kidney disease in the OSEA\textsuperscript{1} region

The most common causes of CKD in 2013 were:

- *diabetes (15.8\%)*
- *glomerulonephritis (17.5\%)*
- *hypertension (26.6\%)\textsuperscript{2}*

**Big difference in End Stage Kidney Disease (ESKD) care outcomes:** a patient is 2-3 times more likely to die from ESKD in Philippines compared to Cambodia despite comparable burden of disease.

**Only 25\%** of countries provide Kidney Replacement Therapy through the public system.

The annual mortality rate due to CKD has increased from 1990 through to 2015 at an average rate of **3.4\% per year**\textsuperscript{2}


One of the highest growth rates of chronic kidney disease (CKD) prevalence worldwide.

30-40% higher burden of kidney disease in members of indigenous communities.

In 2012, in Australia acute kidney injury was recorded as associated-cause of over 4600 deaths.

The number of annual years of healthy life lost per 100,000 people from CKD has increased by 30% from 1990 to 2015.\(^2\)

About ten million people die every year from kidney disease in the Oceania and South East Asia region (OSEA).\(^2\)

The number of annual years of healthy life lost per 100,000 people from CKD has increased by 30% from 1990 to 2015.\(^2\)

Kidney transplantation is available in 10 out of 16 OSEA countries. Even where it is available, access is uneven: in one third of countries in the region, fewer than 10% of eligible patients are able to access transplantation.
Challenges to access to kidney care in South East Asia and Oceania

Geographies
In the Pacific region, the geography of the multiple of dispersed islands, with small populations, inconsistent supply of clean water, disruptions due to natural disasters (drought, typhoons etc.) and inadequate dialytic fluid disposal systems pose huge challenges in access to and deliver of equitable quality kidney care, compounded by a limited workforce and resources. Dialysis is notionally available in all countries, but is often inefficient and the access is inequitable in many island nations. In Samoa, a 2013 World Bank report found that two-thirds of patients on dialysis died within two years. In other areas within the region, such as in rural Australia and other remote areas, there are few services and facilities, which lead to late referral and / or high auxiliary costs (costs of transport, out of work, outpatient accommodation) for patients.

Varying economic structures, cultural and ethnic diversity
The region encompasses a broad heterogenous range of countries and incomes. In the economically weaker countries, government does not support funding for dialysis/kidney replacement therapy (KRT). High out-of-pocket spending prevent up to 90% of patients from accessing KRT in Fiji. Elsewhere, provision of dialysis comes at a high cost. In the Pacific region, one patient on dialysis requires the equivalent of 100 other patients in terms of government health expenditure per person. Even the more affluent countries have vulnerable populations that experience unsurmountable barriers to accessing adequate kidney care, with concerns about ethnic bias affecting access and outcomes. For example, indigenous peoples in Australia experience overall higher burden of kidney disease compared to non-indigenous Australians due to higher risk factors, late referral, remoteness, burden of comorbidities, lack of financial means, poor housing and overcrowding, and have worse long-term survival rates after kidney transplantation.

Societal determinants and socio-economic challenges
The region is seeing a sharp rise in the prevalence of NCDs (e.g., prevalence of diabetes in adults are approximately 20%– 30% in Pacific Island nations and 9%–17.5% in Malaysia). The Pacific community has the most obese populations worldwide. In Fiji, two thirds of CKD cases are due to diabetes. High rates of smoking remain a prominent public health issue. 20% of all Vietnamese have hypertension. There is also a high degree of poor health literacy in most vulnerable communities, along with weak regulatory environments. Changing diets and consumption patterns due to urbanization are other contributors.

Lack of data
Lack of data and / or gaps in available data are major challenges for policy makers in the region seeking to capture the nature of kidney disease, the economic burden, inequities and care outcomes in order to better design appropriate nephrological care services.
The kidney community – health care professionals and patients - needs to support governments in being agents of change, helping governments to **develop locally appropriate solutions and driving innovation** towards patient-centred, self-sufficient care.

Priority should be given to prevention measures targeted at high-risk populations. **Advancing transplantation is key**, from the perspectives of both cost and quality of life, to get people off dialysis lists and back into employment. This necessitates that a suite of treatment services be defined that are sustainable, appropriate and effective in a local context. Innovation is needed to bring down costs for drugs and diagnostics and to develop better care models.

**Multi-morbidity management** must become the norm as NCD landscape changes with patients living with multiple diseases. This is key to recognizing the complex and multilayered needs of patients and empowering them to manage their disease. It is critical to expand the narrow definition of NCDs currently applied by policy-makers and to incentivize health care professionals to practice holistically. To achieve effective unity of care across the “big five” NCDs (heart disease and stroke, lung disease, cancer and diabetes and mental health), advocates must highlight the necessity for integrated, multisector and people-centered approaches to NCD needs (e.g. CKD risk assessment in HEARTS protocol), as well as present the case of an added value of kidney disease prevention as regards the needs of primary care systems and health care professionals.

The **principle of equity** recognizes that different people with different levels of disadvantage require different approaches and resources to achieve equitable health outcomes. The kidney community should push for adapted care guidelines for vulnerable and disadvantaged populations. Moving from a “bang-for-buck” mentality (e.g. number of people treated) towards an equity mentality (e.g. protection from catastrophic healthcare expenditure), equitable kidney care will be achieved by investment in people and processes.
Towards implementing the 12 Recommendations on Global Kidney Health: potential solutions discussed

**Political leadership:**
Kidney Health Australia (KHA) is developing the country’s first National Strategic Action Plan for Kidney Disease to guide policy development, in recognition of the significant and growing impact of kidney disease on the health and wellbeing of the entire community.

**Multilateral partnerships:**
Vietnam has launched a cooperation program with WHO to support the country in strengthening its health system. More multilateral programs are needed to support lower income countries with resources and expertise as they often bear a double burden of communicable and noncommunicable disease.

**Innovation, equity and sustainability of resources in dialysis:**
the island nations in the OSEA region are particularly vulnerable to climate change with frequent droughts, rising sea levels, and limited space for landfill waste. Innovative ‘green’ ideas such as sustainable recycling of peritoneal dialysis waste fluids, e.g. for irrigation, can pave the way for the future of sustainable kidney care.

**Cross-competency training to overcome lack of nephrologists:**
Fiji works increasingly to train non-nephrologists in primary and secondary prevention. Indonesia is involving internists and general practitioners in dialysis care, giving them credentialed dialysis training for three months.
Regulatory policies to curb NCD risk factors:
TV adverts promoting unhealthy lifestyle choices are being actively regulated in Fiji; and Samoa is fighting its obesity crisis by having introduced a tax on sugar-sweetened beverages.

Public-private funded registries:
Indonesia set up a renal registry with initial pharmacy sponsorship and aided uptake by tying dialysis center licenses to mandatory participation in the registry. The registry, whose continuation and maintenance is now funded by the Indonesian Society of Nephrology, is proving valuable in capturing the burden of kidney disease, outcome of dialysis, and financial burden.

Revitalization of and investment in community-based primary care
as key step towards Universal Health Coverage (UHC): Samoa is transforming WHO's Package of Essential NCD Interventions (PEN) initiative by adding a village program component to strengthen NCD early detection and management through community participation and empowerment.

Increase in health and patient literacy:
outreach programs targeting schools, families and women committees to create lifelong healthy habits are key to promoting health literacy and agency for personal health. Culturally appropriate and sensitive patient information and care are being undertaken in New Zealand to fight inequities in kidney health, especially in Maori and other disadvantaged communities.
Main speakers and session chairs in order of appearance

- Welcome To Country, by Wurundjeri Elder Ian Hunter
- David Harris, Past President ISN and Global Kidney Policy Forum Chair
- Brendan Murphy, Australian Government Chief Medical Officer
- Matthew Jose, Professor and Chair of Medicine, University of Tasmania
- Alan Cass, Director, Menzies School of Health Research
- Aminu Bello, ISN Global Kidney Atlas Co-Lead, Department of Medicine, University of Alberta, Edmonton, Canada
- Nicki Scholes-Robertson, Patient, Physiotherapist, Advocate and PhD candidate at the University of Sydney, School of Public Health
- Suetonia Palmer, Professor, Department of Medicine, University of Otago Christchurch, New Zealand Aotearoa
- Colin Tukuitonga, Pacific Community Director, New Caledonia
- Joji Malani, Associate Professor of Medicine and Director, Kidney Foundation of Fiji, Fiji National University
- Talalelei Tuitama, Minister of Health, Samoa
- Philip K.T. Li, President, Asian Pacific Society of Nephrology
- Aida Lydia, President, Indonesian Society of Nephrology (PERNEFRI), Division of Nephrology and Hypertension, Department of Internal Medicine, Faculty of Medicine Universitas Indonesia, Dr. Cipto Mangunkusumo, Hospital
- Huong TB Tran, MD, Vietnam
- Robyn Langham, ISN Advocacy committee, Professor Medicine, Monash University
- Jane Potiki, Principal Advisor, National Services, Electives & National Services, Ministry of Health, New Zealand
- Shilpa Jesudason, Associate Professor, School of Medicine, University of Adelaide, Clinical Director, Kidney Health Australia
- Adeera Levin, ISN Advocacy Chair, Professor University of British Columbia
- Valerie Luyckx, Affiliate, Institute of Biomedical Ethics and the History of Medicine, University of Zurich and Division of Nephrology, Brigham and Womens Hospital, Boston, MA
- Sania Nishtar, Co-Chair, WHO High Level Commission on NCDs
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<th>ISN’s 12 Recommendations to Global Kidney Health</th>
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<tbody>
<tr>
<td>1</td>
<td>Work within current frameworks promoted by the World Health Organization and the United Nations such as the Sustainable Development Goals of Agenda 2030 for Sustainable Development, Universal Health Coverage, and Life Course approach in the context of Health 2020 to develop and implement policies to ensure integration and synergies for kidney disease prevention and treatment within existing initiatives.</td>
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<td>2</td>
<td>Develop and implement public health policies to prevent or reduce risk factors for chronic kidney disease in adults and children, including strategies to promote maternal and child health and nutrition, to reduce the burdens of diabetes, hypertension, obesity and tobacco consumption, to promote safe work environments and prevent infectious diseases.</td>
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<td>3</td>
<td>Implement and support ongoing surveillance mechanisms to better understand and quantitate the burdens of acute and chronic kidney disease within and outside the context of non-communicable diseases, specifically by developing robust national and regional registries for AKI, CKD and ESKD.</td>
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<td>4</td>
<td>Educate the public and people at risk about kidney disease within non-communicable disease education campaigns.</td>
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<td>5</td>
<td>Improve awareness of kidney disease among health care workers at all levels and ensure appropriate access to essential tools and medications required for diagnosis and treatment.</td>
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<td>6</td>
<td>Work towards universal health coverage to permit sustainable access to effective and affordable medication (for hypertension, diabetes, cardiovascular disease) to treat risk factors for kidney disease and delay kidney disease progression.</td>
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<td>7</td>
<td>Support education for a skilled nephrology workforce to implement prevention and treatment of kidney disease at all stages.</td>
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<td>8</td>
<td>Implement early detection, preventive and treatment strategies for AKI.</td>
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<td>9</td>
<td>Integrate early evidence-based treatment for CKD acknowledging the important synergies with diabetes, hypertension and cardiovascular disease.</td>
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<td>10</td>
<td>Develop and implement transparent policies governing just and equitable access to kidney disease care including dialysis and transplantation, according to international standards, and to support, safe, ethical, affordable and sustainable programs.</td>
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<td>11</td>
<td>Promote and expand kidney transplantation programs within countries and across the region.</td>
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<td>12</td>
<td>Support local, regional and transnational research on kidney disease to further understanding of prevention and treatment strategies.</td>
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“We need a breakdown of silos, looking beyond the 5x5 NCDs approach and a collective and integrated advocacy effort.”

Vivek Jha
ISN President