# **ISN** Global Kidney Health Atlas





Online version of ISN–Global Kidney Health Atlas: www.theisn.org/global-atlas

© International Society of Nephrology, 2023

No part of this publication may be reproduced, translated, or transmitted in any form or by any means without the prior written permission of the International Society of Nephrology.

> Design and layout: John Labots Graphic Design Inc. Editing and proofreading: Kara Stephenson Gehman

Citation: Bello AK, Okpechi IG, Levin A, Ye F, Saad S, Zaidi D, Houston G, Damster S, Arruebo S, Abu-Alfa A, Ashuntantang G, Caskey FJ, Cho Y, Coppo R, Davids R, Davison S, Gaipov A, Htay H, Jindal K, Lalji R, Madero M, Osman MA, Parekh R, See E, Shah DS, Sozio S, Suzuki Y, Tesar V, Tonelli M, Wainstein M, Wong M, Yeung E, Johnson DW (2023). ISN-Global Kidney Health Atlas: A report by the International Society of Nephrology: An Assessment of

Global Kidney Health Care Status focussing on Capacity, Availability, Accessibility, Affordability and Outcomes of Kidney Disease. International Society of Nephrology, Brussels, Belgium.

# **Table of Contents**

- 1 FOREWORD
- **3 EXECUTIVE SUMMARY**
- 5 ACKNOWLEDGMENTS
- **11 ABBREVIATIONS**
- 12 KEY TERMS
- **13 ABSTRACT**

Background Objectives

- 14 Methods
- 15 Results
- 17 Conclusion

#### 19 Section 1: INTRODUCTION

- 1.1 Chronic Kidney Disease (CKD)
- 20 1.2 The burden of kidney failure
- 21 1.3 Treatment for kidney failure
- 23 1.4 Access to and quality of kidney failure care worldwide
- 24 1.5 Acute kidney injury
  - 1.6 Climate change and the kidney
- 25 1.7 CKD early identification systems
- 26 1.8 Health information systems
- 27 1.9 National health policies
  - 1.10 A global strategy for CKD and kidney failure

### 29 Section 2: METHODS

- 2.1 Overview
- 30 2.2 Scope
- 31 2.3 Literature review
- 37 2.4 Survey

#### 39 Section 3: LITERATURE REVIEW

Key messages

- 40 3.1 CKD: Prevalence, DALYs, deaths overview of GBD data
- 41 3.2 Global availability of health workforce
- 42 3.3 Total health expenditure
- 43 3.4 Treated kidney failure
- 46 3.5 Chronic dialysis3.6 Chronic hemodialysis
- 48 3.7 Chronic peritoneal dialysis
- 49 3.8 Kidney transplantation
- 52 3.9 Cost of KRT

#### 57 SURVEY RESULTS

58 SURVEY RESPONSE

# 59 Section 4: HEALTH FINANCE AND SERVICE DELIVERY

#### Key messages

- 60 4.1 Healthcare system and funding mechanism
- 64 4.2 Within-country variation in kidney failure care delivery
- 65 4.3 Infrastructure for delivery of kidney failure care

# 67 Section 5: HEALTH WORKFORCE FOR KIDNEY CARE

#### Key messages

- 68 5.1 Clinical responsibility
  - 5.2 Workforce

# 71 Section 6: ACCESS TO ESSENTIAL MEDICATIONS AND HEALTH PRODUCTS

Key messages

- 72 6.1 Capacity for KRT service provision
- 75 6.2 Availability of services for kidney failure care
- 78 6.3 Accessibility of KRT
- 80 6.4 Affordability of KRT
- 82 6.5 Medication funding models for people receiving KRT
- 83 6.6 Vascular access for KRT
- 84 6.7 Quality of KRT services
- 86 6.8 Availability of nutritional services
- 87 6.9 Availability of conservative kidney management
- 89 6.10 Outcomes of people receiving dialysis

# 93 Section 7: HEALTH INFORMATION SYSTEMS

#### Key messages

- 94 7.1 Registries
- 97 7.2 Identification of disease (AKI and CKD)
- 101 7.3 Chronic kidney disease of unknown etiology (CKDu)

# 103 Section 8: LEADERSHIP, ADVOCACY, AND BARRIERS TO KIDNEY FAILURE CARE

Key messages

- 104 8.1 Policy and strategy
- 107 8.2 Advocacy
- 108 8.3 Barriers to optimal kidney care

# 111 Section 9: SURVEY OF PEOPLE LIVING WITH KIDNEY DISEASE

#### Key messages

- 112 9.1 Characteristics of participants and co-payment methods
  - 9.2 Perspectives on workforce shortages and obstacles to kidney care
- 113 9.3 Impacts of kidney disease and its treatment

- 115 Section 10: CHANGES IN KEY ISN-GKHA METRICS (2019 TO 2023)
  - 10.1 Availability of KRT
- 118 10.2 Access to KRT10.3 Affordability / funding for KRT
- 122 10.4 Workforce for KRT

#### 125 Section 11: DISCUSSION

- 11.1 Gaps in services and resources
- 127 11.2 Implications
- 133 11.3 Optimizing kidney care in resourcelimited countries
- 134 11.4 Recommendations
- 136 11.5 Opportunities to build capacity
- 138 11.6 Conclusions

#### 140 References

#### 146 List of Illustrations

Tables Figures

148 Maps

#### 149 **APPENDICES**

#### 151 APPENDIX 1

Countries and population covered by survey responses

#### 152 APPENDIX 2

List of countries by ISN region and World Bank income groups

#### 157 APPENDIX 3

Disciplinary affiliation of survey respondents

158 APPENDIX 4

Survey respondents

165 ISN-GKHA SURVEY

### 187 ISN-GKHA PEOPLE LIVING WITH KIDNEY DISEASE SURVEY

# Foreword

Chronic kidney disease (CKD) is a major public health issue that has reached an alarming level. Currently, approximately 850 million people are estimated to be living with CKD worldwide. Treatment for advanced forms of CKD (kidney failure) is not publicly funded in many countries, leading to economic hardships and premature deaths. These treatment options include



Agnes Fogo ISN President

hemodialysis (HD), peritoneal dialysis (PD), and kidney transplantation, as well as non-dialytic conservative kidney management. Understanding the benefits and limitations of each option requires considering the individual living with kidney disease as well as the local context and capacity for care delivery.

The gap between the number of people needing kidney replacement therapies (KRT) and those able to receive it is wider in low- and middle-income countries than in high-income countries. Lack of public funding for KRT and excessive out-of-pocket costs for treatment remain the major reasons for this gap. In many countries where KRT is not publicly funded, the annual minimum wage is less than US \$2,000 while the annual cost of dialysis is more than US \$25,000. This essentially means a death sentence for anyone developing kidney failure.

Although strategies for prevention, early detection, and treatment to reduce progression of CKD should remain continuous endeavors, public funding for KRT is urgently needed in low-income countries (LICs) and lower-middle income countries (LMICs). Other imperative measures to improve the quality of, and access to kidney care include workforce training and retention programs, the use of reliable health information systems to support policy development, decision-making and resource allocation, and advocacy initiatives to prioritize kidney care delivery.

On behalf of the International Society of Nephrology (ISN), I am delighted to present the third iteration of the ISN–Global Kidney Health Atlas (ISN–GKHA). The ISN–GKHA is part of the ISN's

Closing the Gaps initiative and has been designed to assess the current capacity for kidney care across all world regions. For the first time, this edition includes perspectives on the barriers that people living with kidney disease encounter in accessing kidney care and the impacts of kidney failure. The survey data have appreciable policy implications, as they provide a platform for holding governments and health authorities accountable by measuring progress in countries and regions over time.

We found several common barriers to optimal delivery of kidney failure care across countries and regions, including low (or unavailable) public funding for KRT, critical workforce shortages, and significant variations in the development and organization of care structures. Many of those living with kidney disease who participated also identified excessive cost as a major hindrance to accessing care. Most of these challenges reflect economic differences, as well as political and socio-cultural factors.

These common challenges should be addressed to strengthen health systems and policies for optimal kidney care. We suggest potential strategies to address these challenges and their implications for LICs and LMICs. Our hope is that the findings from this work can be leveraged to improve capacity for kidney care across countries and regions.

Agnes Fogo ISN President

# **Executive Summary**

The ISN–GKHA has been an authoritative and reliable source of evidence on funding, availability, accessibility, affordability, and policy for the delivery of kidney care at the global, regional, and national levels. The aim of this iteration of the ISN–GKHA is to understand the current status of global and regional capacity for the delivery of care to people living with CKD and kidney failure. Using the domains of health services defined by the World Health Organization (WHO), this survey summarizes and compares the availability, accessibility, and affordability of high-quality care for people living with kidney disease across regions and countries worldwide.

The results reveal several pertinent findings. The global median prevalence of CKD is 9.5%, with a median death rate attributable to CKD of 2.4%. Overall, 167 countries representing 97.4% of the world's population responded to the survey.

Approximately two-thirds of countries (63%) worldwide provide public funding for hemodialysis (HD), while 55% and 59% provide public funding for peritoneal dialysis (PD) and kidney transplantation, respectively. Globally, the median prevalence of nephrologists is 11.75 per million population (pmp); 5.8% of nephrologists treat children, and 35% of nephrologists are women. The density of nephrologists in highincome countries (HICs) is over 80-fold higher than in low-income countries (LICs).

Chronic HD services are available in 98% of countries that completed the survey while PD and kidney transplantation are available in 79% and 70% of countries, respectively. Conservative kidney management (CKM) with shared decisionmaking is generally available in 53% of countries, while choice-restricted CKM due to resource constraints is available in 39% of countries.

Access to kidney replacement therapy (KRT) also varies across countries. At least half of people living with kidney disease are able to access dialysis at the onset of kidney failure in 74% of countries where KRT services are available. People living with kidney disease are able to start with PD in just 6% of countries where PD is available and are able to access kidney transplantation in 29% of countries. All KRT modalities are available in lower proportions of LICs compared to countries at other income levels.

Official registries for CKD, dialysis, and kidney transplantation are available in 19%, 63%, and 58% of countries, respectively. Participation in CKD registries is mostly voluntary, whereas participation in dialysis and kidney transplantation registries is mostly mandatory. In many countries, screening (testing) for kidney disease is reserved primarily for those considered to be at high-risk, and only 25% of countries have national CKD detection programs. Overall, 68% of countries have (or are developing) national strategies for noncommunicable diseases; 25% of countries have national CKD-specific strategies.

Among people living with kidney disease who took part in the survey, 37% reported that costs of KRT are privately funded and covered fully out-of-pocket. Many people living with kidney disease identified lack of effective government policies (70%) and excessive costs of KRT (45%) as obstacles to receiving optimal care. Key changes identified from the previous iteration of the ISN–GKHA include increases in the number of KRT centers (HD by 9.8%, PD by 13%, and kidney transplantation by 7%), public funding for dialysis (HD by 3.7% and PD by 21.7%), and the density of nephrologists (from 9.5 pmp in 2019 to 12.4 pmp in 2023).

Overall, these results reveal significant inequities related to key components of high-quality kidney care. Key recommendations for closing these gaps are as follows:

- Increase health care financing for kidney disease prevention and management;
- Address workforce shortages by developing effective multidisciplinary teams, task shifting (e.g., allowing primary care practitioners to play a greater role in treatment) and harnessing the potential of telemedicine;
- Develop and implement context-specific surveillance systems based on available capacity and resources;
- Promote kidney disease prevention and treatment by implementing policies, incorporating CKD into global NCD strategies, supporting advocacy groups, and mitigating barriers to care;
- Support the development of innovative, cost-effective dialysis methodologies;
- Develop appropriate legislative and policy frameworks to support kidney transplantation in all countries; and
- Increase access of conservative kidney management where appropriate.

Previous iterations of the ISN-GKHA demonstrated variability in global kidney care, with significant gaps in kidney care across all of the WHO health domains, particularly in LICs and LMICs. This third edition of the ISN-GKHA focuses on identifying the current status of kidney failure care structures and organization. The results show significant variation in the availability and quality of core KRT services, the proportions of national populations able to access these services, methods of funding KRT and essential medications, the availability of health information systems, the size of the workforce for kidney care, and the perceptions of the quality of and barriers to kidney care delivery among people living with kidney disease. These gaps remain prevalent in LICs and LMICs, although a comparison to the previous iteration reveals some important positive changes.

Despite some improvements, the burdens of CKD and kidney failure are huge and require sustained efforts for mitigation. The next steps to enhance kidney care delivery are multifactorial. Preventing kidney failure through appropriate AKI and CKD detection programs is essential and supporting non-dialysis CKD through enhanced public funding will slow the progression of kidney disease. The findings of this third edition of the ISN–GKHA should be used to guide policy and increase advocacy efforts to support optimal and universal kidney disease care.

# Acknowledgments

The ISN–GKHA Co-chairs would like to extend their profound, heartfelt gratitude to all of the people who contributed to making this third iteration of the ISN–Global Kidney Health Atlas project an even greater success than its earlier versions. The Atlas included one of the largest public health surveys in the world and relied heavily on key stakeholders (leaders of the national nephrology societies and ISN regional board members) to



provide and vet information from individual countries and regions. Several individuals have contributed in different and important ways to the project's accomplishments despite its complexity and tight timelines. In particular, we would like to thank Ikechi Okpechi who led project operations, drafted the report, and contributed to the analysis plan. We also thank Feng Ye who handled every aspect of data storage, cleaning, and analysis. We also thank Syed Saad for his great contribution and leadership with the literature review. We thank Kara Stephenson Gehman (Academe Partners Limited; academepartners.com) for her help in clarifying the report, and John Labots (John Labots Graphic Design Inc.; johnlabots.com) for presenting our analyses so appealingly. We thank Sandrine Damster, Research Associate Director at the International Society of Nephrology (ISN), and Silvia Arruebo, ISN Research Coordinator, for their support in organizing

and conducting the survey and their project management expertise. We thank Deenaz Zaidi, members of the Alberta Kidney Disease Network and ISN staff (Charu Malik, Jo-Ann Donner, Kelly Hendricks, Julia Mackinlay, Anne Hradsky, Dominique Tudor, and Mara Rodrigues) for their support. The leadership and backing of the ISN Executive Committee have been greatly appreciated and were pivotal to the project's success.

#### Support and financial disclosure declaration

This work was funded by the International Society of Nephrology (ISN).

### **PROJECT TEAM**

#### ISN Executive Committee (2021-2023)

Fergus Caskey (United Kingdom) Secretary-Treasurer

Rolando Claure-Del Granado (Plurinational State of Bolivia) Member

Agnes Fogo (United States) President

**Vivek Jha** (India) Past-President **Liz Lightstone** (United Kingdom) Member

Masaomi Nangaku (Japan) President-Elect

**Charu Malik** (United States) ISN Executive Director, Ex-Officio Vladimir Tesar (Czech Republic) Member

**Ifeoma Ulasi** (Nigeria) Member

**Xueqing Yu** (China) Member

# ISN Regional Board Chairs and Deputy Chairs/Council (2021-2023)

#### Africa Regional Board

Gloria Ashuntantang (Cameroon), Chair

Fatiu Arogundade (Nigeria), Deputy Chair

#### Eastern and Central Europe Regional Board

Vladimir Tesar (Czech Republic), Chair Sanjin Racki (Croatia), Deputy Chair

#### Latin America Regional Board

Magdalena Madero (Mexico), Chair Carmen Tzanno-Martins (Brazil), Deputy Chair

#### The Middle East Regional Board

Ali Abu-Alfa (Lebanon), Chair Shokoufeh Savaj (Islamic Republic of Iran), Deputy Chair NIS and Russia Regional Board Abduzhappar Gaipov (Kazakhstan), Chair Larisa Prikhodina

(Russian Federation), Deputy Chair North America and the Caribbean

Regional Board

Rulan Parekh (Canada), Chair Shuchi Anand (United States), Deputy Chair

#### North and East Asia Regional Board

Yusuke Suzuki (Japan), Chair Angela Yee Moon Wang (Hong Kong), Deputy Chair Oceania and South East Asia (OSEA) Regional Board Muh Wong (Australia), Chair Sunita Bavanandan (Malaysia), Deputy Chair

#### South Asia Regional Board

Dibya Singh Shah (Nepal), Chair Narayan Prasad (India), Deputy Chair

Western Europe Regional Board

Rosanna Coppo (Italy), Chair Liz Lightstone (United Kingdom), Deputy Chair

# **ISN-GKHA Steering Committee**

**Prof. David Johnson, PhD** Co-Chair ISN-GKHA

Dr. Aminu Bello, PhD Co-Chair ISN-GKHA

Adeera Levin Founder and Lead, Global Kidney Health Atlas, ISN **Ikechi Okpechi** University of Alberta, Edmonton, Canada

Sandrine Damster Research Associate Director, ISN

Silvia Arruebo Research Coordinator, ISN

# ISN regional leadership team representatives

One board chair or designate from each of the 10 regional teams

# **ISN-GKHA Working Group**

**Prof. David Johnson, PhD** Co-Chair Department of Kidney and Transplant Services at Princess Alexandra Hospital, University of Queensland, Brisbane, Australia

**Dr. Aminu Bello, PhD** Co-Chair Department of Medicine, University of Alberta, Edmonton, Canada

**Dr. Ikechi G. Okpechi, PhD** Project Manager Department of Medicine, University of Alberta, Edmonton, Canada

Feng Ye, MSc Statistician Kidney Health Research Group, Department of Medicine, University of Alberta, Edmonton, Canada

**Dr. Adeera Levin, FRCPC** Division of Nephrology, University of British Columbia, Vancouver, Canada

**Syed Saad, BSci** Department of Medicine, University of Alberta, Edmonton, Canada

**Deenaz Zaidi, PhD** Department of Medicine, University of Alberta, Edmonton, Canada **Ghenette Houston** Department of Medicine, University of Alberta, Edmonton, Canada

**Sophanny Tiv** Department of Medicine, University of Alberta, Edmonton, Canada

**Prof. Fergus Caskey, MD** Population Health Sciences, University of Bristol, Bristol, UK

**Prof. Razeen Davids, FCP(SA)** Division of Nephrology, University of Stellenbosch, Cape Town, South Africa

**Dr. Sara Davison, MD** Department of Medicine, University of Alberta, Edmonton, Canada

**Dr. Htay Htay, MD** Department of Renal Medicine, Singapore General Hospital, Singapore

**Dr. Kailash Jindal, FRCPC** Department of Medicine, University of Alberta, Edmonton, Canada

**Dr. Rowena Lalji, PhD** Department of Nephrology, University of Queensland, Brisbane, Australia

**Dr. Mohamed A. Osman, MD** Department of Medicine, University of Alberta, Edmonton, Canada **Dr. Emily See, MD** School of Medicine, University of Melbourne, Melbourne, Australia

**Dr. Stephen Sozio, MD** Department of Medicine and Epidemiology Johns Hopkins University School of Medicine, Baltimore, United States

**Dr. Marcello Tonelli, SM, FRCPC** Department of Medicine, University of Calgary, Calgary, Canada

**Marina Wainstein, MD** Faculty of Medicine, University of Queensland, Brisbane, Australia

**Dr. Yeoungjee Cho, PhD** Department of Kidney and Transplant Services at Princess Alexandra Hospital, University of Queensland Brisbane, Australia

**Dr. Emily Yeung, MD** Department of Nephrology, Monash Health, Clayton, Victoria, Australia

#### **ISN-GKHA CO-CHAIR**



#### **Professor David Johnson**

PSM, MB BS (Hons, Univ Medal), PhD (Syd), DMed(Res), FASN, FAHMS, FRACP

Director, Metro South Kidney and Transplant Services Medical Director, Queensland Kidney Transplant Service

Building 31 (ARTS Building) Princess Alexandra Hospital 199 Ipswich Road Woolloongabba Qld 4102 Australia

David Johnson is full-time Director of Metro South Kidney and Transplant Service (MSKATS) and Medical Director of the Queensland Kidney Transplant Service (QKTS) at Princess Alexandra Hospital, Professor of Medicine and Professor of Population Health at University of Queensland, and Director of the Centre for Kidney Disease Research in Brisbane, Australia. His international leadership responsibilities include President of the Australian and New Zealand Society of Nephrology (ANZSN), Past President of the International Society for Peritoneal Dialysis (ISPD, 2018-2020), Past Councillor of the International Society of Nephrology (ISN, 2013-2019), Co-Chair of the ISN–Global Kidney Health Atlas (ISN-GKHA), Co-Chair of the Global PDOPPS Steering Committee, Chair of SONG-PD and member of the ISN-ACT, ISN Research and ISN Monitor groups. He is currently a chair or member of 11 national and 7 international guideline groups including Co-Chair of ISPD Peritonitis Guidelines. He has influenced policy and practice through his leadership as Deputy Chair of the Australian BEAT-CKD program, Deputy Chair of the Australasian Kidney Trials

Network (AKTN), Chair of the Primary Healthcare Education Advisory Committee to Kidney Health Australia (PEAK), Co-Chair of the Australasian Creatinine and eGFR Consensus Working Party, Co-Chair of the Australasian Proteinuria Consensus Working Party, Member and Past-Chair of the ANZDATA Registry Peritoneal Dialysis Working Group, and Past-Chair of the Queensland Statewide Renal Clinical Network.

He has published >1100 original manuscripts in peer-reviewed journals, presented >550 abstracts at national and international scientific meetings, and held lead roles in high-impact, large, multicenter RCTs that have informed global clinical practice, including CKD-FIX, IDEAL, balANZ, HONEYPOT, TESTING, HERO, and IMPENDIA. He is currently principal investigator of the TEACH-PD and INCH-HD trials, and chair of the PHOSPHATE Trial Global Steering Committee. He helped establish the Australian Peritonitis Registry and led the highly successful National PD Peritonitis Quality Improvement Project, which reduced national peritonitis rates by two-thirds. He also led the universal implementation of automated laboratory reporting of eGFR in ANZ.

He has won numerous awards for both his clinical service and research, including ANZSN TJ Neale Award for "outstanding contributions to nephrologic science" (2005), Queensland finalist Australian of the Year Award (2009), Australian Honours Public Service Medal (2011), US National Kidney Foundation International Distinguished Medal (2014), Canadian Society of Nephrology Dimitrios Oreopoulos Award (2017) and Asia-Pacific Society of Nephrology Priscilla Kincaid-Smith Award (2021).

#### **ISN-GKHA CO-CHAIR**



#### Dr. Aminu Bello

MD, Ph.D., FRCP, FACP, FASN

Professor of Medicine/Consultant Nephrologist Division of Nephrology & Immunology Faculty of Medicine & Dentistry, University of Alberta

11-107 Clinical Sciences Building Edmonton, AB T6G 2G3 Canada

Dr. Bello qualified as a medical doctor in Nigeria at Usmanu Danfodiyo University, Sokoto, and underwent specialist clinical training in internal medicine and nephrology in Ibadan, Nigeria, Sheffield, UK, and Edmonton, Canada. He obtained the Fellowship of the Royal College of Physicians (FRCP) and completed his Master's with Distinction and Ph.D. degrees in Nephrology/ Epidemiology at the University of Sheffield in the UK. After completing his Ph.D., he completed a postdoctoral clinical and research fellowship in nephrology at the University of Alberta, Canada. Dr. Bello is a physician-scientist with significant research interests in improving outcomes in people living with chronic kidney disease (CKD), preventing disease progression and reducing the risk of complications, developing innovative care delivery models, and quality improvement. He is particularly interested in studying and designing programs to facilitate optimal CKD care delivery among disadvantaged populations with limited resources, remote/rural dwellers, and Indigenous populations.

He has published several peer-reviewed scientific publications (original manuscripts, invited reviews, editorials, and book chapters). He retains excellent academic standing in the field of nephrology (h-index: 58; i10-index: 131; ~58,000 citations on Google Scholar) and is well-recognized internationally for his work, which has been published in leading subspecialty journals and high-impact internal medicine journals such as the Lancet, JAMA, and BMJ. Dr. Bello has contributed chapters as first or senior author in all major nephrology textbooks (Oxford Textbook of Clinical Nephrology, Comprehensive Clinical Nephrology, Brenner and Rector's, among others). Additionally, he has delivered several invited international scientific presentations, most notably at premier nephrology meetings (American Society of Nephrology and the World Congress of Nephrology).

He has supervised several master's students, Ph.D. students, and postdoctoral/clinical fellows. He has also provided academic mentorship to several undergraduate students during the summer session, medical students, and clinical fellows in nephrology on various research projects. Several of these trainees have published and presented their work at scientific meetings. He has served the academic community as a peer reviewer for major medical and nephrology journals He has also served as an abstract reviewer for international and national nephrology scientific meetings (World Congress of Nephrology, the American Society of Nephrology, and the Canadian Society of Nephrology). In addition, He served as a co-chair of the Abstract Selection Committee for the World Congress of Nephrology in 2020. He is the Associate Editor of the Canadian Journal of Kidney Health and Disease (the official journal of the Canadian Society of Nephrology).

#### **ISN-GKHA Fellows**

Atefah Amouzegar

Division of Nephrology, Iran University of Medical Sciences, Tehran, Iran

Yeoungjee Cho Department of Nephrology, University of Queensland Brisbane, Australia Smita Divyaveer Department of Nephrology, PGIMER, Chandigarh, India

**Udeme Ekrikpo** Department of Medicine, University of Uyo, Nigeria

**Isabelle Ethier** Department of Nephrology, Princess Alexandra Hospital, Brisbane, Queensland, Australia

**Moussa Hassane** Division of Nephrology, National Hospital Zinder, Zinder, Niger

**Htay Htay** Department of Renal Medicine, Singapore General Hospital, Singapore

**Dearbhla Kelly** Department of Nephrology, Beaumont Hospital, Dublin, Ireland **Salihu Kwaifa** Garki Hospital, Zone 3, Abuja, Nigeria

**Rowena Lalji** Department of Nephrology, University of Queensland, Brisbane, Australia

Meaghan Lunney Department of Community Health Sciences, University of Calgary, Calgary, Alberta

**Dominic Mudiayi** Department of Medicine, University of Alberta, Edmonton, Alberta

**Aisha Nalado** Department of Medicine, Bayero University Kano, Kano, Kano State, Nigeria

**Brendon Neuen** The George Institute for Global Health, Sydney, Australia

**Timothy Olanrewaju** Department of Nephrology, University of Ilorin, Nigeria

Mohamed Osman Department of Medicine, University of Alberta, Edmonton, Alberta Parnian Riaz Department of Medicine, University of Alberta, Edmonton, Alberta

**Syed Saad** Department of Medicine, University of Alberta, Edmonton, Alberta

Aminu Sakajiki Department of Medicine, Usmanu Danfodiyo University, Sokoto, Nigeria

**Emily See** School of Medicine, University of Melbourne, Melbourne, Australia

Andrea Viecelli Department of Nephrology, University of Queensland, Brisbane, Australia

**Marina Wainstein** Faculty of Medicine, University of Queensland, Brisbane, Australia

**Emily Yeung** Department of Nephrology, Monash Health, Clayton, Victoria, Australia

#### **ISN Headquarters Team**

Charu Malik, ISN Executive Director

Sandrine Damster, ISN Research Associate Director

**Silvia Arruebo**, ISN Research Coordinator **Jo-Ann Donner**, ISN Awards, Endorsements, and ISN-ANIO Programs Coordinator

Kelly Hendricks, ISN Associate Director, Marketing and Communications

Julia Mackinlay, ISN Marcom Project Manager Anne Hradsky, ISN Advocacy Director

**Dominique Tudor**, ISN Governance and Executive Affairs Manager

Mara Rodrigues, ISN Programs Senior Coordinator

# **Abbreviations**

ACE	Angiotensin-converting enzyme	NCD	Non-communicable disease
ΑΚΙ	Acute kidney injury	NGO	Non-governmental organization
ARB	Angiotensin II receptor blocker	NIS	Newly Independent States [of the
BP	Blood pressure		former Soviet Union]
CKD	Chronic kidney disease	OECD	Organisation for Economic Co- operation and Development
CKDu	Chronic kidney disease of unknown origin	OSEA	Oceania and South East Asia
СКМ	Conservative kidney management	PCP	Primary care physician
		PD	Peritoneal dialysis
CVC	Central venous catheter	PMP	Per million population
GFR	Glomerular filtration rate		
HD	Hemodialysis	PPP	Purchasing power parity
ISN	International Society of Nephrology	PROMs	Patient-reported outcome measures
		UHC	Universal health coverage
ISN-GKHA	ISN-Global Kloney Health Atlas	UN	United Nations
KDIGO	Kidney Disease: Improving Global		
	Outcomes	US \$	United States Dollar
KRT	Kidney replacement therapy	WHO	World Health Organization

Note: This list is not comprehensive but covers frequently used abbreviations.

# **Key Terms**

# Appropriate referral and management

Availability of an organized system and/or structures to ensure that people with CKD who may benefit from specialist care are properly referred for specialist assessment.

### Capacity

The ability to perform appropriate tasks effectively, efficiently, and sustainably.

#### Conservative kidney management (CKM)

CKM is defined as care for people with kidney failure that focuses predominantly on providing kidney supportive care to promote quality of life; this includes interventions to delay progression of kidney disease and minimize complications if this aligns with the goals of care of people living with kidney disease but does not include KRT.

# Identification and early detection

Availability of an organized system and/or structures to identify of people with risk factors for CKD: hypertension, diabetes, cardiovascular diseases (e.g., ischemic heart disease, heart failure, peripheral vascular disease, and stroke), urological problems (e.g., structural urinary tract disease, kidney stones, prostatic disorders), multisystem diseases (e.g., systemic lupus erythematosus, rheumatoid arthritis, infective endocarditis, etc.), or a family history of kidney disease.

#### Identification

Measuring key indicators among at risk populations to identify individuals with risk factors or early stages of disease who do not yet have symptoms.

# **KRT** availability

Availability of an organized system and/or structures to deliver dialysis and/or kidney transplantation when and where needed.

# Monitoring of complications, risk factor control, and disease progression

Availability of an organized system and/or structures to ensure that people with established CKD are receiving guideline-concordant clinical care.

#### Non-communicable diseases

Diseases that cannot be transmitted from person to person, notably, cardiovascular diseases (e.g., heart attack, stroke), cancer, chronic respiratory disease (e.g., chronic obstructive pulmonary disease, asthma), and diabetes.

# Policy

An official decision or set of decisions designed to carry out a course of action endorsed by a government body, including a set of goals, priorities, and general directions for attaining these goals. A policy document may include a strategy to implement the policy.

#### Program

A planned set of activities or procedures directed at a specific purpose.

#### Registry

A set of systematically collected data used to evaluate specific outcomes for a defined population to serve one or more predetermined scientific, clinical, or policy purposes.

#### Strategy

A long-term plan designed to achieve a particular goal for AKI or CKD care.

#### Under development

Still being created or finalized, not yet in the implementation phase.

# Abstract

# BACKGROUND

Kidney failure, the advanced stage of chronic kidney disease (CKD), is the irreversible loss of kidney function often requiring kidney replacement therapy (KRT), including dialysis and kidney transplantation. Approximately 850 million people are affected by CKD worldwide, and although people of every age and race are affected, people from disadvantaged populations may be at higher risk. The global burden of kidney failure is significant due to high treatment costs and extensive impacts on the health and well-being of people living with kidney disease.

Previous iterations of the ISN–Global Kidney Health Atlas (ISN–GKHA) uncovered large variations in access to treatment and characteristics of treatment delivery (e.g., quality indicators, funding mechanisms) across ISN regions and World Bank income groups. Findings also highlighted gaps in the scope of kidney-specific health information systems (i.e., registries, electronic health records) and workforce shortages that limit the provision of optimal kidney care around the world. This edition of the ISN–GKHA is the outcome of an ISN initiative aimed at updating these knowledge gaps, coordinating efforts to facilitate the delivery of optimal kidney disease care worldwide, and showing changes in key measures assessed from previous iterations.

# **OBJECTIVES**

- To provide a high-level overview of the burden of kidney failure, as well as the current state of kidney disease care and how it is organized and structured around the world.
- To conduct a comparative analysis of the capacity to deliver care across countries and regions in order to identify key strengths and weaknesses of various systems and explore opportunities for regional networking and collaboration to improve kidney disease care.
- 3. To provide an advocacy tool to engage major stakeholders (e.g., WHO, World Bank, UN,

OECD, European Union, national governments) to support the expansion of available services for kidney disease care.

- To summarize the perspectives of patents with kidney disease regarding barriers to optimal kidney care and the impacts of kidney disease on their health.
- To assess changes in key measures, including KRT availability, accessibility, funding methods, affordability, and workforce capacity, relative to previous iterations of the ISN–GKHA.

# **METHODS**

#### Literature review

In collaboration with an expert librarian, we conducted a two-part comprehensive search of government reports, academic research, and grey literature to synthesize the most current epidemiological data on the burden and treatment of kidney failure. This literature search laid the foundation for a ground-breaking detailed survey of key stakeholders.

#### **ISN-GKHA** survey

To facilitate an understanding of how capacity for kidney care varies over time and between countries, the ISN–GKHA provides concise, relevant, and synthesized information on the delivery of care across different health systems. Together, these components of the ISN–GKHA provide a global perspective of the prevalence and incidence of kidney failure treatments, including hemodialysis (HD), peritoneal dialysis (PD), and transplantation, as well as CKM. In addition, the ISN-GKHA summarizes the costs associated with delivering KRT and compares cost ratios of different treatment modalities across countries and regions. Moreover, it provides an overview of existing health care system structures for kidney failure care, including funding models for CKD and kidney failure care; workforce capacity; availability and quality of KRT; health information systems; and leadership, advocacy, and barriers to optimal kidney failure care. A survey of people living with kidney disease also assessed their perspectives of measures of effective kidney care and barriers to care delivery. Finally, a synthesis, comparison, and analysis of country, regional, and income level data are provided to inform the efforts of policymakers, practitioners, and researchers to enhance access to and quality of care for people living with kidney failure. The overall approach is summarized in Table A.

Objective	Methods/ approach	Coverage/ elements	Primary data source	Secondary data source
To obtain a snapshot of individual country and regional health system characteristics, and specific elements relevant to kidney failure care	Survey	WHO UHC domains <sup>1</sup>	Survey data Interviews	WHO Global Observatory UN, World Bank and OECD reports on NCDs Published data/reports
To obtain data on relevant kidney failure treatment epidemiology (HD, PD, transplantation) across countries and regions	Scoping review	Estimates for kidney failure incidence and prevalence Estimates for KRT cost	Survey data Interviews	Systematic reviews and consortia publications (e.g., GBD) World Health Report World Health Indicators Global NCD Repository IDF Diabetes Atlas WHF World Cardiovascular Disease Atlas Kidney registries

#### Table A Methods and data sources

1 Health finance and service delivery, health workforce, medicines and medical products, information systems, and governance and leadership.

Abbreviations: GBD = global burden of disease, HD = hemodialysis, IDF = International Diabetes Federation, KRT = kidney replacement therapy, NCDs = non-communicable diseases, OECD = Organisation for Economic Co-operation and Development, PD = peritoneal dialysis, UHC = universal health coverage, UN = United Nations, WHF = World Heart Federation, WHO = World Health Organization

# RESULTS

Representatives from 167 United Nations Member States responded to the survey, accounting for 97.4% of the world's population. Most respondents are nephrologists (81%) and the results show extensive variation across nations, regions, and income groups in service delivery, funding mechanisms, and available technologies. Key findings for each domain are summarized below.

#### Health finance and service delivery

Approximately two-thirds (63%) of countries worldwide provide public funding for HD treatment, while 55% and 59% provide public funding for PD and kidney transplantation. In countries where KRT is publicly funded (in whole or in part), aspects not covered include dialysis (7%), kidney transplantation (21%), and management of associated complications (25%). In over half of countries, public funding is also available for HD vascular access surgery (58%), HD fistula or graft creation (54%), PD access surgery (53%), and kidney transplantation surgery (51%). For all KRT modalities and related services, a greater proportion of low-income countries (LICs) and lower-middle income countries (LMICs) rely on private funding models for KRT than countries at other income levels. The majority of countries reported that adults have greater access to HD (74%), PD (53%), and kidney transplantation (80%) than children. Infrastructure for the provision of kidney care was reported to be at least above average in 49% of countries.

#### Health workforce for kidney care

Nephrologists are primarily responsible for the provision of kidney care in most countries (87%), with primary care physicians responsible in 7% of countries. Globally, the median prevalence of nephrologists is 11.75 pmp; 5.8% of nephrologists treat children, and 35% are women. The prevalence of nephrologists varies substantially across regions and income groups; the prevalence of nephrologists in highincome countries (HICs) is over 80-fold higher than in LICs. The prevalence of nephrology trainees is 1.15 pmp, and also varies widely across countries. More than half of countries worldwide reported shortages of key health care workers essential to the delivery of optimal care, including nephrologists (treating adults and children), surgeons, dietitians, access coordinators, transplant coordinators, and dialysis nurses.

#### **Essential medicines and technologies**

Chronic HD services are available in 98% of countries that completed the survey, whereas PD and kidney transplantation are available in 79% and 70% of countries, respectively. More centers are available for HD (5.1 pmp) than for PD (1.6 pmp) or kidney transplantation (0.5 pmp).

Most countries have the capacity to manage anemia; however, only 42% and 53% of LICs have the capacity to do so by providing parenteral iron or erythropoiesis stimulating agents (ESA). Similarly, although most countries are able to measure simple assays of mineral bone disease (e.g., calcium and phosphate), there is a lack of capacity to measure parathyroid hormone in 26% of LICs and 47% of LMICs. Although calciumbased phosphate binders are available in most countries, other treatment strategies for mineral bone disorders are mostly unavailable in low- and middle-income countries. For example, cinacalcet is only available in 5% of LICs, 18% of LMICs, and 32% of UMICs. Most countries have the capacity to measure and treat electrolyte disorders and to monitor blood pressure. However, ambulatory blood pressure monitoring (ABPM) is available in less than half of low- and middle-income countries.

Wide variation exists in the general availability of KRT modality options, including in-center HD (92%), home HD (17%), and PD (58%). Among the countries where in-center HD is available, 81% reported capacity for people living with kidney disease to receive adequate treatment (3 sessions per week, 3 to 4 hours per session). Among countries where PD is available, 61% reported capacity for people living with kidney disease to receive adequate treatment (3 to 4 exchanges per day). Approximately twothirds of countries reported the capacity to provide optimal kidney transplant services, including effective preventive therapy to control infections (65%), timely access to operating spaces (61%), and appropriate facilities to monitor immunosuppression (63%).

Conservative kidney management (CKM) through shared decision-making is generally available in 53% of countries, while choicerestricted CKM due to resource constraints is available in 39% of countries. Established infrastructure, guidelines/written pathways, and multidisciplinary teams for CKM are generally available in 45%, 27%, and 30% of countries, respectively.

Access to KRT also varies across countries. In 74% of countries, more than half of people living with kidney disease who need to access dialysis are able to access it. In contrast, more than half of people living with kidney disease needing dialysis are able to start with PD in just 6% of countries where PD is available. Similarly, more than half of eligible people living with kidney failure are able to access kidney transplantation services in just 29% of countries. Access to all KRT modalities varies based on geography and demographics of people living with kidney disease.

The quality of delivered care is measured and reported similarly for people living with kidney failure treated with HD and PD. More than half of countries measure and report most parameters (e.g., blood pressure, hemoglobin, markers of mineral bone disorders, patientreported outcome measures (PROMs), patient survival, and technique survival) for people living with kidney disease treated with HD or PD. For people living with a kidney transplant, kidney allograft function (79%), graft survival (80%), and patient survival (83%) are almost always reported.

Among people living with kidney disease receiving HD, access-related infections are the most common cause of hospitalization in 32% of countries, while cardiovascular disease is the most common cause of death in 77% of countries. Dialysis withdrawal due to cost is a common cause of death in 18% of LICs and 7% of LMICs. Among people living with kidney disease receiving PD, cardiovascular disease is the most common cause of death in 66% of countries, while PD infections are the most common cause of hospitalization in 51% of countries.

# Health information systems

Overall, official registries for CKD, dialysis, and kidney transplantation are available in 19%, 63%, and 58% of countries, respectively. Participation in CKD registries is mostly voluntary in 45% of countries, and only covers advanced stage CKD (stages 4/5) in 48% of countries. However, participation in dialysis and kidney transplantation registries is mostly mandatory in 57% and 65% of countries, respectively.

In most countries, testing for kidney disease typically is reserved for those considered to be at high-risk (e.g., hypertension, diabetes, elderly, etc.). Only 25% of countries have CKD detection programs based on national policies or guidelines, and half of these countries adopt a reactive approach to CKD evaluation. The capacity to detect CKD and risk factors is mostly available across all levels of health institutions worldwide. Overall, 28% of countries reported CKD of unknown etiology (CKDu), which is most prevalent in agricultural (30%) and mining (13%) communities.

# Leadership and governance

Overall, 68% of countries have national strategies in place (or under development) for non-communicable diseases (NCDs). However, in countries with national NCD strategies, only 35% cover non-dialysis CKD, while 26% and 23% cover chronic dialysis and kidney transplantation, respectively. Only a quarter of countries have national CKD-specific strategies, while 29% have CKD strategies incorporated into their NCD strategies.

Worldwide, AKI, CKD, and kidney failure are

recognized as health priorities by governments in 19%, 48%, and 63% of countries, respectively. Relative to other income groups, a greater share of HICs (70%) have governments that recognize kidney failure as a health priority. However, less than half of countries across all income levels have advocacy groups at higher levels of government to raise awareness of AKI, CKD, or kidney failure. Furthermore, more than two-thirds of countries identified physician factors (71%), patient factors (75%), and nephrologist availability (67%) as specific barriers to optimal kidney care.

# Perspectives on kidney care delivery among people living with kidney disease

Among people living with kidney disease who participated in the survey, just 21% reported that costs of treatment are covered by public funding and free at the point of delivery, while 37% reported that costs of medications and KRT are covered by private funding and paid for fully out-of-pocket. People living with kidney disease also identified workforce shortages, particularly counsellors/psychologists (55%), nephrologists (50%), dietitians (45%), transplant surgeons (45%), and social workers (45%). Moreover, people living with kidney disease identified a lack of effective government policies (70%), excessive costs of KRT (45%), and excessive costs of medicines (45%) as obstacles to receiving optimal care in their countries. All those who participated reported negative impacts of kidney failure on their economic situations. The ability to work (72%) and mobility (56%) are extremely important outcomes to people living with kidney disease.

# Key changes from previous editions

From 2019 to 2023, the number of KRT centers increased worldwide: HD centers increased by 9.8%, PD centers increased by 13%, and kidney transplantation centers increased by 7%. However, these increases were not uniform across regions or income levels. During the same period, the median prevalence of people treated with HD increased by 11.1%, the prevalence of people living with kidney disease receiving PD decreased by 0.4%, from 38.1 pmp in 2019 to 37.9 pmp in 2023, and the prevalence of kidney transplantation increased by 9.4%. The proportion of countries where most people living with kidney disease needing dialysis are able to access it increased, as did the proportion of countries with PD where people living with kidney disease are able to begin dialysis with that modality. Access to kidney transplantation remained the same.

Overall, countries that provide public funding for HD and PD increased by 3.7% and 21.7%, respectively and increased for kidney transplantation by 16.1%. There was no change in the proportion of countries where all dialysis (HD and PD) is funded privately, and costs are covered fully out-of-pocket. However, the proportion of countries using this funding model reduced for kidney transplantation by 25%. The median prevalence of nephrologists increased by 30.4%, from 9.5 pmp in 2019 to 12.4 pmp in 2023. However, the median prevalence of nephrology trainees increased globally by 0.74% and was markedly reduced in LICs.

# CONCLUSION

This third edition of the ISN–GKHA focuses on identifying gaps in key elements of kidney failure care across countries. The results demonstrate significant variations in the availability of core KRT services and their quality, the proportion of national populations with access to these services, methods of funding KRT and essential medications, the availability of health information systems, the size of the workforce for kidney care, and the' perceptions of the quality of and barriers to kidney care delivery among people living with kidney disease. These gaps are particularly prevalent in LICs and LMICs, although a comparison to the previous iteration of the ISN–GKHA reveals some important positive changes.

Despite some improvements, the burdens of CKD and kidney failure are huge and require sustained efforts for mitigation. Early disease detection and strategies focused on disease prevention are necessary in low resource settings due to low availability of, and limited access to high quality care. It is necessary to increase funding for kidney care and to strengthen infrastructure and health systems to provide and sustain care in all regions and across all income levels. Efforts to increase the density of nephrologists and other health professionals essential to optimal care delivery should continue. Finally, the aim of the ISN–GKHA initiative is to summarize the current global state of kidney disease care. By sharing these findings, we hope to guide policy and advocacy efforts to promote optimal and universal kidney failure care, and to provide benchmarks that will help countries track their progress over time. SECTION

# Introduction

# **1.1 CHRONIC KIDNEY DISEASE (CKD)**

Chronic kidney disease (CKD) is an immense public health problem.<sup>1</sup> Today, it is estimated that 850 million people worldwide suffer from CKD, far higher than the number of people living with diabetes mellitus or human immunodeficiency virus (HIV).2-4 The high burden of CKD is increasing relentlessly worldwide, and the cost of providing adequate care for all people living with kidney disease is overwhelming in many countries.<sup>2,5,6</sup> Approximately 10% of the world's population is living with CKD; however, CKD incidence and prevalence differ significantly across countries and world regions.7,8 Although people of every age and race are affected by CKD, people from disadvantaged populations may be at higher risk of the condition (and

It is estimated that 850 million people worldwide suffer from chronic kidney disease. associated morbidity and mortality) due to socio-economic factors and limited access to care.<sup>7-9</sup> Previously known as chronic renal failure, CKD is characterized by a gradual loss of kidney function. Because the kidneys play a critical role in filtering waste and excess fluid from the body, decreased kidney function can have detrimental effects to health. This can also lead to the development of other conditions, such as heart failure or other cardiovascular problems.

Clinically, CKD is defined as persistently abnormal kidney function (>3 months), measured or estimated by a glomerular filtration rate (GFR) consistently below 60 mL/min/1.73m<sup>2</sup>.<sup>10</sup> CKD is divided into six stages of worsening progression based on estimated GFR (eGFR) (Figure 1.1).<sup>10</sup> Kidney failure (formerly known as end-stage kidney disease [ESKD]), occurs when the estimated GFR is less than 15 mL/min/1.73m<sup>2</sup>, at which point kidney replacement therapy (KRT) typically is indicated if desired and available.

Figure 1.1   Classification of CKD  Low risk (if no other markers of kidney disease, no CKD)			Persistent albuminuria categories Description and range				
Moderately increased risk High risk			A1	A2	A3		
verynigniisk				Normal to mildly increased	Moderately increased	Severely increased	
			<30 mg/g <3 mg/mmol	30–300 mg/g 3–30 mg/mmol	>300 mg/g >30 mg/mmol		
GFR categories Description and range		G1	Normal or high	≥90 ml/min per 1.73 m²			
	GFR categories	G2	Mildly decreased	60–89 ml/min per 1.73 m²			
		G3a	Mildly to moderately decreased	45–59 ml/min per 1.73 m²			
	Description and range	G3b	Moderately to severely decreased	30–44 ml/min per 1.73 m²			
		G4	Severely decreased	15–29 ml/min per 1.73 m²			
		G5	Kidney failure	<15 ml/min per 1.73 m²			

Levin A, Stevens PE, Bilous RW, et al. Kidney Disease: Improving Global Outcomes (KDIGO) CKD Work Group. KDIGO 2012 clinical practice guideline for the evaluation and management of chronic kidney disease. Kidney Int Supp. 2013;3(1):1-150. (Adapted with permission.)

# **1.2 THE BURDEN OF KIDNEY FAILURE**

CKD has many known causes, including high blood pressure (hypertension), diabetes mellitus, obesity, autoimmune diseases, kidney stones, kidney infections, kidney cysts, and cigarette smoking, to mention a few. CKD can progress to kidney failure in a number of ways. Hypertension is one of the leading causes of worsening kidney function and can be managed through medications, diet, and increased physical activity, among others. Diabetes is another common cause of CKD, and the incidence of diabetes-related kidney failure has been rising faster than the overall incidence of kidney failure,<sup>11,12</sup> suggesting the importance of appropriate diabetes management practices to reduce the burden of kidney failure. Signs of worsening kidney function are increased protein in the urine (proteinuria) or increased creatinine in the blood. It is important to monitor these markers over time and to use therapies to delay progression in order to manage CKD and prevent further kidney damage. Medications such as angiotensin-converting enzyme inhibitors (ACEi), angiotensin receptor blockers (ARBs), and sodium-glucose cotransporter 2 (SGLT2) inhibitors may help protect kidney function by reducing proteinuria and blood pressure.<sup>13</sup> Dietary changes, such as reduced sodium intake, may also reduce blood pressure and proteinuria,<sup>14</sup> thereby slowing or preventing disease progression to kidney failure. Diets lower in protein may also lighten the workload on the kidneys, thereby reducing proteinuria and slowing the development of kidney failure.<sup>15</sup>

Despite these well-established preventive strategies, many people still progress through CKD to kidney failure. Approximately 0.1% of the world's population has kidney failure, and estimates suggest a higher prevalence in uppermiddle income countries (UMICs) (0.1%) and high-income countries (HICs) (0.2%), compared to low-income countries (LICs) (0.05%) or lower-middle income countries (LMICs) (0.07%).<sup>7</sup> However, the proportion of people with kidney failure who are not receiving treatment in the form of dialysis (hemodialysis [HD] or peritoneal dialysis [PD]) or transplantation is much higher in LICs (98%) and LMICs (94%) than in UMICs (79%) and HICs (30%).<sup>7</sup> This limited access to KRT in LICs and LMICs warrants attention, as associated kidney failure morbidity and mortality rates are high in these nations. Although data on the incidence of kidney failure are sparse, estimates suggest a larger percentage of gross domestic product should be spent on healthcare to improve survival rates among those living with CKD, and increasing access to KRT (thereby preventing death among people with CKD before it progresses to kidney failure).<sup>11,12</sup>

Kidney failure morbidity and mortality depend greatly on the quality of treatment received. Limited access to dialysis is common in LICs and LMICs, resulting in a high number of preventable deaths. Kidney transplantation results in lower mortality and risk of cardiovascular events and improved quality of life compared with dialysis.<sup>16</sup> Regardless, access to transplantation is limited in many countries due to a number of health system (e.g., personnel, infrastructure, system coordination, financing) and cultural (e.g., public and professional attitudes, legal environment) factors.<sup>17</sup> Worldwide, people living with kidney The proportion of people with kidney failure who are not receiving treatment in the form of dialysis (HD or PD) or transplantation is much higher in LICs (98%) and LMICs (94%) than in UMICs (79%) and HICs (30%).

disease are increasingly opting for conservative kidney management (CKM) as an alternative to KRT;<sup>11</sup> however, optimal delivery may not be possible in countries where palliative or endof-life care is limited by resources.<sup>18</sup> Ensuring appropriate treatment for kidney failure, whether dialysis, transplantation, or CKM, is a priority of public health importance by major stakeholders around the world (e.g., ISN, governments, people living with kidney disease, care providers).

# **1.3 TREATMENT FOR KIDNEY FAILURE**

#### 1.3.1 Kidney replacement therapy

KRT involves either dialysis or kidney transplantation. There are two modalities of dialysis: PD and HD. In PD, a catheter is placed into the abdomen of the person with kidney failure and fluid is added to collect and remove waste from the body. PD is administered either continuously or intermittently. For those with very low kidney function, continuous PD is recommended, as it helps to preserve remaining kidney function.<sup>19</sup> Typically, people receiving treatment perform up to four cycles of PD daily in their own homes. In HD, blood is removed from the body and cleaned by a machine which uses a filter to remove waste and excess fluid. The duration and frequency of HD are important factors that influence treatment quality. A longer treatment time may be advantageous, particularly among those who gain weight with dialysis.<sup>20</sup> While standard care practices involve dialysis three times per week, the potential benefits of more frequent treatments are currently

being studied.<sup>20</sup> During HD, blood is collected by the machine through one of three types of vascular access: fistula, graft, or catheter. HD can be performed at a hospital, a dialysis center, or a home of people living with kidney disease..

Deciding which modality is appropriate for each person living with kidney disease is a complex process. Often times, available resources, expertise, and the condition (stability, other health problems) of the person living with kidney disease, guide the modality choice.<sup>21,22</sup> The decision also may depend on other factors, such as the education level or desire for independence of people living with kidney disease, wait time for transplantation, and distance to a dialysis center, among others.<sup>22,23</sup> The age of the person living with kidney disease at the time of treatment initiation may also be an important consideration.<sup>24</sup> The long-term effect of modality choice is unclear. While some researchers are comparing the outcomes of PD and HD in registry studies, 23,25

they cannot consider differences in health at the time of treatment initiation of people living with kidney disease, which likely affects treatment outcomes. Additionally, HD is more resourceintensive and PD may be more optimal than HD in lower-income countries.<sup>26,27</sup>

Kidney transplantation is the other (perhaps preferable) KRT method whereby a recipient receives a kidney from either a live or a deceased donor. Prospective recipients are examined, and if eligible for surgery, are placed on a waiting list until an appropriate match is available. Following the transplantation surgery, kidney transplant recipients are monitored and given anti-rejection medications or immunosuppressive agents to prevent their bodies from attacking their new kidneys. There are a number of barriers to kidney transplantation, especially low socioeconomic status.<sup>28</sup> Kidney transplantation is also highly resource-intensive, and many LICs and LMICs lack the human and financial resources to perform the surgery. Additionally, cultural, legal, religious, and political barriers may impede organ donation, thereby limiting the benefit of this treatment option in some countries.28,29

# Figure 1.2 | Domains of kidney supportive care

CKD - Chronic kidney disease



Gelfand SL, Scherer JS, Koncicki HM. Kidney supportive care: Core curriculum 2020. Am J Kidney Dis. 2020;75(5):793-806. (Adapted with permission.)

The costs of KRT are exceedingly high and consume a significant proportion of healthcare budgets in developed countries. Many developed countries spend 2-3% of their healthcare budgets on treatment for people living with kidney failure, even though these people comprise just 0.1-0.2% of the total population. KRT remains inaccessible in most developing countries due to associated costs.<sup>30,31</sup> It is estimated that more than 80% of all people living with kidney disease receiving treatment for kidney failure reside in developed countries, which have relatively larger elderly populations and universal access to care for kidney disease. Developing countries have similar CKD incidence rates, but much lower prevalence of treated kidney failure than the developed world.<sup>7</sup> Many estimates place the reported prevalence of treated kidney failure in sub-Saharan Africa at less than one-tenth that of the United States. Although comprehensive data are not readily available from less developed countries, it appears that proportionately fewer people living with kidney disease in these regions receive treatment for kidney failure.7

# 1.3.2 Conservative kidney management (CKM)

CKM refers to the management of health conditions using non-invasive practices, whereby the intent is to maintain health as much as possible and mitigate adverse events. The concept of CKM in kidney failure is relatively new.<sup>32</sup> In this context, CKM is the management of kidney failure without the use of KRT. In 2013, the definition of CKM for kidney failure management was established as planned, holistic, patientcentered care for people living with kidney failure who do not wish to pursue maintenance dialysis,<sup>32</sup> which can include a number of components such as interventions to delay worsening kidney function or minimize adverse events; shared decision-making; active symptom management; communication plans; psychological, social, and family support; and cultural or spiritual care.32 People living with kidney disease who receive CKM are likely to experience symptoms, and therefore should supplement treatment with appropriate palliative care (Figure 1.2).33-35

Deciding whether to manage kidney failure through traditional methods (dialysis or kidney transplantation) or CKM requires careful consideration of each person's health status and wishes. The initiation of dialysis in the elderly may actually result in increased frailty, loss of independence, and decreased cognitive functioning.<sup>36</sup> The burden of dialysis is substantial, and many people living with kidney disease prefer CKM due to the impact of dialysis on quality of life.37 Furthermore, dialysis, when compared to CKM, does not appear to prolong life or improve physical and mental health outcomes among people living with kidney disease who are over 80 years of age or those with multiple other health problems.<sup>38</sup> The benefits of CKM on the quality of life of people living with kidney disease, combined with a lack of evidence that dialysis leads to better outcomes in some settings and lower costs of CKM,<sup>39</sup> suggest that CKM may be a more appropriate option for some people living with kidney failure.

CKM may be optimal in resource-limited countries where dialysis is not available. While not a deliberate action intended to limit access to KRT, KDIGO refers to this as "choice-restricted CKM."<sup>32</sup> Efforts to increase international awareness and standardization of CKM, particularly in this setting, is important to optimize care for people with kidney failure, and importantly, improve their quality of life.

# 1.3.3 Essential medications for kidney failure care

The kidneys perform a number of important life functions. For example, they produce vitamin D, control blood pressure, and initiate red blood cell production. As a result, people with kidney failure take many medications, typically 10–12 a day,<sup>40,41</sup> to replace these functions. These often include phosphate binders, vitamin D preparations, calcimimetics, antihypertensives, antidiabetics, erythropoiesis-stimulating agents, and iron supplements.<sup>40</sup>

Not surprisingly, the high cost of medication is a major burden on to people living with kidney disease with kidney failure. Among people with kidney failure receiving HD, those with lower incomes tend to exhibit lower adherence to medication regimens,<sup>42</sup> presumably due to the associated expense. Studies have shown that lower co-payments (i.e., lower out-of-pocket expenses for people living with kidney failure) are associated with better medication adherence among people with chronic conditions such as diabetes and heart failure.<sup>43</sup>

#### **1.4 ACCESS TO AND QUALITY OF KIDNEY FAILURE CARE WORLDWIDE**

Despite therapies such as PD, HD, and kidney transplantation, many people in the world suffer from untreated kidney failure. It has been estimated that over 2 million people die each year due to limited access to KRT, and the majority of these deaths occur in LICs and LMICs.<sup>7</sup> Dialysis is expensive in LICs and LMICs where the annual cost of HD ranges

Dialysis is expensive in LICs and LMICs where the annual cost of HD ranges from US \$5000 to over US \$40,000 per treated person each year. from US \$5000 to over US \$40,000 per treated person each year.44-47 This often makes dialysis unaffordable or can lead to compromised quality of care where people living with kidney disease receive fewer dialysis treatments than they need. Even in countries where KRT is accessible, the quality of care may vary considerably, both within and between countries. Variation in dialysis practices may contribute to differences in KRT outcomes observed worldwide.<sup>11</sup> International guidelines may help narrow gaps in care delivery, where possible. Additionally, government support and prioritization may improve both access to, and quality of dialysis. However, it is important to consider other interventions that may be more cost-effective and pragmatic in settings where the costs of dialysis are a substantial burden.44

For example, CKM may be more appropriate in such settings, allowing people living with kidney disease to receive the best possible care when dialysis is not achievable.

Kidney transplantation is often the preferred type of KRT. However, gaps exist with respect to both organ availability and the systemlevel resources required for the operation. Transplantation is highly resource-intensive, and shortages in deceased donor organs further limit access.<sup>48</sup> Limitations associated with infrastructure, the workforce, and legal frameworks as well as religious, cultural, and social constraints may contribute to low transplantation rates in some countries, among other factors.<sup>49</sup> Due to the success of kidney transplantation and limited organ supply, vulnerable people are at risk of organ trafficking and transplant tourism. Policies to protect donor and recipient safety, enforce standards, and prohibit unethical practices are needed.

### **1.5 ACUTE KIDNEY INJURY**

Acute kidney injury (AKI) is a sudden reduction in kidney function (usually within a time frame ranging from hours to days) and manifests clinically as an acute increase in nitrogen waste products (creatinine and urea) or decrease in urine output. In the past, AKI was referred to as acute renal failure (ARF).<sup>50</sup> AKI is a common condition associated with hospitalization and is especially common among critically ill people (up to 40% of people at ICU admission and 20% of people during hospitalization). In LICs and middle income countries, AKI affects up to 21% of all hospital admissions.<sup>51</sup> Common causes of AKI include fluid losses (e.g., diarrhea and vomiting), infections, drugs, or toxins (e.g., herbal remedies, snake venom).52,53 In developing countries, diarrheal illnesses and nephrotoxins

In LICs and middle income countries, AKI affects up to 21% of all hospital admissions.

(usually herbal medications) contribute significantly to the development of AKI.<sup>50,52,54</sup>

AKI and CKD are closely related; CKD is a known risk factor for AKI and vice versa. Both AKI and CKD increase the risk for cardiovascular disease,<sup>55-57</sup> among other adverse outcomes. Appropriate and timely treatment of AKI is critical, as it can reverse kidney damage; untreated, AKI can lead to CKD progression and ultimately, kidney failure.

#### **1.6 CLIMATE CHANGE AND THE KIDNEY**

In the past few decades, CKD of unknown etiology (CKDu) has emerged as a serious health issue that mostly affects agricultural communities in Central America, South Asia,

It has been proposed that climate change and the associated increase in global temperatures are driving this emerging epidemic. Africa, and other regions with hot climates around the world.<sup>58</sup> It has been proposed that climate change and the associated increase in global temperatures are driving this emerging epidemic.<sup>59</sup> CKDu occurs mostly in resource-poor countries among communities and field workers exposed to excessive heat leading to recurrent episodes of dehydration, fluid loss, and kidney damage.<sup>59</sup> Exposure to agrochemicals (pesticides, herbicides, fertilizers) and heavy metals (cadmium, lead, arsenic, etc.), contamination of drinking water, and certain infections are also suspected to play a role.<sup>58</sup> There is a pressing need to recognize the vulnerability of people living with kidney disease and those working in hot temperatures by building climate-resilient and sustainable health systems to protect communities from the devastating consequences of climate change.<sup>60</sup>

#### **1.7 CKD EARLY IDENTIFICATION SYSTEMS**

Although CKD is present in a substantial proportion of the population, clinicians do not always screen (test) people because early kidney disease is often asymptomatic. Early detection and management reduce the burden of CKD by improving the outcomes of people living with kidney disease and reducing morbidity and mortality. This is particularly relevant in socially disadvantaged and vulnerable populations who bear a disproportionate burden of CKD and are less likely to be diagnosed early.<sup>61</sup>

#### Figure 1.3 | The ISN-KDIGO CKD early detection toolkit



Determine at-risk individuals and populations

Test for CKD in individuals with hypertension, diabetes, and/or cardiovascular disease

#### Consider other factors including

- Demographics, older age, race/ethnicity
- Other systematic diseases that impact kidneys
- Genetic risk factors
- Environmental exposures

<section-header><section-header><section-header><section-header><section-header><section-header><section-header><list-item>



# **Individualized evaluation**

Based on individualized risk of progression

#### **Risk reduction for CKD and CVD progression and complications**

- Lifestyle modifications (e.g., physical activity, maintenance of healthy weight, lower sodium intake)
- Smoking cessation
- Optimize blood pressure control
- Optimize glycemic control
- SGLT2 inhibitors

- RAAS inhibition
- Statins
- Treat metabolic acidosis
- Treat underlying cause of CKD
- Avoid kidney toxins (e.g., NSAIDs)
- Adjust dosing of medications based on eGFR

www.theisn.org/initiatives/ckd-early-screening-intervention/#Quick-Guide-and-Infographics

Targeted early detection (Figure 1.3)<sup>62</sup> offers the potential to substantially reduce morbidity and mortality from CKD and its related complications. Results can inform interventions (treatment initiation, appropriate drug dosing, lifestyle changes, referral to a specialist).<sup>63</sup> The benefits of early detection extend beyond treatments that can slow or even halt the progression of CKD. Reducing cardiovascular risk is equally important, since cardiovascular diseases are a leading cause of death in most countries. Standardizing measurement methods for early detection with a focus on high-risk populations and ensuring appropriate interventions are available to those diagnosed with CKD will improve the value of programs and improve the outcomes of people living with kidney disease.

Given the high healthcare costs of kidney failure, especially in LICs and middle-income countries, early detection offers economic benefits. The simple tests suggested by the ISN-KDIGO toolkit are not expensive or invasive, and they can be administered in a variety of settings.<sup>62</sup>

# **1.8 HEALTH INFORMATION SYSTEMS**

Health information systems are used to collect and manage health-related data. According to the World Health Organization (WHO), a health information system is critical for decision-making; its main functions include data generation and compilation, analysis and synthesis, and communication and use.<sup>64</sup>

Well-designed health information systems are imperative for healthcare. Proper information management helps ensure patient safety and quality of care by reducing mistakes, improving clinical decision-making, and enabling access to information in real time.65 In addition to health information systems that collect and store individual patient health information (e.g., electronic medical records), databases or registries of population health information are important tools for achieving quality healthcare. Patient registries can provide hospital administrators with information on current and future resource demands. Registries also help researchers learn more about health conditions, thereby identifying ways to prevent or manage them. Moreover, the Agency for Healthcare Research and Quality (AHRQ) suggests that patient registries may facilitate the delivery of patientcentered care.<sup>66</sup> Collecting data on population health statistics over time also enables programs targeted at reducing the prevalence or incidence of a specific health condition to be evaluated.

Proper information management helps ensure patient safety and quality of care.

The use of health information systems in kidney disease is important. Early diagnosis is important to slow progression; registries not only help primary care physicians manage people in these early stages, but also provide them with tools to monitor and manage their health.<sup>67</sup> Registries of people with kidney failure are important mechanisms for monitoring trends in disease burden and outcomes, and for policy planning (e.g., to estimate transplantation needs and plan appropriately for organ procurement systems). Despite their importance, kidney registries are lacking, particularly in lower income countries.<sup>68</sup>

Monitoring population health data may be particularly important in LICs and LMICs. Their current status must be documented to assess the impacts of future programs and predict future resource needs. Organizational, behavioral, and economic barriers, limited access to information systems, and a lack of capacity building may impede the creation and functionality of robust health information systems in these settings.<sup>69</sup> Future efforts to determine how to best operate these systems may be beneficial.

# **1.9 NATIONAL HEALTH POLICIES**

Appropriate leadership and governance are essential components of a healthcare system<sup>70</sup> that facilitate priority-setting and strategy development activities that in turn lead to action through policies.<sup>71,72</sup> A policy is a specific official decision or set of decisions designed to carry out a course of action endorsed by a government body, including a set of goals and priorities, and primary directions for attaining these goals. A policy document also may include a strategy for implementing the policy.73 A health policy includes these decisions, plans, and actions intended to achieve a specific healthcare goal.<sup>74</sup> Health policies create standardized approaches to promote equitable delivery of high-quality care and can increase awareness and promote

# Inclusion of CKD in NCD strategies may yield significant global benefits.

advocacy around important health matters. The actions of advocacy groups or non-profit organizations may drive policy creation, or vice versa, by demonstrating need, importance, and interest. Despite the global commitment to implementing non-communicable disease (NCD) prevention and control strategies,<sup>75</sup> kidney disease policies often are lacking. Due to the burden of CKD and its association with other NCDs, its inclusion in these strategies may yield significant global benefits.<sup>76</sup>

# **1.10 A GLOBAL STRATEGY FOR CKD AND KIDNEY FAILURE**

The International Society of Nephrology (ISN) is dedicated to ensuring that all people have equitable access to sustainable kidney health. The ISN has developed several initiatives (www. theisn.org/initiatives/) focused on education, training, and research, and improving kidney disease awareness and detection.

The ISN recognizes the global challenges associated with diagnosis and treatment of CKD, especially in LICs to middle income countries where other challenges abound. The ISN facilitates kidney care by providing educational assistance and guidance, training caregivers, and setting up facilities. When individual countries are unable to meet targets, support can be provided to intergovernmental organizations through existing regional nephrology associations, e.g., the African

Prevention of kidney failure and improving access to care remains a key focus of the ISN Association of Nephrology (AFRAN), the Latin American Society of Nephrology and Hypertension (SLANH), and the Asian Pacific Society of Nephrology (APSN).

Universal healthcare coverage for the prevention and early management of kidney disease greatly reduces disease burden and saves lives. AKI is reversible and early treatment can prevent progression to CKD. By increasing funding for AKI detection and treatment, various affiliated bodies can help prevent progression to more severe and costly conditions. Similarly, including the targeting of associated risk factors as part of the global health agenda may result in a significant reduction of CKD worldwide. National and regional governments can play an important role in this effort by improving legislation and increasing funding for treatment of kidney diseases. Increasing access to adequate treatment for risk factors, dialysis therapies, and kidney transplantation may further contribute to reducing the burden of kidney disease.

A better understanding of the global capacity for kidney care and how that capacity varies

around the world is essential to combatting kidney disease. Knowing which policies and healthcare systems currently facilitate or impede kidney care helps set benchmarks and identify opportunities for improvement. Furthermore, understanding how these capacities vary across regions or countries could inform recommendations and help identify areas where knowledge or resource sharing may yield great benefits.

A central goal of the ISN is its CKD initiative, "Closing the Gaps" (www.theisn.org/initiatives/ the-isn-closing-the-gaps-ckd-initiative/). This program provides a comprehensive strategy to address issues related to the delivery of CKD care worldwide by defining global needs and the current state of care, and closing gaps via ISN research, education, and advocacy activities.77 As part of this "Closing the Gaps" initiative, the ISN-Global Kidney Health Atlas (ISN–GKHA) is a multinational, cross-sectional survey designed to assess the current capacity for kidney care across all world regions. Published in 2017, the first iteration of the ISN-GKHA explored variability between and within countries around the globe with respect to capacity for kidney care delivery, as defined by the World Health Organization's domains of health services.<sup>78</sup> So far, both iterations of the ISN-GKHA (2017 and 2019)78,79 have demonstrated significant inter- and intraregional variability in global kidney care, with

significant gaps related to the kidney health workforce, health service delivery, essential medicines and technologies, health financing, leadership and governance, health information systems, strategies and policy frameworks, and research capacity and development, particularly in LICs and middle income countries. These findings provided a foundation for a global CKD surveillance and benchmarking network.

Prevention of kidney failure and improving access to care is a key focus of the ISN (https://www.theisn.org/initiatives/ckd-earlyscreening-intervention/); its programs are designed to improve understandings of kidney failure and its determinants, highlight the necessary standards of kidney failure care, and enhance the ability to treat kidney failure in resource-constrained settings. This third iteration of the ISN-GKHA survey is aimed at defining the current global status of the structures and organization of kidney disease care. It focuses on the capacity and readiness of nations to achieve universal access to equitable integrated kidney failure care, including KRT and CKM. By understanding and potentially helping to shape relevant health policies, practices, and infrastructure, the ISN aims to facilitate the implementation of equitable and ethical care for people living with kidney disease in all regions and countries of the world.

# SECTION

# **Methods**

#### 2.1 OVERVIEW

Like the previous iterations of the ISN–Global Kidney Health Atlas (ISN–GKHA), this iteration is the product of collaborative efforts with regional and national project leaders. Two key methods were used to produce the atlas (Figure 2.1):

- Literature review, which involved searching literature and other data sources to calculate estimates; and
- A key opinion leader survey, whereby three leaders from each country—a nephrologist (preferably a nephrology society leader), a leader of a consumer representative organization, and a policymaker submitted details on national kidney care practices with a specific focus on various aspects of KRT (funding, workforce, quality and monitoring, and policy).

Assistance from international contacts, collaborators, ISN leaders, and regional board members was sought to facilitate both approaches during the development of the ISN-GKHA. Project leaders at the regional and national levels ensured the inclusion of local nephrology association leaders, consumer representatives, policymakers, and other opinion leaders across regions and countries. Project leaders organized and followed up on responses for all countries within a specific world region; played a liaison role between the steering committee, ISN, and regional stakeholders; helped gain access to additional data sources and contacts for surveys; identified or served as opinion leaders on the project for each specific world region; and identified or served as experts who could examine and review regional data.

#### Figure 2.1 | Literature review and survey research methods

	Literature review Efforts included a review of:
Q	<ul> <li>Published scientific literature</li> <li>Government reports</li> <li>Relevant data sources on the vari (e.g., registries, observational stude)</li> <li>Health systems characteristics conservational stude</li> <li>Service delivery</li> <li>Health workforce</li> <li>Information systems</li> </ul>

- Relevant data sources on the various aspects of kidney failure epidemiology (e.g., registries, observational studies, GODT)
- Health systems characteristics corresponding to each of the WHO UHC domains:
  - Medicines and medical products
  - Financing
  - Leadership

X	

# Survey

The survey was designed in five modules that assessed the national and regional profiles for readiness, capacity, and response to kidney failure corresponding to each of the six UHC domains:

- Health finance and service delivery: questions evaluated funding mechanisms and oversight;
- Health workforce: questions evaluated clinical responsibility and availability of healthcare providers;
- Essential medications and health product access for kidney care: questions evaluated the capacity for KRT service provision, preparation for KRT, access to dialysis and transplant options and the quality of those options; access to CKM; KRT accessibility and affordability, and cost reimbursement plans;
- Health information systems and statistics: questions evaluated the availability of registries and/or other surveillance systems for AKI or CKD;
- Leadership and governance: questions evaluated national health policies and strategies, advocacy (AKI, CKD, kidney failure), and barriers to optimal kidney care delivery.

# 2.2 SCOPE

This report pertains to 218 countries recognized by the World Bank and specifically focuses on countries with ISN affiliate societies. Regional boards for the 10 ISN regions coordinated the work performed in each of the countries (for a complete list, see Appendix 2). Each region's work was led by a steering committee and working group within the stipulated timeline. The 10 ISN regions are:

- 1. Africa
- 2. Eastern and Central Europe
- 3. Latin America<sup>1</sup>
- 4. The Middle East
- 5. North America and the Caribbean<sup>1</sup>
- 6. North and East Asia
- 7. Oceania and South East Asia (OSEA)
- 8. Newly Independent States and Russia (NIS and Russia)
- 9. South Asia, and
- 10. Western Europe

1. Within the ISN, the islands of the Caribbean are affiliated with either North America and the Caribbean or Latin America (see Appendix 2). For simplicity, the main body of the ISN–GKHA refers to these regions as North America and Latin America.

# 2.3 LITERATURE REVIEW

Literature review efforts included a review of published scientific literature, government reports, and other relevant data sources on the various aspects of kidney failure epidemiology and health system characteristics corresponding to each of the World Health Organization (WHO) Universal Health Coverage (UHC) domains (i.e., service delivery, health workforce, information systems, medicines and medical products, financing, and leadership) (Tables 2.1 and 2.2). Although published literature is important to consider, much of the available evidence was expected to be found in gray literature, including websites and reports with limited circulation. The national and regional project leaders helped identify these sources and conducted a detailed gray literature search by following a strategy designed by an expert research librarian. To gather information on current kidney care practices and the burden of kidney failure, two literature reviews were performed:

- A broad literature review of national health system characteristics associated with each of the WHO UHC domains with an emphasis on important elements relevant to the organization and delivery of kidney failure care; and
- 2. A systematic review of relevant kidney failure epidemiology data on disease burden and outcomes across countries and regions, including:
  - Prevalence and incidence of overall kidney failure (treated);
  - Dialysis (HD and PD) incidence and prevalence;
  - HD incidence and prevalence;
  - PD incidence and prevalence;
  - Kidney transplantation incidence and prevalence; and
  - Kidney transplantation by donor type (living or deceased).

# 2.3.1 Broad review of health system characteristics

The objective of the broad review was to obtain a snapshot of individual country and regional health system characteristics and specific elements relevant to kidney care, focused on the general WHO UHC domains (Table 2.1) and specific domains related to kidney disease (Table 2.2). The comprehensive search strategy was developed in conjunction with an expert medical librarian. Data sources included:

- Data and reports published by the WHO Global Observatory, United Nations (UN), World Bank, and Organization for Economic Co-operation and Development (OECD);
- Published and unpublished documents from international organizations/bodies (i.e., OECD, WHO, UN, Commonwealth Fund, World Bank, European Union (EU) and its affiliates, etc.), and reports published by national governments (and occasionally regional governments within countries) on the organization and delivery of kidney care; and
- Additional literature identified by key stakeholders (i.e., opinion leaders, national nephrology society leaders, ISN leaders) and through consultation with national nephrology societies and ISN regional boards.

# 2.3.2 Systematic review of relevant kidney failure epidemiological data

The objective of the systematic review was to collect epidemiological data on the incidence and prevalence of KRT. Data on KRT costs and health system features across countries and regions with implications for kidney care were also reviewed.

Data on key estimates of KRT were defined by the incidence and prevalence of kidney failure (overall) and by different dialysis modalities (HD and PD) and kidney transplantation.

Building blocks	Indicators/metrics	Data sources	Essential elements
Country profile	<ul> <li>Total population (millions)</li> <li>Gross national income per capita (PPP US\$)</li> </ul>	<ul> <li>Literature reviews</li> </ul>	<ul> <li>Demographic and economic characteristics</li> </ul>
Health service delivery	<ul> <li>Description of healthcare system: public/ private health insurance funded by national taxation/income contributions covering all or a proportion of the population; ratio of public/ private MDs, kidney care centers and/or HD centers</li> </ul>	<ul><li>Literature reviews</li><li>Surveys</li><li>Interviews</li></ul>	<ul> <li>Comprehensiveness</li> <li>Accessibility</li> <li>Coverage</li> <li>Quality</li> <li>Coordination</li> <li>Efficiency</li> <li>Accountability</li> </ul>
Health workforce	<ul> <li>Density of physicians (per 10,000 population)</li> <li>Density of nursing and midwifery personnel (per 10,000 population)</li> <li>Density of pharmaceutical personnel (per 10,000 population)</li> </ul>	<ul> <li>Literature reviews</li> <li>Surveys</li> <li>Interviews</li> <li>WHO Global Observatory</li> <li>Global Burden of Disease</li> </ul>	<ul><li>Reach and distribution</li><li>Accessibility</li></ul>
Health information systems	<ul> <li>Health information system performance index</li> </ul>	<ul><li>Literature reviews</li><li>Surveys</li><li>Interviews</li></ul>	<ul><li>Reach</li><li>Scope</li><li>Comprehensiveness</li></ul>
Essential medicines and technologies	<ul> <li>Median availability of selected generic medicines in public and private sectors (%)</li> <li>Median consumer price ratio of selected generic medicines in public and private sectors</li> </ul>	<ul> <li>Literature reviews</li> <li>Surveys</li> <li>Interviews</li> <li>WHO Global Observatory</li> </ul>	<ul> <li>Equitable access</li> <li>Quality and safety</li> <li>Cost-effectiveness</li> </ul>
Health financing	<ul> <li>Total expenditure on health as a percentage of GDP</li> <li>General government expenditure on health as a percentage of total expenditure on health</li> <li>Private expenditure on health as a percentage of total expenditure on health</li> <li>General government expenditure on health as a percentage of total government expenditure</li> <li>Out-of-pocket expenditure as a percentage of private expenditure on health</li> <li>Private prepaid plans as a percentage of private expenditure on health</li> </ul>	<ul> <li>Literature reviews</li> <li>WHO Global Observatory Database</li> <li>Global Burden of Disease</li> </ul>	<ul> <li>Availability of funds</li> <li>Extent of financial risk protection</li> </ul>
Leadership and governance (national policies and frameworks)	<ul> <li>National chronic/non-communicable disease policy – overarching disease policy targeting long term conditions including CVD, diabetes, cancer, CKD, etc. (where it exists)</li> </ul>	<ul> <li>Literature reviews</li> <li>Surveys</li> <li>Interviews</li> <li>WHO Global Observatory</li> <li>WHO NCD Strategy</li> </ul>	<ul> <li>Existence of appropriate policies and strategies</li> <li>Adoption of policies and strategies</li> </ul>

### Table 2.1 | General health system characteristics by WHO UHC domain, with relevant data sources

CKD = chronic kidney disease, CVD = cardiovascular disease, GDP = gross domestic product, HD = hemodialysis, MD = medical doctor, NCD = noncommunicable disease, WHO = World Health Organization
Table 2.2	Kidney	disease-spe	cific health	system o	haracterist	ics by WHO	UHC doma	in, with
relevant da	ta sourc	es						

Building blocks	Indicators/metrics	Data sources	Essential elements
Health service delivery	<ul> <li>Number of health facilities for general CKD care</li> <li>KRT services (e.g., number of health facilities offering HD services per country)</li> <li>Public vs. private</li> <li>Non-dialysis CKD care structure</li> <li>KRT care structure</li> </ul>	<ul> <li>Literature reviews</li> <li>Surveys</li> <li>Interviews</li> </ul>	<ul> <li>Accessibility of dialysis and kidney transplant units in each country</li> <li>Access to medications</li> <li>Reimbursement of treatment and care</li> <li>Kidney transplant waiting list</li> <li>Access to psycho-social counseling and support</li> <li>Existence, strength, role of patient organizations in each country</li> </ul>
Health workforce	<ul> <li>Number of nephrologists (per million population)</li> <li>Number of general physicians (per 10,000 population)</li> <li>Number of community health workers (per 10,000 population)</li> <li>Number of nurses (per 10,000 population)</li> <li>Regional distribution</li> <li>Nephrology trainees/graduates per year</li> <li>Availability of multidisciplinary teams</li> </ul>	<ul> <li>Literature reviews</li> <li>Surveys</li> <li>Interviews</li> <li>WHO Global Observatory</li> </ul>	<ul> <li>Professionals (GPs, nephrologists, diabetologists, endocrinologists, cardiologists, other related disciplines): total and as a ratio to entire population or dialysis population</li> <li>Financial resources, remuneration and incentives (including those for GPs/specialists to identify and manage people living with kidney disease)</li> <li>Presence of other credentialed health care providers (e.g., nephrology nurses, dieticians)</li> </ul>
Health information systems	<ul> <li>CKD (non-dialysis) registry</li> <li>KRT Registry</li> </ul>	<ul> <li>Literature reviews</li> <li>Surveys</li> <li>Interviews</li> </ul>	<ul><li>Reach</li><li>Scope</li></ul>
Essential medicines and technologies	<ul> <li>ACEi/ARBs</li> <li>Statins</li> <li>Aspirin</li> <li>Other BP Meds</li> <li>Anemia meds (Epo/iron)</li> <li>CKD-MBD (calcium binders, renagel, cinacalcet)</li> <li>Specific (GN and transplant)</li> <li>Dialysis availability, access, and coverage</li> <li>Transplant availability, access, and coverage</li> </ul>	<ul> <li>Literature reviews</li> <li>Surveys</li> <li>Interviews</li> <li>WHO Global Observatory (for some essential medicines)</li> </ul>	<ul> <li>Access to medications that manage risk factors to prevent the development or progression of AKI or CKD</li> </ul>
Health financing	<ul> <li>Total expenditure on health for CKD</li> <li>Public and private contributions</li> <li>Out-of-pocket payments for</li> <li>Essential medicines</li> <li>Non-dialysis CKD care</li> <li>Dialysis</li> <li>Transplantation</li> </ul>	<ul> <li>Literature reviews</li> <li>Surveys</li> <li>Interviews</li> <li>WHO Global Observatory</li> </ul>	<ul> <li>Fund medications to prevent the development or progression of AKI or CKD</li> </ul>
Leadership and governance (national policies and frameworks)	<ul> <li>Guidelines/frameworks on CKD care</li> <li>Advocacy efforts and initiatives</li> <li>Early detection and prevention programs</li> <li>eGFR reporting</li> </ul>	<ul> <li>Literature reviews</li> <li>Surveys</li> <li>Interviews</li> <li>WHO Global Observatory</li> <li>WHO NCD Strategy</li> </ul>	<ul> <li>Availability, awareness, and adoption of policies and guidelines targeted toward kidney care</li> </ul>

ACEi/ARBs = angiotensin-converting enzyme inhibitors/angiotensin receptor blockers, AKI = acute kidney injury, CKD = chronic kidney disease, eGFR = estimated glomerular filtration rate, GN = glomerulonephritidis, KRT = kidney replacement therapy, MBD = mineral bone disorder, GP = general practitioner, NCD = non-communicable disease, N = number, WHO = World Health Organization

These data were extracted from key reports, including annual reports of kidney failure registries and databases such as the Global Observatory on Donation and Transplantation (GODT), as well as identified relevant published and gray literature.

Data sources included:

- Statistics/published reports from national and regional government agencies (where available) as identified by our gray literature search and by experts.
- Reports published by international organizations (WHO, World Bank, UN, and OECD), including world health statistics and health system reports.
- Leaders of national and regional nephrology associations and key opinion leaders who helped us gather data relevant to all aspects of the inventory.

- Published scientific literature on the various aspects of KRT epidemiology, economics, and organization of care according to standard guidelines<sup>1,2</sup> which, as in our previous work, provided additional complementary data for the atlas;<sup>3,4</sup>
- A gray literature search based on a strategy developed with assistance from an expert research librarian and tailored to the six UHC domains and the taxonomy developed by the WHO.
- Kidney registries that collect data on people living with kidney failure who receive KRT, which were identified through a rapid review of publications and annual reports produced by governments and kidney professional associations (Table 2.3).<sup>5</sup>

Kidney registry	Year established	Most recent data year accessed	Incidence of kidney failure	Prevalence of kidney failure	Dialysis	Transplant
South Africa	2012	2019	Yes	Yes	Yes	Yes
Romanian Renal Registry Turkish National Registry	1993 1990	2020	Yes¹ Yes	Yes¹ Yes	Yes¹ Yes	Yes¹ Yes
Brazilian Registry of Dialysis Colombia Healthcare Database Latin American Dialysis and Transplantation Registry Sociedad Argentina de Nefrología (SAN) Uruguayan Registry of Dialysis	1998 2008 1991 2004 1981	2020 2019	Yes – Yes Yes Yes	Yes - Yes Yes Yes	Yes Yes Yes Yes Yes	– Yes Yes Yes Yes
United Arab Emirates Renal Diseases Registry	1980		Yes	Yes	_	-
Russian Registry	1998		Yes <sup>1</sup>	Yes <sup>1</sup>	Yes <sup>1</sup>	Yes <sup>1</sup>
British Columbia Renal Database Canadian Organ Replacement Registry (CORR) Canadian Pediatric End-Stage Renal	2008 1994	2020	– Yes	– Yes	– Yes	– Yes
Disease Database Database of the Renal Research Institute (MONDO) North American Pediatric Renal Trials and Collaborative Studies	2010 2000 1992		Yes - No	Yes - No	Yes - Yes	Yes - Yes
	Kidney registrySouth AfricaRomanian Renal RegistryTurkish National RegistryTurkish National RegistryBrazilian Registry of DialysisColombia Healthcare DatabaseLatin American Dialysis and Transplantation RegistrySociedad Argentina de Nefrología (SAN)Uruguayan Registry of DialysisUnited Arab Emirates Renal Diseases RegistryBritish Columbia Renal DatabaseCanadian Organ Replacement Registry (CORR)Canadian Pediatric End-Stage Renal Disease Database North American Pediatric Renal Trials and Collaborative Studies	Kidney registryYear establishedSouth Africa2012Romanian Renal Registry Turkish National Registry1993 1990Brazilian Registry of Dialysis Colombia Healthcare Database Latin American Dialysis and Transplantation Registry1998 2008Sociedad Argentina de Nefrología (SAN)2004Unuguayan Registry of Dialysis1981United Arab Emirates Renal Diseases Registry1998Sucian Registry1980British Columbia Renal Database Conadian Organ Replacement Registry (CORR)2008Sociada Argentina de Nefrología (SAN)2008Russian Registry1998Sociedad Argentina de Nefrología (SAN)2008Sociedad Argentina de Nefrología (SAN)2004United Arab Emirates Renal Diseases Registry1998Sociedad Argentina de Nefrología (SAN)2008Sociedad Argentina de Nefrología (SAN)2008Patabase for Dialysis2010North American Pediatric End-Stage Renal Disease Database2010North American Pediatric Renal Trials and Collaborative Studies1992	Kidney registryYear stablishedMost recent data yearSouth Africa20122019Romanian Renal Registry Turkish National Registry1993 19902020Brazilian Registry of Dialysis Colombia Healthcare Database Latin American Dialysis and Transplantation Registry1998 20082020Sociedad Argentina de Nefrología (SAN)200420192019Vuruguayan Registry of Dialysis2004 198120192019Russian Registry198120192019Russian Registry198020202019Sociedad Argentina de Nefrología (SAN)19812019United Arab Emirates Renal Diseases Registry19982020Russian Registry19982020Sociedad Argentina de Nefrología (SAN)20042010Patabase fortina de Nefrología (SAN)20082020Russian Registry19982020Patabase fortina Renal Database Disease Database20102020North American Pediatric End-Stage Renal Disease Of the Renal Research Institute (MONDO)20002000North American Pediatric Renal Trials and Collaborative Studies19922020	Kidney registryYear establishedMost recent accessedIndidence fidiureSouth Africa20122019YesRomanian Renal Registry Turkish National Registry1993 19902020YesBrazilian Registry of Dialysis Colombia Healthcare Database Latin American Dialysis and Transplantation Registry1998 20082020YesSociedad Argentina de Nefrología (SAN)19912019YesYesUruguayan Registry of Dialysis19982004YesYesUruguayan Registry of Dialysis1981YesYesYesSociedad Argentina de Nefrología (SAN)1980Image: State Stat	Kidney registryYear establishedMost recent data yearIncidence of kidney failurePervalence of kidney failureSouth Africa20122019YesYesRomanian Renal Registry Turkish National Registry19932020YesYes'Brazilian Registry of Dialysis Colombia Healthcare Database Transplantation Registry19982020YesYesBrazilian American Dialysis and Transplantation Registry19912019YesYes20042004YesYesYesYesVinguayan Registry of Dialysis (SAN)19812019YesYesUnited Arab Emirates Renal Diseases Registry1980IYes'Yes'Initish Columbia Renal Database (CORR)19942020YesYes'Pritish Columbia Renal Database Disease Database Institute (MONDO)2010YesYes'Yes'Sourdian Pediatric End-Stage Renal Disease Database of the Renal Research Institute (MONDO)2000YesYesYes'North American Pediatric Renal Trials and Collaborative Studies1992YesYesYesNorth American Pediatric Renal Trials and Collaborative Studies1992YesYesYesNorth American Pediatric Renal Trials and Collaborative Studies1992NoNoNo	Kidney registryYear establishMost recent accessedIncidence fkidney failurePrevalence fkidney failureDialysisSouth Africa20122019YesYesYesRomanian Renal Registry Turkish National Registry1993 19902020YesYes'Yes' YesBrazilian Registry of Dialysis Colombia Healthcare Database Latin American Dialysis and Transplantation Registry1998 20082020YesYesYes2008 Sociedad Argentina de Nefrología (SAN)2004YesYesYesYes1991 Sociedad Argentina de Nefrología (SAN)2004YesYesYesYes1993 Sociedad Argentina de Nefrología (SAN)1981ZoutaYesYesYes1994 Sociedad Argentina de Nefrología (SAN)1981YesYesYesYes19952004YesYesYesYesYes19962004YesYesYesYes19972010YesYesYesYes19982020YesYesYesYes19982020YesYesYesYesRussian Registry19982020YesYesYes19982020YesYesYesYes19982020YesYesYesYes19982020YesYesYesYes19982020YesYesYesYes<

#### Table 2.3 | Kidney registries from the 10 ISN regions used as data sources

1. Covered in ERA-EDTA registry

continued

Table 2.5 continued   Ridney registries from the to isin regions used as data source	Table 2.3 continued	Kidney registries	from the 10 ISN regions	used as data sources
--	---------------------	-------------------	-------------------------	----------------------

ISN region	Kidney registry	Year established	Most recent data year accessed	Incidence of kidney failure	Prevalence of kidney failure	Dialysis	Transplant
North America and the Caribbean continued	The Renal Disease Registry (Ontario Renal Network) US Renal Data System (USRDS)	1981 1988	2019	Yes Yes	Yes Yes	Yes Yes	Yes Yes
North and East Asia	Hong Kong Renal Registry Korean Renal Registry Shanghai Dialysis Registry Taiwan Renal Registry Data System	1985 1985 1996 1987		Yes Yes - Yes	Yes Yes - Yes	Yes Yes Yes Yes	Yes Yes No No
Oceania and South East Asia	Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) Malaysian National Renal Registry Singapore Renal Registry Thailand Renal Replacement Therapy Registry	1963 1993 2001 1997	2019 2020 2015	Yes Yes Yes Yes	Yes Yes Yes Yes	Yes Yes Yes Yes	Yes Yes Yes Yes
South Asia	None						
Western Europe	Austrian Dialysis and Transplant Registry (OEDTR) Belgian Society of Nephrology (NBVN) Catalan Renal Registry (RMRC)	1990 1996		- - Voc1	- - Vos1	- - Voc1	- - Vos1
	Danish Registry on Regular Dialysis and Transplantation (DNSL) Dutch Renal Registry (RENIN) European Renal Association – European Dialysis and Transplant	1990 1986	2020	Yes <sup>1</sup> Yes <sup>1</sup>	Yes <sup>1</sup> Yes <sup>1</sup>	Yes <sup>1</sup> Yes <sup>1</sup>	Yes <sup>1</sup> Yes <sup>1</sup>
	Association (ERA-EDTA) Finnish Registry for Kidney Diseases Greek Registry (Hellenic Society of Nephrology)	1963 1964 2000	2019 2020	Yes Yes <sup>1</sup> Yes <sup>1</sup>	Yes Yes¹ Yes¹	Yes Yes <sup>1</sup> Yes <sup>1</sup>	Yes Yes <sup>1</sup> Yes <sup>1</sup>
	Groupement des Nephrologues Francophones de Belgique (GNFB) Italian Dialysis and Transplant Registry (RIDT)	1995		– Yes	- Yes	– Yes	- Yes
	Norwegian Renal Registry Portuguese Society of Nephrology Scottish Renal Registry (SRR)	1994 1997 1991	2020	Yes Yes¹ Yes	Yes Yes¹ Yes	Yes Yes¹ Yes	Yes Yes <sup>1</sup> Yes
	Register Swedish Renal Registry United Kingdom Renal Registry (UKRR) Valencian Renal Registry	1997 2007 1997 1992	2019	Yes Yes¹ Yes Yes¹	Yes Yes¹ Yes Yes¹	Yes Yes¹ Yes Yes¹	Yes Yes¹ Yes Yes¹

1. Covered in ERA-EDTA registry

ISN = International Society of Nephrology, NIS = Newly Independent States

Source: Liu et al. A global overview of kidney registries: A systematic review. BMC Nephrol. 2015 Mar 19;16:31. doi: 10.1186/s12882-015-0028-2. Adapted with permission.

# 2.3.3 Scoping review of KRT cost estimates

To obtain data on KRT costs with implications for kidney care, we conducted a scoping review of published articles and gray literature in which estimates for any of the different KRT modalities at the country level were reported. We leveraged a 2016 international survey providing data on the costs of HD and PD across 90 countries.<sup>6</sup> The costs were provided in United States dollars (US\$) and were converted to 2021 US dollars with adjustments for inflation using the web-based tool developed by the **Campbell and Cochrane Economics Methods** Group (CCEMG) and the Evidence for Policy and Practice Information and Coordinating Centre (EPPI-Centre) (http://eppi.ioe.ac.uk/ costconversion/default.aspx) (Figure 2.2).

We also searched for studies with KRT cost information for countries not included in the survey.<sup>6</sup> KRT costs in local currency were first adjusted to 2021 values before converting them to 2021 US dollars using the same web-based tool (Figure 2.2). For countries with multiple published reports on KRT costs, we used costs reported in the most recent publication, adjusted, and converted to US dollars. For most countries, we utilized data from different publications to obtain costs of HD, PD, and kidney transplantation. For countries with publications in the same year reporting different KRT costs (e.g., Canada and Bolivia), we averaged the reported values. When KRT costs were reported per session, week, or month, we calculated annual costs based on conventional dialysis schedules i.e., HD performed three times weekly, and PD involving four bag exchanges daily. We also compared the average cost of maintenance HD with that of maintenance PD using an estimated cost ratio.

If the ratio of the two means was greater than 1 (HD/PD >1), the PD cost was less than the HD cost, and vice versa. All cost data reported were adjusted to per-person, per-year values in US dollars to facilitate cross-country comparisons.

#### Figure 2.2 | KRT cost adjustments and standardization



KRT = kidney replacement therapy, US\$ = United States Dollar

#### 2.4 SURVEY

#### 2.4.1 Development and validation

The ISN–GKHA project was a multinational, cross-sectional survey conducted by the ISN to assess current capacity for KRT around the world. Through our international contacts, collaborators, ISN leaders and regional boards, we identified project leaders at the regional and national levels, including national nephrology association leaders and opinion leaders.

Duties for regional project leaders included:

- To organize and follow up on responses for all countries within the region;
- To serve as a liaison between the steering committee, ISN, and regional stakeholders;
- To provide access to additional data sources and contacts for surveys;
- To identify or serve as an opinion leader on the project for the region; and
- To identify or serve as a resource person to vet and review regional data.

Duties for national project leaders included:

- To organize and follow up on responses within the country;
- To serve as a liaison between the steering committee, ISN, and national stakeholders;
- To provide access to additional data sources and contacts for surveys;
- To identify or serve as an opinion leader on the project for the country; and
- To identify or serve as a resource person to vet and review data for the country.

The framework that was applied to the design of the ISN–GKHA survey to derive information about national capacities and responses to NCD prevention and control considered a number of documents, including WHO UHC: Supporting Country Needs, the ISN AKI "0 by 25" initiative, WHO NCD Surveys (2000, 2005, 2010, 2013, 2015, 2017, 2019), the World Heart Federation "25 by 25" initiative, the International Diabetes Federation Global Diabetes Atlas, the WHO Global Atlas on Cardiovascular Disease Prevention and Control, Lancet commissions in other chronic disease domains, as well as multiple UN policy documents on strategies and policies for NCDs.<sup>7-</sup>

The initial survey questions were further developed through a series of reviews with relevant experts, the ISN Executive Committee, and regional leadership. The survey was peer reviewed for content validity and comprehensiveness before it was piloted with the 10 ISN regional boards to identify any logistical and feasibility issues (e.g., translation needs). The format and content of the survey were finalized based on feedback and identified issues, including translating the original English language survey instrument into French and Spanish.

#### 2.4.2 Structure

The survey was designed in five modules that assessed the national and regional profiles for readiness, capacity, and response to kidney failure corresponding to each of the six UHC domains.<sup>11</sup> Specifically, the modules focused on:

- Health finance and service delivery (UHC domains 1 and 2), with questions evaluating funding mechanisms (CKD and KRT) and intra-national variation in kidney failure care delivery and oversight;
- Health workforce for nephrology care (UHC domain 3), with questions evaluating clinical responsibility and availability of healthcare providers essential for kidney failure care delivery;
- Essential medications and health product access for kidney failure care (UHC domain 4), with questions evaluating the capacity for KRT service provision, preparation for KRT, and nutritional services; access to dialysis and transplant options and the quality of those options; access to CKM; KRT accessibility and affordability, and cost reimbursement plans;
- Health information systems and statistics (UHC domain 5), with questions evaluating the availability of registries and/or other surveillance systems for AKI or CKD; and
- Leadership and governance (UHC domain 6), with questions evaluating national health policies and strategies, advocacy (AKI, CKD,

kidney failure), and barriers to optimal kidney failure care delivery.

The survey was accompanied by a detailed information sheet about the ISN–GKHA, detailed instructions for completion, and a glossary defining key terms used in the survey.

#### 2.4.3 Sampling

A non-probability, purposive sampling approach was employed to identify potential survey respondents. Specifically, national, and regional nephrology leaders identified key stakeholders through the ISN, including representatives of national nephrology societies, policymakers (including those directly responsible for the organization of kidney care and those with more general responsibilities), patient organizations, foundations, and other advocacy groups.

Key stakeholders were sent invitations to participate that included a link to the survey's online portal (an electronic survey via REDCap, <u>www.project-redcap.org</u>). Respondents were asked specifically about important within-country heterogeneity and were asked to identify other potential key respondents, thereby increasing the likelihood that relevant information would be widely captured. The survey was conducted from June to September 2022. During this period, intensive follow-ups were conducted by email and telephone with ISN regional and national leaders to ensure complete and timely responses.

# 2.4.4 Survey of people living with kidney disease

A survey of people living with kidney disease was also conducted to assess first-hand the perspectives of people receiving kidney care on the availability and access to kidney care in their region. Members of the ISN–Patient Liaison Advisory Group (ISN–PLAG) (www.theisn. org/in-action/advocacy/advocacy-activities/ patient-liaison-advisory-group/) were contacted to participate in the survey. Members of the ISN-PLAG were sent invitations to participate that included a link to the survey's online portal electronic survey via REDCap. The focus of the survey of people living with kidney disease was to understand the quality of care received, ease of accessing essential medications, funding of care (pre-dialysis, dialysis, and kidney transplantation), availability of healthcare professionals, obstacles encountered in accessing care, and how they perceive and grade health outcomes.

#### 2.4.5 Data handling

To facilitate data collation, responses to the French and Spanish surveys were first converted to English by certified translators. Then, data from all individual surveys were automatically extracted and cleaned using Microsoft Excel and merged into a single file to create the global database. This was housed in a secure, centralized computer system with automated backups. ISN regional leaders were consulted to ensure that collated data were consistent with their understandings and were of high quality. Each regional board reviewed their output to clarify any ambiguity or inconsistencies. Any major inconsistencies that remained after the reviews were systematically addressed during followup inquiries with stakeholders involved with the survey. Further validation was carried out at the national and regional levels by triangulating the findings with published literature and gray sources of information (i.e., government reports and other sources provided by the survey respondents).

#### 2.4.6 Analysis

The framework developed by the WHO, Assessing National Capacity for the Prevention and Control of NCDs, was leveraged during statistical analysis of the collated data.<sup>12</sup> The analysis was conducted using STATA 17 software (Stata Corporation, 2017). Using country as the unit of analysis, responses were summarized based on the key survey domains using a descriptive statistical approach and reported as counts with percentages or medians with interguartile ranges (IQR), where appropriate. Results were stratified by ISN region and by World Bank income group (estimated in June 2022). The results were examined with an emphasis on identification of key gaps and challenges across the various domains based on the pre-existing protocol and reported according to the Guidelines for Accurate and Transparent Health Estimates Reporting (GATHER) statement.13

#### SECTION THREE

### Literature review

### Key messages

- The global median prevalence of CKD is 9.5% and is highest in Eastern and Central European countries (12.8%) and lowest in African countries (4.2%).
- The proportion of deaths related to CKD generally increases with income level, with a slight decrease in HICs: LICs (1.5%), LMICs (2.6%), UMICs (3.1%), and HICs (2.9%).
- There is an immense shortage of health workforce (physicians, medical doctors, and nurses) in LICs with physician density 30-fold higher in HICs than in LICs.
- The incidence and prevalence of treated kidney failure, chronic dialysis (HD and PD), and kidney transplantation increases with income levels.
- Somalia (US \$2) has the lowest government health spending per person compared to the United States (US \$6,578), Norway (US \$6,300), and Luxembourg (US \$5,976) that report approximately 3,000-fold higher spending per person.
- The global annual median cost of KRT is HD (US \$19,380); PD (US \$18,959); and kidney transplantation (1st year – US \$26,903).

#### CKD: PREVALENCE, DALYS, DEATHS - OVERVIEW OF GBD DATA

#### 3.1.1 Overview of CKD prevalence

Information on the prevalence of CKD is available in 73.9% (n = 161) of countries worldwide (Map 3.1), with a global median prevalence of 9.5%. Eighty countries (49.6%) have a CKD prevalence rate higher than the global average. The median prevalence of CKD is highest in Eastern and Central Europe (12.8%; n = 19) and lowest in Africa (4.2%; n = 45). The three countries with the highest prevalence of CKD are Japan (20.2%), Puerto Rico (16.8%), and Estonia (16.8%). The three countries with the lowest prevalence of CKD are in Africa: Uganda (3.0%), Somalia (3.0%), and Chad (3.2%). The prevalence of CKD increases with income level: LICs (3.6%), LMICs (7.5%), UMICs (10.7%), and HICs (11.1%).

# 3.1.2 Overview of DALYs attributable to CKD

Information on the disability-adjusted life years (DALYs) attributable to CKD (i.e., years of full health lost due to CKD) is available in 73.4% (n = 160) of countries worldwide (Map 3.1). Globally, the median percentage of DALYs attributable to CKD is 1.5%, ranging from 3.6% in North America and the Caribbean to 1.0% in Africa. The percentage of DALYs attributable to CKD increases with income levels from LICs (0.9%) to LMICs (1.7%), and UMICs (2.3%). However, it was lower in HICs (1.4%) than in UMICs (1.7%). The three countries with the lowest DALYs are Ukraine (0.4%), Belarus (0.5%), and Niger (0.6%), and the three countries with the highest DALYs are Nicaragua (7.1%), El Salvador (6.5%), and Mexico (6.3%).

#### Map 3.1 | CKD prevalence, DALYs attributed to CKD, death attributed to CKD

• CKD prevalence • DALY attributed to CKD • Death attributed to CKD



1 Estimates as high as 15.8% have been reported from other studies (Kaze et al. BMC Nephrol. 2018 doi: 10.1186/s12882-018-0930-5)

#### 3.1.3 Overview of CKD-related deaths

Information on CKD-related mortality is available in 73.4% (n = 160) of countries worldwide (Map 3.1) with a global median death rate of 2.4%. In 80 countries (50%), the percentage of deaths attributable to CKD is higher than the global average. The percentage of deaths attributable to CKD is lowest in the NIS and Russia (1.4%) and highest in Latin America (5.5%). The three countries with the lowest percentage of deaths attributable to CKD are Ukraine (0.4%), Belarus (0.4%), and Moldova (0.6%), whereas Mexico (9.8%), El Salvador (10.2%), and Nicaragua (11.9%) have the highest percentage of deaths attributable to CKD. The proportion of deaths related to CKD generally increases with income level, with a slight decrease in HICs: LICs (1.5%), LMICs (2.6%), UMICs (3.1%), and HICs (2.9%).

#### **3.2 GLOBAL AVAILABILITY OF HEALTH WORKFORCE**

#### 3.2.1 Global density of physicians

Information on the density of physicians (including generalist and specialist medical practitioners) is available in 73.9% (n = 161) of countries worldwide with a global median density of 1.9 physicians per 1,000 population (Map 3.2). Western Europe has the highest physician density (3.9 per 1,000 population) while Africa has the lowest (0.2 per 1,000 population). The three countries with the highest physician densities are Cuba (8.4 per 1,000 population), Georgia (7.1 per 1,000 population), and Lithuania (6.4 per 1,000 population), whereas the three countries with the lowest

Per 1000 population

#### Map 3.2 | Global density of health workforce

Physicians (including generalist and specialist medical practitioners)
 All medical doctors
 Nurses



densities are in Africa: Tanzania (0.01 per 1,000 population), Somalia (0.02 per 1,000 population), and Sierra Leone (0.03 per 1,000 population). Physician density increases with income level, with HICs having about a 30-fold higher density of physicians (3.0 per 1,000 population) than LICs (0.1 per 1,000 population).

#### 3.2.2 Global density of medical doctors

Information on the density of all medical doctors is available in 72.9% (n = 159) of countries worldwide, with a global median density of 17.7 medical doctors per 1,000 population (Map 3.2). Western Europe has the highest density of medical doctors (42.3 per 1,000 population) while Africa has the lowest density (1.5 per 1,000 population). The density of medical doctors increases with income level: LICs (1.0 per 1,000 population), LMICs (7.3 per 1,000 population), UMICs (22.3 per 1,000 population), and HICs (34.7 per 1,000 population). Cuba (84.2 per 1000 population), Sweden (70.9 per 1000 population), and Greece (63.1 per 1000 population) have the highest densities of medical doctors, while Somalia (0.2 per 1,000 population), Niger (0.4 per 1,000 population), and Malawi (0.5 per 1,000 population) have the lowest densities.

#### 3.2.3 Global density of nurses

Information on the density of nurses is available in 72.9% (n = 159) of countries worldwide, with a global median density of 36.2 nurses per 1,000 population (Map 3.2). Western Europe has the highest density of nurses (117.8 per 1,000 population) while Africa has the lowest density (9.5 per 1,000 population). Accordingly, the three countries with the highest nurse densities are in Western Europe, i.e., Finland (223.1 per 1,000 population), Belgium (200.8 per 1,000 population), and Norway (184.2 per 1,000 population), while the three countries with the lowest densities are in Africa, i.e., Somalia (1.1 per 1,000 population), Chad (2.0 per 1,000 population), and Niger (2.2 per 1,000 population). The density of nurses also increases with income level: LICs (7.7 per 1,000 population), LMICs (15.5 per 1,000 population), UMICs (38.0 per 1,000 population), and HICs (81.2 per 1,000 population).

#### **3.3 TOTAL HEALTH EXPENDITURE**

# 3.3.1 Total health spending per person in 2021

Information on total health spending per person in 2021 is available in 73.9% (n = 161) of countries worldwide, with a global median of US \$353 (Map 3.3). Africa (US \$54) and South Asia (US \$56) have the lowest total health spending per person while Western Europe has the highest total health spending per person (US \$5,088). Total health spending per person is disproportionately higher in HICs (US \$2,218) than in other income groups: LICs (US \$43), LMICs (US \$85), and UMICs (US \$404). The three countries with the lowest total health spending per person in 2021 are in Africa: Somalia (US \$8), Eritrea (US \$17), and the Democratic Republic of the Congo (US \$22). The three countries that spend the most on health per person are the United States (US \$11,705), Switzerland (US \$9,801), and Norway (US \$7,254).

# 3.3.2 Government health spending per person in 2021

Information on government health spending per person in 2021 is available in 73.9% (n = 161) of countries worldwide, with a global median of US \$216 (Map 3.3). By region, South Asia (US \$13) has the lowest government health spending per person, while Western Europe (US \$3,798) has the highest government health spending per person. Somalia (US \$2) has the lowest government health spending per person; in comparison, the governments of the United States (US \$6,578), Norway (US \$6,300), and Luxembourg (US \$5,976) report approximately 3,000-fold higher spending per person. Government health spending per person also increases with income level: LICs (US \$9), LMICs (US \$35), UMICs (US \$247), and HICs (US \$1,642).

# 3.3.3 Development assistance for health per person in 2021

Information on development assistance for health (DAH), defined as the financial and inkind contributions transferred through major development agencies to low- and middleincome countries for maintaining or improving health, in 2021 is available in 73.9% (n = 161) of countries worldwide. (Map 3.3). Global median DAH per person is US \$2, with countries in Africa receiving the highest DAH per person (US \$11). The median DAH received per person in Eastern and Central Europe, The Middle East, North America and the Caribbean, North and East Asia, and Western Europe is US \$0. DAH per person decreases as income level increases: LICs (US \$11), LMICs (US \$6), UMICs (US \$3). Sixty-three countries receive no DAH, while Swaziland (US \$86), Mongolia (US \$59), and Namibia (US \$46) receive the highest DAH per person.

#### Map 3.3 | Health spending



#### **3.4 TREATED KIDNEY FAILURE**

#### 3.4.1 Incidence of treated kidney failure

Data on the incidence of treated kidney failure (i.e., people newly treated with chronic dialysisor kidney transplant recipients) is available in 38.5% (n = 84) of 218 World Bank countries (Map 3.4). The global median incidence of treated kidney failure is 146 pmp [IQR: 107-213]. Taiwan (529 pmp) has the highest incidence while Ecuador (19 pmp) has the lowest incidence. The three regions with the highest incidence are: North America and the Caribbean (309 pmp), North and East Asia (306 pmp), and OSEA (283 pmp). The region with the lowest incidence is South Asia (64 pmp). The incidence of treated kidney failure increases with income: LMICs (106 pmp), UMICs (123 pmp), and HICs (165 pmp). Incidence data are unavailable for any LICs.

#### Map 3.4 | Global incidence of treated kidney failure



#### Map 3.5 | Global prevalence of treated kidney failure

Rate per million population (pmp), age  $\geq$  18 years



#### 3.4.2 Prevalence of treated kidney failure

Information on the prevalence of treated kidney failure (i.e., the number of people treated with dialysis or kidney transplant recipients) is available in 43.6% (n = 95) of countries worldwide (Map 3.5). The global median prevalence of treated kidney failure is 823 pmp [IQR: 556-1114]. The highest prevalence of treated kidney failure is reported in Taiwan (3679 pmp), Japan (2696 pmp), and the United States (2465 pmp). Rwanda (4.4 pmp) has the lowest prevalence and is the only LIC with prevalence data. Surprisingly, North America doesn't rank in the top 3 given the high prevalence in US and Canada. The three regions with highest prevalence of treated kidney failure are North and East Asia (2100 pmp), OSEA (1203 pmp), and Western Europe (1034 pmp), whereas South Asia (116 pmp) has the lowest prevalence. The prevalence of treated kidney failure increases with income: LICs (4 pmp), LMICs (499 pmp), UMICs (610 pmp), and HICs (1009 pmp).

#### 3.5.1 Incidence of chronic dialysis

There are limited data on the incidence of chronic dialysis (i.e., HD and PD), with information available in only 18.8% (n = 41) of countries worldwide (Map 3.6). There are no data for Africa, The Middle East, the NIS and Russia, and South Asia. Globally, the average number of people starting dialysis is 119 pmp, ranging from 103 pmp in Western Europe to 289 pmp in North America and the Caribbean. Data on the incidence of chronic dialysis are unavailable for LICs; for countries in other groups, incidence increases with income: LMICs (105 pmp; n = 4), UMICs (109 pmp; n = 12), and HICs (129 pmp; n = 25). The incidence of chronic dialysis is highest in the United States (374.1 pmp), Singapore (364.2 pmp), and Thailand (308.6 pmp) and the lowest in Ecuador (6.0 pmp).



#### Map 3.6 | Global incidence of chronic dialysis

#### **3.5 CHRONIC DIALYSIS**

# 3.5.2 Prevalence of treated chronic dialysis

Information on the prevalence of chronic dialysis (i.e., HD and PD) is available in 62.4% (n = 136) of countries worldwide (Map 3.7). The global median prevalence of chronic dialysis is 397 pmp; prevalence is highest in North and East Asia (1692 pmp) and lowest in Africa (15 pmp). Taiwan (3510 pmp), Japan (2639 pmp), and Singapore (2030.3 pmp) have the highest prevalences of chronic dialysis while Tanzania (0.5 pmp), the Democratic Republic of the Congo (0.6 pmp), and Mozambique (0.9 pmp) have the lowest prevalences. The prevalence of chronic dialysis also increases with income level: LICs (5 pmp), LMICs (53 pmp), UMICs (399 pmp), and HICs (601 pmp).



#### Map 3.7 | Global prevalence of chronic dialysis

Rate per million population (pmp), age  $\geq$  18 years

#### **3.6 CHRONIC HEMODIALYSIS**

#### 3.6.1 Incidence of chronic hemodialysis

Information on the incidence of chronic HD is available in 12.8% (n = 28) of countries worldwide, all of which are UMICs (115 pmp, n = 6) and HICs (105 pmp, n = 22) (Map 3.8). The global median incidence of chronic HD is 107 pmp, which is higher than the incidence rate in Eastern and Central Europe (104 pmp), North and East Asia (58 pmp), and Western Europe (82 pmp). Only North America and the Caribbean (246 pmp) and OSEA (168 pmp) have higher incidence rates than the global average. The incidence of chronic HD ranges from 22.1 pmp in Hong Kong to 336.1 pmp in the United States. Data are not available for Africa, Latin America, The Middle East, NIS and Russia, and South Asia.

#### Map 3.8 | Global incidence of chronic hemodialysis



#### Map 3.9 | Global prevalence of chronic hemodialysis

Rate per million population (pmp), age  $\geq$  18 years



#### 3.6.2 Prevalence of chronic hemodialysis

Information on the prevalence of chronic HD is available in 59.2% (n = 129) of countries worldwide (Map 3.9). The global median prevalence of the number of people receiving HD is 323 pmp, with much variability across countries and regions. Africa (12 pmp) has the lowest prevalence of chronic HD, while North and East Asia (1575 pmp) have the highest prevalences. Japan (2561.2 pmp), Taiwan (2106.8 pmp), and Turks and Caicos (1882.4 pmp) have the highest prevalences of chronic HD, whereas the Democratic Republic of the Congo (0.3 pmp), the Republic of the Congo (0.4 pmp), and Tanzania (0.5 pmp) have the lowest prevalences. The prevalence of chronic HD increases with income level: LICs (5 pmp), LMICs (35 pmp), UMICs (331 pmp), and HICs (523 pmp).

#### **3.7 CHRONIC PERITONEAL DIALYSIS**

# 3.7.1 Incidence of chronic peritoneal dialysis

Data on the incidence of chronic PD are available in 11.9% (n = 26) of countries worldwide, all of which are UMICs (n = 4) and HICs (n = 22) (Map 3.10). Globally, the number of people initiating chronic PD is 22 pmp, ranging from 2.0 pmp in Romania to 140.6 pmp in Thailand. The highest incidences of chronic PD are found in Thailand (140.6 pmp), Hong Kong (132.6 pmp), and New Zealand (69.7 pmp). The number of people initiating chronic PD is 9 pmp in Eastern and Central Europe, 43 pmp in North America and the Caribbean, 133 pmp in North and East Asia, 46 pmp in OSEA, and 21 pmp in Western Europe. Incidence data are unavailable for Africa, Latin America, The Middle East, the NIS and Russia, and South Asia, as well as LICs and LMICs.

#### Map 3.10 | Global incidence of chronic peritoneal dialysis

Rate per million population (pmp), age ≥ 18 years



# **3.7.2 Prevalence of chronic peritoneal dialysis**

Information on the prevalence of chronic PD is available in 62.8% (n = 137) of countries worldwide, with much variability across countries and regions (Map 3.11). Globally, the number of people receiving chronic PD is 21 pmp and increases with income level: LICs (0.7 pmp), LMICs (1.3 pmp), UMICs (18 pmp), and HICs (56 pmp). The variation in prevalence is high in Africa: several countries report no people living with kidney disease and treated with chronic PD, whereas South Africa reports a prevalence of 23.3 pmp. Hong Kong (620.8 pmp), Mexico (474 pmp), and El Salvador (380 pmp) have the highest prevalences of chronic PD, and the top three regions are North and East Asia (126 pmp), OSEA (95 pmp), and Latin America (60 pmp).



#### Map 3.11 | Global prevalence of chronic peritoneal dialysis

#### **3.8 KIDNEY TRANSPLANTATION**

#### 3.8.1 Incidence of kidney transplantation

Information on the incidence of kidney transplantation is available in 50.5% (n = 110) of countries worldwide, with data available from all income levels and regions (Map 3.12). Globally, the number of people receiving new kidney transplants is 12 pmp, ranging from 2 pmp in Africa to 42 pmp in Western Europe. The three countries with the highest incidences of kidney transplantation are the United States (76.6 pmp), Spain (63.2 pmp), and Israel (54.1 pmp). Four regions have higher incidences of kidney transplantation than the global average: Eastern and Central Europe (20 pmp), The Middle East (15 pmp), North America and the Caribbean (40 pmp), and Western Europe (42 pmp). HICs have a higher incidence of kidney transplantation (29 pmp) than UMICs (6 pmp), LMICs (2 pmp), and LICs (3 pmp).

#### Map 3.12 | Global incidence of kidney transplantation



#### Map 3.13 | Global prevalence of kidney transplantation

Rate per million population (pmp), age  $\geq$  18 years

<58 pmp</p>
58-278.9 pmp
279-491.9 pmp
≥492 pmp
Data not reported



# 3.8.2 Prevalence of kidney transplantation

Data on the prevalence of kidney transplantation (i.e., number of people living with a kidney transplant) are available in 36.2% (n = 79) of countries worldwide, but not in LICs (Map 3.13). Globally, the number of people living with a kidney transplant is 279 pmp, and prevalence increases with country income level: LMICs (12 pmp), UMICs (83 pmp), and HICs (417 pmp). Within each ISN region, countries with the highest prevalences of kidney transplantation are: South Africa (25.4 pmp; Africa), the Czech Republic (490 pmp; Eastern and Central Europe), Mexico (704 pmp; Latin America), Kuwait (402 pmp; The Middle East), the Russian Federation (69 pmp; NIS and Russia), Hong Kong (503 pmp; North and East Asia), the United States (729 pmp; North America and the Caribbean), Australia (505 pmp; OSEA), Bangladesh (6.0 pmp; South Asia), and Spain (751.2 pmp; Western Europe).

# 3.8.3 Incidence of deceased donor kidney transplantation

Information on the incidence of kidney transplantation using organs from deceased donors is available in 48.6% (n = 106) of countries worldwide (Map 3.14). The global median incidence of deceased donor kidney transplantation is 3 pmp. The incidence is higher than the global average in four regions: Eastern and Central Europe (15 pmp), North America and the Caribbean (30 pmp), North and East Asia (5 pmp), and Western Europe (29 pmp). Incidence data on deceased donor kidney transplantation are only available in UMICs (2 pmp) and HICs (21 pmp). Twenty-eight (26.4%) countries report zero transplants of kidneys from deceased donors, suggesting that only living donor transplants occur in these countries. The three countries with the highest incidence rates of deceased donor kidney transplantation are the United States (58.6 pmp), Spain (56.3 pmp), and France (42.1 pmp).

#### Map 3.14 | Global incidence of deceased donor kidney transplantation



# 3.8.4 Incidence of living donor kidney transplantation

Information on the incidence rate for kidney transplantation using organs from living donors is available in 48.6% (n = 106) of countries worldwide (Map 3.15). Globally, the average rate for transplants using organs from living donors is 3.0 pmp, ranging from 1 pmp in Africa to 11 pmp in both The Middle East and North America and the Caribbean. The incidence of living donor kidney transplantation is higher in LICs (3 pmp) than in LMICs (2 pmp) and UMICs (2 pmp). Within each ISN region, the countries with the highest incidences of living donor kidney transplantation are: Egypt (15.5 pmp; Africa), Turkey (26.7 pmp; Eastern and Central Europe), Mexico (11.5 pmp; Latin America), Kingdom of Saudi Arabia (27.0 pmp; The Middle East), Tajikistan (17.2 pmp; NIS and Russia), the Republic of Korea (27.9 pmp; North and East Asia), the United States (17.9 pmp; North America and the Caribbean), New Zealand (18.1

pmp; OSEA), Sri Lanka (9.8 pmp; South Asia), and Israel (37.2 pmp; Western Europe).

# 3.8.5 Incidence of pre-emptive kidney transplantation

Information on the incidence of pre-emptive kidney transplantation (i.e., performed before dialysis is required) is available in 9.2% (n = 20) of countries worldwide (Map 3.16). Only two of the 20 countries with data are UMICs (Serbia and Bosnia and Herzegovina), while the others are all HICs. The global median incidence of pre-emptive kidney transplantation is 5.9 pmp and is highest in North America and the Caribbean (32 pmp). The three countries with the highest incidences of pre-emptive kidney transplantation are the United States (59 pmp), the Netherlands (16.8 pmp), and Iceland (13.9 pmp). The incidence of pre-emptive kidney transplantation is highest in North America and the Caribbean (32 pmp) followed by Western Europe (7 pmp).

#### Map 3.15 | Global incidence of living donor kidney transplantation





#### Map 3.16 | Global incidence of pre-emptive kidney transplantation



#### **3.9 COST OF KRT**

#### 3.9.1 Maintenance HD

Data on cost of in-center maintenance HD are available in half of countries worldwide (50%; n = 109), with data available in 6 LICs, 25 LMICs, 30 UMICs and 48 HICs. The global median annual cost of maintenance HD in 2021 is US \$19,380 per person and ranges from US \$11,818 to US \$38,005. The three regions with the highest annual costs of maintenance HD per person are Western Europe (US \$65,842), North America and the Caribbean (US \$39,826), and The Middle East (US \$26,226) (Map 3.17). The three regions with the lowest annual costs of maintenance HD per person are South Asia (US \$4,310), the NIS and Russia (US \$8,458), and OSEA (US \$10,086). Burkina Faso has the lowest annual cost of maintenance HD (US \$1,646) while Costa Rica has the highest annual cost (US \$103,443). Annual in-center maintenance HD cost increases with income level, with median values of US \$9,065 in LICs, US \$10,115 in LMICs, US \$14,872 in UMICs, and US \$37,685 in HICs (Figure 3.1).



(2021 US\$)



#### Map 3.17 | Median cost of KRT

O In-center HD cost O KT 1st year cost

#### 2021 US\$



#### 3.9.2 Maintenance PD

Overall, data on the annual cost of maintenance PD (i.e., continuous ambulatory PD) are available in 41.7% (n = 91) of countries worldwide, nearly half of which are HICs (49.5%; n = 45). Overall, the median annual cost of maintenance PD is US \$18,959. LICs report the highest annual cost of maintenance PD (US \$30,064); among other groups, the annual cost increases by income level, from US \$7,005 in LMICs to US \$14,474 in UMICs to US \$27,206 in HICs (Figure 3.1). The three regions with the highest annual cost of maintenance PD per person are North America and the Caribbean (US \$39,826), Western Europe (US \$35,218), and Eastern and Central Europe (US \$21,765); only these regions report values higher than the global average. The three regions with the lowest annual costs of maintenance PD are South Asia (US \$5,531), OSEA (US \$8,382), and the NIS and Russia (US \$13,847) (Map 3.17). The cost of maintenance PD is lowest in Turkey (US \$2,592) and highest in the United Arab Emirates (US \$109,721).

#### 3.9.3 Kidney transplantation

Data on the first-year cost of kidney transplantation are only available in 27.5% (n = 60) of countries worldwide. Overall, the average first-year cost of kidney transplantation is US \$26,903, ranging from US \$15,425 to US \$70,749. Only HICs (US \$71,446) report a higher first-year cost of kidney transplantation than the global average (Figure 3.1). The first-year cost of kidney transplantation is disproportionately higher in North America and the Caribbean (US \$265,045) than in other regions, followed by Western Europe (US \$74,089) and North and East Asia (US \$69,900) (Map 3.17). The three countries with the highest first-year costs of kidney transplantation include the United States (US \$451,697), Kingdom of Saudi Arabia (US \$156,050), and Slovenia (US \$140,066), while Nepal (US \$3,969), Bangladesh (US \$4,142), and Myanmar (US \$4,980) are the three countries with lowest first-year costs of kidney transplantation.

#### 3.9.4 Comparison of KRT costs

Data regarding the costs of HD and PD are available in 41.7% (n = 91) of countries worldwide; the cost ratio of HD to PD is greater than 1 in 52.7% (n = 48) of countries and is less than 1 in 41.8% (n = 38) of countries. In five countries (Vietnam, Philippines, Portugal, the United States, and Namibia), the HD to PD cost ratio is exactly 1, meaning the price is the same for both modalities. The three countries with the highest ratios are Costa Rica (4.27), Iceland (4.27), and Turkey (3.88) indicating a much lower cost of PD than HD, while Sudan (0.29), Bosnia and Herzegovina (0.43), and Spain (0.45) have the lowest ratios, indicating a much lower HD cost relative to PD. A comparison of the annual cost of HD to the first-year cost of kidney transplantation shows a disproportionately low ratio for the United States (0.09), suggesting a much lower HD cost relative to kidney transplantation, while this ratio is highest in Switzerland (4.89), suggesting that kidney transplantation is much cheaper than HD in the first year.



# Survey Results

# Survey Response

A total of 167 countries responded to the survey, representing 97.4% of the world's population (Map 4.0; Appendix 1). The list of participating countries, their 2021 World Bank income levels, and their regional grouping within the ISN are provided in Appendix 2. The affiliations of survey respondents were nephrologists (81%), non-nephrologist physicians (5%), non-physician health care professionals (2%), administrators/policymakers (4%), and others affiliated with advocacy groups for people living with kidney disease (5%) (Appendix 3). Details of the respondents are listed in Appendix 4.

#### Map 4.0 | Countries that participated in the ISN survey

Participated Did not participate



SECTION FOUR

# Health finance and service delivery

#### Key messages

- More countries in Western Europe (91%) publicly fund AKIrelated dialysis than countries in other regions.
- Only LICs (20%) and LMICs (9%) fund non-dialysis CKD care through solely private and out-of-pocket methods.
- Publicly funded (and free at point of delivery) chronic HD is only available in 45% of countries worldwide.
- Publicly funded (and free at point of delivery) chronic PD is available in only 42% of countries worldwide.
- By income group, the percentages of countries providing public funding to fully cover the costs of kidney transplant medications is highest among HICs (60%) and lowest among LMICs (4%).
- Only few LICs (13%) and LMICs (18%) provide universal health coverage for all aspects of KRT
- A greater percentage of HICs (85%) provide coverage to all residents for KRT than countries in other income groups: UMICs (84%), LMICs (71%), and LICs (53%).

#### 4.1 HEALTHCARE SYSTEM AND FUNDING MECHANISM

There are extensive regional variations in the funding mechanisms for non-dialysis CKD (Figure 4.1), including public funding with free services at the point of delivery, a mixture of public and private funding, and solely private funding and out-of-pocket payments. The three regions with the highest percentages of countries where costs of non-dialysis CKD are publicly funded by the government and free at the point of delivery are Western Europe (73%), Eastern and Central Europe (44%), and South Asia (37%). Roughly half of the countries in Latin America (59%), The Middle East (55%), and North America and the Caribbean (50%) fund non-dialysis CKD care through a combination of public and private sources, and care may be free or require a co-payment at the point of delivery. A small percentage of countries in Africa (17%) and OSEA (5%) exclusively utilize private funding and out-of-pocket payment systems to fund non-dialysis CKD. The exclusive use of private and out-of-pocket payment methods is reported in LICs (20%) and LMICs (9%), but not in other income groups. Likewise, funding of non-dialysis CKD exclusively through private through health

insurance providers is reported only in a small percentage of HICs (2%). Publicly funded and free non-dialysis CKD services are more common in HICs (46%) than in other income groups. However, similar percentages of countries provide public funding with some fees at the point of delivery for non-dialysis CKD across all income groups: LICs (20%), LMICs (22%), UMICs (15%), and HICs (19%) (Figure 4.1).

Public funding for KRT (including dialysis for AKI, chronic HD, chronic PD, and kidney transplantation) differs by treatment type and region (Map 4.1). More countries in Western Europe (91%) publicly fund AKI-related dialysis than countries in other regions, with countries in North and East Asia (17%), Africa (24%), and South Asia (25%) using this method the least. Publicly funded and free dialysis for AKI increases with income level: LICs (15%), LMICs (22%), UMICs (45%), and HICs (69%) (Figure 4.2). Publicly funded chronic HD that is free at the point of delivery is only available in 45% of countries worldwide and is more readily available in Western Europe (86%), The Middle East (73%),

#### Figure 4.1 | Funding models for non-dialysis CKD

Publicly funded by government and free at the point of delivery (%) Publicly funded by government but with some fees at the point of delivery (%) A mix of publicly funded and private systems (%) Solely private and out-of-pocket (%) Solely private through health insurance providers (%) Multiple systems – programs provided by government, NGOs, and communities (%) Other (%) Africa Eastern and Central Europe Latin America The Middle East NIS and Russia North America & Caribbean North and East Asia OSEA South Asia Western Europe World Bank income group: Low income Lower-middle income Upper-middle income High income

#### Map 4.1 | Publicly funded by government and free KRT

Unialysis for AKI (HD or PD) O Chronic HD Chronic PD O Medications for kidney transplantation



and Eastern and Central Europe (69%). Fewer countries in North and East Asia (17%), OSEA (17%), and Latin America (27%) utilize this model of funding for chronic HD than in other regions (Map 4.1). Publicly funded and free HD increases with income level: LICs (25%), LMICs (29%), UMICs (45%), and HICs (62%) (Figure 4.2).

Publicly funded chronic PD that is free at the point of delivery is available in only 42% of countries worldwide. The proportion of countries using this funding mechanism for chronic PD is below the global average in OSEA (11%), Africa (15%), North and East Asia (17%), Latin America (27%), and South Asia (38%) (Map 4.1). The proportion of countries providing public funding for chronic PD that is free at the point of delivery increases with income level: LICs (15%), LMICs (16%), UMICs (45%), and HICs (67%) (Figure 4.2). Worldwide, medications for kidney transplantation are publicly funded by the government and are free at the point of delivery in only 36% of countries. Use of this method of funding varies

#### Figure 4.2 | KRT publicly funded by the government and free at the point of delivery



across ISN regions (Map 4.1). More countries in Western Europe (86%) provide public funding that fully covers the cost of kidney transplant medications than other ISN regions; in contrast, only 11% of countries in OSEA provide such public funding. By income group, the percentage of countries providing public funding to fully cover the costs of kidney transplant medications is highest among HICs (60%) and lowest among LMICs (4%) (Figure 4.3).

In public funding models, universal coverage for KRT (i.e., KRT covering all residents) increases with income level (Figure 4.3). A greater percentage of HICs (85%) provide universal coverage for KRT to all residents than countries in other income groups: UMICs (84%), LMICs (71%), and LICs (53%). Among countries that provide partial public funding for KRT (49%), some exclude various aspects of KRT, including dialysis (7%), transplantation (21%), management

# Figure 4.3 | Extent of universal coverage for KRT in countries with publicly funded systems

Countries covering all residents (%)
 Countries not covering all residents (%)

Low income	
Lower-middle income	
Upper-middle income	
High income	
rigrinoonic	

Note: 117 countries have publicly funded systems

of associated complications (anemia, bone mineral disorder, malnutrition) (25%), and comprehensive CKM (30%) (Table 4.1). No countries in Eastern and Central Europe, North America and the Caribbean, North and East Asia, OSEA, South Asia, and Western Europe provide public funding for KRT that excludes dialysis, but some countries in Latin America (19%) and Africa (15%) with this funding model do exclude dialysis. A significant percentage of countries in

	Dia N	lysis (%)	Kid transpl N	Iney antation (%)	Compre Ck N	hensive (M <sup>1</sup> (%)	Manag of asso complie N	jement ociated cations <sup>2</sup> (%)	None aspects N	e - all s funded (%)	Oti N (	her (%)
Overall	11	(7)	32	(21)	45	(30)	38	(25)	73	(49)	10	(8)
ISN region												
Africa	5	(15)	18	(53)	19	(56)	15	(44)	7	(21)	2	(11)
Eastern and Central Europe	0	(0)	0	(0)	2	(13)	1	(6)	15	(94)	0	(0)
Latin America	4	(19)	5	(24)	10	(48)	6	(29)	8	(38)	2	(10)
The Middle East	1	(9)	1	(9)	4	(36)	2	(18)	6	(55)	0	(0)
NIS and Russia	1	(10)	3	(30)	6	(60)	6	(60)	3	(30)	1	(10)
North America & Caribbean	0	(0)	4	(33)	1	(8)	2	(17)	5	(42)	0	(0)
North and East Asia	0	(0)	1	(17)	0	(0)	1	(17)	1	(17)	3	(50)
OSEA	0	(0)	0	(0)	1	(8)	2	(15)	7	(54)	1	(8)
South Asia	0	(0)	0	(0)	1	(14)	1	(14)	4	(57)	0	(0)
Western Europe	0	(0)	0	(0)	1	(5)	2	(10)	17	(85)	1	(6)
World Bank income group												
Low income	1	(7)	10	(67)	8	(53)	6	(40)	2	(13)	0	(0)
Lower-middle income	7	(18)	11	(29)	21	(55)	18	(47)	7	(18)	2	(7)
Upper-middle income	3	(8)	8	(22)	12	(32)	10	(27)	19	(51)	3	(8)
High income	0	(0)	3	(5)	4	(7)	4	(7)	45	(75)	5	(9)

#### Table 4.1 | Aspects of KRT excluded from public funding

1. Kidney palliative supportive services

2. Anaemia, bone disease, malnutrition

Africa (53%), North America and the Caribbean (33%), and the NIS and Russia (30%) exclude transplantation from public funding, whereas no countries in Eastern and Central Europe, OSEA, South Asia, and Western Europe exclude

transplantation. Except for dialysis, which a smaller percentage of LICs (7%) exclude from public funding than LMICs (18%), the exclusion of other aspects of KRT from public funding decreases as income level increases (Table 4.1).

#### Figure 4.4 | Funding models for KRT-related surgical services

Publicly funded by government and free at the point of delivery (%)

Publicly funded by government but with some fees at the point of delivery (%)

- A mix of publicly funded and private systems (%)
- Solely private and out-of-pocket (%)
- Solely private through health insurance providers (%)
- Multiple systems programs provided by government, NGOs, and communities (%) Other (%)

Vascular access for hemodialysis (central venous catheters)

Africa Eastern and Central Europe Latin America The Middle East NIS and Russia North America & Caribbean North and East Asia OSFA South Asia Western Europe



#### Vascular access for hemodialysis (fistula or graft creation)

Africa Eastern and Central Europe Latin America The Middle East NIS and Russia North America & Caribbean North and East Asia OSEA South Asia Western Europe

Eastern and Central Europe

Africa

OSEA South Asia Western Europe

Latin America

NIS and Russia

North and East Asia







#### Surgery for kidney transplantation

Africa Eastern and Central Europe Latin America The Middle East NIS and Russia North America & Caribbean North and East Asia OSFA South Asia Western Europe



Coverage for surgical services for KRT (i.e., fistulas, grafts, and central venous catheters [CVCs] for HD, catheter insertion for PD, and kidney transplantation) varies worldwide. In 90% of countries in Western Europe, all surgical services for KRT are publicly funded by the government and free at the point of delivery (Figure 4.4). The proportion of countries providing public funding with some fees and a mix of public and private funding varies by region. The proportion of countries where the costs of CVC insertion (28%) and fistula and graft creation (32%) are covered exclusively via private and out-of-pocket payments is highest in Africa. The proportion of countries using this funding mechanism for PD catheter insertion (28%) is highest in OSEA; for kidney transplantation (37%), the proportion of countries is highest in South Asia.

#### 4.2 WITHIN-COUNTRY VARIATION IN KIDNEY FAILURE CARE DELIVERY

The data show different levels of within-country variation in the organization, cost, and access to kidney failure care. HICs have the lowest within-country variation in organization of kidney failure care (24%) suggesting better structures

### Figure 4.5 | Within country variation in organization and cost

Variation in organization of kidney failure care



and organization of care than in countries with other income levels (Figure 4.5). Within-country variation in cost of kidney failure care is also lowest for HICs (10%) compared to LICs (25%), LMICs (44%), and UMICs (32%) suggesting better organization in the funding structures for kidney failure care in HICs.

There is also much within-country variation in access to KRT modalities between adults and children (Figure 4.6). In 33% of countries in North America and the Caribbean, adults have more access to HD than children; in another 33% of countries in the region, KRT is available for adults but not for children. Likewise, access to HD is also only available to adults and unavailable to children in countries in three other regions: Africa (39%), Latin America (17%), and OSEA (13%). Only countries in The Middle East and the

#### Figure 4.6 | Differences in access to HD, PD, and kidney transplantation between adults and children



NIS and Russia have equal PD access for adults and children; however, in 15% of countries in Africa and 20% of countries in North America and the Caribbean, PD is available to adults and unavailable to children. Africa (23%) is the only region with countries where adults can access kidney transplantation, but children cannot (Figure 4.6).

#### **4.3 INFRASTRUCTURE FOR DELIVERY OF KIDNEY FAILURE CARE**

Overall, infrastructure for the delivery of kidney failure care is rated as extremely poor in only 2% of countries and excellent in 21% of countries. Extremely poor infrastructure is reported only in countries in Africa (5%), OSEA (6%), and South Asia (13%); high percentages of countries in North and East Asia (83%) and Western Europe (68%) report excellent infrastructure for the delivery of kidney failure care (Figure 4.7). The proportion of countries with excellent infrastructure for the delivery of kidney failure care is highest in HICs (52%); in contrast, no LICs have excellent infrastructure (Figure 4.7).

#### Figure 4.7 | Adequacy of infrastructure to deliver kidney failure care

Extremely poor (%)
Poor/below average (%)
Good/above average (%)
Fair/Average (%)
Excellent (%)







# Health workforce for kidney care

#### Key messages

- Nephrologists are primarily responsible for providing kidney failure care in 87% of countries worldwide
- The global prevalence of nephrologists is 11.8 pmp and is lowest in Africa (1.1 pmp) and highest in North and East Asia (28.7 pmp)
- Afghanistan (0.03 pmp), Malawi (0.05 pmp), and Mozambique (0.09 pmp) have the lowest prevalences of nephrologists.
- The global prevalence of nephrology trainees is 1.2 pmp and is almost 40-fold lower in LICs (0.1 pmp) than in HICs (3.9 pmp)
- The median proportion of women nephrologists (treating adults and children) is 35% worldwide.
- Most countries have critical shortages of healthcare providers essential for kidney failure care, especially nephrologists and access / transplant surgeons.

#### **5.1 CLINICAL RESPONSIBILITY**

Worldwide, nephrologists are primarily responsible for kidney failure care delivery in 87% of countries (Figure 5.1). Nephrologists also bear primary responsibility for the delivery of kidney failure care across all ISN regions and income groups. Other healthcare providers involved in the provision of kidney failure care include primary care physicians (7%), nurse practitioners (1%), multidisciplinary care teams (3%), and other specialist healthcare providers (2%).

### Figure 5.1 | Health care providers primarily responsible for kidney failure care

Nephrologists		87%
Primary care physicians	7%	
Nurse practitioners	1%	
Specialized nurses	0%	
Multidisciplinary teams	3%	
Other specialists	2%	

#### **5.2 WORKFORCE**

Worldwide, the median prevalence of nephrologists is 11.8 per million population (pmp) (Map 5.1). This number varies extensively across ISN regions and income groups. The three regions with the highest prevalences of nephrologists are North and East Asia (28.7 pmp), Western Europe (25.0 pmp), and Eastern and Central Europe (24.8 pmp). The three countries with the highest prevalences of nephrologists are Liechtenstein (100.7 pmp), Lesotho (93.4 pmp), and Japan (88.6 pmp). The regions with the lowest prevalences of nephrologists are Africa (1.1

#### Map 5.1 | Global prevalence of nephrologists

Rate per million population (pmp), age  $\geq$  18 years



Note: Following data analysis and its publication, ISN was informed that Uzbekistan has 70 nephrologists (60 adults and 10 paediatric nephrologists). This additional data is not reflected in the map above.


Figure 5.2 | Global proportion of women nephrologists

pmp), South Asia (1.8 pmp), and OSEA (3.2 pmp). Afghanistan (0.03 pmp), Malawi (0.05 pmp), and Mozambique (0.09 pmp) are the countries with the lowest prevalences of nephrologists. There are no nephrologists in Samoa, Solomon Islands, Vanuatu and Andorra (Map 5.1).

Across all regions and income groups, nephrologists who treat adults are more prevalent than pediatric nephrologists, and the prevalences of both increase with income level (Figure 5.2 and Table 5.1). The median proportion of women nephrologists (treating adults and children) is 35% worldwide; only four regions have median values higher than the global median: Eastern and Central Europe (65%), the NIS and Russia (52.5%), Western Europe (41%), and Latin America (38%) (Figure 5.2)

The global median prevalence of nephrologist trainees is 1.2 pmp. Nephrologist trainees are more prevalent in Western Europe (6.0 pmp),

Table 5.1	Distribution of	nephrologists b	y type and	prevalence of	<sup>:</sup> trainees
Rate per millio	n population (pmp)				

	Total prevalence of adult nephrologists		Total pre n	valence of pediatric ephrologists	Total prevalence of nephrologist trainees		
	Median	[Interquartile range]	Median	[Interquartile range]	Median	[Interquartile range]	
Overall	10.08	[1.64 - 22.42]	0.69	[0.03 - 1.78]	1.15	[0.18 - 3.81]	
ISN region							
Africa	1.10	[0.24 - 1.80]	0.05	[0.00 - 0.15]	0.18	[0.00 - 0.95]	
Eastern and Central Europe	23.11	[15.75 - 30.89]	2.41	[1.65 - 2.71]	4.77	[3.42 - 6.97]	
Latin America	11.57	[6.92 - 22.59]	1.02	[0.69 - 2.45]	1.36	[0.92 - 2.72]	
The Middle East	10.59	[3.92 - 34.93]	1.85	[1.00 - 2.79]	0.93	[0.33 - 1.99]	
NIS and Russia	7.09	[2.85 - 14.93]	1.68	[1.37 - 2.72]	1.26	[0.42 - 1.93]	
North America & Caribbean	19.68	[11.77 - 29.90]	0.00	[0.00 - 1.31]	0.00	[0.00 - 1.84]	
North and East Asia	26.39	[15.04 - 63.61]	2.33	[0.57 - 4.24]	2.57	[1.92 - 4.24]	
OSEA	3.18	[0.52 - 12.07]	0.13	[0.00 - 0.79]	0.96	[0.20 - 3.88]	
South Asia	1.64	[0.76 - 1.91]	0.07	[0.00 - 0.19]	0.27	[0.00 - 0.79]	
Western Europe	24.41	[16.98 - 31.86]	1.58	[0.96 - 2.18]	6.01	[3.93 - 9.48]	
World Bank income group							
Low income	0.24	[0.17 - 1.13]	0.03	[0.00 - 0.06]	0.06	[0.00 - 0.24]	
Lower-middle income	1.64	[0.52 - 3.67]	0.13	[0.07 - 0.83]	0.33	[0.13 - 1.22]	
Upper-middle income	10.08	[5.10 - 17.49]	1.22	[0.43 - 1.82]	1.26	[0.60 - 2.72]	
High income	24.41	[16.10 - 34.18]	1.65	[0.71 - 3.74]	3.88	[1.31 - 6.73]	

Note: Following data analysis and its publication, ISN was informed that Uzbekistan has 70 nephrologists (60 adults and 10 paediatric nephrologists). This additional data is not reflected in the table above.

Eastern and Central Europe (4.8 pmp), and North and East Asia (2.6 pmp). The prevalence of nephrologist trainees also increases by income level: LICs (0.1 pmp), LMICs (0.3 pmp), UMICs (1.3 pmp), and HICs (3.9 pmp) (Figure 5.2 and Table 5.1).

Most countries have critical shortages of healthcare providers essential for kidney failure care, and the percentage of countries with these shortages decreases as income level increases (Figure 5.3). Critical shortages of nephrologists (90%), pediatric nephrologists (95%), transplant surgeons (90%), surgeons or interventional radiologists who can provide HD access (100%), surgeons or interventional radiologists who can provide PD access (90%), and dietitians (90%) are reported in LICs.



Figure 5.3 | Shortages of health care providers essential for kidney failure care

1. Surgeons or interventional radiologists (who can put in arteriovenous HD access)

2. Surgeons or interventional radiologists (who can put in PD access)

SECTION SIX

## Access to essential medications and health products

#### Key messages

- Capacity for KRT provision varies widely: HD is available in 98% of countries, PD is available in 79% of countries, and kidney transplantation is available in 70% of countries.
- Modality choice of KRT showed substantial variations with regards to general availability (≥50% of centers): in-center HD (92%), home HD (17%), and PD (58%).
- In 74% of countries with available dialysis services, >50% of people needing KRT can access dialysis at kidney failure onset; only in 6% of countries are >50% of people with kidney failure able to start with PD.
- In nine (5%) countries (six countries from Africa), people treated with HD make 100% co-payment for HD.
- Medications for people with kidney failure are publicly funded (and free) in only 24% of countries and solely private and paid for out-of-pocket in 12% of countries.
- There is limited availability of CKM across ISN regions and country income levels.

#### **6.1 CAPACITY FOR KRT SERVICE PROVISION**

Overall, chronic HD services are available in 98% of countries that participated in the survey and are available in countries of all regions, except OSEA (89%) and South Asia (88%) (Figure 6.1). Chronic HD is available in all UMICs and HICs and in 96% of LMICs and 95% of LICs. Overall, chronic PD services are available in 130 (79%) countries worldwide and are available in all countries in Eastern and Central Europe, The Middle East, North and East Asia, and Western Europe. Availability of chronic PD is lower than the global median in South Asia (75%), OSEA (72%), the NIS and Russia (70%), and Africa (48%). Availability of chronic PD increases with income level: LICs (21%), LMICs (69%), UMICs (89%), and HICs (97%) (Figure 6.1). Home HD is not as readily available as in-center HD, with availability varying by income level: LICs (21%), LMICs (18%), UMICs (11%), and HICs (52%) (Figure 6.2). Availability of automated PD (APD) increases with income level: LICs (50%), LMICs (52%), UMICs (79%), and HICs (98%) (Figure 6.2).

Kidney transplantation services are available in 116 (70%) countries that participated in the survey. All countries in Eastern Europe, The Middle East, and the NIS and Russia have kidney transplantation services; in other regions, the availability of such services ranges from 32% in Africa to 86% in Latin America (Figure 6.1). Access to kidney transplantation increases with income level and is available in 21% of LICs, 60% of LMICs, 82% of UMICs, and 86% of HICs.

Among countries with chronic HD services, the global median density of centers is 5.1 pmp, with the highest densities found in North America and the Caribbean (18.4 pmp), North and East Asia (12.0 pmp), and Eastern and Central Europe (10.5 pmp). HD center densities are lowest in Africa (0.8 pmp) and South Asia (2.3 pmp). Mozambique (0.1 pmp), Chad (0.1 pmp), and Niger (0.2 pmp) have the lowest chronic HD center densities while Taiwan (93.3 pmp), Bermuda (41.5 pmp),

## Figure 6.2 | Availability of home HD and automated PD (APD)







#### Map 6.1 | Availability of centers that provide chronic HD

Rate per million population (pmp), age  $\geq$  18 years



#### Map 6.2 | Availability of centers that provide chronic PD

Rate per million population (pmp), age  $\geq$  18 years

<0.5 pmp 0.5−1.5 pmp 1.6−3.0 pmp ≥3.1 pmp Data not reported</p>



and New Caledonia (40.4 pmp) have the highest densities (Map 6.1).

In countries with available chronic PD services, the global median density of PD centers is 1.6 pmp, with densities above the global median in Eastern and Central Europe (2.0 pmp), Latin America (1.8 pmp), North America and the Caribbean (10.0 pmp), and Western Europe (2.7 pmp). Myanmar (0.02 pmp), Nigeria (0.02 pmp), the Democratic Republic of Congo (0.03 pmp), Egypt (0.03 pmp), and Angola (0.03 pmp) have the lowest densities of chronic PD centers while Bermuda (41.5 pmp), Liechtenstein (25.2 pmp), and the United States (20.8 pmp) have the highest densities of chronic PD centers (Map 6.2).

Among countries that offer kidney transplantation services, the global median density of kidney transplant centers is 0.46 pmp, with the highest density in North and East Asia (1.1 pmp) and the lowest density in South Asia (0.11 pmp). The density of kidney transplant centers also increases with income level, from 0.1 pmp in LICs to 0.61 pmp in HICs. Ethiopia (0.01 pmp), Indonesia (0.03 pmp), Bangladesh (0.03 pmp), Tanzania (0.03 pmp), and Cote d'Ivoire (0.03 pmp) have the lowest densities of kidney transplant centers (Map 6.3). The British Virgin Islands (25.9 pmp), Antigua and Barbuda (10.0 pmp), and New Caledonia (3.4 pmp) have the highest densities of kidney transplant centers. All LICs rely exclusively on live donor organs for kidney transplantation, whereas 63% of LMICs, 29% of UMICs, and 7% of HICs solely use organs from live donors (Figure 6.3). The use of a combination of deceased and live donor organs for kidney transplantation increases with income level: LMICs (37%), UMICs (71%), and HICs (93%).





#### Map 6.3 | Availability of centers that provide kidney transplantation



#### **6.2 AVAILABILITY OF SERVICES FOR KIDNEY FAILURE CARE**

In countries where KRT is available, the ability to select the modality of dialysis (in-center HD, home HD, and PD) varies across regions. For instance, although in-center HD is universally available to people living with kidney disease in all countries in Eastern and Central Europe, Latin America, The Middle East, the NIS and Russia, North America and the Caribbean, North and East Asia, and Western Europe, this option is only available to most people living with kidney disease in 77% of countries in Africa, 83% of countries in OSEA, and 75% of countries in South Asia. Home HD is not generally available in any countries in Africa, the NIS and Russia, and South Asia (Figure 6.4). PD is generally available as a modality option in less than half of the countries in Africa (14%), South Asia (38%), and NIS and Russia (40%).

Availability of services for kidney failure care varies worldwide. Services to measure serum hemoglobin are available in most countries. All countries have the capacity to measure serum hemoglobin, and it is generally available in 99% of countries. Other services related to the management of hemoglobin level that are generally available include measurement of iron parameters (81% of countries), measurement of inflammatory markers (85% of countries), administration of oral iron (100% of countries), administration of parenteral iron (83% of countries), and use of erythropoiesis stimulating agents (87% of countries) (Figure 6.5). Capacity to measure serum hemoglobin is available in 96% of LMICs and

100% of countries in other income groups. The ability to assess other parameters in the management of serum hemoglobin increases with income level. (Figure 6.6).

The capacity to manage CKD mineral bone disease also varies across regions. Most countries that participated in the survey have capacity to measure serum calcium (95%) and serum phosphate (92%), and to administer calcium-based phosphate binders (90%). However, a relatively smaller proportion of countries have capacity to measure serum parathyroid hormone (PTH) (70%), provide surgical services for parathyroidectomy (63%), or administer non-calcium-based phosphate binders (54%) and cinacalcet (48%) (Figure 6.5). Across all assessed parameters in the management of CKD mineral bone disease, UMICs and HICs have more diagnostic and therapeutic capabilities than countries at other income levels. Capacity to measure serum PTH is very low among LICs (26%) and LMICs (47%) and capacity to administer non-calcium-based phosphate binders and cinacalcet is also very low among LICs (16% and 5%, respectively) (Figure 6.7).

Most countries have the capacity to measure serum electrolytes (96%) and monitor acidbase balance (serum bicarbonate) (75%). Potassium exchange resins are generally available in two-thirds of countries (67%) whereas oral sodium bicarbonate is generally available in 81% of countries (Figure 6.5).



#### Figure 6.4 | Availability of modality options for KRT

73%

Peritoneal dialysis

40%

38%

50%

69%

73%

77%

83%

100%

95%

14%

#### Figure 6.5 | Availability of services for kidney failure care

Generally available<sup>1</sup> (%) Generally not available<sup>2</sup> (%)

Never (%)

Unknown (%)

#### Management of hemoglobin level





#### Management of mineral bone disease

Measurement of serum calcium Measurement of serum phosphorus Measurement of serum parathyroid hormone Calcium-based phosphate binders<sup>3</sup> Non-calcium-based phosphate binders<sup>3</sup> Cinacalcet Surgical services for parathyroidectomy

> Measurement of serum electrolytes<sup>4</sup> Measurement of serum bicarbonate Potassium exchange resins Oral sodium bicarbonate



#### Management of blood pressure

Analogue BP monitoring Automated BP monitoring (home or office) Ambulatory BP monitoring (ABPM)

1. Generally available = In 50% or more centers (hospitals or clinics)

2. Generally not available = In less than 50% of centers (hospitals or clinics)

3. e.g., sevelamer

4. e.g., sodium, potassium, chloride, etc.

5. e.g., Kayexalate, patiromer sodium zirconium

#### Figure 6.6 | Management of hemoglobin level



1. Generally available = In 50% or more centers (hospitals or clinics)

2. Generally not available = In less than 50% of centers (hospitals or clinics)

#### Figure 6.7 | Management of CKD mineral bone disease



1. Generally available = In 50% or more centers (hospitals or clinics)

2. Generally not available = In less than 50% of centers (hospitals or clinics)

3. e.g., sevelamer

Although capacity to measure serum electrolytes is high across all income groups, LICs and LMICs have low capacity to measure serum bicarbonate (32% and 58%, respectively) and administer potassium exchange resins (47% and 52%, respectively) and oral sodium bicarbonate (32% and 76%, respectively) (Figure 6.8). Analog equipment for blood pressure (BP) monitoring is generally available in 94% of countries and automated BP monitoring services are generally available in 86% of countries. Capacity to monitor BP using ambulatory BP monitoring (ABPM) equipment is generally available in 53% of countries worldwide (Figure 6.5). Across income groups, the capacity to

#### Figure 6.8 | Management of electrolyte disorders and chronic metabolic acidosis



1. Generally available = In 50% or more centers (hospitals or clinics)

2. Generally not available = In less than 50% of centers (hospitals or clinics)

3. e.g., sodium, potassium, chloride, etc.

4. e.g., Kayexalate, patiromer sodium zirconium

monitor BP using analogue or automated BP equipment is high, however, general availability of ABPM increases with income level: LICs (21%), LMICs (29%), UMICs (47%), and HICs (82%) (Figure 6.9).

Availability of management capacities for the treatment of other common symptoms of kidney failure (e.g., uremic pruritus and chronic

pain) was also assessed. General availability of gabapentinoids increases with income level: LICs (42%), LMICs (49%), UMICs (50%), and HICs (92%). A similar trend is observed for the general availability of non-morphine opioids, with very low availability among LICs (5%) compared to HICs (83%) (Figure 6.10).

#### Figure 6.9 | Management of blood pressure

Generally available<sup>1</sup> (%) Generally not available<sup>2</sup> (%) Never (%)



1. Generally available = In 50% or more centers (hospitals or clinics)

2. Generally not available = In less than 50% of centers (hospitals or clinics)

#### Figure 6.10 | Management of common kidney failure symptoms



1. Generally available = In 50% or more centers (hospitals or clinics)

2. Generally not available = In less than 50% of centers (hospitals or clinics)

#### **6.3 ACCESSIBILITY OF KRT**

Overall, in 74% of countries with available dialysis services, at least half of people living with kidney disease and needing dialysis are able to access it at the onset of kidney failure. This proportion varies widely across ISN regions and income groups, exceeding the global value in all regions except Africa (42%), OSEA (56%), and South Asia (14%). In contrast, more than half of people living with kidney disease can access dialysis at the onset of kidney failure in all countries in three regions: Eastern and Central Europe, The Middle East, and North and East Asia (Figure 6.11). The proportion of countries where KRT is available to more than half of people living with kidney

disease at the onset of kidney failure increases by income level: LICs (32%), LMICs (45%), UMICs (86%), and HICs (98%).

Among countries where chronic PD is available, only 9 countries (6%) reported PD as the initial treatment for more than half of people living with kidney failure (Africa: Kenya and the Gambia; Eastern and Central Europe: Albania; Latin America: Mexico and Nicaragua; North and East Asia: Hong Kong; OSEA: Thailand; Western Europe: Germany and the Netherlands). North and East Asia (17%) and Western Europe (10%) have the highest proportions of countries where the majority of people living with kidney disease

#### Figure 6.11 | Accessibility of KRT at the onset of kidney failure



1. N/A = KRT not available in country

initiate treatment with chronic PD (Figure 6.12). Although proportions are similar across income levels (LICs: 6%; LMICs: 5%; UMICs: 8%; HICs: 5%), they are nevertheless very low, suggesting low utilization of PD as the initial modality of KRT therapy. In 19 countries (13%) worldwide, most people living with kidney failure do not have the option to initiate therapy with PD; the proportion of countries where this occurs is lowest among HICs (2%) and higher among other income groups: LICs (11%), LMICs (22%), and UMICs (16%) (Figure 6.12). Overall, accessibility to kidney transplantation is low. More than 50% of people living with kidney disease eligible for kidney transplantation are able to access it in just 29% of countries worldwide. Over 50% of people living with kidney disease and eligible for transplantation have access to kidney transplantation in 82% of countries in Western Europe, versus no countries in South Asia (Figure 6.13). People living with kidney disease and eligible for kidney transplantation do not have access to transplant services in a significant proportion of



#### Figure 6.12 | Proportion of people living with kidney disease typically initiating treatment with PD

1. N/A = Dialysis (of any kind) not available in country

2. 0% = People living with kidney disease who are able to access some form of dialysis, but none start with PD

countries in Africa (53%), OSEA (39%), and the NIS and Russia (20%). Overall, access to kidney transplantation increases with income level: LICs (5%), LMICs (5%), LMICs (26%), and HICs (56%)

(Figure 6.13). Similarly, lack of access to kidney transplantation becomes more prevalent at lower income levels, with 63% of LICs reporting a lack of access.

#### Figure 6.13 | Accessibility<sup>1</sup> of kidney transplantation



1. The proportion of people living with kidney failure suitable for transplant who are able to access it

2. N/A = Not available in country

#### **6.4 AFFORDABILITY OF KRT**

Overall, people living with kidney diseas are responsible for covering 100% of the costs of HD and medications in 9 (5%) countries. The proportion of countries requiring 100% copayment for HD varies across ISN regions and income groups (Figure 6.14). Africa has the highest proportion of countries (15%) where people living with kidney disease cover 100% of the costs of HD and medications, followed by Eastern and Central Europe (6%), North America and the Caribbean (8%), and OSEA (6%). The regions with the lowest proportions of countries requiring no co-payment for HD and medications are OSEA (11%), South Asia (14%), and Africa (17%) (Figure 6.14). The proportion of countries requiring people living with kidney disease to fully cover the costs of HD and medications decreases as income level increases: LICs (17%), LMICs (7%) and UMICs (8%). There are no HICs where people living with kidney disease pay 100% of the costs of HD and medications.

In countries where chronic PD is available, only 6 (4%) (Congo Republic, the Democratic Republic of Congo, Albania, Fiji, Papua New Guinea, and Greece) require people living with kidney disease to cover 100% of the costs of PD and medications. No countries in Latin America, The Middle East, the NIS and Russia, North America and the Caribbean, North and East Asia, and South Asia require people living with kidney disease to cover 100% of the costs of PD and medications (Figure 6.14). In many countries in Western Europe (77%), Eastern and Central Europe (38%), and North and East Asia (33%), people living with kidney disease make no contributions to cover the costs of PD and medications. The proportion of countries where people living with kidney disease are not responsible for covering any PD-related costs increases with income level: LMICs (9%), UMICs (29%), and HICs (51%). There are no LICs where people living with kidney disease are not responsible for any PD-related costs (Figure 6.14).

## **Figure 6.14** | Proportion of treatment costs (including medications) paid directly by people living with kidney disease



1. N/A = Not available in country.

2. 0% = People living with kidney disease who are able to access some form of dialysis, but none start with PD.

In 10 (6%) countries (Ethiopia, Ghana, Chad, Nigeria, Burkina Faso, Albania, Bosnia and Herzegovina, Fiji, Papua New Guinea, and Greece), people living with kidney disease are required to cover 100% of the costs of kidney transplantation and medications. Africa (13%) and Eastern and Central Europe (13%) have the highest proportions of countries requiring 100% co-payment for kidney transplantation and medications (Figure 6.14). People living with kidney disease cover 100% of the costs of kidney transplantation and medications in a much lower proportion of

HICs (2%) compared to other income groups (LICs: 16%; LMICs: 7%; UMICs: 8%). In half of the countries in North and East Asia (50%) and two-thirds of the countries in Western Europe (67%), people living with kidney disease are not responsible for covering any of the costs of kidney transplantation and medications. The proportions of countries requiring no co-payment for kidney transplantation and medications are much lower in other regions: OSEA (11%), Africa (13%), South Asia (14%), North America and the Caribbean (17%), and the NIS and Russia (20%) (Figure 6.14).

#### 6.5 MEDICATION FUNDING MODELS FOR PEOPLE RECEIVING KRT

In countries where dialysis is available, medications are publicly funded by the government and free at the point of delivery in 24% of countries, publicly funded by the government with some fees at point of delivery in 28% of countries, and privately funded and

paid for completely out-of-pocket in 12% of countries. Only in Eastern and Central Europe are medications publicly funded by the government and free at point of delivery in more than half of countries (63%); the proportions of countries in Africa (8%) and OSEA (6%) utilizing this payment

#### Figure 6.15 | Funding models for KRT

- Publicly funded by government and free at the point of delivery (%)
- Publicly funded by government but with some fees at the point of delivery (%)
- A mix of publicly funded and private systems (%)
- Solely private and out-of-pocket (%)
- Solely private through health insurance providers (%)
- Multiple systems programs provided by government, NGOs, and communities (%)
- Other (%)



#### **Kidney transplantation**



model are very low (Figure 6.15). Countries that solely utilize private and out-of-pocket payment systems are concentrated in Africa (25%), South Asia (25%), and NIS and Russia (20%).

Kidney transplant medications are publicly funded and free at the point of delivery in about a third of countries worldwide (30%). Other payment models for kidney transplant medications include publicly funded by the government but with some fees at the point of delivery (22%), a mixture of public and private funding (23%), solely private and out-of-pocket (14%), solely private through health insurance (2%), and multiple systems of payment (2%). Only countries in three regions use solely private and out of-pocket payment methods for kidney transplant medications: Africa (40%), OSEA (28%), and South Asia (25%) (Figure 6.15). In more than half of the countries in Eastern and Central Europe (56%), The Middle East (73%), and the NIS and Russia (70%), the costs of medications for kidney transplantation are covered by the government and completely free at the point of delivery (Figure 6.15).

#### **6.6 VASCULAR ACCESS FOR KRT**

Among people living with kidney disease and initiating HD, more than 50% are able to begin dialysis with a functioning vascular access (arteriovenous fistula or graft), tunneled dialysis catheter, or temporary dialysis catheter, respectively, in 22%, 15%, and 44% of countries worldwide (Figure 6.16). However, among people living with kidney disease and receiving ongoing dialysis treatment, more than 50% have a functioning vascular access in 52% of countries worldwide. Not many people living with kidney failure receive adequate education on the best means of access and optimal timing of surgery. More than half of people living with kidney failure receive education on the best means of access and surgery in just 43% of countries.

Types of access in use at initiation of dialysis vary by income level. People living with kidney



disease start dialysis with a functional vascular access or a tunneled dialysis catheter in a higher proportion of HICs (38% and 22%, respectively) compared to LICs (12% and 0%, respectively). However, people living with kidney disease start dialysis with a temporary catheter in a lower proportion of HICs (19%) compared to LICs (65%) (Figure 6.17). Also, people living with kidney disease and receiving ongoing dialysis treatment are more likely to dialyze with a functioning vascular access in a higher proportion of HICs (58%) than in countries at other income levels: LICs (39%), LMICs (52%), and UMICs (54%). People living with kidney disease are also more likely to receive education on the best means of access and surgery in a higher proportion of HICs (73%) compared to other income groups (Figure 6.17).

#### 6.7 QUALITY OF KRT SERVICES

The quality of KRT services was measured as the frequency of reporting of key quality indicators, including PROMs, BP, small solute clearance, hemoglobin, bone mineral markers, technique survival, patient survival, and regular monitoring of dialysis water quality. Among countries that almost always measure key indicators (i.e., >75%) for people treated with HD, 26% measure PROMs, 86% measure BP, 60% measure small solute clearance, 89% measure hemoglobin, 67% measure bone mineral markers, 57% measure technique survival, 55% measure patient survival, and 70% regularly monitor dialysis water quality (Figure 6.18). Measurement and reporting of HD





## **Figure 6.19** | Proportion of centers measuring and reporting quality indicators for HD service delivery, by World Bank income group



84 | Access to essential medications and health products



## **Figure 6.21** | Proportion of centers measuring and reporting quality indicators for PD service delivery, by World Bank income group



quality indicators varies by income level and by indicator (Figure 6.19). In most LICs, BP (83%) and hemoglobin (77%) are frequently measured and reported; however, other indicators are reported by fewer countries: PROMs (17%), small solute clearance (27%), bone mineral markers (39%), technique survival (22%), patient survival (22%), and regular monitoring of dialysis water quality (27%) (Figure 6.19). The proportion of countries measuring and reporting all key indicators is higher among HICs (43%) than countries at other income levels.

Among countries where PD services are available, 24% of countries almost always measure PROMs (Figure 6.20). The proportions of countries that almost always report other key quality PD indicators vary: BP (83%), small solute clearance (60%), hemoglobin (90%), bone mineral markers (77%), technique survival (44%), and patient survival (59%). Measurement and reporting of indicators vary by income level (Figure 6.21). Although PROMs are measured in a greater proportion of HICs (33%) relative to other income levels, reporting is not widespread. Greater proportions of HICs also measure and report BP (95%), small solute clearance (84%), bone mineral markers (95%), technique survival (65%), and patient survival (80%) compared to other income levels. No LICs (0%) measure or report technique survival (Figure 6.21).

Among countries where kidney transplantation services are available, variance is observed in the proportion of countries that almost always report the following key quality indicators: PROMs (40%), delayed graft function (57%), rejection rates (57%), kidney allograft function (79%), graft survival (80%), and patient survival (84%) (Figure 6.22). All countries report rejection rates, graft survival, and patient survival among people with a kidney transplant. As with the indicators for HD and PD, measurement and reporting of quality indicators for kidney transplantation increase with income level across all indicators (Figure 6.23). Almost all HICs almost always measure and report kidney allograft function (90%), graft survival (92%), and patient survival (90%). No LICs almost always measure and report PROMs,

delayed graft function, and rejection rates. However, 50%, 75%, and 75% of LICs almost always measure and report kidney allograft function, graft survival and patient survival, respectively (Figure 6.23).

## Figure 6.22 | Proportion of centers measuring and reporting quality indicators for kidney transplantation service delivery



## **Figure 6.23** | Proportion of centers measuring and reporting quality indicators for kidney transplantation service delivery, by World Bank income group



#### **6.8 AVAILABILITY OF NUTRITIONAL SERVICES**

Nutritional services for kidney care are generally available worldwide. Dietary counselling is generally available in 59% of countries, while measurement of serum albumin and oral nutrition supplements are generally available in 91% and 70% of countries worldwide, respectively (Figure 6.24). All aspects of nutritional services assessed increase with country income level. Dietary counselling is generally available in only 5% of LICs compared to 42% of LMICs, 55% of UMICs, and 90% of HICs (Figure 6.25). Whereas measurement

#### Figure 6.24 | Availability of nutritional services for kidney care



Dietary counselling Measurement of serum albumin Oral nutrition supplements

1. Generally available = In 50% or more centers (hospitals or clinics)

2. Generally not available = In less than 50% of centers (hospitals or clinics)

#### Figure 6.25 | Availability of nutritional services for kidney care, by World Bank income group

Generally available<sup>1</sup> (%) Generally not available<sup>2</sup> (%)



Never (%)

1. Generally available = In 50% or more centers (hospitals or clinics)

2. Generally not available = In less than 50% of centers (hospitals or clinics)

of serum albumin is generally available in all HICs, availability decreases with income level: UMICs (97%), LMICs (87%) and LICs (68%). Oral nutrition supplements are generally available in only 32% of LICs compared with 97% of HICs.

Unknown (%)

#### 6.9 AVAILABILITY OF CONSERVATIVE KIDNEY MANAGEMENT (CKM)

CKM is the care for people with kidney failure that focuses predominantly on providing kidney supportive care to promote quality of life. In countries where KRT is readily available, CKM chosen through shared decision making is generally available in 53% of countries worldwide. Choice-restricted CKM is available in 39% of countries when resource constraints prevent or limit access to KRT, and 40% of countries when resource constraints do not prevent or limit access to KRT. CKM chosen through shared decision making is generally available in the vast majority of countries in Western Europe (95%) and North America and the Caribbean (83%) but



1. Generally available = In 50% or more centers (hospitals or clinics)

2. Generally not available = In less than 50% of centers (hospitals or clinics)

3. Where KRT is readily available

4. Where resource constraints exist to prevent or limit access to KRT

5. Where there are no resource constraints to prevent or limit access to KRT

is generally available in less than half of countries in other regions (Figure 6.26). CKM through shared decision making is also generally available in a higher proportion of HICs (72%) compared to LICs (42%), LMICs (33%), and UMICs (50%) (Figure 6.26).

In contexts where resource constraints prevent or limit access to KRT, choice-restricted CKM is generally available in 76% of countries in North America and the Caribbean, 61% of countries in OSEA, and 50% of countries in South Asia, but just 17% of countries in North and East Asia. The proportion of countries where this type of CKM is generally available varies by income level: LICs (47%), LMICs (33%), UMICs (50%), and HICs (35%) (Figure 6.26).

In contexts where resource constraints do not prevent or limit access to KRT, CKM is generally available in all countries in North and East Asia and in less than half of countries in Africa, Eastern and Central Europe, The Middle East, the NIS and Russia, OSEA, and Western Europe (Figure 6.26). Availability of this type of CKM increases with income level but is available in less than half of countries overall: LICs (26%), LMICs (36%), UMICs (42%), and HICs (46%).

Structures and processes for the delivery of CKM were also assessed, including infrastructure to support people living with kidney disease, shared decision-making tools, written pathways or guidelines, essential medicines for pain and palliation, training for care providers, and methods for CKM data collection. More than half of HICs have infrastructure to support people living with kidney disease on CKM (74%), shared decision-making tools for people living with kidney disease and providers (67%), written pathways or guidelines for CKM (51%), and essential medicines for pain and palliative care (84%) (Figure 6.27). More than half of HICs also have processes to train care providers in symptom management (57%) and advance care planning (51%). However, all structures and processes for the delivery of CKM are generally available in less than half of countries at other income levels (Figure 6.27). Systematic methods of CKM data collection are very uncommon across all income levels, being generally available in just 11% of LICs, 14% of LMICs, 13% of UMICs and 16% of HICs (Figure 6.27).

#### Figure 6.27 | Availability of structures and processes for the delivery of CKM



1. Generally available = In 50% or more centers (hospitals or clinics)

2. Generally not available = In less than 50% of centers (hospitals or clinics)

#### 6.10 OUTCOMES OF PEOPLE RECEIVING DIALYSIS

Common causes of hospitalization and death among people treated with dialysis were also assessed in the survey. Overall, in 32% of countries, infections of access points (i.e., arteriovenous fistulas or grafts, central venous catheters) are the leading cause of hospitalization for people treated with HD, followed by cardiovascular diseases (30% of countries), access malfunctions (i.e., a malfunctioning arteriovenous fistula or graft, a blocked central venous catheter) (18% of countries), and other infections (9% of countries).

Across ISN regions, common causes of hospitalization among people treated with HD vary, with cardiovascular disease being the most common cause of hospitalization in countries in Western Europe (59%), Eastern and Central Europe (50%), OSEA (50%), North and East Asia (49%), and the NIS and Russia

#### Figure 6.28 | Common causes of hospitalization among people treated with dialysis





(40%) (Figure 6.28). Access-related infections are the most common cause of hospitalization in countries in Latin America (31%), Africa (54%), South Asia (66%), and North America and the Caribbean (67%). Access malfunction is the most common cause of hospitalization for people treated with HD in countries in The Middle East (36%) (Figure 6.28).

The cause of hospitalization for people treated with HD also varies by income level. People treated with HD are more likely to be hospitalized for cardiovascular disease in HICs (43%), whereas no LICs reported hospitalization due to cardiovascular disease. The proportion of countries reporting accessrelated infections as the most common cause of hospitalization among people treated with HD is inversely related to income level: LICs (59%), LMICs (40%), and UMICs (35%). (Figure 6.28).

In countries where PD is available, PD-related infection (peritonitis, exit site or tunnel tract infection) is the most common cause of hospitalization in 51% of countries overall, and the majority of countries in Africa (58%), Eastern and Central Europe (68%), Latin America (79%), The Middle East (73%), the NIS and Russia (57%), and South Asia (60%) (Figure 6.28). However, cardiovascular diseases are the most common causes of hospitalization among people treated with PD in countries in North America and the Caribbean (40%), North and East Asia (50%), OSEA (46%), and Western Europe (32%). The proportion of countries reporting PD-related infections as the most common cause of hospitalization varies by income level: LICs (75%), LMICs (47%), UMICs (73%), and HICs (39%) (Figure 6.28).

Worldwide, cardiovascular disease is the most common cause of death among people treated with HD in most countries that participated in the survey (77%), followed by access-related infections (11%) and withdrawal from HD due to cost (4%). In all ISN regions and across all country income levels, cardiovascular disease is the most common cause of death among people treated with HD (Figure 6.29). Relative to other regions, a greater proportion of countries in Africa reported access-related infections (28%) and cost-related dialysis withdrawal (13%) as common causes of death among people treated with HD. Only LICs (18%) and LMICs (7%) reported cost-related dialysis withdrawal as a common cause of death among people treated with HD (Figure 6.29).

Among people treated with PD, cardiovascular disease is the most common cause of death in countries across all ISN regions except Africa, where some countries identified access-related infections (26%) and cost-related dialysis withdrawal (16%) as the most common causes of death among people treated with PD (Figure 6.29). In 9% of countries in The Middle East, a common cause of death among people treated with PD is dialysis withdrawal due to social factors. Cardiovascular disease is the most common cause of death among people treated with PD in 43% of LMICs, 58% of UMICs, and 87% of HICs. No LICs reported cardiovascular disease as a common cause of death among people treated with PD. However, in a quarter (25%) of LICs, access-related infections, dialysis withdrawal due to social reasons, and cost-related dialysis withdrawal are common causes of death among people treated with PD (Figure 6.29).

#### Figure 6.29 | Common causes of death among people treated with dialysis

- Cardiovascular disease (%)
- Access-related infections<sup>1</sup> (%)
- Other infections (%)
- Malignancy (%)
- Dialysis withdrawal (social factors) (%)
- Cost-related dialysis withdrawal (%)
- Others (%)
- Unknown (%)

#### HD

Africa Eastern and Central Europe Latin America The Middle East NIS and Russia North America & Caribbean North and East Asia OSEA South Asia Western Europe

#### World Bank income group:

Low income Lower-middle income Upper-middle income High income

Africa
Eastern and Central Europe
Latin America
The Middle East
NIS and Russia
North America & Caribbean
North and East Asia
OSEA
South Asia
Western Europe

PD					
				_	
		-	-		

#### World Bank income group:

Low income Lower-middle income Upper-middle income High income

1. For HD: Includes infected AVF/AVG, CVC catheter-related bacteremia For PD: Includes peritonitis, exit-site or tunnel tract infection



#### SECTION SEVEN

# Health information systems

#### Key messages

- Registries for non-dialysis CKD, dialysis, and kidney transplantation are available in 31 (19%), 102 (63%), and 94 (58%) of countries, respectively.
- More than three-quarters of countries in Eastern and Central Europe, Latin America, NIS and Russia, Western Europe, and all countries in North and East Asia have a dialysis registry.
- In countries with available registries, provider participation varies as voluntary methods are often used for non-dialysis CKD registries, while mandatory methods are mostly utilized in dialysis and kidney transplantation registries.
- Modality of dialysis is more frequently reported across country income levels: LICs (75%), LMICs (88%), UMICs (93%), and HICs (100%).
- More countries in HICs provide testing for CKD than countries in other income levels.
- In countries that implement a detection program for CKD, 50% use a reactive approach and 42% use an active testing of at-risk populations through routine health encounters.

#### 7.1 REGISTRIES

Worldwide, registries for non-dialysis CKD, dialysis, kidney transplantation, and CKM are available in 31 (19%), 102 (63%), 94 (58%), and 9 (6%) countries, respectively. More countries in Latin America (52%) have non-dialysis CKD registries than countries in other regions; no countries in OSEA have non-dialysis CKD registries (Figure 7.1). UMICs have the highest proportion of non-dialysis CKD registries (35%), compared to 6% of LICs, 9% of LMICs, and 20% of HICs.

More than three-quarters of countries in Eastern and Central Europe (94%), Latin America (76%), the NIS and Russia (80%), and Western Europe (90%), and all countries in North and East Asia (100%) have dialysis registries, compared to less than a third of countries in South Asia (29%) and Africa (31%). Availability of dialysis registries increases with income level: LICs (22%), LMICs (38%), UMICs (81%), and HICs (81%) (Figure 7.1). Kidney transplant registries are available in all regions, but coverage varies: 100% of countries in the NIS and Russia and North and East Asia have kidney transplant registries, versus just 13% of countries in Africa. No LICs have kidney transplant registries, and availability increases with income level: LMICs (30%), UMICs (81%), and HICs (81%) (Figure 7.1). CKM registries are only available in 9 countries/jurisdictions worldwide: Botswana, Guinea, Albania, Costa Rica, Puerto Rico, Oman, Ukraine, Iceland, and Sweden. The proportion of

countries with available CKM registries is similar across income levels: LICs (6%), LMICs (2%), UMICs (8%), and HICs (6%) (Figure 7.1).

In countries with available registries, provider participation varies across regions and country income levels. In the majority of countries in several regions, provider participation is voluntary for non-dialysis CKD: Africa (67%), Eastern and Central Europe (60%), The Middle East (100%), North and East Asia (50%), and Western Europe (50%) (Figure 7.2). Voluntary participation also is more common in countries at lower income levels: LICs (100%), LMICs (25%), UMICs (54%), and HICs (38%). Participation in dialysis registries is mandatory in the majority of countries in Latin America (81%), The Middle East (72%), the NIS and Russia (63%), North America and the Caribbean (60%), North and East Asia (67%), OSEA (55%), and Western Europe (65%). Across income levels, the proportion of countries with mandatory participation in dialysis registries is similar: LICs (50%), LMICs (53%), UMICs (57%), and HICs (59%) (Figure 7.2).

In several regions, participation in kidney transplantation registries is mandatory in less than half of countries where kidney transplantation is available: Africa (40%), Eastern and Central Europe (47%), and the NIS and Russia (40%). Participation in kidney transplant registries is mandatory in less than



#### Figure 7.1 | Prevalence of kidney disease registries



#### Figure 7.2 | Provider participation in CKD and KRT registries

half of LMICs (47%), compared to 60% of UMICs, and 73% of HICs. No LICs have kidney transplant registries (Figure 7.2).

In LICs, non-dialysis CKD registries only provide coverage at the local/hospital/community level. Similar registries in LMICs mostly provide coverage at the regional/state/provincial level (75%) (Figure 7.3). However, in the majority of UMICs (54%) and HICs (69%), non-dialysis CKD registries provide coverage at the national level. In 75% of LICs, dialysis registries provide coverage at the local level, whereas in other income groups, dialysis registries typically are provided at a national level: LMICs (82%), UMICs (83%), and HICs (94%) (Figure 7.3). Similarly, kidney transplant registries provide national coverage in 85% of LMICs, 90% of UMICs, and 92% of HICs (Figure 7.3).

Most CKD registries (52%) cover all spectrum of CKD i.e., stage 1 to stage 5. However, CKD registries in more countries in Africa (67%), Eastern and Central Europe (60%), The Middle



#### Figure 7.3 | Geographic coverage of CKD and KRT registries

N/A = Data is not available

East (100%), and Western Europe (67%) only cover advanced stages of CKD i.e., stage 4 and stage 5 (Table 7.1). Dialysis registries tend to cover similar content, with slight variations at the country level. Across all income groups, countries with dialysis registries cover etiology of kidney failure, modality of dialysis, dialysis prescriptions, dialysis access types, process-based measures (e.g., anemia and mineral bone disease), and the outcomes of people living with kidney disease (hospitalization and mortality). Modality of dialysis is reported in most countries across income levels: LICs (75%), LMICs (88%), UMICs (93%), and HICs (100%). Across all outcomes of people living with kidney disease assessed (quality of life, hospitalization, and mortality), quality of life is the least reported across all income levels: LICs (0%), LMICs (29%), UMICs (23%), and HICs (24%). In contrast, mortality is reported most often: LICs (75%), LMICs (76%), UMICs (80%), and HICs (90%) (Figure 7.4).

Only LMICs, UMICs, and HICs have kidney transplant registries, and content coverage is similar across income levels (Figure 7.5). Most countries report the source of the kidney transplant (i.e., donor type): LMICs (92%), UMICs (97%), and HICs (98%). In LMICs, types and episodes of infection are reported least (46%) in kidney transplant registries, whereas quality of

#### Table: 7.1 | Content coverage of CKD registries

	The whole spectrum of CKD (stages 1-5)		Advanced CKD only (stages 4/5)	
Overall	16	(52)	15	(48)
ISN region				
Africa	1	(33)	2	(67)
Eastern and Central Europe	2	(40)	3	(60)
Latin America	6	(55)	5	(45)
The Middle East	0	(0)	1	(100)
NIS and Russia	1	(100)	0	(0)
North America & Caribbean	1	(100)	0	(0)
North and East Asia	2	(100)	0	(0)
OSEA	١	N/A	N	I/A
South Asia	1	(100)	0	(0)
Western Europe	2	(33)	4	(67)
World Bank income group				
Low income	0	(0)	1	(100)
Lower-middle income	3	(75)	1	(25)
Upper-middle income	7	(54)	6	(46)
High income	6	(46)	7	(54)

N/A = Data is not available

#### Figure 7.4 | Content coverage of dialysis registries



1. Vascular access for HD, PD catheter

2. Anemia, bone disease, BP control markers

75%

50%

53%

69%

75% 76%

80%

90%

50%

88%

93%

100%



#### Figure 7.5 | Content coverage of kidney transplantation registries

1. Deceased/live donor

life is reported least in UMICs (33%) and HICs (25%) (Figure 7.5). Other items covered in kidney transplant registries, including etiology of kidney failure, type of immunosuppression, episodes of graft rejection, hospitalization rates, and mortality rates, vary across income levels.

Overall, methods to identify CKD in high-risk groups are common. People with hypertension, diabetes mellitus, cardiovascular disease, and auto-immune diseases are tested for CKD in 89%, 91%, 79%, and 81% of countries, respectively. People with diabetes are tested for CKD in all countries in Eastern and Central Europe, The Middle East, North America and the Caribbean, and Western Europe (Figure 7.6). Similarly, the proportion of countries that test people with hypertension for CKD ranges from 75% in South Asia to 100% in North America and the Caribbean. There is variability in the proportion of countries that routinely test elderly people for CKD; less than half of countries in the NIS and Russia (30%), The Middle East (45%), and Africa (49%) do so (Figure 7.6). Few countries test populations at high-risk for CKD or kidney failure (e.g., Aboriginal populations), ranging from 2% of countries in Africa to 42% of countries in North America and the Caribbean; no countries in the NIS and Russia and North and East Asia test high-risk ethnic populations for CKD (Figure 7.6).

Across country income levels, people with hypertension, diabetes mellitus, cardiovascular diseases, auto-immune disorders, and urological conditions are more likely to be tested for CKD. More HICs provide testing for CKD in all categories assessed than countries at other income levels (Figure 7.6). Across all income levels, less than half of countries report casefinding in populations at high-risk for CKD: LICs (0%), LMICs (9%), UMICs (8%), and HICs (30%) (Figure 7.6).

#### 7.2 IDENTIFICATION OF DISEASE (AKI AND CKD)

Worldwide, only 6 (4%) countries have AKI detection programs based on national policies or guidelines. AKI detection programs are only available in Africa (8%), Eastern and Central Europe (6%), the NIS and Russia (10%), and Western Europe (5%) (Figure 7.8). The proportion of countries with AKI detection programs is similar across income levels: LICs (6%), LMICs (5%), UMICs (5%), and HICs (2%).

Although more countries (25%) have CKD detection programs based on national policies or guidelines, less than half of countries in all regions have such programs. Latin America has the highest proportion of countries (48%) with

#### Figure 7.6 | Adoption of practices to identify CKD in high-risk groups



1. Ischemic heart disease, stroke, peripheral vascular disease, heart failure

2. Systemic lupus erythematosus, rheumatoid arthritis

3. Aboriginal, African, Indo-Asian

4. Routine testing for CKD not offered

#### Figure 7.7 | Existence of current AKI and CKD detection programs



CKD detection programs, and about a third of countries in North and East Asia (33%), Western Europe (32%), and Eastern and Central Europe (31%) report having such programs. No countries in South Asia have CKD detection programs based on national policies or guidelines (Figure 7.7). The availability of CKD detection programs increases with income level: LICs (6%), LMICs (11%), UMICs (30%), HICs (36%).

#### Figure 7.8 | Methods of implementing AKI detection programs

- Reactive approach cases managed as identified through practice (%)
- Active testing of at-risk population through routine health encounters (%)
- Active testing of at-risk population through specific processes (%)
- Automated electronic alert system
- Data not available

Africa Eastern and Central Europe Latin America The Middle East NIS and Russia North America & Caribbean North and East Asia OSEA South Asia Western Europe World Bank income group: Low income Lower-middle income

Upper-middle income High income



There are sharp differences in the methods used to detect AKI across country income levels (Figure 7.8). Only countries in Africa (100%) adopt a reactive approach to testing for AKI, only countries in the NIS and Russia (100%) test atrisk populations during routine health encounters, only countries in Eastern and Central Europe (100%) actively test at-risk populations, and only countries in Western Europe (100%) use an automated electronic alert system for detection of AKI. All LICs and LMICs adopt a reactive approach, where cases are managed after they are identified through practice. However, half of UMICs (50%) test at-risk populations (e.g., the elderly, people undergoing cardiac surgery) during routine health encounters while the other half actively test at-risk populations (Figure 7.8). All HICs that actively test for AKI use automated electronic alert systems.

Among countries with CKD detection programs, half (50%) adopt a reactive approach (cases managed after they are identified through practice), 42% actively test at-risk populations during routine health encounters, and only 8% actively test at-risk populations using specific processes. Most countries in Western Europe (86%), The Middle East (67%), and Latin America (60%) adopt a reactive approach to CKD detection, whereas most countries in the NIS and Russia (100%), Africa (80%), and Eastern and Central Europe (80%) actively test at-risk populations during routine health encounters

(Figure 7.9). Relatively few countries in Latin America (10%), Western Europe (14%), and The Middle East (33%) actively test at-risk populations using specific processes (Figure 7.9).

Relative to LMICs (20%), UMICs (45%) and HICs (57%), more LICs (100%) adopt a reactive approach to CKD detection. Only UMICs (18%) and HICs (4%) actively test at-risk populations using specific testing processes (Figure 7.9).

Availability of services for monitoring CKD at the primary care level varies across regions.

#### Figure 7.9 | Methods of implementing CKD detection programs

- Reactive approach cases managed as identified through practice (%)
- Active testing of at-risk population through routine health encounters (%)
- Active testing of at-risk population through specific processes (%)
- Data not available

Africa Eastern and Central Europe Latin America The Middle East NIS and Russia North America & Caribbean North and East Asia OSFA South Asia Western Europe



World Bank income group: Lower-middle income Upper-middle income

Low income High income

Availability of tests to assess glycated hemoglobin (HbA1C) levels are available in all countries in The Middle East, North America and the Caribbean, North and East Asia, and Western Europe (Figure 7.10). HbA1C tests are available at the primary care level in less than half of countries in Africa (49%). Less than half of countries in Africa (33%), the NIS and Russia (40%), and South Asia (43%) have capacity to report serum creatinine with automated eGFR reporting (Figure 7.10). All countries in Western Europe (100%) are able to measure and report urine albumin-to-creatinine ratio (UACR) or urine protein-to-creatinine ratio (UPCR) at the primary care level, compared to less than half of countries in Africa (36%), the NIS and Russia (40%), OSEA (44%), and South Asia (43%) (Figure 7.10).

At the secondary and tertiary care levels, CKD monitoring services are more widely available across all regions. HbA1C tests are available in 87% of countries in Africa, 86% of countries in South Asia, and all countries in other regions. Similarly, UACR or UPCR measurements are available in all countries in Eastern and Central Europe, The Middle East, the NIS and Russia. North America and Caribbean, North and East Asia, and Western Europe (Figure 7.11).

More than half of countries in all regions have the capacity to measure serum creatinine with automated eGFR reporting, including 62% of countries in Africa and 57% of countries in South Asia (Figure 7.11). All countries in Eastern and Central Europe, North America and the Caribbean, and North and East Asia are able to

Figure 7.10 | Availability of services for CKD monitoring in primary care levels

Available (%) Not available (%)



1. With automated eGFR reporting

#### Figure 7.11 | Availability of services for CKD monitoring in secondary and tertiary care levels





1. With automated eGFR reporting

2. Kidney biopsy interpretation facilities

measure serum creatinine with automated eGFR reporting at the secondary or tertiary care levels. Pathology services (kidney biopsy interpretation facilities) are available in most countries. All countries in The Middle East and North and East

Asia have capacity for pathology services at the secondary or tertiary care levels, while less than half of countries in Africa (46%) have such capacity (Figure 7.11).

#### 7.3 CHRONIC KIDNEY DISEASE OF UNKNOWN ETIOLOGY (CKDu)

Chronic kidney disease of unknown etiology (CKDu) is a type of chronic kidney disease known to mainly affect marginalized agricultural communities where a large number of people develop an unexplained, deadly form of kidney disease. Across country income levels, CKDu affects a similar proportion of countries: LICs (22%), LMICs (23%), UMICs (38%), and HICs (29%) (Figure 7.12). Overall, agricultural (30%) and mining (13%) communities are the most likely to be affected. Across income levels, agricultural

#### Figure 7.13 | Industries affected by CKDu



#### Figure 7.12 | Occurrence of CKDu or populations disproportionately affected with CKD







#### SECTION EIGHT

## Leadership, advocacy, and barriers to kidney failure care

### Key messages

- Worldwide, only 91 (56%) of countries have a national strategy for non-communicable diseases (NCDs) with most of these countries being in OSEA, North and East Asia, and Western Europe.
- There are more countries (61 [38%]) without a national strategy for improving the care of people living with CKD than countries with a specific strategy (n=41; 25%) or countries with strategies embedded within the national NCD strategy (n=47; 29%).
- Overall and among countries with a CKD-specific strategy, only 22% included chronic dialysis in their strategy and 20% included kidney transplantation into their strategy.
- Worldwide, only 19%, 48%, and 63% of governments recognize the treatment and/or prevention of AKI, CKD, and kidney failure, respectively, as a health priority.
- Major barriers to optimal delivery of kidney care were identified to include physician-factors (availability, access, knowledge), patient-factors (knowledge, attitude), nephrologist availability, and healthcare systems factors (availability, access, capability).

#### **8.1 POLICY AND STRATEGY**

Worldwide, 91 (56%) countries have national strategies for non-communicable diseases (NCDs) and 19 (12%) countries are developing national strategies for NCDs that have not been implemented yet. In three regions-Latin America (48%), The Middle East (45%), and the NIS and Russia (10%)—the proportions of countries with national NCD strategies are lower than the global median (Figure 8.1). The proportions of countries with national NCD strategies in place are higher in OSEA (77%), North and East Asia (66%), and Western Europe (64%) than in other regions. Some countries are developing national NCD strategies that have not yet been implemented in Africa (18%), Latin America (19%), the NIS and Russia (30%), North America and the Caribbean (26%), OSEA (6%), and Western Europe (5%). The percentage of LICs with NCD strategies in place (45%) is lower than the percentage of HICs (65%) (Figure 8.1). Compared to other income groups, the proportion of HICs with NCD strategies under development is smaller (8%) (Figure 8.1).

Overall, 61 countries (38%) do not have a national strategy for improving the care of people living with CKD; relatively fewer countries have a specific strategy (n = 41; 25%) or have strategies embedded within national NCD strategies (n =

## Figure 8.1 | Existence of a national strategy for NCDs



47; 29%). North and East Asia (49%), Eastern and Central Europe (38%), and The Middle East (36%) are the regions with the highest proportions of countries with national strategies for improving the care of people living with CKD (Figure 8.2). Africa has the lowest proportion of countries (13%) with specific national strategies for care of people living with CKD. Less than half of countries in all regions have CKD care strategies embedded in NCD strategies (Figure 8.2). Across all income levels, fewer than half of countries have national strategies for CKD care: LICs (11%), LMICs (23%), UMICs (22%), and HICs (33%). Likewise, less than half of countries across all income levels have CKD strategies incorporated into NCD strategies: LIC (22%), LMICs (27%), UMICs (34%), and HICs (29%) (Figure 8.2).

Among countries with CKD-specific strategies, the proportions of countries that include chronic dialysis (22%), non-dialysis CKD (21%), and kidney transplantation (20%) in their strategies are similar. In Africa, more countries include chronic dialysis (12%) and kidney transplantation (10%) in their CKD strategies than non-dialysis CKD (7%), although the overall percentages are much lower (Figure 8.3). In The Middle East, the NIS and

## Figure 8.2 | Existence of a national strategy for improving CKD care

- National CKD-specific strategy exists (%)
- CKD strategy is incorporated into an NCD strategy that includes other diseases (%)
- No (%)
- Africa Eastern and Central Europe Latin America The Middle East NIS and Russia North America & Caribbean North and East Asia OSEA South Asia Western Europe










Populations are covered in the national CKD-specific strategy



Russia, North America and the Caribbean, and Western Europe, the proportions of countries that include chronic dialysis in their CKD strategies are the same as the proportions of countries that include kidney transplantation (Figure 8.3).

Among countries where CKD strategies are incorporated into national NCD strategies, 35% include non-dialysis dependent CKD strategies, while 26% and 23% include chronic dialysis strategies and kidney transplant strategies, respectively. In OSEA, 53% and 5% of countries include people with non-dialysis dependent CKD and people treated with chronic dialysis, respectively, in their NCD strategies (Figure 8.3). No countries in North America and the Caribbean, North and East Asia, and OSEA include kidney transplantation as a CKD strategy within the general NCD strategy compared to half of countries in Eastern and Central Europe (50%) and Latin America (50%).

Overall, 60 (37%) countries have CKD-specific policies in place. Larger proportions of countries in North and East Asia (67%), Eastern and Central Europe (63%), and the NIS and Russia (60%) have policies in place to address issues related to CKD than in other regions (Table 8.1). The proportions of countries with CKD-specific policies in The Middle East (36%), Western Europe (32%), OSEA (22%), Africa (21%), and South Asia (0%) are lower than the global median. Less than half of countries have CKD-specific policies across all income levels, and the proportion increases with income: LICs (11%), LMICs (25%), UMICs (43%), and HICs (49%) (Table 8.1).

Among countries with CKD-specific policies, 82% reported having national policies, while 22% reported having regional policies. Across all regions, only North America and the Caribbean have a larger share of countries with regional CKD policies (40%) than countries with national policies (20%). All countries in Latin America, the NIS and Russia, and Western Europe have national CKD policies, whereas 0%, 17%, and 43% of countries in those regions, respectively, have regional CKD policies (Figure 8.4). In countries with CKD policies, the vast majority of LICs (100%), LMICs (91%), UMICs (94%), and HICs (71%) have national policies, whereas relatively fewer have regional policies: LICs (0%), LMICs (27%), UMICs (6%), and HICs (29%) (Figure 8.4).

#### Table: 8.1 | Existence of CKD-specific policies

	No		Yes		Unknown	
Overall	91	(56)	60	(37)	11	(7)
ISN region						
Africa	29	(74)	8	(21)	2	(5)
Eastern and Central Europe	5	(31)	10	(63)	1	(6)
Latin America	8	(38)	12	(57)	1	(5)
The Middle East	7	(64)	4	(36)	0	(0)
NIS and Russia	3	(30)	6	(60)	1	(10)
North America & Caribbean	6	(50)	5	(42)	1	(8)
North and East Asia	1	(17)	4	(67)	1	(17)
OSEA	14	(78)	4	(22)	0	(0)
South Asia	7	(100)	0	(0)	0	(0)
Western Europe	11	(50)	7	(32)	4	(18)
World Bank income group						
Low income	15	(83)	2	(11)	1	(6)
Lower-middle income	32	(73)	11	(25)	1	(2)
Upper-middle income	18	(49)	16	(43)	3	(8)
High income	26	(41)	31	(49)	6	(10)

#### Figure 8.4 | Types of CKD policies in use





N/A = Data not available

#### 8.2 ADVOCACY

Worldwide, 19% of governments recognize AKI and/or its treatment and prevention as a health priority. Although the proportions of governments that recognize AKI as health priority vary across ISN regions, proportions are relatively similar across income levels (Figure 8.5). Greater proportions of countries recognize AKI as a health priority in The Middle East (36%), NIS and Russia (30%), and North America and the Caribbean (25%) than in other regions. Fewer than a quarter of countries across all income levels recognize AKI as a health priority: LICs (22%), LMICs (18%), UMICs (16%), and HICs (19%) (Figure 8.5).

Worldwide, 48% of national governments recognize CKD and/or its treatment and prevention as a health priority. The proportions of governments that recognize CKD and/or its treatment and prevention as a health priority fall below the global median in Eastern and Central Europe (38%), OSEA (33%), South Asia (29%), and Western Europe (23%) (Figure 8.5). Larger proportions of LICs (56%), LMICs (45%), and UMICs (57%) recognize CKD as a health priority than HICs (43%).

Worldwide, governments in 63% of countries recognize kidney failure and/or KRT as a health priority. Governments in the majority of HICs (70%), UMICs (57%), and LMICs (66%) recognize kidney failure and KRT as health priorities, whereas the governments in just 44% of LICs do so (Figure 8.5). The percentages of countries with governments that recognize kidney failure and KRT as health priorities exceed the global median in The Middle East (91%), North America and the Caribbean (83%), North and East Asia (83%), OSEA (83%), and Western Europe (64%) (Figure 8.5).

Overall, advocacy groups at higher levels of government (e.g., parliamentary committees) or NGOs that increase advocacy, and raise awareness about AKI, CKD, and kidney failure/ KRT exist in 11%, 40%, and 34% of countries, respectively. Only a small percentage of countries across all ISN regions have advocacy groups for AKI, ranging from 0% in North and East Asia and in South Asia to 20% in the NIS and Russia (Figure 8.6). Less than a fifth of countries across all income groups have parliamentary advocacy groups or NGOs to raise awareness about AKI: LICs (17%), LMICs (7%), UMICs (11%), and HICs (13%) (Figure 8.6).

There is high variability in the availability of advocacy support for CKD across ISN regions, ranging from 14% of countries in South Asia to 67% of countries in North and East Asia. Only a third of countries in OSEA (33%) and half of countries in North America and the Caribbean (50%) and Western Europe (50%) have advocacy support for CKD (Figure 8.6). Advocacy support for CKD exists in a greater



### Figure 8.5 | Government recognition of AKI, CKD, and KRT (treatment and prevention) as health priorities

#### Figure 8.6 | Availability of support for AKI, CKD, and KRT (treatment and prevention)



share of HICs (48%) relative to UMICs (46%) or LMICs (23%) or LICs (39%).

The proportions of countries with advocacy groups (government organizations and NGOs) to raise awareness of kidney failure/KRT are below the global median in several regions, including Africa (26%), Latin America (24%), The Middle East (18%), North America and the Caribbean (33%), North and East Asia (33%), OSEA (28%), and South Asia (14%) (Figure 8.6).

#### **8.3 BARRIERS TO OPTIMAL KIDNEY CARE**

All countries reported barriers to the provision of optimal kidney care, including geography, physician-related factors, patient-related factors, nephrologist availability, capacity of healthcare systems, lack of political prioritization, and economic factors (Figure 8.7). Overall, physicianrelated factors (availability, access, knowledge, attitude), patient-related factors (knowledge and attitude) and availability of nephrologists were reported as barriers in 71%, 75%, and 67% of countries, respectively. However, specific barriers vary by region. For instance, in Africa, the vast majority of countries identified geography (85%), economic factors (85%), and availability of nephrologists (83%) as barriers, whereas much lower proportions of countries identified geographic barriers in North America and the Caribbean (42%) and economic barriers in North

and East Asia (17%) (Figure 8.7). More than half of countries in Africa (63%), OSEA (74%), and South Asia (88%) identified lack of political will as a barrier to the provision of optimal kidney care.

With minimal variation across income levels, the percentages of countries reporting each barrier decrease as country income level increases (Figure 8.7). Compared to HICs, greater percentages of LICs identified geography (35% vs 85%), physician-related factors (59% vs 70%), patient-related factors (67% vs 75%), nephrologist availability (57% vs 80%), healthcare system factors (44% vs 75%), lack of political will (41% vs 60%), and economic factors (30% vs 85%) as barriers to optimal kidney care (Figure 8.7).

#### Figure 8.7 | Barriers to optimal kidney failure care



Knowledge, attitude
 Availability, access, capability

5. Limited funding, poor reimbursement mechanisms



### SECTION

# Survey of people living with kidney disease

#### Key messages

- People living with kidney disease from ten countries (Burundi, Canada, India, Kenya, Lebanon, Nigeria, Pakistan, United Kingdom, United States, and Zimbabwe) participated in the survey.
- More people living with kidney disease (37%) make payment for their medications and treatments (including KRT) though private and fully out-of-pocket means than those who use other payment modalities.
- Several people living with kidney disease identified shortages of counsellors / psychologists, nephrologists, dietitians, transplant surgeons, and social workers in their countries.
- Most people living with kidney disease identified lack of effective government policies (70%), excessive cost of KRT (45%), excessive cost of medicines (45%), and limited access to workforce as major barriers to receiving kidney care.
- The top three outcomes that are extremely important to people living with kidney disease are ability to work (72%), mobility (56%), and the financial impact of kidney disease and its treatment (55%).

#### 9.1 CHARACTERISTICS OF PARTICIPANTS AND CO-PAYMENT METHODS

Twenty people living with kidney disease from 10 countries (Burundi, Canada, India, Kenya, Lebanon, Nigeria, Pakistan, the United Kingdom, the United States, and Zimbabwe) participated in the survey (age: 18 years to 79 years; 55% female). Half of the participants (50%) were kidney transplant recipients, 25% were receiving HD, 10% were receiving PD, 10% had kidney failure and were not yet receiving KRT, and 5% had early-stage CKD (Figure 9.1).

#### Figure 9.1 | Demographic features of people living with kidney disease included in the survey



Participants were diagnosed with CKD during assessments for other risk factors (diabetes or hypertension) (40%), routine PCP visits (25%), hospital emergency room visits (20%), and examinations for insurance/employment purposes (15%) (Figure 9.1).

For 21% of the participants, treatment was free at the point of delivery and fully covered by public funding from the government. A small proportion of participants (5%) reported being responsible for co-payments to supplement public funding for their care (Figure 9.2). Other participants reported either partial payment through insurance (21%) or full payment through insurance (11%). However, the largest share of participants (37%) paid for their medications and treatments (including KRT) privately and fully out-of-pocket. (Figure 9.2).

### Figure 9.2 | Responsibility for the costs of kidney disease treatment



#### 9.2 PERSPECTIVES ON WORKFORCE SHORTAGES AND OBSTACLES TO KIDNEY CARE

Although the perspectives of people living with kidney disease on workforce shortages varied, approximately half of those surveyed reported shortages of counsellors/psychologists (55%), nephrologists (50%), dietitians (45%), transplant surgeons (45%), and social workers (45%) (Figure 9.3). About a third of the participants surveyed reported shortages of nurse practitioners (30%), dialysis nurses (35%), and primary care physicians (30%) in their countries. Only one person living with kidney disease (5%) reported no shortage of healthcare workers (Figure 9.3).

### Figure 9.3 | Perspectives on workplace shortages of people living with kidney disease



Obstacles to kidney care were also assessed. Most people living with kidney disease (70%) reported a lack of effective government policies as the main obstacle to receiving the best quality of care. Other obstacles include excessive cost of medicines (45%), excessive cost of dialysis (20%) or transplantation (25%), limited access to a nephrologist (15%), among others. (Figure 9.4). Six of the people living with kidney disease (30%) reported no obstacles to receiving the highest quality kidney care.

Figure 9.4 | Perspectives of people living with kidney disease on obstacles to kidney care



People living with kidney disease commonly identified economic factors when asked about ways to improve kidney care in their countries. Reducing the cost of KRT was most commonly identified (30%), followed by reducing the cost of essential medicines (15%), providing an adequate workforce (15%), and providing opportunities to participate in kidney disease research (15%) (Figure 9.5).

## Figure 9.5 | Perspectives of people living with kidney disease on strategies to improve kidney care



#### 9.3 IMPACTS OF KIDNEY DISEASE AND ITS TREATMENT

People living with kidney disease also identified the physical, mental, social, economic, and professional impacts of kidney disease. Across all factors assessed, the vast majority of people identified kidney disease as having major negative economic (100%) and professional (80%) impacts. Multiple people living with kidney disease also identified negative impacts on physical health (40%), mental/emotional health (40%), and social wellbeing (30%) (Figure 9.6).





People living with kidney disease also provided perspectives on the effects of kidney disease on aspects of their overall wellbeing (Figure 9.7). People living with kidney disease identified effects on their ability to work (72%) as extremely important, followed by effects on mobility (56%), and financial impacts of kidney disease and treatment (55%). Half of those surveyed (50%) identified fatigue, depression, impacts on the ability to travel, and impacts on sleep as extremely important. Only about a third of people living with kidney failure identified impacts on sexual function (38%) and impacts on their friends and family (33%) as extremely important (Figure 9.7).



#### Figure 9.7 | Perspectives of people living with kidney disease on its effects on wellbeing

SECTION

### Changes in key ISN–GKHA metrics (2019 to 2023)

#### **10.1 AVAILABILITY OF KRT**

Worldwide and in countries that participated in both surveys, the median densities of HD centers, PD centers and kidney transplantation centers increased by 9.8%, 13%, and 7%, respectively. In the same period, the density of HD centers in The Middle East decreased by 13.1% but increased across other regions from 4% in Latin America to 58.8% in Africa. The density of HD centers decreased in HICs by 1.3% but increased in countries at other income levels (Figure 10.1). The density of PD centers decreased in several regions: Eastern and Central Europe (-14.5%), The Middle East (-7.8%), North and East Asia (-34.5%), and OSEA (-31.5%). However, the density of PD centers decreased only in LICs (-33.3%) but increased in other income groups, with the highest increase recorded in LMICs (29.4%) followed by UMICs (27.4%). (Figure 10.1). The median density of kidney transplantation centers only increased in Western Europe (0.52 pmp to 0.55 pmp), while

all other regions recorded reductions in kidney transplantation centers ranging from 0.9% in North and East Asia, to 19.5% in The Middle East. The median density of kidney transplantation centers decreased in LICs by 6.3%, from 0.16 pmp in 2019 to 0.0.15 pmp in 2023. Kidney transplantation centers increased in all other income groups (Figure 10.1).

Globally and in countries that participated in both surveys, the median prevalence of people treated with HD (pmp) increased by 11.1% from 2019 to 2023. This proportion remained the same in Africa, NIS and Russia, North America and the Caribbean, and South Asia, but increased in other regions ranging from 4.8% in Western Europe to 25.6% in Latin America (Figure 10.2). The median prevalence of people treated with HD decreased 16.1%, from 41.7 pmp to 35 pmp in LMICs, and increased by 6.9% in UMICs and 1.9% in HICs. Worldwide, the median prevalence of people treated with PD in the same period

#### Figure 10.1 | Change in density of KRT centers

2019 (pmp) 2023 (pmp)

			% change
Hemodialysis (HD) Overall		4.41 4.84	+9.75%
Africa		0.51 0.81	+58 82%
Eastern and Central Europe		9 55	+10.26%
Latin America		4 56	+3 95%
The Middle East		3.75	-13.07%
NIS and Pussia		3.73	+29 03%
North America & Caribbean	1/1 81	3.72	22 23 +50 10%
North and East Asia	14.01	9.55	+25 76%
OSEA		5.55	+28.02%
South Asia		155 196	+26.02%
Western Europe		6.93	+10.97%
World Bank income group:			
Low income		0.18 0.31	+72.22%
Lower-middle income		1.34 1.65	+23.13%
Upper-middle income		4.66 5.42	+16.31%1
High income		8.68 8.57	-1.27%
Peritoneal dialysis (PD)			
Overall		1.39 1.57	+12.95%
Africa		0.09 0.13	+44.44%
Eastern and Central Europe		2.34 2.00	-14.53%
Latin America		1.13 1.76	+55.75%
The Middle East		0.77 0.71	-7.79%
NIS and Russia		0.41 0.61	+48.78%
North America & Caribbean		1.65 3.56	+115.76%
North and East Asia		1.94 1.27	-34.54%
OSEA		2.16 1.48	-31.48%
South Asia		0.13 0.14	+7.69%
Western Europe		2.41 2.72	+12.86%
World Bank income group:			
Low income		0.09 0.06	-33.33%
Lower-middle income		0.17 0.22	+29.41%
Upper-middle income		0.84 1.07	+27.38%
High income		2.33 2.48	+6.44%
Kidney transplantation (KT)			
Overall		0.43 0.46	+6.98%
Africa		0.15 0.14	-6.67%
Eastern and Central Europe		0.71 0.70	-1.41%
Latin America		0.48 0.46	-4.17%
The Middle East		0.41 0.33	-19.51%
NIS and Russia		0.33 0.32	-3.03%
North America & Caribbean		0.75	-5.33%
North and East Asia		1.14 🔜 🖬 1.13	-0.88%
OSEA		0.41 0.34	-17.07%
South Asia		0.13 0.11	-15.38%
Western Europe		0.52 0.55	+5.77%
World Bank income group:		016 0 15	0.050
			-0.25%
			+11.11%
			+0.13%
High income		0.59 📃 0.59	0.00%

#### Figure 10.2 | Change in treated KRT prevalence

2019 (pmp) 2023 (pmp)

% change

Hemodialvsis (HD)					70 change
Overall		298.35	331.35		+11.06%
Africa		13.80	13.80		0.00%
Eastern and Central Europe		477.60	522.05		+9.31%
Latin America		399.30	501.50		+25.59%
The Middle East		256.65	276.58		+7.77%
NIS and Russia		137.60	137.60		0.00%
North America & Caribbean		515.40	515.40		0.00%
North and East Asia	1661.40			1840.90	+10.80%
OSEA		553.68	653.91		+18.10%
South Asia		26.15	26.15		0.00%
western Europe		473.30	495.80		+4.75%
World Bank income group:					
Low income		5.10	5.10		0.00%
Lower-middle income		41.70	35.00		-16.07%
Upper-middle income		300.30	321.00		+6.89%
High income		512.00	531.40		+3./9%
Peritoneal dialysis (PD)		_	-		
Overall		38.05	37.90		-0.39%
Africa		2.10	2.10		0.00%
Eastern and Central Europe		37.15	34.69		-6.62%
Latin America		48.00	62.00		+29.17%
The Middle East		17.50	17.50		0.00%
NIS and Russia		14.50	14.50		0.00%
North America & Caribbean		114.20	114.20		0.00%
North and East Asia		107.45	103.44		-3.73%
OSEA		101.12	95.00		-6.05%
South Asia		1.65	1.91		+15.76%
Western Europe		49.90	56.30		+12.83%
World Bank income group:					
Low income		1.70	1.70		0.00%
Lower-middle income		7.95	4.55		-42.77%
Upper-middle income		26.54	22.35		-15.79%
High income		54.30	57.50		+5.89%
Kidney transplantation (KT)					
Overall		255.00	279.00		+9.41%
Africa		25.29	25.4		+0.43%
Eastern and Central Europe		282.00	280.00		-0.71%
Latin America		68.75	99.50		+44.73%
The Middle East		277.00	279.00		+0.72%
NIS and Russia		27.00	33.00		+22.22%
North America & Caribbean		6.80	6.80		0.00%
North and East Asia		141.00	170.00		+20.57%
OSEA		190.80	245.45		+28.64%
South Asia		-	-		-
Western Europe		535.50	569.70		+6.38%
World Bank income group:					
Low income		2700	13.00		-51 950/
Linner-middle income		27.00 65 15	81.50		+25 10%
High income		360 50	405.00		+12 3/1%
		000.00			.2.3470

decreased from 38.1 pmp in 2019 to 37.9 pmp in 2023 (-0.39%), with the largest decrease in Eastern and Central Europe (-6.6%). Only HICs showed an increase in the median prevalence of people living with kidney disease and treated with PD (5.9%) with decreases in LMICs (-42.8%), and UMICs (-15.8%) and no change in LICs (Figure 10.2). The overall median prevalence of people living with kidney failure treated with kidney transplants increased by 9.4%. Only Eastern and Central Europe showed a reduction in the median prevalence of kidney transplantation between 2019 and 2023 (-0.7%). Data were unavailable for LICs, however LMICs had a reduction in median kidney transplant prevalence, from 27 pmp in 2019 to 13 pmp in 2023 representing a 51.9% reduction (Figure 10.2).

#### **10.2 ACCESS TO KRT**

Worldwide and in countries that participated in both surveys, the proportion of countries where more than half of those needing dialysis are able to access it increased by 2.8% between 2019 and 2023. This proportion increased in Africa (17.7%), Eastern and Central Europe (6.4%), The Middle East (22%), and in North and East Asia (20.5%) (Figure 10.3). By income level, this proportion increased in LICs by 138.5%, from 13% in 2019 to 31% in 2023. There was a 10.6% reduction in dialysis access in LMICs and increases of 3.7% and 2% in UMICs and HICs, respectively. In countries where PD is available, the median proportion of countries where more than half of those starting dialysis are able to begin with PD increased from 4% in 2019 to 6% in 2023. This proportion reduced by 45.5% in Latin America (Figure 10.3). Worldwide, there was a 3.3% reduction in the proportion of countries where more than half of those eligible for kidney transplants are able to receive them. This proportion doubled (100% increase) in Africa, and increased by 29.4% in Latin America, and 41.7% in Western Europe. By income level, the proportion of countries where more than half of those eligible for transplants are able to receive them increased in HICs (1.8%) (Figure 10.3).

#### **10.3 AFFORDABILITY / FUNDING FOR KRT**

Worldwide and in countries that participated in both surveys, the proportion of countries where HD (and medications) is publicly funded by the government and free at the point of delivery increased by 3.7% from 2019 to 2023. The proportion of countries reporting this payment scheme increased by 61.3% in Eastern and Central Europe and 45.5% in Western Europe (Figure 10.4). During this period, there was a reduction in the proportion of countries where HD is publicly funded by the government and free at point of delivery in LICs (-100%) and LMICs (-35.3%), and UMICs (-14.3%). However, this proportion increased in HICs (37.5%). Worldwide, there was a 21.7% increase in the proportion of countries where PD is publicly funded by government and free at point of delivery, with the greatest increase reported in Latin America

(94.1%). This proportion decreased in Africa (-18.2%), The Middle East (-25%), the NIS and Russia (-32.6%), and OSEA (-65%) (Figure 10.4). By income level, the proportion of countries where PD is publicly funded by government and free at the point of delivery increased in HICs (47.2%), declined in LMICs (-45.5%), and remained unchanged in UMICs. Worldwide and in countries that participated in both surveys, the proportion of countries where kidney transplantation is publicly funded by government and free at the point of delivery increased by 16.1%, with decreases reported in Eastern and Central Europe, NIS and Russia, North America and the Caribbean, and South Asia (Figure 10.4). By income level, this proportion decreased in LMICs (-38.5%), increased in HICs (28.6%) and was unchanged in LICs and UMICs.

### Figure 10.3 Change in the proportion of national population with kidney failure able to access KRT 2019 (%) 2023 (%)



### **Figure 10.4** | Change in the proportion with kidney failure receiving KRT (and medications) from public government funds and free at point of delivery

2019 (%) 2023 (%)

		% change
Hemodialysis (HD)	27%	+3 70%
		15.70%
Africa	20% 11%	-45.00%
Eastern and Central Europe	31% 50%	+61.29%
Latin America		-21.43%
I ne Middle East		0.00%
NIS and Russia	43% 29%	-32.00%
North America & Caribbean		-51.72%
		-
South Asia		100.00%
Western Europa		
Western Europe	55%	/0 +40.40/0
World Bank income group:		
Low income	19% 0%	-100.00%
Lower-middle income	17% 11%	-35.29%
Upper-middle income	21% 18%	-14.29%
High income	40% 55%	+37.50%
Peritoneal dialvsis (PD)		
Overall	23% 28%	+21.74%
Africa	11% 🔜 🔜 9%	-18.18%
Eastern and Central Europe	38%	0.00%
Latin America	17% 33%	+94.12%
The Middle East	36% 27%	-25.00%
NIS and Russia	43% 29%	-32.56%
North America & Caribbean	0% 14%	-
North and East Asia	0% 33%	-
OSEA	20% 7%	-65.00%
South Asia	0% 0%	-
Western Europe	50% 80	% +60.00%
World Bank income group:		
Low income	0% 0%	-
Lower-middle income	11% 6%	-45.45%
Upper-middle income	26% 26%	0.00%
High income	36% 53%	+47.22%
Kidney transplantation (KT)		
Overall	31% 36%	+16.13%
Africa	17%	0.00%
Eastern and Central Europe	44%	-13.64%
Latin America	19% 38%	+100.00%
The Middle East	27%	0.00%
NIS and Russia	43%	-67.44%
North America & Caribbean	40% 20%	-50.00%
North and East Asia	0% 50%	-
OSEA	20%	0.00%
South Asia	17% 0%	-100.00%
Western Europe	56% 78%	+39.29%
World Bank income group:		
Low income	25% 25%	0.00%
Lower-middle income	13% 8%	-38.46%
Upper-middle income	28% 28%	0.00%

42%

High income

+28.57%

54%

### Figure 10.5 | Change in the proportion with kidney failure receiving KRT (and medications) through solely private out-of-pocket payment system

2019 (%) 2023 (%)

Hemodialysis (HD)		% change
Overall	6% 6%	0.00%
Africa	11%	+54.55%
Eastern and Central Europe	13% 6%	-53.85%
Latin America	0% 0%	-
The Middle East	0% 0%	-
NIS and Russia	0% 0%	-
North America & Caribbean	14%	0.00%
North and East Asia	0% 0%	-
OSEA	7% 0%	-100.00%
South Asia	0% 0%	-
Western Europe	0% 0%	-
World Bank income group:		
Low income	13% 19%	+46.15%
Lower-middle income	6% 6%	0.00%
Upper-middle income	9%	0.00%
High income	2% 0%	-100.00%
5		
Peritoneal dialysis (PD)		
Overall	4% 4%	0.00%
Africa	6% 6%	0.00%
Eastern and Central Europe	13% 6%	-53.85%
Latin America	0% 0%	-
The Middle East	0% 0%	-
NIS and Russia	0% 0%	-
North America & Caribbean	0% 0%	-
North and East Asia	0% 0%	-
OSFA	0% 7%	_
South Asia	17%	-100 00%
Western Europe	0% 5%	
World Pank income group		
wond Bank income group:	C0/ C0/	0.000/
	6% 6%	0.00%
Lower-middle income	3% 3%	0.00%
Upper-middle income	6% 6%	0.00%
High income	2% 2%	0.00%
Kidnov transplantation (KT)		
Overall	8% 6%	-25.00%
Δfrica	17% 25%	+4706%
Eastern and Central Europe	13%	0.00%
		100.00%
The Middle Feet		-100.00%
		-100.00%
		-
North America & Cambbean		-
North and East Asia	0% 0%	-
USEA	0% 0%	-
South Asia	0% 0%	-
Western Europe	0% 6%	-
World Bank income group:	050/	
Low income	25%	0.00%
Lower-middle income	13%	-38.46%
Upper-middle income	7% 7%	0.00%
High income	6% 2%	-66.67%

Worldwide and in countries that participated in both surveys, there was no change in the proportion of countries where HD is funded privately, and costs are covered solely out-ofpocket between 2019 and 2023. This proportion increased only in Africa (54.6%); six regions (Latin America, The Middle East, the NIS and Russia, North and East Asia, South Asia, and Western Europe) had no countries reporting this funding scheme in both 2019 and 2023 (Figure 10.5). By income level, the proportion of countries where HD is funded privately, and costs are covered solely out-of-pocket increased by 46.2% in LICs with no change in LMICs and UMICs. There was also a 100% reduction in HICs, as no country in this income category reported this funding scheme for HD. Similarly, the proportion of countries worldwide where PD is funded privately, and costs are covered

solely out-of-pocket remained unchanged for the period but reduced in Eastern and Central Europe (-53.9%) and South Asia (-100%). By income level, the proportion of countries with this payment scheme remained the same for all income categories in both periods (Figure 10.5). The proportion of countries worldwide where kidney transplantation is funded privately and costs are covered solely out-of-pocket decreased by 25%, with proportion of countries in Latin America and The Middle East that previously used this payment scheme for kidney transplantation reduced to zero in 2023 (Figure 10.5). By income level, the proportion of countries where kidney transplantation is paid for privately and solely out-of-pocket decreased in LMICs (-38.5%) and HICs (-66.7%) but remained the same in LICs and UMICs.

#### **10.4 WORKFORCE FOR KRT**

Globally and among countries that participated in both surveys, the median density of nephrologists increased from 9.5 pmp in 2019 to 12.4 pmp in 2023, growing by 30.4%. During this period, the median density of nephrologists increased in all regions except in Eastern and Central Europe and North America and the Caribbean where it reduced by 4.9% and 0.99%, respectively (Figure 10.6). The density of nephrologists increased across all income groups: LICs (15.4%), LMICs (38.5%), UMICs (35.1%), and HICs (10.6%) (Figure 10.6). Globally and in countries that participated in both surveys, there was an increase in the median density of nephrology trainees (0.74%) in the period between 2019 and 2023. Reductions in the density of nephrology trainees were reported in Africa (-52.8%), The Middle East (-48.9%), NIS and Russia (-3.1%), North and East Asia (-14.1%), and OSEA (-1.9%) (Figure 10.7). The median prevalence of nephrology trainees fell by more than half in LICs (-58.8%) and also reduced in LMICs (-16.2%) but increased in UMICs (14.4%) and HICs (5.4%) (Figure 10.7).

#### Figure 10.6 | Change in global prevalence of nephrologists

2019 (pmp) 2023 (pmp)

% change

Overall		9.51	12.40		+30.39%
Africa		0.66	1.10		+66.67%
Eastern and Central Europe	26.03			24.76	-4.88%
Latin America		9.55	17.1	5	+79.58%
The Middle East		8.27	15.8	6	+91.78%
NIS and Russia	14.4	1	17.0	)7	+18.46%
North America & Caribbean	18.13		17.	95	-0.99%
North and East Asia	22.51			28.72	+27.59%
OSEA		5.67	8.87		+56.44%
South Asia		1.15	1.80		+56.52%
Western Europe	24.36			26.17	+7.43%
World Bank income group:					
Low income		0.26	0.30		+15.38%
Lower-middle income		1.30	1.80		+38.46%
Upper-middle income		9.26	12.51		+35.10%
High income	23.15			25.61	+10.63%

#### Figure 10.7 | Change in global prevalence of nephrology trainees

2019 (pmp) 2023 (pmp)		% change
Overall	1.35	+0.74%
Africa	0.36 0.17	-52.78%
Eastern and Central Europe	3.05 4.77	+56.39%
Latin America	1.35	+5.93%
The Middle East	1.82 0.93	-48.90%
NIS and Russia	1.60 1.55	-3.13%
North America & Caribbean	0.00 0.00	-
North and East Asia	2.99 2.57	-14.05%
OSEA	1.08 1.06	-1.85%
South Asia	0.29 0.43	+48.28%
Western Europe	5.80 6.41	+10.52%
World Bank income group:		
Low income	0.17 0.07	-58.82%
Lower-middle income	0.37	-16.22%
Upper-middle income	1.25 1.43	+14.40%
High income	3.73 3.93	+5.36%





### Discussion

#### **11.1 GAPS IN SERVICES AND RESOURCES**

Through diverse programs and initiatives, the ISN continues to promote and work toward a future in which all people have equitable access to sustainable kidney health. Through development initiatives and partnerships with other organizations and agencies to drive health policies, practices, and infrastructure, the ISN seeks to facilitate the implementation of equitable and ethical care for people living with kidney disease in all regions and countries of the world. Developing and implementing strategies to improve kidney care with regard to availability, equity, and access remains a focus of the ISN in the current decade. Improving understanding of the status of kidney care around the world is a major tool for bringing stakeholders together to facilitate the implementation of equitable access to kidney care.

The ISN–GKHA is a worldwide initiative with the goal of identifying and evaluating global capacity for kidney care, using the WHO's key building blocks of a functional health system as

a framework. The first two editions in 2017 and 2019 revealed significant gaps and variability in availability of, and accessibility to kidney care across all WHO domains, especially in LICs and LMICs. This edition presents the results of the third iteration of the ISN-GKHA survey, which is aimed at describing the global status of the burden of CKD and kidney failure and the structures and organization of care delivery across ISN regions and country income groups. This information can be useful for guiding strategic development, identifying areas of unmet needs as targets for increased resource allocation, documenting the status of kidney care as a means to inform advocacy efforts and strategies, and monitoring progress toward closing identified gaps.

There are substantial differences across countries, regions, and income groups for measures of kidney care that were evaluated in the survey. Several key findings were identified; major findings are summarized below, and their implications are discussed in the sections that follow relative to the key domains covered in the survey.

- Publicly funded (and free at point of delivery) chronic HD is available in less than half of countries (45%) worldwide.
- Few LICs (13%) and LMICs (18%) provide universal health coverage for all aspects of KRT.
- Most countries have critical shortages of healthcare providers essential for kidney failure care.
- The global prevalence of nephrologists is lowest in Africa (1.1 pmp) and highest in North and East Asia (28.7 pmp); Afghanistan (0.03 pmp), Malawi (0.05 pmp), and Mozambique (0.09 pmp) have the lowest prevalences of nephrologists.
- Worldwide, 1 in 3 nephrologists (treating adults and children) is a woman.
- Worldwide, capacity for the provision of KRT varies; HD is widely available in 98% of countries, whereas PD and kidney transplantation are available in 79% and 70% of countries, respectively.
- In 74% of countries with available dialysis services, more than half of people living with kidney disease who need dialysis are able to access it at onset of kidney failure; however, these people are able to start treatment with PD in only 6% of countries.
- Medications for people living with kidney failure are publicly funded by the government and free at the point of delivery in only 24% of countries, and solely covered with private funding and paid for out-of-pocket in 12% of countries.
- Registries for non-dialysis CKD, dialysis, and kidney transplantation are available in 31 (19%), 102 (63%), and 94 (58%) countries, respectively.
- In countries with available registries, provider participation varies across regions and income levels; participation in non-dialysis CKD registries is voluntary in many countries, but typically is mandatory for dialysis and kidney transplantation registries in countries where these are available.
- In countries with detection programs for CKD, 50% use a reactive approach (cases managed

as they are identified through practice), 42% actively test at-risk populations through routine health encounters, and only 8% actively test at-risk populations through specific processes.

- Worldwide, only 91 (56%) countries have national strategies for non-communicable diseases (NCDs).
- Among countries with CKD-specific strategies, few (22%) include chronic dialysis and even fewer (20%) include kidney transplantation.
- Worldwide, only 19%, 48%, and 63% of governments recognize treatment and/or prevention of AKI, CKD, and kidney failure, respectively, as health priorities.
- Among people living with kidney disease surveyed, the largest proportion (37%) reported paying for CKD medications and treatments (including KRT) privately and fully out-of-pocket.
- Most surveyed people living with kidney disease identified lack of effective government policies (70%), excessive cost of KRT (45%), excessive cost of medicines (45%), and limited access to the workforce as major barriers to receiving kidney care.
- The three outcomes that are most important to surveyed people living with kidney disease are the ability to work (72%), mobility (56%), and the financial impact of kidney disease and its treatment (55%).
- Worldwide, the number of centers that provide HD, PD, and kidney transplantation increased by 9.8%, 13%, and 7%, respectively between 2019 and 2023. Whereas the prevalence of HD and kidney transplantation increased, the prevalence of PD decreased by 0.4%.
- Overall, between 2019 and 2023, the percentage of countries where KRT (and medications) are covered by the government through public funding and are free at the point of delivery increased for HD (3.7%), PD (21.7%), and kidney transplantation (16.1%).
- The density of nephrologists increased worldwide between 2019 and 2023, from 9.5 pmp to 12.4 pmp (30.4% increase) while the density of nephrology trainees only increased by 0.74%.

#### **11.2 IMPLICATIONS**

#### 11.2.1 Health finance and service delivery

There are vast differences in funding mechanisms for treatment of non-dialysis CKD worldwide. Overall, non-dialysis CKD treatment is publicly funded by the government and free at the point of delivery in only 45 countries (27%). Western Europe (73%), Eastern and Central Europe (44%), and South Asia (37%) have the highest proportions of countries where nondialysis CKD treatment is publicly funded by the government and free at the point of delivery. Pre-dialysis care of people living with CKD is vital for preventing or slowing CKD progression to kidney failure. Elements of this care, including using medications and monitoring kidney function to minimize disease complications can be costly to people living with kidney disease. Countries that do not cover these care costs may bear a higher burden of kidney failure and manifest poor outcomes of people living with kidney disease because they are unable to afford appropriate care.

In less than half of countries worldwide, the costs of dialysis for AKI (44%), chronic HD (45%), and chronic PD (42%) are covered by public funding provided by the government and free at point of delivery. For all treatment types, approximately a third of HICs provide public government funding to cover the costs of dialysis for AKI, chronic HD, and chronic PD, while less than half of countries in other income groups have adopted this payment scheme. Failing to provide public government funding for KRT, especially in lowand middle-income countries, may be associated with increased mortality and other poor outcomes, even in cases of AKI, which is often reversible with preventable mortality. Delivering appropriate KRT is expensive and implementing universal coverage for all people living with kidney disease worldwide would be challenging. However, implementing methods to reduce the costs of treatment and increasing the use of CKM can lead to improved outcomes.

More than half of countries provide full or partial public government funding to cover the costs of access for dialysis (HD or PD) or surgery for kidney transplantation. Public funding for central venous catheter insertion for HD, fistula creation for HD, PD catheter insertion, and surgery for kidney transplantation is available in 58%, 54%, 53%, and 51% of countries, respectively. Less than half of LICs and LMICs provide public government funding for access surgeries and other surgical services for KRT, increasing overall KRT costs for people living with kidney disease in these countries, especially if dialysis and kidney transplantation also are not publicly funded. Appropriate and proper access to dialysis is essential for effective dialysis treatment outcomes. Including this element of care in government coverage (in places that fund dialysis treatments) may result in improved dialysis outcomes for people living with kidney disease, reducing unnecessary complications which are costly.

With regard to kidney failure care, significant amounts of within-country variations in organization, cost, and access were identified. HICs have the lowest within-country variations in organization of kidney failure care (24%) and cost of kidney failure care (10%) suggesting better infrastructure, methods of care organization, and funding structures than countries at other income levels. There is also variation in KRT access between adults and children, with KRT scarcely available or unavailable for children in many countries. Reducing inequalities in children's access to KRT remains a global challenge, indicating a need to raise awareness and develop effective interventions and policies.

Overall, health infrastructure for the delivery of kidney failure care is rated as below average in 22% of countries and above average or excellent in 49% of countries. LICs (55%) and LMICs (44%) have a higher prevalence of below average infrastructure for care, compared to only 2% of HICs. Reliable infrastructure for care of people living with kidney disease (e.g., dialysis machines, dialysis beds/chairs, monitoring equipment, clean water, electricity, etc.) is essential to ensure adequate provision of care. The availability of basic infrastructure and a structured system enables the standardized delivery of kidney care as well as systematic monitoring of process measures, which are important to ensure high quality and equitable care.<sup>1</sup>

#### 11.2.2 Health workforce for kidney care

Nephrologists are primarily responsible for delivery of kidney failure care in 87% of countries, followed by primary care physicians in 7% of countries. The median number of nephrologists worldwide is 11.75 pmp; most treat adults living with kidney disease (10.1 pmp), 35% of nephrologists are women, and the prevalence of nephrologists increases with country income level: LICs (0.30 pmp), LMICs (1.78 pmp), UMICs (11.91 pmp), and HICs (25.33 pmp). Similarly, the global density of nephrology trainees is 1.15 pmp and increases with country income level: LICs (0.06 pmp), LMICs (0.33 pmp), UMICs (1.26 pmp) and HICs (3.88 pmp). While these workforce densities do not account for other factors such as burden of kidney failure, densities of other health care professionals, availability of training facilities, and rising costs of medical education and specialist training, it is clear that low- and middle-income countries lack adequate nephrology workforces with the capacity to tackle the high burden of kidney disease. Methods to improve workforce efficiency, including use of task shifting (training primary care providers, nurses, or other appropriate professionals to provide kidney failure care with remote guidance from nephrologists and/or support from standard algorithms) and optimizing available resources for training (including telenephrology) may help improve capacity to deliver high quality kidney failure care in countries with limited nephrologist availability.2,3

Most countries reported workforce shortages that inhibit the effective delivery of kidney care. Workforce shortages are most prevalent in LICs. The vast majority of LICs reported critical shortages of nephrologists (90%), pediatric nephrologists (95%), transplant surgeons (90%), surgeons or interventional radiologists who can provide HD access (100%), surgeons or interventional radiologists who can provide PD access (90%), and dietitians (90%). Augmenting the workforce with these health care professionals is important to developing the multidisciplinary care teams necessary to manage the complexities of kidney failure. Furthermore, distributing the workload for kidney care across multiple providers increases overall capacity of care, which is particularly important in areas with significant nephrologist shortages.

#### 11.2.3 Access to essential medications, health products, and technologies for kidney failure care

Worldwide, 98% of countries that participated in the survey have chronic HD services available. These services are available in all countries in all regions, except in OSEA and South Asia, where 89% and 88% of countries, respectively, have chronic HD services. However, just over threequarters of countries (79%) have chronic PD services. Chronic PD services are available in 21% of LICs and 69% of LMICs, compared to 97% of HICs. Similarly, in countries where PD is available, most HICs (98%) have automated PD, compared to 50% of LICs. Increasing PD utilization could be a strategy for increasing access to kidney failure care and improving outcomes of people living with kidney disease, especially in resourcelimited settings where use of this modality is extremely low. Low PD use in LICs and LMICs is often attributed to limited infrastructure (e.g., an inability to manufacture PD fluids locally), limited training and experience in delivering PD, lack of motivation among people living with kidney disease due to socio-cultural and economic factors, and costs of PD in these settings.<sup>4</sup> These factors should be addressed.

Over two-thirds of countries (70%) worldwide have kidney transplantation services. Availability of kidney transplantation increases with country income level, ranging from 21% of LICs to 86% of HICs. Kidney transplantation is well-established as the preferred method of KRT. Access to kidney transplantation can be improved by promoting kidney donation, increasing capacity to use organs from deceased donors, and increasing the number of facilities and workforce for kidney transplantation (e.g., nephrologists, transplant coordinators, and transplant surgeons), particularly in LICs.

Kidney failure is a complex disorder, and services to detect, monitor, and manage anemia, bone

disease, electrolyte disorders, and metabolic acidosis are crucial for optimal care delivery. While most countries have the capacity to monitor complications of kidney failure, not all countries have access to the full spectrum of options for treating these complications. For instance, while capacity to measure serum calcium (95%) and serum phosphate (92%) is high worldwide, only 54% and 48% of countries are able to administer non-calcium-based phosphate binders and cincalcet, respectively, to treat mineral bone disease. Increasing the availability of medications to manage or prevent the complications of kidney failure is important for improving outcomes of people living with kidney disease.

At least half of people living with kidney disease and needing dialysis are able to access it at onset of kidney failure in 74% of countries worldwide. The proportion of countries where this is possible is low in South Asia (14%) and Africa (42%), and LICs (32%) and LMICs (45%) worldwide. Timely access to dialysis at the onset of kidney failure is important to reduce the risk of associated complications, including hospitalization and death.<sup>5</sup> In countries where chronic PD is available, only 6% (n = 9) reported its use as the initial treatment modality for over half of people living with kidney disease and needing dialysis. PD use has been associated with improved survival, lower cost relative to HD, greater convenience (given that it can be performed at home on a flexible schedule), and improved reported outcomes among people living with kidney disease.<sup>4</sup> Although the initiation of KRT with PD should be promoted in all countries, LICs may particularly benefit due to the lower associated costs. Similarly, although 70% of countries have kidney transplantation services, more than half of people living with kidney disease who need kidney transplantation are able to access it in only 29% of countries. This proportion is very low in LICs (5%), LMICs (5%), and UMICs (26%). Although increasing capacity to perform kidney transplantation can pose major challenges in LICs and LMICs due to cost, a lack of requisite infrastructure and expertise, and socio-cultural factors, efforts to improve such services will still be required to improve outcomes among people living with kidney disease.

Many countries do not have public funding models for KRT or necessary medications; as a result, people living with kidney disease in those countries bear full responsibility for the costs of kidney care, especially in LICs and LMICs. Worldwide, people living with kidney disease fully cover the costs of HD, PD, and kidney transplantation in 9 (5%), 6 (4%), and 10 (6%) countries, respectively. Excessive out-of-pocket payments for KRT place a huge financial burden on most people living with kidney disease and their families, and have often been linked to poor outcomes among people living with kidney disease.<sup>6</sup> Some ways of increasing public funding for these services may include increasing the overall healthcare allocation or budget, strengthening government financial planning and monitoring, ensuring oversight of allocated funds, and providing services according to need.7

Worldwide, more than half of people living with kidney disease who initiate HD start with a temporary dialysis catheter in 44% of countries, and a tunneled dialysis catheter in 15% of countries. More people living with kidney disease in LICs are more likely to start HD with a temporary catheter than people living with kidney disease in countries at other income levels. Implementing methods to reduce late presentation of people living with kidney disease and needing urgent dialysis and improving the quality of predialysis care can reduce the use of temporary catheters in people living with kidney failure. Initiating treatment with functioning vascular access is important to ensure effective outcomes among people living with kidney disease and efficient dialysis treatment.

The proportion of centers that measure and report quality indicators for KRT delivery varies across countries. Quality indicators are similarly measured and reported for most KRT modalities across countries. PROMs are infrequently reported across all KRT modalities (HD: 26%, PD: 24%, kidney transplantation: 40%). The blood pressure of people treated with dialysis (HD: 86%, PD: 83%), hemoglobin (HD: 89%, PD: 90%), and markers of mineral bone disease (HD: 67%, PD: 77%) are measured often in a large majority of countries. For kidney transplant recipients, graft function (79%) and graft survival (80%) are frequently measured and reported. Patient survival is frequently reported in more than half of countries across all KRT modalities (HD: 55%, PD: 59%, kidney transplantation: 84%). Systematic and consistent monitoring and reporting of process indicators is important to ensure all people living with kidney disease within a country receive high quality and equitable care. Efforts to promote the use of quality indicators in KRT care through access to guidelines, incentives, and feasible monitoring systems (i.e., databases or registries) may improve the quality of care provided.

Nutritional services for kidney care are generally available in most countries. Dietary counselling is generally available in 59% of countries, measurement of serum albumin is generally available in 91% of countries, and oral nutrition supplements are generally available in 70% of countries. Kidney failure is associated with substantial changes in nutrient and fluid requirements and utilization and is accompanied by multiple nutritional and metabolic abnormalities. Increasing availability and early access to dietitians or other dietary counselors is important to reduce risks of hyperkalemia, bone mineral disease, and protein-energy wasting, among others.<sup>8</sup>

CKM is available in different forms in most countries of the world and does not appear to be associated with country income level. CKM (chosen through shared decision making) is available in 86% of countries, CKM (choice-restricted in locations with resource constraints) is available in 70% of countries, and CKM (choice-restricted in locations without resource constraints) is available in 75% of countries. However, structures and processes for the delivery of CKM (e.g., infrastructure to support people living with kidney disease, shared decisionmaking tools, written pathways or guidelines, essential medicines for pain and palliation, training for care providers and methods for CKM data collection) vary across country income levels. For instance, essential medicines for pain and palliative care are available in 37% of LICs, 43% of LMICs, 45% of UMICs, and 84% of HICs, while training of care providers in symptom management is available in 16% of LICs, 23% of LMICs, 21% of UMICs, and 57% of HICs.

It is important to recognize that KRT may not always be optimal or feasible-that is, treatment may not be appropriate for people living with kidney disease. CKM is more than just the default option when dialysis and kidney transplantation are unavailable or inaccessible (i.e., due to resource constraints or geographic barriers), but should be available to people living with kidney disease (where and when appropriate) from initiation of treatment. The decision to choose CKM over other KRT approaches is important; providers and people living with kidney disease must collaborate during the decision-making process to ensure that the most optimal treatment option is delivered, considering factors such as lifestyle, health outcomes (comorbidity index, life expectancy), and resource availability. CKM involves multiple health care providers, a range of medical and psychological treatments, and ongoing symptom monitoring. To ensure greater uptake and quality, guidelines and provider education and training programs about how to optimally deliver CKM are needed, especially in low resource settings where KRT modalities may be unavailable and CKM is choice-restricted. Evidence-based guidelines<sup>9</sup> to increase awareness, standardization, and uptake of practices recommended for CKM are needed to ensure high quality of care.

There are some differences in causes of hospitalization and death in people living with kidney disease and treated with dialysis across countries. Overall, access-related infection (i.e., infected arteriovenous fistula or graft, central venous catheter related infection) was identified as the most common cause of hospitalization in people treated with HD. This was also the most common cause of hospitalization in LICs (59%). However, in HICs (43%) cardiovascular disease is the most common cause of hospitalization, with no LICs reporting cardiovascular disease as a common cause of hospitalization. Across all income groups, PD-related infections (including peritonitis, catheter-related infections, tunnel infections, and exit site infections) are the most common causes of hospitalization: LICs (75%), LMICs (47%), UMICs (73%), and HICs (39%). Accesses (i.e., vascular access for HD or catheters for PD), are lifelines for people living with kidney failure and serve as the only

conduits for administering specific treatments. People living with kidney disease and caregivers, especially dialysis nurses, need adequate training on procedures to protect and preserve accesses and avoid complications such as infections, thrombosis, and bleeding to reduce the frequency of hospitalizations in people living with kidney disease and treated with dialysis. The absence of cardiovascular disease as a cause of hospitalization in people receiving dialysis in LICs may reflect reduced patient survival on dialysis due to several factors, including personal costs for treatment, quality of dialysis delivery, and quality of monitoring for risk factors.

Causes of death among people treated with dialysis vary substantially across countries. Among people treated with HD, cardiovascular disease is the most common cause of death in 77% of countries, and this percentage increases with country income level: LICs (29%), LMICs (64%), UMICs (81%), and HICs (97%). Dialysis withdrawal due to lack of funding for care was only reported as a common cause of death among people treated with HD in 18% of LICs and 7% of LMICs. Similarly, among people treated with PD, cardiovascular disease was reported as the most common cause of death in 66% of countries, and this proportion increases with country income level: LICs (0%), LMICs (43%), UMICs (58%), and HICs (87%). Death due to withdrawal from PD due to lack of funds was only reported in LICs (25%) and LMICs (7%). Although KRT prevents imminent death in people living with advanced kidney failure, those treated with dialysis still have a higher mortality rate than the general population. Several factors predict mortality in people treated with dialysis; however, preventable causes of death can be addressed by increasing the availability of essential medicines, increasing public funding for KRT, and ensuring adequate training to improve outcomes among people living with kidney disease.

#### **11.2.4 Health information systems**

Registries for kidney disease are necessary for monitoring but are not widely available worldwide. Dialysis registries are available in 63% of countries, kidney transplantation registries are available in 58% of countries, non-KRT registries are available in 19% of countries, and CKM registries are available in 6% of countries. Availability of dialysis registries increases with income level: LICs (22%), LMICs (38%), UMICs (81%), and HICs (81%). Likewise, although there are no transplant registries in LICs, the availability of kidney transplant registries increases with income level: LMICs (30%), UMICs (81%), and HICs (81%). While participation in non-KRT registries typically is voluntary, participation in dialysis or kidney transplantation registries typically is mandatory in countries where such registries are available. Content coverage of registries is similar across countries where these are available. Registries are essential to support research related to epidemiology, health outcomes, and health economics; they also allow clinicians and healthcare management organizations to audit practice patterns, evaluate and monitor service quality, and ensure regulatory oversight.<sup>10</sup> Global capacity to develop and implement kidney disease registries must be improved, along with data comprehensiveness and quality. Furthermore, mandatory provider participation helps to ensure that registries are complete and reliable.

Overall, CKD case-finding among high-risk groups are common, as people with hypertension, diabetes mellitus, cardiovascular disease, and auto-immune diseases are evaluated for CKD in 89%, 91%, 79%, and 81% of countries worldwide, respectively. However, these detection programs are based on national policies or guidelines in just one-quarter (25%) of countries, and in half of countries, they are often implemented through a reactive approach. Capacity for monitoring identified cases of CKD is largely available in primary, secondary, and tertiary care in most countries. The goals of early detection are to prevent disease progression and associated complications, thereby improving outcomes of people living with kidney disease and reducing the impacts of CKD on health care resources. This is important in low resource settings where KRT may be largely unavailable or unaffordable. As has been suggested, early detection programs appear to be more effective when targeting highrisk populations and accompanied by appropriate intervention strategies (e.g., education, medications, and/or referral).<sup>11,12</sup>

### 11.2.5 Leadership, advocacy, and barriers to kidney failure care

Globally, only 56% of countries have national strategies for non-communicable diseases (NCDs) and 12% of countries reported that such strategies are still under development. Fewer LICs (45%) have NCD strategies in place compared to HICs (65%). Also, 38% of countries do not have national strategies for improving care for people living with CKD, whereas just 25% of countries have specific strategies and 29% have strategies embedded within national NCD strategies. Among countries with CKD-specific strategies in place, more include chronic dialysis (22%) than non-dialysis CKD (21%) or kidney transplantation (20%). Given that NCDs such as hypertension and diabetes are often risk factors for developing CKD, efforts to establish and strengthen NCD strategies focused on detection, prevention, and treatment must be developed. The huge costs associated with KRT provide a compelling economic incentive for establishing NCD programs that incorporate CKD strategies,<sup>13</sup> especially in LICs and LMICs.

Worldwide, only 19% of governments recognize AKI and/or its treatment and prevention as a health priority, whereas 48% and 63% of governments recognize CKD and kidney failure, respectively, as health priorities. Increased governmental recognition of AKI, CKD, and kidney failure as health priorities is necessary to support the prioritization of policies and strategies that ensure adequate care for these conditions, which ultimately have great impacts on health care costs and residents' well-being.

Many countries have few advocacy groups at high levels of government or NGOs to increase advocacy and raise awareness of kidney disease. AKI advocacy groups are particularly rare (operating in less than 20% of countries across all income groups) and although CKD advocacy groups are more common, they are present in less than half of countries across all income levels: LICs (39%), LMICs (23%), UMICs (46%), and HICs (48%). Advocacy groups play an important role in kidney disease management and care. They provide platforms for creating awareness, raise funds for detection and treatment, coordinate health outreach services, liaise with political leaders to take specific actions, and help organize and prioritize regional and national resources to support prevention and management of kidney disorders. Increasing public awareness of the impacts of kidney failure and prevention practices through media and other resources may help promote advocacy for CKD.

Several barriers to effective delivery of care to people living with kidney disease were identified across countries. Overall, physician-related factors (e.g., availability and access), patientrelated factors and availability of nephrologists are common barriers to optimal kidney care in 71%, 75%, and 67% of countries, respectively. Notably, barriers to optimal kidney care vary by country income level. Compared to HICs, more LICs identify geography (35% vs. 85%), physician factors (59% vs. 70%), patient factors (67% vs. 75%), nephrologist availability (57% vs. 80%), healthcare system factors (44% vs. 75%), lack of political will (41% vs. 60%), and economic factors (30% vs. 85%) as barriers to optimal kidney care. Efforts to understand why these barriers exist and importantly, how they can be reduced or mitigated, are crucial to increase global capacity to deliver kidney care.

#### 11.2.6 Perspectives of people living with kidney disease on adequacy of kidney care

For the first time, we have included a survey of people living with kidney disease to understand their perspectives on the adequacy and structure of kidney care, and barriers to receiving optimal care in their countries (Burundi, Canada, India, Kenya, Lebanon, Nigeria, Pakistan, the United Kingdom, the United States, and Zimbabwe). Only 21% of the people living with kidney disease reported that their treatment costs are fully covered by public funding from the government and free at the point of delivery, whereas 37% reported paying for medications and treatments (including KRT) privately and fully out-ofpocket. People living with kidney disease also identified workforce shortages in their countries, particularly counsellors/psychologists (55%), nephrologists (50%), dietitians (45%), transplant surgeons (45%), and social workers (45%). Many people living with kidney disease identified economic factors (usually excessive out-ofpocket payments for medicines or KRT) and lack

of effective government policies (political factors) as the major barriers to optimal delivery of kidney care in their countries. Finally, people living with kidney disease identified physical and emotional health as the most affected by kidney disease, and the ability to work (72%), mobility (56%), and financial impacts of kidney disease and treatment (55%) as the most important outcomes.

In healthcare decision making, it is vital to consider patients' values, perceptions, and preferences, which are tied to their lived experiences. Although they identified various factors that facilitated or acted as barriers to optimal delivery of kidney care, economic factors were critically important. Efforts should be made, especially in low resource settings, to significantly reduce the costs of kidney care and out-of-pocket payments. Because the views of people living with kidney disease are likely to change over time, clinicians should routinely discuss the impacts of kidney disease and outcomes that are relevant to them, and appropriately adjust their treatment plans to ensure optimal delivery of care.

#### 11.2.7 Changes in KRT availability, accessibility, affordability, and workforce from 2019 to 2023

Important positive and negative changes were identified when comparing key aspects of the previous edition (2019) and the current edition (2023) of the ISN-GKHA with regard to KRT availability, accessibility, affordability, and workforce. During this period, global availability of centers for HD, PD, and kidney transplantation increased by 9.8%, 13%, and 7%, respectively. Of the three KRT modalities, PD is the only one that decreased in prevalence, from 38.1 pmp in 2019 to 38 pmp in 2023; this decrease was observed in LMICs and UMICs. In contrast, the prevalence of HD increased from 298.4 pmp to 331.4 pmp and the prevalence of kidney transplantation increased from 255 pmp to 279 pmp between 2019 and 2023.

The proportion of KRT delivered via PD may be declining in many countries due excessive proliferation of HD centers, private dialysis provider penetration, low reimbursement rates, a lack of education for people living with kidney disease, physician bias, resource availability, and the high cost of imported PD fluids.<sup>4,14</sup> Although countries where more than 50% of people initiating dialysis are able to start with PD increased by 50%, this reflected a change from 4% of countries in 2019 to 6% in 2023 (compared to a 3% increase in this same statistic for HD, from 72% to 74% of countries worldwide).

The proportion of countries where dialysis is publicly funded and free at the point of delivery increased by 3.7% for HD and 21.7% for PD between 2019 and 2023. Similarly, the proportion of countries providing public funding for kidney transplantation services increased by 16.1%, mostly in HICs (28.6%). However, the proportion of countries where costs of KRT are covered by private funding and fully out-of-pocket remained the same for HD and PD, but was reduced for kidney transplantation (from 8% to 6%) between 2019 and 2023 representing a 25% reduction. Outof-pocket costs are associated with high drop-out rates from treatment programs, fewer dialysis/ treatment sessions, poor medication adherence, and several complications, including premature mortality.<sup>6,15</sup> Additional strategies to reduce the proportion of out-of-pocket expenses for KRT should be developed.

Overall, the prevalence of nephrologists increased by 30.4% between 2019 and 2023, from 9.5 pmp in 2019 to 12.4 pmp. Similarly, the global prevalence of nephrology trainees increased by 0.74%. In regions where the prevalence of nephrologists increased by seemingly large percentages, the increase in absolute numbers is not very remarkable. For instance, the median prevalence increased in Africa by 66.7%, from 0.66 pmp to just 1.1 pmp. Similarly, the median prevalence increased in South Asia by 56.5%, from 1.15 pmp to 1.8 pmp. Despite these increases, the prevalence of nephrologists in low- and middleincome countries remains critically low. The current prevalence of nephrologists in Africa and South Asia are more than 10-fold lower than that of Western Europe, which has a lower population than these regions. It is important to explore, develop, and implement programs to increase the number of trainees in nephrology, retain trained nephrologists, stimulate innovation and rapid advancement in kidney disease management, and improve task-shifting strategies to improve access to care, especially in LICs and LMICs.

#### 11.3 OPTIMIZING KIDNEY CARE IN RESOURCE-LIMITED COUNTRIES

Low- and middle-income countries bear a huge burden of CKD and kidney failure. Unfortunately, many people who need KRT in these settings are unable to receive it, leading to premature mortality for millions of people due to a lack of access to treatment.<sup>16</sup> More than 90% of adults and children have been presumed dead within one year of kidney failure onset due to a lack of access to KRT.6 The high cost of KRT is limiting, particularly when countries do not provide public government funding for it. All KRT modalities are expensive and including these services in UHC plans is not feasible in all countries, especially in LICs and LMICs where they are unaffordable to the average person living with kidney disease. In LICs, the median annual cost of KRT is US \$9,065 for HD, US \$30,064 for PD, and US \$18,296 for the first year of kidney transplantation. Although choice-restricted CKM should be in place, it may not be accepted as an alternative in these settings because many people with kidney disease are young. For elderly people living with kidney disease, CKM may be a more suitable KRT option than dialysis or transplantation. It is important to develop strategies to increase funding and support for KRT and reduce associated costs as well as the proportion of costs covered by people living with kidney disease. Increasing knowledge and resource sharing between countries with similarities is another approach to reduce

financial barriers. However, support for KRT services should be provided in the context of a comprehensive approach to prevention, early detection of CKD and risk factors, and early treatment of kidney disease with the long-term objective of reducing the burden of CKD and kidney failure.

NCD policies with CKD specific strategies need to be in place. Also, approaches to increase advocacy to governments and the wider population to recognize kidney disease as a health priority and increase kidney disease awareness should be targeted. Only 45% of LICs have NCD strategies in place; among these, only 11% have CKD-specific strategies, and only 22% have CKD strategies incorporated into NCD policies. Few advocacy groups at high levels of government (e.g., parliamentary committees) exist in LICs to support AKI (17%) or CKD (39%) care.

LICs and LMICs have smaller workforces for kidney care than countries in other income groups. Approaches to increase training, competence, and retention should be established. Delegating workloads amongst a variety of health care professionals can not only help address shortages of nephrologists or other providers, but also help create multidisciplinary teams which are essential for delivering optimal kidney care.

#### **11.4 RECOMMENDATIONS**

This third edition of the ISN–GKHA focuses on kidney failure management from the perspective of caregivers and people living with kidney disease, highlights key areas requiring attention, reveals global capacity for kidney failure care, and documents important changes in availability, accessibility, and affordability of kidney care delivery from 2019 to 2023. The literature review findings illustrate the global burden of kidney failure, particularly treatment needs that go unmet in many low- and middleincome countries. The survey results reveal the global status of kidney care. While it is relevant to document where we are today to evaluate progress over time, it is even more relevant to provide benchmarks that enable countries to set priorities for capacity improvement. Public funding for KRT is limited, particularly in LICs and LMICs. Workforce shortages are noteworthy across all country income levels, and nearly all LICs reported shortages of nephrologists, interventional radiologists, surgeons, and transplant coordinators. KRT is not uniformly available in most countries. Although HD is available in most countries, fewer countries offer PD, transplantation, and CKM, whether chosen, medically-advised, or choice-restricted. Few registries exist for CKD, dialysis, and transplantation, and detection programs are uncommon and often implemented through a reactive approach. More registries and detection programs are needed to help prevent kidney failure. Furthermore, additional policies, government support, and advocacy efforts across the spectrum of kidney care are needed. Lastly, people living with kidney disease identified economic factors and a lack of effective government policies as barriers to optimal kidney care. In this section, we describe each of these priorities and suggest remedial strategies.

## 11.4.1 Increase health care financing for kidney failure prevention and management.

Less than 30% of countries provide public funding for non-dialysis CKD care, with no costs to people living with kidney disease at the point of care delivery. Public funding for dialysis and transplantation is more common; however, less than half of countries surveyed fully cover all KRT costs, with no fees at the point of care delivery. In countries that do provide public funding, coverage is not always equal across all residents,17,18 particularly in LICs. Affordability of chronic HD treatment is a non-medical barrier for people living with kidney disease,<sup>19</sup> and other KRT options, such as PD or home-administered HD, may address this gap in care.<sup>20</sup> Furthermore, it is important to increase coverage for dialysis to reduce cost of KRT for people living with kidney disease, where possible. The costs of dialysis and transplantation are high, and governments need to decide where to best allocate funding. Priority-setting tools (e.g., lists of essential medicines, health benefit plans, and health technology assessment agencies) may help guide evidence-based priority-setting;<sup>21</sup> however, the local context should be considered when making such decisions.

## 11.4.2 Address workforce shortages through multidisciplinary teams and telemedicine.

Most countries—particularly LICs —report shortages of at least one health care professional that is essential for kidney failure care delivery. While more nephrologists are needed, high costs of training are a barrier. Delegating tasks for kidney failure care delivery across a number of appropriate health care professionals is important, not only to increase the availability of existing nephrologists, but also to promote the use of multidisciplinary teams. Involving nurses, dietitians, pharmacists, and other professionals in decision-making and kidney failure care delivery will make services more comprehensive and increase overall capacity to respond to the needs of people living with kidney disease. There is also an opportunity for telemedicine to expand the reach of nephrologists and other health care professionals, both nationally and internationally. For example, the Extension for Community Healthcare Outcomes (ECHO) model improves access to care for underserved populations with complex health problems and has been used across a variety of disciplines.<sup>22</sup> Telemedicine services have been boosted during the COVID-19 pandemic through technological advancements, regulatory waivers, and user acceptance.<sup>23</sup> The application of telemedicine in kidney care (i.e., telenephrology) to increase the capacity of kidney failure care delivery in limited-resource settings is a promising direction.24

## 11.4.3 Incorporate the collection and reporting of quality indicators into kidney failure care.

While increased accessibility to KRT in general is a great achievement, access to highquality kidney failure treatment is important. Measurement and reporting of quality indicators for the delivery of HD, PD, and transplantation vary globally. In dialysis care, blood pressure and hemoglobin are measured often; however, small solute clearance, bone mineral markers, and technique survival are only measured and reported in 50–70% of countries. Quality indicators for kidney transplant recipients are more commonly measured and reported. Irrespective of KRT type, measuring and reporting of quality indicators decrease with country income level. Furthermore, the use of PROMs in care delivery and evaluation is low across all forms of KRT. Increasing the use of PROMs may help measure clinical effectiveness and promote the use of patientcentered care. Moreover, PROMs may serve as potential prognostic markers to help monitor the health status of people living with kidney disease.<sup>25</sup> Developing platforms to collect and evaluate quality indicators for KRT is important to optimize the delivery of kidney failure treatment. Monitoring quality indicators helps identify when the quality of care is not ideal; such information can initiate and guide the development of appropriate guality improvement programs. Furthermore, these global indicators provide benchmarks to help guide practice for kidney failure care delivery.

### 11.4.4 Expand health information systems to prevent and manage kidney failure

Health information systems play a broad role in the health care system. They can be used to track individual health data (e.g., electronic health records) which can help guide care delivery, and population data which can be used to research health conditions and guide decisions around priorities, policies, and resource allocation. Few countries have existing registries for AKI and non-dialysis CKD. These tools are essential for monitoring and preventing progression to kidney failure. Furthermore, information on the prevalence of early-stage CKD may help guide resource allocation decisions by enabling future demand for kidney failure care to be predicted. Similarly, systems for detecting AKI and CKD through active testing approaches are important. The use of electronic alert systems to detect AKI has had significant effects on improving recovery and reducing the severity of AKI events.<sup>26</sup> Incorporating prompts into primary care electronic medical records (EMRs) to detect people at high risk for CKD could be a cost-effective strategy to prevent kidney

failure.<sup>27</sup> Decision aids integrated into EMRs have been shown to significantly reduce eGFR loss,<sup>28</sup> suggesting the potential of these tools to help reduce the prevalence of kidney failure.

#### 11.4.5 Promote kidney failure prevention and treatment by implementing policies, strategies, and advocacy, and mitigating barriers

Lastly, delivering high quality kidney care requires effective strategies and policies. Increasing governmental recognition of CKD and kidney failure as health priorities may facilitate the development of strategies and policies to improve kidney care. Connecting CKD and kidney failure care with existing NCD strategies is practical, as CKD is associated with significant increases in cardiovascular mortality and acts as a risk multiplier for other major NCDs, such as diabetes and hypertension.<sup>29</sup> Strategies on how to incorporate CKD into existing NCD strategies have been proposed.<sup>29</sup> Increasing awareness about the health and cost consequences of kidney disease may help strengthen government support for kidney care policies and initiatives worldwide.<sup>29</sup> It is also critical to address the variability in access to care among marginalized population groups, particularly women and children. This work has demonstrated inequities in kidney care delivery amongst children, particularly in LICs and LMICs. Furthermore, this survey highlights a need to address issues of equitable treatment as a key policymaking priority for governments and international stakeholder organizations. Decisions about these issues are complex due to competing demands for scarce resources available for health care and other social services. For instance, the costs to deliver and sustain KRT are generally high and may be out of reach for the governments of many countries. Nevertheless, strategies such as increasing awareness about the burden of kidney disease and promoting kidney failure prevention (early detection and treatment) activities with appropriate cost-effective therapies would be affordable in many settings.30

#### **11.5 OPPORTUNITIES TO BUILD CAPACITY**

Tackling global kidney care is a challenging endeavor that requires joint efforts from multiple organizations, health care professionals, government agencies, and researchers. The ISN Global Kidney Policy Forum (GKPF) is an annual high-level meeting organized by the ISN that brings together key decision-makers and stakeholders to address the burden of kidney disease in a specific country or region and to share strategies for prevention and improved management of CKD at both the regional and global levels. At the first GKPF in 2017, stakeholders developed a set of 12 recommendations<sup>31</sup> to guide future efforts to collaboratively reduce the burden of kidney disease worldwide:

- Work within current frameworks promoted by the WHO and the United Nations, such as the Sustainable Development Goals, the 2030 Agenda for Sustainable Development,<sup>32</sup> UHC,<sup>33</sup> and the life-course approach in the context of Health 2020,<sup>34</sup> to develop and implement policies to ensure integration and synergies for kidney disease prevention and treatment within existing initiatives.
- Develop and implement public health policies to prevent or reduce risk factors for CKD in adults and children. These include strategies to promote maternal and child health and nutrition; reduce the burdens of diabetes, hypertension, obesity, and tobacco consumption; promote safe work environments; and prevent infectious diseases.
- Implement and support ongoing surveillance mechanisms to better understand and quantify the burdens of AKI and CKD within and outside the context of NCDs, specifically by developing robust national and regional registries for AKI, CKD, and kidney failure.
- 4. Educate the public and at-risk populations about kidney disease within NCD education campaigns.
- 5. 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.

- Work towards UHC to permit sustainable access to effective and affordable medication to treat risk factors for kidney disease and delay kidney disease (e.g., hypertension, diabetes, cardiovascular disease) and its progression.
- Support education for a skilled nephrology workforce to implement prevention and treatment of kidney disease at all stages.
- 8. Implement early detection, prevention, and treatment strategies for AKI.
- Integrate early evidence-based treatment for CKD, acknowledging important synergies with diabetes, hypertension, and cardiovascular disease.
- 10. 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.
- 11. Promote and expand kidney transplantation programs within countries and across regions.
- 12. Support local, regional, and transnational research on kidney disease to advance understandings of prevention and treatment strategies.

The ISN–GKHA aims to align with the objectives and activities of the WHO, World Bank, and other stakeholder organizations which are already working to close the identified gaps in health care. Examples of where kidney services could align include:

 The WHO Triple Billion Target,<sup>35</sup> which aims to enhance primary health care to improve access to and quality of essential services. Strategies include sustainable financing and financial protection; improving access to essential medicines and health products; ensuring an adequate workforce and providing advice on labor policies; refining national health policies; and enhancing surveillance systems to improve monitoring, data, and information.

- 2. The Thirteenth General Programme of Work (GPW 13) Impact Framework,<sup>35</sup> which provides a strategic approach to tracking joint efforts by Member States, the WHO Secretariat, and partners to achieve the Sustainable Development Goals. The proposed GPW 13 is the WHO's five-year strategy outlining the programme's mission, strategic priorities, and strategic and organizational shifts to achieve the healthrelated Sustainable Development Goals.
- 3. The Global Strategy on Human Resources for Health: Workforce 2030;<sup>36</sup>
- 4. The WHO Framework on integrated peoplecentered health care;<sup>37</sup>
- The United Nations Sustainable Development Goals;<sup>32</sup>
- 6. The United Nations Children's Fund (UNICEF): Inequities in children/variations in care;<sup>38</sup> and
- 7. World Bank-led initiatives to support UHC.<sup>39</sup>

#### **11.6 CONCLUSIONS**

This third edition of the ISN-GKHA continues to identify gaps in key elements of kidney care across ISN regions and World Bank country income groups. Variations in the availability of KRT core services and their quality, the proportions of countries and populations with access to these services, methods of funding KRT and essential medications, availability of health information systems, the size of the workforce for kidney care, and the perceptions of people living with kidney disease of the quality of and barriers to kidney care delivery have been reported. These gaps are particularly prevalent in LICs and LMICs. Despite ongoing challenges, including the impact of the COVID-19 pandemic on infrastructure, the health workforce, supply chains, etc., a comparison of the current edition with the 2019 edition of the ISN-GKHA reveals important positive changes. The COVID-19 pandemic placed a tremendous strain on all aspects of medical research including global health related work such as the ISN-GKHA. Public health restrictions hindered the ability of members of our teams (especially new members) to visit our research sites and familiarize themselves with various aspects of the research. The ISN-GKHA team members, including investigators and staff, have made concerted efforts to ensure continuity of activities and updates to participants and other collaborators across regions and countries by telephone, email and through virtual meetings via Zoom. The

attendant slowdown in clinical research activities had a disproportionate effect on early career researchers (the various ISN-GKHA fellows) under our mentorship and research staff such as the statisticians and epidemiologists in the group. Moreover, the outcomes of its findings might have also been affected by the pandemic. For example, there was a positive trend in the uptake of all components of KRT (HD, PD, kidney transplant) across all regions. The capacity for HD increased by ~10% overall, and all regions showed a positive trend except The Middle East. PD utilization has increased by 13%, but the trend was negative in 4 regions (Eastern and Central Europe, The Middle East, North and East Asia and OSEA). The modality most affected was kidney transplantation where even though there was a positive increase by 7% compared to previous iteration, the trend was negative in all regions except Western Europe. Importantly, there have been increases in the global density of centers where KRT can be provided, the proportion of people needing KRT who are able to access it, the proportion of countries where costs of dialysis (HD and PD) are covered by public government funding and free at the point of delivery, and the global prevalence of nephrologists has increased. Although the proportion of countries with private funding systems that require people living with kidney disease to pay fully out-ofpocket stayed the same for HD and PD, it was reduced for kidney transplantation.

Despite these important improvements, it is clear that they remain insufficient to tackle the rising burden of CKD and kidney failure, especially in LICs and LMICs where small magnitudes change is often noted. In LICs and LMICs, early disease detection and strategies focussed on disease prevention and slowing progression are urgently needed due to low availability of, and access to high quality care. It is important to provide infrastructure, guidelines, and training for CKM, especially in regions where KRT is currently unavailable. Efforts aimed at increasing funding for kidney care and strengthening infrastructure and health systems to provide and sustain care are needed in all regions and across all income levels.<sup>7</sup> Over half of countries reported shortages of nephrologists (treating

adult and pediatric people living with kidney disease), transplant surgeons, vascular access coordinators, dietitians, and other workers who play essential roles in the optimal delivery of kidney care. It is necessary to sustain the global increase in nephrologists, identify strategies to address shortages of other professionals in the nephrology workforce, increase advocacy, and develop policies, health information systems and detection programs to prevent kidney failure. Finally, it is important that the findings identified in this atlas show where efforts should be directed to improve global capacity to deliver high quality kidney care. Efforts should focus largely on improving public funding for all domains of kidney care, especially in low-resource settings.

### References

#### **1.0 INTRODUCTION**

- Levey AS, Atkins R, Coresh J, et al. Chronic kidney disease as a global public health problem: approaches and initiatives - a position statement from Kidney Disease Improving Global Outcomes. Kidney Int 2007; 72(3): 247-59.
- Jager KJ, Kovesdy C, Langham R, Rosenberg M, Jha V, Zoccali C. A single number for advocacy and communication-worldwide more than 850 million individuals have kidney diseases. Kidney Int 2019; 96(5): 1048-50.
- World Health Organization. Diabetes. 2022. <u>https://</u> <u>www.who.int/health-topics/diabetes#tab=tab\_1</u> (accessed 21 June 2022.
- 4. World Health Organization. HIV/AIDS. 2020. <u>https://www.who.int/data/gho/data/themes/hiv-aids</u>.
- 5. Kovesdy CP. Epidemiology of chronic kidney disease: an update 2022. Kidney Int Suppl (2011) 2022; 12(1): 7-11.
- GBD Chronic Kidney Disease Collaboration. Global, regional, and national burden of chronic kidney disease, 1990-2017: a systematic analysis for the Global Burden of Disease Study 2017. Lancet (London, England) 2020; 395(10225): 709-33.
- Liyanage T, Ninomiya T, Jha V, et al. Worldwide access to treatment for end-stage kidney disease: a systematic review. Lancet (London, England) 2015; 385(9981): 1975-82.
- Jha V, Garcia-Garcia G, Iseki K, et al. Chronic kidney disease: global dimension and perspectives. Lancet (London, England) 2013; 382(9888): 260-72.
- Ene-Iordache B, Perico N, Bikbov B, et al. Chronic kidney disease and cardiovascular risk in six regions of the world (ISN-KDDC): a cross-sectional study. The Lancet Global health 2016; 4(5): e307-19.
- Levin A, Stevens PE, Bilous RW, et al. Kidney Disease: Improving Global Outcomes (KDIGO) CKD Work Group. KDIGO 2012 clinical practice guideline for the evaluation and management of chronic kidney disease. Kidney international supplements 2013; 3(1): 1-150.
- Robinson BM, Akizawa T, Jager KJ, Kerr PG, Saran R, Pisoni RL. Factors affecting outcomes in patients

reaching end-stage kidney disease worldwide: differences in access to renal replacement therapy, modality use, and haemodialysis practices. Lancet (London, England) 2016; 388(10041): 294-306.

- Thurlow JS, Joshi M, Yan G, et al. Global Epidemiology of End-Stage Kidney Disease and Disparities in Kidney Replacement Therapy. Am J Nephrol 2021; 52(2): 98-107.
- Kalantar-Zadeh K, Jafar TH, Nitsch D, Neuen BL, Perkovic V. Chronic kidney disease. Lancet (London, England) 2021; 398(10302): 786-802.
- McMahon EJ, Campbell KL, Bauer JD, Mudge DW, Kelly JT. Altered dietary salt intake for people with chronic kidney disease. The Cochrane database of systematic reviews 2021; 6(6): Cd010070.
- Hahn D, Hodson EM, Fouque D. Low protein diets for non-diabetic adults with chronic kidney disease. The Cochrane database of systematic reviews 2020; 10(10): Cd001892.
- Tonelli M, Wiebe N, Knoll G, et al. Systematic review: kidney transplantation compared with dialysis in clinically relevant outcomes. American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons 2011; 11(10): 2093-109.
- Muralidharan A, White S. The need for kidney transplantation in low- and middle-income countries in 2012: an epidemiological perspective. Transplantation 2015; 99(3): 476-81.
- Martin DE, Harris DCH, Jha V, et al. Ethical challenges in nephrology: a call for action. Nat Rev Nephrol 2020; 16(10): 603-13.
- Andreoli MCC, Totoli C. Peritoneal dialysis. Revista da Associação Médica Brasileira 2020; 66: s37-s44.
- 20. Himmelfarb J, Ikizler TA. Hemodialysis. The New England journal of medicine 2010; 363(19): 1833-45.
- de Jong RW, Stel VS, Rahmel A, et al. Patientreported factors influencing the choice of their kidney replacement treatment modality. Nephrol Dial Transplant 2022; 37(3): 477-88.
- de Jong RW, Jager KJ, Vanholder RC, et al. Results of the European EDITH nephrologist survey on factors influencing treatment modality choice for end-stage kidney disease. Nephrol Dial Transplant 2021; 37(1): 126-38.
- van de Luijtgaarden MW, Jager KJ, Segelmark M, et al. Trends in dialysis modality choice and related patient survival in the ERA-EDTA Registry over a 20-year period. Nephrology, dialysis, transplantation : official publication of the European Dialysis and Transplant Association - European Renal Association 2016; 31(1): 120-8.
- Han SS, Park JY, Kang S, et al. Dialysis Modality and Mortality in the Elderly: A Meta-Analysis. Clinical journal of the American Society of Nephrology : CJASN 2015; 10(6): 983-93.
- 25. Thiery A, Severac F, Hannedouche T, et al. Survival advantage of planned haemodialysis over peritoneal dialysis: a cohort study. Nephrology, dialysis, transplantation : official publication of the European Dialysis and Transplant Association - European Renal Association 2018.
- Niang A, Iyengar A, Luyckx VA. Hemodialysis versus peritoneal dialysis in resource-limited settings. Curr Opin Nephrol Hypertens 2018; 27(6): 463-71.
- 27. Okpechi IG, Jha V, Cho Y, et al. The case for increased peritoneal dialysis utilization in low- and lower-middle-income countries. Nephrology (Carlton, Vic) 2022.
- Vanholder R, Domínguez-Gil B, Busic M, et al. Organ donation and transplantation: a multi-stakeholder call to action. Nat Rev Nephrol 2021; 17(8): 554-68.
- Danovitch GM. Cultural barriers to kidney transplantation: a new frontier. Transplantation 2007; 84(4): 462-3.
- Vanholder R, Annemans L, Brown E, et al. Reducing the costs of chronic kidney disease while delivering quality health care: a call to action. Nat Rev Nephrol 2017; 13(7): 393-409.
- Vanholder R, Lameire N, Annemans L, Van Biesen W. Cost of renal replacement: how to help as many as possible while keeping expenses reasonable? Nephrol Dial Transplant 2016; 31(8): 1251-61.
- Davison SN, Levin A, Moss AH, et al. Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care. Kidney Int 2015; 88(3): 447-59.
- Raghavan D, Holley JL. Conservative Care of the Elderly CKD Patient: A Practical Guide. Advances in chronic kidney disease 2016; 23(1): 51-6.
- Wong SPY, Rubenzik T, Zelnick L, et al. Long-term Outcomes Among Patients With Advanced Kidney Disease Who Forgo Maintenance Dialysis: A Systematic Review. JAMA network open 2022; 5(3): e222255.

- Gelfand SL, Scherer JS, Koncicki HM. Kidney Supportive Care: Core Curriculum 2020. American journal of kidney diseases : the official journal of the National Kidney Foundation 2020; 75(5): 793-806.
- Jassal SV, Watson D. Dialysis in late life: benefit or burden. Clinical journal of the American Society of Nephrology : CJASN 2009; 4(12): 2008-12.
- Morton RL, Snelling P, Webster AC, et al. Factors influencing patient choice of dialysis versus conservative care to treat end-stage kidney disease.
   CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne 2012; 184(5): E277-83.
- Verberne WR, Dijkers J, Kelder JC, et al. Value-based evaluation of dialysis versus conservative care in older patients with advanced chronic kidney disease: a cohort study. BMC nephrology 2018; 19(1): 205.
- Morton RL, Kurella Tamura M, Coast J, Davison SN. Supportive Care: Economic Considerations in Advanced Kidney Disease. Clinical journal of the American Society of Nephrology : CJASN 2016; 11(10): 1915-20.
- Ghimire S, Castelino RL, Lioufas NM, Peterson GM, Zaidi ST. Nonadherence to Medication Therapy in Haemodialysis Patients: A Systematic Review. PloS one 2015; 10(12): e0144119.
- Kimura H, Tanaka K, Saito H, et al. Association of Polypharmacy with Kidney Disease Progression in Adults with CKD. Clinical journal of the American Society of Nephrology : CJASN 2021; 16(12): 1797-804.
- Browne T, Merighi JR. Barriers to adult hemodialysis patients' self-management of oral medications. American journal of kidney diseases : the official journal of the National Kidney Foundation 2010; 56(3): 547-57.
- Gourzoulidis G, Kourlaba G, Stafylas P, Giamouzis G, Parissis J, Maniadakis N. Association between copayment, medication adherence and outcomes in the management of patients with diabetes and heart failure. Health policy (Amsterdam, Netherlands) 2017; 121(4): 363-77.
- Mushi L, Marschall P, Flessa S. The cost of dialysis in low and middle-income countries: a systematic review. BMC health services research 2015; 15: 506.
- 45. Oguejiofor F, Kiggundu DS, Bello AK, et al. International Society of Nephrology Global Kidney Health Atlas: structures, organization, and services for the management of kidney failure in Africa. Kidney Int Suppl (2011) 2021; 11(2): e11-e23.
- 46. Divyaveer SS, Ramachandran R, Sahay M, et al. International Society of Nephrology Global Kidney Health Atlas: structures, organization, and services for the management of kidney failure in South Asia. Kidney International Supplements 2021; 11(2): e97-e105.

- Wainstein M, Bello AK, Jha V, et al. International Society of Nephrology Global Kidney Health Atlas: structures, organization, and services for the management of kidney failure in Latin America. Kidney Int Suppl (2011) 2021; 11(2): e35-e46.
- Wu DA, Watson CJ, Bradley JA, Johnson RJ, Forsythe JL, Oniscu GC. Global trends and challenges in deceased donor kidney allocation. Kidney Int 2017; 91(6): 1287-99.
- Chamsi-Pasha H, Albar MA. Kidney transplantation: ethical challenges in the Arab world. Saudi journal of kidney diseases and transplantation : an official publication of the Saudi Center for Organ Transplantation, Saudi Arabia 2014; 25(3): 489-95.
- Kellum JA, Lameire N. Diagnosis, evaluation, and management of acute kidney injury: a KDIGO summary (Part 1). Critical care (London, England) 2013; 17(1): 204.
- Susantitaphong P, Cruz DN, Cerda J, et al. World incidence of AKI: a meta-analysis. Clinical journal of the American Society of Nephrology : CJASN 2013; 8(9): 1482-93.
- Mehta RL, Burdmann EA, Cerda J, et al. Recognition and management of acute kidney injury in the International Society of Nephrology 0by25 Global Snapshot: a multinational cross-sectional study. Lancet (London, England) 2016; 387(10032): 2017-25.
- 53. Horton R, Berman P. Eliminating acute kidney injury by 2025: an achievable goal. Lancet (London, England) 2015; 385(9987): 2551-2.
- 54. Perico N, Remuzzi G. Acute kidney injury in low-income and middle-income countries: no longer a death sentence. The Lancet Global health 2016; 4(4): e216-7.
- Hsu RK, Hsu CY. The Role of Acute Kidney Injury in Chronic Kidney Disease. Seminars in nephrology 2016; 36(4): 283-92.
- Chawla LS, Bellomo R, Bihorac A, et al. Acute kidney disease and renal recovery: consensus report of the Acute Disease Quality Initiative (ADQI) 16 Workgroup. Nat Rev Nephrol 2017; 13(4): 241-57.
- 57. Lameire NH, Levin A, Kellum JA, et al. Harmonizing acute and chronic kidney disease definition and classification: report of a Kidney Disease: Improving Global Outcomes (KDIGO) Consensus Conference. Kidney Int 2021; 100(3): 516-26.
- Paidi G, Iroshani Jayarathna AI, Salibindla D, et al. Chronic Kidney Disease of Unknown Origin: A Mysterious Epidemic. Cureus 2021; 13(8): e17132.
- Johnson RJ, Sánchez-Lozada LG, Newman LS, et al. Climate Change and the Kidney. Ann Nutr Metab 2019; 74 Suppl 3: 38-44.
- 60. The ISN. ISN Emphasizes Link between Kidney Health and Climate Change in COP26 Consultation.

2021. https://www.theisn.org/blog/2021/11/15/isnemphasizes-link-between-kidney-health-and-climatechange-in-cop26-consultation/.

- Shlipak MG, Tummalapalli SL, Boulware LE, et al. The case for early identification and intervention of chronic kidney disease: conclusions from a Kidney Disease: Improving Global Outcomes (KDIGO) Controversies Conference. Kidney Int 2021; 99(1): 34-47.
- The ISN. ISN-KDIGO CKD Early Identification and Intervention Toolkit. 2022. <u>https://www.theisn.org/</u> <u>initiatives/ckd-early-screening-intervention/</u> (accessed 24 June 2022.
- Okpechi IG, Caskey FJ, Gaipov A, et al. Early Identification of Chronic Kidney Disease–A Scoping Review of the Global Populations. Kidney international reports 2022; 7(6): 1341-53.
- 64. World Health Organization. Monitoring the building blocks of health systems: a handbook of indicators and their measurement strategies. 2010. <u>https://apps.who.int/iris/handle/10665/258734</u>.
- 65. Harrison JP, Palacio C. The role of clinical information systems in health care quality improvement. The health care manager 2006; 25(3): 206-12.
- 66. AHRQ Methods for Effective Health Care. In: Gliklich RE, Dreyer NA, Leavy MB, Christian JB, eds. 21(st) Century Patient Registries: Registries for Evaluating Patient Outcomes: A User's Guide: 3(rd) Edition, Addendum. Rockville (MD): Agency for Healthcare Research and Quality (US); 2018.
- 67. Tuot DS, Velasquez A, McCulloch CE, et al. The Kidney Awareness Registry and Education (KARE) study: protocol of a randomized controlled trial to enhance provider and patient engagement with chronic kidney disease. BMC nephrology 2015; 16: 166.
- See EJ, Alrukhaimi M, Ashuntantang GE, et al. Global coverage of health information systems for kidney disease: availability, challenges, and opportunities for development. Kidney Int Suppl (2011) 2018; 8(2): 74-81.
- Kumar M, Gotz D, Nutley T, Smith JB. Research gaps in routine health information system design barriers to data quality and use in low- and middle-income countries: A literature review. The International journal of health planning and management 2018; 33(1): e1-e9.
- World Health Organization. Monitoring the building blocks of health systems: a handbook of indicators and their measurement strategies. 2010. <u>https://apps.who. int/iris/handle/10665/258734</u> (accessed July 16, 2020 2020).
- Lunney M, Alrukhaimi M, Ashuntantang GE, et al. Guidelines, policies, and barriers to kidney care: findings from a global survey. Kidney Int Suppl (2011) 2018; 8(2): 30-40.

- Okpechi IG, Bello AK, Luyckx VA, Wearne N, Swanepoel CR, Jha V. Building optimal and sustainable kidney care in low resource settings: The role of healthcare systems. Nephrology (Carlton, Vic) 2021; 26(12): 948-60.
- 73. Sydney Uo. What is policy. <u>http://sydney.edu.au/legal/</u> policy/what/index.shtml2018).
- Organization WH. Health Policy. 2018. <u>http://www.who.</u> <u>int/topics/health\_policy/en/</u> (accessed October 18, 2018 2018).
- 75. Pariyo GW, Wosu AC, Gibson DG, Labrique AB, Ali J, Hyder AA. Moving the Agenda on Noncommunicable Diseases: Policy Implications of Mobile Phone Surveys in Low and Middle-Income Countries. Journal of medical Internet research 2017; 19(5): e115.
- Couser WG, Remuzzi G, Mendis S, Tonelli M. The contribution of chronic kidney disease to the global burden of major noncommunicable diseases. Kidney international 2011; 80(12): 1258-70.

- 77. Levin A, Tonelli M, Bonventre J, et al. Global kidney health 2017 and beyond: a roadmap for closing gaps in care, research, and policy. Lancet (London, England) 2017.
- Bello AK LA, Tonelli M, Okpechi IG, Feehally J, Harris D, Jindal K, Salako BL, Rateb A, Osman MA, Qarni B, Saad S, Lunney M, Wiebe N, Ye F, Johnson DW ISN–Global Kidney Health Atlas: A report by the International Society of Nephrology on the current state of organization and structures for kidney care across the globe, 2017.
- 79. Bello AK Levin A, Lunney M, et al. ISN–Global Kidney Health Atlas: A report by the International Society of Nephrology on the Global Burden of End-stage Kidney Disease and Capacity for Kidney Replacement Therapy and Conservative Care across World Countries and Regions, 2019.

#### 2.0 METHODS

- Bello AK, Wiebe N, Garg AX, Tonelli M. Basics of systematic reviews and meta-analyses for the nephrologist. Nephron Clinical practice 2011; 119(1): c50-60; discussion c1.
- Tonelli M, Wiebe N, Culleton B, et al. Chronic kidney disease and mortality risk: a systematic review. Journal of the American Society of Nephrology : JASN 2006; 17(7): 2034-47.
- Garg AX, Hackam D, Tonelli M. Systematic review and meta-analysis: when one study is just not enough. Clinical journal of the American Society of Nephrology : CJASN 2008; 3(1): 253-60.
- Tonelli M, Hackam D, Garg AX. Primer on systematic review and meta-analysis. Methods in molecular biology (Clifton, NJ) 2009; 473: 217-33.
- Liu FX, Rutherford P, Smoyer-Tomic K, Prichard S, Laplante S. A global overview of renal registries: a systematic review. BMC nephrology 2015; 16: 31.
- van der Tol A, Lameire N, Morton RL, Van Biesen W, Vanholder R. An International Analysis of Dialysis Services Reimbursement. Clinical journal of the American Society of Nephrology : CJASN 2019; 14(1): 84-93.
- Huffman MD, Perel P, Beller GA, et al. World Heart Federation Emerging Leaders Program: An Innovative Capacity Building Program to Facilitate the 25 x 25 Goal. Global heart 2015; 10(4): 229-33.

- Mehta RL, Cerda J, Burdmann EA, et al. International Society of Nephrology's 0by25 initiative for acute kidney injury (zero preventable deaths by 2025): a human rights case for nephrology. Lancet (London, England) 2015; 385(9987): 2616-43.
- Guariguata L, Whiting D, Weil C, Unwin N. The International Diabetes Federation diabetes atlas methodology for estimating global and national prevalence of diabetes in adults. Diabetes research and clinical practice 2011; 94(3): 322-32.
- Moran AE, Roth GA, Narula J, Mensah GA. 1990-2010 global cardiovascular disease atlas. Glob Heart 2014; 9(1): 3-16.
- World Health Organization. Monitoring the building blocks of health systems: a handbook of indicators and their measurement strategies. 2010. <u>https://apps.who. int/iris/handle/10665/258734</u> (accessed July 16, 2020 2020).
- Leowski J, Krishnan A. Capacity to control noncommunicable diseases in the countries of South-East Asia. Health policy (Amsterdam, Netherlands) 2009; 92(1): 43-8.
- Stevens GA, Alkema L, Black RE, et al. Guidelines for Accurate and Transparent Health Estimates Reporting: the GATHER statement. Lancet (London, England) 2016; 388(10062): e19-e23.

### **11.0 DISCUSSION**

- Bello AK, Alrukhaimi M, Ashuntantang GE, et al. Global overview of health systems oversight and financing for kidney care. Kidney Int Suppl (2011) 2018; 8(2): 41-51.
- Vachharajani TJ, Bello AK, Evans R, Dreyer G, Eichbaum Q. Nephrology education and continuing education in resource-limited settings. Semin Nephrol 2017; 37(3): 224-33.
- Okel J, Okpechi IG, Qarni B, et al. Nephrology training curriculum and implications for optimal kidney care in the developing world. Clin Nephrol 2016; 86(13): 110-3.
- Okpechi IG, Jha V, Cho Y, et al. The case for increased peritoneal dialysis utilization in low- and lower-middleincome countries. Nephrol 2022.
- Takagi K, Mizuno M, Kawase K, Minoshima K, Yamaha M, Horie M. Impact on survival of urgent dialysis initiation in patients with end-stage renal disease: A case-control study. Clin Exp Nephrol 2020; 24(12): 1154-61.
- Ashuntantang G, Osafo C, Olowu WA, et al. Outcomes in adults and children with end-stage kidney disease requiring dialysis in sub-Saharan Africa: A systematic review. Lancet Glob Health 2017; 5(4): e408-e17.
- Okpechi IG, Bello AK, Luyckx VA, Wearne N, Swanepoel CR, Jha V. Building optimal and sustainable kidney care in low resource settings: The role of healthcare systems. Nephrol 2021; 26(12): 948-60.
- MacLaughlin HL, Friedman AN, Ikizler TA. Nutrition in kidney disease: Core curriculum 2022. Am J Kidney Dis 2022; 79(3): 437-49.
- Davison SN, Levin A, Moss AH, et al. Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: Developing a roadmap to improving quality care. Kidney Int 2015; 88(3): 447-59.
- Ng MSY, Charu V, Johnson DW, O'Shaughnessy MM, Mallett AJ. National and international kidney failure registries: Characteristics, commonalities, and contrasts. Kidney Int 2022; 101(1): 23-35.
- Levin A, Stevens PE. Early detection of CKD: The benefits, limitations and effects on prognosis. Nat Rev Nephrol 2011; 7(8): 446-57.
- Okpechi IG, Caskey FJ, Gaipov A, et al. Early identification of chronic kidney disease—a scoping review of the global populations. Kidney Int Rep 2022; 7(6): 1341-53.
- Neuen BL, Chadban SJ, Demaio AR, Johnson DW, Perkovic V. Chronic kidney disease and the global NCDs agenda. BMJ Glob Health 2017; 2(2): e000380.
- Zimmerman AM. Peritoneal dialysis: Increasing global utilization as an option for renal replacement therapy. J Glob Health 2019; 9(2): 020316.

- Dodd R, Palagyi A, Guild L, Jha V, Jan S. The impact of out-of-pocket costs on treatment commencement and adherence in chronic kidney disease: A systematic review. Health Policy Plan 2018: czy081-czy.
- Liyanage T, Ninomiya T, Jha V, et al. Worldwide access to treatment for end-stage kidney disease: A systematic review. Lancet 2015; 385(9981): 1975-82.
- Piccoli GB, Cabiddu G, Breuer C, Jadeau C, Testa A, Brunori G. Dialysis reimbursement: What impact do different models have on clinical choices? J Clin Med 2019; 8(2).
- Bello AK, Levin A, Tonelli M, et al. Assessment of global kidney health care status. JAMA 2017; 317(18): 1864-81.
- Pancras G, Shayo J, Anaeli A. Non-medical facilitators and barriers towards accessing haemodialysis services: An exploration of ethical challenges. BMC Nephrol 2018; 19(1): 342.
- Vanholder R, Annemans L, Brown E, et al. Reducing the costs of chronic kidney disease while delivering quality health care: A call to action. Nat Rev Nephrol 2017; 13(7): 393-409.
- Sakuma Y, Glassman A, Vaca C. Priority-setting processes for expensive treatments for chronic diseases. In: Prabhakaran D, Anand S, Gaziano TA, Mbanya JC, Wu Y, Nugent R, eds. Cardiovascular, respiratory, and related disorders. Washington, DC: The International Bank for Reconstruction and Development, The World Bank; 2017.
- Addala A, Filipp SL, Figg LE, et al. Tele-education model for primary care providers to advance diabetes equity: Findings from Project ECHO Diabetes. Front Endocrinol 2022; 13: 1066521.
- Lew SQ, Wallace EL, Srivatana V, et al. Telehealth for home dialysis in COVID-19 and beyond: A perspective from the American Society of Nephrology COVID-19 Home Dialysis Subcommittee. Am J Kidney Dis 2021; 77(1): 142-8.
- Osman MA, Okel J, Okpechi IG, Jindal K, Bello AK. Potential applications of telenephrology to enhance global kidney care. BMJ Glob Health 2017; 2(2): e000292.
- Aiyegbusi OL, Kyte D, Cockwell P, Anderson N, Calvert M. A patient-centred approach to measuring quality in kidney care: Patient-reported outcome measures and patient-reported experience measures. Curr Opin Nephrol Hypertens 2017; 26(6): 442-9.
- Tome ACN, Ramalho RJ, Dos Santos KF, et al. Impact of an electronic alert in combination with a care bundle on the outcomes of acute kidney injury. Diagn 2022; 12(12).

- Mosa AI, Watts D, Tangri N. Impacting management of chronic kidney disease through primary care practice audits: A quality improvement study. Can J Kidney Health Dis 2022; 9: 20543581221144840.
- Carroll JK, Pulver G, Dickinson LM, et al. Effect of 2 clinical decision support strategies on chronic kidney disease outcomes in primary dare: A cluster randomized trial. JAMA Netw Open 2018; 1(6): e183377.
- 29. Tonelli M, Agarwal S, Cass A, et al. How to advocate for the inclusion of chronic kidney disease in a national noncommunicable chronic disease program. Kidney Int 2014; 85(6): 1269-74.
- 30. Ashu JT, Mwangi J, Subramani S, Kaseje D, Ashuntantang G, Luyckx VA. Challenges to the right to health in sub-Saharan Africa: Reflections on inequities in access to dialysis for patients with end-stage kidney failure. Int J Equity Health 2022; 21(1): 126.
- International Society of Nephrology (ISN). 12 Recommendations for Global Kidney Health. 2022. <u>https://www.theisn.org/in-action/advocacy/advocacy-activities/12-recommendations-for-global-kidney-health/</u> (accessed January 8, 2023).
- United Nations. The Sustainable Development Goals Report, 2019. 2019. <u>https://unstats.un.org/sdgs/</u> report/2019/#.
- World Health Organization. Universal Health Coverage—Overview. 2021. <u>https://www.who.int/health-topics/universal-health-coverage#tab=tab\_1</u> (accessed January 8, 2023).

- World Health Organization. The Minsk Declaration: The life-course approach in the context of Health 2020.
   2015. <u>https://apps.who.int/iris/handle/10665/349095</u> (accessed January 8, 2023).
- World Health Organization. Thirteenth General Programme of Work 2019-2023. 2018. <u>https://www. who.int/about/what-we-do/thirteenth-generalprogramme-of-work-2019---2023</u> (accessed January 8, 2023).
- World Health Organization. Global strategy on human resources for health: Workforce 2030. 2016. <u>https://apps.who.int/iris/handle/10665/250368</u> (accessed January 8, 2023) 2022).
- World Health Organization. Framework on integrated, people-centred health services. 2016. <u>https://apps.who. int/iris/handle/10665/252698</u> (accessed January 8, 2023).
- UNICEF. For every child, a fair chance. 2015. <u>https://www.unicef.org/reports/every-child-fair-chance</u> (accessed January 8, 2023).
- World Health Organization. Delivering quality health services: A global imperative for universal health coverage. 2018. <u>https://apps.who.int/iris/ handle/10665/272465</u> (accessed January 8, 2023).

## **List of Illustrations**

#### **TABLES**

- 14 A Methods and data sources
- 32 2.1 General health system characteristics by WHO UHC domain, with relevant data sources
- 33 2.2 Kidney disease-specific health system characteristics by WHO UHC domain, with relevant data sources
- 34 2.3 Kidney registries from the 10 ISN regions used as data sources

- 62 4.1 Aspects of KRT excluded from public funding
- 69 5.1 Distribution of nephrologists by type and prevalence of trainees
- 96 7.1 Content coverage of CKD registries
- 106 8.1 Existence of CKD-specific policies

#### **FIGURES**

- 20 1.1 Classification of CKD
- 22 1.2 Domains of kidney supportive care
- 25 1.3 The ISN-KDIGO CKD early detection toolkit
- 30 2.1 Literature review and survey research methods
- 36 2.2 KRT cost adjustments and standardization
- 53 3.1 Median cost of KRT
- 60 4.1 Funding models for non-dialysis CKD
- 61 4.2 KRT publicly funded by the government and free at the point of delivery
- 62 4.3 Extent of universal coverage for KRT in countries with publicly funded systems
- 63 4.4 Funding models for KRT-related surgical services
- 64 4.5 Within country variation in organization and cost
- 64 4.6 Differences in access to HD, PD, and kidney transplantation between adults and children

- 65 4.7 Adequacy of infrastructure to deliver kidney failure care
- 68 5.1 Health care providers primarily responsible for kidney failure care
- 69 5.2 Global proportion of women nephrologists
- 70 5.3 Shortages of health care providers essential for kidney failure care
- 72 6.1 Availability of chronic dialysis and kidney transplantation services
- 72 6.2 Availability of home HD and automated PD (APD)
- 74 6.3 Source of donated kidneys
- 75 6.4 Availability of modality options for KRT
- 76 6.5 Availability of services for kidney failure care
- 76 6.6 Management of hemoglobin level
- 77 6.7 Management of CKD mineral bone disease
- 77 6.8 Management of electrolyte disorders and chronic metabolic acidosis

- 78 6.9 Management of blood pressure
- 78 6.10 Management of common kidney failure symptoms
- 79 6.11 Accessibility of KRT at the onset of kidney failure
- 79 6.12 Proportion of people living with kidney disease typically initiating treatment with PD
- 80 6.13 Accessibility of kidney transplantation
- 81 6.14 Proportion of treatment costs (including medications) paid directly by people living with kidney disease
- 82 6.15 Funding models for KRT
- 83 6.16 Types of vascular access for KRT
- 83 6.17 Types of vascular access for KRT
- 84 6.18 Proportion of centers measuring and reporting quality indicators for HD service delivery
- 84 6.19 Proportion of centers measuring and reporting quality indicators for HD service delivery, by World Bank income group
- 85 6.20 Proportion of centers measuring and reporting quality indicators for PD service delivery
- 85 6.21 Proportion of centers measuring and reporting quality indicators for PD service delivery, by World Bank income group
- 86 6.22 Proportion of centers measuring and reporting quality indicators for kidney transplantation service delivery
- 86 6.23 Proportion of centers measuring and reporting quality indicators for kidney transplantation service delivery, by World Bank income group
- 86 6.24 Availability of nutritional services for kidney care
- 87 6.25 Availability of nutritional services for kidney care, by World Bank income group
- 87 6.26 Availability and characteristics of CKM
- 88 6.27 Availability of structures and processes for the delivery of CKM
- 89 6.28 Common causes of hospitalization among people treated with dialysis

- 91 6.29 Common causes of death among people treated with dialysis
- 94 7.1 Prevalence of kidney disease registries
- 95 7.2 Provider participation in CKD and KRT registries
- 95 7.3 Geographic coverage of CKD and KRT registries
- 96 7.4 Content coverage of dialysis registries
- 97 7.5 Content coverage of kidney transplantation registries
- 98 7.6 Adoption of practices to identify CKD in high-risk groups
- 99 7.7 Existence of current AKI and CKD detection programs
- 99 7.8 Methods of implementing AKI detection programs
- 100 7.9 Methods of implementing CKD detection programs
- 100 7.10 Availability of services for CKD monitoring in primary care levels
- 101 7.11 Availability of services for CKD monitoring in secondary and tertiary care levels
- 101 7.12 Occurrence of CKDu or populations disproportionately affected with CKD
- 101 7.13 Industries affected by CKDu
- 104 8.1 Existence of a national strategy for NCDs
- 104 8.2 Existence of a national strategy for improving CKD care
- 105 8.3 Kidney conditions covered by CKDspecific and general NCD strategies
- 106 8.4 Types of CKD policies in use
- 107 8.5 Government recognition of AKI, CKD, and KRT (treatment and prevention) as health priorities
- 108 8.6 Availability of support for AKI, CKD, and KRT (treatment and prevention)
- 109 8.7 Barriers to optimal kidney failure care
- 112 9.1 Demographic features of people living with kidney disease included in the survey
- 112 9.2 Responsibility for the costs of kidney disease treatment

- 112 9.3 Perspectives of people living with kidney disease on workforce shortages
- 113 9.4 Perspectives of people living with kidney disease on obstacles to kidney care
- 113 9.5 Perspectives of people living with kidney disease on strategies to improve kidney care
- 113 9.6 Perspectives of people living with kidney disease on the negative impacts of kidney failure and treatment
- 114 9.7 Perspectives of people living with kidney disease on its effects on wellbeing
- 116 10.1 Change in density of KRT centers
- 117 10.2 Change in treated KRT prevalence

- 119 10.3 Change in the proportion of national population with kidney failure able to access KRT
- 120 10.4 Change in the proporation with kidney failure receiving KRT (and medications) from public government funds and free at point of delivery
- 121 10.5 Change in the proportion with kidney failure receiving KRT (and medications) through solely private out-of-pocket payment sytem
- 123 10.6 Total number of nephrologists
- 123 10.7 Total number of nephrology trainees

### MAPS

- 40 3.1 CKD prevalence, DALYs attributed to CKD, death attributed to CKD
- 41 3.2 Global density of health workforce
- 43 3.3 Health spending
- 44 3.4 Global incidence of treated kidney failure
- 44 3.5 Global prevalence of treated kidney failure
- 45 3.6 Global incidence of chronic dialysis
- 46 3.7 Global prevalence of chronic dialysis
- 47 3.8 Global incidence of chronic hemodialysis
- 47 3.9 Global prevalence of chronic hemodialysis
- 48 3.10 Global incidence of chronic peritoneal dialysis
- 49 3.11 Global prevalence of chronic peritoneal dialysis
- 50 3.12 Global incidence of kidney transplantation
- 50 3.13 Global prevalence of kidney transplantation

- 51 3.14 Global incidence of deceased donor kidney transplantation
- 52 3.15 Global incidence of living donor kidney transplantation
- 53 3.16 Global incidence of pre-emptive kidney transplantation
- 54 3.17 Median cost of KRT
- 4.0 Countries that participated in the ISN survey
- 61 4.1 Publicly funded by government and free KRT
- 68 5.1 Global prevalence of nephrologists
- 6.1 Availability of centers that provide chronic HD
- 6.2 Availability of centers that provide chronic PD
- 74 6.3 Availability of centers that provide kidney transplantation

# **Appendices**



### COUNTRIES AND POPULATION COVERED BY SURVEY RESPONSES

	Number of countries	Total populations (millions)	Number of countries that completed the survey	Total population of countries that completed survey (millions)
Overall	218	7,903.3	167	7,700.2
ISN region				
Africa	54	1,412.3	41	1,310.2
Eastern and Central Europe	20	207.3	16	199.4
Latin America	31	650.4	22	627.8
The Middle East	13	255.2	11	222.7
NIS and Russia	11	284.6	10	278.9
North America and the Caribbean	14	381.2	12	381.1
North and East Asia	8	1,647.3	6	1,618.1
OSEA	30	733.3	19	730.9
South Asia	8	1,891.7	8	1,891.7
Western Europe	29	439.9	22	439.5
World Bank income group				
Low income	28	720.2	20	616.2
Lower-middle income	54	3,410.7	45	3,350.2
Upper-middle income	55	2,526.6	39	2,493.1
High income	81	1,245.7	63	1,240.7

### LIST OF COUNTRIES BY ISN REGION AND WORLD BANK INCOME GROUP

Countries that participated in the survey

Countries that did not participate in the survey

Country	ISN region	World Bank income group
Afghanistan	South Asia	Low income
Albania	Eastern and Central Europe	Upper-middle income
Algeria	Africa	Lower-middle income
American Samoa	OSEA	Upper-middle income
Andorra	Western Europe	High income
Angola	Africa	Upper-middle income
Antigua and Barbuda	North America and the Caribbean	High income
Argentina	Latin America	Upper-middle income
Armenia	NIS and Russia	Lower-middle income
Aruba	North America and the Caribbean	High income
Australia	OSEA	High income
Austria	Western Europe	High income
Azerbaijan	NIS and Russia	Upper-middle income
Bahamas, The	North America and the Caribbean	High income
Bahrain	The Middle East	High income
Bangladesh	South Asia	Lower-middle income
Barbados	North America and the Caribbean	High income
Belarus	NIS and Russia	Upper-middle income
Belgium	Western Europe	High income
Belize	Latin America	Lower-middle income
Benin	Africa	Lower-middle income
Bermuda	North America and the Caribbean	High income
Bhutan	South Asia	Lower-middle income
Bolivia	Latin America	Lower-middle income
Bosnia and Herzegovina	Eastern and Central Europe	Upper-middle income
Botswana	Africa	Upper-middle income
Brazil	Latin America	Upper-middle income
British Virgin Islands	Latin America	High income
Brunei Darussalam	OSEA	High income
Bulgaria	Eastern and Central Europe	Upper-middle income
Burkina Faso	Africa	Low income
Burundi	Africa	Low income
Cabo Verde	Africa	Lower-middle income

Country	ISN region	World Bank income group	
Cambodia	OSEA	Lower-middle income	
Cameroon	Africa	Lower-middle income	
Canada	North America and the Caribbean	High income	
Cayman Islands	North America and the Caribbean	High income	
Central African Republic	Africa	Low income	
Chad	Africa	Low income	
Channel Islands	Western Europe	High income	
Chile	Latin America	High income	
China	North and East Asia	Upper-middle income	
Colombia	Latin America	Upper-middle income	
Comoros	Africa	Lower-middle income	
Congo, Dem. Rep.	Africa	Low income	
Congo, Rep.	Africa	Lower-middle income	
Costa Rica	Latin America	Upper-middle income	
Cote d'Ivoire	Africa	Lower-middle income	
Croatia	Eastern and Central Europe	High income	
Cuba	Latin America	Upper-middle income	
Curacao	North America and the Caribbean	High income	
Cyprus	Eastern and Central Europe	High income	
Czech Republic	Eastern and Central Europe	High income	
Denmark	Western Europe	High income	
Djibouti	Africa	Lower-middle income	
Dominica	Latin America	Upper-middle income	
Dominican Republic	Latin America	Upper-middle income	
Ecuador	Latin America	Upper-middle income	
Egypt, Arab Rep.	Africa	Lower-middle income	
El Salvador	Latin America	Lower-middle income	
Equatorial Guinea	Africa	Upper-middle income	
Eritrea	Africa	Low income	
Estonia	Eastern and Central Europe	High income	
Ethiopia	Africa	Low income	
Faeroe Islands	Western Europe	High income	
Fiji	OSEA	Upper-middle income	
Finland	Western Europe	High income	
France	Western Europe	High income	
French Polynesia	OSEA	High income	
Gabon	Africa	Upper-middle income	
Gambia, The	Africa	Low income	
Georgia	NIS and Russia	Upper-middle income	
Germany	Western Europe	High income	
Ghana	Africa	Lower-middle income	
Gibraltar	Western Europe	High income	
Greece	Western Europe	High income	
Greenland	Western Europe	High income	
Guam	OSEA	High income	
Grenada	Latin America	Upper-middle income	
Guatemala	Latin America	Upper-middle income	

Country	ISN region	World Bank income group
Guinea	Africa	Low income
Guinea-Bissau	Africa	Low income
Guyana	Latin America	Upper-middle income
Honduras	Latin America	Lower-middle income
Haiti	Latin America	Lower-middle income
Hong Kong SAR, China	North and East Asia	High income
Hungary	Eastern and Central Europe	High income
Iceland	Western Europe	High income
India	South Asia	Lower-middle income
Indonesia	OSEA	Lower-middle income
Iran, Islamic Rep.	The Middle East	Lower-middle income
Iraq	The Middle East	Upper-middle income
Ireland	Western Europe	High income
Isle of Man	Western Europe	High income
Israel	Western Europe	High income
Italy	Western Europe	High income
Jamaica	North America and the Caribbean	Upper-middle income
Japan	North and East Asia	High income
Jordan	The Middle East	Upper-middle income
Kazakhstan	NIS and Russia	Upper-middle income
Kenya	Africa	Lower-middle income
Kingdom of Saudi Arabia	The Middle East	High income
Kiribati	OSEA	Lower-middle income
Korea, Dem. Rep.	North and East Asia	Low income
Korea, Rep.	North and East Asia	High income
Kosovo	Eastern and Central Europe	Upper-middle income
Kuwait	The Middle East	High income
Kyrgyz Republic	NIS and Russia	Lower-middle income
Lao PDR (Laos)	OSEA	Lower-middle income
Latvia	Eastern and Central Europe	High income
Lebanon	The Middle East	Upper-middle income
Lesotho	Africa	Lower-middle income
Liberia	Africa	Low income
Libya	Africa	Upper-middle income
Liechtenstein	Western Europe	High income
Lithuania	Eastern and Central Europe	High income
Luxembourg	Western Europe	High income
Macao SAR, China (Macau)	North and East Asia	High income
Macedonia, FYR	Eastern and Central Europe	Upper-middle income
Madagascar	Africa	Low income
Malawi	Africa	Low income
Malaysia	OSEA	Upper-middle income
Maldives	South Asia	Upper-middle income
Mali	Africa	Low income
Malta	Western Europe	High income
Marshall Islands	OSEA	Upper-middle income
Mauritania	Africa	Lower-middle income

Country	ISN region	World Bank income group	
Mauritius	Africa	Upper-middle income	
Mexico	Latin America	Upper-middle income	
Micronesia, Fed. Sts.	OSEA	Lower-middle income	
Moldova	Eastern and Central Europe	Upper-middle income	
Monaco	Western Europe	High income	
Mongolia	North and East Asia	Lower-middle income	
Montenegro	Eastern and Central Europe	Upper-middle income	
Morocco	Africa	Lower-middle income	
Mozambique	Africa	Low income	
Myanmar (Burma)	OSEA	Lower-middle income	
Namibia	Africa	Upper-middle income	
Nauru	OSEA	High income	
Nepal	South Asia	Low income	
Netherlands	Western Europe	High income	
New Caledonia	OSEA	High income	
New Zealand	OSEA	High income	
Nicaragua	Latin America	Lower-middle income	
Niger	Africa	Low income	
Nigeria	Africa	Lower-middle income	
North Macedonia	Eastern and Central Europe	Upper-middle income	
Northern Mariana Islands	OSEA	High income	
Norway	Western Europe	High income	
Oman	The Middle East	High income	
Palau	OSEA	High income	
Pakistan	South Asia	Lower-middle income	
Panama	Latin America	Upper-middle income	
Papua New Guinea	OSEA	Lower-middle income	
Paraguay	Latin America	Upper-middle income	
Peru	Latin America	Upper-middle income	
Philippines	OSEA	Lower-middle income	
Poland	Eastern and Central Europe	High income	
Portugal	Western Europe	High income	
Puerto Rico	Latin America	High income	
Qatar	The Middle East	High income	
Romania	Eastern and Central Europe	Upper-middle income	
Russian Federation	NIS and Russia	Upper-middle income	
Rwanda	Africa	Low income	
Samoa	OSEA	Upper-middle income	
Sao Tome and Principe	Africa	Lower-middle income	
San Marino	Europe and Central Asia	High income	
Senegal	Africa	Lower-middle income	
Serbia	Eastern and Central Europe	Upper-middle income	
Seychelles	Africa	High income	
Sierra Leone	Africa	Low income	
Singapore	OSEA	High income	
Slovak Republic (Slovakia)	Eastern and Central Europe	High income	
Slovenia	Eastern and Central Europe	High income	

Country	ISN region	World Bank income group
Somalia	Africa	Low income
Solomon Islands	OSEA	Lower-middle income
South Africa	Africa	Upper-middle income
South Sudan	Africa	Low income
Spain	Western Europe	High income
Sri Lanka	South Asia	Lower-middle income
St. Kitts and Nevis	North America and the Caribbean	High income
St. Lucia	North America and the Caribbean	Upper-middle income
St. Maarten (Dutch part)	Latin America	High income
St. Martin (French part)	Latin America	High income
St. Vincent and the Grenadines	North America and the Caribbean	Upper-middle income
Sudan	Africa	Low income
Suriname	Latin America	Upper-middle income
Swaziland (Eswatini)	Africa	Lower-middle income
Sweden	Western Europe	High income
Switzerland	Western Europe	High income
Syrian Arab Republic (Syria)	The Middle East	Low income
Taiwan, China	North and East Asia	High income
Tajikistan	NIS and Russia	Lower-middle income
Tanzania	Africa	Lower-middle income
Thailand	OSEA	Upper-middle income
Timor-Leste	OSEA	Lower-middle income
Тодо	Africa	Low income
Tonga	OSEA	Upper-middle income
Trinidad and Tobago	North America and the Caribbean	High income
Tunisia	Africa	Lower-middle income
Turkey	Eastern and Central Europe	Upper-middle income
Turkmenistan	Eastern and Central Europe	Upper-middle income
Turks and Caicos Islands	Latin America	High income
Tuvalu	OSEA	Upper-middle income
Uganda	Africa	Low income
Ukraine	NIS and Russia	Lower-middle income
United Arab Emirates	The Middle East	High income
United Kingdom	Western Europe	High income
United States	North America and the Caribbean	High income
Uruguay	Latin America	High income
Vanuatu	OSEA	Lower-middle income
Uzbekistan	NIS and Russia	Lower-middle income
Venezuela, RB	Latin America	Upper-middle income
Vietnam	OSEA	Lower-middle income
Virgin Islands (U.S.)	Latin America	High income
West Bank and Gaza	The Middle East	Lower-middle income
Yemen	The Middle East	Low income
Zambia	Africa	Lower-middle income
Zimbabwe	Africa	Lower-middle income

### DISCIPLINARY AFFILIATION OF SURVEY RESPONDENTS

	Nephro	ologist	Pedia nephro	atric ologist	No nephro (phys	n- ologist ician)	Hea profes (no physi	llth sional n- cian)	Admini policy civil s	istrator/ maker/ servant	Ot	her
Overall	265	(81)	8	(3)	18	(5)	6	(2)	14	(4)	17	(5)
ISN region												
Africa	49	(80)	1	(2)	5	(8)	0	(0)	6	(10)	0	(0)
Eastern and Central Europe	29	(94)	0	(0)	0	(0)	0	(0)	1	(3)	1	(3)
Latin America	39	(88)	3	(7)	2	(5)	0	(0)	0	(0)	0	(0)
The Middle East	18	(85)	2	(10)	0	(0)	1	(5)	0	(0)	0	(0)
NIS and Russia	15	(70)	1	(5)	2	(10)	0	(0)	1	(5)	2	(10)
North America & Caribbean	23	(92)	0	(0)	0	(0)	0	(0)	0	(0)	2	(8)
North and East Asia	16	(88)	0	(0)	1	(6)	1	(6)	0	(0)	0	(0)
OSEA	28	(70)	1	(3)	5	(12)	2	(5)	1	(3)	3	(7)
South Asia	12	(70)	0	(0)	2	(12)	0	(0)	1	(6)	2	(12)
Western Europe	36	(72)	0	(0)	1	(2)	2	(4)	4	(8)	7	(14)
World Bank income group												
Low income	17	(71)	2	(8)	3	(13)	0	(0)	2	(8)	0	(0)
Lower-middle income	67	(74)	4	(4)	10	(12)	0	(0)	5	(6)	4	(4)
Upper-middle income	71	(88)	2	(2)	2	(2)	1	(1)	3	(5)	2	(2)
High income	110	(83)	0	(0)	3	(2)	5	(4)	4	(3)	11	(8)

### SURVEY RESPONDENTS

The following list comprises the survey respondents who consented to have their details published in the ISN–Global Kidney Health Atlas.

ISN region	Country	Respondent
Africa	Angola	Matadi Daniel
	Benin	Jacques Vigan
	Botswana	Gordana Cavric Morrison Sinvula
	Burkina Faso	Gerard Coulibaly
	Burundi	Joseph Nyandwi
	Cabo Verde	Helder Tavares
	Cameroon	Francois Folefack Kaze Roukaya Fonfatawuo
	Central African Republic	Ousmane Gamarko Gerard Grezenguet
	Chad	Hamat Ibrahim
	Congo, Dem. Rep.	Ernest Sumaili Kiswaya
	Congo, Rep.	Justine Bukabau Pierre Eric Gandzali-Ngabe
	Côte d'Ivoire	Hubert Yao
	Djibouti	Daniel Gebremichael
	Egypt, Arab Rep.	Zaghloul Gouda May Hassaballah
	Ethiopia	Yewondwossen Tadesse
	Gabon	Marie Touly
	Gambia, The	Abubacarr Jagne
	Ghana	Dwomoa Adu Charlotte Osafo Elliot Tannor
	Guinea	Alpha Oumar Bah
	Guinea-Bissau	Catarina Carvalho
	Kenya	George M. Moturi
	Madagascar	E. M. Ranivoharisoa
	Malawi	Samuel Kumwanje Henry Mzinganjira
	Mali	Sevdou Sv

ISN region	Country	Respondent
Africa continued	Mauritania	Abdellatif Sidi Aly Sidi Mohamed
	Mauritius	Davy Ipminwan
	Morocco	Tarik Sqalli Houssaini
	Mozambique	Elsa Rosalia Chissico
	Namibia	Cathy Reyneke
	Niger	Hassane Diongole
	Nigeria	Fatiu Abiola Arogundade Ebun Bamgboye Babatunde Salako Ifeoma Ulasi
	Senegal	Abdou Niang
	South Africa	Lindsey Jacobs Graham Paget
	Sudan	Hisham Abdelwahab
	Swaziland	Thandiwe Dlamini Simon Zwane
	Tanzania	Francis Fredrick Kajiru Kilonzo
	Тодо	Kossi Akomola Sabi
	Tunisia	Rim Goucha
	Uganda	Anthony Batte
	Zambia	Justor Banda Aggrey Mweemba
	Zimbabwe	Rumbi Dahwa Rumbidzai Mashing
Eastern and Central Europe	Albania	Alma Idrizi
	Bosnia and Herzegovina	Amela Beciragic Halima Resic
	Bulgaria	Emil Paskalev Evgueniy Vazelov
	Croatia	Nikolina Basic Jukic Mario Laganovic Sanjin Racki
	Cyprus	Kyriakos Ioannou
	Czech Republic	Ivan Rychlik Vladimir Tesar Ondrej Viklicky
	Estonia	Kadri Lilienthal Mai Rosenberg
	Hungary	Laszlo Rosivall
	Kosovo	İbrahim Rudhani
	Latvia	Aivars Petersons
	Lithuania	Inga Bumblyte Marius Miglinas
	Macedonia, FYR	Dusko Gjorgievski Goce Spasovski
	Moldova	Adrian Tanase

ISN region	Country	Respondent
Eastern and Central Europe continued	Poland	Jolanta Malyszko Michal Nowicki Andrzej Wiecek
	Romania	Liliana Tuta
	Serbia	Nada Dimkovic
	Slovak Republic	Adrian Oksa
	Turkey	Mustafa Arıcı Timur Erk Rumeyza Kazancioglu
Latin America	Argentina	Guillermo Javier Rosa Diez Walter Douthat Hernan Trimarchi
	Bolivia	Rolando Claure-Del Granado Maya Herbas
	Brazil	Osvaldo Merege Carmen Tzanno Martins Irene Noronha
	Chile	Carlos Zuniga
	Colombia	Jaime Restrepo Jorge Rico
	Costa Rica	Guillermo Rodriguez
	Dominican Republic	Hector Martinez
	Ecuador	Fabian Ortiz Herbener Cristobal Santa Cruz Tania Silva Sanchez
	El Salvador	Carlos Henriquez Zulma Cruzde Trujillo
	Guatemala	Ever Olivie O. Cipriano Maldonado Agualuzdel Carmen A. Hernandez Paredes Jose Vicente Sanchez Polo
	Haiti	Audie Metayer
	Mexico	Guillermo Garcia Garcia Magdalena Madero Gregorio Obrador
	Nicaragua	Mabel Sandoval Diaz
	Panama	Karen Courville Regulo Valdes Miranda
	Paraguay	Francisco Santa-Cruz Silvio Franco
	Peru	Mario Encinas Aranas Cesar Loza Munarriz Boris Medina Santander
	Puerto Rico	Jose Cangiano
	Uruguay	Maria Carlota Gonzalez Bedat Alejandro Ferreiro Pablo Rios Laura Sola
	Venezuela	Raul Carlini
The Middle East	Iran, Islamic Rep.	Nakisa Hooman Shahrzad Ossareh Shokoufeh Savaj

ISN region	Country	Respondent
The Middle East continued	Iraq	Safa Ezzaddin
	Jordan	Mohammad Ghnaimat Riyad Said
	Kingdom of Saudi Arabia	Saeed M. G Al-Ghamdi Ahmad Mitwalli
	Kuwait	Torki Alotaibi Ali Alsahow Anas Alyousef
	Lebanon	Ali Abu-Alfa Sola Aoun Hiba Azar Robert Nakhoul Najm
	Oman	Fatma Al Rahbi Issa Al Salmi
	Qatar	Abdullah Ibrahim Hamad
	Syrian Arab Republic	Bassam Saeed
	United Arab Emirates	Ali Alobaidli Eman Al-Shamsi
	West Bank and Gaza	Mohammad Bourini Zakaria Hamdan
NIS and Russia	Armenia	Helen Nazaryan Ashot Sarkissian Milena Voskanyan
	Azerbaijan	Cabrail Cabrailov Elgun Haziyev
	Belarus	Aleh Kalachyk
	Georgia	Irma Tchokhonelidze Georgie Tomadze
	Kazakhstan	Abduzhappar Gaipov
	Kyrgyz Republic	Tuganbaev Nurlan Ayilchievich Abdukerimova Nazgul Mamatbekovna
	Russian Federation	Irina Bobkova Konstantin Vishnevsky Elena Zakharova
	Tajikistan	Ismoil Rashidov
	Ukraine	Dmytro Ivanov Oleg Negurin
	Uzbekistan	Sherzod Abdullaev Javokhir Khalmukhamedov Olimkhon Sharapov
North and East Asia	China	Jianghua Chen Ping Fu Xueqing Yu Minghui Zhao
	Hong Kong SAR, China	Cheng Yuk Lun Siu Fai Lui Angela Wang
	Japan	Naoki Kashihara Masaomi Nangaku Motoko Yanagita
	Korea, Rep.	Chun Soo Lim Kook-Hwan Oh

ISN region	Country	Respondent
North and East Asia continued	Macao SAR, China	Chiu Leong Li
	Taiwan, China	Chih-Hsiang Chang Chih-Cheng Hsu Chih-Wei Yang
North America and the Caribbean	Antigua and Barbuda	Leon Cox George Mansoor Ian Thomas
	Aruba	Mauro Cuba Agustin Garcia-Sanz Ali Garcia Marquez
	Bahamas, The	Ronald L. Knowles Rhea Thurston-Carroll
	Barbados	Danielle Dotin
	Bermuda	Raphael Loutoby Wendy Outerbridge
	British Virgin Islands	Chrisell Bovell
	Canada	Peter Blake Paul Kidston
	Cayman Islands	Nelson Iheonunekwu
	Curaçao	Nouaf Ajubi
	Jamaica	Lori Fisher Racquel Lowe-Jones Adedamola Soyibo
	St. Lucia	Merle Clarke
	St. Vincent and the Grenadines	St. Clair Prince
	Trinidad and Tobago	Leslie Roberts Villarroel
	Turks and Caicos Islands	Vancelee Forbes
	United States	Jeffrey Berns Tod Ibrahim Holly Kramer Franklin Maddux Donald Molony
	Virgin Islands (U.S.)	Wishburne Hunte
Oceania and South East Asia (OSEA)	American Samoa	Dorothy Faye Olita Tafiti
	Australia	Martin Gallagher David Johnson Breonny Robson
	Brunei Darussalam	Pengiran Khalifah Pengiran Ismail Jackson Tan
	Cambodia	Chanseila Hy Toru Hyodo Samkol Pen Niv Rathvirak Pichthida Thim
	Fiji	Yogeshni Chandra Amrish Krishnan
	Indonesia	Pringgodigdo Nugroho Aida L. Sutranto
	Lao PDR	Chanmaly Keomany Noot Sengthavisouk

ISN region	Country	Respondent
Oceania and South East Asia (OSEA) continued	Malaysia	Halim Abdul Gafor Siva Kumar Ragavan Zaki Morad Zaher
	Myanmar	Khin T. Thwin Khin Phyu Pyar
	New Caledonia	Fadi Haidar Thomas Lamy Jean-Michel Tivollier
	New Zealand	Drew Anderson Noravander Schrieck Robert Walker
	Papua New Guinea	Steven Bogosia Cassius Maingu
	Philippines	Maaliddin Biruar Francisco Sarmiento
	Samoa	Leituala Ben Matalavea Folototo Leavai Malama Tafuna'i David Voss
	Singapore	Yeo See Cheng Jason Choo Chon Jun Job Loei
	Solomon Islands	Emire Meone-Maefiti
		Rebecca Pinau
	Thailand	Pongsathorn Gojaseni Surasak Kantachuvesiri Warangkana Pichaiwong
	Vanuatu	Sale Tamata Vurobaravu
	Vietnam	Huong Thi Bich Tran
South Asia	Afghanistan	Fraidoon Faizar Ahmad Naseer Kaihan
	Bangladesh	Justice Borhanuddin Shubharthi Kar
	Bhutan	Pandup Tshering
	India	Anil Bhalla Vivek Jha Siddharth Kapahtia Narayan Prasad Bharat Shah
	Maldives	Ibrahim Shiham
	Nepal	Rishi Kafle Pratap Prasad Dibya Singh Shah
	Pakistan	Syed Akhtar Ahad Qayyum
	SriLanka	Chulani Herath Dilushi Wijayaratne
Western Europe	Austria	Gert Mayer
	Belgium	Kathleen Claes Raymond Vanholder
	Denmark	Michael Buksti Bo Feldt-Rasmussen

ISN region	Country	Respondent
Western Europe continued	Finland	Jaakko Helve Sari Högström Niina Koivuviita
	France	Pierre Bataille Gabriel Choukroun Benedicte Stengel
	Germany	Isabelle Jordans Hermann Pavenstädt
	Greece	Gerasimos Bamichas Dimitrios Petras
	Iceland	Hrefna Gudmundsdottir
	Ireland	George Mellotte Carol Moore Liam Plant
	Israel	Gil Chernin Victor Frajewicki Talia Weinstein
	Italy	Roberto Costanzi Massimo Morosetti
	Liechtenstein	Clemens Jäger
	Luxembourg	Françoise Ortola
	Malta	Emanuel Farrugia
	Netherlands	F. J. Ittersum Dick De Jonge Anita van Eck van der Sluis
	Norway	Sigrid Beitland Marit Solbu
	Portugal	Edgar Almeida Rui Alves José António Lopes
	Spain	Manuel Macía Alberto Ortiz Emilio Sanchez Alvarez
	Sweden	Anders Christensson
	Switzerland	Patrice Ambuehl Isabelle Binet Olivier Bonny
	United Kingdom	Lydia Ball Paul Bristow Paul Cockwell

## **ISN-GKHA** survey

The International Society of Nephrology (ISN) works collaboratively with existing organizations and initiatives at international and national levels - to promote early detection and effective treatment of kidney diseases in order to improve people living with kidney disease's health and quality of life. Through understanding and potentially helping to shape relevant health policies, practices, and infrastructure, ISN aims to facilitate the implementation of equitable and ethical care for people living with kidney disease s in all regions and countries of the world.

The ISN has conducted a research exercise on the status of care for people living with kidney disease across all countries of the world published in its ISN–Global Kidney Health Atlas with 1st iteration (2017; www.theisn.org/wp-content/ uploads/2021/05/GKDAtlas\_2017\_FinalVersion-1. pdf) and 2nd iteration (2019; www.theisn.org/ wp-content/uploads/2021/05/GKHAtlas\_2019\_ WebFile-1.pdf).

The ISN–GKHA demonstrated significant interand intra-regional variability in global kidney care, with significant gaps in kidney health workforce, health service delivery, essential medicines and technologies, health financing, leadership and governance, health information systems, strategies and policy frameworks, and research capacity and development, particularly in lowand middle-income countries. This has provided a platform for championing the cause of chronic kidney disease (CKD) using the identified gaps in Universal Healthcare domains and has provided a foundation for a global CKD surveillance and benchmarking network.

This third iteration of the survey by the ISN is to understand, compare and monitor how different countries around the world detect, treat, monitor, and advocate for people with kidney disease with a key focus on capacity, availability, accessibility, affordability, and outcomes.

It will determine the capacity and readiness of nations towards achieving universal access to equitable integrated kidney care (including kidney replacement therapy and conservative care). This iteration also includes a people living with kidney disease's survey which provides people's perspective on access to, and quality of care being delivered.

This survey is designed to address the core areas which inform aspects of universal health coverage specific to integrated kidney care: health financing, workforce, essential medications and health products access, health information systems and statistics, policies, and service delivery and safety as well as the response of the nephrology community and capacity for research and development in kidney care. Using this framework, we will be able to develop an appropriate global perspective on the state of access to, and quality of kidney care globally. Obtaining universal, complete, and accurate responses is critical to closing the gaps that exist in kidney care globally.

 Online version of ISN-Global Kidney Health Atlas survey: <u>www.theisn.org/global-atlas</u>.

Thank you for your involvement and readiness to participate.

les to

Professor Agnes Fogo President International Society of Nephrology



Survey ID (provided in email):

Current position:

Role: Please check all that apply.

- Nephrologist
- Pediatric nephrologist
- □ Non-nephrologist (physician)
- □ Health professional (non-physician) (specify)
- Administrator/policymaker/civil servant
- Other (please specify)

In which country do you reside?

In which city do you reside?

#### List of abbreviations:

AKI: Acute kidney injury AV fistula: Arteriovenous fistula APD: Automated peritoneal dialysis BP: Blood pressure CKD: Chronic kidney disease CKM: Conservative kidney management ESKD: End-stage kidney disease KRT: Kidney replacement therapy (i.e., hemodialysis, peritoneal dialysis, kidney transplantation) NCD: Non-communicable disease NGO: Non-governmental organization HD: Hemodialysis PD: Peritoneal dialysis PROMs: Patient-reported outcome measures PTH: Parathyroid hormone

### A - HEALTH FINANCE AND SERVICE DELIVERY

### A.1 Healthcare system and funding mechanism

## A.1.1 In general, what best describes your healthcare system funding structure for non-dialysis chronic kidney disease (CKD)? (please choose the most appropriate response)

- Publicly funded by government and free at the point of delivery
- □ Publicly funded by government but with some fees at the point of delivery
- A mix of publicly funded (whether or not publicly funded component is free at point of delivery) and private systems (please explain)
- □ Solely private and out-of-pocket
- □ Solely private through health insurance providers
- □ Multiple systems programs provided by government, NGOs, and communities
- $\Box$  Other (please specify)

## A.1.2 In general, what best describes your healthcare system funding structure for KRT (kidney replacement therapy)? (please choose the most appropriate response)

	Publicly funded by government and free at the point of delivery	Publicly funded by government but with some fees at the point of delivery	A mix of publicly funded (whether or not publicly funded component is free at point of delivery) and private systems	Solely private and out-of- pocket	Solely private through health insurance providers	Multiple systems – programs provided by government, NGOs, and communities	Other (please specify)	N/A (this modality is not available in my country)
A.1.2.1 – Acute dialysis for AKI (hemodialysis or peritoneal dialysis)								
A.1.2.2 – Chronic Hemodialysis								
A.1.2.3 – Chronic Peritoneal dialysis								
A.1.2.4 – Medications for kidney transplantation								

#### A.1.3.1 If KRT is publicly funded (in whole or in part), is this coverage universal (that is, are all residents of your country eligible to participate)?

- Yes, all residents (including children) are included in the coverage
- No, not all vulnerable populations are included (please provide details)

## A.1.3.2 If KRT is publicly funded (in whole or in part), are vulnerable populations (refugees, displaced populations) eligible to participate?

- Yes, all vulnerable populations are included in the coverage
- No, not all vulnerable populations are included (please provide details)

## A.1.3.3 If KRT is publicly funded (in whole or in part), which aspects of care are not included in the coverage? Please check all that apply.

#### 🗆 Dialysis

- □ Transplantation
- Comprehensive conservative care (kidney palliative supportive services)
- Management of associated complications (anaemia, bone disease, malnutrition)
- □ None all aspects funded
- $\Box$  Other (please specify)

## A.1.4 What best describes your healthcare system's coverage for surgical services for KRT? (please choose the most appropriate response for each row) (skip this section if KRT is unavailable in your country)

	Publicly funded by government and free at the point of delivery	Publicly funded by government but with some fees at the point of delivery	A mix of publicly funded (whether or not publicly funded component is free at point of delivery) and private systems	Solely private and out-of- pocket	Solely private through health insurance providers	Multiple systems – programs provided by government, NGOs, and communities	Other (please specify)
A.1.4.1 – Vascular access for hemodialysis (central venous catheters)							
A.1.4.2 – Vascular access for hemodialysis (fistula or graft creation)							
A.1.4.3 – Access surgery for peritoneal dialysis (PD catheter insertion)							
A1.4.4 – Surgery for kidney transplantation							

### A.2 Within-country variation

We are interested in understanding within-country variation in kidney failure (or end-stage kidney disease [ESKD]) care delivery as well as between-country variation.

## A.2.1.1 Does the organization or delivery of kidney failure (ESKD) care differ regionally within your country?

□ Yes (if possible, please provide brief details)

- 🗆 No
- 🗆 Unknown

## A.2.1.2 Does cost of kidney failure (ESKD) care differ regionally within your country?

- □ Yes (if possible, please provide brief details)
- 🗆 No
- 🗆 Unknown

# A.2.1.3 Does organization or delivery of kidney failure (ESKD) care differ between children and adults in your country?

- □ Yes (if possible, please provide brief details)
- □ No
- 🗆 Unknown

## A.2.1.4 Does the access to KRT differ between children and adults in your country?

- $\Box$  Yes (if possible, please provide brief details)
- □ No
- 🗆 Unknown

## A.2.2.1 If KRT services are not equal between adults and children, what is the difference in access to hemodialysis?

- $\hfill\square$  More HD access for adults than for children
- $\hfill\square$  More HD access for children than for adults
- □ HD access available for adults, unavailable for children
- □ HD access available for children, unavailable for adults

#### A.2.2.2 If KRT services are not equal between adults and children, what is the difference in access to peritoneal dialysis?

- $\hfill\square$  More PD access for adults than for children
- $\Box$  More PD access for children than for adults
- $\hfill\square$  PD access available for adults, unavailable for children
- $\hfill\square$  PD access available for children, unavailable for adults

#### A.2.2.3 If KRT services are not equal between adults and children, what is the difference in access to kidney transplant?

- □ More KT access for adults than for children
- □ More KT access for children than for adults
- $\hfill\square$  KT access available for adults, unavailable for children
- $\hfill\square$  KT access available for children, unavailable for adults

### A.3 Oversight

## A.3.1 What best describes the management/oversight of kidney care in your country? Please check all that apply.

- □ Managed/overseen by a national body
- Managed/overseen by provincial/regional/state level authorities only
- □ Managed by individual hospitals/trusts/organizations
- □ Managed by NGOs
- $\Box$  Other (please specify)
- □ No organized system

#### A.3.2 How would you rate the health infrastructure in your country, in terms of adequacy for providing kidney failure (ESKD) care?

- Extremely poor
- Poor/below average
- Fair/Average
- □ Good/above average
- Excellent

#### **B – HEALTH WORKFORCE FOR NEPHROLOGY CARE**

#### **B.1 Clinical responsibility**

B.1.1 Who bears primary clinical responsibility for the delivery of kidney failure (ESKD) care in your country? Please check all that apply.

- Nephrologists
- Primary care physicians
- Nurse practitioners
- □ Specialized nurses
- □ Multidisciplinary teams
- □ Health officers/extension workers
- □ Other specialists (please specify)

#### **B.2 Workforce**

### B.2.1.1 Approximately how many nephrologists are there in your country? Please leave blank if unknown.

Nephrologists: Adult nephrologists:

Pediatric nephrologists:

B2.1.2 What is the percentage of female nephrologists (adults and pediatrics combined) in your country? Please leave blank if unknown.

B2.2.1. Approximately how many nephrologist trainees are there in your country? Please leave blank if unknown.

### B.2.2.2 Does a training program for adult nephrologists exist in your country?

- Yes
- 🗆 No
- Not sure

## B.2.2.3 If yes to question B2.2.2 above, what is the length of the training program?

- 🗆 <1 year
- □ 1 2 years
- 2 4 years
- □ >4 years

## B.2.2.4 Does a training program for pediatric nephrologists exist in your country?

- Yes
- 🗆 No
- Not sure

## B.2.2.5 If yes to question B2.2.4 above, what is the length of the training program?

□ <1 year

- □ 1 2 years
- 2 4 years
- $\Box$  >4 years

B.2.2.6 Is the training program for nephrologists (adults or pediatrics) linked with a research component (e.g., PhD, M.Sc., MPhil, MMed, etc)?

- Yes
- 🗆 No
- Not sure

B.2.3 In your opinion, is there a shortage of any of the following providers in your country for kidney care? Please check all that apply.

- □ Nephrologists
- □ Pediatric nephrologists
- □ Transplant surgeons
- Surgeons or Interventional radiologists (who can put in arteriovenous hemodialysis access)
- Surgeons or Interventional radiologists (who can put in peritoneal dialysis access)
- Dietitians
- Laboratory technicians

- Radiologists to conduct and interpret kidney ultrasounds
- □ Vascular access coordinators
- Counsellors/psychologists
- □ Transplant coordinators
- Dialysis nurses
- Renal nurses
- Dialysis technicians
- Social workers
- Palliative care physicians
- □ Kidney supportive care nurses
- □ No shortage of any of the staff mentioned above

### **C – ESSENTIAL MEDICATIONS AND HEALTH PRODUCT ACCESS FOR KIDNEY CARE**

<b>C.1</b>	Capacity	/ for	KRT	service	provision
------------	----------	-------	-----	---------	-----------

C.1.1 Is in-centre hemodialysis (adult and pediatric) available in your country?

🗆 Yes

🗆 No

C.1.1.1 If yes, how many centres in your country provide chronic hemodialysis (HD)?

C.1.1.2 Is home hemodialysis (adult and pediatric) available in your country?

🗆 Yes

🗆 No

C.1.2 Is peritoneal dialysis (PD) (adult and pediatric) available in your country?

🗆 Yes

🗆 No

C.1.2.1 If yes, how many centres in your country provide chronic PD?

C.1.2.2 If PD is available, under what circumstances can be PD be accessed in your country? (Select one)

- Acute PD only
- □ Acute and chronic PD
- Chronic PD only

C.1.2.3 Is automated peritoneal dialysis (APD) (adult and pediatric) available in your country?

- □ Yes □ No
- L No

C.1.3 Is adult kidney transplantation performed in your country?

Yes

🗆 No

C1.4. Is pediatric (age <18 years) kidney transplantation performed in your country?

Yes

🗆 No

## C.1.5.1 If yes, what is the source of donated kidneys? (Please choose the most appropriate response)

- □ Deceased donors only
- □ Live donors only
- $\hfill\square$  A combination of deceased and live donors

If kidneys for transplant come from both deceased and live donors, what percentage are live?

## C.1.5.2 If kidney transplantation is available in your country, what kind of kidney transplant waitlist or waitlists are there?

- 🗆 National
- Regional only
- None

C.1.5.3 If kidney transplantation is available in your country, how many centres perform kidney transplantation?

### C.2 Essential medications and health products access

## C.2.1 Essential medications and technologies for KRT – Accessibility, affordability and reimbursement plans and quality (choose the most appropriate response for each question)

	Publicly funded by government and free at the point of delivery	Publicly funded by government but with some fees at the point of delivery	A mix of publicly funded (whether or not publicly funded component is free at point of delivery) and private systems	Solely private and out-of- pocket	Solely private through health insurance providers	Multiple systems – programs provided by government, NGOs, and communities	Other (please specify)
C.2.1.1 – For all people living with chronic kidney disease (not on dialysis): How are medications funded?							
C.2.1.2 – For all people living with kidney disease on dialysis: How are medications funded?							
C.2.1.3 – For all people living with a kidney transplant: How are medications funded?							

### **C3. Preparation for KRT**

Optimal kidney failure (ESKD) care: In the context of the ISN Vision, Mission and Values, we believe all people living with kidney disease approaching kidney failure (ESKD) should receive timely preparation for KRT, so the complications and progression of their disease are minimized, and their choice of clinically appropriate treatment options is optimized. The answers to the following questions are important to improve our understanding of current service provision.

## C.3.1 Please indicate the availability of the following services (tests and treatments) for kidney failure (ESKD) care in your country.

'Generally available' means in 50% or more centres (hospitals or clinics) and 'Generally not available' means: in less than 50% of centres (hospitals or clinics)

	Generally available	Generally not available	Never	Unknown
C.3.1.1 Management of haemoglobin level				
C.3.1.1.1 Measurement of serum haemoglobin				
C.3.1.1.2 Measurement of iron parameters (iron, ferritin, transferrin saturation)				
C.3.1.1.3 Measurement of inflammatory markers (for example, serum C-reactive protein)				
C.3.1.1.4 Oral iron				
C.3.1.1.5 Parenteral iron				
C.3.1.1.6 Erythropoiesis stimulating agent (e.g., Erythropoietin)				
C.3.1.2 Management of mineral bone disease				
C.3.1.2.1 Measurement of serum calcium				
C.3.1.2.2 Measurement of serum phosphorus				
C.3.1.2.3 Measurement of serum parathyroid hormone (PTH)				
C.3.1.2.4 Calcium-based phosphate binders				
C.3.1.2.5 Non-calcium-based phosphate binders (for example, sevelamer)				
C.3.1.2.6 Cinacalcet				
C.3.1.2.7 Surgical services for parathyroidectomy				

	Generally available	Generally not available	Never	Unknown		
C.3.1.3 Management of electrolyte disorders and chronic metabolic acidosis			·			
C.3.1.3.1 Measurement of serum electrolytes (sodium, potassium, chloride, etc.)						
C.3.1.3.2 Measurement of serum bicarbonate						
C.3.1.3.3 Potassium exchange resins (for example, Kayexalate, patiromer sodium zirconium)						
C.3.1.3.4 Oral sodium bicarbonate						
C.3.1.4 Management of blood pressure						
C.3.1.4.1 Analogue BP monitoring						
C.3.1.4.2 Automated BP monitoring (home or office)						
C.3.1.4.3 Ambulatory BP monitoring (ABPM)						
C.3.1.5 Management of common kidney failure (ESKD)-associated symptoms (uremic pruritus, restless legs, pain)						
C.3.1.5.1 Gabapentinoids (gabapentin or pregabalin)						
C.3.1.5.2 Non-morphine opioids (e.g., hydromorphone, oxycodone, methadone, and/or sublingual or transdermal fentanyl)						

### **C4.1 Nutritional services**

#### C4.1.1. Please indicate the availability of the following nutritional services for kidney care in your country.

'Generally available' means in 50% or more centres (hospitals or clinics) and 'Generally not available' means: in less than 50% of centres (hospitals or clinics)

	Generally available	Generally, not available	Never	Unknown
C.4.1.1.1 – Dietary counselling by a person trained in nutrition (for example, a dietitian)				
C.4.1.1.2 – Measurement of serum albumin				
C.4.1.1.3 - Oral nutrition supplements (for example, vitamins, oral meal supplements)				

### C5. Dialysis treatment – quality and choice

#### C5.1. Please indicate the availability of the following services for dialysis care in your country.

'Generally available' means in 50% or more centres (hospitals or clinics) and 'Generally not available' means: in less than 50% of centres (hospitals or clinics).

	Generally available	Generally, not available	Never	Unknown	N/A (dialysis not provided)
Modality choice					
C.5.1.1 - Centre-based Hemodialysis					
C.5.1.2 – Home hemodialysis					
C.5.1.3 – Peritoneal dialysis					
Quality					
C.5.1.4 – Centre-based hemodialysis service of adequate frequency (treatment three times a week for three or four hours)					
C.5.1.5 – Home hemodialysis (treatment three times a week for three or four hours)					
C.5.1.6 – Peritoneal dialysis exchanges of adequate frequency (3–4 per day or equivalent cycles on automated PD)					
C.5.1.7 – Determination of the effectiveness of peritoneal dialysis (that is, by measurement of urea reduction ratio [URR] and/or Kt/V)					
C.5.1.8 – Affordable transport services for people living with kidney disease					

### C.6 Transplant – quality and choice

Transplant choice: In the context of the ISN Vision, Mission and Values, we believe all people living with kidney disease with kidney transplant are to receive a high-quality service which supports them in managing their transplant and enables them to achieve the best possible quality of life. The answers to the following questions are important to improve our understanding of current service provision.

#### C.6.1 Please indicate the availability of the following services for transplantation services in your country.

'Generally available' means in 50% or more centres (hospitals or clinics) and 'Generally not available' means: in less than 50% of centres (hospitals or clinics). If transplantation is NOT available in your country, select N/A.

	Generally available	Generally, not available	Never	Unknown	N/A (transplantation not available)
C.6.1.1 – Early provision of culturally appropriate information to people living with kidney disease, relatives and caregivers about the risks and benefits of transplantation with a clear explanation of tests, procedures, and results					
C.6.1.2 – Effective preventive therapy to control infections (for example, antivirals, antifungals, etc.)					
C.6.1.3 – Timely access to operating space for kidney transplantation					
C.6.1.4 – Appropriate immunosuppression and anti-rejection treatment					
C.6.1.5 – Appropriate facilities to monitor administration of immunosuppression drugs					
C.6.1.6 – Multidisciplinary team to support people living with kidney transplant					
C.6.1.7 – Standard framework for organ procurement (for example, legislation around brain death)					

### C.7 Conservative kidney management (CKM)

Conservative Kidney Management: Conservative kidney management is defined as the people living with kidney disease's choice for holistic, patient-centered care without the use of KRT for those with CKD stage G5. The goals of conservative kidney management are to support people living with CKD stage G5 who are not receiving KRT by optimizing quality of life, managing symptoms, treating psychosocial distress, facilitating advance care planning and, where appropriate, preserving residual kidney function. This care includes supporting the family and carers of the people living with kidney disease and continues throughout the illness trajectory. This is appropriate for people living with kidney disease may receive similar conservative care when resource constraints (healthcare system or people living with kidney disease) prevent or limit access to KRT. We term this choice-restricted conservative care.

We would like to know more about the capacity to deliver conservative kidney management or choice restricted conservative care in your country (that is, the capacity to support/manage people living with kidney disease who will not receive KRT despite having CKD stage G5).

#### C7.1. Considering the definitions above, is conservative care available in your country?

	Generally available	Generally not available	NA (CKM not available)	Unknown			
C.7.1.1 – Established conservative kidney management that is chosen through shared decision making (where KRT is readily available)							
You should only answer one of the questions below based on whether there are resource constraints or none limiting access to KRT in your country.							
C.7.1.2 – Established choice-restricted conservative care (where resource constraints to prevent or limit access to KRT)							
C.7.1.3 – Established choice-restricted conservative care (where there are no resource constraints to prevent or limit access to KRT)							

# C.7.2 Please indicate the average likelihood of a nephrologist from your country offering conservative kidney management as a treatment option to people living with CKD stage G5?

- 🗆 Always
- Often
- Sometimes
- Rarely
- Never
- 🗆 I don't know

## C.7.3 Where access to dialysis is choice restricted, what is the principal reason

□ Financial – healthcare system

- □ Financial people living with kidney disease
- Geographic

C.7.4 Please indicate the availability of the structure and process for the delivery of conservative kidney management (i.e., conservative care that is chosen or medically advised where KRT is readily available) for people living with CKD stage G5):

'Generally available' means in 50% or more centres (hospitals or clinics) and 'Generally not available' means: in less than 50% of centres (hospitals or clinics).

	Generally available	Generally, not available	Not available	Unknown
C.7.4.1 – Established infrastructure to support people living with kidney disease on a conservative kidney management pathway				
C.7.4.2 – Shared decision-making tools for people living with kidney disease and providers to help make the decision for conservative kidney management				
C.7.4.3 – Established services where people living with kidney disease receiving conservative kidney management can be seen in home / care home / hospice if unable to attend hospital or clinic				
C.7.4.4 – A written pathway / blueprint / or guidelines for conservative kidney management encompassing preservation of residual kidney function, symptom control, advance care planning, and end of life care				
C.7.4.5 – A multidisciplinary team				
C.7.4.6 – The multidisciplinary team includes formal links with kidney clinicians trained in conservative care				
C.7.4.7 - The multidisciplinary team includes formal links with palliative care				
C.7.4.8 – Regular use of validated screening tools, documentation, and management of symptoms				
C.7.4.9 – Availability of essential medicines for pain and palliative care at all levels of care (primary and specialty)				
C.7.4.10 – Infrastructure to document and share advance care planning conversations including decisions around preferred place of care and death and resuscitation.				
C.7.4.11 – Provision of psychological, social, and spiritual support				
C.7.4.12 – Training of care providers in symptom management				
C.7.4.13 – Training of care providers in advance care planning				
C.7.4.14 – Systematic data collection on numbers of people living with kidney disease receiving conservative kidney management and their outcomes				

## C.7.5 Please indicate the availability of the structure and process for the delivery of choice-restricted conservative care (i.e., conservative care for people living with kidney disease in whom resource constraints prevent or limit access to KRT) for people living with CKD stage G5):

'Generally available' means in 50% or more centres (hospitals or clinics) and 'Generally not available' means: in less than 50% of centres (hospitals or clinics).

	Generally available	Generally, not available	Not available	Unknown
C.7.5.1 – Established infrastructure to support people living with kidney disease receiving choice-restricted conservative care				
C.7.5.2 – Established services where people living with kidney disease receiving choice- restricted conservative care can be seen in home / care home / hospice if unable to attend hospital or clinic				
C.7.5.3 – A written pathway / blueprint / or guidelines for conservative care encompassing preservation of residual kidney function, symptom control, advance care planning, and end of life care				
C.7.5.4 – A multidisciplinary team				
C.7.5.5 – The multidisciplinary team includes formal links with kidney clinicians trained in conservative care				
C7.5.6 - The multidisciplinary team includes formal links with palliative care				
C.7.5.7 – Regular use of validated screening tools, documentation, and management of symptoms				
C.7.5.8 – Availability of essential medicines for pain and palliative care at all levels of care (primary and specialty)				
C.7.5.9 – Infrastructure to document and share advance care planning conversations including decisions around preferred place of care and death and resuscitation.				
C.7.5.10 - Provision of psychological, social, and spiritual support				
C.7.5.11 - Training of care providers in symptom management				
C.7.5.12 – Training of care providers in advance care planning				
C.7.5.13 – Systematic data collection on numbers of people living with kidney disease receiving choice-restricted conservative care and their outcomes				

### C.8 Affordability

C.8.1. What is the national average co-payment (including medications but no other ancillaries) for hemodialysis people living with kidney disease in your country (that is, the proportion of the treatment cost paid for directly (out-of-pocket) by the people living with kidney disease?

- □ N/A (not available in my country)
- 0%
- 🗆 1–25%
- 26-50%
- □ 51–75%
- □ >75%
- 🗆 100%

## C.8.1.1 Does this proportion vary in different parts of the country?

- □ Yes (please explain below)
- 🗆 No
- □ Other (please explain below)

# C.8.1.2. Does this proportion vary depending on people living with kidney disease' characteristics (for example, age, gender, employment status)?

- □ Yes (please explain below)
- □ No
- □ Other (please explain below)

C.8.1.3 What proportion (national average) of people living with kidney disease with kidney failure (ESKD) on hemodialysis withdraw dialysis within a year due to financial reasons in your country?

```
    N/A (not available in my country)
    0%
```

- □ 1−10%
- 11–25%
- 26-50%
- □ 20° 30 □ >50%

174 | Survey

C.8.2 What is the national average co-payment (including medications but no other ancillaries) for people treated with peritoneal dialysis in your country, that is, the proportion of the treatment cost paid for directly (out-of-pocket) by the people living with kidney disease?

- $\Box$  N/A (not available in my country)
- 0%
- 🗆 1–25%
- 26-50%
- 🗆 51–75%
- □ >75%
- □ 100%

## C.8.2.1 Does this proportion vary in different parts of the country?

□ Yes (please explain below)

- 🗆 No
- □ Other (please explain below)

## C.8.2.2 Does this proportion vary depending on people living with kidney disease' characteristics (for example, age, gender, employment status)?

□ Yes (please explain below)

- 🗆 No
- □ Other (please explain below)

C.8.3 What is the national average co-payment (including medications but no other ancillaries) for people living with a kidney transplant in your country, that is, the proportion of the treatment cost paid for directly (out-of-pocket) by the people living with kidney disease?

□ N/A (not available in my country)

- □ 0%
- 🗆 1–25%
- 26-50%
- □ 51–75%
- □ >75%
- 100%

## C.8.3.1 Does this proportion vary in different parts of the country?

- □ Yes (please explain below)
- 🗆 No
- □ Other (please explain below)

## C.8.3.2 Does this proportion vary depending on people living with kidney disease' characteristics (for example, age, gender, employment status)?

□ Yes (please explain below)

- 🗆 No
- $\Box$  Other (please explain below)

## C.8.4 What proportion (national average) of people living with kidney failure (ESKD) are able to access dialysis in your country?

□ N/A (not available in my country)

- 🗆 1–10%
- 🗆 11–25%
- 26-50%
- □ >50%

## C.8.4.1 Does this proportion vary in different parts of the country?

- □ Yes (please explain below)
- 🗆 No
- □ Other (please explain below)

# C.8.4.2 Does this proportion vary depending on people living with kidney disease' characteristics (for example, age, gender, employment status)?

- □ Yes (please explain below)
- 🗆 No
- □ Other (please specify)

#### C.8.5 Out of those people living with kidney disease in your country who have kidney failure (ESKD) and are able to access dialysis, what proportion usually start with peritoneal dialysis?

- N/A dialysis (of any kind) is not available in my country
- 0% (means that there are people living with kidney disease who are able to access some form of dialysis, but none of them start with PD)
- 🗆 1–10%
- 🗆 11–25%
- 26-50%
- □ >50%

## C.8.5.1 Does this proportion vary in different parts of the country?

- □ Yes (please explain below)
- 🗆 No
- $\Box$  Other (please specify)

# C.8.5.2 Does this proportion vary depending on people living with kidney disease' characteristics (for example, age, gender, employment status)?

- □ Yes (please explain below)
- 🗆 No
- $\Box$  Other (please specify)

#### C.8.6 Out of those people living with kidney disease in your country who have kidney failure (ESKD) and are suitable for transplant, what proportion are able to access kidney transplantation?

- □ 0% (not available in my country)
- 🗆 1–10%
- 🗆 11–25%
- 26-50%
- □ >50%

## C.8.6.1 Does this proportion vary in different parts of the country?

- □ Yes (please explain below)
- 🗆 No
- $\Box$  Other (please specify)

C.8.6.2 Does this proportion vary depending on people living with kidney disease' characteristics (for example, age, gender, employment status)?

- □ Yes (please explain below)
- 🗆 No
- □ Other (please specify)

#### C.9 Peritoneal dialysis quality

If peritoneal dialysis is available in your country, what proportion of centres routinely measure and report the following to assess the quality of the dialysis that is provided? Skip this section if peritoneal dialysis is NOT available in your country.

## C.9.1 What proportion of people treated with PD start with less than full dose PD (i.e., incremental)? (less than full dose is considered <8L/day)

- □ 0%
- □ 1–10%
- 🗆 11-25%
- 26-50%
- □ >50%

# C.9.2 Patient-reported outcome measures (PROMs) (for example, fatigue, quality of life, satisfaction, pain):

- 🗆 0% (None)
- 🗆 1–10% (Few)
- 🗆 11–50% (Some)
- 🗆 51–75% (Most)
- □ >75% (Almost all)

#### C.9.3 Blood pressure:

0% (None)
 1–10% (Few)
 11–50% (Some)
 51–75% (Most)
 >75% (Almost all)

## C.9.4 Small solute clearance (for example, Kt/V or creatinine clearance):

0% (None)
 1–10% (Few)
 11–50% (Some)
 51–75% (Most)
 >75% (Almost all)

#### C.9.5 Haemoglobin/haematocrit:

0% (None)
 1–10% (Few)
 11–50% (Some)
 51–75% (Most)
 >75% (Almost all)

## C.9.6 Bone mineral markers (calcium, phosphate, parathyroid hormone [PTH]):

0% (None)
 1–10% (Few)
 11–50% (Some)
 51–75% (Most)
 >75% (Almost all)

#### C.9.7 Technique survival (Transfer to HD):

0% (None)
 1–10% (Few)
 11–50% (Some)
 51–75% (Most)
 >75% (Almost all)

#### C.9.8 People living with kidney disease survival:

0% (None)
 1–10% (Few)
 11–50% (Some)
 51–75% (Most)
 >75% (Almost all)

## C.9.9 What is the nursing staff to people living with kidney disease ratio per shift in $\ge$ 50% of peritoneal dialysis centres in your country?

1:1 to 1:3
1:4 to 1:6
1:7 to 1:9
1:10 to 1:13
≥1:14
unknown

### C.10 Hemodialysis quality

If hemodialysis is available in your country, what proportion of centres routinely measure and report the following to assess the quality of the dialysis that is provided? Skip this section if hemodialysis is NOT available in your country.

## C.10.1 What proportion of people treated with HD start with less than 3x/week of HD (i.e., incremental HD)?

○ 0%
○ 1−10%
○ 11-25%
○ 26-50%
○ >50%

## C.10.2 PROMs (for example, fatigue, quality of life, satisfaction, pain, etc.):

0% (None)
 1–10% (Few)
 11–50% (Some)
 51–75% (Most)
 >75% (Almost all)
### C.10.3 Blood pressure:

0% (None)
 1–10% (Few)
 11–50% (Some)
 51–75% (Most)
 >75% (Almost all)

# C.10.4 Small solute clearance (for example, Kt/V or creatinine clearance):

0% (None)
 1–10% (Few)
 11–50% (Some)
 51–75% (Most)
 >75% (Almost all)

### C.10.5 Haemoglobin/haematocrit:

0% (None)
 1–10% (Few)
 11–50% (Some)
 51–75% (Most)
 >75% (Almost all)

# C.10.6 Bone mineral markers (calcium, phosphate, PTH):

0% (None)
 1–10% (Few)
 11–50% (Some)
 51–75% (Most)
 >75% (Almost all)

### C.10.7 Technique survival:

0% (None)
 1–10% (Few)
 11–50% (Some)
 51–75% (Most)
 >75% (Almost all)

### C.10.8 People living with kidney disease survival:

0% (None)
 1–10% (Few)
 11–50% (Some)
 51–75% (Most)
 >75% (Almost all)

## C.10.9 Monitoring Hepatitis B and C and HIV virology at least twice a year:

0% (None)
 1–10% (Few)
 11–50% (Some)
 51–75% (Most)
 >75% (Almost all)

### C.10.10 Regular monitoring of dialysis water quality for bacteria and chemical components as per AAMI or equivalent national regulatory body recommendation:

0% (None)
 1–10% (Few)
 11–50% (Some)
 51–75% (Most)
 >75% (Almost all)

## C.10.11 Regular people treated with HD review by nephrologist at least once every 3 months:

0% (None)
 1–10% (Few)
 11–50% (Some)
 51–75% (Most)
 >75% (Almost all)

# C.10.12 What is the nursing staff to people living with kidney disease ratio per shift in ≥50% of hemodialysis centres in your country?

1:1 to 1:3
1:4 to 1:6
1:7 to 1:9
1:10 to 1:13
≥1:14
unknown

### C.11 Kidney transplantation quality

If kidney transplantation is available in your country, what proportion of centres routinely measure and report the following to assess the quality of the transplantation that is provided? Skip this section if kidney transplantation is NOT available in your country.

# C.11.1 Patient-reported outcome measures (for example, fatigue, quality of life, satisfaction, pain, etc.):

0% (None)
 1–10% (Few)
 11–50% (Some)
 51–75% (Most)
 >75% (Almost all)
 unknown

### C.11.2 Delayed graft function:

0% (None)
 1–10% (Few)
 11–50% (Some)
 51–75% (Most)
 >75% (Almost all)
 unknown

### C.11.3 Rejection rates:

0% (None)
 1–10% (Few)
 11–50% (Some)
 51–75% (Most)
 >75% (Almost all)
 unknown

### C.11.4 Kidney allograft function:

0% (None)
 1–10% (Few)
 11–50% (Some)
 51–75% (Most)
 >75% (Almost all)
 unknown

### C.11.5 Graft survival:

- 0% (None)
   1–10% (Few)
   11–50% (Some)
   51–75% (Most)
   >75% (Almost all)
- 🗆 unknown

### C.11.6 People living with kidney disease survival:

- 0% (None)
- □ 1–10% (Few)
- □ 11–50% (Some)
- □ 51–75% (Most)
- >75% (Almost all)
- 🗆 unknown

### C.12 Access

Skip this section if hemodialysis is NOT available in your country.

C.12.1 For hemodialysis, what proportion of people living with kidney disease routinely start dialysis with a functioning vascular access (AV fistula or graft):

□ 0% (None) □ 1–10% (Few)

- □ 11–50% (Some)
- □ 51–75% (Most)
- □ >75% (Almost all)
- 🗆 unknown

### C.12.2 For hemodialysis, what proportion of people living with kidney disease routinely start dialysis with a tunnelled dialysis catheter:

🗆 0% (None)

- 🗆 1–10% (Few)
- □ 11–50% (Some)
- □ 51–75% (Most)
- □ >75% (Almost all)
- 🗆 unknown

### C.12.3 For hemodialysis, what proportion of people living with kidney disease commonly start dialysis with a temporary dialysis catheter:

- 🗆 0% (None)
- □ 1–10% (Few)
- 🗆 11–50% (Some)
- 🗆 51–75% (Most)
- □ >75% (Almost all)
- 🗆 unknown

# C.12.4 For hemodialysis, what proportion of prevalent people living with kidney disease dialyse with a functioning vascular access (AV fistula or graft):

0% (None)
 1–10% (Few)
 11–50% (Some)
 51–75% (Most)
 >75% (Almost all)
 unknown

Access for all dialysis – answer only if hemodialysis or peritoneal dialysis is available in your country

C.12.5 For either hemodialysis or peritoneal dialysis, what proportion of people living with kidney disease routinely receive education about the best means of access and timely surgery (for example, six months before start of hemodialysis, one month before start of peritoneal dialysis):

0% (None)
 1–10% (Few)
 11–50% (Some)
 51–75% (Most)
 >75% (Almost all)
 unknown

### C.13 Outcomes (hemodialysis)

Skip this section if hemodialysis is NOT available in your country.

### C.13.1 What proportion (national average) of people living with kidney failure (ESKD) on hemodialysis died in the first year of dialysis (first-year mortality) in your country?

- □ 1–10%
- 🗆 11–20%
- 21–30%
- □ 31–50%
- □ >50%
- 🗆 unknown

## C.13.2 What is commonest cause of death among hemodialysis patents in your country?

- Cardiovascular disease (ischemic heart disease, arrythmia, cerebrovascular disease)
- □ Infection (access-related infection, infected AVF/AVG, catheter-related bacteraemia)
- Infection (other sources, pneumonia, gangrene of limbs, etc.)
- Malignancy
- $\Box$  Withdraw dialysis (due to social reasons)
- □ Withdrew dialysis (due to cost of care)
- □ Others (please specify)
- 🗆 unknown

C.13.3 What proportion (national average) of people living with kidney disease with kidney failure (ESKD) on hemodialysis requires at least one hospitalization in the first year of dialysis (first-year hospitalization) in your country?

- □ 1–10%
- □ 11–20%
- 21-30%
- 31–50%
- □ >50%
- 🗆 unknown

# C.13.4 What is commonest cause of hospitalization among people treated with hemodialysis in your country?

- Cardiovascular disease (ischemic heart disease, arrythmia, cerebrovascular disease)
- Access malfunction (malfunction AVF/AVG, or blocked central venous catheter)
- Access-related infection (infected AVF/AVG, CVC catheter-related bacteraemia)
- Infection (other sources, pneumonia, gangrene of limbs, etc.)
- □ Others (please specify)
- 🗆 unknown

### C.14 Outcomes (peritoneal dialysis)

Skip this section if peritoneal dialysis is NOT available in your country.

C.14.1 What proportion (national average) of people living with kidney disease with kidney failure (ESKD) on peritoneal dialysis died in the first year of dialysis (first-year mortality) in your country?

- 🗆 1–10%
- 🗆 11–20%
- 21–30%
- 31–50%
- □ >50%
- 🗆 unknown

## C.14.2. What is commonest cause of death among peritoneal dialysis patents in your country?

- Cardiovascular disease (ischemic heart disease, arrythmia, cerebrovascular disease)
- PD-related Infection (PD-related peritonitis, exit-site, or tunnel tract infection)
- Infection (other sources, pneumonia, gangrene of limbs, etc.)
- Malignancy
- Withdraw dialysis
- □ Others (please specify)
- 🗆 unknown

C.14.3 What proportion (national average) of people living with kidney disease with kidney failure (ESKD) on peritoneal dialysis require at least one hospitalization in the first year of dialysis (first-year hospitalization) in your country?

- □ 1–10% □ 11–20% □ 21–30%
- 31–50%
- □ >50% □ unknown

# C.14.4 What is commonest cause of hospitalization among people treated with peritoneal dialysis in your country?

- Cardiovascular disease (ischemic heart disease, arrythmia, cerebrovascular disease)
- Access malfunction (PD catheter block, catheter tip migration)
- PD-related infection (peritonitis, exit-site or tunnel tract infection)
- Infection (other sources, pneumonia, gangrene of limbs, etc.)
- $\Box$  Others (please specify)
- 🗆 unknown

### C.15 Demographics

# C.15.1 What proportion (national average) of people living with kidney failure (ESKD) are aged above 65 years in your country?

- 0%
  1–10%
  11–25%
  26–50%
- □ >50% □ unknown

# C.15.2 What proportion (national average) of people living with kidney failure (ESKD) are female in your country?

0%
1–10%
11–25%
26–50%
>50%
unknown

### C.16 Aetiology of kidney failure (ESKD)

## C.16.1 What is commonest cause of kidney failure (ESKD) in your country?

Diabetes kidney disease

- Polycystic kidney disease
- □ Hypertension
- □ Glomerulonephritis
- □ Others (please specify)
- 🗆 unknown

### C.16.2 What proportion (national average) of people living with kidney failure (ESKD) are due to diabetes kidney disease in your country?

0%

- □ 1–10%
- □ 11-25%
- 26-50%
- □ 50- 75%
- □ >75%
- 🗆 unknown

C.16.3 What proportion (national average) of people living with kidney failure (ESKD) are due to glomerulonephritis in your country?

- 0%
- □ 1–10%
- 🗆 11–25%
- 26-50%
- □ 50- 75%
- □ >75%
- 🗆 unknown

### C.16.4 What proportion (national average) of people living with kidney failure (ESKD) are due to polycystic kidney disease in your country?

- □ 0%
- □ 1–10%
- □ 11–25%
- 26-50%
- □ 50- 75%
- □ >75%
- 🗆 unknown

C.16.5 What proportion (national average) of people living with kidney failure (ESKD) are due to hypertensive kidney disease in your country?

- 0%
- 🗆 1–10%
- □ 11–25%
- 26-50%
- 0 50- 75%
- □ >75%
- 🗆 unknown

### C.17 Use of technology in kidney care

# C.17.1 Is there capacity for telehealth / telenephrology reviews for management of CKD and kidney failure (ESKD) in your country?

- □ Yes (if possible, please provide brief details)
- 🗆 No
- 🗆 Unknown

# C.17.2 Do people with kidney disease have the option to receive communication (i.e. test results, appointment reminders) from clinics / hospitals via text message or email?

- □ Yes (if possible, please provide brief details)
- 🗆 No
- 🗆 Unknown

### C.17.3 Is there funding / reimbursement for providers who provide telehealth / telenephrology remote reviews for CKD and kidney failure (ESKD)?

- Publicly funded by government and free at the point of delivery
- Publicly funded by government but with some fees at the point of delivery
- □ A mix of publicly funded (whether or not publicly funded component is free at point of delivery) and private systems (please explain)
- □ Solely private and out-of-pocket
- □ Solely private through health insurance providers
- Multiple systems programs provided by government, NGOs, and communities
- N/A (telehealth / telenephrology is not available in my country)
- □ Other (please specify)

# C.18 Disaster management / vulnerable populations

C.18.1 Are there guidelines regarding measures that should be taken for disaster preparedness (i.e. at dialysis facilities) in the event of an earthquake / flood / drought in your country?

- □ Yes (if possible, please provide brief details)
- 🗆 No
- 🗆 Unknown

## C.18.2 Does your country have a representative in the Renal Disaster Relief Task Force?

- □ Yes (if possible, please provide brief details)
- 🗆 No
- 🗆 Unknown

### C.18.3 Are there means of identifying vulnerable populations (i.e. people with housing insecurity, racial/ ethnic minorities, people living in poverty, people with food insecurity) in your country?

- □ Yes (if possible, please provide brief details)
- 🗆 No
- 🗆 Unknown

## C.18.4 What best describes your healthcare system funding structure for treatment of CKD and kidney failure (ESKD) in refugee populations?

	Publicly funded by government and free at the point of delivery	Publicly funded by government but with some fees at the point of delivery	A mix of publicly funded (whether or not publicly funded component is free at point of delivery) and private systems	Solely private and out-of- pocket	Solely private through health insurance providers	Multiple systems – programs provided by government, NGOs, and communities	Other (please specify)	N/A (refugees do not routinely have access to treatment for kidney disease)
C.18.4.1 – Hemodialysis (some or all aspects of)								
C.18.4.2 – Peritoneal dialysis (some or all aspects of)								
C.18.4.3 – Kidney transplantation (some or all aspects of)								
C.18.4.4 – Conservative care (some or all aspects of)								

### **D – HEALTH INFORMATION SYSTEMS AND STATISTICS**

### **D.1 Registries**

### Definitions

**Registry:** A systematic collection of data to evaluate specified outcomes for a defined population in order to serve one or more predetermined scientific, clinical, or policy purposes.

## D.1.1 For which conditions or treatments is there an 'official' registry in your country?

CKD (non-KRT)	🗆 Yes	🗆 No	🗆 Unknown
Dialysis	🗆 Yes	🗆 No	🗆 Unknown
Transplantation	🗆 Yes	🗆 No	🗆 Unknown
AKI	🗆 Yes	🗆 No	🗆 Unknown
Conservative care	🗆 Yes	🗆 No	🗆 Unknown

D.1.2 If there is a CKD registry for people living with kidney disease who do not require KRT, what is the basis of participation in the CKD registry?

- □ Voluntary
- ☐ Mandatory
- Unknown

D.1.3 If there is a CKD registry for people living with kidney disease who do not require KRT, what is the geographical coverage of the CKD registry? (please check all that apply)

🗆 National

Regional/state/provincial

□ Local/hospital/community

# D.1.4 If there is a CKD registry for people living with kidney disease who do not require KRT, what does it cover? (please check all that apply)

- $\Box$  The whole spectrum of CKD (stages 1–5)
- □ Advanced CKD only (stages 4/5)

# D.1.5 If there is a dialysis registry, what is the basis of participation in the dialysis registry?

- Voluntary
- Mandatory
- 🗆 Unknown

# D.1.6 If there is a dialysis registry, what is the geographical coverage of the dialysis registry? (please check all that apply)

- National
- □ Regional/state/provincial
- □ Local/hospital/community

# D.1.7 If there is a dialysis registry, what information does the dialysis registry collate? (please check all that apply)

- $\Box$  Aetiology of kidney failure (ESKD)
- □ Modality of dialysis
- □ Dialysis prescription
- Dialysis access (e.g., vascular access for HD, PD catheter)
- Process-based measures (e.g., anaemia, bone disease, BP control markers)
- People living with kidney disease outcome measures (e.g., hospitalizations)
- People living with kidney disease outcome measures (e.g., satisfaction, quality of life)
- People living with kidney disease outcome measures (e.g., mortality)

## D.1.8 If there is a transplantation registry, what is the basis of participation in the transplant registry?

- □ Voluntary
- Mandatory
- 🗆 Unknown

# D1.9 If there is a transplantation registry, what is the geographical coverage of the transplant registry? (please check all that apply)

- 🗆 National
- □ Regional/state/provincial
- Local/hospital/community

### D.1.10 If there is a transplantation registry, what information does the transplant registry collate? (please check all that apply)

- □ Aetiology of kidney failure (ESKD)
- □ Transplant source (deceased/live donor)
- □ Type of immunosuppression
- Episodes of rejection
- $\hfill\square$  Types and episodes of infection
- People living with kidney disease outcome measures (e.g., hospitalizations)
- People living with kidney disease outcome measures (e.g., satisfaction, quality of life)
- People living with kidney disease outcome measures (e.g., mortality)

# D.1.11 If there is an AKI registry, what is the basis of participation in the AKI registry?

- □ Voluntary
- Mandatory
- 🗆 Unknown

# D.1.12 If there is an AKI registry, what is the geographical coverage of the AKI registry? (please check all that apply)

- 🗆 National
- □ Regional/state/provincial
- Local/hospital/community

# D.1.13 If there is an AKI registry, what does it cover? (please check all that apply)

- $\Box$  The whole spectrum of AKI (stages 1–3)
- $\Box$  AKI requiring kidney replacement therapy

# D.1.14 If there is an AKI registry, what information does the AKI registry collate? (please check all that apply)

- Risk factors for AKI
- Aetiology of AKI
- Incidence of AKI
- People living with kidney disease outcome measures (hospitalizations)
- People living with kidney disease outcome measures (requirement for KRT, for example, dialysis or slow dialysis therapies like CKRT)
- People living with kidney disease outcome measures (mortality)

# D.2 Identification of disease (AKI and CKD)

### Definitions:

*Guidelines:* Evidence-based recommended courses of action for prevention or management of disease.

*Identification:* Measures performed in at-risk populations in order to diagnose individuals who have risk factors or early stages of disease but may not yet have symptoms.

**Policy:** A specific official decision or set of decisions designed to carry out a course of action endorsed by a government body; including a set of goals, priorities and main directions for attaining these goals. The policy document may include a strategy to give effect to the policy.

**Program:** A planned set of activities or procedures directed at a specific purpose.

# D.2.1 For which of the following high-risk groups do practitioners in your country routinely offer testing for CKD? (please check all that apply)

- □ Those with hypertension
- □ Those with diabetes
- Those with cardiovascular disease (ischaemic heart disease, stroke, peripheral vascular disease, heart failure)
- Those with autoimmune/multisystem diseases (systemic lupus erythematosus, rheumatoid arthritis)
   The addacture
- □ The elderly
- Those with urological disorders (structural, stone diseases)
- □ Chronic users of nephrotoxic medications
- Members of high-risk ethnic groups (Aboriginal, African, Indo-Asian)
- $\Box$  Those with a family history of CKD
- □ N/A routine testing for CKD not offered

## D.2.2 In your country, are there ethnic groups considered to be at increased risk for CKD?

□ Yes (please specify below)

- 🗆 No
- 🗆 Unknown

D.2.3 In your country, is a CKD detection program in use that is based on national policy or guidelines?

- Yes
- 🗆 No
- 🗆 Unknown

## D.2.3.1 If there is a program, how is it implemented (please check all that apply):

- Reactive approach cases managed as identified through practice
- Active screening of at-risk population through routine health encounters
- Active screening of at-risk population through specific screening processes
- □ Other (please specify)

## D.2.4 In your country, are there specific groups considered to be at increased risk for AKI?

□ Yes (please specify below)

- □ No
- 🗆 Unknown

# D.2.5 In your country, is an AKI detection program in use that is based on national policy and/or guidelines?

- 🗆 Yes
- □ No
- 🗆 Unknown

# D.2.5.1 If there is an AKI detection program, how is it implemented? (please check all that apply):

- Reactive approach cases managed as identified through practice
- □ Active screening of at-risk population through routine health encounters
- Active screening of at-risk population through specific screening processes
- Automated computation by pathology systems with electronic alerts
- $\Box$  Other (please specify)

# D.3 Do you have mechanisms to ensure the validity and quality of data contained within health information systems?

- Yes
- 🗆 No
- 🗆 Unknown

### D.4 Capacity for identification and management of CKD

# D.4.1 Indicate the availability of the following services for CKD monitoring and management at PRIMARY care level in your country

	Available	Not Available
D.4.1.1 – Blood pressure measurement		
D.4.1.2 - Height and weight measures to calculate body mass index		
D.4.1.3 – Serum glucose measurement		
D.4.1.4 – HbA1C test		
D.4.1.5 – Serum cholesterol measurement		
D.4.1.6 – Serum creatinine measurement without automated eGFR reporting		
D4.1.7 – Serum creatinine measurement with automated eGFR reporting		
D4.1.8 – Urinalysis using test strips for albumin/protein (qualitative assays)		
D4.1.9 – Urinalysis using test strips for albumin/protein (quantitative assays)		
D4.1.10 – Urine albumin: creatinine ratio (ACR) or protein: creatinine (PCR) measurements		

## D.4.2 Indicate the availability of the following services for CKD monitoring and management at SECONDARY OR TERTIARY care level in your country.

	Available	Not Available
Blood pressure measurement		
Height and weight measures to calculate body mass index		
Serum glucose measurement		
HbA1C test		
Serum cholesterol measurement		
Serum creatinine measurement without automated eGFR reporting		
Serum creatinine measurement with automated eGFR reporting		
Urinalysis using test strips for albumin/protein (qualitative assays)		
Urinalysis using test strips for albumin/protein (quantitative assays)		
Urine albumin: creatinine ratio (ACR) or protein: creatinine (PCR) measurements		
Radiological services (e.g. facilities for kidney ultrasound)		
Pathology services (kidney biopsy interpretation facilities)		

# D.5 CKD of unknown origin and populations disproportionately affected with CKD

This is a section to understand whether regional hotspots of kidney disease exist (specifically, CKD of unknown origin) in your country.

D.5.1 Do you suspect that there are regional variations in the rate of kidney disease in your country? (By this we mean population clusters with high risk of kidney failure requiring dialysis or transplant, or people dying of kidney failure?)

- □ Yes (please specify)
- 🗆 No

### D.5.2 Age groups affected (select all that apply):

- $\Box$  <18 years of age
- □ 18-44 years of age
- □ 45-64 years of age
- 🗆 65+ years

# D.5.3 In your opinion what are some of the likely causes or contributors to kidney disease in these areas (select all that apply):

- Diabetes
- Obesity
- □ High blood pressure
- Environmental (e.g., water, soil)
- Climate (e.g., high temperature)
- 🗆 Genetic
- □ Biological (e.g., high HIV or TB prevalence, stones)
- Cultural (e.g., diet, use of NSAIDs, herbs)
- $\Box$  Other (please specify)

# D.5.4 Types of industry in this region (select all that apply):

- Agriculture
- Manufacturing
- 🗆 Mining
- 🗆 Tourism
- Service/Professional
- □ Other (please specify)

## D.5.5 Predominant type of climate in that region (select only one)

- Tropical
- Semi-arid
- Temperate
- $\Box$  Other (please specify)

#### D.5.6 What is the altitude of this region

- 🗆 High
- At Sea-level
- Low
- □ Other (please provide details)

### **E – NATIONAL HEALTH POLICY**

### Definitions:

**Policy:** A specific official decision or set of decisions designed to carry out a course of action endorsed by a government body; including a set of goals, priorities and main directions for attaining these goals. The policy document may include a strategy to give effect to the policy.

**Program:** A planned set of activities or procedures directed at a specific purpose.

**Strategy:** a long-term plan designed to achieve a particular goal.

### E.1 Policy and strategy

Non-communicable diseases (NCDs): Diseases that cannot be transmitted from person to person, notably cardiovascular diseases (like heart attacks and stroke), cancers, chronic respiratory diseases (such as chronic obstructive pulmonary disease and asthma) and diabetes.

### E.1.1 Does your country have a national strategy for non-communicable diseases?

- □ Yes, in place (please provide details below)
- Under development but not yet being implemented (please provide details below)
- 🗆 No
- 🗆 Unknown

### E.1.2 Does your country have a national strategy for improving the care of people living with CKD?

- □ Yes, a national CKD-specific strategy exists
- Yes, but the CKD strategy is incorporated into an NCD strategy that includes other diseases.
- 🗆 No
- 🗆 Unknown

#### E.1.2.1 Please select which populations are covered in the national CKD-specific strategy (check all that apply)

- Non-dialysis dependent CKD
- Chronic dialysis
- □ Kidney transplantation

### E.1.2.2 Please select which populations are covered in the national general NCD strategy (check all that apply)

- Non-dialysis dependent CKD
- Chronic dialysis
- Kidney transplantation

### E1.3 Are CKD-specific policies available?

- Yes
- 🗆 No
- 🗆 Unknown

# E.1.3.1 If yes, please specify which type of CKD policies are available in your country (check all that apply)

- National policies
- □ Regional policies

### E2. Advocacy

# E.2.1 In your opinion, is CKD recognized as a health priority by the government in your country?

- □ Yes (please provide details below)
- No (please explain why not below)

### E.2.2 Is there an advocacy group at the higher levels of government (for example, a parliamentary committee) or an NGO to raise the profile of CKD and its prevention?

- □ Yes (please provide details below)
- No (please explain why not below)
- 🗆 Unknown

# E.2.3 In your opinion, is AKI and/or its prevention recognized as a health priority by the government in your country?

- □ Yes (please provide details below)
- No (please explain why not below)

### E.2.4 Is there an advocacy group at the higher levels of government (for example, a parliamentary committee) or an NGO to raise the profile of AKI and its prevention?

- □ Yes (please provide details below)
- □ No (please explain why not below)
- 🗆 Unknown

# E.2.5 In your opinion, is kidney failure (ESKD) and/or its treatment by KRT recognized as a health priority by the government in your country?

- □ Yes (please provide details below)
- □ No (please explain why not below)

### E.2.6 Is there an advocacy group at the higher levels of government (for example, a parliamentary committee) or an NGO to raise the profile of kidney failure (ESKD)/KRT?

- □ Yes (please provide details below)
- □ No (please explain why not below)
- 🗆 Unknown

### E.2.7 Are there existing national/regional physicianoriented organizations or people living with kidney disease organizations that provide resources for kidney failure (ESKD) care?

- □ Yes (please provide details below)
- □ No (please explain why not below)
- 🗆 Unknown

### E.3 Barriers to optimal kidney care

# E3.1. Are there specific barriers to optimal kidney care in your country? Please check all that apply.

- Geography (distance from care or prolonged travel time)
- 🗆 Physician (availability, access, knowledge, attitude)
- □ People living with kidney disease (knowledge, attitude)
- □ Nephrologist (availability)
- □ Healthcare system (availability, access, capability)
- □ Lack of political will and enabling policies
- Economic factors (limited funding, poor
- reimbursement mechanisms)
- $\Box$  Other (please specify)

# E.4 How did you gather the information to complete this survey? Please check all that apply.

- □ Personal opinion/knowledge
- Gathered knowledge from other sources (for example, published literature or reports)
- $\Box$  Consultation with other colleagues
- $\Box$  Other (please specify)

# ISN–GKHA People living with kidney disease survey

The International Society of Nephrology (ISN) works collaboratively with organizations and initiatives – at international and national levels - to promote early detection and effective treatment of kidney disease in order to improve people living with kidney disease health and quality of life. Through understanding and potentially helping to shape relevant health policies, practices and infrastructure, ISN aims to facilitate the implementation of equitable and ethical care for people living with kidney disease in all regions and countries of the world.

ISN conducts a research exercise on the current status of care for people living with kidney disease across all countries.

Your response to this survey will facilitate a better understanding of how to provide quality healthcare that is accessible and delivered in a timely and efficient manner with courtesy and respect to people living with chronic kidney disease (CKD).

The survey is about your overall perceptions of the care you receive for CKD. This survey is not

about looking for faults or deficiencies in care delivery, but instead will help us to understand how to improve care for everyone. Your opinion is very important, as it will contribute to making CKD care more accessible, affordable, and equitable around the world.

All responses received will be kept completely confidential and you will not be identified in any report or publication arising from the survey as all the analyses will be aggregate and not based on individual responses.

 Online version of ISN-GKHA people living with kidney disease survey: <u>www.theisn.org/globalatlas</u>

Thank you for your involvement and readiness to participate.

nes to

Professor Agnes Fogo President, International Society of Nephrology



### List of abbreviations:

CKD: Chronic kidney disease HD: Hemodialysis PD: Peritoneal dialysis

### **Contact Information**

Name (optional):

Country (required):

Email Address (required):

Phone Number (optional):

What is your gender? (select only one option)

- 🗆 Man
- 🗆 Woman
- 🗆 Trans
- □ Other (please specify)
- □ I do not want to answer

How old are you (years)?

- 🗆 18-29
- 🗆 30-39
- 40-49
- □ 50-59□ 60-69
- 00-03
- □ 70-7. □ 80+

### What is your current work status?

- □ Employed (including self-employed)
- Unemployed
- Student
- $\Box$  On long sick leave
- □ Housewife/househusband
- Retired
- □ Other (please specify)

What is the highest level of education you have completed?

- □ Primary / Elementary School
- 🗆 High School
- College Diploma or Trade School
- University Degree
- Graduate Degree

Would you like us to send you a copy of the survey report?

□ Yes □ No

### 1. Where were you diagnosed with kidney disease?

- □ I was diagnosed at a routine visit with my general practitioner/family doctor.
- □ I was diagnosed while receiving care for another condition (e.g., diabetes or high blood pressure, other)
- I was diagnosed at a general medical examination for insurance, employment, etc.
- I was diagnosed at the Accident & Emergency unit of a hospital
- 🗆 I don't know
- □ Other (please specify)

### 2. What is your kidney disease stage?

- □ Early chronic kidney disease [Stage 1 to 3]
- Advanced chronic kidney disease or kidney failure [end-stage kidney disease] but I am not yet receiving dialvsis
- □ I am currently on hemodialysis
- □ I am currently on peritoneal dialysis
- □ I am living on a kidney transplant

## 3. How is your chronic kidney disease currently being treated?

- □ I attend a nephrologist's pre-dialysis clinic
- □ I am managed by a general practitioner
- □ I am on hemodialysis treatment
- □ I am on peritoneal dialysis treatment
- □ I have a working kidney transplant
- □ I use native / herbal / complementary medications

## 4. Are you affected by any of the following (please tick all that apply)?

- □ I have high blood pressure (hypertension)
- 🗆 I have diabetes
- □ I have glomerulonephritis (nephrotic syndrome i.e. lots of protein in the urine)
- I have cardiovascular disease (heart attack, bypass surgery, angioplasty, stroke, heart failure)
- □ I have lupus, rheumatoid arthritis, or another autoimmune disease
- □ I am part of a high-risk ethnic groups (Aboriginal, African, Indo-Asian)
- □ I have an inherited chronic kidney disease (polycystic, Alport's etc.)

ney disease? 3. How is treated?

5. In your opinion, do you receive care for your kidney disease in a timely and efficient manner?

- Always
- 🗆 Often
- Sometimes
- Rarely
- Never
- 0 I don't know

### 6. How do you rate the quality if your kidney care?

- Extremely poor
- □ Below average
- Average
- □ Above average
- Excellent
- 🗆 I don't know

7. What one overall change would you suggest which might improve the quality of care for your kidney care?

# 8. Which one of the following do you think would best lead to improvements in your kidney care? (check only the most important to you)

- □ Reduce cost of medicines
- □ Reduce cost of kidney replacement therapies (dialysis and transplantation)
- □ Have better equipped hospitals
- Have well trained and adequate numbers of hospital/ clinic staff
- □ Improve access to new treatments
- □ Improve access to kidney transplants
- Improve access to home-based treatment options
- $\hfill\square$  Be able to participate in the care of my condition
- Increase opportunities to participate in kidney research

## 9. How do you receive medications for the care of your kidney disease?

- □ I receive all medications for free
- I pay only part of the cost of my medications and the government pays the rest
- □ I pay the full price of my medications
- □ My insurance pays partly for my treatment
- $\hfill\square$  My insurance pays fully for my treatment
- $\Box$  Other (please specify)

## 10. Please rate the quality of information given to you about your medications.

- Extremely poor
- □ Below average
- □ Average
- Above average
- Excellent
- 🗆 I don't know

# 11. If you're a person on dialysis, who is responsible for payment of your dialysis?

- □ I receive my dialysis for free
- I pay only part of the cost of my dialysis and the government pays the rest
- □ I pay the full price of my dialysis
- My insurance pays partly for my dialysis and I pay the rest
- □ My insurance pays fully for my dialysis
- □ Other (please specify)

# 12. If you have had a kidney transplant, who was responsible for the payment of your kidney transplant surgery?

- □ I received my kidney transplant for free
- I paid only part of the cost of my kidney transplant and the government paid the rest
- □ I paid the full price of my kidney transplant
- My insurance paid partly for my kidney transplant, and I paid the rest
- □ My insurance paid fully for my kidney transplant
- □ Other (please specify)

## 13. If you are on HD, how many times on average are you able to receive dialysis every week?

- Less than once a week
- Once a week
- □ Twice a week
- □ Three times a week
- $\Box$  More than three times a week

## 14. If you are on PD, how many PD bag exchanges (1.5 to 2.5 litres) do you carry out daily?

- □ 1 bag or sometimes no bags a day
- 🗆 2 bags a day
- 🗆 3 bags a day
- □ 4 bags a day
- $\Box$  More than 4 bags a day

# 15. In your opinion, is there a shortage of the following health professionals in your country (please tick all that apply)?

- Dietitians
- □ Vascular access coordinators
- □ Nurse practitioners
- Counsellors/Psychologists
- Transplant surgeons
- Transplant coordinators
- Dialysis nurses
- □ General practitioners/Family doctor
- Nephrologists
- Social workers
- □ No shortage of any of the staff mentioned
- I don't know

## 16. Please rate the quality of kidney care provided by general practitioners/family doctors in your country.

- Extremely poor
- □ Below average
- □ Average
- Above average
- Excellent
- 🗆 I don't know
- I do not have a general practitioner/family doctor looking after me

### 17. Please rate the direct involvement of your nephrologist in your kidney care.

- Extremely poor
- Below average
- Average
- □ Above average
- Excellent
- 🗆 I don't know
- □ I do not have a nephrologist looking after me

# 18. In your opinion, are there obstacles stopping you from receiving the best kidney care? (Select all that apply)

- □ Long distance to treatment centre
- □ Limited access to general practitioner family doctor
- □ Limited access to a nephrologist
- □ Limited access to nurses, dietitians, etc.
- □ Unavailability of important medicines
- □ Excessive costs of important medicines
- $\hfill\square$  Excessive / unaffordable cost of dialysis
- $\hfill\square$  Kidney transplants are unavailable or too costly
- $\Box$  Other (please specify)
- 🗆 No obstacle

## 19. In your opinion, where are the main obstacles to the provision of high-quality kidney care?

- Government
- Hospitals
- Doctors
- People living with kidney disease organizations/groups
- Insurers
- □ Other (please specify)

# 20. Please rate how well healthcare professionals respect your values, aspirations, and preferences in the delivery of your kidney care.

- Extremely poor
- Below average
- Average
- Above average
- Excellent
- 🗆 l don't know

# 21. Please rate the efficiency of your experience of the healthcare system in delivering kidney care to you.

- Extremely poor
- □ Below average
- 🗆 Average
- Above average
- Excellent
- 🗆 I don't know

22. What change would you suggest, to improve the efficiency of care for chronic kidney disease?

### 23. In your opinion, what proportion of your kidney care is provided by:

	0%	1-10%	11-25%	26-50%	51-75%	>75%
23.1 Nephrologists						
23.2 General practitioner / Family doctor						
23.3 Other Specialists: Your (diabetic/heart),						
23.4 Nurse / Nurse practitioner						
23.5 Other healthcare Practitioner (dietitians)						
23.6 Yourself						

## 24. To what extent do you agree or disagree with the statement:

I receive adequate information and education from my kidney care team about how to live with kidney disease?

- Strongly disagree
- Disagree
- Agree
- Strongly agree
- Unsure

## 25. To what extent do you agree or disagree with the statement:

I am involved in the decision-making process for my chronic kidney disease care.

- □ Strongly disagree
- Disagree
- Agree
- Strongly agree
- 🗆 Unsure

## 26. To what extent do you agree or disagree with the statement:

I feel that I receive adequate information about the treatment I am receiving

- Strongly disagree
- Disagree
- □ Agree
- □ Strongly agree
- Unsure

## 27. To what extent do you agree or disagree with the statement:

I know where to get information or resources to educate myself about how to manage my kidney disease

- Strongly disagree
- Disagree
- □ Agree
- Strongly agree
- Unsure

# 28. Where do you get most of the information / resources to educate yourself about how to manage your kidney disease?

- My doctors
- The internet
- □ Media (Television / Newspapers)
- Friends
- $\Box$  Other people living with kidney disease
- Complementary medicine practitioners
- □ Others (specify)

### 32. If yes, please grade all that apply

### 29. To what extent do you agree or disagree with the statement:

My overall health now has improved compared to when I first got diagnosed with chronic kidney disease.

- □ Strongly disagree
- Disagree
- Agree
- Strongly agree
- Unsure

## 30. To what extent do you agree or disagree with the statement:

My quality of life now has improved compared to when I first got diagnosed with chronic kidney disease

- □ Strongly disagree
- Disagree
- Agree
- □ Strongly agree
- 🗆 Unsure

# 31. Do you feel debilitated/affected by kidney disease in any way?

🗆 Yes

🗆 No

	No affect	Minor affect	Neutral	Moderate affect	Major affect
32.1. Physically					
32.2. Mentally/Emotionally					
32.3. Socially					
32.4. Economically					
32.5. Professionally					
32.6. Other areas affected by CKD (please specify)					

### 33. Do you receive any emotional support to help you live with kidney disease?

🗆 Yes

🗆 No

### 34. If yes, please grade all that apply from the following list. (most = 1 and least = 5)

	Never	Rarely	Sometimes	Often	Always
34.1. General practitioner/Family doctor					
34.2. Nephrologist					
34.3. Nurses, dietitians, social workers etc.					
34.4. Family					
34.5. Friends					
34.6. People living with kidney disease 's association					
34.7. Other sources of support (please specify)					

### 35. How important are the following outcomes to your care? (please select and grade all that apply)

	Not at all important	Fairly important	Important	Extremely important
35.1. Fatigue				
35.2. Depression				
35.3. Mobility				
35.4. Ability to travel				
35.5. Ability to work				
35.6. Pain				
35.7. Cardiovascular disease				
35.8. Financial impact				
35.9. Appearance				
35.10. Dizziness				
35.11. Sleep				
35.12. Sexual function				
35.13. Impact on friends / family				
35.14. Hospitalization				
35.15. PD-infection (for people on Peritoneal Dialysis only)				
35.16. Vascular access (for people on Hemodialysis only)				
35.17. Graft health (for people with kidney transplants only)				
35.18. Cancer (for people with kidney transplants only)				
35.19. Mortality				





This 2023 edition of the ISN-Global Kidney Health Atlas is made available to the global kidney health community thanks in part to continued support of ISN Members.

Join/renew with the ISN and help us advance kidney health - together:

https://theisn.org/membership



Discover all the **open-source**, **scientific & educational resources** that the ISN has to offer:

https://theisn.org





https://theisn.org

ISN INTERNATIONAL SOCIETY OF NEPHROLOGY

### **Global Operations Center**

Avenue des Arts 1-2 1210 Bruxelles, Belgium Tel: +32 2 808 04 20 Fax: +32 2 808 44 54 info@theisn.org

### **Americas Operations Center**

340 North Ave 3rd Floor Cranford, New Jersey 07016 United States of America Tel: +1 567 248 9703 Fax: +1 908 272 7101

Online version of ISN–Global Kidney Health Atlas: www.theisn.org/global-atlas