SLIDE 3:

Overview of presentation

- Aim
- Methods
- Key results

SLIDE 4:

Aim of the ISN-GKHA:

- The incentive for the ISN-GKHA initiative arose from unavailability of consolidated reliable data on the status of kidney care either globally or major world regions, especially in low-resource countries that have a higher burden of kidney disease. Previous iterations of the ISN-GKHA have identified gaps in availability and access to care. Hence, in order to improve kidney care worldwide, there is need to document and update the status of kidney care globally to allow monitoring and implementation of necessary change.

- The vision of the ISN-GKHA is to achieve optimal and equitable kidney care worldwide by identifying gaps and processes to close gaps related to the capacity or equity of kidney care. Hence, the ISN-GKHA serves to collect data using standardized indicators that measure kidney care delivery to provide evidence-based recommendations to relevant stakeholders.

- Overall, the goal of the ISN-GKHA is to improve the understanding of inter- and intranational variability across the globe with respect to capacity for kidney care delivery. Through assessing and documenting capacity for kidney care across all world regions, we can work toward improving the quality and equity of kidney care worldwide.
- Key focus on availability, accessibility, affordability, and quality of kidney failure care.
- To achieve this mission, the strategy of the ISN-GKHA is to collect data using standardized indicators that measure kidney care delivery to provide evidence-based recommendations to relevant stakeholders.
- Previous iterations (2017 and 2019) documented capacity of kidney care and identified major gaps across countries. Both iterations allowed for the establishment of overall benchmarks, within ISN regions, and across World Bank income groups.
- The current iteration was conducted in 2022 and published in 2023 and will be repeated every 4 years to monitor progress and optimally measure and address new gaps.
- Today’s discussion will focus on the 2022 results, which were published in the 2023 Atlas.

SLIDE 5:
Timelines of the ISN-GKHA

SLIDE 6:
Design and scope:
- **Desk research (across countries and regions)**
  - Published and grey literature review
  - Systematic review of kidney failure burden and outcomes
  - Data extraction from major kidney registries (USRDS, ERA-EDTA) and relevant national registries where available
  - Scoping review of KRT cost estimates
- **Online questionnaire-based survey July – September 2022**
  - 3 languages (English, French, Spanish)
  - 191 countries were contacted.
  - ≥3 stakeholders per country
    - National nephrology society leadership
    - Healthcare policymakers
    - Patients / patient advocacy groups
  - Discrepancies were resolved by follow-up conferences with regional board chairs and country nephrology leaders.
SLIDE 7:

- The survey followed a framework developed by the World Health Organization (WHO) on health systems evaluation.
- This framework was released in 2010, which was a handbook of indicators and measurement strategies to monitor the building blocks of a health system. The WHO recognized that information is needed to track how health systems respond to increased inputs and improved processes, and the impact they have on improved health indicators. Therefore, a set of core indicators of health system performance was established, along with sustainable measurement strategies, to generate the required data.
- The framework considers health systems in terms of six core components or “building blocks”:
  - Service delivery.
  - Health workforce.
  - Health information systems.
  - Access to essential medicines.
  - Financing; and
  - Leadership/governance.
- Through addressing each of these domains, the overall goals of the WHO strategy are to improve health (level and equity), health system responsiveness, protect social and financial risk, and improve efficiency.
- The ISN-GKHA models this framework to similarly aim to achieve these objectives, specific to kidney care.

SLIDE 8:

- Of the 191 countries we invited, 167 (92%) countries participated in the 2022 survey representing 97% of the world’s population.
- Individual response was obtained from 329 individuals representing a 63% response rate.
- There was a median response of 2 respondents/country (IQR 2-3).
- 108 countries participated in the 2017, 2019, and 2023 GKHA surveys.

SLIDE 9:

- The ISN-GKHA reports overall global results for each indicator and separates the data by ISN region and income group.
The ISN-GKHA is therefore able to examine the level of variability across income levels and geographical regions. Knowing if there is variation between countries, either within a common ISN region or income group, is helpful when trying to promote equity of care.

SLIDE 10:
- This talk focuses on the ISN Newly Independent States (NIS) and Russia region.

SLIDE 11 – 12:
- Responses were received from 10 of the 11 countries (91%) representing 98% of the region’s population.
- Of the 10 countries, 4 (40%; Kyrgyz Republic, Tajikistan, Ukraine, and Uzbekistan) and 6 (60%; Armenia, Azerbaijan, Belarus, Georgia, Kazakhstan, and Russian Federation) are LMICs. There are no LICs or HICs in the region.
- At the time of the survey, there were 278,947,557 people living in all the countries that participated in the study. The Russian Federation had the highest population (142 million) while Armenia had the lowest population (3.0 million).
- GDP (PPP) in the region ranges from US$ 35.4 billion (Kyrgyz Republic) to US$ 4.79 trillion (Russian Federation).
- Total health spending as a percentage of GDP ranged from 2.8% in Kazakhstan to 11.3% in Armenia.
- Total health spending per capita ranged from US$ 57 (Tajikistan) to US$ 559 (Russian Federation). However, government health spending per capita ranged from US$ 15 (Tajikistan) to US$ 350 (Russian Federation).

SLIDE 13:
- The median CKD prevalence in the NIS and Russia region was 11.4% (global median was 9.5%) and ranged from 7.4% in Tajikistan to 19.2% in the Russian Federation.
- Median disability adjusted life years (DALYs) attributed to CKD was 1.25%; lowest in Belarus (0.48%) and highest in Uzbekistan (1.61%).
- Median deaths attributable to CKD was 1.38%; lowest in Belarus (0.4%) and highest in Uzbekistan (1.75%).
The prevalence of other risk factors (hypertension, obesity, and smoking) varied across countries in the region.

SLIDE 14 – 15:

- Incidence and prevalence data on treated kidney failure (dialysis and kidney transplantation) were available for a few countries in the region.
- Overall, the median incidence and prevalence of treated kidney failure were 90.5 per million population (pmp) and 411 pmp, respectively.
- Incidence of treated kidney failure ranged from 40 pmp in Ukraine to 203 pmp in Georgia. Prevalence of treated kidney failure ranged from 211 pmp in Kazakhstan to 713 pmp in Georgia.
- Data on the incidence of chronic dialysis (HD + PD) was not available from any country, however, prevalence of chronic dialysis was 209 pmp and was highest in the Russian Federation (334 pmp) and lowest in Georgia (179.3 pmp).
- The overall prevalence of HD and PD in the region was 137.6 pmp and 10.8 pmp, respectively.
- Overall incidence of KT was 8.6 pmp and ranged from 2.3 pmp in Ukraine to 35.7 pmp in Belarus. Median prevalence of KT in the region was 33 pmp and ranged from 25 pmp in Kazakhstan to 69 pmp in the Russian Federation.
- The overall median incidence of deceased donor KT and living donor KT were 0.2 pmp and 5.4 pmp, respectively. Data on pre-emptive KT is unavailable in the region.
- Incidence of deceased donor KT was highest in Georgia (34.9 pmp) and living donor KT was highest in Tajikistan (17.2 pmp).

SLIDE 16:

- The median annual cost of in-centre HD, PD, and first year KT were US$ 8,457.5, US$ 13,847.4, and US$ 8,950, respectively.
- Belarus had the lowest annual cost of HD (US$ 5,603) and lowest annual cost of PD (US$ 7,503) while Kazakhstan had the lowest annual cost of first year KT (US$ 7,816).
- Annual cost of HD was less than annual cost of PD across all countries with cost data in the region.
SLIDE 17:

- Scorecards were created for each country to allow comparison of results with other countries in the same region as well as between the previous (2019) survey and current (2023) survey.
- Green represents availability, red represents not available and grey represents unknown or not applicable if they didn’t complete a survey that year.
- In-centre HD was available in all countries in the region in both periods. However, PD services were unavailable in Armenia and Tajikistan in 2019 and remain so in 2023. PD services are also unavailable in Uzbekistan in 2023.
- Use of public funds for kidney care varied widely in the region. Few countries fund dialysis through public funds including Belarus in 2023. However, more countries fund KT through public funds in the region.
- Most countries that had dialysis and KT registries in 2019 still had them in 2023. Kazakhstan without a dialysis registry in 2019, now has one in 2023.
- Advocacy groups for CKD, kidney failure and KRT remains very low in the region.

SLIDE 18 – 19:

- Different reimbursement methods are used to cover the cost of non-dialysis CKD (ND-CKD) services. Overall, 30% of countries (Belarus, Kazakhstan, and Russian Federation) reimbursed ND-CKD services through public funds (and free), 30% (Kyrgyz Republic, Tajikistan, and Uzbekistan) though public funds (with some fees), and 30% (Azerbaijan, Georgia, and Ukraine) through a mix of public and private funding systems.
- Public government funding that is free for acute dialysis, chronic HD, chronic PD, and KT medications were available in 5 (45.5%), 6 (54.5%), 6 (54.5%), and 6 (54.5%) of countries respectively. Solely private, and out-of-pocket payment systems is only used for acute dialysis in Azerbaijan, for chronic HD and PD in Tajikistan, and for KT in Azerbaijan and Kyrgyz Republic.

SLIDE 20:

- Nephrologists bear primary responsibility for kidney failure care in all countries (100%) in the region (global median was 87%).
Across most domains or healthcare workers, there were high levels of shortages reported in the region. The region reported critical shortages of nephrologists (70%), dietitians (90%), counsellors (70%), transplant coordinators (70%), social workers (90%), palliative care physicians (70%), and kidney supportive care nurses (80%).

The median prevalence of nephrologists in NIS and Russian was 9.8 pmp (lower than global median of 11.75 pmp). Georgia had the highest density of nephrologists (31.2 pmp) while Tajikistan had the lowest (3.5 pmp).

(Following data analysis, we were informed that Uzbekistan has 70 nephrologists [60 adults and 10 paediatric nephrologists])

The median prevalence of nephrology trainees in the region was 1.26 pmp and was highest in Georgia (3.2 pmp) and lowest in Ukraine (0.34 pmp).

Estimates of the number of centres providing KRT was assessed across all countries.

Median prevalence of HD centres in the region was 4.8 pmp. Tajikistan had the lowest density of HD centres (0.44 pmp) while Georgia had the highest density of HD centres (6.7 pmp).

Median prevalence of PD centres in the region was 0.46 pmp (compared to 1.57 pmp globally). Belarus had the highest density of PD centres (1.9 pmp) while Kyrgyz Republic had the lowest (0.16 pmp).

KT centres are available in all countries in the region; median prevalence of KT centres was 0.27 pmp and was highest in Belarus (0.64 pmp) and lowest in Uzbekistan (0.10 pmp).

Six (60%) countries (Armenia, Azerbaijan, Georgia, Kyrgyz Republic, Tajikistan, and Uzbekistan) rely on a live only KT program while all other countries use a combined donor KT program (40%).
Two (20%) countries (Belarus and Uzbekistan) have a national KT waitlist; four (40%) countries (Kazakhstan, Kyrgyz Republic, Russian Federation, and Ukraine) use others do not have a KT waitlist.

SLIDE 28:

- Capacity to provide adequate frequency of HD i.e., three times weekly for 3 – 4 hours per session, was available in 100% of countries in NIS and Russia (compared to 81% globally).
- Capacity to provide adequate PD exchanges i.e., three to four exchanges per day was available in 4 (40%) countries (Belarus, Georgia, Kazakhstan, and Ukraine) (compared to 61% globally).

SLIDE 29:

- Home HD was not available in any country in the region.

SLIDE 30 – 31:

- Conservative kidney management (CKM) established through shared-decision making was available in 4 (40%) countries (Belarus, Kyrgyz Republic, Tajikistan, and Ukraine) (compared to 53% global median)
- Choice restricted CKM (where resource constraints prevent or limit access) was available in 3 (30%) of countries (Kyrgyz Republic, Tajikistan, and Ukraine).
- Choice restricted CKM (where no resource constraints prevent or limit access) was also available in 4 (40%) of countries (Kyrgyz Republic, Tajikistan, Ukraine, and Uzbekistan).

SLIDE 32 – 34:

- Multiple methods are used for funding cost of kidney care medications in this region.
- Medications for ND-CKD are available through public government funds with some fees in 5 (50%) countries (Belarus, Kazakhstan, Tajikistan, Ukraine, and Uzbekistan) while solely private and out-of-pocket is used for funding medications in 2 (20%) countries (Azerbaijan and Kyrgyz Republic).
- However, medications for dialysis patients (HD or PD) are free in 4 (40%) countries while publicly funded with some fees was used in 2 (20%) countries (Georgia and Ukraine). Medications for dialysis patients is funded through private and solely out-of-pocket methods in Armenia and Tajikistan.
Finally, more countries fund KT medications through public and free methods in 7 (70%) countries while public funds with some fees are used in 3 (30%) countries in the region.

SLIDE 35:

- Availability of official kidney registries varied across countries.
- ND-CKD registry was available only in Ukraine; dialysis registries in 8 (80%), and KT registries are available in all countries (100%) in the region. Acute dialysis registries are available Belarus and Ukraine and only Ukraine reported having a CKM registry.

SLIDE 36-37: SUMMARY OF FINDINGS

In summary, the 2023 ISN-GKHA highlights several important findings for the NIS and Russia region.

**KRT availability, access, and quality is high.**
- HD services are available in all countries in the region. However, PD services were unavailable in Armenia, Tajikistan, and Uzbekistan
- Capacity to provide adequate frequency of HD i.e., three times weekly for 3 – 4 hours per session, was available in all countries in the region.
- Capacity to provide adequate PD exchanges i.e., three to four exchanges per day was available in 40% of countries.
- Home HD was unavailable in the region.
- KT centres are available in all countries in the region with a median prevalence of 0.27 pmp.

**CKM is available and predominately chosen or medically advised.**
- Conservative kidney management (CKM) established through shared-decision making was available in 40% of countries.
- Choice restricted CKM (where resource constraints prevent or limit access) was available in 30% of countries.
- Choice restricted CKM (where no resource constraints prevent or limit access) was also available in 40% of countries.

**Government funding for kidney care services and medication is low.**
- Reimbursement for medications that is free at point of delivery for ND-CKD, dialysis, and KT are available in 0%, 4 (40%), and in 7 (70%) countries, respectively.
Reimbursement that is free for acute dialysis, chronic HD, and chronic PD were available in 5 (45.5%), 6 (54.5%), and 6 (54.5%) countries, respectively.

*Most have registries for advanced kidney disease, few for CKD or AKI*

- Availability of kidney registries varied across countries in the region.
- ND-CKD registry was available only in Ukraine; dialysis registries in 8 (80%), and KT registries are available in all countries (100%) in the region. Acute dialysis registries are available Belarus and Ukraine and only Ukraine reported having a CKM registry.

*Many workforce limitations are present.*

- The median prevalence of nephrologists was 9.8 pmp with the highest prevalence in Georgia (31.2 pmp) and the lowest in Tajikistan (3.5 pmp).
- The median prevalence of nephrology trainees in the region was 1.26 pmp and was highest in Georgia (3.2 pmp) and lowest in Ukraine (0.34 pmp).
- The region reported critical shortages of nephrologists (70%), dietitians (90%), counsellors (70%), transplant coordinators (70%), social workers (90%), palliative care physicians (70%), and kidney supportive care nurses (80%).

*Moderate advocacy for kidney disease in the NIS and Russia.*

- Advocacy groups for CKD, kidney failure and KRT remains low in the region.

**SLIDE 38-39: IMPLICATIONS**

There are important implications to consider. Based on these survey findings, key recommendations to drive future activities for optimizing kidney care globally are proposed:

*Increase health care financing for kidney failure prevention and management.*

- While resource limitations are an obvious barrier, focusing on preventing kidney failure through appropriate hypertension and diabetes management may be more cost-effective overall. Government funding to cover medication costs may allow more patients to treat earlier stage CKD, thereby preventing the need for more costly kidney failure treatment and the obvious burden this has on patients wellbeing.
Address workforce shortages through multidisciplinary teams and telemedicine

- Shortages of nephrologists, surgeons, dialysis nurses, and other key allied health professionals were noted across most countries. Similarly, simply producing more nephrologists may not be feasible or appropriate, and sharing the workload across multiple providers will not only promote the use of multidisciplinary teams but further, allow for more and better care delivery across more patients. Telemedicine may help particularly in addressing gaps in care among rural patients, and enhancing capacity through training programs such as ISN Fellowship, visiting ambassador programs, etc.

Incorporate the collection and reporting of quality indicators in kidney failure care.

- Measuring and reporting on key quality indicators is an important driver in healthcare improvement. Ensuring facilities are supported with information systems that allow for the systematic measurement and reporting of indicators is a first key step to increasing the rate of monitoring among countries. Further, understanding if or how the collection and reporting of indicators are being used to improve care is needed.

Expand health information systems to prevent and manage kidney failure.

- Similarly, good quality HIS are vital for kidney disease management within a country. A lack of data on disease prevalence, incidence, resource use, and quality of care limits government and provider ability to monitor and evaluate the care provided as well as predicts appropriate resource allocation so that sufficient facilities, medicines, and healthcare professionals are trained and available.

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

- Lastly, policies and strategies are important for consistent approaches within a country for optimal care delivery, as well as for accountability, leadership, and knowledge exchange. Advocacy may help promote the increase of government prioritization and further, public awareness of how to prevent and manage kidney disease. Without acknowledging and mitigating barriers, it would be a challenge to achieve of successes out of these recommendations. Competing priorities and needs (for example, clean water supply and basic sanitation, maternal and child health, malnutrition, etc.)