

Kidney Disease Aging Research Collaborative (KDARC) Kickoff Meeting October 8, 2024



Agenda

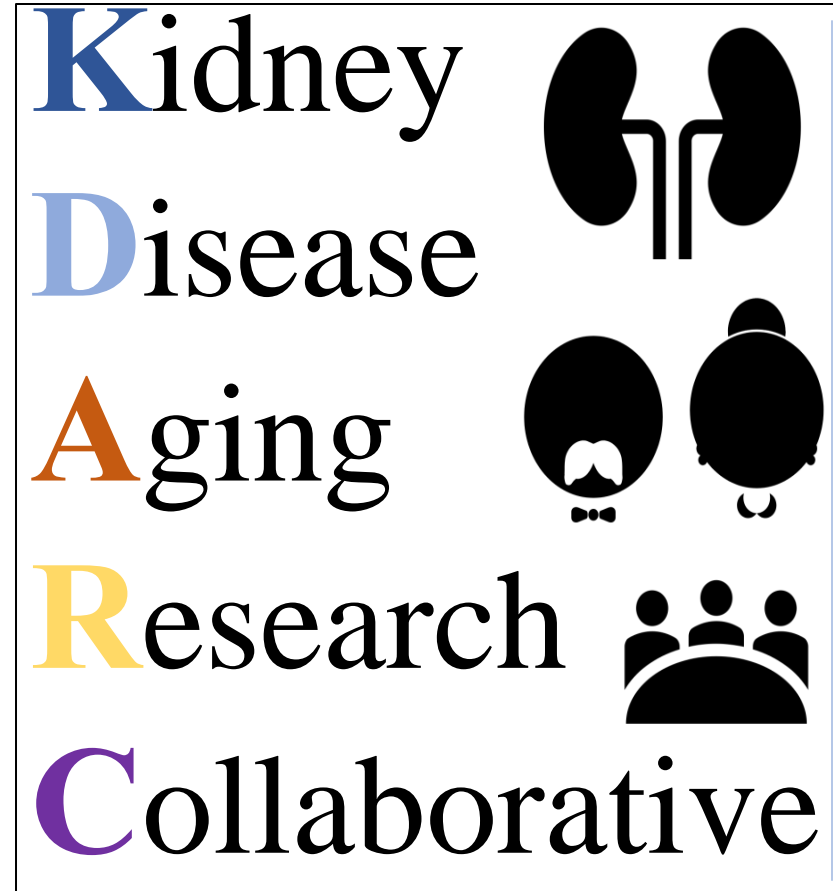
- Overview
- Introductions
- Formalize KDARC organizational structure
 - Shared Vision
 - Formal governance policies
- Preferred meeting time

BREAK

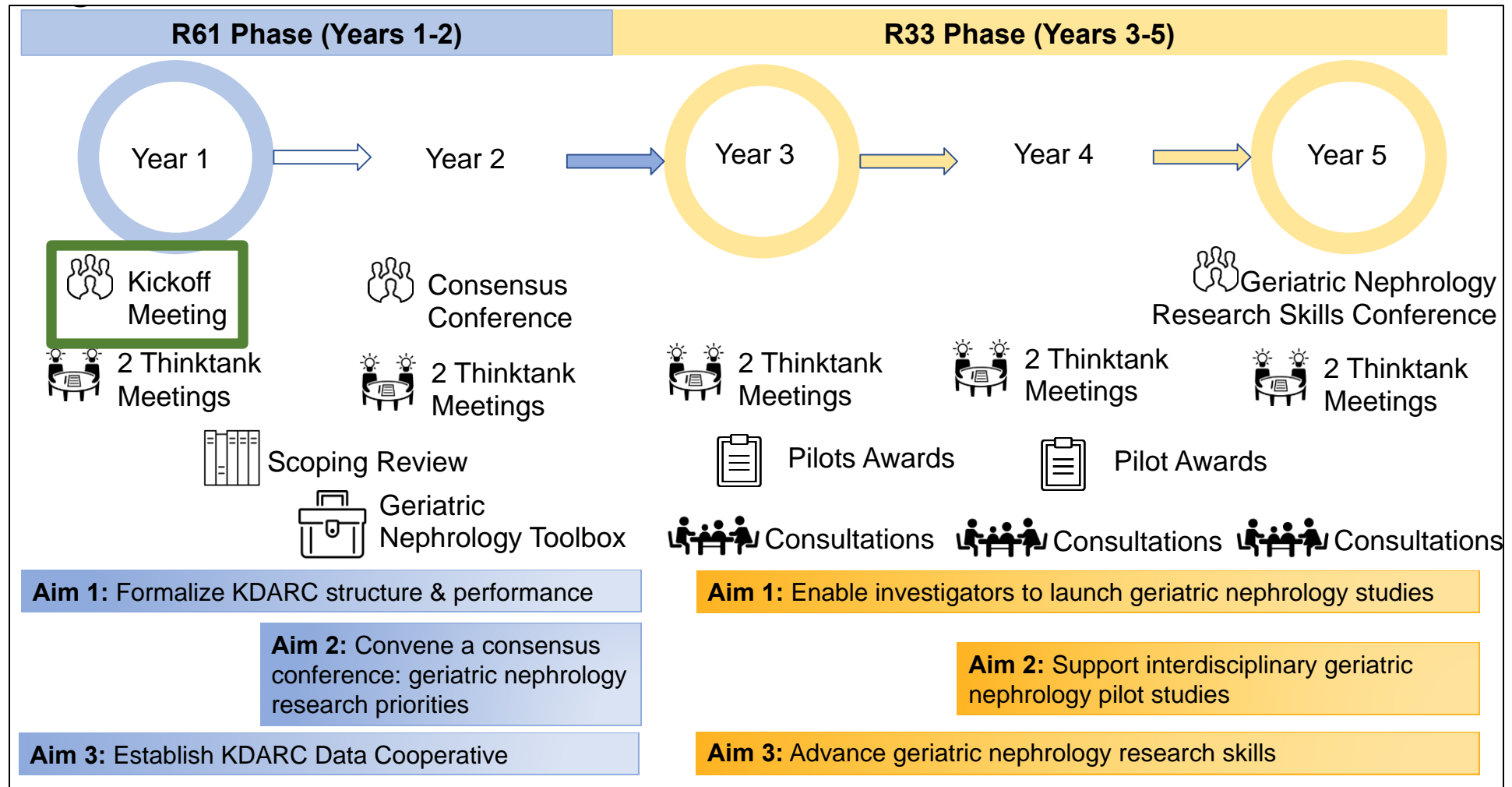
- 4 cores
- Delphi study
- Scoping reviews
- Think Tank meetings

BREAK

- Team Science Initiative
- KDARC website
- Conferences



Overview



Milestones

[illegible]

Milestones continued

[illegible]

External Advisory Board

Meet twice a year to:

- 1) Review and guide milestone progress
- 2) Advise the Principal Investigators (Mara & Rasheeda) on leading KDARC
- 3) Address potential problems

Member	Institution(s)	Position and Roles
Karen Bandeen-Roche, PhD MS	Johns Hopkins Bloomberg School of Public Health	<ul style="list-style-type: none">• Co-Director, Johns Hopkins Pepper Center
Harvey Cohen, MD	Duke University School of Medicine; Department of Medicine; Division of Geriatrics	<ul style="list-style-type: none">• Walter Kempner Distinguished Professor of Medicine• Emeritus Director, Duke Aging Center• Past President of AGS & GSA• Member, Cancer & Aging Research Group
Dorry L Segev, MD PhD	NYU Grossman School of Medicine; Dept. of Surgery and Population Health	<ul style="list-style-type: none">• Director, Center for Surgical and Transplant Applied Research; Vice Chair of Research• Member, National Academy of Medicine
Manjula Kurella Tamura, MD MPH	Stanford University	<ul style="list-style-type: none">• Former Director, VA Palo Alto Geriatrics Research and Education Clinical Center• Director of Clinical Research and Deputy Editor, JASN
Patrick Gee, PhD, JLC	iAdvocate, P. Gee consulting, LLC	<ul style="list-style-type: none">• Founder and Chief Executive Hope Dealer, iAdvocate



Department
of Medicine

UW Medicine



DREXEL UNIVERSITY
College of
Medicine



Tell us about you

- We want to connect members for peer review, co-investigators, promotion letters
- Complete the zoom poll
 - What are 3 key terms/phrases that you would use to describe your research?


KDARC Word Cloud

What are 3 key terms or phrases you would use to describe your research?



Goals for today (according to grant)

- Development Phase Kickoff Meeting

- 
1. Identify 3 working groups to launch scoping reviews which will be prepared prior to the Consensus Conference
 2. Refine KDARC shared vision, formal governance and goals
 3. Identify KDARC members who will participate in each KDARC Core
 4. Review the final results of the Delphi study

Shared Vision and Mission

We have incorporated recent feedback and now provide an opportunity for you to review and suggest edits:

Shared Vision:

Because of KDARC, there will be more scientific evidence available to improve care and outcomes for persons with kidney disease.

Shared Mission:

KDARC's shared mission is to conduct and promote interdisciplinary collaborative research that encompasses the study of both physiological and chronological aging and related concepts in persons with kidney disease.

Shared Mission (Details)

KDARC will:

- Serve as an interdisciplinary research network spanning mechanistic to health services and bioethical issues.
- 1) identify and fill key knowledge gaps in geriatric nephrology research,
- 2) facilitate multisite studies (clinical trials and observational studies),
- 3) encourage uniform outcome selection, and
- 4) promote community-academic partnerships and inclusion of this patient population in clinical trials.

Shared Mission (Details)

KDARC will:

- Emphasize the application of new and existing evidence for
 - 1) educational content for persons with kidney disease and their caregivers, and
 - 2) clinical resources that facilitate care of persons with kidney disease who have aging-related problems (e.g., clinical practice guidelines)
- Promote and conduct professional development activities for clinicians and researchers engaged in work focused on the aging in patients with kidney disease.

Formal Governance Policies

- *Written 2 years ago, if you want to modify any parts, let us know now*
- Authorship
- Acknowledgements
- Data Sharing
- Transfer of primary data
- Management of intellectual property
- Development of Single-IRB applications
- Grant Submissions
- Research Integrity
- Other topics?

Formal Governance: Authorship

- Authorship will be decided at onset of the project.
- Based on criteria set by the Internal Committee of Medical Journal Editors (ICMJE)
- 1st author provide significant contribution to writing and/or analyses
- Senior author provides funding, mentoring, and/or supervision
- Co-first and co-senior will be allowed where appropriate
- Encourage early career members to be considered for role/responsibility as first author
- Opportunity to present abstracts at scientific meetings
- Corresponding author will be decided by the authors of each manuscript
- Corresponding author must provide significant contribution, be responsible for all correspondence about the manuscript, and have experience with publishing
- Prior to full manuscript draft, a manuscript outline must be submitted to KDARC for review

Formal Governance: Acknowledgements

- KDARC acknowledgement in manuscripts arising from KDARC to consider the intellectual input of members who did not meet full criteria as authors.
- Practically, this will be an acknowledgement with members who do not meet ICMJE authorship criteria to be listed there as collaborators.

Formal Governance: Data sharing

- Data sharing among KDARC members will involve a formal process with data use agreement. The data use agreement could function in at least two approaches:
- 1) Data is collected locally and stored in a single location (e.g., REDCap) and everyone has access to the data or
- 2) Data is collected locally, stored locally behind institutional firewall, and then pooled as deidentified data for use by KDARC members.
- In each instance, the data collected locally belongs to the KDARC member/team who collected it.
- Data use agreements will have to be completed and approved before data sharing occurs.
- Approach to data collection and data harmonization across sites will be prioritized for each project.

Formal Governance: Transfer of primary data (gerontologic measures and specimens)

- Similar to data sharing, any transfer of primary data will involve a data use agreement to be completed and approved before data sharing occurs.
- Transferred data will have minimal patient identifiers.

Formal Governance:

Management of intellectual property

- KDARC recognizes the importance of having formal process for management of intellectual property.
- Rely on examples from existing research consortiums.
- Alternatively, intellectual property is owned by a KDARC member's institution.

Formal Governance:

Development of Single-IRB applications

- The primary institution for a study will be the PI's institution (site of an awarded grant) and/or the site that conducts the most data collection.
- Reliance agreements will then be arranged with other institutions involved in data collection.

Formal Governance: Grant Submissions

- KDARC members who would like to KDARC support for a grant submission will have to formally request assistance. Lead times may vary by type of request, but a minimum of 4 weeks is required.
- Types of Support:
 - Letter of Support
 - Identification of co-investigators
 - Grant and/or Specific Aims review
 - Example language for specific sections
- Emphasis on upholding confidentiality and integrity throughout the process

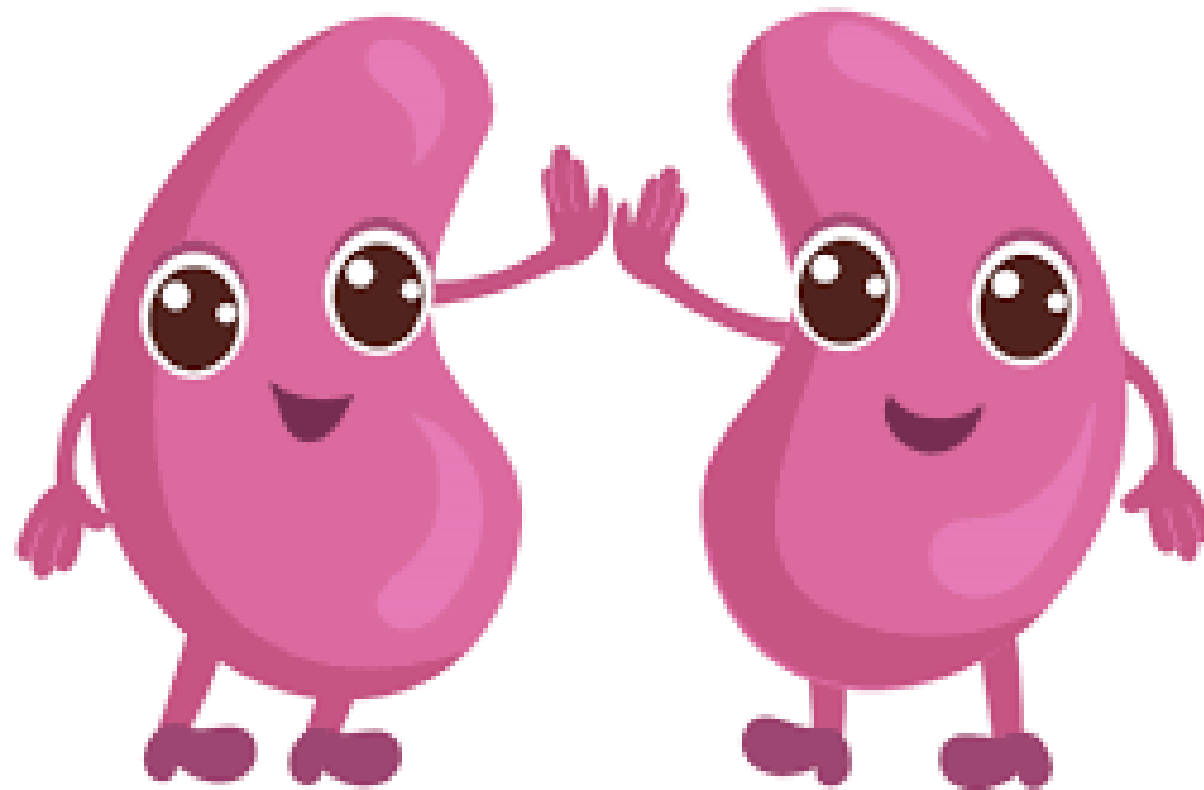
Formal Governance: Research integrity

- KDARC will aim to promote research integrity and collegiality and minimize research misconduct.
- KDARC will follow current and evolving guidance on responsible conduct of research, including data management and ethical considerations with study participants.

Preferred meeting times

- Alternating meeting times every other month
- Qualtrics survey to share preferences
- Second Thursday afternoons are best as an alternate
 - 1pm-2pm EST
 - Thursday February 13, 2025
- Let me know if you have a conflict for both our regular time (2nd Tuesday 2pm EST) and alternate time of Thursdays

BREAK



4 Cores

Research

Measurement

Patient
Engagement

Workforce
Development

Why join a Core Committee?

- Be a part of the planning/leadership role in the creation of KDARC and setting priorities for geriatric nephrology research
- Provide guidance/resources in a specific subject/area to support fellow researchers
- Opportunity to present at Geriatric Nephrology Research Skills Conference (Year 5)
- 4 cores will establish research infrastructure and procedures
- Enhance your CV: Papers, Presentations → enhancing your regional and national reputation
- Time commitment: ~ 1-2 hours/month

Research Core

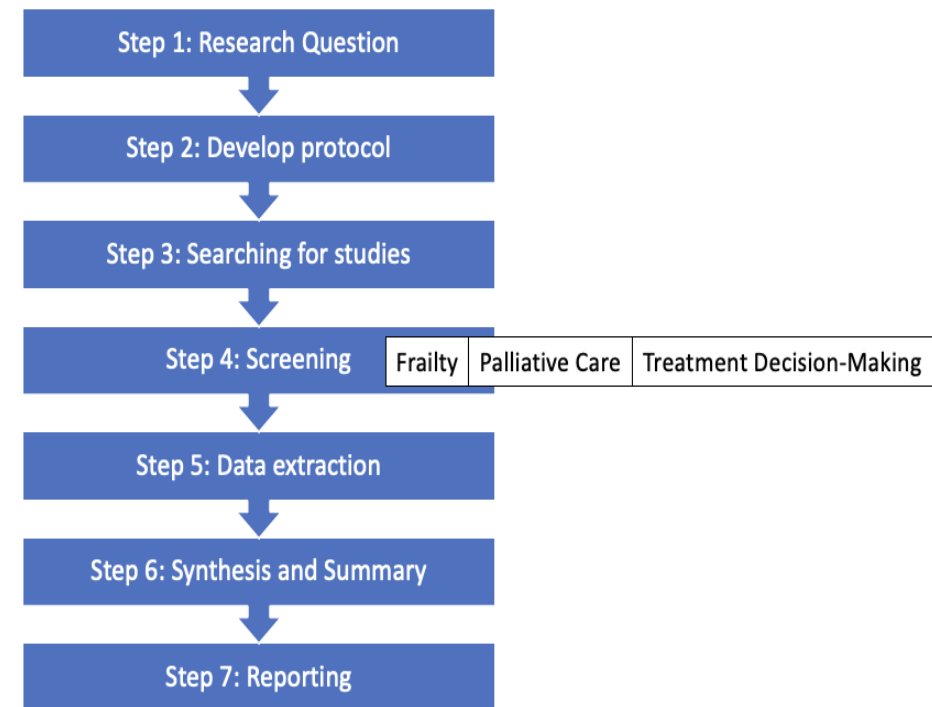
- Team Lead: Mara McAdams DeMarco, PhD
- Goals
 - Identify research priorities from scoping reviews
 - Oversee KDARC Data Collaborative and develop relevant protocols
 - Provide training/consultation on existing/new data use and design

Scoping Reviews

- If you are taking a key role in one of the scoping reviews, consider joining the Core
- Key steps remaining:
- Completion of articles screening based on title and abstract for broad concept relevance
- Screen full text of articles
- Data abstraction of eligible articles
- Summarize data by categories (e.g., study design, measures, results) to identify the potential size and scope of available literature and uncover knowledge gaps
- Record constructs measured and the tools used to facilitate Geriatric Nephrology Toolbox development
- Summarize their scoping review in a peer reviewed manuscript

Scoping reviews progress in the next hour

Scoping Reviews Update



Data Cooperative

- The goal of the KDARC Data Cooperative is to help investigators address geriatric nephrology knowledge gaps using tools that are included in the Geriatric Nephrology Toolbox
- In the Development Phase (R61), there will be 2 types of existing data housed in the Data Cooperative:
 - 1) data from existing, retrospective registries/Medicare claims
 - 2) data from existing, prospective cohort studies, trials, and mixed methods studies conducted by KDARC members.
- New data will be added in the Application Phase (R33)

Example KDARC Data Cooperative Consulting Services			
Study Phase	Core	Data Cooperative Consulting Service	Approach
Study Design	Research & Measurement	<ul style="list-style-type: none"> Recommendations for study cohort construction, outcome definitions, choice of statistical models 	<ul style="list-style-type: none"> Proposal review and regular meetings Code library/standard operating procedures Geriatric Nephrology Toolbox
Regulatory Approval	Research	<ul style="list-style-type: none"> Advice on IRB and DUA processes 	<ul style="list-style-type: none"> IRB and DUA Templates
Analysis	Research	<ul style="list-style-type: none"> Analytical support Result interpretation 	<ul style="list-style-type: none"> Weekly analytical office hours 5 free hours of analyst time for registry data
Stakeholder Engagement	Patient Engagement	<ul style="list-style-type: none"> Engagement of Kidney Health and Aging CAB 	<ul style="list-style-type: none"> Creation of a forum to present research findings and receive feedback from a CAB
Dissemination	Workforce Development	<ul style="list-style-type: none"> Advice on journal selection Connect investigators to opportunities to publish/present findings 	<ul style="list-style-type: none"> Office hours Provide templates Email notifications

Measurement Core

- Team Lead: Megan Huisingh-Scheetz, MD, MPH, AGSF, FGSA
- Goals for Years 1-2:
 - Year 1, current-5/2025: ***Generate harmonization table of aging measures in kidney-disease cohort studies.***
 - **Product 1:** Non-peer reviewed publication on Center website (tracking of views/downloads)
 - **Product 2:** Geriatric syndrome prevalence across kidney datasets manuscript or workshop
 - Year 2, 6/2025-5/2026: ***Create Aging Measure Toolbox.***
 - **Product 1:** Non-peer reviewed publication on Center website (tracking of views/downloads)
 - **Product 2:** Preconference workshop at kidney conference: “Geriatricizing your Kidney Studies”

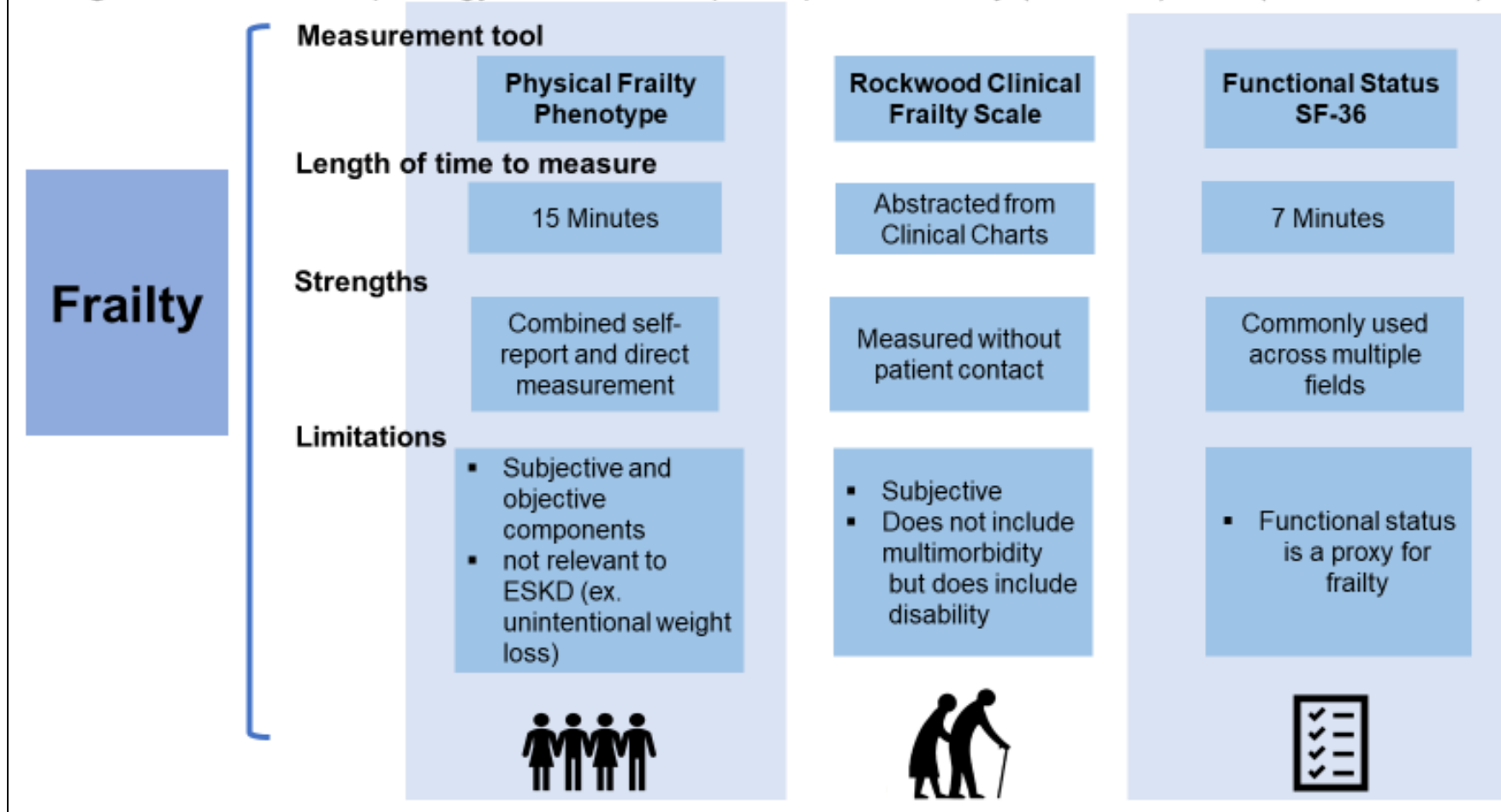


Example table

Dataset	Frailty	Physical Function	Cognition	Kidney Disease symptoms	Kidney Disease QOL
CRIC					
ARIC					
Mara Data					

Toolbox Example

Figure 4: Geriatric Nephrology Toolbox; Example of potential frailty (construct) tools (measurements).



Measurement Core Expectations & Benefits

- Responsibilities
 - Assist with one Core Project
 - Attend Core Project Meetings (short-term)
 - Attend Core Meetings (quarterly)
- Preferred skills and experience
 - Familiarity of public kidney datasets that include older adults OR
 - Familiarity of aging measures (frailty/physical function, cognition, QOL/Symptoms)
- Benefits of joining
 - Learn about publicly available datasets for secondary data analyses
 - Learn about aging measures in key assessment domains



Patient Engagement Core

- Team Lead: Jennifer Scherer, MD, MSCI

Goals

- To establish best practices in recruitment and retention of older adults into research.
 - Clinical trials
 - Qualitative work
 - Community Engagement
 - Cultural adaptations
- Standardize CAB partnership for research trials, starting with our pilot study section.
- Trainings in recruitment and retention of older adults.

Patient Engagement Products and Deliverables

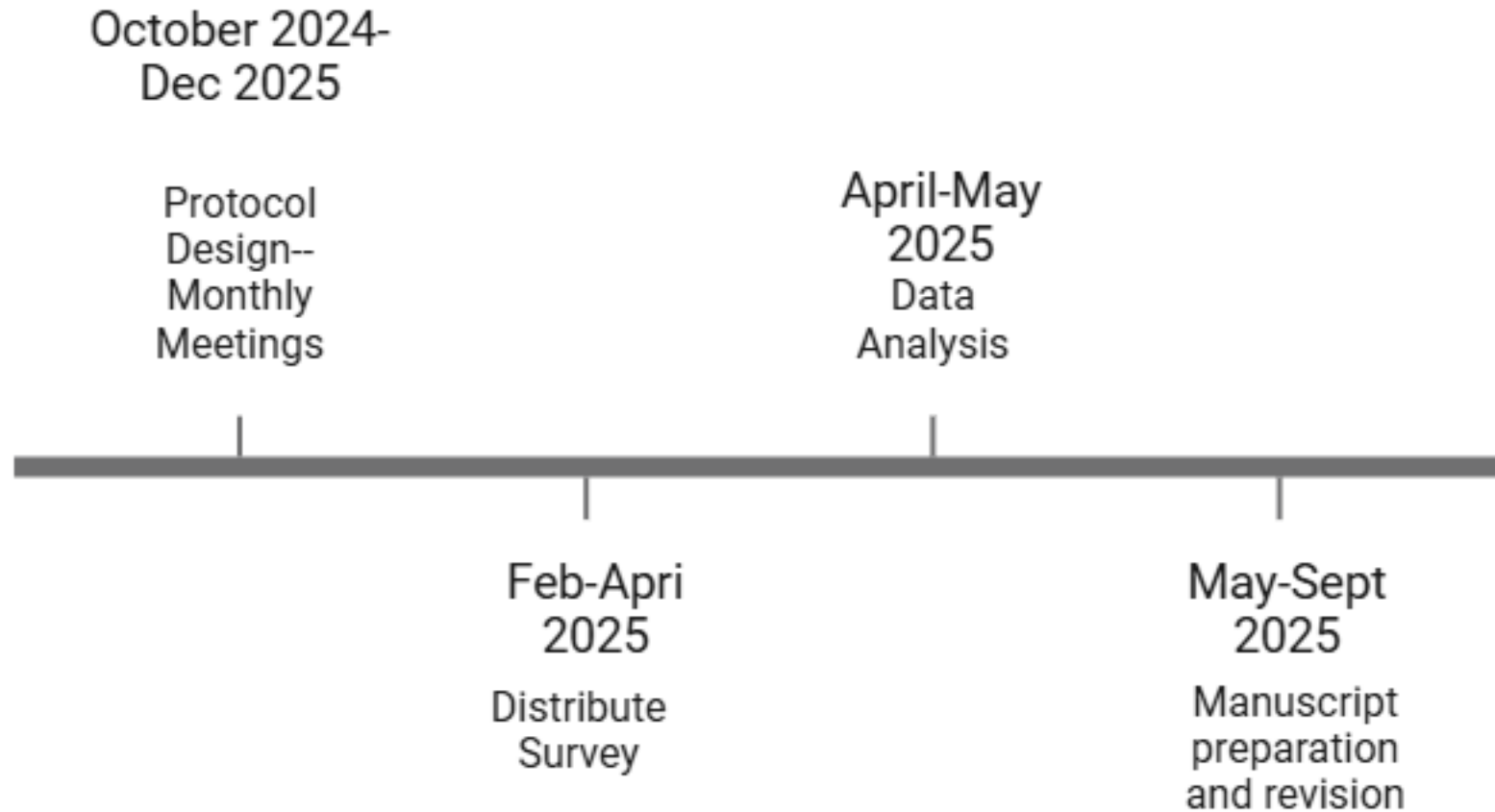
Years 1 - 2

- Survey study from PIs, research coordinators, administrators, and assistants on best practices for recruitment and retention of older adults. (May 2025)
- Recruitment and retention training videos for the KDARC website.
- Paper on best practices on recruitment/retention of this population.

Years 3 - 5: Training Project

- Short interviews with PI/Research Coordinators
- Group Observed Structured Clinical Encounter (GOSCE) on recruitment of older adults
 - Discussing with families
 - Interviewing/recruiting people with cognitive impairment

Timeline of Best Practices Manuscript



Patient Engagement Expectations & Benefits

- Responsibilities
 - Attend Core Project Meetings (short-term)
 - Attend Core Meetings (quarterly)
- Preferred skills and experience
 - Familiarity with developing surveys
 - Experience recruiting and retaining patients with kidney disease in research studies
- Benefits of joining
 - Identify best practices for patient engagement in research studies
 - Co-author a manuscript

Workforce Development Core

- Team Lead: Rasheeda Hall MD, MBA, MHS
- Goals
 - Grow KDARC to include more diverse cadre of faculty (Year 1)
 - Develop foundation of effective collaboration in KDARC (Team Science Initiative) (Year 1)
 - Finalize consultation services on journal selection, grant support (Year 2)
 - Establish and Oversee Mentoring Program with embedded research capacity plan (Year 3)
 - Lead KDARC Geriatric Nephrology Research Skills Conference (Year 5)

Workforce Development Core Expectations & Benefits

- Responsibilities
 - Participate in Core activities (attend meetings (quarterly) and/or email inquiries)
 - Collect information from others
 - Contribute to writing through drafts or providing feedback
- Preferred skills and experience
 - Experience and/or interest in mentoring new investigators OR
 - Interest in how teams function
- Benefits of joining (SHORT-TERM)
 - Enhanced understanding of team science may improve your research effectiveness (potential manuscript opportunity)
 - Demonstrates leadership for your CV
 - Networking outside of your institution → grow your reputation

Apply to Join a Core

- Qualtrics survey
 - Link in the chat, use this brief survey to select cores you are interested in
- Any Questions?
- Panel discussion

Research

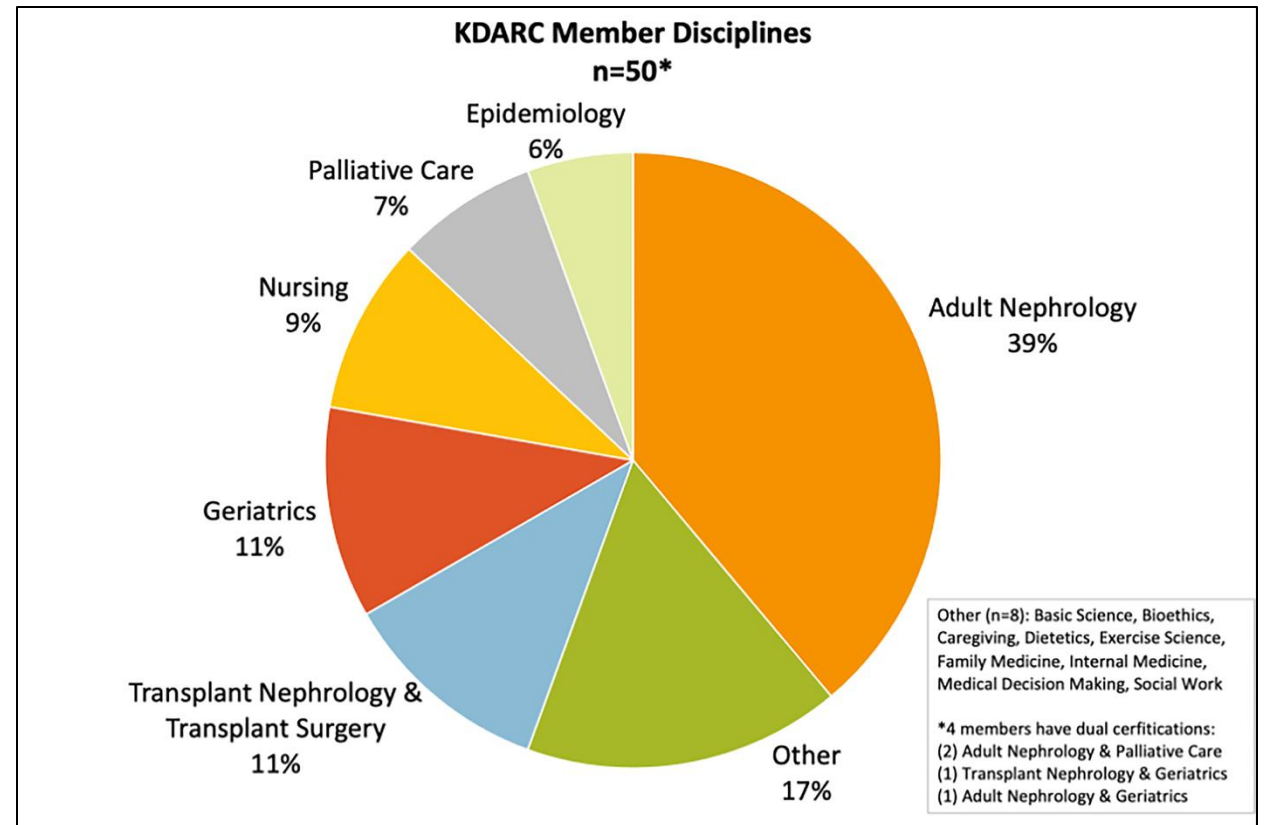
Measurement

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Development

JAGS White Paper Introducing KDARC

- Kidney Disease Aging Research Collaborative (KDARC): Addressing Barriers in Geriatric Nephrology Research
- Highlights KDARC addressing 3 barriers:
 1. Organizational
 2. Absence of Research Priorities
 3. Data

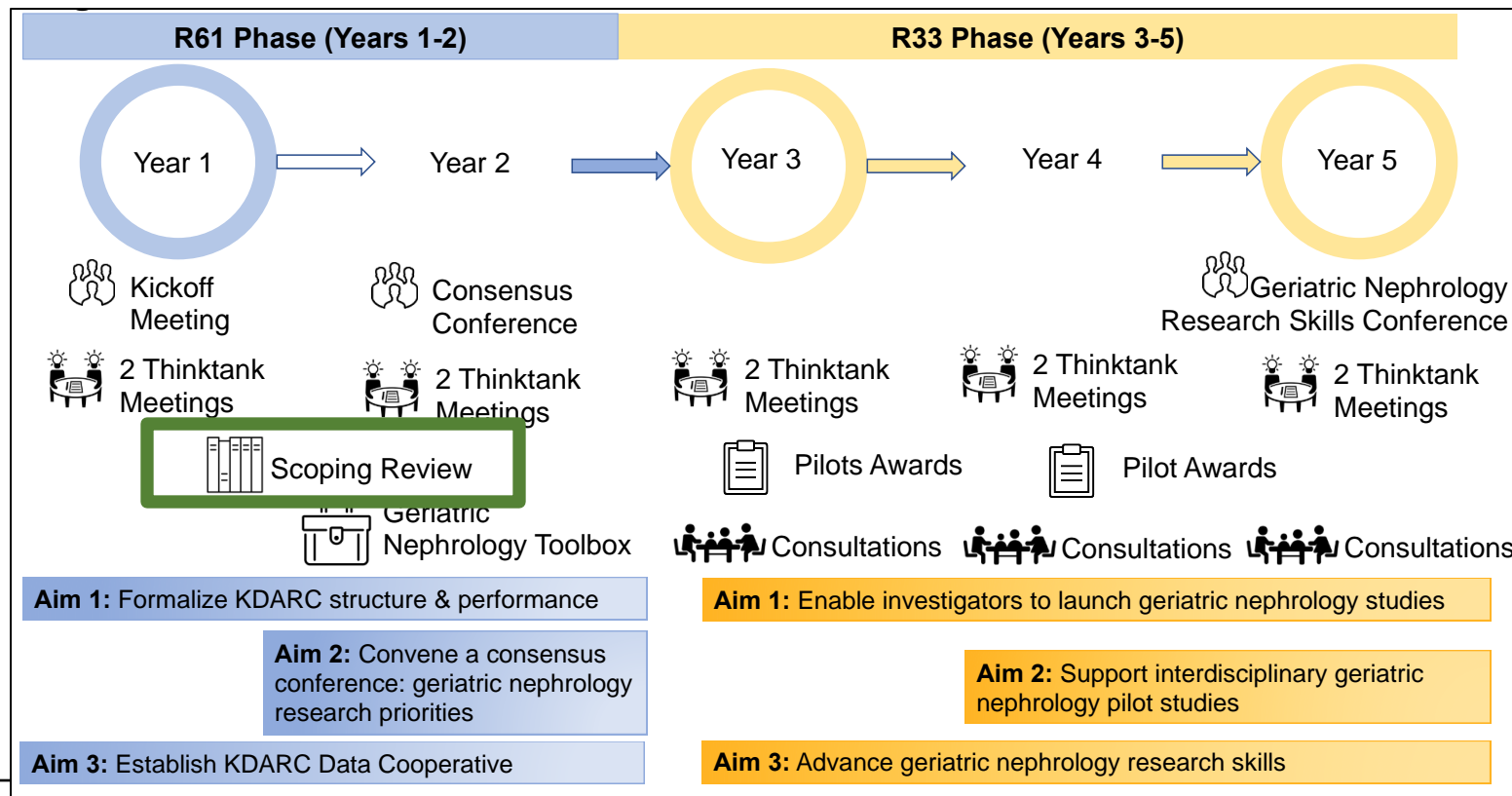
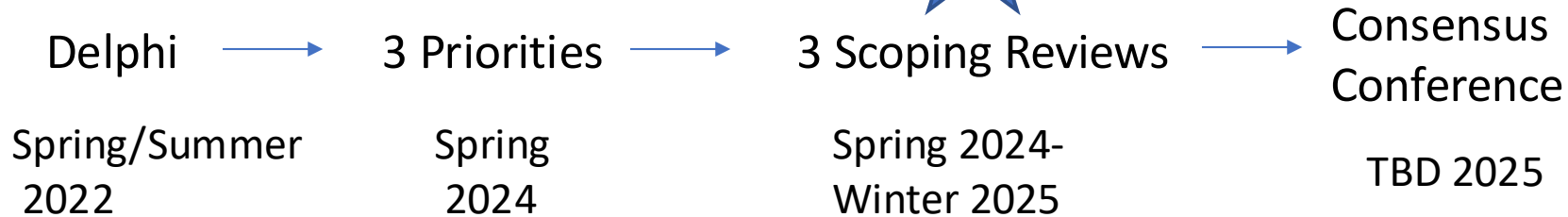


Delphi Study Update

- Publication resubmitted in August to AJKD
- Table: Research Priorities in Geriatric Nephrology after the Final Delphi Round

1	Communication and Decision-Making about Treatment Options for Older Adults with Kidney Failure
2	Quality of Life, Symptom Management, and Palliative Care
3	Frailty and Physical Function
4	Tailoring Therapies for Kidney Disease to Specific Needs of Older Adults
5	Caregiver and Social Support
6	Health Equity for Older Adult Populations
7	Conservative Kidney Management
8	Medication Management and Deprescribing
9	Equitable and High-Value Healthcare Delivery for Older Adults
10	Access to Transplant for Older Adults
11	Self-Management and Empowerment for Older Adults
12	Cognitive Impairment

Roadmap to Our Goal



Proposal: Hybrid meeting

1. Groups present knowledge gaps
2. All present Rank/Vote by Importance

Scoping Reviews: A Key Step in R61/R33 Activities

- Rationale: Review breadth of evidence and identify knowledge gaps in 3 topics
- If topic is a geriatric construct, gather details for Geriatric Nephrology Tool Box
- Products/Deliverables: Manuscripts, Toolbox, Consensus on Research Priorities

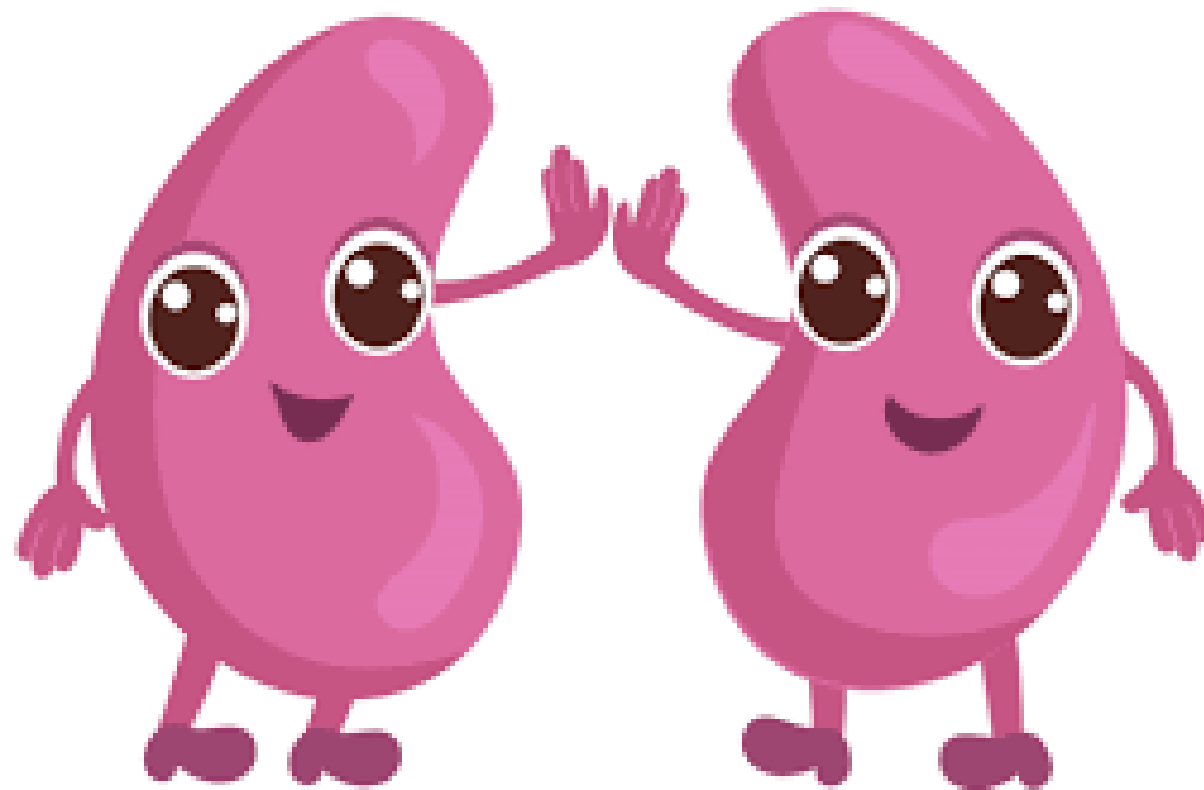
Scoping Reviews Update



Scoping Review Research Questions

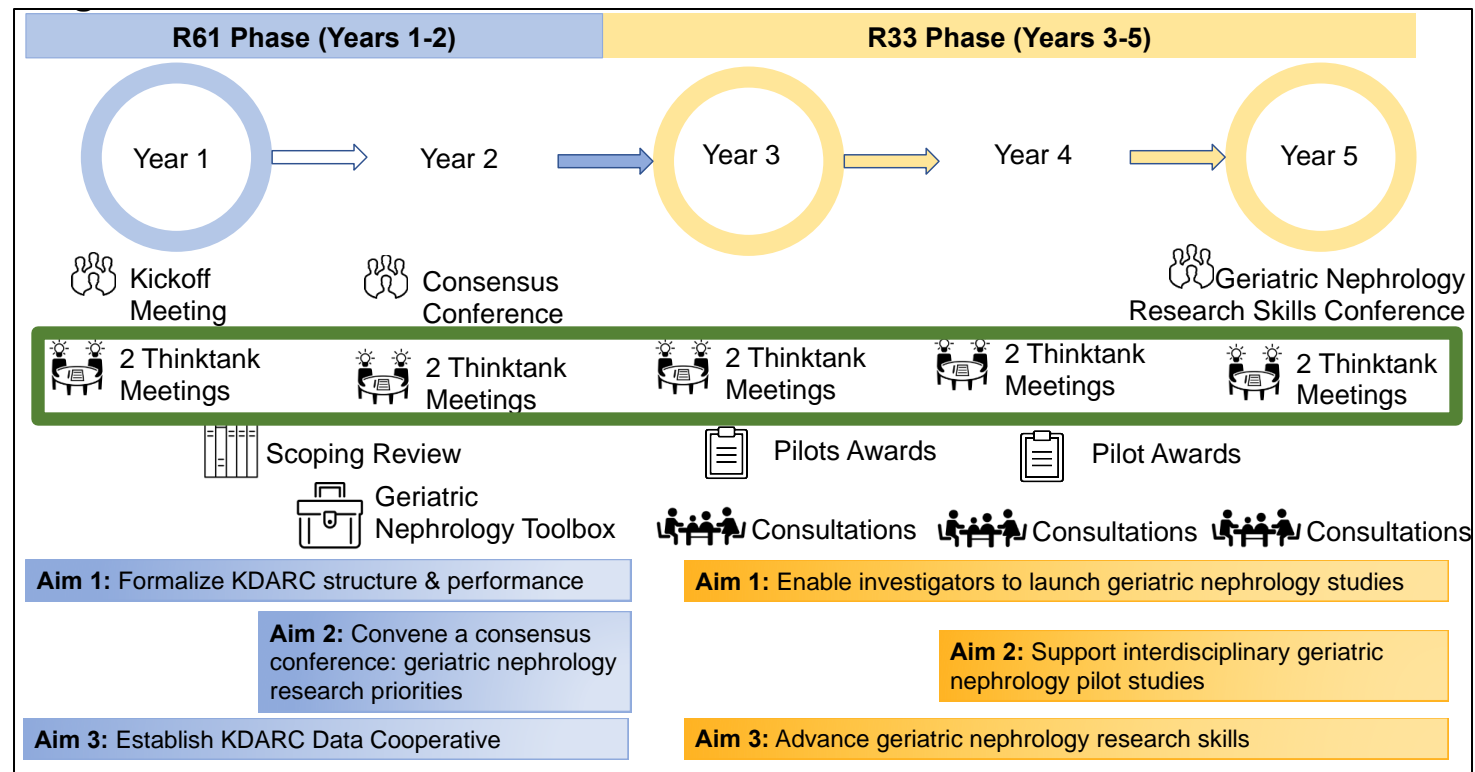
- Frailty
 - What are existing validated methods used to measure frailty in adults with Chronic Kidney Disease, End Stage Kidney Disease, Kidney Transplant and Acute Kidney Injury?
- Palliative Care
 - How does the existing scientific literature describe palliative care options for patients with kidney disease?
- Treatment Decision Making
 - What is the evidence base for decision-making interventions for end-stage kidney disease treatment options?

BREAK



Think Tank Meetings

- Share research in progress and get feedback
 - Biannual Thinktank Meetings during which KDARC members can brainstorm together and present



Potential Think Tank Meeting Topics

- Examples:
 - What are appropriate research questions to ask in USRDS?
 - Identifying geriatric cohort studies that measure eGFR and frailty.
 - How to define older patients that are soon to start dialysis or receive a transplant?
- Other ideas?

KDARC's Team Science Initiative

- What does team science mean to you?
- What makes a successful team?
- What do you do when a team is not working well?

KDARC's Team Science Initiative

- Objective: To achieve KDARC Milestones through effective Interdisciplinary, Interinstitutional Teams
- Initiative activities:
 - SWOT analysis (complete)
 - Collaboration Plan development (in process)
 - Team science trainings
 - Collaboration evaluation: surveys, observation, KDARC member reflections
 - Publication

STRENGTHS

- Motivated, focused individuals
- Passionate about topics
- Hardworking
- Diverse representation
- Diversity of practice
- Members are supportive/collaborative
- Early career folks bring new perspectives
- Bring existing resources that haven't been shared yet
- Goal – oriented, organized

WEAKNESSES

- Coordination difficulties – schedules, time zones
- Competing priorities
- Competing responsibilities
- Consensus can be challenging with diverse perspectives
- We are new – figuring out who we are and what works best

OPPORTUNITIES

- Clin-Star
- International collaboration
- Community Advisory Board
- leverage our expertise/skill to establish consensus on persistently unaddressed issues in our area(s) of research
- Increased 'press' for geri topics in general in setting of Baby Boomers all being Medicare eligible in the next few years
- National Institute on Aging support research – toolbox
- CARG, GEAR – other groups like us
- Collaboration on submitting conference topics to ASN
- Leveraging letters of support
- Multidisciplinary and/or less traditional funding sources
- GEMSTAR
- Knowledge to practice/influence where resources are put

THREATS

- Shifting funding priorities
- What we try to accomplish as a group (milestones) v. trying to accomplish as an individual
- productivity products that are things our employers care about so people can maintain their commitment
- Nephrology community to recognize importance of geriatrics/gerontology and convince geriatrics/gerontology why pts with kidney disease matter
- Geriatrics and nephrology are not popular medical specialties → pipeline problem
 - Long-term sustainability

KDARC's Team Science Initiative

- Team Science Trainings that address the SWOT analysis:
 - Facilitated Retreat on KDARC member engagement
 - Develop boundary-spanning Communication Competence

SHORT-TERM GOALS

Know Value of
Team Science

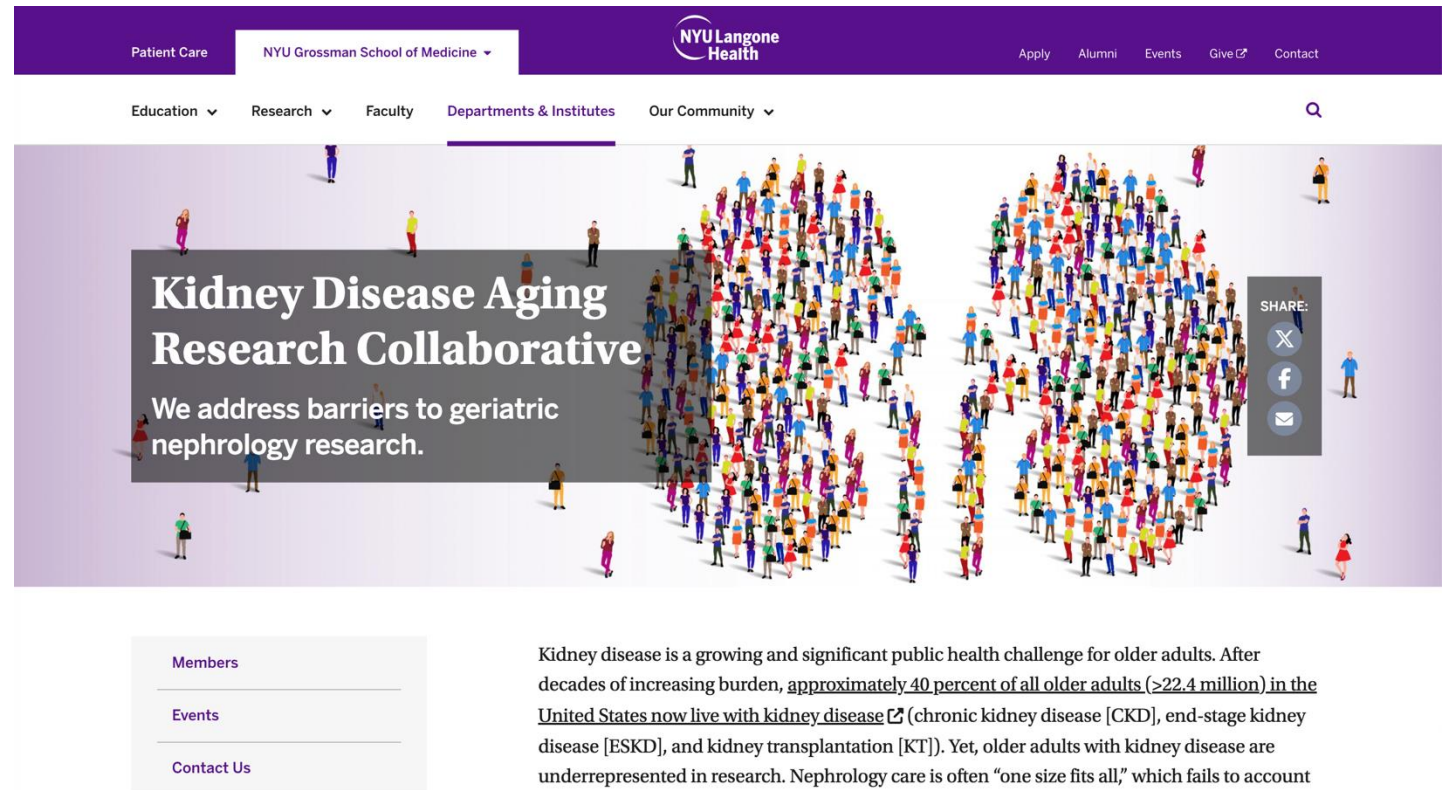
Practice Team
Science Principles

LONG-TERM GOALS

Papers, Grants,
KDARC Sustainability

KDARC Website

- Member Spotlight
 - Name, institution, research interests, what drives you to do research in this field, photo
 - <https://med.nyu.edu/centers-programs/kidney-disease-aging-research-collaborative/>



Kidney disease is a growing and significant public health challenge for older adults. After decades of increasing burden, approximately 40 percent of all older adults (>22.4 million) in the United States now live with kidney disease (chronic kidney disease [CKD], end-stage kidney disease [ESKD], and kidney transplantation [KT]). Yet, older adults with kidney disease are underrepresented in research. Nephrology care is often “one size fits all,” which fails to account for the conditions and syndromes that are more common in older adults. Age disparities in kidney disease result in suboptimal care for older adults.

ASN

- Are you going to ASN?
 - Meetup: Saturday Oct 26, 10-10:30 am PDT at poster session. Walk to palliative care talk together after.
 - KDARC member presentations/posters guide



Upcoming conferences

- Gerontological Society of America (GSA)
 - November 13 - 16, 2024 in Seattle
 - Megan is going!
- International Society of Nephrology
 - February 6- 9, 2025 in India
- International Conference on Frailty and Sarcopenia Research (ICFSR)
 - March 12-15, 2025 in Toulouse, France
 - Abstracts due 12/18/24
- American Geriatrics Society (AGS)
 - May 8-10, 2025 in Chicago
 - Abstracts due 12/2/24
- World Transplant Congress 2025
 - August 2-6, 2025 in San Francisco
 - Abstracts due 2/19/25

Thank you for joining us!

