UK Strategy for Kidney Research Using Data:
A Framework for Education and Training, Transparency, Accountability, and Inclusivity

1. Objectives

Advance Education and Training in Data Research

- Develop and signpost training programs for researchers at all career stages to ensure proficiency in the application of data science methods, responsible data handling, and ethical considerations.

Position the Kidney Community to Use Available UK Health Data for Meaningful Change

- The Sudlow Review may clarify aspects of the UK Health Data environment.
- UK Health Data likely to be recognised as critical national infrastructure (CNI), reducing complexity and fragmentation, and assuring long-term planning and investment.
- A National Health Data Service with a single access system is expected, as is focus on secure data environments (SDEs) for access and management.
- National public bodies will need to agree on a coordinated health data strategy.
- The kidney community must be recognised and actively involved.

Ensure Transparency in Data Practices

- Develop and promote open data standards to enable community wide access to research datasets, methodologies, and results.
- Where possible, ensure:
    - transparency in how data is collected, processed, and analysed.
    - Clear communication of data provenance and any limitations or uncertainties in research findings.
- Encourage stakeholder engagement around data use and its implications for the kidney community.

Promote Ethical and Inclusive Data Use

- Ensure that research using data reflects and benefits all of the UK kidney community, with previously underrepresented groups both contributing to and benefitting from data-driven research.
- Commit to eliminating bias in data collection, analysis, and interpretation, and actively address structural inequalities in research practices.

- Support inclusive data practices that enable under-represented groups to be involved as active participants in the research process.

2. **Key Actions and Initiatives**

Education and Training

- Create a comprehensive training framework for researchers to develop competencies in data management, ethical data use, bias reduction, and transparent research methodologies.

Supporting Infrastructure and Collaboration

- Convene a working group to assess,prepare, and position the UK kidney community to benefit from the changes resulting from the Sudlow Review.
- Deliver an action plan with concrete recommendations ensuring the community benefits from changes identified in the review.

Data Ethics and Governance

- Develop a national Kidney Code of Practice for ethical data research, aligned with international standards, which incorporates inclusivity, accountability, and transparency in all stages of data use.
- Lobby funders to require grant awardees to adhere to this Code.

Building Inclusive Data Practices

- Mandate that research involving data collection, analysis, and dissemination includes diverse groups in its design and decision-making processes, either through advisory panels or inclusive research teams.
- Promote partnerships between researchers, under-represented communities, and data users to ensure that the data collected benefits all sectors of the kidney community.

3. **Monitoring and Evaluation**

To ensure that the strategy remains relevant and effective, there will be regular monitoring and evaluation:
- The UK Renal Health Data Research Network will publish an annual report on the progress of this strategy, including metrics on inclusivity, accountability, and transparency in data research.
- Continuous feedback from all stakeholders will be collected in order to refine and improve the strategy.

- Periodic assessments will measure the benefits of data-driven research to the UK kidney community.

4. **Conclusion**

This strategy aims to position the UK kidney community as a leader in data-driven research, not only through technical innovation but through a commitment to ethical principles. By prioritising education, inclusivity, accountability, and transparency, the community will ensure that data research contributes to meaningful improvement in kidney health outcomes. Collaboration across sectors, clear governance, and continuous investment in human capacity will be key to realising this vision.