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Kidney Disease Research and Clinical Data Reporting Standardization - Survey

Greetings,

Welcome to the Genetic Kidney Disease Research and Clinical Data Reporting Standardization survey!

Aim:

To review items proposed for a genetic kidney disease research and clinical data reporting standard.

Why?

Due to mass data generation, standardization is crucial to promote effective healthcare and research quality, particularly in the context of heterogeneous kidney diseases, to harmonize information captured regarding patients, diseases and research investigations.

Instructions:

1) Provide your email address and specify your profession and years of experience.
2) Indicate whether items are essential (E), optional (O) or not applicable (NA) in the context of genetic kidney disease reporting.
i) Clinicians will review patient- and disease-specific information from a clinical perspective.ii) Researchers will review study- and disease-specific information from a research perspective.iii) Those who function as both, will review patient-specific information from a clinical perspective and disease- and study-specific information from a research perspective.

*The survey will be anonymised and should take between 10 to 15 minutes.

About us
The Centre for Proteomic and Genomic Research (CPGR) is a non-profit organisation providing state-of-the-art 'omics' services to the life science and biotech communities in South Africa. As part of H3ABioNet, we aim to support the H3Africa consortium and broaden bioinformatics capacity in Africa. Please direct any queries to Dr Judit Kumuthini (judit.kumuthini@cpgr.org.za) or Lyndon Zass (lyndon.zass@cpgr.org.za).

Before we begin:

1 Email (institutional, if available): _____

2 What is your profession?
◯ Clinician
◯ Researcher
◯ Clinician & Researcher

3 Years of Experience
◯ 0 - 5 years
◯ 5 - 10 years
◯ 10 - 20 years
◯ > 20 years

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Participant/Patient-specific Information

From a clinical healthcare perspective, please indicate whether the following items are essential (E), optional (O) or not applicable (NA) to be captured with every patient case and (or) participant recruitment.

Participant/Patient-specific information refers to data to be routinely captured in patients and (or) study participants in order to improve clinical decision-making, reproducibility and interoperability, as well as participant selection, respectively.

1	Patient Identification (name and contact details)	◯ E ◯ O ◯ NA
2	Date of Birth	◯ E ◯ O ◯ NA
3	Laboratory Identifier (i.e name/address/weblink/code)	◯ E ◯ O ◯ NA
4	Health/Research Institute	◯ E ◯ O ◯ NA
5	Nationality	◯ E ◯ O ◯ NA
6	Residency	◯ E ◯ O ◯ NA
7	Sex	◯ E ◯ O ◯ NA
8	Ethnicity	◯ E ◯ O ◯ NA
9.a	Clinical Diagnosis	◯ E ◯ O ◯ NA

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9.b If E/O, please specify applicable clinical diagnoses:

- ☐ Adenine phosphoribosyltransferase (APRT) deficiency
- ☐ Alport syndrome
- ☐ Alström syndrome
- ☐ Bardet-Biedl syndrome
- ☐ Bartter syndrome
- ☐ Congenital nephrotic syndrome
- ☐ Cystinuria
- ☐ Dent disease
- ☐ Denys-Drash syndrome
- ☐ Distal renal tubular acidosis
- ☐ Ellis-van Creveld syndrome
- ☐ Fabry disease
- ☐ Familial amyloidosis
- ☐ Familial hypomagnesemia hypercalcuria with nephrocalcinosis (FHHNC)
- ☐ Focal Segmental Glomerulosclerosis
- ☐ Genetic SRNS
- ☐ Gitelman syndrome
- ☐ Glomerulonephritis
- ☐ IgA Nephropathy
- ☐ Joubert syndrome
- ☐ Kidney Stones
- ☐ Lowe syndrome
- ☐ Nephrogenic diabetes insipidus
- ☐ Nephronophthisis
- ☐ Nephropathic cystinosis
- ☐ Nephrotic Syndrome
- ☐ Oro-facial-digital syndrome
- ☐ Polycystic kidney disease
- ☐ Primary hyperoxaluria type 1
- ☐ Primary hyperoxaluria type 2
- ☐ Primary hyperoxaluria type 3
- ☐ Proximal renal tubular acidosis
- ☐ Renal Coloboma syndrome69, Renal cysts & diabetes (RCAD)
- ☐ X-linked hypophosphatemic rickets
- ☐ All
- ☐ Other

Specify "Other": _____

10.a Family History
(cases of genetic kidney disease in family)

◯ E ◯ O ◯ NA

10.b If E/O, please specify applicable family members:

- ☐ Aunt
- ☐ Brother
- ☐ Cousin
- ☐ Father
- ☐ Grandfather
- ☐ Grandmother
- ☐ Mother
- ☐ Sister
- ☐ Uncle
- ☐ All
- ☐ Other

Specify "Other": _____

11.a Diagnosis Method

◯ E ◯ O ◯ NA

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11.b If E/O, please specify applicable diagnosis methods:

- ☐ Blood tests
- ☐ Clinical/Physical examination
- ☐ Urine tests
- ☐ All
- ☐ Other

Specify "Other": _____

12.a Comorbidities (co-occurring diseases) ◯ E ◯ O ◯ NA

12.b If E/O, please specify most common comorbidities:

- ☐ Diabetes
- ☐ Cardiovascular Disease
- ☐ Neurological Deficits
- ☐ Peripheral Vascular Disease
- ☐ Respiratory Disease
- ☐ Urinary System Disease
- ☐ All
- ☐ Other

Specify "Other" _____

13.a Symptomolagy (symptoms patient exhibits) ◯ E ◯ O ◯ NA

13.b If E/O, please specify applicable symptoms:

- ☐ Anuria
- ☐ Dysuria
- ☐ Fatigue/Anaemia
- ☐ Hematuria
- ☐ Proteinuria
- ☐ Oedema
- ☐ Oliguria
- ☐ Persistent Nausea
- ☐ All
- ☐ Other

Specify "Other" _____

14.a Risk Factor Index (measures of modifiable risk factors) ◯ E ◯ O ◯ NA

14.b If E/O, please specify applicable measures and associated units:

- ☐ Alcohol use frequency (in weeks)
- ☐ Alcohol use frequency (in months)
- ☐ Blood pressure (in mmHg)
- ☐ Recreational Drug use frequency (in weeks)
- ☐ Recreational Drug use frequency (in months)
- ☐ Tobacco use frequency (in weeks)
- ☐ Tobacco use frequency (in months)
- ☐ Other

Specify "Other": _____

15.a Anthropometry (human body measurements) ◯ E ◯ O ◯ NA

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15.b If E/O, please specify applicable measures and associated units:

- ☐ BMI (in kg/m2)
- ☐ BMI (in kg/cm2)
- ☐ BMI (in pounds/ft2)
- ☐ BMI (in pounds/inches2)
- ☐ Height (in cm)
- ☐ Height (in m)
- ☐ Height (in ft)
- ☐ Height (in inches)
- ☐ Weight (in g)
- ☐ Weight (in kg)
- ☐ Weight (in pounds)
- ☐ Other

Specify "Other": _____

16.a Urine Test Index (results) ◯ E ◯ O ◯ NA

16.b If E/O, please specify applicable urine tests:

- ☐ Creatine Clearance
- ☐ Microalbuminuria
- ☐ Urinalysis
- ☐ Urine Protein
- ☐ All
- ☐ Other

Specify "Other": _____

17 Medication Inventory - Type and Dosage (according to The Drug Ontology) ◯ E ◯ O ◯ NA

18 Adverse Drug Reactions History (according to ADReCS) ◯ E ◯ O ◯ NA

19 Allergies ◯ E ◯ O ◯ NA

20.a Therapy History ◯ E ◯ O ◯ NA

20.b If E/O, please specify applicable therapies:

- ☐ Transplant Surgery
- ☐ Renal Replacement Therapy
- ☐ Other

Specify "Other": _____

21 Doctor Identification (name & contact number) ◯ E ◯ O ◯ NA

22 Are there any additional E/O items you might include under this field? Please provide reasoning for your choices. If need be, also provide commentary on the previously listed items. _____ (Any essential/optional items, you as professional might include under this field)

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Disease-specific Information

From a research/study perspective, please indicate whether the following items are essential (E), optional (O) or not applicable (NA) to be reported with regards to genetic kidney diseases.

Disease-specific information refers to information which provides context to a disease in question given a specific patient case or research study, ultimately providing better diagnosis and treatment, as well as clinical and research reporting.

1	Disease Investigated	◯ E ◯ O ◯ NA
2.a	Subtype	◯ E ◯ O ◯ NA
2.b	If E/O, please specify applicable subtypes:	☐ Acute ☐ Chronic ☐ Primary ☐ Secondary ☐ Type I ☐ Type II ☐ Type III ☐ All ☐ Other
	Specify "Other":	_____
3.a	Prevalence	◯ E ◯ O ◯ NA
3.b	If E/O, please specify prevalence context:	☐ Depends on disease ☐ In country of birth ☐ In country of residence ☐ In ethnicity/race ☐ All
4	Known Risk factors	◯ E ◯ O ◯ NA
5	Are there any additional E/O items you might include under this field? Please provide reasoning for your choices. If need be, also provide commentary on the previously listed items.	_____ (Any essential/optional items, you as professional might include under this field)

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Research/Study-specific Information

From a research/study perspective, indicate whether the following items are essential (E), optional (O) or not applicable (NA) with regards to genetic kidney disease research.

Research/Study-specific information refers to information to be reported to appropriately reproduce and interpret a given research/clinical investigation.

1.a	Study Design	◯ E ◯ O ◯ NA
1.b	If E/O, please specify applicable study designs:	☐ Animal Research Studies ☐ Case-control Study ☐ Case Reports and Series ☐ Cohort Study ☐ Cross-sectional study ☐ Meta-Analysis ☐ Randomized Controlled Trial ☐ Systematic Review ☐ Test-tube Lab Research ☐ All ☐ Other
	Specify "Other":	_____
2	Study Aim	◯ E ◯ O ◯ NA
3	Sample Number and Classification	◯ E ◯ O ◯ NA
4	Specimen Type/Source	◯ E ◯ O ◯ NA
5	Sample Collection, Storage & Shipping (management protocol/details)	◯ E ◯ O ◯ NA
6	Quality Control Procedures (e.g. NanoDrop; Bioanalyzer)	◯ E ◯ O ◯ NA
7	Protocol(s) Used	◯ E ◯ O ◯ NA
8	Instrumentation Used	◯ E ◯ O ◯ NA
9	Tertiary Data-Analyses Performed (pipelines, statistical tools used etc.)	◯ E ◯ O ◯ NA
10.a	Results	◯ E ◯ O ◯ NA
10.b	If E/O, please specify results context:	☐ Incidental findings ☐ Relative to experiments conducted ☐ Relative to study aim ☐ Relative to tertiary data-analyses ☐ All ☐ Other
	Specify "Other":	_____
11	Raw Data Files (location and access level)	◯ E ◯ O ◯ NA
12	Missing Data	◯ E ◯ O ◯ NA

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13 Are there any additional E/O items you might include under this field? Please provide reasoning for your choices. If need be, also provide commentary on the previously listed items.

_____
(Any essential/optional items, you as professional might include under this field)

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Additional Questions

1	Is a kidney disease clinical or research reporting standard currently being implemented at your institute?	◯ Yes ◯ No
	Please provide the standard's name and(or) link:	_____
	How is the standard implemented?	_____
	How strict is your institute regarding standard compliance?	◯ Minimum ◯ Average ◯ Maximum
	Who has access to the standard?	_____
2	Are any additional reporting standards implemented in your institute?	◯ Yes ◯ No
	Please provide standards' names and(or) links:	_____