

Example entry of The Minimum Information Required Guideline: Kidney Disease Research and Clinical Data Reporting (Version 1.0).				
Participant-level information				
Elements		Importance	Definition	
Demographics	Date of Birth		E 18-Jun-1979	
	Sex		E Male	
	Self-reported Race/Ethnicity		E South Asian	
	Country of Birth (COB)		E United Kingdom	
	Country of Residence		O Australia	
	Native Language(s)		E English	
	Tribal Affiliation		O -	
	Father's Country of Birth		O Kenya	
	Mother's Country of Birth		O Tanzania	
Lifestyle Factors	History of Hypertension	Has a healthcare worker ever said that you have high blood pressure or hypertension?	E Yes	
		If yes, then at what age were you first told this?	E 34	
		FOR WOMEN ONLY: Was this during pregnancy?	E N/A	
		Have you ever taken medication for hypertension / high blood pressure?	E Yes	
		If yes, then at what age did you begin taking medicine for this?	E 34	
	Physical Activity	7-Day Frequency	E	7
		Time		45 min
		Intensity		Strenuous
	Alcohol Use	Lifetime Use	E	Current
		Age of Initiation		18
		30-Day Frequency		4
		30-Day Quantity		4
	Tobacco Use	Lifetime Use	E	Never
		Lifetime Frequency		N/A
		Age of Initiation		N/A
	Lifetime Use	E	Never	

	Recreational Drug Use	Age of Initiation		N/A	
		30-Day Type		N/A	
		30-Day Frequency		N/A	
Anthropometrics	Average Height		E	165	
	Average Weight		E	65	
	Waist Circumference		O	80	
	Head Circumference		O	57.5	
	Body Surface Area		O	1.66	
	Prosthesis (if applicable)		E	None	
Blood Pressure	Average Systolic Blood Pressure		E	120	
	Average Diastolic Blood Pressure			75	
Adverse Drug Reactions	Medication		O	None	
	Type			N/A	
	Date			N/A	
Urine-Related Test Index	Urinary Albumin		E	650	
	Urinary Creatinine		E	7.3	
	Urinary Total Protein		E	1100	
	Serum Albumin		O	-	
	Serum Creatinine		O	94	
	Serum Urea		O	6.0	
	Estimated Glomerular Filtration Rate (eGFR)		E	88ml/min/1.73m ²	
Kidney Disease History	Personal History of Kidney Failure	Has a doctor or healthcare worker ever told you that you had kidney failure?	E	Yes	
		How old were you when you were first told by a medical person that you had kidney failure?		34	
		If Yes, are one or both working well now?		Yes	
		Are you currently on renal dialysis?		No	
		Have you ever had a kidney transplant?		No	
	Family History of Kidney Failure	Has anyone in your family either had kidney disease or died from it?		E	Yes
		Do you know what type of kidney disease?			No
		If Yes, please specify:			N/A

	Consanguinity	Any cases of consanguineous mating in the family?	O	No
		'If Yes, please specify:'		N/A
Sample-specific Information	Sample Identifier		E	10101010_9A9A
	Sample's Case or Control Status		O	N/A
	Consent		E	Yes
Kidney Disease-related Information	Clinical Diagnosis		E	Chronic Kidney Disease Stage 2P
	Date of Diagnosis		E	01-Jul-2016
	Instrumentation		E	None
	Clinical Signs and Symptoms		E	Chronic Microscopic Haematuria Chronic Proteinuria
	Congenital Conditions		O	None
	Histopathology		O	-
	Co-morbidities (Systemic)		E	Hypertension
	Co-morbidities (Pathogenic)		E	None
	Allergies		O	None
Prescribed Medication	Medication		E	Losartan
	Dosage			37.5
	Strength			Once Daily, PO
	Reason			Hypertension
	Start Date			01-Jul-2016
	Stop Date			Ongoing
Non-Prescribed Medication	Medication		E	None
	Dosage			N/A
	Reason			N/A
	Start Date			N/A
	Stop Date			N/A
Therapy	Therapy		E	None
	30-Day Frequency			N/A
	Start Date			N/A
	End Date			N/A
	End Date			N/A

Study-level information			
Study-specific information	Research Institute	E	Australian Genomics Health Alliance
	Study Duration	O	5
	Study Start Date	O	01-Jan-2016
	Study ID	E	HREC/16/MH/251 – Amendment Approved 16 th June 2017
	Disease	E	Cancer and Rare Disease – Inherited Kidney Disease Substudy
	Clinical Subtype	O	Genetic or Heritable Kidney Disease
	Study Design	E	Observational Study
	Study Aim	E	To characterise phenotypes, genotypes and clinical outcomes
	Sample Size	E	361
	PMID	O	-
DOI	O	-	
Experiment-level information			
General	Biospecimen Type	E	DNA
	Sample Management Protocol	E	Australian Genomics Health Alliance, Protocol V9
	Quality Control Protocol	E	Australian Genomics Health Alliance, Protocol V9
	Experimental Aim	E	To identify genetic causes and aetiologies for kidney disease
	Experimental Protocol	E	Whole exome sequencing with analysis of known inherited kidney disease genes
	Instrumentation	E	Illumina HiSeq XTen RStudio 1.1.456
	Data Analysis	E	11-Nov-2017
	Experimental Result	E	No variant identified
	Output Location	O	AGHA KidGen Flagship RedCap Database; Royal Brisbane and Women's Hospital clinical records
Footnote: E – Essential; N/A – Not Applicable; O – Optional			