

## Registry linkage in the 3C Study

As stated in the protocol, the 3C Study will use linkage to routinely collected data in the UK to follow participants for the long-term. One such registry is the Hospital Episode Statistics registry which collects information on all hospitalizations in England. HES records detailed information about hospital admissions including patient demographics, dates of admission and discharge, admitting speciality, the primary diagnosis and important secondary diagnoses (coded using the International Statistical Classification of Diseases and Related Health Problems [ICD]) and all procedures accompanied by their dates (coded using the Office of Population Censuses and Surveys [OPCS]). These data have not been widely used for trial purposes before, so we wished to validate their use.

The cause of kidney failure (primary renal diagnosis) was collected for all participants in the 3C Study, based on a study nurse report. A common cause of kidney failure is autosomal dominant polycystic kidney disease (ADPKD) which has suitable ICD codes such that it should be readily identifiable in HES data. It is an inherited condition so should appear in any hospitalisation episode before or after transplantation. We compared a reported primary renal diagnosis of ADPKD among participants randomized at English centres with reports of ADPKD from HES data for the same participants.

**Table: 2 x 2 table of agreement of the recording of APKD.  
Comparison from 3C database and all-England HES**

		ADPKD recorded as a diagnosis in all-England HES <sup>†</sup>		
		Yes	No	Totals
Cystic kidney disease recorded as primary cause of ESRD* in 3C	<b>Yes</b>	108	1	109
	<b>No</b>	15	529	544
	<b>Totals</b>	123	530	<b>653</b>

**Kappa Statistic = 0.92 (95% CI 0.88-0.96)**

\* ESRD=End stage renal disease

† ICD-10 terms "Q612" and "Q613" mentioned in any position in any hospital spell

This table shows excellent agreement between these two data sources, supporting the use of HES in the 3C Study. Further validation studies are ongoing.