

Supplementary Material and Methods

Supplementary Table 1. Question guide

- What are your experiences (or thoughts) of genetic counselling/screening for ADPKD - in people who don't have symptoms but are at risk (i.e. because it is known to occur in the family)?
- What advantages (kidney donation, family planning)/disadvantages (anxiety, financial/insurance, uncertainty of the future) do you think are important when/if you make decisions about genetic screening - why?
- What about for children/family members? Do you think prenatal counselling would be useful/helpful?
- What are some of the emotional, ethical/moral issues around genetic testing for ADPKD?

Supplementary Table 2. Attendance in focus groups

Group ID	Country	N
1	Australia	9
2	Australia	10
3	Australia	6
4	Australia	9
5	Australia	10
6	Australia	6
7	Australia	8
8	Australia	7
9	Australia	7
10	Australia	13
11	France	6
12	France	12
13	France	11
14	France	11
15	Korea	12
16	Korea	8
17	Korea	9