

Supplementary Online Section

Table S1: Tabulated demographics and diagnostic information for each semi-structured interviewee

Participant ID	Patient /parent	Gender of PCD patient	Country	Diagnosis	Situs abnormality	Congenital heart defect	Age at testing	Time waiting for results	No. of visits to doctor
001	Patient	Male	UK	Positive	No	No	>65	<1 day	>40
002	Parent	Female	UK	Positive	No	No	5-12	<6 months	21-40
003	Parent	Male	Ireland	Inconclusive	Yes	Yes	0-4	>1 year	0
004	Parent	Female	UK	Positive	No	No	0-4	<1 day	11-20
005	Parent	Male	UK	Inconclusive	No	No	0-4	Still waiting	21-40
006	Patient	Female	UK	Positive	No	No	36-50	<6 months	>40
007	Patient	Female	UK	Negative	No	No	51-65	<6 months	1-10
008	Patient	Male	UK	Inconclusive	No	No	>65	<1 month	0
009	Patient	Female	US	Positive	No	No	36-50	6-12 months	>40
010	Parent	Female	UK	Positive	No	No	5-12	6-12 months	>40
011	Patient	Male	Switzerland	Positive	No	No	51-65	>1 year	>40
012	Patient	Female	Bulgaria	Probable*	No	No	18-35	>1 year	>40
013	Parent	Female	Spain	Positive	No	No	5-12	<6 months	21-40
014	Parent	Male	US	Positive	No	No	13-17	< 1 week	21-40
015	Parent	Female	US	Positive	Yes	No	5-12	<1 year	21-40
016	Patient	Female	Canada	Positive	No	No	36-50	<1 year	0
017	Parent	Female	US	Positive	Yes	No	5-12	6-12 months	1-10

018	Parent	Female	US	Positive	No	No	18-35	<1 week	0
019	Parent	Female	Australia	Positive	Yes	No	0-4	<6 months	0
020	Parent	Female	Denmark	Positive	No	No	0-4	<1 month	21-40

*Probable based on doctors assessment but not formally tested

Table S2: Comparing age at diagnostic testing, time taken to receive test results, the number of visits to the doctor before referrals, and the type diagnostic tests completed in USA, Germany and UK.

	USA Total 66 (100%)	Germany Total 77 (100%)	UK Total 45 (100%)	p-value
Age at initial testing				
< 1 year old	13 (19.7%)	-	8 (17.8%)	<0.001
> 1 year old	49 (74.2%)	68 (88.3%)	32 (71.1%)	
Missing	4 (6.1%)	9 (11.6%)	5 (11.1%)	
Average age at initial testing in years (+/- SD)	7.43 years (+/- 8.18)	9.86 (+/- 11.63)	14.95 (+/- 21.05)	0.026
Congenital heart defect	6 (9.1%)	6 (7.79%)	9 (20%)	0.90
Situs inversus	30 (45.5%)	40 (51.9%)	16 (35.6%)	0.17
Number of visits to doctor before diagnosis				
<40 visits	37 (56.1%)	50 (64.9%)	34 (75.5%)	0.050
≥40 visits	29 (43.9%)	27 (35.1%)	11 (24.4%)	
Time to diagnosis				
<1 month	21 (31.8%)	33 (42.9%)	14 (31.1%)	0.195
>1 months	30 (45.5%)	26 (33.8%)	21 (46.6%)	
Missing	15 (22.7%)	18 (23.4%)	10 (22.2%)	
Diagnostic test: Nno	34 (51.5%)	36 (46.8%)	27 (60.0%)	0.369
Diagnostic test: nasal scraping	52 (78.8%)	58 (75.3%)	41 (91.1%)	0.099
Diagnostic test: bronchoscopy	27 (40.9%)	39 (50.7%)	5 (11.1%)	<0.001
Diagnostic test: genetics	38 (57.6%)	32 (41.6%)	8 (17.8%)	<0.001
Diagnostic test: saccharine	4 (6.1%)	3 (3.9%)	6 (13.3%)	0.132
Diagnostic test: nuclear medicine scan	3 (4.5%)	3 (3.9%)	1 (2.2%)	0.813
Diagnostic test: X-ray or CT scan alone	25 (37.9%)	1 (1.3%)	0 (0%)	0.159
Diagnosis based on symptoms only	1 (1.5%)	7 (9.1%)	0 (0%)	0.022

Diagnostic test: Not sure	1 (1.5%)	4 (5.2%)	0 (0%)	0.783
Diagnostic test: other	4 (6.1%)	0 (0%)	0 (0%)	0.260