

Demographic data for parents/caregivers and their children who participated in interviews.

Data were available for 24 parents/caregivers as follows: Cs01= 9; Cs02= 8; Cs03= 6; Cs04= 1

N=24		
Gender of participant	F n=18 M n=6	
Age of parent /caregiver	25-34 n=6 35-44 n=5 45-54 n=9 55-64 n=2 65+ n=2	
Relationship with child	Biological parent n=21 Adoptive/foster parent n=3	
Living arrangements	Living with partner n=20 Living with other family members n=3 Living with friends n=1	
Child lives with caregivers	Yes n=23 No n=1	
Highest educational level	No formal education n=4 GCSE O Level n=4 NHD, Diploma, professional qualification n=9 Bachelor's degree n=5	
Occupation using ONS SOC 2010 version 7	Corporate manager/Director n=1 Health Professionals n=4 Teaching & Education Professionals n=1 Science Engineering & Technology n=2 Administrative /secretarial n=2 Caring Leisure & other service occupations n=7 Elementary trades and related occupations n=1 Missing n=5	
Ethnicity	White (UK, Irish, traveller, other) n=22 Asian, Asian British n=1 Black (African Caribbean, Black British, other) n=1	
Age of Child	0-4 n=4 5-9 n=10 10-14 n=9	

	Missing n=1	
Primary diagnosis of child	Cerebral palsy	n=13
	Rare disease/syndrome	n=6
	Other	n=5
Amount of time child had a gastrostomy	0-11 months	n=2
	1-4 yrs	n=2
	5-9 yrs	n=5
	10-14 yrs	n=3
	Children without gastrostomy	n=5

Professionals who participated in the economic costings survey and interviews who contributed demographic data n=48

Schools n=6

Teaching assistant, 2
Support worker 1
Principal teacher 1
School nurse, 2

Community Nursing n=4

Community Children's nurse 3
Health visitor, 1

Psychology n=2

Child Clinical psychologist 1
Clinical psychologist 1

Dietetics n=7

Paediatric/specialist/community dietician 6,
Nutrition nurse specialist 1

SLT n=7

SLT/dysphagia 7

Gastroenterology/surgery n=10

Consultant paediatric gastroenterology 1
Consultant Paediatric surgeon 4
Paediatric surgical nurse specialist 3
Children's gastroenterologist nurse 2

Consultant Paediatrician/disability consultant n=9

Other n=3

Children's disability social worker 1
Senior nurse in charge 1
Service manager 1

Gender: Male 7 : Female 45

Age Range

25-34 n=9

35-44 n=17

45-54 n=16

55-64 n=6

Ethnicity:

White (UK,Irish, traveller, other) n=47

Asian/ Asian British (Indian, Pakistani, Bangladeshi, Chinese, other n=1

Demographic characteristics of participants in Willingness to Pay study

Demographic	Attribute	n(%)
Sex	Male	6(6%)
	Female	86(91%)
	Do not identify as male or female	3(3%)
	Total	95
Age bands	16-24	1(1%)
	25-34	24(25%)
	35-44	28(30%)
	45-54	28(30%)
	55-64	13(14%)
	65+	0(0%)
	Total	94
Highest Education Level	GCSE, CSE, GCE O Levels or equivalent	6(6%)
	GCE A Levels, HNC, GNVQ or equivalent	3(3%)
	HND, other Diploma, professional qualification or equivalent	3(3%)
	Bachelor's degree (e.g. BSc, BA)	43(46%)
	Masters or Doctoral degree	38(40%)
	Other (please specify)	1(1%)
	Total	94
Employment Status	Paid employment	76(81%)
	Unemployed	1(1%)
	Unable to work as I am looking after a child/or other dependents	10(11%)
	Unable to work due to long term illness or disability	0(0%)
	In full educational training	3(3%)
	Other (please specify)	4(4.26%)
	Total	94
Annual Household Income	<£20,000	7(8%)
	£20,000-£39,000	16(18%)
	£40,000-£59,000	25(28%)
	£60,000-£79,000	20(22%)
	£80,000-£99,000	8(9%)

	£100,000-£149,000	10(11%)
	>£150,000	4(4%)
	Total	90
Country	England	74(80%)
	Wales	3(3%)
	Scotland	15(16%)
	Total	92
Ethnicity	English/Welsh/Scottish/Northern Irish/British	69(77%)
	Irish	3(3%)
	Gypsy or Irish Traveller	1(1%)
	Other White Background	1(1%)
	White and Asian	1(%)
	Indian	2(2%)
	Pakistani	1(1%)
	Chinese	1(1%)
	Arab	2(2%)
	Other Ethnic Group	1(1%)
	Total	90