

Results of survey –unweighted and weighted

Demographic Data				
	Unweighted		Weighted	
	N	%	N	%
Sex				
Male	504	45%	544	49%
Female	606	55%	566	51%
Socioeconomic Group				
A	41	4%	44	4%
B	215	19%	244	22%
C1	311	28%	322	29%
C2	233	21%	233	21%
D	145	13%	178	16%
E	165	15%	89	8%
Age				
18-24	135	12%	133	12%
25-34	184	17%	189	17%
35-44	198	18%	200	18%
45-54	184	17%	189	17%
55-64	176	16%	167	15%
65+	233	21%	233	21%
Occupation				
Higher managerial	41	4%	44	4%
Intermediate managerial	215	19%	244	22%
Supervisory or clerical level	288	26%	299	27%
Student	23	2%	23	2%
Skilled manual worker	233	21%	233	21%
Semi or unskilled manual work	145	13%	178	16%
Casual worker	12	1%	6	1%
Housewife	9	1%	5	0%
Retired	81	7%	45	4%
Unemployed	46	4%	24	2%
Carer	17	2%	9	1%
Other	0	0%	0	0%
Region				
Channel Islands	0	0%	0	0%
East of England	92	8%	100	9%
East Midlands	57	5%	78	7%
London	213	19%	144	13%

Appendix IV

Results of survey –unweighted and weighted

North East	40	4%	44	4%
North West	121	11%	122	11%
Northern Ireland	30	3%	33	3%
Scotland	76	7%	89	8%
South East	165	15%	155	14%
South West	81	7%	89	8%
Wales	51	5%	55	5%
West Midlands	94	8%	100	9%
Yorkshire/Humberlands	90	8%	100	9%
Not on map	0	0%	0	0%
Ethnicity				
White or White British	1057	95%	1065	96%
Mixed race	7	1%	8	1%
Asian or Asian British (not Chinese)	18	2%	17	1%
Black or Black British	19	2%	12	1%
Chinese	2	0%	2	0%
Other ethnic group	4	0%	2	0%
Prefer not to say	3	0%	2	0%
Religion				
Christianity	677	61%	673	61%
Islam	13	1%	11	1%
Hinduism	6	1%	6	1%
Sikhism	0	0%	0	0%
Judaism	6	1%	4	1%
Buddhism	11	1%	1	0%
Other religion	15	1%	8	0%
No religion	370	33%	205	38%
Prefer not to say	12	1%	7	1%
To what extent do you consider yourself religious?				
Not at all religious	234	32%	234	32%
Moderately religious	422	58%	424	59%
Very religious	64	9%	56	8%
Prefer not to say	8	1%	7	1%
Education				
No formal qualification	70	6%	66	6%
GCSE, O level, Scottish Standard Grade or equivalent	264	24%	252	23%
GCE, A-level, Scottish Higher or similar	214	19%	214	19%
Vocational (BTEC/NVQ/Diploma)	230	21%	237	21%

Results of survey –unweighted and weighted

Degree level or above	317	29%	330	30%
Prefer not to say	15	1%	10	1%

Q9 How would you describe your own level of knowledge about the medical research process including the use of human tissue samples?

	Unweighted		Weighted	
	N	%	N	%
No knowledge	463	42%	466	42 %
Some knowledge	603	54 %	602	54 %
Good knowledge	44	4 %	43	4 %

Q10 Are you or have you ever been affected by a long-standing illness, disability or infirmity which has required continuous or frequent medical attention

	Unweighted		Weighted	
	N	%	N	%
Yes	399	36 %	391	35%
No	711	64 %	719	65%

Q11 Has a close family member ever been affected by a long-standing illness, disability or infirmity which has required continuous or frequent medical attention

	Unweighted		Weighted	
	N	%	N	%
Yes	767	69 %	765	69%
No	343	31 %	345	31%

Q12 Have you ever had blood or tissue removed during a medical or surgical procedure?

	Unweighted		Weighted	
	N	%	N	%
Yes	446	40 %	444	40%
No	553	50 %	551	50%
Don't Know	111	10 %	115	10%

Q13 Have you ever been asked to donate any blood or tissue for medical research?

	Unweighted		Weighted	
	N	%	N	%
Yes	182	16 %	177	16%
No	904	81 %	907	82%
Don't Know	24	2 %	25	2%

Results of survey –unweighted and weighted

Q14 Did you agree to donate?				
	Unweighted		Weighted	
	N	%	N	%
Yes	155	85 %	153	86%
No	23	13 %	21	12%
Don't Know	4	2 %	3	2%

Q15 On a scale of 1 to 5 with 1 being Not At All Important and 5 being Extremely Important, how important do you think it is for people to donate samples for medical research?				
	Unweighted		Weighted	
	N	%	N	%
1 Not at all important	5	0 %	4	0%
2	10	1 %	9	1%
3	78	7 %	76	7%
4	406	37 %	408	37%
5 Extremely important	554	50 %	567	51%
Don't know	57	5 %	46	4%

Q16 In general, would you like to be asked to donate samples for medical research?				
	Unweighted		Weighted	
	N	%	N	%
Definitely yes	317	29 %	327	29%
Probably yes	513	46 %	526	47%
Probably not	157	14 %	145	13%
Definitely not	42	4 %	35	3%
Don't know	81	7 %	77	7%

Q17 Would you donate the following types of samples for medical research if they were left over following the procedure?											
		Unweighted					Weighted				
		Def yes	Prob yes	Prob not	Def not	Don't know	Def yes	Prob yes	Prob not	Def not	Don't know
Blood	N	587	433	48	23	19	599	425	48	20	8
	%	53%	39%	4%	2%	2%	54%	38%	4%	2%	2%
Skin Tissue	N	520	451	72	32	35	533	451	67	28	32

Appendix IV

Results of survey –unweighted and weighted

	%	47%	41%	6%	3%	3%	48%	41%	6%	3%	3%
Fat	N	530	450	60	32	38	541	449	56	26	37
	%	48 %	41%	5%	3%	3%	49%	40%	5%	2%	3%
Cancerous Tissue	N	572	425	52	26	35	586	420	49	22	34
	%	52 %	38%	5%	2%	3%	53%	38%	4%	2%	3%
Liver Tissue	N	463	468	100	38	41	474	476	96	34	39
	%	42 %	42%	9%	3%	4%	43%	42%	9%	3%	4%
Bone or Cartilage	N	472	460	90	46	42	482	460	87	41	40
	%	43 %	41%	8%	4%	4%	43%	41%	8%	4%	4%
Spare eggs not fertilised during IVF *	N	133	159	121	104	89	128	149	111	93	86
	%	22 %	26%	20%	17%	15%	23%	26%	20%	16%	15%
Spare embryos	N	225	245	217	223	200	230	254	210	213	203
	%	20 %	22%	20%	20%	18%	21%	23%	19%	19%	18%

*Female Only

Q18 Would you agree to donate the following samples specifically for medical research?

		Unweighted					Weighted				
		Def yes	Prob yes	Prob not	Def not	Don't know	Def yes	Prob yes	Prob not	Def not	Don't know
Saliva	N	568	423	54	30	35	581	413	55	27	34
	%	51 %	38%	5%	3%	3%	52%	37%	5%	2%	3%
Urine	N	553	432	61	33	31	566	424	60	30	30
	%	50 %	39%	5%	3%	3%	51%	38%	5%	3%	3%
Blood	N	455	448	118	47	42	496	446	107	46	42
	%	41 %	40%	11%	4%	4%	42%	40%	10%	4%	4%
Tissue collected requiring a local anaesthetic	N	273	463	197	100	77	283	471	190	88	78
	%	25 %	42%	18%	9%	7%	26%	42%	17%	8%	7%
Tissue collected	N	166	286	310	235	113	172	300	309	214	115

Appendix IV

Results of survey –unweighted and weighted

Understanding how our body fights disease	N	390	558	72	27	63	399	554	71	24	62
	%	35 %	50%	6%	2%	6%	36%	50%	6%	2%	6%
Understanding how our genetic makeup...	N	305	558	115	47	85	312	564	107	43	83
	%	27 %	50%	10%	4%	8%	28%	51%	10%	4%	8%
Research that is testing new treatments	N	318	511	132	52	97	325	502	133	50	99
	%	29 %	46%	12%	5%	9%	29%	45%	12%	5%	9%
Research involving cells from embryos	N	157	304	228	214	207	167	319	225	199	200
	%	14 %	27%	21%	19%	19%	15%	29%	20%	18%	18%
Research involving animals	N	107	270	281	318	134	117	285	271	304	132
	%	10%	24%	25%	29%	12%	11%	26%	24%	27%	12%
Research outside the UK	N	109	273	350	199	179	115	277	349	199	170
	%	10 %	25%	32%	18%	16%	10%	25%	31%	18%	15%

Q22 Would you be willing to donate samples to be used by the following organisations?

		Unweighted					Weighted				
		Def yes	Prob yes	Prob not	Def not	Don't know	Def yes	Prob yes	Prob not	Def not	Don't know
NHS Hospitals	N	367	570	69	31	73	379	569	65	28	70
	%	33 %	51%	6%	3%	7%	34%	51%	6%	2%	6%
Universities	N	243	515	185	56	111	255	519	173	54	108
	%	22 %	46%	17%	5%	10%	23%	47%	16%	5%	10%
Medical Research Charities	N	307	563	107	41	92	311	561	108	39	91
	%	28 %	51%	10%	4%	8%	28%	51%	10%	4%	8%
Pharmaceutical Companies	N	138	487	233	93	159	139	490	227	95	161
	%	12 %	44%	21%	8%	14%	12%	44%	20%	9%	14%
Diagnostic Companies	N	187	515	180	74	154	182	511	183	74	159
	%	17 %	46%	16%	7%	14%	16%	46%	17%	7%	14%

Q23 How important do you think it is that you are first asked for your permission (often known as 'consent') for any leftover samples to be used for medical research?

	Unweighted	Weighted
--	------------	----------

Results of survey –unweighted and weighted

	N	%	N	%
1 Not at all important	40	4 %	42	4%
2	41	4 %	43	4%
3	104	9 %	103	9%
4	274	25 %	268	24%
5 Extremely important	615	55 %	614	55%
Don't know	36	3 %	40	4%

Q24 How important do you think it is that you are first asked for your permission (often known as 'consent') for any leftover samples to be used for medical research?

	Unweighted		Weighted	
	N	%	N	%
Opt-in	605	55 %	598	54%
Opt-out	308	28 %	321	29%
No preference	151	14 %	146	13%
Don't know	46	4 %	45	4%

Q25 Which of these three approaches do you prefer?

	Unweighted		Weighted	
	N	%	N	%
Consent every time	472	43 %	480	43%
Consent once for life	231	21 %	237	21%
Consent at certain points	301	27 %	298	27%
No preference	82	7 %	72	7%
Don't know	24	2 %	22	2%

Q26 If you were going to be asked to donate left over samples for medical research every time you had a medical procedure, would you rather this was discussed with you by a health professional before the medical procedure or afterwards?

	Unweighted		Weighted	
	N	%	N	%
Before	897	81 %	908	82%
After	48	4 %	48	4%
No preference	151	14 %	142	13%
Don't know	14	1 %	12	1%

Q27 If a consent once for life system was in place, when would you prefer to be asked about consenting left over samples for medical research?

	Unweighted		Weighted	
	N	%	N	%
When registering at a GP surgery	425	39 %	419	38%
During a routine GP appointment	386	35 %	380	34%
When applying for a driving license	83	8 %	88	8%
When applying for a passport	75	7 %	80	7%
The first time I visit the hospital	233	21 %	228	21%
The first time I have a medical procedure	513	47 %	510	46%

Q28 If a consent once for life system was in place, when would you prefer to be asked about consenting left over samples for medical research?

	Unweighted		Weighted	
	N	%	N	%
Face to face with a health professional	720	65 %	727	65%
Letter	66	6 %	64	6%
Email	30	3 %	32	3%
Telephone	14	1 %	13	1%
Via a website	60	5 %	61	6%
Completing a form and returning it by post	161	15 %	160	14%
Other (please specify)	4	0 %	4	0%
Don't know	55	5 %	49	4%

Q29 If you later decided you didn't want your samples to be used for medical research, what would be your preferred way to withdraw that consent?

	Unweighted		Weighted	
	N	%	N	%
Face to face with a health professional	421	38 %	424	38%
Letter	95	9 %	92	8%
Email	89	8 %	93	8%
Telephone	56	5 %	51	5%
Via a website	137	12 %	144	13%
Completing a form and returning it by post	243	22 %	244	22%
Other (please specify)	8	1 %	6	1%
Don't know	61	5 %	55	5%

Q30 How likely would you be to donate samples for medical research using the following models of consent?

		Unweighted					Weighted				
		Def yes	Prob yes	Prob not	Def not	Don't know	Def yes	Prob yes	Prob not	Def not	Don't know
Generic	N	216	528	163	64	139	228	538	154	52	38

Results of survey –unweighted and weighted

	%	19 %	48%	15%	6%	13%	21%	48%	14%	5%	12%
Tiered	N	242	549	125	55	139	244	560	124	49	133
	%	22 %	49%	11%	5%	13%	22%	50%	11%	4%	12%
Specific	N	336	553	88	28	105	339	551	89	29	102
	%	30 %	50%	8%	3%	9%	31%	50%	8%	3%	9%
Specific consent for every new study	N	293	560	110	27	120	300	560	109	26	115
	%	26 %	50%	10%	2%	11%	27%	50%	10%	2%	10%

Q31 Which of these four types of consent do you prefer?				
Generic				
Preferences	Unweighted		Weighted	
	N	%	N	%
1 st	200	18%	207	19%
2 nd	159	14%	163	15%
3 rd	168	15%	168	15%
4 th	344	31%	327	30%
Tiered				
1 st	156	14%	152	14%
2 nd	246	22%	252	23%
3 rd	360	32%	355	32%
4 th	105	10%	106	10%
Specific (once only)				
1 st	198	18%	183	17%
2 nd	306	28%	304	27%
3 rd	202	18%	209	19%
4 th	161	15%	169	15%
Specific (every time)				
1 st	341	31%	323	29%
2 nd	157	14%	146	13%
3 rd	138	12%	133	12%
4 th	258	23%	263	24%
Don't Know	63	6%	62	6%
No Preference	181	16%	183	17%

Q32 If your preferred system of consent was not available, what would you do?				
	Unweighted		Weighted	
	N	%	N	%
I would agree to give generic consent	348	52 %	350	53%
I would rather my sample was not used at all	187	28 %	172	26%
Don't know	133	20 %	135	21%

Q33 If there was a sample that you considered to be sensitive, but were still willing to donate for medical research, which of the four types of consent would you prefer to give?

	Unweighted		Weighted	
	N	%	N	%
Generic Consent	131	12 %	135	12%
Tiered Consent	105	9 %	101	9%
Specific Consent – once only	246	22 %	228	21%
Consent for every new study	278	25 %	288	26%
No Preference	206	19 %	216	19%
Don't Know	144	13 %	142	13%

Q34 Would you be willing to have your anonymised medical records linked to your sample?

	Unweighted		Weighted	
	N	%	N	%
Definitely yes	266	24 %	279	25%
Probably yes	493	44 %	497	45%
Probably not	165	15 %	157	14%
Definitely not	77	7 %	71	6%
Don't know	109	10 %	107	10%

Q35 Would you be willing to have your anonymised lifestyle information linked to your sample?

	Unweighted		Weighted	
	N	%	N	%
Definitely yes	377	34 %	398	35%
Probably yes	530	48 %	527	47%
Probably not	90	8 %	90	8%
Definitely not	48	4 %	43	4%
Don't know	65	6 %	61	5%

Q36 How would you like to get information on medical research including research on a particular condition that might use your sample?

	Unweighted		Weighted	
	N	%	N	%
Website	295	27 %	304	27%
Newsletter	104	9 %	97	9%
Email	302	27 %	315	28%
Letter	241	22 %	228	21%
Would not be interested in additional information	168	15 %	166	15%

Q37 Are there any particular organs you would not feel comfortable donating in the event of your death?				
	Unweighted		Weighted	
	N	%	N	%
Brain	337	31%	329	30%
Eyes	307	28%	308	28%
Heart	128	12%	121	11%
Kidneys	60	5 %	59	5%
Liver	68	6 %	65	6%
Lungs	67	6%	63	6%

Q38 If you were considering donating whole organs for medical research in the event of your death, are there any particular organs you would not feel comfortable donating?				
	Unweighted		Weighted	
	N	%	N	%
Yes, I would donate an organ for research if it was not suitable for transplant	755	68 %	766	69%
No, if they can't be used for transplant I would prefer they were not used at all	125	11 %	121	11%
I would not agree to donate an organ for transplant	96	9 %	95	9%
Don't know	134	12 %	128	12%

Q39 Would you be willing to have your anonymised lifestyle information linked to your sample?)				
	Unweighted		Weighted	
	N	%	N	%
It should be obtained at the same time as consent for organ transplantation and recorded on the organ donor register	580	52 %	579	52%
It should be discussed at a GP appointment and recorded in the patients' notes	270	24 %	267	24%
It should be discussed at a hospital and recorded in the patients' notes	140	13 %	143	13%
Other	13	1 %	14	1%
Don't know	107	10 %	108	10%

Q40 Would you be willing to have your anonymised lifestyle information linked to your sample?)				
	Unweighted		Weighted	
	N	%	N	%
Yes	174	16 %	166	15%
No	789	71 %	800	72%
Don't know	147	13 %	144	13%

Appendix IV

Results of survey –unweighted and weighted

Note: percentages may not add up to 100% due to rounding.