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# Update to Survey of Public Attitudes to Organ Donation: Key figures from Wave 16

# **Update Report**

# **Background**

The Human Transplantation (Wales) Act received Royal Assent on 10 September 2013. The Act introduced a soft opt-out system for consent to deceased organ and tissue donation in Wales, which came into effect on 1 December 2015.

An ongoing communications campaign is being undertaken by the Welsh Government to ensure members of the public are fully informed about what the changes mean and the choices they can make. In order to monitor the effectiveness of the campaign and inform its development, information is required on public awareness and understanding of organ donation law, and attitudes to changes in the legislation in Wales.

To meet these research needs, the Welsh Government has commissioned questions in the Wales Omnibus Survey, conducted by Beaufort Research Ltd. Data are being collected at six-monthly intervals between September 2017 and March 2020, building on the work undertaken as part of the evaluation of the Human Transplantation (Wales) Act and updates on these data are published.

Fieldwork for wave 16 was conducted between 17 and 30 September 2018 (1,015 respondents). A few interviews were conducted after these dates. The survey is designed to be representative of the population resident in Wales aged 16 years and over. The questions asked in this wave of the survey are included at Annex 2. Details of methods used have been published previously<sup>1</sup>.

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<sup>&</sup>lt;sup>1</sup> Public attitudes to organ donation

# **Key findings**

## Awareness and understanding of the current organ donation system

- Respondents were asked, unprompted, if they were aware of the current system of organ donation. Nearly nine out of ten (86 per cent) reported that they were aware of the current system, this had increased from 82 per cent in wave 15. In previous waves of the survey, respondents were asked, unprompted, if they were aware of any changes that have taken place to the organ donation system. As the system has been in place for two years now, the wording of the question has been amended. Whilst not strictly comparable due to the change in the wording, it is interesting to note that 70 per cent reported that they were aware of changes in wave 14².
- As Table 1 in annex 1 shows, females, and those in the social grades ABC1 were more likely to report that they were aware of the current system. Those aged 16 – 24 were less likely to report awareness.
- Respondents who reported they were aware of the current system of organ donation were asked how they thought the system works. This question was unprompted. Table 2 in annex 1 shows that three quarters (75 per cent) correctly outlined how the system works. This was slightly lower that in the previous wave, where 79 per cent correctly outlined how the system works. There was a small difference in understanding of the system between genders, with slightly more women correctly identifying how the system works than men (77 percent of women, 73 per cent of men). A lower proportion of those in social grades C2DE correctly identified how the system works (69 per cent compared to 80 per cent of those in social grades ABC1). With regards to age, there was very little difference in understanding across the age groups
- All respondents were shown a description of the current system of organ donation and asked if they had previously seen or heard anything about it. Almost eight out of ten respondents (79 per cent) reported that they had seen or heard something about the system. Similar proportions of both genders reported having previously seen or heard something about the system (78 per cent males, 80 per cent females). Just under three-quarters of those in social grades C2DE reported having seen or heard something about the system (73 per cent) compared to over eight out of ten (86 per cent) of those in social grades ABC1. The youngest respondents were least likely to report having seen or heard anything about the system (74 per cent of 16 34 year olds compared to 81 and 82 per cent of 35 54 year olds and 55+ respectively).

### Support for deemed consent

Respondents were asked to what extent they agreed that if an individual chooses not to register a decision that should be treated as a decision to be a donor, which families should be encouraged to accept. Three quarters (75 per cent) agreed with the statement (with just under four in ten strongly agreeing). The proportion of respondents who agree with the statement has fluctuated between two thirds and three quarters since this question was first asked in wave 11 (March 2016), with just over seven out of ten (73 per cent) agreeing in wave 15.

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<sup>&</sup>lt;sup>2</sup> Public attitudes to organ donation: waves 13 and 14

• Table 3 in annex 1 shows that the proportions of men and women agreeing were slightly different with more men (77 per cent) agreeing than women (73 per cent). Eight out of ten (80 per cent) of those in social grades ABC1 agreed, with the corresponding figure for those in social grades C2DE being seven out of ten (69 per cent). Agreement with the statement was highest amongst those aged 35 – 54 at nearly eight out of ten, whilst it was approximately three-quarters for those aged 16 – 34 and just over seven out of ten for those aged 55+ (74 per cent and 72 per cent respectively).

## Discussing wishes with a family member

- All respondents were asked 'Have you ever discussed your wishes regarding organ
  donation after your death with a family member?'. Over half (56 per cent) of respondents
  said that they had discussed their wishes with their family. This is similar to the figure of
  55 per cent reported in wave 14, and an increase since wave 13 when approximately
  half (51 per cent) said they had discussed their wishes with a family member.
- Table 4 shows that men were more likely to report that they had not discussed their wishes (48 per cent, compared to 40 per cent of women). Just over half of respondents in social grades C2DE stated that they had not discussed their wishes with a family member, compared with just over a third of those in social grades ABC1 (53 per cent of those in C2DE, 35 per cent of those in ABC1). Less than two fifths (37 per cent) of those aged 35 54 reported that they had not discussed their wishes with their family, compared to half of 16 34 year olds and over two fifths of those aged 55+ (50 per cent for 16 34 year olds and 44 per cent for those aged 55+).

# Action taken since the new system of organ donation was introduced

- All respondents were asked what they had done with regards to a decision on organ
  donation since the new system of organ donation was introduced on the 1 December
  2015. Approximately a fifth said that they had opted in (21 per cent), whereas fewer than
  one in twenty had opted out (four per cent). Just over half (52 per cent) said that they
  had done nothing as they were happy for deemed consent to apply and approximately a
  fifth had either not thought about it yet, or were still considering their options (15 percent
  and six per cent respectively).
- Table 5 shows that women were more likely to have opted in than men (23 per cent versus 18 per cent) and men were more likely to have done nothing as they were happy for deemed consent to apply (56 per cent for men, 49 per cent for women). Almost a quarter (24 per cent) of those in social grades ABC1 said that they had opted in, compared to less than a fifth of those in social groups C2DE (17 per cent). Respondents in social groups C2DE were also less likely to say that they were happy for deemed consent to apply (48 per cent, compared to 56 per cent for groups ABC1). Over a quarter of C2DE respondents said that they were either still considering their options (eight per cent), or hadn't thought about it yet (20 per cent), compared to just over a tenth of respondents in groups ABC1 (with three per cent stating that they were still considering their options, and 11 per cent saying they hadn't thought about it).
- Differences were also observed by age group. Just over a fifth (22 per cent) of 16 34 year olds said that they hadn't thought about it yet, compared to approximately one out of eight 35 54 year olds and those aged 55+ (12 per cent and 14 per cent respectively). Over half of those aged 35 54 and 55+ said that they had done nothing as they were happy for deemed consent to apply (55 and 56 per cent respectively), whereas less than

half of the younger age group said that this was the case (45 per cent). A quarter of those aged 35-54 had opted in, with the corresponding figures for the other age groups being lower (21 per cent for those aged 16-34 and 17 per cent for those aged 55+). Those in the oldest age group were slightly more likely to have opted out (six per cent, compared to three per cent for those aged 35-54 and four per cent for those aged 16-34).

• Respondents who indicated that they had opted in, opted out, or done nothing as they were happy for deemed consent to apply, were then asked whether they had discussed that decision with a family member. Approximately seven out of ten respondents had discussed the decision (69 per cent). The proportion was higher for women (72 per cent, compared to 66 percent of men). Nearly three-quarters (73 per cent) of respondents in social grades ABC1 said that they had discussed their decision, compared to just under two-thirds (63 per cent) of those in groups C2DE. Respondents aged 35 – 54 were most likely to have discussed their decision with a family member (73 per cent saying they had, compared to 65 per cent of 16 – 34 year olds and 68 per cent of those aged 55+) (Table 6).

ANNEX 1

Table 1: Are you aware of the current organ donation system?

		Ge	nder			Social	Grade				Age	
	Total	Male	Female	AB	C1	C2	DE	ABC1	C2DE	16-34	35-54	55+
Base												
Unweighted	1,015	422	593	187	311	186	326	498	512	271	295	449
Weighted	1,015	493	522	191	318	186	315	509	501	297	331	386
Yes	875	416	460	182	293	152	244	475	396	240	293	343
	86%	84%	88%	95%	92%	82%	78%	93%	79%	81%	88%	89%
No	127	74	54	8	23	33	62	31	96	55	35	37
	13%	15%	10%	4%	7%	18%	20%	6%	19%	18%	11%	10%
Don't know	12	4	8	1	2	1	8	3	9	2	4	6
	1%	1%	2%	0%	1%	0%	3%	1%	2%	1%	1%	2%

Base: all respondents

Table 2: Can you tell me how you think the system works? (Unprompted)

		Ge	nder			Social	Grade				Age	
	Total	Male	Female	AB	C1	C2	DE	ABC1	C2DE	16-34	35-54	55+
Base Unweighted Weighted	877 875	356 416	521 460	179 182	288 293	152 152	254 244	467 475	406 396	218 240	261 293	398 343
OVERALL 1, 2 or 3	655	302	353	147	232	115	158	380	273	178	220	257
	75%	73%	77%	81%	79%	75%	65%	80%	69%	74%	75%	75%
1. Opt out system\ will need to opt out	541	247	295	119	201	97	123	320	220	148	194	200
	62%	59%	64%	66%	69%	63%	51%	67%	56%	61%	66%	58%
2. Presumed consent	236	107	129	65	77	38	55	142	93	76	68	92
	27%	26%	28%	36%	26%	25%	23%	30%	24%	32%	23%	27%
Opt in system	88	44	44	15	25	14	32	41	46	32	31	25
	10%	11%	10%	8%	9%	9%	13%	9%	12%	13%	10%	7%
3. You have to opt in or opt out \ register either way (or do nothing)	20 2%	6 2%	13 3%	-	6 2%	3 2%	11 5%	6 1%	14 3%	4 2%	5 2%	11 3%
Family will decide	25	11	14	6	11	4	3	17	8	9	7	10
	3%	3%	3%	3%	4%	3%	1%	4%	2%	4%	2%	3%
For the better	5	4	1	2	1	1	2	3	3	1	3	1
	1%	1%	0%	1%	0%	1%	1%	1%	1%	0%	1%	0%
All others	41	18	23	3	9	6	21	12	27	10	16	15
	5%	4%	5%	2%	3%	4%	9%	3%	7%	4%	6%	4%
Don't know	53	27	26	7	16	11	19	23	30	13	13	27
	6%	7%	6%	4%	5%	7%	8%	5%	8%	5%	5%	8%

Base: respondents aware of the current system

Table 3: To what extent do you agree or disagree that, if an individual chooses not to register a decision, this should be treated as a decision to be a donor which families should be encouraged to accept?

		Ge	nder			Social	Grade			Age		
	Total	Male	Female	AB	C1	C2	DE	ABC1	C2DE	16-34	35-54	55+
Base Unweighted Weighted	1,015 1,015	422 493	593 522	187 191	311 318	186 186	326 315	498 509	512 501	271 297	295 331	449 386
Strongly agree	382	193	189	87	126	58	109	213	167	108	145	128
	38%	39%	36%	46%	40%	31%	35%	42%	33%	36%	44%	33%
Agree	378	188	190	75	119	75	106	194	181	112	117	149
	37%	38%	36%	39%	38%	40%	34%	38%	36%	38%	35%	38%
Neither agree nor disagree	89	42	48	16	26	13	34	42	47	26	19	44
	9%	8%	9%	8%	8%	7%	11%	8%	9%	9%	6%	11%
Disagree Strongly	102 10% 39	45 9% 17	58 11% 21	9 5% 2	28 9% 11	28 15% 8	37 12% 17	37 7% 13	65 13% 26	27 9% 17	31 9% 12	44 11% 10
disagree	4%	3%	4%	1%	3%	4%	6%	3%	5%	6%	4%	3%
Don't know	25	9	16	1	7	5	11	9	16	7	7	11
	2%	2%	3%	1%	2%	3%	4%	2%	3%	2%	2%	3%
Overall	760	380	379	162	246	132	215	408	347	221	262	277
AGREE	75%	77%	73%	85%	77%	71%	68%	80%	69%	74%	79%	72%
Overall	141	62	79	12	39	36	55	50	91	44	43	54
DISAGREE	14%	13%	15%	6%	12%	19%	17%	10%	18%	15%	13%	14%

Base: all respondents

Table 4: Have you ever discussed your wishes regarding organ donation after your death with a family member?

		Ge	nder			Social	Grade				Age	
	Total	Male	Female	AB	C1	C2	DE	ABC1	C2DE	16-34	35-54	55+
Base												
Unweighted	1015	422	593	187	311	186	326	498	512	271	295	449
Weighted	1015	493	522	191	318	186	315	509	501	297	331	386
Yes	570 56%	257 52%	313 60%	140 73%	192 60%	88 47%	147 47%	331 65%	236 47%	149 50%	209 63%	212 55%
No	442 44%	235 48%	206 40%	51 27%	126 39%	97 52%	167 53%	177 35%	263 53%	148 50%	122 37%	171 44%
Don't know	3 0%	1 0%	2 0%	- -	1 0%	1 1%	1 0%	1 0%	2 0%	-	-	3 1%

Base: All respondents

Table 5: Since the new system of organ donation was introduced on the 1 December 2015, which of the following best describes what you have done?

	Gender		nder			Social	Grade		Age			
	Total	Male	Female	AB	C1	C2	DE	ABC1	C2DE	16-34	35-54	55+
Base Unweighted Weighted	1,015 1,015	422 493	593 522	187 191	311 318	186 186	326 315	498 509	512 501	271 297	295 331	449 386
Registered to opt in	210	87	122	52	71	35	48	123	83	61	82	66
	21%	18%	23%	27%	22%	19%	15%	24%	17%	21%	25%	17%
Registered to opt out	44	15	28	6	15	3	19	21	22	12	10	22
	4%	3%	5%	3%	5%	2%	6%	4%	4%	4%	3%	6%
Nothing – as happy for presumed consent to apply	530 52%	275 56%	255 49%	105 55%	182 57%	93 50%	150 48%	287 56%	242 48%	133 45%	181 55%	217 56%
Nothing – but still considering my options	58	28	30	6	12	16	25	18	41	20	18	20
	6%	6%	6%	3%	4%	8%	8%	3%	8%	7%	5%	5%
Nothing – haven't thought about it yet	157	80	77	20	36	34	68	56	102	65	39	54
	15%	16%	15%	10%	11%	18%	21%	11%	20%	22%	12%	14%
Don't know	13	6	8	2	2	6	4	4	10	5	1	7
	1%	1%	1%	1%	1%	3%	1%	1%	2%	2%	0%	2%
Refused	2 0%	1 0%	1 0%	-	1 0%	-	1 0%	1 0%	1 0%	1 0%	1 0%	-

Base: All respondents

Table 6: Have you ever discussed that decision with a family member? (Decision made since new legislation was introduced)

		Gender				Social	Grade		Age			
	Total	Male	Female	AB	C1	C2	DE	ABC1	C2DE	16-34	35-54	55+
Base												
Unweighted	780	322	458	160	261	131	223	421	354	185	241	354
Weighted	784	378	406	164	268	131	217	431	348	206	273	305
Yes	540	248	292	134	183	79	140	317	219	134	198	209
	69%	66%	72%	82%	68%	61%	64%	73%	63%	65%	73%	68%
No	244	130	114	30	85	51	77	115	129	72	75	97
	31%	34%	28%	18%	32%	39%	36%	27%	37%	35%	27%	32%

Base: Respondents who have registered to opt in, registered to opt out or have done nothing as happy for presumed consent to apply

### **ANNEX 2**

Organ donation omnibus questions September 2018

Q1. (UNPROMPTED) Are you aware of the current organ donation system?

- Yes
- No
- Don't know

### **ASK IF AWARE OF ANY CHANGES AT Q2**

Q2. Can you tell me how you think the system works?

**OPEN ENDED** 

### Please take a look at this card

### **SHOWCARD**

The Welsh Government introduced a new organ donation system on 1 December 2015. People can now formally 'opt out' of organ donation by placing their name on a register. If they choose not to do so, having had the opportunity, then this will be treated as a decision to be a donor, and one which families will be sensitively encouraged to accept. The new system allows family members to object to donation on the basis that they know the deceased person would not have wished to consent. The opportunity to 'opt in' and register a decision to be a donor continues.

Q3. (PROMPTED) Before today, have you seen or heard anything about this change?

- Yes
- No
- Don't know

Q4. To what extent do you agree or disagree that, if an individual chooses not to register a decision, this should be treated as a decision to be a donor which families should be encouraged to accept?

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree
- Don't know

Q5. Have you ever discussed your wishes regarding organ donation after your death with a family member?

- Yes
- No

Q6. Since the new system of organ donation was introduced on the 1 December 2015, which of the following best describes what you have done?

01: Registered to opt in

02: Registered to opt out

03:Nothing – as happy for presumed consent to apply

04: Nothing - but still considering my options

05: Nothing - haven't thought about it yet'

### ASK Q7 IF ANSWER CODES 1 OR 2 OR 3 AT Q6

Q7. Have you ever discussed that decision with a family member?

- Yes
- No

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