

## Health and Wellbeing Board Friday 29<sup>th</sup> August 2014

### SHROPSHIRE ORGAN DONATION SURVEY REPORT

#### Responsible Officer

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## 1. Summary

1.1. During summer 2014 Shropshire's Public Health department undertook a research project to gather the views of Shropshire residents in regard to organ and tissue donation. The objective of this research was to ascertain whether residents supported the current 'opt-in' policy or favoured a move to 'opt-out' for organ and tissue donation (please see full report for definitions).

1.2. The survey was completed online through the consultation pages of Shropshire Council's website and was available as a hard paper copy. The survey was open for six weeks between 1<sup>st</sup> June and 14<sup>th</sup> July 2014. The consultation period coincided with the NHS Blood and Transplant's (NHSBT) 'National Transplant Week' campaign. Significant publicity was undertaken via social media as well as promotion through partner agencies (please see Appendix 2 of full report for distribution channels and methods of promotion).

#### 1.3. Main findings:

- We received 1179 responses to the survey.
- 76% of respondents were in favour of an 'opt-out' scheme\*
- 68% of respondents were female.
- The majority of respondents (61%) would like to receive information on organ donation via leaflets available in pharmacies, GP practices or dentist surgeries.
- A significant number of responses to the survey were received but the total number of responses represented less than 1% of the Shropshire population.

\*This figure includes the combination of responses: 'an opt-out policy' and 'an opt-out policy if certain measures are in place'.

#### 1.4. Discussion

1.4.1. The survey results indicate that the majority of respondents favoured an opt-out policy whereby individuals are automatically placed on the organ and tissue donation

register and must remove themselves from the register if they do not wish to donate their organs.

1.4.2. The survey was well publicised and a significant number of responses to the survey were received over the six week consultation period. The consultation coincided with the NHSBT's national 'Transplant Week'. The number of responses compared favourably with a similar consultation in Wales during 2012 (see Appendix 4 of full report) but the total number of responses represented less than 1% of the Shropshire population.

1.4.3. Question 5 asked respondents about their preferred methods of receiving further information on the topic. The results indicated that preferred methods were information leaflets left in medical venues (GP practices, pharmacies, dentists) and researching on the internet. This information may be useful for future health-related campaigns or information-sharing by health professionals as it may indicate the most effective methods for transmitting information of receiving residents' views.

1.4.4. Thematic analysis of the comments sections of the survey indicated common matters of interest for respondents. In particular, the topics of 'family' (family members having/not having the 'final say'), 'ethical considerations' (robust systems of recording, medical assurance of no chance of recovery) and 'ability to specify organs for donation' were key matters for respondents. Analysis and application of these results should take these qualitative responses into account.

## 1.5. Limitations

- The results of this survey are representative of the sample consulted over a consultation period of six weeks.
- Caution should be applied for wider application of these results.
- To produce a more representative sample of results, a greater number of residents should be given the opportunity to form part of the consultation. This could be achieved by organising a survey/leaflet distribution to every Shropshire household.
- A similar consultation, undertaken across Wales during 2012, received a total of 2,891 responses. See Appendix 4 of full report for detail of organ donation developments in Wales.

## 1.6. Next Steps

- Shropshire Council Elected Members wished to hear the views of Shropshire residents with regard to the current England organ and tissue donation policy and the future Welsh policy.
- Shropshire Council Elected Members can interpret these survey results as an accurate representation of the population consulted.
- The policy favoured by the majority of respondents is apparent, however this must be considered with the limitations stated above.
- The cost-effectiveness of a more comprehensive campaign (such as survey/leaflet distribution to all Shropshire Council households) is open to question.

## **2. Recommendations**

- A. We recommend that the Health and Wellbeing Board take note of the results of this survey and report.
- B. The Health and Wellbeing Board should discuss the next steps regarding taking the results forward to Full Council. Options include:
  - i. Recommending that Full Council takes these results as representative of a Shropshire-wide consultation.
  - ii. Recommending that Full Council considers the need for further consultation via methods such as survey/leaflet distribution to all Shropshire households in order to reach a wider audience and increase the rate of response. This recommendation would have financial implications.
  - iii. Recommending that Full Council monitors the implementation of the change in policy in Wales (active from December 2015) and makes a decision for action based upon Welsh outcomes.

## **R E P O R T**

### **3. Risk Assessment and Opportunities Appraisal**

(NB This will include the following: Risk Management, Human Rights, Equalities, Community, Environmental consequences and other Consultation)

3.1. Mitigation of health inequalities in Shropshire.

### **4. Financial Implications**

4.1. There are no immediate financial implications for this report.

4.2. There may be financial implications if the Health and Wellbeing Board is to recommend to Full Council that further consultation work is undertaken.

### **5. Background**

5.1. The research project came as a result of a Full Council debate about organ and tissue donation during late 2013. During this debate, the merits of the current England 'opt-in' policy and Welsh 'opt-out' policy (to commence from December 2015) were discussed.

5.2. More information is available in the documents available for the Health and Wellbeing Board meeting, 22<sup>nd</sup> November 2013, Agenda Item 10 'Organ Donation'.

### **6. Additional Information**

6.1. None

### **7. Conclusions**

7.1. The survey results indicate that the majority of respondents (76%) favoured a form of opt-out policy whereby individuals are automatically placed on the organ and tissue donation register and must remove themselves from the register if they do not wish to donate their organs.

**List of Background Papers (This MUST be completed for all reports, but does not include items containing exempt or confidential information)**

[Health and Wellbeing Board Meeting, 22<sup>nd</sup> November 2013, Agenda Item 10 'Organ Donation'](#)

**Cabinet Member (Portfolio Holder)**

Cllr Karen Calder

**Local Member**

None

**Appendices**

Full Report – Appendices 1-6

**APPENDIX 1**  
**Shropshire Organ Donation Survey:**  
**Report to Health and Wellbeing Board**  
**August 2014**

## **Introduction**

During summer 2014 Shropshire's Public Health department undertook a research project to gather the views of Shropshire residents in regard to organ and tissue donation. The research project came as a result of a Full Council debate about organ and tissue donation during late 2013. During this debate, the merits of the current England 'opt-in' policy and Welsh 'opt-out' policy (to commence from December 2015) were discussed.

The objective of this research was to ascertain whether residents supported the current 'opt-in' policy or favoured a move to 'opt-out' (please see Appendix 1 for definitions).

This report will give an overview of the results from the survey.

## **Methodology**

The survey was completed online through the consultation pages of Shropshire Council's website and was available as a hard paper copy. The survey was open for six weeks between 1<sup>st</sup> June and 14<sup>th</sup> July 2014. The consultation period coincided with the NHS Blood and Transplant's (NHSBT) 'National Transplant Week' campaign. Significant publicity was undertaken via social media as well as promotion through partner agencies (please see Appendix 2 for distribution channels and methods of promotion).

The survey questions were refined through consultation with a number of partners including HealthWatch, Shrewsbury and Telford Hospital's Organ Donation Specialist Nurse, Shropshire's Health and Wellbeing Co-ordinator and a local Patient Participation Group membership.

## **Main Results**

Please see Appendix 3 for the list of questions included in the survey.

- We received 1179 responses to the survey.
- 76% of respondents were in favour of an 'opt-out' scheme\*
- 68% of respondents were female.
- The majority of respondents (61%) would like to receive information on organ donation via leaflets available in pharmacies, GP practices or dentist surgeries.
- A significant number of responses to the survey were received but the total number of responses represented less than 1% of the Shropshire population.

\*This figure includes the combination of responses: 'an opt-out policy' and 'an opt-out policy if certain measures are in place'.

Questions 4, 5, and 7 allowed qualitative responses in the comments sections. Thematic analysis has been applied to the data and the key themes have been explored (see Appendix 4 for a word cloud created using qualitative responses to the survey).

## Analysis of Results

Chart 1 Percentage of respondents selecting an opt-in or opt-out policy for organ donation (n=1179)

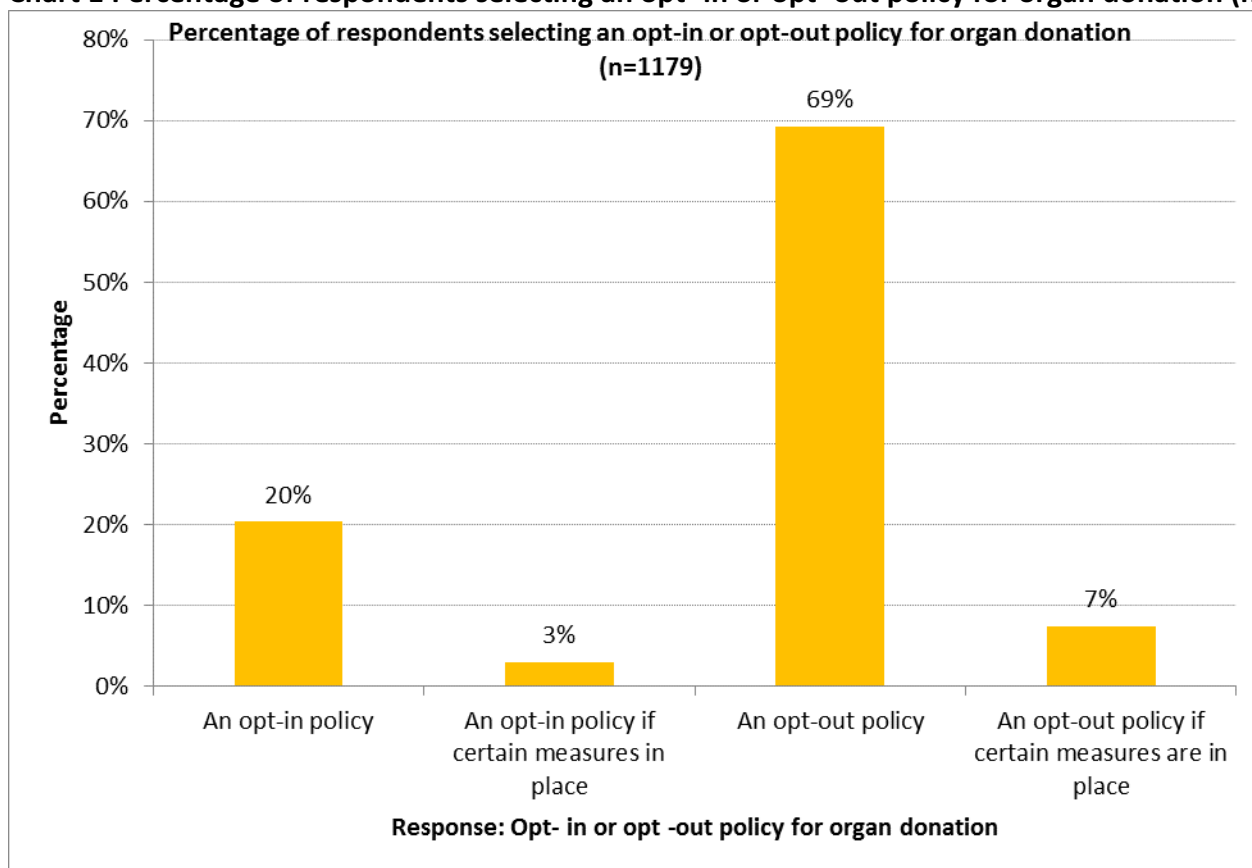


Chart 1 indicates the percentage distribution of responses to the survey's main question; 'which policy do you favour?' The majority of respondents (69%) favoured an opt-out policy. When this is combined with the number favouring 'an opt-out policy if certain measures are in place', the total becomes 76%.

### **Question 4. Which policy do you favour?**

For those selecting 'an 'opt-in' policy if certain measures are in place' or 'an 'opt-out' policy if certain measures are in place', thematic analysis of responses has been applied. This allows us to consider the main qualifications respondents applied to their response.

**Family** Respondents debated the role of relatives having the 'final say'. Twenty respondents felt that the family should be able to make the final decision regarding organ and tissue donation regardless of whether the individual has already expressed their desire. However, eleven respondents felt it was important that the family should not have a final say and that a decision should be made by the individual's presence on or off the donor register. A handful of respondents made reference to the status of children: several felt that only over 18s should be automatically registered if there were to be an opt-out policy. A small number of respondents stated that parents should make the decision about whether or not a child should appear on the register. The respondents expressed differing views as to the status of an adult (being over 16 or over 18) and how this would affect an opt-out system.

**Specify organs** Around twenty-five references were made to the need for individuals to be able to express the organs that they are happy/not happy to donate. This applied to both an opt-in and an opt-out system.

**Mental capacity** Five references were made to the mental capacity of the individual and their ability to make decisions around organ donation. This extended to those with learning difficulties and other vulnerable populations. A small number of references were made to the effect of dementia and other conditions upon decision making.

**Religion and culture** Less than ten references were made to religious beliefs needing to be taken into account and the requirement for consultation with religious groups.

**Ethical considerations** Respondents made reference to the need for robust checks and balances being in place to ensure that the process is ethical. This includes the methods of medical assurance that there would be no chance of recovery.

**Awareness** For both policy decisions, a small number of respondents passed comment about the requirement for more information/education on the topic to ensure that the public is aware about what is required to opt-in or opt-out. This would be to ensure that the population is clear on the policy and how to express their wishes.

**Other** A very small number of respondents made reference to a policy whereby signing up to the organ donation register should enable the donor to receive organs; those who were not on the register should either be unable to receive donations or should be a lower priority for receiving organ donations. Two respondents suggested that donors should be able to specify those who could receive their donations. Three comments also made reference to priority being given to NHS patients or UK citizens.

**Chart 2 Gender distribution of respondents**

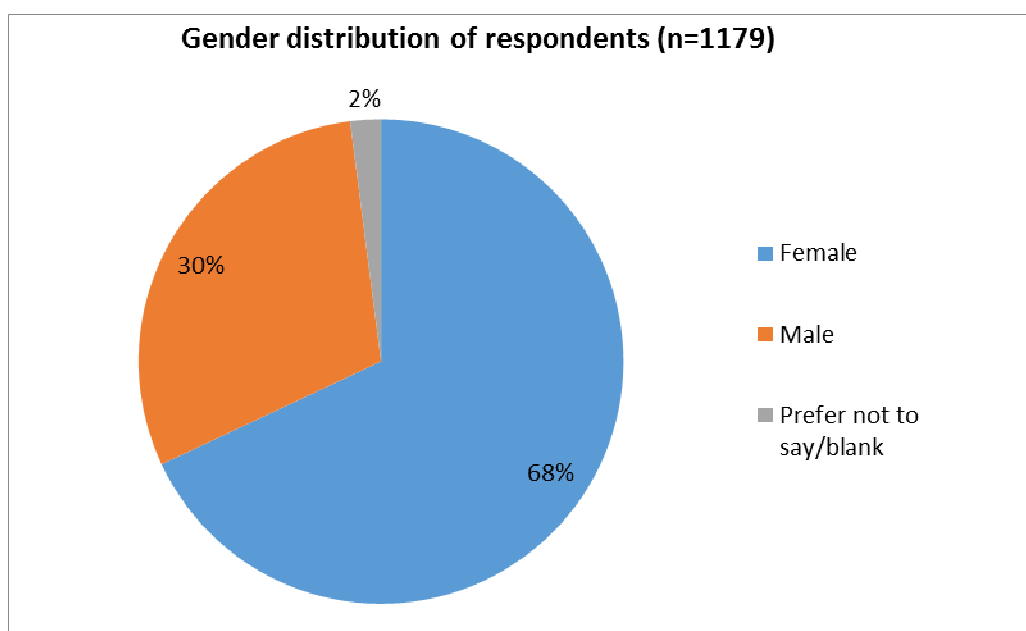


Chart 2 depicts the gender distribution of respondents. The results highlight that a significant percentage of the respondents reported being female (68%). This distribution not representative of the gender distribution across the county.

This could reflect both the locations and methods of promotion. Paper copies of the survey and posters advertising the research were distributed to libraries, GP surgeries, Children’s Centres and through customer contact points (see Appendix 2 for a full list of distribution channels). It is possible that these distribution points may be more regularly frequented by females. The gender distribution amongst respondents could indicate that the topic of organ donation is predominantly of interest to females. Data from the NHS Blood and Transplant (NHSBT)<sup>1</sup> authority demonstrates that more females than males are signed up to the organ donation register (54% women, 46% men) and a consultation by the European Commission<sup>2</sup> on ‘Europeans and organ donation’ in 2007 indicated that females are more likely than men to have discussed the topic of organ donation with their families (45% women, 37% men).

<sup>1</sup> NHSBT. (2011). Did you know? Factsheet. Available at: [http://www.organdonation.nhs.uk/newsroom/fact\\_sheets/did\\_you\\_know.asp](http://www.organdonation.nhs.uk/newsroom/fact_sheets/did_you_know.asp)

<sup>2</sup> European Commission. (2007). Europeans and organ donation. Available at: [http://ec.europa.eu/public\\_opinion/archives/ebs/ebs\\_272d\\_en.pdf](http://ec.europa.eu/public_opinion/archives/ebs/ebs_272d_en.pdf)

**Chart 3 Age distribution of respondents**

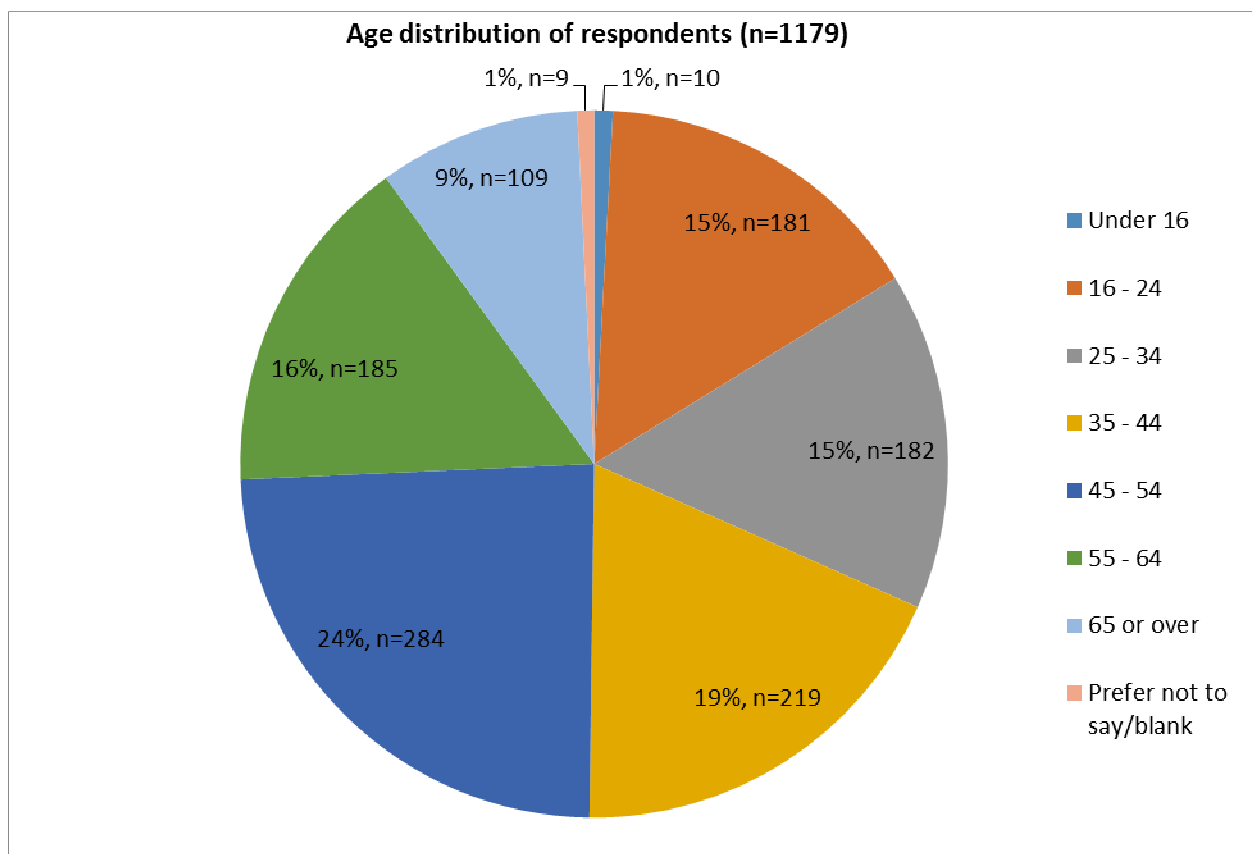


Chart 3 indicates the age distribution of respondents. The vast majority of respondents were aged between 35-64 (59%). Few respondents under the age of 16 participated in the research. Again, it is possible that locations for promotion influenced the audience reached. Although attempts were made to engage with schools to promote the survey, few responses were received from those of school age. However, promotion of the survey within one college in the county resulted in a significant number of responses for those aged 16-24.

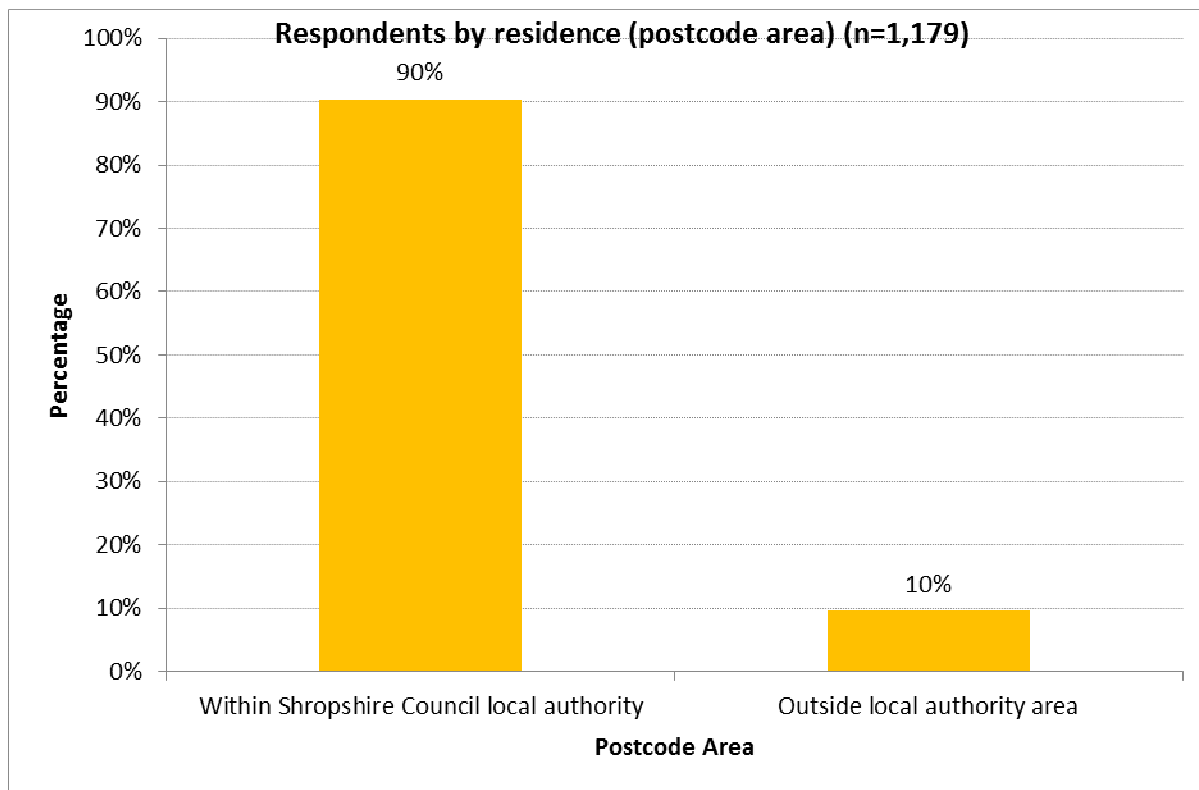
### **Postcode**

Results from analysis of postal codes indicates that most participants lived within the Shrewsbury area, with approximately 16% of responders living within the SY3 postcode. Largely, the data reflects the population distribution across the county with most respondents living within the vicinity of Shrewsbury and the larger market towns where population is greatest.

Chart 4 (below) indicates that 10% of all respondents lived in areas with postcodes outside of the Shropshire Council local authority area. This may reflect the numbers of border populations who access services within Shropshire (e.g. GP surgeries, libraries, hospitals) but are resident within Telford, Wolverhampton, Powys and other neighbouring authorities.



**Chart 4 Respondents by residence (postcode area)**



**Chart 5 Preferred methods of finding out more information about organ donation, split by gender.**

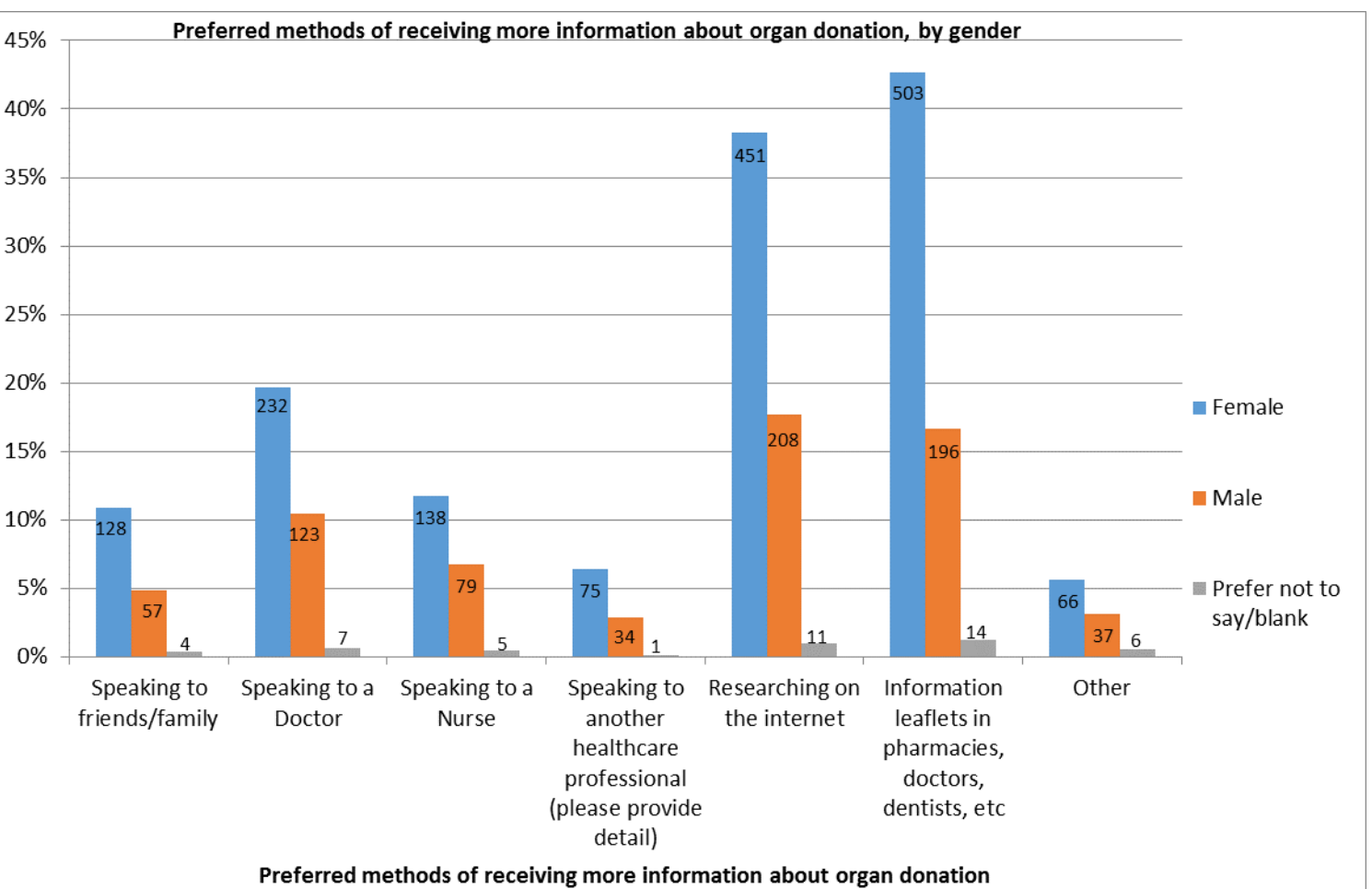


Chart 5 depicts respondents' preferences for receiving more information about the topic of organ donation. The responses have been split by gender to allow for more comprehensive analysis. Respondents were able to select more than one option in their preferred methods of communication and some respondents chose to leave this question unanswered.

The chart indicates that the majority of respondents selected information leaflets as a preferred method of receiving more information about organ and tissue donation. In total (including male, female and prefer not to say/blank), 61% of the total number of respondents would prefer to find out more information through leaflets left in public spaces, and 57% would want to find more information by researching online. Although these responses are in relation to finding out further information about organ and tissue donation, it is possible that this learning could be applied to broader health-related messages when considering the best methods to reach individuals.

#### ***Question 5. Where would you like to find out more information about organ and tissue donation?***

The majority of respondents selected methods defined in Chart 4, however, 109 respondents selected 'other'. Other methods included:

**Media coverage** Around forty respondents felt it was important for the topic of organ donation to be communicated via radio, television or social media.

**Educational institutions** Schools, colleges, universities and adult education venues were highlighted as locations where the topic of organ donation should be discussed, or where information should be available. Several respondents felt that it was important to start communication about the topic as early as possible in order to remove stigma and to encourage choice.

**Community venues** Suggestions were made for further locations where information should be made available to the public. These included; libraries, community centres, opticians, supermarkets and shops, pubs, banks, children's centres, nursing homes and work places.

**Information sent to homes** A small number of respondents suggested that information about organ donation should be sent to homes along with other documentation such as health appointment letters or alongside formal documentation such as new passports.

**Sharing experiences** A number of respondents highlighted personal stories as a method of sharing information about organ donation.

**More information not necessary** It was indicated by more than twenty respondents that no further information regarding the topic of organ donation would be necessary.

#### ***Question 7. Further comments***

Many of the comments in this section were similar to those received in answer to Question 4.

**Family** A small number of respondents mentioned the ability for family members to override/not override the individual's wishes. More than five respondents made note of the fact that discussion at the time of death is difficult and it is important for families to have had the conversation at an earlier stage. Some respondents felt it was important that there is greater encouragement for parents to sign their children up to the register. Respondents considered how the policy should apply to children.

**Ethical considerations** Respondents discussed the need for medical assurance that there is no chance of recovery and that methods should be in place to avoid manipulation of the system. There was significant discussion of 'the state' and 'ownership' of organs or the deceased. Around 10 comments were made in regard to the potential for mistakes and any correlation with decisions around euthanasia and other ethical consequences. A very small number of comments were raised regarding the system in place for an opt-out policy and recording those who have opted-out. Several respondents expressed a lack of confidence that the system for this would be robust.

**Awareness** Similar to the responses to Questions 4 and 5, nearly twenty respondents stated that publicity around organ donation should be improved with more advertisement in mainstream media including

particular focus with the elderly, schools and attendees at GP surgeries. It was felt that there should be greater clarification of the current/any changed process.

**Securing donors** Around ten respondents made reference to individuals' 'laziness', 'apathy' or 'not getting around' to signing up to the organ donation register. Many felt that an opt-out system would help to combat this. Reference was made to how a change in policy would save lives by increasing the number of available donors.

**Homosexuality/Bi-sexuality** One comment was made in regard to reassessment of the restrictions on organ and blood donations from gay/bisexual men.

**Medical research** There were a small number of suggestions that any unused organs or tissue should be donated to medical/scientific research.

**Already registered** Many respondents made note of the fact that they were already longstanding members of the organ donation register.

## **Discussion**

The survey results indicate that the majority of respondents favoured an opt-out policy whereby individuals are automatically placed on the organ and tissue donation register and must remove themselves from the register if they do not wish to donate their organs.

The survey was well publicised and a significant number of responses to the survey were received over the six week consultation period. The consultation coincided with the NHSBT's national 'Transplant Week'.

The number of responses compared favourably with a similar consultation in Wales during 2012 (see Appendix 5) but the total number of responses represented less than 1% of the Shropshire population. Question 5 asked respondents about their preferred methods of receiving further information on the topic. The results indicated that preferred methods were information leaflets left in medical venues (GP practices, pharmacies, dentists) and researching on the internet. This information may be useful for future health-related campaigns or information-sharing by health professionals as it may indicate the most effective methods for transmitting information of receiving residents' views.

Thematic analysis of the comments sections of the survey indicated common matters of interest for respondents. In particular, the topics of 'family' (family members having/not having the 'final say'), 'ethical considerations' (robust systems of recording, medical assurance of no chance of recovery) and 'ability to specify organs for donation' were key matters for respondents. Analysis and application of these results should take these qualitative responses into account.

## **Limitations**

- The results of this survey are representative of the sample consulted over a consultation period of six weeks.
- Caution should be applied for wider application of these results.
- To produce a more representative sample of results, a greater number of residents should be given the opportunity to form part of the consultation. This could be achieved by organising a survey/leaflet distribution to every Shropshire household.
- A similar consultation, undertaken across Wales during 2012, received a total of 2,891 responses. See Appendix 5 for detail of organ donation developments in Wales.

## **Next Steps**

- Shropshire Council Elected Members wished to hear the views of Shropshire residents with regard to the current England organ and tissue donation policy and the future Welsh policy.
- Shropshire Council Elected Members can interpret these survey results as an accurate representation of the population consulted.
- The policy favoured by the majority of respondents is apparent, however this must be considered with the limitations stated above.
- The cost-effectiveness of a more comprehensive campaign (such as survey/leaflet distribution to all Shropshire Council households) is open to question.

## **Recommendations**

We recommend that the Health and Wellbeing Board take note of the results of this survey and report. The Health and Wellbeing Board should discuss the next steps regarding taking the results forward to Full Council. Options include:

1. Recommending that Full Council takes these results as representative of a Shropshire-wide consultation.
2. Recommending that Full Council considers the need for further consultation via methods such as survey/leaflet distribution to all Shropshire households in order to reach a wider audience and increase the rate of response. This recommendation would have financial implications.
3. Recommending that Full Council monitors the implementation of the change in policy in Wales (active from December 2015) and makes a decision for action based upon Welsh outcomes.

## **Appendix 2 – Definitions**

### **Organ Donation**

Organ and tissue donation is the gift of an organ (e.g. heart, lungs or kidneys) or soft tissue such as corneas (the transparent front part of your eye) when you die to help someone who needs a transplant. People who need organs and/or tissue replacement go on transplant lists to wait for a suitable donor to become available.

#### **An example of an 'opt-in' system**

The current policy in England is 'opt-in'; this means that people must sign up to the organ and tissue donation register, specifying which organs and/or tissues they are willing to donate after they die.

- You can join the organ and tissue donation list regardless of your age or health.
- You can choose to donate only specific organs.
- Your family can still choose to override your request (and if you are under 18 your parents need to agree to your wishes).
- If you are not signed up to the register, your family can still choose to donate your organs and/or tissues if they believe this is what you would have wished.

#### **An example of an 'opt-out' system**

The 'opt-out' policy means that everyone is automatically considered to be a potential donor. An example option of an 'opt-out' policy would be:

- If you **do not** wish to donate your organs you would need to register a decision not to be a donor.
- If you do not register a decision it will be assumed that you are happy to donate your organs after you die.
- You can choose to donate only specific organs.
- You can appoint a representative to make a decision about consent on your behalf.
- If you lack capacity to understand the policy, a representative will make a decision upon your behalf.
- This is a 'soft' opt-out system as the family can still refuse the donation on the individual's behalf if they believe that they did not want to be a donor.

## **Appendix 3 – Distribution Channels and Promotion**

### **Distribution**

#### **Paper copies**

Paper copies of the survey were distributed through the following channels:

- GP surgeries
- Libraries
- Patient Participation Groups
- Children's Centres
- Customer contact points
- Leisure Centres
- Councillors
- Supermarkets in Shrewsbury

The paper survey was also available by request.

#### **Online survey**

The online survey was promoted through the following channels:

- Shrewsbury and Telford Hospital
- Robert Jones and Agnes Hunt Orthopaedic Hospital
- Shropshire Council (intranet and newsroom article)
- Shropshire Council Members
- Shropshire Council Adult Services
- Shropshire Council's social media
- Shropshire CCG
- Shropshire Community Health Trust
- Healthwatch
- Shropshire VCSA
- GP surgeries
- Shropshire Libraries
- Shropshire PPGs
- Children's Centres
- Leisure Centres
- Shrewsbury Town Football Club
- Shropshire Learning Gateway
- Various Shrewsbury businesses
- Shropshire Silver – Emergency Planning group
- Shropshire Young Farmers
- Shropshire and Shrewsbury Women's Institute
- Kinlet Women's Institute
- Shropshire Youth Support Services (YSS)
- Barnabas Community Church
- Shropshire Family Information Service
- Tesco Shrewsbury
- Asda Shrewsbury
- Youth Parliament
- Shropshire Youth Association
- Shropshire Health Champions
- Shrewsbury and Shropshire Chamber of Commerce
- Federation of small businesses
- BBC Radio Shropshire

## **Promotion**

Whilst the survey was live, a number of press releases were issued to promote the research and to encourage people to discuss the topics of organ donation and how to keep healthy (reducing their likelihood of requiring donation). Local newspapers published stories encouraging their readership to participate and BBC Radio Shropshire aired three interviews in relation to the research. Three press releases and a blog were circulated via Shropshire Council Newsroom, receiving a total of 230 hits. Social media was effectively harnessed to promote the survey. Existing Shropshire Council Twitter accounts were utilised to increase reach.

49 surveys were completed outside a major local supermarket in Shrewsbury. Completing surveys with individuals face-to-face allowed respondents the opportunity to clarify the research objectives. It also incited discussion of organ donation amongst family members.

## **Appendix 4 – Survey Questions**

Questions from Shropshire's Organ and Tissue Donation survey 2014

**Question 1.** Your gender:

Male

Female

Prefer not to say

**Question 2.** Your age:

Under 16      45-54

16-24        55-64

25-34        65 or over

35-44        Prefer not to say

**Question 3.** Please provide the first half of your postcode:

List of Shropshire Council postcodes

I live outside the authority area

**Question 4.** After reading the background information which explains the project and the difference between the policies, are you in favour of:

- A. An opt-in policy
- B. An opt-in policy if certain measures are in place (please indicate these measures)
- C. An opt-out policy
- D. An opt-out policy if certain measures are in place (please indicate these measures)

**Question 5.** Where would you like to find out more information about organ and tissue donation?

Speaking to friends/family

Speaking to a doctor

Speaking to a nurse

Speaking to another healthcare professional (please specify)

Researching on the internet

Information leaflets in pharmacies, GP practices, dentist surgeries etc.

Other (please specify)

**Question 6.** Where did you hear about this research?

Shropshire Council website

Through my employer

Word of mouth

Local newspaper

GP practice

Radio

Shrewsbury and Telford Hospital Trust

Social media

Robert Jones and Agnes Hunt Hospital

Other (please specify)

**Question 7.** Further comments





## **Appendix 6 – Organ Donation Developments in Wales**

As of December 2015, Wales will be moving to a soft 'opt-out' system. From the 1<sup>st</sup> December 2015 residents who do not wish to be on the organ donation register must register a decision to opt-out. This change in policy is as a result of the Human Transplant (Wales) Act 2013. Consent will be assumed for those who do not register a decision to 'opt-out'. For more information please see [www.organdonationwales.org](http://www.organdonationwales.org).

Prior to the passing of this legislation, Wales carried out a consultation to understand residents' views in regard to 'opt-in' or 'opt-out' for organ donation. The consultation involved a number of events held across the country. Events were principally held to consult stakeholders on the draft bill, but members of the public were welcome to attend.

Wales received 2,891 responses to their consultation. The majority, (2,601), were received as a result of a campaign by the Society for the Protection of the Unborn Child (SPUC). SPUC distributed leaflets and letters amongst religious communities across Wales.

An implementation project team has been established to continue communication with the public around the policy change. E-bulletins are released on a bi-weekly basis. For more information, please contact the Wales Organ and Tissue Donation Legislation Project Team.