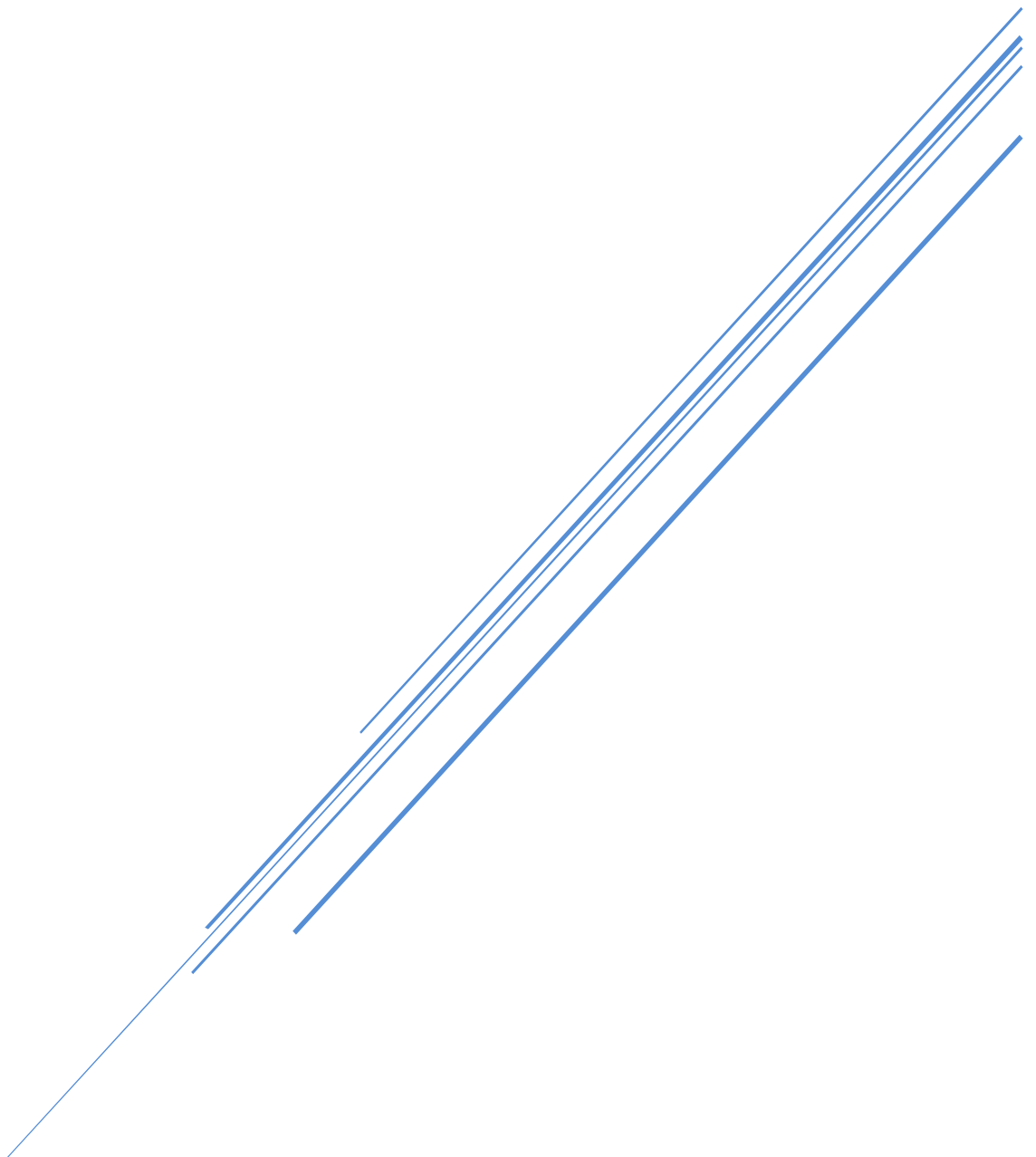


Professional Portfolio plus 1,500 word Reflective Written Summary

Stacey Coleman



M7X01445
Professional Research Skills

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Reflective Written Summary

After reading the handbook provided for the Professional Research Skills module I was excited. The main aim of the module was to develop practical research skills through hands on experience in preparing and applying research materials, and working with a range of literature and data, therefore I had one main expectation: I would be *doing* psychology and putting things into practice instead of just learning about how theories and models could potentially be applied in the real world. What I did not expect was for the module and the project that we ultimately conducted to be so interesting, challenging, thought provoking and, above all, incredibly rewarding in more ways than I anticipated.

Before the module started I was aware that I would be expected to work in a research team for the majority of the time spent on the module. As I was already friendly with all the other individuals on the course and knew everyone relatively well, I did not have any reservations about the level of teamwork required. I quickly learned that each of us has very different ways of learning and quite different personalities. Regardless of this, each individual had the opportunity for input on most, if not all, elements of the research project from inception to completion.

One of the biggest obstacles we faced when working as a team was trying to arrange times to meet outside of our scheduled learning times. As most of the team were balancing jobs and other commitments, plus some geographical constraints, it was sometimes difficult to get together physically to discuss or complete parts of the project as a team. Due to this, we decided to utilise social media to arrange virtual get-togethers via Facebook to discuss our data analysis plans, for example, between 7pm and 8pm one evening. I personally found this incredibly useful and it allowed me to get further engaged in the project alongside the module itself and in addition to my work commitments. We also set up a private OneDrive account where we all shared work that was related to the project in order to edit as appropriate. Again, I found this useful but it got slightly disorganised and chaotic with multiple people working on the same documents, or when people did not upload work to the OneDrive at all.

As a team, the first challenge we faced was the submission of the expression of interest. Each member took the lead on separate parts of this form and my contribution to this was the completion of the brief outline of the project (Evidence 1: Section A). As a result of

carrying out this task, I have learned the importance of producing lay summaries for applied research, however I do recognise that I still need far greater development in order to refine this as a skill; to effectively communicate what can be complex psychological information to members of the general public.

In order to be able to conduct our study, we had to submit a full ethics proposal to the Faculty Ethics Committee for approval. Whilst I did not take the lead on the first draft of this ethics form, I quickly learned the importance of ensuring that every member of the team reviewed all documents prior to them being sent or used. I contributed to the main ethics submission by adding some information to Version 2 of the form (see Evidence 1: Section B – Version 1 to version 2 changes in red), but my main contribution was in the development and piloting of the online study information, consent and debrief (see Evidence 1: Section C). As we had proposed to conduct the study online, I sought to adhere to the British Psychological Society's ethics guidelines for internet-mediated research (BPS, 2013) as well as the code of human research ethics (BPS, 2010). As can be seen in Evidence 1: Section C, I created logics within SurveyGizmo to ensure that we met all of the criteria we had outlined in the ethics submission regarding consent processes: most notably, to restrict access for any individuals who were under the age of 18, had not lived in Wales for longer than 12 months, or anyone who declined to take part in the study after reading the study information.

I feel the biggest contribution that I made to the project were the main piloting of Versions 2 and 3 of the Organ Donation Survey (see Evidence 2: Sections 2 & 3) and the study information and consent (Evidence 1: Section C). I volunteered to lead on this as I was able to ask undergraduate students to complete the survey during skills week and again during a taught seminar when the survey was constructed online. During the first mass pilot, students were provided with a hard copy questionnaire, an evaluation sheet (Evidence 2: Section B), and the study information and consent (Evidence 1: Section C). Teijingen and Hundely (2001) state that pilot studies are important for 'trying out' questionnaires and scales to ensure they are appropriate for the target audience and easy to fill in. From the responses gained through this piloting I was able to feed back to the team and subsequently make suitable changes to the survey regarding the wording and order of the questions. We also gained valuable insight through free text comments in relation to information that we later decided to would like to use in the qualitative phase of the study (see Evidence 2: Section B for full evaluation of the survey).

In addition to using participants comments I also used SPSS to assess the internal consistency of each of the five sub-scales (not including those with only one item) to ensure they met appropriate Cronbach's alpha levels (Cronbach, 1951). As a result of this analysis, one item measuring perceived behavioural control was changed due to a very strange alpha level (see Evidence 2: Section B). Without the data that was gained from the piloting of this survey it is likely to we would not have picked up that participants were not answering that particular question in the way that we expected (Peat, Mellis, Williams & Xuan, 2002).

Furthermore, I decided to develop my competency in using SPSS further due to a cease in engagement with the quantitative element of the project by the other team members. Although we have currently received over 130 responses to the survey, it was agreed that the planned data analysis would not take place until the data analysis protocol had been finalised and the team had met to discuss these plans (currently scheduled for May). I created a Syntax file that included reliability analysis, reverse scoring items, calculating mean scores, and a hierarchical multiple regression (see Evidence 4: Section B) that could be used by the team when the time came for analysis to proceed.

The task that I found the most challenging was the construction of the qualitative interview questions and interview scheduled (Evidence 3: Sections A & B). I am highly quantitative in my passion and approach to research and psychology in general, therefore I felt out of my comfort zone with this element. I volunteered to put together the interview scheduled including the pre-interview information that would be delivered to participants (Evidence 3: Section B) due to lacking confidence with qualitative methodologies and was keen to develop this skill by pushing my boundaries. The whole team had input into the development of the final questions and I discovered that I learned a lot from listening to other members of the team, also. I subsequently decided to opt out of conducting the interviews following the completion of the module because I felt that I did not have the time to develop the skill of interviewing well enough to do it properly. I would like, however, to try and incorporate a qualitative element into my dissertation project to further develop this as a competency.

I feel that the element of the module and the research project that I have succeeded with the most is managing my time effectively. I have always regarded myself as having good organisational skills with the ability to effectively manage multiple roles, particularly in

my job, but the tasks and additional engagement I have put into this project beyond the required elements of the module have definitely pushed me to be far more disciplined with my time and plan things extensively.

Finally, another aspect that I regard as both a struggle and a success was the teamwork itself. It is clear to see why interpersonal skills are so highly sought by employers: I quickly came to recognise that the skill of being able to work in a group of people who may not hold the same views or opinions as you can be a challenging one to grasp. There were times throughout the project that I completely disagreed with other members of the team about one thing or another, however I believe that as a result of these disagreements I am far more willing, and likely, to be assertive and make my voice heard within a group.

I feel that everything that I have been involved with throughout this module has helped my confidence immensely. Prior to the module I was apprehensive about how or where to begin with research generally and also in specific relation to my dissertation project. Now, however, I have at the very least a solid idea of where to start. I am confident that I can apply the skills I have gained, from using online tools to engaging in the development of qualitative interview schedules; not only to my dissertation but towards further research in the future. Although the process of teamwork and the work involved throughout the module itself has been challenging for many reasons, I have thoroughly enjoyed my experience of this module over and above what I expected at the beginning of the year. In my opinion, it has been invaluable in terms of beginning to learn how to *apply* psychology that can have an impact on the real world. I am confident that I can continue to engage in research in the future to develop my own portfolio, to aid my teaching and, most importantly, to continue developing my skills and competencies along the way.

References

- British Psychological Society. (2010). *Code of human research ethics*. Retrieved from http://www.bps.org.uk/sites/default/files/documents/code_of_human_research_ethics.pdf
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Evidence 1

Core documents produced as a team.

Section A:

Expression of interest form: Final Version

Section B:

Applied Research Ethics: Version 1 → Version 5
Online study information, consent and debriefing

Each of the four members of the research team contributed to both the expression of interest and the development of the ethics form to submit to the University Ethics Committee for approval. Whilst each member led on specific elements of each of these two forms, the final versions were agreed upon by all prior to submission.

Section A: Expression of interest form

Project Title: *this can be a temporary title for now and may be changed if invited for full application*

Signing a life away?: Exploring predictors of decision making in the Welsh population following legislation change

Brief description of the purpose of the project (200 words max):

The aim of this project is to explore individuals' knowledge and attitudes towards organ donation following the recent legislation change in Wales. On 1 December 2015, Wales became the first country in the UK to introduce a 'soft opt-out' system for organ and tissue donation, meaning that all adults living in Wales, automatically become donors unless they choose to opt out before they die. People living in Wales now have three choices regarding organ donation; (1) they can register to be an organ donor, (2) they take no action and this will be regarded as the individual having no objection to being an organ donor, or (3) they can opt out if they do not wish to be a donor.

Based on this objective, an extended version of the Theory of Planned Behaviour (TPB) plus semi-structured interviews will be implemented to gather quantitative and qualitative data, with the intention of predicting the strength of the decision to become an organ donor. Additionally the factors that impact upon this decision and the reasons why individuals' choose to opt out of organ donation will subsequently be explored.

Proposal summary and what is expected to be achieved by this project (500 words max):

In December 2015, legislation regarding organ donation in Wales changed to a 'soft opt-out' system. Previous research in the UK has explored the intention to register to become an organ donor (Coad, Carter & Ling, 2013; O'Carroll, Ferguson, Hayes & Shepherd, 2012) however there is a lack of research exploring the difference between intention and action. A unique element of this project is therefore to investigate psychological predictors of a decision that has already been made in relation to the change in organ donation legislation in Wales.

Using an extended version of the TPB (Ajzen, 1991), this project will explore the extent to which self-reported attitudes, intentions, perceived behavioural control, subjective norm, anticipated regret,

self-identity, past behaviour and moral norms can explain the strength of conviction in ones decision of organ donation. A sample of the general Welsh population will be studied given the direct influence that legislation may have on this population following the recent changes in law.

Moreover, the use of the TPB is well documented within the literature exploring the variables of, attitude, subjective norm and perceived behavioural control which may be associated with the intention to become an organ donor or not (Armitage & Connor, 2001; Simmons, Schimmel & Butterworth, 1993; Terry, Hogg & White 1999). The extended model of the TPB however, allows for the incorporation of additional variables such as self-identity, moral norms, past behaviour and anticipated regret. Results from studies using self-identity and moral norms to predict intention to donate blood, organs and bone marrow have reported a significant increase in the models predictive success (Hyde & White, 2009).

Additionally, anticipated regret and past behaviour (France, France & Himawan, 2007; Godin et al., 2007; Masser et al., 2009) significantly increased the frequency of blood donation. In relation to organ donation however, it is expected that participants who view their role as an organ donor as a significant part of their self-concept will be more likely to remain as an organ donor following the legislation change.

Equally, the concept of moral norm as an additional significant predictor to the TPB refers to an individuals' perception of a particular behaviour as primarily right or wrong. The application of moral norm has been documented among various studies in relation to organ donation. Blondeau, Godin, Gagne and Martineau (2004) for example explored the construct of moral norm in the context of organ donation in association with ethical principles of autonomy, beneficence and justice. Results presented significant relations among the ethical variables, however only beneficence (i.e., obligation to do something good for others) was related to moral norm; consequently this offers support for the impact of moral norm in the organ donation context. Similarly, Hyde and White (2009) amalgamated the construct of moral norm into the TPB model in predicting individuals' intention to register and discuss the decision of organ donation. Moral norm was identified as a significant predictor and thus supports the assumption that organ donation decisions involve an ethical or moral component.

How the work is going to be carried out (300 word max):

The study will consist of two phases; phase one will include online quantitative data collection with phase two comprising of qualitative interviews. Participants will initially be recruited through Facebook and Twitter with the researchers posting a link to invite individuals to partake in an online survey on a voluntary basis. The link will direct participants to Survey Gizmo where they will be presented with study information and a consent form. Providing that participants consent, they will subsequently be directed to the questionnaire, with access to the questionnaire being available for a period of three weeks. Based on reported response rates for online surveys ranging between approximately 42% and 85%, the study aims to target 500 individuals to gain a minimum final sample of 100 participants based on a 25% response rate. To be eligible to take part in the survey, participants must have lived in Wales for over 12 months, be aged 18 or over and have the mental capacity to understand the new system.

Phase two will utilise semi-structure interviews in the form of telephone and face-to-face interaction to collect qualitative data regarding reasons for opting out. Participants for this phase will be recruited via Facebook and Twitter also, however only individuals who have registered their decision to opt out will be eligible to take part. The aim of this phase is to recruit a minimum of 12 participants comprising of males and females of all ages.

What are the expected outputs from this project? (200 words max)

This study will report the action taken regarding organ donation and information concerning reasons for opting out. The results of the study will be reported in English in a standalone executive summary and may be submitted to academic conferences as well as providing a partial element to an MSc module. Additionally, given the real-time value of the research to the population of Wales, and future relevance to the remainder of the UK, these findings will also be disseminated at appropriate public engagement events.

Costs and brief justification:

- Telephone recording equipment

Section B:

Applied Research Ethics: Version 1 to Version 5



PRIFYSGOL CYMRU

Y Drindod Dewi Sant

UNIVERSITY OF WALES

Trinity Saint David

E2 FORM

APPLICATION FOR ETHICAL APPROVAL – MA level

CAIS AM GYMERADWYAETH MOESEGOL – Lefel MA

CEFNOGWYD /

APPROVED

A GYFEIRIWDYD /

REFERRED

NIS CEFNOGWYD/

NOT SUPPORTED

Mae'r ffurflen hon i'w llenwi gan bob myfyriwr MA cynnal ymchwil, prosiectau neu gynyrchiadau. Dylai'r ffurflen hon gael ei chwblhau gan y myfyriwr mewn ymgynghoriad â thiwtor y modiwl. Rhaid i bob ffurflen gael ei ystyried gan y Pennaeth Ysgol/Cyfadrn / Gyfadrn. Rhaid i bob ffurflen gael ei gyflwyno i Fwrdd y Gyfadrn Moeseg. Bydd y ffurflen yn cael ei adrodd i'r Pwyllgor Moeseg y BrifYsgol/Cyfadrn os anarferol a / neu y tu allan arfer arferol.

This form is to be completed by all MA students conducting research, projects or productions. This form should be completed by the student in consultation with the module tutor. All forms must be considered by the Head of School/Faculty. All forms must be presented to the Faculty Ethics Board. The form is only to be reported to the University Ethics Committee if it is unusual and/or falls outside of normal practice.

**ADRAN 1 – MANYLION MYFYRIWR
DETAILS**

SECTION 1 - STUDENT

Enw Llawn

Full Name

Ysgol/Cyfadrn/
Cyfadrn

School/Faculty

School of Psychology

Rhif
Myfyriwr

Student
Number

Tiwtor y Modiwl/
Cydlunydd Rhaglen

Module Tutor/
Programme Co-ordinator

Dr Ceri Phelps, Dr Paul
Hutchings

Enw'r Gradd
Name of
Degree

MSc Applied Social
and Health
Psychology

Teitl dangosol yr Traethawd Hir:

Indicative Title of Dissertation:

ADRAN 2 – GWEITHGAREDD YMCHWIL

SECTION 2 – RESEARCH ACTIVITY

Ydy'r prosiect yn cynnwys:	Does the project include:	Ydy / Yes	Nac ydy/N
Defnyddio holiadur neu offeryn ymchwil tebyg (atodwch gopi drafft)	Use of questionnaire or similar research instrument (attach draft copy)	Yes	
Defnyddio prawf ysgrifenedig neu gyfrifiadurol	Use of written or computerised test		No

Cyfweliad (cysylltwch gwestiynau posibl)	Interview (attach provisional questions)	Yes	
Dyddiaduron	Diaries		No
Arsylwi ar gyfranogwyr a hwythau'n ymwybodol o hynny	Participant observation with their knowledge		No
Arsylwi ar gyfranogwyr a hwythau ddim yn ymwybodol o hynny	Participant observation without their knowledge		No
Recordio fideo neu sain	Video or audio-taping	Yes	
Mynediad i wybodaeth bersonol neu gyfrinachol heb gydsyniad penodol y cyfranogwyr	Access to personal or confidential information without the participants specific consent		No
Defnyddio unrhyw gwestiynau, ysgogiadau prawf, cyflwyniad y gallai rhai cyfranogwyr eu profi fel rhywbeth sy'n achosi niwed / tramgwydd corfforol, meddyliol neu emosiynol	Administration of any questions, test stimuli, presentation that may be experienced as physically, mentally or emotionally harmful / offensive	Yes	
Cyflawni unrhyw weithredoedd allai achosi embaras neu effeithio ar hunan-barch	Performance of any acts which may cause embarrassment or affect self-esteem		No
Ymchwilio i gyfranogwyr sy'n ymwneud â gweithgareddau anghyfreithlon	Investigation of participants involved in illegal activities		No
Gweithdrefnau lle defnyddir twyll	Procedures that involve deception		No
Gweini unrhyw sylwedd, cyfrwng neu blasebo	Administration of any substance, agent or placebo		No

Dull arall o gasglu data neu fformat cyflwyno (esboniwr)	Other method of data collection or presentation format (please explain)		No

Os 'Na' wedi cael ei dicio ym mhob blwch, dylai'r ffurflen gael ei llofnodi gan Bennaeth yr Ysgol/Cyfadrn / Gyfadrn a'r canlyniad a adroddwyd i'r Pwyllgor Moeseg ar ddiwedd y semester.

Os 'Ydw' wedi cael ei dicio mewn un neu fwy o'r blychau, rhaid i'r myfyriwr gwblhau'r ffurflen hon a'i chyflwyno i diwtor y modiwl. Rhaid i'r ffurflen wedyn yn cael ei ystyried yn y Bwrdd Moeseg Gyfadrn cyn dechrau ar unrhyw waith ymchwil.

If 'No' has been ticked in each box, the form should be signed by the Head of School/Faculty/Faculty and the outcome reported to the Ethics Committee at the end of the semester.

If Yes has been ticked in one or more boxes, the student must complete this form and submit it to the module tutor. The form must then be considered at the Faculty Ethics Board prior to the start of any research.

Llofnodau

Os nad oes unrhyw faterion moesegol sylweddol, dylid ffurflen hon gael ei chwblhau a'i llofnodi gan y myfyriwr a'r goruchwyliwr ac yna llofnodi gan Bennaeth yr Ysgol/Cyfadrn.

Signatures

If there are no significant ethical issues, this form should be completed and signed by both the student and the supervisor and then signed by the Head of School/Faculty.

Myfyriwr / Student	Dyddiad: / Date:
Cydllynydd y prosiect / Tiwtor	Dyddiad: / Date:
Project co-ordinator / Tutor	
Arolygwr / Supervisor	

Pennaeth Ysgol/Cyfadrn / Head of School/Faculty

Dyddiad: / Date

**ADRAN 3 – MANYLION Y PROSIECT / YMCHWIL /
CYNHYRCHIAD**

**SECTION 3 – PROJECT / RESEARCH /
PRODUCTION DETAILS**

1. Braslun o'r prosiect

Project outline

The aim of this project for which we seek ethical approval, is to explore individuals' knowledge and attitude towards organ donation following the recent legislation change in Wales. On 1 December 2015, Wales became the first country in the UK to introduce a 'soft opt-out' system for organ and tissue donation, meaning that all adults living in Wales, automatically become donors unless they choose to opt out before they die. People living in Wales now have three choices regarding their organ donor status; (1) they can register to be an organ donor, (2) they take no action and this will be regarded as the individual having no objection to being an organ donor, or (3) they can opt out if they do not wish to be a donor.

Based on this objective, an extended version of the Theory of Planned Behaviour (TPB) plus semi-structured interviews will be implemented to gather quantitative and qualitative data, with the intention of predicting the strength of the decision to become an organ donor. Additionally the factors that impact upon this decision, and the reasons why individuals' choose to opt out of organ donation will subsequently be explored.

2. Disgrifiad

Rhowch fraslun cryno o'r prosiect, heb unrhyw jargon, ac yn cynnwys beth bydd angen i'r cyfranogwyr ei wneud. Esboniwch unrhyw dermau technegol neu derminoleg sy'n benodol i'r ddisgyblaeth (Uchafswm 300 o eiriau.)

Description

Provide a brief outline, free from jargon, of the project including what participants will be required to do. Explain any technical terms or discipline specific terminology (Max 300 words.)

In December 2015, legislation regarding organ donation in Wales changed to a 'soft opt-out' system. Previous research in the UK has explored the intention to register to become an organ donor (Coad, Carter & Ling)

2013; O'Carroll, Ferguson, Hayes & Shepherd, 2012) however there is a lack of research exploring the difference between intention and action. A unique element of this project is therefore to investigate psychological predictors of a decision that has already been made in relation to the change in organ donation legislation in Wales.

Using an extended version of the TPB (Ajzen, 1991), this project will explore the extent to which self-reported attitudes, intentions, perceived behavioural control, subjective norm, anticipated regret, self-identity, past behaviour and moral norms can explain the strength of conviction in one's decision of organ donation. A sample of the general Welsh population will be studied given the direct influence that legislation may have on this population following the recent changes in law.

Participants will be invited to complete an online questionnaire relating to their organ donor status grounded on the constructs of the TPB. The opportunity to participate in a further interview will be extended to a subset of participants.

3.	Dulliau Arfaethedig: Rhowch fraslun o'r dulliau casglu data neu o natur yr amser mewn ymarferiadau (hyd at 500 o eiriau).	Proposed Methods: Outline how the data will be collected or the nature of the rehearsal time (up to 500 words).
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The study will consist of two phases; phase one will include online quantitative data collection with phase two comprising of qualitative interviews. Participants will initially be recruited through Facebook and Twitter with the researchers posting a link to invite individuals to partake in an online survey on a voluntary basis. The link will direct participants to Survey Gizmo where they will be presented with study information and a consent form. Providing that participants consent, they will subsequently be directed to the questionnaire, access to the questionnaire will be available for a period of three weeks. Based on reported response rates for online surveys ranging between approximately 42% and 85%, the study aims to target 500 individuals to gain a minimum final sample of 100 participants based on a 25% response rate. To be eligible to take part in the survey, participants must have lived in Wales for over 12 months, be aged 18 or over and have the mental capacity to understand the new system.

Phase two will utilise semi-structure interviews in the form of telephone and face-to-face interaction to collect qualitative data regarding reasons for opting out. **Participants for this phase will be recruited through expressions of interest from extended family and friends of the research team**, however only individuals who have registered their decision to opt out will be eligible to take part. The aim of this phase is to recruit a minimum of 12 participants comprising of males and females of all ages.

The initial quantitative questionnaire will be piloted as a paper version and administered to an opportunistic sample of university students and lay individuals over a period of one week. Any amendments will be identified and remedied, with the final online version ready for administration one week later. Data collection for the online study will run for a maximum of three weeks. The qualitative interviews will be scheduled to begin two weeks after the end of the quantitative data collection.

weeks after the initiation of the online survey and will run for a further three weeks. The interviews are estimated to take no longer than thirty minutes to complete.

5.	Lledaenu Gwybodaeth / Cynulleidfa: Rhestrwch i bwy y rhoddir neu y dangosir copi o'r canlyniadau neu adroddiad / cyflwyniad terfynol.	Dissemination of Information / Audience: List to whom a copy of the results or final report or presentation will be given or shown.
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This study will report the action taken regarding organ donation and information concerning reasons for opting out. The results of the study will be reported in English in a standalone executive summary and may be submitted to academic conferences as well as providing a partial element to an MSc module. Additionally, given the real-time value of the research to the population of Wales, and future relevance to the remainder of the UK, these findings will also be disseminated at appropriate public engagement events.

6.	Lleoliad y Prosiect: Nodwch bob lleoliad lle y cesglir data neu y cynhelir ymarferiadau / cynhyrchiad.	Location of Project: Identify all locations where data will be collected or rehearsals/ production will take place.
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Data collection for the questionnaire element of the proposed study will take place online using the software package `SurveyGizmo`. Participants will be directed to the survey via links from Facebook and twitter. The interviews will be conducted via telephone or face to face at an agreed date, time and location.

7.	Cymeradwyaeth Arall: Oes angen cael cymeradwyaeth unrhyw sefydliad arall cyn cychwyn neu gwblhau'r prosiect? Os felly, gan bwy ac a ydy wedi'i sicrhau eisoes?	Other Approvals: Is there a requirement for approval from any other organisation / institution prior to starting or completing the project? If so, by whom and has it been obtained?
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Not applicable.

Pwy yw'r cyfranogwyr arfaethedig?	Who are the intended participants?	Ydw / Yes	Na / No
Myfyrwyr / staff Y Drindod Dewi Sant	Students / staff of Trinity Saint David	Yes	
Oedolion (dros oed 16 ac yn gymwys i gydsynio)	Adults (over the age of 16 and competent to give consent)	Yes	
Plant a phobl ifanc dan oed	Children / legal minors		No
Cleifion neu gleientiaid gweithwyr proffesiynol	Patients or clients of professionals		No
Rhywun sy'n cael ei gadw yn y ddalfa neu y mae'r llys wedi cymryd cyfrifoldeb amdano	Anyone in custodial care or for whom the court has assumed responsibility		No
Aelod o unrhyw sefydliad lle mae'n bosibl bod angen i unigolyn arall hefyd gydsynio.	A member of any organisation where another individual may also need to give consent.		No
Erill: Nodwch: / Others: please identify: The study will include those individuals who are identified as having resided in Wales for a minimum period of twelve months and are over the age of eighteen.			

Nifer, Oed a Ffynhonnell y Cyfranogwyr	Participant / Audience Number and Age
Rhowch fanylion yr demograffeg y cyfranogwyr / gynulleidfa.	Provide details of the demographics of the participants / audience.

Nifer o Gyfranogwyr / yn y Gynulleidfa	Participant/ Audience number	The study aims to target 500 individuals to obtain a minimum final sample of 100 participants based on a 25% response rate.
Grŵp oedran y Cyfranogwyr/y Gynulleidfa	Participant/ Audience age group	The survey will include male and female participants who have lived in Wales for over 12 months, be aged 18 or over and have the mental capacity to understand the new legislation system.

ADRAN 5 – RISGIAU YN PROSIECT

SECTION 5 – RISKS IN PROJECT

Bydd y diffyg ateb cadarnhaol i bob un o'r cwestiynau hyn yn arwain at y gofyniad eglurhad a gallai arwain at oedi yn eich ymchwil. Dim neu Dim NID yn dderbyniol.	A lack of a positive answer to all of these questions may result in the requirement of further explanation and a delay in your research. None or Nil is not acceptable.
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Risg Posibl:		Potential Risk:		
(corfforol, seicolegol, cyfreithiol, cymdeithasol neu economaidd)		(physical, psychological, legal, social or economic)		
A oes unrhyw risg bosibl i:		Is there any potential risk to:	Ydw / Yes	Na / No
A	Cyfranogwyr?	Participants?	Yes	
B	Ymchwilydd?	Researcher?	Yes	
C	BrifYsgol/Cyfadrn?	University?	Yes	

2	Rheoli Risg:	Management of Risk:
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	Os oes, beth yw'r risg a sut y bydd yn cael ei reoli?	If yes, what is the risk and how will it be managed?
--	---	--

Risk to participants:

The main ethical considerations for the potential participants are:

- Feeling uncomfortable discussing a topic of a sensitive nature.
- Placing participants in a situation where they are made to feel embarrassed or distressed regarding their decision.
-

The British Psychological Society produces specific guidelines for the delivery of online research to ensure ethical consideration of the participants' welfare. Given the sensitive nature of the study topic, participants may not feel comfortable disclosing personal information, therefore from the initial consent form it will be made clear to participants that their responses will be collected anonymously and stored confidentially in the form of an electronic document. Additionally, during the consent stage respondents will be advised that participation is entirely voluntary and should they wish to withdraw they may do so at any point throughout the study. Should any participant experience unease as a consequence of taking part in the study they will be advised on the consent form to seek additional information from the website <http://organdonationwales.org>

Risk to researcher:

Risk to the University:

It is not anticipated that there will be any risks to the University in the conduct or dissemination of the research.

3	Os ydych yn delio â phlant ac oedolion sy'n agored i niwed a ydych wedi gwneud cais am dystysgrif DRS?	If you are dealing with children and vulnerable adults have you applied for a DRS certificate?
Not applicable		

1.	Monitro: Os ydych yn sylwi ar unrhyw ymddygiad sy'n groes Cod y BrifYsgol/Cyfadrn Ymarfer, unrhyw ganllawiau a gyhoeddir gan y gymdeithas broffesiynol priodol neu weithred anghyfreithlon. Amlinellwch eich strategaeth adrodd.	Monitoring: Should you observe any behaviour contravenes the University's Code of Practice, guidelines published by the appropriate professional association or is illegal outline strategy of your reporting action.
----	--	---

		Ydw / Yes	Na / No
A wnewch chi roi gwybod am unrhyw ymddygiad sydd yn erbyn Cod Ymarfer y BrifYsgol/Cyfadrn neu sy'n anghyfreithlon?	Will you report any behaviour that is against the University's Code of Practice or is illegal?	Yes	
A ydych yn darparu adborth i'r cyfranogwyr?	Will feedback be provided to participants?		No
A fyddwch yn dogfennu'r 'caniatâd i gymryd rhan yn y prosiect'	Will you be documenting the 'consent to participate in the project'	Yes	

ADRAN 7 – STORIO, DIOGELWCH A MYNEDIAD I DDATA SECTION 7 - DATA ACCESS, STORAGE AND SECURITY

		Ydw / Yes	Na / No
1.	Ydych chi'n gyfrifol am storio a diogelwch y data eu casglu?	Yes	
2.	Sut y bydd y data yn cael ei storio?	How will the data be stored?	

All quantitative data will be collected anonymously and will be stored in an electronic document. Consent forms will be stored separately from all data. The interview data will be audio recorded and transcribed. Only the researchers will have access to the recordings and transcriptions, which will be kept in a secure place within the University. The tapes will be destroyed within 48 hours of the interviews taking place, once they have been uploaded onto the computer which is password protected.

Following completion of the study, no data will be identifiable to any participant's names or consent forms.

3.	Mynediad i Ddata: Pwy fydd yn cael mynediad at y data? A oes unrhyw amodau i gael mynediad?	Data Access: Who will have access to the data? Are there any conditions to access?
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Members of the research team:

Dr Ceri Phelps; Principal Investigator.

Dr Paul Hutchings; Principal Investigator.

Stacey Coleman

Zoe Cooke

Karen Eaton-Thomas

Lucy King

4.	Cyfrinachedd / Anhysbysrwydd: Rhestrwch y dulliau a fydd yn cael eu defnyddio i sicrhau cyfrinachedd ac anhysbysrwydd y cyfranogwyr.	Confidentiality / Anonymity: List the methods that will be used to ensure the confidentiality and anonymity of participants.
----	--	--

All quantitative data will be collected anonymously through SurveyGizmo and subsequently stored in an electronic document for confidentiality purposes.

During the interviews, participants will be informed that their names will be changed to protect their identity and give them anonymity. Confidentiality is paramount given that participants will be discussing personal responses regarding their organ donor status, therefore data will be anonymised in accordance with the Data Protection Act 1998.

Rhaid i'r adran hon gael ei chwblhau gan bob parti perthnasol cyn y gellir cyflwyno' r cais i'r Bwrdd Moeseg Gyfadran.

This section must be completed by all concerned parties before it can be submitted to the Faculty Ethics Board.

Datganiad

Mae'r wybodaeth a gynhwysir yma yn gywir, hyd eithaf fy ngwybodaeth a'm cred. Rwyf wedi ceisio dynodi unrhyw risgiau a phroblemau sy'n gysylltiedig â'r prosiect / ymchwil neu gynhyrchiad ac rwyf yn cydnabod f'ymrwymadau innau a hawliau'r cyfranogwyr.

Declaration

The information contained herein is, to the best of my knowledge and belief, accurate. I have attempted to identify any risks and issues related to the project/research or production and acknowledge my obligations and the rights of the participants.

Llofnodau

Dylai'r ffurflen hon gael ei chwblhau a'i llofnodi gan y myfyriwr a'r goruchwyliwr lofnodi ac yna gan Bennaeth yr Ysgol/Cyfadrn/

Signatures

This form should be completed and signed by both the student and the supervisor and then signed by the Head of School/Faculty

Myfyriwr / Student

Dyddiad: / Date:

Cydllynydd y prosiect / Tiwtor

Project co-ordinator / Tutor

Arolygwr / Supervisor

Dyddiad: / Date:

Pennaeth Ysgol/Cyfadrn / Head of School/Faculty

Dyddiad: / Date

Rhaid i bob cais am ymchwil ar sail cyfweiliadau gynnwys y dogfennau canlynol:	All interview based research applications must provide the following pro-forma documents:
1. Ffurflen gydsynio ddrafft 2. Sampl o'r cwestiynau a ofynnir 3. Taflen wybodaeth am yr ymchwil sy'n esbonio'n glir ddiben y prosiect, y deilliannau disgwylledig a'r rheini y dangosir y canlyniadau iddynt.	1. A draft consent form 2. A sample of the questions that will be asked 3. An information sheet on the research that clearly explains what the project is, what the expected outcomes are and who the results will be shown to.

DYCHWELWCH I'R GYFADRAN MOESEG CYDLYNYDD
PLEASE RETURN TO THE FACULTY ETHICS CO-ORDINATOR

Cadeirydd y Pwyllgor Moeseg Gyfadran /Chair of the Faculty Ethics Committee

Dyddiad: / Date:



PRIFYSGOL CYMRU
Y Drindod Dewi Sant
UNIVERSITY OF WALES
Trinity Saint David

Rhif Adnabod Cyfranogwr:

Participant Identification
Number:

CWESTIYNAU CYFWELIAD SAMPL

SAMPLE INTERVIEW QUESTIONS

Teitl Y Prosiect: / Project Title:

1	
2	
3	
4	
5	
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7	
8	
9	
10	

ENW A CHYFEIRIAD YR YMCHWILYDD

NAME & ADDRESS OF RESEARCHER

--	--



PRIFYSGOL CYMRU
Y Drindod Dewi Sant
 UNIVERSITY OF WALES
Trinity Saint David

Rhif Adnabod Cyfranogwr:

Participant Identification Number:

--

FFURFLEN GANIATÂD CYFRANOGIAD

PARTICIPATION CONSENT FORM

Teitl Y Prosiect: / Project Title:

Enw'r Ymchwilydd / Name of Researcher:

Blwch Cychwynnol /
Please initial box

1	Cadarnhaf fy mod wedi darllen a deall y daflen wybodaeth dyddiedig XXXX ar gyfer yr astudiaeth uchod. Rwyf wedi cael y cyfle i ystyried y wybodaeth, gofyn cwestiynau, ac rwyf wedi cael ateb boddhaol i'r rhain.	I confirm that I have read and understand the information sheet dated XXXX for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2	Deallaf fy mod yn cymryd rhan o'm gwirfodd a bod croeso i mi dynnu'n ôl ar unrhyw adeg, heb roi rheswm.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.	
3	Deallaf y gellir defnyddio unrhyw wybodaeth a roddir gennyf mewn adroddiadau, erthyglau neu gyflwyniadau gan y tîm ymchwil.	I understand that any information given by me may be used in future reports, articles or presentations by the research team.	

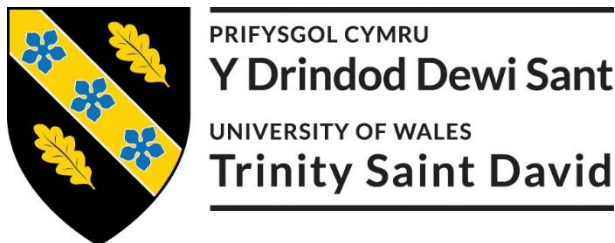
4	Deallaf na fydd fy enw'n ymddangos mewn unrhyw adroddiadau, erthyglau neu gyflwyniadau.	I understand that my name will not appear in any reports, articles or presentations.	
5	Cytunaf i gymryd rhan yn yr astudiaeth uchod.	I agree to take part in the above study	
Enw'r Cyfranogwr Name of Participant		Llofnodwyd Signature	
Ymchwilydd Researcher		Llofnodwyd Signature	

Cewch wrthod cymryd rhan yn yr astudiaeth hon. Cewch ddod â'ch cyfranogiad yn yr astudiaeth hon i ben unrhyw bryd. Os penderfynwch barhau'n ddienw, bydd sicrhau hynny'n flaenoriaeth a chymerir pob cam ymarferol i guddio pwy ydych. Os yw'n well gennych fod yn anhysbys, ni fydd unrhyw wybodaeth yn eich enwi ar dapiau sain na thrawsgrifiadau o'r cyfweiliad hwn nac o unrhyw un arall. Ni fydd neb yn clywed unrhyw dapiau sain nac yn gweld unrhyw drawsgrifiadau heb eich cydsyniad o flaen llaw. Bydd deunyddiau a grëir yn sgil y cyfweiliad hwn neu unrhyw gyfweiliad arall yn aros yn gyfrinachol.	You may decline to participate in this study. You may end your participation in this study at any time. If you decide to remain anonymous, maintaining your anonymity will be a priority and every practical precaution will be taken to disguise your identity. If you prefer anonymity, there will not be any identifying information on audiotapes or transcripts of this or any interview. No-one will hear any audiotapes or see any transcripts without your prior consent. All materials generated from this or any interview will remain confidential.
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Ar ôl llenwi'r ffurflen, dychwelwch hi yn yr amlen a ddarperir (lle bo'n berthnasol). Rhoddir un copi i'r cyfranogwr a chedwir y gwreiddiol yn ffeil y tîm ymchwilio yn:	When completed please return in the envelope provided (if applicable). One copy will be given to the participant and the original to be kept on the file of the research team at:
---	--

ENW A CHYFEIRIAD YR YMCHWILYDD	NAME & ADDRESS OF RESEARCHER



Rhif Adnabod Cyfranogwr:

Participant Identification
Number:

FFURFLEN GANIATÂD CYFRANOGIAD

SAMPLE PARTICIPANT INFORMATION
SHEET

Teitl Y Prosiect: / Project Title:

***THIS FORM IS TO BE AMENDED AND ADAPTED AS NECESSARY**

Dear Participant:

My name is **XXXX** and I am studying in the School of **XXXX**.

I would like to invite you to participate in my research project. This project will **xxx** and aims to **xxx**

*Attached to this letter is a short questionnaire developed by **XXX** which will assess **XXXX**. I believe your opinions will be extremely helpful to me.

Through your participation in the questionnaire and/or interviews, I hope to ascertain **XXXX**.

All questionnaires will be kept strictly confidential to the researchers involved and at **NO** time will individual questionnaires be released to the general public. This gives you a chance to

express your views on your programme a confidential and anonymous forum and still be able to make a difference. Your participation in this study is completely voluntary so you can withdraw from the questionnaire at any stage.

Our questionnaire should take about **XXX** minutes to complete, but there is no time constraint. There are also no right or wrong answers. Attached to this letter along with the questionnaire is **XXX** (e.g. an instruction sheet / a consent form /a feedback sheet). As this is a new project, your feedback is also important to us and we would be much obliged if you could also complete the feedback sheet along with the questionnaire. We understand that your time is at a premium but your opinions are very valuable to us.

After careful and precise analysis of the data obtained from this questionnaire, I will be happy to provide you with a copy of the findings at your request. The results of this questionnaire will hopefully enhance my understanding of XXXX and will be stored on XXX. The results of the research will be fed back to **XXX**.

We thank you in advance for your time and participation. If any questions do arise, feel free to contact me at your convenience.

ENW A CHYFEIRIAD YR YMCHWILYDD	NAME & ADDRESS OF RESEARCHER

Changes: Version 1 to Version 5

There were significant changes made between Version 1 and Version 5 for this project before it was ready for submission. The below table outlines the changes in detail, with information regarding construction of the online study information, consent and debrief following this.

Version 1 to Version 2:

Indicative title added	‘Signing a life away?: Exploring predictors of decision making in the Welsh population following legislation change regarding organ donation in Wales.’
Full study information and consent process included	See overleaf – Evidence 1: Section B Study Information and Consent
Full questionnaire included (Version 4)	See Evidence 2: Section D for full survey
Sample interview questions were added	See Evidence 3: Section A for these

Project outline expanded significantly to include a rationale for conducting the study over two phases

The proposed project is part of a specific Masters module with the researchers named on this proposal forming a research team.

The aim of the proposed project ~~for which we seek ethical approval~~, is to explore individuals' knowledge and attitudes towards organ donation following the recent legislation change in Wales. On 1 December 2015, Wales became the first country in the UK to introduce a 'soft opt-out' system for organ and tissue donation, meaning that all adults living in Wales, automatically become donors unless they choose to opt out before they die. People living in Wales now have three choices regarding their organ donor status; (1) they can register to be an organ donor, (2) they take no action and this will be regarded as the individual having no objection to being an organ donor, or (3) they can opt out if they do not wish to be a donor.

The project is intended to be conducted over two phases. Phase I will involve a survey administered online to collect quantitative data. The primary aim of this phase is to gain an insight into how strongly Welsh residents believe in their decision regarding their organ donor status (i.e., whether they have opted in, taken no action to be automatically opted in, or taken action to opt-out). This phase of the research will also seek to explore other factors that may have an impact on the decision making process (namely self-identity, moral norms, anticipated regret following the decision that is made, attitudes towards organ donation, intentions to become a donor prior to the legislation change, how much control participants feel they have over the decision regarding their organ donor status and what pressure they feel is put upon them to make a decision).

Phase II of the project will involve qualitative face-to-face interviews with individuals who have gone through the process of opting-out of organ donation following the change in legislation. The aim of this phase is to explore the reasons people choose to opt out.

Based on this objective, an extended version of the Theory of Planned Behaviour (TPB) plus semi-structured interviews will be implemented to gather quantitative and qualitative data, with the intention of predicting the strength of the decision to become an organ donor. Additionally the factors that impact upon this decision, and the reasons behind why individuals' choose to opt out of organ donation will subsequently be explored.through qual interviews? I would separate out the two methods here and make it clear why both help answer the question in different ways

You probably also need to start this section with a brief statement re how this project is part of a specific MSc module – group project etc

Description expanded significantly to include more information on the theory being used and a thorough justification of why the study was being proposed	Previous research in the UK has explored the intention to register to become an organ donor (Coad, Carter & Ling, 2013; O'Carroll, Ferguson, Hayes & Shepherd, 2012) however there is a lack of research exploring the difference between intention and action.explain a bit more. A unique element of this project is therefore to investigate psychological predictors of a decision that has already been made in relation to the change in organ donation legislation in Wales. Explain what you mean by predictors in non psych language – what type of stuff are you looking to explore etc Previous research has been conducted in the UK to explore people's intentions to register to become an organ donor, however there is a lack of research that explores the difference between intending to become an organ donor and the behavioural action involved in actually becoming an organ donor. This project provides a novel way to explore this behavioural gap and aims to investigate the factors that impact upon the decision making process in relation to organ donation following the recent legislation change in Wales. Specifically, the research will be looking to determine what factors can predict how strongly individuals believe in their decision to either 'opt-in' or 'opt-out' of becoming an organ donor. The Theory of Planned Behaviour (TPB) has been used extensively in psychological research to measure individual's intentions to perform a behaviour. This research proposes to use an extended version of the TPB in order to measure the behaviour that has already been conducted in relation to the change in legislation in Wales. The model will, therefore, seek to measure participants self-reported attitudes towards organ donation, previous intentions to become an organ donor prior to the legislation change, how much control people feel they have over the decision they make regarding their organ donor status, what pressures people feel to make a decision, how much regret they may feel following making a decision, how their organ donor status forms part of their self-identity and how moral norms may impact the decision people make. Information regarding past organ donation behaviour (i.e., assessing whether participants had registered to an become organ donor prior to the change in legislation) will also be collected. The target population for this project is the general Welsh population given the possible influence the change in legislation may have on this population. Participants will be invited to take part in both phases of the study through advertisements posted from each of the four researcher's personal Facebook and Twitter accounts. Although advertised together, it will be made clear that the separate phases of the study intend to recruit different participants. The online survey will be open to any individual who meets the eligibility criteria (see section below) and give consent to take part after reading the study information provided. It will be stated that the interview element of this project requires participants who have already made the decision to opt-out of becoming an organ donor as a direct impact of the legislation change.	
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Information included in the method regarding the pilot quantitative materials plus further elaboration in some parts to tighten up method information.

The study will consist of two phases; ~~Phase one~~ will include online quantitative data collection with ~~Phase two~~ comprising of qualitative interviews. Participants will initially be recruited through Facebook and Twitter with the researchers posting a link to invite individuals to partake in an online survey on a voluntary basis ([see Appendix A](#)). The link will direct participants to Survey Gizmo where they will be presented with study information and a consent form. ([see appendix B for online consent](#))~~(See appendix etc)~~ Providing that participants [give](#) consent, they will subsequently be directed to the questionnaire. ~~Access~~ Access to the questionnaire will be available for a period of three weeks [with the researchers re-posting the advert to participate on Facebook each \(pick a day\) morning during this period.](#) Based on reported response rates for online surveys ranging between approximately 42% and 85%, the study aims to target 500 individuals to gain a minimum final sample of ~~400-125~~ participants based on a 25% response rate. To be eligible to take part in the survey, participants must have lived in Wales for over 12 months, be aged 18 or over and have the mental capacity to understand the new system. [Participants will be required to read the information sheet and consent form before answering questions regarding their eligibility \(see Appendix B\).](#) [As this will be administered online, the system will be set up to ensure that any individuals who respond 'no' to either of the questions asked \(i.e. are ineligible to take part\) will not be directed to the questionnaire and will instead be taken to a state how you ensure this as part of your consent process. How long does the survey take? What type of questions – refer to appendix etc.](#) The survey will take approximately 15 minutes to complete ([see appendix C for the most recent version of the full questionnaire](#)).

[The initial questionnaire has been piloted as a paper version and administered to an opportunity sample of university students during a university workshop. Students were asked to report any issues they encountered when completing the questionnaire and used an evaluation form to include any further comments to be fed back to the research team. There were a number of amendments that were made to the questionnaire to fine-tune some of the issues identified. Following an assessment of reliability of each of the scales contained within the questionnaire, it was decided by the research team that the items reflecting one specific factor \(namely perceived behavioural control\) would be changed due to very low reliability. The final amended version of the questionnaire will be piloted once more before making the online version live and commencing data collection. This phase of data collection will then run for a maximum of three weeks.](#)

Phase ~~two~~ will utilise ~~semi-structure interviews in the form of telephone and face-to-face interviews~~ [interaction](#) to collect qualitative data [exploring decision making and regarding](#) reasons for [choosing to](#) opting out. Participants for this phase will [again](#) be recruited through [social media](#) and will therefore be [limited to friends and family of the researcher team](#). It will state in the initial advertisement that the requirement for this phase is to recruit individuals who have already registered their decision to opt out. The aim is to recruit a minimum of 12 participants. Participants will be eligible to participate in the interview phase as long as they are over 18 years of age, have lived in Wales for more than 12 months and have already registered their decision to opt out. To protect the validity of the research, members of the project team will not interview their own friends or family. The interviews for this project will be scheduled to commence two weeks after the initiation of the online survey and will run for a further three weeks. The interviews are estimated to take no longer than 30 minutes to complete with each participant ([see Appendix D for full interview schedule and Appendix E for interview consent](#)).

Clearer guidance included in relation to number of participants the study was hoping to recruit for each phase	Participant / Audience Number and Age Provide details of the demographics of the participants / audience. The study aims to target 500 individuals to obtain a minimum final sample of 100 participants based on a 25% response rate in order to have sufficient numbers for planned analysis <u>Phase I: This element of the study aims to target 500 individuals in order to obtain a minimum final sample of 125 (based on a 25% response rate) in order to have sufficient numbers to be able to conduct the planned analysis.</u> <u>Phase II: A minimum of 12 participants will be required for this phase with each of the four researchers hoping to interview three participants each.</u> The survey ~~will seek to recruit~~ include male and female participants who are over 18 years of age, have lived in Wales for more than 12 months, and have the mental capacity to understand the new legislation system. <u>The interviews will also require participants to be over 18 years of age and have lived in Wales for more than 12 months but in addition, participants will only be eligible to participate in the interviews if they have already registered their decision to opt out of organ donation.</u>	
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Proposed advert for Facebook recruitment included	Appendix A: Proposed advert for Facebook and Twitter accounts. <u>As part of a research team for an MSc module, I am conducting a study on the topic of attitudes towards organ donation following the recent legislation change in Wales. This study is split into two separate phases:</u> <u>Phase I: An online survey regarding people's knowledge and attitudes towards organ donation. This phase is directed at any individual who is over 18 and who has lived in Wales for more than 12 months. Please click the link below for more information on this study and to take part.</u> <u>www.surveymozmo.etc.....</u> <u>Phase II: This element of the study requires any individuals who are over the age of 18 and had lived in Wales for more than 12 months who have made the decision to opt-out of organ donation following the legislation change in Wales. The aim of this phase is to conduct face-to-face interviews with individuals who have opted out. If you have registered to opt out or organ donation and are interested in taking part in this study, please contact me on the following email:</u> <u>STUDENT EMAIL(s)??</u>
Version 2 to Version 3:	
Method changed slightly to accurately reflect proposed recruitment process for the qualitative phase of the project	Phase II will utilise <u>a small number of</u> face-to-face interviews to collect qualitative data exploring decision making and reasons for choosing to opt-out. <u>Potential participants for this phase will be targeted via word of mouth through friends and family. People who express possible interest to a member of the research team will be provided with a study information sheet and consent form. Participants for this phase will again be recruited through social media and will therefore be limited to friends and family of the research team. It will state in the initial advertisement that the requirement for this phase is to recruit individuals who have already registered their decision to opt out.</u> The aim is to recruit a minimum of 12 participants. Participants will be eligible to participate in the interview phase as long as they are over 18 years of age, have lived in Wales for more than 12 months and have already registered their decision to opt out. To protect the validity of the research, members of the research team will not interview their own friends or family. The interviews for this project will be scheduled to commence two weeks after the initiation of the online survey and will run for a

Proposed advert changed to reflect the above, also – recruitment for the quantitative phase only will be via Facebook	<u>As part of a research team for an MSc module, I am conducting a study on the topic of attitudes towards organ donation following the recent legislation change in Wales. This study is split into two separate phases:</u> <u>Phase 1: We are seeking participants to complete an online survey regarding people's knowledge and attitudes towards organ donation. This phase is directed at any individual who is To take part you need to be over 18 and have who has lived in Wales for more than 12 months. Please click the link below for more information on this study and to take part.</u> <u>www.surveymzmo.com</u>
Version 3 to Version 4:	
Qualitative consent information added	Dear Participant: My name is XXXX and I am studying in the School of Psychology I would like to invite you to participate in my research project. This project will involve a 30-minute interview that aims to explore individuals' knowledge and attitudes towards organ donation following the recent legislation change in Wales. Through your participation in the interview, I hope to establish the factors that may impact upon an individuals' decision to opt-out of organ donation. Your participation in this study is entirely voluntary <u>so and therefore you can you can withdraw at any time without giving a reason. In order to maintain your anonymity and protect your identity your name will be replaced with a pseudonym and any identifiable context will be changed</u> following completion of this interview and prior to transcription. Any data obtained from this interview will hopefully enhance my understanding of the factors that impact upon the decision to opt-out of organ donation. This interview will be transcribed following completion and stored electronically within a password protected file. The results of the <u>research</u> will be We thank you in advance for your time and participation. If any questions do arise, feel free to contact me at your convenience.
Version 4 to version 5:	
Interview consent sheet, online debrief and interview debrief finalised	See overleaf

FFURFLEN GANIATÂD CYFRANOGIAD

SAMPLE PARTICIPANT INFORMATION SHEET

Teitl Y Proiect / Project Title: Signing a life away?: Exploring predictors of decision making in the Welsh population following legislation change.

Study information sheet

We would like you to take part in our research study. Please read the following information carefully and discuss it with others if you wish. Please take time to decide whether or not you wish to take part. This study forms part of an MSc project for the researchers below, who are studying at the School of Psychology, University of Wales Trinity Saint David, Swansea. If there is anything that is unclear or if you would like more information please contact one of the researchers via email:

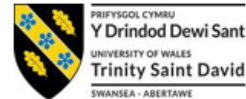
Stacey Coleman: scoleman.110400@student.uwtsd.ac.uk
Zoe Cooke: zcooke.115632@student.uwtsd.ac.uk
Karen Eaton-Thomas: keatonthomas.148267@student.uwtsd.ac.uk
Lucy King: lking.128002@student.uwtsd.ac.uk

We want to find out about the decision's people have made about organ donation following the recent legislation change in Wales. We are interested in those who have chosen to 'opt-out' and are hoping to ask around 12 people to take part in a 30 minute interview to discuss their decision making process.

You will have received this information sheet because you have expressed an interest in potentially taking part in this study. If you have decided you would like to take part please make contact with one of the researchers using the details above. Your participation in this study is entirely voluntary and therefore you can withdraw at any time without giving a reason. To keep your information confidential your name will be replaced with a pseudonym and any identifiable context will be removed.

Any data obtained from this interview will hopefully enhance our understanding of the factors that impact upon the decision to opt-out of organ donation. We thank you in advance for your time and participation. If you have any other questions please feel free to contact one of us at your convenience.

Appendix F: Online Debrief



Signing a life away?: Exploring predictors of decision making in the Welsh population following legislation change.

Thank you for taking part in this study.

The aim of the study was to explore individuals' knowledge and attitudes towards organ donation following the recent legislation change in Wales to introduce a 'soft opt-out' system. We are specifically looking to explore what factors may predict how strongly people believe in the decision they have made regarding their organ donor status following this change.

If you wish to withdraw your data from the study you must inform the researcher now. After this point all of your data will remain anonymous, therefore will not be able to be traced back to you as an individual.

If taking part in this study has raised any questions please contact a member of the research team via email:

Stacey Coleman: scoleman.110400@student.uwtsd.ac.uk
Zoe Cooke: zcooke.115632@student.uwtsd.ac.uk
Karen Eaton-Thomas: keatonthomas.148267@student.uwtsd.ac.uk
Lucy King: lking.128002@student.uwtsd.ac.uk

Or contact the principal investigator Dr Ceri Phelps on ceri.phelps@uwtsd.ac.uk

In addition, if participating in this study has raised any questions relating to organ donation or you wish to access more information about this topic, please refer to the relevant link below:

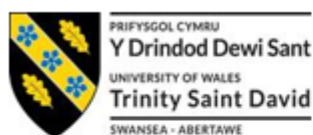
➤ <http://organdonationwales.org>

Thank you once again for taking the time to participate in this study.

Research Team,

University of Wales Trinity Saint David, Swansea

Appendix F: Interview Debrief



School of Psychology
Swansea

Study Debrief Sheet

Signing a life away? Exploring predictors of decision making in the Welsh population following legislation change

Thank you for taking part in the study.

The aim of the study was to explore individuals' knowledge and attitudes towards organ donation following the recent legislation change in Wales. We specifically wanted to explore the factors that impact upon an individuals' decision to opt-out of organ donation.

If you do not wish the researchers to use your interview data for the purposes of analysis, please inform the researcher now.

If taking part in this study has raised any questions please speak to a member of the researcher via email:

Scoleman.110400@student.uwtsd.ac.uk

lking.128002@student.uwtsd.ac.uk

zcooke.115632@student.uwtsd.ac.uk

keatonthomas.148267@student.uwtsd.ac.uk

Or contact the principal investigator: Dr. Ceri Phelps on: ceri.phelps@uwtsd.ac.uk

In addition, if participating in this study has raised any questions relating to organ donation or you merely wish to access more information about this topic, please refer to the relevant link below:

➤ <http://organdonationwales.org>

Thank you once again for taking time to participate in this study.

Research Team
University of Wales Trinity St David, Swansea

Online study information, consent and debriefing

The study information and consent was piloted with 27 undergraduate students as a hard copy prior to being included in the full survey online. The students were asked to critically consider the information that was provided in the information sheet and to include any comments or offers for any changes they felt could be made on the evaluation sheet that was also provided (see Evidence 2: Section B for this).

Study Information and Consent

You are being invited to take part in a research project being conducted by MSc students from UWTSD, Swansea.

On December 1st 2015, legislation in Wales changed regarding organ donation. Welsh residents now have three choices regarding their organ donor status; (1) they can register to be an organ donor, (2) they can 'opt-out' if they do not wish to be an organ donor, or (3) they take no action and are automatically opted in.

The aim of this survey is to explore knowledge and attitudes towards organ donation following the recent legislation change in Wales. If you consent to take part we would like you to answer a series of questions regarding your attitudes towards organ donation and your current organ donor status. The study will take approximately 15 minutes to complete.

Your participation in this study is voluntary and you are free to withdraw at any time by closing the browser. The survey will be completely anonymous and the information you provide will be confidential.

If you would like any more information about the study before participation please contact one of the following researchers:

Stacey Coleman: scoleman.110400@student.uwtsd.ac.uk

Zoe Cooke: zcooke.115632@student.uwtsd.ac.uk

Karen Eaton-Thomas: keatonthomas.148267@student.uwtsd.ac.uk

Lucy King: king.128002@student.uwtsd.ac.uk

I confirm that I have read and understood the information sheet for the study	Yes / No
I confirm that I am over 18 years of age and have lived in Wales for longer than 12 months	Yes / No
I understand that my participation is voluntary and I am free to withdraw at any time without giving any reason and decline to answer any questions I do not want to answer.	Yes / No
I give my consent to take part in the study	Yes / No

Participant's signature

Date|

Following this pilot, the only comment that was noted in regards to the study information and consent was that the questionnaire was only aimed at Welsh people. Due to this comment, the team recognised the clear importance of firstly making it explicit when advertising the study that it was aimed at Welsh residents only, and also just as importantly to set up the online consent procedure using logics to exclude illegible participants from taking part. As Survey Gizmo was used to set up the online version of the survey, it was relatively easy to create these logics to ensure that only participants who responses YES to all four of the questions below were able to progress and complete the survey. If any individual responded NO to any of these questions, they would be directed to the following page thanking them for their interest in the research but explaining that they were ineligible to take part.

This allowed us to adhere to ethical concerns regarding under 18's taking part in the survey or any individual who had not been residing in Wales for long enough to have been affected by the legislation change, but also allowed participants who read the information and did not consent to be able to decline to take part at that point.

I confirm that I have read and understood the information provided for the study

☐ Yes

☐ No

I confirm that I am over 18 years of age and have lived in Wales for longer than 12 months

☐ Yes

☐ No

I understand that my participation is voluntary and I am free to withdraw at any time without giving any reason and decline to answer any questions I do not want to answer.

☐ Yes

☐ No

I give my consent to take part in the study

☐ Yes

☐ No

[Next](#)



Skip/disqualify Action

Page Logic

IF

The answer to Question I confirm that I have read and understood the information provided for the study is one of the following answers **Yes**

AND

The answer to Question I confirm that I am over 18 years of age and have lived in Wales for longer than 12 months is one of the following answers **Yes**

AND

The answer to Question

I understand that my participation is voluntary and I am free to withdraw at any time without giving any reason and decline to answer any questions I do not want to answer.

is one of the following answers **Yes**

AND

The answer to Question I give my consent to take part in the study is one of the following answers **Yes**

THEN

Jump to page 2 - (untitled)



What is your current organ donor status? *

☐ Registered (Opted-in)

☐ Presumed consent (taken no action)

☐ Opted-out

At this moment, to what extent do you feel the choice you have made is the right one? *

0 1 2 3 4 5 6 7 8 9 10

Completely the wrong choice ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ **Completely the right choice**

Had you registered as an organ donor prior to the legislation change? *

☐ Yes

☐ No

☐ Don't know

[Back](#) [Next](#)

YES to all four questions
→ continue with survey

I confirm that I have read and understood the information provided for the study

☐ Yes

☐ No

I confirm that I am over 18 years of age and have lived in Wales for longer than 12 months

☐ Yes

☐ No

I understand that my participation is voluntary and I am free to withdraw at any time without giving any reason and decline to answer any questions I do not want to answer.

☐ Yes

☐ No

I give my consent to take part in the study

☐ Yes

☐ No

Next



Skip/disqualify Action

Page Logic

IF

The answer to Question I confirm that I have read and understood the information provided for the study is one of the following answers **No**
OR
The answer to Question I confirm that I am over 18 years of age and have lived in Wales for longer than 12 months is one of the following answers **No**
OR
The answer to Question
I understand that my participation is voluntary and I am free to withdraw at any time without giving any reason and decline to answer any questions I do not want to answer.

is one of the following answers **No**

OR

The answer to Question I give my consent to take part in the study is one of the following answers **No**

THEN

Jump to page 9 - Thank you



NO to any one or more
questions → Thank you
page informing participant
of not meeting the criteria
to take part

Thank you

Thank you for your interest in this study.

Unfortunately, you have not met one or more of the criteria to be eligible to take part in this study.

Thank you for your time. If you have any questions, please feel free to contact one of the researchers on the email addresses below:

Stacey Coleman: scoleman.110400@student.uwtsd.ac.uk

Zoe Cooke: zcooke.115632@student.uwtsd.ac.uk

Karen Eaton-Thomas: keatonthomas.148267@student.uwtsd.ac.uk

Lucy Hill: lking.128002@student.uwtsd.ac.uk

Debrief

Thank you for completing this online survey.

The aim of the survey was to explore individuals' knowledge and attitudes towards organ donation following the recent legislation change in Wales to introduce a 'soft opt-out' system. We are specifically looking to explore what factors may predict how strongly people believe in the decision they have made regarding their organ donor status following this change.

If taking part in this study has raised any questions please contact a member of the research team via email:

Stacey Coleman: scoleman.110400@student.uwtsd.ac.uk

Zoe Cooke: zcooke.115632@student.uwtsd.ac.uk

Karen Eaton-Thomas: keatonthomas.148267@student.uwtsd.ac.uk

Lucy Hill: lking.128002@student.uwtsd.ac.uk

Or contact the principal investigator/academic supervisor Dr Ceri Phelps on ceri.phelps@uwtsd.ac.uk

In addition, if participating in this study has raised any questions relating to organ donation or you wish to access more information about this topic, please refer to the relevant link below:

> <http://organdonationwales.org>

Thank you once again for taking the time to participate in this study.

MSc Research Team,

University of Wales Trinity Saint David, Swansea

Evidence 2

Questionnaire and Scale Development

Section A:

Version 1 / Pilot 1

Section B:

Version 2 / Pilot 2

Reliability analyses

Evaluation of survey

Section C:

Pilot 3 – First online version

Section D:

Final ‘live’ online survey

Section A:

Questionnaire Version 1 / Pilot 1

All members of the research team initially piloted version 1 of the questionnaire as a hard copy on friends and family. Version 1 consisted of a short information statement plus 17 questions measuring each of the constructs of interest. No demographic questions were included in this version; this was an assessment of the ease of readability and acceptability of the questions used for the topic, the order of the questions and the overall suitability of the survey.

From the comments obtained from friends and family, a significant amount of changes were made to Version 1 of the questionnaire. Firstly, and almost independently of the responses gathered from the pilot, the research team recognised an error in that the questionnaire did not currently contain a measure of the strength of belief participants had in the decision they had made. Due to this being pinpointed as the measure of the dependent variable in the study, a single item scale was added to Version 2

“At this moment, to what extent do you feel the choice you have made is the right one?” Responses anchored between 0 (completely the wrong choice) and 10 (completely the right choice).

A second addition to Version 2 was the inclusion of a measure of current organ donor status. Whilst the current version assessed previous organ donor status, the research team decided that including current organ donor status would offer an interesting comparison for analysis.

A number of participants commented that they did not think they had to respond to each of the three semantic differential pairs related to measuring general and personal attitudes towards organ donation. The research team decided to clarify this in Version 2 and split the attitude scales and have the scale responses (1-7) above each pair of words.

The biggest change made to Version 2 of the survey was the change of the anchor from *‘to become an organ donor or not’* to incorporate the decision-making element in regards to *‘current organ donor status’*. Five questions were, therefore, altered to pilot in Version 2,

plus a change to the instructions provided to participants to answer questions to include the 'regarding organ donor status'.

Participants noticed and commented that the two measures of attitudes using the same semantical differential scales did not match. This was rectified in Version 2.

Similar to the comments made regarding the attitude measures, participants noted that the questions anchored to '*If I become an organ donor...*' did not make sense and caused confusion in regards to what they had to answer. The research team decided to add the anchor to the start of each of the two questions.

An additional text box was added to Version 2 to allow participants the opportunity to provide any further comments, or to elaborate on anything they felt was important or not covered in the questionnaire itself.

Finally, the research team decided to change the order of the questions to pilot for Version 2 after comments from participants regarding similarity in questions.

Version 1.

Following the recent legislation change (1st December 2015) people in Wales now have three choices regarding their organ donor status. (1) They can register to be an organ donor, (2) they can 'opt-out' if they do not wish to be an organ donor or (3) they take no action and are automatically opted in.

The aim of this survey is to explore knowledge and attitudes towards organ donation following the recent legislation change in Wales.

Had you registered as an organ donor prior to the legislation change?

Yes ☐ No ☐

In general, I think that organ donation is...

	1	2	3	4	5	6	7	
Unimportant	☐	☐	☐	☐	☐	☐	☐	Important
Wise	☐	☐	☐	☐	☐	☐	☐	Foolish
Bad	☐	☐	☐	☐	☐	☐	☐	Good

For me, donating my organs would be...

	1	2	3	4	5	6	7	
Unimportant	☐	☐	☐	☐	☐	☐	☐	Important
Foolish	☐	☐	☐	☐	☐	☐	☐	Wise
Bad	☐	☐	☐	☐	☐	☐	☐	Good

How strong was your intention to become an organ donor?

	1	2	3	4	5	6	7	
Not strong	☐	☐	☐	☐	☐	☐	☐	Strong

Nothing to assess current organ donor status – add question to assess this in terms of the three possible

Split each of these with scale responses above each pair of words. Wise/foolish needs to be swapped to match the above in Version

For the following questions, please answer according to how strongly you agree with each statement:

1= Strongly disagree 2= Disagree slightly 3= Disagree 4= Neither agree nor disagree
5 = Agree 6 = Agree slightly 7= Strongly agree

I feel that those people who are important to me would be supportive of my decision

1 2 3 4 5 6 7
☐ ☐ ☐ ☐ ☐ ☐ ☐

I felt under pressure to make a decision

1 2 3 4 5 6 7
☐ ☐ ☐ ☐ ☐ ☐ ☐

I have complete control over whether or not I become an organ donor

1 2 3 4 5 6 7
☐ ☐ ☐ ☐ ☐ ☐ ☐

I did not feel that it was up to me to decide whether or not to become an organ donor

1 2 3 4 5 6 7
☐ ☐ ☐ ☐ ☐ ☐ ☐

Major change to
Version 1:

Remove 'organ donor or not' as reported as confusing by participants. Research team decision to change anchor to focus on decision-making element in regards to current organ donor status

$$\}$$

Add anchor to each separate question for clarity

[illegible]

It will bother me

1 2 3 4 5 6 7

○ ○ ○ ○ ○ ○ ○

It is in accordance with my principles to become an organ donor or not

1 2 3 4 5 6 7

○ ○ ○ ○ ○ ○ ○

Becoming an organ donor or not would be according to my moral values

1 2 3 4 5 6 7

○ ○ ○ ○ ○ ○ ○

To be an organ donor or not is an important part of who I am

[illegible]

Section B:

Questionnaire Version 2 / Pilot 2

Version 2 of the questionnaire was piloted on 27 first, second and third year undergraduate students from UWTSD, Swansea. For this version, the research team added demographic variables to the beginning of the questionnaire which resulted in a total of 25 questions. In addition to further comments regarding the acceptability of this version following the changes outlined in Section A, the research team were interested in assessing whether the questions capturing demographic information were relevant to participants.

Four participants commented that there was no option to choose '*in a relationship*' for marital status. The research team thus decided to add this as an option for Version 3.

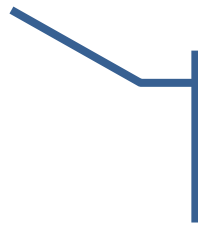


“No issues, all understandable and clear! Only issue I have with ALL questionnaires is that the option of ‘single’ is the only one I can tick even though I’m in a relationship.”

A number of comments were made regarding the fact that the questions were not numbered. The research team decided to consider numbering the questions in Version 3 which would be piloted online. The research team were also interested in any comments regarding the order and similarity of questions after changing the order from Version 1, however no comments were noted so it was decided to keep the order of the questions as they were for Version 3.

Further comments came from participants regarding the measures of attitudes. The research team had decided to add the scale response scores above each of the semantic differential pairs in order to clarify that participants had to respond to each of the pairs. After a number of comments regarding the slightly confusing structure of these sections in particular, and issues surrounding not being fully aware of the need to answer all three questions, the research team will consider how best to address this for the next pilot online. In addition to this, three participants commented about the reversal of the ‘wide-foolish’ scale in each of the measures

of attitudes. The research team noted these comments but decided to keep the order of the questions with the inclusion of the negatively coded items to match previous uses of the scale – i.e., keep wise and foolish as flipped/negatively worded.

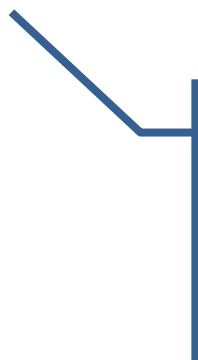


“Should follow the same systematic manner, i.e., good and bad on the same ends of the spectrum.”

The research team noticed a response scale error with some participants highlighting this, also. The responses were changed to match previous uses of 7-point Likert scales in order to ensure accurate total scores.

1 = Strongly Disagree, 2 = Disagree, 3 = Slightly Disagree, 4 = Neither disagree nor agree, 5 = Slightly Agree, 6 = Agree, 7 = Strongly Agree.

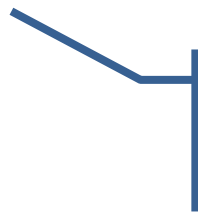
Two participants included additional information in the free text comments at the end of the questionnaire which interested the research team greatly. In regards to the questions measuring perceived behavioural control, one participant noted:



“Feel that the legislation is completely wrong. You have to respect human views, using the law against people’s wishes is wrong. I really do not want to have to opt out to voice my views. The word DONATION speaks volumes, they have completely got it wrong.”

This was of great interest in relation to potential influences or factors that impact upon individuals making the decision to opt-out following the legislation change. It was decided that a question assessing this element may be able to be incorporated into the qualitative interview phase of the study due to the potential of people feeling their right to make an informed decision has been taken away.

The second additional comment of interest was regarding cultural beliefs and organ donation in general.



“My parents will be disgusted by my organ donation decision due to cultural beliefs.

As above, the research team will consider incorporating a question assessing the potential influence of cultural or religious beliefs on the decision to opt-out in the qualitative interviews.

Reliability analyses

Reliabilities were calculated using Cronbach’s alpha for each of the sub-scales based on responses provided by each of the 27 participants in this pilot study. Each of the sub-scales reported appropriate alphas in accordance with previous studies with the exception of the two items making up the **perceived behavioural control** sub-scale. The research team considered the wording of these two items critically and discussed the option of rewording one or both of these prior to the next pilot study.

Scale	No. Items	Cronbach’s Alpha
Attitudes	6	.93
Intention	1	N/A
Subjective norms	2	.53
Anticipated regret	2	.77
Self-identity	1	N/A
Moral norms	2	.79
Perceived behavioural control	2	-1.79

Re-worded question:

I did not feel that it was up to me to decide whether to become an organ donor



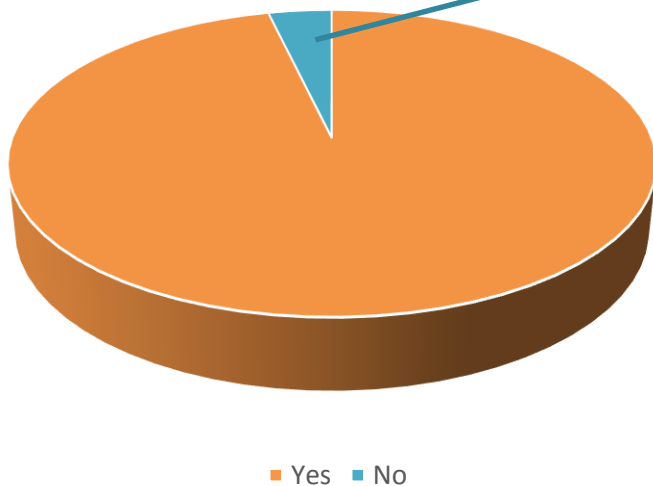
The decision whether to become an organ donor was completely up to me

Evaluation of survey

Each of the participants who piloted this version of the questionnaire were given the below evaluation sheet and asked to complete this as honestly as possible in order to give the research team further information to adapt or change the questionnaire if they needed to. The responses to each question are outlined in the subsequent pages.

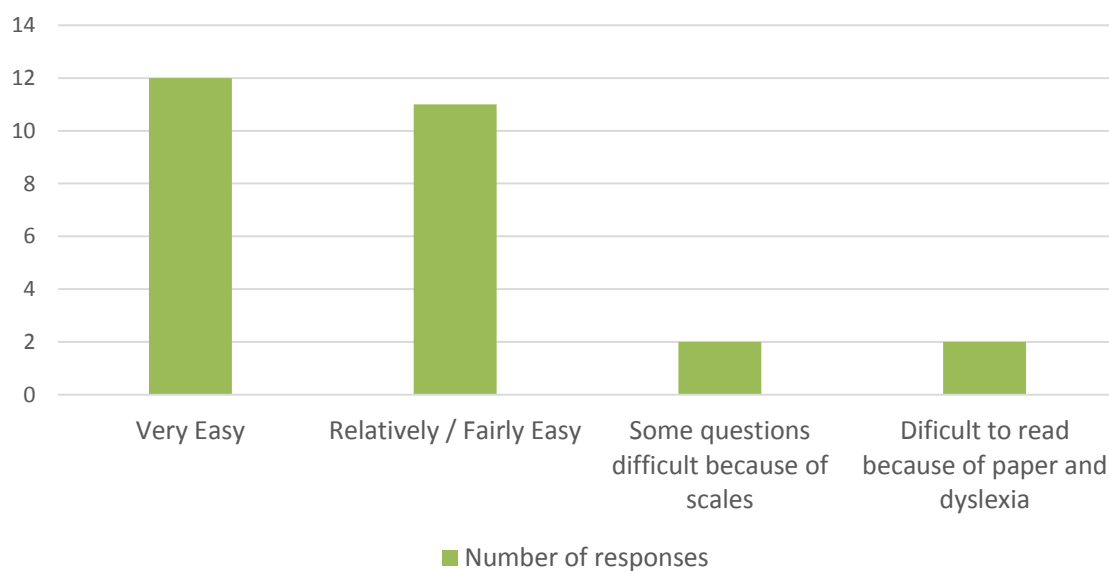
<u>Organ Donation Pilot Questionnaire</u> <u>Evaluation Sheet</u> 1) Did you understand all of the questions? Yes / No If no, please indicate which questions you did not understand: 2) How easy did you find the questionnaire to complete? 3) Did you feel the questionnaire was relevant to the topic of organ donation and current organ donor status of participants? 4) Was there anything that you did not like about the questionnaire?

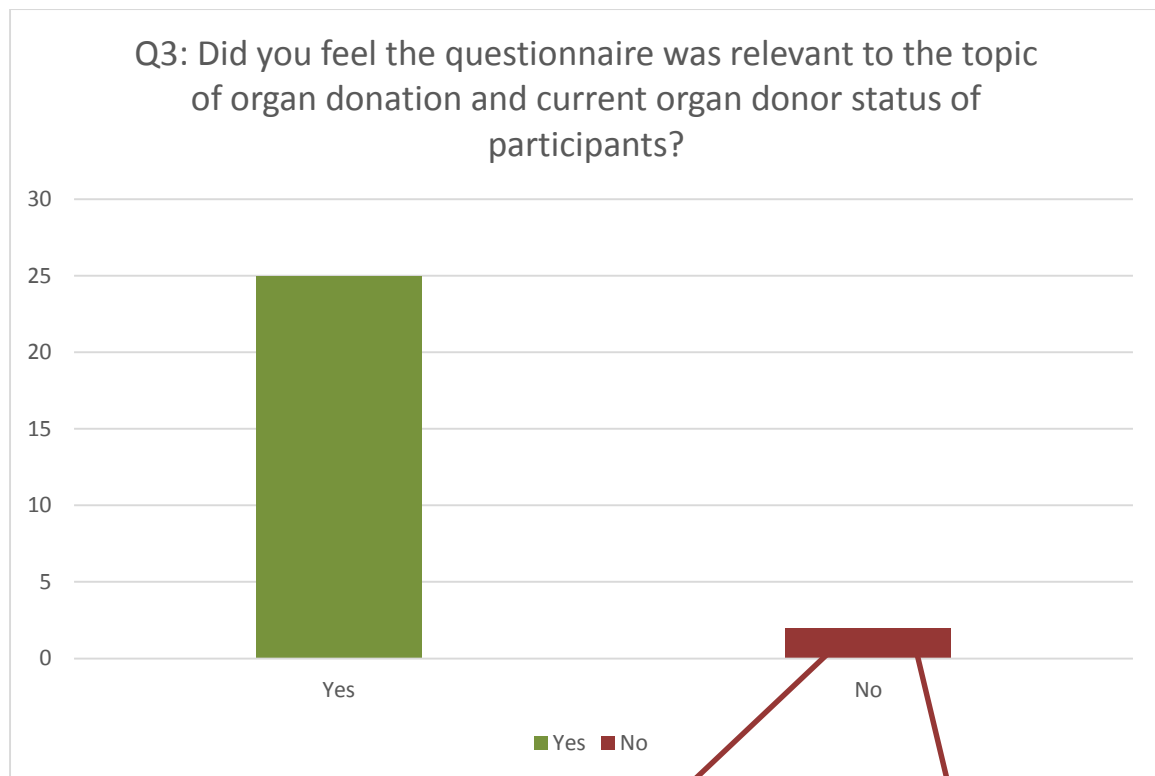
Q1: Did you understand all of the questions?



The 'slightly' responses should be swapped with the agree/disagree

Q2: How easy did you find the questionnaire to complete?





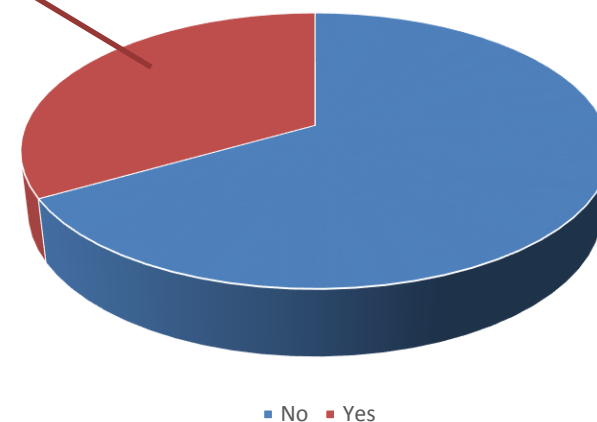
Not sure of the relevance of survey if people have not thought about organ donation or are not aware of the legislation change

I feel the questionnaire is aimed only at Welsh people

Of the nine YES responses to the question 4, each comment was dealt with appropriately by the research team:

1) Relationship status	✓ Team included 'in a relationship' to marital status question
2) Wise/foolish scale not easy to consider	✓ Team decision to keep this scale to remain consistent with previous attitudes measures using TPB
3) Not numbered	✓ Team to consider numbering questions for online pilot testing
4) Scale responses need to swap slightly and agree	✓ Team swapped these responses for accuracy
5) Don't like the question regarding current organ donor status	✓ Team decision to keep this question as important for exploratory analyses
6) Too many Likert scales	✓ These scales need to stay
7) Aimed only at Welsh people	✓ Due to the nature of the study to assess attitudes towards organ donation as a result in the change of legislation, it must be made clear that the survey is only aimed at constituents of Wales. Consideration to be made regarding the consent procedures for online version of the survey. The research team will decide on exclusion processes dependent upon length of residency in Wales (see Evidence 1; Section B).
8) Not dyslexia friendly (2 comments)	✓ Research team will ensure that the online version of the survey has a beige or yellow background with dark writing in consideration of participants with dyslexia. The next pilot study will incorporate consideration of further comments regarding acceptability and ease of reading for dyslexic participants.

Q4: Was there anything you didn't like about the questionnaire?



Version 2.

Following the recent legislation change (1st December 2015) people in Wales now have three choices regarding their organ donor status. (1) They can register to be an organ donor, (2) they can 'opt-out' if they do not wish to be an organ donor or (3) they take no action and are automatically opted in.

The aim of this survey is to explore knowledge and attitudes towards organ donation following the recent legislation change in Wales.

Male ☐ Female ☐ Prefer not to say ☐ Other (please specify) ☐ _____

Your age

At the moment, are you? (Please tick one)

- ☐ Single (never married)
- ☐ Married or living with partner
- ☐ Divorced or separated
- ☐ Widowed

Addition of 'in a relationship' for next version

What is the highest level of education you have attained? (Please tick one)

- ☐ Left school before 16 (no formal qualifications)
- ☐ Left school at 16 (GSCE, CSE, O levels or equivalent)
- ☐ Left school at 18 (A levels or equivalent)
- ☐ College certificate or diploma
- ☐ University degree or higher
- ☐ Other (please state)

How many children do you have?

In which county of Wales do you reside?

What is your current organ donor status?

Registered ☐ Presumed consent (taken no action) ☐ Opted-out ☐

At this moment, to what extent do you feel the choice you have made is the right one?

0	1	2	3	4	5	6	7	8	9	10
Completely the wrong choice					Not sure					Completely the right choice

Had you registered as an organ donor prior to the legislation change?

Yes ☐ No ☐ Don't know ☐

How strong was your intention to become an organ donor?

	1	2	3	4	5	6	7	
Not strong	☐	☐	☐	☐	☐	☐	☐	Strong

In general, I think that organ donation is...

	1	2	3	4	5	6	7	
Unimportant	☐	☐	☐	☐	☐	☐	☐	Important
	1	2	3	4	5	6	7	
Wise	☐	☐	☐	☐	☐	☐	☐	Foolish
	1	2	3	4	5	6	7	
Bad	☐	☐	☐	☐	☐	☐	☐	Good

Comments to match the good and bad words for each pair noted but research team to keep this as is to coincide with previous use and measure of attitudes

For me, donating my organs would be...

	1	2	3	4	5	6	7	
Unimportant	☐	☐	☐	☐	☐	☐	☐	Important
	1	2	3	4	5	6	7	
Wise	☐	☐	☐	☐	☐	☐	☐	Foolish
	1	2	3	4	5	6	7	
Bad	☐	☐	☐	☐	☐	☐	☐	Good

For the following questions, please answer according to how strongly you agree with each statement regarding your organ donor status:

1= Strongly disagree 2= Disagree slightly 3= Disagree 4= Neither agree nor disagree
5 = Agree 6 = Agree slightly 7= Strongly agree

My current organ donor status is a reflection of my principles

1	2	3	4	5	6	7
☐	☐	☐	☐	☐	☐	☐

I felt under pressure to make my decision

1	2	3	4	5	6	7
☐	☐	☐	☐	☐	☐	☐

If I become an organ donor I will regret it

1	2	3	4	5	6	7
☐	☐	☐	☐	☐	☐	☐

My current organ donor status is an important part of who I am

1	2	3	4	5	6	7
☐	☐	☐	☐	☐	☐	☐

I feel that those people who are important to me would be supportive of my decision

1	2	3	4	5	6	7
☐	☐	☐	☐	☐	☐	☐

The 'slightly' versions of each will be swapped with 'agree/disagree'

I have complete control over my organ donor status

1	2	3	4	5	6	7
☐	☐	☐	☐	☐	☐	☐

If I become an organ donor it will bother me

1	2	3	4	5	6	7
☐	☐	☐	☐	☐	☐	☐

My current organ donor status is in accordance with my moral values

1	2	3	4	5	6	7
☐	☐	☐	☐	☐	☐	☐

I did not feel that it was up to me to decide whether to become an organ donor

1	2	3	4	5	6	7
☐	☐	☐	☐	☐	☐	☐

Please feel free to use the text box below to add any additional comments

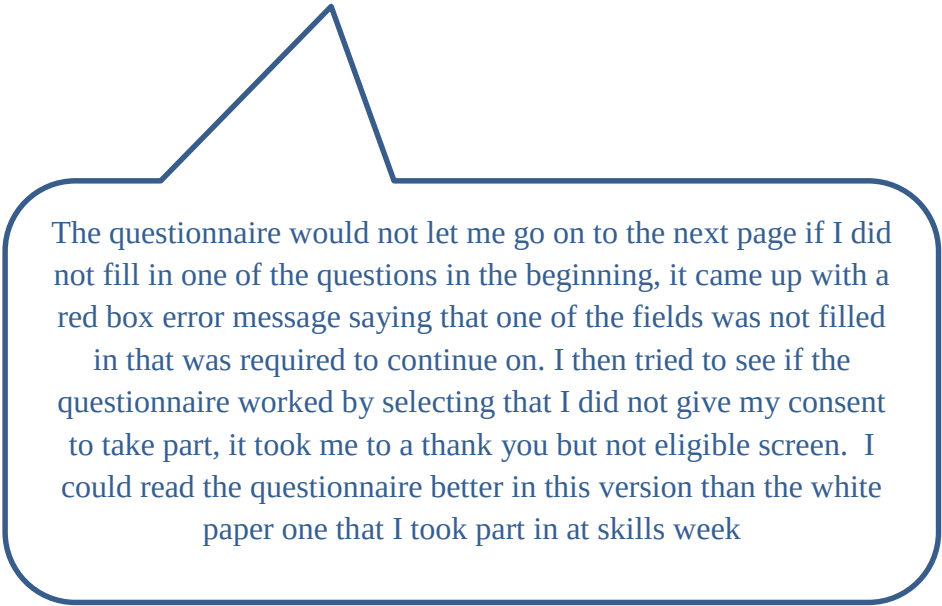
Section C:

Pilot 3 – Online

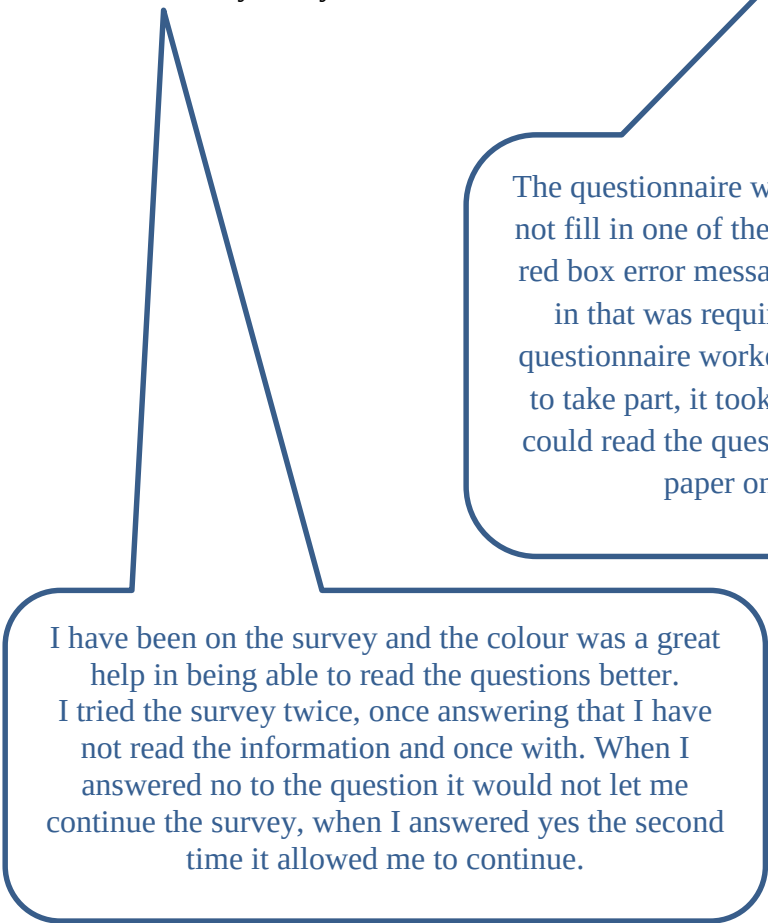
After changes had been made as a response to each of the comments provided from participants during Version 2 piloting, the survey was created on SurveyGizmo and pilot 3 was, therefore, conducted online.

All first year students who piloted version 2 of the survey were asked to complete the online survey and feed any comments they had back in order for the research team to continue to alter the survey if needed. With the addition of the study information sheet and consent in this online version, the students were asked to attempt to ‘break’ the survey by not filling questions in, answering ‘no’ to give consent and to leave fields blank to see what response they got. In addition, it was noted that any comments considering the ease of readability for dyslexic participants would be very helpful.

In total, ten first year students (all female) completed the first online version of the survey, with two feeding comments back; one via the comments section available on the survey and one directly to my email.



The questionnaire would not let me go on to the next page if I did not fill in one of the questions in the beginning, it came up with a red box error message saying that one of the fields was not filled in that was required to continue on. I then tried to see if the questionnaire worked by selecting that I did not give my consent to take part, it took me to a thank you but not eligible screen. I could read the questionnaire better in this version than the white paper one that I took part in at skills week



I have been on the survey and the colour was a great help in being able to read the questions better. I tried the survey twice, once answering that I have not read the information and once with. When I answered no to the question it would not let me continue the survey, when I answered yes the second time it allowed me to continue.

Section D:

Final 'live' online survey

On Wednesday 10th February 2016, the final online version of the survey went 'live' and data collection commenced. Advertisements were sent via the research team's personal Facebook accounts and the School of Psychology Twitter account. To date, the survey has received 155 responses. Data analysis and further plans for this study are due to commence in May 2016.

The final version of the survey incorporated all previous changes, alterations and considerations that were taken from comments made by piloting participants. Due to the online tool automatically showing progress along the bottom of the screen, the research team decided to not number each of the questions individually. The questions measuring attitudes were also further illuminated in this online version and the anchors of 'in general, I think that organ donation is...' and 'for me, donating my organs would be...' were included above each of the respective semantic differential pairs of responses.

After version 3 of the survey, the research team themselves took to piloting the questionnaire and determined that there was the need to change the wording of a number of the questions further. In relation to the items measuring Anticipated Regret, it was noted that there was a significant error in the current wording of the questions that did not reflect the fact that we were looking for information regarding a decision people had already made. Due to this, both items were changed as below:

Previous items	New items
If I become an organ donor I will regret it	Sometimes I wonder if I made the right decision
If I become an organ donor it will bother me	My decision has sometimes bothered me

Finally, it was decided that the order of the questions themselves would be changed a final time. It was decided that demographic information would be at the end of the survey instead of at the beginning. This is reflected in the final version below.

Organ Donation Survey

Study Information and Consent

You are being invited to take part in a research project being conducted by MSc students from UWTSD, Swansea.

On December 1st 2015, legislation in Wales changed regarding organ donation. Welsh residents now have three choices regarding their organ donor status; (1) they can register to be an organ donor, (2) they can 'opt-out' if they do not wish to be an organ donor, or (3) they take no action and are automatically opted in.

The aim of this survey is to explore knowledge and attitudes towards organ donation following the recent legislation change in Wales. If you consent to take part we would like you to answer a series of questions regarding your attitudes towards organ donation and your current organ donor status. The study will take approximately 15 minutes to complete.

Your participation in this study is voluntary and you are free to withdraw at any time by closing the browser. The survey will be completely anonymous and the information you provide will not be identifiable to you as an individual.

If you would like any more information about the study before participation please contact one of the following researchers:

Stacey Coleman: scoleman.110400@student.uwtsd.ac.uk

Zoe Cooke: zcooke.115632@student.uwtsd.ac.uk

Karen Eaton-Thomas: keatonthomas.148267@student.uwtsd.ac.uk

Lucy King: lking.128002@student.uwtsd.ac.uk

This study has received ethical approval from the University of Wales Trinity Saint David, Swansea.

I confirm that I have read and understood the information provided for the study

- ☐ Yes
☐ No

I confirm that I am over 18 years of age and have lived in Wales for longer than 12 months

- ☐ Yes
☐ No

I understand that my participation is voluntary and I am free to withdraw at any time without giving any reason and decline to answer any questions I do not want to answer.

- ☐ Yes
☐ No

I give my consent to take part in the study

- ☐ Yes
☐ No

Next

0%

Organ Donation Survey

What is your current organ donor status? *

- ☐ Registered (Opted-in)
- ☐ Presumed consent (taken no action)
- ☐ Opted-out

At this moment, to what extent do you feel the choice you have made is the right one? *

	0	1	2	3	4	5	6	7	8	9	10	
Completely the wrong choice	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	Completely the right choice

Had you registered as an organ donor prior to the legislation change? *

- ☐ Yes
- ☐ No
- ☐ Don't know

Back

Next

10%



Organ Donation Survey

How strong was your intention to become an organ donor? *

1234567

Not strong☐ ☐ ☐ ☐ ☐ ☐ ☐ Strong

In general, I think that organ donation is... *

1234567

Unimportant☐ ☐ ☐ ☐ ☐ ☐ ☐ Important

In general, I think that organ donation is... *

1234567

Wise☐ ☐ ☐ ☐ ☐ ☐ ☐ Foolish

In general, I think that organ donation is... *

1234567

Bad☐ ☐ ☐ ☐ ☐ ☐ ☐ Good

Back

Next

20%

Organ Donation Survey

For me, donating my organs would be... *

1234567

Unimportant☐ ☐ ☐ ☐ ☐ ☐ ☐ Important

For me, donating my organs would be... *

1234567

Wise☐ ☐ ☐ ☐ ☐ ☐ ☐ Foolish

For me, donating my organs would be... *

1234567

Bad☐ ☐ ☐ ☐ ☐ ☐ ☐ Good

Back

Next

30%

Organ Donation Survey

For the following questions, please answer according to how strongly you agree with each statement regarding your organ donor status:

1= Strongly disagree 2= Disagree 3= Slightly Disagree 4= Neither agree nor disagree 5 = Slightly Agree 6 = Agree 7= Strongly agree

My current organ donor status is a reflection of my principles *

Strongly disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly agree
☐	☐	☐	☐	☐	☐	☐

I felt under pressure from others to make my decision *

Strongly disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly agree
☐	☐	☐	☐	☐	☐	☐

I sometimes wonder if I made the right decision *

Strongly disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly agree
☐	☐	☐	☐	☐	☐	☐

My current organ donor status is an important part of who I am *

Strongly disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly agree
☐	☐	☐	☐	☐	☐	☐

Back

Next

40%

Organ Donation Survey

I feel that those people who are important to me would be supportive of my decision *

Strongly disagree

☐

Disagree

☐

Slightly disagree

☐

Neither agree nor disagree

☐

Slightly agree

☐

Agree

☐

Strongly agree

☐

I have complete control over my organ donor status *

Strongly disagree

☐

Disagree

☐

Slightly disagree

☐

Neither agree nor disagree

☐

Slightly agree

☐

Agree

☐

Strongly agree

☐

My decision has sometimes bothered me *

Strongly disagree

☐

Disagree

☐

Slightly disagree

☐

Neither agree nor disagree

☐

Slightly agree

☐

Agree

☐

Strongly agree

☐

My current organ donor status is in accordance with my moral values *

Strongly disagree

☐

Disagree

☐

Slightly disagree

☐

Neither agree nor disagree

☐

Slightly agree

☐

Agree

☐

Strongly agree

☐

The decision whether to become an organ donor was completely up to me *

Strongly disagree

☐

Disagree

☐

Slightly disagree

☐

Neither agree nor disagree

☐

Slightly agree

☐

Agree

☐

Strongly agree

☐

Please feel free to use the box below to add any additional comments

Back

Next

50%

Organ Donation Survey

General information

Please indicate your gender *

☐ Male

☐ Female

☐ Prefer not to say

☐ Other - Write In

Please provide your age *

At the moment are you? (Please tick one) *

☐ Single (never married)

☐ In a relationship

☐ Married or living with partner

☐ Divorced or separated

☐ Widowed

Back

Next

60%



Organ Donation Survey

General information

What is the highest level of education you have attained? *

☐ Left school before 16 (no formal qualifications)

☐ Left school at 16 (GCSE, CSE, O levels or equivalent)

☐ Left school at 18 (A levels or equivalent)

☐ College certificate or diploma

☐ University degree or higher

☒ Other - Write In

How many children do you have? *

In which county of Wales do you reside? *

Back

Next

70%



Debrief

Thank you for completing this online survey.

The aim of the survey was to explore individuals' knowledge and attitudes towards organ donation following the recent legislation change in Wales to introduce a 'soft opt-out' system. We are specifically looking to explore what factors may predict how strongly people believe in the decision they have made regarding their organ donor status following this change.

If taking part in this study has raised any questions please contact a member of the research team via email:

Stacey Coleman: scoleman.110400@student.uwtsd.ac.uk

Zoe Cooke: zcooke.115632@student.uwtsd.ac.uk

Karen Eaton-Thomas: keatonthomas.148267@student.uwtsd.ac.uk

Lucy Hill: lking.128002@student.uwtsd.ac.uk

Or contact the principal investigator/academic supervisor Dr Ceri Phelps on ceri.phelps@uwtsd.ac.uk

In addition, if participating in this study has raised any questions relating to organ donation or you wish to access more information about this topic, please refer to the relevant link below:

> <http://organdonationwales.org>

Thank you once again for taking the time to participate in this study.

MSc Research Team,

University of Wales Trinity Saint David, Swansea

Back

Submit

Evidence 3

Qualitative Material Creation

Section A:

Development of interview questions

Section B:

Interview schedule

Section A:

Development of interview questions

The interview questions for the qualitative phase of this project were developed by the whole research team. Some questions were included as a result of the comments made by participants during the piloting stage of the quantitative survey (see Evidence 2: Section B). It was decided that the interview was to focus on individuals who had opted out of organ donation only, with the team recognising the limitation of having nothing to compare these individuals' attitudes towards organ donation with those who had register prior to the legislation change. We sought to structure the interview questions to include opening, key, and closing questions.

Version 1:

- 1) Ok to set the scene, can you tell me a little bit about how you first became aware of the organ donation legislation change?
 - a. Prompt: was it on social media? Did you see any adverts on TV? Hear any information on the radio? Did you hear about it from family members?
- 2) How did you feel when you first heard about the change in legislation?
 - a. Prompt: did you have any strong feelings towards the change?
- 3) Did you feel you had enough information to make an informed decision to opt-out or did you search for more information before you made your decision?
- 4) Can you tell me approximately when you made the decision to opt-out?
- 5) Thinking back to your decision to opt-out, was it a decision you made very quickly after learning about the organ donation legislation?
 - a. Prompts: for example, was it a decision that came easily to you or was it something you had to think about for some time?
- 6) Can you tell me the sort of things that may have influenced your decision?
- 7) Did you discuss your decision to opt out with you friends and family?
 - a. Prompt: can you tell me more?
- 8) Do you feel that you were influenced by something you saw on the news or social media?

Opening questions

Key Questions

- a. Prompt: you mentioned earlier about how you became aware of the legislation change – do you feel this could have affected your decision?
- 9) Do you feel there were any particular moral or religious beliefs that may have influenced your decision?
 - a. Prompt: yes – can you please expand on this?
- 10) What, in your opinion, was the strongest influence on your decision?
- 11) Since making your decision have you found yourself in a position where you feel you may reconsider your decision to opt out?
- 12) Can you think of any situations that might occur that could make you reconsider your decision?
- 13) So overall, to what extent do you feel that you have made the right decision for you?
- 14) We are pretty much coming to the end of the interview now so I'd like to ask one final question: If you were to give one piece of advice to other people to help them make the right decision for them, what would it be?
 - a. Prompt: for example, would you tell them to ensure they talk to friends and family? Offer a particular source of information? Anything you'd suggest for them to consider?

Closing questions

Following a brief pilot period with members of family and friends, a number of the questions were altered and changed. This is reflected in the final schedule in the following section.

Section B:

Interview Schedule

The team decided to share the work required to construct all the elements for the qualitative phase of the study. The role I had to play in this was the development of the pre-interview information.

Interview Schedule for Organ Donation Interviews

Hello _____, I'm _____. Thank you for taking the time to be here today and for agreeing to take part in this interview. Before we start, I am aware you have already returned your consent and read the information sheet but I will begin by giving you a brief overview of what we are here to discuss today. Before that, can I please just check that you are happy for this interview to be recorded? And if you are, just to confirm that everything that is discussed by us today will only be listened to by those involved in the research.

[Switch on tape recorder]

So, the purpose of this interview today is to explore the reasons why individuals in Wales have decided to opt-out of organ donation. As you are already aware, the data collected from this interview is for the purposes of a research project developed by Masters Students from UWTSU, Swansea. Any information that you provide today will be kept strictly confidential and the audio recording will only be listened to by those involved in the research. If you do wish to discuss anything that is not relevant to the specific questions being asked today please do not hesitate to ask me today or to contact one of the research team. Is that ok?

Great. Finally I'd just like to let you know that if this research is written up as a report that your name will be replaced with a pseudonym and any identifiable context will be removed. I'd just like to remind you that if you want to pause or stop the interview at any time because you feel uncomfortable please just let me know.

Do you have any questions before we begin?

Great.

- 1) So first of all, can you please tell me a little bit about how you first became aware of the organ donation legislation change?

Prompt: was it on social media? Did you see any adverts on TV? Hear of any information on the radio? Did you hear about it from a family member?

- 2) How did you feel when you first heard about the change in legislation?

Prompt: Did you have any strong feelings towards the change?

- 3) Did you feel you had enough information to make an informed decision to opt-out?

Prompt: Or did you search for more information before you made your decision?

- 4) Thinking back to your decision to opt-out, was it a decision that you made very quickly after learning about the organ donation legislation?

Prompt: For example, was it a decision that came easily to you? Or was it something you had to think about for some time?

- 5) Ok, let's move on and talk about the sort of things that may have influenced your decision. Did you discuss your decision to opt-out with your friends and family?

Prompt: Can you tell me more?

- 6) Do you feel that you were influenced by something you saw on the news or on social media?

Prompt: you mentioned earlier about how you become aware of the legislation change – do you feel this could have affected your decision?

- 7) Do you feel there were any particular moral beliefs that you feel may have influenced your decision?

Prompt: Yes – can you please tell me more / expand on this?

No – What about any religious or spiritual beliefs?

- 8) What, in your opinion, was the strongest influence on your decision?

- 9) Can you think of any situations that might occur that could make you reconsider your decision?

- 10) So overall, to what extent do you feel that you have made the right decision for you?

- 11) We are pretty much coming to the end of the interview now, so I'd like to just ask one final question: If you were to offer one piece of advice to other people to help them make the right decision for them, what would it be?

Prompt: For example, would you tell them to talk to friends and family? Offer a particular source of information? Anything you'd suggest for them to consider?

[End of interview – close by summarising the conversation and relaying your thoughts back to the participant for approval. Thank the participant and remind them about the consent for recording and how the information will be used. Hand participant the debrief form and inform them that, if they have any further questions, to please get in touch with a member of the research team at any time.]

Evidence 4

Quantitative Data Protocol/Analysis

Section A:

Blank SPSS data set

Section B:

Use of Syntax

Section A:

Blank SPSS data set

In order to analyse the data that was collected during the quantitative phase of this project from the responses provided on Survey Gizmo, I allocated variable names to each of the questions included within the survey (including free text comments), allocated numerical responses to each question for ease of downloading the data, and created a blank SPSS data set to allow the data to easily be transferred ready for analysis. Examples of this can be seen on the following pages. The data set that was created matched the order and codes that were included in the codebook, also.

SPSS Variable Name

CurrentODStatus

Multiple Choice Options

OPTION

Registered (Opted-in)

Presumed consent (taken no action)

Opted-out

REPORTING VALUE

1

2

3

SPSS Variable Name

AR1

Multiple Choice Options

OPTION

Strongly disagree

Disagree

Slightly disagree

Neither agree nor disagree

Slightly agree

Agree

Strongly agree

REPORTING VALUE

1

2

3

4

5

6

7

ID	Gender	Age	MaritalStatus	Education	Children	County	CurrentODstatus	RightChoice	PreviousOD	intention
----	--------	-----	---------------	-----------	----------	--------	-----------------	-------------	------------	-----------

attitudegen1	attitudegen2	attitudegen3	attitudeme1	attitudeme2	attitudeme3	moralnorms1	SN1	AR1	self	SN2	PBC1	AR2	moralnorms2	PBC2	Comments
--------------	--------------	--------------	-------------	-------------	-------------	-------------	-----	-----	------	-----	------	-----	-------------	------	----------

ID	Numeric	8	2			None	None								
Gender	Numeric	8	2			{1.00, male}...	None								
Age	Numeric	8	2			None	99.00								
MaritalStatus	Numeric	8	2			{1.00, single...	99.00								
Education	Numeric	8	2			{1.00, left s...	99.00								
Children	Numeric	8	2			None	None								
County	Numeric	8	2			None	99.00								
CurrentODs...	Numeric	8	2	What is your c...		{1.00, regist...	99.00								
RightChoice	Numeric	8	2	To what extent ...		None	99.00								
PreviousOD	Numeric	8	2	Were you previ...		{1.00, yes}...	99.00								
intention	Numeric	8	2	How strong wa...		None	99.00								
attitudegen1	Numeric	8	2	unimportant-im...		None	99.00								
attitudegen2	Numeric	8	2	wise-foolish		None	99.00								
attitudegen3	Numeric	8	2	bad-good		None	99.00								
attitudeme1	Numeric	8	2	unimportant-im...		None	99.00								
attitudeme2	Numeric	8	2	wise-foolish		None	99.00								
attitudeme3	Numeric	8	2	bad-good		None	99.00								
moralnorms1	Numeric	8	2	reflection of prin...		{1.00, stron...	99.00								
SN1	Numeric	8	2	under pressure		{1.00, stron...	99.00								
AR1	Numeric	8	2	i will regret it		{1.00, stron...	99.00								
self	Numeric	8	2	important part o...		{1.00, stron...	99.00								
SN2	Numeric	8	2	those who are i...		{1.00, stron...	99.00								
PBC1	Numeric	8	2	complete contr...		{1.00, stron...	99.00								
AR2	Numeric	8	2	bother me		{1.00, stron...	99.00								
moralnorms2	Numeric	8	2	accordance wit...		{1.00, stron...	99.00								
PBC2	Numeric	8	2	did not feel it w...		{1.00, stron...	99.00								
Comments	String	150	0			None	None								

Blank SPSS data set
created prior to
analysis

Section B:

Use of Syntax

I decided to create a Syntax file for this project to reverse score the appropriate items, create total scores (or mean scores in this case), run reliability analyses on each of the relevant sub-scales and to provide the basic outline of the primary analysis that we were wishing to conduct: hierarchical multiple regression.

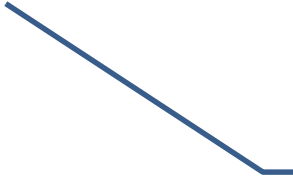
```
1
2 DATASET ACTIVATE DataSet1.
3 RECODE attitudegen2 attitudeme2 SN1 (7=1) (6=2) (5=3) (4=4) (3=5) (2=6) (1=7) INTO attitudegen2RC
4   attitudeme2RC SN1RC.
5 VARIABLE LABELS attitudegen2RC 'attitudegen2RC' /attitudeme2RC 'attitudeme2RC' /SN1RC 'SN1RC'.
6 EXECUTE.
7
8
9 COMPUTE attitudeMEAN=(attitudegen1 + attitudegen3 + attitudeme1 + attitudeme3 + attitudegen2RC +
10   attitudeme2RC) / 6.
11 EXECUTE.
12
13
14 COMPUTE SNMEAN=(SN1RC + SN2) / 2.
15 EXECUTE.
16
```

Conducting reliability
analyses on scales

```
32 RELIABILITY
33 /VARIABLES=moralnorms1 moralnorms2
34 /SCALE('moralnormsREL') ALL
35 /MODEL=ALPHA
36 /STATISTICS=DESCRIPTIVE SCALE CORR
37 /SUMMARY=TOTAL CORR.
38
39
40
41 RELIABILITY
42 /VARIABLES=AR1 AR2
43 /SCALE('regretMEAN') ALL
44 /MODEL=ALPHA
45 /STATISTICS=DESCRIPTIVE SCALE CORR
46 /SUMMARY=TOTAL CORR.
47
```

Reverse scoring
&
Calculation of
total/mean scores

```
18 REGRESSION
19 /DESCRIPTIVES MEAN STDDEV CORR SIG N
20 /MISSING LISTWISE
21 /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL CHANGE ZPP
22 /CRITERIA=PIN(.05) POUT(.10)
23 /NOORIGIN
24 /DEPENDENT RightChoice
25 /METHOD=ENTER PreviousOD Gender Age
26 /METHOD=ENTER regretMEAN PBCMEAN SNMEAN moralnormsMEAN selfidentityMEAN intentionMEAN attitudeMEAN
27 /SCATTERPLOT=(*ZRESID ,*ZPRED)
28 /RESIDUALS NORMPROB(ZRESID)
29 /CASEWISE PLOT(ZRESID) OUTLIERS(3).
30
```



Hierarchical Multiple
Regression analysis outline