

*Italics* are for your information only Do not read out this information to the participants.

- You will need to interpret the focus group topic guide and the consent form into the appropriate language. We would suggest that the questionnaire remains in English and this will be completed as a group with the facilitator translating each question.
- Prior to beginning the focus group ask the participants to help themselves to drinks/food

Start:

- Introduce self and thank participants for attending
- Provide a brief oral summary of the project (based on the information sheet). We would suggest something along the lines of:

The research project is looking at why there are low rates of organ donor registration and low family consent rates from people with minority ethnic backgrounds. The researchers are conducting a series of focus groups with people from Indian, Pakistani, Bangladeshi, African and Caribbean backgrounds. These want to explore and discuss the views and attitudes that people have towards organ donation. You are free to leave at any time and you will not be identifiable from anything that you say in the discussion as any personal data will be anonymised. The results of the all the focus groups will contribute to the DonaTE research programme.

Do you have any questions about the study?

I would now like you to complete the consent form which means that you have agreed to take part in the discussion. This is not to sign you up to the organ donor register.

- Go through the consent form and ask participants to initial in the boxes and sign at the end *Depending on the group it might mean the facilitator and CK or SD going round and assisting where necessary to ensure the forms are completed.*
- Hand out the questionnaires and get the group to complete this together with the facilitator translating where necessary.

*(The consent forms and questionnaires will be collected at the end – we normally ask people to sign for the payment and collect the forms one-by-one to ensure that the forms are complete and everyone is paid)*

I would just like to explain how the discussion will work today. I have some information, questions and short scenes relating to organ donation which will guide the discussion. We are interested in knowing what your views and opinions are and we are not looking for any right answers rather we want to know what you honestly think. You may find that you agree or disagree with others in the group, but please respect what other people have to say.

The discussion is being recorded, so please try not to talk over one another and I have to type up what has been said. Whatever you say cannot be traced back to you. At the end of the discussion we will collect your consent form and questionnaire and ask you to sign a piece of paper to receive the payment.

Is everyone ready to begin?

[TURN ON RECORDERS]

To begin with I'm [name] and I will be leading the discussion. I would like to go round and for the tape, please say your name.

We'd like to start with a general topic which will give us a little bit of background about you. There are no right or wrong answers and it's your views and experiences we're after.

Where do you look for health information?

*Prompts*

- If you wanted to know about how to stay healthy
- If you wanted to know more about kidney disease, where would you look for that information?

Where would you look if you wanted information about:

A new job or a change of career?

If you wanted to know how you could register with a new GP practice?

What each of the main political parties stand for?

What benefits you might be entitled to?

If you have children, which are your local schools?

*Prompts*

- Why would you go there?

Is anyone involved in any local community activities?

*Prompts*

- What sorts of things?
- Who else is involved (similar age, background)

Beyond your local community, are you involved in any other community activities?

*These are a couple of warm-up questions. We're interested in knowing where people go for information about a range of topics to see where they go and then whether they use formal or informal services or networks.*

*The community questions are wanting to establish the extent to which people are involved in community activities (this can be any sort of community) to try to establish individuals' participation (as it has been suggested that those who are more likely to participate in things are more likely to sign the organ donor register).*

## SECTION 1: Organ Donation

We're now going to move onto the main discussion about organ donation. To give you some background information. The first kidney transplant took place over 50 years ago and since then many thousands of transplants have taken place. There are not enough organs (e.g. heart, kidneys, lungs) being donated to meet the demand for organ transplants. When someone dies their organs can be transplanted into others to help them live. In today's discussion we are interested in **donation after death** and not live donation e.g. a father gives one of his kidneys to his son.

Thinking about this, generally what are your views on organ donation and organ transplants?

*Prompts (probe the answers using*

- Is it a good thing/bad thing; reservations
- Do you agree or disagree (*ask this to other members of the group, perhaps those who have not commented*)

*The information is to provide participants with a little background information – we are unsure what people know about organ donation. This information is saying that organ donation is new-ish, there aren't enough organs being donated to be used in transplants and that the discussion is focusing on deceased donation.*

*At this stage we want to get a general feel for the participants' views towards organ donation/transplantation. As facilitator it will help you to know generally who is for/against and the reservations people may have. If you try to remember broadly what people said it can help you during the discussion e.g. someone may originally say they are for organ donation and that it's a good thing, but later in the discussion add in caveats e.g. in one group a participant was form organ donation, but would not agree to make the decision to turn off a relative's life support machine, so this earlier pro-organ donation view is not as straight forward as it seems.*

I would now like to give you some further factual information:

When people are in a situation where a loved one dies unexpectedly e.g. after an accident, heart attack or stroke, 40% of White British people **refuse** to donate the organs of a loved one and 75% of Black and South Asian people **refuse** to donate the organs of a loved one

Why do you think Black and South Asian people appear not to agree to organ donation of their relatives?

*This question is trying to establish suggestions for reasons why members of the group broadly feel that members of minority ethnic groups appear not to donate the organs of a relative (not their own). This should identify a number of reasons and these are likely to include: religion/faith reasons and cultural/faith reasons specific to the body. If possible try to ask if there are any reasons beyond these and probe whatever answers are given e.g. if religion is offered as a reason you might want to ask what their religion says about this and see if others in the group agree or have other reasons and again probe these and see if others in the group agree or disagree or have a different view.*

## SECTION 2: Organ donation not thought about on a daily basis

I would now like to use a short scene to explore one issue connected with organ donation and then I have a few questions to ask which are connected to the scene.

*Hand round the scene on paper for people to read [if you feel this is appropriate] and read out the scene using appropriate character names for the group*

**[male name] has seen on the news that somebody's life was saved after having a kidney transplant. This has made him want to donate his organs after his death.**

- How should [NAME] go about registering as an organ donor?
- Who do you think he should tell that he wants to be an organ donor after his death?
- What would influence you to donate your organs?
- What would influence you to NOT donate your organs?
- Would you talk to your family about organ donation

*Prompt: explore the reasons why people would or would not donate their organs and would or would not talk to their family about this e.g. why/why not*

*This scenario is trying to look at what people know about registering as an organ donor. People who want to register can sign up to the organ donor register in several ways including: via their driving licence, Boots Advantage card, online, via a leaflet, via their GP.*

*Next of Kin have the final say whether or not their relative's organs are donated, but people don't tend to discuss their wishes with their family and this is the issue that the next question considers – depending on the answers probe why they would tell that particular person/organisation.*

*The questions then move from 'John' to ask what the individuals would do themselves – what would influence the individual (incl. knowing someone who needs a transplant, altruism/helping others, having seen an advert for organ donation) and following on would/have they talked to their family.*

Do any of you carry an organ donor card or has anyone joined the organ donor register?

*For those participants who say YES ask the following questions:*

- A number of you have said you are registered to give your organs why have you decided to do this?
- Just out of interest how did you go about registering?

*For those participants who say NO ask the following questions:*

- Is this something that you have thought about?
- What made you think about it?

*This may have already been covered by the group, so it may just need to be asked briefly as a way to check who is/isn't on the organ donor register or carrying a donor card.*

*If it hasn't been brought up before, this question is trying to identify why people are or are not on the organ donor register – try to follow up the reasons people give by asking those who have registered what has influenced this view (NB. the recent media coverage of organ being taken from donor's beyond those specified might come up) and how they registered.*

*For those who are not on the organ donor register try to probe whether they have thought about it or not and if they have thought about it, but have not registered to be an organ donor try to find out why – be careful as we don't want to make moral judgements on people's personal decisions whether their actions are right or wrong or make them feel like they should sign the organ donor register.*

### **SECTION 3: Individual & Society**

I'd now like us to think a little bit more about why people may or may not want to donate their organs for transplantation, so using another scene:

*Hand round the scene on paper for people to read [if you feel this is appropriate] and read out the scene using appropriate character names for the group*

**[female name] is thinking of joining the organ donor register because she won't need her organs after she has died. Her brother [male name] says that he doesn't really see the point because she won't benefit from donating her organs.**

- Do you share [male name] view? That there's no point in [female name] donating her organs as she won't benefit?
- Do you share [female name]'s view that she won't need her organs after she's died
- Who in your opinion benefits from organ donation (individual benefit, NHS benefit people off waiting lists, society benefit – doing a good deed)

*This scenario considers who benefits from organ donation –We're interested in seeing how participants perceive benefit – whether it's something an individual has to experience or whether altruism is important.*

*The second question about [female name]'s view is considering whether participants take this at a literal level i.e. no longer needing organs after death or whether this raises cultural and/or faith beliefs around the body needing to remain intact.*

*In terms of who benefits – participants are likely to identify the transplant recipient as the person who benefits. Try to probe e.g. do other people also benefit from organ donation – people may take more of a structural view and consider things from the view point of the NHS or society – if they do follow this up – why they think this.*

Still thinking about [female and male name]

*Read out the next section of the scene (no need to have this printed out)*

**Later on [male name, same as above] wonders whether you can trust health professionals.**

Do you have any views on this?

- Probe views e.g. what has informed their views (media, personal experience)
- Do you trust all health professionals (Drs, nurses, etc)

*This is exploring the extent to which people trust or don't trust health professionals - e.g. Drs, nurses. This is exploring whether people trust the health system (NHS) as a whole or whether their level of trust varies e.g. someone may trust their GP, but has reservations about their trust in hospitals based on their own or another experience (a relative's or via the media. We're interested in where people's views are from.*

### **Further factual information**

I have some further factual information to give you.

8% of the UK population come from minority ethnic groups. But ethnic minorities represent 25% of those on the kidney transplant waiting list and often have to wait longer to receive an organ because fewer Black and South Asian are on the organ donor register which means they have agreed to donate their organs in the event of their death and because families are less likely to agree to organ donation after their relative has died. There is no single reason to explain these facts.

Using a final scene I'd like you to consider what issues may prevent people from minority ethnic groups from becoming organ donors.

*This factual information is to give the participants an idea of the difference in terms of the UK population from minority ethnic groups (relatively low) but that the need for kidney transplant for this group is relatively high and that there are fewer organs being donated from minority ethnic groups.*

*In general, organs from deceased donors to recipients have a better chance of success if the tissue and blood type of the donor and recipient match which is more likely if the donor and recipient share the same ethnic background.*

*Hand round the scene on paper for people to read [if you feel this is appropriate] and read out the scene using appropriate character names for the group*

### **Religion/Faith & Organ donation**

**[female name]'s 22 year old son, [male name], was run over and he is only being kept alive on a life support machine in intensive care.**

**The doctors have said that [male name] will not recover and later ask [male name]’s parents whether they would consider donating his organs.**

**[female name] is unsure because she thinks their religion won’t allow it, but her husband would like to donate his son’s organs.**

- What is your view on this situation
- What would you do if you were in this situation?

*Prompt: why would you do that? (trying to find the underlying reason that informs people’s views/opinions e.g. might be informed by religion/faith)*

- When is the appropriate time for a specialist nurse to ask families if they would consider organ donation

*Prompt: as soon as someone arrives in intensive care, when the family is told that their relative will not recover, after the family have been told that their relative will not recover?*

- What would encourage you from donating family member’s organs?

*Prompts: they are on the organ donor register, they have said they would like to donate their organs*

- What would discourage you from donating family member’s organs?

*Prompts: they have said that they don’t want to donate their organs, faith reasons, cultural reasons*

- Would your faith influence your decision to donate a relative’s organ?

*Prompts: in what ways?*

*This scenario is looking at the situation in intensive care. The request process and the decision process around agreeing to donate the organs of a relative. We are also interested in considering whether faith would affect someone’s decision to donate the organs of a relative.*

Thinking more broadly, do you know what your religions perspective is on organ donation?

What is you religion’s perspective on organ donation?

*Prompts*

- Why is religion for or against
- Why uncertain – what would you need to feel sure

***IF THE MAJORITY SUPPORT THE IDEA THAT RELIGION DOES NOT ALLOW THEN SAY:***

Did you know that [relevant religion] does not oppose organ donation. Does this change any of your views about organ donation?

*This is a straight forward question about the participant’s religion’s view to organ donation – it might cause some debate if people are unsure, or some might say that they know for certain either for or against.*

Where would you like to be able to get information from about organ donation?

In what format would you like to receive information about organ donation?

*Format prompts:* leaflet, via email/online, face to face from a Dr or Nurse, from local community leaders, language preferences

*A couple of broad questions about where people would like to get information from re: organ donation and the format that they would prefer this in – just spend a few minutes on this – the responses are likely to be quite straight forward e.g. information from a GP, health centre or community space, but try explore other less usual spaces e.g. online and whether these would work or not for those in the group. In terms of format, again just spend a few minutes to find out how participants would like to receive information about organ donation.*

As a final question, we're interested in why people have agreed to take part in these discussions, what were your reasons (try to get a reason from each individual)

*A general question to ask just before ending - we're simply interested in what motivates people to take part – it might be the payment, a new experience, some prior interest in organ donation e.g. knowing someone who needs or has had a transplant*

### **Finish**

I've come to the end of the topics and questions, before we finish is there anything else anyone would like to add or comment on about the discussion?

*Allow a few minutes for people to add anything - may or may not have things they want to say or possibly ask.*

I'd like to thank you all for coming along and giving up your time and taking part in the discussion. It has been really useful for us.

[STOP RECORDING]

*CK/SD will be on hand. We need to ensure that we have completed questionnaires and completed and signed consent forms from each participant. These will be collected from each individual and in return they will be asked to sign a piece of paper confirming that they have received £25 from us.*