



Eye Donation from Palliative and Hospice care contexts: investigating Potential, Practice, Preference and Perceptions (EDiPPPP).

Focus group guide: Carers

| Site ID Date: Time: Location | | | | | | | | | | | | | | | | | | |
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| Demographics: Participants N Relationship | | | | | | | | | | | | | | | | | | |
| Opening | We would like to break the ice a little now, by asking you all to introduce yourselves to EEDACH other. | | | | | | | | | | | | | | | | | |
| Introduction | Item No | <p>You have been invited here today so that we can ask you about your thoughts and views about the option of donation, specifically eye donation, being discussed with people during their care in a palliative or Hospice Service (delete as needed). As you will have read in the PIS this is an urgent matter as there is a shortage. We know this is a sensitive issue to discuss and therefore we would value your commentary.</p> <p>Researcher to Discuss group rules (listen to EEDACH other, confidentiality etc).</p> | | | | | | | | | | | | | | | | |
| | | <table border="1"> <thead> <tr> <th></th> <th>Key question</th> <th>Prompts</th> </tr> </thead> <tbody> <tr> <td rowspan="4">Perceptions Preference</td> <td>1</td> <td>Could you share your thoughts about how you feel about donation generally?</td> <td>Would you consider donation if it was possible?</td> </tr> <tr> <td>2</td> <td>Had you heard about eye donation before you were invited and agreed to be participate in this study?</td> <td>Would you consider eye donation? If not supportive of donation – could you tell us about why this is not something that you would consider?</td> </tr> <tr> <td>3</td> <td>What are your feelings and thoughts about eye donation?</td> <td>How did you hear about eye donation?</td> </tr> <tr> <td>4</td> <td>There will be changes to legislation around donation shortly as we move from an opt in system to an opt out system, what are your thoughts about this change?</td> <td>Do you, or anyone you know, have a donor card? Were you surprised to learn that people with conditions such as cancer can donate? Is this an important issue for you?</td> </tr> </tbody> </table> | | Key question | Prompts | Perceptions Preference | 1 | Could you share your thoughts about how you feel about donation generally? | Would you consider donation if it was possible? | 2 | Had you heard about eye donation before you were invited and agreed to be participate in this study? | Would you consider eye donation? If not supportive of donation – could you tell us about why this is not something that you would consider? | 3 | What are your feelings and thoughts about eye donation? | How did you hear about eye donation? | 4 | There will be changes to legislation around donation shortly as we move from an opt in system to an opt out system, what are your thoughts about this change? | Do you, or anyone you know, have a donor card? Were you surprised to learn that people with conditions such as cancer can donate? Is this an important issue for you? |
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| Propriety | 4 | Is this an option that should be offered to patients under the care of *palliative care and *hospice care services? (* delete as appropriate). | Do you have any concerns about this option? |
| | 5 | Research indicates that Health Care Professionals are reluctant to raise the issue of donation as part of care planning. Do you think that they should raise this issue? | Do you think that there should be information available for patients and their family members? |
| Practice | 6 | Who should raise the issue? | How do you think that patient's views and wishes should be recorded? What sort of information and in what format do you think it should be? |
| | 7 | When do you think this should happen? | |
| | 8 | Do you think that information about donation option should be available to patients? | |
| | | | |
| Knowledge | 9 | Do you know how many people are in need of a corneal transplant | |
| | 10 | Do you know how people can register their decision about being a donor? | |
| Ending | | Is there anything you would like to say? Have we missed anything? | |
| Closure | | Thank you for attending this focus group today, we very much appreciate the time you have given us. Explain follow up procedure. | |
| Close | | Thank you for your time today. Is there anything that you would like to ask me? My contact details are on this card. Please contact me if you have any questions resulting from this conversation. | |