

FORM B Organ Donation Study: Questionnaire for SNOD to document outcome of all approach conversations

Record of conversation with (tick all that apply): spouse or partner parent or child brother or sister grandparent or grandchild niece or nephew stepfather or stepmother half-brother or half-sister friend of long standing
 appointed representative (referred to as 'family' hereafter)

Age range of deceased person: 0-18 19-35 36-50 51-70 >71

What region in Wales did family members/friends come from (tick all that apply): Isle of Anglesey Conwy Gwynedd
 Denbighshire Flintshire Wrexham Powys Ceredigion Pembrokeshire Carmarthenshire Swansea
 Neath Port Talbot Bridgend Rhondda Cynon Taff Merthyr Tydfil Blaenau Torfaen Monmouthshire
 Caerphilly Newport Cardiff Vale of Glamorgan Outside of Wales

1. Was a SNOD involved in the donation conversation?

Yes No

2. Did the patient die in hospital in:

Wales (go to Q3b) England (go to Q3)

3. For Welsh patients that died in England what was the patient registered decision on ODR? Opt In Opt Out
 Appoint Representative Not Registered

Would the patient have fitted deemed consent criteria if they had died in Wales? Yes No

Did the family think that deemed consent would apply?

Yes No Uncertain Non Applicable (N/A)

Was consent obtained? Yes No N/A

Had the family heard or read about the Act from the media campaign (Radio, TV, newspapers, postal leaflet etc)?

Yes No Uncertain N/A

Were the family positive about the new Act?

Yes No Uncertain N/A (go to Q.19)

3b. For Welsh patients who died in Wales, what was their registered decision on the ODR? Opt In Opt Out
 Appoint Representative Not Registered

4. If patient was under 18 was their decision recorded on ODR?

Yes No Non Applicable (N/A)

5. For patients of any age, did the family know of any other expressed decision?

Yes No Uncertain N/A

6. Did the family agree with the patient's expressed donation decision? Yes No Uncertain N/A

7. Was there disagreement between one or more family members about the patient's expressed decision?

Yes No Uncertain N/A

8. Was the patient's registered or expressed donation decision supported? Yes No N/A

9. Only for patients who appointed a representative (AR).

Did the AR give consent? Yes No

Did the AR support new Act? Yes No Uncertain

Were the family aware of AR? Yes No Uncertain

Did the family agree with the decision of the AR?

Yes No Uncertain N/A

10. Did deemed consent apply? Yes No N/A

11. Did the family agree with the deemed consent of the patient?

Yes No N/A

If no, did you feel able to get the family to support the deemed consent? Yes No N/A

12. Was there disagreement within the family and close friends involved in the deemed consent conversation?

Yes No Uncertain N/A

If yes, did you feel able to get the group to support the deemed consent? Yes No N/A

13. Was consent obtained? Yes No N/A

14. Who consented? family member friend other N/A

15. Had the family heard or read about the Act from the media campaign (Radio, TV, newspapers, postal leaflet etc)?

Yes No Uncertain N/A

16. Did the family have a correct understanding of the Act BEFORE you spoke to them? Yes No Uncertain N/A

17. Did the family have a correct understanding of the Act AFTER you spoke to them? Yes No Uncertain N/A

18. Had the new Act changed the family views of organ donation?

Yes No Uncertain N/A

If yes, were they positive about the new Act? Yes No

19. Did any person suggest that they would register their decision in light of your conversation?

Yes No N/A

If yes, would they: Opt in Opt out
 Appoint Representative Do nothing

20. Has this Act influenced your approach conversation with this family? Yes No Uncertain N/A

Anything else that could be helpful (e.g. Was there a pre-approach, a complaint or anything in this case that impacted upon you getting consent under the new law?)

Return by email to organdonationstudys@nhsbt.nhs.uk (for South Wales team) as soon as possible.