



FiSh Pilot Study

Parent/Guardian Consent Questionnaire

Directions

- The following questions are about the FiSh Pilot Study consent process that you took part in
- We refer to people agreeing to take part in research as 'consenting'
- As your child received treatment as an emergency, consent for your child to take part in the FiSh Pilot Study would have been sought after the emergency situation
- This is known as research without prior consent, or deferred consent

Completing this questionnaire

Today's date

Are you the child's

Mother Father Other _____
(Please specify)

Your home postcode

Your child's age

days / weeks / months / years *(circle as appropriate)*

Your child's initials



1. Please indicate how strongly you agree or disagree with the following statements by placing a circle around the answer that best fits your opinion or decision



Statements	Agree	Neither agree nor disagree	Disagree
a. The doctor or nurse checked that it was a convenient time to discuss research before discussing FiSh	1	2	3
b. I was initially surprised to find out that my child had already been entered into FiSh	1	2	3
c. The information I received about FiSh was clear and straightforward to understand	1	2	3
d. I understood why consent for my child's participation in FiSh was sought after the treatment had been given	1	2	3
e. I had enough opportunity to ask questions about FiSh	1	2	3
f. I was satisfied with the deferred consent process for FiSh	1	2	3
g. It was difficult to take in the information I was given about FiSh	1	2	3
h. It was difficult to make a decision about FiSh	1	2	3
i. I made this decision	1	2	3
j. Someone took this decision away from me	1	2	3
k. I was not in control of this decision	1	2	3
l. The decision about the research was inappropriately influenced by others	1	2	3

If the answer to this question is 'Agree', please state who you think influenced the decision about the research:





2. Did you consent for your child to participate in FiSh?

- Yes (Go to Question 3) No (Go to Question 4)

3. What were your reasons for providing consent for your child to participate in FiSh?

Please tick all that apply and then circle your main reason (e.g.)

- | | |
|---|--------------------------|
| a. To help my child | <input type="checkbox"/> |
| b. To help other children in the future | <input type="checkbox"/> |
| c. I felt that medical studies like FiSh are important | <input type="checkbox"/> |
| d. Because I trusted the doctor or nurse who explained FiSh | <input type="checkbox"/> |
| e. The treatment had already been given to my child | <input type="checkbox"/> |
| f. My child recovered | <input type="checkbox"/> |
| g. I didn't feel comfortable saying no to the nurse or doctor who explained the study | <input type="checkbox"/> |
| h. Other (Please state): | <input type="checkbox"/> |

4. If you did not provide consent, please provide your reasons for deciding that your child would not take part in FiSh
(If you do not wish to do so, please leave this space blank)

5. We would value any comments or suggestions you have to improve the recruitment and consent process for FiSh

**We would like to thank you for taking the time to complete this questionnaire.
Please place the questionnaire in the envelope provided, seal it and give it back to the
doctor or research nurse.**