

Topic Guide for the Family Route Map Project Focus Group

Facilitator: *(name)*

Date:

Time: 11.00 *(example)*

Venue:

11.00

Arrival/Greetings & Hospitality

11.15

Welcome & Introductions (everyone to introduce themselves)

11.25

Discussion of first topic

“All about the diagnosis for you or your family member of your genetic condition”

- how did you find out this was a genetic condition
- did you request a referral to the genetics service or were you referred by a healthcare professional
- what information were you given about the condition
- in what way was it helpful
- what further information would have helped you
- were you given any information that was unhelpful
- were you given any information about how this condition could affect other family members.

11.50

Discussion of second topic

“All about your experiences of the current services you receive”

- what types of treatment and/or surveillance do you currently receive
- do you receive these locally or at specialist centres
- how far do you travel to receive these services and how often
- if you had a genetic test was it through a regional genetics clinic
- how was it arranged to give you your test results
- were you given contact details of other help or support

12.15

Discussion of third topic

“Designing a route for patients and families with the condition”

- which hospital department(s) has the most expertise with the condition
- are there any healthcare professionals that you have found very helpful e.g. specialist nurse or genetic counsellor
- how did you get information you needed
- did you understand the information
- would you want to attend the genetics service if you were a new patient
- what service would you most like to have received as a newly diagnosed patient
- what service was of least benefit for your condition
- do you have access to benefits or other services outside of the National Health Service
- how often do you think you should receive treatment or surveillance for the condition

12.40

Summary/Feedback of discussion

Take questions

Thanks

CLOSE