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## Family Route Map Survey

### **Introduction**

#### *Example:*

Family Route Maps can help to signpost patients, their families and carers to information and services for *your condition here*.

Together with you and healthcare professionals, we will initially build up a picture of the services families currently receive in the United Kingdom.

If you or a member of your family has one of the above conditions, your views on patient information and services will help us understand the way in which patients experience available services. We should be grateful for your feedback to help inform the development of this important project.

We would also be pleased to receive copies or details of patient information that you and your family have found useful. Please return your completed questionnaire to our address below, you can also include useful information leaflets if you wish.

*Address*

**By completing this survey in confidence, you are giving permission for the information to be used by the *your charity* for the purposes of the project. Nothing that could reveal your identity will be disclosed outside the project group. After analysing the information, some or all of it may appear in open publications. Procedures for handling, processing, storage and destruction of your information are compliant with the Data Protection Act 1998.**

**To agree to the use of information please tick the box**   
**Please tick *one* box only for each question.**

Question Are you a patient with this genetic condition(s)?

1

Yes

No

Question Are you related to, or a carer of, someone with the genetic condition(s)?

2

Yes

No

Question 3 Which condition do you or a relative have?

- Name of the condition here
- Name of the condition here if more than one
- Name of the condition here if more than one
- Name of the condition here if more than one
- Name of the condition here if more than one
- Name of the condition here if more than one

Question 4 How many hospitals do you regularly visit for treatment or monitoring of this condition? **Please list below together with the approximate distance for the round trip to each one e.g. Royal Free Hospital, London, 200 miles.**

Hospital and/or area	Approx. miles from home

Question 5 Have you ever been given information or received guidance about what care should be provided for a person with this condition?

- Yes
- No → Please go to Question 9

Question 6 What tests, treatment and/or surveillance does the information or guidance suggest you or your family member should have and how often are these recommended? (please continue on a separate sheet if necessary if you are completing this survey by post)

Test/Surveillance	Frequency

Question 7 Which organisation provided the information or guidance?  
e.g. Patient Support Group/Charity, Contact-A-Family, hospital etc.

Question 8 Was this on a website, in the form of written information or verbal guidance?  
(if you have more than one source of information relating to this please specify the type and source e.g. 1. *Written information from a hospital*, 2. *Verbal information from Patient Support Group etc.*)

Question 9 Have you found any patient information helpful?

Yes

No → Please go to Question 12

Question 10 Which organisation(s) provided the information?  
e.g. Patient Support Group/Charity, Contact-A-Family, hospital etc.

Question 11 Was this on a website, in the form of written information or verbal guidance?  
(if you have more than one source of information relating to this please specify the type and source e.g. 1. *Written information from a hospital*, 2. *Verbal information from Patient Support Group etc.*)

Question 12 What sort of difficulties did you experience in accessing services for this condition?

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Question 13 What sort of improvements would help you (and others) to access services for this condition?

Question 14 Any other comments?

The following questions are optional. However, if you would like to help us further with this project then please do provide your contact details or alternatively, phone, email or write to GIG.

Name:

Address:

Post Code:

Home phone number:

Mobile phone number:

Email address:

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Please give us some information about your background. To which of these ethnic groups would you say you belong? **(tick one only)**

**White**

- British
- Irish
- Any other White background (please write in box below)

**Mixed**

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other Mixed background (please write in box below)

**Asian or Asian British**

- Indian
- Pakistani
- Bangladeshi
- Any other Asian background (please write in box below)

**Black or Black British**

- Caribbean
- African
- Any other Black background (please write in box below)

**Chinese or Other Ethnic Group**

- Chinese
- Any other ethnic group (please write in box below)

**Thank you very much for your help**