



*Working to benefit all people
affected by genetic disorders*

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Clinical Networks for Rare Conditions

An early finding of the current Family Route Map project has been that the majority of patients and families affected by the six genetic conditions in this project would prefer to have a multidisciplinary approach to care with a clinician who has expertise in that condition coordinating their care. As a result GIG would like to find out if this is also the case for members of your organisation.

Would you be kind enough to complete and circulate this brief survey to those involved in your organisation and any clinicians who you feel may wish to contribute. In this way we may be able to put together a bid for funding to initiate and support some Pilot Networks.

This survey is also available on the GIG website www.gig.org.uk
Please return your completed questionnaire in an envelope to our Freepost address below or by email to melissa@gig.org.uk;

Freepost RRAR-SZJE-YSTU
Genetic Interest Group
Unit 4D, Leroy House
436 Essex Road
LONDON, N1 3QP

By completing this survey in confidence, you are giving permission for the information to be used by the Genetic Interest Group for the purposes of the scoping 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 1 Do you or a relative, or someone you are a carer for, have a genetic condition?

Yes

No → Please go to question 3

Question 2 What is the name of the genetic condition?

Question 3 Are you a member of a Patient Support Group?

Yes

No → Please go to question 5

Question 4 What is the name of the Patient Support Group?

Question 5 Do you work for or run a Patient Support Group?

Yes

No → Please go to question 7

Question 6 What is the name of the Patient Support Group?

Question 7 Are you a healthcare professional involved in the care of patients with a genetic condition(s)?

Yes

No → Please go to question 9

Question 8 What is the name of the genetic condition(s)?

Question 9 Do you think a network of clinicians who have experience and knowledge of treating and managing this genetic condition(s) is a good idea?

Yes

No

Question 10 Are you, a family member, or anyone you care for, **already under the care** of a network of clinicians who have experience and knowledge of treating and managing this genetic condition(s)?

Yes

No

Question 11 Could you recommend any clinicians and/or healthcare professionals who are interested in, or already working in this way? (continue in Question 14 if you need more space to list names & their details)

i)	Name	
	What is their speciality?.e.g. Dermatology	
	Are they a Consultant or Nurse etc.	
	Contact details	
ii)	Name	
	What is their speciality?.e.g. Dermatology	
	Are they a Consultant or Nurse etc.	
	Contact details	

Question 12 What sort of improvements would help you (and others) to access services for this condition?

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Question 13 Do you know of any funding that would possibly contribute towards a Pilot Project to develop and support Clinicians Networks in this way? (if yes please give details)

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:

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