

Genetic Interest Group: Patient Quality Indicators Questionnaire

Please tell us about your experience of genetic services by working through this questionnaire.

Your feedback is very important and it will only take a few minutes to complete.

Don't worry if you can't answer all the questions as some may not be relevant to you.

A) How were you referred to the genetics clinic? (Please tick one answer only)

By your family doctor	By a specialist doctor or hospital department	By yourself	Other (please specify)	Don't know

B) For whom were you seeking genetic advice? (Please tick one answer only)

Yourself	Your child/children	Another family member	Other (please specify)	Don't know

C) Before your genetics clinic appointment: (Please tick one answer only)

	Yes Strongly agree	Yes Agree	No Disagree	No Strongly Disagree	Don't know
Were you given sufficient information about the referral?	1	2	3	4	5
Did you understand it?	1	2	3	4	5
Was it given in a way that was helpful to you?	1	2	3	4	5
Did you have the opportunity to ask questions and discuss concerns?	1	2	3	4	5

D) At your 1st genetics clinic appointment: (please tick one answer only)

	Yes Strongly agree	Yes Agree	No Disagree	No Strongly Disagree	Don't know
Were you given sufficient information?	1	2	3	4	5
Did you understand it?	1	2	3	4	5
Was it given in a way that was helpful to you?	1	2	3	4	5
Did you have the opportunity to ask questions and discuss concerns?	1	2	3	4	5

E) If you or your family were offered genetic testing: (Please tick one answer only)

	Yes Strongly agree	Yes Agree	No Disagree	No Strongly Disagree	Don't know
Were you given sufficient information about the tests?	1	2	3	4	5
Did you understand it?	1	2	3	4	5
Was it given in a way that was helpful to you?	1	2	3	4	5
Did you have the opportunity to ask questions and discuss concerns?	1	2	3	4	5

F) How were you given the results of these tests? (Please tick one answer only)

During a clinic appointment	Over the phone	By letter	Other (please specify)

	Yes Strongly agree	Yes Agree	No Disagree	No Strongly Disagree	Don't know
Were you given sufficient information about the test results?	1	2	3	4	5
Did you understand it?	1	2	3	4	5
Was it given in a way that was helpful to you?	1	2	3	4	5
Did you have the opportunity to ask questions and discuss concerns?	1	2	3	4	5

G) If the genetics clinic suggested any further medical investigation or treatment: (Please tick one answer only)

	Yes Strongly agree	Yes Agree	No Disagree	No Strongly Disagree	Don't know
Were you given sufficient information?	1	2	3	4	5
Did you understand it?	1	2	3	4	5
Was it given in a way that was helpful to you?	1	2	3	4	5
Did you have the opportunity to ask questions and discuss concerns?	1	2	3	4	5

H) Did the genetic clinic give you information about other help and support? (Please tick one answer only)

Yes (Please indicate what type of support offered, e.g. social services or patient support group information)	No	Not needed

THANK YOU very much for completing the questionnaire. You're responses are very important to us.
If you have any further comments please feel free to write them below.