



Report from GIG Members Survey and  
Interviews  
*Research Conducted in Spring 2009*

*by Stephanie Yin*

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## Outline of Research:

A survey was designed to gather information on Member's views and perspectives on GIG, its work and aims. The survey attempted to explore Member's perceptions of what GIG does and assess the efficiency of GIG's communications and relationship with its members.

An email was sent out to all GIG members, requesting them to complete the online survey hosted on an external website (Survey Monkey). Participants were also invited to provide their contact information if they agreed to participate in follow up interviews.

A selection of willing participants was subsequently contacted and 6 interviews were conducted. Interviewees were selected based on the size of their organisation and the length of time for which they had been GIG members, with a view of selecting a broadly representative sample.

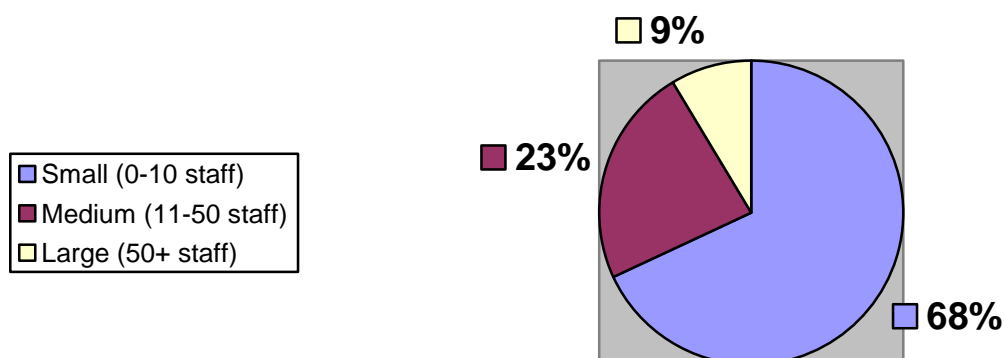
## Survey Participants:

The survey was sent via email to all subscribers of the GIG mailing list (161) and a total of 45 participants completed the online survey representing an approximate response rate of 30%.

Of the 45 participants, 25 provided their contact information as potential interviewees. For analytical purposes, results were also interpreted taking into consideration the following criteria: Size of Organisation and Duration of GIG membership.

**Fig.1**

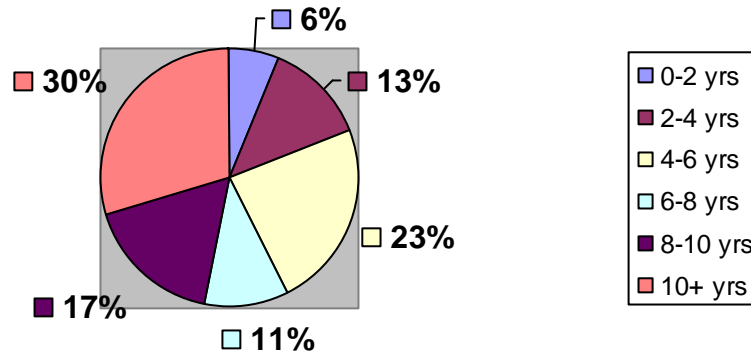
### Size of Organisation



N.B Organisations were identified as Small, Medium or Large depending on the amount of staff both paid and voluntary.

**Fig. 2**

**Duration of GIG Membership**



***Interview Participants:***

A total of 6 semi-structured interviews were conducted with interviews lasting on average 45mins. All participants gave consent for the interview to be recorded and information gathered to be used both internally and for fundraising purposes.

**Fig. 3**

<b>Participant code:</b>	<b>Date Interview was conducted:</b>	<b>Duration of Interview:</b>	<b>Size of Organisation: (as classified in Fig.1)</b>	<b>Duration of GIG Membership:</b>
A	07-04-09	35:36	Small	4-6 yrs
B	17-04-09	53:51	Small	6-8 yrs
C	20-04-09	1:27:02	Small	8-10 yrs
D	23-04-09	16:10	Medium	6-8 yrs
E	27-04-09	27:43	Medium	0-2 yrs
F	30-04-09	52:50	Small	2-4 yrs

N.B. See Appendix B.2 for full details of Interview Participants

## Summary of Survey Results:

See file: C:/backup/critical/final-survey-results-05-09.xls for full results

### **Key Findings:**

- The majority of Participants (64.4%) responded that their own members were aware of the organisation's membership with GIG
- Campaigning on members behalf to Government and Policy makers was often selected (77.8%) as the most important aspect of GIG's role
- Raising General Public awareness was seen as second most important (40.5%)
- Participants selected: "For a stronger campaigning voice" (73.2%) as the most important reason for joining GIG
- When asked how well GIG fulfils its 4 primary goals, the most selected answer was "Agree Completely" with approximately 70% of all responds choosing that answer for each statement. (See p.10 - Survey results summary for full details)
- 25 of the 45 participants (55.6%) stated that they interacted with GIG on a monthly basis
- The majority (55.6%) also stated that they usually dealt with the same members of staff (Communications manager)
- 32 Participants (71.1%) rated their experience with that member of staff as "Very Helpful" and when unable to deal with their usual contact, other members of staff were rated as "Helpful" (31.1%) and "Very Helpful" (26.7%)
- Email was the preferred method of communication with GIG (93.3%) though comments suggest an occasional phone call and more selective information dissemination
- The majority of participants (56.8%) stated that they did not circulate the GIG newsletter amongst their own members
- The majority of participants (47.7%) stated that they accessed the GIG website "Less than once a month", with 40.9% stating that their last visit was over 2 months ago
- When browsing the GIG website, participants engaged in "Reading the Publications" Often (29.5%) whilst 47.7% stated that they Never accessed the Forum (See Survey results summary for further comments on the website and forum)




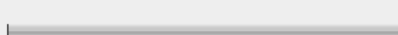
## About Your Organisation:



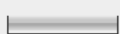


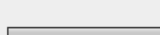
1. Name of Organisation:		Response Count
		45
	<i>answered question</i>	45
	<i>skipped question</i>	0

See Appendix A.1 for full details

2. Number of Staff (Voluntary and/or Paid):		Response Count
		45
	<i>answered question</i>	45
	<i>skipped question</i>	0

See Appendix A.1 for full details

3. How long has your organisation been established?		
	Response Percent	Response Count
0-2 yrs 	2.2%	1
2-5 yrs 	6.7%	3
5-10 yrs 	11.1%	5
10+ yrs 	80.0%	36
	<i>answered question</i>	45
	<i>skipped question</i>	0

4. How long have you been a member of GIG?		
	Response Percent	Response Count
0-2 yrs 	6.7%	3
2-4 yrs 	11.1%	5
4-6 yrs 	22.2%	10
6-8 yrs 	11.1%	5
8-10 yrs 	17.8%	8
10+ yrs 	31.1%	14
	<i>answered question</i>	45
	<i>skipped question</i>	0

See Appendix A.1 for full details

5. Which areas does your organisation cover? (Please select all that apply)		
	Response Percent	Response Count
All of the UK <input type="checkbox"/>	93.3%	42
England <input type="checkbox"/>	11.1%	5
Wales <input type="checkbox"/>	11.1%	5
Scotland <input type="checkbox"/>	4.4%	2
Northern Ireland <input type="checkbox"/>	8.9%	4
<b>answered question</b>		<b>45</b>
<b>skipped question</b>		<b>0</b>

6. Does your organisation offer membership?		
	Response Percent	Response Count
Yes <input type="checkbox"/>	84.4%	38
No <input type="checkbox"/>	15.6%	7
<b>answered question</b>		<b>45</b>
<b>skipped question</b>		<b>0</b>

7. Are your members aware of your organisation's membership to GIG?		
	Response Percent	Response Count
Yes <input type="checkbox"/>	64.4%	29
No <input type="checkbox"/>	4.4%	2
Don't know <input type="checkbox"/>	31.1%	14
<b>answered question</b>		<b>45</b>
<b>skipped question</b>		<b>0</b>

8. How do you contact your members? (Please select all that apply)		
	Response Percent	Response Count
Phone <input type="checkbox"/>	60.0%	27
E-mail <input type="checkbox"/>	84.4%	38
Post <input type="checkbox"/>	91.1%	41
N/A <input type="checkbox"/>	2.2%	1
<b>answered question</b>		<b>45</b>
<b>skipped question</b>		<b>0</b>

9. Does your organisation have a website?			Response Percent	Response Count
No			0.0%	0
Yes (please enter the website address)	<input type="text"/>		100.0%	45
<b>answered question</b>				<b>45</b>
<b>skipped question</b>				<b>0</b>

See Appendix A.1 for full details

### GIG's Role:

10. What do you think is GIG's Role? (Please select all that apply and rate by order of importance)						
	1 (Most Important)	2	3	4	5 (Least Important)	Response Count
Providing Information to members	17.6% (6)	20.6% (7)	47.1% (16)	14.7% (5)	0.0% (0)	34
Campaigning on members behalf to Government and Policy makers	77.8% (28)	19.4% (7)	0.0% (0)	0.0% (0)	2.8% (1)	36
Facilitating communication between member organisations	7.9% (3)	18.4% (7)	28.9% (11)	42.1% (16)	2.6% (1)	38
Raising General Public awareness	16.7% (7)	40.5% (17)	21.4% (9)	19.0% (8)	2.4% (1)	42
Other	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	100.0% (3)	3
					Other (please specify)	3
<b>answered question</b>						<b>45</b>
<b>skipped question</b>						<b>0</b>

Comments were as follows: Participant 29 : "GIG gives confidence to small groups"; Participant 35: "I would rate all questions equally but was unable to tick no 1 each time"



11. Why has your organisation joined GIG? (Please select all that apply and rate by order of importance)					
	1 (Most Important)	2	3	4 (Least Important)	Response Count
As a source of information	28.2% (11)	38.5% (15)	30.8% (12)	2.6% (1)	39
To network with other organisations	10.3% (4)	46.2% (18)	38.5% (15)	5.1% (2)	39
For a stronger campaigning voice	73.2% (30)	7.3% (3)	19.5% (8)	0.0% (0)	41
Other	0.0% (0)	33.3% (1)	0.0% (0)	66.7% (2)	3
				Other (please specify)	2
<b>answered question</b>					<b>45</b>
<b>skipped question</b>					<b>0</b>

Comments were as follows: Participant 35: "again I would rate no 1 in all cases, but not allowed to tick box each time"



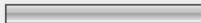

**12. The following four statements are GIG's Primary Goals. Please select the extent to which you Agree or Disagree with how well GIG fulfills these statements.**

	Disagree Completely	Disagree Slightly	Neither Agree nor Disagree	Agree Slightly	Agree Completely	Rating Average	Response Count
"To promote awareness and understanding of genetic disorders so that high quality services for people affected by genetic conditions are developed and made available to all who need them."	0.0% (0)	2.2% (1)	4.4% (2)	15.6% (7)	77.8% (35)	4.69	45
"GIG seeks to educate and raise awareness amongst opinion formers, people of influence and the public about human genetics & genetic disorders."	0.0% (0)	0.0% (0)	4.4% (2)	17.8% (8)	77.8% (35)	4.73	45
"GIG provides a common platform from which effective programmes can be launched to raise awareness, inform the media and influence government, industry and the NHS."	0.0% (0)	0.0% (0)	6.7% (3)	28.9% (13)	64.4% (29)	4.58	45
"GIG focuses on issues of policy and practice keeping an active watch on developments within the UK and Europe that will influence the effective transfer of knowledge and understanding into products and services for families that are supported by our member groups."	0.0% (0)	2.2% (1)	11.1% (5)	22.2% (10)	64.4% (29)	4.49	45
<i>answered question</i>							45
<i>skipped question</i>							0



**13. Have you ever used the GIG member list to obtain contact details of other member organisations?**


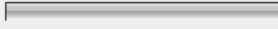

	Response Percent	Response Count
Yes 	26.7%	12
No 	73.3%	33
<i>answered question</i>		45
<i>skipped question</i>		0





**14. How often do you communicate with other GIG members?**

	Response Percent	Response Count
Never 	8.9%	4
Rarely 	42.2%	19
Occasionally 	40.0%	18
Often 	8.9%	4
<i>answered question</i>		45
<i>skipped question</i>		0




## Your Experience with GIG:




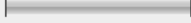
15. Does your organisation have a central contact in charge of its communications with GIG?		
	Response Percent	Response Count
Yes 	86.7%	39
No 	13.3%	6
<i>answered question</i>		45
<i>skipped question</i>		0




16. How frequently do you interact with GIG staff?		
	Response Percent	Response Count
Weekly 	4.4%	2
Monthly 	55.6%	25
Annually 	40.0%	18
<i>answered question</i>		45
<i>skipped question</i>		0

17. Do you generally deal with the same member of staff at GIG? (please select most appropriate)		
	Response Percent	Response Count
No 	15.6%	7
Don't know 	15.6%	7
Yes - Director	0.0%	0
<b>Yes - Communications Manager</b> 	55.6%	25
Yes - Policy Officer	0.0%	0
Yes - Project Staff (please specify name or project) 	13.3%	6
<i>answered question</i>		45
<i>skipped question</i>		0

Participant I.D	Response:
8	Melissa Hillier
20	Melissa Hillier
24	Melissa Hillier
29	Family Route Map
35	Claire Cotterill
40	Varies according to topic rather than Project

18. Thinking about your usual contact, how do you rate your experience with that member of staff?		
	Response Percent	Response Count
Very Unhelpful	0.0%	0
Unhelpful	0.0%	0
Helpful 	17.8%	8
Very Helpful 	71.1%	32
N/A 	11.1%	5
<b>answered question</b>		<b>45</b>
<b>skipped question</b>		<b>0</b>

19. If you are unable to deal with your usual contact, how helpful are other members of staff?		
	Response Percent	Response Count
Very Unhelpful	0.0%	0
Unhelpful 	4.4%	2
Helpful 	31.1%	14
Very Helpful 	26.7%	12
N/A 	37.8%	17
<b>answered question</b>		<b>45</b>
<b>skipped question</b>		<b>0</b>

20. What is your preferred method of communication with GIG?		
	Response Percent	Response Count
Phone 	2.2%	1
E-mail 	93.3%	42
Post 	4.4%	2
N/A	0.0%	0
<b>answered question</b>		<b>45</b>
<b>skipped question</b>		<b>0</b>

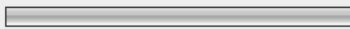


21. Do you have any suggestions on how GIG could improve communication with its members?		Response Count
		9
<b>answered question</b>		<b>9</b>
<b>skipped question</b>		<b>36</b>

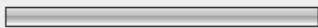


<b>Participant I.D</b>	<b>Comment:</b>
2	More regular Mailings
6	Be more selective as to what emails they send me. I get too many
14	None
28	I think the occasional phone call or email asking how the organisations are getting on would be helpful. As it would increase the communication especially if you haven't heard from an organisation in a long time.
29	Doing alright !!
30	I am not sure how well GIG understands its members. Certainly I am not sure if GIG is aware of the ethos of the XLP RT nor its aims and goals.
32	Not really. I find you do a very good job already
33	No
35	no, more than satisfied






## ***GIG Newsletter and Mail-outs***


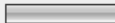

22. Are you happy with the frequency of the Newsletter? (Quarterly)		Response Percent	Response Count
Yes	<input type="checkbox"/>	97.7%	43
Don't Know	<input type="checkbox"/>	0.0%	0
No (would you like us to increase or decrease frequency?)	<input type="checkbox"/>	2.3%	1
<b>answered question</b>			<b>44</b>
<b>skipped question</b>			<b>1</b>

23. Would you prefer an online version of the Newsletter?		
	Response Percent	Response Count
Yes 	70.5%	31
No 	18.2%	8
Don't know 	11.4%	5
<b>answered question</b>		<b>44</b>
<b>skipped question</b>		<b>1</b>



24. If an online version were available would you opt out of receiving the paper copy?		
	Response Percent	Response Count
Yes 	63.6%	28
No 	27.3%	12
Don't know 	9.1%	4
<b>answered question</b>		<b>44</b>
<b>skipped question</b>		<b>1</b>



25. Do you circulate the GIG Newsletter amongst your members?		
	Response Percent	Response Count
Yes 	34.1%	15
No 	56.8%	25
N/A 	9.1%	4
<b>answered question</b>		<b>44</b>
<b>skipped question</b>		<b>1</b>





26. Please rate the extent to which you Agree or Disagree with the following statements?						
	Disagree Completely	Disagree Slightly	Neither Agree nor Disagree	Agree Slightly	Agree Completely	Response Count
"The information provided in the Newsletter is relevant to my organisation"	2.3% (1)	9.1% (4)	15.9% (7)	<b>47.7% (21)</b>	25.0% (11)	44
"I find the Newsletter interesting"	0.0% (0)	0.0% (0)	6.8% (3)	36.4% (16)	<b>56.8% (25)</b>	44
"The Newsletter is the only communication I have with GIG"	<b>61.4% (27)</b>	18.2% (8)	11.4% (5)	6.8% (3)	2.3% (1)	44
"The Newsletter is a good way to keep up with GIG's activities"	0.0% (0)	2.3% (1)	4.5% (2)	27.3% (12)	<b>65.9% (29)</b>	44
"I find the articles difficult to understand"	<b>50.0% (22)</b>	18.2% (8)	13.6% (6)	13.6% (6)	4.5% (2)	44
"I like the presentation and layout"	0.0% (0)	2.3% (1)	20.5% (9)	<b>45.5% (20)</b>	31.8% (14)	44
<i>answered question</i>						44
<i>skipped question</i>						1




27. Have you received any consultation documents from GIG?			Response Percent	Response Count
Yes			54.5%	24
No			22.7%	10
Don't know			22.7%	10
<i>answered question</i>				44
<i>skipped question</i>				1

## Consultation Documents:

28. Do you understand the issues addressed in the documents?			Response Percent	Response Count
Yes			95.8%	23
No			4.2%	1
Don't know			0.0%	0
<b>answered question</b>				<b>24</b>
<b>skipped question</b>				<b>21</b>

29. Do you respond to the documents?			Response Percent	Response Count
Yes			70.8%	17
No			29.2%	7
Don't know			0.0%	0
<b>answered question</b>				<b>24</b>
<b>skipped question</b>				<b>21</b>

30. If you do not respond, what is the reason? (Please select all that apply)			Response Percent	Response Count
Lack of resources			57.1%	4
Time constraints			71.4%	5
I am satisfied with GIG's response			57.1%	4
No response required			42.9%	3
Other (please specify)			0.0%	0
<b>answered question</b>				<b>7</b>
<b>skipped question</b>				<b>38</b>

31. Would online methods increase your response rate?			Response Percent	Response Count
Yes			87.5%	21
No			4.2%	1
Don't know			8.3%	2
<b>answered question</b>				<b>24</b>
<b>skipped question</b>				<b>21</b>

## GIG Website:

32. When was the last time you visited the GIG website?			Response Percent	Response Count
In the last 7 days	<input type="checkbox"/>		11.4%	5
In the last month	<input type="checkbox"/>		25.0%	11
In the last 2 months	<input type="checkbox"/>		22.7%	10
Over 2 months ago	<input type="checkbox"/>		40.9%	18
<b>answered question</b>				<b>44</b>
<b>skipped question</b>				<b>1</b>


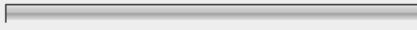
33. How frequently do you access the GIG website?			Response Percent	Response Count
Once a week or more	<input type="checkbox"/>		2.3%	1
Once every 2 weeks	<input type="checkbox"/>		2.3%	1
Once a month	<input type="checkbox"/>		22.7%	10
Less than once a month	<input type="checkbox"/>		47.7%	21
Less than once every 6 months	<input type="checkbox"/>		25.0%	11
<b>answered question</b>				<b>44</b>
<b>skipped question</b>				<b>1</b>



34. When browsing the GIG website how frequently do you engage in the following activities?						
	Never	Rarely	Sometimes	Often	Always	Response Count
Looking at GIG's current projects	11.4% (5)	18.2% (8)	43.2% (19)	18.2% (8)	9.1% (4)	44
Reading the "About Genetics and Genetic conditions" section	15.9% (7)	18.2% (8)	34.1% (15)	25.0% (11)	6.8% (3)	44
Looking for information on genetic services	18.2% (8)	20.5% (9)	36.4% (16)	15.9% (7)	9.1% (4)	44
Reading the publications	13.6% (6)	25.0% (11)	27.3% (12)	29.5% (13)	4.5% (2)	44
Checking the "Latest News" section	11.4% (5)	11.4% (5)	29.5% (13)	27.3% (12)	20.5% (9)	44
Using the website as a signpost to further information (e.g by using the "Useful Links" section)	13.6% (6)	29.5% (13)	38.6% (17)	15.9% (7)	2.3% (1)	44
Accessing the Forum	47.7% (21)	29.5% (13)	20.5% (9)	2.3% (1)	0.0% (0)	44
Getting contact information on Member organisations	27.3% (12)	36.4% (16)	31.8% (14)	4.5% (2)	0.0% (0)	44
<b>answered question</b>						<b>44</b>
<b>skipped question</b>						<b>1</b>



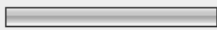
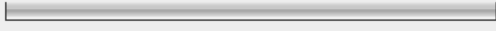
35. Do you have any comments or suggestions regarding the GIG website?	
	<b>Response Count</b>
	5
<i>answered question</i>	5
<i>skipped question</i>	40

<b>Participant I.D</b>	<b>Comment:</b>
14	Easy to read and inviting to read more
16	Easy to use and find way around.
29	I do not use the Web site very often for GIG
31	Since I am the only person running group on day-to-day basis I don't have time to look at websites. I may quickly look at info received by email, e.g. newsletters, but don't seek out such information.
35	no, more than happy

## GIG Forum:

36. Have you registered to use the Forum?		
	Response Percent	Response Count
Yes 	15.9%	7
No 	84.1%	37
<b>answered question</b>		<b>44</b>
<b>skipped question</b>		<b>1</b>

37. How frequently do you access the Forum?		
	Response Percent	Response Count
Never	0.0%	0
Rarely 	85.7%	6
Sometimes 	14.3%	1
Often	0.0%	0
<b>answered question</b>		<b>7</b>
<b>skipped question</b>		<b>38</b>

38. What is your reason for accessing the Forum? (Please select all that apply)		
	Response Percent	Response Count
To find out about other organisations and their activities 	14.3%	1
To exchange information with other GIG members 	14.3%	1
To get in touch with GIG staff	0.0%	0
To promote your own organisation and its activities 	42.9%	3
To post information for the general public	0.0%	0
For general browsing 	100.0%	7
<b>answered question</b>		<b>7</b>
<b>skipped question</b>		<b>38</b>

39. Do you have any comments or suggestions regarding the Forum?	
	Response Count
	2
<b>answered question</b>	<b>2</b>
<b>skipped question</b>	<b>43</b>

Participant I.D	Comment:
13	At present we do not access the forum
32	I don't have enough time to use it more frequently sadly!

### ***Interview Participation and Comment page:***

40. Please enter your contact information		
	Response Percent	Response Count
Name: <input type="text"/>	100.0%	25
Company: <input type="text"/>	100.0%	25
Email Address: <input type="text"/>	100.0%	25
Phone Number: <input type="text"/>	100.0%	25
<i>answered question</i>		25
<i>skipped question</i>		20

See Appendix A.2 for full details

41. You may also leave questions and comments here	
	Response Count
	5
<i>answered question</i>	5
<i>skipped question</i>	40

Participant I.D	Comment:
2	Long Survey
7	Some questions could have done with answers like sometimes and not N/A. I would have liked to leave my contact but afraid that if you got touch at a busy time I might not have the time to answer then and that would not be good after I have said that I will take part.
16	Advice on how to secure funds would be useful and also on setting up websites.
19	A lot of my answers were more complex than simple "yes" or "no". For instance we forward emails of interest to people on our emailing list but we cannot afford to send information to people via the post. Also, a lot of what GIG does isn't really relevant to us, as PWS isn't normally hereditary.
31	I think you're doing a great job, but our conditions are rare and there are many associated difficulties that are not directly related to it being a genetically determined condition, e.g. psycho-social rather than medical problems, so we probably don't have a lot in common with groups supporting other genetic conditions. The main genetic issue for us is probably the provision of carrier testing for XX relatives. There is no routine NHS service although it can be arranged through Addenbrooke's in Cambridge and our members are aware of this so

I'm not sure what role GIG could play in this, if any. Many thanks for all you do
---

## Interview Results Summary:

See Appendix B.1 for Interview questions

See Appendix B.2 for full details of Interview Participants

### Key Findings

- Majority of participants described GIG as a campaigning voice which unites them and gives more clout to their organisation
- GIG's responsibility, according to all participants, is to raise awareness on a public and parliamentary level
- Some participants also stated that they looked to GIG for support with running their charity (i.e. help with practical issues)
- Though none of the participants were able to recall current projects without prompting, all expressed familiarity once details were given
- Those that expressed the most familiarity stated they actively kept up to date by visiting the GIG website, reading the newsletters or having one of their staff on the GIG trustee board (Participant D)
- Some participants stated that they found it difficult to distinguish which members of staff were associated to each project
- Some confusion was expressed with regards to Rare Disease UK and its relationship with GIG (see Interview F in Appendix B.3 for full details)
- Overall, participants expressed positive feedback towards upcoming projects and felt that if it was not necessarily related to their own organisation's aim, it was still in line with GIG's primary role
- Future projects received mixed reports with the SWAN co-ordinator and Changing Genes projects invoking slightly negative responses (see notes from interviews C, D and F in Appendix B.3 for full details)
- Although the majority of participants were happy with their communications and interactions with GIG, several mentioned that they would appreciate the occasional call to check on how they were doing and one participant (Participant F) also suggested that GIG should listen and consult with its members more (see notes from Interview F in Appendix B.3 Interview F for full details)
- With regards to facilitating GIG's communication with its members' members, the majority of participants said that the best way was to relay them the information in electronic format and they would then disseminate it themselves

### Conclusions:

- A monthly update which reminds members of projects both current and future and informs them of how they can get involved would enable them to feel more included in GIG's activities
- It became apparent through the interviews that members appreciated their opinion being sought out and valued and that this enhanced their experience with GIG. A yearly "review" which gives members the opportunity to give feedback or raise concerns would be beneficial
- Some participants stated that they looked to GIG for support on how to run a charity. Workshops addressing this issue or a section on the website may be helpful

- Negative reactions to projects were based on the assumption that this would detract resources (i.e. time and financial) from other more worthwhile projects
- Although GIG members contact their own members through various mediums, all participants are happy with GIG providing information in electronic format. The most important factor for GIG to consider when asking members to relay information is Lead Time. Because most of the organisations are run by a small amount of staff with limited resources (both time and material) it is important to take into account that information may not be disseminated as quickly as anticipated

## Appendix A

### 1. Survey Participants

See file: c:/backup/critical/final-results-05-09.xls for full Survey Results

Participant I.D.	Organisation Name:	Number of Staff:	Duration of GIG Membership:	Website Address:
1	Narcolepsy Association (UK)	1	8-10 yrs	www.narcolepsy.org.uk
2	Cavernoma Alliance UK	4	2-4 yrs	www.cavernoma.org.uk
3	Stickler Syndrome Support Group	2	10+ yrs	www.stickler.org.uk
4	Niemann-Pick Disease Group (UK)	30	6-8 yrs	www.niemannpick.org.uk
5	The PXE Support Group - PiXiE	2	10+ yrs	www.pxe.org.uk
6	British Porphyria Association	0 FT	4-6 yrs	www.porphyria.org.uk
7	East London Sickle Cell Society	3	10+ yrs	N/A
8	Cri du chat Syndrome Support Group	11	4-6 yrs	www.criduchat.co.uk
9	Uk Thalassaemia Society	2	4-6 yrs	www.ukts.org
10	CMT United Kingdom	9	10+ yrs	www.cmt.org.uk
11	Rubinstein Taybi Syndrome UK Support Group	12	4-6 yrs	www.rts.uk.org
12	Making It Better - The Daniel Courtney Trust	7	2-4 yrs	www.makingitbetter.org.uk
13	Laurence-Moon-Bardet-Biedl Society	13	8-10 yrs	www.lmbbs.org.uk
14	Arrhythmia Alliance	12	2-4 yrs	www.heartrhythmcharity.org
15	Polycystic Kidney Disease Charity	10	4-6 yrs	www.pkdcharity.org.uk
16	The Fragile X Society	6	10+ yrs	www.fragilex.org.uk
17	Jennifer Trust for Spinal Muscular Atrophy	12	4-6 yrs	www.jtsma.org.uk
18	FSH support group	4	6-8 yrs	FSH-MD Support Group
19	Prader-Willi Syndrome Association (UK)	10	4-6 yrs	www.pwsa.co.uk
20	The Fragile X Society	6	10+ yrs	www.fragilex.org.uk
21	Sense	2000	0-2 yrs	www.sense.org.uk
22	RP Fighting Blindness	108	10+ yrs	www.rpfb.org.uk
23	Myrovlytis Trust	1	0-2 yrs	www.myrovlytistrust.org
24	Shwachman Diamond support UK	4	6-8 yrs	Re-building website under construction

25	Down's Heart Group	2	4-6 yrs	<a href="http://www.dhg.org.uk">www.dhg.org.uk</a>
26	The Primary Immunodeficiency Association	56	8-10 yrs	<a href="http://www.pia.org.uk">www.pia.org.uk</a>
27	Batten Disease Family Association	15	2-4 yrs	<a href="http://www.bdfa-uk.org.uk">www.bdfa-uk.org.uk</a>
28	The Klinefelter Organisation	3	8-10 yrs	<a href="http://www.klinefelter.org.uk">www.klinefelter.org.uk</a>
29	Myotonic Dystrophy Support group	35	10+ yrs	<a href="http://www.mdsguk.org">www.mdsguk.org</a>
30	The XLP Research Trust	5	2-4 yrs	<a href="http://www.xlpresearchtrust.org">www.xlpresearchtrust.org</a>
31	AIS Support Group (ASSG)	2	8-10 yrs	<a href="http://www.aissg.org">www.aissg.org</a>
32	Unique	8	10+ yrs	<a href="http://www.rarechromo.org">www.rarechromo.org</a>
33	East London Sickle Cell Society	3	10+ yrs	N/A
34	Gorlin Syndrome Group	6	6-8 yrs	<a href="http://www.gorlingroup.org">www.gorlingroup.org</a>
35	Laurence-Moon-Bardet-Biedl Society	10	8-10 yrs	<a href="http://www.lmbbs.org.uk">www.lmbbs.org.uk</a>
36	Barth Syndrome Trust	10	4-6 yrs	<a href="http://www.barthsyndrome.org.uk">www.barthsyndrome.org.uk</a>
37	CMT United Kingdom	10	10+ yrs	<a href="http://www.cmt.org.uk">www.cmt.org.uk</a>
38	Behcets Syndrome Society	15	0-2 yrs	<a href="http://www.behcets.org.uk">www.behcets.org.uk</a>
39	The International Autistic Research Organisation/Autism Research Ltd.	5	8-10 yrs	<a href="http://www.iaro.org.uk">www.iaro.org.uk</a>
40	CGD Reseach Trust	5	8-10 yrs	<a href="http://www.cgd.org.uk">www.cgd.org.uk</a>
41	DebRA	211	10+ yrs	<a href="http://www.debra.org.uk">www.debra.org.uk</a>
42	Motor Neurone Disease Association	1	10+ yrs	<a href="http://www.mndassociation.org">www.mndassociation.org</a>
43	Huntington's Disease Association	29	6-8 yrs	<a href="http://www.hda.org.uk">www.hda.org.uk</a>
44	NPSUK	4	4-6 yrs	<a href="http://www.npsuk.org">www.npsuk.org</a>
45	The Fragile X Society	6	10+ yrs	<a href="http://www.fragilex.org.uk">www.fragilex.org.uk</a>

## 2. Potential Interview Participants

Participant I.D	Organisation:
2	Cavernoma Alliance UK
3	Stickler Syndrome Support Group
4	Niemann-Pick Disease Group (UK)
5	The PXE Support Group - PiXiE
6	British Porphyria Association
8	Cri du chat Syndrome Support Group
9	UK Thalassaemia Society
11	RTS UK SUPPORT GROUP
12	Making it Better - The Daniel Courtney Trust
13	Laurence-Moon-Bardet-Biedl Society
16	The Fragile X Society
17	Jennifer trust for SMA
18	FSH SG
24	Shwachman diamond support uk
28	Klinefelter Organisation
29	Myotonic Dystrophy Support Group
30	The XLP Research Trust
32	Unique
34	Gorlin Syndrome Group
38	Behcets Syndrome Society
39	Autism Research Ltd.
41	DebRA
43	Huntington's Disease Association
44	NPSUK
45	The Fragile X Society

## Appendix B:

### 1. Interview Questions

1. What do you think *is* GIG's Primary role/goal?
2. What do you think *should* be GIG's Primary role/goal?
3. Why has your organisation joined GIG?
4. Are you satisfied with the communications/interactions you have with GIG?
5. Is there more GIG could do to improve this?
6. Are you aware of the projects currently running at GIG?
  - a. Which of these have you heard of? (*see Current Projects list*)
  - b. How much do you know about them?
7. Do you know about the upcoming projects for which GIG has already secured funding? (*see Upcoming Projects list*)
8. I'd like to quickly and briefly talk about some of the projects for which we are applying for funding (*see Future Projects list*). Could you tell me what your thoughts/views on these projects are and if you think these are relevant:
  - a. To GIG's aims
  - b. Beneficial for your organisation
9. Has your organisation ever contributed to any of the work undertaken during past or current projects (e.g. been contacted by GIG staff for information or input)?
  - a. *If yes*: How was your experience? Would you do it again?
  - b. *If No*: Why not? Would you consider contributing to future projects?
10. Have you ever used any of the resources that have been produced out of a result of the projects? (e.g. Patient leaflets, Route maps, visiting the projects website, etc.)
11. We're aware that sometimes it is difficult for organisations to pass information along because of lack of resources however GIG would like to improve not only its communications with its members, but also with its members' members. Do you have any suggestions on how this could be achieved? (*This is particularly useful when asking individuals to raise issues with their MP, or MEP, letter writing campaigns, and information on events and in some cases media work*)
12. How do you feel about the following suggestions:
  - a. Enabling/facilitating GIG in its communications with your members

*GIG is embracing web2.0 so contact through Forum/email/Facebook etc...*  
(e.g. getting them to send an email or whatever to tell them to sign up to GIG,  
we could have a category for them in the mailer e.g. GIG submembers)

- b. Placing a link on your website to GIG's webpage (possibly including  
Facebook page)

13. Is there anything you'd like to add? Comments, suggestions, etc.?

## Current Projects:

### 1. Asking Relevant Questions (Insurance Templates) – Ben Francis

- 2yr project funded by BUPA
- Aims to ensure correct info provided to insurers at point of application
- Extension of Patient Supplementary Questionnaire
- Attempting to include other insurance products i.e. Travel
- Consulting with insurance companies as well as patient organisations

### 2. Facilitating Networks – Krystle Kontoh

- Optimising healthcare for patients with rare genetic conditions:
  - Rare Dermatological conditions
  - Rare Cancer conditions
  - Rare Neurological conditions
- Developing networks of Health professionals to improve co-ordination, communication, awareness and understanding between professionals and patients
- Working with Patient Support Groups

### 3. EuroGenTest – Celine Lewis

- Increase the harmonisation of standards in practice for Genetic Testing throughout the EU
- Produce patient leaflets about Genetics and testing translated in many European Languages and ethnic minority languages

### 4. EuroGenGuide – Alex McKeown

- 3yr initiative funded by the European Commission for Life Sciences and Biotechnology
- Run in collaboration with 12 partner organisations
- Provide public information and professional guidelines relating to:
  - Informed consent
  - DNA / Bio banking
  - Access to the outcomes of genetic research and the development of treatments
  - Gender perspectives in genetic testing and research
  - Ethnic minority perspectives in genetic testing and research

### 5. Patient Engagement – Clare Cotterill

- Representing interest, views and experiences of patients to the Scottish Government and NHS Scotland commissioners

### 6. Over the counter Genetic Testing Leaflet – Melissa Hillier and Laura Gilbert

- Create a leaflet which looks at issues and advises on Genetic Tests which are available to purchase over-the-counter or online

## **Upcoming Projects (funding confirmed):**

1. **Nanomed** – Melissa Hillier
  - 5 working parties which provide recommendations regarding Nanomedicine and innovations and advances in Nanotechnology from different perspectives:
    - a. Regulation
    - b. Economic Impact
    - c. Communication
    - d. Patient needs (Alastair)
    - e. Ethical and Societal Impact
2. **Patient Partner** – Melissa Hillier
  - Identifying patient's needs for partnership in the clinical trial context
3. **RAPID** – Melissa Hillier
  - Develop information to help patients make informed decisions regarding NIPD (non-invasive DNA test) which can identify some genetic conditions in unborn babies
4. **Family Risks, Common Cancers and People from Minority Ethnic Groups Project** - Helen Parr
  - Partnership with Division of Primary Care at Nottingham University
  - why people from minority ethnic groups with a significant family history of cancer are less likely to access clinical genetics services than the mainstream UK population
  - inform the development of interventions in order to improve access to genetics services for people from minority ethnic groups

## Future Projects (seeking Funding)

1. **Citizen's Jury** – Helen Parr
  - Identifying key factors for patients and families when considering acceptable balance between risk and benefits of new therapies
2. **SWAN co-ordinator** – Helen Parr
  - Appointing a part-time co-ordinator at GIG for Syndromes Without A Name
  - Provides support and information for families with children affected by undiagnosed genetic conditions
3. **Changing Genes (Arts project)** – Helen Parr
  - Collaborative project between GIG, a digital artist and 2 molecular geneticists
  - Installation supported by information about genetic mutation, how this leads to conditions and how it affects individuals and families
  - Aims to engage new audiences in genetics
4. **Route Maps for Rare Diseases** – Helen Parr
  - Based on *Family Route Map* template
  - Improve access and care for patients with rare conditions

### **3. Comments from Interviews**

#### **Interview A:**

- GIG's role was to provide support and network of facilities
- Joined GIG for support and to pull on resources and expertise
- Very satisfied with interactions and communications with GIG
- Very satisfied with how they are kept up to date with news and events
- Usually deals with the same contact (Melissa) because of good rapport and working relationship however is very satisfied with the helpfulness of other members of staff
- Was unable to recall any of the projects however explained that due to personal reasons, she had been out of touch with many aspects including GIG's progress over the last few months
- Usually tried to keep up with projects online and through the newsletter
- Stated that many of the Upcoming projects were very interesting and "close to my heart"
- Of the upcoming projects that weren't necessarily relevant to her organisation, she believed they were still worthwhile and in line with GIG's role
- When hearing about the Family Routes Map for Rare Diseases, showed particular enthusiasm as her organisation had been involved in previous Route Maps and she found the experience very beneficial and rewarding
- Expressed some surprise towards the Changing Genes project as did not expect GIG to be involved in the Arts but thought it was a very beneficial project and worthwhile
- Recalled positive experiences of working with GIG in the past and expressed willingness to participate again
- Is happy with using the internet and thinks this is the most practical method of communication with GIG even though she uses varies methods with her own members
- Only negative she could think of was that she regretted not being able to attend more of the events as London is far for her to get to and also because she suffers from her condition

#### **Interview B:**

- Feels GIG's role has changed since they started. Sees GIG as a national umbrella organisation for smaller organisations which is "driving forward the genetics agenda in terms of policy making, raising awareness. Something that smaller groups don't have the resources to do"
- GIG has assisted them in the last 1-2yrs by enabling them to provide a valuable resource (family route map) which they would have been unable to complete on their own. Expressed gratefulness.

- Joined GIG to add voice to what they were doing. Gives their organisation extra clout. Provides them with know-how and means to get in at a national level in terms of parliament, policy, department of health. GIG helps put their condition on the map
- On the whole satisfied with communications with GIG. But feels like they receive a lot of information however does not necessarily feel that should be reduced, just feels like it can be confusing sometimes
- Expressed confusion over what people's roles are within the organisation
- Had difficulty recalling projects apart from Rare Disease UK which participant knew quite a lot about. Wasn't familiar with insurance project. Heard of facilitating networks project but was surprised to not know much about it since their group represents is a dermatological syndrome. Had heard of Eurogentest and recalls receiving information relating to it but says that she's been "out of action" due to personal reasons recently. Is slightly familiar with Eurogenguide. Was aware of the Scotland project and actually published it on their website. Is also familiar with the leaflet project
- Could not really comment on Nanomed project as she didn't understand what nanomedicine was but was confident that it would be beneficial since it was representing patient views
- Recalls doing a survey on patient partnership but was unsure on whether it was from the GIG website
- Had no problem with the SWAN co-ordinator job in principal however expressed some reservation because knowing the nature of the voluntary sector, "how far will GIG go supporting other groups?" It therefore raised a few questions for her
- Saw the Arts project as in line with GIGs aim but was slightly hesitant and felt that other projects were more important and considering budgetary concerns, should take priority over it
- Found resources from previous projects very useful, was happy to participate and would happily do so again
- Stated timing was the most important issue in relation to passing GIG information along to their members but they are happy to do this
- If GIG had to have contact with their members they are happy to act as intermediaries but it is vital that GIG goes through them first because of data protection
- Wished that not all events were located in London because it means it is difficult for them to attend

### **Interview C:**

- Sees GIG's role as supporting organisations to raise awareness of different conditions so that they get the proper care within the health system. As well as everything related to genetics and rare diseases. Praised the Rare Disease project
- Joined GIG to be united voice

- Satisfied with communications with GIG but would like GIG to touch base with the organisation once in while through the odd email or phone call a couple of times a year
- Is happy to include GIG information via his newsletter, phone calls and emails
- Is happy with the way things are of GIG contacting him and then him deciding what is relevant to his members and should be filtered down
- Stated he has nothing negative to say about GIG. He is very happy with his communications with them and their “honesty”. He appreciates the way in which his organisation is looked upon, feels like the balance is equal
- Had heard of the majority of the projects and expressed positive feelings towards them
- Was very positive about upcoming projects and saw them all in line with GIG’s aims even though not all were directly relevant to his organisation

### **Interview D:**

- Sees GIG’s primary role as putting together organisations concerned with genetic diseases
- Joined GIG because they are relatively small charity and it was important for them to get together with other organisations which may experience similar problems to them
- Satisfied with interactions and communications with GIG and cannot suggest any improvements as they believe GIG has gotten the balance right (i.e. not bombarding with too much information but keeping their members well informed at the same time)
- Not able to actively recall any of the projects currently running at GIG however once prompted, expressed familiarity with all of them
- Is very up to date on the projects at GIG because one of their staff members is a Trustee at GIG and therefore keeps them well informed
- Although some of the upcoming projects weren’t necessarily in line with her organisation, she felt they were interesting and definitely within GIG’s remit
- Very interested in Citizen’s Jury project
- Did not see the relevance of the SWAN co-ordinator and expressed reservations towards GIG’s involvement. Since GIG is suppose to be an umbrella organisation which represents a broad range of conditions it should not affiliate itself with any one charity or condition
- In the past they’ve been involved with work on insurance etc. Rated previous working experience with GIG as “good” and would be happy to participate again if it was relevant to their organisation
- Happy with the quality and availability of resources from projects and have used them in the past
- Is happy to pass information along through their website or their newsletter. Stated that they had “clear lines of communication” and all

GIG needed to do was send whatever information they wanted passed along. Did express a preference for electronically based information as it was easier to slot in

## Interview E:

- Sees GIG's primary role as assisting with research in genetic diseases
- Thinks there's a big movement within government on both a national and European level with regards to research into genetic diseases therefore they are looking to GIG to work with them and assist them in working with government to support that
- Because their disease is rare getting information and keeping up to date is difficult therefore they want GIG to be proactive in giving information to more rare disease group
- The main reason for joining GIG is from seeing how active GIG was in and around the area of genetics and therefore wanted to be a part of that
- Very satisfied with communications with GIG, answered yes confidently and stated there were no problems at all
- Would appreciate a weekly update with little highlights. "Weekly synopsis of what's going on would not go amiss"
- Says he is unable to recall even one project as he's not recently looked it up
- Expressed familiarity with all projects once prompted however stated he did not keep up to date because many weren't directly relevant to his organisation
- Not sure if he remembers info regarding Patient involvement within clinical trials from GIG but certainly feels this is a relevant issue and of interest to both GIG and his organisation
- Citizen's Jury: "Excellent and good that the debate is being had, and I'm sure that would add to it, it is something we're interested in [...] as a project, it would help us, it would affect us and yeah we would be happy to take part if asked, certainly"
- Positive feedback for the majority of Future projects except Changing Genes which he stated would not be on his list of priorities
- They've kept on the periphery for many projects and come along to meetings when relevant but recently were keen to get involved with the APPG on Rare Diseases
- Very active on visiting and keeping up to date with website so using those resources that have come out of projects
- They are keen to help facilitate the communication but at the moment it takes 3 months to fully reach ALL the members since the newsletter is only quarterly and not everyone is internet based, though they are working themselves on improving this
- Mentioned responses from the organisation and the trustees could be quick but feedback and access to all members is slower because of lead time

## Interview F:

- Not certain what GIG's primary role is. Seems it is involved in lobbying government organisations so sees GIG as primarily that
- Thinks GIG's role should be lobbying but feels that GIG lobbies on behalf of its members without listening to its members. GIG assumes that since they're lobbying on behalf of organisations they are representing their (the org.) views however participant states that he has never been asked what his view was
- States that they have never received any consultation documents
- Joined GIG with the hope that GIG would be a lobbying group on their behalf but in the last 2 trustee meetings he's had to very strongly defend the membership to GIG
- When asked about whether he was satisfied with the interactions and communications with GIG, participant said that he read the newsletter cover to cover, but wanted to add that GIG says it talks on behalf of its member, but doesn't actually listen to their views
- Certain things GIG have lobbied on (from their organisations point of view) they didn't agree with and he found it quite alarming that GIG claims to represent a whole host of patient groups, yet he's not fully convinced GIG listens to its members
- Participant suggested using the web more for consultation documents
- Mentioned the only real interaction he'd had with GIG in the past was to endorse some fundraising, which made him pause
- Doesn't state his organisation's membership with GIG on their newsletter because he does not see the value of it
- Not fully convinced GIG represents the views of the trust and because of his concerns for that would be very reluctant for GIG to contact his members
- Repeated several times that he felt as though GIG should improve on listening to his organisation
- Had suspicions that GIG worked closely with the bigger charities and was not terribly concerned with those "at the bottom"
- Was not able to recall any projects
- Expressed confusion over Rare Disease UK and saw it as a way of GIG trying to expand its base. Did not understand how it fit within the original GIG mandate and felt it was watering down GIG's lobbying abilities
- Mentioned having heard of insurance project and having offered help with it but never receiving a response
- Stated finding the Family Route Map very useful and tailored it to fit with their condition however when he sent the tailored version back to GIG, never received any feedback
- Seemed to show a lot of disinterest with current and upcoming projects and failed to see their relevance to his organisation
- Showed interest and some positivity for future projects however expressed negative sentiment towards the SWAN co-ordinator position

and Changing Genes project because he did not believe these were a priority with regards to GIG's role

- Though they'd not participated in previous projects they were happy to participate in future projects if asked and the project is relevant to his organisation
- Stated that he appreciated taking part in the interview and this gave him hope. He would be delighted if GIG would try and get to know his organisation better
- Wanted GIG to give more practical support to its members and re-iterated that he felt the Art project was not something GIG should attempt. Stated that he did not think it was within GIG's remit "to what end?" Felt that GIG should be concentrated on the lobbying and other charities such as Jeans for Genes were more suitable for raising public awareness
- Feels as though GIG is expanding into too many realms and not sticking to what his organisation joined for (i.e. lobbying and providing support)
- Final comments were about GIG getting to know his organisation better. Stated he would be happy to pop in for an hour to discuss what their aims are and they could work together to achieve common aims