



Genetic Alliance UK
Supporting. Campaigning. Uniting.

Report of Genetic Alliance UK Members Survey
Autumn / Winter 2010

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Outline of Research

During the last year, we have seen major changes at Genetic Alliance UK including the renaming of our organisation, the introduction of our new monthly member e-updates as well as the development of various new projects (see Appendix 3).

To gather information on members' views and perspectives on Genetic Alliance UK, its work and aims we designed a survey. It was designed to explore members' perceptions of what Genetic Alliance UK does and assess the efficiency of Genetic Alliance UK's communications and relationship with its members.

At the end of October 2010 an email was sent out to all Genetic Alliance UK members, requesting them to complete the online survey hosted on an external website (Survey Monkey).

In order to gain more in-depth information for the Member Survey we were also looking to conduct a series of telephone interviews with a selection of our members. Therefore participants were invited to provide their contact information at the end of the survey if they agreed to participate in follow up interviews.

Response to the survey was initially slow so reminders were sent out to encourage members to participate. The reminder also included the latest edition of our newsletter, a copy of the survey and a pre-paid envelope to return it in. Irrespective of their participation in the online survey, we also contacted members to ask whether they would be willing to take part in a follow up telephone interview.

Survey and Interview Participants

The survey was sent via email to all subscribers of the Genetic Alliance UK mailing list (142) and a total of 21 participants completed the online survey. In addition, we sent out approximately 190 paper surveys attached to the newsletter and got back 11 responses. Thus, 32 members completed the survey.

Of the 32 participants, 16 provided their contact information as potential interviewees. All but 4 of these were contacted to seek their agreement to participate in the interview taking into consideration the size of organisations. In addition we contacted another 13 members of different sized organisations to request their willingness to participate in the interviews. At the end a total of six interviews were conducted with interviews lasting on average 20 minutes. All participants gave consent for the interview to be recorded. The following table provides an overview of interview participants.

Organisation	Size of organisation	Date of Interview	Duration of interview
Polycystic Kidney Disease	Small	19.11.2010	34.04
Debra Charitable Activities	Large	22.11.2010	23.12
Fragile X Society	Medium	30.11.2010	17.59
Cavernoma Alliance UK	Small	3.12.2010	20.04
Save babies through screening Foundation UK	Small	1.12.2010	19.35
Histiocytosis Research Trust	Small	18.11.2010	14.02

Summary of Survey Results

- Most of the members of Genetic Alliance UK (77.4%) consist of small organisations (0-10 staff)
- Half of the Participants (48.4%) responded that their own members were aware of the organisation's membership with Genetic Alliance UK
- Most of the members think that the new name of Genetic Alliance UK (82.1%), the logo (92.9%) and the new tagline (100%) is a good representation of what we do.
- Campaigning on members behalf to Government and Policy makers was often selected (69.2%) as the most important aspect of Genetic Alliance UK's role
- Raising General Public awareness was seen as second most important (55.6.%)
- Participants selected: "For a stronger campaigning voice" (77.8%) as the most important reason for joining Genetic Alliance UK
- When asked how well Genetic Alliance UK fulfils its primary goals, the most selected answer was "Agree Completely" with around 70% of all respondents choosing that answer for each statement. Nevertheless just 40% agreed completely that Genetic Alliance UK fulfils the goal of "Providing support and information to patients and families"
- 14 of 26 participants (53.8%) stated that they interacted with Genetic Alliance UK on an annual basis
- The majority (65.4%) also stated that they usually dealt with the same members of staff (Communications manager)
- 20 Participants (76.9%) 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" (19.2%) and "Very Helpful" (38.5%)
- Email was the preferred method of communication with Genetic Alliance UK (76.9%)
- The majority of participants (73.1%) stated that they did not circulate the Genetic Alliance UK newsletter amongst their own members but amongst their Trustees (76.9%)
- The majority has received the monthly e-updates (72%) and find them helpful (78%)
- Most of the members circulate the e-updates amongst their trustees/colleagues (57.9%) but not amongst their members (84.2%)
- Near half of the participants (46.2%) find the e-updates a useful way of disseminating the information
- The majority does receive the consultation documents (76.9%) and does comment on them (65.4%).
- The highest amount of participants (38.5%) stated that they accessed the Genetic Alliance UK website "Less than once a month".
- When browsing the Genetic Alliance UK website, participants engaged in "Checking the latest news section" Often (30.8%).
- The majority (76.9%) didn't know that Genetic Alliance UK has a Facebook page and of those who knew that genetic Alliance UK has a Facebook page just 50% are sure that they have signed up.
- The largest proportion of participants wouldn't find it helpful to create a blog (38.5%) but would find it helpful to register with twitter (38.5).

Detailed illustration Survey Results

Does your organisation offer membership?		
Answer Options	Response Percent	Response Count
Yes	67.7%	21
No	32.3%	10
<i>answered question</i>		31
<i>skipped question</i>		1

Number of Staff (Voluntary and/or Paid):		
Answer Options	Response Percent	Response Count
Small (1-10 staff)	77.4%	24
Medium (11-50 staff)	22.6%	7
Large (50+ staff)	0.0%	0
<i>answered question</i>		31
<i>skipped question</i>		1

How long has your organisation been established?		
Answer Options	Response Percent	Response Count
0-2 yrs	6.5%	2
2-5 yrs	9.7%	3
5-10 yrs	16.1%	5
10+ yrs	67.7%	21
<i>answered question</i>		31
<i>skipped question</i>		1

How long have you been a member of Genetic Alliance UK?		
Answer Options	Response Percent	Response Count
0-2 yrs	12.9%	4
2-4 yrs	9.7%	3
4-6 yrs	19.4%	6
6-8 yrs	9.7%	3
8-10 yrs	19.4%	6
10+ yrs	29.0%	9
<i>answered question</i>		31
<i>skipped question</i>		1

Which areas does your organisation cover? (Please select all that apply)

Answer Options	Response Percent	Response Count
All of the UK	83.9%	26
England	19.4%	6
Wales	9.7%	3
Scotland	0.0%	0
Northern Ireland	3.2%	1
<i>answered question</i>		31
<i>skipped question</i>		1

Does your organisation offer membership?

Answer Options	Response Percent	Response Count
Yes	67.7%	21
No	32.3%	10
<i>answered question</i>		31
<i>skipped question</i>		1

Are your members aware of your organisation's membership of Genetic Alliance UK?

Answer Options	Response Percent	Response Count
Yes	48.4%	15
No	3.2%	1
Don't know	48.4%	15
<i>answered question</i>		31
<i>skipped question</i>		1

How do you contact your members? (Please select all that apply)

Answer Options	Response Percent	Response Count
Phone	67.7%	21
E-mail	90.3%	28
Post	80.6%	25
N/A	0.0%	0
<i>answered question</i>		31
<i>skipped question</i>		1

Does your organisation have a website?

Answer Options	Response Percent	Response Count
No	3.2%	1
Yes (please enter the website address)	96.8%	30
<i>answered question</i>		31
<i>skipped question</i>		1

Do you think our name (Genetic Alliance UK) is a good representation of what we do?

Answer Options	Response Percent	Response Count
Yes	82.1%	23
No	17.9%	5
<i>answered question</i>		28
<i>skipped question</i>		4

Do you think our logo is a good representation of what we do?

Answer Options	Response Percent	Response Count
Yes	92.9%	26
No	7.1%	2
<i>answered question</i>		28
<i>skipped question</i>		4

Please see our tagline: Supporting: We seek to raise awareness of genetic conditions and improve the quality of services and information available to patients and families. Campaigning: We actively campaign on issues of policy and practice to influence governments, policy makers, industry and care providers such as the National Health Service. Uniting: We provide a united voice for all those affected by genetic conditions, enabling us to work together towards a common goal of making life better for patients and families at risk. Do you think our tagline (Supporting, Campaigning, Uniting) represents Genetic Alliance UK's Primary Goals?

Answer Options	Response Percent	Response Count
Yes	100.0%	28
No	0.0%	0
<i>answered question</i>		28
<i>skipped question</i>		4

What do you think is Genetic Alliance UK's Role? (Please select all that apply and rate by order of importance)

Answer Options	1 (Most Important)	2	3	4	5 (Least Important)	Response Count
Providing Information to members	11	10	2	3	1	27
Campaigning on members behalf to Government and Policy makers	18	5	3	0	0	26
Facilitating communication between member organisations	1	14	3	3	6	27
Raising General Public awareness	15	6	3	3	0	27
Generating evidence of the needs of families with genetic conditions	11	7	7	1	1	27
Other	2	0	0	0	1	3
Other (please specify)						2
answered question						27
skipped question						5

Others:

Specific projects to support campaigning and evidence roles

Providing practical support and guidance to member organisations

Why has your organisation joined Genetic Alliance UK? (Please select all that apply and rate by order of importance)						
Answer Options	1 (Most Important)	2	3	4 (Least Important)	Response Count	
As a source of information	13	10	3	0	26	
To network with other organisations	3	13	8	2	26	
For a stronger campaigning voice	21	2	4	0	27	
Other	3	0	0	0	3	
Other (please specify)					2	
answered question						27
skipped question						5

Others:

To lend support as an organization to the work of Genetic Alliance UK

Loyalty to organisation

I was involved in funding

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

Answer Options	Agree Completely	Agree Slightly	Neither Agree nor Disagree	Disagree Slightly	Disagree Completely	Rating Average	Response Count
"Promoting awareness and understanding of genetic conditions through a wide range of activities."	21	5	1	0	0	4.74	27
"Campaigning on issues of policy and practice."	21	5	1	0	0	4.74	27
"Providing support and information to patients and families."	11	7	6	2	1	3.93	27
"Educating policy makers, health professionals, patients and families and the general public."	19	4	4	0	0	4.56	27
"Supporting the development of high quality services and information and ensuring they are available to all."	14	8	5	0	0	4.33	27
"Providing a common platform to unite the voice of patients and families affected by genetic conditions."	21	6	0	0	0	4.78	27
answered question							27
skipped question							5

Have you ever used the Genetic Alliance UK member list to obtain contact details of other member organisations?

Answer Options	Response Percent	Response Count
Yes	19.2%	5
No	80.8%	21
answered question		26
skipped question		6

How often do you communicate with other Genetic Alliance UK members?

Answer Options	Response Percent	Response Count
Never	23.1%	6
Rarely	42.3%	11
Occasionally	23.1%	6
Often	11.5%	3
<i>answered question</i>		26
<i>skipped question</i>		6

Does your organisation have a central contact in charge of its communications with Genetic Alliance UK?

Answer Options	Response Percent	Response Count
Yes	65.4%	17
No	34.6%	9
<i>answered question</i>		26
<i>skipped question</i>		6

How frequently do you interact with Genetic Alliance UK staff?

Answer Options	Response Percent	Response Count
Weekly	7.7%	2
Monthly	38.5%	10
Annually	53.8%	14
<i>answered question</i>		26
<i>skipped question</i>		6

Do you generally deal with the same member of staff at Genetic Alliance UK? (please select most appropriate)

Answer Options	Response Percent	Response Count
No	23.1%	6
Don't know	11.5%	3
Yes - Director (Alastair Kent)	3.8%	1
Yes - Assistant Director (Melissa Hillier)	50.0%	13
Yes - Policy Analyst (Nick Meade)	0.0%	0
Yes - Public Affairs (Stephan Nutt)	3.8%	1
Yes - Project Staff (please specify name or project)	7.7%	2
<i>answered question</i>		26
<i>skipped question</i>		6

Project Staff

Route Maps Project

Lauren Limp Rare Disease UK

Thinking about your usual contact, how do you rate your experience with that member of staff?

Answer Options	Response Percent	Response Count
Very Helpful	76.9%	20
Helpful	7.7%	2
Unhelpful	0.0%	0
Very Unhelpful	0.0%	0
N/A	15.4%	4
<i>answered question</i>		26
<i>skipped question</i>		6

If you are unable to deal with your usual contact, how helpful are other members of staff?

Answer Options	Response Percent	Response Count
Very Helpful	38.5%	10
Helpful	19.2%	5
Unhelpful	0.0%	0
Very Unhelpful	0.0%	0
N/A	42.3%	11
<i>answered question</i>		26
<i>skipped question</i>		6

What is your preferred method of communication with Genetic Alliance UK?

Answer Options	Response Percent	Response Count
Phone	19.2%	5
E-mail	76.9%	20
Post	0.0%	0
N/A	3.8%	1
<i>answered question</i>		26
<i>skipped question</i>		6

The membership of Genetic Alliance UK is very diverse. Different groups have different needs, and Genetic Alliance UK is looking to address this by developing tailored membership packages. If we were to develop such packages what areas would you welcome more involvement in?

Answer Options	Very Helpful	Helpful	Unhelpful	Very Unhelpful	N/A	Response Count
Networking with other members	8	13	1	0	3	25
Policy(e.g. consultation responses) and public affairs	12	8	2	1	2	25
Sharing fundraising knowledge	6	12	3	0	4	25
Being involved in projects	10	10	0	1	3	24
Other (please specify)						0
<i>answered question</i>						26
<i>skipped question</i>						6

Do you have any suggestions on how Genetic Alliance UK could improve communication with its members?

Answer Options	Response Count
	5
<i>answered question</i>	5
<i>skipped question</i>	27

Answer given:

No

Online forums? There are a large number of these though so would need to be well used to be successful.

It is doing alright so far.

Don't think so, the newsletter and e-mail communications keep us abreast of your activities

I think your e-mail bulletins are an ideal way to communicate generally with member groups as they provide the necessary updates without burdening the groups with too much paperwork/ e-mails etc

Are you happy with the frequency of the Newsletter? (Quarterly)

Answer Options	Response Percent	Response Count
Yes	100.0%	26
Don't Know	0.0%	0
No (would you like us to increase or decrease frequency?)	0.0%	0
	<i>answered question</i>	26
	<i>skipped question</i>	6

Do you circulate the Genetic Alliance UK Newsletter amongst your colleagues and/or Trustees?

Answer Options	Response Percent	Response Count
Yes	76.9%	20
No	15.4%	4
Don't know	7.7%	2
	<i>answered question</i>	26
	<i>skipped question</i>	6

Do you circulate the Genetic Alliance UK Newsletter amongst your members?

Answer Options	Response Percent	Response Count
Yes	15.4%	4
No	73.1%	19
Don't know	11.5%	3
	<i>answered question</i>	26
	<i>skipped question</i>	6

Please rate the extent to which you Agree or Disagree with the following statements?

Answer Options	Agree Completely	Agree Slightly	Neither Agree nor Disagree	Disagree Slightly	Disagree Completely	Response Count
"The information provided in the Newsletter is relevant to my organisation"	8	14	4	0	0	26
"I find the Newsletter interesting"	14	12	0	0	0	26
"The Newsletter is the only communication I have with Genetic Alliance UK"	2	8	1	4	11	26
"The Newsletter is a good way to keep up with Genetic Alliance UK's activities"	19	6	0	0	1	26
"I find the articles difficult to understand"	1	5	3	3	14	26
"I like the presentation and layout"	12	8	6	0	0	26
<i>answered question</i>						26
<i>skipped question</i>						6

Recently we started to circulate monthly e-updates. Have you received them?

Answer Options	Response Percent	Response Count
Yes	72.0%	18
No	28.0%	7
N/A	0.0%	0
<i>answered question</i>		25
<i>skipped question</i>		7

Do you find these useful?

Answer Options	Response Percent	Response Count
Very Helpful	15.8%	3
Helpful	78.9%	15
Unhelpful	0.0%	0
Very Unhelpful	0.0%	0
N/A	5.3%	1
<i>answered question</i>		19
<i>skipped question</i>		13

Below you see a list of the different sections of our monthly e-update. Please select how helpful you rate the different sections.

Answer Options	Very Helpful	Helpful	Unhelpful	Very Unhelpful	Rating Average	Response Count
Policy	7	12	0	0	3.37	19

Projects	8	11	0	0	3.42	19
Announcements & Events	7	10	2	0	3.26	19
Our Team	5	13	1	0	3.21	19
Useful News	7	12	0	0	3.37	19
External announcements & events	5	10	4	0	3.05	19
answered question						19
skipped question						13

Do you circulate the monthly e-update amongst your colleagues and/or Trustees?

Answer Options	Response Percent	Response Count
Yes	57.9%	11
No	31.6%	6
Don't know	10.5%	2
answered question		19
skipped question		13

Do you circulate the monthly e-update amongst your members?

Answer Options	Response Percent	Response Count
Yes	10.5%	2
No	84.2%	16
Don't know	5.3%	1
answered question		19
skipped question		13

Did you know that Genetic Alliance UK is happy to send out e-updates to more than one contact at your organisation?

Answer Options	Response Percent	Response Count
Yes	23.1%	6
No	73.1%	19
N/A	3.8%	1
answered question		26
skipped question		6

Would this be a useful way of disseminating our information?

Answer Options	Response Percent	Response Count
Not very Useful	7.7%	2
Not Useful	7.7%	2
Useful	46.2%	12
Very Useful	30.8%	8
N/A	7.7%	2
answered question		26
skipped question		6

Please do let us have email addresses of colleagues or Trustees of your charity that you would like to add to our e-update mailing list.

Answer Options	Response Count
	9
<i>answered question</i>	9
<i>skipped question</i>	23

Have you received any consultation documents from Genetic Alliance UK?

Answer Options	Response Percent	Response Count
Yes	76.9%	20
No	7.7%	2
Don't know	15.4%	4
	<i>answered question</i>	26
	<i>skipped question</i>	6

Do you understand the issues addressed in the documents?

Answer Options	Response Percent	Response Count
Yes	80.8%	21
No	7.7%	2
Don't know	11.5%	3
	<i>answered question</i>	26
	<i>skipped question</i>	6

Do you wish to receive more consultation documents?

Answer Options	Response Percent	Response Count
Yes	57.7%	15
No	19.2%	5
Don't know	23.1%	6
	<i>answered question</i>	26
	<i>skipped question</i>	6

Do you respond to the documents?

Answer Options	Response Percent	Response Count
Yes	65.4%	17
No	15.4%	4
Don't know	19.2%	5
	<i>answered question</i>	26
	<i>skipped question</i>	6

We recognise that members are very busy. However sometimes we ask your members to comment on our consultation responses. We often have short deadlines but we try to give as much time as possible. On average, how long would you need to comment on a consultation document?

Answer Options	Response Percent	Response Count
1-2 days	0.0%	0
3-5 days	11.8%	2
a week	29.4%	5
two weeks	29.4%	5
more than two weeks	29.4%	5
<i>answered question</i>		17
<i>skipped question</i>		15

If you are unable to respond, we would very much like to know why this is, so we can improve our communication. (Please select all that apply)

Answer Options	Response Percent	Response Count
Lack of resources	35.7%	5
Time constraints	71.4%	10
I am satisfied with Genetic Alliance UK's response	42.9%	6
No response required	7.1%	1
Other (please specify)	14.3%	2
<i>answered question</i>		14
<i>skipped question</i>		18

Others:

Often not relevant to XLP

As campaigning is the one thing we don't have time to do (without neglecting our core duties) we are grateful that Genetic Alliance UK can be our voice on these important issues.

If we had to disagree with your views, we would contact you about those issues. Silence is assent.

When was the last time you visited Genetic Alliance UK's website?

Answer Options	Response Percent	Response Count
In the last 7 days	11.5%	3
In the last month	19.2%	5
In the last 2 months	30.8%	8
Over 2 months ago	38.5%	10
<i>answered question</i>		26
<i>skipped question</i>		6

How frequently do you access Genetic Alliance UK's website?

Answer Options	Response Percent	Response Count
Once a week or more	3.8%	1
Once every 2 weeks	3.8%	1
Once a month	23.1%	6
Less than once a month	38.5%	10
Less than once every 6 months	30.8%	8
<i>answered question</i>		26
<i>skipped question</i>		6

When browsing Genetic Alliance UK's website how frequently do you engage in the following activities?

Answer Options	Always	Often	Sometimes	Rarely	Never	Response Count
Looking at Genetic Alliance UK's current projects	4	6	9	3	4	26
Reading the "About Genetics and Genetic conditions" section	3	3	8	7	5	26
Looking for information on genetic services	4	3	4	9	6	26
Reading the publications	2	3	9	7	5	26
Checking the "Latest News" section	5	8	5	4	4	26
Using the website as a signpost to further information (e.g by using the "Useful Links" section)	3	1	7	8	7	26
Getting contact information on Member organisations	2	0	5	13	6	26
<i>answered question</i>						26
<i>skipped question</i>						6

Do you have any comments or suggestions regarding the Genetic Alliance UK website?

Answer Options	Response Count
	1
<i>answered question</i>	1
<i>skipped question</i>	31

Comment:

Well presented and easy to navigate

Did you know that Genetic Alliance UK has a facebook page? (<http://www.facebook.com/pages/Genetic-Alliance-UK/141545872543707?ref=ts>)

Answer Options	Response Percent	Response Count
Yes	23.1%	6
No	76.9%	20
<i>answered question</i>		26
<i>skipped question</i>		6

Have you signed up?

Answer Options	Response Percent	Response Count
Yes	50.0%	3
No	33.3%	2
Don't know	16.7%	1
<i>answered question</i>		6
<i>skipped question</i>		26

Do you think this is useful way to expand Genetic Alliance UK's networks?

Answer Options	Response Percent	Response Count
Yes	46.2%	12
No	11.5%	3
Don't know	42.3%	11
<i>answered question</i>		26
<i>skipped question</i>		6

We are thinking of setting up a blog where we can post current news from our Director. Do you think this would be helpful?

Answer Options	Response Percent	Response Count
Yes	23.1%	6
No	38.5%	10
Don't know	38.5%	10
<i>answered question</i>		26
<i>skipped question</i>		6

In addition we are also thinking about using twitter(<http://twitter.com/>) to communicate with a wider audience. Do you think this would be a helpful way to expand our networks?

Answer Options	Response Percent	Response Count
Yes	38.5%	10
No	26.9%	7
Don't know	34.6%	9
<i>answered question</i>		26
<i>skipped question</i>		6

Please enter your contact information

Answer Options	Response Percent	Response Count
Name:	100.0%	15
Company:	100.0%	15
Email Address:	93.3%	14
Phone Number:	73.3%	11
<i>answered question</i>		15
<i>skipped question</i>		17

You may also leave questions and comments here

Answer Options	Response Count
	5
<i>answered question</i>	5
<i>skipped question</i>	27

Comments:

- Hi, I found it hard to answer several of your questions.
- Some were ambiguous or vague.
- It seemed to cover too many topics at once.
- I answered a few don't knows but I really would have liked to say not really due to information over-load
- Being fairly new to this job I have now from this survey become more aware of our connection and its importance to us and I will be reading a lot more of your information. May I comment on the few occasions I have contacted Genetic Alliance UK how very supportive and friendly everyone has been and convey our thanks for your support. There is one of the questions on the 1st page that may be inaccurately answered but would not let me past - it asks how long we have been members - this information I do not know. Thank you and I hope you have plenty of response to this very well constructed survey.
- Whilst the developing technology, Facebook and twitter can be of use for networking there can be a risk of over duplication leading to non-action at recipient end, concerning the blog: I do the same but has to be regularly updated to be useful concerning twitter: Twitter is more about communication with individuals than organisations

Summary of Interview Results

- Majority of participants described Genetic Alliance UK as a campaigning voice which brings together everyone who is interested in the topic of genetic conditions
- All participants like the new name and think that it is a good representation of the Genetic Alliance's Aims and Work
- Most of the participants are satisfied with the communication they have with Genetic Alliance UK.
- The majority say that the communication with members' members is quite difficult and partly not welcome
- Most of the Participants interviewed aren't so sure about the idea of tailoring news packages as it could fragmenting the organisation and could lead to a loss of information
- Participants find favour with the e-updates
- Interviewed Members seem to have not more that a brief knowledge about current projects running at Genetic Alliance UK
- Overall, participants expressed positive feedback towards future projects and felt that if it was not necessarily related to their own organisation's aim, it was still in the scope of Genetic Alliance UK

Detailed illustration Interview Results

Interview A

- Joined Genetic Alliance UK as he/she thought that Genetic Alliance UK is able to reach the scientific community and discovers solution to difficulties their members face
- Expects Genetic Alliance UK to counteract the ignorance of severe genetic illness
- Participant thinks that the new name sums up what Genetic Alliance UK is doing. Nevertheless he/she regret that there isn't a short acronym available for the new name
- In general he/she likes the new logo but thinks it is a little bit childlike and leads to the assumption that Genetic Alliance UK is a organisation just for children
- Participant thinks that quality of communication with Genetic Alliance UK has been declined since Melissa isn't the communication manager any more. Information available has been limited since then
- Participant likes the monthly e-updates but isn't sure whether his members have received the e-update
- Didn't know that Genetic Alliance UK is using facebook a lot but likes the idea
- Likes the idea of tailored news packages
- Participant is involved in *Facilitating Networks* and therefore has a broad knowledge of this project but doesn't know any of the other projects currently running at Genetic Alliance UK
- In terms of the *SWAN Project* the participant isn't sure how Genetic Alliance UK could intervene
- In terms of the *New insurance Project* the participant is a little bit unsure of Genetic Alliance UK entering the commercial arena

Interview B

- Primarily sees Genetic Alliance UK as a representative for all patient organisation, as a campaigning and lobbying organisation
- Genetic Alliance UK is a helpful network to meet with other groups with similar conditions
- Says that Genetic Alliance UK's primary goal is to maintain its position as (and become) the foremost organisation in the UK representing people with genetic conditions with the aim of influencing policy and practice to benefit people with genetic conditions
- The new name "Genetic Alliance UK" is a better name than "Genetic Interest Group" and sums up better what Genetic Alliance UK is doing. The name "Genetic Interest Group" might have been a little bit confusing for people not involved within the organisation
- According to the participant the new logo does imply the human involvement

- Very satisfied with communication with Genetic Alliance UK and thinks that the organisation he/she represents gets the information at the right time and at the right sort of level
- Participant assumed that the communication with the members' members is much more difficult and that in future Genetic Alliance UK must come up with ideas how to improve the communication with member's members
- Thinks that they as a member group are not very good at cascading information down because the communication tends to get stuck at the trustees level
- Would prefer a way of communication in which the member's members could focus on themselves rather than on relying on the participant's organisation in passing by the information received from Genetic Alliance UK
- Participant thinks the best way would be a kind of channel communication that everyone can access
- Concerning the tailored news packages the participant sees the challenge in not fragmenting the organisation; as an alternative the participant proposed to have a standard news packages which everyone receives and then have additions for some organisations with deeper interested (e.g. special clinical research news for the organisations interested in this field)
- Important is the sense of solidarity and speaking with the same voice which might be undercut with tailoring information
- Knows some of the projects running at Genetic Alliance UK (e.g. *Facilitating Networks, Patient Partner, Route Maps*) but is often unclear what they focus on. Participant hasn't got an in-depth knowledge of projects running at Genetic Alliance UK
- Participants wish to have more knowledge of the projects running at Genetic Alliance UK
- Propose that Genetic Alliance UK ask members whether they want to join in the projects/ if they want to have more information. Sees it as important that members have access to documents that are produced within the projects (e.g. minutes of staff meetings)
- Thinks that the future projects are relevant to Genetic Alliance UK's aims and that some are beneficial for his/her organisation (e.g. *New insurance Project, Patient-led Service Commissioning, Psychological Support, in which field participants have done some research work*)
- Would be interested in contributing to the *Patient-led Service Commissioning Project*
- Used the website quite frequently

Interview C

- Participant is from a small charity which is just a few years old and therefore a lot of the work Genetic Alliance UK is doing is not applicable to the organisation of the participant
- Joined Genetic Alliance UK because they didn't want to be left out of areas concerning genetic diseases
- Participant assume that Genetic Alliance UK was set up to bring together anyone who has an interest in rare diseases and to raise awareness of genetic disease not only in

England but also throughout Europe. Moreover it should help to work together collaboratively and having improvements for families affected by genetic diseases.

- Participant thinks that the European law of public health services need to be more focused by Genetic Alliance UK
- Participants thinks that the new name is more positive than GIG and is better to take Genetic Alliance UK to the future
- Concerning the tagline the participant thinks that “Campaigning. Supporting” is credible regarding the work of Genetic Alliance UK. According to the participant to reach the goal of uniting “there is a way to go”
- Interview partner don’t get a sense of uniting from the organisation
- Participant is very happy with the communication he/she has with individual people of Genetic Alliance UK
- As participant visited the first Genetic Alliance UK coverage he/she introduced herself to staff of Genetic Alliance UK and found them to be quite uninterested. He/she was quite disappointed about this reaction as each member should have equal importance
- Likes the monthly e-updates but doesn’t use facebook
- Participant don’t like the idea of tailoring news packages as regardless the size of a organisation everyone wants to involvement in key issues
- Participant favours the printed newsletter than the electronic one
- Participant has an overview about the projects running at Genetic Alliance UK. He/ She picks up the information from conferences and the newsletter
- Participant has no special interest in the future projects apart from the *New Insurance Project*

Interview D

- Joined Genetic Alliance UK because it is an umbrella body for rare diseases
- Sees Genetic Alliance UK’s primary role in rise awareness about genetic condition and improve communication about them through cooperating with professionals
- Participant think the new name Genetic Alliance UK sounds much better than the former one Genetic Interest Group
- Participant likes the new tagline and thinks it represents Genetic Alliance UK’s goals
- Participant is satisfied with the communication he/she has with Genetic Alliance UK
- Participant thinks that the monthly e-updates aren’t patient friendly enough and therefore hasn’t forwarded them on
- Participant recommends making the communications more patients friendly: Wants Genetic Alliance UK to send out guidelines on how to access genetic services e.g. in terms of leaflets or sections on the website
- Participant thinks the website of Genetic Alliance UK is more for professionals than for patients
- Participant is very informed of the *Route Maps Project* as they were involved but hasn’t heard of the others at all
- Participant is very positive about the current projects and saw them as all in line with Genetic Alliance UK’s aims and most of them are beneficial for its organisation

- Would consider contributing to the *Psychological Support Project and Accessing Services Project*

Interview E

- Joined Genetic Alliance UK to be connected with other genetic patient groups through meetings and workshops
- Sees Genetic Alliance UK as a conduit for information between their charity and the NHS and policy makers
- Expects Genetic Alliance UK to be aware of what's going on nationally and internationally, to read policy documentations, to change nature of genetic health care and to be a voice of the patient groups it represents
- Sees a main problem in the department of health and other governmental organisations not giving enough time to individuals or patient groups to respond as all the deadlines are quite short. Participant expects Genetic Alliance UK to speak for longer to comment on these documents.- to provide more in depth coverage as Genetic Alliance UK's deadlines aren't quite as short.
- If Genetic Alliance UK notices that the deadline for the consultation documents comes close it should make sure that it is on the top of the e-updates
- Participant barely noticed the new logo
- Participant wasn't aware of the tagline before the survey. He/She would prefer a tagline which is less generic
- Participant is satisfied with the communication with Genetic Alliance UK
- Thinks facebook is a good way to improve communication but Genetic Alliance UK has to monitor how active people are posting
- Participant likes the monthly e-updates and passes them to their trustees and if there is a article relevant for the condition participant represents they pass he/pass it on to the members
- Participants thinks that Genetic Alliance UK needs to decide whether it's members are patient groups or patients; both at the same time doesn't work
- Participant thinks that Genetic Alliance UK has to decide whether it communicates to patient groups or patients
- Participant thinks it is too time consuming to develop tailored news packages and argues that Genetic Alliance UK doesn't know which topics the different members are interested in. Participant would prefer the same news package for all.
- Participant couldn't recall any current project of Genetic Alliance UK except the *Route Map Project* of which the participant was confused of with finding the name quite irritating
- Participant likes the *New Insurance Project* but wants Genetic Alliance UK to do it properly and make sure that we work together with all the insurance companies
- Participant thinks that there has been a *Psychological Support Project* by Guy's hospital in the past.
- Concerning the *Information Resource Project* the Participant thinks that there is an organisation called "Medikidz" which provides information in a children friendly way

and there is no need to spend money if there are others who have already done the work

- Participant proposed that Genetic Alliance UK provides a guide on its website of how to access genetic services

Interview F

- Joined Genetic Alliance UK to exchange with others
- Thinks Genetic Alliance UK primary role is to raise awareness of genetic conditions and pulling together people from different backgrounds to make sure that resources are targeted toward those who have genetic conditions
- Thinks that the rebranding “is possibly not the most wonderful piece of rebranding ever happened” without the explanation of why this has happened
- Participant likes the logo and thinks the tagline represents what Genetic Alliance UK is doing
- Is satisfied with the communication with them as a society but argues that their members might not be interested in a communication with Genetic Alliance UK unless they are particularly interested in topics like research. Those are already on the email list to receive documents from the Genetic Alliance UK. Therefore he recommends Genetic Alliance UK to concentrate on the communication with them as an organisation and not with their members
- The organisation of the participant has also a facebook page and registered with twitter but reports that it is not used very often. He /She thinks these are important tools that people can find patient groups but he argues that it wouldn't help their members
- Is afraid that if the tailored news packages are tailored too much they won't receive enough information. Thinks that tailoring is not the best way forward!
- Participant was involved in the *Route Map Project* and therefore has a broad knowledge about the project but wasn't aware of any other project.
- Thinks that all of the future projects are in the scope of Genetic Alliance UK
- For them the *New insurance Project*, the *Accessing Service Project* and the *Patient-led insurance Project* would be beneficial for their organisation
- Reports that they currently produce an “Easy read booklet”
- Would like to be involved in further projects of Genetic Alliance UK
- “Everyone is always very polite and helpful”
- “I think you are doing a really good job”
- “We are glad to be a member”

Appendix

Survey Participants

Participant ID	Name of Organisation:	Number of Staff:	Duration of membership:	Website Address:
1	The information point for centronuclear and Myotubular Myopathy	Small (1-10 staff)	5-10 yrs	www.centronuclear.org.uk
2	Sickle Cell And Young Stroke Survivors	Small (1-10 staff)	5-10 yrs	www.scyss.org
3	The society for Mucopolysaccharide Disease	Small (1-10 staff)	10+ yrs	www.mpssociety.co.uk
4	Barth Syndrome Trust	Small (1-10 staff)	5-10 yrs	barthsyndrome.org.uk
5	A-T Society	Small (1-10 staff)	10+ yrs	www.atsociety.org.uk
6	Down's Heart Group	Small (1-10 staff)	10+ yrs	www.dhg.org.uk
7	Liverpool Womens's	Medium (11-50 staff)	10+ yrs	www.liverpoolwomens.nhs.uk
8	FAP GENE	Small (1-10 staff)	5-10 yrs	www.fapgene.org.uk
9	Huntington Disease Association	Medium (11-50 staff)	10+ yrs	www.hda.org.uk
10	Batten Disease Family Association	Small (1-10 staff)	10+ yrs	www.bdfa-uk.org.uk
11	RP Fighting Blindness	Small (1-10 staff)	10+ yrs	www.brps.org.uk
12	no answer	Small (1-10 staff)	10+ yrs	www.pdsq.org.uk
13	The Fragile X Society	Small (1-10 staff)	10+ yrs	www.fragilex.org.uk
14	Save Babies through Screening Foundation UK	Small (1-10 staff)	0-2 yrs	www.savebabiesuk.org
15	Narcolepsy UK	Small (1-10 staff)	10+ yrs	www.narcolepsy.org.uk
16	CLIMB CAH SUPPORT GROUP	Small (1-10 staff)	10+ yrs	WWW,LIVINGWITHCAH.COM
17	East London Sickle Cell Society	Small (1-10 staff)	10+ yrs	

18	The XLP Research Trust	Small (1-10 staff)	2-5 yrs	www.xlpresearchtrust.org
19	Prader-Willi Syndrome Association (UK)	Medium (11-50 staff)	10+ yrs	www.pwsa.co.uk
20	Restricted Growth Association	Medium (11-50 staff)	10+ yrs	www.restrictedgrowth.co.uk
21	PHG Foundation	Medium (11-50 staff)	2-5 yrs	www.phgfoundation.org
22	NIGB	Medium (11-50 staff)	2-5 yrs	www.nigb.nhs.uk
23	Fragile X Society	Small (1-10 staff)	10+ yrs	www.fragilex.org.uk
24	Gorlin Syndrome Group	Small (1-10 staff)	10+ yrs	www.gorlingroup.org
25	Unique	Small (1-10 staff)	10+ yrs	www.rarechromo.org
26	BWS Support Group	Small (1-10 staff)	10+ yrs	bws-support.org.uk
27	The PXE Support Group - PiXiE	Small (1-10 staff)	10+ yrs	www.pxe.org.uk
28	Cri du chat Syndrome Support Group	Small (1-10 staff)	10+ yrs	www.criduchat.org.uk
29	PKD CHARITY	Medium (11-50 staff)	5-10 yrs	www.pkdcharity.org.uk
30	Androgen Insensitivity Syndrome Support Group (AISSG)	Small (1-10 staff)	10+ yrs	www.aiissg.org
31	Noonan UK	Small (1-10 staff)	0-2 yrs	www.noonansyndrome.org

1. Interview Question

Genetic Alliance UK's Role:

1. Why has your organisation joined Genetic Alliance UK?
2. What do you think *is* Genetic Alliance UK's Primary role/goal?
3. What do you think *should be* Genetic Alliance UK's Primary role/goal?

Rebranding of Genetic Alliance UK:

1. Do you think our new name "Genetic Alliance UK" is a better representation of what we do than our former name (Genetic Interest Group)?
2. When you look at our new logo, what do you think it says about the organisation it represents?
3. Do you think the tagline "Supporting.Campaigning.Uniting" is credible, and does it make sense given the work of Genetic Alliance UK?

Communications with Genetic Alliance UK:

1. Are you satisfied with the communications/interactions you have with Genetic Alliance UK?
2. We're aware that sometimes it is difficult for organisations to pass information along because of lack of resources however Genetic Alliance UK would like to improve not only its communications with its members, but also with its members' members.

Therefore we recently

- a. started to circulate monthly e-updates
- b. registered with facebook.

Do you think this is a good way to improve communication with Genetic Alliance UK's members and with its members' members?

3. The membership of Genetic Alliance UK is very diverse. Different groups have different needs, and Genetic Alliance UK is looking to address each of these needs by developing tailored membership packages. How do you feel about this suggestion?
4. Do you have any other comments regarding our communication?

Genetic Alliance UK's Projects:

1. Are you aware of the projects currently running at Genetic Alliance UK?
 - a. Which of these have you heard of? (see *Current Projects list*)
 - b. How much do you know about them?

2. 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 Genetic Alliance UK's aims
 - b. Beneficial for your organisation
3. Has your organisation ever contributed to any of the work undertaken during past or current projects (e.g. been contacted by Genetic Alliance UK's 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?
4. 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.)

Further Question:

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

Current Projects

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

Patient Partner – Melissa Hillier

- Identifying patient's needs for partnership in the clinical trial context

RAPID – Celine Lewis

- Develop information to help patients make informed decisions regarding NIPD (non-invasive DNA test) which can identify some genetic conditions in unborn babies

Family Risks, Common Cancers and People from Minority Ethnic Groups Project – Anna Alford

- 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

Route Maps for Rare Conditions – Jessica Burke

- improving the health and well being of people with rare conditions at a national level
- develop a practical and cost-effective framework for improving information, access and coordination of health and social care services for individuals and families with a wide range of rare conditions

Risks and Benefits - Amy Simpson

- examine how patients and their families affected by genetic conditions perceive the balance between the risks and the benefits of new biomedical therapies

Paving the Way to Self-Management – Douglas Caldow

- Families with rare conditions discuss how they self manage their condition

Future Projects

SWAN co-ordinator – Helen Parr

- Appointing a co-ordinator at Genetic Alliance UK for Syndromes Without A Name
- Providing support and information for families with children affected by undiagnosed genetic conditions

New Insurance Project – Helen Parr

- Collaborative project with ESRC Innogen and industry partners.
- Research into difficulties people with pre-existing conditions have in accessing health-related insurance products such as life assurance.
- Creation of a resource for patients.

Patient-led Service Commissioning – Helen Parr

- Working with patient groups.
- Development, pilot and evaluation of a new framework for service commissioning.
- Addressing patchy and poorly integrated service provision for people with rare genetic conditions.

Scotland – Helen Parr

- Extension of Scottish Development Officer's role, with a focus on supporting and representing people with rare genetic conditions.

Psychological Support – Helen Parr/Celine Lewis

- Partnership with Guy's Hospital.
- Conducting an evaluation of the impact a Clinical psychologist to support generic genetics referrals.

Genetics and Obesity – Kristina Elvidge

- Partnership research into genetic link to obesity and the implications of this for families.

Accessing Services – Helen Parr/Buddug Williams

- Development of a resource to help patients/patient groups to access treatments and services on the NHS.

Information resources – Helen Parr

- Information about genetic conditions for children.
- Resource for teenagers/adults with genetic conditions who are starting relationships/dating.