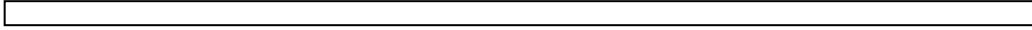


“Asking Relevant Questions”

Yearly Report



A charity registered in England and Wales (no. 1114195)
and in Scotland (no. SC039299).
Company Registration no: 05772999

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“Asking Relevant Questions” Project Summary

The Genetic Interest Group (GIG) is a national umbrella organisation for all people affected by genetic disorders. GIG’s main aims are 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 and to stimulate research and development of products and services that will address unmet medical needs. We have been working for a number of years with the insurance industry to improve the access and information that patients receive when they are applying for a range of insurance products.

This two year project funded by Bupa focuses on patients and their needs, GIG, as a patient organisation is keen to see its members able to access insurance when they need it, at a price which is fair and through a process which is robust and transparent. GIG’s concern arising from dialogue with patients is that many, whose conditions are stabilised by a long term medical care and/or treatment feel that they are currently being unfairly penalised when trying to obtain insurance.

This action research project aims to assess the patient experience of applying for insurance products and to work with the industry to understand the underlying reasons for any possible problems that may occur and to create innovative solutions. There are six key aims of this project;

- 1) A conceptual framework of insurance templates and the benefits they can provide to both insurers and patients
- 2) A series of templates for a range of insurance products and conditions
- 3) A communication strategy that is appropriate with all the key stakeholder perceptions and expectations.
- 4) Publications in relevant professional and key media
- 5) A final report and launch conference
- 6) Dissemination.

GIG will look at a range of conditions in order to achieve these objectives, the rare and the not so rare and the numbers of potential clients actuarial set to increase as screening methods improve.

The final nine groups were chosen at an early stage and have been actively involved in the research thus far. These groups have been chosen specifically with the knowledge that individuals with these particular conditions should be able to achieve an insurance decision either on standard terms or with a rating. Conditions with variable management and symptoms were chosen to highlight the problems facing individuals in trying to explain the condition to insurance companies who often are unsure of the details or treatments.

The groups are as follows;

- **Breakthrough UK.** There are approximately 45,000 diagnosed with Breast cancer annually, that's around 125 women a day. If 5% of the population with the condition use insurance, the number of new cases per annum stands at 2250
www.breakthrough.org.uk
- **Cystic Fibrosis Trust.** Around 8-10,000 people in the UK are affected by the Cystic Fibrosis gene.
www.cftrust.org.uk/
- **Diabetes UK** there are currently over 2.2 million people with diabetes in the UK and there are more than half a million people with diabetes who have the condition and don't know it & research demonstrates that Diabetes is on the increase. Again if 5% of people affected by this condition require insurance this equates to 5500 possible applications.
www.diabetes.org.uk/
- **Gauchers Disease.** 10,000 people worldwide affected by Gauchers
www.gaucher.org.uk
- **Haemochromatosis Society.** In the UK, about 250,000 people have a genetic predisposition to Haemochromatosis. Only some 5,000 are currently diagnosed but there is evidence that several times that number have tissue damage and disease caused by iron overload.
www.haemochromatosis.org.uk/home.html
- **Macmillan/Cancerbackup.** Bowel Cancer is one of the most common forms of genetic cancer and affects around 35,000 people each year. If 5% of these people use insurance the number of new cases each year would be around 1750
www.macmillan.org.uk/
- **Multiple Endocrine Neoplasia Type 2A** MEN 2 is a rarer condition. On average, fewer than 1 person in every 20,000 will carry the **gene** for MEN 2.
www.amend.org.uk/
- **Neurofibromatosis Association** Around 24-25,000 people in the UK affected which means a possible 1200 people requiring insurance
www.nfauk.org/
- **Tuberous Sclerosis.** Roughly 8000 people in the UK are affected by the Tuberous Sclerosis gene, around 400 insurance cases predicted.
www.tuberous-sclerosis.org/

Executive Summary

The project has now been running successfully for one year. Within that time it has been possible to make significant progress in regards to recruiting a wide range of individuals from a variety of support groups to participate

Research Data

It has been an interesting and diverse six months in terms of the qualitative research which has been undertaken. GIG has utilised some of the information gathered from the quantitative survey as a basis of discussion for the further research. Responses have been highly interesting and the need for clear patient information has repeatedly arisen and is something that GIG is committed to finding innovative solutions to.

A December deadline for all interviews and qualitative research to be completed has been put in place. This will ensure adequate time in order to undertake a full analysis of the data. This analysis has already initially started and will be undertaken jointly with Dr Gill Haddow, research fellow and academic project support at Innogen¹.

The questionnaire link was sent out to all of the groups recruited for the project and also via associated online networking websites and organisations.

GIG has been able to orchestrate two patient focus groups on the subject of insurance. This has been with the annual general meeting of the Association of Multiple Endocrine Neoplasia and at a patient meeting of the Tuberous Sclerosis Association. From these sessions the overarching issue of the difficulty in obtaining Travel Insurance continued to come up with many patients requiring further information, not only on the best practise methods of applying for Travel Insurance but also on the product itself. This has helped form the information that has featured on the patient information leaflets.

Trade Relations

The Genetic Interest Group has continued to work closely with a variety of insurance companies building relationships including the travel insurance arm of Bupa UK. This is a fundamental development in terms of creating a clear dialogue with the industry. It has been important to ensure we can continue to work with these companies to work through any of the issues that may arise as a result of GIG's extensive research.

GIG's relationship with trade organisations, regulatory bodies and individual insurance companies has helped to create an affective dialogue between all stakeholders with assist with dissemination work.

¹ <http://www.genomicsnetwork.ac.uk/innogen/>

Insurance Policy

Regulatory reform has been an important development within the past six months given the new regulatory powers awarded to the Financial Services Authority officially began on the 1st of January 2009. The development of this new regulatory landscape has been an important step to achieving equity for consumers affected by pre-existing medical conditions. It is currently too early to identify whether this new form of regulation has been affective in opening up the travel insurance market and made it more competitive to the advantage of UK consumers, however this is something that GIG aims to learn more about over the following twelve months.

Further to this, the Government has recently launched a white paper exercise called Reforming Financial Markets² aimed at assessing the plausibility of setting up a new financial education authority which will see the syncing together of powers from the Financial Services Authority and other government departments. This new organisation would be industry funded, which given the current economic and political climate may mean the proposals will not have the maximum impact within the short term. However, although the likely outcome of this exercise will be set after the current timescales of this project it is a development worthy of note.

Extending Networks

GIG has spoken at the meeting of the North East Consumer Cancer Research (NECCR) Hub in May. This group which is part of the National Cancer Research Institute (NCRI) deal with all of the trends and issues that consumers living with cancer continue to face. The majority of this research is concerned with working with the NHS to improve patient services and the goals of the NECCR were very interested in GIG's research and in participating further.

GIG has also been contributing to further research surrounding the Moratorium and Concordat on using Genetic testing within Life Assurance applications currently being undertaken by the UK Forum for Genetics and Insurance(UKFGI). The UKFGI research proposal will take the form of a series of interviews of key stakeholders to assess the appetite for change when the Moratorium ends in 2014. This research is an important development in shaping policy in regards to consumers affected by genetic conditions and so GIG will be continuing this dialogue and taking part in further qualitative research.

Unforeseen changes.

There has been an overwhelmingly positive response to the online questionnaire with a fair representation from most of the support groups.

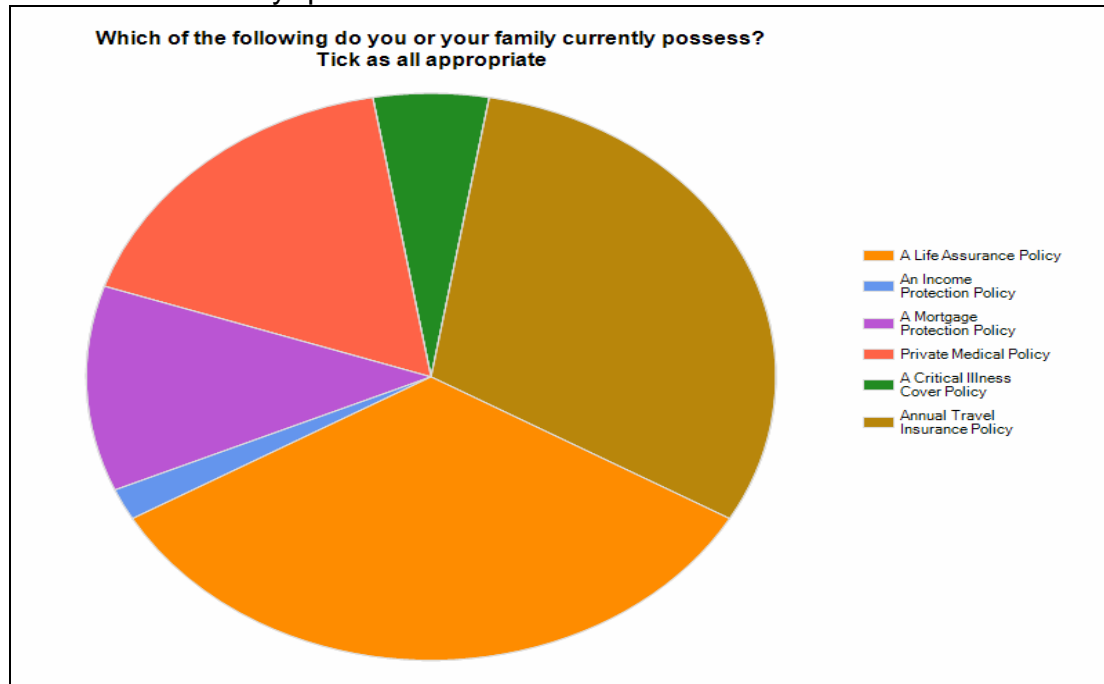
² http://www.hm-treasury.gov.uk/reforming_financial_markets.htm

However, one of the support organisations GIG initially recruited to work with the project has been unable to contribute as much as was initially hoped. This was the result of the individual organisation undertaking rudimentary structural changes to its organisation, namely the time and monetary consuming process of a re-branding exercise.

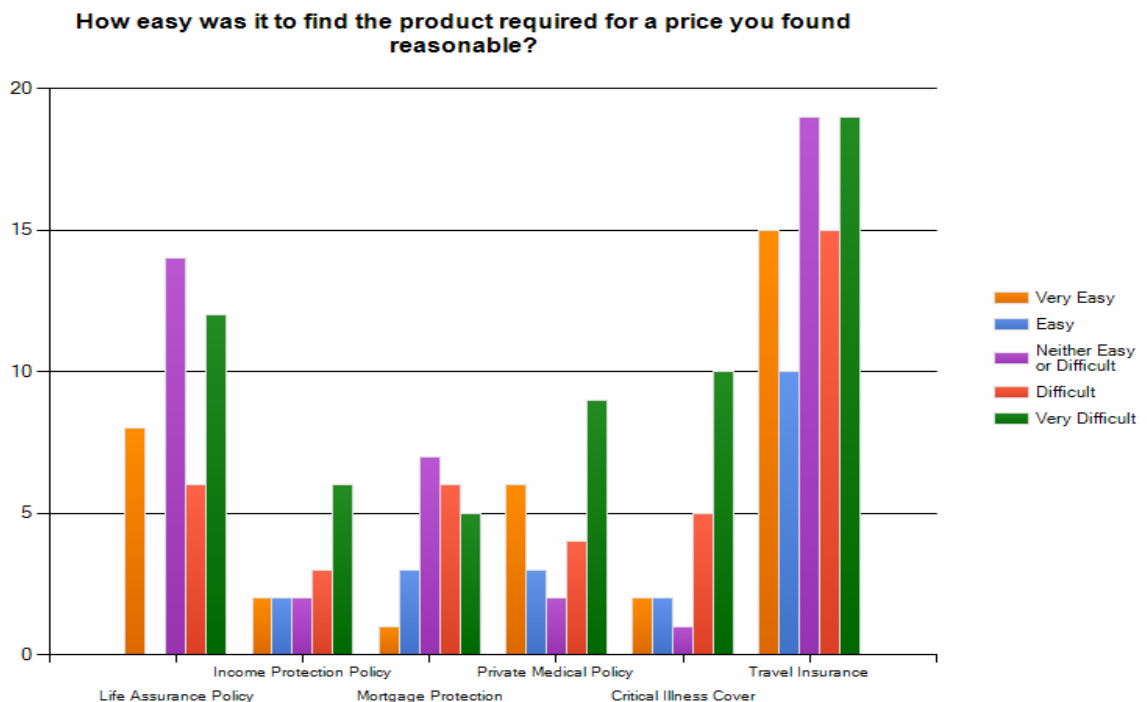
Due to this unforeseen circumstance, it was decided that GIG would seek to establish links with other support organisations working with the same condition. Luckily the timing has proved efficient as a new group, specialising in the same condition but with an emphasis on providing specialist assistance in Scotland only, has recently been launched and they are very keen to get involved with the research. This has been a positive development and GIG has been able to ensure that patients affected by this condition will still be able to contribute to this research project.

Initial Research Analysis

As previously stated the GIG virtual questionnaire which has been set up with assistance from Innogen³ Centre, has been running since September 2008 and an estimated end date of December 2009. This ensure a broad range of consumers have had the chance to complete this questionnaire and will allow GIG to cultivate key quantitative data.



As of the July 1st there have been a total of 127 responses encompassing respondents from all 8 condition groups.



³ <http://www.genomicsnetwork.ac.uk/innogen/>

Of these responses, 10 of them are related to condition groups outside of the research remit and so cannot be included

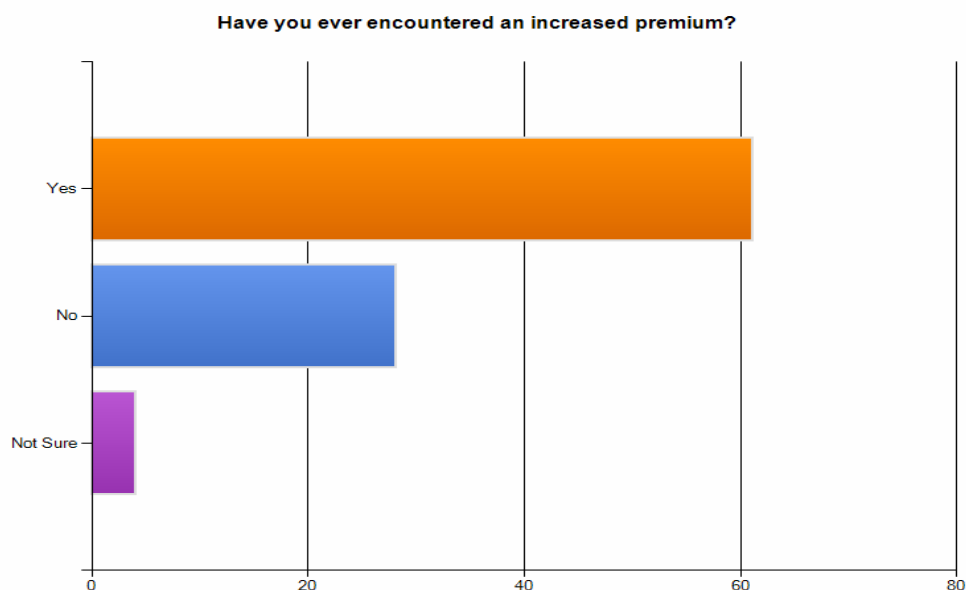
There are currently only 2 respondents affected by Neurofibromatosis due to the problems in soliciting a response from the Neurofibromatosis Association. This situation will hopefully be rectified when Confer (the Scottish equivalent rolls out the questionnaire to its members)

The age of the respondents is well spread however 40.7% of respondents thus far are aged 25-40 and 39.8% are aged 46-64 with the rest spread out evenly. This is an interesting result which reflects the age at which many people consider insurance.

The majority of respondents (60%) have taken out a Single Trip travel insurance policy in the past

Many respondents (19 people) noted that obtaining travel insurance was 'very difficult' followed closely by Life Assurance (12 people noting it as 'very difficult') and Critical Illness (10 people)

60 respondents noted that they had received an increased premium because of their medical condition with 43 saying they had been declined altogether.



Ongoing consumer concern surrounding the Moratorium and Concordat that is currently in place to protect consumers in regards to Life Assurance applications has become more evident recently. In terms of the research GIG has been conducting the issue has not been widely discussed however, through the promotion of GIG's research, we have received several calls and emails from members of the public who required further clarification on this matter. This is an important point and clearly one that is not isolated. GIG will continue to press this issue in ongoing research to detail the exact anxieties consumers are feeling towards the Moratorium and Concordat and research possible solutions.

Key Research Findings

The questionnaire has now reached the desired 100 responses. However upon initial analysis of the data it became apparent that not all responses were complete and some were received from condition groups outside the remit of this project. As a result of this, it was agreed that the questionnaire continue to run until the desired amount of full responses has been reached. At this moment there are 10 responses that will not be able to be included within the full analysis. We currently have circa 124 responses. A decision to allow the questionnaire to continue has been made in order to allow time for all the groups to participate. Problems have arisen with one group in particular, however solutions to these problems have been identified and so it has been possible to allow extra time for these responses which will be completed by December 2009.

Travel Insurance continues to dominate as the type of insurance product that causes the most issues and anxieties throughout both the quantitative and qualitative research. It appears to be the product that most people have experience of dealing with in various ways. There appears to be a divide between consumers who have struggled to find a travel insurance product for a price they found to be reasonable and those consumers who seem content with their travel insurance given that it is provided free of charge as a 'benefit' of their holding of another financial product, usually a bank account.

“ It's a nightmare, countless telephone calls, countless knockbacks, long hours spent on the telephone, answering the same questions, only to get a no at the end of it. It's makes the holiday planning process extremely stressful”⁴

This in itself presents problems. Consumers are relying on this insurance when they travel abroad and it is not always apparent that they still must tell the insurance company about their pre-existing medical condition or else they will not have the cover they need when they travel abroad.

Life Assurance, and insurance related to mortgage cover has also featured heavily throughout the research. It is apparent that difficulties in obtaining Life Assurance is more of a problem for younger consumers. At the focus group held at the Multiple Endocrine Neoplasia annual general meeting in May, it was the younger participants (aged 20-40) who reported the most problems in obtaining Life Assurance in order to obtain a mortgage. There could be several possible reasons for this, including stricter lending requirements being put in place due to the current economic climate or a move away from cases which insurance companies class as a higher risk due to an appetite to cut

⁴ Consumer Feedback

down on exposed risk, again due to the current global economic problems. This is proving a big issue and one which GIG will be taking up with Life Offices when talks with DOUG commence and the Life Insurance Templates are rolled out.

Travel Insurance Regulation.

The regulation of connected travel insurance by the Financial Services Authority took effect on 01st January 2009. The aim of the regulatory changes was to create a responsible selling environment and was a welcomed development although it is still too early to look at the positive changes this may have created. It has also not yet addressed the problems many consumers face when trying to apply online and the problems surrounding the definition of a 'pre-existing medical condition' As predicted many travel agents appear to have passed the travel insurance business out to a specific company rather than deal with FSA regulation, the results of which have assisted in the fiercely competitive market place that Travel insurance has become.

Now that regulation has been in effect for over six months it is perhaps a good point to reflect on the way in which the industry will or may change over the coming months. It is now the traditionally busy summer period and so it will be highly interesting to see the affect the global financial crisis has had on the sales of travel insurance as many consumers opt out of holidaying abroad. The fear is that Travel Insurance will be seen by many as an 'extra' which can be eliminated in order to cut costs, or that consumers living with pre-existing medical conditions will fail to disclose the details of their genetic condition to their insurer for fear of increased premiums. This may well result in some intriguing news stories in Autumn of claims being denied and could result in further negative public relations for the travel insurance industry.

GIG has met with the Financial Ombudsman Service (FOS), a division of the Financial Services Authority (FSA) to discuss the details about the project. It became clear that although the FOS deal with complaints about Travel Insurance, it is mainly Life Assurance and associated mortgage related products that make up the bulk of the health related insurance complaints (although complaints around this subject remain small in comparison to other financial product complaints) The development of the Life Assurance Templates was thoroughly explained and the FOS expressed interest in their function and praised the way in which the templates mitigate an open application method and they way in which more emphasis is placed on the consumer to disclose all of the relevant information at point of application. It was indicated that the templates would ensure that any complaints received by the FOS would be dealt with easily and hastily.

The FOS also mentioned that a department within the Financial Services Authority could be interested in GIG's research. The Financial Capability division deals with the way in which consumers interact with financial services. This department may play a key role in furthering GIG's research in regards to looking at associated insurance products, such as Private Medical Insurance and so further discussion will continue.

Case Studies.

As the initial analysis demonstrated the growing problem of consumers affected by pre-existing medical conditions being unable to find and secure travel insurance, steps were taken to create a series of case studies in order to examine the problems and work with external insurance companies to look at the issues and the methodologies behind the quotes that are provided.

The case studies were completed with assistance from some of the support groups to ensure the case studies were indicative of their members. The case studies ranged from the highly complex and rare to the relatively common and conditions that should be easy to risk rate.

Initial feedback has been excellent with 2 of the 4 insurance companies approached able to quote for the majority of the case studies and where it was not possible to provide a quote, clear reasons and further solutions were given. (For example the suggestion of taking out a single trip policy as opposed to an Annual one whereby the risk is much reduced and the price more competitive) The case studies have also allowed us to build on the contacts made at the early stages of the project to further the working relationship. This has meant we can feedback certain experiences and both parties can learn and adapt the application process. By involving consumers at every stage it enables both the insurance company and GIG to develop a system highly indicative of 'real life' applications and thus learn from the patient experience. It then allows insurance companies insight into the problems that consumers face and adds to the valuable research GIG is doing throughout the project.

Macmillan Cancer Research are conducting a similar exercise dealing with consumers affected by cancer and it will be beneficial to follow their research throughout and utilise their expertise if possible. It is hoped through the continuation of GIGs working relationship with Macmillan that we will be able to work together on research of this nature.

GIG has also forwarded on the case studies to Bishopscourt Affinity Solutions – an Insurance company. As previously reported Bishopscourt have been interested in GIG's research from the outset and have been able to open a constructive communication channel in regards to testing out the case studies. The cases were forwarded to Bishopscourt to test their risk rating system and the results are keenly awaited. Further to this. Bishopscourt are running the case studies in models outside of the Travel Insurance product remit. They are looking at the cases to see if other insurance products (such as Life Assurance or Critical Illness Cover) could be offered. This is an important and vital step. Once this exercise has been completed we will be able to effectively look at any of the problems insurance companies have in accepting certain levels of risk and work closely with them to research possible solutions to these problems.⁵

⁵ Case Studies available in appendix

A Holiday Risk?

Throughout GIG's ongoing work with patient groups it has become very clear that one of the biggest areas of concern for all stakeholders has been the issue of education and information provided for consumers.

It was quite clear from preliminary research that there were pockets of excellent information within various groups, be it patient support organisations or individual insurance companies or even trade organisations however there was no one place where this information was collected or stored. One of the action points that has been addressed within this reporting period has been the creation of a consumer information leaflet. This information was drawn from various places such as the Association of British Insurers, the National Health Service and many other patient support information literature. The idea was to create a helpful pocket guide to travel insurance to help all consumers affected by genetic conditions not only understand the product they are buying but also the reasons why it is necessary to purchase it.

GIG evaluated all of this key information and incorporated it into a short information leaflet that will be placed on the GIG website to accompany other information material provided to our members and the public and will be fully accessible to anyone who wishes to download it. We will also be able to provide (limited) amounts of paper copies to consumers who wish to receive it non electronically or patient support groups to hand out to their members. GIG felt it was important to involve another organisation with the development of this information and so Which? Consumer group were approached. This has been a relatively recent development but Which have indicated they would be open in allowing the use of their logo and further assistance for the leaflet such as employing an editorial consultancy to ensure the leaflet reflects a maximum impact. This would be an important step, by involving a well respected consumer advocate within the development process will provide a useful service not only to GIG members but also to others seeking help and advice within this area. The leaflet has been sent to Which and also a select group of participating members for feedback. The Which group has also indicated their interest on collaborating on further developments which could include patient information guidance for the Moratorium and Concordat that is currently in place protecting consumers within Life Assurance applications.

Further to this, the Association of British Insurers (ABI) and Breakthrough Breast Cancer research are involved in the early stages of a consultation exercise surrounding the changes to the ABI's consumer information. This information deals mainly with the Moratorium and Concordat and the frequently asked questions that many consumers have surrounding this. GIG has become involved with this initiative early on to ensure that consumers with other genetic conditions, not just those affected by BRCA1 & 2 genes can benefit from an improved access to information on insurance. GIG will continue with this exercise involving our members where possible looking into the future.

This is a highly interesting time to be looking at the education of consumers in regards to financial products. As part of the Lord Turner review the Treasury has recently launched a White Paper consultation entitled Reforming Financial Markets⁶. This paper sets out plans to create a new financial education authority to help consumers buy financial products such as insurance, mortgages or loans. If created this new body would help alleviate the lack of an independent consumer organisation offering advice to consumers in regards to financial matters. This positive step could have constructive consequences in regards to helping consumers affected by a range of pre-existing medical conditions (including genetic) Although the initial outcome of this exercise is likely to be finalised after this project has reached its objectives it is an important development worth noting⁷.



⁶ http://www.hm-treasury.gov.uk/d/reforming_financial_markets080709.pdf

⁷ Leaflet available in Appendix

Challenges

Challenges identified in the interim report have been vigorously assessed and as part of the action points rising from the initial report have been addressed through various methods.

It is perhaps also important to note that not all condition groups have responded well to the online questionnaire. Some groups were reluctant to advertise the link to their members via their websites or literature preferring instead to advise their members to contact themselves for paper copies or for the link, or to visit the GIG website. This has presented some difficulties in recruiting responses however the overall response has been extremely satisfactory.

Further research with key groups was initially proving to be difficult. It was originally reported that there were difficulties in re-establishing key contacts at Cancerbackup which has recently merged with Macmillan Cancer Research. Contact was initially difficult but we have been able to begin to open up a working relationship with this group and this is something that will be monitored moving into the next reporting period.

Given the difficulties explained above, tactical decisions were made to ensure that Cancer, as a condition group, could still be involved within the research. Other associated cancer support groups were approached and details of the project given in order to facilitate access to consumers affected by cancer who wished to give their experience of dealing with cancer and insurance.

GIG initially approached the following groups and has been successful in gaining their support for the project;

- **Teenage Cancer Trust** - Every day in the UK, up to 6 teenagers or young adults (between the ages of 13 and 24) will find out they have cancer that is approximately 2,100 new cases a year. The Teenage Cancer Trust grew by chance, out of the eagerness of a group of women to organise a fashion show to fund a children's intensive care heart unit at Guy's Hospital, London. <https://www.teenagecancertrust.org/>
- **National Cancer Research Network** - The NCRN was established by the Department of Health in April 2001 to provide the NHS with an infrastructure to support prospective trials of cancer treatments and other well-designed studies and to integrate and support research undertaken by cancer charities. Its aim is to improve the speed, quality and integration of research, ultimately resulting in improved patient care. <http://ncrndev.org.uk>

Both of these groups have advanced patient networks which will assist in the gathering of both quantitative and qualitative data. The Teenage Cancer Trust in particular was very interesting in the research due to the large level of enquiries they handle on the subject of insurance and due to the demographics of their membership. They have also historically looked at

possible solutions to common problems their members have experienced and entered into discussions with individual banks and insurance companies to understand the industry perspective on the rating of risk.

GIG has recently been able to open a further dialogue with Macmillan Cancer Research and it has become immediately apparent that the aims of this research and the goals Macmillan have begun to look at surrounding the application methods of Travel Insurance are aligned. GIG has been able to orchestrate the beginnings of a working relationship with Macmillan which will allow access to consumers affected by genetic cancers which will then allow us to obtain completed quantitative questionnaires and then arrange further qualitative data to be collected via either patient interview or focus groups facilitated by GIG. It would appear that now the merger between Macmillan and Cancerbackup has been completed we will be able to continue the working relationship as originally planned. This development will add to the work already conducted with other cancer groups and thus further the research.

The questionnaire reached the desired 100 responses. However upon initial analysis of the data it became apparent that not all responses were complete and some were received from condition groups outside the remit of this project. This problem has now been rectified by creating a 'twin' survey which is running alongside the main questionnaire which allows other member groups who are not able to be included within this research but still wish to give their experiences. This is important data that should be recorded to analysis at future stages.

It is perhaps also important to note that not all condition groups have responded well to the online questionnaire. Some groups were reluctant to advertise the link to their members via their websites or literature, preferring instead to advise their members to contact themselves for paper copies, or for the link, or to visit the GIG website. This has presented some difficulties in recruiting responses. However, the smaller groups, with good links with their members have responded well and the aim of getting 8-10 responses per condition group has nearly been achieved with the exception of the Neurofibromatosis Association.

The Neurofibromatosis Association was initially recruited to work with the project and responded well to setting up meetings. However, the Association has been going through a difficult time, undertaking a re-branding exercise and re-launch. It has been understandable that they have found it difficult to participate in external research during this time. As a result of this it has been decided that the Neurofibromatosis Association will not participate further in the project at this time. There is only one survey respondent and this was the result of a recommendation and not via the Association. This is an unfortunate decision but given the timescales enforced within the project it is not possible to delay the research further. I was still keen to involve consumers affected by Neurofibromatosis and noted the recent membership of GIG by a small Charity called Confer.

Confer

“Confer the only Scottish charity working to support people with Neurofibromatosis. Confer does this by providing accurate and up to date information on Neurofibromatosis to the people with the condition, their families, friends, carers, employers, health and educational professionals working with them”⁸

Confer is the Scottish equivalent of the NF Association and works to support families and individuals affected by NF in Scotland. The association has only recently been set up and a formal charitable launch took place in June where it was possible for GIG to talk about ‘Asking Relevant Questions’ This new charity has excellent patient networks and it is hoped that by working closely with Confer we will be able to include consumers affected by NF within the research. The organisation is new but already has excellent links with patients, medical professionals and specialist advisers. This means it will be possible to quickly and effectively carry out further research by working closely with their members. Insurance is a problem commonly reported by their members and they are extremely enthusiastic about getting involved with the project.

The screenshot shows the Confer website homepage. The browser window title is "Confer - Mozilla Firefox" and the address bar shows "http://www.confer-scotland.org.uk/". The website features a blue header with the Confer logo and the tagline "Supporting those living with Neurofibromatosis in Scotland". A navigation menu on the left includes links to Home Page, Aims and objectives, Board of Trustees, NF Nurse, Groups Glasgow, Groups Other Regions, Useful Links, Personal stories, Fundraising, News Blog, and Contact Page. The main content area has a "Welcome" section with a photo of four children and text explaining the charity's mission. Below this is a "WHAT IS NEUROFIBROMATOSIS?" section with a detailed description of the condition. On the right side, there are contact details (Phone: 0141 554 1382, Email: info@confer-scotland.org.uk), a "DONATE HERE" button, and a "Join Now" button with a "download membership form" link. The browser's taskbar at the bottom shows several open applications, including Microsoft Outlook, British Airways Experience, and BUFA YEARLY REPORT.

⁸ <http://www.confer-scotland.org.uk/>

Action Points - Deliverables.

There were 7 action points from the last reporting period that were to be actioned within the following 6 months;

- 1) **ACTION POINT:** Further study into the interpretation of the qualitative data being collected via the online questionnaire and forums will take place in early 2009. This will result in a comprehensive analysis of all qualitative data from this research. Attendance on the Social Research Association course has been confirmed for February 5th 2009.

Outcome Attendance on the course took place as originally scheduled. Further analysis has continued alongside the day to day activities of the project. It has been important to look at some of the key trends (notably the problems surrounding travel insurance) when orchestrating and holding further qualitative research sessions. A full extensive analysis of all questionnaire respondents has been delayed due to the problems experienced in recruiting patients with Neurofibromatosis. As a result of this there has been no feedback from this group. Further analysis with input from Dr Gill Haddow of Innogen⁹ has already begun. Qualitative research is also ongoing with further patient interviews and focus groups scheduled. Due to the problems in finding a cancer partner to work with this has been re-scheduled to take place towards the end of the summer. With the excellent working relationship now in place with the National Institute for Cancer Research, The Teenage Cancer trust, and the opening of an effective partnership with Macmillan, development with this group will accelerate rapidly.

- 2) **ACTION POINT:** GIG to continue the dialogue with Diabetes UK and families affected by Diabetes to gain a more detailed picture of the problems associated with travel insurance and the condition. This information can then be taken to the industry to help insurance companies to understand the problems people face.

Outcome GIG has indeed continued with dialogue with Diabetes UK. This has been particularly important given the prediction that Diabetes will be the next condition to champion the use of the Templates. The relationship with Diabetes UK has been an important part of this project and will continue to be in the future. Representatives from Diabetes UK have been informed about the progress of the research and further meetings are scheduled to take place within the autumn months.

- 3) **ACTION POINT :** GIG is well placed to work with both its member organisations and independently on helping to educate the consumer on relevant insurance issues. GIG can work to seek a consumer voice within this field and help to communicate any issues our members have

⁹ <http://www.genomicsnetwork.ac.uk/innogen/>

directly to the insurance industry This could possibly be done either via informative leaflets, or website guidelines either via the recently re-launched GIG website or from an external independently created site or through a working partnership with an insurance provider.

Outcome This has now been completed. By working with a variety of stakeholders, including support organisations and industry contributors, we have created a consumer information leaflet. GIG felt it was important to include an independent organisation within this and so Which? consumer organisation was approached. Further discussion is needed in order to cement this relationship further but initial dialogue is positive and it is an issue that Which? Have looked into previously and remain concerned about.

- 4) **ACTION POINT:** One of the key frustrations for many consumers is the way in which the premium is calculated. Many people utilise online price comparison websites such as Moneysupermarket.com which is able to compare the prices of various policies and produce a rough quote. Again GIG is well placed within this arena. We are able to work closely with industry contacts to help create consumer based education tools to ensure people understand the basics of the risk analysis process. These can either be in the form of a series of info sheets or via the online travel map currently in development by Bishops court

Outcome The development of GIG's case studies is a step forward in completing this action. The case studies have been sent on to several insurance companies and brokers and the feedback has played an important role within the research. Initial replies managed to successful quote for the majority of the cases, even those which were highly complex. A handful of the cases resulted in a high premium and GIG is no able to work with these companies to gain a better understand as to how the risk has been calculated and how this risk then translates into a monetary loading. It is vital that this process is understood in order for us to understand the processes insurance companies have in place and for us to look at the 'real' risk that consumer feel is appropriate. The Bishops court online travel map and advice tool is still in development and it is hoped that we will be able to cement our working relationship within the coming months.

- 5) **ACTION POINT :** Throughout the course of this project GIG will work with the industry in order to feedback any key trends apparent from our research. It is beneficial that there are several insurers who are looking to expand their products and are looking to solve some of the issues highlighted by our members. The hopeful outcome of this will be the creating of clear, transparent products that are easy to apply for and ensure that consumers get the best deal in sourcing their insurance needs.

Outcome The case studies have been crucial in extending the working dialogue initially set up at the commencement of the project. By working with companies operating within both the travel and Life assurance sector it has been possible to obtain a typical example of the kind of feedback GIG's members would expect to receive should they be applying for an insurance product. This has been a constructive exercise because it allows us to work with the industry to create innovative solutions to any problems which become apparent through the trials of the case studies.

- 6) **ACTION POINT** : GIG is uniquely qualified to be able to significantly contribute to the development of new technological tools to help families affected by pre-existing medical conditions. By utilising our medical expertise and relationship with patient groups we will be able to help build a picture of the best and worst places to travel to in regards to certain conditions.

Outcome This has been achieved by working with individual companies on the development of their online educational tools. Due to developmental delays and the current economic climate, progress on this has been slower than predicted. This action point will be carried over into the next reporting period.

- 7) **ACTION POINT**: GIG will continue to contribute to forthcoming meetings and discussions and the UKFGI has expressed interest in the results of the project and possible future research projects in the area of the feasibility of the creation of social insurance policies.

Outcome There is now a concrete project proposal from the UKFGI to undertake a study looking at the appetite for change in regards to the UK Moratorium and Concordat which is in place to protect consumers. This is a highly significant time to be contributing this report given the current political debate surrounding the 'buy now, test later' phenomenon. GIG will take an advisory role within this project contributing patient views and further ideas to the report. The aim of this research is to utilise some of the data to gain further understanding of public confidence with current practises.

Action Points – Next Step.

Over the next one year reporting period the following action points have been developed to be achieved within the lifetime of the project:

- 1) **Interviews.** – GIG will concentrate on finalising all of the qualitative research to allow an appropriate amount of time is secured to ensure an in depth analysis of the data can take place. Through further dialogue with Innogen¹⁰ it has been decided that the aim should be to complete a further ten interviews over the next reporting period. This will ensure all participatory groups have substantially contributed to the project. A tactical decision to perform interviews has been taken due to the potential problems of analysing different data formats. Two of the groups involved within the research are unable to participate in focus groups due to the nature of the condition itself (Cystic Fibrosis & Neurofibromatosis) Thus it has been decided that interviews will ensure the maximum amount of constructive data is cultivated. GIG's excellent links with all patient groups will enable us to complete interviews at an increased pace and all qualitative research will be completed by December 2009.
- 2) **Case Studies.** – The case studies will continue to be issued out to key insurance contacts. The feedback from these will then be recorded and utilised for analysis purposes. The case studies represent a large cross section of the groups involved within this research and the results of which will help to further develop the analysis. It will assist in understanding the problems that individuals face and by liaising directly with individual companies, construct possible solutions for the most common problems. The templates have initially been developed for testing travel insurance, however moving forward these can be extended so that further analysis in regards to other insurance products will be possible such as Life Assurance of Private Medical Insurance. This development can be achieved quickly and efficiently and Bishops court Affinity Solutions are already working on the cases in regards to Life Assurance applications.
- 3) **Dissemination** - Assessment of preferred dissemination route. – Once the full analysis of the data has been completed, it is vital that possible dissemination ideas are identified. It is important to ensure that the data is used within constructive channels to achieve the best outcome for the patients GIG represents. Part of this action point will involve the analysis of the best way to achieve this. From March 2010 a full assessment will take place to find the best way to achieve this aim. It is important that the research and information that GIG has collected and analysed is used to benefit our members. Much of the

¹⁰ <http://www.genomicsnetwork.ac.uk/innogen/>

dissemination will involve working with the industry to assess possible solutions to the most common held problems and anxieties.

- 4) **Data** - The survey monkey online questionnaire will reach its first anniversary in September 2009. This will mean decisions must take place as to the longevity of the study. It is important that all groups have had the opportunity to contribute to this and so the survey. Most groups have responded extremely well to this medium of research with only one condition group yet to complete a survey. – Neurofibromatosis. A tactical decision to keep the survey up and running has been made and it will remain open until at least five patients, affected by Neurofibromatosis have completed a questionnaire to ensure this particular group can be included within this research. However, given the current timescales in operation and absolute final date of October 2009 has been put in place.