



Patients Participate! Case Study Report



***Bridging the Gap between Information Access and
Understanding in Health Research***



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<http://www.jisc.ac.uk/whatwedo/programmes/digitisation/econtent11.aspx>

More information on the project is available at:

<http://www.bl.uk/science-patients-participate>

http://www.amrc.org.uk/our-members_patients-participate

<http://blogs.ukoln.ac.uk/patientsparticipate/about/>

Background

This report presents Case Studies inspired by a workshop organised as part of the JISC-funded **Patients Participate project** in June 2011. The project brought The British Library, UKOLN and the Association of Medical Research Charities together in partnership, for a feasibility study which aimed to explore the potential of developing a useful body of lay information for patients and those interested in biomedical and health research.

The **Patients Participate workshop** brought together people from different communities - patients, carers, researchers, charities, and technologists - to explore the motivations and challenges to biomedical information access, comprehension, and use. In order to explore some of the issues raised in the workshop in more detail, we sought to answer the question: **Who is currently producing easy-to-understand information relating to biomedical research for the public and how do they do it?** To this end, we interviewed people within key information-providing organisations to provide the case study narratives contained in this report.

Patients and the general public are interested in understanding biomedical research for a number of reasons. Some members of the public have a general interest in science and would like to understand where public funding and their own donations are being invested. Patients tend to have more personal reasons such as to: build up knowledge of their own conditions; understand how new findings are relevant to them; and feel empowered to make informed decisions on treatments and whether to participate in clinical trials. With the ever expanding amount of online information available to patients, a number of questions arise such as how best to meet their biomedical information needs; what types of information do they find most useful?; what formats are easiest to access?; and how do they identify reliable and trustworthy sources?

The types of organisations helping to make this type of information more accessible for patients include charities, universities, patient organisations, the NHS and scientific publishers. Many medical research charities involve patients in making funding decisions and therefore require scientists to include a lay description of their research in their funding applications. This shift towards patient and public involvement has developed in recent years. A broad range of approaches and varying relationships with patients and the public now exist. Many organisations also translate and communicate research outputs to the public, by producing plain English summaries of biomedical research findings. This requires significant time and effort and not all organisations are able to dedicate resources to such a service.

These case studies are not intended to be a comprehensive analysis of all approaches undertaken to communicate biomedical research but they are illustrative of the methods some organisations employ and highlight the challenges in doing it well. We hope they will serve as examples of useful methodologies and approaches for others who are starting out and those trying to increase the volume or improve the quality of their lay communications or seeking to include patients in their activities in meaningful ways.

Case Study 1: CancerHelp UK (CRUK)

A dedicated team of specialist nurse writers

Cancer Research UK (CRUK), employing over 3,500 staff and with a research budget of over £300 million, is a large and diverse UK charity. The charity uses a range of channels to communicate and engage with patients and the public, including blogs, Facebook, Twitter and their own website. Through these platforms they have built strong connections with patients and the public and regularly recruit people from this network to review a range of activities and services. CancerHelp UK is their flagship patient information website, providing easy-to-understand information about cancer and cancer care. As part of this service, the CancerHelp UK team list all cancer trials and studies that recruit UK participants – these trials and the volunteers who take part in them are vital to developing new treatments and methods of cancer detection. Having clear, easy-to-understand information about a trial is crucial for patients considering enrolling in it.

The CancerHelp UK team recognises that clinical researchers often find it challenging to write in lay terms. As a result, CancerHelp UK employs a dedicated team of specialist nurse writers, with defined skills and training in writing for lay audiences. The team has years of clinical knowledge and experience; this breadth of knowledge is considered critical in translating clinical information relating to the trials in a way that patients will find useful. Having dealt with patients' questions in a clinical setting, the team also understands the types of practical issues that will concern patients.

Once a new UK cancer trial has been identified, CancerHelp UK makes contact directly with the trial team to ask permission to list relevant information on their website. Obtaining agreement from the trial team is not usually a problem and CancerHelp UK works with a range of sponsors and funders, including a growing number of pharmaceutical companies.. Any trials that are funded by Cancer Research UK through the Clinical Trials Awards and Advisory Committee (CTAAC), are required to submit their protocols to CancerHelp UK as a condition of funding.

CancerHelp UK produces a plain English summary for each trial, which includes information from the trial protocol and the patient information sheet. The patient information sheet is intended to provide all the necessary information relevant to patients and the public so they can make an informed decision about participating in a trial. However, as they are usually written by a member of the trial team who may not have specialist training or skills in writing for lay audiences, the patient information sheets are highly variable in quality, length and content, despite the availability of National Research Ethics Service (NRES) guidelines.

The variability of patient information sheets is one of the main reasons that CancerHelp UK felt that it was necessary and valuable to provide plain English summaries relating to cancer trials on their website. When developing the CancerHelp UK website, extensive evaluation and review was undertaken to test whether the information it provided was easy to understand and answered patients' questions. The team have since developed their own guidelines, editorial policies and style guides (all available on their website), founded on this patient feedback. In addition to the summaries themselves, general supporting information describing trials, trial phases and outcomes is provided for patients. CancerHelp UK still finds, however, that the skill of plain English writing is universally undervalued and the difficulty in getting it right is underestimated.

From a pragmatic point of view, the sheer volume of information posted on the CancerHelp UK website means that it is impossible to test all of it with patients. Therefore, to ensure the quality of their summaries, the CancerHelp UK team employs a rigorous internal editorial process to ensure that the information provided will answer patients' questions, is pitched at the appropriate level and avoids jargon of any kind. The trial team is asked for final approval on the summary, a process that is often iterative and it can take some time to come to a consensus on summary content, style and language. The team works hard to make sure that the information relating to a trial is kept up-to-date. They also include plain English information on trial results, but have found that agreeing on the interpretation of results can sometimes be a more difficult process.

Although there is a function on the website for on-going patient comment/feedback on the information provided, this is not used a great deal to comment specifically on the content.. Patients tend to ask questions relating to their own health and there is a separate team of Cancer Information Nurses that responds to these enquiries by telephone and email. Feedback from patients on the service as a whole has been very positive and the team continues to provide a much-needed service.

Central to the CancerHelp UK approach is empathy for patients:

'We always try to think of the patients - what they will want to know and what their main concerns might be. It is key to remember less is more - to take a step back and think what it is you want to say in the simplest terms.'

For further information contact:

cancerhelpuk@cancer.org.uk

Website: cancerhelp.cancerresearchuk.org/

CancerHelp UK policies and guidelines are all available online:

<http://cancerhelp.cancerresearchuk.org>

Case Study 2: Muscular Dystrophy Campaign

Involving patients and researchers in producing lay information

The Muscular Dystrophy Campaign (MDC) is the leading UK charity focusing on muscle disease and employs nearly 70 people. MDC developed its current research communication service following a review of its communication strategy and associated patient consultation a number of years ago. The central aim of the service is to make research advances in neuromuscular conditions more accessible for patients and the public. A very small team, who themselves have worked in research, interpret scientific articles into a language that is easy for everyone to understand. They provide patients with different layers of useful information, including weekly news stories on the charity's website, and a research magazine which was initially produced annually but has recently changed format to a quarterly publication. Priority coverage is given to the outputs from research groups funded by MDC and stories covered in the popular press relating to neuromuscular conditions.

In developing their research communication strategy, MDC recognised the challenge of knowing what information would matter most to patients and their families and providing that information at a level they would find useful. MDC appreciated the importance of patient input in helping to define their communication approach at the outset and

established a research communications focus group, 'Talk Research'. The group meets annually to consider whether the service continues to meet the needs of patients, and provides feedback on language, content and structure for the MDC website and publications. Members of this group are consulted on an on-going basis e.g. when stories arise that are technically complex or particularly difficult to translate, however their feedback is mostly in the form of a retrospective review of the previous year's news stories. They help MDC to come up with ideas for articles that appeal to a wide audience. The patients who participate in 'Talk Research' find the process very rewarding and often become involved in other aspects of the charity's activities, including lay review of grant applications.

Interestingly, MDC have found that the level of patient feedback and commenting outside of the formalised process ('Talk Research') is variable. The MDC website has a forum, which patients use primarily for socialising, rather than commenting on the information on the website. The forum has only been in place for a short time, so it will be interesting to see if use changes in the future. The MDC Facebook and Twitter pages are the place that most questions and comments are posted. These comments sometimes include questions about the effect that a particular piece of research will have on individual cases.

MDC recognised, through consulting with patients, that there is a wide range of understanding and information requirements amongst patients and the general public. In order to address these different needs, information on their website is carefully structured. Short, simple overview paragraphs lead on to more detailed information, covering background contextual information, research findings, what this means for patients themselves and those with related conditions and finally, links to individual papers and further information are provided. In order to allow patients access to the research articles that underpin their news stories, MDC have become the first UK charity member of Patient Inform. This service allows them to place links on their web page to the participating journal, which provides access to the full journal article. The team often needs to respond rapidly to media coverage of new research published in subscription-based journals, so access to research articles can be an issue for the MDC team, particularly when the research is not funded by MDC.

MDC also produces lay summaries of clinical trials and being a small team, they struggle to cover the volume of new studies. They therefore decided to try to involve the researchers they fund in this process and asked PhD students and postdoctoral researchers to write lay summaries. The response was positive; fifteen early-stage researchers saw this as a useful opportunity to gain experience in research communication. In order to support these researchers, MDC provided them with instructions, a template and examples of well written summaries, along with a glossary of common technical, scientific and medical terms to avoid. The team found the researchers involvement valuable and hope to expand this programme. While this approach has helped increase the number of trials MDC is able to cover, the bottle neck in the process now occurs at the point of editing summaries authored by the volunteer researchers.

Setting up their communication research group (Talk Research) has proved beneficial to the charity in a number of ways:

'The Talk Research group has been central in changing the way we communicate research information at the Muscular Dystrophy Campaign ,we now do it with our patients. It has also become an important entry route for patients to become further involved in the committees that make decisions on our research funding'

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Website: www.muscular-dystrophy.org/

Patient Inform: <http://www.patientinform.org/>

Case Study 3: Asthma UK

Established Patient and Public Involvement

Asthma UK has a well-established programme of working closely with people affected by asthma to ensure that the research they fund is responsive to their needs. Asthma UK started to involve people affected by asthma in the research process in 2003. As a result, patient representatives helped to develop their research strategy in 2006 and continue to be involved in a variety of ways. Research and Policy volunteers review proposals for new research and will help to decide the charity's new funding priorities. A Reader's Community also comments on health information produced by the charity.

When lay involvement on funding review panels was first introduced, the charity surveyed researchers to understand their attitude to involving lay people in funding reviews and also to understand the barriers researchers faced in writing lay summaries. Taking on board the issues and concerns raised through this evaluation exercise, they posted information on their website to explain why the charity had decided to involve lay people, alongside practical guidelines and tips for writing lay summaries. Communicating the value of the process to researchers has taken some time, but feedback from researchers has been positive. In fact, scientists on the Research Review Panel say they find the lay summaries very useful especially when reviewing proposals outside their own area of expertise.

By involving people affected by asthma, the charity considered the particular types of support; guidelines and information lay people would need to feel empowered to take an active role in reviewing lay summaries. They worked with the Alzheimer's and MS Societies to develop and deliver training on understanding the basics of research for volunteers. The training included a session on science and the media. In developing their own guidance notes for patients, Asthma UK also sought advice from a range of organisations who work in this area, including Involve, the NIHR and other charities. The guidance document they produced includes an explanation of peer review, a description of the role of a lay reviewer and a set of questions that should be considered while reviewing a lay summary. Volunteers review lay summaries in groups, thereby benefiting from peer support. Clarification on research terms can also be provided by the Asthma UK team, though the idea is for Asthma UK to get involved as little as possible.

Asthma UK is also cognisant of the level of trust the public places in the information it provides. This is particularly salient now that such a large volume of information of variable quality is available on the internet. For example, the charity is often approached by external researchers and organisations looking to involve people with asthma in their work. Each opportunity is assessed against an established set of criteria before being circulated to people affected by asthma. Asthma UK also provides patients who may wish to take part in studies with an information pack including details of what is expected from participants and a glossary of terms.

The charity is currently updating its research strategy and is keen to build evaluation and measurement of the benefits of Patient and Public Involvement in their activities.

Asthma UK recognises the particularly valuable input that people affected by a condition are bringing to the overall knowledge base of the condition:

'A lot of people think that doctors and scientists are the experts but actually people with asthma are experts themselves – they're the ones who know what it's like to live with their condition. To me, both types of knowledge are important and have equal value.'

For further information contact:

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Website: www.asthma.org.uk/

Research Strategy:

www.asthma.org.uk/researchers/our_research_strategy/index.html

Case Study 4: PLoS Medicine

Editor-authored lay summaries with every article

PLoS Medicine is a peer-reviewed, international, open-access, web-based journal publishing original research and analysis relevant to human health. The journal is produced by the Public Library of Science (PLOS), which was founded by scientists in order to provide unrestricted access to scientific research outputs. PLoS journals have, as one of their core principles, the aim of;

'developing tools and materials to engage the interest and imagination of the public and helping non-scientists to understand and enjoy scientific discoveries and the scientific process'.

To this end, some PLoS journals provide lay summaries alongside research articles. PLoS Medicine includes a lay summary embedded within every research article they publish. Following article acceptance for publication, summaries are written by the journal's staff and freelance editors and are pitched at a level that the general public, with no medical or biomedical background, can understand.

This type of information would clearly be useful to someone with no subject knowledge or expertise, giving them an overview of how a piece of research fits into the field. Equally, lay summaries can be useful to a scientist who does have knowledge of the field, but wants to assess quickly whether an article is one they would like to read in more detail.

Even professional editors, who have experience in writing for a variety of audiences, admit that it can be challenging to write lay summaries well. A set of internal style guides helps to ensure consistency in structure and language. These guides consist of broad headings (background, rationale for undertaking the research, research findings and the importance of the results in a wider context) that provide a framework for the information that needs to

be included and a list of 'Do's and Don'ts'. Editors also include links to further information including patient stories that might be useful to the reader. The summary and links are included in the copy-edited version of the article, sometimes with a set of questions for clarification which is sent back to authors for sign-off. This process gives researchers the opportunity to check summaries, comment on the information and add links to other websites and resources. For the most part, researchers do not change the content of the lay summaries substantively. PLoS Medicine has not yet actively promoted or marketed their journal to non-professionals or highlighted the lay summaries to a wider readership. Making patients and the public aware of these summaries is therefore something they could consider in the future.

PLoS Medicine is a highly selective journal, publishing a small number of high quality research articles within the journal's scope, allowing their editors to feasibly write a summary for every research article. Writing them takes time and skill and so scaling up these efforts is not possible for journals publishing larger numbers of papers (for example PLoS ONE publishes about 1000 articles a month). Other PLoS journals therefore take a different approach; they ask researchers to author summaries aimed at a broader scientifically literate audience when submitting their papers. These summaries tend to be a little more technical in language and so are less accessible for the general public. While this model does allow a higher volume of summaries to be written, their usefulness to a lay audience may be reduced.

PLoS is an innovative publisher, pushing traditional boundaries and pioneering new approaches to communicating science. It has experimented with rapid publication platforms in 'PLoS Currents' and novel online tools in all their journals. Such tools allow users to engage with the information in new ways - adding ratings, notes, links, and threaded discussions to articles. It also provides readers with a set of guidelines on good practice for this kind of on-line activity. Despite the availability of these tools, readers do not utilise them routinely. It would be interesting to understand the reasons that researchers and the public do not engage in a two-way communication process offered by these technologies.

It is clear that the best way to achieve the mass production of lay summaries has not yet been worked out, and is a challenge facing publishers too:

'I would love to see lay summaries with all research articles and scientists interacting more with the lay public. I think the scale of the task is one of the biggest issues facing us in this area.'

For further information contact:

Melissa Norton, mnorton@plos.org

Website: <http://www.plosmedicine.org/home.action>

Guidelines for comments:

<http://www.plosmedicine.org/static/commentGuidelines.action>

Case Study 5: EuroStemCell

A public website emerging from scientific collaboration

Stem cell research and regenerative medicine are complex cutting-edge areas of science generating a great deal of public interest. The eurostemcell.org website aims to help

European citizens make sense of stem cells, by providing a central multilingual resource of reliable, independent information and educational resources on stem cells and their impact on society. The project emerged from a scientific research project on stem cells funded through an EU Framework 6 grant. In this original project, the outreach component comprised a small element but it was so successful, that the project partners continued the outreach and communications work beyond the end of the project by funding maintenance of the web site through other projects they were involved with.

Further funding for a large-scale 4-year project was obtained through an EU Framework 7 programme grant with a dedicated focus on engaging the public with stem cell science, using the website as a hub. The project continues to have the support of scientists; it brings together more than 90 European stem cell and regenerative medicine research labs from 12 contributing partner organisations. The experiences of the original project members formed the basis of the project strategy which was developed through formal testing with key audiences and feedback and enquiries received via the website.

A team of six people developed the website, to provide information and educational tools, including short films, interviews, frequently asked questions, news pieces, fact sheets and teaching materials. They come from a range of backgrounds including scientific research, education, business, social science and professional science communication. This core team works closely with researchers, ethicists and clinicians from the 12 project partners and beyond, and considers the input of scientists essential to all aspects of the project, providing the team with expert knowledge about the latest scientific developments and the key issues in the field. Written materials for the website are developed with the researchers, who draft content for editing and adaptation for lay audiences before final review by a second researcher. This editorial process ensures that all content on the website has an expert stamp of approval. In general, feedback from researchers who write for the website or deliver engagement activities using EuroStemCel tools has been positive - researchers report that it is a valuable and enjoyable experience. However, the demands on their time can be an issue for the team, as most researchers are time poor.

The project team aimed to embed reflection and evaluation into the project from the outset and have a dedicated evaluation component, led by a social scientist with a background in public engagement with stem cell research. All resources and activities are piloted and then evaluated with audiences on an on-going basis. A formal evaluation of the website through an online survey and a series of telephone interviews has just been completed. Scientists interviewed said they consider the information to be accurate, clear and reliable and educators using the teaching materials have indicated that they find them useful. The evaluation demonstrated a clear need for multilingual materials. From the outset, the project planned to translate the website and the educational materials into 10 languages, and the availability of accurate information and educational materials in local languages is likely to be one of the central positive outcomes of this project.

The feedback gathered will be used to inform the future direction of the project and one of the key challenges facing the team will be to increase the visibility of these resources. Another important outcome has been feedback obtained from patients on how to better cater for their needs. The project had plans to develop new, dedicated materials for patients but had focussed in its first year on educational materials for other groups and had yet to actively involve patients in its work. The evaluation, in combination with ongoing consultation with patient groups, will now help guide plans for patient resources. Although patient involvement in the project has been limited to date, the project members are keen for this to increase and are planning to approach patient groups more actively for input and

feedback on website content. Plans include new patient-oriented material for the website, such as disease-specific factsheets and clinical trials information. The project also hopes to develop a tool for face-to-face engagement between scientists and patients, with a particular focus on stem cell research in neurological diseases.

The current funding for the project will end in 2014; demonstrating the benefit to patients, the public and researchers will be vital in securing the projects future. Early feedback has been positive and a range of new opportunities for collaborations across the EU have arisen. The team is pragmatic about what they can do with their current resources and while they are enthusiastic about pursuing new opportunities, this must be carefully balanced with delivery of the project's key priorities.

The EuroStemCell team is aware of the importance of continually evaluating their service and approach:

'Never become complacent - it is easy to lose your own sensitivity to jargon when you work in a particular area for a while, even as a lay person. Keep going back to the audience and to your goals.'

For further information contact:

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Website: www.eurostemcell.org

Case Study 6: CRUK Wikipedia Project

Embracing existing crowd-sourced health information resources

One of the central aims of Cancer Research UK is to provide the public with reliable high-quality information about cancer. Like many other charities, Cancer Research UK has embraced new technologies such as online forums, Facebook, Twitter and blogs as routes to communicate and engage with patients and the public. Cancer Research UK communications are driven by a dedicated department comprising several units with different functions, including the science communication, news and multimedia and patient-, health- and statistical- information teams.

Although many organisations, like Cancer Research UK, play an important role in providing specific information, the information landscape is becoming dominated by a small number of key players. Increasingly, Wikipedia the online encyclopedia website, features at the top of results when doing a Google search. Wikipedia works on a model of crowd-sourcing its content – anyone can sign up to create and edit pages. This model works on the assumption that most users can be trusted and that the community will work to filter out incorrect or conflicting information.

Many organisations might be wary about taking on the vast task of editing the information contained on Wikipedia, since finding the resources, while also maintaining their own communication and information channels, is a challenge. In addition, the information on Wikipedia is dynamic and although large volumes of information can be created quickly, issues of trust and ownership arise since, no one person or organization has ownership, and no-one can 'sign off' a final version.

Until recently, Cancer Research UK had only peripheral interaction with Wikipedia but a project in the US inspired them to explore this possibility. The National Institutes of Health worked with Wikipedia to teach scientists how to edit pages relating to their science to improve the quality of the information provided, a so called 'Wiki Academy'. Cancer Research UK contacted the UK branch of Wikipedia to arrange a similar in-house training session, thus initiating the first UK 'Wiki Academy'. Participants learnt about social etiquette amongst editors, how to engage with other users and the practicalities of creating and editing pages.

This development represents an exciting new departure for charity communications and has received a high level of media interest, including a leader and a full-page article in The Times. Some of the coverage in the press was slightly misleading however; intimating that Cancer Research UK was about to quality-assure cancer-related information on Wikipedia. This misunderstanding highlights potential issues for charities who want to engage with Wikipedia and communicate their activities on the site while being clear that they are not responsible for all of the related information and cannot guarantee its reliability.

Having learned how to create Wikipedia pages, a small group of Cancer Research UK communications staff volunteered to contribute in their spare time. Having staff from the various communication sections represented in the group, means that the editorial process benefits from different perspectives and expertise of the individuals involved. When publishing a scientific news story, blog post or press release, this team now tries to find time to check and edit the appropriate Wikipedia pages, before linking to them.

The Cancer Research UK group has been careful not to contravene any Wikipedia etiquette. For example, the Wikipedia community frowns upon organisations linking out to their own websites too frequently, as this can sometimes be an attempt to improve a site's Google rankings. So far, most of Cancer Research UK's efforts appear to have been accepted by the wider Wikipedia community; the next step will be trying to develop some sort of metric or analysis of how effective this work has been. As a charity that must be prudent with its resources, Cancer Research UK has to consider the impact of its engagement with Wikipedia, the level of resource that should be devoted to this initiative and how to integrate it with existing activities.

In the same way that Cancer Research UK was inspired by hearing about the NIH initiative, so, their work has begun to inspire others:

'The Wellcome Trust, Medical Research Council and others are currently looking into hosting their own 'Wiki Academies'. It feels like there is a ground swell of interest in engaging with Wikipedia and I would like to see organisations such as charities and funders coming together to share resources and work together'

For further information contact:

Henry Scowcroft, Henry.Scowcroft@cancer.org.uk

Wikipedia: http://en.wikipedia.org/wiki/Main_Page

CRUK created page: http://en.wikipedia.org/wiki/Cervical_screening

Key findings

The Patients Participate! workshop participants produced a set of recommendations on how best to enhance the communication of biomedical research. These were further explored through the case studies, demonstrating that where patients and the public have been involved in the research process, a number of positive outcomes have been observed. Patients themselves find the experience to be rewarding and charities benefit from their unique and valuable perspectives and their experiences.

If patient involvement is to increase, biomedical research needs to be made more accessible alongside more extensive production of easy-to-understand, plain English information relating to biomedical research.

This was expressed as the desire to have: **'A lay summary with every UKPMC article'**

In order to achieve this goal there is a clear need for further action, including the need to;

1. Share learning across organisations on the best approaches to producing lay information relating to conditions, treatments and the latest scientific research findings, including mechanisms to;
 - **Share guidelines, structures and standards** for producing lay summaries
 - **Develop methods to evaluate** lay summaries
 - **Involve patients, the public and researchers** in the process
 - **Improve visibility of existing lay summaries**, and link to research articles
2. Explore of the best **online mechanisms to deliver lay information** relating to biomedical research to patients and the public. These could include use of existing platforms, websites and social media or purpose built technologies and tools. If quality of communications are to be maintained, on-going feedback will be essential. It would be interesting to look at the reasons why existing on-line feedback mechanisms are not being used.
3. Investigate the resource implications and sustainability. Biomedical research funders' and publishers' support in producing lay summaries of biomedical research will be key to achieving the goal.

Definitions

Patient is used in this report to describe any individual who has an interest in a disease-condition from a personal perspective; they may also be carers, parents, advocates, survivors etc. This is to differentiate them from the general public who may have an awareness of a given condition, but not personal experience of it and its impact. Definition from the AMRC Natural Ground Report.

Patient and public Involvement 'An active partnership between the public and researchers in the research process, rather than the use of people as the 'subjects' of research. Active involvement may take the form of consultation, collaboration or user control. Many people define public involvement in research as doing research 'with' or 'by' the public, rather than 'to', 'about' or 'for' the public.' Definition from the National advisory group, INVOLVE.