Natural Ground
Paths to patient and public involvement for medical research charities

OCTOBER 2009
The Association of Medical Research Charities (AMRC) is a membership organisation of the leading medical and health research charities in the UK. Working with our member charities and partners, we aim to support the sector’s effectiveness and advance medical research by developing best practice, providing information and guidance, improving public dialogue about research and science, and influencing government.

Established in 1987, AMRC now has 120 member charities that contributed approximately £935 million\(^1\) to research in 2008-09, aimed at tackling diseases such as heart disease, cancer and diabetes, as well as rarer conditions like cystic fibrosis and motor neurone disease. Over the past six years AMRC charities have spent approximately £4 billion on research in the UK, contributing significantly to our knowledge and understanding in the life sciences, medicine and health.

\(^{1}\) Based on AMRC subscription data collected 2008-09
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It should be no surprise - given their often natural and unique relationship with patients and the public - that many medical research charities are developing models of patient and public involvement (PPI) as an integral part of the way in which they allocate funds to medical and health research.

A significant number of AMRC’s 120 members already involve patients and the public extensively - in setting their research strategy and priorities, as part of the peer review process for deciding what research to fund, and in communicating the results of this work more widely. Some involve patients and the public at some point in this cycle but not throughout.

But for many others, PPI represents uncharted territory. These charities are not just seeking to identify the most appropriate model of involvement for the type of research they fund and the patient group they serve, but to better understand the potential benefits as well as practical implications.

AMRC established our ‘Natural Ground’ project on PPI two years ago with this diversity within the sector very much in mind. Our intent was to provide member charities and others with an honest appraisal of the challenges and opportunities, examples of best practice, and a presentation of the different approaches that might be adopted. We hope that the reader will feel we have succeeded in these endeavours.

An important operating principle of Natural Ground was that it should be led by our members, in this case, the ten charities that met regularly as a ‘learning set’ to share experience and opinions. These organisations encompassed a diverse collection of views - from PPI sceptics to avowed champions – and the account you will read in the following pages is richer, more authentic and more credible because of this mix. We thank them for their active contribution and hope we have done justice not just to their collective voice but to the individual perspectives shared so willingly with us.

‘Natural Ground – paths to patient and public involvement for medical research charities’ is the first report to pull together the insights of those exploring PPI in charities. In keeping with the intent and style of the work leading up to it, the report has just one recommendation: that all members of AMRC should actively consider the evidence and insights in this report, what it means for them, and the models of involvement they might appropriately adopt as they review their research strategy and associated activities in the coming year.

We have endeavoured to facilitate this process by concluding the report with some brief discussion points for use by research staff and colleagues working for our members. As ever, AMRC is here to support our members in this dialogue and guide them through whatever process they adopt to take forward their conclusions. PPI is here to stay and medical research charities can be an important and influential voice in ensuring that it evolves in a pragmatic, practicable and meaningful fashion for scientists and patients. After all, their common ground is our natural ground.

Simon Denegri
Chief Executive
AMRC
acknowledgements

With thanks to the learning set:

Susanne Sorensen, Alzheimer’s Society; Leanne Metcalf, Asthma UK; Ivor Cook, Asthma UK; Julie Greenfield, Ataxia UK; Nigel Kilvington, Ataxia UK; Norman Freshney, Breakthrough Breast Cancer; Laura Shalev Greene, Breakthrough Breast Cancer; Caroline Sharpe, Breakthrough Breast Cancer; Catherine Foot, Cancer Research UK; Abigail Evans, Cancer Research UK; Rachel Connor, Juvenile Diabetes Research Foundation; Jo Lileystone, Juvenile Diabetes Research Foundation; Linda Glennie, Meningitis Research Foundation; Kate Rowe, Meningitis Research Foundation; Marita Pohlschmidt, Muscular Dystrophy Campaign; Helen Stockdale, Muscular Dystrophy Campaign; Michelle Bendix, Parkinson's Disease Society; Icki Iqbal, Parkinson's Disease Society; Peter Coleman, The Stroke Association; Julie Hart, The Stroke Association.

To additional speakers:

Harry Cayton, National Information Governance Board for Health and Social Care (NIGB), formerly National Director for Patients and the Public; Fergus Logan, Arthritis Research Campaign; Shirley Nurock, Alzheimer’s Society; Amarjit Kaur, Breast Cancer Care.

And to the Natural Ground working party:

Simon Denegri, AMRC Chief Executive, chair; Les Turnberg, AMRC Scientific Adviser; Bec Hanley, TwoCan Associates; Philippa Yeeles, UKCRC PPI Group; Sarah Buckland, INVOLVE.
What is PPI and why is it important now?

Patient and public involvement (PPI) is the term used to describe the process by which non-professionals are included in the decision-making processes that affect them as 'users'. The term is used synonymously with consumer involvement and service user involvement and is a growing trend within many policy areas. The public sector, particularly in health, is increasingly being mandated to incorporate involvement of the public in decision making (eg involvement in NHS foundation hospitals¹ and PPI in research networks²), which has lead many to comment that involving the patient/public voice is necessary in a modern society.

In this climate, many outside the sector assume that medical research charities, with their focus on patient and public benefit, would find it relatively straightforward to take forward this agenda. But this ignores the fact that, while charities often have a natural instinct for PPI and an innate desire to take it forward, implementation often presents considerable cultural and practical challenges. Given this context, AMRC decided that its role was not to roll-out another manifesto in support of PPI, but rather, to support and enable our members to navigate it, through the evidence and learning of their peers.

The Natural Ground project

This project began with a request for member organisations to join a learning set that would meet six times over a year to share experiences, discuss areas of concern and identify topics where they felt further work was needed. Each organisation was asked to bring a member of staff and a lay member, to ensure that a rich picture of involvement was obtained.

Ten organisations of different sizes and with varying approaches to PPI agreed to participate (many other member charities are taking PPI forward, but chose not to join the learning set for a variety of reasons). Each meeting focussed on a different area with presentations from the group and discussions of activities. In this way, members of the learning set shared their practices and described a variety of different ways of involving people in research-related decision making. All quotes and case studies are taken from these meetings.

AMRC also established a working party to, in the first instance, help guide the work programme of the learning set and then, more latterly, the format and content of this report.

About this report

This report is aimed primarily at AMRC member charities, who may be interested in understanding how other medical research charities are developing and incorporating PPI methods into their grant-giving activities. The report is arranged in sections related to areas of research funding: developing a research strategy, making funding decisions, on the research itself and in communicating research. Members of the learning set provided examples of how they have worked with patients in these different areas. By examining these, it was possible to develop some generic learning points which would be useful for any organisations thinking of involving patients or the public in these areas. More information on the learning set can be found in Appendix 1. The individual case studies are presented in Appendix 2, with contact details and links to supporting documentation.

A note on terminology

While the public sector uses the term PPI to mean patient and public involvement, members of the learning set used a wide range of terms to describe the people they involved, including advocates, consumers, survivors, carers and members. In this report, the term ‘patient’ is used to describe an individual who has an interest in a disease-condition from a personal perspective, they may also be carers, parents 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. We have used the organisation-specific term when describing involvement at one of the learning set members’ organisations.

INVOLVE, the national advisory group, funded by the National Institute for Health Research (NIHR) to support and promote active public involvement in NHS, public health and social care research defines involvement as:

‘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.’

This is the definition that members of the learning set agreed with. It was also noted that PPI can be used as a mechanism to engage with these specific stakeholder groups, and so could be seen as a type of stakeholder engagement.
All AMRC member charities have a research strategy that defines the areas of research supported, and the methods used by the charity to do this. (AMRC provides advice on our website). Research strategies also explain where a charity fits within the broader field of research funders, supporting organisations and researchers, and thus acts as a basis for developing collaborations.

In the past, good research was often judged solely on what was scientifically valid, and not necessarily linked to questions of interest to people with the condition. The PPI agenda has highlighted the importance of services, including research, being consistent with patient needs, with added impetus for this when patients are funding the research via charitable donations.

**Experience from the learning set: Case studies 1–2**

A common theme to emerge from the learning set was that because research strategies were often developed by researchers, there could be a tendency for them to focus on areas of ‘exciting science’ rather than that which mattered most to those outside the research community. However, there could be tensions between the desire to support ‘the best quality’ research and encouraging research into areas that were felt to be important by patients. A number of charities used PPI to encourage dialogue with patients and develop a strategy responsive to their needs.

Key learning points included:

- The importance of getting a clear mandate from trustees to support the incorporation of patients’ views into strategy development.

- The need to be able to reach patients in ways that facilitate their full involvement, by providing appropriate material, supporting participation and clarifying objectives.

- The importance of involving clinicians, who are not always researchers and can bring practical considerations to clinical research.

- Working with external organisations, such as the James Lind Alliance, can allow a funder to access other stakeholder groups, and use different methods to identify areas of need.

- The process of developing the strategy and what will happen next needs to be clear to all who are involved.

- It is important to consider how best to involve people – via asking opinion and collating internally, or by bringing patients, clinicians and researchers together. This will depend on a charity’s resources as well as the type of people being involved.

- Patients should have the opportunity to endorse the final version of a strategy developed with patient involvement, for example by asking the membership to approve it at an AGM, or by reporting on the process to supporters.

- The resulting strategy needs to be accessible to lay people, written in plain English and available in appropriate formats.

- The process of patient involvement can lead to the development of active patient/researcher partnerships which can work on future areas of mutual interest.


• The strategy can be used to categorise on-going and future research, and thus make research activities more real to patients and the public.

Quotes from the learning set

‘It was clear that by having researchers discuss their research areas in the context of the concerns of people with asthma, views of both people with asthma and researchers changed – people with asthma gained a clearer understanding of the topics considered, while researchers developed a clearer understanding of the relevance of these topics to people with asthma.’ Asthma UK

‘In 2004, the trustees reviewed the society’s current research strategy in the context of an increased urgency to support Parkinson’s research within the UK. A number of key recommendations were made to address the gaps that had been identified as important for people living with Parkinson’s disease. This resulted in the development of a research agenda which reflected both the members’ and research community’s views on the specific areas of Parkinson’s disease research where the society should try to focus its future spending.’ Parkinson’s Disease Society
patient and public involvement in making research funding decisions

All medical research funders need to use a transparent, independent process to decide what to support. Peer review is the system used by most funders, where ‘peers’ (experts from the same field) assess individual grant applications and provide feedback to the funder via a second group of experts (the scientific advisory panel). The latter meet in person to discuss these assessments and make recommendation to trustees on which applications to fund. AMRC member charities all operate their peer review according to a number of key principles including: accountability, balance, independence, rotation and impartiality.¹

Although this decision-making process has traditionally focused on the views of scientific experts, there has been increasing interest in including the voice of patients or carers, who not only have a direct interest in the outcomes of the research and experience of the disease, but also have views on the feasibility of undertaking research with that patient group. Indeed, a number of medical research charities that derive funding from patient groups feel that including the patient voice in funding decisions is vital to demonstrate that funds are being used on projects that will ultimately lead to improvements for patients with the condition.

Other public funders have also adopted PPI in funding decisions. The National Institute of Health Research is now committed to having members of the public on their research commissioning boards² which make funding decisions on research supported by the Department of Health within the NHS (£116 million in 2008-09).³

Experience from the learning set: Case studies 3–5

A number of members of the learning set had patients or the public involved in their research funding decision processes. For some, such as Ataxia UK, having patients on the scientific advisory committee alongside scientists worked well. Other charities, such as The Stroke Association, decided that lay members would be better served reviewing applications in parallel to the scientific review. This led to the development of a plain English summary form, which asks questions that stroke survivors feel are important. At the Alzheimer’s Society, members of the Quality Research in Dementia (QRD) Consumer Network (a panel of carers, former carers and people with dementia) comment on each application and score it based on its importance and relevance to the research priorities of the society. Only applications that qualify at this stage are then sent for scientific peer review.

Key learning points included:

- Beware of tokenism: be clear about what you hope PPI will add to your current system, as well as what patients and the public are being asked to comment on.
- Provide adequate training and mentoring and on-going support for patients, so they feel able to make a contribution.
- Consider whether the information currently provided by researchers is adequate to allow PPI members to make decisions. This may mean training researchers to write better lay summaries, or asking for additional information.

• Explain to researchers why this additional information is needed, and stress the importance of doing it well.

• Think about the best mechanism for PPI members to score applications, to ensure that the scoring system accounts for the different abilities of those participating.

• If scientific and lay reviewers are commenting on different aspects of the application, ensure that this is clear to all panel members. The chair of the peer review panel should be briefed on how to manage any confusion.

**Quotes from the learning set**

‘This triage by ‘users’ of research ensures that only research which is deemed relevant to carers and people with dementia is funded by the charity.’  
**Alzheimer’s Society**

‘Our USER committee looks at the practicality of doing research and questions the assumptions of researchers. Our patient reviewer was the only person to spot that a researcher had assumed that people would only have one artificial joint – many people with arthritis have more than one replacement joint, and so the suggested blood tests would provide unclear results.’ **Arthritis Research Campaign**
The research cycle is a term used to describe the process whereby a research project is designed, delivered, analysed, disseminated and its findings incorporated into the next piece of research. Traditionally, the only role that patients have played in this has been as the subject of the investigation. However they can play an active role in many areas. INVOLVE has worked extensively on this, providing advice and support to patients, researchers and research funding organisations on how best to support and encourage PPI throughout the research cycle.1

Experience from the learning set: Case studies 7–11

Members of the learning set provided a number of examples of how patients were involved in research activities. The common theme of these is that patients had invaluable experience of living with the relevant condition and so are able to assess the feasibility of planned projects (even those that had been successfully peer reviewed), and provide a ‘reality check’.

Key learning points included:

- Even research that has been peer reviewed and approved by research ethics committees can raise practical issues that make the project unacceptable to patients asked to participate.

- Consider what information patients and carers might need in order to comment on specific aspects of the research.

- Involving patients and the public in monitoring research can be beneficial for researchers as it allows them to have a deeper understanding of the condition under study.

- PPI within committees (such as trial steering committees) requires chairs to support lay members to encourage active participation.

Quotes from the learning set

‘A network of Experimental Cancer Medicine Centres (ECMCs), jointly funded by Cancer Research UK and the devolved Departments of Health, has been established across the UK to drive the discovery, development and testing of biomarkers and new anti-cancer treatments. ECMCs involve patients and carers in early phase trial research through a range of activities. Examples of how ECMCs have benefited from patient and public involvement include the contribution of a local consumer group to the shaping of a phase II trial for haematological malignancies. Another ECMC has involved patients in the drafting of a patient information leaflet on early phase clinical trials for display in the oncology outpatients department.’ Cancer Research UK

1 INVOLVE, http://www.invo.org.uk/
Given that patients and the public are becoming increasingly involved in research, many funders are now grappling with ways of making information about the research they fund accessible to lay people. Traditionally, research grant applications contained a lay summary or abstract, which is meant to allow a non-expert to understand why the research is being suggested, what researchers aim to achieve and how this may impact on the rest of the research community. However, many funders have found that researchers provided insufficiently clear information, and despite requests to simplify it, researchers often continued to provide summaries that were impenetrable to patients and the public.

Experience from the learning set: Case studies 12–15

Members of the learning set approached the communication of research to lay audiences in a variety of ways depending on the needs of their audience. For some, this was a long-standing activity that the organisation felt should be carried out by experts in communication, for example, Cancer Research UK has a specialist team, CancerHelp UK, who develop lay summaries of clinical research for the public. Other members, such as Arthritis Research Campaign and The Stroke Association, required researchers to write plain English/lay accessible summaries of their research in order to help lay reviewers make funding decisions. Muscular Dystrophy Campaign developed a research communications group to act as an educational steer for their communications staff, ensuring the information provided is appropriate and useful.

Key learning points included:

- The method used to develop plain English versions of research will depend on the organisation, its resources and the perceived need for the information.
- Information provided to lay members should be relevant to their needs and to the task they are being asked to do.
- Different groups of lay people will require information in different formats or even different information – it is vital that participants are involved in the process of deciding what information is relevant to them and how it should be presented.
- Researchers need to be assured that providing a truly lay abstract will not mean their application is marked down by scientific peer reviewers as being unscientific.
- Providing more detailed lay-friendly information was a culture change for researchers. They require guidance on what information should be provided and clarity on what will happen if they do not comply.

Quotes from the learning set

‘Researchers are now obliged to write a decent lay summary. It is driving home to them that the voluntary sector is changing, and that people affected by a condition are having more say in research.’ The Stroke Association, cited in TwoCan Associates, 2008.¹

‘A lay summary has been part of our grant application for a long time. However, the word “lay” in this context is very often a matter of definition and it in our experience the summaries can be very hard to understand. Bringing our families closer to the research we fund and the process by which research is funded is right and timely and works both ways – by also bringing the scientists closer to the public.’ Muscular Dystrophy Campaign

For many government funders in health and social care, patient and public involvement (PPI) is a valuable mechanism for ensuring that services are ‘fit for purpose’ and responsive to their recipients needs. There is a strong case that PPI makes for better medical research, as it allows those with direct experience of a condition to be involved in deciding the most useful strategies to understand and tackle it.

While some charities agree with this philosophical point, and have adopted this way of working, they are also keen to evaluate the effectiveness of PPI as a way to ensure that publicly donated funds really are being used in the most effective way. The UK Clinical Research Collaboration (UKCRC) has recently evaluated the use of PPI within its advisory groups and found that while, in many ways, it has been a successful process, with well supported lay members whose input was valued, it was hard to measure the impact of this involvement. The report recommends that wherever PPI is used, its purpose should be defined to allow its impact to be identified.\(^1\) Another report examining the impact of public involvement on research has highlighted that while there is evidence that involvement can improve the design of, and recruitment into, clinical trials, the lack of robust ways to assess impact means that the evidence of other benefits is not yet clear.\(^2\)

**Experience from the learning set: Case study 16**

Members of the learning set recognised that there was little academic literature evaluating PPI in research funding. Many charities that had developed a PPI ‘aspect’ to their research funding systems had included on-going internal evaluation of its efficacy, but it was unclear how this information could be added to the evidence base.

The Alzheimer’s Society has evaluated its Quality Research in Dementia (QRD) programme in two ways. First, by looking at the research that has been funded during the programme and comparing it with the research portfolio prior to 2000, they showed that they now fund treatment research which had not been funded previously and they have stopped funding service evaluation studies. A second longer-term project is looking at the influence of the QRD programme on members of the panels (both scientific and lay). An early observation is that the ability of researchers to communicate about science has been enhanced.

**Key learning points included:**

- Evaluation of PPI activities needs to be planned as part of their development and roll-out.
- Providing evidence of the efficacy of the process can be helpful in encouraging researchers, particularly at the basic ‘end’, to engage with charities’ requirements for them to outline how their research will link with patient benefit.
- Evaluations show that PPI can also have beneficial effects on the lay members who participate.
- PPI is a relatively new initiative, so lack of evidence of efficacy does not mean it does not work.

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It may not be possible to prove, in empirical terms, the outcomes and benefits of PPI in research. Those who involve patients need to be bold in communicating why they do it, and how it fulfils their charitable objectives and activities. This offers a different type of evidence in support of PPI and will build an alternative evidence base for its value and application.

**Quote from the learning set**

‘Applicants have slightly simplified their presentations at the interview stage because of consumer involvement. This has meant that these presentations are also easier for the scientists on the panel to understand, as they are unlikely to be specialist in the particular field that the applicant is working in.’ Alzheimer’s Society
how to make it work

Much of the time in learning set meetings focused on the importance of developing ‘meaningful’ PPI. While there was much that could be learned from other medical research charities, it was vital for each organisation to understand what value the PPI activity would add to their own organisation, how it would fit with existing activities and whether it was something that their patients were interested in or able to undertake.

Training to support patients or the public undertaking this role was felt to be vital. We have summarised some of the various resources and links that are available for this in Appendix 3. As organisations such as the National Institute for Health Research (NIHR) continue to involve patients and the public in research, the availability of such training should increase.

Experience from the learning set

Examining the different activities seen within the learning set, it was clear that PPI was not something that could be taken ‘off the shelf’. Perhaps unsurprisingly, organisations and individuals found it most rewarding when the activity fitted with the needs of the organisation, and was allowed to develop in ways that respected the views of all participants. It became clear that charities where PPI was successful were those that found ways to understand how individuals wished to be involved, the appropriate mechanisms of doing so and matching these roles to the needs of the organisation.

Key learning points included:

- Do not assume that everyone will want to help in the same way – provide patients and the public with a variety of opportunities to allow inclusion.
- Patient populations include people with diverse mental and physical issues, which can make engagement more challenging for them. Working with hard to reach groups is a problem for all those interested in involving patients, but it is important to be aware that your PPI may be missing some voices.
- Develop links with other organisations that are working with a particular patient group, or using similar techniques, in order to share experiences.
- Many charities are already interacting with patients and lay members; including PPI in research can be seen as an extension of these activities.

Quotes from the learning set

‘Our organisation already works extensively with families affected by meningitis in fundraising and communications, but this had not been expanded into the research funding area. We are now extending the opportunities for people to be involved in the research process by arranging monitoring visits. In this way, we can expand our PPI activities.’ Meningitis Research Foundation

‘Asthma UK recognised that there were a number of ways in which people affected by asthma might like to be involved in its research activities. So, before deciding what opportunities we were going to offer, we asked a large group of people affected by asthma exactly how they wanted to be involved in research and the support they would need in order to do that effectively. By collecting this information, we have ensured we are catering to a wide variety of needs and that we are also involving people affected by asthma in the ways that they want to be involved, and supporting them appropriately, in order to maximise the benefits of PPI.’ Asthma UK
The medical research charity sector in the UK covers a broad range of organisations, with varying relations with patient groups. Thus, in developing this report, it has been clear that any conclusions would have to be broad. This is not an area where one-size fits all, and thus policy and practice must reflect the reality of meaningfully engaging with patients and public to increase the quality and relevance of research funded by an individual charity.

Having said that, there are a number of conclusions that we can reach:

• Medical research charities have a strong connection with patients and are in a unique position to develop PPI in ways that are meaningful and not tokenistic.

• PPI is now an area of real interest in the research community. There is growing evidence that it allows researchers to get closer to patients and to also develop significant conversations about living with medical conditions in ways which can lead to new areas of patient-focused research being carried out (eg assessment of breathing exercises in asthma).

• The diversity of funders, even within the charity sector, inevitably means that different drivers lie behind the adoption of PPI by different organisations. The key is that funders are clear about why they are doing it, with what aim, and that they have set appropriate expectations with patients, the public and researchers as well as other partners – both internal and external.

• As with all other aspects of their work, charities will want to ensure that PPI has clear and measurable outputs which they can link back to their aims for delivering public benefit.

• In adopting the right model of involvement for their organisation, charities must think carefully about the particular needs of their patient group. For instance, people with rapid-onset conditions and/or those that lead to decreasing mental capacity will require particular assistance and support to be able to participate. The mechanisms by which they are involved may also need to be more flexible to accommodate their needs.

• To be successful, patient and public involvement must be built-in rather than bolted-on to how a charity thinks and works. Organisations should take time to explore and identify models of PPI which best suit them, their aims and how they operate.

• PPI can have benefits for all, but partners may need to be persuaded. Not everyone will buy-in at the beginning and the anticipated benefits and processes will need to be spelt out. For researchers, PPI can be perceived as an additional burden until they see for themselves the benefits of working more closely with patients; using positive examples from other fields can help to win the battle.

• PPI is here to stay; it is vital that any organisation using it collects information about its impact, both for good practice and to contribute to the wider knowledge-base. Building this evidence will continue to be important in making the case for PPI with those organisations who are cautious about whether PPI can increase the quality of research by making it more responsive to patient needs.

Effective implementation of PPI requires leadership from the top of the organisation coupled with an ongoing commitment of appropriate resources and a willingness to be innovative, flexible and creative.
In keeping with our role as an organisation that seeks to support its members on an ongoing basis and as their needs change, AMRC intends to follow up Natural Ground in a number of ways. First, we will be looking to add to the resources and help listed in the appendices, making it accessible through our website. Second, we will be holding a developmental workshop for members in 2010 where they will be able to discuss the report and its insights in more detail with their peers. Third, our learning set plans to continue to meet on a regular basis and will be opening-up these meetings to staff from other interested charities. And finally, in our peer review audit of members next year, we will begin tracking more formally the different ways in which PPI is being taken forward by them. Through this process of support, monitoring and evaluation our aim is not only to build on our understanding of what is happening in PPI, but to strengthen and improve good practice across the sector.
AMRC recommends that all its member charities actively consider the narrative on PPI contained within this report, what it means for them and the possible models of involvement that they might adopt as they review their research strategy and associated activities in the coming year.

In reviewing the report and identifying a potential role for PPI in their funding activities, members may find it helpful to explore the following discussion points with colleagues from across their organisation. We would recommend that this discussion be led by the research director or equivalent within the charity in the first instance:

**What are the opportunities and challenges of involvement in research?**

Looking at the case studies and learning points in this report, what do you see as being the main challenges and opportunities for you as an organisation in taking forward PPI? What does this ‘scorecard’ look like to you and your colleagues?

**How do you currently involve patients and the public?**

What has been your charity’s approach to involving patients and the public in research up to now? And if not in research, what about in the other activities of your organisation? Are there models and experience which might help inform how you would take PPI forward in research? Are beneficiaries and supporters of your charity interested in becoming more involved?

**Where could involvement have the greatest impact?**

This report looks at PPI at different points in the research cycle – from developing a research strategy to providing information and in respect of different types of research. Where could PPI make the greatest difference to what your charity does in respect of these activities?

**What do your other stakeholders think?**

How do your other internal and external stakeholders view the issue of public and patient involvement in research? If you were to begin tackling PPI, where would the leadership for it come from within your organisation?

**What are the resource implications for you?**

What would it require for you and other colleagues to support public and patient involvement in research, including ongoing training and support needs?

**What are you going to do next?**

Is it worth proposing that your charity’s approach to PPI be considered at the next trustee meeting or away day or your AGM – somewhere where your organisation can begin to distil the agenda into something meaningful for the research you fund and the patients you serve?
## Natural Ground Learning Set

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Additional speakers:

Harry Cayton, National Information Governance Board for Health and Social Care  
Fergus Logan, Arthritis Research Campaign  
Shirley Nurock, Alzheimer’s Society  
Amarjit Kaur, Breast Cancer Care

### Remit

A shared learning set that will meet regularly to share experiences of undertaking PPI in medical research funding, working under the ‘Chatham House Rule’. By sharing experiences, we aim to avoid ‘reinventing the wheel’. At each meeting, one charity will talk about what they are doing, the challenges and how they are addressing them.

### Key PPI activities of the learning set during 2008-09

**Alzheimer’s Society**

- Quality Research in Dementia (QRD) Consumer Network members make up half of the panel at the society’s grant panel meetings.

- The society is investigating how to improve training for panel members and how to maintain motivation.

- Evaluation of the QRD programme is ongoing.
Asthma UK

- Consulted with approximately 100 people affected by asthma regarding how they would like to get involved in the charity’s research activities and the support they would need in order to do that effectively.

- Piloted lay review and the facilitation of recruitment of people affected by asthma to high-quality research studies external to Asthma UK. Following the success of these pilots, both of these initiatives have been rolled out as core functions of Asthma UK’s research activities.

- Evaluated previous research lay involvement activities undertaken by the charity

- Recruited nearly 100 people affected by asthma with an interest in getting involved in research and policy-related activities (known as Asthma UK Research and Policy volunteers) – almost all of these have been involved in at least one research-related activity since they were recruited.

- In November 2008, the Council of Trustees agreed to increase lay involvement in all aspects of research. Ongoing funding has been approved to develop training and a support handbook, and for expenses for people who get involved.

- The first grant round to include lay reviewers in the triage process and on the research review panel took place from February to July 2009, following agreement from the Council of Trustees. Evaluation shows researchers, reviewers and all members of the panel are happy with the new process; 21 people affected by asthma were involved in total, with seven on the panel.

- Developed a joint training programme with the Alzheimer’s Society and MS Society on research skills for volunteers; four sessions took place across the UK during September and early October 2009.

- The charity is finalising the first version of a handbook for Research and Policy volunteers, to support them in their various activities.

Ataxia UK

- Had three lay members on their scientific advisory committee when the learning set started meeting and are now examining which areas of involvement to develop. This might include providing additional support to the lay members, for example through pre-meetings.

- The charity is considering a consultation on research priorities, using workshops and a questionnaire.

Breakthrough Breast Cancer

- Until now, Breakthrough has involved people affected by breast cancer in developing research priorities and in a large population study, for which two participant representatives now sit on the governing body. The advocates have encouraged the study team to develop mechanisms for members of the cohort to ask questions of the researchers and thus develop an on-going dialogue.

- There is interest in developing involvement in research funding decisions on large programme and unit grants.

- Breakthrough has developed a list of cancer-specific training for lay members
• There is now one lay representative on Breakthrough’s scientific advisory committee.

• Breakthrough conducts tours of their flagship research centre, providing an informal opportunity for scientists to network with Breakthrough’s supporters and people affected by breast cancer.

Cancer Research UK

• As a National Cancer Research Institute (NCRI) partner, Cancer Research UK is a major funder of the NCRI Clinical Studies Groups. Each group benefits from consumer representation and these members have an important role in providing the patient perspective on trial design at an early stage.

• The Consumer Liaison Group, which raises the quality and value of cancer research through consumer involvement is also supported by the same model. In addition, consumers are offered subsidised places at NCRI conferences and trial fora.

• A consumer representative attends meetings of the Clinical Trials Advisory and Awards Committee, ensuring a high standard of the review process is maintained and that consumer issues with respect to the trials are considered.

• Cancer Research UK senior research nurses are actively involved in local and national initiatives to engage and support user involvement in research activity.

• Increasing patient and public involvement in early phase research is a priority of the Experimental Cancer Medicine Centre (ECMC) Initiative and consumers are represented on both the ECMC Steering Committee and on the management boards of many of the 19 ECMCs.

• The ECMC Secretariat has encouraged and facilitated patient and public involvement in the research pathway by supporting open days, identifying interested consumers and assisting ECMCs in the set up of trial advisory groups.

• When Cancer Research UK launches the re-designed CancerHelp UK website in October 2009, it will include plain English summaries of trial results for the first time – in response to requests to do so, highlighted both via feedback to CancerHelp UK and through usability testing. People affected by cancer are becoming increasingly interested in the results of clinical trials and Cancer Research UK believes results should be available and accessible to whoever wants them.

• Recruits patients to review content on its CancerHelp UK website, ensuring that content is written in lay language and relevant passages accurately reflect the experiences of cancer patients and carers.

• Recruits patients to review the style and content of ‘patient information’ materials including leaflets, booklets and posters.

• Recruits and trains patients and carers to become Cancer Research UK Ambassadors. Their role is to meet politicians and decision-makers across the UK to lobby on cancer and patient issues.

Juvenile Diabetes Research Foundation (JDRF)

• Has a well-established system of lay involvement on peer review panel, in the USA. The recession led to the cancellation of a grant round and the restructuring of research programmes. There is now an opportunity to look at the training provided for new lay members
(currently one week in USA, shadowing an existing lay member), as well as examine how committees work (ie virtual meetings).

- JDRF is now reviewing their overarching strategy with the UK committee of eight scientists and four lay members.

**Meningitis Research Foundation**

- Activities are at an early stage, but the foundation has chosen to start by involving people in site visits.
- Volunteers were recruited through the newsletter and website with first site visits took place in spring 2009.

**Muscular Dystrophy Campaign (MDC)**

- Has now set up a research communications focus group, “Talk Research”. This consists of lay people and professionals whose remit is to comment on the information about advances in research for the MDC website and publications.
- Focus group meetings are underway, with initial feedback positive; it is now planned to expand membership of the group. Immediate plans are for the group to concentrate on how to take PPI a step further and actively involve lay people in decision-making for funding research.
- The trustees endorsed a proposal for MDC to promote lay involvement from early 2010, and the charity is currently working on implementation.

**Parkinson’s Disease Society (PDS)**

- Has a lay Research Network consisting of approximately 90 members. One of their functions is to assess research grant applications, each of which is reviewed by up to ten members of the network
- Has an annual meeting to provide training for new members and allow existing members to be updated in the primary areas of Parkinson’s research with talks from key researchers. Also provides an opportunity for members to meet, as much of their work in research grant assessment is carried out over the internet.
- Conduct very popular visits to researchers in their laboratories, to which both network and branch members are invited. This allows the lay members to meet the researchers carrying out projects, and discuss the projects that have been funded by the PDS. Members have an opportunity to ask questions about the research and how it is progressing.
- The charity is conducting a review with members, as part of the development of a new, larger, member-led network, in which lay involvement will encompass all areas of PDS research activities (including research campaigning, communications and fundraising).
- The review is also expected to highlight where PDS can improve and expand the potential of lay involvement – for example by developing role descriptions for all volunteers in the different areas in which they work, or by providing information on how research is conducted in universities and ‘who does what’.

**The Stroke Association**

- Currently has one lay member on each of the two research awards committees. For the first few rounds, each lay member collated and fed in comments from a panel of lay reviewers. This has recently been re-assessed.
There have been problems with the lay summary application forms inaccurately reflecting the project.

The Stroke Association is recruiting more people to its service users review panel, with the aim to expand the pool to 100.

Following feedback from lay reviewers on the frustrations of reviewing projects that would not get funded as they were scientifically 'weak', the association is piloting a change to their review process: the lay review stage will follow a scientific review stage, with the final funding decision equally based on rankings from the scientific and lay reviewers (a high degree of correlation is observed). The lay reviewers’ experience of the pilot will be evaluated in late 2009.

The charity has funded a UK-wide survey into the needs of people affected by stroke that will inform their corporate and research strategy.
Patient and public involvement in developing a research strategy

Case study 1

Asthma UK has been working with patients and the public over the past 5 years or so, to develop their research strategy and ensure that the research that they fund is responsive to the needs of people affected by asthma. Working with partner organisations, such as the Royal Society of Medicine (RSM) and the James Lind Alliance, Asthma UK has held a number of public engagement events, to provide fora in which patient’s concerns about their condition are given top priority. In 2004, Asthma UK was involved in the ‘Medicine and Me: Asthma’ event with the RSM. The resulting report ‘Shaping the future’ provided a snapshot of the presentations and discussions, introduced some of the priorities highlighted and outlined how Asthma UK’s research programme would meet this challenge.

Developing the revised Basic Asthma Research Strategy in 2006, Asthma UK included patient representatives on the panel for each priority area. The resulting strategy was published as a scientific and lay volume. In the lay interpretation, key research questions for each priority area were summarized.

This document was then used as the foundation of a second ‘Medicine and Me’ event in February 2007. The event featured people with asthma and researchers taking the stage together to discuss the relevance and importance of the priority areas that had been defined in the strategy. Participants were able to vote for the research areas that they felt were most important before and after the presentations.

It was clear that by having researchers discuss their research areas in the context of the concerns of people with asthma, views of both people with asthma and researchers changed – people with asthma gained a clearer understanding of the topics considered, while researchers developed a clearer understanding of the relevance of these topics to people with asthma.

Asthma UK is now working towards developing a new translational research strategy which should be in place by 2011; this will be developed with the full involvement of people affected by asthma throughout.

For further information contact: Leanne Metcalf, lmetcalf@asthma.org.uk

Website: http://www.asthma.org.uk/

Documents to download:

Medicine and Me;
Asthma Research;
Basic Asthma Research Strategy II (BARSII);
Clinical Asthma Research Strategy (CARS);

Available at http://www.asthma.org.uk/researchers/our_research_strategy/index.html
Case study 2

In 2004, the Board of Trustees of the Parkinson’s Disease Society (PDS) agreed to review the society’s current research strategy and a number of key recommendations were made. This resulted in the development of a research agenda which reflected both the members’ and research community’s views on which specific areas of Parkinson’s disease research the society should focus future spending.

Thus, the research agenda was generated following input from a variety of stakeholders, including the society’s Board of Trustees, Parkinson’s disease researchers, patients, their carers, physicians, other members of the society and PDS staff.

The research agenda helped to prioritise the society’s research programme for 2005-09. It identifies clear research priorities and outcomes and highlights the importance of an effective communication of research progress for the membership and fundraisers.

The priority research areas identified include:

• slowing or halting the progression of Parkinson’s disease
• the establishment of guidelines for the clinical management of Parkinson’s disease
• the treatment of non-motor symptoms
• evaluating the role of, and support for, carers
• evaluation of “classical” (eg physiotherapy, speech therapy) and complementary non-drug therapies
• implementing Parkinson’s disease research findings into practice

These priorities were endorsed by the members at the society’s AGM in September 2005.

For further information contact: Bunia Gorelick, bgorelick@parkinsons.org.uk
Website: http://www.parkinsons.org.uk
Patient and public involvement in making research funding decisions

Case study 3

The Alzheimer’s Society developed the Quality Research in Dementia (QRD) programme in 2000, which works with the QRD Consumer Network, a panel of 170 carers, former carers and people with dementia. Researchers are required to submit funding applications in fully accessible lay terms and to answer questions that have been set by members of the network in parallel with the full scientific protocol. Members of the network comment on each application and score it based on its importance and relevance to the research priorities of the Alzheimer’s Society.

Once members of the network have scored and commented on applications, scores are collated and applications that qualify are sent for scientific peer review. This triage by users of research ensures that only research which is deemed relevant to carers and people with dementia is funded by the charity.

Applicants that pass the consumer review and scientific peer review processes are invited to an awards panel. Each panel consists of an equal number of researchers and members of the QRD Consumer Network. The selection panel has access to the applications, referee comments, consumer comments and applicants' responses. At the panel they hear a presentation by the applicants and are able to ask questions. Following all presentations, QRD Consumer Network members participate fully in the discussions on funding decisions.

For further information contact: Susanne Sorensen, ssorensen@alzheimers.org.uk
Website: http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200296

Case study 4

The Arthritis Research Campaign (arc) has developed a Stakeholders Research Review (USER) committee with the remit to provide a user perspective on research that arc may fund. USER is chaired by arc’s medical director and comprises front-line healthcare professionals, who are not research-active, and informed lay members.

USER members are pre-circulated with a lay case for support for each application and can access the full application if they wish. USER members consider: strategic importance; potential of the research to lead to clinical benefit; issues of practicality. USER provides a brief report which is circulated to the relevant funding committee which is expected to take this into account alongside the formal peer review process.

For further information contact: Lisa Croucher, l.croucher@arc.org.uk
Website: http://www.arc-research.org.uk/med_director/stakeinputresstrat.asp
Case study 5

Ataxia UK involves patients in research by having representatives on both its scientific advisory committee and board of trustees. The scientific advisory committee consists of six scientific members, three representatives from Ataxia UK and three lay members. The lay members either themselves have ataxia, or are close family members of someone who does (currently there are two people with ataxia and the father of a child with ataxia). The board of trustees has to consist of at least a third of people with ataxia or with close links to someone with ataxia (eg parents).

Ataxia UK’s scientific advisory committee meets three times a year to discuss funding applications and advises Ataxia UK’s trustees who then make the final decision on whether to award a grant. Lay members of the scientific advisory committee are encouraged to participate in discussions on the value of the research projects to people affected by ataxia.

For further information contact: Julie Greenfield, research@ataxia.org.uk
Website: http://www.ataxia.org.uk

Case study 6

For most of its history, The Stroke Association funded research chosen solely by medical and clinical researchers. However, the arrival of a new chief executive and a refocusing of the trustee board meant the time was right to examine how stroke survivors could be included in this decision-making process.

To allow meaningful lay involvement, The Stroke Association decided to set up a service-users review process in parallel to the existing peer review process. Applicants to The Stroke Association now complete a plain English summary form, alongside a traditional research application form. The plain English summary is sent to the service user review panel, for comments. The panel is made up of 22 individuals with experience of stroke recruited via advertising in national newspapers, within The Stroke Association’s newsletter and on the INVOLVE website. Two service user representatives attend The Stroke Association’s research awards committee, where they supply the perspective of stroke survivors and have equal status to academic and clinical members of the research awards committee.

For further information contact: Peter Coleman, peter.coleman@stroke.org.uk
Website: http://www.stroke.org.uk/
Documents to download:
The Stroke Association Plain English Summary Form
Available at http://www.stroke.org.uk/research/apply_for_funding/research_project_grants/developmental.html
Involving patients and the public in the research cycle

Case study 7

As well as funding and supporting basic and clinical research related to asthma, Asthma UK is often approached to help recruit people affected by asthma to take part in research studies external to the charity. Following some focus groups and consultation with people affected by asthma, the charity was aware that once it had ‘advertised’ a research opportunity to people affected by asthma in order to encourage recruitment, they saw this as Asthma UK’s endorsement of the project. While the research team could make basic checks (for example to ensure the project had ethical approval), Asthma UK didn’t have clear guidelines on this process.

In 2007-08, Asthma UK took part in a Wellcome Trust funded project to look at how charities could assess when to tell service users about opportunities to take part in research. Working with a facilitator and three other charities, they developed new policies and procedures in collaboration with service users. Asthma UK developed a generic form for researchers to complete if they wanted help recruiting patients for their study, either in developing the protocol, commenting on the design or as participants in clinical studies. To support people affected by asthma who may wish to take up these opportunities, Asthma UK also developed guidance on what would be expected from participants, and a glossary of terms, in collaboration with service users.

All of Asthma UK’s Research and Policy volunteers are now receiving information about these opportunities in accordance with their areas of interest and any eligibility criteria set by the study organiser.

The experiences from this project and example documentation have been drawn together in TwoCan Associates, 2008.

For further information contact: Leanne Metcalf, lmetcalf@asthma.org.uk
Website: http://www.asthma.org.uk/

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Case study 8

Breakthrough Breast Cancer funds research programmes at its own research centre and satellite units and utilises PPI in some of its research management processes. Opportunities mainly exist on specific committees for ongoing projects eg two participant representatives sit on the Breakthrough Generations Study Advisory Committee and one patient representative sits on the steering group for the Breast Cancer Clinical Outcome Measures (BCCOM) Project, an audit of symptomatically detected breast cancer. Breakthrough's scientific advisory committee is attended by a lay trustee. Breakthrough is also working with partner organisations, such as the National Cancer Research Institute, to enable women with breast cancer to participate in the governance of clinical trials, via being on trial steering committees.

For further information contact: Laura Shalev Greene, laurag@breakthrough.org.uk
Website: http://breakthrough.org.uk/

Case study 9

Cancer Research UK is a partner in the UK’s Experimental Cancer Medicine Centre initiative (ECMC), which aims to bring together laboratory and clinical patient-based research to drive the development of biomarkers and new anti-cancer treatments. The initiative has funded a number of collaborations between academic and NHS institutions that will develop and undertake these studies.

As the ECMC units will be undertaking early stage clinical trials of new substances or identifying mechanisms of disease in people with cancer, Cancer Research UK feels that it is vital that people with cancer are involved in the development of clinical trials as well as the governance of the units.

For further information contact: Abigail Evans, abigail.evans@cancer.org.uk
Website: http://www.ecmcnetwork.org.uk/ecmc/consumers/
Case study 10

The Meningitis Research Foundation has recently set up a programme of site visits, where members are invited to visit the laboratories and see research funded by the charity. The idea behind this is to involve people who have been touched by meningitis in the research by the most direct means - going to see the work itself. Researchers also say that meeting people who have experienced the disease that they work on can be very inspirational and motivating. Feedback from the first visit to Imperial College London has been very positive, and more visits are planned for later in the year.

For further information contact: Kate Rowe, katheriner@meningitis.org
Website: http://www.meningitis.org/site-visits

Case study 11

The Parkinson's Disease Society (PDS) has a group of lay members who form their Research Network. The members of this panel initially assess the research grant applications from the perspective of a person living with Parkinson's disease. They subsequently act as monitors for the society, visiting the research teams to assess how the research is progressing and reporting their findings. This ongoing evaluation is useful for both the charity and the researchers, as it is often the first time those non-clinical researchers have met people living with the disease. Young researchers are encouraged to remain in this field of research as they realise that they can make a difference to the lives of people with the condition, either in the short or longer term. Members of the network find it interesting to see how the research is progressing (in part as they were involved in the assessment of the original grant application) and can see if problems have arisen that need to be addressed by the society. Most importantly, they provide input from the perspective of people living with Parkinson's disease.

With academic researchers focusing on gaining publishable outputs from research grants, it is important that they are reminded of the need for their studies to have the potential to deliver a real impact on people living with Parkinson's. The society’s monitors ensure that researchers understand the importance of the research.

For further information contact: Bunia Gorelick, bgorelick@parkinsons.org.uk
Website: http://www.parkinsons.org.uk/research/about_our_research/research_funding_process/research_network.aspx
Providing information about research to patients and the public

Case study 12

As part of the development of PPI within Arthritis Research Campaign (arc), it was recognised that the abstract provided by researchers within the traditional grant application form did not provide sufficient information for the USER committee members to allow them to make a judgement on the value of the project.

arc has thus restructured its application form, and now asks for more specific information within this section. Applicants are told that the lay case for support will be used to allow assessment of the application by representatives of the user committee, and in press releases and fundraising/marketing.

The lay case must include the objectives, background (context, research question, justification and a statement on why the research is novel) and endpoints (either direct patient benefit, or route to patient benefit) of the research. Applicants who do not provide adequate information are asked to re-submit.

For further information contact: Lisa Croucher, l.croucher@arc.org.uk
Website: [http://www.arc-research.org.uk/med_director/enhancedlaysum.asp](http://www.arc-research.org.uk/med_director/enhancedlaysum.asp)

Case study 13

CancerHelp UK is the patient information website of Cancer Research UK. The website provides an information service about cancer and cancer care which is available to all and written in a way that people can easily understand. As part of this service, the CancerHelp UK team provides summaries of on-going clinical trials and of trial results, written in plain English. They have found that clinical researchers often do not have the necessary skills to write in lay terms, and employ a team of people with defined skills and training in writing for a lay audience.

For further information contact: Liz Woolf, cancerhelpuk@cancer.org.uk
Website: [http://www.cancerhelp.org.uk/](http://www.cancerhelp.org.uk/)
Case study 14

One of the Muscular Dystrophy Campaign (MDC)’s aims is to make complex research advancements in neuromuscular conditions more accessible and understandable to families, supporters and the public. This requires the correct interpretation of scientific articles written in technical and scientific terms into a language that is easy for everybody to understand.

A couple of years ago, the charity reviewed its research communication strategy and since then has developed a diverse communication program that provides information on various levels. This includes a weekly news service on the charity’s website to provide snapshots of the latest research advances as well as the publication of a yearly research magazine with a focus on education that provides background information.

Research communications are written by staff members who have previously carried out research themselves and are knowledgeable in this area of expertise. It is a challenge to provide information at the right level and to report on those issues that are most important for families. MDC decided that this can only be achieved with the involvement of those it is intended for, and set up a communication research focus group called “Talk Research”. This group is open to anybody with an interest in research, individuals can chose the level at which they want to be involved and members of the group are regularly asked for feedback and new ideas.

The involvement of families has been a great success and the feedback is overwhelmingly positive. “Talk Research” has led to a new way of communicating research and increasing website visits. The MDC does not only write for but, more importantly, with the people who are affected by muscle disease.

For further information contact: Marita Pohlschmidt, m.pohlschmidt@muscular-dystrophy.org

Website: http://www.muscular-dystrophy.org/research/talk_research

Case study 15

When it considered redesigning the grant review processes, The Stroke Association recognised that stroke survivors and carers would require different information from that in the traditional application form. As part of the ‘Getting it Right’ project, The Stroke Association recruited six stroke survivors and carers, using their link with stroke service managers to identify individuals across the UK.

Working with members of the research department and facilitated by TwoCan Associates, they developed a list of questions that they wanted to ask researchers about their project, from the perspective of a stroke survivor. These questions were tested with other groups of stroke survivors.

in stroke clubs across the country to check that these were the ‘right’ questions – relevant and important. Conducting these feedback sessions in a supported environment allowed stroke survivors with speech and language problems to be involved, as staff were able to suggest appropriate communication devices to allow them to give their views.

The Stroke Association was concerned that if this section was incorporated into the expert form, it would look very similar to the traditional ‘abstract’ and there was a risk that researchers would not understand the importance of the information. They thus decided to have this information on a separate ‘Plain English Summary Form’ and applicants are also provided with detailed guidance on how to complete this, setting out the charity’s expectations and underlining the importance of this new process. Applicants are reminded that failure to adequately complete the form will lead to the application being automatically rejected and returned.

For further information contact: Peter Coleman, peter.coleman@stroke.org.uk

Website: [http://www.stroke.org.uk/](http://www.stroke.org.uk/)

Documents to download:
The Stroke Association Plain English Summary Form

Available at [http://www.stroke.org.uk/research/apply_for_funding/research_project_grants/developmental.html](http://www.stroke.org.uk/research/apply_for_funding/research_project_grants/developmental.html)

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Evaluation: measuring the impact of patient and public involvement in research

Case study 16

The Alzheimer’s Society has included PPI as part of its research funding processes since 2000. Although the society believes that involvement of people with Alzheimer’s disease and their carers is important, it also felt that the time was right to evaluate the Quality Research in Dementia (QRD) programme. As explained more fully below, the evaluation looked in part at the impact of being a QRD member on the people themselves – those with the disease, their carers and former carers. They found that people who are involved in QRD had also been asked to serve on research council groups, attend workshops to develop funding streams for dementia research, comment on research related issues and speak at conferences.

The Alzheimer’s Society also evaluated the type of research that the QRD programme selected. By looking at the research that has been funded during the programme and comparing it with the research portfolio prior to 2000, they showed that they now fund more treatment research than previously, for example trials of complementary therapies. They have also stopped funding service evaluation studies.

As well as evaluating the impact of PPI on the programme overall, the society is examining the influence of the QRD programme on members of the panels (both scientific and lay). By recording panel sessions and holding semi-structured interviews with panel members, this is assessing changes in the behaviour of researchers applying for funding. Early observations are that the ability of researchers to communicate about science has been enhanced. Applicants have slightly simplified their presentations because of consumer involvement. This means that they are also
easier to understand for the scientists attending the panels, who are unlikely to be specialist in the particular field where the applicant is working.

The evaluation project has also canvassed opinion from all participants on how the impact of the programme could be assessed. It has been unanimously agreed that measures such as the number of publications in high impact journals will not be sensitive to this change, so there is a challenge in developing a sensitive measure which has validity with the scientific community.

For further information contact: Susanne Sorensen, ssorensen@alzheimers.org.uk
Website: http://alzheimers.org.uk/
Links

James Lind Alliance

What is it? The James Lind Alliance aims to identify the most important gaps in knowledge about the effects of treatments, by bringing together patients and clinicians in priority setting partnerships.

How can it help? The JLA priority setting partnerships identify and prioritise unanswered questions that both parties agree are most important. This information can inform those who fund health research of what matters to patients and clinicians. Partnerships cover a variety of areas including asthma, urinary incontinence, vitiligo, prostate cancer and diabetes.

Website: http://www.lindalliance.org/index.asp

INVOLVE

What is it? INVOLVE is a national advisory group that supports and promotes active public involvement in NHS, public health and social care research

How can it help? INVOLVE has a wide range of publications that can help organisations that wish to include patients and the public’s view in their research funding process, as well as information on training, and a database of publications about the use of PPI in the research process

Website: http://www.invo.org.uk/

People in Research

What is it? A website that helps members of the public make contact with organisations that want to actively involve them in clinical research

How can it help? By adding your organisation to the website directly, you can advertise your activities and recruit potential help

Website: http://www.peopleinresearch.org/

invoNET

What is it: invoNET is a network of people working to build evidence, knowledge and learning about public involvement in NHS, public health and social care research

How can it help: invoNET houses a library of publications in the peer-reviewed and grey literature that features PPI

Website: http://www.invo.org.uk/invoNET.asp

National Centre for Involvement

What is it? The NCI supports and encourages the NHS and other organisations to involve patients and the public in health and social care decision-making

How can it help? Although focused primarily on encouraging PPI in the NHS, this website contains a lot of information on how to involve patients and the public in different scenarios

Website: http://www.nhscentreforinvolvement.nhs.uk/
Resources

This section contains a summary of material (available in October 2009) which can be useful if you are implementing PPI in research.

Courses


Training material

PPI Induction day: programme & support materials. Stroke Association, contact Peter Coleman Peter.Coleman@stroke.org.uk

Manual and training material. Parkinson’s Disease Society, contact Michelle Bendix mbendix@parkinsons.org.uk

Workshop: bench to bedside. Breakthrough Breast Cancer, contact Laura Shalev Greene laurag@breakthrough.org.uk


Supporting Documentation

Manual for users. Epilepsy Action, contact Margaret Rawnsley mrawnsley@epilepsy.org.uk

QRD consumer network handbook. Alzheimer’s Society, contact Susanne Sorensen ssorensen@alzheimers.org.uk


Service user review panel research application comment sheet. Stroke Association, contact Peter Coleman Peter.Coleman@stroke.org.uk

Getting it right for service users and carers, getting it right for research: How to decide whether to help researchers find people to take part in research. TwoCan Associates, available at http://www.twocanassociates.co.uk/pubs.htm

