

Charities Research Involvement Group

How does involvement in research add value for charities?

Introduction

Many individuals and organisations know that patient and public involvement (PPI) in research studies adds value – to the research, to the organisation and its staff, and to the people who get involved. An increasing number of charities are now investing to support involvement in research. But what is the evidence that this adds value for charities themselves, rather than just for the research they support? This paper aims to address this question – one which is likely to become increasingly important, as the financial pressures on charities grow as a result of COVID-19.

Method

We used PubMed (an online search engine for abstracts and papers) to briefly review some published work in this area. Some of the papers we found identified a range of themes to describe how involvement in research adds value for charities (see themes 1 – 9 of 10 below).

We then searched the websites of member charities of the [Charities Research Involvement Group](#) (CRIG) for any examples of how involvement adds value within their context. We found some examples on members' websites. Some of these examples fit with themes found in our literature search, and others did not. We created one additional theme (theme 10 below) to describe these additional examples.

We presented an initial report to the CRIG. We sought case studies from CRIG members about how involvement has added value for their charity. A total of 40 case studies were shared. Some of these have been included as case studies in this report. All are included in a version of this report that is for CRIG members only.

Findings

Our findings can be grouped into ten themes, as listed below.

1. Involvement informs research strategy and research priority setting

A number of member charities have run one or more James Lind Alliance (JLA) Priority Setting Partnerships (PSP). This initiative was established to bring patients, carers and clinicians together to determine research priorities and questions which are of importance. The JLA PSP process is considered by many as the 'gold-standard' for involving patients, carers and the public in research priority setting.

The Cystic Fibrosis Trust, when discussing their PSP stated, "*the **community had some very strong views, which were different from health professionals!** We are delighted that this list [of questions] has been adopted by some...*"

Many charities who have led a PSP have been able to use the priorities to inform their research strategies. Marie Curie acknowledged the value of their PSP and how: "...members of the group helped to **identify key priorities** for palliative and end of life care research

*funding. These **questions now form a vital part of our charity's overall research strategy***".

When developing their research strategy, the MS Society chose to focus on the top few priorities from their PSP where they felt they could "*make the most difference - the fastest*".¹ They also felt that that PSP process gave them "*justification to prioritise and rationalise with the research community because **people with MS have told us what they want us to do***".¹

Many CRIG member charities that have not taken part in PSPs have nevertheless involved patients and carers in the development of a research strategy in other ways. They report finding that this gave added credibility and accountability to the strategy, and that the final strategy placed an emphasis on areas that were most important to patients and carers.

Case study: Blood Cancer UK

Blood Cancer UK's primary focus is to beat blood cancer, through the funding of blood cancer research. A key part of the research strategy setting process involved getting the views of patients and carers, to understand where they would like to see blood cancer funding focused.

Blood Cancer UK invited people affected by blood cancer to join a 'Research Strategy Patient Panel'. All Patient Panel members took part in one-to-one conversations with research strategy team members. Themes from these conversations were discussed further in a group/ workshop format, in order to prioritise these themes. This process was incredibly valuable in helping Blood Cancer UK further understand where those directly affected by blood cancer would like to see research funding focused. This will help inform the charity's research strategy and investment decisions moving forward. Findings have also been shared across the organisation, to continue to highlight the areas which are most important for patients.

2. Involvement ensures more relevant funding decisions are made

Through our literature search we found that involvement improves the quality of research and ensures charities make more relevant funding decisions.^{2,3} It also ensures that the research which is funded is of importance to the communities affected.⁴ These findings were echoed on member websites. For example, Asthma UK and the British Lung Foundation explain how "*...without their [people with asthma at all stages] input, we wouldn't have the **confidence that we're funding research that will make a difference to lives of people with Asthma***".

Likewise, Bliss UK explain that by working with those affected by a baby being born premature or sick they make sure that "*...research is **looking at things the public feel are important***". Versus Arthritis similarly describe how involvement in critiquing funding applications guarantees that the projects which are ultimately funded are "*...**most relevant to people with arthritis***".

Many more examples of how involvement enables charities to make relevant funding decisions were given on CRIG members' websites and shared by CRIG members as case studies.

Case study: Pancreatic Cancer UK

Pancreatic Cancer UK now has involvement embedded in the review processes for all of its funding schemes and uses every opportunity to gain insight from people with lived experience to help ensure that the research funded has maximum impact on patients. During 2019, Pancreatic Cancer UK had two funding calls, the Future Leaders Academy and the Clinical Pioneer Awards. For the Future Leaders Academy, members of the Research Involvement Network (a network of people affected by pancreatic cancer who want to be involved in research) were invited to take part in the external peer review process for the first time. People with lived experience of the disease also played a key part in making the final recommendations for funding for both schemes as part of the Scientific Advisory Board (SAB) and grant review panel, which are both made up of a mix of technical and lay members.

Funding in pancreatic cancer is limited. It is therefore even more important that the investments made have maximum impact. PPI has added value to the process by:

- Lay reviewers making recommendations and giving feedback to awardees in order to help shape the research projects to make them more effective and centred around the needs of patients.
- Helping the SAB and review panels to see people affected by pancreatic cancer as equals, resulting in them pushing for stronger commitments to PPI from applicants.
- Increasing engagement and understanding from supporters about how the charity goes about funding research, and about new and upcoming research in pancreatic cancer.

3. Involvement aids transparency and accountability

We also found, in the literature, that involvement aids the transparency and credibility of decisions that are made within the charity.^{3,4,5} It helps to provide congruency between real and stated aims.⁶ In the Alzheimer's Society 2018 report on Impact of their Research Network they describe how the Network provides accountability. The same report details how involvement "...**adds to the depth of information available to inform decisions**".⁷

Case study: MS Society

The MS Society has a Research Strategy Committee, which reviews how the Society's research programme is progressing and plans what the next research strategy should look like. The Committee has one person who is personally affected by MS as co-chair, and two more people affected by MS as members. They bring a unique perspective on how the research programme is serving the MS community and ensure that the charity's research is relevant and of a high quality.

This involvement has added a layer of accountability to the charity's research programme and embeds real-life experiences in the Committee's decisions.

4. Involvement allows for increased recognition of the charity

Increased recognition of the charity, as a result of involvement, was another of our findings which was highlighted on the Alzheimer's Society website. It states how "...*the Research Network **boosts the Society's reputation** for funding research that is relevant to, and supported by, people affected by dementia*". On an international scale, the website details how a charity in Norway looked to the UK to "...*find inspiration and advice on how to work with PPI*".

Some charities also felt that the JLA PSP they led was an important factor in increasing their visibility and credibility, with one PSP Lead reporting that it had helped their charity to "**establish ourselves, we're now the UK's X charity now**".¹ They cited their JLA PSP as one of the factors that supported that: "**we've started talking with confidence as well, which comes from having the authority, knowing that you're speaking to people's priorities**".¹

Case study: Parkinson's UK

Parkinson's UK is a partner in the €7million [Innovative Medicines Initiative](#) research project PD-MitoQUANT. The project brings together academic experts, businesses and pharmaceutical companies to investigate the role of mitochondria in Parkinson's. Parkinson's UK wanted to involve people affected by Parkinson's to help shape the communication and dissemination of project results.

The charity recruited two people from their Research Support Network to become PPI representatives on the project Communication and Dissemination Committee. Their role is to advise on how information about the project is communicated, and how findings are shared with the Parkinson's community and the public.

The project is lab-based and so many of the researchers involved in the project don't have direct experience of working with people affected by Parkinson's. The PPI representatives have brought important insights to the project and their involvement helps ensure that the consortium communicates about the project effectively with people affected by Parkinson's and the wider public. It has also enabled other project partners to get a better understanding of the day-to-day experience of living with Parkinson's. The charity's leadership in facilitating PPI for the project has reinforced its position as a leader in bringing key stakeholders in research together to collaborate in order to drive Parkinson's research forward.

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5. Involvement helps to influence other organisations and develop relationships

Several charities report that the priorities that have emerged from the JLA PSP they have led have helped them to influence other research funders to prioritise their area of research, thereby bringing more money into research. They specifically cited the fact that PSP results reflect what matters most to those affected by a condition as a key reason for this influence. In the 'more than a top 10 report', one PSP lead expressed their belief that the priorities from their PSP successfully influenced large US charities funding research in their field as they were able to use the priorities to demonstrate that "*mental health is a clear priority for our members*".¹

The PSP process has also helped charities to develop partnerships with other organisations, which have continued past the end of the formal process. These partnerships have developed because the PSP priorities reflect the most important issues for patients and give the organisations a shared agenda to work to.¹ Discussing a partnership of four charities to address Age-related Macular Degeneration - AMD (one of the priorities from the Sight Loss and Vision PSP), Michelle Acton, former CEO of Fight for Sight (one of the partner charities), reflected:

*“The PSP was incredibly useful not just for Fight for Sight, but also as a great coalescing piece of evidence. **Identifying the AMD priority for patients gave us a shared goal we could all get behind**, based on a strong sense that we could achieve so much more for this group of patients if we all worked together”.*¹

The PSP process may also support stronger internal collaboration within organisations. Kamini Shah, Head of Research Funding at Diabetes UK, felt that the type 2 diabetes PSP was a great opportunity to work collaboratively across the organisation to help deliver the shared ambition of a world where diabetes can do no harm. She saw an opportunity to ensure that the charity was able to work and engage with people affected with diabetes right across the organisation, and involved them from the start in the development of the PSP through to dissemination and delivery of the outcomes. The outcomes of the PSP have been embedded into the work of the Diabetes Research Steering Groups and helped to shape the development of the organisational and research strategies.¹

Case study: Bowel and Cancer Research

Bowel & Cancer Research was keen to see developments in effective polyp screening. Staff supported people affected by bowel disease to work with the bio-medical engineering team to help them to understand the patient experience of undergoing a colonoscopy - none of the research team had ever had one. They also helped them to understand the impact of the diagnosis on an individual and family. A PPI steering group has now been set up to support this strand of work.

In addition to influencing the engineering team, Bowel & Cancer Research is increasingly being approached by other teams within UCL to support PPI in other relevant research. The charity is continuing to work with the biomedical engineering team in supplying ongoing PPI for a recently NIHR funded clinical trial to use the technology in hospitals across the UK.

6. Involvement supports fundraising

In the ‘more than a top 10’ report, several PSP Leads reported that their PSP priorities had helped with fundraising for their research:

*“If you can show with clarity that **you’re representing the priorities of your people...** that is enormously powerful **and it gives you enormous confidence in terms of going out there and speaking about what we do especially with donors**”.*¹

In addition, a patient interviewed for the report felt that the PSP priorities could be used to galvanise a charity’s patient and carer communities to fundraise for their research:

*“If you ask people what they want funded and then give them an opportunity to contribute to that, then they are even more engaged... if the patient community could do more to fundraise... then there would be a bigger grant available... because **it’s about patients***

shaping the direction of research and patients saying, ‘this is what needs to be answered and we’re going to help fund that’.¹

Case study: Diabetes UK

By sharing case studies of people with diabetes who are involved in research and illustrating how Diabetes UK use their priorities to set strategic funding calls, the charity is able to create compelling fundraising asks. At both an individual giving and major donor level this can help make a stronger case for support.

The charity asks people with diabetes who are involved in research to share their personal experiences of life with diabetes and their motivations for getting involved in diabetes research. This could be at fundraising events or through sharing personal stories on the charity’s website, social media and publications. This enables Diabetes UK to tell the stories behind why certain research priorities or funding calls came to light in a more human and emotive way. They’ve been able to mould compelling fundraising asks off the back of these. For example, the charity centred a major donor event around the work of the Diabetes Research Steering Groups, and invited a member who is living with type 2 diabetes to share their perspective on why the first priorities to be taken forward are so critical. This brought supporters closer to specific areas of the charity’s research, and helped make the case for why their support is needed.

7. Involvement helps empower individuals and builds skills and confidence

We found that involvement, and the act of coming together in groups to share experience and expertise, can be a real confidence booster for individuals. Getting to know others with the same condition and/or a similar lived experience can be empowering.⁶ On the Alzheimer’s Society website, a volunteer states how the Research Network provides “**a sense of purpose and hope**”. A different member of the Research Network in a video linked on the site speaks about how her role is “**inspiring**” and a “**massive highlight**” for her. The Alzheimer’s Society’s impact report for PPI continues to highlight these themes, with examples of how being involved helps to build members’ knowledge base, gives an opportunity to use existing skills, and provides support and friendship.

Case study: Tenovus

Like many charities, Tenovus Cancer Care involves people affected by cancer in making decisions about which research should be funded. In addition to helping the charity, Tenovus has found this involvement has been empowering for the people affected by cancer who get involved.

Following a cancer diagnosis and corresponding treatment, many people find they are unable to return to work or other activities and some report feeling frustrated and helpless, unable to make a contribution or ‘give something back’.

The Tenovus Research Advisory Group is made up of a group people affected by cancer in different ways. They help to review and decide upon research applications. Through this activity, many are able to utilise their skills, putting them towards meaningful activity which makes a vital contribution to the charity’s research portfolio and furthering cancer research in Wales and beyond.

Many of those involved like doing so because they feel that some of the negative experiences they had undergoing treatment can help them to change things for the better for others. This can give an enormous sense of empowerment. Others report the enjoyment and confidence they gain from the activity, particularly those who had no previous knowledge or experience of research.

This contribution is vital in ensuring the research funded by Tenovus Cancer Care is useful, impactful, more likely to succeed and, most importantly, keeps the patient at its heart. There is a real sense of responsibility and recognition of the importance to the work being undertaken for Tenovus, which the organisation does not take lightly.

8. Involvement leads to more involvement

Involvement of patients, carers and the public in PSPs led by several charities has led to an increased level of involvement of those communities in their organisations as a result. Leading the Autism PSP led to Autistica setting up their 'Discover' Network of autistic people, their carers, and researchers, to support involvement of autistic people in research.¹

The McPin Foundation have continued to fund the Young Person's Advisory Panel and Young People's Network that were set up as part of the Mental Health in Children and Young People PSP, in order for those groups to continue working with the charity as they address the PSP priorities.¹

The continued existence of these groups has also had an influence on the researchers they work with; Thomas Kabir, Head of Public Involvement at the McPin Foundation reported "*now with this new resource... we're getting researchers coming to us. They want our help with young people's involvement in their bids*".¹ The benefits of involving patients and the public in research have been widely reported, so it's possible to assume that increased involvement in funding applications will also benefit the McPin Foundation, as it will allow them to fund research that is more relevant to their community.

Case study: Cancer Research UK

Staff at Cancer Research UK wanted to put together an internal guidance document about how to involve people affected by cancer in the design of their early phase clinical trials. As this project was about patient involvement, it was important to get the perspective of people affected by cancer on where they thought they could add value and how they would like to share their views. To ensure the guidance document would be fit for purpose this project was run alongside and, in turn, piloted on a clinical trial for lung cancer that was at the design stage.

The charity carried out one-to-one telephone calls, an e-consultation and a focus group with a group of people affected by lung cancer who had experience of early phase clinical trials. By drawing on their experiences, the group were able to feedback on the design of the clinical trial, as well as on the process by which they were being consulted, suggesting changes for future patient involvement in the design of early phase clinical trials.

The feedback from patients informed the guidance document titled, 'Patient Involvement in Early Phase Clinical Trials', that will be used by teams when designing any clinical trial that enters the portfolio. As patients fed into the process, CRUK is confident that the guidance document will be an accessible and useful tool, ensuring that patient involvement becomes the norm and the patient voice is incorporated into the design of all future clinical trials.

9. Involvement enthuses staff members

In the literature we found that involvement can help to increase staff enthusiasm which in turn leads to a more productive working environment and outcomes.⁸ Anecdotally we are aware that staff members whose job, or part of their job, is to support involvement activities feel it brings them a sense of purpose and serves as a reminder of issues that are important to individuals and their day-to-day lives.

Case study: Marie Curie

The Research Voices Group at Marie Curie provide their opinion on the research proposals received, feedback on progress reports for funded grants and help the team to plan and facilitate key events and workshops amongst many other activities. Dr Sanjay Thakrar, Senior Research Manager at Marie Curie, expressed his gratitude for the group, and enthusiasm for the involvement aspect of his job:

*“We are **indebted for the time, effort, enthusiasm and passion** the Research Voices Group share with us to ensure our research activities are **grounded by the experiences** of those living with a terminal illness, as well as their carers, families and friends. Working with the group **really brings home that our research funding is vital**, as palliative and end of life care research is one of the lowest funded areas of healthcare research in the UK, despite it being an issue that affects everyone. Our Research Voices Group are an **utter delight to facilitate**, and the **patient, carer and public involvement aspect of my role is one of the most fulfilling parts of my job**”*

10. Involvement helps shape policy and media messaging

We found that involvement can help to shape policy and media messaging. For instance, on the British Heart Foundation (BHF) website information is provided about a panel which helped to “...**develop standard lines** on patient data that can be included in any press stories resulting from research that has used patient data.” The importance of this is further emphasized as it also states how public opinion varies greatly around patient data and how “...**communicating about this important area can be tricky**”.

Cancer Research UK (CRUK) also cites how involvement helped to shape their ‘style guide’, a guide which ensures everyone writes in a clear way to reflect CRUK appropriately. They state:

*“We asked people affected by cancer **how they felt about the way we talk about topics** like death and dying, cancer symptoms and curing cancer. We wanted to make sure our style guide was giving people across the charity the **right advice to talk sensitively** about these topics.”*

Case study: Stroke Association

There have been lots of stories in the media about the links between COVID-19 and stroke, and the Stroke Association was being asked by both the media and people affected by stroke to comment on the stories. The charity wanted to ensure that its messaging around this was sensitive to the concerns of people affected by stroke and the public, that the information was evidence-based and accessible, and that it covered the points that people affected by stroke wanted to know about.

Staff sent out news pieces for its website to a group of people affected by stroke who had previously said they wanted to be involved in developing and reviewing content about stroke research.

They were asked to answer a number of open questions and provide feedback on the news pieces. They included their thoughts on the main messages, the helpfulness and what they'd want to know next.

The feedback added value for the charity in many ways: it informed updates to the news pieces and it will guide how the charity communicates with various audiences on the impact of coronavirus on stroke care and treatment, and risk of stroke in future. This includes communications around a report on a survey of over 2,000 people's experiences during the pandemic, and a funding call on the links between coronavirus and stroke. Their feedback has also been an important source of quotes and case studies that have been used to share the stroke survivor perspective on research, adding a human element to the charity's research communications

Conclusion

This paper discusses the value that involving people with lived experience brings to charities. This added value ranges from ensuring that the research strategy focuses on areas that are most important to the community the charity serves, to supporting fundraising efforts, through to motivating and enthusing staff.

We believe that the involvement of patients and carers is vital. However, this involvement does not happen on its own. Effective and meaningful involvement requires staff with the necessary skills, experience and relationships to support both the process and the people who get involved. This paper demonstrates the importance of involving people with lived experience and why it is vital that this work, and the roles of those who support it, is protected.

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For the Charities Research Involvement Group

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Appendix

As part of this project we asked Charities Research Involvement Group members to share case studies of how PPI in research adds value for their organisations. Some of these have been used throughout this report. This table shows all of the case studies received, grouped by theme.

Theme	Organisations offering case studies
1. Informs research strategy and research priority setting	Psoriasis Association
	MS Society
	Alopecia UK
	Tenovus (also theme 2)
	CRUK
	Blood Cancer UK
	Parkinson's UK (also themes 3 and 8)
	Diabetes UK
	Stroke Association
2. Ensures more relevant funding decisions are made	Psoriasis Association
	Bowel and Cancer Research
	MS Society
	Pancreatic Cancer UK
	Alopecia UK
	CRUK
	JDRF
	Diabetes UK
	Parkinson's UK
	DEBRA
	Stroke Association (also 3)
3. Aids transparency and accountability	CRUK
4. Promotes increased recognition of the charity	CRUK
	Parkinson's UK (also themes 6 and 8)
5. Helps shape policy and media messaging	Bowel and Cancer Research
	CRUK
	JDRF
	Diabetes UK
	GUTS UK
	Stroke Association
6. Helps to influence other organisations and develop relationships	CRUK
7. Supports fundraising	CRUK
	Diabetes UK
8. Helps empower individuals and builds skills and confidence	Bowel and Cancer Relief
	DEBRA
9. Leads to more involvement	MS Society
	Pancreatic Cancer UK
	CRUK
	Stroke Association
10. It entuses staff	Marie Curie