

BUILDING RESEARCH PARTNERSHIPS

Shared learning for professionals
and members of the public:
supporting patient and public
involvement (PPI) in health and
social research

Report from the pilot
November 2011–October 2012

Summary

Introduction

Building Research Partnerships is an updated version of an internationally peer-reviewed, commended free course run by Macmillan and the National Institute for Health Research Cancer Research Network (NCRN) since 2007.

Building on our successful partnership with the NCRN, we've developed this course to explore health and social research, as well as the various ways the public can be constructively involved in the research process.

The aim is to strengthen mutual understanding and working relationships between researchers and the public. It is also to support researchers in developing and delivering quality research that is accessible, acceptable and patient-focused to benefit patients and the NHS.

This course has been updated so that it is relevant to other types of health and social research not just cancer. The course's audience comprises a mix of professionals and members of the public.

The course is run by members of the public.

What we did

More than 200 people took part in the 15 Building Research Partnerships courses run between November 2011 and October 2012. They were delivered with a range of organisations and groups across the UK already working together to support patient involvement in research. Locations included London, Belfast, Cambridge, Bristol, Oxford, Manchester, Leeds and Southampton.

The course works around a series of interactive discussions and activities involving professionals and members of the public.

Crucially, we worked to make the course and supporting materials relevant to any type of health research, including cancer, with a range of supporting learning resources also available for free online at **macmillan.org.uk/researchlearning**

The Building Research Partnerships course has been delivered as part of a successful national pilot and is facilitated by trained members of the public as part of Macmillan's quality-assured training scheme.

How we did it

Our approach in leading this pilot was to facilitate local ownership and delivery of Building Research Partnerships courses within an agreed operating framework. At the same time, we wanted to incorporate planning for future capacity building using a 'train the trainer' model.

We delivered Building Research Partnerships courses through established local networks and organisations, often involving collaborations between a range of research and service delivery organisations, academia and patient groups.

We encouraged less-established networks to work and plan together to manage the delivery of their own courses and to build local partnerships.

Findings

Successes

77% of participants said they felt the course had helped improve the way the public are involved in research in their area.

Nearly one in four of all participants did not identify themselves as being affected by cancer, with a wide range of conditions represented. These include diabetes, stroke, chronic obstructive pulmonary disease, heart disease, vision and sight problems and dementia, as well as people with experience and knowledge of medicines for children.

Building Research Partnerships has helped build collaboration and partnerships at local and national level, promoting sustainability and local ownership.

Each course was unanimous in recognising the value of mixing members of the public with professionals, and also people with experience or knowledge of different conditions. The mix of professionals, members of the public and the use of local content and resources, which were relevant across a range of health research, areas, helped build mutual understanding.

Participants cited the experience of gaining different perspectives from the 'mixed company' as being valuable. We asked participants what they found most valuable about the course. Here are two examples:

'Gaining an understanding of what patients think they bring to the process and meeting such experienced lay members.'

Researcher

'Allowing health care professionals to interact and engage with each other. It was very informative.'

Member of the public, carer

The first co-facilitator in the UK has now been trained in Belfast as part of the train the trainer model. There is evidence that this is part of a wider pattern of local ownership and the management of learning and development using Macmillan's quality assurance framework.

Learning points

While the feedback indicates Building Research Partnerships met the needs of participants, it was clear some would have liked the opportunity to attend further training. They would have liked something that provided more detail and included some more advanced information to support their learning. As a result, we're developing a more advanced course with a range of partner organisations.

Throughout the feedback, there was a strong theme that three to six months was too early to say when measuring impact or results.

We've used learning gathered from the pilot to develop a model service level agreement and quality assurance framework to support organisations hosting future workshops.

We had a high level of interest from health and research organisations in Europe, Canada, the USA and Australia who are all interested in finding out more about the Building Research Partnerships pilot. Learning from the pilot will be fed back to these organisations with a view to exploring future international collaborations in learning for public involvement in research.

Conclusions

Building Research Partnerships has made a measurable impact on practice.

The mixture of professionals and members of the public with experience or knowledge of a range of different conditions was highly beneficial. It gave an equal voice to everyone and helped develop mutual understanding and strengthen and build partnerships.

There are clear benefits to sharing resources in a free and open way, and pooling expertise and experience through partnership working to ensure the long-term sustainability and embedding of public involvement in research.

We were able to build capacity at local and national level using a quality-assured 'train the trainer' model. The national framework, in conjunction with a collaborative local-ownership approach, provided a free and flexible structure for organisations. This enabled them to make the best use of limited resources in a changing NHS and research environment.

Recommendations

More resources should be made available across the UK to support members of the public to get involved. They should also exist to support researchers in making better use of the skills and experiences members of the public can bring to developing research.

The third sector – including leading charities, voluntary, not for profit and non-governmental organisations – need to work together more effectively to pool limited resources and create a more lasting impact.

The approach used for this pilot could be used to develop other learning resources. In addition, it could be expanded as part of a wider learning and development framework for public involvement in research.

More information, including the full report, can be found at macmillan.org.uk/researchlearning

Alternatively, please contact us at research.learning@macmillan.org.uk or call Jack Nunn on **020 7840 7882**.

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Introduction

Background and activities

History

Building Research Partnerships is an updated version of an internationally peer-reviewed, commended course we've been running together since 2007. It remains part of the National Institute for Health Research Cancer Research Network's (NIHR CRN) wider induction training programme for members of the public working with researchers at the National Cancer Research Institute (NCRI) and the National Cancer Research Network (NCRN).

The course came about as a result of the annual survey of patient and public representatives, and discussions with research staff. These investigations identified a range of learning needs from the public, patients and research staff. All parties shared the common goal of working together more effectively and collaborating to develop good-quality research.

NCRN recognised the benefits of collaborating with Macmillan and being able to draw on Macmillan's recognised skills in this area. Equally, we've had the chance to improve our reach through NCRN's networks.

At Macmillan, we've been working with NCRN to meet this learning need – and deliver training for a mixed audience of professionals and public – since 2007.

An international peer review of NCRN's Patient and Public Involvement Induction Training commended our course as key to the success of the NCRN's patient and public involvement programme. Reviewers from Europe and the USA also pointed to the course as an example of international best practice. In particular, the fact the courses were 'lay led' and not directed by professionals was highlighted as a proactive approach.

Responding to a changing environment

Across other research networks, there was a clear need for better collaboration between patients, carers, members of the public and researchers.

The NIHR Clinical Research Network Coordinating Centre (NIHR CRN CC) identified Macmillan and NCRN's work as a useful resource.

They asked NCRN and Macmillan to take a lead in making Building Research Partnerships available across their eight Clinical Research Networks, and wider.

By 2010, the external landscape had changed, with the advent of NIHR's Clinical Research Networks (NIHR CRN) and its patient and public involvement programme. Collaboration between the networks was strengthened to include the learning offer to all clinical research networks as part of the NIHR CRN's patient and public involvement programme.

In response to the changing environment and identified learning needs, Macmillan and NCRN decided to build on the success of previous work. Together we adapted the existing training resources to make them generic rather than cancer specific and therefore relevant to all health and social research areas.

Where we are today

Building on success

The NIHR CRN CC asked NCRN to lead a workstream on learning and development in patient and public involvement across all areas of research the NIHR CRN covers. This was as a result of the success of NCRN's previous work on their patient and public involvement induction training programme.

Aside from cancer, the NIHR CRNs cover research into diabetes, medicines for children, stroke, dementia and neurodegenerative diseases, mental health, primary care and all other disease areas (collectively known as the Comprehensive Clinical Research Network).

By sharing the course across all networks and working with other organisations, we hope the resource will become relevant to anyone with an interest in public involvement in research.

Building capacity for the future

Macmillan and NCRN have delivered the course at various centres across the country and attempted to recruit facilitators in each one. We hope to make this model sustainable by training local facilitators to deliver the course in their area, employed by the relevant centre. Macmillan has designed a quality assurance framework to fit with this flexible model.

We also hope that the decentralised model will encourage cross-network partnerships and a sense of local ownership.

Where we're going

By sharing this course and working with other organisations, we anticipate the resources we've developed will become relevant to anyone with an interest in public involvement in research.

We hope to license all our work under Creative Commons. Creative Commons licence provides a flexible range of protections and freedoms for authors, artists, and educators. We aim to use this license to encourage others to build on and share our work.

What we did

More than 200 people took part in the 15 Building Research Partnerships courses run between November 2011 and October 2012. They were delivered with a range of organisations and groups across the UK already working together to support patient involvement in research. Locations included London, Belfast, Cambridge, Bristol, Oxford, Manchester, Leeds and Southampton.

The course explores health and social research, as well as the various ways the public can be actively involved in the research process. We also support researchers to engage with the public, with the aim of strengthening mutual understanding and working relationships.

We wanted participants to be able to apply their knowledge and experience in a practical way to help improve public involvement and participative decision-making in research.

The day works around a series of interactive discussions and activities involving professionals and members of the public. The activities are designed to promote shared learning around topics including the 'research cycle' and real examples of research taking place in the area. We explore why it is important for members of the public, including people living with cancer and carers – to work with professionals at every stage of a research project. In addition, we see how this can support researchers to meaningfully engage with members of the public people when developing research.

Crucially, we made the course and supporting materials relevant to any type of health research, including cancer, with a range of supporting learning resources also available for free online.

Please see the Appendix for an example outline of the day.

Macmillan paid the facilitators £300 each a day (plus travel expenses) while local centres covered the costs of venues, lunch and – in some cases – members of the public's travel expenses.

The Building Research Partnerships course was delivered as part of a successful national pilot and is facilitated by trained members of the public as part of Macmillan's quality assured training scheme.

Macmillan recommended that while people were being trained to run the course, they would be paid at a rate of £25 an hour. Once they had been assessed, and accredited as facilitators, they should be paid Macmillan's rate of £50 an hour.

Macmillan made this decision based on the advice of INVOLVE, which recommends that, when appropriate, members of the public should be paid for being involved. More information can be found at invo.org.uk/posttypepublication/payment-for-involvement

Partner organisations

The course was delivered with a range of partner organisations, including research networks, research design services, hospitals and Biomedical Research Centres.

The organisations included:

- Great Ormond Street Hospital, Moorfields Eye Hospital and University College Hospital
- Medical Research Council – Clinical Trials Unit
- Thames Valley Cancer Network
- Guy's and St Thomas' NHS Foundation Trust
- Leeds Teaching Hospitals NHS Trust
- North Tyne & Wear, County Durham & Tees Patient and Public Involvement collaboration
- West Yorkshire NIHR Comprehensive Local Research Network
- North West Patient and Public Involvement Forum
- South Yorkshire Patient and Public Involvement collaboration, Yorkshire Cancer Research Network
- Southwest Patient Public Involvement Forum
- Northern Ireland Cancer Trials Centre, Northern Ireland Clinical Research Network, Public Health Agency
- Southampton National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre.

How we did it

Our approach in leading this pilot was to facilitate local ownership and delivery of Building Research Partnerships courses within an agreed operating framework. At the same time, we would incorporate planning for future capacity building using the 'train the trainer' model.

How we organised the courses

We delivered Building Research Partnerships courses through established local networks and organisations, often involving collaborations between a range of research and service delivery organisations, academia and patient groups.

We encouraged less established networks to work and plan together to manage the delivery of their own courses and build local partnerships. Work continues through these local networks to facilitate the training of future local lay facilitators as part of Macmillan's quality assured train the trainer scheme.

People interested in running a course with their organisation or group approached NCRN or Macmillan. After checking mutual expectations, we identified a facilitator and set a date. The centre was responsible for promoting the course, with support from NCRN and Macmillan when appropriate.

The centres also organised venues and lunches and in some cases, paid participants' travel expenses.

Quality assurance

Macmillan designed a quality assurance framework for the course which was flexible, secure and administration light while still providing crucial feedback and other data.

The framework allows for continuous improvement and decentralised management of the course using online registration forms.

The data summarised in this report was collected using this quality assurance framework.

For more information about how we analysed and collected this data, see the section Numbers and data collection.

Find more information about the quality assurance framework in the Operational guidance.

Findings

Successes

The learning environment created in the course promoted shared learning, collaborative working and networking between people from a range of backgrounds. The course content was relevant and useful across all conditions not just cancer.

The mix of professionals and the public and the cross-condition content worked

Each course was unanimous in recognising the value of mixing members of the public with professionals and, also people with experience or knowledge of different conditions.

The course successfully brought together a diverse range of people from various backgrounds. Many comments suggested that working together helped enhance people's understanding of public involvement.

It is clear Building Research Partnerships provided a unique joint-learning opportunity for researchers and members of the public, as well as people with experience or knowledge of different conditions.

'I enjoyed being able to meet other people from various backgrounds and life experiences – the whole event was valuable.'

Patient representative

Helping build new connections

Building Research Partnerships has helped build collaboration and partnerships at local and national level, promoting sustainability and local ownership.

The course developed working relationships between many different organisations such as research networks, local patient groups, hospitals, research institutes and universities.

'Very informative. It allowed health care professionals and non-professionals to interact and engage with each other.'

Member of the public

'It was very useful to be in a forum where a number of service users and health professionals meet. As a researcher I personally have had little contact with users.'

Member of the public, carer

'I gained more knowledge about research itself, as well as certain aspects of cancer research. I am not, and have never been, involved in cancer research myself and it was quite valuable for me to interact with people from different fields and engaged in research at different levels.'

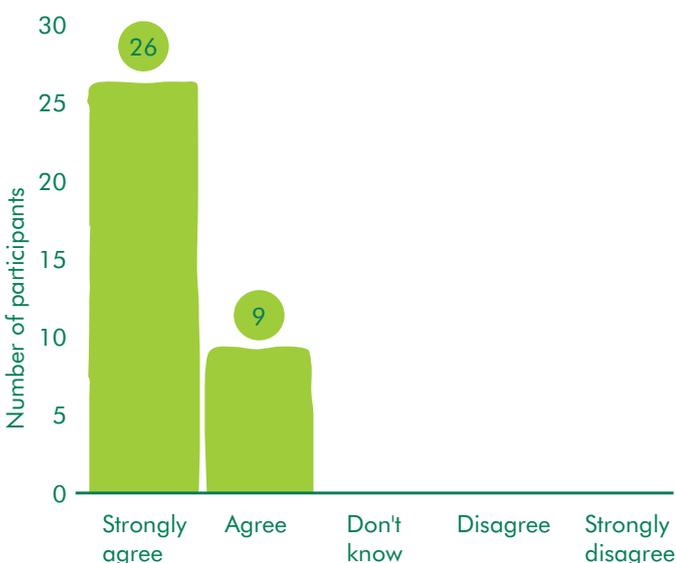
Research professional

The course successfully brought together people from various backgrounds. Many comments suggested working together helped enhance people's understanding of public involvement across all conditions.

Connections were made with various professionals and researchers. In addition, 26 out of 35 respondents strongly agreed the course had provided them with a useful opportunity to learn and share with other people affected by cancer. While the remaining nine agreed that it had. See the graph below.

We asked how strongly people agreed they had an opportunity to learn and share with other people affected by cancer so we could show the value of sharing across conditions. In the future we will adapt this question to say 'affected by long-term conditions' rather than 'cancer'.

I found the opportunity to learn and share with other people affected by cancer useful



Meeting the learning needs of researchers and the public

The learning environment created by the facilitators allowed the participants to build relationships in a safe and confidential environment. This helped meet the entire range of participant learning needs and had a clear measurable impact on improving research practice and involving the public.

It was also clear that the style of learning helped people gain confidence.

The course successfully met a range of learning needs simultaneously. A member of the public described it as 'relevant to a beginner in research'. While professionals involved in research said the material on communication in a health setting and group working was invaluable.

'I gained confidence, as I have been rather frightened of attending courses in the past.'

Member of the public

'The discussion with professional researchers was of particular importance, it was interesting learning how to contact them and fostering relationships with them.'

Member of the public

All participants said the experience of gaining a different perspective from the 'mixed company' was valuable. One researcher said they gained 'an understanding of what patients think they bring to the process' and added that they found it 'valuable meeting such experienced lay members'.

The results below come from the immediate feedback surveys from professionals and members of the public who answered the questions.

We asked what participants gained from the course.

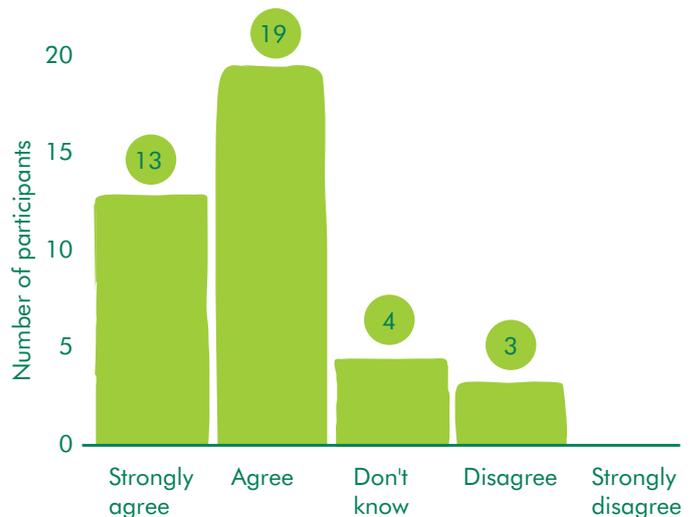
'A much greater insight into the fundamental nature of health research and how patients can contribute to it effectively.'

Member of the public

Overall I would rate this course as...



The event material used helped me to learn



New insights into the impact of learning

Participants were invited to give additional feedback three months after attending the course. We asked a range of questions so we could establish whether the course had helped them take any action.

One example was do you feel that this course helped improve the way the public are involved in research in your area?

Of the nine people who responded, seven said they felt the course had helped improve the way the public are involved in research in their area.

The follow-up results show the course has increased participants' involvement in research and the application of what they've learned in other projects related to their field of expertise. This data has provided a valuable insight into the impact that learning opportunities such as Building Research Partnerships can have and demonstrates the value of investing in quality assurance.

'Participating enabled me to take part in reviewing applications from universities. It made me appreciate the need to see research outcomes as a benefit for patients and for the general public, rather than just academic achievements.'

Volunteer reviewer

Cost-effective and admin light

We had a new online registration system designed for the course which streamlined the administrative process. It allowed the efficient and accurate collection of important information about learning needs, namely whether people considered themselves to have a disability and what their support needs were.

Other advantages:

- Facilitators received detailed information about participants' learning needs in advance.
- This process worked to minimise costs as it needed little maintenance and manual data input.
- The majority of participants completed online registration forms. Forms were accessed via URL shortcuts or quick response codes on paper posters. It was also possible to fill the form out over the phone too.
- Multiple organisations could edit and work on the same up-to-date document. A central database was held securely online as participants entered real-time registration data.
- Participants who wanted information about the financial support available, such as transport costs, could request this in advance.

Participants' summary

Nearly one in four of all participants did not identify themselves as coming from a cancer background with a wide range of conditions and areas represented. These included diabetes, stroke, chronic obstructive pulmonary disease, heart disease, vision and sight problems, dementia, and people with knowledge or experience of medicines.

Nearly a third of participants were professionals involved in research, with the remainder consisting of members of the public, including patients, carers and volunteers. The gender make-up comprised almost equal numbers of males and females.

This graph is a summary of information provided by the 74 people who gave us their information between November 2011 and May 2012. The category 'Other' included a significant proportion of people with long-term conditions other than cancer.

Participant background



Learning points

This section explains the learning points and challenges faced by this project. In each case, we mention solutions and actions that were taken to overcome them and, where appropriate, actions that are still to be taken.

Measuring impact

Throughout the feedback, there was a strong theme that three to six months was too early to say when measuring impact or results. This is reflected in the answers below.

These graphs show all the responses at the follow-up feedback stage.

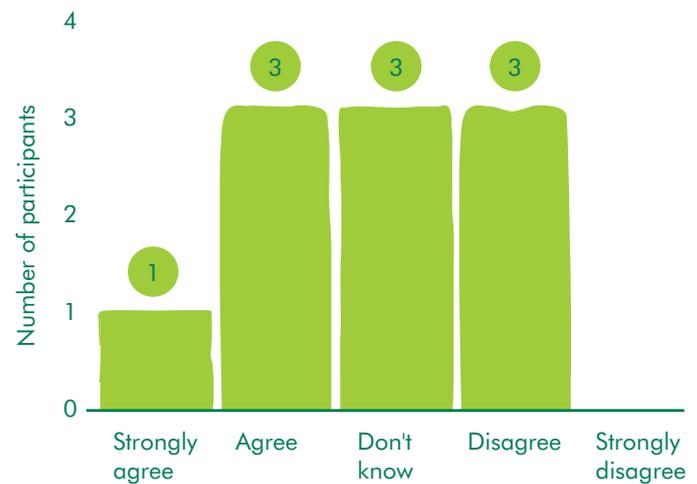
When people were asked whether they'd a chance to apply the learning, the sentiment appeared to be similar. One response was: 'It's too early to say but I fully expect to'.

Rather than suggesting the course was not effective, these results may indicate that follow-up feedback 12–18 months later could be a useful addition to our quality assurance framework. This would give more time to measure significant impact.

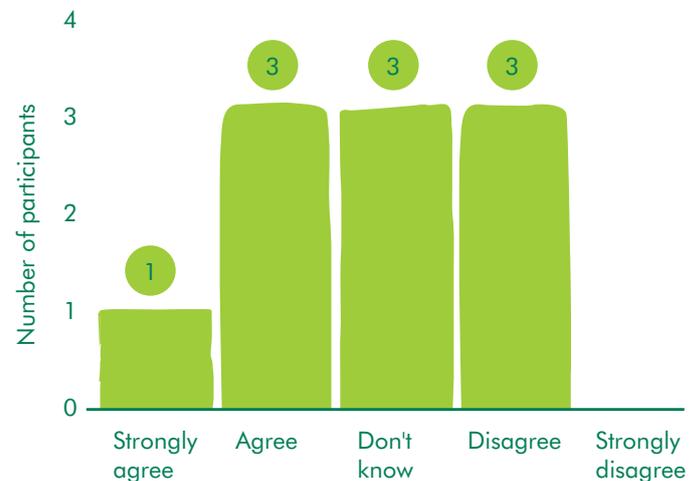
This may also lead to contacting participants on a regular basis which would be an opportunity to provide targeted information about further ways to get involved and other relevant learning opportunities.

Finally, it is worth mentioning that after more than three months, some people found it difficult to remember details and struggled to answer the more specific questions about the course content. It's important to take issues such as memory loss into consideration when planning any long-term feedback model.

The course increased my knowledge of ways to get involved in improving services



I have been involved in user involvement opportunities (formal or informal)



More detail

The feedback indicates that Building Research Partnerships met the needs of participants. However, it was clear that some would have liked an opportunity to attend further training which provided more detail and included some advanced information to support their learning. Some participants also said they would have liked more time.

As a result, we are working with a number of partner organisations to develop a more advanced version of the course. Organisations include University College Hospital, the Wellcome Trust, Guy's and St Thomas' NHS Foundation Trust.

'Research cycle and lay involvement session was useful, though it could have been more in depth I think. Hearing people involved talk about what they've done and what helps them participate would be useful and stimulating as would input from clinical champions.'

Research professional

'I think the role of patient and public involvement could have been further developed.'

Member of the public

We've created an advisory forum to guide and influence this work. This group has been established to provide an objective council for all organisations involved in learning and development. The idea is also to support patient and public involvement across all areas of health and social research. You can find more information about this in the Operational guidance on our Building Research Partnerships website macmillan.org.uk/researchlearning

We also need to work with partner organisations to develop more effective marketing and promotion strategies. That way, we can make sure that the course's reach is as wide as possible, rather than perhaps reaching only those who are already engaged.

One way of achieving this will be to develop more flexible delivery models which may involve distance learning and facilitated online learning. Another suggestion by one course participant was for Macmillan to organise a series of lectures at the University of the Third Age.

Uncertainty, funding and evidence

It is important to acknowledge the impact that the external climate has had on this project. Often, funding from partner organisations is limited, and in some cases there may be posts at risk which can impact on longer-term planning. Equally, while some individuals from organisations seemed keen to work with Building Research Partnerships, their intentions could be thwarted by a range of factors, in particular an apparent lack of funding.

A response from more than one potential centre was that patient and public involvement is not covered by reimbursement policies or that there was limited funding to pay members of the public to get involved or deliver training.

We've provided a summary of the challenges faced, with some solutions, actions taken and the outcomes of those actions.

Challenge	Solutions and actions	Outcome
<p>Influencing local ownership</p> <p>We realised individuals in local and national organisations needed support to make a better case to managers, budget-holders and other stakeholders when influencing them to offer support.</p>	<p>This report has been created to communicate the unequivocal success of this project.</p>	<p>We hope that this report will influence many other individuals and organisations to get involved and support this project.</p>
<p>Roles and responsibilities unclear</p> <p>Centres lacked clear documentation outlining what was expected of them and what support they would receive.</p>	<ul style="list-style-type: none"> • Draft service level agreement documents have been created to communicate roles, remits and responsibilities for all parties involved at each stage of the project. • The Operational guidance document was updated to outline a timeline of responsibilities. • We are working to develop relationships between Macmillan regional staff and centres to support this project. 	<p>We've used learning gathered from the pilot to develop a model service level agreement and quality assurance framework to support organisations hosting future workshops.</p>
<p>Uncertainty</p> <p>The climate of uncertainty and change in many organisations means over reliance on any organisation, including Macmillan, could threaten to long-term sustainability of the project.</p>	<ul style="list-style-type: none"> • We will create an advisory forum to decentralise the ownership of this course and spread it among a number of interested organisations and individuals. We aim to create a free to access, self-sustaining, quality assured and decentralised model of learning and development that will support patient and public involvement in research. We also plan to support collaborative working to ensure the model is adaptable and resistant to any foreseeable future organisational and funding changes. • We continue to work across the NIHR Cancer Research Network, INVOLVE and wider national and international partners to embed learning from the Building Research Partnerships model in practice. We are also developing other patient and public involvement learning resources as part of a wider patient and public involvement learning and development framework. 	

Networking and cooperation

Challenge

In general, this course appeared to be an excellent force of cohesion at a local level. It often became an event which the activities of local organisations could focus around. As ownership was decentralised, in many cases lasting and valuable partnerships were formed and strengthened. However, in a small number of cases some organisations and individuals expressed a preference for working independently as opposed to working in partnership.

In many cases this impacted on the success of the course owing to reduced reach and diversity. This preference also went against the spirit of the course, which is to build partnerships across conditions as much as between the public and professionals across conditions. Overcoming this challenge will be complex, but we made a start by taking actions to try and cross-condition cooperation.

Solution

We strongly encouraged centres to ensure that there were at least three to five people from outside the local network or immediate area involved. These people might have been from neighbouring groups or organisations. The decision was informed by facilitators' experience that when people from outside the immediate area have attended it has brought a different perspective and added to the richness of learning and sharing. We refer to this encouragement towards partnership working when individuals in some networks are resistant to cross-condition networking.

What next?

Challenge

Many people left the course inspired and enthusiastic about public involvement in research but often felt that it wasn't always clear where to go next.

Solution

We've incorporated action plans into the day and introduced an activity encouraging people to make a note of participants' contact details or other contacts they want to stay in touch with. We've also introduced an opportunity for people to swap action plans with others so they can support each other in the future.

For example, on the course with the West Yorkshire Comprehensive Local Research Network, organisers designed an Olympic-themed postbox where participants could write action plans to themselves.

Still to do

A great deal of work needs to be done locally and nationally to improve the links between learning opportunities and opportunities to apply learning.



The postbox course participants used to send action-plan postcards to themselves. With thanks to West Yorkshire Comprehensive Local Research Network

Recruiting new facilitators

As mentioned previously, the Building Research Partnerships project set out with the intention of training local facilitators from the centres where we ran courses. The aim is that centres can pay these individuals to run courses as often as they need without being dependent on us to fund them. Macmillan offers support with the quality assurance and continuous improvement.

At the time of writing we have now trained our first facilitator in Belfast. We have also had expressions of interest from facilitators, potential centres and we have begun the training process with five other facilitators.

There are many complicated reasons why more local facilitators have not yet completed training. On the next page is a table summarising the numerous challenges and detailing some solutions which have been adopted.

Challenge	Solutions and actions	Outcome
<p>Time</p> <ul style="list-style-type: none"> An ambitious schedule of 12 months and 10 pilots were planned to support the training of new facilitators. Centres and the members of the public working with them often felt they needed to attend the course before making any future commitments. 	<ul style="list-style-type: none"> We developed a more flexible training model which allowed some people to be trained as co-facilitators rather than being expected to lead a course independently. Service level agreements and longer-term plans and budgets were discussed more formally with partner organisations. We ran courses with some centres two or more times so that people could come and plan a specific date to co-facilitate and build up a local awareness and sense of ownership. 	<p>There are now three centres in the UK with identified facilitators. These centres are committed to running future courses.</p>
<p>Recruitment of facilitators</p> <ul style="list-style-type: none"> Confidence <p>While many people initially expressed an interest in being trained, there was a perception that making the transition to becoming a facilitator was too difficult or daunting.</p>	<ul style="list-style-type: none"> Macmillan revised the training offer to allow people to become co-facilitators for an indefinite period of time. More established facilitators adjusted their facilitation style so it was less reliant on their knowledge and brought more out from the group. 	<p>Many more people have now come forward expressing an interest in the co-facilitation role saying they would feel more confident in this.</p>
<p>Recruitment not open to professionals</p> <ul style="list-style-type: none"> We pursued the model of lay-led facilitators for the pilot, however, a significant number of professionals expressed an interest in being trained to facilitate the course. 	<ul style="list-style-type: none"> We are developing a training model that will train professionals to train members of the public to co-facilitate. This model will have its own challenges, particularly around quality assurance, but it's felt by many professionals involved that this would be valuable and increase the reach of the project. 	<p>A number of professionals have come forward stating they would be very interested in this role. It also is viewed as an excellent opportunity for professional development.</p>

Challenge	Solutions and actions	Outcome
<p>Information needs not met</p> <ul style="list-style-type: none"> • It became clear that there was a lack of clarity around applying to become a facilitator, commitment, skills required and support available. • We were exclusively relying on centres to give out complex information and recruit facilitators. 	<ul style="list-style-type: none"> • We built an online space for the project including areas for people wanting information about how to become a facilitator and what was involved. It also provided a direct route for applying to become a facilitator, ending the direct reliance on centres to recruit. • The space also has additional information for past participants, an electronic copy of an information resource to support distance learning, and maps showing where future courses will take place. • We created an easily remembered link to take people straight to the page: macmillan.org.uk/researchlearning 	<p>Within a week of creating the new online space, three people had applied to be facilitators and feedback on the space was good. However, the use of the forums has been limited, possibly owing to complicated navigation.</p>
<p>Funds and matching</p> <ul style="list-style-type: none"> • Funding for public involvement was not always in place, or when it was it was not always clear whether it would be possible to use it to fund the training of individuals. • In some cases, centres had funds, but no members of the public came forward and vice versa. 	<ul style="list-style-type: none"> • We adjusted our role to one of matchmaker. When individuals came forward to be trained as facilitators, we worked to match these individuals with centres who could commit to running courses in the future and paying facilitators. • In one case, a centre said they did not have the budget to pay for individuals to be trained but could pay them once they were. We agreed to pay for their training on the understanding that a certain number of courses would be run in the future. We then drafted a service level agreement to ensure the centre secured funds for future courses. 	<p>Two centres have now set aside funding for the training of local facilitators over the next year, with other centres hoping to make similar commitments.</p>

Audience mix

Challenge

When running this course we aim for a ratio of one third professionals to two thirds members of the public. The ideal number is between 12 - 16 although some courses had as many as 24 attend, with two facilitators supporting the group.

It became apparent early on that there was often no difficulty in recruiting professionals to courses. The marketing strategies of centres running courses often consisted of internal emails to colleagues, with engagement of members of the public naturally more challenging. In one case, an individual with 'patient and public involvement' in their job title remarked on the ease of getting colleagues to come and stated that it was quite hard to get members of the public to come.

In addition to the difficulty of recruiting members of the public, approximately 90% of the professionals who registered for the event attended on the day whereas the public attendance rate was closer to 60%. Although we did not formally investigate this difference, it's likely that certain members of the public may have had additional barriers to some professionals. Suggestions included:

- Some people may have had to undergo treatment or had caring responsibilities.
- Financial reasons may have been a significant issue. Professionals were naturally being paid for their time while members of the public at best were offered travel expenses.
- Promotion of the course was largely, but not exclusively, email-based or online – some members of the public may not have access to these channels of communication.

Solution

- A clear Operational guidance document was produced to support centres at each stage of recruitment.
- The centres were encouraged to use two tactics to boost public attendance. The first was to only recruit professionals after 16 members of the public were recruited. The second was that if professionals wanted to come, they must recruit at least two members of the public.

In addition, if the following three elements were in place, the course was more likely to run successfully:

- a local public and patient involvement lead
- an appropriate budget agreed for public involvement
- pre-established relationships between local organisations with similar aims.

International interest

There was a high level of interest from health and research organisations in Europe, Canada, the USA and Australia wanting to find out more about the Building Research Partnerships pilot. These organisations include the Danish Cancer Society and the University of Western Australia. Learning from the pilot will be fed back to these organisations, with a view to exploring future international collaborations in learning for public involvement in research.

There may also be an opportunity for the roll-out of a programme which includes a more thorough and robust level of evaluation. That way, we may have a potentially larger international influence.

Numbers and data collection

About the data in this report

In this summary we have attempted to highlight themes in the qualitative and quantitative feedback we collected. By doing so, we have identified areas of success and where there were learning points, as well as challenges and areas for improvement.

We will share all the anonymised raw data which we collected during this course.

Data collection

We collected feedback at three distinct stages.

Stage one – Learning needs assessment and monitoring

This was where we asked participants what they wanted to learn. We also collected monitoring and other important information such as whether people consider themselves to have a disability or condition which means they may need support taking part in learning activities. This data was often collected using an online registration link rather than by telephone or email. It was then shared with facilitators to help them tailor course material and was kept on record to compare with their responses in the next two stages.

Stage two – Immediate evaluation

This was filled in right after the course had finished, usually on a paper form. The information assisted us in identifying how effective the learning event was in meeting participants' needs. It also helped us to gather the immediate impressions participants had of the course. Open questions included 'Please describe the area/s of the event that you found most valuable/most enjoyable' and 'How do you intend to apply what you learnt on the event? What will you do differently? What do you think will be the effect of this?'.

Owing to the time and resources needed to electronically log the handwritten data, only courses which took place between November 2011 and May 2012 were included in this dataset. However, we have securely stored a facsimile of all these forms.

Stage three – Follow-up evaluation

We followed up with participants approximately three months after attending the course. To establish if they had applied anything and to estimate the impact of the learning opportunity, we asked them a number of questions.

In addition, we created a form for facilitators.

Facilitator self-assessment

To support our quality assurance framework, we've also used a self-assessment form for facilitators to reflect on the day and how it could have been improved. Most of the questions are open but it includes specific questions asking participants to evaluate the materials used and the support they received on the day.

Please note that not everyone who came on the course completed every stage of the feedback process. Any figures or numbers reflect data collected from the raw data and may be incomplete or not fully representative.

Data quality

A perfect data line for this course would be a participant who completed all three stages of our feedback. Naturally, in some cases only one or two of these stages has been recorded for a participant. This can be examined in the raw data.

This pilot began in November 2011 with the quality assurance framework starting simultaneously. While courses continue to run at the time of writing, the data presented in this report reflects data gathered from November 2011 to May 2012. This was to ensure that we were able to collect the three-month follow-up data in time for the publication of this report.

So while more than 200 people have attended over 15 courses since November 2012, the data in this report reflects the 74 participants who attended the seven courses between November 2011 and May 2012.

Number of courses between November 2011 and May 2012	7
Number of people who provided monitoring data (Stage 1)	74
Number of participants who articulated their learning needs (Stage 1)	60
Number of people who gave immediate feedback (Stage 2)	74
Number of people who completed follow-up feedback (Stage 3)	12

Conclusions

Building Research Partnerships is beginning to show some impact on practice and has received international recognition.

The mixture of professionals and members of the public with experience or knowledge of a range of different conditions gave an equal voice to everyone. They helped develop mutual understanding and strengthen and build partnerships around a common focus. This was developing and delivering accessible quality patient-focused research to benefit patients and the NHS.

There are clear benefits to sharing resources in a free and open way and pooling expertise and experience through partnership working. This will ensure the long-term sustainability and embedding of public involvement in research.

Participants found Building Research Partnerships useful and it met the needs of participants. It was clear, however, that some would have liked an opportunity to attend further training providing more detail and including some advanced information to support their learning.

Capacity building at local and national level was achieved using a quality-assured 'train the trainer' model. The national framework, in conjunction with a collaborative local ownership approach, provided a free and flexible framework for organisations. It also enabled them to make the best use of limited resources in a changing NHS and research environment.

Recommendations

More resources should be made available across the UK to support members of the public to get involved. Similarly, researchers need more support in order to make better use of the skills and experiences that members of the public can bring in developing research. Investing in public involvement – in particular learning and development – will support research that is more likely to benefit patients, the NHS and beyond.

Leading charities and the third sector need to work together more effectively to pool limited resources by freely sharing and co-producing materials and resources. This will create a more lasting impact than could be achieved by organisations independently.

Government and shareholder-funded research by pharmaceutical companies needs to take the lead in a more international outlook with public involvement. The interest shown in the project from organisations in other countries suggests that there is no reason that learning from this project could not benefit the English-speaking world and beyond.

More work needs to be done locally and nationally to improve the links between learning opportunities and opportunities to apply learning. For example, we need to ensure that members of the public have clear information about how and where they can apply their skills and knowledge. We must also see that researchers are supported to connect more formally with these individuals.

The approach used for this pilot could be used to develop other learning resources and be expanded as part of a wider learning and development framework for public involvement in research.

Appendix

Example course outline

Agenda for Building Research Partnerships

9.30am–4.30pm

9.30am	Registration
10.00am	Welcome and introductions
10.25am	What is research?
10.45am	Research methodology and terminology (interactive group session)
11.30am	Tea/coffee break
11.45am	The research cycle and lay involvement (all group session)
12.30pm	Lunch
1.15pm	Examples of current research and public involvement
2.00pm	The six Rs – role, remit, responsibilities, representation, relationships and readiness
2.45pm	Tea/coffee break
3.00pm	Communication in a research team setting
3.20pm	Examination of research proposals, patient information sheets and members' roles
4.10pm	Summary and evaluation
4.30pm	Close

Further information

Please visit our webpage dedicated to Building Research Partnerships.

You'll find more information, including the full report, learning resources, information about forthcoming courses, organising courses and becoming a facilitator at macmillan.org.uk/researchlearning

Alternatively, please contact research.learning@macmillan.org.uk or call Jack Nunn on **020 7840 7882**

Useful links

National Institute for Health Research
Clinical Research Network
www.crncc.nihr.ac.uk

Building Research Partnerships page:
macmillan.org.uk/researchlearning

National Cancer Research Institute
www.ncri.org.uk

National Institute for Health Research Cancer
Research Networks
www.ncrn.org.uk

INVOLVE
www.invo.org.uk

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Thank you to everyone who has supported Building Research Partnerships so far.

Macmillan is here for everyone affected by cancer, whatever you need. For support every step of the way, call the Macmillan Support Line free on **0808 808 00 00**

Macmillan couldn't provide all the support that they do without you. If you want to get involved, in whatever way you can, call the Macmillan team today on **0300 1000 200**

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