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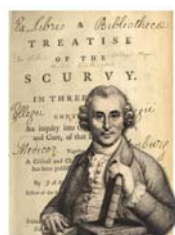


**National Institute for
Health Research**

Building on Success

Opportunities to progress patient
and public involvement in research
prioritisation and commissioning

Event report
Tuesday 9th February 2010
Chandos House, London



INVOLVE

Promoting public involvement
in NHS, public health and
social care research

This is the report of a 'think tank' event jointly organised by the Association of Medical Research Charities (AMRC), the James Lind Alliance (JLA) and INVOLVE, with the support of the UK Clinical Research Collaboration. It brought together representatives from large and small research funding organisations, research commissioners and other groups and individuals with experience of patient and public involvement in research priority setting and commissioning. The purpose of the meeting was to reflect on progress and to consider the future development of patient and public involvement in research priority setting and commissioning processes.

This report is available to download from the websites of the AMRC, the JLA and INVOLVE. If you need a copy of this report in another format, please contact INVOLVE. Contact details for all three organisations are given on the back cover of the report.

The report was written by Katherine Cowan (JLA) with editorial input from the AMRC, INVOLVE and other members of the JLA team.

This report should be cited as:

Cowan, K. (2010) Building on Success – Report of an event organised by the Association of Medical Research Charities, INVOLVE and the James Lind Alliance: James Lind Alliance

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Introduction

The involvement of patients and the public in health research prioritisation and commissioning is increasingly accepted, and expected by the clinical research community as a significant aspect of ensuring the development of high quality, relevant and necessary research. For example, this agenda is firmly backed by Professor Dame Sally C. Davies, Director General of Research and Development at the Department of Health:

I have always taken the view that public involvement in research should be the rule not the exception. It is fundamental to ensure high quality research that brings real benefits for patients, the public and the NHS.¹

Drawing together key messages from a number of projects that they had undertaken, long-term proponents of patient and public involvement, the Association of Medical Research Charities (AMRC), INVOLVE and the James Lind Alliance (JLA), with support from the UK Clinical Research Collaboration decided it was a timely moment to consider progress to date and discuss how to most effectively build the future development of patient and public involvement in research priority setting and commissioning.

On Tuesday 9th February 2010, these three organisations jointly hosted a think tank event which brought together representatives from large and small research funding organisations, research funding commissioning organisations and other groups and individuals with experience in patient and public involvement in research prioritisation and commissioning. This provided participants with an excellent opportunity to pool expertise, share views, experiences and identify good practice

¹ Foreword to *Exploring Impact*, Staley K, INVOLVE (2009)

and challenges. Attendees accounted for an impressive level of influence and were estimated by one speaker to represent around 90 per cent of funding providers to commissioned clinical research in the UK. A list of participants is at **Appendix 1**.

The event began with introductions from the co-Chairs (Simon Denegri, Chief Executive, AMRC and Dr Russell Hamilton, Director of Research & Development, Department of Health), followed by presentations from Sir Nick Partridge (Chair, INVOLVE) and Lester Firkins (Chair, JLA). A plenary discussion ensued, followed by smaller group discussions on specific topics. The event programme is at **Appendix 2**.

Dr Russell Hamilton noted that from a strategic perspective, patient and public involvement is about “doing the right thing”. From an operational perspective it is about “doing the thing right”. **Building on Success** primarily focused on the strategic perspective.

Building on Success: where we are now

Prior to this event, the AMRC, INVOLVE and the JLA had each undertaken work that explored different aspects of patient and public involvement in research prioritisation and commissioning. Reports of these activities, briefly summarised below, were circulated to participants as background information.

The AMRC's report 'Natural Ground – paths to patient and public involvement for medical research charities' (published in October 2009) (see **Appendix 3**) was developed in response to the fact that many but not all of its members already involve patients and the public in setting the research strategy and priorities. The project aimed to explore good practice and the different methods of involvement and provide members with an appraisal of the challenges and opportunities involvement can present. The report notes that medical research charities, with their strong connection to patients, are in a unique position to develop patient and public involvement in meaningful, integrated and non-tokenistic ways. It concluded that research funders' drivers for patient and public involvement need to be clear and should have measurable outputs. The report acknowledges that while patient and public involvement is "here to stay", its benefits and processes need to be spelt out to ensure all partners are persuaded to embrace it.

In 2007, INVOLVE conducted a survey of commissioners of health research to scope the nature and extent of public involvement in commissioning and funding processes (see **Appendix 4**). The survey found that depending on whether commissioners and funders were part of the statutory or voluntary sector, their basic approaches to, and subsequent policies for, patient and public involvement in the commissioning of health research would vary. For example, research programmes funded by the National Institute for Health Research (NIHR)

have been guided towards developing standardised policies and procedures for integrating public involvement within their commissioning processes whilst a less formalised and responsive approach has been taken by medical research charities. A divergence of approaches was also evident from the responses of all respondents, half of whom said that they always involved members of the public in funding decisions and half of whom said they never or hardly ever did. The absence of routine mechanisms for monitoring involvement was also evident, making it difficult to assess the impact of patient and public involvement on the commissioning of research.

The JLA commissioned a scoping study to find out whether and how clinical research organisations currently set research priorities and whether and how patients and the public are involved in this work (see **Appendix 5**). The study found that most research funders rely on researchers to submit ideas and are reluctant to place restrictions on researchers by asking them to address priority topics. Consultation to develop a research strategy tends to be carried out with researchers, with patients and public generally being more likely to be asked to review research proposals than identify research priorities important to them. There is no agreed best practice or consistent approach for identifying priorities, or for involving patients and the public in that process. The report notes that there is a growing trend towards patient and public involvement among patient organisations that fund research, but that there is limited evidence of the impact being measured or evaluated. A key challenge is the lack of agreed best practice or consistent approach for identifying priorities, and approaches for involving patients and the public therein.

All three reports suggest that while progress is clearly being made, there is still work to do to ensure the value of patient and public involvement is understood in all scientific areas. In order to be accepted it must be delivered in ways that are meaningful, useful, with consistent

outcomes and to a high standard. **Building on Success** participants recognised the need to share evidence of patient and public involvement that has led to significant research findings, and important scientific discoveries. Three examples are included in Appendix 6, with further reading suggested.

Strengths, Weaknesses, Opportunities, Threats (SWOT)

A wide range of views were voiced and knowledge, information and evidence relating to patient and public involvement were shared in discussions throughout the day. Key themes were captured and have been organised below using the structure of a SWOT analysis of patient and public involvement as mainstream practice in research prioritisation and commissioning.

SWOT Analysis

STRENGTHS

- For many, involving patients and the public in deciding what gets researched simply makes sense and is the right thing to do.
- Patient and public involvement provides another methodology for generating topics which enable quality research.
- Engaging patients in the research process can lead to research which is relevant and useful.
- The experiences of patients can lead to fundamental discoveries which might not otherwise have been identified.
- Bringing different stakeholders together to work in partnership allays misgivings and increases trust, insight and understanding.
- Many researchers find it intellectually exciting to develop other people's ideas.
- Patient and public involvement in decision-making makes the distinction between patients as subjects and patients as partners, allowing people to be heard.
- There is evidence of patient and public involvement where individuals can look beyond a personal agenda to provide a wider view and input.

WEAKNESSES

- A perceived lack of evidence of the benefits to research of patient and public involvement.
- A lack of information persists on how, when and how much to involve patients and the public.
- Clarity is lacking on how to evaluate the impact of patient and public involvement.
- The collection of information enabling the evaluation of the impact of patient and public involvement is poor.
- Confusion sometimes arises from a lack of clarity in the use of terminology and the absence of definitive definitions for patient and public involvement in research.
- A perception that patient and public involvement is cumbersome and complicated.

OPPORTUNITIES

- Develop and publicise evidence of the positive impact of patient involvement on research.
- Capture evidence of patient and public involvement through comprehensive record keeping, as well as site visits.
- Collaborate by information-sharing and mutual support between voluntary sector and statutory organisations to involve patient and the public.
- Commission programmes across funders to incorporate patient and public involvement in their processes.
- Collaborate and create a community of interest, involving patients, clinicians and researchers.
- Engage and involve clinicians as well as patients, who often ask the same questions, in identifying research needs.
- Involve researchers in developing patients' research questions and priorities to be taken forward for research.
- Use varied ways to involve patients and the public, including online media and social networking – there is no 'one size fits all' solution.
- Develop training and support for patients and practitioners to ensure patient and public involvement is effective.
- Generate positive public attitudes towards health research by involving people in the process.

THREATS

- Tokenistic involvement with no real meaning or value.
- Poor or inconsistent reporting of patient and public involvement.
- Lack of congruence between researchers' drive to do research, and patients' expectations.
- Patient research priorities may not necessarily be researchable.
- Uncertainty about whether representativeness can or should be achieved when recruiting patients and the public.
- Evidence of excellent research without patient involvement removing the incentive for involvement.
- A perceived lack of incentive to involve patients and the public in research prioritisation and commissioning.

Next steps

The AMRC, INVOLVE and the JLA greatly valued the high calibre and influential participant base that **Building on Success** attracted. It was felt that this was evidence of the growing recognition of patient and public involvement as an important consideration in the commissioning and prioritisation of health research, and key organisations' acknowledgement of the role they have to play.

All three organisations are committed to responding to the lessons learnt from this event, and to continue to work together to contribute to the development of what is an important and increasingly scrutinised agenda.

The following reflective statements from the three convening organisations indicate how they will respond to the challenges and the opportunities.

Simon Denegri

Chief Executive, Association of Medical Research Charities

“The fact that such a senior grouping of individuals came together for this event is indicative of the importance now afforded to patient and public involvement (PPI) in research. The discussion was robust but constructive. Light was shed on areas of tension and disagreement. Less was shed on the solutions. The dialogue was no poorer for this.

I was pleased to see so many AMRC members present. It was no surprise to find them expressing different shades of opinion about PPI, the ‘why’ and the ‘how.’ This diversity has always been a source of strength for the sector and we should not lose or forget that. What ultimately binds us is common cause and common principles. And, on the day, I heard much to confirm that we all share a common aim in wanting to increase patient participation in research. Assisting charities to develop the best models of PPI for their organisation that meet this aim is work that AMRC will continue to take forward.

It worries me little that we did not emerge with an action plan for the future - perhaps our aims for the day were set too high in that regard. In any event, the history and development of PPI has over the years not been straightforward. Indeed, I would go as far as to say it has been messy. No one could have predicted we would have reached this point. Nor that we would reach it in this way. All we can be certain of is that its advancement will continue to be messy.

So, we may wish to be visionaries and at times we will need to be. But when it comes to getting things done we must continue to be empathetic pragmatists. We need to understand the many significant pressures and demands on our colleagues. We need to show how PPI can ease some of those pressures. We need to demonstrate its relevance. We must show its value – seeing is believing.

What we must not do is get lost in introverted arguments or foster the

creation of a self-serving industry. At the end of the day this is about making opportunities for patients to be active citizens in science and research in whatever way they choose and are able to be.

Those opportunities now loom large. We have a new Coalition Government and have been promised a 'new politics.' The 'Big Society' agenda is open to definition and has much room in which PPI can live and breathe. NIHR continues to be a worthy and sensible champion. And we know that patients and the public and their lifelong treatment by the NHS is a unique factor in the UK attractiveness to industry and others as a place to research.

Grasping these opportunities is our challenge, not finding them. How we have moved on."

Lester Firkins

Chair, James Lind Alliance

“The James Lind Alliance is committed over the next 2½ years to support and see the conclusion of many Priority Setting Partnerships that gather and prioritise treatment uncertainties from both clinical and patient perspectives. These will include diabetes, schizophrenia, stroke, aspects of balance, pressure ulcers, prostate cancer, eczema, and many other conditions.

This will give the clinical research community a robust body of evidence of the process and outcomes of developing shared priorities for research. By 2012, we will also have evidence of how these priorities can be translated into funded studies.

The Alliance will make all of their data publicly available via the JLA website, peer reviewed publications and other relevant outlets. The commitment to transparency will be further enhanced by regular updating of the JLA guidebook <http://www.jlaguidebook.org/> which provides a step-by-step guide, with lessons learnt from priority setting, and the evidence that underpins methods and approaches.

For the JLA, involving patients and the public, as well as clinicians and researchers in deciding what gets researched simply makes sense, and is the right thing to do. Our role is to explore the practice of achieving this, and making it as easy as possible for others to adopt a similar approach.

There are many other outputs of successful JLA Priority Setting Partnerships. They help identify significant research gaps, highlight areas for improvement in clinical and patient information, (unknown knowns), and establish significant and reciprocal partnerships that can work together on funding applications for priorities.

I believe that whilst the JLA challenges the current status quo in clinical research commissioning it perhaps more importantly, contributes to a

culture change where patients, clinicians and the public have more influence in where resources are allocated for clinical research, and that research is more relevant as a result.”

Nick Partridge

Chair, INVOLVE

Public involvement in research has come a long way since the early 1990s when I was demonstrating outside the Medical Research Council (MRC) demanding greater research into HIV and AIDS and greater community representation on the AIDS Therapeutic Trials Committee. Meanwhile inside the MRC, a heated debate was taking place on whether a community representative should be asked onto the committee - a proposition that was finally agreed by just one vote. This was the first time the MRC had ever had a community representative on a trials committee.

Today, public involvement on trial committees is common practice and patients and the public are genuinely influencing many aspects of the whole research process. Examples of involvement in research commissioning include membership of commissioning programme research boards and panels, peer reviewing grant applications alongside academic peer reviewers as well as being joint applicants on research grant applications.

As an organisation that is funded by the Department of Health, INVOLVE has always worked closely with the National Institute for Health Research (NIHR) Programmes, providing guidance and support as well as facilitating a shared learning group for patient and public involvement leads in the Programmes and offering support and advice to individual Programmes on specific issues as they arise. The activities of the NIHR Programmes continue to play an important role in influencing attitudes to public involvement in research and in developing and sharing models of good practice.

Another linked and core area of activity for INVOLVE is in helping to develop a greater understanding of the nature, processes, extent and impact of public involvement. Like any other area of applied research, a well-developed evidence base is needed to learn what work works

well and what doesn't. Last year INVOLVE published a literature review on the impact of public involvement (Staley, 2009) and this year we are working with the Health Services Research Board at the NIHR Evaluations, Trials and Studies Coordinating Centre (NETSCC) to commission a programme of research on public involvement in research. _

Our work on public involvement in research commissioning is also greatly informed and developed through a process of working in collaboration with others such as the Association of Medical Research Charities, the James Lind Alliance and the organisations that were represented at the **Building on Success** event.

This event highlighted to me both the commitment and achievement of many research funders in encouraging and supporting public involvement, but also many of the challenges we still need to address. At INVOLVE we will continue to work towards providing greater understanding about the nature, extent and impact of involvement, and explore opportunities to support public involvement through the gathering and dissemination of knowledge and evidence and through further collaboration with researchers, research commissioners, research funders and the public.



Building On Success

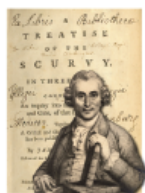
9th February 2010
Delegate List

Name	Role / Organisation
Prof David Armstrong	Director of the National Institute for Health Research for patient benefit Programme, King's College London
Patricia Atkinson	Administrator, James Lind Alliance
Angela Barnard	INVOLVE member & Independent Consultant
Sarah Buckland	Director, INVOLVE
Joseph D Calabrese	Cannon Research Fellow, Green Templeton College, University of Oxford
Sir Iain Chalmers	Coordinator, James Lind Initiative
Dr Peter Coleman	Deputy Director of Research and Development, The Stroke Association
Katherine Cowan	Independent Consultant, James Lind Alliance
Dr Lisa Croucher	Research Manager, Strategy and Evaluation, Arthritis Research Campaign
Sally Crowe	Chair, Monitoring and Implementation Group, James Lind Alliance
Simon Denegri	Chief Executive, Association of Medical Research Charities
Dr Stuart Eglin	Director of Research & Development, NHS North West
Lester Firkins	Chair, JLA Strategy and Development Group, James Lind Alliance
Prof Adrian Grant	Health Services Researcher. Director, NIHR Programme Grants for Applied Research Programme, University of Aberdeen and NIHR
Emma Halls	Chief Executive, Prostate Cancer Research Foundation
Dr Russell Hamilton	Director of Research and Development, Department of Health
Malcolm Harrison	Patient and Public Involvement advocate and independent volunteer
Prof Simon Heller	Director of Research and Development, Clinical researcher in diabetes and Chair Clinical Studies Advisory Group, Diabetes Research Network, University of Sheffield
Jeremy Hughes	Chief Executive, Breakthrough Breast Cancer
Dr David King	Director, NIHR Central Commissioning Facility (CCF)

Dr John Larsen	Head of Research and Evaluation, Rethink
Rachel Matthews	Programme Lead for Patient and Public Involvement, NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) for Northwest London
Dr Mona Nassar	Department of Health Information, German Institute for Quality and Efficiency in Healthcare. Coordinator Cochrane Developing Countries Network, Cochrane Collaboration
Prof Sandy Oliver	Professor of Public Policy, Institute of Education, University of London
Sir Nick Partridge	Chair, INVOLVE, Deputy Chair, UK Clinical Research Collaboration and Chief Executive, Terrence Higgins Trust
Dr Kay Pattison	NIHR Programme Manager, Department of Health
Nicola Perrin	Senior Policy Adviser, Wellcome Trust
Dr Sophie Petit-Zeman	Head of External Relations, Association of Medical Research Charities
Dr Morven Roberts	Trials Portfolio Manager, Medical Research Council
Jude Rogers	Independent Consultant and Event Organiser, James Lind Alliance
Tony Sargeant	NIHR Peer Reviewer, member of Commissioning Panel, Board member Greater Manchester CLAHRC, Board Member Bury Local Involvement Network
Prof Sir John Savill	Chief Scientist, Scottish Government Health Directorates
Laura Shalev Greene	Involvement and CAN manager, Breakthrough Breast Cancer
Dr Peter Sneddon	Executive Director of Clinical and Translational Operations and Funding, Cancer Research UK
Maryrose Tarpey	Project Manager, INVOLVE
Prof Peter Weissberg	Medical Director, British Heart Foundation
Dr Glenn Wells	Head of Research Programmes, Department of Health
Maxine Whitton	Patient Advocate. Cochrane Skin Group Member, Patron of Vitiligo Society
Pamela Young	Specialist Programme Manager, NIHR Evaluation, Trials and Studies Coordinating Centre

20 Building on Success

Opportunities to progress patient and public involvement in research prioritisation and commissioning



Event supported by



Building On Success

Opportunities to progress patient and public involvement in research prioritisation and commissioning

Tuesday 9th February 2010, 9am – 1pm, Chandos House, London

Co-chaired by:

Dr Russell Hamilton, Director of Research and Development, Department of Health and

Simon Denegri, Chief Executive, Association of Medical Research Charities

Programme

09.00	Registration and refreshments.
09.30	Welcome and introduction from co-chairs.
09.45	The road less travelled – the journey so far... Sir Nick Partridge Chair INVOLVE, Deputy Chair UKCRC Board
09.55	A reality check – a personal perspective, but with evidence. Lester Firkins Chair James Lind Alliance
10.15	Discussion –What is the value of public involvement in decisions of competing research need, and funding distribution?
11.00	Refreshment break.
11.30	Improving the impact of PPI in research prioritisation and commissioning. <i>Themed small discussion groups led by facilitators from James Lind Alliance and INVOLVE.</i> <ul style="list-style-type: none"> • Assessing and reporting evidence on public involvement in research prioritisation and commissioning • Creating incentives for researchers to research areas prioritised through processes where patients/public have been included • Increasing the role and value of PPI in established peer review processes for commissioning research
12.30	Feedback from the floor. <i>'Stand out' discussion points from small groups</i>
12.50	Summing up and next steps, followed by lunch at 13.00

Summary of 'Natural Ground' Report

'Building on Success' workshop: 9th February 2010



The Association of Medical Research Charities' (AMRC) report 'Natural Ground – paths to patient and public involvement (PPI) for medical research charities' was published in October 2009. It marked the culmination of an 18 month programme of work conducted by AMRC with a 'learning set' group of member charities to explore different approaches to PPI. The foreword and conclusions of the report are summarised below. Copies of the report can be downloaded from AMRC's website at: <http://www.amrc.org.uk/HOMEPAGE/Default.aspx?Nav=479,946&ith=20>

Foreword

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 adopted 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.

Conclusions

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.

INVOLVE

Summary INVOLVE Survey (2007)

Public Involvement in Health Research Commissioning and Funding Processes

Introduction

INVOLVE is funded by the National Institute for Health Research (NIHR) to support the development of active public involvement in health and social care research. As well as working with researchers and members of the public INVOLVE works with commissioners and funders of research to encourage the embedding of public involvement in the earliest possible stages of the research cycle [1].

About this survey

In 2007 INVOLVE conducted a web based snapshot survey of commissioners of health research to scope the nature and extent of public involvement in commissioning and funding processes. It included a set of questions focusing on specific activities involved in commissioning or funding decisions for health research. Thirty-two organisations responded from both the statutory and voluntary sector. This included 6 NIHR funded programmes, 3 Research Councils, 3 Offices in the Devolved Nations and 20 Medical Research Charities all of whom were members of the Association of Medical Research Charities [2].

Findings

The responses highlighted that commissioners and funders have various starting points with regard to the role and purpose of public involvement in the commissioning of health research and this depended upon whether they were part of the statutory or voluntary sector. Consequently, this created very different policies and approaches to the way in which public involvement has been developed. In the analysis of the responses it became evident that, for example:

NIHR funded programmes have been encouraged to introduce formalised and relatively standardised policies and procedures to develop implementation of public involvement within their commissioning processes. This is in line with NIHR guidance and the role INVOLVE plays within NIHR to provide such a steer to achieve greater public involvement in NIHR funded research.

However this is in contrast to some of the **medical research charities** who pointed to their constitution, membership base and volunteer structures as implicit evidence of public involvement throughout their organisations including their research funding decision-making processes [3]. Their approach to public involvement did not appear to be as formalised as the NIHR programmes.

These different perspectives were reflected in the responses to detailed questions about the extent to which certain procedures are used as a way of addressing public involvement in the various stages of the commissioning processes.

This included a set of linked questions about public involvement in **research funding applications and research reports**, whether used as a **criterion for funding research**, in **peer review** and providing related **guidance** on public involvement to applicants, peer reviewers and members of commissioning panels.

In answer to these questions, NIHR respondents reported that they asked for evidence of public involvement in outline and full research applications but did not yet follow through in interim or final reporting of research. Other respondents said they generally did not ask for evidence at any of these stages. In terms of public involvement as a criterion of funding, most (25) replied that public involvement was never or hardly ever a criterion of funding. Those that did include it always or nearly

always as a criterion came from across the different types of organisations - NIHR(3) research councils(2) and medical charities(2).

Four of the 6 NIHR programmes said they nearly always or always involve members of the public in peer reviewing for full applications but not for final reports and 3 of the medical charities reported sometimes involving people in peer reviewing final reports. Guidance was provided where relevant by the NIHR programmes for research applicants and by some of the medical research charities (6).

Public involvement in funding decisions

Across all the types of organisations who responded, half said that they always involved members of the public in funding decisions and half said they never or hardly ever involved. This included medical research charities that referred to the fact that their Board, management committee and advisory group membership by their very constitution had lay representation.

Payment covering expenses and input of time for public involvement

Respondents reported that reimbursement for expenses covering travel and subsistence are usually offered by all organisations. In addition, NIHR funded programmes are guided by payment rates agreed with the Department of Health for attending meetings, peer reviewing documents and other tasks associated with public involvement in the commissioning process.

Evaluation of public involvement

Respondents pointed to a lack of monitoring data currently collected on their involvement activities; however some were planning to evaluate public involvement in their commissioning programmes. This included the NIHR programmes and 10 medical research charities.

Concluding comment

This survey took place in 2007 and it is worth noting that since then this has been a fast changing environment as demonstrated by the AMRC's Natural Ground Report [3]. However the information provided by respondents to our survey suggests there is limited provision in place for embedding public involvement in health funding and commissioning processes. Where it does happen for one part of the process it rarely connects or is followed through to other related activities. This makes it difficult to assess and report the nature, extent or impact of public involvement on the commissioning of research [1]. More generally, the survey illustrates that public involvement in research is a complex process and reflects the need to acknowledge the very different contexts within which commissioning organisations operate.

Notes

[1] Staley (2009) *Exploring Impact: Public involvement in NHS, public health and social care research*, INVOLVE.

[2] Survey: Breakdown of respondents

Statutory Sector (12): 6 National Institute of Health Research (NIHR) funded programmes including the Policy Research Programme; 3 Research Councils - the Medical Research Council, the Economic and Social Research Council and the Biotechnology and Biomedical Sciences Research; 3 Offices of the Devolved Nations – Chief Scientist Office Scotland, Wales Office of Research and Development (WORD) and the Office for Health and Social Care Northern Ireland.

Voluntary Sector (20): These included the Alzheimer's Society, Asthma UK, BUPA Foundation (Project Grants), Motor Neurone Disease (MND) Association, Parkinson's Disease Society, Research into Ageing Sparks The Children's Medical Research Charity and the Wellcome Trust (full list available on request).

[3] AMRC (2009) *Patient and Public Involvement: Natural Ground Project* www.amrc.org.uk

Appendix 5

The James Lind Alliance Scoping research priority setting, and the presence of patient and public involvement, with UK clinical research organisations and funders

SUMMARY

Background

Research on the effects of medical treatments often overlooks the shared interests of patients and clinicians. Questions important to both these groups may not be identified by others who influence the research agenda, such as industry or academia, and vital research areas may therefore be neglected.

The James Lind Alliance (JLA) was established in 2004 to bring patients and clinicians together to identify and prioritise the unanswered questions about treatments they agree are most important. The JLA aims to raise awareness among those who fund health research of what matters to both patients and clinicians so that clinical research is relevant and beneficial to the end user.

Aims of the research

The JLA commissioned this scoping study to find out whether and how clinical research organisations currently set research priorities and whether and how patients and the public are involved in this work. Given the growing profile of the public and patient involvement agenda, the JLA was interested to see if this stated commitment was being translated into practical action.

The exercise involved a review of the websites of 104 UK clinical research organisations and further analysis of 55 of those, of which 52 fund research. Of these, 49 were voluntary sector organisations or medical charities and three were government funding bodies. Twenty two of those UK clinical research funding organisations that identify research priorities or commission research were interviewed, and a brief review of the literature on peer review and public and patient involvement in making funding decisions was conducted.

Key findings

Identifying priorities for research

- Most research funders operate in responsive mode, relying on researchers to submit ideas rather than themselves identifying priorities.
- Fewer than half the organisations surveyed state priorities for research. They are reluctant to place restrictions on researchers by asking them to address priority topics.
- The organisations which do identify research priorities do so for a range of reasons, in a number of different ways, including surveying patient members or researchers or simply relying on informal communication with them.

Involving patients and the public

- Few organisations identify the research priorities of clinicians and patients. Only a small proportion is aiming to address the priorities of both groups.
- There is a tendency to consult the research community as part of developing a research strategy, rather than consulting clinicians and patients.

- The type of patient and public involvement in decision-making processes varies between the organisations surveyed. Where patients and public are involved, they are more likely to be asked to review research proposals than to identify priorities for research which is important to them.
- There is a growing trend towards patient and public involvement among patient organisations that fund research, but the impact of this on funding decisions is not currently measured.

Challenges to identifying research priorities

- There is no agreed best practice or consistent approach for identifying priorities.
- Some organisations have faced resistance to developing a research strategy and to identifying research priorities, because researchers are concerned about the usefulness of the research and potential funding cuts.
- Where organisations have involved patients in the prioritisation process, they have found it difficult to interpret and summarise views accurately and to manage expectations of how quickly priorities can be addressed, if at all.

The current influence of research priorities

- Only a small number of organisations that identify priorities actually commission research to address them.
- A minority of organisations interviewed allocate funding solely to applications that address one of their identified research priorities.
- Most organisations do not take a systematic approach to addressing identified priorities and very few ring-fence budgets to fund prioritised research.
- Funding decisions are largely based on judgements about scientific merit, rather than on the relevance and importance of outcomes to end-users.

Recommendations for the James Lind Alliance

While this research adds to the evidence base around research priority setting and patient and public involvement, it also makes recommendations to help the JLA consider how to encourage UK clinical research funders to address the priorities of patients and clinicians, including:

- Encourage clinical research funders to rethink the purpose of identifying research priorities.
- Offer and promote a robust process for identifying and interpreting priorities.
- Share the results of its Priority Setting Partnerships, which bring patients, carers and clinicians together to identify and prioritise questions for research.
- Support Priority Setting Partnerships to develop more detailed commissioning briefs from lists of identified research priorities.
- Develop best practice for identifying and funding research priorities.

For further information

The full report is available at www.lindalliance.org.

December 2008

Appendix 6

Examples of patient and carers influencing the identification and prioritisation of basic and biomedical research

Example 1: An individual carer

In the late 1960s, there was an increased incidence of vaginal adenocarcinoma (a very rare malignant tumour) in young women. It was the mother of one of these young women who first suggested that her daughter's cancer might have resulted from exposure to the hormone (diethylstilboestrol - DES) which had been prescribed for the mother during pregnancy (Ulfelder 1980). The mother's hypothesis was confirmed in subsequent research, and thus provided the first known example of transplacental carcinogenesis.

Ulfelder H. The stilbestrol disorders in historical perspective. Cancer 1980;45:3008-3011.

Example 2: A patient group working with researchers

The genetic disease Pseudoxanthoma Elasticum (PXE) has benefited from a bespoke charity founded by a family affected with the condition. By helping to establish a Blood and Tissue Bank fellow sufferers were able to generously and eagerly generate biological samples that helped in discovering the PXE gene. As a community of families came together they networked with interested researchers forming the PXE International Research Consortium, which is now working on a clinical trial to test treatments for symptoms of the condition.

Terry S, Terry P, Rauen K, Uitto J, & Bercovitch L (2007) Advocacy groups as research organisations; the PXE International Example Nature Reviews Genetics, vol 8, no2pp 157 - 164

Example 3: Patients and carers as part of a multidisciplinary group

People with Chronic Obstructive Pulmonary Disease (COPD), asthma and kidney disease worked with clinicians and other health professionals, as well as researchers and scientists, to identify research questions.

Professionals were drawn from "a variety of medical and paramedical disciplines", including biomedical, social, clinical and epidemiological scientists researching

asthma and COPD. Initially different stakeholder groups (healthcare professionals, biomedical scientists, socio-cultural scientists and patients) identified their research priorities. A mixed group of 24 stakeholders, which included representatives from each of these groups, then met to identify a shared list of research questions and identified 14 high priority questions.

Caron-Flinterman JF, Broerse JEW, Teerling J, van Alst MLY, Klaasen S, Swart LE et al.

Patients influence. Stakeholder participation in health research agenda setting: the case of

asthma and COPD research in The Netherlands. Science and Public Policy 2006; 33(4):291-304.

Further examples can be found in:

Testing Treatments: better research for better healthcare

Imogen Evans, Hazel Thornton, Iain Chalmers, with a new foreword by Ben Goldacre

Pinter & Martin, 2010, £9.99, paperback, ISBN 978-1-905177-35-6

Exploring Impact: Public involvement in NHS public health and social care research

Staley K. (2009) INVOLVE, Eastleigh ISBN 978-0-9557053-2-8

A systematic map of studies of patients' and clinicians' research priorities.

Stewart R and Oliver S (2008) London: James Lind Alliance.

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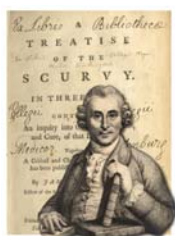
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