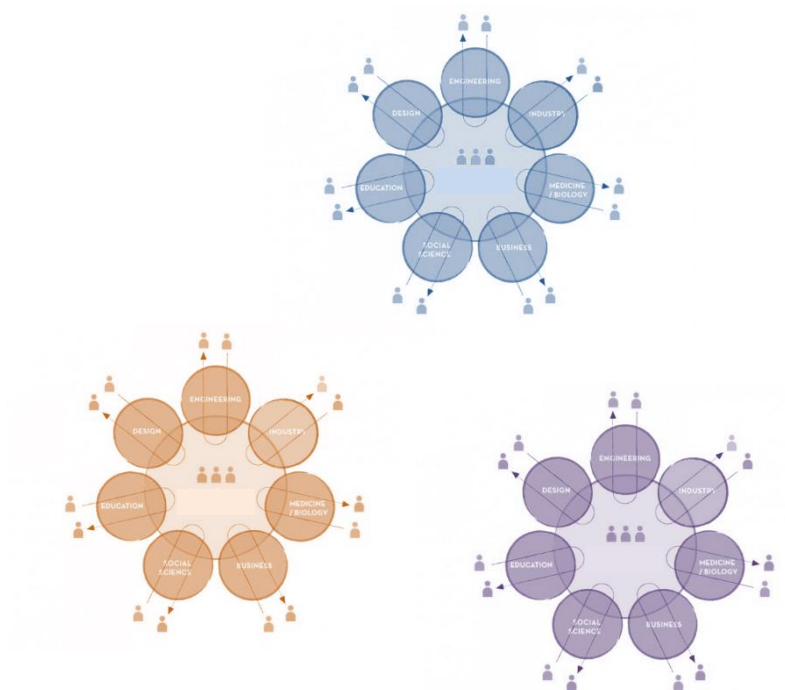


Examples of regional networks for public involvement in research



March 2016

About this report

This report has been written by **Katherine Cowan**, an independent consultant commissioned by the INVOLVE Coordinating Centre, drawing on information provided by members of the three networks included as examples.

This report is not intended to provide a critical review of existing regional networks, but to explore the characteristics of a limited number of established collaborations, in full knowledge that other models exist and flourish.

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CONTENTS

1. Introduction and background	3
2. The three examples	4
3. The benefits of regional networks	12
4. The challenges for regional networks	15
5. Opportunities for future learning	18
6. Conclusions and next steps	21

1. Introduction and background

Examples of work to support public involvement in research at a local and regional level are increasing. In many areas, research forums or networks have been established which span different parts of the National Institute for Health Research (NIHR) and include partner organisations. The approaches and models adopted vary, as does the management of information and resources. Aims may include coordinated strategic planning, pooling of resources and expertise, shared learning, and support between those who carry out patient and public involvement roles.

The Research Design Services (RDS) are currently mapping their links with local and regional networks. To complement this work, INVOLVE commissioned the development of examples of existing regional networks that are supporting public involvement in research, to explore the characteristics of successful collaborations and to highlight some of the lessons learnt in developing and maintaining these initiatives.

The aim was to inform discussions on how INVOLVE and the NIHR can best support and develop regional partnerships and their strategic coordination. It is hoped that this will support locally inspired collaborations, in line with the *Going the Extra Mile*¹ report recommendations from the *Breaking Boundaries* strategic review of public involvement in the NIHR. The report emphasises the importance of locally driven work that is strategically consistent with the NIHR's overall goals, specifically recommending the development of regional public involvement partnerships within and beyond the NIHR's boundaries.

This report gives examples of three regional partnerships, each offering a different perspective:

- East Midlands REPP (Research Engaging Patients and Public) Forum
- People in Health West of England (PHWE)
- West Midlands PILAR (Public Involvement Lay Accountability in Research and Innovation)

¹ [Going the extra mile: Improving the nation's health and wellbeing through public involvement in research](#) (2015)

It describes their development, aims, infrastructure, operation and activities. The report then goes on to explore the benefits of regional partnerships, the challenges that they can face, future learning and potential next steps.

Method

INVOLVE commissioned an independent consultant, Katherine Cowan, to carry out telephone interviews with three to four individuals, including one public contributor, from each regional group. In line with INVOLVE policy, the public contributors were paid an involvement fee for their time. The interviews were semi-structured, using an agreed interview schedule, and lasted between 30 and 60 minutes.

2. The three examples

Example 1:

East Midlands REPP (Research Engaging Patients and Public) Forum

Setting up

The East Midlands REPP started at a local level across Leicestershire, Northamptonshire and Rutland in 2008, led by the East Midlands Research Design Service (RDS). Its primary focus was the support and development of public involvement staff. A second REPP was then established to cover Nottinghamshire, Derbyshire and Lincolnshire. Its emphasis was on working with patients to showcase public involvement good practice. These two REPPs then merged to become the East Midlands REPP.

Aims and purpose

The East Midlands REPP exists to raise awareness of the importance and relevance of public involvement within healthcare research. It aims to encourage patients, members of the public and professionals to become more actively involved and engaged in research, and to encourage healthcare academic groups, networks and

other organisations to promote public involvement throughout the research process. It encourages organisations and groups within the East Midlands to work collaboratively to share best practice and knowledge in order to increase the effective implementation of public involvement. It also works to communicate local public involvement initiatives to members, partner organisations and the public.

Membership

Membership of the REPP is open to any health or research organisation in the region with an interest in or responsibility for public involvement. This includes NHS organisations, Research and Development teams, Biomedical Research Units, the Clinical Research Network East Midlands, the East Midlands Collaboration for Leadership in Applied Health Research and Care (CLAHRC) and the East Midlands Academic Health Science Network (AHSN), as well as organisations from the community and voluntary sector, such as Healthwatch. It is also open to public contributors.



Funding and resources

In 2014 the East Midlands AHSN agreed to coordinate and support three regional REPP events over the course of a year. From 2015, the REPP Steering Group is deciding on a new direction and model of working to ensure that it will continue to deliver for all stakeholders. A mapping exercise will capture the offers of each of the region's organisations and opportunities for collaboration.

Operation

The administration of the REPP is currently supported and funded by the AHSN, while the chairing and hosting of meetings is rotated between members. This includes providing rooms and refreshments. Bi-monthly meetings include presentations from guest speakers.

Public involvement

The REPP aims for patients and members of the public to be actively involved in the design and delivery of its activities. Presentations are always prepared and jointly delivered by both a professional and a public contributor. Public contributors are supported by member organisations to participate in the REPP, including the remuneration of their time and expenses.

Activities and achievements

The REPP has hosted a series of events involving presentations from guest speakers on issues such as inclusion, diversity, ethics and the barriers / enablers to effective public involvement. As well as examining local issues, national agendas are explored, such as the implications of *Going the Extra Mile*. REPP meetings have been an opportunity for individuals working in public involvement to come together and share ideas, problem solve and develop templates and resources. An online series of public involvement 'how to' guides were produced, covering a range of topics including engaging seldom heard groups, involving people as co-authors and writing about public involvement in a research funding bid. A regular newsletter, *Public Face*, publicises public involvement news and opportunities across the East Midlands.

Find out more

How to guides: <http://emahsn.org.uk/useful-document-and-links/how-to-guidance>

Public Face: <http://emahsn.org.uk/public-involvement/public-face-newsletter/>

Example 2:

People in Health West of England (PHWE)

Setting up

PHWE was formally established in 2014, building on the work of People in Research West of England (PRWE), a smaller initiative that provided advice and information to professionals and members of the public involved in health and social care research. An evaluation found that PRWE was a valuable resource. When its funding period came to an end, with strong input from the West of England Academic Health Science Network (AHSN), PHWE was formed in order to develop a wider reaching public involvement initiative working across health research, commissioning and service provision.

Aims and purpose

PHWE aims to create a critical mass of networks, organisations and individuals working on patient and public involvement. The goal is to enable collaboration, the pooling of resources, knowledge and expertise, and mutual support for those working in public involvement, not just in research but also service improvement and commissioning.

West of England Academic Health Science Network Map

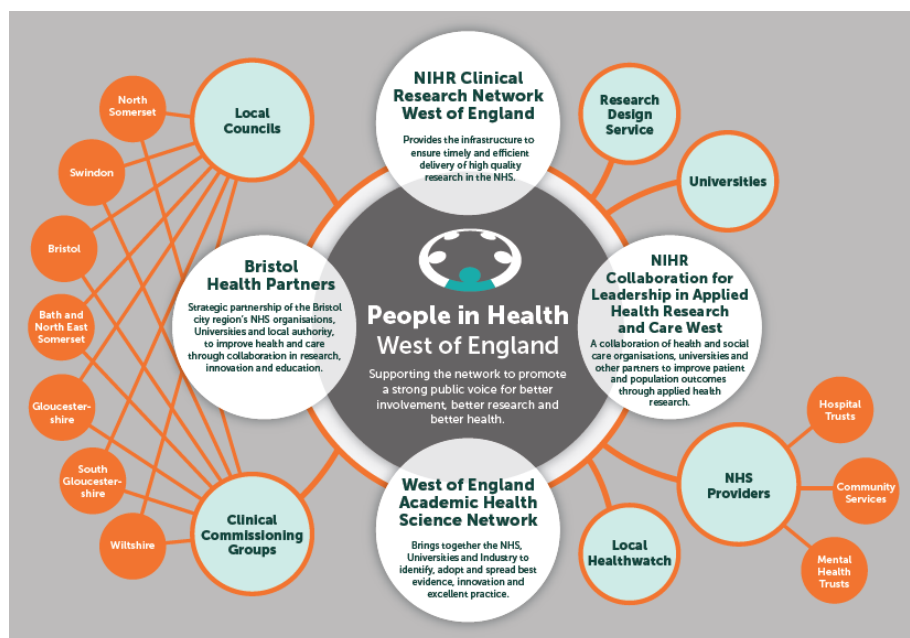
A	South Gloucestershire
B	Bristol
C	North Somerset
D	Bath and North East Somerset
E	Gloucestershire
F	Swindon
G	Wiltshire



Membership

PHWE brings together four networks as core partners: West of England AHSN, Collaboration for Leadership in Applied Health Research and Care (CLAHRC) West, Clinical Research Network (CRN) West of England and Bristol Health Partners. Additional partners include the University of the West of England (UWE) (which provides the academic lead), the Health Protection Research Unit (HPRU)

Evaluation, the Research Design Service South West, the Cardiovascular Biomedical Research Unit (BRU) and local Healthwatch. More widely, PHWE links with Universities, NHS providers, local authorities and the Clinical Commissioning Groups in the region. Boundaries are aligned with the AHSN and CRN boundaries.



Funding and resources

Funding and resources are pooled between the four core partners, and other partners that have chosen to do so, in particular UWE, HPRU and the BRU. This makes a shared budget available for meetings, events, resource development and public contributor input. Agreements with local Human Resources teams have been negotiated to create a core team of public involvement staff employed by the respective partner organisations.

Operation

PHWE is staffed by a core team of eight people. This is a co-managed public involvement team working across all four core partners. Significant negotiations took place to ensure the cross-organisational model would work in terms of contracts, policies and finance. This team is part of a wider Strategy Group that meets every two months and also includes eight public contributors. The core team is co-located in two sites (CLAHRC and UWE). It meets fortnightly and the public contributors also meet on their own every two months. The directors of the core partner organisations

examine the overall governance of the initiative annually, and an evaluation programme is running across all the partners to develop methodology for evaluating public involvement.

Public involvement

PWHE is committed to having an equal number of public contributors and professionals on its Strategy Group. Eight members of the public were appointed following an open recruitment process – along with representatives of the four core partners – to form a Strategy Group working across all four networks. Each core partner supports two public contributors to sit on the group and to sit within their respective executive groups or boards. Public contributors are remunerated on an hourly rate from a budget to which the partners have allocated funds. The opportunity to meet separately from the core team has helped the eight public contributors to clarify their perspective and feel more confident expressing it.

Activities and achievements

PHWE promotes public involvement among professionals and members of the public through publicising involvement opportunities in the West of England and nationally, delivering training to the public and researchers, running conferences and seminars, and by sharing news through its website and fortnightly newsletter. The activities also deliver on the core partners' business and strategic goals for public involvement, as part of a collective work programme. Relationships are being built across the region with researchers and patient / citizen groups, including marginalised communities. PWHE provides a link to these groups if researchers are looking for particular groups to involve. Workshops have been held to support members of the public to suggest ideas for research and an Electronic Citizens Panel has been formed to enable interested members of the public to comment on new materials and ideas. Internally, a journal club and a writing group have been established to help the team develop their skills and thinking.

Find out more

PHWE website: www.phwe.org.uk/

PHWE Annual Report 2014-15: www.phwe.org.uk/wp-content/uploads/2015/05/PHWE-Annual-Report-2014-15.pdf

PHWE resources and guides: www.phwe.org.uk/resources/phwe-resources-guides/

Example 3:

West Midlands PILAR (Public Involvement and Lay Accountability in Research and Innovation)

Setting up

PILAR is a leadership forum that was established in 2013. It is a strategic partnership of professional and lay leaders in public involvement in research and in service quality improvement in the West Midlands. Initial discussions to explore the idea of a regional partnership took place between public involvement leads in the Research Design Service (RDS) West Midlands, the West Midlands Collaboration for Leadership in Applied Health Research and Care (CLAHRC) and the West Midlands Clinical Research Network (CRN). The group was convened to ensure it reflected the whole research cycle.

Aims and purpose

The overarching purpose of PILAR is to promote patient and public involvement and engagement in health research in the West Midlands. It aims to encourage patients, the public, researchers and health care professionals to realise the potential of public involvement, and to ensure that it is embedded in all stages of research and into practice and innovation. PILAR works to improve the ways in which the public can learn about and become involved in research and provides leadership to encourage NIHR and research organisations to adopt INVOLVE's Values and Principles Framework for public involvement in research. It also aims to improve the diversity and inclusiveness of public involvement in research in the West Midlands. It encourages members to coordinate, share learning and good practice, and not duplicate their efforts.



Membership

Members are selected because they have influence and can make a difference within their organisation in terms of public involvement. They include at least one professional and lay representative from each of the West Midlands CLAHRC, the West Midlands AHSN, the RDS and the West Midlands Strategic Clinical Networks (part of NHS England), as well as other NIHR and NHS organisations in the West Midlands including the CRN, Biomedical Research Unit and the Clinical Research Facility. All members provide a strategic viewpoint on public involvement issues. Representatives from other organisations are invited, according to the needs of the network.

Funding and resources

PILAR has no direct funding. Hosting of meetings is done in rotation, with the host organisation covering the costs of the venue and refreshments. Its operation is coordinated by the RDS.

Operation

The RDS provides the secretariat for PILAR, in the form of a coordinator and an administrator, whose involvement in the network is integrated into their existing role. Members meet every quarter, either in person or via telephone-conferencing to share updates and plan and reflect on the PILAR strategy. An internet-based Hub has been set up to enable sharing of information between meetings. Members are also kept informed via email about public involvement developments and local events, enabling them to cascade that information within their own organisations.

Public involvement

The Chair of PILAR is a public contributor, and this is written into its Terms of Reference. All members (professional and lay) are expected to provide a strategic viewpoint on a range of issues related to public involvement. A role description sets out expectations and specifications. The public contributors are linked to a health or research organisation and may be able to claim for their time and travel according to that organisation's policy. All members have access to the network's coordinator who can offer guidance on procedures and the materials sent prior to meetings, and answer any questions or concerns.

Activities and achievements

PILAR has designed its work programme to address three priorities drawn from *Going the Extra Mile*: to improve the ways in which the public can learn about and become involved in research; to provide regional leadership for public involvement in NIHR and other research organisations; and to improve the diversity and inclusiveness of public involvement in research in the West Midlands. The PILAR Hub, an online shared resource for members, brings together best practice examples, information about events, public involvement evidence and relevant training materials, as well as PILAR documentation, agendas and minutes. Currently it is a closed resource for PILAR members, but there are plans to develop it into a public resource as part of a future PILAR website.

Find out more

Contact Dr Steven Blackburn, PILAR Coordinator: s.blackburn@keele.ac.uk.

3. The benefits of regional networks

It was clear from the interviews across the three regions that the development of a regional network for public involvement could be advantageous on many levels. This section explores the benefits in terms of public involvement itself, as well as for the organisations and individuals that collaborate.

Benefits for public involvement in research

A key benefit for improving public involvement in research is that a regional partnership creates a critical mass of expertise, knowledge, resources and relationships. Bringing together different research and health organisations is an opportunity to embed public involvement throughout the research cycle regionally, from the design and delivery of research, to the implementation of research findings and service delivery improvement.

Understanding the current nature of public involvement at a regional level will help to identify gaps in knowledge as well as duplication in delivery. It may also be a chance

to understand gaps in expertise and therefore work regionally to offer opportunities for learning and development for the public and professionals delivering public involvement, to efficiently work together, rather than address the same limitations separately.

It was clear from the interviews that coordinating involvement at a regional level can help minimise duplication of effort and create opportunities for collaboration. In practical terms, developing this at a regional level can minimise the risk of researchers continually trying to involve or consult with the same communities, by sharing networks and spreading their reach, potentially bringing more diverse groups into research.

Benefits for the organisations

By enabling public involvement contributors and professionals to network at a regional level, organisations can benefit from an enhanced public involvement resource. Networks can bring together people with different skill sets, enabling members and their individual organisations to learn new concepts and ways of working. Access to each other's' materials, knowledge and evidence can save time and money. They can provide access to public contributors who are well connected and knowledgeable.

A regional partnership may provide better means of communication. Members bring their own networks and can use those to cascade information about public involvement opportunities, raising awareness about the remits and activities of the different organisations among new audiences.

Regional networks can also create a unified regional voice that can contribute powerfully to national policy and consultation processes, rather than inputting separately, with potential duplication or inconsistency. Collaboration may extend to events, conferences and the development of resources, again drawing on a wider network of expertise and with potentially increased efficiency and reach.

When networks identify specific issues to address, all member organisations can benefit. Developing strategies to address challenges, a network can draw on the expertise and connections of multiple sources, and produce a knowledge base that all members, and the research communities they host and support, can benefit from.

Regional networking builds useful relationships and awareness of different organisations' activities. As well as sharing ideas, this may instil a healthy sense of competition, and an improvement in the delivery of public involvement.

Benefits for the individual members

For staff working in public involvement, a clear benefit of network membership is the opportunity to learn and acquire new ideas, solutions, approaches, resources, research and materials. In some organisations, individuals may work alone or in very small teams. A regional network enables a connection with peers and a source of shared learning and development.

With this, comes peer support. This is especially valuable for those working in an environment where public involvement is not yet universally understood, supported or prioritised. In a structured regional setting, shared frustrations can be aired in a positive and productive way. Indeed, public involvement work can be challenging. Members of the public may find the work physically and emotionally challenging, and the salaried professionals supporting them can find the work difficult and emotionally draining. Bringing people together can help them process the challenges they are dealing with as part of a community, rather than in isolation. This is good for morale and motivation.

For public contributors, a regional setting can also provide a new perspective and generate ideas and awareness of the breadth of public involvement activity and methodology. It can also help people – both public contributors and salaried staff - to demystify and map the complex research and healthcare delivery landscape, and understand how different organisations fit together. In the interviews, some public contributors described feeling increasingly valued and trusted as they developed their contribution at regional level.

4. The challenges for regional networks

While the benefits of regional networks for public involvement are clear, a number of associated challenges also emerged from the interviews. These range from the strategic to the operational, along with challenges for the individuals involved.

Strategic challenges

There is no template for setting up and maintaining a regional network for public involvement. Networks can draw on other national groups' experiences, such as the AHSNs, but regional networks for public involvement are a relatively new concept, so the process of establishing and sustaining a group is evolving. Current groups are learning in action.

Existing networks have reported taking an inclusive approach to collaboration, involving the multiple organisations working on public involvement across the NIHR family and within NHS organisations. However where one organisation takes the lead, difficulties may arise if they are perceived to take credit for success, or the backlash for challenges. A regional network needs to be co-owned, with more than one organisation taking responsibility for the delivery of its aims, regardless of the point of coordination or resource provision.

It may be a challenge to agree a remit and shared purpose that will benefit all member organisations and public involvement across the region. Decisions may include whether a group will be purely strategic, working with leaders for public involvement to support their work; or more operational, developing resources and activities for researchers and the public.

Developing a work programme that delivers on the public involvement priorities of a range of different partner organisations may take time. This includes identifying common agendas and working out how to develop overarching priorities that will address the local or contextual concerns of the different partners. Different organisations may have very different motivations for participating in networks or interests in what public involvement aims to achieve. They may also define their geographical boundaries differently.

As with much public involvement activity, attracting diverse members, particularly in terms of the public contributors, can be difficult. Diversity is often an issue that regional groups focus on, but their membership may not reflect the communities that they are trying to reach. In addition, the ways in which partner organisations approach public involvement may vary, with some much more able to support and remunerate their public contributors than others. Some organisations may have the confidence and experience of working with a co-production model, while others may not.

It may also be difficult for a regional network to demonstrate its value or impact in the measurable terms that some, including those in a position to provide resources, may expect.

Operational challenges

The infrastructure of a regional network needs planning. Challenges will almost certainly arise if there is no continuity in the coordination and administration of the group, including meeting arrangements and member database and website maintenance. Where coordination is centralised, staff might be required to use booking and finance systems in other institutions. When working across organisational boundaries there may also be resource required to negotiate contracts and, potentially, line management responsibilities.

The cost of events, meetings and other activities may impose a limitation on what the group can undertake and achieve. If a network is not able to hold a central budget, it may look to the member organisations to provide resource, including the remuneration of public contributors. Organisations' payment policies and systems may vary, leading to an inconsistency in whether public contributors are offered payment for their time and how this is processed. A network may benefit from additional involvement from its public contributors, to deliver discrete activities on top of regular meetings, and will need to consider how to resource this.

Time can be an issue. Most groups require input from individuals who have a day job. Depending on the level of support their employer offers them, they may struggle to make a consistent and sustained commitment. Public involvement teams are rarely large, so taking time out to contribute to a regional group can be problematic.

Deciding on the location of meetings may not be straightforward. In larger regions substantial travel time might be required of at least some members. While telephone conferencing is an option, it is generally agreed that some face-to-face time is needed for a partnership to gel.

Maintaining momentum, interest and relevance is also a challenge to consider. Many networks that are not operating as full time entities are only convening around once every two to three months. The productivity of the Network will depend on the commitment and input of all the members.

Challenges for individuals

Individual members, whether salaried staff or public contributors, may struggle to define their role within a regional group. Knowledge, experience, seniority and confidence can all impact on the ability to input and affect change in the network and in their own organisation. If an individual's employer does not prioritise public involvement, it can be difficult for that person to justify the time they may spend on the group. Demonstrating an impact can be difficult. Members might not receive feedback on the difference their contribution is making.

Public contributors may only be engaging with the network at meetings, and may not have capacity to carry out work between times. Thought may need to be given to how to maintain their interest without burdening them or expecting more than can be resourced. Public contributors may also need time to become accustomed to a regional group and to understand the wide context and level at which it operates.

Indeed, the complex and ever-changing nature of the health research arena, and the NHS more broadly, can be bewildering for individual members, particularly public contributors who are newer to the work. Public involvement in a research project is contained, defined and usually directly relevant to the experience of an individual. Involvement at regional level may be less so. Understanding how the different organisations work together and applying principles of public involvement at a strategic level can be difficult if it is not well-defined at the start. Being assertive in a strategic setting may be a challenge for both professionals and public contributors, and asking questions may be intimidating.

5. Opportunities for future learning

The three examples offer different learning points based on varied approaches to establishing a regional network for public involvement. This section describes a number of the factors that were observed to have worked well in the development of the three networks. It then goes on to discuss where there might be scope to build on this work for existing regional networks, and for regions where a network is yet to be convened.

Success factors

It is clear from the three examples that many of the challenges can be addressed, and that the development of a successful regional network for public involvement is likely to be underpinned by a number of key factors.

Senior leadership: Many regional groups have been established on the back of relationships made at senior level within the participating organisations. Those good relationships are vital in gaining commitment, resource and support. With senior support, a regional network will have greater influence.

Resources and funding: While not all regional networks operate with funding, it has been suggested that the resourcing of the coordination of the group, as well as the public contributors, is a key success factor. This may take the form of one or more jointly-funded posts, or simply a person whose role in the group is formally integrated into their existing job. Funding for public contributors may come via specific member organisations, or from a shared budget. Whatever the arrangement, it should be clear, discussed and agreed up front, and regularly reviewed.

Central coordination and administration: A network needs at least one coordinator and administrator to organise and maintain it. They will manage activities, maintain member databases, arrange meetings (bookings, agendas, minutes), coordinate resources (such as website or shared drives), be a first point of contact and support for public contributors.

Taking time to plan: A network's remit and ways of working need to be planned for. This can take time. Different members' contributions and requirements should be

considered in order to develop a strategy that is practical, realistic and can meet expectations within the time and budget available.

Allowing momentum to build: It may take time to attract the interest of regional and local organisations and members of the public. The experience of existing groups suggests that initial low-attendance should not be viewed as discouraging.

A clear remit: A network's purpose must be clear and easy to understand. This is especially important given the complexity of the health research and NHS landscape. Not all members or potential stakeholders will automatically understand this context or how the different partners fit together.

Clear roles and responsibilities: It is important to ensure all members – public and professional - agree what their role is within a regional group. Each individual should have a clear idea of what they are expected to contribute, underpinned by a code of conduct. This is particularly important for public contributors, whose role may not be defined by a condition or a specific experience, as it would often be in a research project. A clear role description is vital, and an induction programme may be useful.

Agreeing manageable priorities: Regional groups rely on the input of people with existing organisational and personal commitments. It is therefore important that the aims and objectives are clear, uncomplicated and achievable. Over-ambitious plans may lead to disengagement.

A programme of activities: Networks must actively maintain momentum and track impact. Existing groups advise that annual events are not enough. Meetings may only take place quarterly, but reporting and promotion should be regular to ensure members address their actions and see progress.

Taking a national perspective: Existing networks remain relevant by delivering on regional needs while reflecting national best practice and responding to national agendas. Going the Extra Mile has been instrumental in providing focus and enabling the prioritisation of key public involvement objectives regionally.

Partnership and ownership: Genuine partnership working and buy-in from those partners are key factors in a successful regional network. A shared sense of ownership, through defined roles, strategy and resourcing, will encourage commitment.

A collaborative ethos: Regional networks depend on collaboration between organisations and individual members. Some existing members have suggested that the naturally collaborative culture of public involvement, where people are open to sharing ideas, lends itself well to a regional way of working.

Creating an identity: A regional network may seek to create a recognisable identity through a name, a logo or basic branding. This is likely to provide a clearer message about the group's regional identity than relying heavily on the identity or image of a host or funding partner, which may create assumptions about the group's ownership or remit. This may be a core cost consideration.

Communication: Communication between members can help maintain momentum and motivation to contribute to the network. Communication with wider partners and stakeholders, including researchers and the public, can promote the group as a resource, as well as flag opportunities for public involvement across the region. This might be through e-bulletins, websites, social media or traditional newsletters, depending on the time and resources available.

Taking time to review: There is no blueprint for regional networks for public involvement. Those that have formed have done so with a pioneering spirit. As a partnership evolves it is important to reflect on its achievements, its limitations and its value to both members and public involvement in the region. Over time, it may need to revise its purpose and its membership to remain relevant.

Valuing members: Members will bring a range of experience, expertise, styles, knowledge and networks. The contribution of public members and professionals, regardless of their organisation, should be acknowledged as equally valuable.

Evaluation: Networks should plan for how they will demonstrate their impact and value for public involvement in the region. Being able to articulate and eventually demonstrate this will be of benefit to the development of the group as well as to the individual members whose organisations support their attendance.

6. Conclusion and next steps

This report has brought together three examples of regional networks for public involvement. It has described different models for convening and resourcing a regional network, and the successes and challenges they have faced. Regional networks operate within a complex, multi-disciplinary environment. They require collaboration between diverse partners and commitment from busy individuals. Networks need time, resource and consistent coordination to function well.

The interviews indicated an appetite for regionally coordinated approaches to public involvement. Even in areas with little or no resource, the buy-in of key research and health organisations is strong.

The absence of national guidance and support for the development of regional networks was noted. It was suggested that this could provide steer, accountability and coordination between regions and across NIHR's organisations. It was also felt that there is a need to give greater consideration to how to demonstrate the value of regional working for public involvement. Demonstrating their value is critical to long-term sustainability.

Nevertheless, some were wary of the notion of too many centralised arrangements for regional networks. It was felt that networks needed to operate independently and flexibly, to respond to the unique needs of their populations and their partner organisations. While a shared set of principles and broad objectives could be useful, it would be important to avoid imposing an inflexible approach and potentially inappropriate structure.

Some interviewees indicated that they would like to see a national network of regional groups developed. Many regions have features in common, such as large rural areas and areas of high ethnic diversity. A network of networks could be an opportunity to share experiences of addressing the issues these raise for public involvement, at a regional level. It would also enable networks to compare and contrast operational approaches and infrastructures, to learn and share ideas.

It was broadly felt that the agenda should be led nationally, and that lessons could be learned from the shared learning initiatives within the CLAHRCs, the RDSs and

others across the NIHR family. It was suggested that work was needed to establish what is working well within existing networks and where they need additional support, and to then identify regions where partnerships actually need to start developing.

It was however noted that regional networks are affected by potential changes in national policies. There were concerns that while the AHSNs have provided a strong focus on public involvement in service delivery, there is uncertainty as to what will happen when their initial licenses run out, and the implications this will have for regional groups.

The following questions were posed for the INVOLVE and RDS partnership, NIHR and the wider public involvement community:

- Could a network of regional networks for public involvement be nationally coordinated?
- Could practical guidance on how to collaborate regionally for public involvement be developed?
- Could the developing of ideas for demonstrating the impact of regional networks be facilitated?
- Could an INVOLVE member or other nationally-connected representative be assigned to sit on each regional group?
- Would official INVOLVE or NIHR endorsement of a regional group help to recruit more members, particularly from organisations which continue not to prioritise public involvement?
- Could national funding be allocated to cover the core costs of regional networks?

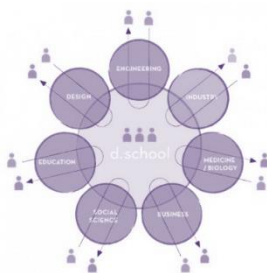
INVOLVE commissioned this report because it recognised the variation in approaches, and the need to explore the opportunities and challenges of establishing and sustaining regional networks for public involvement. The new INVOLVE contract is a partnership between the Coordinating Centre team at the Wessex Institute, University of Southampton and the hosts of the NIHR RDS. The

primary reason for establishing this partnership was to support improved national to regional ways of working, in line with the *Going the Extra Mile* recommendations.

In developing its plans to address the challenges identified in this report, INVOLVE will work closely with RDS public involvement leads and directors, to stimulate discussion with existing networks, regional partners and communities, and to explore opportunities in regions without established networks. The INVOLVE-RDS partnership's initial approach will be to facilitate, guide and advise a small number of regions so that solutions can be developed that best meet the local needs, and for these to be shared with other regions in time. A fundamental principle in undertaking this work will be that one size will not fit all, as has been highlighted in this report.

INVOLVE is a national advisory body that is funded by the National Institute for Health Research to promote and support public involvement in NHS, public health and social care research.

If you would like to know more about what we do, please contact us:



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