Working Together: A toolkit for health professionals on how to involve the public

People in Health
West of England

Better involvement · Better research · Better health

West of England
Academic Health
Science Network

Acknowledgements

This Toolkit has been written with the encouragement and support from a number of staff and public contributors from both the West of England Academic Science Network and People in Health West of England.

In particular I would like to thank the following for their suggestions, taking the time to read early drafts and providing me with helpful comments. These include Anna Burhouse, Rosie Davies, Peter Dixon, Chris Dunn, Dave Evans, David Evans, Deborah Evans, Andy Gibson, Natasha Owen, Joanna Parker, Emma Stone, Natasha Swinscoe, Sandra Tweddl, Adele Webb. In addition I would like to thank Nathalie Delaney for formatting the text into a Toolkit template.

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This document is version 1.0 August 2016

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Why a Public Involvement Toolkit?

As a result of legislation and current policy in health and social care, involving the public (service users, their families, carers and citizens) is increasingly becoming the 'way we do things'. Co-production as a method of involvement is also being increasingly promoted. Many clinicians are unprepared for this and whilst there are several Toolkits or guides available (see section on Useful Resources) they are each written with a specific target audience in mind, such as commissioners or researchers. There is little available for busy clinicians and other healthcare professionals who need something they can use in their daily practice.

The interpretation of 'involvement' and co-production can vary between the different disciplines of health research, quality improvement, service provision and commissioning. These can be confusing for staff on the ground, who then may not be sure whether they are doing the 'right' thing. This Toolkit aims to reassure and encourage the practical application of involvement and co-production.

Toolkits by their very nature are intended to be of immediate practical use. As policy changes, they become out of date. Users of the Toolkit should bear this in mind. However the principles of involvement and the practical applications suggested should apply whatever policy changes take place.

Who this toolkit is for

Whilst this toolkit has been written with the busy, front line clinician in mind, it should be useful for anyone who wants a beginner's guide to understanding public involvement in the health sector.

How to use it

The toolkit has been designed to be a quick reference tool on 'how to do it', with links taking you to more detailed text that explains either the theoretical framework in more depth or offers practical suggestions. It draws on both research and quality improvement traditions. Attention is drawn to where there are differences. Where a topic has been addressed usefully elsewhere, the reader is directed to that source.

Definition of involvement

For the purposes of this toolkit, involvement refers to:

All activities and interventions that involve the public (service users, their families, carers and citizens) in health research, the design of services and the shared decisions made about the care of their health and well-being.

For detailed discussion see the **Terminology** section.

'Sandra is an invaluable member of our team. She's been with us from the start bringing her contacts with local and national networks. Sandra has really helped the vision of our project come alive, bringing to life what the project will mean for people with diabetes.'

Dr Elizabeth Dymond, WEAHSN

'My independence is really important to me. Although I've got a disability (cerebral palsy) in my head I'm not disabled. So I want to do what everyone else can do. That's one of the reasons why I wanted to take part in the workshops. '

Bethan Griffiths attendee at Design Together Live Better workshop

'Public members bring another perspective. Having a fresh wind blowing in now and again (from the lay perspective) acts as a fail-safe device.'

Public contributor with People in Health West of England

Because we have to

There are a number of pieces of legislation that support the implementation of public involvement, in particular, The Health & Social Care Act of 2012. This placed duties on Clinical Commissioning Groups (CCGs) and NHS England to promote the involvement of patients and carers in decisions which relate to their care or treatment. The Act also places a requirement on CCGs and NHS England to ensure public involvement and consultation in commissioning processes and decisions.

In support of this, the NHS Standard Contract, that is applicable to any provider of NHS services, states that providers must actively engage with the public and involve them in service redesign and implementation of new developments. .

The evidence is that it makes interventions more effective and efficient

There is increasing evidence that patients who are involved in making decisions about their own condition show faster rates of recovery. It has also been shown that involving people in all aspects of the development and provision of health services makes it more effective; involvement in research ensures that the focus is on areas that patients and the public want to know more about and involvement in the design and provision of services makes sure that services are designed to fit round the requirements of patients and their carers.

Because it is the right thing to do

It is increasingly recognised that it is ethical to involve patients and their carers in any decision that affects their health care. Involving the public at all levels of health helps to create a culture of openness and transparency and prevent a repeat of some of the scandals that have hit the headlines such as occurred in Mid-Staffordshire.

Increases a sense of wellbeing amongst the public

Involving people can make a contribution to the general well-being of society. Carers and families who are closely involved in sharing the management of a health condition have a greater understanding of the issues and the choices available and as a result are less stressed.

Volunteering generally has been found to be beneficial to general sense of well-being. The social nature of the activity and the sense of contributing altruistically to the greater good of society helps to alleviate loneliness and develop a stronger feeling of usefulness. Those who are involved in the health sector as volunteers or as public contributors also benefit and report an increased sense of well-being.

Health services that meet the needs of the public

A public that is involved at all stages of design and implementation are more likely to understand the restraints on the provision of healthcare. The Five Year Forward View aims to establish health as a social movement. This can only be done if there is a culture of involvement and inclusivity.

Effectiveness of research

The Chief Medical Officer, Dame Sally Davis has led the way in promoting public involvement in research to ensure that research undertaken in the NHS reflects the health needs of our population. Research that involves the public from the beginning is more likely to be relevant and effective. Patients do better in research active Trusts.

The words associated with public involvement are used interchangably which can be confusing. Here is a guide to some key terms:

Citizen Engagement
Introduced by NHS England to democratise the relationship between the public and NHS. The term 'citizen' is increasingly being used to denote a shared responsibility for services between health professionals and the general public

Co-production
Co-production is often used to describe the relationship between service user and professional in health and social care, for example in shared decision-making and social prescribing. The important ingredient that all these 'co-'words share: co-produce, co-design and co-create, is an approach which regards each individual, regardless of their role, as having a valuable contribution to make. Central to this approach are principles of reciprocity and equality.

Engagement
Information and knowledge is provided and disseminated

Health research
INVOLVE, the body supporting active public involvement in NHS, public health and social care research defines public involvement in research as 'research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials and undertaking interviews with research participants.' (www.invo.org.uk).

Health service improvement
Policy and legislation issued by the NHS defines involvement in terms of individual patient participation in the planning and management of their care and patient choice. The Five Year Forward View refers to NHS Citizens, volunteering, supporting carers and working with voluntary organisations as some of the ways of involving the public.

Participation
People taking part in a research study as participants for example in clinical trials.

Patient Experience
Used in relation to measuring the experience of services and derived from surveys such as the Friends & Family Test and other activities.

Patient participation
Refers to the role of patients in shared decision-making around the management of their condition

Patient Participation Groups (PPGs)
Set up by GP practices to involve their patients in improving their services

Public Involvement
Patients and members of the public are actively involved in helping to design and share research projects and service improvement. There should be a named person in your organisations leading on public involvement in research and someone leading on public involvement in service improvement

People who engage or get involved can be called...

- Service User
- Patient
- Carer
- Public Contributor
- Lay Representative
- Patient Representative
- Patient Ambassador
- Expert by Experience

These terms are used depending on personal preference, the situation or clinical specialty.

What types of involvement and when should we use them?

Involvement can take place at three different levels:

The individual, including:

- Shared decision-making and self-care
- Participant in a research project
- Helping you co-design services
- Acting as observers
- Giving you individual feedback

Small groups, including

- Existing condition specific support groups
- Advisory groups, steering groups, governance bodies
- Focus groups or discussion groups

Broader engagement activities including

- Events
- Communicating with Trust membership
- Developing relationships with charitable/voluntary sector
- Using social media

Involvement as an individual

In addition to their experiences of being a patient, members of the public bring other useful skills and experiences. Retired health professionals are able to bridge the world of patient and professional and offer an institutional memory, preventing services from re-inventing the wheel. Others can act as a critical friend, asking the questions that staff and patients feel too inhibited to ask. For more on the roles that public contributors can fulfil, see the NIHR's Menu of Service User Involvement: https://www.crn.nihr.ac.uk/wp-content/uploads/mentalhealth/sites/21/Menu-of-service-user-involvement.pdf

Public contributors can also bring a fresh approach to identifying solutions to service improvement. For more on this see the Kings Fund Experience Based Design Toolkit http://www.kingsfund.org.uk/projects/ebcd/carrying-out-observations

Joanna Parker is a public contributor on the WEAHSN Patient Safety Collaborative Board

I formally retired six years ago, having worked at regional and national levels in healthcare for the last 15 years of my career; the last seven specifically in patient safety.

I am a volunteer with Healthwatch South Gloucestershire and their 'Enter and View' lead, and also Chair of the Healthwatch Advisory Group.

Since my retirement I've discovered what it means to be on the receiving end of healthcare and it has amazed me. I've had positive and negative experiences, and been the 'victim' of two patient safety incidents. Although I think I can be assertive and articulate and know my way around the 'system', my voice has often not been heard in the care process, or it is ignored, and I've been left feeling disempowered and disappointed.

My work experience, my experience as a patient, and my belief that patients should be 'co-producers' of care, make me feel passionate about trying to improve patient experience and patient safety.

Karen Gleave, from Sirona Care describes how patients can contribute to staff induction:

Stephen is a service user living in one of our Extra Care Services, and is a volunteer with Sirona Care & Health. He also sits on the service user panel/ forum. The panel aims to embed service user voices at the heart of the organisation and they collaborate on, and are consulted about, a wide variety of issues.

I met Stephen just over a year ago when I approached members of the panel about working with me to provide a service user perspective on what it is like to receive a service for the Sirona support worker Induction. Once Stephen started it became quickly apparent that he was a "natural" talking with people and able to get his message across about how important communication and human factors are when supporting people. Stephen is able to bring the scenarios alive for the audience and has made people laugh, and at times brought people to tears.

On the back of this success, and with the introduction of the Care Certificate our organisational induction went through a period of change. Stephen now talks to all staff at Induction as we felt that his message is relevant to all staff irrelevant of their role.

Stephen is very eloquent and speaks with such passion as to the importance of staff teams and particularly support workers in his daily life. By Stephen sharing his story he is able to show how the differing teams and services across Sirona and across Health and Social Care have supported him along the whole pathway, from the Social Work Team to Reablement, Physio, Extra Care etc. and how Sirona has supported Stephen to "get his life back."

Focus or discussion groups

The term focus group has a specific meaning in qualitative research. To avoid confusion, in the context of public involvement it is advisable to use the term 'discussion group'. This describes a workshop that brings people together to focus on a particular aspect of healthcare. Careful thought needs to be put into the running of this – how where and when - and a skilled facilitator used to run it. By bringing people together experiences get shared and ideas and suggestions for improvement stimulated. For a useful guide on how to go about setting up a focus group visit the Scottish Health Council's Participation Toolkit on Focus Groups http://www.scottishhealthcouncil.org/patient__public_participation/participation_toolkit/the_participation_toolkit.aspx#.V5jF70YrIsY

Advisory/ steering/ reference groups, governing bodies/ public involvement forums

The value of having a member of the public participating at Board level or on advisory and steering groups as a way of involving the public in your work should not be underestimated. They provide the voice of the critical friend and assurance of public accountability.

Sirona Care Services – service user panel

The Service User Panel is made up of members of the public and service users who have an interest in health and social care at Sirona. The Panel has been in existence since 2010. At present we have eleven members from across Bath & North East Somerset and South Gloucestershire. The Panel's role is to be an organisation-wide body that works at a strategic planning level within Sirona. The Panel aims to embed service user voices at the heart of the organisation and they collaborate on, and are consulted about, a wide variety of issues. Over the past year they have been consulted on, amongst other things, the following:

- Service user information leaflets e.g. a chaperone poster for the Community Neuro and Stroke Service, a Stop Abuse leaflet and poster for the Local Safeguarding Adults Board, a pressure ulcers leaflet and the End of Life Care Strategy;
- The new Integrated Respiratory Service and the new Diabetes Specialist Nursing Service in South Gloucestershire;
- The BANES Your Care Your Way review of health and social care.

Communication team

Link in with your communications team to organise large scale events as they will have the expertise and contacts in place.

Trust membership

Most acute services have a membership list of hundreds of former or current patients with regular mail outs. This network is a valuable way to reach out to involve patients, their carers and families.

Voluntary/ third sector

Many voluntary and 3rd sector organisations have been set up to support people with specific conditions. Some are large organisations such as Diabetes UK, MacMillan Trust and Dementia UK. Others are small, local self-help organisations. It is always useful to have initial conversations with these organisations when thinking about what kind of involvement is suitable. Most areas still have some kind of umbrella organisation that supports voluntary organisations locally, though with funding cuts these are fast disappearing. You can find out from them which voluntary sector organisations are operational in your area.

For example, at the time of writing, Swindon has Voluntary Action Swindon (www.vas-swindon.org), Wiltshire has Community First (www.communityfirst.org.uk), Gloucestershire has VCS Alliance (www.glosvcsalliance.org.uk/contact) and Bristol VOSCUR (www.voscur.org). For other areas try the National Association for Voluntary and Community Action website (www.navca.org.uk)

The Design Together Live Better (DTLB) initiative

DTLB is a co-design project aimed at sourcing ideas from members of the public living with challenging health conditions and teaming them up with product designers to co-create new concepts that could significantly increase the quality of life for many people.

We brought people together online and at a series of public workshops. Ideas for new product concepts were discussed and developed with potential users, and then refined and brought to life in real time by our design partners, Designability (Bath Institute of Medical Engineering), through rapid concept sketching and illustration.

Ten concepts were selected for further exploration by Designability, three of which were taken onto design and prototype development: a seatbelt buckle and harness design that can be easily fastened with one hand; a 'companion' trolley which offers a more personalised approach than existing walker trolleys in the home; and a portable bidet that can be used in public conveniences.

Bethan Griffiths is a student at the National Star College in Cheltenham, a specialist further education college for people with disabilities and acquired brain injuries, and took part in one of the Design Together, Live Better workshops. This is what she thought of the experience…

"Maximising independence was the big theme behind the Design Together, Live Better workshops. My independence is really important to me. Although I've got a disability (cerebral palsy), in my head I'm not disabled. So I want to be able to do what everyone else can do.

"That's one of the reasons I wanted to take part in the workshops. I have quite a lot of my own ideas that could help me and others. I like art and design and I wanted to be able to share my ideas with others.

"At the workshop in Cheltenham it was nice to hear other people like you because the things that came up I wouldn't have thought of. It didn't really apply to me. It opened up my own ideas. It was a really good experience meeting others in a similar place to me.

"We liked the bidet idea that came out of the workshop – it was a really clever idea. Kia from Designability came to college to show us the prototype. I could see that lots of people would find it very useful.

"It was great to be able to share my ideas at the workshop… I hope there will be more opportunities to keep contributing like this."

The portable bidet designed by the Design Together Live Better workshops is demonstrated at the West of England Academic Health Science Network annual conference.

Don't re-invent the wheel. Find out what has already been done and build on the information that is already available.

1. Decide which piece of work you want to involve people in and which methods would help you achieve what you want to achieve. Think about what can/ cannot be achieved by involving people in this way.

2. Identify the **resources** you have available

- Staffing – who will be managing the project?
- Funding – have you the resources to pay travel expenses and/or their time (see section on Payment)
- Timing – involving people properly takes longer. What is your time-line?
- Identifying suitable people – what kind of selection process would be fair and appropriate?

3. Develop a **role description** which clearly states the skills required, the time commitment expected from your public contributors, the length of their involvement and payment details (See Useful Resources section for a sample role description). It is good practice to identify an end date when their involvement will come to an end. Depending on the frequency of involvement in the role, a maximum of two years is advised to allow for fresh skills and new perspectives to be introduced. This should be made clear at the outset.

4. Involve your patients or public as early as possible in the process. Be honest if you are treading new ground and that you are learning as you go along. This way they will learn with you and won't be feeling at a disadvantage.

5. Identify where power imbalances can exist and take steps to minimise them. For example don't have meetings at a time that excludes public contributors from attending and from taking part in the background thinking and development of a project.

6. Work with a wide range of people, using different people for different pieces of work for the greatest range of perspectives.

7. Aim to build up a bank of skilled and experienced individuals who are familiar with your organisation on whom you can draw to participate in advisory groups, attending one-off focus groups, commenting on materials etc.

8. Offer a range of methods to maximise involvement. While face to face is ideal, this may not always be possible. Offer telephone conferences, Skype, email or phone calls. This may work best when the project is in 'full flow' rather than at set-up.

Top tips for successful co-design

1. Try and involve public contributors from the beginning, whilst you are still working things out. This way they can grow and develop their thinking alongside the others in the group and contribute more effectively.
2. Develop a role description (see sample role description in Useful Resources) which details what kind of commitment is required and what kind of payments they can expect to receive.
3. Be clear about the length of commitment required at the beginning and set an end date. This can be reviewed as the needs of the project changes.
4. It is good practice to have at least two public contributors on the group at any one time so that one person doesn't have all the pressure of representing the non-professional/ user voice and the two public contributors can support each other. This way you can also draw on different perspectives.
5. Build in regular time with your public contributors to review progress.

Selection process

For long term pieces of work that will require specific skills and a substantial time commitment, a selection process is advised. A role description with the required skills should be advertised widely. Depending on the number of people responding, either hold a group interview or a standard one-to-one interview. Group interviews are useful for assessing the social skills of individuals. Whether adopting a group interview or individual interview process, standard scoring methods should be followed.

Payment

Some form of remuneration should always be given. As a minimum, travel expenses should be offered. For one-off meetings, you might want to consider incentives such as a thank you gift, voucher from a local supermarket or cash. For more long-term commitments, it is advisable to include in your budget a fee to pay people for their time. This demonstrates that you value what they are contributing, will help you attract a wide range of people and ensure their commitment and consistency in attendance.

Different Trusts and Universities have different approaches to the payment of public contributors. You will need to talk to your Finance Department to work out a fair system. For more information look at the INVOLVE website. Some people may find accepting payment affects their benefit payments. They can obtain advice on a special advice line set up by INVOLVE to answer their queries.

Support for the role – induction, training

It is good practice to make sure your public contributors feel supported in their role. They should be given the name and contact details of the person they are responsible to and who they can contact with any queries or concerns. An introduction to the organisation and an induction programme which enables them to contribute effectively should always be given. The volunteer coordinator in your organisation may already have a suitable induction programme drawn up that you can use.

Managing expectations

Involving members of the public as public contributors are an important part of the partnership between the NHS and the public. However managing expectations can be tricky. Here are some tips that might help you:

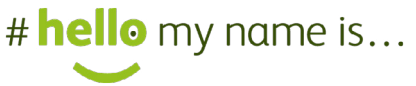
- Have clear role descriptions with clear lines of accountability
- Build in regular review sessions where any misunderstandings can be ironed out
- A clear end date is also important. This can always be extended. For long term, continuous involvement you might want to consider regularly refreshing the role, every two years for example. This gives you the opportunity to bring in new skills as your project develops as well as keep a fresh perspective.

Promoting interest in public involvement

The voluntary sector organisations often produce regular newsletters and welcome information that encourages people to get involved in their local community. Trusts have membership lists and can also be happy to promote involvement opportunities. People in Health West of England (www.phwe.org.uk) have a website where they list involvement opportunities as well as distribute a fortnightly electronic bulletin.

Dos and don'ts for successful meetings

- **Do** make new members feel welcome – a friendly smile goes a long way



- **Do** introduce yourself
- **Don't** use jargon and acronyms without explaining what they are first
- **Don't** assume everyone shares the same knowledge
- **Do** encourage a culture of 'It's OK to ask'
- **Do** make sure papers are sent out beforehand
- **Do** check whether public members would like hard copies printed out for them
- **Do** offer to brief members before meetings and de-brief after the meetings

There are no easy answers to addressing issues of equalities and diversity in PPI, mainly because it is about relationship building and therefore takes time and effort. Key to having a strong equalities component to your work is making sure you get to know your public health colleagues and the community and voluntary sector organisations around you.

Here are some useful tips.

- Your organisation should have an Equalities Policy which describes how it intends to meet the requirements of the Equalities Act 2010 and Equalities Delivery System. Find out who is responsible for leading on this and what has been drawn up in terms of Equalities in service delivery.
- Understand the population you serve. Find out from your public health colleagues the local demographics and the priorities for addressing health inequalities that your local Health & Wellbeing Board or Joint Strategic Needs Assessment (JSNA) has identified for your area – what does your population look like? Is it mainly elderly? Does it have a strong student population? Is there a significant ethnic minority population? What are the health conditions these different groups are likely to experience? What about people with special access needs e.g. how do deaf people access your services?
- Be clear about what are you trying to achieve. Some outcomes you might be trying to achieve are in the box to the right.
- Are there people with certain characteristics that may be having particular issues around accessing services such as people with hearing loss, homeless, young people or those who don't speak English? Find ways of meeting with them to listen to the problems they have and what you can do to improve their access to the health services they need. You should be prepared to go out and meet them in their space, a community/day centre, hostel, café and so on.

Example - Involvement in research: Autism in the Somali Community. This example illustrates the value of identifying advocates within a seldom heard community to help you reach others in that community: http://www.phwe.org.uk/wp-content/uploads/2015/05/Autism-in-Somali-migrant-community-Exploring-families-perceptions-and-experiences-of-diagnosis-and-services.pdf

Option 1 - It may be that you just want to make sure your group of public contributors are generally representative of the population you serve. In which case make sure you promote your involvement activities through local voluntary action organisations (see Section 5.6. for Voluntary and 3rd Sector links). See where their gaps are and try and reach out through other means – lunch clubs, faith groups and so on.

Option 2 - It may be that you want your public contributors to be more representative of users of your services. You need to have access to the equalities data for users of your services – not always easy to come by. Once again you may want to talk to colleagues in your local council's public health department to help you with this. You should then come up with a rough benchmark to help you decide what a representative group would look like.

Option 3 - On the other hand you may want to improve a particular service that is used predominantly by a community with shared characteristics.

Public contributors should be regarded as equal members of the team. However the nature of their status means that care should be taken over certain areas.

Confidentiality

Make sure public contributors sign a confidentiality agreement which makes clear the limits of their role. They should not be able to access patient information without close supervision by a member of staff. Speaking in public and to the media should also be done in close conjunction with the appropriate member of staff.

Disclosure & Barring Service (DBS) checks

Your organisation will have its own policies about DBS checks. It is worth noting that it is not always necessary for your public contributors to be DBS checked. As long as they will not be alone with patients or have access to confidential patient information, this is not necessary.

Ethics of public involvement in research

The ethics of public involvement in research is related to the involvement of patients and the public as participants in research. For more information consult your local Research Design Service or visit www.invo.org.uk . INVOLVE and the Health Research Authority guidance makes clear that you do not need ethical review for public involvement in research.

Public contributors generating ideas at a workshop

In addition to the professional skills you bring, for public involvement to be a success, you need a range of interpersonal skills. This section identifies some of the ones public members have told us they find most helpful.

Social skills

Being able to reach out and connect with people of all backgrounds and ages is one of the most important attributes for good public involvement. Another is the ability to make people welcome and included. One of the most common complaints by members of the public involved in the health sector is the lack of basic common courtesy in introducing them to the other people in a meeting and vice versa.

There are number of guides and checklists that can help you create a welcoming and inclusive environment. As well as the link in the section on running a Focus Group, INVOLVE have a useful guide to what to think about when holding a meeting. http://www.invo.org.uk/getting-started/

Listening skills

Body language conveys as much if not more impact than words. Some reminders are

- Allow the patients or public contributors to do most of the talking
- Demonstrate by your body language that you understand what they are saying.
- Nod and maintain eye contact without staring and appear interested
- Sit or stand in a similar way and at a comfortable distance, not too close or not too far away
- Ask the public contributor to repeat or clarify something to make sure that you have understood correctly
- Repeat back or summarise what has been said to ensure sure you have understood what is being said
- Do not judge
- Treat everyone respectfully

Facilitation/ group work

Working with the public will always require some form of group work and facilitation skills, whether this is with a formal group of people coming together for a workshop or an informal small group of people.

NHS Improving Quality has produced some useful resources on helping you with facilitation skills. They provide the following summary:

Facilitation requires:

- an environment of mutual trust
- the ability to generate a sharing environment
- a willingness to listen
- a desire to seek understanding
- the ability to be diverse and flexible
- the ability to challenge yet stay supportive
- the ability to work with people from a wide range of backgrounds and
- a toolkit of styles, approaches and techniques.

To be effective as a facilitator, you should help the group you are working with get further, faster and in a more focused way than they would alone – and help them have some fun along the way! For more information see http://www.nhsiq.nhs.uk/media/2757715/2010_handy_guide_to_facilitation_final__low-res_.pdf

Social Media

Facebook, Twitter, Linked In are all methods that should be considered to help you communicate with members of the public. You should discuss this with your Communications Team as they may have a policy about this. Key is deciding who you want to reach and the best way to do this. There will always be people who can't be reached through social media, so a variety of communication methods should be used.

Communication

The use of acronyms and jargon is one of the most excluding habits that all of us in the health sector are guilty of. Its effect is demoralising and can contribute to a power imbalance in our relationships with patients and members of the public. In order to get the best out of participants, they need to be in an environment which encourages them to feel comfortable and relaxed and confident about their contribution. The use of jargon and abbreviations means that anyone not familiar with the terms can feel excluded.

Top tips for written communication

1. Use plain English, keep your style as simple and direct as possible, and ensure your meaning is clear.
2. Avoid using jargon, long sentences and complicated structures
3. Using complex or technical language is sometimes necessary, but always consider whether it is possible to use simpler terms. For example 'use' instead of 'utilise'.
4. Spell out acronyms. If you need to use an acronym, make sure that you spell out what the letters stand for as well as the meaning of the acronym.
5. Communicate with people as individuals rather than homogenous groups wherever possible. Where you do need to refer to a group and are unsure of the most appropriate terminology, check with someone from that group or someone who works with that group. Try not to. It is very easy to make assumptions about people without realising.
6. Think about the physical design of your text as well as the words. Consider whether it should be available in alternative format such as 'easy read',

How well am I doing?

There is an unresolved debate around how to measure the impact of public involvement in improving health research and improvement, with a number of different schools of thought. The danger of focusing on the different arguments is that it can lead to inaction in this area. This section is to help you value the steps you have taken to put in place good public involvement and celebrate your successes. It aims to help you identify the good practice involvement standards you can put in place and how to measure them. It should contribute to your workplace culture of reflective practice.

Measuring success in PPI

Finding ways to measure the success of your involvement activities can at first seem daunting. Activities relating to public involvement don't lend themselves easily to the traditional measures commonly used in the health sector, based on the traditions of Randomised Control Trials (RTC). Often the benefits of involvement are unintended and unexpected. There is evidence that public involvement contributes to greater changes in working relationships between multidisciplinary professionals. The assumption being made in this Toolkit therefore is that public involvement works, can lead to unpredictable outcomes which need to be captured, and need to be celebrated.

Drawing up measures

Be clear what you want to achieve and ensure it is achievable and measureable. Make sure you keep the focus on involvement. If you need information on other types of measures such as patient satisfaction, then work with the patient experience team to get this. Patient experience is not involvement. Decide whether you will want to measure process or outcomes or both. Choose a maximum of three to five strategic measures.

The measures you identify very much depend on the involvement approach you are using

Different types of measures

There are different types of measures:

- **Process measures**, e.g. the number of public contributors involved.
- **Outcome measures**, e.g. survey of perception of using public contributors
- **Balancing measures**. e.g. any negative perceptions for example linked to the known issues.

Example 1 - Measuring Co-production

Objective: Using co-production in a quality improvement project.

Example measures of success;

- Links made with relevant 3rd sector organisation to ensure relevancy and reach
- Public contributors selected to participate in advisory group from the beginning
- Discussion held with staff and public contributors about each of the roles on the project
- Systems in place to support the public contributors with payments, distribution of papers and communication needs
- Feedback obtained from staff as to what difference the public contributors made
- Feedback obtained from public contributors about the improvements they recommend

Example 2 – Measuring public involvement in service improvement

Objective: Involvement of members of the public in observing ED waiting area to monitor the level of courtesy with which patients are treated

Example measures of success:

- Three members of the public are recruited through transparent process
- Standards of courtesy drawn up by the three public contributors
- Training provided on carrying out observations in the health setting – boundaries of the role, what to look for, health & safety issues
- Observations from the three members fed into a report.
- Feedback from the three members obtained about their experience

References and useful websites

Patient and public involvement in quality improvement (2016) Healthcare Quality Improvement Partnership Ltd. (HQIP) London. www.hqip.org.uk

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

Experienced based design toolkit (2013) Kings Fund, London. http://www.kingsfund.org.uk/projects/ebcd

Transforming participation in health and care 'The NHS belongs to us all' (2013) Patients and Information Directorate, NHS England https://www.england.nhs.uk/wp-content/uploads/2013/09/trans-part-hc-guid1.pdf

A Handy Guide to Facilitation NHS Institute for Innovation and Improvement (2009) http://www.nhsiq.nhs.uk/media/2757715/2010_handy_guide_to_facilitation_final__low-res_.pdf

Six principles for engaging people and communities: Putting them into practice (2016) People & Communities Board http://www.nationalvoices.org.uk/our-work/five-year-forward-view/new-model-partnership-people-and-communities

People in Health West of England www.phwe.org.uk

Scottish Health Council Participation Toolkit http://www.scottishhealthcouncil.org/patient__public_participation/participation_toolkit/the_participation_toolkit.aspx#.V7suMU0rlsY

Sample Templates

Sample Role Description http://www.phwe.org.uk/wp-content/uploads/2015/05/Public-Contributor-Role-Profile-General-Template1.pdf

Sample Expenses policy http://www.phwe.org.uk/wp-content/uploads/2015/05/Guidelines-for-Payments-to-public-contributors2.pdf

Code of Conduct http://www.phwe.org.uk/wp-content/uploads/2015/05/Code-of-Conduct-for-public-contributors.pdf

The NHS have set up an Involvement Hub to support involvement and participation https://www.england.nhs.uk/participation/resources/

Coalition for Collaborative Care; action for long term conditions. Co-production model http://coalitionforcollaborativecare.org.uk/a-co-production-model/

Quality Improvement

West of England Academic Health Science Network Improvement journey http://www.weahsn.net/what-we-do/west-of-england-academy/improvement-resources-and-tools/the-improvement-journey/steps-in-the-improvement-journey/

Good luck with your public involvement activities!

We hope you found this brief guide helpful. If you find any corrections, resources to share or any suggestions for future editions please contact us at enquiries@phwe.org.uk

People in Health West of England (PHWE) is a new initiative promoting innovative and effective public involvement in research and evidence-based service improvement.

Find out more at our website http://www.phwe.org.uk/

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West of England

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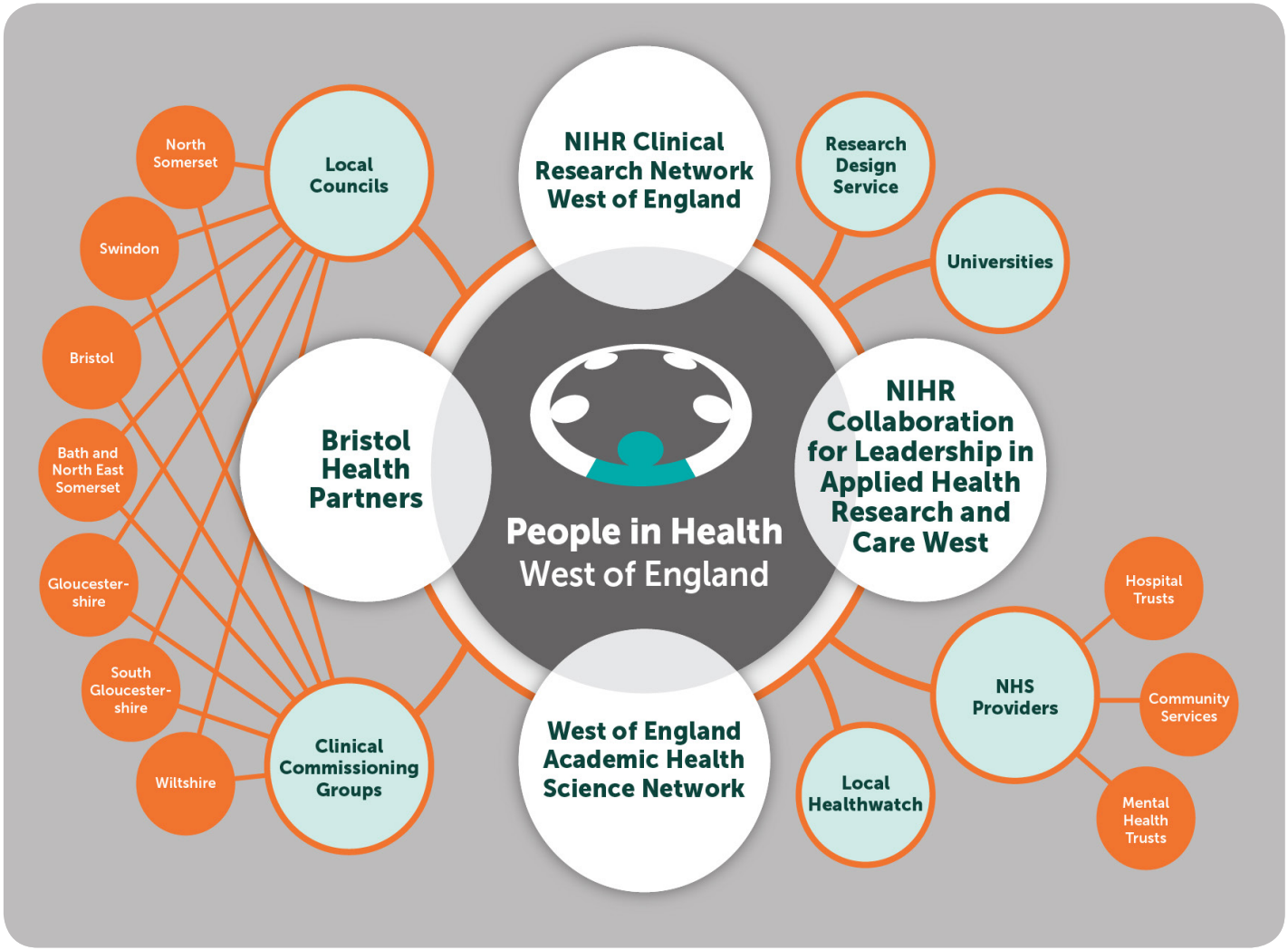


About the West of England Academic Health Science Network

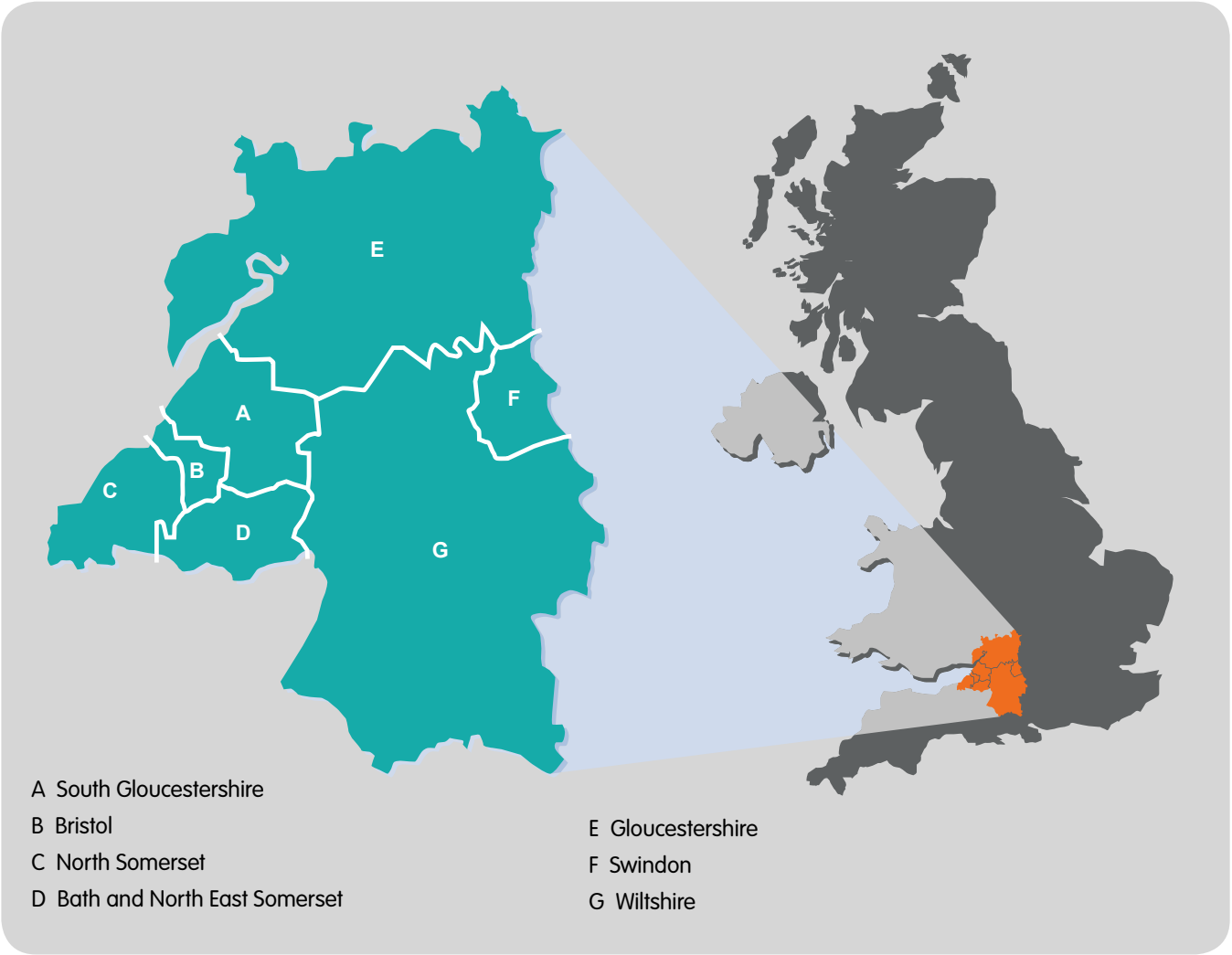
The West of England Academic Health Science Network (AHSN) is delivering positive healthcare outcomes locally and nationally by driving the development and adoption of new innovations and making a meaningful contribution to the economy.

We are one of 15 AHSNs across England, established by NHS England in 2013 to spread innovation at pace and scale.

As the only bodies that connect NHS and academic organisations, the third sector and industry, we are catalysts that create the right conditions to facilitate change across whole health and social care economies, with a clear focus on improving outcomes for patients.

Find out more at our website http://www.weahsn.net/

Follow us on Twitter at @WEAHSN



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

Notes

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