

WORKING TOGETHER:

An essential guide for healthcare practitioners, researchers, educators and regulators looking to work with service users, patients, carers and members of the public.

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INTRODUCTION

Service users, patients, carers and members of the public have a right to be involved in all aspects of service provision. This guide aims to facilitate the process of working together by summarising the existing literature, clarifying some of the terminology used and presenting examples of good practice. We hope that in doing so this guide can be used as a practical tool for those looking to improve systems by working together.

In this guide we use 'working together' as an inclusive term to refer to the effective involvement of individuals and service providers collaboratively working to achieve common goals. We use the phrase 'service user, patient, carer and members of the public' to identify individuals

involved in this process, as these are the most common terms found in our comprehensive [review of the evidence](#). This is not to ignore the distinctions between different populations and approaches available, (there are lots!) but for the purposes of consistency, and to avoid getting caught up in issues of language as opposed to focusing on the important task at hand – **working together to improve service provision.**

TIP: Whilst it is important to be aware of semantics, it is perhaps of greater importance to be aware of the context in which you are working. Individuals should be asked at the beginning of any project how they would like to be identified. This will help to ensure people involved have a form of self-identity they feel comfortable with, and empowered by.

The information presented in this guide is the result of a comprehensive evidence review of the existing peer and grey literature across health and social care services, research, regulation and education. Unlike other reviews, this includes online guides and tools published between 2010 - 2016 to capture current practice. Find out more at www.camera-pupsmid.org.uk/our-research/completed-research/ This guide synthesises and translates this evidence into practical advice available in one accessible document.

WHO IS THIS GUIDE FOR?

This guide is for health and social care providers, researchers, educators, and regulators wanting to work with service users, patients, carers and members of the public. Based on an extensive review of existing work, and validated by a global expert panel, it provides information that will help you to start, or further develop, a variety of working together initiatives. The information provided may also be of wider interest to people in other areas.

HOW CAN THIS GUIDE HELP YOU?

This guide aims to:

- Explain what *working together* is, requires and involves
- Outline a number of underlying principles
- Provide useful tips and illustrative case studies
- Suggest ways to work together
- Respond to frequently asked questions
- And provide a useful tool of things to consider when starting out, setting up and maintaining your *working together* initiative

This guide does not claim to cover all aspects of *working together* - we would need a bigger, heavier and not quite so handy book! It is not a prescriptive step by step formula for *working together* as each individual, group and project will have different needs and requirements, calling for a uniquely tailored approach.

Relevant information is signposted throughout this document as shown by the ► symbol with a more comprehensive resource list provided on pages 38-47. You may wish to use the guide in its entirety, or dip into areas most relevant to you.

We hope this guide will help you to shape, develop and support your *working together* approach.

WHY IS IT IMPORTANT?

“When the Chairman of the Trust asks ‘what do you guys want us to do?’ it’s a bit of a stunner! I don’t know whether to be delighted or worried sick! We seem to have made something of an impression - and not by being ‘poodles’ either.”

NHS Hospital, Patient Representative

Although working together is often driven by compulsory policies or funding requirements, the reasons behind its importance are much broader than this. Working together can:

- **Enhance the quality, relevance and appropriateness of services provided:** by making sure you are investing in areas most relevant to service users, patients, carers and members of the public. This can help improve the overall quality, safety and responsiveness of the services provided.
- **Enhance social, cultural and religious inclusivity of the services provided:** by understanding and respecting social, cultural and religious sensitivities.
- **Maximise impact and limit wasteful use of existing resources:** by challenging wasteful and unnecessary work. Go to page 19 to find out how working together can save money.
- **Empower everyone involved:** by encouraging and supporting personal and professional development.
- **Strengthen and sustain working relationships:** by building familiarity, trust and respect between individuals, professionals and communities. Professionals and members of staff can learn from service users, patients, carers and members of the public and vice versa.
- **Enhance physical and mental wellbeing of communities and individuals:** by helping to develop a sense of community by encouraging individuals to take greater responsibility for, and interest, in their own health and well-being.
- **Challenge detrimental attitudes, assumptions and behaviours:** by working closely with individuals, communities and organisations to learn about their needs and aspirations.
- **Respond to wider cultural and social change:** by reducing passive or tokenistic involvement. There is a strong moral and ethical drive behind more meaningful involvement with working together seen as a ‘right’ informed by wider democratic principles of citizenship, accountability and transparency. We all have a responsibility to respond to this wider social and cultural change.

UNDERLYING PRINCIPLES

PUTTING IT INTO PRACTICE

By its nature, *working together* cannot, and should not, be a one size fits all model. No single method will work for all situations, individuals or issues. However, the principles needed to work together effectively will remain the same.

The underlying principles identified by the evidence reviewed are presented below. The essential principles refer to those that, if ignored, can significantly limit effective *working together* strategies. Those listed as desirable are the principles that will help shape a workable program into good or excellent *working together* practice. These should therefore not be ignored and included wherever possible.

“These questions are difficult because so many of them seem essential... I have tried to tick some as desirable rather than essential but particularly in the last box [underlying principles] I feel that all are essential really.”

Delphi Respondent

“...we need support, and can give more as a consequence.”

Patient Safety Ambassador

ESSENTIAL

- **Share** information, experiences, knowledge and power. Sharing information both good and bad can help improve *working together* methods and avoid others repeating the same mistakes.
- **Listen, assess and respond** to the information shared. Regularly update people involved. Don't collect information and then ignore it as this is disrespectful and tokenistic. Act on information shared and offer clear explanations as to why suggested changes have not been acted on.
- **Work in equal partnerships** built on mutual trust, respect and transparency.
- **Communicate and inform** regularly, clearly, and inclusively. Do not rely on one method of communication; this is unlikely to be suitable for all those involved - be creative.
- **Support and prepare** everyone involved before, during and after any *working together* initiative. This includes offering relevant training, information, practical, emotional and financial support.
- **Acknowledge, reward and value** everyone involved. Celebrate good practice.
- **Accommodate** individual and collective needs to ensure inclusivity.
- **Evaluate** throughout your *working together* initiative to identify best practice and areas that can be improved.
- **Tailor** your approach, materials, training and evaluations provided to match your aim, purpose, local context and individual choices of people involved.

DESIRABLE

- **Be proactive** in your approach. Go out into relevant communities and get involved. Don't expect people to come to you.
- **Resource and invest:** Effective *working together* takes time, money and resources. Be prepared to invest time and effort in *working together*; it will nearly always take longer than you think.
- **Empower** all members involved. Ensure information, resources and skills are shared so that everyone can contribute to decision making processes.
- **Commit** to *working together* on a personal, organisational and long-term basis. Involvement should be consistent, not sporadic.

WHAT CAN HELP OR HINDER?

Whilst some barriers may be experienced when working together, these can often be resolved with careful consideration, clear communication, preparation and planning. A number of suggestions are discussed

BARRIERS

- **Lack of sufficient resources:** A lack of time, money and support can prevent both individuals and organisations from being able to work together. However, evidence shows that time becomes less of a concern once individuals start to work together effectively.
- **Power imbalance – intimidation, domination and inequality:** Sharing power with service users, patients, carers and/or members of the public can be challenging and ‘threatening’ for some individuals. Although many people appear committed to, and discuss the importance of equal partnerships, power is often retained by those who hold the resources and make the final decisions.

throughout this guide and on pages 13-16 to help you think about how some of the barriers you may face can, and will, be overcome.

“Working together’ [is] time consuming and involves delays in arranging mutually agreeable appointments. Be reasonable and let individuals/groups get on with the job”

Patient Representative

“When I was asked to be a patient rep on a NHS working group I was very wary of being the token patient. Especially when joining a group with eminent highly trained experts....While the organisers plan and meet all the time. It is not a fair relationship and to really hear the true voice it needs to be, otherwise I am in danger of being the ventriloquist’s dummy!”

Patient Representative

TIP: Consider having a Chair for your *working together* group who is well respected by all those involved. This can help limit feelings of inequality and intimidation. If events are not chaired well, some members can dominate discussions and others may be reluctant to attend future events. It is therefore essential that the person chairing your group is well supported, respected by those involved and clearly understands their roles and responsibilities. Individuals involved should have the opportunity to learn how to chair meetings if desired and the opportunity to take up this role once they feel confident. Don’t repeatedly use the same individuals. Be inclusive.

- **Attitudes and assumptions:** An organisation’s existing culture and individual prejudices, attitudes or discriminatory behaviours can significantly inhibit effective *working together* as can a lack of mutual trust and respect.

TIP: Where possible offer training to be attended by everyone involved including providers and staff members regardless of status. This will demonstrate commitment and reduce feelings of inferiority by building a team identity and providing an important opportunity to challenge detrimental attitudes and behaviours from the outset. As an integral partner in your project, service users, patients, carers and member of the public should also undergo similar induction processes to other members of staff where appropriate.

- **Lack of knowledge:** A lack of professional and/or individual knowledge about how to work together and a failure to use local or existing knowledge can restrict joint efforts.

TIP: Share information and resources. Find out what other people are doing; look at examples of previous work. Use identified areas of good practice to influence your own approach.

- **Competing agendas:** The views, aims and expectations of providers and service users, patients, carers and members of the public may differ. This can cause conflict if not resolved.

TIP: Involve people you are looking to work with in the design and implementation of your *working together* approach. Discuss the aims, purpose and expected outcomes of your project. Agree these before you progress. Do not ignore an individual’s input as this is likely to cause conflict or ‘drop out’ later on.

- **Exclusivity/unequal opportunities:** Whilst opportunities for involvement have improved in recent decades, we know that certain groups such as those with protected characteristics experience fewer opportunities. Go to pages 21-22 to see how you can involve people who are seldom heard.

- **Confidentiality:** Uncertainty about how information provided will be used and who will have access to that information can cause anxiety amongst organisations and those involved, particularly if information shared is critical or sensitive in nature. Consider the ethical nature of your project.

TIP: Reassure individuals involved that information shared will remain confidential wherever possible. You may wish to ask members of a group to sign a confidentiality agreement with clear reasons why this is required. It is important to clearly explain what confidentiality means, the steps taken to ensure it and to then check individuals’ understanding of your explanation. This will help limit any potential misunderstandings.

- **Identifying individuals/recruitment:** Identifying and recruiting individuals and/or organisations can be difficult, as can maintaining interest. Turn to page 21 to see the different ways you can recruit.

TIP: Involving service users, patients, carers and members of the public should be a continuous process. Individuals can become 'professionalised'. Keep widening your net to attract fresh voices and recent experiences. Continually recruiting can also help maintain the sustainability of your approach, prevent involvement fatigue and overcome issues that arise if, and when, individuals have to drop out. An important question to ask is whether you would want to be involved if you were approached using your methods or recruitment strategies. Is it engaging? Can it be improved?

BARRIERS FOR INDIVIDUALS

"I was approached by a senior service manager in a meeting [and] told, [I would] like to hear your views, speak to me after, as a way of closing the debate then. I never heard from them again, despite trying to contact them. They have gone off to chair very important initiatives!!"

Patient representative

- **Confidence and self-esteem:** Individuals may not feel confident working with, or in, environments/ organisations they are not familiar with. This can cause people to feel isolated, withdrawn and unable to offer anything meaningful.

TIP: Recruit at least two individuals. This will help to ensure they feel supported by one another and have an 'ally' to talk to. Involving two individuals is also pragmatic in case one person is unable to attend a meeting etc. It places less responsibility on one individual, shares required commitment or work load and provides more diversity within your group.

- **Payment and reimbursement:** Delays in payment, expenses or long complicated forms and systems can discourage individuals from being involved. It is good practice to promptly pay or reimburse any expenses on the day if not before wherever possible. People's time and money is equally valuable, treat it so.

THINGS TO CONSIDER:

Payment can have implications for those in receipt of tax credits or other benefits. It is therefore essential people receive expert advice before accepting payment including vouchers or financial gifts. If necessary, be creative in the payment methods offered. Individuals can donate their payment fee to a charity, accept a lower amount, be rewarded in other ways or simply reject payment offered. One of the biggest difficulties faced by those receiving benefits is that Jobcentre Plus offices can interpret involvement as readiness for work or employment regardless of

whether payment is received or not. NHS England has developed a standard letter which clearly explains involvement opportunities are not an indication of readiness to work or employment. The NHS also offer a service to provide help with any benefit concerns or questions around payment of fees and expenses for public involvement. Staff will provide support and advice on individual circumstances and help individuals make informed decisions about whether or not to get involved in NHS England's work.

► For more information please email the Patient and Public Voice team at england.nhs.participation@nhs.net or see HMRC and Citizens Advice Bureau for more information.

TIP: Not everyone has a bank account so payment by cheque or bank transfer can be problematic. Work with finance departments early on to identify flexible ways to reimburse individuals quickly.

- **"Involvement fatigue"** There is a real danger of "involvement fatigue" for certain groups, organisations and/ or individuals who are repeatedly asked to be involved in a number of projects, events and developments.

TIP: Check that you are not replicating existing work or looking to work with individuals already involved in other projects or events.

- **Evidence of change or abandonment:** Service users, patients, carers and members of the public can become frustrated and disappointed when repeatedly asked for their opinion and then later 'abandoned' with little evidence of change or impact following their contributions. This can lead individuals and communities to strongly resist future involvement.

TIP: Check you are keeping everyone involved updated, and informed about any decisions made following their contributions. Develop a "feedback loop".

WHAT CAN HELP?

Below are a number of suggestions that may help address some of the barriers discussed.

- **CLARITY: BE CLEAR ABOUT:**

- Why you want to work together. What is your purpose? What are you going to do and why?
- The benefits of working together for all those involved. What are your expected outcomes? How will working together add value?
- Who you will work with and why. Do you need a specific group of individuals with a particular skill set or are you looking to work with individuals who have a certain experience? Why would your work be relevant to them?
- What is involved and expected. What will people involved need to provide in terms of time, commitment, travel, skills and/or experience? What are your expectations?
- What resources are available for individuals involved in terms of support, payment, training and reimbursement.

TIP: A short description about your project and desired person or job description can help provide clarity about what is required and expected. It can also help reduce tokenism by recruiting individuals who have the necessary skills, experience or attributes rather than status. If you involve individuals based on status alone your approach is likely to lose significant credibility limiting its impact and acceptance.

► See Co-production in commissioning (Rethink mental illness, 2015); Patient and Public involvement in health and social care research (National Institute for Health Research, 2014) and Start up guide for general practice (Scottish Health Council, 2012) for example advert and role description templates.

- **Plan:** It is essential that you carefully consider your working together approach and plan each individual event, such as a meetings (if it's yours to plan!) or evaluations, well in advance. Take time to prepare with the individuals and/or communities involved: don't leave it until the last minute. People notice if working together is no more than a tick box exercise. Pages 31-37 provides a checklist of things to consider when setting up, starting up and maintaining a working together approach.

"Patient's families who have been through the system can sense tokenism a mile off"

Patient Representative

- **Embed:** working together into everyday practice rather than viewing it as an additional 'add on' event. It is important staff members, commissioners and professionals alike see this as an integral activity in their day-to-day practice. This can be facilitated by the development of an organisation strategy, or by including working together responsibilities in job roles, descriptions and/or contracts.
- **Develop terms of reference and ground rules together** and review these regularly. Terms of reference and ground rules can help challenge dominating behaviour and make people feel supported on an equal basis.
- See *Guidance on involving Adult NHS service users and carers (NHS Wales, 2010)* and *Co-production in commissioning (Rethink mental illness, 2015)* for example terms of reference and ground rules used.
- **Use existing knowledge, expertise and networks:** These can be invaluable. Contact local networks such as charities, faith or voluntary organisations that may already have established relationships with individuals or communities you are looking to involve. Include carers, gatekeepers and other stakeholders who have important and unique insights to offer. Be mindful that working together should be reciprocal in nature. Make sure you can offer something back to the organisations or individuals who share their knowledge, expertise and contacts.
- **Create a database of interested people and organisations:** Identifying people, communities and organisations who are willing to work together can take time and often those involved may already have received specialised training, support and other forms of investment. Why let this go to waste? Develop a database or list of people and organisations who have taken part in previous projects, are interested

in taking part, or have applied unsuccessfully for other working together projects. A detailed database (with written consent to hold information) can help identify people for future projects helping to build capacity and maintain interest.

- **Be creative, flexible and fun** in your approach. Consider creative, novel and interesting ways to work together. Be prepared to compromise or negotiate; flexibility and an open mind are key. This may include arranging evening and weekend meetings, going to local venues or other places people frequently visit. Make your face familiar to those you wish to involve.

TIP: You may have to work outside regular working hours so review your lone worker policy if applicable.

- **Tailor your approach to an individual level:** Not everybody will want to be contacted, involved, supported or communicated with in the same way. You can use different approaches within the same initiative involving different people in different ways, at different levels and at different times. Equally, what you plan to do may not work; this is not failure, but useful learning.

TIP: Every opportunity must be built in to ask each individual or organisation you are working with how and when they would like to be contacted, involved, supported and communicated with. Do not assume or guess their preferences.

- **Regularly update and feedback:** It is essential that people involved are frequently updated about the outcomes, impact and developments of their contributions. Ways to feedback or update include emails, texts, phone-calls, letters/ newsletters, posters, presentations, websites, social media and written reports.

TIP: It is good practice to have one ongoing point of contact for all those involved. This helps to maintain continuity and build rapport whilst also acting as a way to ensure all individuals involved are regularly updated, but not inundated with information.

- **Be honest, transparent and open:** Do not try to bury 'bad' findings. Sharing misfortunes or 'poor' results can be empowering by blurring the lines between professionals/members of staff and service users, patients, carers and members of the public. Openness, transparency and honesty are therefore essential for building trust and mutual understanding.
- **Treat people with respect, kindness and compassion:** this includes being respectful of people's roles, experiences and choices. Challenge detrimental attitudes wherever possible and avoid making assumptions about people's needs, abilities or desires.
- **Involve early:** Good practice means involving service users, patients, carers and members of the public as early as possible. This will help to ensure your purpose and aim of *working together* is clear, relevant, valued and achievable. Involving people early can also enhance dissemination, reduce misunderstandings and identify numerous solutions, helping individuals involved to feel they are an integral part of the project and that they have some form of ownership.
- **Offer choice and opportunities:** do not restrict opportunities, information or feedback methods to one type or level; it is unlikely to be suitable for all those involved.

TIP: Involve service users, patients, carers and members of the public in the production of information to ensure its content, format and length is appropriate. If this is not possible, at a minimum, a draft version should always be shared before finalisation. Check for people's understanding from time to time to keep misunderstandings or mistakes minimal.

- **Communicate clearly and inclusively:** Keep it varied. Ensure all language used is respectful, simple and accessible. Avoid the use of acronyms, abbreviations and jargon. If technical words must be used, provide a clear definition and glossary of terms. Where necessary, ensure that information is translated into minority languages, dialects and Braille. Use a range of both verbal and non-verbal communication methods such as emails, texts, social media, phone-calls, pictures, and audio/video tape. Be considerate of all aspects of communication including body language and eye contact.
- **Make it worthwhile:** It is vital that you acknowledge, value and reward everyone involved. Say thank you, offer refreshments (the attraction of good food should never be underestimated!), reward those involved. This does not have to be financial. Different individuals value different forms of reward. Tailored consideration should therefore be given to different types of recognition including: social or group activities such as meals out or public trips; formal acknowledgement such as co-authorship or payment; CV references; or training and employment opportunities.
- **Accommodate individual needs:** Consider the practical and non-physical issues that may prevent people from working together and accommodate their individual needs. For example: does the timing of your meeting exclude certain individuals; are interpreters required; are auxiliary aids such as a hearing loops available; is information available in Braille or large print; are there good public transport links and disabled parking spaces available; do people involved require longer or more frequent breaks; have you provided printed copies of documents for those without printer access. Choose environments that are accessible, neutral and familiar to those you are looking to work with. Avoid venues associated with a particular treatment or condition. The best way to achieve this is to ask those you are working with to suggest venue locations.

"Need a variety of ways – I hated the visual minutes of the meeting I was at. Lots of cartoons – I find lots of cartoons hard to read and digest and so asked for a text version of key points... we need novel AND traditional – why not ask participants"

Patient Representative

TIP: Try to use the same venues wherever possible so people become familiar with their location and transport links.

- **Provide training where needed or desired:** individuals involved need to feel well supported and prepared before, during and after any initiative. It is important not to impose what you believe individuals need but to ask people involved to identify areas of need. Remember staff members/professionals may also need or desire training to feel confident and empowered when working together.

WHERE TO WORK TOGETHER

There is great variation in how working together is happening and where. Below is a list of areas where working together has been achieved to help get you thinking about where you can either start or develop your ideas.

Where *working together* has and can happen

- Advisory/steering groups
- Appraisal
- Assessment
- Audit
- Commissioning and decommissioning
- Course review
- Critical friends/advisers
- Delegates
- Dissemination (sharing of results)
- Ethics applications
- Evaluation
- Funding
- Fundraising
- Full academic position
- Guideline development
- Identifying and prioritising needs, desires and concerns
- Implementation
- Interviewing, selection and recruitment education and research
- Joint grant holders, co-applicants and co-authors
- Lay membership
- Marketing
- Mystery shopper
- Peer review
- Personal testimony
- Planning, designing, development and delivery – Curriculum, Healthcare, research and regulation
- Policy strategy
- Presentations/conference speakers
- Providing feedback
- Quality management and control processes
- Research - Data collection, Literature review, Data analysis, Write up – lay summaries
- Site visits
- Teaching and assessment
- Training

DECIDING YOUR APPROACH TO WORKING TOGETHER

As already stated, there is no single right way to work together. Below are a number of suggested ways and a quick selection process to help identify best working together methods. We strongly encourage individuals to 'think outside the box' to reach the widest possible number of individuals or communities. Remember to consider the desires, needs and choices of the people you are working with.

► See *A PPI Good Practice Handbook for UK Health care regulator*, (Joint Health and Social Care Regulators' Patient and Public involvement group, 2010); *Dialogue by Design: A handbook of public and stakeholder engagement* (2012); *Personal and Public involvement toolkit for staff* (NHS Leicester City, 2014); *Good practice guide: service user involvement* (Turning point Scotland, 2011) and *Service user involvement methods a guidance document* (Health service executive, 2010) for more information regarding strengths, weaknesses, associated costs and checklists for each method.

WAYS WE CAN WORK TOGETHER

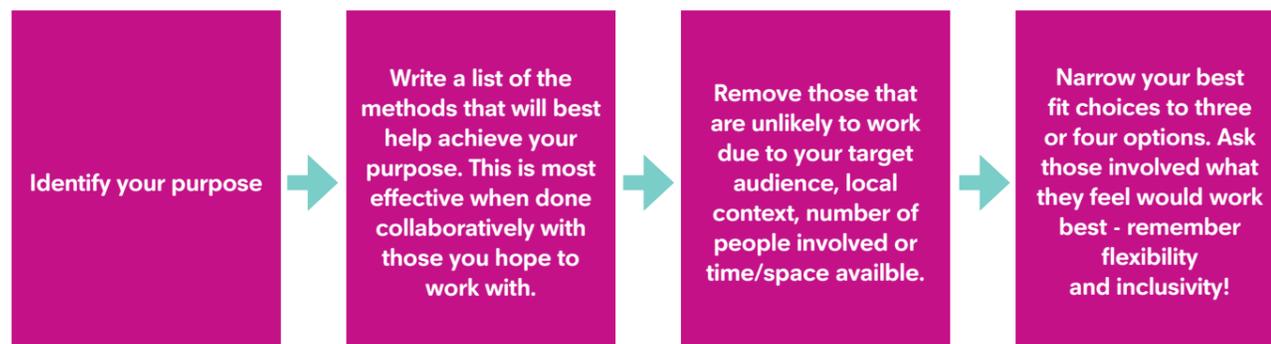
- | | | |
|---|--|---|
| <ol style="list-style-type: none"> 1. Focus groups 2. Interviews (one to one semi-structured, discovery telephone) 3. Citizen juries/panels 4. Surveys/Questionnaires (postal, online, telephone) 5. Meetings - (Public, closed, one to one) 6. Public consultation 7. Newsletters/letters 8. Notice boards 9. Designing leaflets 10. Producing bulletins 11. Designing posters 12. Creating presentations 13. Presenting at conferences 14. Reports/publications 15. Lectures 16. Fact sheets 17. Case studies 18. Suggestion box 19. Email | <ol style="list-style-type: none"> 20. Texting 21. Phone-calls 22. Open days 23. Displays and exhibitions 24. Festivals and public events 25. Games 26. Workshops 27. World café events 28. Films and video 29. Debates 30. Community champions or ambassadors 31. After action reviews 32. Patient diaries 33. Online discussion groups /forums 34. Virtual readers panel 35. Websites 36. Opinion polls 37. Exit polls 38. Reviews of complaints 39. Co-authorship 40. Open space | <ol style="list-style-type: none"> 41. Social media – Twitter, Facebook, Tumblr Intagram, flickr, pintrest, youtube 42. Talking mats 43. Journey mapping 44. Using the creative arts, music, arts and crafts, pictures, poetry, creative writing and dance 45. Story telling 46. Role playing and forum theatre 47. Mystery shopper 48. Ask me 3 and answer 3 questions 49. Comment cards 50. Digital stories 51. Dragons den 52. Emotional touchpoints 53. Observational exercises 54. Talking wall 55. Experience based design |
|---|--|---|

TRADITIONAL



CREATIVE

A QUICK PROCESS DIAGRAM FOR SELECTING APPROPRIATE WORKING TOGETHER METHODS.



FREQUENTLY ASKED QUESTIONS

How much will it cost?

There is no fixed cost or price to working together. Each project will have its own associated costs. Pages 31-37 provides a list of the things to consider when budgeting for working together. However, whilst working together may require a small financial investment, projects that involve individuals or communities often enjoy large social and financial benefits.

EXAMPLES FROM THE EVIDENCE REVIEW:

People Powered Health

A business case for People Powered Health (a co-production model) led by Nesta estimates that based on the most reliable evidence available adopting the People Powered Health approach could reduce the cost of delivering healthcare by approximately 7% through reducing A&E attendances, hospital admissions, length of stay if admitted and decreased patient attendance. This could lead NHS to **save £4.4 billion a year** across England if People Powered Health innovations that involve service users, patients, carers and member of the public more directly were to be adopted.

► See The Business Case for People Powered Health (Nesta, 2013) for more details.

Turning Point Connected Care system

A social return on investment study conducted by a London School found Turning Point's Connected Care system of enabling communities to design their services reported a **saving of over £14 for every £1 spent**.

► See Service User involvement in the delivery of mental health services (Together, National Survivor User Network, 2014) for more details.

Changing Minds

A service user led changing minds programme evaluated by an East London University using a social return on investment approach reported **savings of £8.78 for every £1 spent**.

► See Service User involvement in the delivery of mental health services (Together, National Survivor User Network, 2014) for more details.

Working together can also identify local priorities and concerns, improve planning, design and implementation of services provided, and enhance credibility – many things money can't buy.

Well London's Health Champion programme

Well London's Health Champion programme involving 2,000 people making decisions about services they received result in 79% feeling more positive about their life and having a better understanding of their mental wellbeing, 82% making healthier eating choices and 85% engaging in more exercise.

► See Service User involvement in the delivery of mental health services (Together, National Survivor User Network, 2014) for more details.

The question therefore becomes not whether you can afford to work together, but whether you can afford not to. Some see the initial cost of *working together* as a burden, but not *working together* is likely to reduce the quality, relevancy and credibility of your work, leading to greater costs, both social and financial, later on. Invest in the present to save time and money in the future.

► See *Budgeting for involvement: practical advice* (National Institute for Health Research, 2013) and *How to guide: How to estimate the costs of public involvement* (East Midlands Academic Health Science Network, 2015) for examples of estimated involvement costs and budgets.

HOW LONG WILL IT TAKE?

The evidence is clear that it will, in nearly all cases, take longer than you think. However, time should not be the sole reason for choosing certain methods over others. It is the purpose and aim of your initiative that should drive these selections. There are no short cuts to building relationships and connections, it simply takes time. Make sure you are prepared and have allocated sufficient time to do this well and ensure all are involved.

HOW CAN WE TELL IF WORKING TOGETHER IS WORKING?

This is largely dependent on what you are trying to achieve, and how. Below are a number of ways to help judge whether your approach is going well. These may not be relevant in all cases, but together they demonstrate a variety of ways you can check your *working together* progress:

- Routinely **collect feedback** from everyone involved; don't collect just one perspective. Feedback can be collected in a number of ways including questionnaires/surveys, diaries, pictures, social media, informal discussions and focus groups. Page 18 provides a list of ways to work together including feedback.

TIP: Do not restrict feedback opportunities to numbers. People like to tell a story, and the details in these stories are often important to know. Allow individuals to freely express their opinions, experiences and suggestions in their own words and ways they are comfortable with. Collecting numbers may not help you to catch the intricate details that matter most.

- **Look at statistics** such as the number of people using a service, discharge rates, complaints, satisfaction scores and number of targets met before and after you any intervention. Have there been any changes? Can these be linked to *working together* decisions?

- **Evaluate** your *working together* initiative.

► See *Evaluation: What to consider* (Health Foundation, 2015); *A PPI Good Practice Handbook for UK Health Care Regulators* (Joint Health and Social Care Regulators' Patient and Public Involvement Group, 2010); *Evaluating participation: a guide and toolkit for health and social care practitioners* (Scottish Health Council, 2013); *The Public Involvement Impact Assessment Framework Guidance* (Popay et al, 2014).

HOW CAN I GET PEOPLE INVOLVED?

Getting people together can be difficult. However, there are a number of things you can do to help make this process easier:

- **Personally invite** – contact people directly (via individual invitations). Ask colleagues, community members or voluntary/charity organisations to suggest individuals who may be interested. Think about inviting those who use specific services such as those with long term conditions, disabled children and young mums or provide an open invitation for anyone who may be interested (often the most popular and democratic way). Consider holding an open day to provide individuals with some background information about who you are, what you're hoping to do and why it is important. Or alternatively, randomly select a number of people if it is a general working together approach you are looking to develop.
- **Advertise** – well in advance. Give people plenty of notice. Ask your local practice, service, or other community facility to put up a poster, tell people, share leaflets etc. Advertising can be achieved using a number of different methods including: leaflets; word of mouth; local media such as local radio stations, news channels, parish magazines etc.; national and local support groups or voluntary organisations; websites, texting and social media. Social media often have relevant pages or hash tags for specific conditions etc. It can be useful to explore these and approach other existing groups. Areas you can advertise include: schools; shops; faith organisations; pharmacies; language classes; parent and toddler groups; interest groups, sports clubs; social clubs; age based groups; universities and youth centres. www.peopleinresearch.org is an example relevant to research where researchers can advertise their projects for free.

► See Guidance on the use of social media, (INVOLVE, 2010) and the Patients Association Patient Participation Group information and support pack for advice on how to use social media in your working together initiatives.

TIP: Consider including a photograph of the individual to be contacted. This will help individuals to develop a rapport with that individual early on and identify them when they first meet, helping to personalise the process.

- **Ask people for help and advice** – ask staff and community members to promote your event. Ask those who have already worked with individuals or groups for assistance. Do they have existing networks you could access? Link up with other existing organisations. This is particularly useful for involving people who are seldom heard.

TIP: Remember to ask people how they found out you were recruiting so you know what worked best and then use that information next time around.

- **Offer food, refreshments, reimbursement of expenses and/or payment** wherever possible. Make it beneficial, fun and worthwhile for all those involved.

HOW CAN I INVOLVE PEOPLE WHO ARE OFTEN NOT HEARD FROM?

Involving seldom heard groups may require extra thought, preparation, time and money. However the benefits of reaching people who often do not have a voice are likely to exceed any difficulties experienced because of their specific expertise or experience. There is no single approach to this and you will need to learn as you go along and adapt your methods accordingly. However, one particularly useful method is community mapping.

Community mapping

Begin by listing organisations, groups or individuals where there are already informal or formal working relationships and connections. Then make a list of those you know about but have not established relationships with; then those who are normally excluded or exist outside existing networks. This shifts the perspective to the people who are often not heard and allows you to identify who you are missing. It can also be useful to map both formal and informal places where patients, service users, carers and members of the public can be reached in your local community. For example schools, shops, faith organisations, pharmacies, language classes, parent and toddler groups, interest groups, sports clubs, social clubs, age based groups and youth clubs. Local libraries often have extensive listings of local voluntary and community groups and can be a useful resource to complete your community map.

Through the creation of your community map, you can then begin to see who you are missing, how you could make connections to these groups, where they may be

found and identify intermediaries who may be able to help. Community maps can also provide a snap shot of your community from which you can map any progress or change.

A community map is best achieved when developed in partnership with service users, patients, carers and/or members of the public.

► See *Tools for improvement Co-producing services - Co-creating health* (NHS Wales, 2013); *A PPI Good Practice Handbook for UK Health Care Regulators* (Joint Health and Social Care regulators Patient and public involvement group, 2010) for more information on community mapping and *Personal and Public Involvement Toolkit for Staff* (Southern Health and social care trust, 2011); *Patient and Public involvement toolkit for staff* (NHS Leicester City, 2014); *How to engage seldom heard groups* (East Midlands Academic Health Science Network, 2015) and *Beyond the usual suspects* (Shaping our lives, 2013) for more information on how to engage those seldom heard.

SHOULD I WORRY ABOUT BEING REPRESENTATIVE?

Whether your *working together* initiative needs to be representative or not is largely dependent on your aims and purpose. If, for example you are looking to recruit someone to a steering group, they may not be representative of all your community members but they will be able to contribute important insights and present a range of people's views providing they have been selected for their skill set or experience and not their status. However, if the aim of your initiative is about a communal change or development, then assessing a wider number of community members opinions will be important. Representativeness is important when: you want to canvass broad opinions of a community as a whole, a specific group; or when the results collected from your project will lead to democratic decision making, policy or communal changes. It is less important if you are looking to generate ideas and the source of these ideas is not important, or if you are looking to work with as many people as possible and are happy to report your findings based on the individuals or groups of individuals you managed to work with. You should be able to clearly identify and document the steps you have taken to involve any underrepresented groups. Don't rely on the "usual suspects".

CONCLUDING THOUGHTS:

By way of a conclusion it seems appropriate to reflect on the production of this guide.

The core principles identified from the evidence review seemed quite straightforward and it would have been acceptable to produce the guide from this. However, Rebecca suggested that we should practice what we preach and evaluate these principles. We used a Delphi consensus method to confirm the validity and the individual importance of the identified principles for those working on the ground.

Unexpectedly this produced no consensus whatsoever about the most important principles. But it did clearly signal that the importance ascribed to a given principle was determined by the context and the perspective of the Delphi respondent. This made us realise that we all have very different ideas about what working together should look like, what the barriers are and what the most effective ways of working.

We recognised the impossibility and danger of providing a prescriptive 'how to' for all contexts, but recognised the importance of suggesting 'ways of thinking about' it applicable to a variety of contexts.

Feedback from Heather Eardley and our wider stakeholder group on initial drafts challenged us in unexpected ways. Strong opinions were given, awkward questions asked and challenges made about the academic practices we have internalised.

As a result the guide developed in ways we did not anticipate, but think it is better for it. We changed the title to better reflect our target audience, altered the layout used and adapted the language to improve accessibility. Overall working together in developing the guide has been a valuable experience and we hope the guide will reflect some of the lessons learnt.

WORKING TOGETHER - SOME EXAMPLES

Working together: Example 1

Setting up a Patient Participation Group

Our medical practice differs from most other GP practices in that it is a new GP practice, in a new town, which has recently been awarded Healthy Town status, with a new building. Our demographic is also untypical. It has more than three times the national average number of 0 to four-year-olds and above national average numbers of 24 to 55-year-olds.

Given the challenge of setting up a patient participation group we used a variety of methods to advertise for interested patients:

- Posters in our reception and waiting areas.
- Information, including a fantastic animation, on our website.
- We placed flyers in the waiting room alongside information from the Patients Association.
- A press release was forwarded to the free local paper
- The reception staff and the GP approached patients as they attended for appointments at the surgery.

Before the first get-together, I searched the internet for useful information and came up with some very helpful advice and supporting information, particularly from the Patients Association website.

We held three such meetings at the surgery at 6.30pm on a Thursday night. At the first we had four attendees as well as myself and two apologies; the second brought an additional two people; and at the third we were back to four. They were positive meetings with some initial interests and ideas raised. It was agreed that the time and day suited all present and that all would contact possible additions to the group in person and via email.

It was then arranged for us to try and promote the group at the local indoor market held on a Thursday evening. Three of us turned up to help.

Setting up the group has not been without its challenges:

- The local newspaper failed to run our article promoting the group.
- One member of the group secured a full-time job which left little time to offer the group and another took on a part-time job which gave him less family time and, therefore, he was unable to commit to the group.
- Only one contact was made at the market – it was a poorly attended event with a low footfall.

We are now down to a core of three. We have begun yoga sessions at the surgery and are keen to develop a breastfeeding support group and a virtual patient participation group.

Our local residents are busy working, with many commuting, and also raising young families. They are a very digitally driven population and, therefore, this is now where we will focus our efforts. With the continuing growth of the surgery we strongly believe that it is important to the future development and success of the practice that our patients are involved and have a voice through a PPG.

Practice Manager

WORKING TOGETHER - SOME EXAMPLES

Working together: Example 2

Working together in education

Social engagement has long been an area of personal interest, so when I was offered the opportunity to research what healthcare students could learn from Patient and Public Involvement in the design of a health promotion event I was delighted. The research team had pre-existing links with the underserved community so we got in touch with the founder of their local community centre and set to work.

Between a fruit machine and a vodka-jelly shot poster we discussed the community's health needs and the expertise the students could offer, there forming our patient and public involvement partnership with the Community Centre Founder and Neighbourhood Warden. The community we worked with has a high prevalence of depression and their main desire was that the health promotion event would steer away from the traditional biomedical model and focus on a more holistic approach to well-being.

It was initially difficult to convey that, although the event itself was to be community-focussed, our research was more interested in the learning value to the healthcare students involved. In order to better align the two, we worked with our patient and public partners to design a questionnaire to scope happiness levels in the area to be given out at the event. By enabling our partners to use the collected questionnaires as part of their own work there was a clear ongoing benefit to them as well as us. Throughout the process it was important that we were proactive in our approach; we joined the community centre's Facebook page and attended local partnership meetings to inform other community stakeholders about the project.

As our event was to be part of the larger, annual 'Love Barne Barton' celebration we invited our partners to collaborate with the healthcare student participants in designing activities for the event during a planning workshop at the university. On the day itself, we set up alongside a face-painter, a magician and a reptile petting zoo, a combination the research team were far from used to and the event was thoroughly enjoyed by all.

Working in partnership with community leaders allowed us to tailor the event to the health needs of the local population in a way that would have been impossible had we simply parachuted in with pre-existing ideas and we are now in the process of developing a continued partnership between the university and the community which we hope will lead to continued collaborative medical education research in the future.

Intercalating Medical Student

WORKING TOGETHER - SOME EXAMPLES

Working together: Example 3

Maintaining a patient participation group in a GP practice

Our patient participation group has existed for over 15 years, but has evolved over the last few years. It is now chaired by a patient, rather than a GP. The group has developed a 'Terms of Reference' that is reviewed annually and is referred to inform decision making, for example with respect to recruiting new members. Monthly editions of the National Association for Patient Participation newsletters, local and national documents that affect the Practice and services are circulated to keep the group informed. A local Health and Care Forum offers two way information flow between the forum and patient participation group and we ensure the patient view is represented in both groups.

Our patient participation group meets every 6 weeks. Agenda items are requested before circulation. Notes and action points are circulated promptly to help ensure actions are clear and completed. Task and finish groups are used as required outside of the core group meetings. The patient participation group chair writes a briefing paper prior to each partners' meeting. We have a quarterly newsletter which is printed for circulation and is posted onto the website. We have worked closely with the Practice, providing a presence in waiting rooms to encourage patients to sign up to using SystemOnline which allows online booking of appointments and ordering prescriptions.

Each year the group works with the Practice to complete 700-800 practice surveys. In previous years these are done face to face in the waiting rooms, but this year some were done using Survey Monkey via the website. The survey gives us a good sample to check Practice progress and inform priorities for future action. Sometimes, survey findings and direct patient approaches require the patient participation group to exercise their critical friend role to the Practice and assert what needs to be done.

Recently the Practice has asked our advice about how to raise awareness and provide information to patients about a new Clinical Commissioning Groups shared patient record. This demonstrates their confidence in our advice and suggestions.

Most recently the patient participation group has organised and delivered a 'Be Well, Be Healthy, Be Fit Festival' in partnership with the local District Council. This was a first for the town and has attracted attention from other areas and suggestions of repeating next year. Nearly 200 people attended this event which offered information and activities for all ages, including interactive stands, exercise tasters, cooking and lots of opportunity to find out from a range of informative stands. Our exit graffiti wall will inform next year's planning.

Patient Participation Group Chair

WORKING TOGETHER - SOME EXAMPLES

Working together: Example 4

Working together in commissioning

Following discussion and case study work to test approaches and ideas in practice, the five Wessex Healthwatch networks worked together with NHS England and the Wessex Strategic Clinical Networks to develop a Wessex-wide Framework for Good Practice to ensure effective patient and public participation and voice in commissioning decisions. Initially this has been delivered as a time limited project which aimed to:

- Improve the outcome of commissioning through the active involvement of patients and the public throughout all aspects of the commissioning cycle
- Bring together patients, carers and members of the public who have a range of skills and experiences to work closely with health professionals to inform future provision of services
- Facilitate patient, carer and public participation in service redesign contributing to the development of services, the implementation of national initiatives and local commissioning decisions
- Involve, patient, carers and public representatives in becoming active participants in healthcare

What did we achieve?

- Provision of a dedicated point of contact between all the partners in the form of a project manager
- Actively engage voluntary and community sector networks in the project
- Provide awareness raising and support for the involvement of local people in NHS England/ Wessex Regional and SCN commissioning activities.
- Support to enable a strong and active voice for people and groups who are seldom heard and often excluded from mainstream participation and voice opportunities.
- Created A Framework for Good Practice in Patient and Public Participation (see link). The framework has been used in draft form to support planning on re-location of pharmacies and the Wessex Communications and Engagement Network have taken part in its development and have registered interest in adapting it for use.
- Tested the practical aspects of the toolkit on two live commissioning projects (CAMHS Tier 4 and Maternity).
- Provide training courses for patients and the public in order to enable them to be actively involved in the commissioning cycle. A cohort of 45 are now trained and keen to be involved in commissioning locally.
- Provide a training opportunity for staff in the value of patient and public participation and voice in commissioning and use of the framework and tools. Staff training feedback has been positive with 100% of attendees saying it was a good use of their time and that they would recommend it to others.
- An agreed approach to managing the capacity of Healthwatch in supporting the implementation of the Good Practice Framework and Toolkit post March 2015. The Wessex patch is a large geographical area which has issues of rural isolation, urban locations (including several large towns and cities) and an island! This posed some challenges when trying to find a location to hold meetings and training sessions for patients and service users. The best results came when we accessed people in their own communities through the networks Healthwatch have built up locally.

The momentum from the project was not lost as NHS England (Wessex) and the Wessex Strategic Clinical Networks have agreed an approach to managing the capacity of Healthwatch in supporting the implementation of the Good Practice Framework and Toolkit post March 2015.

Patient Experience and Safe Guarding Manager

www.healthwatchdorset.co.uk/sites/default/files/choosing_and_buying_services_together.pdf

WORKING TOGETHER - SOME EXAMPLES

Working together: Example 5

Working together in research

Finding gatekeepers who can bridge the gap between the world of academic research and hard to reach populations within the community can be a challenge in all PPI research. Hard to reach populations can be difficult to recruit in any research environment and was a particular issue in this project due to the perceived irrelevance of PPI to the individuals lives. With some friendly encouragement and the promise of tea and cakes, a good number attended what was a thought provoking and beneficial round table discussion.

What did you do:

With my experience of research within academia and close ties with a population of foreign nationals where I live, I was asked to facilitate a round table discussion with my international peers as a PPI research partner.

What were the outcomes or impacts of working together.

- Conducting research as a PPI partner, as opposed to an 'academic', for me was an innovative and refreshing and method of conducting research. I approached the research activity as a peer, not feeling the often hierarchical boundary of 'researcher' and 'participant' often present in academic research. As a result, I felt a level of connection with the discussants that I have not experienced in my previous work within academia.
- Themes emerged for both the research team and the participants that were unexpected as the discussion gave a voice to a population often unheard in healthcare research.
- The participants appreciated the invitation to take part in the research and thanked me for allowing them to have their voice heard on what they initially had believed to be a topic of little relevance to themselves.

Did you face any challenges?

- Recruitment was a challenge initially, even with access to the population. The promise of tea and cakes was a big help!
- Language was another small issues as everyone attending the discussion was from a different country. Although all participants spoke English, enough time needs to be allowed for clarification of terms

Would you do anything different next time around?

The experience was worthwhile for the PPI partners and myself. I would follow the same format again next time but allow a little extra time! It always takes longer than you think.

Patient and public involvement Research Partner

WORKING TOGETHER - SOME EXAMPLES

Working together: Example 6

Friends of Cumberland Surgery

Cumberland Surgery is only three years old. It was started as collaboration between the local University and a social care provider to bring clinical care plus teaching for healthcare students into Devonport, a neighbourhood with the highest social deprivation levels in the city. The surgery provides outreach services for the homeless population, many of whom register at the practice meaning that the practice population is very mixed.

We wanted to invite everyone to participate in our patients group so we decided to hold two open meetings. We used posters and letters to advertise the meetings but we also sent text messages to the whole registered population giving details. Meetings were attended by around 25 patients and happened at a momentous time for the practice which was then in the hands of NHS England since the social care provider had ended the contract. The "friends of Cumberland Surgery" group that formed immediately set about fighting to keep the surgery open. They wrote to and later met officials from NHSE and the Clinical Commissioning group and have since been included in the appointing of a new provider.

As well as a crash course in NHS politics the group has sent a delegate to a Patients Association conference in London about the use of data to improve healthcare and patient representation and has "twinned" with another PPG just starting up in Cranbrook, a new town outside Exeter. Having identified a major gap in services to help with weight loss, we are now starting up our own service – to be called the "Cumberland Sausage". A lot has been achieved in a short time and we now have an active group with a Chair and a deputy providing both support and representation to our growing practice.

General Practitioner

WORKING TOGETHER - SOME EXAMPLES

Working together: Example 7 Medical Revalidation (regulation)

My Patient and Public involvement (PPI) experiences in revalidation has shown that patient/lay representatives can play a meaningful role in the health service by ensuring 'all licensed doctors continue to demonstrate on a regular basis that they are up to date and fit to practise in their chosen field and able to provide a good level of care'

It is a long term example of how patient and lay representatives can work together with the medical profession and others to create a system that seeks to protect the public and ensure that doctors comply with the requirement of 'Good Medical Practice'

Patient/Lay representatives like me have been involved in the design, piloting, and implementation stages of revalidation and continue to play an ongoing part as we move into the review process. The revalidation system created has provided a range of opportunities for the patient/lay voice to be heard. It includes the ability of individual patients being able feedback on their personal experiences. Since revalidation began at the end of 2012, it is estimated that over 3.5 million patients have done so.

There is also the wider role of the PPI representative, which has grown in many different ways. There is now participation in the governance and the quality assurance(QA) of the system and the ability to contribute to the debate on revalidation policies and procedures at different levels. This includes QA e visits to different health locations, input into the production of advisory documents, reports on various topics and involvement in relevant meetings.

As part of the QA team, PPI representatives contribute freely to discussions and are involved in decision making processes when commenting on different aspects of the local revalidation system.

A recent report on QA visits describes patient/lay participation as having 'the public in the room.' It also said that "Lay representation should become a standard practice, clarification of their role is important and should include their ability to comment widely on the performance of the organisation and not limit their role to patient feedback or PPI" This report is further confirmation of the important role that PPI representatives can play in revalidation and is very good example of medical and patient/lay reps successfully working together.

This trend in Patient/Lay involvement in revalidation will continue and the indications are that it will increase and become more widespread with more lay reps becoming involved. These will include those lay reps who are being trained under Leading Together Training Programme in NHS England (South) which is based on the concept of medical professionals working in partnership with lay/ patient representative in the future.

For further information see www.oxfordahsn.org/our-work/patient-and-public-engagement-involvement-and-experience/leading-together/

Patient/Lay Representative

THINGS TO CONSIDER

Planning is essential for effective *working together*. You can use the table below as a prompt for starting out, setting up and maintaining your *working together* initiative.

STARTING OUT

THING TO CONSIDER:	NOTES:
Purpose: Being clear about your purpose throughout your planning and <i>working together</i> initiative will help to inform future decisions and ensure your project remains grounded.	
What it is you want to achieve?	
What are your specific aims and objectives?	
Are these realistic?	
How are you going to achieve them?	
Who do you need to work with?	
Do they need a specific skill set or experience?	
How are you going to identify and contact those you wish to work with?	
Are your methods of working together appropriate for your purpose, community and available resources?	
Are there any potential barriers?	
How are you going to overcome these?	
What are your timeframes?	
Do they allow for any extra time working together might take?	
How and when is your purpose going to be evaluated?	
Have you provided a definition of your method/s or level/s used?	

THING TO CONSIDER:	NOTES:
<p>Available resources: It is important to consider what available resources you have access to before budgeting for any working together initiative so suitable costs can be added. It can also help to identify areas of cross over where resources can be saved. It is worth asking yourself the following questions:</p>	
Are you replicating other work?	
What resources do you currently have access to? e.g. staffing levels, time, money.	
Are these enough?	
Can you draw on existing resources or expertise?	
Do you need access to more resources to provide ongoing support etc.? If so, how can you get them?	
What will happen to individuals involved at the end of your working together initiative? Are there other projects they can be involved in?	
Are you going to develop a database of contact details for future use?	
Are individuals happy to share their details with you?	
Reimbursement	
Are you going to follow good practice and promptly reimburse expenses involved in working together? This can include: child care and/or carer costs; travel time; accommodation; refreshment and sustenance costs; telephone/fax, printing and postage costs, conference fees; training expenses.	
Has what is going to be reimbursed been made clear to those involved?	
Will individuals have their expenses reimbursed before the session, on the day, or after an event? Before or on the day is preferable.	

THING TO CONSIDER:	NOTES:
Payment methods	
Are you going to pay individuals for their involvement?	
Will this be a flat sum, monthly or by the hour?	
Will your method of payment exclude individuals you can work with?	
Are there payment choices available?	
How will people be told about the payment and/or reimbursement process?	
Is your method of payment inclusive for all individuals? Bear in mind some people do not have access to a bank account so payment by cheque can be problematic.	
Does your method or amount of payment affect an individual's employment status or benefit allowance? ▶ See HMRC employment indicator tool to check an individual's employment status or gov.uk for useful information on this topic although it is important to remember these quickly become out of date so check regularly.	
Are systems in place to provide flexible and prompt payments?	
Have individuals been told about the possible impact accepting payment may have on benefits received?	
Have they sought or been directed to professional advice?	
Has what is going to be reimbursed been made clear to those involved?	
Will individuals have their expenses reimbursed before the session, on the day, or after an event? Before or on the day is preferable.	

THING TO CONSIDER:	NOTES:
Other associated costs	
Have you budgeted for other costs involved? This can include: recruitment, training and learning costs; advertising; venue hire; catering; provision of equipment; conference fees; printing and postage costs; staffing; administrative support; interpreters, translators and transcribers; carer and child care cover; production of resources; accommodation and rewards.	
Recruitment	
Who do you need to recruit and how many people need to be involved?	
How are you going to recruit? What methods will you use?	
Do individuals involved need to have a specific skill set or experience? If so, what are they?	
Have you provided a short job/role description that makes this clear? Is it needed?	
Are the expectations, commitment required, any travel involved, payment/reimbursement offered and benefits for those involved and the wider community clear and appropriate?	
Have you asked individuals of your group how they would like to be identified? Have you provided a definition of the word/s chosen?	
Are there clear and well-advertised opportunities for new members to become involved?	
Do you need to consider a time-limited length of involvement to maintain freshness?	

THING TO CONSIDER:	NOTES:
Training Requirements	
Will individuals involved require training?	
Who will provide this training? Can you offer it in house or will you need external assistance?	
What training do people involved want?	
Do you need to provide more training as a result of this?	
Do staff members need training?	
Would staff members like to receive training?	
Have you considered the costs of training involved?	
Meeting individual and collective needs to ensure you are being as inclusive as possible	
Have you asked what the preferences, needs and abilities of those involved are in terms of desired involvement level, type, communication method etc.?	
Can you meet these? If not, what do you need to do?	
Gate keeper involvement	
Are you going to involve gatekeepers?	
Will this be beneficial?	
Do separate or parallel events need to be held for gatekeepers and individuals involved?	
Involving seldom heard groups or individuals	
Have you considered how you can work with those who are not normally involved or whose voices are rarely heard?	
Can you clearly evidence this?	

THING TO CONSIDER:	NOTES:
Timing	
Does the time you have suggested exclude certain individuals? Such as those in full time employment or those involved in religious holidays?	
Communication	
Is your method of communication inclusive?	
Is there more than one option available?	
Is information available in other formats such as large print, audio, Braille, minority languages or dialects where needed?	
Is the language you are using simple, respectful and accessible? Does it avoid jargon, acronyms and technical language?	
Have you designed the information with individuals involved?	
If not, why not?	
Have you checked for understanding?	
Does a glossary of terms need to be provided?	
Venue considerations	
Have you worked with individuals involved to identify suitable venues? Are there venues individuals already use such as a village hall, social club or library?	
Is your venue safe, easy to find and accessible for all individuals involved?	
Is it close to public transport links?	
Are there disabled parking spaces, wheel chair access, suitable facilities and audio loops available?	
Is your venue familiar or at least appealing to those involved? Is it associated with any specific condition?	

THING TO CONSIDER:	NOTES:
Do you need to provide regular breaks?	
Ethical considerations	
Do you have emergency contact details for all those involved?	
Do you need parental consent?	
Do you need to keep information shared confidential? If so, how will you do this?	
Have you provided contact details for individuals to contact if they can no longer continue to be involved or attend an event?	
Evaluation: It is important to evaluate your working together initiative as it can help to improve accountability and transparency by reporting what was done, what was achieved and improve future practice by exploring what worked well and what might need changing. Similar to all working together initiatives there is no single approach or method to evaluate working together projects as each activity needs to be viewed in its own right and an evaluation framework developed to match the purpose, community, type and scale of working together.	
What is it you want to evaluate? Is it the process, outcome, satisfaction, quality, delivery and/or impact of your working together initiative?	
Have you worked with those involved to assess what it is you are going to evaluate?	
How are you going to achieve this? What tools or methods do you need?	
When will you evaluate?	
Who needs to be involved?	
What are you going to do with your evaluation findings?	
Dissemination	
How will you report and share your working together findings and evaluation findings?	
Is this inclusive of different audiences?	

WHERE CAN I FIND OUT MORE?

Information signposted throughout this guide is presented in the table below.

EXAMPLE ADVERT AND JOB ROLE DESCRIPTION TEMPLATES	AVAILABLE FROM:
<p>Toolkit: Co-production in commissioning (Rethink mental illness, 2015)</p> <p>Guide: Patient and Public involvement in health and social care research (National Institute for Health Research, 2014)</p> <p>Guide: Start up guide for general practice (Scottish Health Council, 2012)</p>	<p>https://www.rethink.org/media/1658112/getting_started_guide.pdf</p> <p>http://www.rds.nihr.ac.uk/wp-content/uploads/RDS-PPI-Handbook-2014-v8-FINAL.pdf</p> <p>http://www.scottishhealthcouncil.org/patient_public_participation/patient_participation_groups/ppg_start_up_guide.aspx#.Vugk9-asV8E</p>
EXAMPLE TERMS OF REFERENCE AND GROUND RULES	
<p>Guidance: Guidance on involving Adult NHS service users and carers (NHS Wales, 2010)</p> <p>Toolkit: Co-production in commissioning (Rethink mental illness, 2015)</p>	<p>http://www.wales.nhs.uk/sitesplus/documents/829/NLIAH%20Guidance%20on%20Involving%20Adult%20NHS%20service%20users%20E.pdf</p> <p>https://www.rethink.org/media/1658112/getting_started_guide.pdf</p>
FURTHER INFORMATION ON WAYS OF WORKING TOGETHER THEIR STRENGTHS AND LIMITATIONS	
<p>Handbook: A PPI Good Practice Handbook for UK Health care regulator (Joint Health and Social Care Regulators' Patient and Public involvement group, 2010)</p> <p>Handbook: Dialogue by Design: A handbook of public and stakeholder engagement (2012)</p> <p>Guidance Service user involvement methods a guidance document (Health service executive, 2010)</p> <p>Toolkit: Personal and Public involvement toolkit for staff (NHS Leicester City, 2014)</p> <p>Guide: Good practice guide: service user involvement (Turning point Scotland, 2011)</p>	<p>http://www.hpc-uk.org/assets/documents/100032B6A_PPI_Good_Practice_Handbook_for_UK_Health_Care_Regulators.pdf</p> <p>http://designer.dialoguebydesign.net/docs/Dialogue_by_Design_Handbook.pdf</p> <p>http://www.hse.ie/eng/services/yourhealthservice/Documentation/MethodsResource2010.pdf</p> <p>http://www.leicestercity.nhs.uk/Library/ppi_toolkit-1.pdf</p> <p>http://www.turningpointscotland.com/wp-content/uploads/2011/08/Service-User-Involvement-Good-Practice-Guide.pdf</p>
EXAMPLES OF FINANCIAL AND SOCIAL COSTS SAVED WHEN WORKING TOGETHER	
<p>Report: The Business Case for People Powered Health (Nesta, 2013)</p> <p>Briefing document: Service User involvement in the delivery of mental health services (Together, National Survivor User Network, 2014)</p>	<p>http://www.nesta.org.uk/sites/default/files/the_business_case_for_people_powered_health.pdf</p> <p>http://www.together-uk.org/wp-content/uploads/downloads/2014/06/Service-User-Involvement-briefing.pdf</p>
EXAMPLES OF ESTIMATED INVOLVEMENT COSTS AND BUDGETS	
<p>Guidance: Budgeting for involvement: Practical advice on budgeting for actively involving the public in research studies (National Institute for Health Research: 2013)</p> <p>Guide: How to estimate the costs of public involvement (East Midlands Academic Health Science Network, 2015)</p>	<p>http://www.nihr.ac.uk/documents/get-involved/INVOLVEMHRNBudgeting09Jul2013.pdf</p> <p>http://emahsn.org.uk/images/resource-hub/PPI%20documents/How%20to%20guidance/How_to_estimate_the_costs_of_public_involvement.pdf</p>

COST CALCULATOR	AVAILABLE FROM:
<p>Guidance: Guidance on the use of social media, (INVOLVE, 2010)</p> <p>Support pack: Patient Participation Group information and support pack (Patients Association).</p> <p>Guide: aimed at clinical commissioning groups but useful for anyone who wants to understand more about what social media is and how it can be used to work together. Contains links to other examples of health services using social media.</p>	<p>http://www.invo.org.uk/posttypepublication/guidance-on-the-use-of-social-media/</p> <p>www.patients-association.com</p> <p>https://www.networks.nhs.uk/nhs-networks/smart-guides/documents/Using%20social%20media%20to%20engage-%20listen%20and%20learn.pdf</p>
FURTHER INFORMATION ON COMMUNITY MAPPING METHODS	
<p>Toolkit: Tools for improvement Co-producing services - Co-creating health (NHS Wales, 2013)</p> <p>Handbook: A PPI Good Practice Handbook for UK Health Care Regulators (Joint Health and Social Care regulators Patient and public involvement group, 2010)</p>	<p>http://www.1000livesplus.wales.nhs.uk/sitesplus/documents/1011/T4!%20%288%29%20Co-production.pdf</p> <p>http://www.hpc-uk.org/assets/documents/100032B6A_PPI_Good_Practice_Handbook_for_UK_Health_Care_Regulators.pdf</p>
FURTHER INFORMATION ON WAYS TO INVOLVE THE SELDOM HEARD	
<p>Toolkit: Personal and Public Involvement Toolkit for Staff (Southern Health and social care trust, 2011)</p> <p>Toolkit: Patient and Public involvement toolkit for staff (NHS Leicester City, 2014)</p> <p>Guidance: How to engage seldom heard groups (East Midlands Academic Health Science Network, 2015)</p> <p>Report: Beyond the usual suspects (Shaping our lives, 2013).</p>	<p>http://www.southerntrust.hscni.net/pdf/PPISStaffToolkit.pdf</p> <p>http://www.leicestercity.nhs.uk/Library/ppi_toolkit-1.pdf</p> <p>http://emahsn.org.uk/images/resource-hub/PPI%20documents/How%20to%20guidance/How_to_engage_seldom_heard_groups.pdf</p> <p>http://www.shapingourlives.org.uk/documents/BTUSReport.pdf</p>
FURTHER INFORMATION ON EVALUATING WORKING TOGETHER	
<p>Guide: Evaluation: what to consider (Health Foundation, 2015)</p> <p>Guide: Evaluating Participation a guide and toolkit for health and social care practitioners (Scottish health council, 2013)</p> <p>Handbook: A PPI Good Practice Handbook for UK Health Care Regulators (Joint Health and Social Care Regulators' Patient and Public Involvement Group, 2010);</p> <p>Framework: a framework designed to assess the impact of public involvement in research</p> <p>Document: contains a list of commonly used publications and resources when evaluating or reporting patient and public involvement (Pages 38-39)</p>	<p>http://www.health.org.uk/publication/evaluation-what-consider</p> <p>http://www.scottishhealthcouncil.org/publications/research/evaluation_toolkit.aspx#.Vuwo2OasV8E</p> <p>http://www.hpc-uk.org/assets/documents/100032B6A_PPI_Good_Practice_Handbook_for_UK_Health_Care_Regulators.pdf</p> <p>http://piaf.org.uk/documents/piaf-guidance-jan14.pdf</p> <p>http://www.nihr.ac.uk/funding/how-we-can-help-you/RDS-PPI-Handbook-2014-v8-FINAL.pdf</p>

Further information that may also be of interest is presented below.

GUIDANCE ON WAYS TO IMPROVE THE ACCESSIBILITY OF YOUR WORK

RESOURCE	AVAILABLE FROM:
Practical handbook: for anyone organising an event and wants to make it accessible.	Social Care Institute for excellence www.scie.org.uk/publications/accessibleevents/index.asp
Resource: an organisation campaigning against gobbledegook, jargon and misleading public information.	Plain English Campaign www.plainenglish.co.uk
Website: make it clear campaign, guidance on how to prepare good quality plain English summaries.	INVOLVE www.invo.org.uk/makeitclear/
Website: a commercial organisation equipped with advanced solutions to transform your global communications and interactions with international stakeholders. Translation and interpretation services offered.	The big word www.thebigword.com/en-gb/ @thebigword The big word
Website: The Digital Accessibility Centre (DAC) works with clients to create digital media that is accessible to all members of a population, and meets best practice accessibility standards and legislation.	The Digital Accessibility Centre www.digitalaccessibilitycentre.org/ @DACcessibility Digital Accessibility Centre

JARGON BUSTERS

RESOURCE	AVAILABLE FROM:
Resource: an online glossary of words sometimes used in public involvement research.	INVOLVE www.invo.org.uk/resource-centre/jargon-buster/
Resource: a plain English guide to the most commonly used health and social care words and phrases and what they mean.	Think local act personal www.thinklocalactpersonal.org.uk/Browse/Informationandadvice/CareandSupportJargonBuster/ @TLAP1 Think Local Act Personal

GUIDANCE ON PAYMENT AND REIMBURSEMENT

RESOURCE	AVAILABLE FROM:
Website: the UK's tax, payments and customs authority.	HM Revenue and Customs www.hmrc.gov.uk @HMRCgovuk HMRC www.youtube.com/user/hmrcgovuk
Tool: a tool to check the employment status of an individual or group of workers to see if they are employed or self-employed - that is, whether they're employed or self-employed for tax, National Insurance contributions or VAT	HM Revenue and Customs www.gov.uk/guidance/employment-status-indicator @HMRCgovuk HMRC www.youtube.com/user/hmrcgovuk
Document: rates and allowances for travel including mileage and fuel allowances as suggested by HM Revenue and Customs (2013)	HM Revenue and Customs www.gov.uk/government/publications/rates-and-allowances-travel-mileage-and-fuel-allowances @HMRCgovuk HMRC www.youtube.com/user/hmrcgovuk

RESOURCE	AVAILABLE FROM:
Website: wealth of resources discussing volunteer placements, rights and expenses.	GOV.UK www.gov.uk/volunteering
Website: provides free, independent, confidential and impartial advice on benefits and tax credits.	Citizens Advice Bureau www.citizensadvice.org.uk/benefits/
Article: money advice regarding child care costs	Money Advice service www.moneyadviceservice.org.uk/en/articles/childcare-costs
Website: This page links to guides and practical advice on payment and non-monetary methods for recognising the time, skills and expertise provided by members of the public. Resources available include benefit advice, cost calculator and budgeting for involvement.	INVOLVE www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/
Guidance: of payment options – currently under review.	INVOLVE www.invo.org.uk/wp-content/uploads/2012/11/INVOLVEPayment-Guiderev2012.pdf (Currently under review)
Document: published document discussing the recent changes, caveats and things to consider when paying individuals in receipt of benefits.	Social care institute for excellence www.scie.org.uk/publications/ataglance/ataglance50.asp
Document: provides an overview of the main changes to benefit policies relevant to working together in research. Please note the rules and regulations of receiving benefits are regularly updated. Check you are working with the most up to date version.	INVOLVE www.invo.org.uk/wp-content/uploads/2014/01/Benefit-regulations-update-May-2013.pdf
Document: a guide for public contributors describing the Central Commissioning Facility policy on the payment of fees and expenses to members of the public. Based on guidance that has been agreed with the Department of Health 'National Institute for Health Research (NIHR) programmes: Payment and reimbursement rates for public involvement (2009) and aligns with guidance developed by the NIHR Evaluation Trials and Studies Coordinating Centre (NETSCC) Reward and recognition for public contributors: A guide to honorarium, travel and subsistence payments (2012) (link below)	Central Commissioning Facility www.nihr.ac.uk/CCF/PPI/CCF_Public_Payment_Guide.pdf
Document: guidance developed by the NIHR Evaluation Trials and Studies Coordinating Centre (NETSCC) Reward and recognition for public contributors: A guide to honorarium, travel and subsistence payments (2012)	National Institute for Health Research www.netscc.ac.uk/getting_involved/PDFs/Honorarium_payments_to_public_contributorsFINAL.pdf

GROUPS OF INTEREST

RESOURCE	AVAILABLE FROM:
Resource: Patient UK has a comprehensive list of national and local support groups and organisations. Each entry gives a brief description of the organisation, plus full contact details including web links.	Patient UK http://patient.info/ List of support groups and organisations: http://patient.info/forums @patient Patient uk.pinterest.com/patient www.youtube.com/patient

GROUPS OF INTEREST

RESOURCE	AVAILABLE FROM:
Website: Association of Medical Research Charities is the national membership organisation of leading medical and health research charities in the UK. The website includes a list of all member charities.	Association of Medical Research Charities (AMRC) www.amrc.org.uk
Website: "National Council for Voluntary Organisations champions the voluntary sector and volunteering because they're essential for a better society. We do this by connecting, representing and supporting voluntary organisations."	National Council for Voluntary Organisations (NCVO) www.ncvo.org.uk @NCVO www.youtube.com/user/NCVOnline
Website: Scottish Council for Voluntary Organisations (SCVO) works in partnership with the voluntary sector to advance shared values and interests. They have over 1500 members who range from individuals and grassroots groups, to Scotland-wide organisations and intermediary bodies. "Our services help charities and third sector organisations across Scotland focus on what they do best, whether that's supporting the most vulnerable people in our communities or conducting cutting edge research".	Scottish Council for Voluntary Organisations (SCVO) www.scvo.org.uk @scvotweet SCVO
Website: "The Northern Ireland Council for Voluntary Action, is a membership and representative umbrella body for the voluntary and community sector in Northern Ireland. With around a thousand members - that range from household name charities to grass roots community groups - we lobby and campaign to advance the interests of the people and communities that our members support. We offer a wide range of practical services, products and support to our members to help them do what they do best - find innovative solutions for social challenges."	Northern Ireland Council for Voluntary Action www.nicva.org
Website: a resource designed to help all Parkinson's researchers whatever their area of interest to effectively and meaningfully involve people affected by Parkinson's in their research,	Parkinson's UK www.parkinsons.org.uk/content/patient-and-public-involvement-ppi-your-study. @ParkinsonsUK
Website: The Dementia Engagement & Empowerment Project (DEEP) brings together groups of people with dementia from across the UK. DEEP supports these groups to try to change services and policies that affect the lives of people with dementia	The Dementia Engagement & Empowerment Project http://dementiavoices.org.uk/ www.youtube.com/user/NCVOnline
Website: A UK charity that offers specialist one-to-one support and expert advice for people living with dementia.	Dementia UK www.dementiauk.org @DementiaUK Dementia UK
Website: a specialist knowledge portal, bringing together people, organisations and networks to share knowledge and learning across the Well Pathway for Dementia to improve services and promote living well with dementia.	Dementia Partnerships www.dementiapartnerships.com @dementiapartner Dementia Partnerships
Website: The Scottish Dementia Working Group (SDWG) is a national campaigning group, run by people with dementia.	Scottish Dementia Working Group www.sdwg.org.uk @S_D_W_G

GROUPS OF INTEREST

RESOURCE	AVAILABLE FROM:
Website and Youtube videos: the UK's leading dementia support and research charity for people living with dementia their families and carers.	Alzheimer's Society www.alzheimers.org.uk www.youtube.com/user/AlzheimersSociety @alzheimerssoc Alzheimer's society
Website: the UK's leading asthma research charity.	Asthma UK www.asthma.org.uk
Website: A charity fighting to improve treatment and care to help people with MS take control of their lives.	Multiple Sclerosis Society live.mssociety.org.uk/ms-research/get-involved-in-research @mssocietyuk MS Society UK
Website: network for mental health is an independent service user led charity that connects people with experience of mental health issues to give us a stronger voice in shaping policy and services.	Network for mental health www.nsun.org.uk @NSUNnews National Survivor User Network, NSUN
Website: a charity who provide advice and support to empower anyone experiencing a mental health problem. They campaign to improve services, raise awareness and promote understanding.	Mind www.mind.org.uk @MindCharity Mind
Website: a charity helping millions of people affected by mental illness by challenging attitudes, changing lives.	Rethink Mental Illness www.rethink.org @Rethink_ Rethink Mental Illness
Website: Together is a national charity working alongside people with mental health issues on their journey towards independent and fulfilling lives.	Together www.together-uk.org @TogetherUK www.youtube.com/channel/UCxj59733gNXydcfbMLmFnCw
Website: YoungMinds is the UK's leading charity committed to improving the emotional wellbeing and mental health of children and young people	Youngminds www.youngminds.org.uk @YoungMindsUK YoungMinds www.youtube.com/user/youngmindscharity
Website: a national charity who believe in children regardless of their circumstances, gender, race, disability or behaviour. Their purpose is to transform the lives of the UK's most vulnerable children	Barnardo's www.barnardos.org.uk @barnardos Barnardo's www.youtube.com/user/barnardosuk
Website: A charity who work with people with a learning disability to change laws, challenge prejudice and support them to live their lives as they choose.	Mencap www.mencap.org.uk @mencap_charity Mencap www.flickr.com/photos/mencap_photos
Website: National Voices is a coalition of health and social care charities in England. They campaign for people to have a stronger voice in the design and delivery of NHS and social care services. They involve a number of service users on their Service User Panel.	National Voice www.nationalvoices.org.uk @NVTweeting www.youtube.com/user/NationalVoices1
Website: Shaping Our Lives is a national organisation and network of user-led groups, service users and disabled people. They are a user-led organisation committed to inclusive involvement and specialise in the research and practice of involving diverse communities in policy, planning and delivery of services.	Shaping our lives www.shapingourlives.org.uk @Solnetwork1 Shaping our lives www.youtube.com/user/shapingourlives1

RESEARCH

RESOURCE	AVAILABLE FROM:
Website: the Clinical Research Network provides a support system to help researchers set up clinical studies quickly and effectively, provide health professionals with research training and work with patients to ensure their needs are at the very centre of all research activity. It has 15 local clinical research networks across England. See www.crn.nihr.ac.uk/networks to find your local network.	National Institute for Health Research - Clinical Research Networks www.crn.nihr.ac.uk @NIHRCRN NIHR Clinical Research Network
Website and Youtube Videos: provides national guidance and advice to improve health and social care including patient and public involvement policy.	National Institute for Health and Care Excellence (NICE) www.nice.org.uk Public involvement page: www.nice.org.uk/get-involved @NICEcomms www.youtube.com/user/NICEmedia
Website: Collaborations for Leadership in Applied Health Research and Care carry out research to find practical solutions for the NHS, and the results are used to improve health care for patients. Each CLAHRC has a patient and public involvement lead contact your local organisation to find out more about what they do and to get involved.	National Institute for Health Research – Collaborations for leadership in Applied Health Research and Care www.clahrcpp.co.uk @OfficialNIHR
Website: The Joseph Rowntree Foundation is an independent organisation working to inspire social change through research, policy and practice.	Joseph Rowntree Foundation www.jrf.org.uk @jrf_UK Joseph Rowntree Foundation
Website: The Medical Research Council (MRC) is a publicly funded organisation, which supports research across health and the medical sciences. To help inform their work, the MRC has a group of volunteers, known as the Public Panel, who provide advice and guidance on projects that need a public or patient perspective.	Medical Research Council www.mrc.ac.uk Public involvement page: www.mrc.ac.uk/about/how-the-public-can-get-involved/public-involvement/
Website: Health Research Authority Research Ethics Service (RES) protects the rights, safety, dignity and wellbeing of research participants. It includes Research Ethics Committees (RECs) in England. All RECs have members of the public on them.	Health Research Authority Research Ethics Service (RES) www.hra.nhs.uk/about-the-hra/our-committees/res Public involvement page: www.hra.nhs.uk/patients-and-the-public-2 Vacancies page: www.hra.nhs.uk/working-with-us
Journal: an interdisciplinary, health and social care journal focusing on patient and wider involvement and engagement in research. The journal is co-produced by all key stakeholders, including patients, academics, policy makers and service users.	Research Engagement and Involvement http://researchinvolvement.biomedcentral.com/
Peer reviewed paper: Guidance for reporting involvement of patients and public checklist to enhance the quality of patient and public reporting.	Stainszewska et al 2011 http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8407090&fileId=S0266462311000481
FUNDING	
Website and Youtube videos: an independent global charitable foundation dedicated to improving health.	Wellcome trust www.wellcome.ac.uk/Funding/Public-engagement/index.htm @wellcometrust Wellcome Trust www.youtube.com/user/wellcometrust

RESEARCH

RESOURCE	AVAILABLE FROM:
ADVERTISING/RECRUITMENT	
Website: a resource managed by INVOLVE to help members of the public find opportunities to get involved in research and for research organisations/researchers to advertise their involvement opportunities for free.	People in research www.peopleinresearch.org @People_Research
Website: a service that helps give people the confidence to join clinical trials, by providing useful information about how trials work – while helping link them to researchers running trials they might be interested in.	UK Clinical Trials Gateway www.ukctg.nihr.ac.uk
Website: Join Dementia Research is a service that allows people to register their interest in participating in dementia research and be matched to suitable current studies. The service shows what dementia research is taking place, both locally and nationally, and connects researchers with people who want to participate in studies.	Join Dementia Research www.joindementiaresearch.nihr.ac.uk @beatdementia
Website: The James Lind Alliance (JLA) brings patients, carers and clinicians together in Priority Setting Partnerships (PSPs) to identify and prioritise the Top 10 uncertainties, or ‘unanswered questions’, about the effects of treatments that they agree are most important. This will help future research be focussed on the questions that will be of most benefit to patients, carers, and health and social care professionals.	James Lind Alliance Website: www.jla.nihr.ac.uk Telephone: 023 8059 5489 Email: jla@southampton.ac.uk
COSTING AND BUDGETING HELP	
Tool: Practical advice on how to budget for involving patients, carers and the public in research. Included is a dummy study and a worked example. (2013)	National institute for Health Research and INVOLVE: www.invo.org.uk/wp-content/uploads/2014/11/10002-INVOLVE-Budgeting-Tool-Publication-WEB.pdf
Tool: to work out the actual costs of involving people in your study	INVOLVE www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator
Guide: a how to guide of estimating the cost of public involvement How to estimate the costs of public involvement	East Midlands Academic Health Science Network http://emahsn.org.uk/images/resource-hub/PPI%20documents/How%20to%20guidance/How_to_estimate_the_costs_of_public_involvement.pdf
TRAINING GUIDANCE	
Guidance: for people who are planning, training and supporting involvement in research. It offers advice and guidance to help develop training and support packages specific to your context – whether that’s for members of the public, researchers or both.	INVOLVE www.invo.nihr.ac.uk/resource-centre/training-resource

HEALTHCARE

RESOURCE	AVAILABLE FROM:
<p>Website: healthtalk.org (formally Healthtalkonline) provides free, reliable information about health issues, by sharing people's real-life experiences. You can watch people sharing their stories about cancer, autism, motor-neurone disease, pregnancy, drugs, depression and much more.</p>	<p>Healthtalk www.healthtalk.org Public involvement page: www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/topics Younghealthtalk www.healthtalk.org/young-peoples-experiences @healthtalkorg Healthtalk www.youtube.com/user/Healthtalkonline</p>
<p>Website: "The Patient Voices programme aims to facilitate the telling and hearing of some of the unwritten and unspoken stories of ordinary people so that those who devise and implement strategy in health and social care, as well as the professionals and clinicians directly involved in care, may carry out their duties in a more informed and compassionate manner."</p>	<p>The Patient Voices www.patientvoices.org.uk @PatientVoicesUK</p>
<p>Website: Each of the 15 Academic Health Science Networks (AHSN) in England focus on working in genuine partnership with local people and organisations to improve the health of the local community and contribute to building a thriving local economy. Collectively, as a national network, AHSNs support improvements around common themes such as improving patient safety.</p>	<p>Academic Health Science Networks www.ahsnnetwork.com</p>
<p>Website: The department of health provides health and social care policy, guidance and publications. Many of their publications can be downloaded from the gov.uk website.</p>	<p>Department of health www.gov.uk/government/organisations/department-of-health @DHgovuk www.youtube.com/user/departmentofhealth www.flickr.com/photos/departmentofhealth</p>
<p>Website: NHS England leads the National Health Service (NHS) in England by setting the priorities and direction of the NHS and encouraging and informing the national debate to improve health and care. They commission the contracts for GPs, pharmacists, and dentists and support local health services that are led by groups of GPs called Clinical Commissioning Groups (CCGs).</p>	<p>National Health Service www.engage.england.nhs.uk</p>
<p>Website: The Social Care Institute for Excellence (SCIE) improves the lives of people who use care services by sharing knowledge about what works. They co-produce their products and services with people who use services and carers. The website holds a wealth of resources including guides, training materials and published research case studies etc.</p>	<p>Social Care Institute for Excellence www.scie.org.uk @SCIE_socialcare Social Care Institute for Excellence</p>
<p>Website: The National Institute of Healthcare Research School for Social Care Research is one of the leading funders of research into adult social care practice in England, and aims to improve adult social care practice in England through conducting and commissioning research.</p>	<p>National Institute of Healthcare Research www2.lse.ac.uk/LSEHealthAndSocialCare/aboutUs/NIHRSSCR/home.aspx</p>
<p>Website: Self management UK (previously expert patients) collaborates with commissioners and clinicians to improve clinical outcomes for patients with any long-term health condition including diabetes, arthritis, and COPD.</p>	<p>Self management UK www.selfmanagementuk.org @SelfManageUK www.youtube.com/user/EPPCIC</p>

HEALTHCARE

RESOURCE	AVAILABLE FROM:
<p>Website: Participation Works enables organisations to effectively involve children and young people in the development, delivery and evaluation of services that affect their lives. They are a partnership made up of the following six agencies: the British Youth Council, Children's Rights Alliance for England, KIDS, National Council for Voluntary Youth Services, National Youth Agency and Save the Children UK.</p>	<p>www.participationworks.org.uk @partworks Participation works</p>
<p>Website: The site and app provides you with information, advice, case studies and opportunities to share experiences with others to help you make your public participation activities as effective as possible. The Participation Compass contains information on:</p> <ul style="list-style-type: none"> • Methods of participation • Case studies of participation in action • Written resources and guides about participation • Organisations that provide expertise around participation • News about participation 	<p>INVOLVE www.participationcompass.org</p>
<p>Website: The new economics foundation (NEF) and the National Endowment for Science, Technology and the Arts (NESTA's) lab have developed a network for frontline practitioners in service delivery. The network provides a forum for frontline practitioners to discuss their work, the approach they take and the challenges they face.</p>	<p>NEF and NESTA http://coproductionnetwork.com/</p>
<p>Website: an executive agency sponsored by the Department of Health to protect and improve the nation's health and wellbeing and reduce health inequalities.</p>	<p>Public Health England www.gov.uk/government/organisations/public-health-england @PHE_uk Public Health England www.youtube.com/user/PublicHealthEngland</p>
<p>Website: The Patients Association is a charity that aims to ensure that the opinions of patients are gathered on a wide variety of health and social care issues. This knowledge is used to campaign for improvements across the UK. Variety of resources available on website</p>	<p>The Patients Association www.patients-association.org.uk Helpline email: helpline@patients-association.com @PatientsAssoc Patients Association</p>
<p>Website: the National Association for Patient participation is the only UK umbrella organisation for patient-led groups in general practice. They provide essential support to GPs and practice teams through a comprehensive range of evidence based resources developed from over thirty years experience and formation of hundreds of Patient Participation Groups. They also provide essential support to clinical commissioning groups.</p>	<p>National Association for Patient Participation www.napp.org.uk</p>
<p>Website: An independent site about patient experiences of UK health services, good or bad. Founded in 2005 it is now the UK's leading independent non-profit feedback platform for health services.</p>	<p>Patient opinion www.patientopinion.org.uk @patientopinion Patient Opinion</p>
<p>Website: the UK's largest public service collaboration platform. It's the place where people working across public services go to exchange knowledge experiences and ideas of how to improve services and create connections with peers and experts in a secure environment. It offers a platform that supports professional social networking, collaboration and the sharing of information in the public sector</p>	<p>Knowledge Hub https://khub.net/ @KnowledgeHub www.youtube.com/channel/UCXmI9n3gWOMsaUQwZOOgWCg</p>

GETTING INVOLVED

Find opportunities to get involved at:

- Do-it website
- Volunteering Matters website
- noticeboard in your local library, or in local newspapers
- VSO website for overseas placements
- local Volunteer Centre website
- Reach website for volunteers with specific skills - like accountancy, marketing, law, management, mentoring or IT
- retired and senior volunteer programme website for volunteers aged 50 or older
- Volunteering Wales website
- Volunteer Scotland website
- www.peopleinresearch.org opportunities for public involvement in NHS public health and social care research.
- www.nihr.a.uk/get-involved
- www.nihr.ac.uk/get-involved/take-part-in-research.htm
- www.nihr.ac.uk/get-involved/ok-to-ask.htm
- www.nihr.ac.uk/get-involved/public-involvement-at-ccf.htm
- www.netscc.ac.uk/getting_involved
- www.asthma.org.uk/research/get-involved
- www.nihr.ac.uk/get-involved/shape-research.htm

GLOSSARY

CONFIDENTIALITY: means not sharing information about people without their knowledge or agreement and ensuring that written, spoken or electronically shared information cannot be seen or read by people unauthorised to see it.

DELPHI METHOD: is a widely used and accepted method of gathering data from individuals within a certain area of expertise. The technique is designed as a group communication process which aims to achieve convergence of opinion on a specific real-world case – in this instance working together. See www.pareonline.net/pdf/v12n10.pdf for more information.

EMPOWER: where information, rewards, skills and resources are shared so individuals are able to take control over decisions and resources although this does not mean they can take control over all decisions or resources.

ETHICAL: ethical behaviour is characterized by honesty, fairness and equality in personal, professional, academic relationships and in research and scholarly activities. Ethical behaviour respects the dignity, diversity and rights of individuals and groups of people.

GREY LITERATURE: information that is less formal than a research paper in an academic journal or a chapter in a book. It includes reports, committee minutes, fact sheets newsletters etc. This kind of material is often found on the internet.

PEER-REVIEWED: a process where scholarly work such as a research paper or proposal is read and commented on by people who have similar interests and expertise to make sure it meets certain standards before it is published or accepted.

PROFESSIONALISED: where an occupation, activity or individual gains professional qualities through things such as training or qualifications.

PROTECTED CHARACTERISTICS: a phrase used in the Equality Act (2010) covering age, disability, gender reassignment, race, religion or belief, sex, sexual orientation, marriage and civil partnership, and pregnancy and maternity. See www.fpb.org/business-support/equality-act-2010-protected-characteristics-and-types-discrimination for further information.

REVALIDATION: a process by which licensed doctors are required to demonstrate on a regular basis that they are up to date and fit to practise.

SELDOM HEARD: a term used to describe groups who may experience barriers to accessing services or are under-represented in decision making processes.

SEMANTICS: the study of the meanings of words and phrases in language or in particular contexts.

STAKEHOLDERS: a person with an interest or concern in something.

TOKENISTIC: doing something such as hiring an individual belonging to a minority group only to tick a box or prevent criticism and to give the appearance that people are being treated fairly and inclusively.



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Your Name:		
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How did you find out about the guide?		
What were you using the guide for?		
What were your overall impressions of the guide?		
Overall, was the guide helpful to you or not?		
Did It encourage you to have a go?	YES	NO
Please explain your answer		
Did it change your working together approach?	YES	NO
Please briefly explain why		
Is there any information not covered in the guide that you feel should be added?		
Could we do anything to improve the guide?		
Any other comments:		

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