UK STANDARDS FOR PUBLIC INVOLVEMENT

Implementation Stories
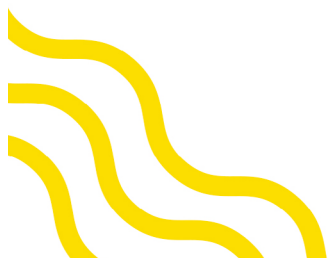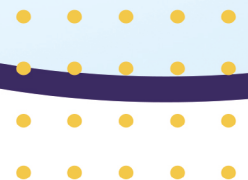
UK Standards
for Public Involvement

Introduction

This handbook shares stories of implementing the UK Standards for Public Involvement in England, Wales, Scotland and Northern Ireland. The stories are designed to give you a glimpse of different ways the standards were implemented and integrated into 'business as usual' in research, or as part of special projects. As well as setting out the context for each story, there are details about what happened, some reflections about public involvement, and the experience of implementing the standards. The stories were written in partnership with the testing organisations, links to further information and contacts are provided for you to find out more.

A range of organisations tested the draft standards during 2018 – 2019, providing feedback and suggestions for improvements to the standards. These organisations varied in their size, context, experience of public involvement and research focus. Some have significant public involvement functions and budgets, others have less resources to work with. A few were at the beginning of their experience of public involvement in research.

The UK Standards for Public Involvement Partnership acknowledge and thank all the testing organisations for their hard work, openness and feedback about what worked for them, and what didn't. Their experiences had a significant impact on the final version of standards released in November 2019.

Summary of Standards

Inclusive Opportunities
Offer public involvement opportunities that are accessible and that reach people and groups according to research needs.

Working Together
Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

Support and Learning
Offer and promote support and learning opportunities that build confidence and skills for public involvement in research.

Communications
Use plain language for well timed and relevant communications, as part of involvement plans and activities.

Impact
Seek improvement by identifying and sharing the difference that public involvement makes to research.

Governance
Involve the public in research management, regulation, leadership and decision making.

Contents

Contents

IMPLEMENTING ALL STANDARDS

Story 1

Co-producing a plan for implementing the new standards to support Patient and Public Involvement and Engagement in research at Keele University

Context

The School of Primary Care, Community and Social Care at Keele University co-produced an action plan with the Steering Group of its Research Users Group (RUG) and secured funding from the NIHR School of Primary Care Research to support 'Implementing New Standards for Public Involvement in Research Environments' (INSPIRE) programme. INSPIRE started with an audit across the primary care research community to assess which standards were met, and where improvement was needed. A three-level star rating process was adopted; zero represented absent PPIE; 1 was good quality, but could be improved; and 2 high quality PPIE. Public involvement practice against the Communication and Impact standards were the lowest scoring.

More Information

Dr Steven Blackburn, PPIE Lead, School of Primary, Community and Social Care, Keele University.
Email: s.blackburn@keele.ac.uk

Carol Rhodes PPIE Advisor
Email: c.a.rhodes@keele.ac.uk

Website: www.keele.ac.uk/pcsc/research/ppie/
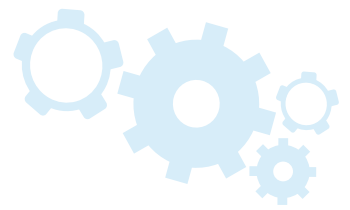
What happened?

Following the audit, the RUG Steering Group reflected on the results. Information resources to support PPIE that were needed to improve PPIE in primary care research were identified. This was an open and liberating process, with RUG members taking a leadership role in reviewing resources, suggesting improvements and prioritising them for action. Funding from the NIHR School of Primary Care Research allowed protected time to action the priorities. A range of resources were developed including: new role descriptions

- an online feedback process
- a new peer-support initiative for RUG members ('RUG Buddy') (see page 22)
- a 'how to' guide for capturing and documenting the impact of public involvement
- an updated 'Reward and Recognition' policy and guide.

These were developed in the co-production model of working; equal ownership of resources, starting together at the very beginning, shared decision making and equal effort from all. The RUG Steering Group of 12 members met bi-monthly to deliver INSPIRE, with small 'task and finish' groups working on different resources and projects. A final Task and Finish group reviewed the experience of working together on the resources, as well as the more general experience of being a Test Bed for the standards. The RUG Steering Group expressed their empowerment during the process and now see themselves as the guardian of the quality standards at Keele. An easy-read report of this experience was co-developed with RUG members who described what type of report they would want to read, shaped its content and provided their viewpoints. A RUG member co-presented the INSPIRE project at the NIHR School for Primary Care Research Showcase in November 2019.

The test-bed year was one of intense activity, in which the standards provided a framework to review, improve and identify where change was needed. INSPIRE and the standards *"provided a mechanism for self-reflecting on how we do public involvement. As a result of this project, we have improved the quality of our public involvement at Keele."* PPIE Lead

The leadership and achievement in PPIE is valued throughout the research organisation, and the UK Standards for Public Involvement have helped to further reinforce an organisational culture for meaningful and high quality PPIE in primary care research.

IMPLEMENTING ALL STANDARDS

Story 2

Evaluating the Patient and Public Involvement Advisory Group of the 'GIFT-Surg' Project, experience from the Public Programmes team at Manchester University NHS Foundation Trust

Context

The Public Programmes Team at Manchester University NHS Foundation Trust were commissioned to evaluate mid-term public involvement as part of the GIFT-Surg project. GIFT- Surg (www.gift-surg.ac.uk) is a £10m seven-year project, led by Kings College London in collaboration with University College London and KU Leuven (Belgium). The project is developing advanced surgical tools and novel imaging techniques to treat congenital problems with babies in the womb. A Patient and Public Involvement Advisory Group (PPIAG) consisting of charity representatives (with lived experience of womb congenital problems) have been inputting to the project. The group addresses aspects of safety, ethics, parental concerns concerning new techniques and has helped develop research outcome measures.

More Information

Public Programmes Telephone: 0161 276 6614
Email: publicprogrammes@mft.nhs.uk
Website: www.gift-surg.ac.uk
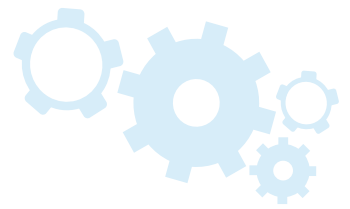
What happened?

The evaluation consisted of a document review (e.g. PPIAG Terms of Reference, meeting minutes), interviews, an online survey and workshops at a project celebration event in 2019. The team decided to use the UK Standards for Public Involvement as an evaluation framework. They did this by using the standards in all the materials used for the evaluation and as the basis for some of the reflective questions. There was consistency across items such as the discussion guide for interviews and the properties and development of the participant survey.

The standards were also used to frame workshops at the midway project celebration event, which was attended by PPIAG group members and collaborating researchers. One workshop introduced the standard set and asked participants to focus on one standard (except Impact) noting achievements and challenges related to it from their experience of being involved in the GIFT-Surg project. They were then asked to focus on the Impact standard and consider the effects of the advisory group on the project, and how this had been captured. Discussion questions included; *'What impact has being involved had on you, your organisation and the project? What's challenging about assessing impact? What does GIFT-Surg currently do well in terms of assessing impact?'*

The second workshop looked forward to the project's future. Participants were asked to imagine they were describing three important achievements of the project and the advisory group to colleagues. The whole standard set was reintroduced and participants prioritised the standards for the future development of the project (the PPIAG in particular), giving rationales for their order of importance. An academic paper will be published about the outcomes of the evaluation and using the standards to frame the process.

There were some challenges in using the draft standards in this evaluation. The need for 'translating' some of the language (the draft version was wordier and has been substantially simplified since the testing phase) and encouraging people to move beyond the 'examples' given for meeting each standard. These examples were subsequently removed from the final version and replaced with reflective questions.

The evaluation team felt that the standards provided a simple and manageable framework for participants to think about and describe their involvement experience as part of the GIFT-Surg research programme. This seemed especially important for people new to public involvement in research.

IMPLEMENTING ALL STANDARDS

Story 3

Using a three-tiered approach for assessing Patient and Public Involvement and Engagement in a large public programme setting in Manchester

Context

The Public Programmes team at Manchester University NHS Foundation Trust provide Patient and Public Involvement and Engagement (PPIE) leadership, support and services across research organisations such as: NIHR Manchester Biomedical Research Centre, NIHR Manchester Clinical Research Facilities, Welcome Research Centres and others. The research portfolio is varied in terms of topics such as Early Prevention and Detection of Cancer, Skin disease, and Primary Care research, as well as the types of research undertaken e.g. health technology assessment. The 12 strong team (full and part time) support a range of public contributors, researchers and research staff, including people that are experienced in research involvement and first-timers.

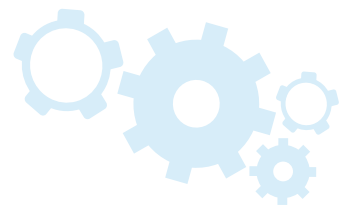## More information

Contact: bella.starling@mft.nhs.uk
Blog: www.nihr.ac.uk/blog/testing-the-uk-standards-for-public-involvement/24101

What happened?

The team plotted the majority of their every day public involvement activities against the six draft UK Standards for Public Involvement in two ways. Firstly activity information is collected in the teams' Client Relationship Management System (CRM), which is bespoke software that captures activity with and between the public, researchers and research groups.

Secondly, to reflect the very real and different contexts that exist across the public programmes' PPIE work with researchers and the public, the team decided to categorize public involvement activity into three levels. These were;

- First Steps contexts in which researchers and public contributors are more inexperienced, or first-timers
- Everyday Practice where those undertaking PPIE 'business as usual' do so with good groundings and levels of competency
- Aiming High where there are well-versed PPIE partners (researchers and public contributors) who are trying new approaches and taking more risks.

These categorizations were also recorded in the management system. Each activity was reviewed against the Standards as a baseline, and as part of routine work. More formally it was reviewed at monthly team meetings, bringing the whole team and public experience into the discussions.

To keep it manageable, progress against the standards was reviewed one standard at a time. As well as discussing how public involvement could improve against each standard, the team also collected suggestions to improve the standards and fed these back to the UK Standards for Public Involvement Partnership group. The three-tier categorisation was adopted in the final standard set, as it was seen as helpful by the partnership and other test beds had taken similar approaches. The partnership particularly liked the wording of the Manchester levels approach as realistic, and aspirational.

Overall, implementing the Standards and this three-tier approach has helped the team assess and improve their PPIE practice; *"A framework that gives guidance on areas we should be assessing our performance in, allowing us to reflect on how we are performing in these areas and prioritizing where we most want to improve."* Public Programmes Project Manager

IMPLEMENTING ALL STANDARDS

Story 4

The role of standards in developing the purpose, scope and operations of the Kidney Patient Involvement Network

Context

The Kidney Patient Involvement Network (KPIN) combines kidney organisations, charities and individuals committed to good quality Patient and Public Involvement and Engagement (PPIE). They aim to improve standards in renal treatment, care and research, and develop kidney patient leaders of the future. Members include professional organisations e.g. British Renal Society, patient organisations e.g. Kidney Care UK, and affiliated research groups. People affected by kidney disease may make little distinction between involvement in kidney research, care, and commissioning kidney treatments and services, and are *'sick of going into boxes'*. They want to see change and improved outcomes for kidney disease so work across all sectors, researchers and research staff, people that are experienced in research involvement and first-timers.

More information

Email: info@KPIN.org.uk
Twitter: @KPIN_UK
Website: www.kpin.org.uk

What happened?

KPIN started as a 'massive vision' for improved information and involvement of people affected by kidney disease in all sectors of healthcare and research. Starting a network and partnership requires energy, skill, enthusiasm and belief, and can take time. KPIN has been no exception and there has been a lot of discussion to agree its' purpose, who it would benefit, how it would work and how people would know it was having an impact. Conversations highlighted the need to develop trust across the partnership, to ensure that efforts and the outcomes are shared by all, and everyone gets recognition for progress.

Once the foundation work had been done (about a year) an audit was conducted to assess the state of PPIE across the network organisations, using the six standards as a framework for the process. Participants included health care professionals, researchers and people affected by kidney disease. KPIN found being a testing site for the UK Standards for Involvement helped with momentum during the audit and review process, as well as providing a useful structure. Using the different standards identified the core elements of engagement and involvement and 'cut through conversations' which can become complex. In addition, being

a standards testing site gave KPIN extra credibility for PPIE across the kidney disease and care network, as well as visibility to potential new partners. The audit results established a baseline of activity, identified areas of inconsistency, and where there was variable quality of involvement. The team is reporting separately on this work in a research paper in 2020.

KPIN is in a good place in early 2020, as the hub for PPIE in kidney healthcare and research. The website has information and guidance for people and organisations wanting to work with those affected by kidney disease. A recent award of funds to support patient leaders who coordinate the network has been a welcome development. There will be constant effort to secure sustainable funding, as the current model deploys goodwill and 'in kind' contributions from network members. There is also a real 'danger of success' with not enough patients and Patient Leaders to meet the interest from researchers, service providers and commissioners who want to progress their PPIE. However KPIN remains *'for patients – run by patients'*.

IMPLEMENTING ALL STANDARDS

Story 5

Standards as a framework for public involvement in PhD research projects, experience from University of Glasgow

Context

A small group of UK and international PhD students are being supervised by staff experienced in research in End of Life and Palliative Care at the School of Medicine, Dentistry & Nursing, University of Glasgow and NHS Greater Glasgow and Clyde. The PhD projects are at different stages of completion and topics are varied, for example; improving cultural issues in advanced heart failure and developing an intervention for carers of people with life limiting illnesses. Meeting with others testing the standards in Scotland proved helpful, with an opportunity to reflect on how the standards for public involvement could be incorporated into the PhD programme.

More information

Email: Bridget.johnston@glasgow.ac.uk
Twitter: @BridgetJohnst
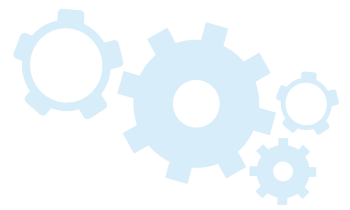
What happened?

Originally, it was envisaged that the PhD programme team and students would work with a Patient and Public Involvement Group. This moved to a different model of individual members of the public, (living with a life limiting disease or a current or past carer), being involved in each of the PhD projects. The PhD students use different mechanisms to work with their public partner, including online interaction as well as face to face meetings which are mostly in community settings, rather than health or academic settings. As some of the students are new to public involvement in research the team provided them with information and guidance for planning their recruitment and involvement activity.

The standards provide a useful reminder of the six core areas for attention to ensure good quality involvement in their research, for example reimbursing public partners costs and time. The team provided students with suggested 'scripts' for introductory conversations with their public partners. It is easy to underestimate how these initial conversations can be challenging, especially if English is not the first language of the researcher or the public partner, and the discussion topic is care of the dying.

Students are encouraged to keep notes of the meetings with their public partners. These provide a reflective tool, as well as monitoring information for supervisors. Regular meetings and supervision focus on support for their research, sharing progress with involvement, and reflecting on the ideas and comments from public partners. Supervision meetings are also an important opportunity to discuss the relational aspects of public involvement in research e.g. special considerations of working with people who are living with life limiting conditions, or are recently bereaved.

The standards provided a rationale for insisting that the PhD programme embraces public involvement, even with students and co supervisors who are new to this way of working. Whilst it is too early to comment on evaluation of this initiative, all students will have a chapter or section in their PhD thesis (report) on the role and contribution from their public involvement partner. All students will also co-write a paper with their public partner for publication in a research journal.

IMPLEMENTING INCLUSIVE OPPORTUNITIES

Story 6

Increasing diversity of public involved in research at Sheffield Clinical Research and Innovation Office

Context

Public involvement in health research at Sheffield Teaching Hospitals is supported by a small team based at their Clinical Research & Innovation Office. Over 200 members of the public get involved in different types of research, at various stages of the research process. The team originally wanted to work on the Inclusive Opportunities standard by improving access for everyone to be involved in research. Sheffield is a culturally and racially diverse city and ethnic minority groups are under-represented in public involvement in research. The team acknowledged that some people are less likely to get involved in research, and this could be for a variety of reasons.
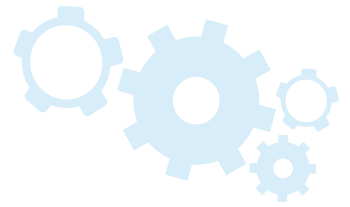
More information

Email: sth.getinvolved@nhs.net
Twitter: @Shef_Research
Website: www.sheffieldclinicalresearch.org

What happened?

Following discussion and reflection the team realised that it would be more complex to meet the standard than originally envisaged, and they needed to take more basic steps to begin with. They identified a lack of diversity and inclusive opportunity training and skills, but were keen to learn more and improve.

The team decided to focus on engagement and awareness raising about research, rather than involvement in research. They wanted to build connections, relationships and trust with local people and relevant communities. Meetings with the local Healthwatch (an independent national champion for people who use health and social care services), NHS Trust staff and research nurses (who were motivated to increase the diversity of recruitment to clinical studies), and the Sheffield Addiction Recovery Research Panel, experienced in outreach approaches to involvement proved good starting points.

Having informal conversations enabled a greater awareness of the potential of local people, groups and organisations to work with in research. The team was advised that cultural, community and contextual considerations are important in relation to involvement in research. These conversations also highlighted the potential and

importance of people being able to engage with others of similar culture or backgrounds to talk about health and health research, and that this may increase trust in research relationships. More formally, mapping these connections and contacts helps the team get a clearer picture of Sheffield communities that exist, and how they connect and collaborate with each other.

This case study stresses that reflection and honest appraisal helped the team have conversations about where to start, and acknowledge that they were trying to run before they could walk'. They are now taking small steps to widen networks and improve collaborations with people and groups that have a shared interest in health and healthcare research in the Sheffield area.

IMPLEMENTING INCLUSIVE OPPORTUNITIES

Story 7

Working with inmates to shape research into palliative and end of life care in Scottish prisons

Context

As part of a programme of research in End of Life and Palliative Care in Glasgow the research team were commissioned to evaluate an End of Life project conducted across Scottish prisons. There is extensive research in experiences of treatment, care and nursing in End of Life and Palliative Care settings, but less so in prison settings. The team, working at the School of Medicine, Dentistry & Nursing, University of Glasgow and NHS Greater Glasgow and Clyde, decided to integrate prison inmate involvement in the planning of the project. The draft UK Standards for Public Involvement provided a framework to shape the strategy for prison inmate involvement in the design and research process.

More information

Email: Bridget.johnston@glasgow.ac.uk
Twitter: @BridgetJohnst

Photographer: Kristi Herd

What happened?

The Macmillan Cancer Support charity funded and introduced a co-ordinator role into Scottish prisons (2017–2019) to improve End of Life and Palliative Care in an aging prison population. The evaluation took a multiple method approach including surveying Scottish Prison healthcare staff and prison officers to assess changes, and a telephone interview study with all Scottish hospices. Prison inmates were also approached to seek their experiences.

As part of the research process a Steering Group was convened (of mostly prison and associated professions) to provide contextual information and support for the project. Public involvement in research was '*a new world*' for the project steering group, and for the prison service. The proposed evaluation methods were introduced to the group and the role of stakeholder and inmate involvement in these was described, using the standards as a framework and rationale for involvement.

The Inclusive Opportunity standard challenges researchers to broaden the type of people that get involved in research, and make it easier for people to get involved. Working with prison inmates represented a new challenge for the research team. With the support of the steering group the practical, technical and ethical requirements of working within a prison environment and with inmates and staff were fully aired, e.g. using Dictaphones in interviews, and personal security.

Working with prison inmates provided additional context and guidance especially for the inmate interview programme. Two discussion groups were held with ten inmates in each, prison staff were helpful in coordinating this. The conversations covered various aspects of the evaluation project, and concerns that inmates might have in taking part in the evaluation project. Issues discussed included; language and words used in interviews, maximising interactions between research participants and researchers, and barriers to recruitment to the study. The discussion groups also highlighted the importance of their personal and research participant confidentiality. For some inmates on the Sex Offender Register there were very particular reasons for assurances about this. There were also considerations about reporting evaluation findings and identification issues. This highlighted aspects of the Governance standard which touches on privacy and using personal information in research involvement.

"I know they're prisoners and I know Joe Public will probably disagree…but as a nurse caring for a patient, they should be getting the same treatment as folk outside get. I think if that's their wish then we should do our utmost to support that." Research participant

IMPLEMENTING INCLUSIVE OPPORTUNITIES

Story 8

Avoiding tokenism in working with speech and language therapy service users to prioritise research

Context

The Royal College of Speech and Language Therapists (RCSLT) promotes speech and language therapy i.e. the care for people with communication and swallowing difficulties. Service user involvement is part of 'Quality Practice' and is supported by a range of college staff. RCSLT also supports research, and recently set research priorities in Learning Disability and Developmental Language Disorder, with service users. An observation is that service users are often left out of research as adaptations needed to fully meet their needs can prove challenging for researchers. There is a real danger that this can lead to tokenistic involvement, and the potential for service user involvement in research is not fully realised.

More information

Contact: info@rcslt.org

All research priorities information: www.rcslt.org/members/research/research-priorities#section-1

Podcast: soundcloud.com/rcslt/setting-research-priorities-for-speech-and-language-therapy

What happened?

The RCSLT aims to increase and broaden the type of service users that get involved and stay involved in research, and the research priority setting exercises in particular. They are then at the heart of shaping the direction of research and highlighting areas of speech and language therapy currently under-researched.

Working with the draft UK Standards for Public Involvement provided the legitimacy and advantage to explore and develop ways to improve service user involvement. The RCSLT also benefited from the interactions with other 'test bed' research organisations that were exploring similar issues.

To ensure that speech and language therapy service users were fully integrated into the research priority setting process the team decided to devolve the conversations about research (and priorities) to Speech and Language Therapists across the UK. The RCSLT effort would be directed at supporting practitioners with training and a toolkit. Having conversations about research can be tricky for anyone, but there are special considerations for speech and language therapy service users. The Communications Standard stresses the importance of accessible and appealing approaches to talking about research. The emphasis was on developing and testing novel methods to facilitate these conversations in safe, accessible and nurturing environments. Consideration was given to what 'research' means and what

and why 'priorities' matter. Resources included letters to parents, consent forms, surveys and assisted formats for running discussion groups.

Visual communication resources were developed including; picture cards, visual images for research scenarios and spider diagrams (for organising discussion points). 'Uncertainty cards' enabled participants to move their priorities around and indicate their preferences. There were also adapted resources for ranking and scoring participants' priorities. Gathering all the resources in a toolkit enables Speech and Language Therapists to choose from and use approaches that meet the specific needs of service users.

Feedback forms (for parents to see what had been discussed in the session if they weren't present) and evaluation tools to assess how involved people felt in the process of discussing research and research priorities are also part of the toolkit.

"Overall, the RCSLT feels that implementing the standards and evaluating our approach to service user involvement through them has helped us develop a strong foundation for meaningfully involving people with speech, language and communication needs in our research priority setting exercises. This in turn should ensure that future research in speech and language therapy considers what is most important to people with communication and swallowing needs."

IMPLEMENTING WORKING TOGETHER
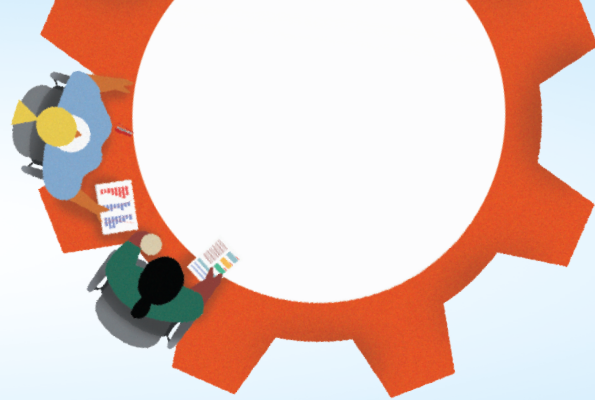
Story 9

Introduction and expansion of Research User Group 'Buddy' role in the School of Community and Social Care Research, Keele University

Context

The School of Primary Care, Community and Social Care at Keele University developed an INSPIRE programme to implement the standards and this was funded by the NIHR School for Primary Care Research. The school hosts the Primary Care Centre Versus Arthritis. It has a mature Public and Patient Involvement and Engagement (PPIE) programme consisting of a core PPIE staff team and over 130 Research User Group (RUG) members. During implementation of the INSPIRE Programme there were over 100 live primary care research projects in various stages of development. Each of these had on average six members of the public working with the research team in different roles and at different stages of the research.
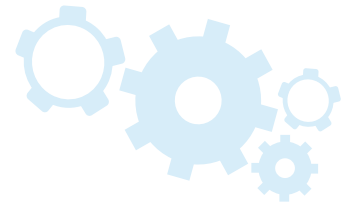
More Information

PPIE Project Coordinator: Adele Higginbottom
Email: a.higginbottom@keele.ac.uk
Website: www.keele.ac.uk/pcsc/research/ppie/whatisppie/whatisitliketo-bearugmember

What happened?

The Learning and Support standard is all about building confidence and skills for public involvement in research. The School of Primary Care, Community and Social Care has created a welcoming, friendly and supportive environment for public involvement in primary care research at Keele. With such a large group of public contributors spread over many projects RUG members thought there was more scope for support. Previously a RUG member worked as a volunteer with the School's PPIE team, and attended research meetings to welcome and support RUG. RUG members felt the benefit of this peer-support and wanted to expand the idea. Following discussion, they decided that buddies would be available for new RUG members, and for existing members undertaking new types of public involvement in research. Working with the PPIE team, RUG members developed a Buddy role description and practicalities were addressed such as training, induction and financial arrangements. RUG members also explored how to share and learn about buddying together, and decided on six-monthly meetings. All the current RUG members were then invited to express interest in becoming a Buddy and eight members were appointed to the voluntary role. An induction and training session has been arranged and the scheme will be piloted for six months.

RUG Buddies are not about replacing the Public and Patient Involvement and Engagement (PPIE) staff, but acknowledging that peer support is complementary, providing a different perspective of what public involvement is about. It is hoped that working with buddies may make the experience of being a RUG member more positive and impactful. RUG members also felt that this initiative *"gives something back to the PPIE team"* after all the years of their support.

As well as providing companionship in public involvement RUG buddies can encourage and help new members speak at research meetings, and navigate the jungle of research terms and concepts. It is also hoped that this scheme will support longer term involvement in primary care research by having a sustainable source of support. The support and learning will also benefit the PPIE team, as they learn from buddies as the programme evolves, adding to their existing knowledge of the needs and expectations of RUG members. This new knowledge will encourage and identify where improvements can be made to support, learning in public involvement in primary care research at Keele University.

IMPLEMENTING WORKING TOGETHER
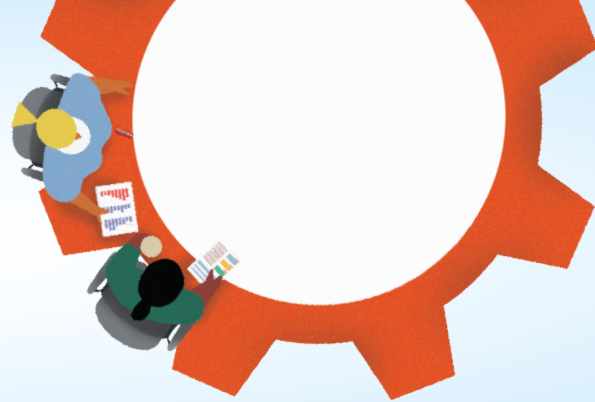
Story 10

Developing a Volunteering Handbook for lay members of the Centre for Ageing and Dementia Research, Wales

Context

The Centre for Ageing and Dementia Research (CADR) develops expertise in ageing and dementia research. The aims of CADR are to improve the lives of older people through the integration of research on ageing, policy and practice. Public involvement in CADR research is supported by a team across the three partner universities.

Feedback from CADR's lay members described an information gap in some of the practical information needed to effectively take part in research. They suggested a guide for existing and new members, containing all the essential information required in one place.

More information
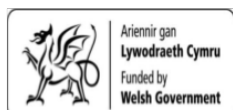
To contact the team visit: www.cadr.cymru/en/contact-us.htm

What happened?

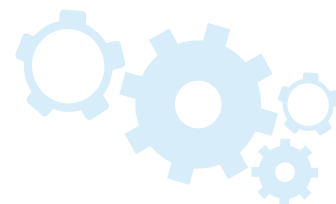The Working Together standard specifies that understanding of roles, responsibilities and managing expectations between the public and researchers is an important part of working together. Developing a guide which they called a volunteering handbook contributes to meeting this standard.

The handbook is a working document developed by CADR staff and lay members (as part of an involvement and engagement group). It covers the aims and purpose of the Centre with some information about the context for CADR research in aging and dementia such as environmental, psychosocial, social care and genetic perspectives.

Team members are introduced by role and responsibilities with an accompanying photo and contact information. The role and requirements of being a lay member is described along with the benefits of being part of the CADR team such as; *'gaining new knowledge and understanding; having fun and meeting new people; developing new skills and free training'*.

Also included in the handbook is a Volunteer Agreement which sets out the commitments and expectations from all parties. Lay members and CADR staff both sign this document. Practical information about working together is described in detail and this includes; induction and support, the amount of time that being a lay member might involve, travel and payment policies and advice including how payments might affect benefits. Training opportunities, health and safety considerations and how to find out about and register for involvement activity is also described.

Some of the more challenging areas of public involvement in research are also covered, for example problem resolution and complaints and working with and protecting the personal data of fellow volunteers and staff.
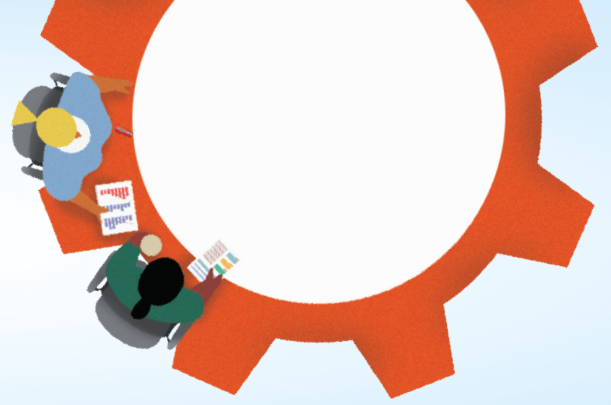
One of CADR's researchers said, *"this is a useful resource for managing expectations from the perspective of both the researcher and our lay members"*.

General feedback to date from lay members suggests this is a useful part of the induction and introduction to CADR.

IMPLEMENTING WORKING TOGETHER

Story 11

Setting up a new Public Involvement Group for the Northern Ireland Cerebral Palsy Register

Context

The Northern Ireland Cerebral Palsy Register (NICPR) aims to establish a systematic approach to recording cases of cerebral palsy in Northern Ireland, and support research in this condition. A completed assessment form describes how the condition affects people living with cerebral palsy. This helps to provide accurate and complete information about the number and needs of children and young people with cerebral palsy for planning services and population research. The NICPR team from Queen's University Belfast recognised the importance of working with people with cerebral palsy to ensure that research is relevant and useful to those that need it.

More information

Northern Ireland Cerebral Palsy Register Email: nicpr@qub.ac.uk

Website: www.qub.ac.uk/research-centres/NorthernIrelandCerebralPalsy Register/GetInvolved/PublicInvolvementGroup/
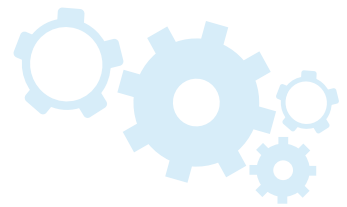
What happened?

The UK Standards for Public Involvement provided a structure and quality aspiration for the NICPR to recruit and involve people with cerebral palsy in the ongoing work of the Register. As a first step, they launched a new community mailing list for people who are interested in the work and activities of the Register. The NICPR team engaged with local charities, voluntary sector organisations, sports clubs and special education schools to share information about the new mailing list. The flyer included information about cerebral palsy in Northern Ireland and a QR (bar) code that directed people to the sign-up form. Once the community mailing list was up and running the NICPR team sent a survey to gauge people's interest in, and help plan a family coffee morning. The date, time and venue of the coffee morning were selected to minimise inconvenience for families. Members of four families, including children and young people with cerebral palsy, their parents, siblings and friends, attended the event and talked about how they might like to get involved in the work of the NICPR.

One of the important features of successful public involvement in research is pacing and managing expectations. This project has grown gradually; the community mailing list has 84 subscribers with regular newsletters, a website presence and the coffee morning resulted in two families getting more involved. The NICPR's newly established Public Involvement Group has set their objectives for a year and these include; updating the NICPR family information leaflet and website content, creating new resources for children, developing training for new NICPR Public Involvement Group members and growing the group in size. Finally, members will start to input and influence future NICPR research applications.

The team have assessed their progress against three of the six standards and have noted where they felt that they met them, or needed more work. They identified that using the standards requires sufficient investment of time from both public members and researchers, dedicated and sustained funding and focused activities. Sharing experiences and reflections informally have been just as important as more formal impact evaluation of public involvement. The feedback from the NICPR team from testing the draft standards helped simplify the content and structure of the final version, released in November 2019.

IMPLEMENTING SUPPORT & LEARNING

Story 12

Helping people with kidney disease find their voice – support and training from the Kidney Patient Involvement Network

Context

The Kidney Patient Involvement Network (KPIN) combines kidney organisations, charities and individuals committed to good quality Patient and Public Involvement and Engagement (PPIE). They aim to improve standards in renal treatment, care and research, and develop kidney patient leaders of the future. The network includes professional organisations, patient facing organisations and affiliated research networks. KPIN has developed its role, purpose and ways of operating to achieve its aims, and this is underpinned by network coordination and information. Despite being *'for patients–run by patients'* members can be overwhelmed with requests for help and advice, whilst living with the daily challenges of kidney disease.

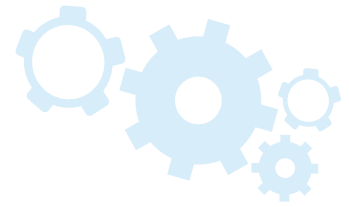## More information

Email: info@KPIN.org.uk
Twitter: @KPIN_UK
Website: www.kpin.org.uk

What happened?

If there are patients 'sitting at the table' but they say very little, then on paper they have been 'involved', but in reality, they haven't and this is tokenistic and empty involvement—KPIN wants to avoid this. Whilst people affected by kidney disease come from all walks of life bringing existing skill sets to involvement, it can be difficult to be heard sometimes. In some contexts people are not encouraged or enabled to add their voice to decision making. KPIN wants to increase the impact of the patient and carer voice in research, services and other contexts for patient involvement. There are also real dangers of burn out of patient leaders who are approached repeatedly for involvement in multiple sectors and contexts.

The aim was to increase the number of patient leaders engaged with KPIN initiatives and harness enthusiasm across a wider kidney patient and carer population. The network also wants to improve engagement from minority groups that are currently underrepresented in kidney research, both as participants and involved patients and carers. The concept of 'voice' has grown into a training programme and a social media peer support group to develop a more sustainable network of patient leaders. The UK Standards for Public Involvement has a Support and Learning Standard as a core part of involvement, urging organisations to focus on building confidence and skills to support effective involvement.

The training which supports this Standard, has been delivered via workshops (facilitated by a KPIN Patient Leader). Content includes role definitions and expectations, developing and feeling confident about your voice, and the difference between speaking from a personal capacity and on behalf of others. It also addresses practical issues such as how to prepare and participate in meetings, influencing skills, managing conflicts of interest and working as a team to ensure that others have a voice.

The KPIN network will explore different modes of delivery for future training, and evaluate the workshops to see what difference they made to confidence and capacity in involvement from KPIN members.

IMPLEMENTING SUPPORT & LEARNING

Story 13

Connecting people in Wales and further afield with research, by investing in and using online and web-based learning

Context

The Centre for Ageing and Dementia Research (CADR) aims to improve the lives of older people through the integration of research on ageing, policy and practice. Public involvement in CADR research is supported by a team across three partner universities. The team wanted to increase the audience and participation of its lay membership in research through involvement and learning opportunities. However, with research centres geographically spread across Wales (Bangor, Swansea and Cardiff) there are potential barriers for public members of CADR to participate. This story focuses on meeting the Inclusive Opportunities and Support and Learning standards
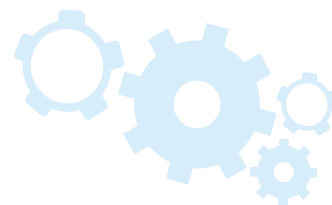
More information

To contact the team visit: www.cadr.cymru/en/contact-us.htm
Facebook: www.facebook.com/groups/1219519074755864/
Facebook: www.facebook.com/CADRCymru
Website: www.cadr.cymru/en

What happened?

With such a geographically spread centre, face to face meetings present barriers to involvement such as lengthy travel times, with some CADR members being unable to travel at all. The team wanted to explore other ways of connecting and learning together about aging and dementia research. Despite the team not having a great deal of experience in this area they wanted to extend their public involvement and research activities to an online setting.

Initially it was about investing in and learning how to use new technology, in this case 'gottomeeting' software, a spend of about £1K. Despite some *'bumps in the road'* the team have been able to explore this new way of communicating with live streaming and webinars, including a recent conference held in a rural setting (Aberystwyth) which had participants viewing from across Wales. The team are able to see who and where people were participating from. So far these have included members of the public, voluntary organisations, local and national government staff and researchers from across Wales.

They also discovered the value of recorded webinars (that have been edited and a voice over added) which can be made available to anyone at any time, via home computers or a mobile phone. The presentation slides from public seminars are uploaded to the CADR website, and the link sent out to the network.

Increased use of social media has also been a focus, with a variety of accounts set-up including; Twitter, LinkedIn, YouTube and Facebook. One example is the North Wales Dementia Network Facebook page, which was developed with people with dementia. Users can share dementia related ideas and promote locally relevant activities and events.

The team hopes that keeping abreast of new routes for public engagement may increase their profile, raising awareness and interest in CADR's work. Overall, the team feel that this is a sustainable response to public engagement and involvement throughout Wales and beyond. The use of technology helps overcome the distance barriers between the research centres. It also addresses current environmental concerns, and issues of limited funds and capacity for face to face meetings, seminars and conferences. Finally, team members have developed new skills and insights to online communication.

IMPLEMENTING GOVERNANCE

Story 14

Public involvement in the management and oversight of large multicentre research projects, experience from the Asthma UK Centre for Applied Research

Context

The Asthma UK Centre for Applied Research is virtual, with 15 partner Universities across the UK. The Centre is led by the University of Edinburgh and Queen Mary University of London. The network brings together leading researchers, clinicians, people with asthma, and other specialists, with a focus on applied asthma research. Through the Centre, members of the public are involved in and contribute to a range of projects, from qualitative research to data extraction projects. This is mainly operationalised through a Patient Advisory Group, matching lay members to research projects based on interests and skills, and identifying lay co-applicants for larger projects.

More information

Dr Tracy Jackson Email: tracy.jackson@ed.ac.uk
Telephone: +44 (0)131 650 4617
Website: www.aukcar.ac.uk/public-involvement
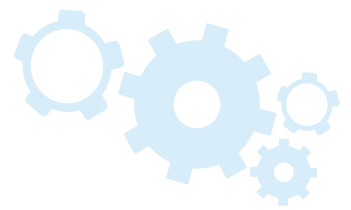
What happened?

The team were enthusiastic to address all the standards across all the research projects when they applied to test the UK Standards for Public Involvement. They were an early adopter and report on their experience of working on two of the standards for this booklet.

Their process started with an audit of their network activity using the 'RAG' approach (Red, Amber and Green). Public involvement activity was mapped across the standards and there was reflection and discussion about the results and gaps. The Governance standard merited more attention, so was prioritized for action.

A good starting place was public involvement in the management and oversight of flagship (large, multicentre) projects at the Centre, such as IMP^{2}ART. This project aims to develop, refine and test an appropriate implementation strategy to support general practices across the UK to embed self-management into routine asthma care. Ten lay members from the Centre network are involved in this project, including a patient lead as a grant holder for the study, who also reviewed the grant application and study plan (protocol). The lay members contributed to the development and refinement of the IMP^{2}ART project strategy and application through meetings, teleconferences and email.

In addition, the Centre Management Committee now has public membership with input on day to day decisions. Four 'Patient Leads' are members of this committee ensuring that the patient voice is central to everything the Asthma UK Centre for Applied Research does. One of the most helpful aspects of adopting the UK Standards for Public Involvement at the Centre has been the realisation that it is not always appropriate to meet all standards for every research project. It is more important to look at what is feasible and helpful in terms of improving public involvement. The 'stepping back' process of reflecting and prioritising involvement effort across the research portfolio has been a worthwhile strategy in itself.

"The Centre were delighted to be chosen as a test bed site for the standards and it was a really worthwhile experience for us. Originally, we were doing things because it's what we thought it was the best thing to do. Being part of the standards really made us assess our strategy, processes and behaviour and it has been a really positive experience for researchers and patients."

IMPLEMENTING COMMUNICATIONS
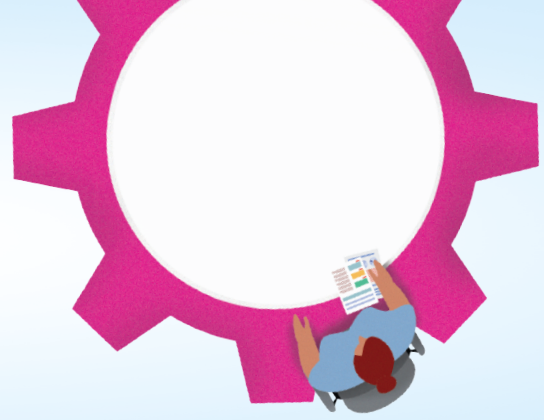
Story 15

Enabling better communication between researchers and lay members at the Asthma UK Centre for Applied Research

Context

The Asthma UK Centre for Applied Research is virtual, with 15 partner Universities across the UK. The Centre is led by the University of Edinburgh and Queen Mary University of London. The network brings together leading researchers, clinicians, people with asthma, and other specialists, with a focus on applied asthma research. Through the Centre, members of the public are involved in and contribute to a range of projects, from qualitative research to data extraction projects. This is mainly operationalised through a Patient Advisory Group, facilitated by the Centre, and matching lay members to research projects, based on their interests and skills.

More information

Dr Tracy Jackson Email: tracy.jackson@ed.ac.uk
Telephone: +44 (0)131 650 4617
Website: www.aukcar.ac.uk/public-involvement

What happened?

Once the Centre was confirmed as a test bed for the draft Standards for Public Involvement in research, an audit of their network activity using the RAG approach (Red, Amber and Green) was initiated. The Communication standard was the only standard with red (poor) scores, so the team decided to focus on improving communication across the different research projects, and with network members.

One example of poor communication was how researchers approached lay members of the network for help with research projects. Feedback highlighted different styles and levels of information in email requests from researchers. Sometimes communication was in an overly academic language that was not very accessible for the lay members. The team worked with the Patient Advisory Group to co-develop a new request form and process. This involved agreeing core information for email requests that specified the purpose and nature of research involvement sought. Practical aspects of the planned involvement were also described, making it easier for lay members to consider requests, and decide if they wanted to and were able to get involved. Guidance was made available for researchers about using more accessible language in their requests to work with the Centre's Patient Advisory Group. The new process was tested and modifications were made to the form,

and overall process. For example, lay members wanted more detail on what the commitment to each project would be, such as the number of face-to-face meetings a year.

Patient Advisory Group members liked the new approach and found the process clearer and easier to understand, specifically what was being requested from them. Since its introduction, response rates to requests for patient and public involvement have increased.

"Good work, I would personally like to see this implemented. It certainly looks like it could help us PPI volunteers be better informed about the study and whether to agree to be involved."

Lay members of the Patient Advisory Group also liked the new process of sharing feedback to requests for involvement from fellow lay members. *"It's fascinating to read what other reviewers have written."* Sharing this feedback helped create a more community feel to the group and their communications–especially important in a virtual network.

Researchers at the Centre also welcomed the changes, as the process and guidance enables them to prioritise what is important to communicate about their research opportunity, and in what way.

IMPLEMENTING COMMUNICATIONS
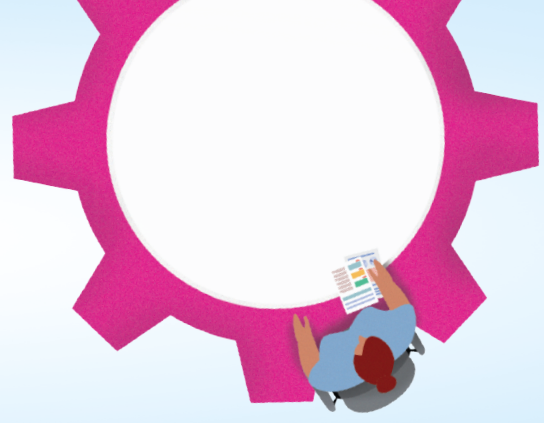
Story 16

Breaking down barriers in public involvement in ageing and dementia research at the Centre for Ageing and Dementia Research, Wales

Context

The Centre for Ageing and Dementia Research (CADR) develops expertise in ageing and dementia research. The aims of CADR are to improve the lives of older people through the integration of research on ageing, policy and practice. Public involvement in CADR research is supported by a team across the three partner universities. The people who get involved in CADR's research activities are reflective of the diversity within an ageing population including; people living with and affected by dementia, people with disabilities and employed/work less/and retired older people. The CADR team wanted to consider the potential barriers to working together effectively and take actions where possible.

More information

To contact the team visit: www.cadr.cymru/en/contact-us.htm
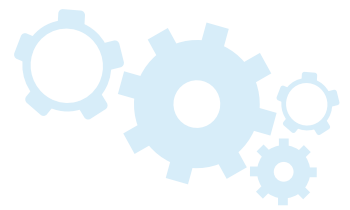
What happened?

As part of working towards the Inclusive Opportunities and Communications standards the CADR team aimed to identify and address potential barriers to involvement in ageing and dementia research. Groups that are frequently excluded from research were considered a priority and these included; black and minority ethnic groups, those ageing with a sensory disability and older people in disadvantaged and remote areas. Drawing on evidence-based engagement techniques and using community connections, CADR carried out a 'roadshow' of events whereby they met people in their own communities, to find out what was important to them. The feedback from this process informed adaptations to involvement processes.

Some examples of improvements for more inclusive involvement included using RNIB (Royal National Institute for the Blind) guidance to meet the Accessible Information Standard for printed materials and audio-visual resources. The team has invested in a portable hearing loop that is available for use in meetings and conferences, rather than relying on venues that are often ill equipped for people with impaired hearing or loss. CADR operates throughout Wales and needs to consider the needs of a bi lingual population. Welsh is the first language for many who prefer to speak and converse in Welsh thereby preserving their identity and voice. Translation services are sourced and provided when required and CADR'S documents are bilingual, as per the Welsh language standards.

Another barrier to communication and working together in research are stereotypes in aging and dementia, which can be harmful. The team were tired of using stock photos such as the 'caring hands' or images that only portray older people as frail or dependent when their experiences of working with people was very different. To redress this the team asked their networks to send in pictures representing different aspects of ageing, for a photo competition called 'Framing Age'. These are now used for CADR's work and a selection were made into a calendar and widely distributed and received very well in the community. Following the success of the calendar they are repeating it for the next calendar year.

Feedback collected at the CADR roadshow events has enabled the team to make changes and seek solutions to improve accessibility for public contributors to research.

The standards have provided a focus for this work, and helped improve aspects of communication and working together that are the backbone of public involvement in research.

IMPLEMENTING COMMUNICATIONS
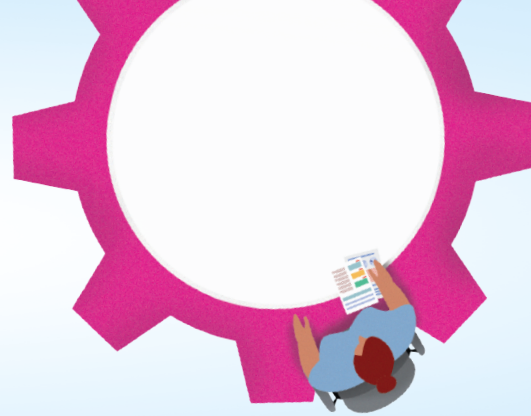
Story 17

Improving feedback to public contributors involved in research, experience from Sheffield Clinical Research and Innovation Office

Context

The Clinical Research and Innovation Office (CRIO) at Sheffield Teaching Hospitals coordinate research with hundreds of healthcare studies running at any one time. A small team leads public involvement across studies. Following their Annual Impact Framework which assesses public involvement in research, a picture emerged. Specifically a need for more (and consistent) feedback from researchers to the public involved in research. Researcher feedback helped value their input, especially when it described the changes made to the research as a result. Implementing the Working Together and Communications standards provided an impetus for overhauling the internal feedback process, as previous efforts had been unsystematic, with variable responses from researchers.
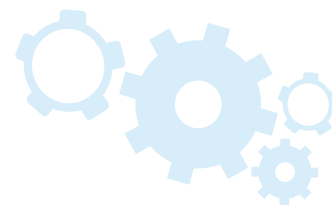
More information

Email: sth.getinvolved@nhs.net
Twitter: @Shef_Research
Website: www.sheffieldclinicalresearch.org

What happened?

The Working Together standard asks users to reflect on whether people's influence, ideas and contributions have been recognised and addressed. The team recognised that the feedback process could be improved and together with involved members of the public reviewed the current feedback system and documentation. Conversations focussed on the use of an online Researcher Feedback Form which was sent to researchers along with a summary of the feedback from the public panel where the research had been discussed.

Improvements to the process were agreed and implemented, including;

- Changes to the rationale that accompanied the form, stressing the importance and value of receiving feedback *"It is really important that public involvement contributors receive feedback on their involvement activities, it helps both us and them to see how we can improve, and where you can/cannot take on board their feedback or suggestions etc."*
- A more robust follow up procedure such as scheduled email 'chasers' at set time frames (2–4 weeks) was implemented.
- Setting up a simple email alert to receive a notification when a researcher has completed the feedback form. This prompts the team to download the feedback and share it with the coordinator of the specific public involvement group or panel.

The refreshed process has made it easier to, and more compelling for researchers to provide public involvement feedback. The team observed an upward trend of returned feedback forms from researchers and note that the new process may be stimulating more informal feedback in research meetings and communications. They also observe an increase in recognition of public involvement in research publications. Some panels now have researcher feedback as a standing agenda item, to keep it in focus.

Some challenges remain, such as sustaining longer term feedback when research timelines stretch over many years. Where research proposals are unsuccessful there is still a tendency to 'move on' to the next project and not fully reflect on and discuss the less successful aspects of public involvement in research. This has led the team to question if sometimes there is a 'halo effect' of 'good' feedback, with researchers less willing to challenge public members where their feedback and suggestions haven't been helpful, or could not be implemented in the research.

IMPLEMENTING IMPACT

Story 18

Royal College of Speech and Language Therapists learning from successive research priority exercises, resulting in improved service user involvement

Context

The Royal College of Speech and Language Therapists (RCSLT) is the professional association for Speech and Language Therapists in the UK. It provides leadership, professional guidance and support for speech and language therapy professionals, who care for people with communication and swallowing difficulties.

The RCSLT has been setting research priorities in a range of conditions, including in Learning Disability. Throughout this process they have been continually learning about service user involvement in the process. Whilst they have learnt from other organisations with relevant experience, their service users require special considerations and 'on the job' learning.

More information

Email: info@rcslt.org
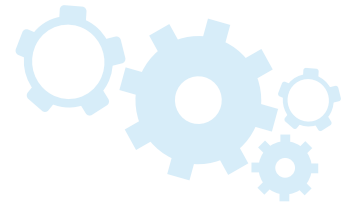
What happened?

The RCSLT have carried out several research priority setting exercises, the second of which was in speech and language and learning disabilities. The team had frequent conversations and reflections after each 'event', teasing out the challenges, things that went well, and the less successful aspects. The standards provided a useful framework for these reflections and the indicators in the draft version (now reflective questions in the final version) provided a structure and a sense of priority to the different aspects of service user involvement.

With each subsequent priority setting process the learning increased and was applied to good effect e.g. in person and phone support for Speech and Language Therapists gathering the opinions and preferences of service users. A toolkit of resources were developed based on the initial experiences, more detail in Story 13 (pages 20-21).

There was a strong feeling that devolving the research conversations (either 1:1 or as part of group discussions) to speech and language therapists built on the existing therapeutic relationships, enabled the conversations to take part in familiar settings and contexts, and built research capacity in the therapists involved. By reducing communication barriers, service users were more empowered to share their ideas, and

the team were able to involve them at a greater and more meaningful degree in the subsequent research priority setting processes, with more input into the developing priorities. Retention of service users throughout the priority setting process improved with subsequent exercises, but remains a challenge.

More formal evaluation to assess service user involvement in the priority setting projects was designed to reflect the UK Standards for Public Involvement, with sections for each standard. The Impact standard also prompted the team to think about the value of service user involvement to the priority setting exercises much earlier on in the process. Ongoing challenges include negotiating payment for service users' time in research processes, and the time it takes to produce appropriate materials for priority setting research, such as infographics and consent documents. Adapting priority setting processes (such as ranking) require careful thought and testing to ensure that they work in practice with people with communication difficulties.

"Enriching service user involvement in our research priority setting, through using the standards, has had a big impact in our confidence that we have helped collaboratively identify priorities that are meaningful to the people with lived experience of speech, language and communication difficulties."

Acknowledgements

UK Standards
for Public Involvement