KIS advice about patient and public involvement

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KING'S HEALTH PARTNERS

About this resource

Involving people who have personal experience of using NHS services is a priority for King's Improvement Science (KIS). Professor Diana Rose, a professor of user-led research at King's College London, leads this work and the KIS team includes a patient and public involvement coordinator, dedicated to supporting the involvement of patients, service users, their families and members of the public, in KIS projects.

This resource includes recommendations based on the involvement work we have carried out in three quality improvement projects that were led by health professionals and supported by KIS. We have learned important lessons about how to collaborate with individuals and groups and work on projects that integrate and act on the interests of patients and service users. We believe we managed some aspects of involvement well, but the recommendations also reflect our thoughts about how the involvement process could have been improved within the three projects.

We have also included links to recommended resources about involvement produced by other organisations.

If any of the links within this resource do not open straightaway, please copy them into your browser.

Who is this resource for?

This resource is for anyone who wants to involve patients, service users and members of the public in quality improvement projects in a meaningful and productive way. It may be particularly helpful to health and social care professionals, managers and other staff involved in providing health and social care services, researchers, students, patients, service users and members of the public.

Our recommendations and the resources may be useful in any type of project where the perspectives of patients, service users and members of the public can strengthen and enhance aims and outputs, including evaluation and implementation projects.

How to cite this resource

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Contents

What KIS has learned about involving patients, service users and members of the public

Timing and timeliness

Involve patients, service users and members of the public at the start of the project.

If patients, service users and members of the public are to have meaningful influence in quality improvement projects, they need to be involved as soon as possible.

Think about how much time people will need to dedicate to meetings.

How many meetings will there be; what time will be needed to prepare for them?

Prepare a draft role description for people who have personal experience of using services and members of the public.

Anticipate how much time might be needed to attend meetings, carry out tasks in addition to, or in preparation for, meetings, and other activities. However, flexibility is also essential as projects develop and individual circumstances change.

Diversity

Try to recruit a diverse group of people from different backgrounds, of different ages, ethnicities and gender, with different experiences of services.

Different perspectives can influence the design of the project, including aims, processes, outcomes, and methods used to make an improvement.

Joint decision-making

Work collaboratively with patients and service users to co-design the way in which they will be involved and their roles within the project.

Decide at the very beginning how everyone will communicate and contribute during the lifespan of the project, and how decisions will be made.

Make sure everyone has the opportunity to contribute to discussions, and that everyone is present when vital decisions are taken.

Everyone should have a say in how the project is designed, including setting aims, choosing methods and measurements, setting schedules etc. You may need to prepare material that explains certain aspects of the project.

Transparency

Be open about the project's aims and any limitations (eg budget, time).

Make sure everyone involved in the project is aware of each others' roles and responsibilities, and what they are expected to deliver.

Power sharing

| Work as equal partners and collaborators.

| All contributions and suggestions should be equally considered.

| Everyone's perspective and opinion is equally important and should have an equal chance of influencing the direction of the project.

Adaptability

| Be adaptable and open-minded.

| Be prepared to make changes to certain parts of the project or planned outcomes as a result of listening to different perspectives.

| Be prepared to make changes to the organisation of the project – eg meeting times or venues – so that everyone can attend.

Accessibility

| Arrange meetings in locations and at times that are convenient for everyone.

| Check whether any member of the team has access needs and make arrangements beforehand (eg setting up a hearing loop or arranging tables to accommodate a wheelchair).

| Remember that disabilities and health conditions are not always visible. Take advice from the individual about the best way to make arrangements.

| Speak and write clearly, in a way that is accessible to everyone.

| Specialist terms and acronyms should be avoided. If that's not possible, they should be broken down and explained.

£ Budget

Allocate a budget to support involvement activities.

Patients, service users and members of the public should be paid for their time and reimbursed for any expenses.

It is advisable to ensure that your payment policies and procedures for patient and public involvement are in line with your organisation's policies and procedures. Check with your finance and human resources departments.

Consider any access costs.

If an individual or group of people require facilities or technology to attend and contribute to meetings (for example, a hearing loop, verbal description or enlarged text), there may be cost implications.

Useful guides and resources

Developing a patient and public involvement panel for quality improvement
Healthcare Quality Improvement Partnership, April 2016

| https://www.hqip.org.uk/wp-content/uploads/2018/02/developing-a-patient-and-public-involvement-panel-for-quality-improvement.pdf

This guide is designed to help healthcare organisations involve patients, service users, carers, and members of the public in all aspects of quality improvement, through the development and implementation of a patient and public involvement panel.

4Pi, National Involvement Standards
NSUN network for mental health, 2014

| www.nsun.org.uk/faqs/4pi-national-involvement-standards

The 4Pi National Involvement Standards have been developed by the National Involvement Partnership (NIP) project hosted by the National Survivor User Network (NSUN). The project aimed to "hard wire" the service user and carer voice and experience into the planning, delivery and evaluation of health and social care services.

Beyond the usual suspects
Towards inclusive user involvement
A research report by Peter Beresford, published by Shaping Our Lives, 2013

| www.shapingourlives.org.uk/documents/BTUSReport.pdf

The report is about how certain groups and individuals experience particular barriers to involvement and includes recommendations for involving more diverse groups of people.

National standards for public involvement
The standards development partnership, May 2018

> http://www.invo.org.uk/posttypepublication/national-standards-for-public-involvement/

This document provides recommended standards for public involvement in research. The standards can be used to help plan public involvement, or to assess and improve existing involvement, in a research project or organisation.

Approaches to public involvement in research
INVOLVE, National Institute for Health Research

> www.invo.org.uk/posttyperesource/approaches-to-public-involvement

This web page includes a brief description of different ways of involving patients, service users and members of the public in healthcare research and planning – from consulting groups about aspects of projects to collaborating throughout the whole process.

Patients as partners – building collaborative relationships among professionals, patients, carers and communities
Becky Seale, King's Fund, June 2016

> www.kingsfund.org.uk/sites/default/files/field/field_publication_file/Patients_as_partners.pdf

A guide based on work exploring collaborative working in pairs to make improvements and system changes by tackling leadership challenges.

The 10Cs of user involved care planning
University of Manchester

> http://research.bmh.manchester.ac.uk/equip/10Cs

This short video contains 10 recommendations about important factors to consider when involving patients and the public in mental healthcare research and planning.

The recommendations are based on interviews with patients and members of the public who had been previously involved in healthcare research and planning.

Exploring impact: public involvement in NHS, public health and social care research
INVOLVE, National Institute for Health Research, October 2009

www.invo.org.uk/wp-content/uploads/2011/11/Involve_Exploring_Impactfinal28.10.09.pdf

The results of a literature review by INVOLVE that explored evidence of the impact of public involvement on health and social care research. The report investigates the different areas of research impacted by public involvement as well as the impact on individuals.

Developing a policy for payment and recognition
INVOLVE, National Institute for Health Research

www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/developing-a-policy-for-payment-and-recognition/

Recommendations from INVOLVE about how to develop a policy on payment and recognition that helps service users, patients and members of the public make informed decisions about involvement.

Changing our worlds: examples of user-controlled research in action
INVOLVE, National Institute for Health Research, October 2010

www.invo.org.uk/wp-content/uploads/2011/09/INVOLVEChangingourworlds2010.pdf

A report written by Alison Faulkner, who has experience as a user of mental health services and a background in research and training. The report describes research where service users or people with disabilities controlled the research process.

A guide to patient and public involvement in quality improvement
Healthcare Quality Improvement Partnership (HQIP), November 2017

www.hqip.org.uk/resources/patient-and-public-involvement-in-quality-improvement/

A comprehensive guide to the benefits of patient and public involvement in quality improvement and how to implement it effectively. The guide is aimed at people involved in quality improvement projects in healthcare organisations including patients, the public, managers, clinicians, or quality improvement specialists.

Using patient experience for improvement
Point of Care Foundation

www.pointofcarefoundation.org.uk/resource/using-patient-experience-for-improvement/

This online guide provides practical advice to help quality improvement teams to use patient experience data in improvement projects. The guide is based on the experience of six clinical teams who took part in a research project to understand how frontline NHS staff use patient experience to drive improvement.

Examples of patient and public involvement in quality improvement projects supported by KIS

Lung health in addiction services

Introducing a screening tool that assesses the lung health of people who use a community drug and alcohol service.

The project involved five service users who were recruited through an existing service user involvement group at King's College London and a local user-led peer support organisation.

A project-specific service user group (SUG) was set up.

SUG meetings were held once a month at the offices of the peer support organisation and all five service users attended as well as the lead clinician and patient and public involvement coordinator from the project.

The project team meetings were attended by health professionals, KIS team members and two service users on rotation from the SUG. The meetings were held once a month on NHS premises.

Service users were reimbursed £20 an hour for time at meetings and time spent preparing beforehand.

Service users co-produced a learning event with the KIS team and professionals. The event was held to share findings from the project with other drug and alcohol services and other service user groups.

Atrial fibrillation and atrial flutter

Setting up a new care pathway linking primary and secondary care to help reduce the risk of stroke for people who have atrial fibrillation or atrial flutter.

The project involved three patients and service users, two of whom were recruited through an existing cardiovascular advisory group at the NHS trust where the project was based, and one recruited during clinic.

Project team meetings were held on NHS premises and were attended by all service users, health professionals and members of the KIS team.

Patients and service users were reimbursed £20 an hour for time at meetings and time spent preparing beforehand.

Safety briefing in critical care

Introducing a morning safety briefing in critical care.

The project was part of an existing large-scale initiative that involved staff, patients, service users and members of the public. The project's aim was one of the priorities for improvement that had been identified by patients, service users, members of the public and staff as part of the large-scale initiative.

An advisory panel of patients and service users had been set up as part of the pre-existing initiative by the project lead (who had personal experience of using critical care services).

Patients and service users were not present at project team meetings: these were attended by healthcare professionals and members of the KIS team.

Patients and service users attended teleconferences with healthcare professionals where the quality improvement project was discussed as part of the wider initiative.

There is more information about each project on the KIS website: www.kingsimprovementscience.org/kis-projects-2013-2016.

Help available from the King's Improvement Science team

This resource was created by King's Improvement Science (KIS), a specialist team of improvement scientists, senior researchers and fellows, based at King's College London. KIS was set up in 2013 by King's Health Partners, an academic health science centre comprising three NHS trusts – Guy's and St Thomas' NHS Foundation Trust, King's College Hospital NHS Foundation Trust and South London and Maudsley NHS Foundation Trust – as well as King's College London. The work of the KIS fellows has been funded by Guy's and St Thomas' Charity and the Maudsley Charity. The work of KIS fellow Louise Hull has also been supported by the NIHR CLAHRC South London.

KIS is now part of the Centre for Implementation Science at King's College London. The Centre for Implementation Science is part of the NIHR CLAHRC South London.

KIS resources

The KIS team have developed the following resources:

Quality improvement guides
- Step 1: KIS Introduction to quality improvement
- Step 2: KIS guidance for deciding what to improve and assessing the feasibility of a quality improvement project
- Step 3: KIS template for planning and evaluating a quality improvement project

KIS advice about patient and public involvement

Implementation Science Research Development (ImpRes) tool and guide

KIS guide to evaluation resources

Communication: a practical resource

KIS glossary of terms used in improvement and implementation

You can download the resources at: www.kingsimprovementscience.org.
This website also contains information about quality improvement projects carried out by the KIS team.

The KIS team can advise anyone who wants to carry out a quality improvement project in south London, or further afield.

Advice clinic for quality improvement and implementation science projects

If you are planning a quality improvement or implementation science project and need expert advice, you can book a place at our advice clinic at King's College London. To find out more, visit: www.clahrc-southlondon.nihr.ac.uk/training-and-education/advice or email: clahrcshortcourses@kcl.ac.uk.

Monthly seminars about improvement and implementation

Leaders in the field of improvement and implementation share and debate their experiences at these monthly seminars. They are open to anyone interested. Find out more: www.clahrc-southlondon.nihr.ac.uk/centre-implementation-science/research-team/seminars.

Evaluation

Any organisation can commission the KIS team to evaluate improvement / implementation programmes or projects, or to help set up ongoing evaluation procedures. We are also happy to discuss the possibility of collaborating as an evaluation partner on a grant application. Email us to find out more: kis-team@kcl.ac.uk.

Training and education

Members of the KIS team teach on the following courses:

Principles of Implementation and Improvement Science: This is a standalone masters module at King's College London. It involves 10 days in the classroom spread over one or two terms. For more information, email clahrcshortcourses@kcl.ac.uk.

Implementation Science Masterclass: This is a two-day Masterclass for health professionals and researchers held each summer in London. Patients and service users who have experience of research may also be interested. Find out more: www.clahrc-southlondon.nihr.ac.uk/short-courses.

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