Engaging and involving Patients and the public in clinical research
Opportunities across the research pathway
“No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost effective”.

Professor Dame Sally Davies
Chief Medical Officer and Chief Scientific Advisor
Department of Health
PPIE in Research delivery

Infrastructure
Lay Representatives

Engagement
Visibility
Opt out
JDR

Getting involved
Opportunities
Research Ambassadors

Experience
PEQ
<table>
<thead>
<tr>
<th>Number</th>
<th>Title</th>
<th>Description</th>
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<tbody>
<tr>
<td>1</td>
<td>Optimise the visibility of research opportunities</td>
<td>Visible branding of NHS organisations as Research Active organisations</td>
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<td>2</td>
<td>Optimise use of social and digital media to engage and involve the public</td>
<td>NHS to support LOFN funded staff to have easy access to the NHU Hub, digital and social media and other developing sites: • to develop and deliver engagement and involvement activities • reach out and engage diverse audiences in the development and delivery of engagement and involvement activities • evidence of use of social and digital media in the delivery of PIIE activities and projects</td>
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<td>3</td>
<td><strong>Optimise the accessibility to research participation opportunities</strong></td>
<td>Accessible, consistent local patient information about involvement in clinical research</td>
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<td>3a</td>
<td><strong>Optimise the visibility and accessibility to Join Dementia Research Service across the NHS</strong></td>
<td>Optimise the use of “Join Dementia Research” to support recruitment into Dementia studies on the NHU CRN Portfolio (Target: 10% of people recruited to Dementia studies on the NHU CRN Portfolio identified via Join Dementia Research) Visible promotion of Join Dementia Research within all KSS partner organisations</td>
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<td>4</td>
<td>Actively engage and involve patients in all aspects of local research processes</td>
<td>Partners actively engage and involve patients, carers and the wider public in all aspects of local research to improve the quality and delivery of NHU CRN Portfolio research. Local activities reflect relevant priority projects • e.g. ask to Alex, Patient Research Ambassadors, Building Research Partnerships Evidence of processes to involve patients and within the activities of the research department</td>
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<td>5</td>
<td><strong>Recruit Patient Research Ambassadors (PRAs)</strong></td>
<td>Le voluntary promoting and supporting research. PRAs in a minimum of 50% of NHS organisations LOFN to promote and support LOFN Research Ambassador network to cultivate a best practice support community. Share good practice, celebrate PRA activities and share evidence of impact. All KSS partners to have at least 2 new Research ambassadors in FY17/18 and for all to be registered with the National PRA Initiative</td>
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<td>6</td>
<td><strong>Listen to patients’ and volunteers’ experience and continuously improve our services</strong></td>
<td>Participant Experience Gather feedback from study participants and potential participants in NHU CRN Portfolio studies and in line with the CRN Patient Experience and Continuous Improvement Framework Lay volunteers experience Evaluate experience of Patient Research Ambassadors (PRAs) and other volunteers involved in research including e.g. induction programmes, On line learning e.g. Improving Healthcare through Clinical Research, Patient Research Ambassadors development programme, Building Research Partnerships Systematic approach to gathering feedback from study participants and volunteers (PRAs) Clear process for sharing, acting upon and auditing against the findings</td>
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<td>7</td>
<td><strong>Promoting and enabling patient access to Learning and support resources</strong></td>
<td>Collaborative work across CRN and partners with measurable outcomes for provision of learning resources (e.g. Building Research Partnerships, Massive Online Open Courses (MOOCs) Clear process for enabling and auditing the learning and training of patient volunteers and key representatives</td>
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<td>8</td>
<td><strong>Build relationships with 3rd sector voluntary organisations</strong></td>
<td>Share up-to-date information on contact with patient, carer, public groups and organisations Research departments to be aware of established relationships with 3rd sector voluntary organisations</td>
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## KSS CRN draft Framework

<table>
<thead>
<tr>
<th>Focus</th>
<th>Evidence</th>
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<td><strong>2. Optimise use of social and digital media to engage and involve the public:</strong>&lt;br&gt;NHS to support LCRN funded staff to have easy access to the NIHR Hub, digital and social media and other developing sites:&lt;br&gt;• to develop and deliver engagement and involvement activities&lt;br&gt;• reach out and engage diverse audiences in the development and delivery of engagement and involvement activities.&lt;br&gt;• Evidence of use of social and digital media in the delivery of PPIE activities and projects</td>
<td>Social and digital media integral to Research communications strategy to maximise engagement with patients and members of public</td>
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<td><strong>3a. Optimise the accessibility to research participation opportunities</strong>&lt;br&gt;Accessible, coherent and consistent local patient offer of information about, access to, and involvement in clinical research.</td>
<td>Evidence of process for provision of research participation opportunities – direct from research department</td>
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<td><strong>3b. Optimise the visibility and accessibility to Join Dementia Research Service across the NHS:</strong>&lt;br&gt;Optimise the use of “Join Dementia Research” to support recruitment into Dementia studies on the NIHR CRN Portfolio.&lt;br&gt;(Target: 10% of people recruited to Dementia studies on the NIHR CRN Portfolio identified via “Join Dementia Research”)</td>
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### Framework continued..

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<th><strong>5. Increasing Patient Research Ambassadors (PRAs)</strong>&lt;br&gt;i.e. volunteers promoting and supporting research&lt;br&gt;PRAs in a minimum of 85% of NHS organisations&lt;br&gt;LCRN to promote and support LCRN Research Ambassador network to cultivate a best practice support community&lt;br&gt;Share good practice, celebrate PRA activities and share evidence of impact</th>
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<td>Systematic approach to gathering feedback from: study participants and volunteers (PRAs)&lt;br&gt;Clear process for sharing, acting upon and auditing against the findings.</td>
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Patient Research Ambassadors

PRA role and KSS PRA Network
someone who promotes health research from a patient point of view. They could be a patient, service user, carer or lay person who is enthusiastic about health research and willing to communicate that to other patients and public as well as healthcare professionals.
Examples of PRA involvement

- **Research promotional events and themed days**
  - Getting involved locally to promote national research initiatives such as the ‘OK to Ask’ ... about research campaign or international clinical trials days
  - Organising events to promote research during national health campaigns e.g. national diabetes day.

- **Talking to others and Sharing your views and experience**
  - Sharing views about research at local NHS events, patient groups, charities, or societies e.g. Rotary, Women’s Institute
  - Sharing research leaflets in clinics
  - In house staff training

- **Understanding and Improving patient’s experience of taking part in research**
  - Supporting the NHS to capture patient experience by asking patients to take part in local patient experience surveys at the NHS organisation

- **Promoting the research ambassador role**
  - Special interest as lay research champion e.g. Dementia, Cancer, diabetes
  - Share ideas, promote Lay involvement and meet similar minded people as part of the local, or national network of Research Ambassadors Research Ambassador Initiative
“Research has the power, not only to transform the future health and wellbeing of our world, but to transform the way in which you and I live our day-to-day lives.”

Simon Stones
research ambassador

“Patient Research Ambassadors raise awareness of research taking place within their local hospitals. Local people - local research.”

Frances Mossie
research ambassador

“The importance of research is simple: it is through research that we are able to treat, and eventually cure, conditions affecting the lives of millions of people.”

Sophie
research ambassador

“We see our role as encouraging patients’ participation in clinical trials, by using everyday language to convey the importance of their help for the NHS and the community.”

Will and John
research ambassadors
KSS PRA Network

- Build a network of PRAs
- Connect local PRAs and Trust representative working with PRAs
- Meet @ 3 times per year
  - Support one another
  - Share practice, discuss ideas etc.
  - Share learning resources
  - Identify PRA training, support needs

Becoming part of the National Research Ambassador Network
Sign up for Newsletters
Find out more about learning, support and other resources
Ambassador of the month
You Tube: Patient Research Ambassador Initiative
Building Research Partnerships

Building Research Partnerships - Welcome to the site!

“People focused research in the NHS simply cannot be delivered without the involvement of patients and the public”

Professor Dame Sally Davies, former Chief Medical Officer, England

What is Building Research Partnerships all about?
Building Research Partnerships (BRP) brings together patients, public and researchers to learn and talk about research to improve people's health and well-being. BRP can be delivered as one day workshops or in shorter learning sessions as part of other meetings and activities. It is designed to inform and advise those taking part about practical ways that patients and the public can be involved in research.
Why: By evaluating the impact of research and public involvement in research, you can help to build an evidence base and let others know about what worked well and what didn’t.

How: involve the public in:
- how you are going to monitor and evaluate the impact of the research, and the public involvement in the research!
- writing up (and publishing) an evaluation of the public involvement itself!

Why: Members of the public involved in research are often passionate advocates for the research and are often able to establish relationships with key agencies and provide valuable feedback.

Example: The UK Clinical Research Collaboration published a report of a project to evaluate patient and public involvement in research.

Example: Service user researchers and a nursing researcher co-delivered training in therapeutic interventions to staff teams in a mental health trust (St George’s University of London).

Example: The Eve Appeal sent a letter to everyone who took part in the UKCTOCS screening trial and offered them the chance to continue to receive updates.

Why: Dissemination is critical in the knowledge gained from the research to have an impact. Good dissemination can also help identify the need for further research in a particular area.

How: involve the public in:
- developing the dissemination plan
- Summarising the research findings in clear and accessible ways
- Presenting at conferences, speaking to patients, support groups and service providers
- Publication in open access peer-reviewed scientific journals
- Publishing on websites, writing to journalists, creating leaflets for waiting rooms or community centres.

Why: Publishing linked data and results in the public domain allows others to analyse any findings and facilitates a range of people to give their time, scrutiny and perspective to the

How- involve the public in:
- interpreting and commenting on results
- Analysing publicly available open data

Why: Many funding organisations now involve members of the public in commissioning research. This gives a broader perspective to the review process, by considering the issues that are important from a public perspective.

How:
- involve members of the public in reviewing research proposals
- Have a members of the public on research commissioning panels or boards
- research grant applications
- Organisations representing groups or organisations commissioning research.

Example: The James Lind Alliance facilitates Priority Setting Partnerships. These partnerships bring patients, carers and clinicians together to identify and prioritise the treatment uncertainties which they agree are the most important for research.

Example: A randomised controlled trial for people with multiple sclerosis, the MS Society decided to fund research into improving the day-to-day lives of the people it affects, as well as biomedical research.

Example: The Workplace Impact of Supported Employment Study involved service users in the design of study through a local group. The purpose was to investigate the impact of individual Placement and Support in a mental health catchment area.

Example: The University of Western Australia founded a programme to support researchers, consumers and the community to work in partnership to make decisions about research development using linked data.

Example: The Macmillan Listening Study trained people affected by cancer to carry out research to identify the cancer research priorities of people affected by cancer.

How: involve the public in:
- reviewing proposals and commenting on any potential difficulties in the design
- developing research tools: information such as questionnaires, patient information sheets and consent forms
- monitoring and managing the research process
- the selection process of staff and

Why: Involving members of the public in the design of research helps to ensure that the research is relevant to the needs of people, helps ensure the research question and outcomes are clear and ensures the research method has thought about the needs of anybody participating in the research.

Example: After asking people affected by multiple sclerosis, the MS Society decided to fund research into improving the day-to-day lives of the people it affects, as well as biomedical research.

Example: The Workplace Impact of Supported Employment Study involved service users in the design of study through a local group. The purpose was to investigate the impact of individual Placement and Support in a mental health catchment area.

Why: Involving members of the public in undertaking research can mean that research is carried out by people with a personal experience of the area of research or with relevant knowledge of a

Example: The Macmillan Listening Study trained people affected by cancer to carry out research to identify the cancer research priorities of people affected by cancer.