NIHR | National Institute for Health Research

Patient and public involvement in health research – what difference is it making?

PIER Group Meeting, 11th June 2019, Belfast.

Simon Denegri, NIHR National Director for Patients, Carers and the Public, United Kingdom

From protest……

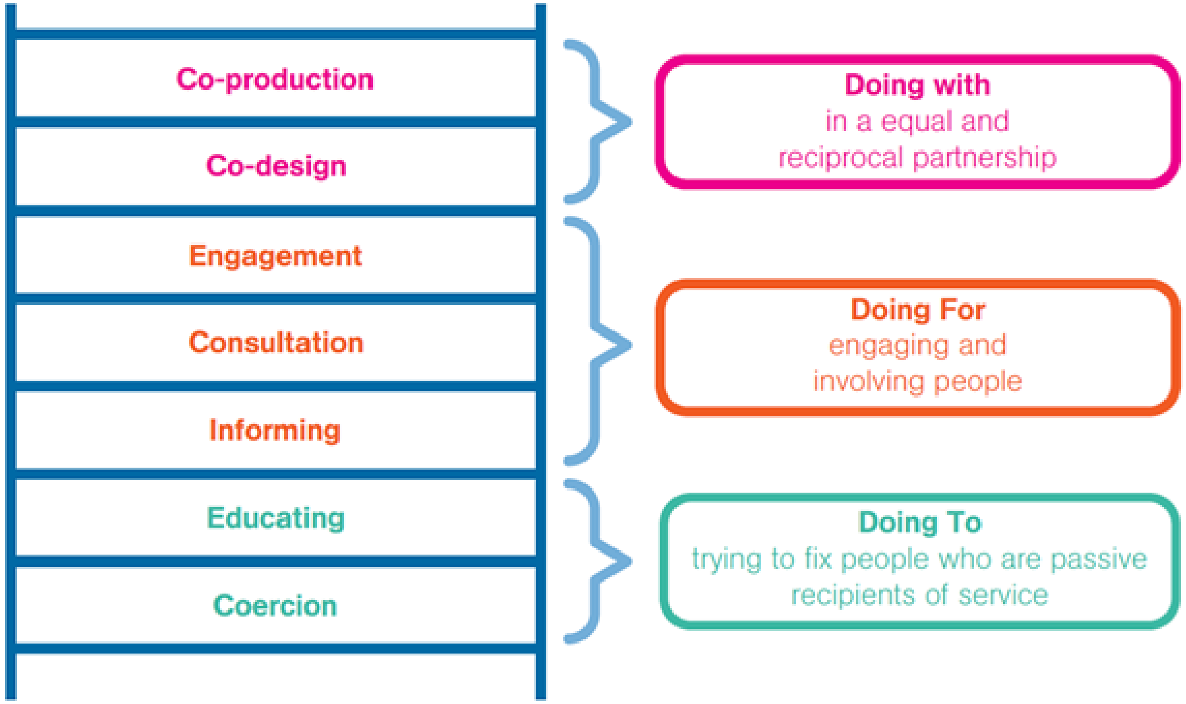
Subject
noun noun: subject;
plural noun: subjects
1.
a person or thing
that is
being discussed,
described,
or dealt with.

…..to partnership and collaboration.

Partner
noun: partner

….public involvement in research is research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them.

INVOLVE’s re-working of Arnstein’s ladder…



Co-production

Co-design

Engagement

Consultation

Informing

Educating

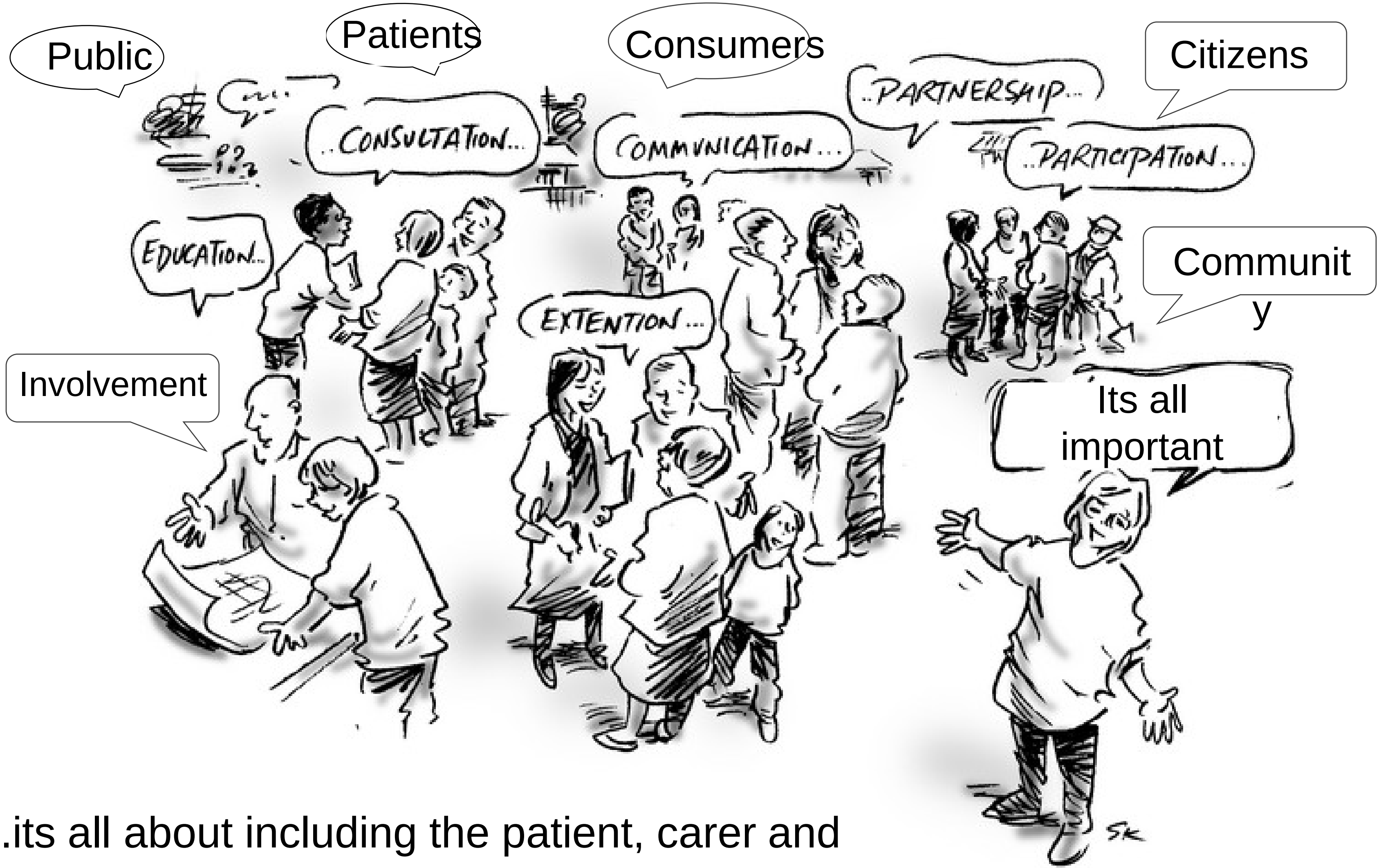
Coercion

Doing with
in a equal and
reciprocal partnership

Doing For
engaging and
involving people

Doing To
trying to fix people who are passive
recipients of service

A Ladder of Citizen Participation. – S R Arnstein. (1969) Journal of the American Institute of Planners, 35(4); 216-224. http://lithgow-schmidt.dk/sherry-arnstein/ladder-of-citizen-participation.html



……..its all about including the patient, carer and public ‘voice’ in research

Source: INVOLVE UK 2008

The world of research works better with patients, carers and the public involved

NIHR’s approach to public involvement 2006-2019

- Core part of NIHR vision, mission and objectives for doing the best research
- Essential to helping us define future research agenda and priorities
- Integrated throughout our funding, infrastructure and activities
- Clear expectation set with researchers and institutions in application process
- Aim to provide funding and help to support involvement
- Increasing focus on understanding and demonstrating impact

“I have always taken the view that public involvement in research should be the rule not the exception.” Professor Dame Sally Davies, Chief Medical Officer (CMO)

Very brief copy here explaining why research is important for the NHS, for you, for your friends and family, and for society.

Close with text about putting as much or as little time as you want, and fit in a very brief overview of the ‘in trial’, ‘shaping’ and ‘managing’ (the ways to get involved).

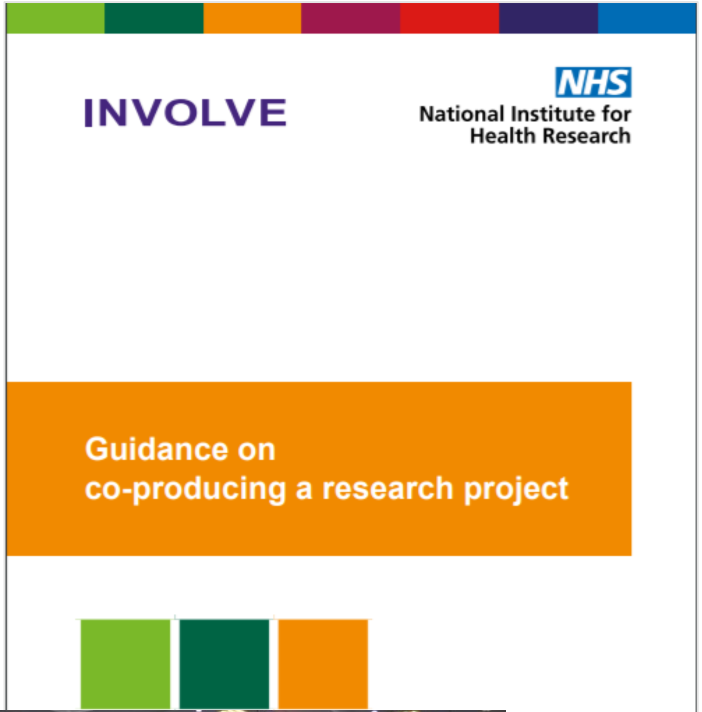
INVOLVE

Est.1996. Funded by, and part of the
National Institute for Health Research (NIHR) since 2006.

National Leadership Areas
- Diversity & Inclusion
- Learning & Development
- Community, partnership, networks (Co-production, Intl PPI network)
- Standards (with NIHR CCF)

Resources, Tools & Guidance
- National enquiry service
- People in Research: matchmaking
- Briefing notes for researchers/resources
- Benefits advice service

@NIHRINVOLVE, www.invo.org.uk



INVOLVE

NHS
National Institute for
Health Research

Guidance on
co-producing a research project

NIHR ‘Going the Extra Mile’ 2015 -2025

A population actively involved in research to improve health and wellbeing for themselves, their family and neighbours.

Objectives:

- Improving access to NHS research
- Increasing the diversity of our community
- Developing public involvement standards
- Supporting learning and development
- Enabling regional and local collaboration
- Impact = reach, relevance, refinement, relationships
- Emphasising co-production and new methods
- Maintaining our global reputation

Going the extra mile:

What is Co-Production?

NIHR | INVOLVE

Being Inclusiv
Health Resear
Things to think ab

Public Programmes
People | Research | Dialogue

Progress Report

Issue 1, 20 December 2018

NHS
National Institute for Health Research

Reaching Out North Essex

New research partnerships

Diverse community research collaborations in the making

Needs based and place based research

Our voices matter

Young People as equal partners

Defining what good looks like – UK public involvement (PPI) standards

NATIONAL STANDARDS for PUBLIC INVOLVEMENT

NATIONAL STANDARDS for PUBLIC INVOLVEMENT

Standard 1: INCLUSIVE OPPORTUNITIES

We offer public involvement opportunities that are accessible and that reach people and groups according to research needs.

Standard 2: WORKING TOGETHER

We work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

Standard 3: SUPPORT & LEARNING

We offer and promote support and learning that builds confidence and skills for public involvement in research.

Standard 4: COMMUNICATIONS

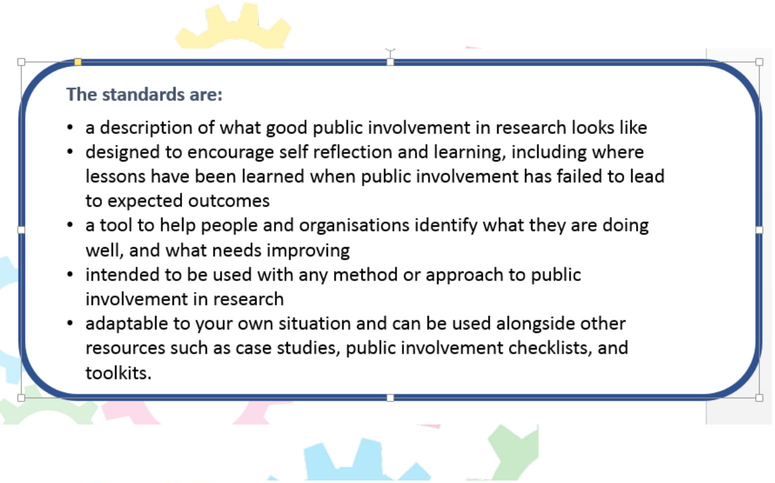
We use plain language for timely, two way and targeted communications, as part of involvement plans and activities.

Standard 5: IMPACT

To drive improvement, we capture and share the difference that public involvement makes to research.

Standard 6: GOVERNANCE

We involve the public in our governance and leadership so that our decisions promote and protect the public interest.



The standards are:

- a description of what good public involvement in research looks like
- designed to encourage self reflection and learning, including where lessons have been learned when public involvement has failed to lead to expected outcomes
- a tool to help people and organisations identify what they are doing well, and what needs improving
- intended to be used with any method or approach to public involvement in research
- adaptable to your own situation and can be used alongside other resources such as case studies, public involvement checklists, and toolkits.

NATIONAL STANDARDS
for PUBLIC INVOLVEMENT
Official Test Bed Site 2018-19

Public involvement - making it happen

Leadership

- Policy
- Professional
- Patient

Infrastructure

- Training
- Tools
- Awareness

Practice

- Demonstration
- Measurement
- Coordination

Making it happen – leadership, infrastructure

Our community

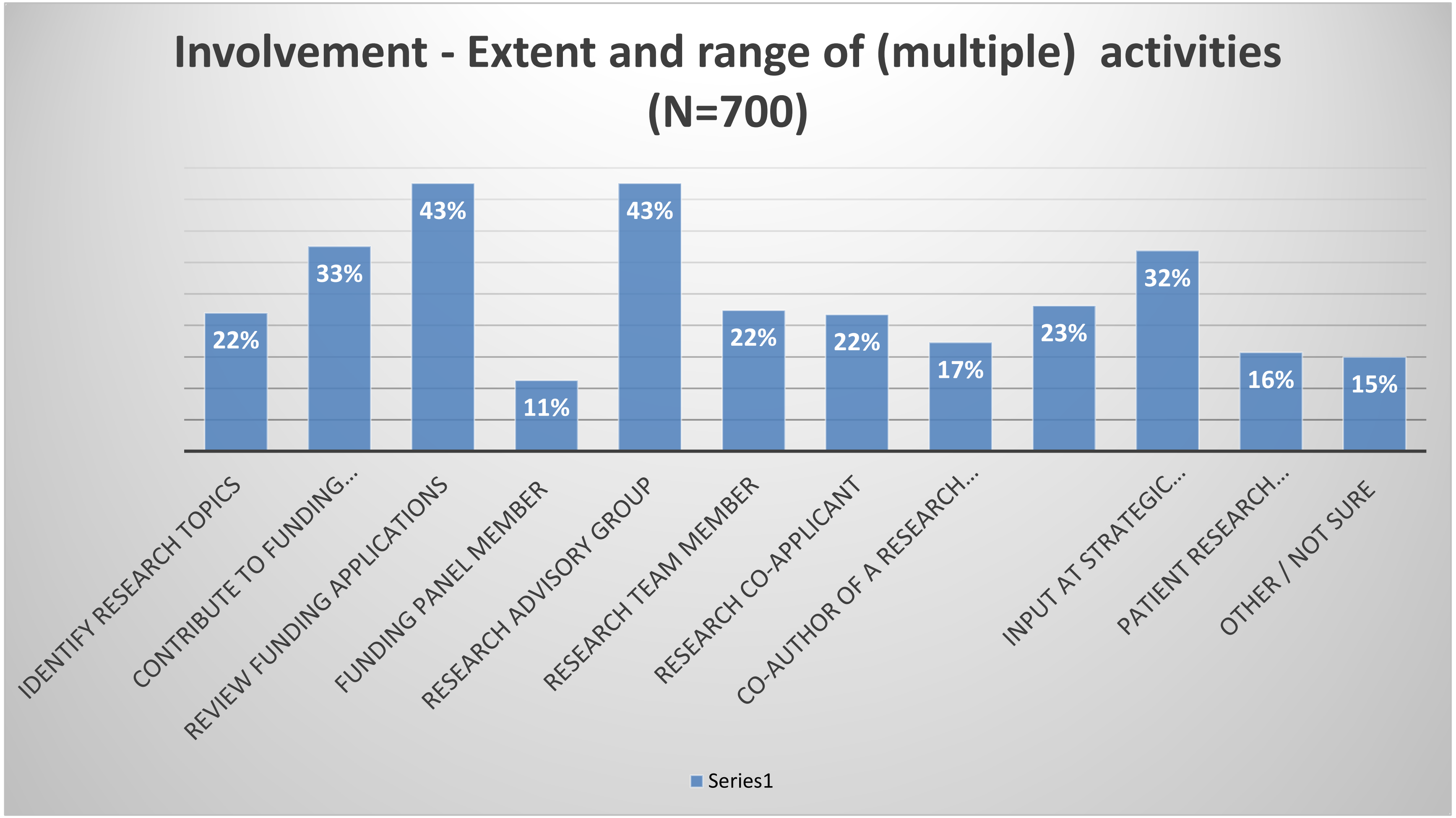
What's it like being involved in NIHR research?* National Survey 2019

- We have a strong, supportive and highly motivated public involvement community
- Vast majority feel they make a difference and that their contribution is valued
- People form their view about research and the NIHR based upon their 'local' relationship
- They are partnership builders fulfilling a range of roles for us and other bodies
- Diversity remains a significant issue for us – age, ethnicity etc.
- There is considerable variety and inconsistency in practice 'Sometimes, but…'
- Communications, feedback and acknowledgement areas for clear improvement

*Full survey results expected to be published May 2019 (n=809)

Key points:

- Our public contributors are involved in many other organisations and have an important role in the future in building partnerships and collaborations
- Social care and industry are key areas where we need to support the development of involvement



Key Points:

- People are playing a number of roles within their part of the NIHR
- But based on comments these may not all be accurate descriptions of their activities. For example: when people ticked the ‘co-applicant’ and/or ‘co-author’ boxes, their comments were generally about involvement in reviewing research applications or final reports.

“ these categories need greater definition in accessible language for me to understand and answer fully (maybe with some examples)”[Comment from a respondent]

Institutional commitment

- UCLH Biomedical Research Centre (BRC)
- £111M from NIHR over 5 years
- Public involvement strategy and plan a
- Pre-requisite for funding
  - ✓Public involvement as a cross-cutting theme
  - ✓Dedicated PPI team and budget
  - ✓Community panels for each theme i.e. dementia
  - ✓Strong focus on researcher training and support
  - ✓Increasing emphasis on community outreach
  - ✓Strategic partnerships – In2Science, Yale

Celebrating Research

Have a stall at UCLH's Research Open Day

4 July 2019

University College London Hospitals Biomedical Research Centre

NHS National Institute for Health Research

Publicity and PPI within the Hearing Theme

- Two patients as BRC Hearing Theme board members
- Lay panel to guide hearing researchers and their research
- Newsletters
- Event to celebrate WHO World Hearing Day March 2019
- Hearing BRC research showcase event May 2019
- Close collaboration with hearing charities

Careers, training, learning and development

NIHR Academy

- NIHR Infrastructure Doctoral Training Camp
- ≃ 80 early career researchers / 3 days

Includes PPI workshops, PPI surgery sessions, advice and guidance from public advisors, scrutiny from public panel member

"My key learning point from today is ... PPI. I am a lab based researcher and have never heard about PPI before; though I was not very convinced about PPI, by the end of the course I definitely was!
NIHR Trainee

Thank you to the public and patient advisor for useful feedback. Meeting constructive and comments incorporated into our plan.
NIHR Trainees

A really useful meeting which has helped us really think about how we explain complex ideas in our study design. Good to meet the panel. **NIHR Trainees**

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Making it happen – practice

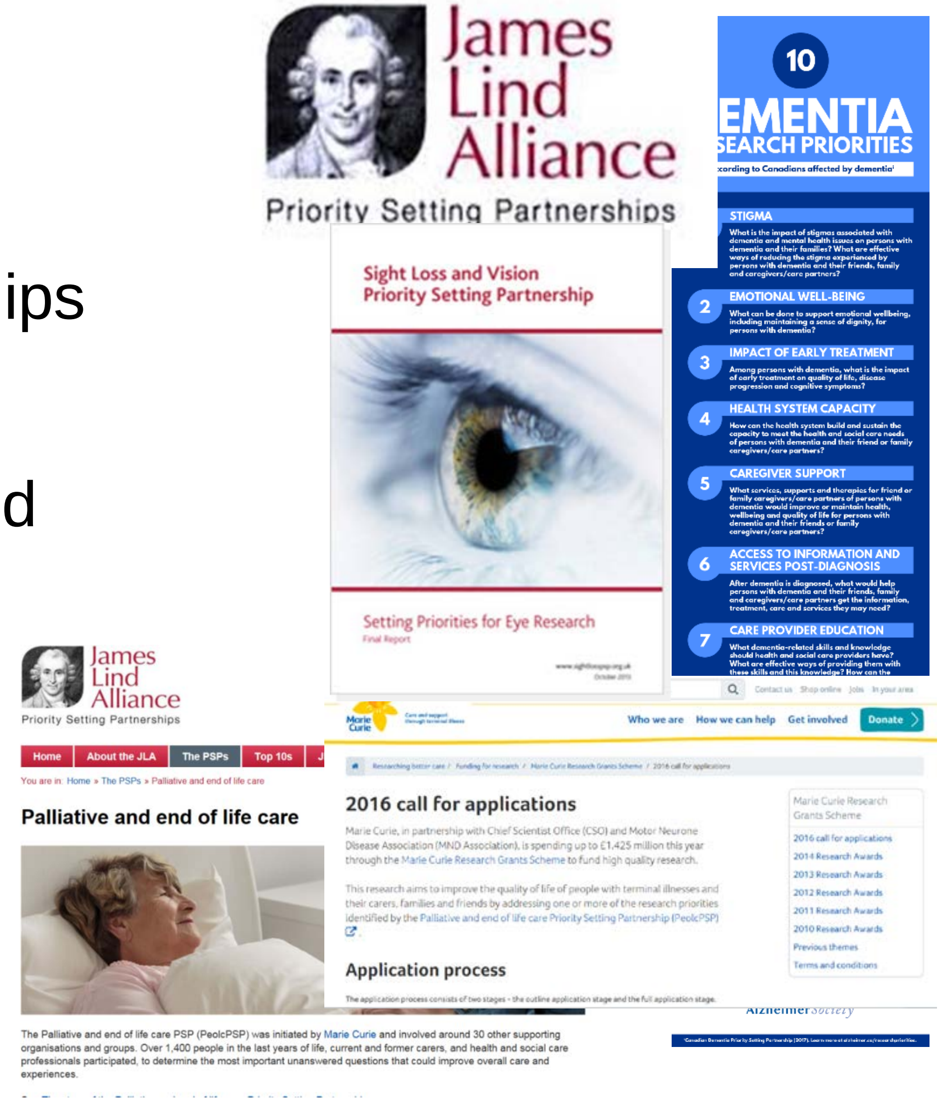
Research relevance - informing research priorities

James Lind Alliance Priority Setting Partnerships (PSPs) established 2006

80+ completed PSPs -including alcohol-related liver disease, womb cancer and autism

29 + active: Type 2 Diabetes, Emergency Medicine, Young People, Heart Surgery, Mental Health

Canada, Netherlands, Germany, Australia



10
EMENTIA
SEARCH PRIORITIES
cording to Canadians affected by dementia¹

STIGMA
What is the impact of stigmas associated with dementia and mental health issues on persons with dementia and their families? What are effective ways of reducing the stigma experienced by persons with dementia and their friends, family and caregivers/care partners?

2 EMOTIONAL WELL-BEING
What can be done to support emotional wellbeing, including maintaining a sense of dignity, for persons with dementia?

3 IMPACT OF EARLY TREATMENT
Among persons with dementia, what is the impact of early treatment on quality of life, disease progression and cognitive symptoms?

4 HEALTH SYSTEM CAPACITY
How can the health system build and sustain the capacity to meet the health and social care needs of persons with dementia and their friend or family caregivers/care partners?

5 CAREGIVER SUPPORT
What services, supports and therapies for friend or family caregivers/care partners of persons with dementia would improve or maintain health, wellbeing and quality of life for persons with dementia and their friends or family caregivers/care partners?

6 ACCESS TO INFORMATION AND SERVICES POST-DIAGNOSIS
After dementia is diagnosed, what would help persons with dementia and their friends, family and caregivers/care partners get the information, treatment, care and services they may need?

7 CARE PROVIDER EDUCATION
What dementia-related skills and knowledge should health and social care providers have? What are effective ways of providing them with these skills and this knowledge? How can the

Alzheimer Society

Sight Loss and Vision Priority Setting Partnership

Setting Priorities for Eye Research
Final Report

James Lind Alliance
Priority Setting Partnerships

Home | About the JLA | The PSPs | Top 10s

You are in: Home » The PSPs » Palliative and end of life care

Palliative and end of life care

The Palliative and end of life care PSP (PeolcPSP) was initiated by Marie Curie and involved around 30 other supporting organisations and groups. Over 1,400 people in the last years of life, current and former carers, and health and social care professionals participated, to determine the most important unanswered questions that could improve overall care and experiences.

Contact us | Shop online | Jobs | In your area

Marie Curie

Who we are | How we can help | Get involved | Donate

2016 call for applications

Marie Curie, in partnership with Chief Scientist Office (CSO) and Motor Neurone Disease Association (MND Association), is spending up to £1.425 million this year through the Marie Curie Research Grants Scheme to fund high quality research.

This research aims to improve the quality of life of people with terminal illnesses and their carers, families and friends by addressing one or more of the research priorities identified by the Palliative and end of life care Priority Setting Partnership (PeolcPSP).

Application process

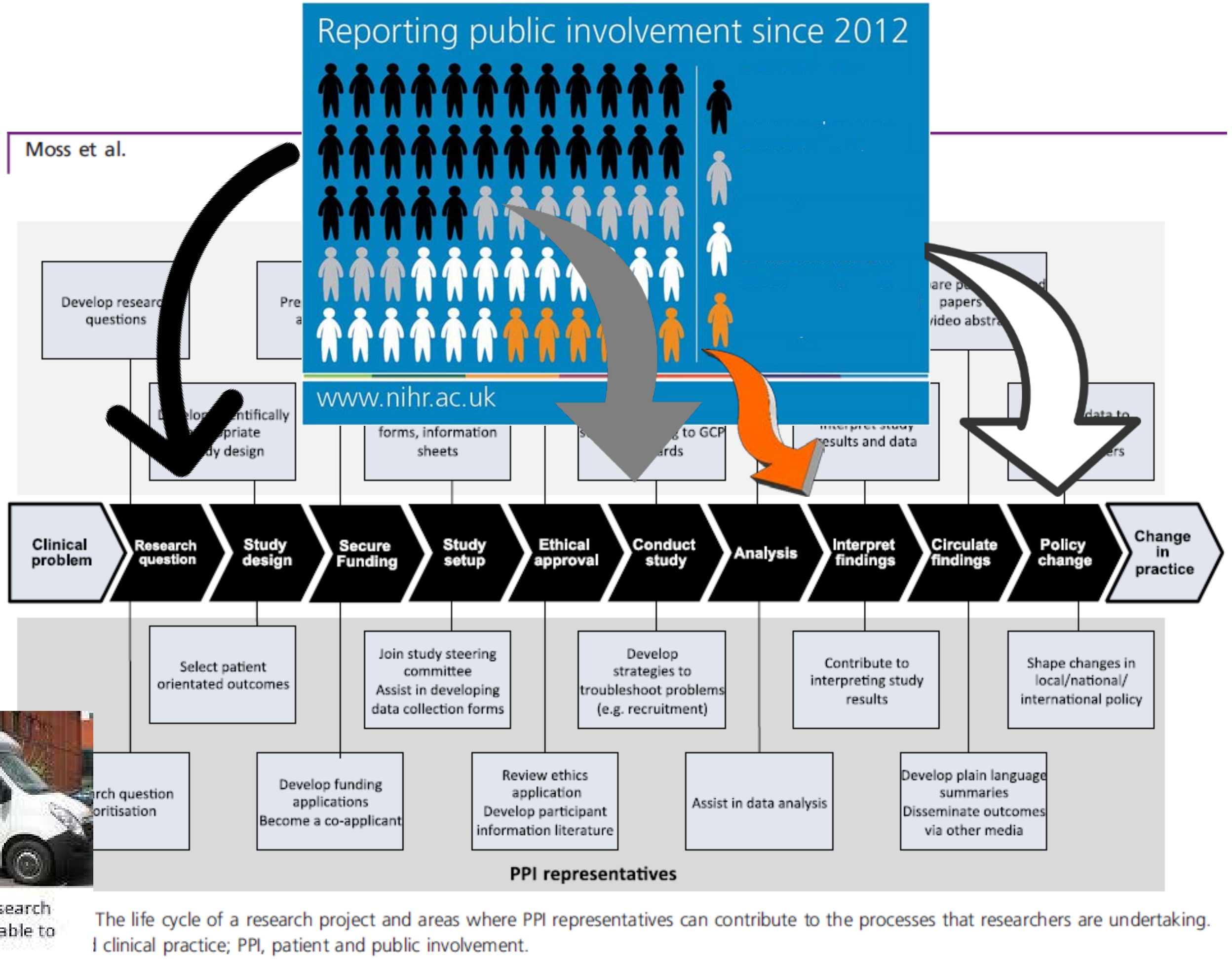
The application process consists of two stages - the outline application stage and the full application stage.

Marie Curie Research Grants Scheme
- 2016 call for applications
- 2014 Research Awards
- 2013 Research Awards
- 2012 Research Awards
- 2011 Research Awards
- 2010 Research Awards
- Previous themes
- Terms and conditions

Research relevance – visual impairment

- Sight Loss and Vision PSP – published May 2013
- Fight for Sight: over £11,000,000 awarded to over 180 projects
- NIHR: £2,000,000 for three clinical trial addressing priorities in cataract, glaucoma and keratoconus
- Macular Society: £700,000 grants for 12 projects
- 2 NIHR horizon scanning reports for new and emerging treatments (corneal disorders and inherited retinal diseases)
- Multi-charity partnership formed to address the top priority in AMD
- www.sightlosspsp.org.uk

Involvement across the research pathway



Reporting public involvement since 2012

www.nihr.ac.uk

Moss et al.

Develop researc questions

Pre

Develo ntifically priate dy design

forms, information sheets

to GCP rds

nterpret study esults and data

are papers video abstra

data to rs

Clinical problem → **Research question** → **Study design** → **Secure Funding** → **Study setup** → **Ethical approval** → **Conduct study** → **Analysis** → **Interpret findings** → **Circulate findings** → **Policy change** → **Change in practice**

Select patient orientated outcomes

Join study steering committee
Assist in developing data collection forms

Develop strategies to troubleshoot problems (e.g. recruitment)

Contribute to interpreting study results

Shape changes in local/national/ international policy

rch question oritisation

Develop funding applications
Become a co-applicant

Review ethics application
Develop participant information literature

Assist in data analysis

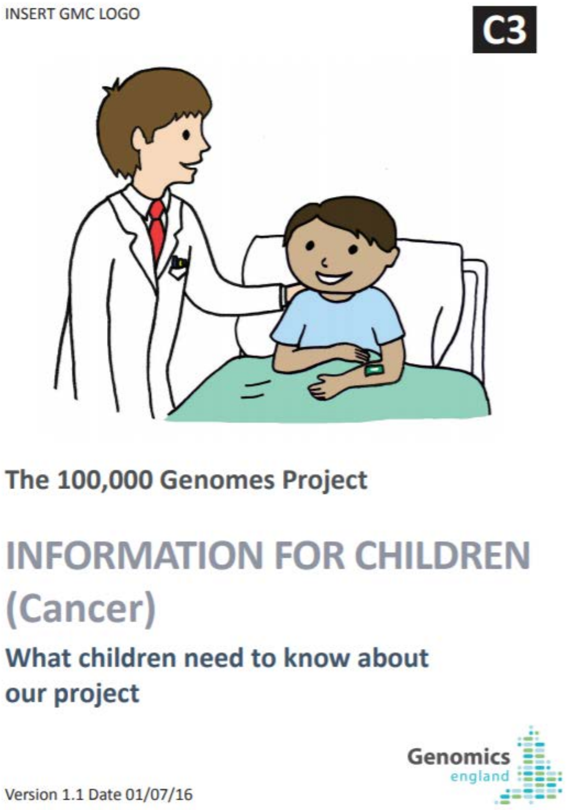
Develop plain language summaries
Disseminate outcomes via other media

PPI representatives

The life cycle of a research project and areas where PPI representatives can contribute to the processes that researchers are undertaking.
l clinical practice; PPI, patient and public involvement.

Moss N, Daru J, Lanz D, Thangaratinam S, Khan KS. Involving pregnant women, mothers and members of the public to improve the quality of women's health research. BJOG 2016; DOI: 10.1111/1471-0528.14419.

"The unique mobile hearing van will allow us to take our research out to families, and this should mean more of them will be able to participate in this much needed study"
- Professor Kevin Munro, Ewing Professor of Audiology



INSERT GMC LOGO

C3

The 100,000 Genomes Project

INFORMATION FOR CHILDREN (Cancer)

What children need to know about our project

Version 1.1 Date 01/07/16

Involvement to improve people's access to NHS research

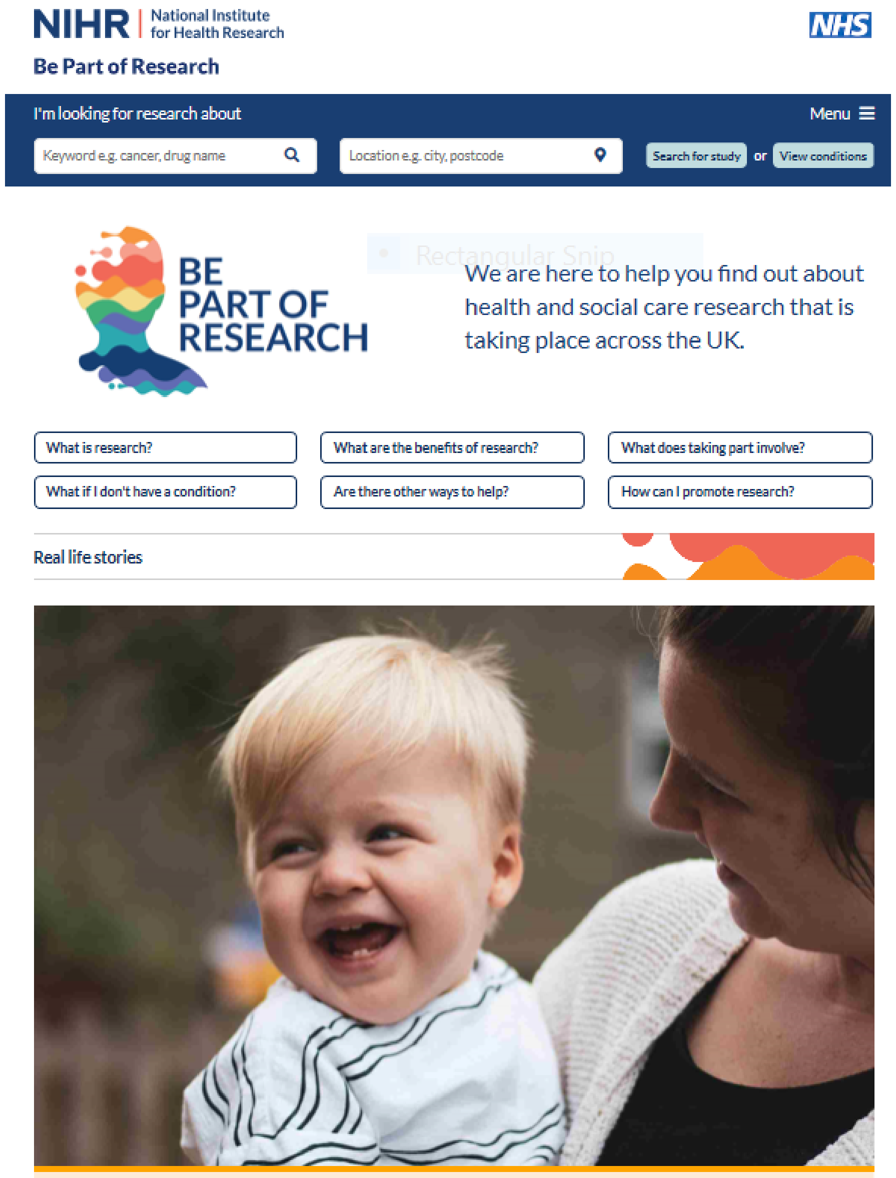
‘Every willing patient a research patient’

83% of the public say that health research is very important.

But 32% do not think research opportunities are offered in their local hospital and almost half do not know

Top 3 research priorities for the UK – cancer (68%), dementia (58%), genetic diseases (32%).

Figures taken an HRA/NIHR Omnibus Survey 2017 to be published in March 2018: *https://www.hra.nhs.uk/about-us/news-updates/survey-finds-strong-public-support-health-research/*



NIHR | National Institute for Health Research

NHS

Be Part of Research

I'm looking for research about

Menu ☰

Keyword e.g. cancer, drug name

Location e.g. city, postcode

Search for study or View conditions

BE PART OF RESEARCH

Rectangular Snip

We are here to help you find out about health and social care research that is taking place across the UK.

What is research?

What are the benefits of research?

What does taking part involve?

What if I don't have a condition?

Are there other ways to help?

How can I promote research?

Real life stories

Patients and the public

- **Opportunities**
- **Why joining in makes a difference**
- **How to join in**
  - The Research Cycle
  - Join a study
  - UK Clinical Trial Gateway
  - NIHR Bioresource
  - People in Research
  - Shape a research project
  - Suggest a research topic
  - Review a research application
  - Join an advisory panel
  - Patient Research

Patient Research Ambassadors

Patient Research Ambassadors
Putting people at the heart of research

What is a Patient Research Ambassador?

A Patient Research Ambassador is 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 is willing to communicate that to other patients, the public, as well as other healthcare professionals.

Why do we need Patient Research Ambassadors?

We would like to involve both patients and NHS researchers to recognise the importance of research in delivering health care. As a Patient Research Ambassador you can help to ensure that people using local NHS care have the best opportunities and choices about taking part in research studies.

Many of us are already Patient Research Ambassadors

Welcome to 'Join dementia research', a place to register your interest in participating in dementia research.

Anyone, with or without dementia, can register as a volunteer or sign-up for someone else (with permission). Signing up is the first step in becoming involved in supporting vital research studies across the country.

If you already have an account please login.

What's new

Keep up-to-date with latest developments on our 'News & Info' page.

Your stories

Hear from people who have taken part in dementia research in 'Your stories'.

Key things you should know about the service

- Sign up today
- Answer as many of the questions as you can
- View the studies you match to
- Share and encourage your friends & family to join
- Visit the website regularly to see your study matches
- Subscribe to hear about new dementia research first
- Keep your information up-to-date

Public involvement input has ensured:

- Clarity of purpose
- Mission focus
- Better design: ‘service’ v ‘research’
- ‘Political’ support
- Awareness
- Partnership

Join Dementia Research in numbers

Join dementia research

916
trained researchers using the service

253
NHS, University & commercial sites have used the system

102
studies open to recruitment

29%
of volunteers have participated in a study

80,779
volunteers screened for studies

40,286
total volunteers

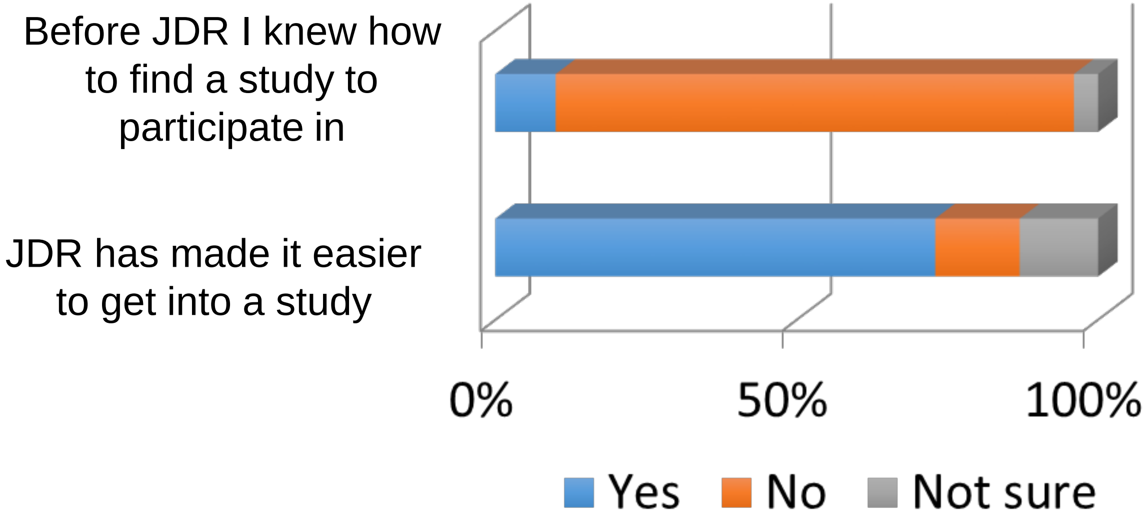
371
studies have recruited

12,881
participants enrolled in studies to date

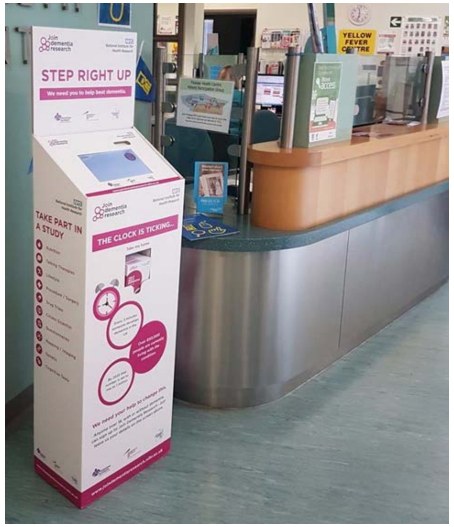
These statistics are accurate as of 31 March 2019

NIHR | National Institute for Health Research

Improving access, increasing opportunities



Join dementia research



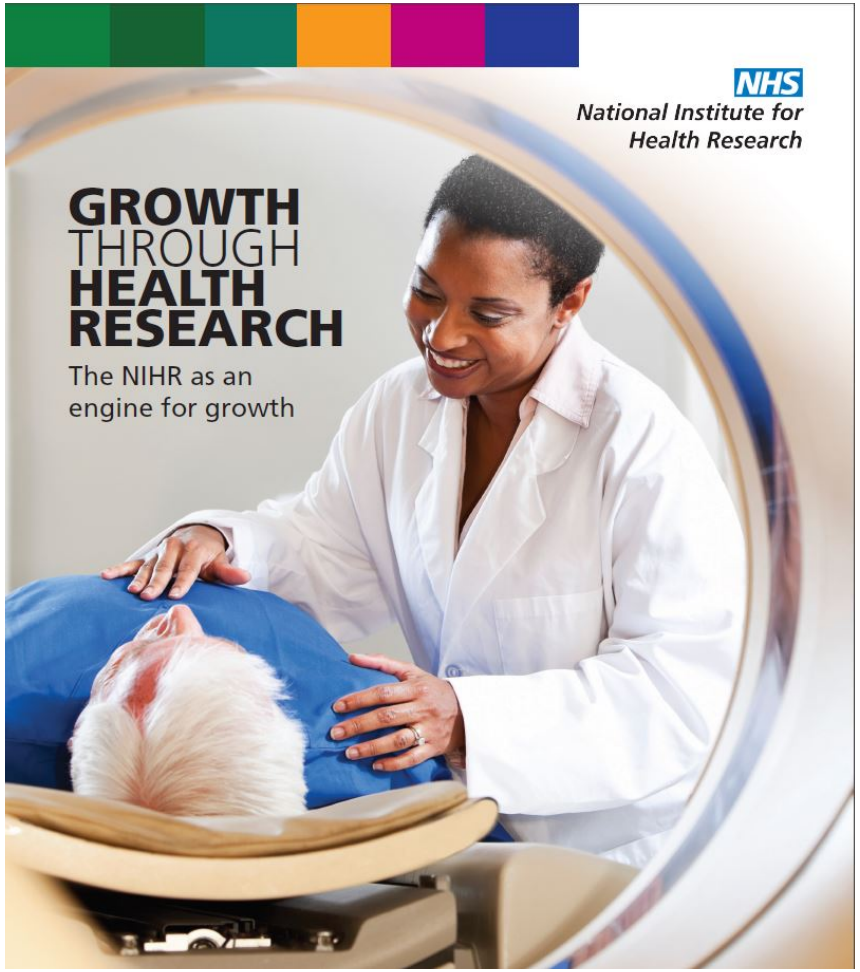
Step Up for Dementia Research

https://www.stepupfordementiaresearch.org.au/

NIHR | National Institute for Health Research

‘The aim of patient and public involvement
is to improve the quality, feasibility and
translational value of research...[This] is
the first time we can see that patient involvement
is linked to higher likelihood of reaching recruitment
target – and as a result, study success.’

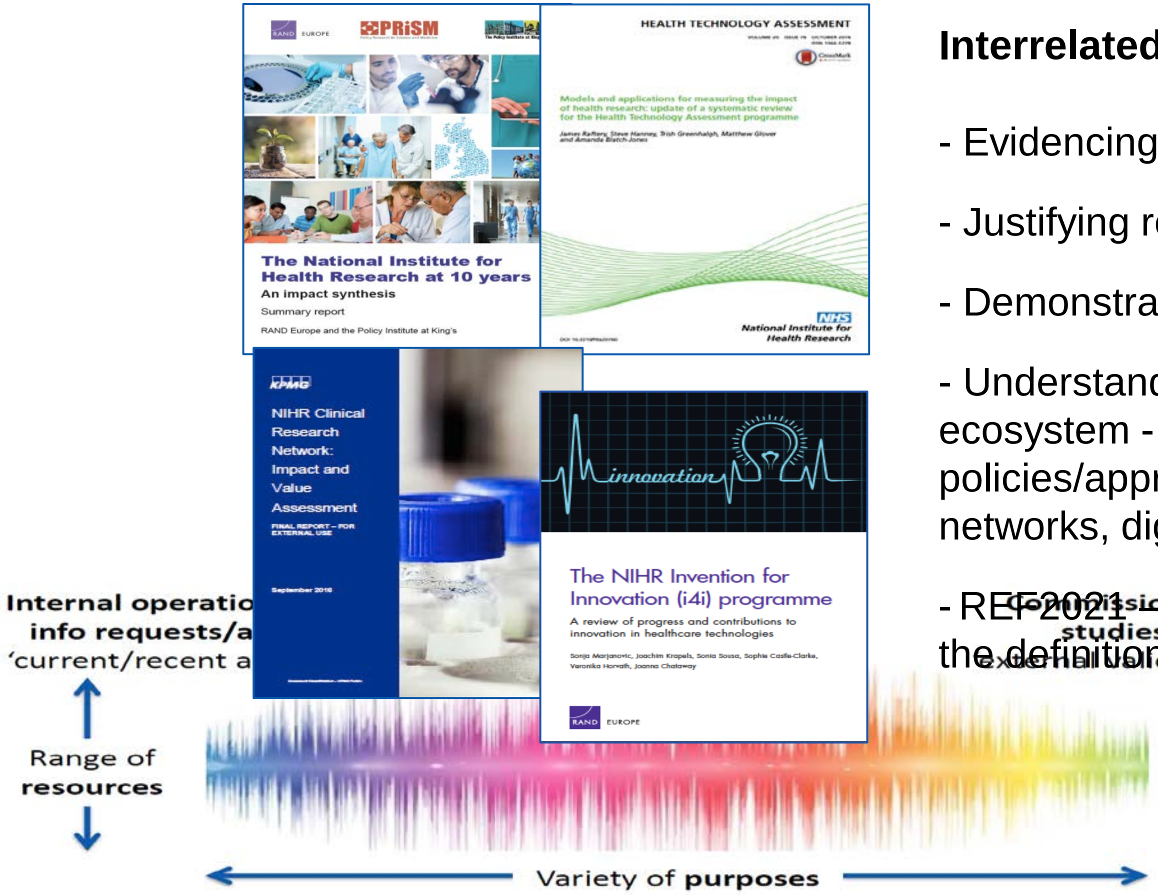
Professor Til Wykes, Director, MHRN ‘Patient involvement in research boosts success,’ The Guardian, 16/09/13 Paper reference: Ennis, L. et al. ‘Impact of patient involvement in mental health research: longitudinal study’ British Journal of Psychiatry (Sept 2013) doi: 10.1192/bjp.bp.112.119818


GROWTH THROUGH HEALTH RESEARCH

The NIHR as an engine for growth

Measuring the impact of PPI

NIHR IMPACT: improving the health and wealth of the nation through research


RAND EUROPE

PRiSM

The National Institute for Health Research at 10 years

An impact synthesis

Summary report

RAND Europe and the Policy Institute at King's

HEALTH TECHNOLOGY ASSESSMENT

Models and applications for measuring the impact of health research: update of a systematic review for the Health Technology Assessment programme

James Raftery, Steve Hanney, Trish Greenhalgh, Matthew Glover and Amanda Blatch-Jones

NHS National Institute for Health Research

KPMG

NIHR Clinical Research Network: Impact and Value Assessment

FINAL REPORT – FOR EXTERNAL USE

September 2016

The NIHR Invention for Innovation (i4i) programme

A review of progress and contributions to innovation in healthcare technologies

Sonja Marjanovic, Joachim Krapels, Sonia Sousa, Sophie Castle-Clarke, Veronika Horvath, Joanna Chataway

RAND EUROPE

Interrelated drivers for understanding our impact:

- Evidencing patient and public benefit
- Justifying research investment
- Demonstrating a difference from research
- Understanding the part we play in the wider health research ecosystem - coproduction and the impact of our policies/approaches e.g. Athena SWAN, PPIE, social networks, digital
- REF2021 – broadening and deepening the definition of impact

Where does PPI fit?

- Develop and agree a definition of public involvement impact – akin to the overarching ambition for PPI in the NIHR Value Framework? (aligned with GtEM & NIHR Strategy)
- NIHR public contributors feedback exercise – will give us a sense of how far we are from achieving our ambition
- Facilitate a ‘Community Conversation’ on impact – sharing best practice and stimulating the community to pull together in the same direction.
- NIHR ‘microsite’ to share – creating systems to identify, collate and curate examples of impact
- UK standards for public involvement & PPI routine data – understanding what we have already got, how we can use data to greater effect and highlight what where the gaps are to direct future work.
- Case studies/ stories: Develop a framework for refreshing and reporting case studies tailored to the interests of specific audiences
- Opportunities to share the load – nationally/internationally.

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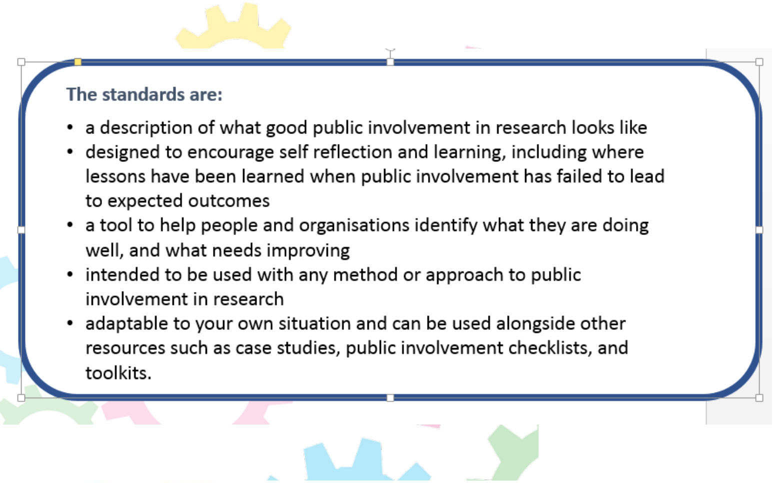
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NATIONAL STANDARDS
for PUBLIC INVOLVEMENT
Official Test Bed Site 2018-19

Measurement and evaluation

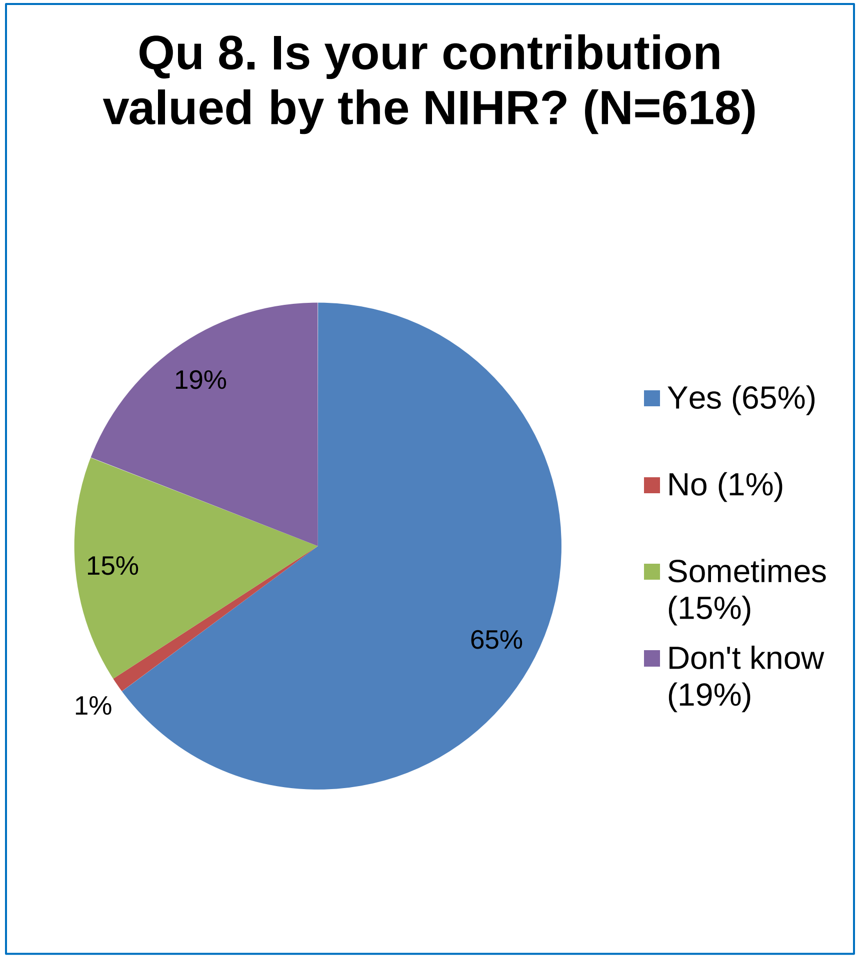
Reach

Relevance

Refinement

Relationships, partnerships, collaboration

Is your contribution valued by the NIHR?



Qu 8. Is your contribution valued by the NIHR? (N=618)

- "**Yes** 'I feel that it has been appreciated by the teams that I work for**, but** I haven't had direct contact with NIHR to know what they think."

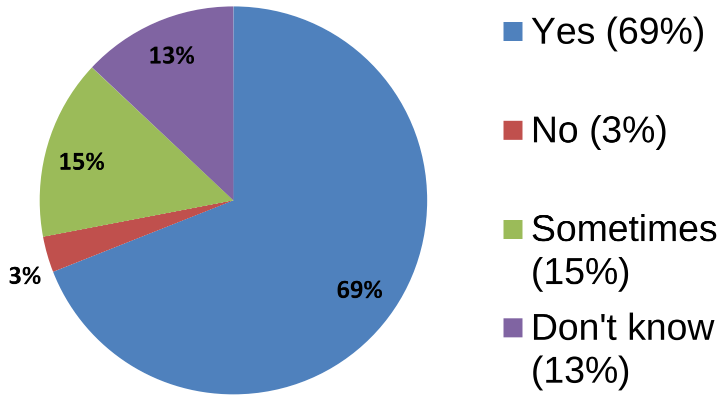
- "I think it is valued **but** it is not always clear that it is or why."

- "**Sometimes** researchers have given the impression that they are involving the public because they have to 'tick the box'."

[Comments from respondents]

Do you think you are making a difference?

Qu 11. Do you think your involvement made a difference (N=607)



“Yes but can only tell when you get **feedback** which I have mostly but not always had….

Quite often the feedback is that it was very useful **but** then there is little or no indication after the event of anything happening as a result. … it may just be a task too many but lack of feedback makes it difficult to know whether my involvement is useful”

[Comment from a respondent]

What difference you would like your involvement to make (N=519)

Final outcome: result in tangible changes to the health care system – improved services and better treatments for patients

By:

- influencing the research itself – inclusion of patient voices - improving the quality and relevance of the research
- supporting research participants in clinical trials or studies – better understanding of and access to taking part in research.
- working with researchers – acknowledging the benefits of involving patients in their work
- producing information about research for the public - providing accessible/ easy to read articles / presentations

Creating a culture of learning – feedback, the missed opportunity

NIHR Survey

- 45% of respondents (n=607) said that they did not, sometimes did or didn't know if they had received feedback on their contribution
- 51% said (n=608) they had never, only sometimes or did not know if they'd been asked for feedback on the contribution they had made

NIHR CLAHRC East of England

- Reciprocal relationships and the importance of feedback in patient and public involvement: A mixed methods study. Mathie et al: https://onlinelibrary.wiley.com/doi/pdf/10.1111/hex.12684

- Acknowledgement only versus opportunity for learning.

"[I[can only tell [if I have made a difference] when you get **feedback** which I have mostly but not always had….Quite often the feedback is that it was very useful **but** then there is little or no indication after the event of anything happening as a result. … it may just be a task too many but lack of feedback makes it difficult to know whether my involvement is useful"

What does the future hold?

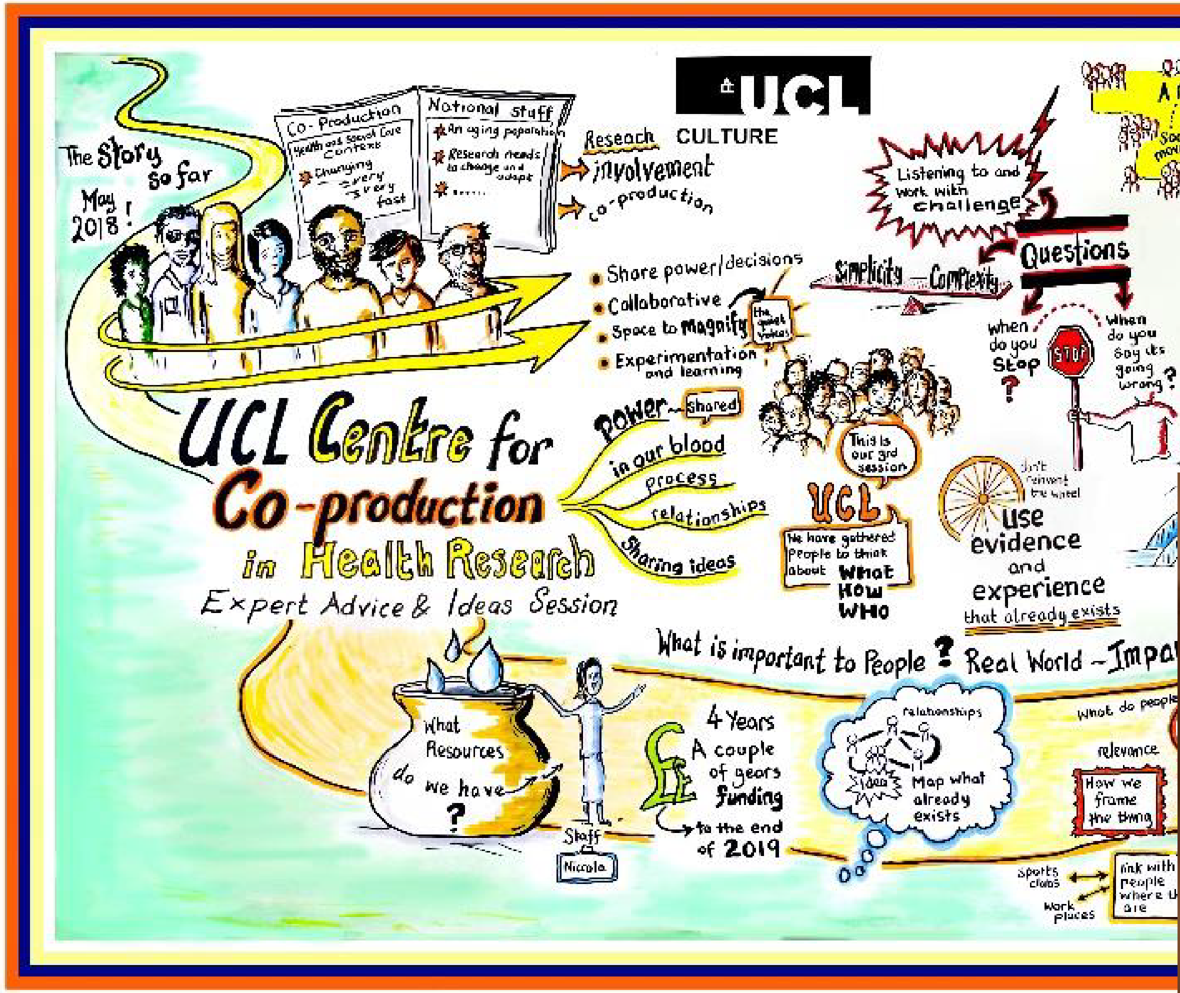
Our changing relationship with the public

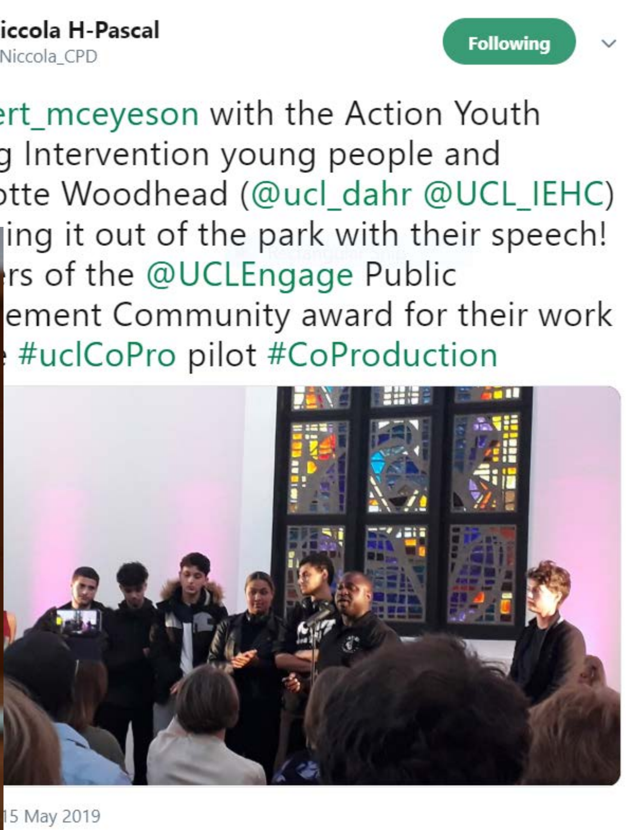
Past and present

- Involvement, engagement and participation
- The individual
- Clinical research, clinical trials, clinical studies
- Process
- Centrally controlled and driven
- Partnership
- The committee room
- Patients, carers, the public
- National focus
- NIHR and ‘the few’

The future

- Co-production, co-creation
- Mobilisation
- The community
- Public health, social care research
- Outcomes
- Citizen driven, Grassroots
- Collaboration
- Digital, tech, AI, social media
- Consumers
- Global movement – thinking ‘globally acting locally’
- Charities and industry





Niccola H-Pascal
@Niccola_CPD

@albert_mceyeson with the Action Youth Boxing Intervention young people and Charlotte Woodhead (@ucl_dahr @UCL_IEHC) ing it out of the park with their speech! rs of the @UCLEngage Public ement Community award for their work e #uclCoPro pilot #CoProduction

15 May 2019

‘Reaching Out’ to diverse communities

- Pilot programme launched by INVOLVE and the Research Design Service (RDS) in 2018
- Aim is to encourage the development of new public involvement and engagement relationships
- Emphasis is on parts of the community who are not usually, or consistently, involved in health, social care and public health research
- Four pilots – RDS South Central, RDS North East, RDS Yorks & Humberside, RDS Eastern Region

Progress Report

Issue 1, 20 December 2018

NHS National Institute for Health Research

Reaching Out North Essex

New research partnerships

Diverse community research collaborations in the making

Needs based and place based research

Tendring, North Essex is one of the 20% most deprived districts in England. Jaywick Sands is the most deprived ward of all and 40% of children in Clacton live in poverty. There are significant health and social care inequalities and yet, as far as we know, the young voices of this area have not been heard in shaping research. Our first action was to visit the Jaywick Neighbourhood team and invite them to collaborate. They accepted and introduced us to other local grass roots organisations working to change the inequalities. In just two weeks we developed together our ‘Reaching Out’ bid with the help of the East of England NIHR Public Involvement Collaborative. By developing the bid together, we have a strong platform for the partnership and shared ownership for the project.

Our voices matter

“The Reaching out Project has had a transformational effect on two of our client participants – both refugees of a young age, 16 and 23. Being asked for opinions and having them heard by young people, researchers and other involved parties has made them feel appreciated and able to contribute. For those coming to a country where often their thoughts are never given an opportunity to be voiced this has been empowering and inclusive in an extremely positive way. Being asked to contribute to a subject area so relevant to them and their families and contemporaries has also made this have extra meaning.”

Maria, Refugee Action Colchester, Director

“I’m really enjoying being a part of the Reaching Out Project! It’s so refreshing to see that the voices of young people are being put first, and already we’re seeing some fantastic ideas being discussed that I know would benefit so many people like myself. The project is an opportunity for us to express what we think our community needs, which really inspires me, and I feel it will inspire many others as well. We’re making great progress, and I’m very excited to see what the New Year brings!”

Jess, Friends not Foes Age 17

“I’m enjoying being part of this project and looking forward to further contributions I can make. This is a wonderful opportunity for the voices of young people with mental health issues to be heard, something that is far too rare. I can’t wait to make a real difference to research and as a result to the lives of young individuals who are struggling to cope”.

Molly, Young Art Kommunity, Age 25

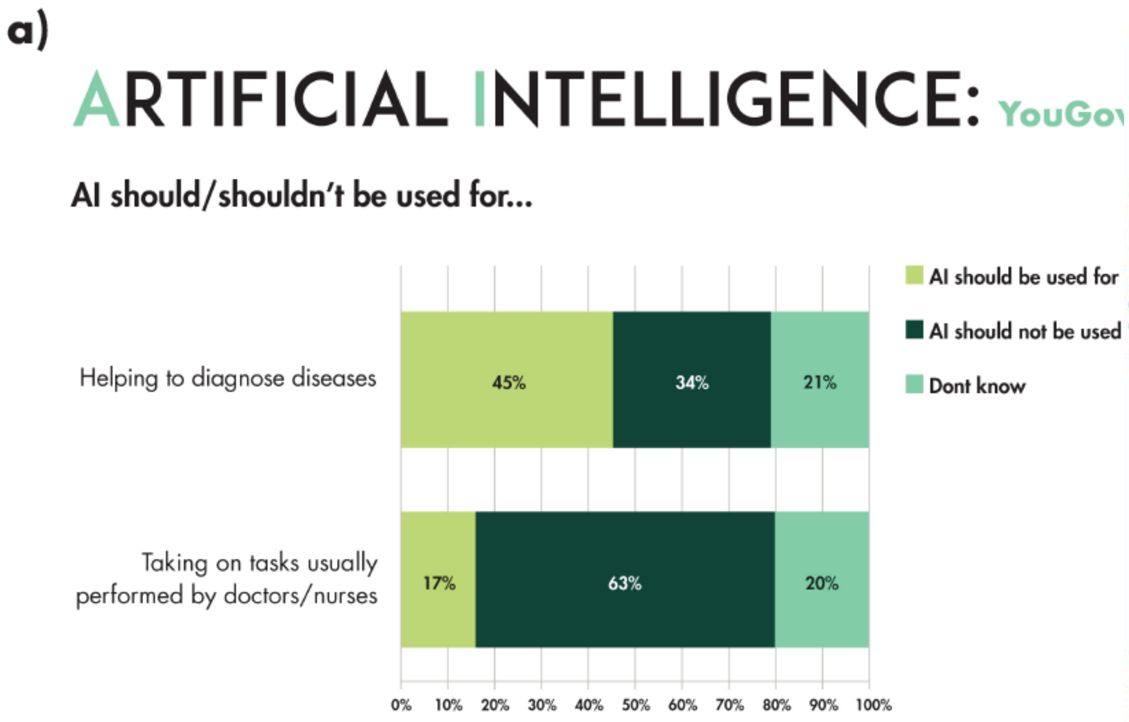
“The United Kingdom saved my life and it gave me hope! It’s my pleasure to say thank you practically by participating in these kind of projects”

Omar, Refugee Action Colchester, Age 23

Young People as equal partners

Katie, Jess, Jessie, Molly, Omar, Izzy and Zak are all young people involved in various community projects locally. Between them they have lived experience and insights into the diversity of issues impacting young people in North Essex. They are committed to ensuring more young diverse views and voices are served by our project and have volunteered to help us as members of the partnership group. So far they have attended three meetings and actively contributed and led discussions and decisions creating our project plan. The University of Essex has offered Community Fellowships to enable these young partners access to appropriate learning, support and use of campus facilities. Zak, aged 16 from Syria was extremely proud to have been awarded the first of these in November. Read more about these amazing young people and other members of the partnership group overleaf.

The future will be about empathy and coding



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Res Involv Engagem. 2017; 3: 12. PMCID: PMC5611650

Published online 2017 Aug 1. doi: 10.1186/s40900-017-0063-1 PMID: 29062537

Tea, talk and technology: patient and public involvement to improve connected health 'wearables' research in dementia

Lamiece Hassan,[1] Caroline Swarbrick,[1] Caroline Sanders,[2] Angela Parker,[3] Matt Machin,[1] Mary P. Tully,[4] and John Ainsworth[1]

This article has been cited by other articles in PMC.

Abstract

Plain English summary

There are a growing number of mobile phones, watches and electronic devices which can be worn on the body to track aspects of health and well-being, such as daily steps, sleep and exercise. Dementia researchers think that these devices could potentially be used as part of future research projects, for example to help spot changes in daily activity that may signal the early symptoms of dementia. We asked a range of older people, including people living with dementia and their carers, to participate in interactive discussions about how future participants might find using these devices as part of research projects. We also invited volunteers to borrow a range of devices to test at home, giving them further insights. Discussions revealed that people were generally supportive of this type of research, provided they gave informed consent and that devices were discreet, comfortable and easy to use. They also valued technical support and regular feedback on study progress to encourage ongoing participation. These findings were used to develop a pool of devices for researchers, with computer software and written guidance to help plan, design and support studies. Our work shows that when given the right opportunities, people who are

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MSD

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MHRA

NCRI National Cancer Research Institute

NHS England

NIGHTSCOUT FOUNDATION

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Partners in shaping research

2017/18 Milestones:

- More than 700,000 people in clinical studies
- Public involved in the design and delivery of 100% NIHR research
- Over 80% of contributors feel their involvement has made a difference to NIHR research
- UK ‘PPI’ Standards launched at the AMRC/ABPI ‘Patients First’ event in March 2018
- Guidance produced on co-production, diversity and inclusion
- Pilot service launched for industry partners to involve patients
- New international PPI network set-up and active programme of Community Engagement and Involvement in NIHR Global Health Initiative

A few references

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- Follow #WhyWeDoResearch on Twitter

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Thank you

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