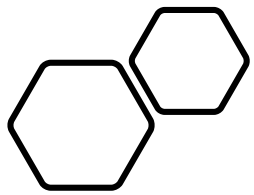


Looking Back, Forging Forwards

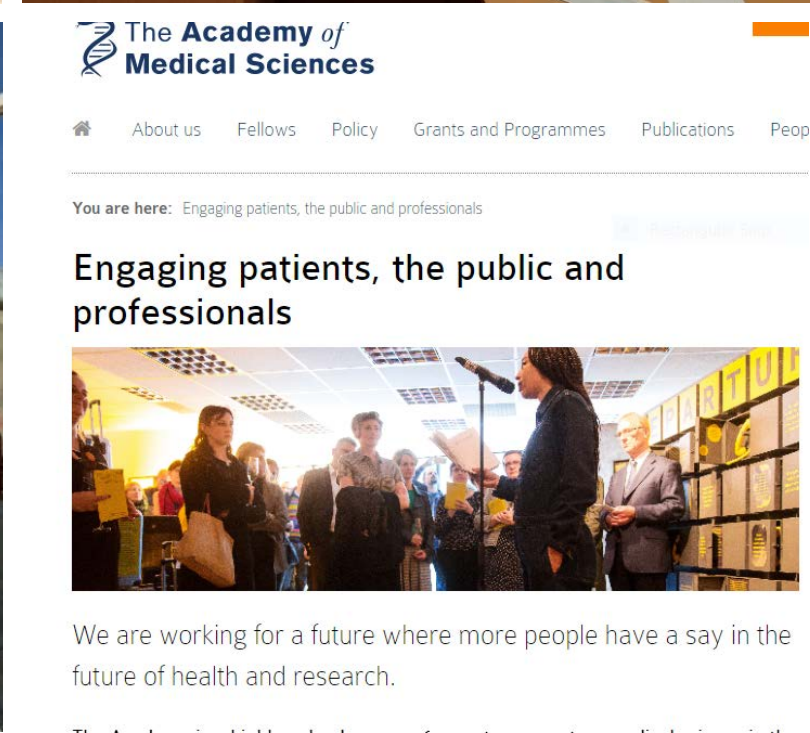
SC Research & Development Division

Thursday 9th March 2023

Simon Denegri OBE



A bit about
me....



Subject

noun noun: subject;
plural noun: subjects
1.

a person or thing that is
being discussed, described,
or dealt with.

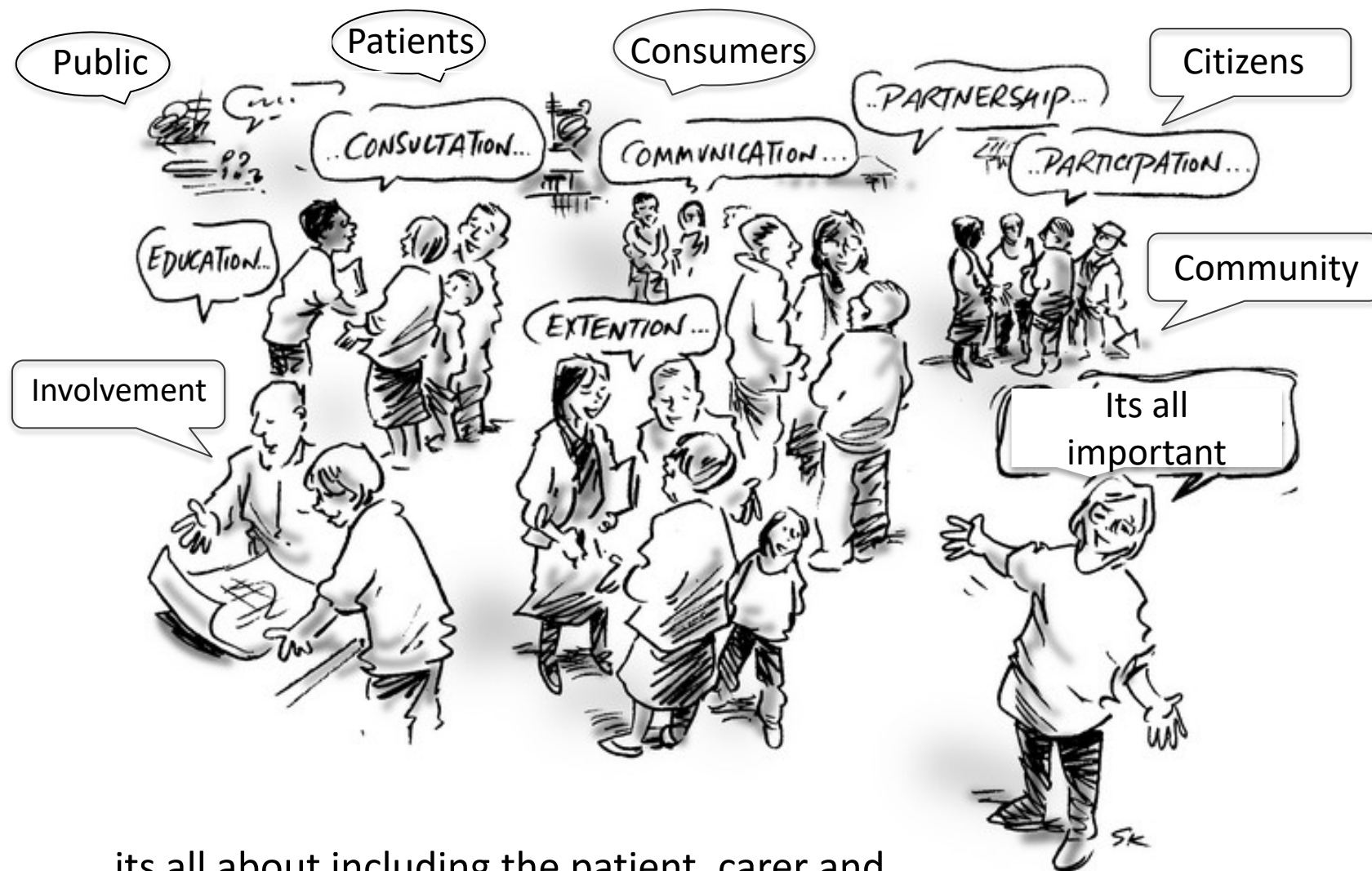


Partner

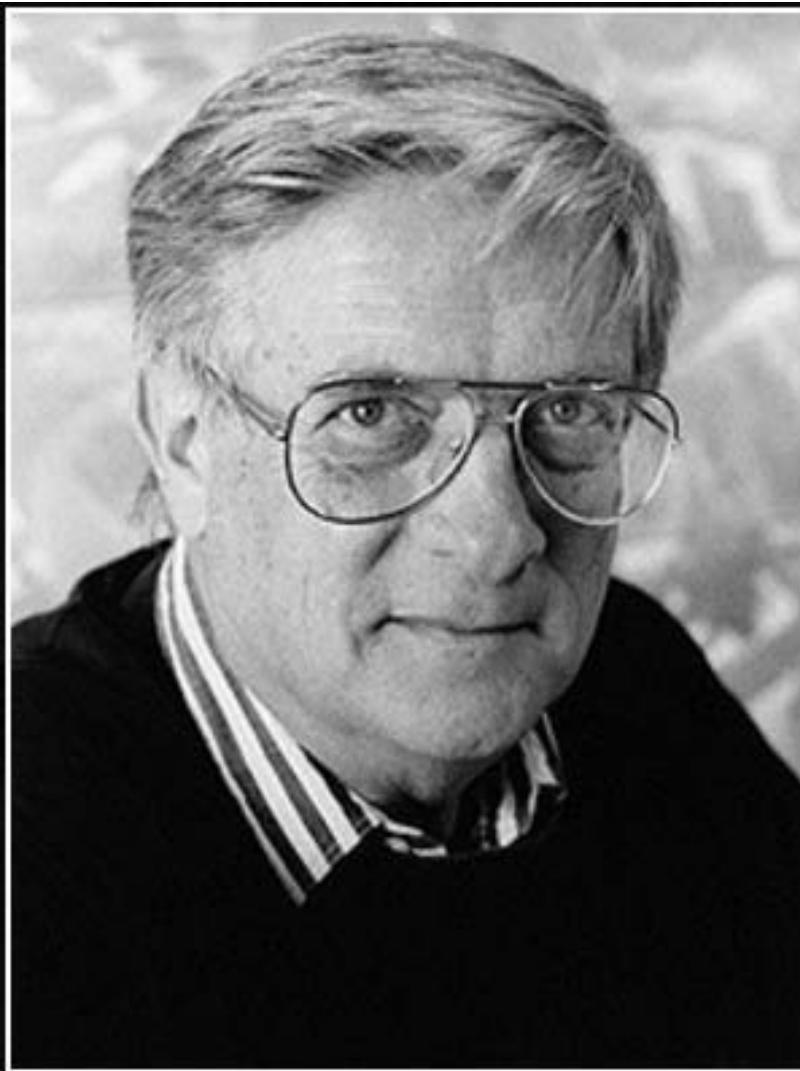
noun: partner

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





.....its all about including the patient, carer and public 'voice' in research



For me context is the key - from that
comes the understanding of
everything.

— *Kenneth Noland* —

AZ QUOTES

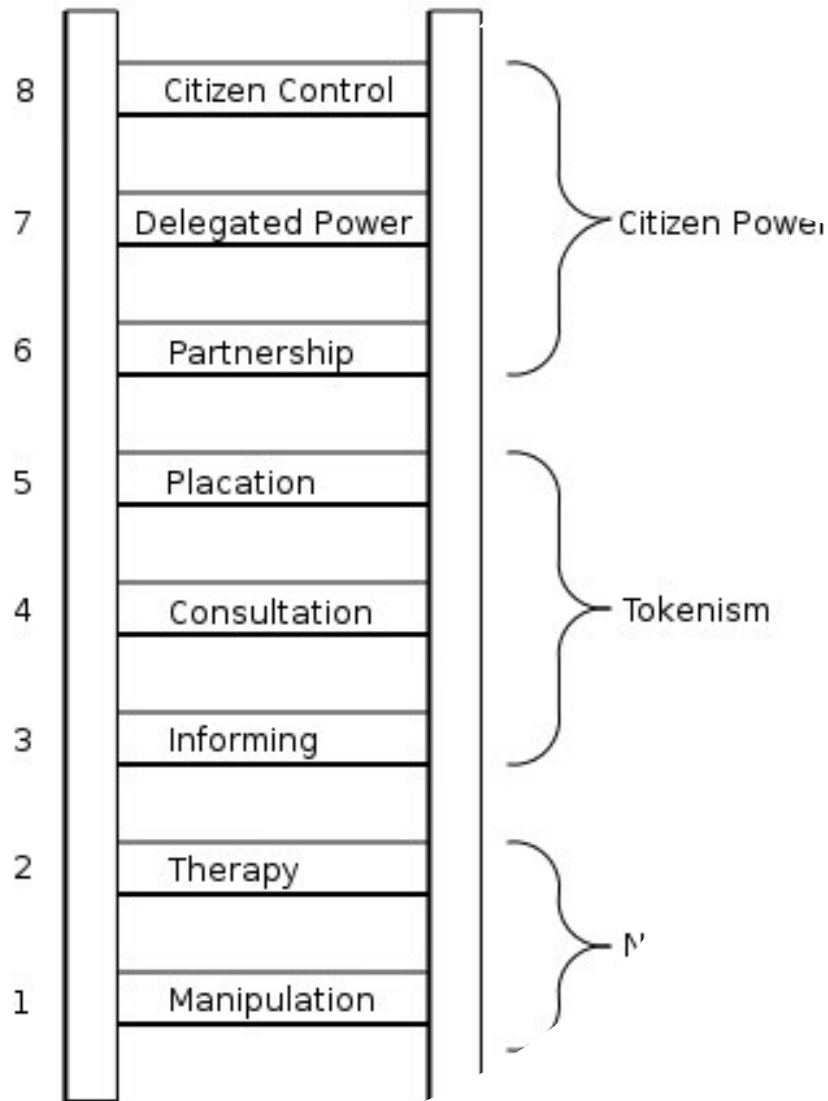
The forever changing relationship between research and the public

• From this...

- Involvement, engagement and participation
- The individual
- Focus on clinical research, clinical trials, clinical studies
- Process
- Centrally controlled and driven
- Partnership
- The committee room
- Patients, carers, the public
- National focus
- An enlightened few

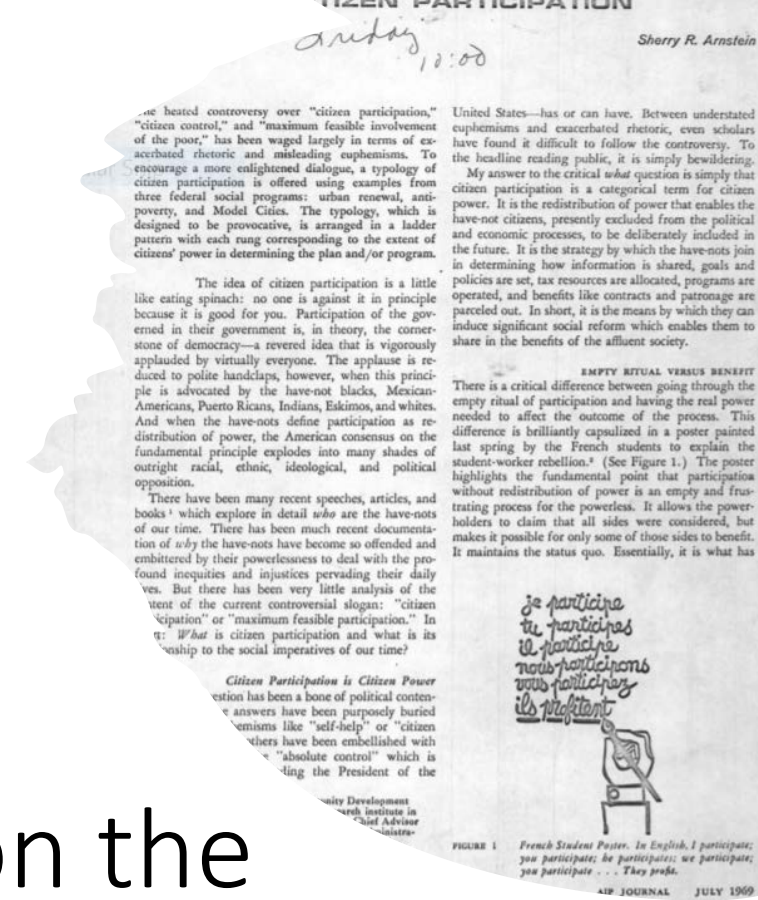
• To this....

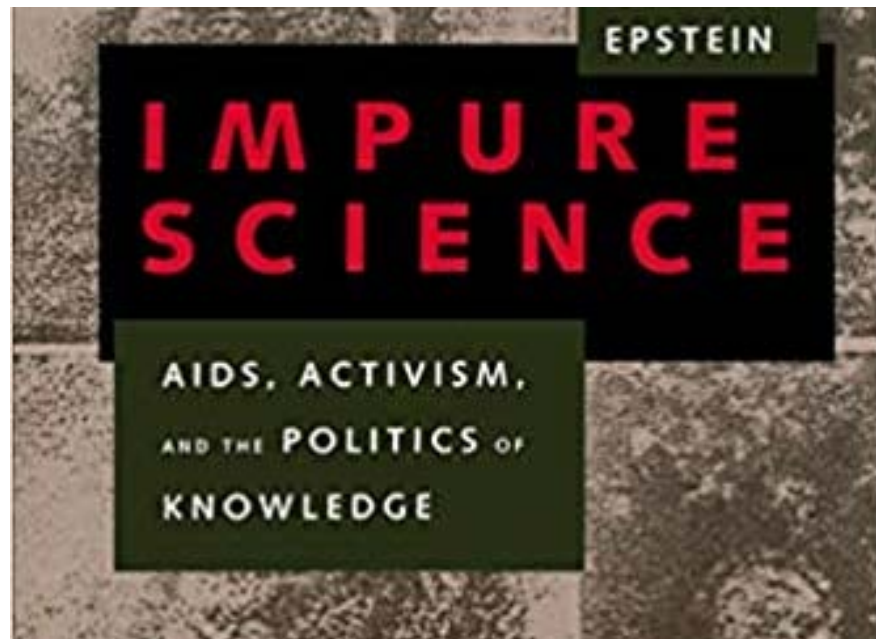
- Co-production, co-creation
- Mobilisation
- The community
- Public health, social care research
- Outcomes
- Citizen driven, grassroots
- Collaboration
- Digital, tech, AI, social media
- Consumers
- Global movement – thinking ‘globally acting locally’
- Charities and industry



1969: First steps on the 'Ladder of Participation'

- Arnstein, S. (1969) A Ladder of Community Participation. Journal of the American Institute of Planners, 35, 216-224.
- <http://lithgow-schmidt.dk/sherry-arnstein/ladder-of-citizen-participation.html>
- <https://doi.org/10.1080/01944366908977225>





Health Activism 1980s



Storming Norming Performing

Exploring Impact:

Public involvement in NHS, public
health and social care research



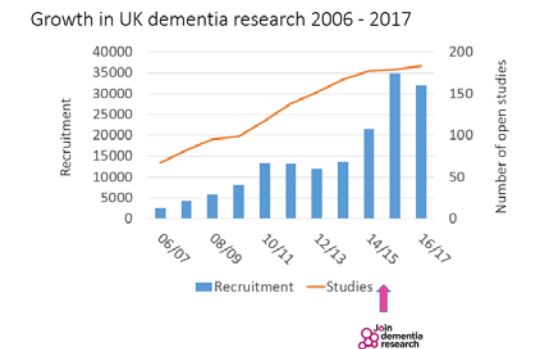
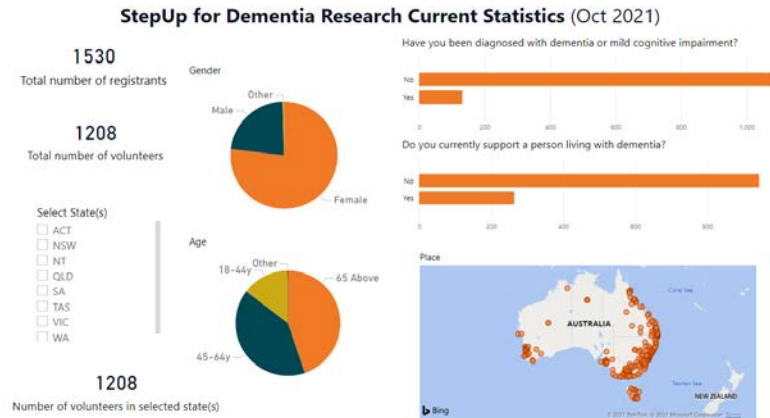
1996 - 2010 INVOLVE Laying the foundations

- INVOLVE defines public involvement as “research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them”. By 'public' INVOLVE means patients and their relatives as well as members of the general public.



Focus on clinical trials

- “...public involvement in research should be the rule not the exception.” Professor Dame Sally Davies, CMO



Involvement across the research cycle



Moss N, Daru J, Lanz D, Thangaratinam S, Khan KS. Involvement of the public in research: Improving the quality of women's health research. BJOG 2016; DOI: 10.1111/1471-0541.14710

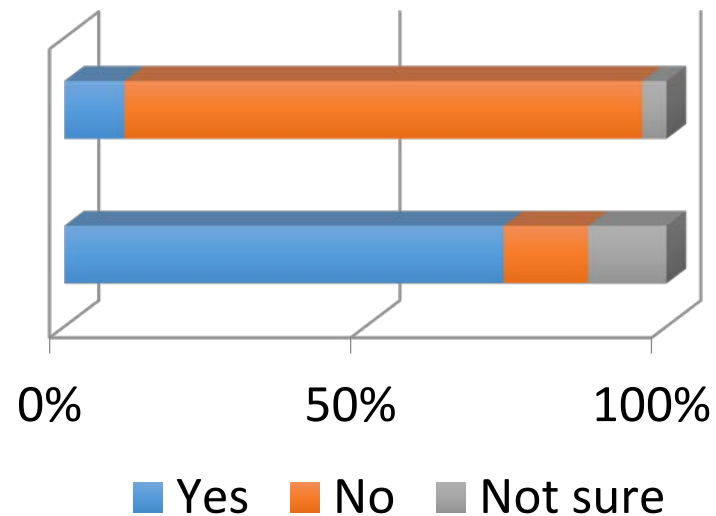
"The unique mobile hearing van will allow us to take our research out to families, and this should mean more of them will be able to participate in this much needed study"

- Professor Kevin Munro, Ewing Professor of Audiology

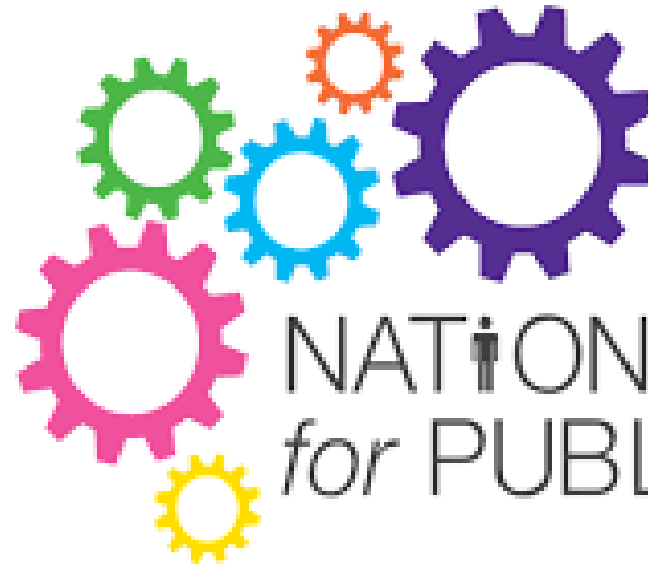
Improving access, increasing opportunities

Before JDR I knew how to find a study to participate in

JDR has made it easier to get into a study



Regulation,
refinement,
evolution



NATIONAL STANDARDS for PUBLIC INVOLVEMENT

Methods and Levels of Influence and Participation



Home > Planning and improving research > Best Practice > Public involvement >

Putting people first - embedding public involvement in health and social care research

Last updated on 6 May 2022

The Health Research Authority, the National Institute for Health Research and a host of organisations across the UK have been working together to bring about changes which will drive up standards in health and social care research. Together we have signed up to a shared commitment to public involvement.



Using new tools and methods



npj | Digital Medicine

www.nature.com/npjdigita

ARTICLE OPEN

How the weather affects the pain of citizen scientists using : smartphone app

William G. Dixon^{1,2,3*}, Anna L. Beukenhorst⁴, Belay B. Yimer¹, Louise Cook¹, Antonio Gasparini^{5,6}, Tal El-Hay⁷, Bruce Hellman⁸, Ben James⁷, Ana M. Vicedo-Cabrera⁹, Malcolm Maclure⁸, Ricardo Silva^{8,10}, John Ainsworth¹¹, Hual Leng Pisaniello^{1,11}, Thomas House^{12,13}, Mark Lunt¹⁴, Carolyn Gamble^{14,15}, Caroline Sanders^{14,15}, David M. Schultz¹⁶, Jamie C. Sergeant^{17,18} and John McBeth^{1,2,18}

Patients with chronic pain commonly believe their pain is related to the weather. Scientific evidence to support their beliefs is inconclusive, in part due to difficulties in getting a large dataset of patients frequently recording their pain symptoms during a variety of weather conditions. Smartphones allow the opportunity to collect data to overcome these difficulties. Our study *Cloud with a Chance of Pain* analysed daily data from 2658 patients collected over a 15-month period. The analysis demonstrated significant yet modest relationships between pain and relative humidity, pressure and wind speed, with correlations remaining even when accounting for mood and physical activity. This research highlights how citizen-science experiments can collect large datasets on real-world populations to address long-standing health questions. These results will act as a starting point for a future system for patients to better manage their health through pain forecasts.

npj Digital Medicine (2019)2:105

; <https://doi.org/10.1038/s41746-019-0180-3>





Check for updates

CO-PRODUCTION OF KNOWLEDGE

Co-production of knowledge: the future

A new collection highlights the role of co-production in strengthening health systems

S Redman,¹ T Greenhalgh,² L Adedokun,³ S Staniszewska,⁴ S Denegri,⁵ on behalf of the Co-production of Knowledge Collection Steering Committee

Co-production is a collaborative model of research that includes stakeholders such as patients, the public, donors, clinicians, service providers, and policy makers. It is a sharing of power, with stakeholders and researchers working together to develop the agenda, design and implement the research, and interpret, disseminate, and implement the findings.

Co-production has been embraced because of its potential to improve the quality and relevance of research and its effect on policy and practice.¹⁻³ This is nicely captured in the Thai concept of the "triangle that moves the mountain," whereby researchers, citizens, and policy makers work together to achieve change.⁴

However, co-production is not straightforward; it requires additional resources and takes much longer than traditional research.⁵ It can be associated with additional conflict, although surfacing and working through stakeholder conflicts may be highly productive in the longer term.⁶ Despite the burgeoning literature, few studies have evaluated

develop shared expectations.¹⁷ Critically, trust is built by working together over time—sharing views and tackling challenges as a team.

Trust is particularly important in working with less powerful stakeholders.^{4,7,11-14} In low and middle income countries funders and donors may need to reorient their views to place more trust in local knowledge^{15,16}; new kinds of funding from USAID and other donors have supported initiatives to build trust and facilitate co-production.¹⁵ In Australia, research involving Aboriginal people has often been perceived as exploitative. Despite this history, long term partnerships, leadership by Aboriginal communities, commitment to capacity building, and upfront agreement about who determines priorities and owns the information can enable trust and effective co-production.¹⁷

Thirdly, there is now substantial interest in the practical requirements for co-production, including skills, systems, and incentives. For example, it has proved possible to build skills and systems to increase the use of research by policy agencies¹⁸ and to

BMJ: first published as 10.1136/bmj.m34 on 16 February 2021. Downloaded from http://

Co-producing change together

Co-Product Collective

@UCL_CoPro Follows you

We are a co-production community where everyone is welcome! Together we learn, connect and champion co-production for lasting change.

London, UK coproductioncollective.co.uk/sign-up Joined July 2019



The rise of co-production



Structures Organisation Culture

Across whole research systems

Central hub providing support and guidance to a network of locally based public involvement as part of a single initiative.

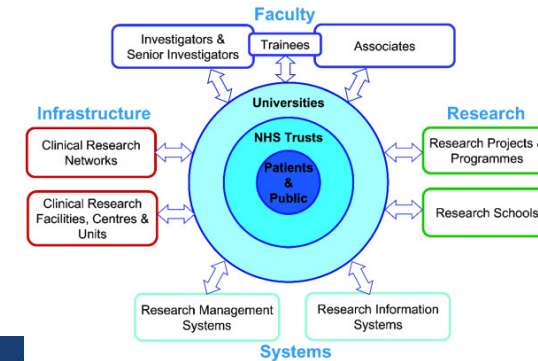
- Develops values, ethos, culture with community
- Provides intellectual support and guidance
- Constantly balancing government agenda and community priorities
- Significant resource constraints

INVOLVE



NIHR | INVOLVE

The National Institute for Health Research



Strategy for Patient-Oriented Research



Institutionally based

- Dedicated public involvement budget and team included within core funding
- Often part of larger communications and stakeholder engagement
- 'Advisory group' of patient and public voices or equivalent part of formal governance
- Patient voices also part of the Board
- Cross-cutting research and care themes probably supported by community panels i.e. dementia
- Strong on researcher learning and development
- Collaboration with health care partners
- Outreach and engagement

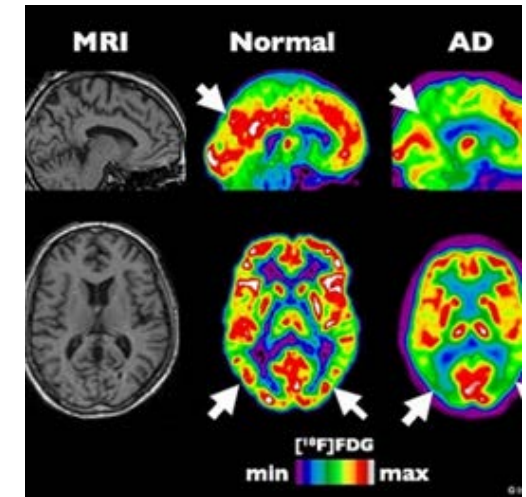
An example: NIHR UCLH Biomedical Research Centre (BRC), Neuro-SysMed in Bergen

uclh

Celebrating research
annual open event



Tuesday 4 July, 2.30-5.30pm



Neuro-SysMed

Project focused

The typical osteoarthritis patient



Osteophyte
formation

Joint Space
Narrowing

Subchondral
Sclerosis

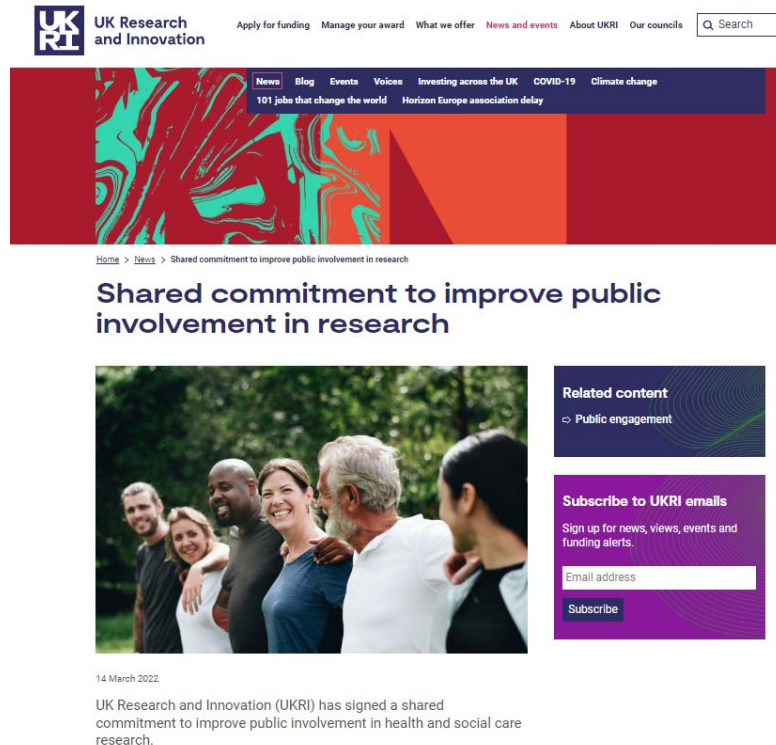


Patient engagement in APPROACH

• 2 organisations are consortium partners (Arthritis Research UK
and Dutch Arthritis Foundation)



Networks and alliances



UK Research and Innovation

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News Blog Events Voices Investing across the UK COVID-19 Climate change

101 jobs that change the world Horizon Europe association delay

Home > News > Shared commitment to improve public involvement in research

Shared commitment to improve public involvement in research

14 March 2022

UK Research and Innovation (UKRI) has signed a shared commitment to improve public involvement in health and social care research.

Related content

Public engagement


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A growing global movement

Growing global movement

NIHR | INVOLVE



Strategy for Patient-Oriented Research



Neuro-SysMed

The European Picture

- *‘The studies imply a growing interest and support for the idea of PPI in health services and, to a lesser extent, in health research. There seems to be a convergence of conceptualisations of PPI across Europe, with internationally significant areas of innovative work taking place in countries such as the Netherlands and the Scandinavian countries. However, the implementation of PPI is highly uneven, and PPI is not yet firmly embedded or adequately formalised in European healthcare systems and research, possibly due to a lack of infrastructure, guidance and support.’*



Figure 2

[Open in figure viewer](#)

[PowerPoint](#)

Map showing the geographical spread of included studies across Europe [Colour figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com)]

REVIEW ARTICLE | [Open Access](#) | [CC](#) | [i](#)

Attitudes and approaches to patient and public involvement across Europe: A systematic review

Michele S. Y. Biddle BPharm(Hons), MScPH [✉](#), Andy Gibson BAHons, MA, PhD, David Evans BA, MA, DPhil

First published: 23 July 2020 | <https://doi.org/10.1111/hsc.13111> | Citations: 19

> BMJ Open. 2022 May 24;12(5):e063356. doi: 10.1136/bmjopen-2022-063356.

Rectangular Sign

How common is patient and public involvement (PPI)? Cross-sectional analysis of frequency of PPI reporting in health research papers and associations with methods, funding sources and other factors

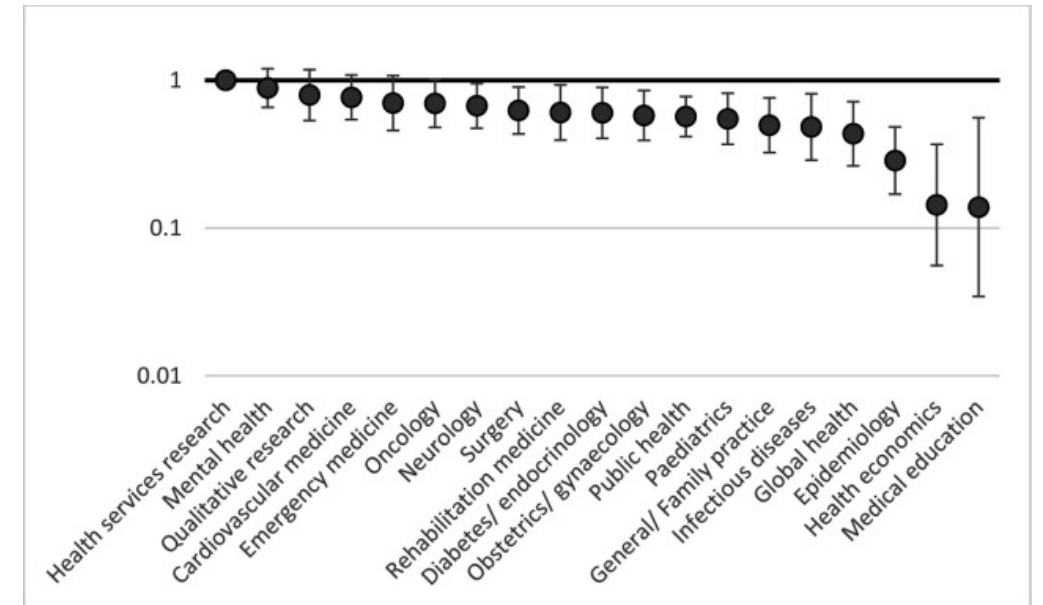
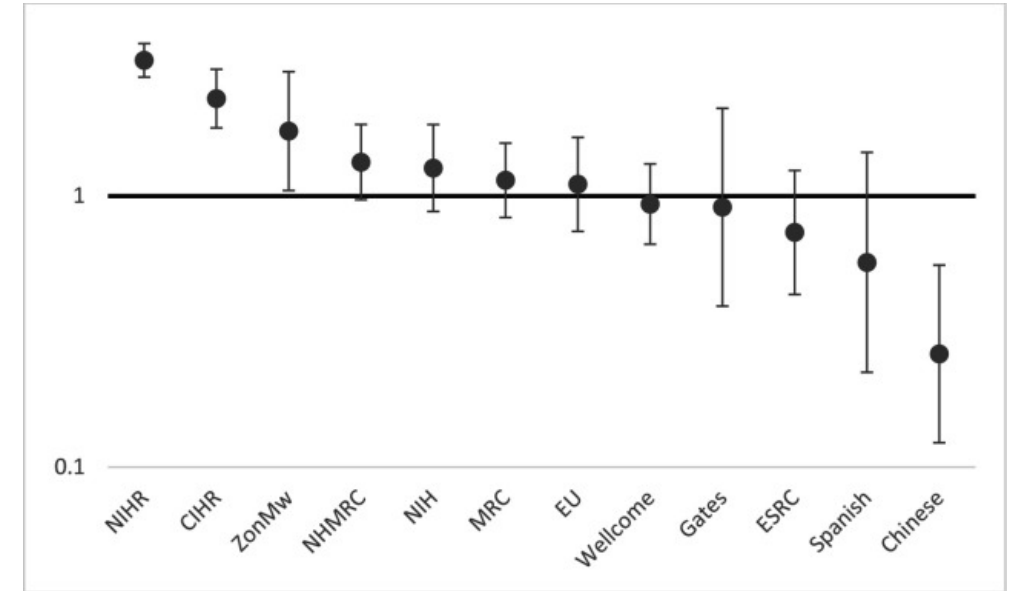
Iain Lang¹, Angela King², Georgia Jenkins², Kate Boddy², Zohrah Khan², Kristin Liabo²

Affiliations + expand

PMID: 35613748 PMCID: PMC9131100 DOI: 10.1136/bmjopen-2022-063356

[Free PMC article](#)

Conclusions 618 (20.6%) of the papers in our sample included PPI. The proportion of papers including PPI varied in relation to location (from 44.5% (95% CI 40.8% to 48.5%) in papers from the UK to 3.4% (95% CI 1.5% to 5.3%) in papers from China)



The shadow of COVID-19

Coronavirus

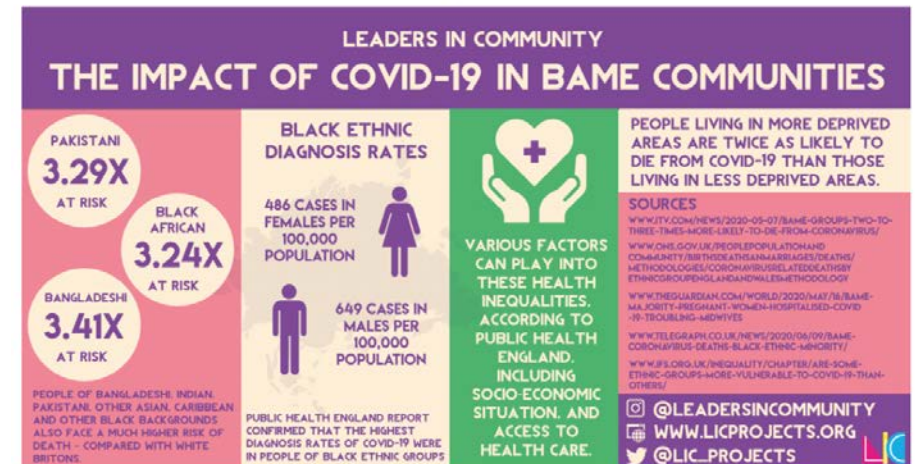
“COVID-19 threatened to be a time of crisis for patient engagement and the valuable lessons learned should not be wasted.”

Simon Denegri and Bella Starling

<https://doi.org/10.1503/cmaj.210998>



COVID-19 and Health Inequalities





Academy Fellow Stephen Holgate and patient representative Lynn Laidlaw interviewed together about our COVID-19 winter policy work on BBC News in July 2021

"I very much enjoyed being part of the project and feeling part of something bigger. The Academy is fantastic at supporting and facilitating inclusive discussions."







Forging forwards....

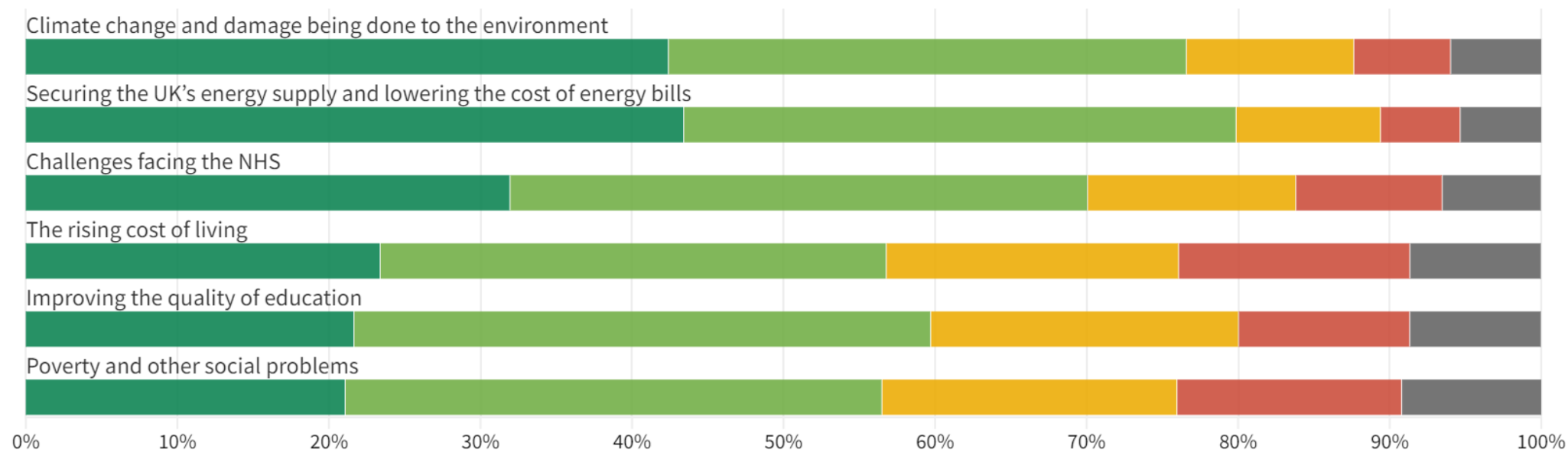


1 of 6

Does R&D have a role to play in solving the UK's problems?

In our February 2023 polling, more than 40% think new research is essential to securing the UK's energy supply and addressing climate change

■ New research is essential to solve this problem ■ New research is an important part of solving this problem
■ New research is slightly important for solving this problem ■ New research will not help solve this problem ■ Don't Know



Source: Public First polling for CaSE • February 2023

How important, if at all, do you think new research is for solving the following problems in the UK? n=4,005

Opportunities for engagement with R&D

Self-reported activities in the past six months

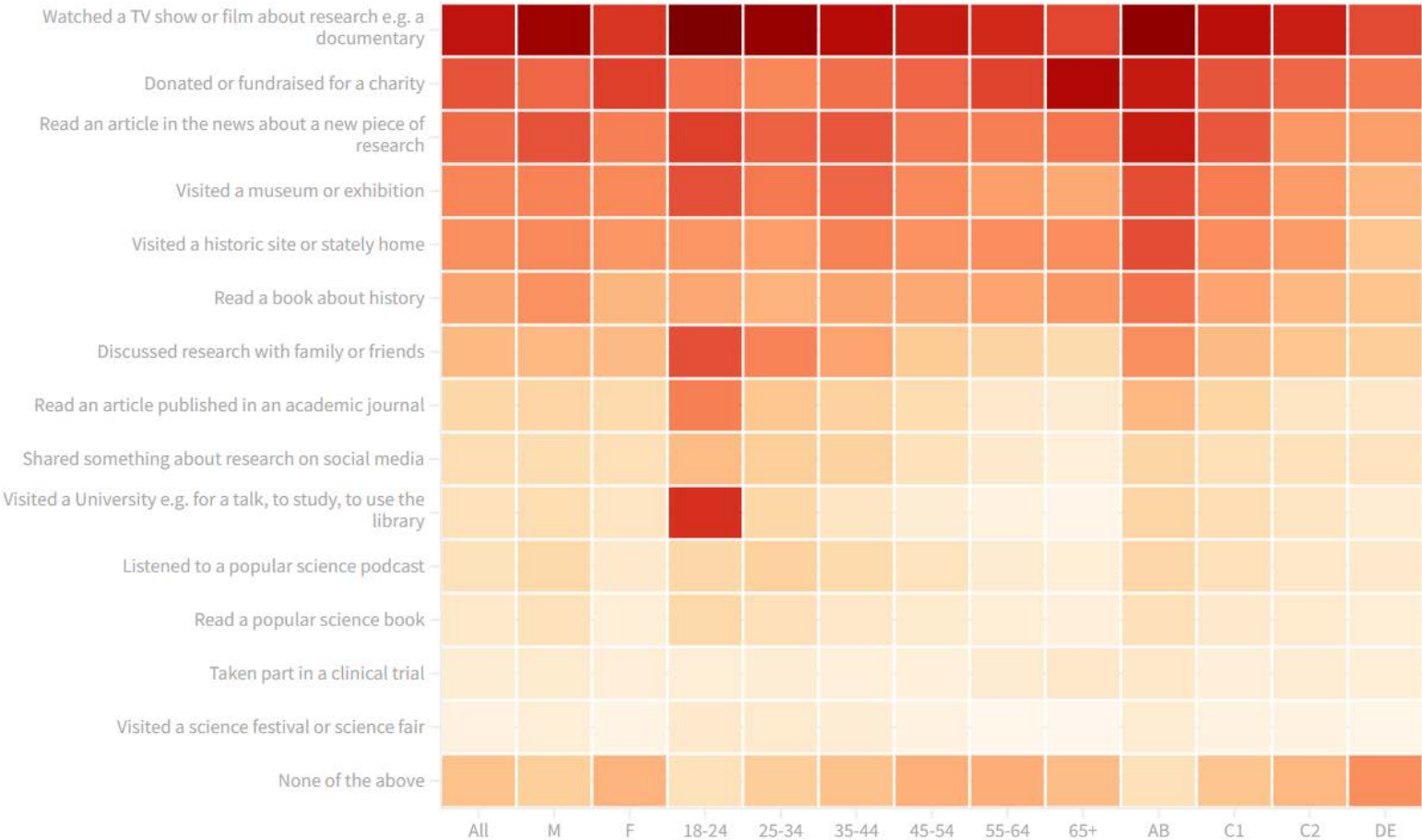
All

Gender

Age

Socioeconomic group

% with activity ticked 0% 55%



Source: Public First polling for CaSE • July 2022
Which of the following, if any, have you done in the last six months? Select all that apply. n=8,474

Key challenges in public involvement



Making it happen
across all forms of
health research



Embracing equity,
diversity and inclusion



Developing standards,
processes and
incentives



Digital
engagement and
adapting to new tools



Capacity
building including
training and learning



Impact

What would success look like?

Citizen voice at the heart of Government policy-making

Health outcomes that reflect people's needs and priorities

Communities and researchers working in partnership to improve lives

Alliances and networks openly learning and innovating


A movement where we support one another



**Health Research
Authority**

- Principle 1: Involve the right people
 - Principle 2: Involve enough people
 - Principle 3: Involve those people enough
 - Principle 4: Describe how it helps
-
- <https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/>

Keep it simple



Remember, we are
here to challenge....

Thank you



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simondenegri@gmail.com
@SDenegri