



Mapping Patient, Public and Practitioner Involvement and Engagement

16 June 2021



Mapping PPPIE activities across Alliance members...

Health Data Research UK, we are committed to working with patients and the public to shape our work and influence our decisions.

The UK Health Data Research Alliance is continuing to grow. Whilst we have different workstreams in which we want to embed the patient and public voice, we can't do it alone.

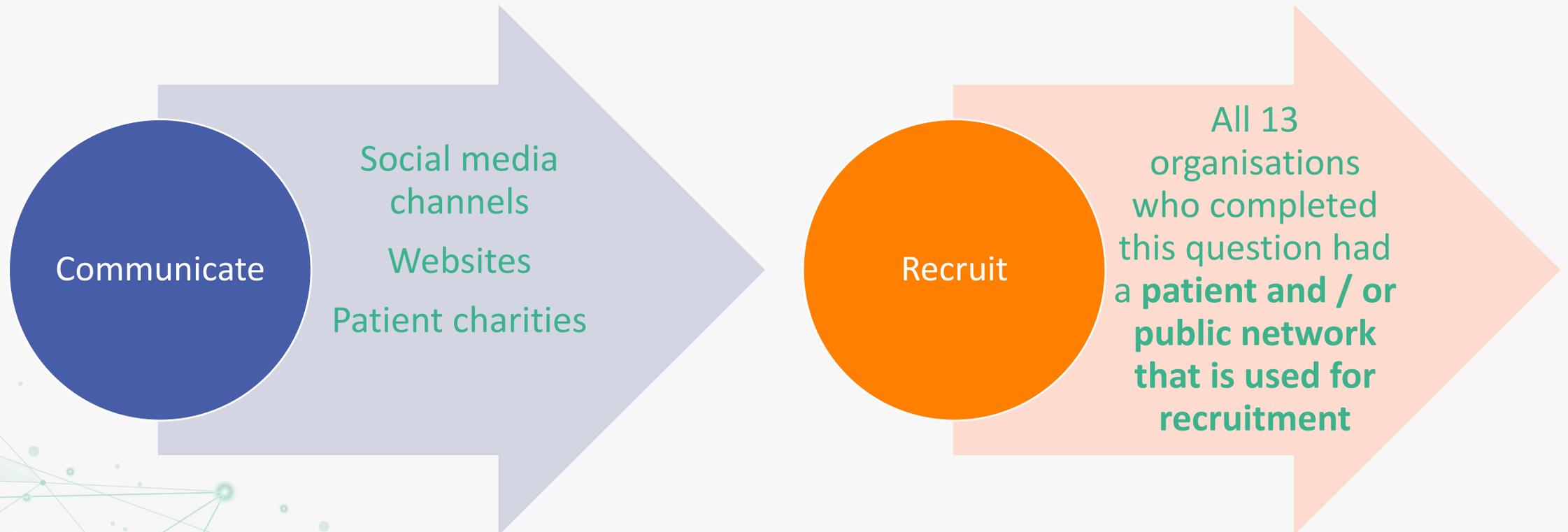
Thank you to everyone who completed the survey! This was the first time we've tried to identify and map out patient, public and practitioner involvement and engagement activities across Alliance members. Not only will it enable sharing of best practice but can be used to help us collaborate further.

For reference: We use the NIHR INVOLVE definitions of engagement and involvement.

- Involvement is where members of the public are actively involved in research projects and in research organisations.
- Engagement is where information and knowledge about research is provided and disseminated.
- By 'practitioners' we refer to those who directly collect health data from others e.g., clinicians and nurses.

Communicating opportunities...

The need and strong desire to work with a wide range of people was clear with **11 of 13 organisations** actively working to involve or engage seldom-heard and/or vulnerable communities in their work on health data



Ways in which patients and the public have been involved

Co-designing scientific protocols

Co-designing public facing information effectively and meaningfully

Setting strategy

Oversight and / or Steering Groups and Committees

Funding Committees

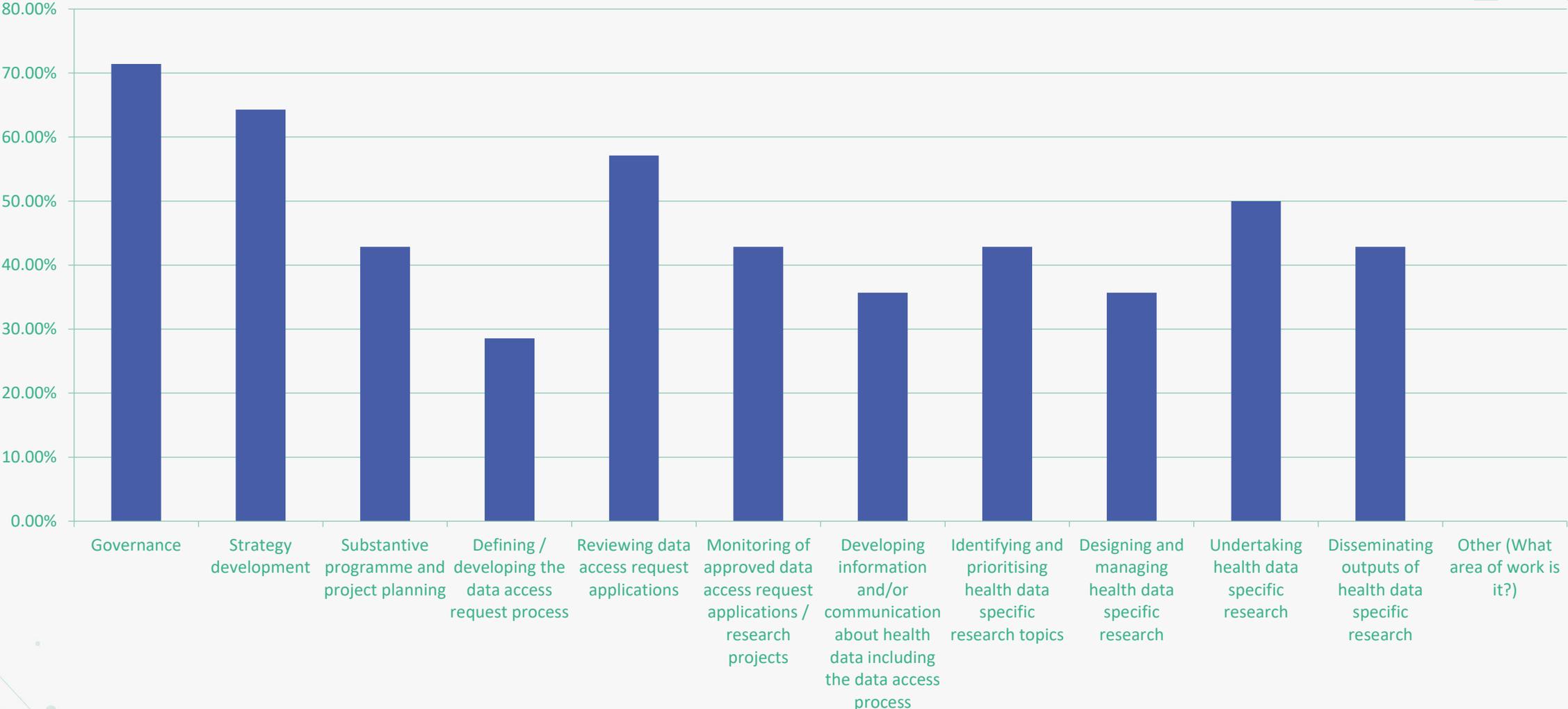
Data Access Committee

Activities to understand attitudes, motivators and barriers, including what gives patients confidence in the use of their data for research

Research champions - decision making, advocacy and dissemination of information around health data relevant to these projects

Science festivals

In relation to your work in health data, do you have patient and public involvement and engagement in...



No standard format for measuring impact, ranging from measuring against UK Standards to using PIIAF framework to feedback from stakeholders on how PPI has shaped project design.

What's worked well...

Large group of public contributors, and a good record on equality, diversity and inclusion

Clear examples of where patient and public involvement has shaped direction of travel for projects

Fully embedded in all aspects of data science research and involve the public (and patients where relevant) at all stages for authentic involvement.

Helpful general discussions on what matters most to patients in terms of their being used for research



Achieved trust in our efforts

What's been most challenging...

-  Determining how to scale up plans
-  Overcoming barriers e.g., around prior knowledge
-  It's a confusing landscape
-  Concern that involvement can become tokenistic due to the complexity of governance or technical issues
-  Building public trust and sustaining engagement
-  Reaching **all** of the voices
-  Not specific to health data but 'getting researchers involved' and 'getting the balance between being involved and becoming 'too knowledgeable''

What members would like to see from HDR UK...

Improve baseline knowledge and understanding amongst the public

Leverage influence on researchers and stakeholders to embed PPIE

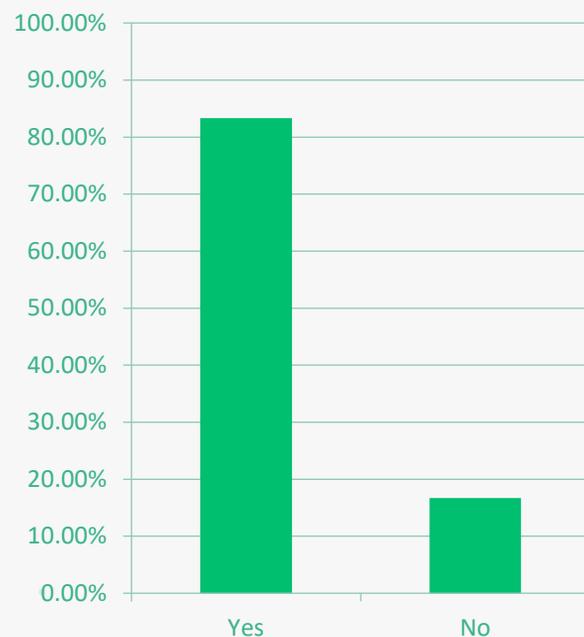
Share learnings, guidance and examples

Promoting opportunities to a wider audience

Address complex issues e.g., commercial gain from use of data

Practitioner Involvement and Engagement...

Do you involve or engage with Practitioners in your work in health data?



10 of the 12 organisations that responded involved and/or engaged practitioners in their work

Examples include:

- Focus groups and interviews in Primary Care and wider health care settings to grow understanding of their perceptions.
- Research nurses and practitioners lead a significant amount of work around patient experience and patient involvement at a grass-roots level.
- Registry data is entered by practitioners at NHS sites and as a Registry have run annual meetings with practitioners and workshops to gain feedback on software development and on the annual reports.
- Clinicians advising on project development e.g., work closely with clinicians to validate the data points in our models prior to the release of any extracts for use in research projects.
- Dissemination of information.

Practitioner involvement and engagement – looking to the future

10 of 11 organisations said they would like to develop this area of work



Formalise networks



Supporting skills development for nurses and NHS managers in involvement, engagement and key topics around health data



Raising awareness of role of practitioners in health data science



Share learning, guidance and examples



Continue to have this conversation (and offer) as organisation develop their work in health data



UK Health Data
Research Alliance