

# IAMHEALTH: Grounded or Isolated? The practice and experience of researchers, patients and carers in collaborative research

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IAMHealth



Improving Autism  
Mental Health

FUNDED BY

**NIHR**

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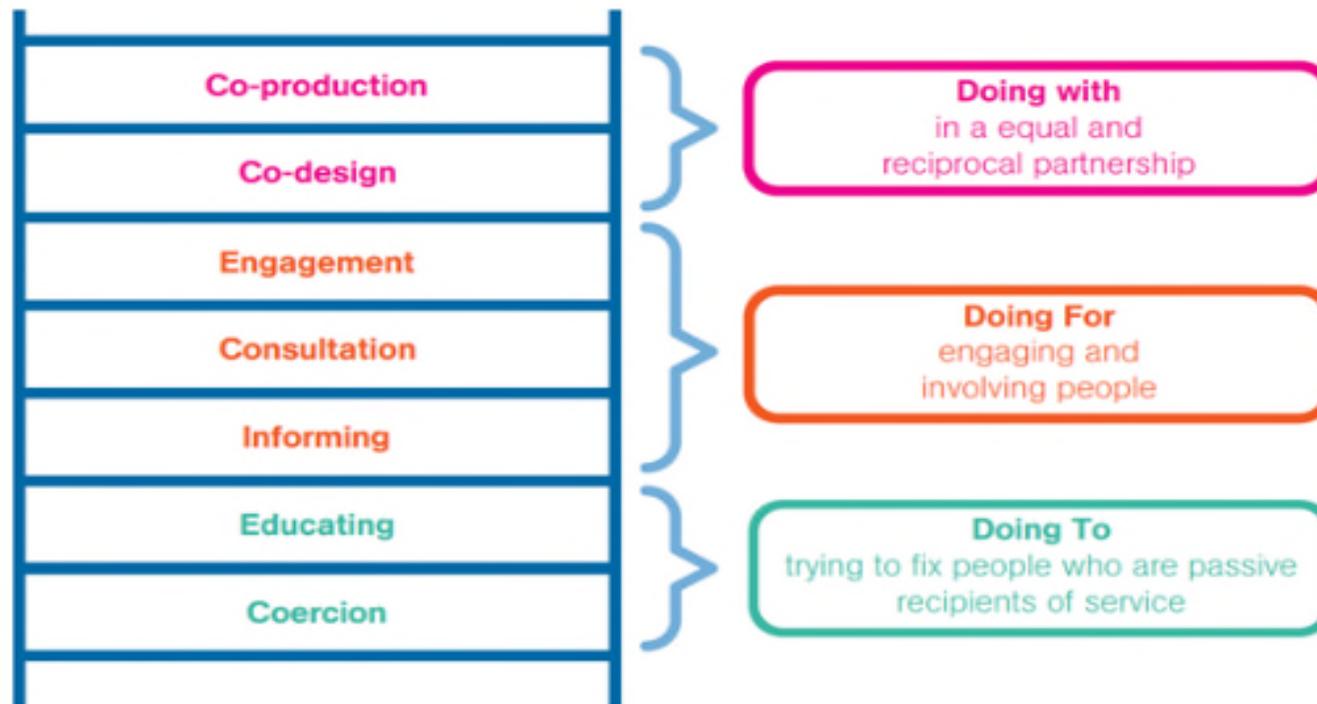
**KING'S**  
*College*  
**LONDON**



# Community priorities in Autism Research

- Autism research has not always represented the opinions of people with autism and their families/carers.
- There is a growing recognition of the value of designing and conducting research using a collaborative partnership.

# What is Patient and Public Involvement?

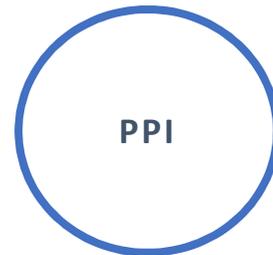


*A Ladder of Citizen Participation.* – S R Arnstein. (1969) Journal of the American Institute of Planners, 35(4); 216-224. <http://lithgow-schmidt.dk/sherry-arnstein/ladder-of-citizen-participation.html>

# IAMHealth



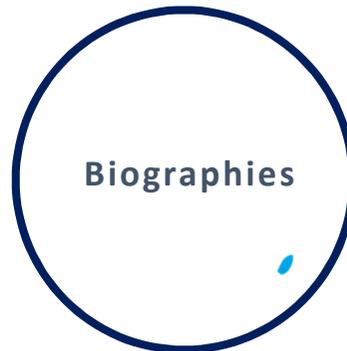
Improving Autism  
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PPI



Development  
of an  
Assessment  
of  
Concerning  
Behaviour  
(ACB)



Biographies



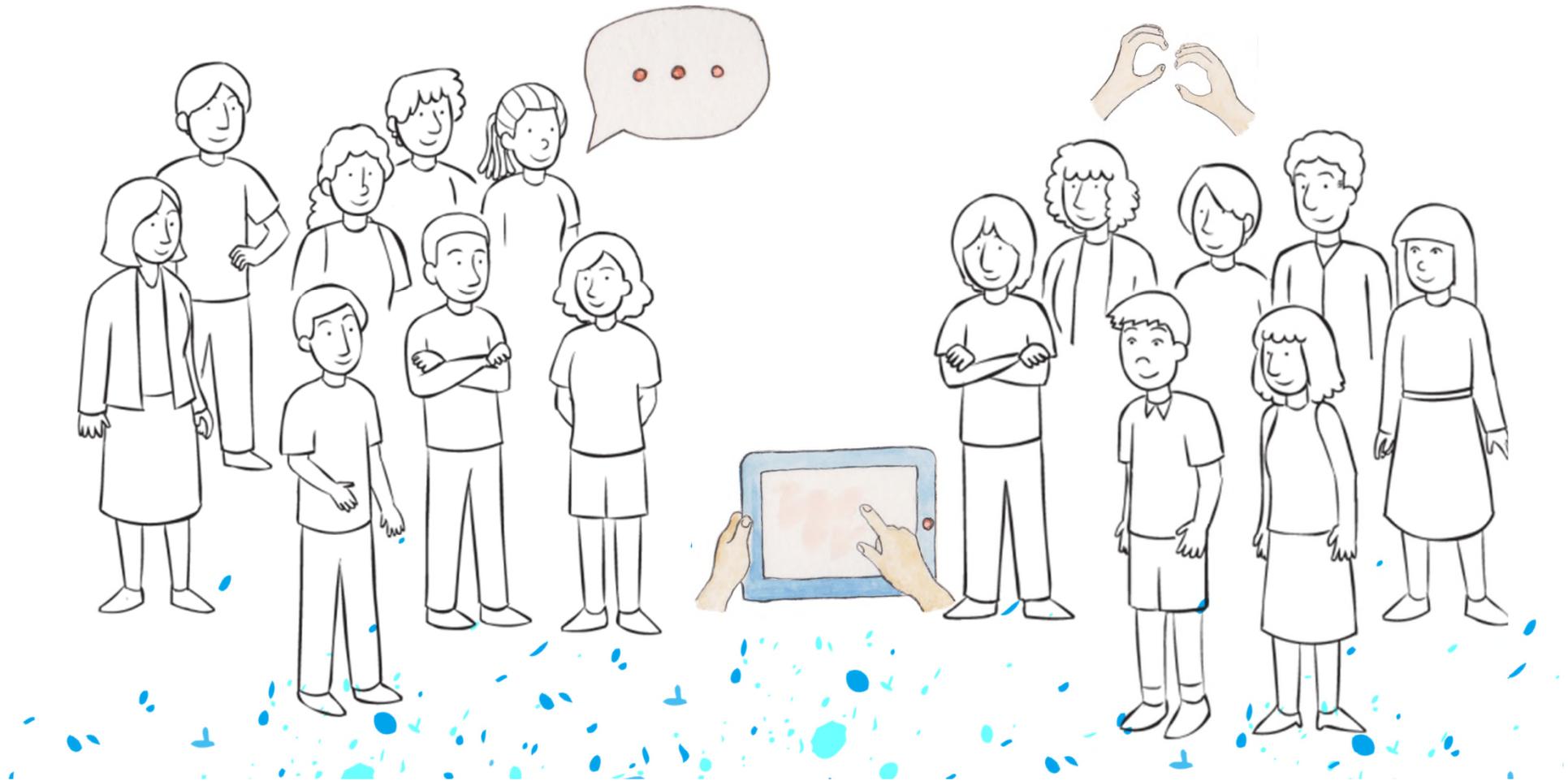
Predictors



Treatment



# Recruiting the Patient and Public Involvement groups



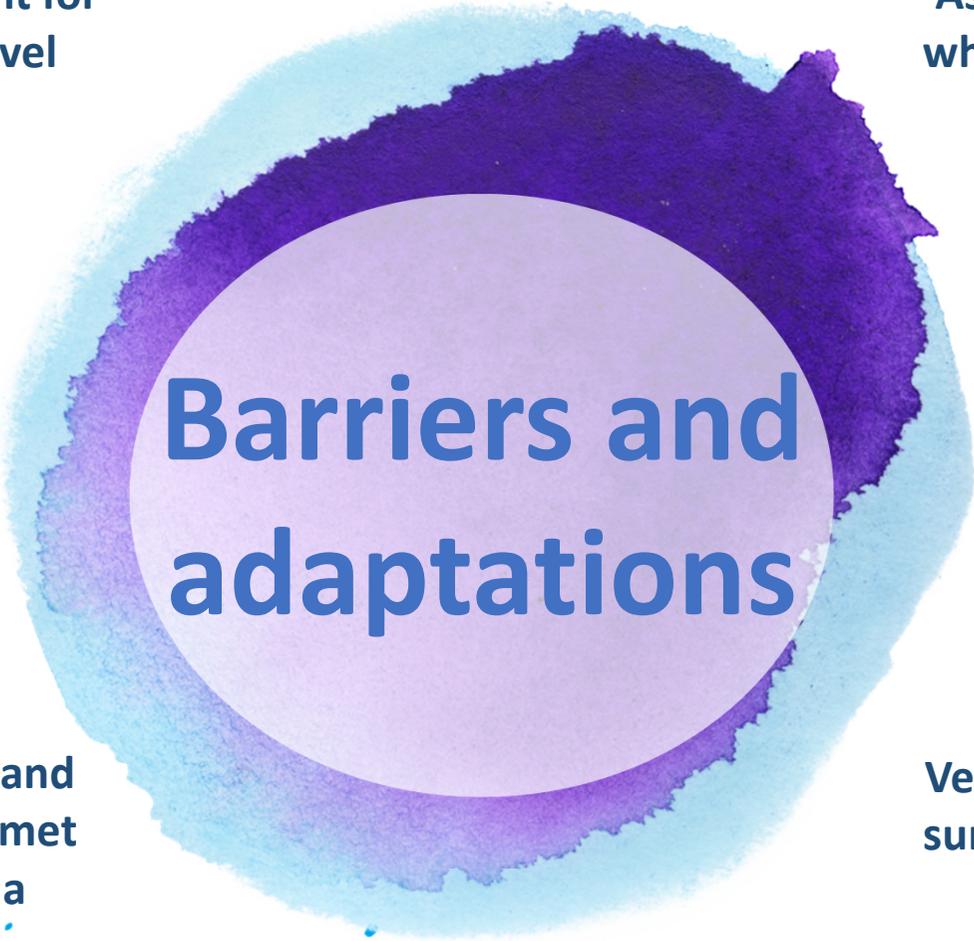
# Diversity in PPI groups



**Reimbursement for  
time and travel**

**Assumptions about  
which costs could be  
met**

**Adapted  
communication**



# **Barriers and adaptations**

**Distance  
involvement options  
(email, skype,  
conference call)**

**PPI autistic adults and  
PPI parents group met  
separately with a  
shared lunch**

**Verbatim notes with  
summaries for panel  
members**

# The Impact of PPI in IAMHealth

[BMJ Open](#). 2016 Mar 22;6(3):e010693. doi: 10.1136/bmjopen-2015-010693.

## Protocol for the development and validation of a questionnaire to assess concerning behaviours and mental health in individuals with autism spectrum disorders: the Assessment of Concerning Behaviour (ACB) scale.

[Santosh P](#)<sup>1</sup>, [Tarver J](#)<sup>2</sup>, [Gibbons F](#)<sup>2</sup>, [Vitoratou S](#)<sup>3</sup>, [Simonoff E](#)<sup>2</sup>.

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Advice ranged from use of language to thinking about a child, adult and parental perspective on the actual aims of the work. With respect to the intervention this helped form ways the team thought about the content of the group as well as what was important to capture in the research protocol.

“Practically, they helped with the design of the... study interview schedule and with the tools we used... They provided feedback around our data analysis which helped us with deciding on areas of importance...”

It was extremely satisfying knowing that the research grant was solely focused on what the ASD population wanted and felt was missing in their current clinical treatment...I found that when recruiting participants it was easier as this was a research project that felt relevant for families to take part in.



## Examples of Involvement

### **Patient context**

- PPI in research (INVOLVE)
- Expert by Experience
- Patient advisor board
- Patients as part of the **workforce**
- Peer support work

### **Education context**

- Parent – teacher associations
- School governors
- Student councils
- Buddy systems
- Disabled students networks
- Pastoral care systems

Please get in to groups to consider how  
you could introduce or improve your  
strategies for including people with  
autism in any role  
i.e. autistic patients, students and/or  
colleagues.

- a) People who currently include autistic people in their workplace (in health or education or other settings) and feel this needs improvement
  
- b) People who do not yet formally include autistic people in their work setting but would like to do so
  
- c) Autistic people and parents of autistic people who are contributing in a PPI or similar role or who would like to contribute in the future



**Thank you!**

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Emily Simonoff**

