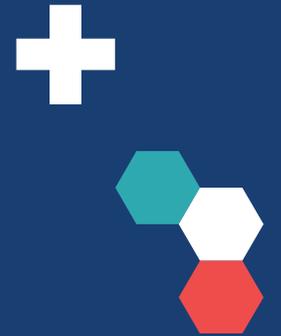
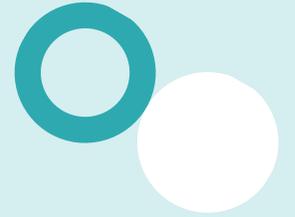


# Working effectively with public contributors



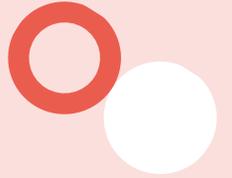


Chair – Carmel McGrath

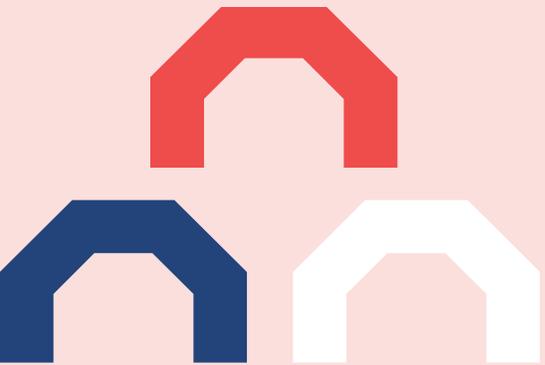
Public contributors – Sarah and Louise

Young people's advisory group members – Ella and Alex





# Patient and public involvement: Why, who, how and what?



# Strategic context

“We are guided by the strategy set out in our [Going the Extra Mile report](#) (NIHR 2015), with its vision of a population ‘actively involved in research to improve health and wellbeing for themselves, their families and their communities’.

We know that we have much further to go if we are to ensure that the involvement of diverse patients, service users, carers and communities in research is inclusive, consistently makes a difference and avoids tokenism.”

Best Research for Best Health: The Next Chapter, June 2021



Partnering with patients, service users, carers and communities

improving the relevance, quality and impact of our research

## Going the extra mile:

Improving the nation's health and wellbeing through public involvement in research

In 2014 an independent panel conducted a review of public involvement in the National Institute for Health Research (NIHR). This review was called **Breaking Boundaries**. Hundreds of public contributors, researchers and health professionals took part. Approximately 80 UK and international organisations gave evidence.

Following its inquiry, the review panel submitted a report to the Director General Research and Development / Chief Medical Officer (CMO), Professor Dame Sally Davies. This was published as **Going the Extra Mile** on 27 March 2015.

# Why should researchers use public contributors and what do the contributors get out of it?

For researchers, PPI can provide...

- A perspective outside the research agenda
- A focus on the value, scope, ethics and impact of research on **service** users. Ideas for new and valuable research
- A challenge!

For contributors, involvement can provide...

- An opportunity to have a voice and make a difference
- An opportunity to build confidence, earn money and feel valued

# Who will you ask?

**Patients, carers, communities**

Those whose voices aren't often heard.

Can you reach out to those with disability, learning or language difficulties?

Can you find a platform that they can use to contribute?

# How and when will you engage?

Later in this session we will cover the opportunities for public involvement throughout the research cycle

You can engage at many stages and in different ways – lots of support and guidance available

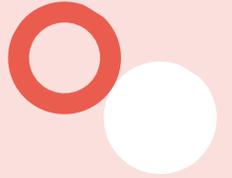
# Opportunities for involvement

- Steering group membership
- Early reviews of proposed projects
- Help with the plain English summary
- Group workshops
- Sense checking user documents
- Knowledge dissemination

# What does good look like?

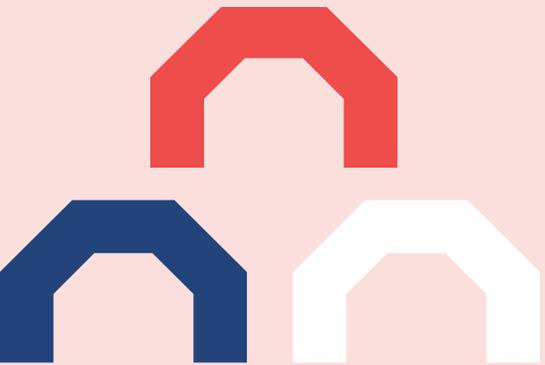
## Recipe for PPI success

- Clarity about joint objectives
- Clarity about progress, next steps and timelines
- Openness to suggestions and honest discussions
- Timely information and feedback



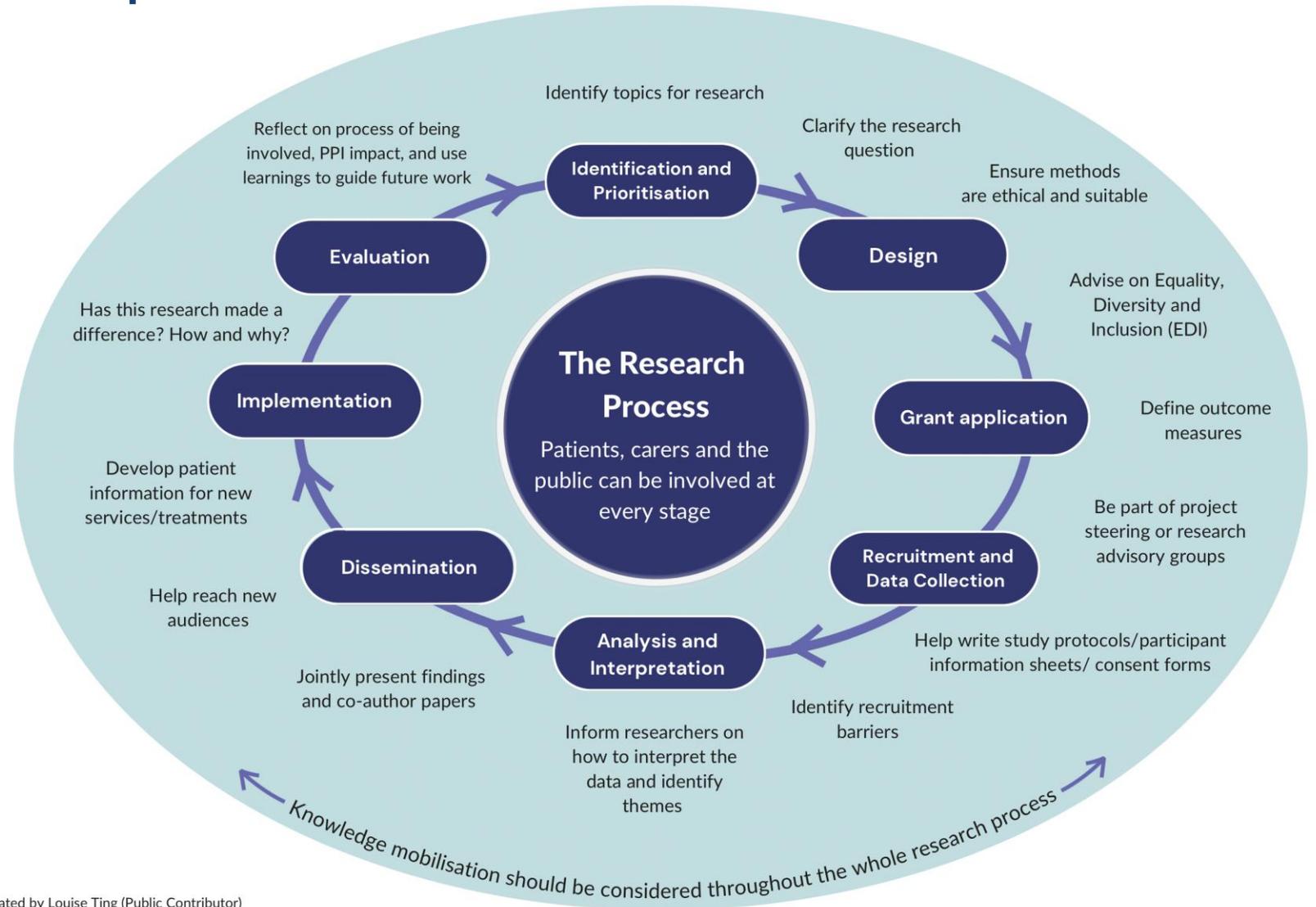
# Louise's background

- patient, carer, advocate
- marginalised groups
- charity work
- PPI experiences



# PPI and the research process

- PPI resource
- Went viral on Twitter / X in July (almost 70,000 views)
- @louiseting87
- Used globally by researchers to inform practice
- Downloadable from Twitter, Flickr and ARC West website



Created by Louise Ting (Public Contributor)  
Funded by NIHR ARC West and with support from colleagues

# Good practice and Equality, Diversity & Inclusion (EDI)

- Good communication
- Mutually beneficial relationships
- Trust and transparency
- Sufficient budget
- Training



# Under-served communities



- Health inequalities
- Different needs
- Marginalised and vulnerable groups
- Addressing hidden barriers
- Cultural humility

LGBTQIA communities

Ethnic minorities

Disabled people

Refugees/ asylum seekers/  
migrants

People in prison

Geographic disparities

Homeless people

Income status

# EDI – practical tips



- Use of language
- Multiple ways to contribute
- Additional support
- Creativity and flexibility
- Reasonable deadlines
- Regular check-ins
- Say thank you / show appreciation!