

Centre for Academic  
Primary Care,  
University of Bristol

**NIHR** | School for Primary  
Care Research

# Community engagement: menopause and beyond

Webinar 19 April 2023

#capcwebinar

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@capcbristol



# CAPC Public Involvement & Engagement in research



Julie  
Clayton



Victoria  
Wilson



Shoba  
Dawson



Lindsay  
Pryce

# What is Public Involvement in research?



# Why do public involvement in research?



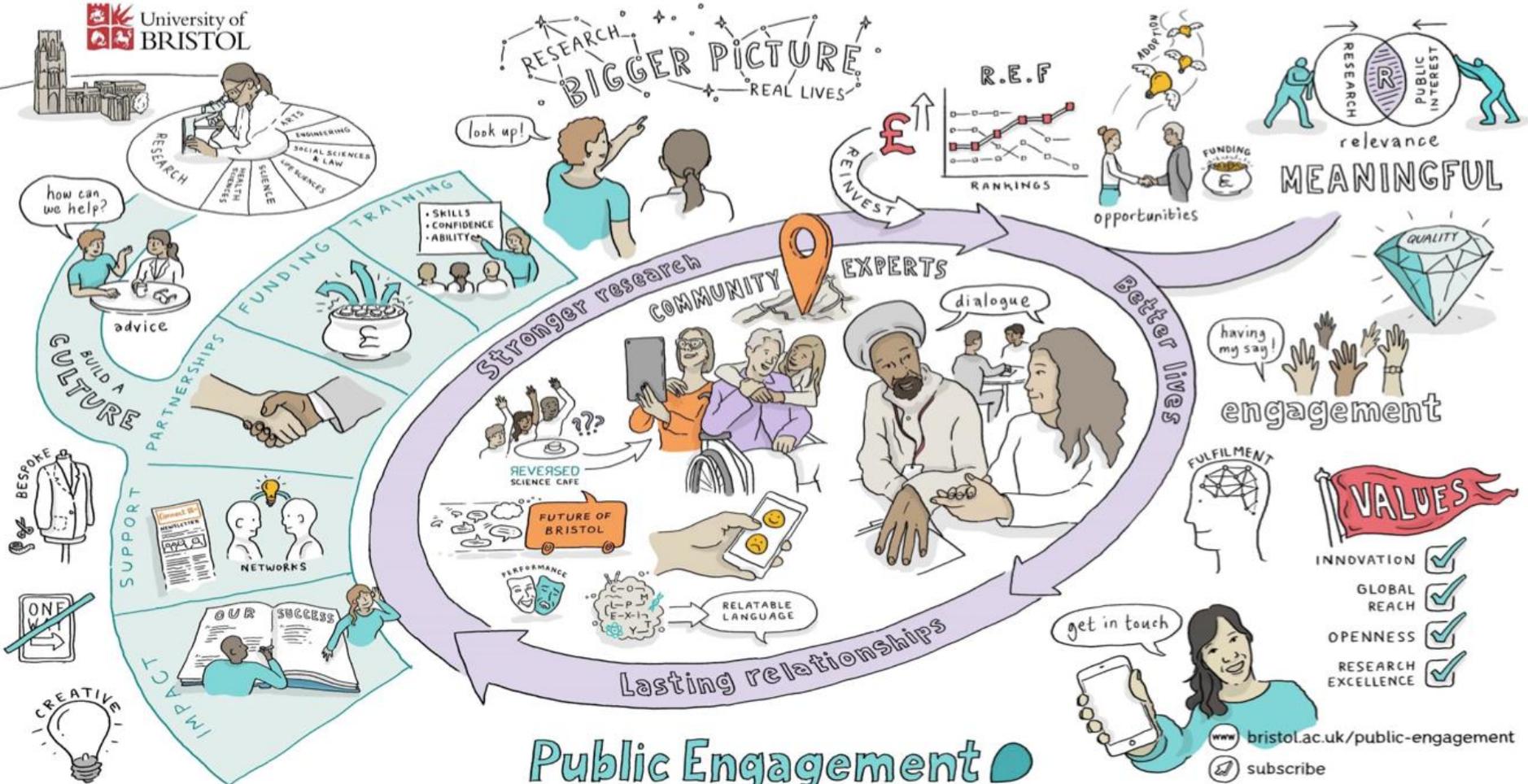
***“I think that the public needs to have a voice in the research that’s actually meant to be benefiting them.”***

Louise Ting – public contributor  
CAPC Patient/Public Involvement and Engagement Steering Group

# What about Engagement?



# What is Engagement?



## Public Engagement

Strengthening research with conversations that count

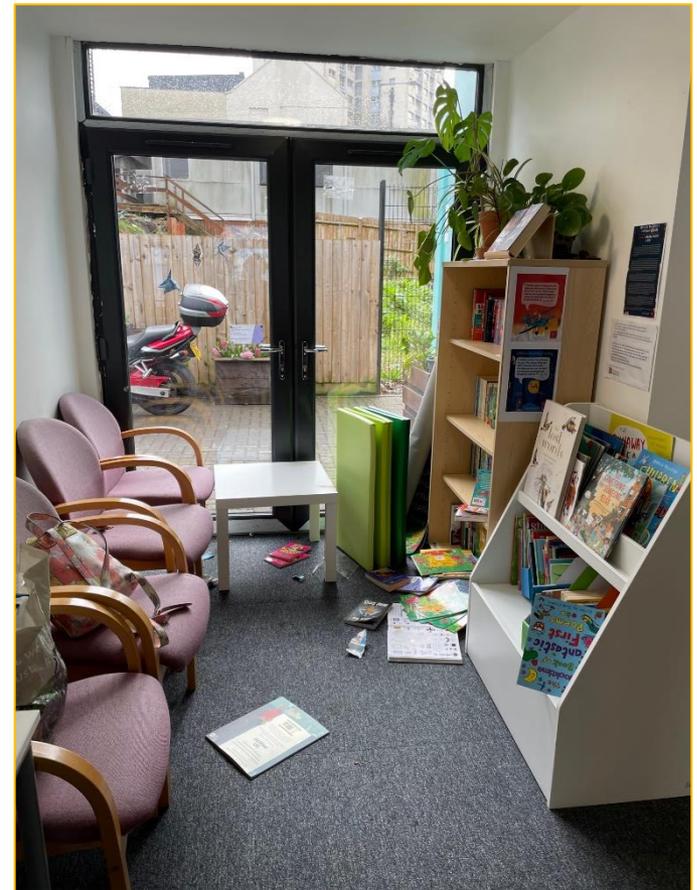
# Canynge Hall, BS8



# Easton & Barton Hill, BS5



# Barton Hill Micro-campus



# Community partners



Zahra Kosar  
Somali Resource Centre



Samira Musse  
Barton Hill Activities Club

# Barton Hill coffee mornings

- History - who / where / why



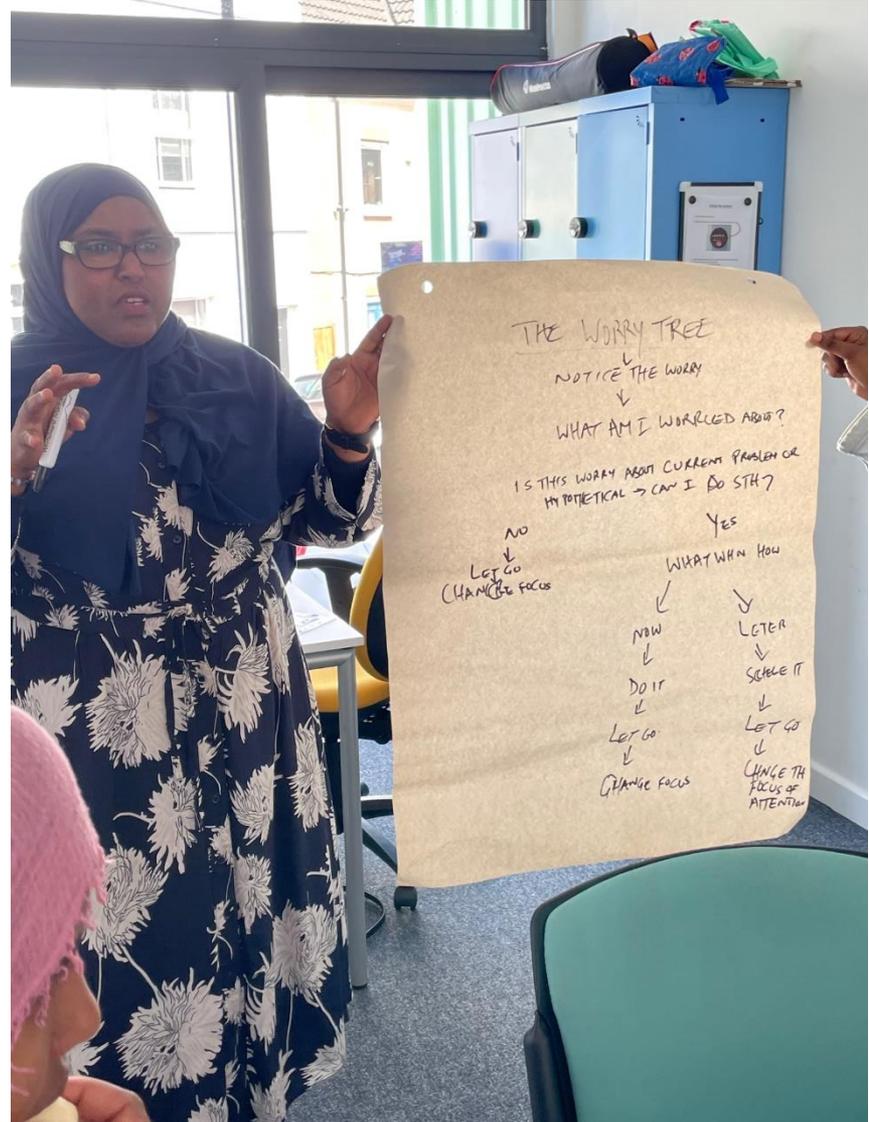
# What makes the coffee mornings work?

- No hierarchy
- Informal
- Food and drink
- All community members
- Open-door
- During school day
- Trust
- Fun!
- Women come back again

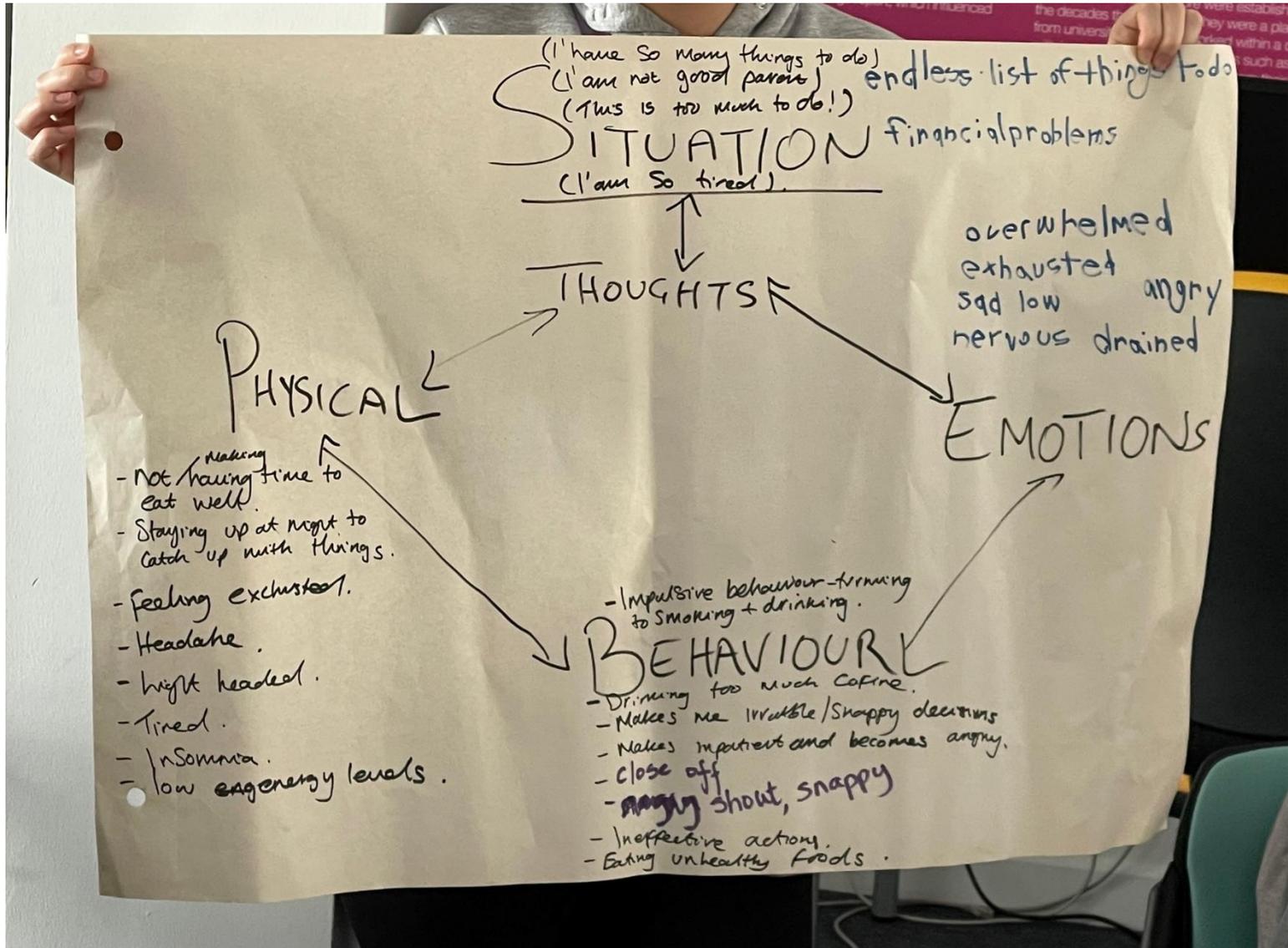


# More than just research

- Local policing
- Housing advice service
- mental health and wellbeing
- community health
- Education and training



# Wellbeing support



# Impact of coffee mornings – for community members

- Friendship
- Trust
- Confidence
- Better informed about local services
- Involvement in research
- Professional skills



# Impact of coffee mornings – for researchers

- Better informed about community experiences
- Relationship-building
- Improved research design
- New research and engagement ideas
- Invite members to be advisors on projects (PPI contributors, co-applicants)
- Extended engagement activities – to gain wider community perspectives
- >>>>> case study: ***menopause***



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# *Perimenopause and PPI: Person, Project, Place (and a few other Ps)*

Dr. Jo Burgin & Dr. Yvette Pyne

19<sup>th</sup> April 2023

# Person(s)

- Dr. Yvette Pyne - GP In-Practice Fellow
- Dr. Jo Burgin - GP Academic Clinical Fellow
- Special interest in Menopause research



# Project

- Elizabeth Blackwell Institute funding call for Research for Equality, Diversity & Inclusion in Health and Biomedicine
- Listening workshops with underserved communities in Bristol



# Place

## 1. CAPC PPI

- Connections
- Interest
- Availability

## 2. UoB Researchers

- Relationships
- Recent research
- Future research

## 3. Demographics

- Underserved communities

# Partnerships



# Publicise

- Email
- WhatsApp
- Community newsletter
- Coffee mornings



# Practicalities

- Introductions
- Venue
- Food
- Registration
- Translation
- Childcare
- Reimbursement





## Workshops

- Two workshops
- Barton Hill & Easton Community Centre
- Women aged 40-60
- 2 hours each duration
- Total of more than 50 women attended.
- Offered refreshments, childcare and payment for their time.



# *Aims*

Experiences and knowledge of the perimenopause

Do these groups seek healthcare for perimenopausal symptoms?

What would these groups want to know about the perimenopause and how would they want to receive this information?

distressed  
memory loss  
unknown  
no more babies  
getting old  
mood swings  
reason  
confused  
quiet  
tired  
dry  
hot flushes  
fear  
depressed  
stress  
hair loss  
old  
lost  
anxiety  
swings  
ageing  
periods stopped





Presentation Title



## Menopause - first impressions

What blood tests? Why? How accurate?

Early menopause - why?

Is HRT safe? Does it still cause symptoms? → hot flashes, physical stuff

Why don't GPs pick up on it quickly?

Why are people being given antidepressants?

What is vaginal atrophy?

Options for alternative tx? Do herbal remedies really work?

Why isn't it as talked about as it is seen?

How to manage w/ family/friends/work?

When do you need to see your GP?

What symptoms are included?

Mythbusters associated? Hair loss? Bone? Sexual deprivation? Hair loss? Mood?

What happens after menopause?

How long on HRT?

Other side effects?

Stress

tired

HRT

## Things you wish you had known?

What blood tests? Why? How accurate?

Early menopause - why?

Is HRT safe? Does it still cause symptoms? → hot flashes, physical stuff

Why don't GPs pick up on it quickly?

Why are people being given antidepressants?

What is vaginal atrophy?

Options for alternative tx? Do herbal remedies really work?

Why isn't it as talked about as it is seen?

How to manage w/ family/friends/work?

When do you need to see your GP?

What symptoms are included?

Mythbusters associated? Hair loss? Bone? Sexual deprivation? Hair loss? Mood?

What happens after menopause?

How long on HRT?

Other side effects?

## Experiences

Cake shops some have leaflets

Leaflets some have text from GP - better

Text from GP - better

Experiences some have leaflets

Medical info

Some people

For a book to write it

Lots of things were experienced

Video - different languages

GP research in waiting room

British - Post menopause

Menopause skills - Caraji Health

Triggers on GP records

but not just conversation more

language / can see - why information is key

## How/where to get info?

Search engines (individual pages)

at the right age

Leaflets & website

some are good

Some are not so good

Leaflets for your records

NHS health check - ask about menopause

Specialist menopause clinic that GP can refer to

Education & advice

are better at leaving

PRE can be better to prevent symptoms

hard for women

hard to consider people that don't manage

PRE

Menopause comes in many

local support groups

local advice organisations

Social media support

going round to help

to individuals

Do changes start in 40s?

How long will it last

How do you know when menopause starts if you have an IUD and no periods?

What mimics oestrogen?

Any benefits of cupping?

Is there a link between the start of your period and the start of the menopause?

If you take HRT early enough does it prevent or delay the onset of osteoporosis?

Is HRT more suitable for different ethnic groups as some ethnic groups are more at risk of stroke?

Does your experience of your periods affect your menopause journey and determine what will happen in the future?

Can HRT lead to breast cancer?

Can I pray during menopause?

Does diet affect symptoms?

Can you synch your menopause like with periods?

What clothes can I wear?

Is menopause a cycle?

Does HRT make you have periods?

Hair loss – what will help?

# Challenges

- The problem that has no name
- Lack of generational understanding
- Men – lack of knowledge impacts ability to support, strain on relationships
- Work – lack of understanding, service work
- Medical support – poor access, misdiagnosis, dismissal
- Anxiety around early menopause – at higher risk due to ethnicity?

# ***What more could be done?***

- Starting the conversation; talking to own daughters about the menopause
- Increasing awareness; partners, employers, doctors
- Information for women on EVERYTHING!
  - Leaflets, Podcasts, Webinars, Support groups, School education

# Ongoing work...

- Leaflet co-production
- Website for women in Bristol
- More work to be done!



## Bristol Menopause Toolkit

### Welcome

Welcome to the website for the "Understanding Perimenopause in Underserved Bristol Communities" project. This is a project run by [Dr. Yvette Pyne](#) and [Dr. Jo Burgin](#), researchers from the [Centre for Academic Primary Care](#) at the University of Bristol sponsored by the [Elizabeth Blackwell Institute](#) via a Research for Equality, Diversity and Inclusion in Health and Biomedicine grant.

We have collated a list of resources to support people experiencing menopause and perimenopause, please check out the links at the top.



# *What worked?*



ESTABLISHED  
RELATIONSHIPS



SET  
EXPECTATIONS



FOLLOW  
THROUGH



FOLLOW UP

# Perimenopause Resources for Bristol's Underserved Communities

A catered evening for health professionals to launch and discuss multi-lingual resources related to menopause and perimenopause.

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*@JoBurgin3*

yvette@digitalgp.net  
*@yvettepyne*



## Date and time

Wed, 19 Apr 2023 19:30 - 21:00 BST



## Location

Room LG08, Canynge Hall Canynge Hall, 39  
Whatley Road Clifton Bristol BS8 2PN

[Show map](#) ▾

# Range of projects and researchers who have visited coffee mornings

- CAPC: test results anxiety, DVA, chest infections, dementia, menopause, priority-setting in primary care research
- MSK Unit (Cat Jamieson)
- Dental School (David Dymock & students)
- Education (Cecile Jagoo)
- HPRU (Carmel McGrath)
- PHWE (Andy Gibson)
- Public Engagement (Jo Stubbs & Mireia Bes)

# Lessons learned

- Not 'hard to reach' – 'If you make the effort you know where we are'
- Importance of relationship-building
- Lived experience
- Informal conversations – both sides listening – removing barriers
- More than just dialogue
- Active partnership – more active role for community members
- Enthusiasm for research
- Need for skills training for community members
- Need to invest time and funding (EBI, Temple Quarter Engagement Fund, RCF, NIHR)
- Platform for engagement which needs to be sustained.



**Thank you for listening!**

**Email: [capc-ppi@bristol.ac.uk](mailto:capc-ppi@bristol.ac.uk)**

**Now for Q&A...**

# Keep in touch

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Follow us on Twitter: @capcbristol

Email: [phc-info@bristol.ac.uk](mailto:phc-info@bristol.ac.uk)

Information about future webinars in the series and other CAPC events are available on the [events page](#) of our website:

The next webinar in the series is on 12 June 2023 on '[Managing primary care 'same day' demand: workforce opportunities](#)' with Dr Matthew Booker and Dr Helen Baxter.