

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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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?



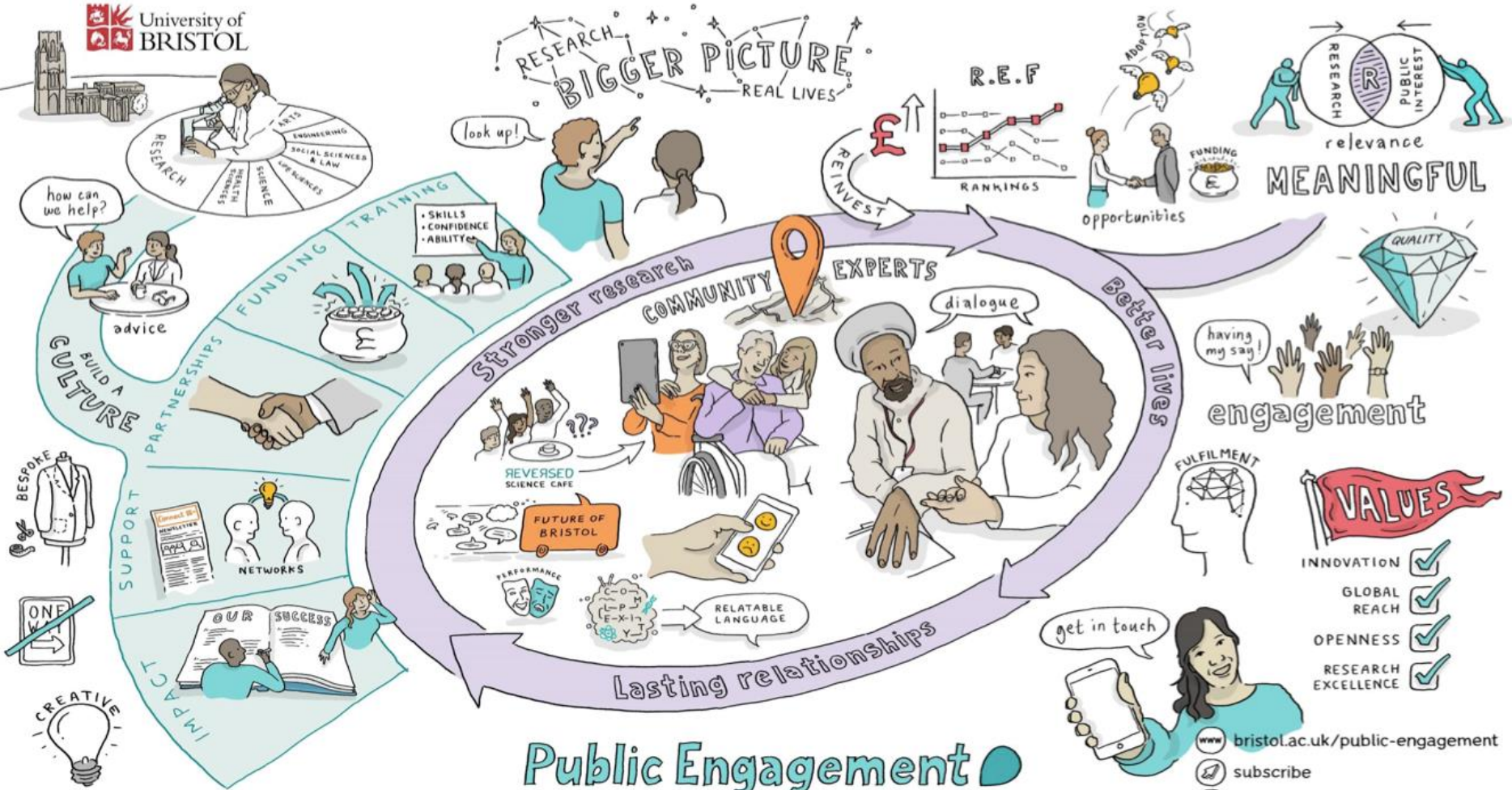
“I think that the public needs to have a voice in the research that’s actually meant to be benefiting them.”

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

- www.bristol.ac.uk/public-engagement
- subscribe
- attend an event

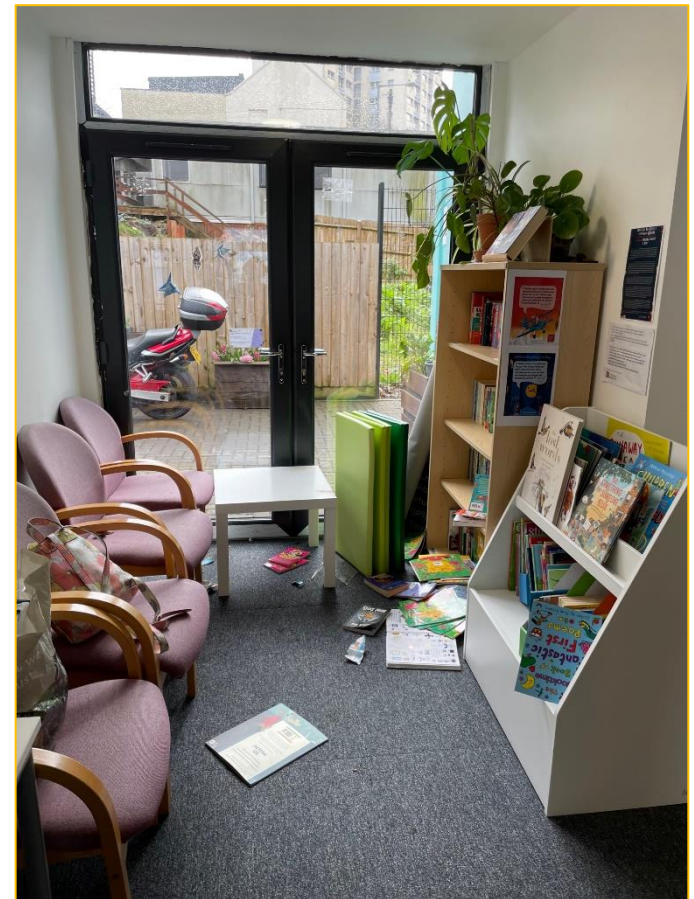
Canynge Hall, BS8



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



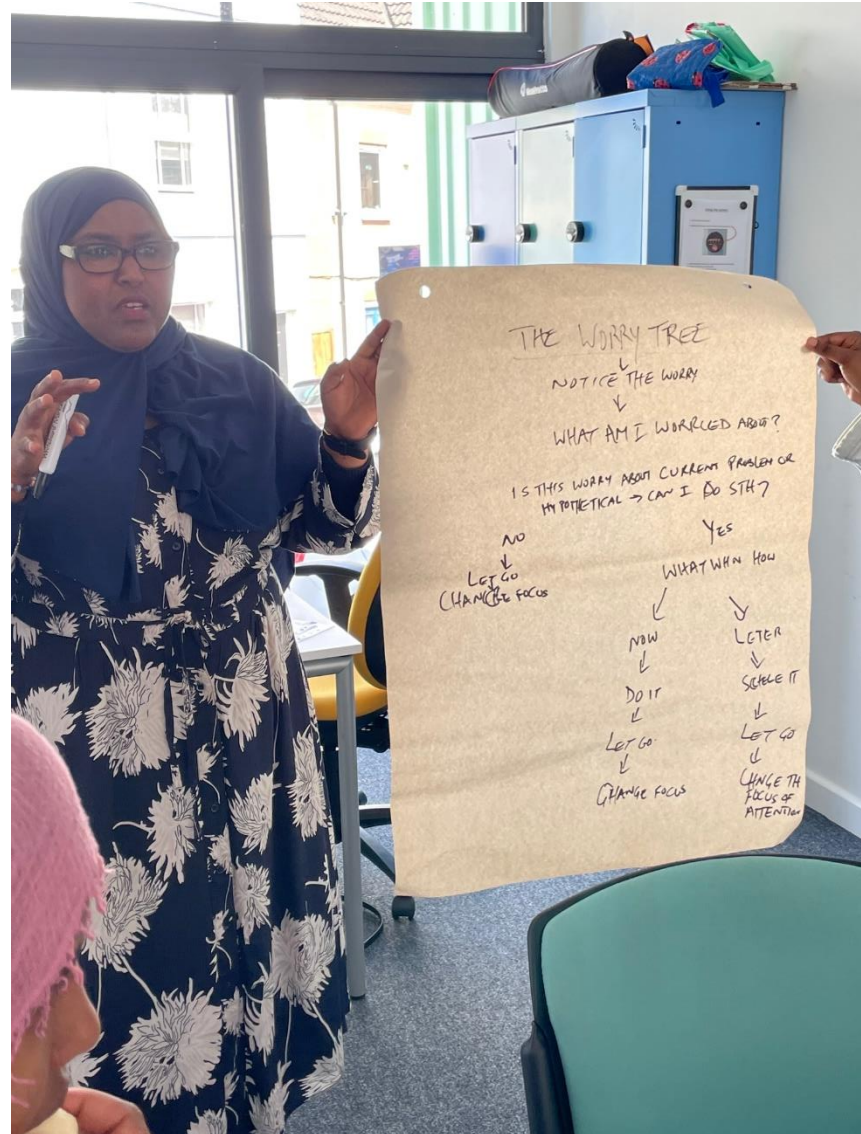
What makes the coffee mornings work?

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

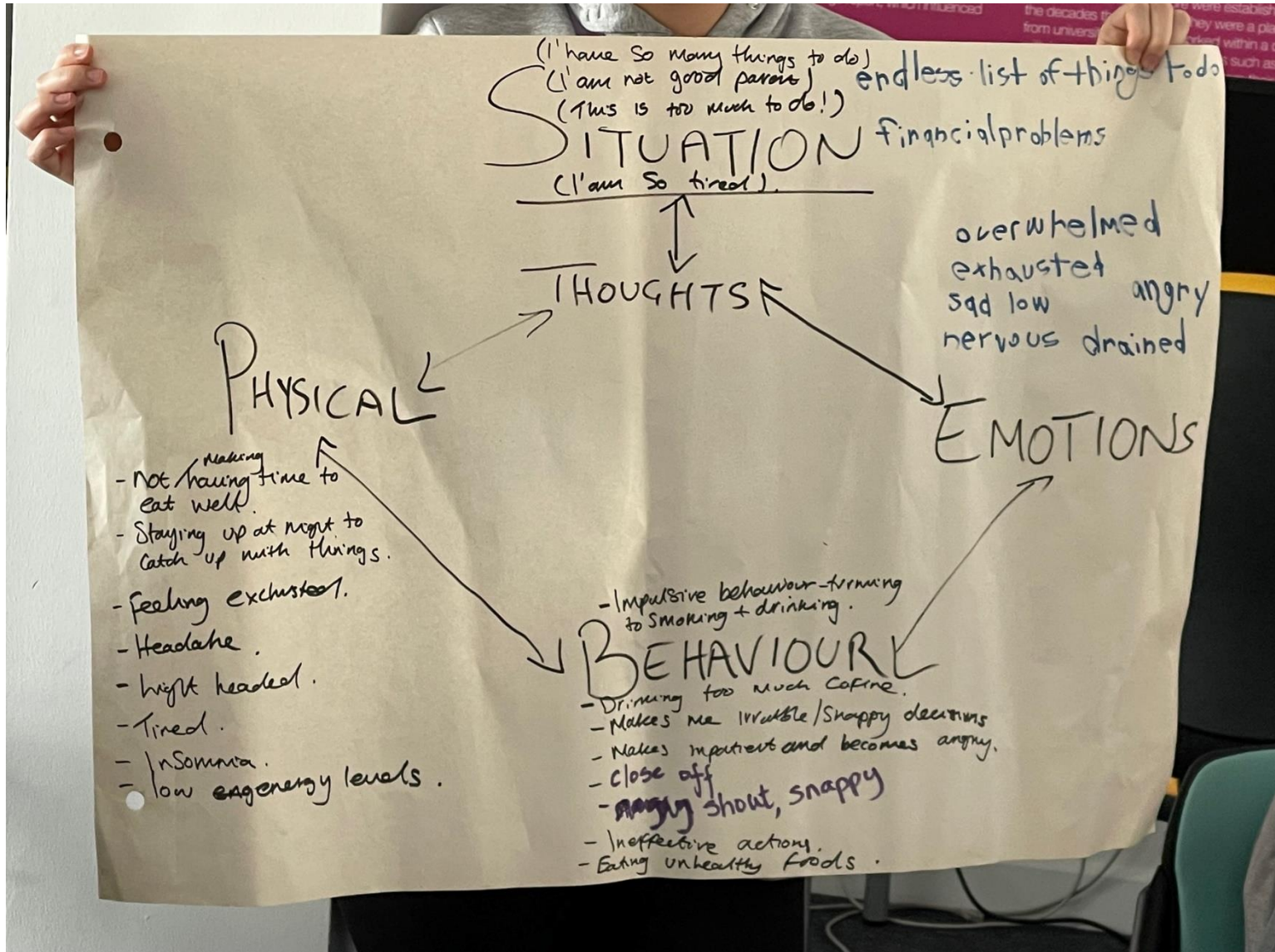


More than just research

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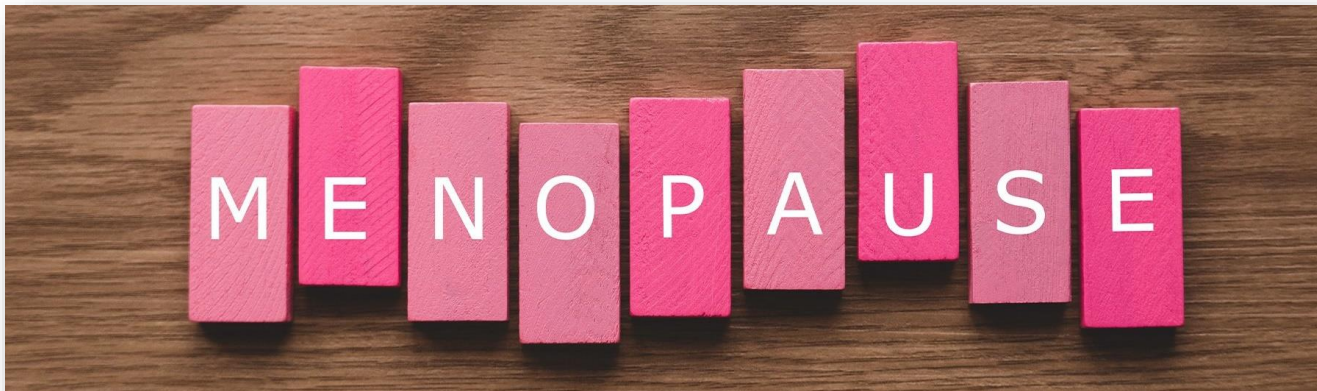
Perimenopause and PPI: Person, Project, Place (and a few other Ps)

Dr. Jo Burgin & Dr. Yvette Pyne

19th 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.

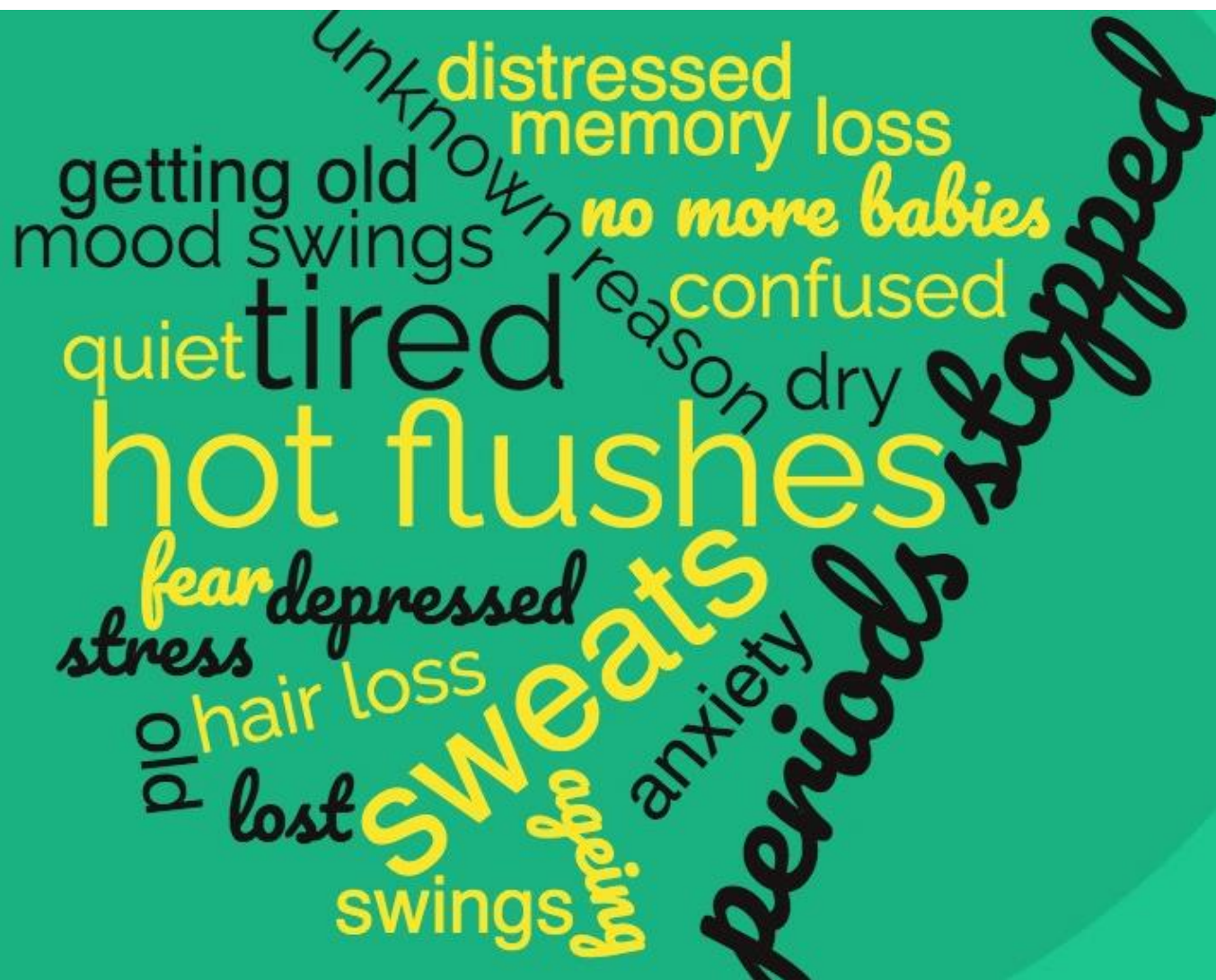


Aims

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?



MYSELF

- LOW SEX DRIVE NONE
- PAIN DURING SEX
- Low sex drive
- LOW SEX DRIVE
- WEIGHT GAIN
- POOR MEMORY
- LOW SEX DRIVE
- MUSCLE JOINT ACHES

FRIENDS / FAMILY

- HOT FLASHES

OTHER

- Worried about weight gain
- Worried about sex drive
- Worried about memory
- Worried about muscle joint aches
- Worried about hot flashes
- Worried about weight gain
- Worried about sex drive
- Worried about memory
- Worried about muscle joint aches
- Worried about hot flashes





Menopause - first impressions

Sticky notes on the poster include:

- What blood tests? Why? How accurate?
- Early menopause - why?
- Is HRT safe? Does it still cause symptoms?
- 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 or in schools?
- How to manage w/ family/friends/work?
- When do you need to see your GP?
- What symptoms are included?
- Menopause associated? Hair loss? Mood?
- Sexual deprivation? How long? How long on HRT?
- 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?
 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 or in schools?
 How to manage w/ family/friends/work?
 When do you need to see your GP?
 What symptoms are included?
 Menopause associated? Hair loss? Mood?
 Sexual deprivation? How long? How long on HRT?
 What happens after menopause?
 How long on HRT?
 Other side effects?

Experiences

Take steps
 Leaflets - some bad
 Text from GP - better
 Laminated questionnaire
 Laminated 'tips' booklet
 Video - different languages
 GP research in waiting room
 Bristol - Post menopause advice site
 Menopause skills - Caraji Health
 Triggers on GP records
 Get out your questionnaire more
 (helpful) can see why information is helpful

How/where to get info?

Search engines (individual pages)
 NHS health check - ask about menopause
 Specialist menopause clinic that offer access to specialist services
 Education & advice
 Menopause awareness day
 Local support groups
 Social media (Facebook)

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

Now for Q&A...

Keep in touch

[Sign up for our newsletter](#)

Visit our website: www.bristol.ac.uk/capc

Follow us on Twitter: @capcbristol

Email: 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.