



Food & Eating during a Pandemic: Methodological & Ethical Challenges of Public Involvement in Research



Wendy Wills
Professor of Food and Public Health
University of Hertfordshire
Email: w.j.wills@Herts.ac.uk



Name: Wendy Wills

Affiliation (role and org): Professor of Food and Public Health, University of Hertfordshire

Primary role within org: Director, Centre for Research in Public Health and Community Care (CRIPACC) / Theme Lead – NIHR ARC East of England – Prevention and Early Detection in Health and Social Care

Experience with / interest in approaches to understanding lived experiences of FEs: 20+ years of leading qualitative research with families/ households / young people / older people and organisations that support them to eat 'well'/sufficiently to maintain good health [nutritionist + sociologist]

What you can contribute to the CoP: Sharing knowledge from own and team' collective experience of qualitative research as well as involving public/patients/service users/carers in research and implementation projects

What you hope to gain from participation in the CoP: New ideas, pushing forward agendas to take account of lived experience in policy/service development

Important distinctions – When, why and how to consider lived experience

- ‘Patient/public involvement’ vs ‘research participation’
- Co-production vs co-design vs PPI
[<https://www.invo.org.uk/current-work/co-production/>]
- Important way to address inequalities and unintended consequences
 - [see <http://www.hiat.org.uk/index.html>]

The impact of coronavirus on **food and eating** in the East of England

Study reference: HSK/SF/UH/04132

COVID-19 is affecting how people are accessing food, shopping, cooking and eating and the way food is distributed.


We are undertaking research to enable immediate lessons to be learned, help plan for future challenges, and find out who is and is not getting the help they need.

We are looking for people to take part in our research.

And then Covid-19 arrived ...

- The lived experiences of and local responses to Covid-19 must be documented to inform targeted interventions throughout the crisis period and beyond and contribute to the evidence base on dietary health inequalities

Aim: to understand how Covid-19 is affecting local food systems, household food practices across the life course, and efforts to mitigate dietary health inequalities.



Setting: the East of England is a diverse region including a mixture of both wealthy and deprived populations, coastal, urban and rural settings.



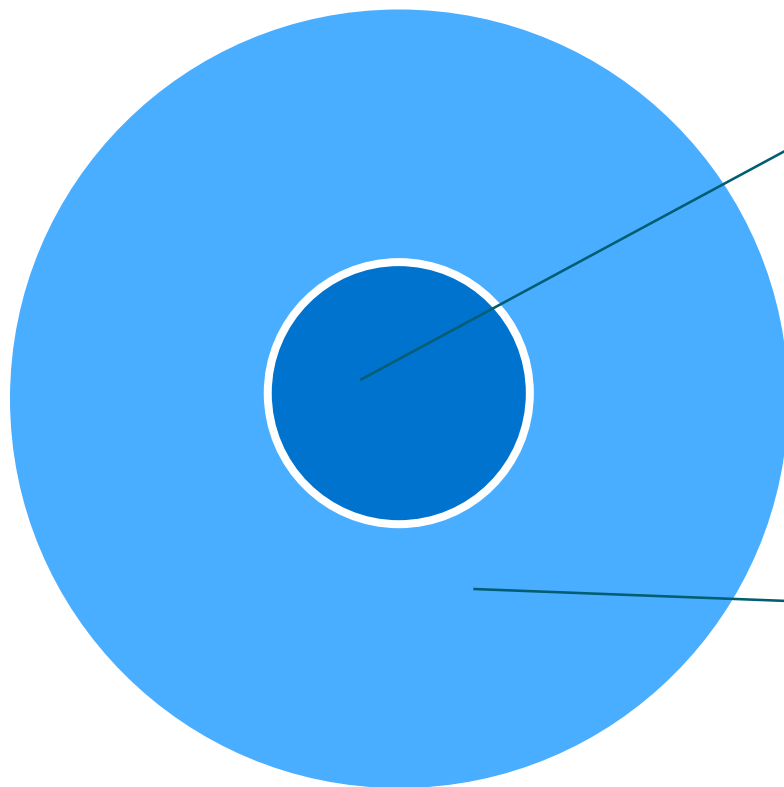
Research questions:

How are Covid and the lockdown impacting upon household food practices?

What are the challenges facing local responses around food and which groups might not be reached by these efforts?

Methods

We started in-depth telephone and video call interviews in May 2020.
Qualitative interviews are being conducted with:



40 – 60 East of England volunteers and professionals - providing support around dietary health for vulnerable groups.

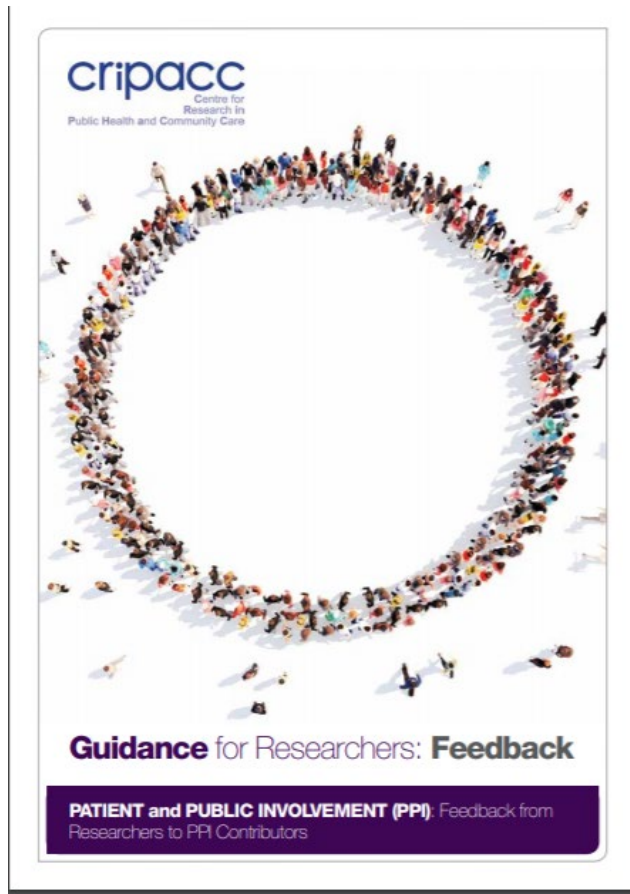
80-100 East of England residents - we are focusing on: those with infants and young children; the over 70s; those on a low-income; recipients of free school meals; households including people self-isolating due to a health condition, and households including key workers.

How we 'do' patient and public involvement (PPI)

- Attend University's Public Involvement in Research Group (PIRG) meeting to seek advice from lay members as well as consult via email and telephone with PIRG and other PPI contributors [<https://www.herts.ac.uk/research/centres/cripacc/public-involvement-in-research-group-pirg>]
- Enabling factors [for PPI during a pandemic]: well-established group/s, relationships already developed, individuals keen to input and not afraid to speak out/up, all voices/input valued, researchers 'reach out' to engage/seek input
- Barriers during Covid-19: Recruiting new PPI contributors more challenging [and paying them...]
- Important to 'close the loop' and feedback to PPI contributors about how they informed the study



Closing the feedback loop



<https://www.clahrc-oe.nihr.ac.uk/2016/05/impact-patient-public-involvement-ppi-completing-feedback-cycle/>

[Mathie, E., Wythe, H., Munday, D., et al. \(2018\) Reciprocal Relationships and the Importance of Feedback in Patient and Public Involvement: A Mixed Methods Study, Health Expectations. DOI: 10.1111/hex.12684](#)

How does PPI contribute?

- Designing/refining a study –
 - Input into research questions/topic guide, method/data collection refinement, recruitment strategy, volunteering to be a pilot participant, highlighting information/organisations to us

“The most obvious and inclusive way to recruit is over the phone. But people these days are wary of answering the phone now we have caller display.”

“The most vulnerable are on lists but access to these will probably be difficult because of GDPR”

“Flyers e.g. at supermarkets and food banks could help. Or through the post”

“Interviewing by phone is the most inclusive as even these days not everyone has a smart phone and so not everyone can do video calls [or is happy to]”

“Many thanks. I really enjoyed it and thought it went very well. I was very anxious with Zoom for a while when first using it, so some interviewees might be, but am happy with it now and almost forget about it. I guess if there is a choice of contact methods though, people will naturally self select which they prefer anyway”. [Pilot study participant feedback]

Adjusting to the ‘new normal’ for research

- How to recruit a diverse range of participants when you can't visit community groups/organisations?
 - Importance of ‘warm’ relationships
 - Gatekeepers keep the gate more tightly closed
 - Organisations experiencing instability during Covid-19 [e.g. furloughing of paid staff]
 - Snowballing now challenging
 - Some groups [even] harder to recruit
- How to provide written details of a study when researchers are not on campus?
 - *“Difficulty going through the consent form via telephone – the way it is written is for the participant reading it, rather than for us reading it to them, felt unstuck at times. Found it strange to do this over the telephone. May feel more natural via video call”* [Pilot study; researcher fieldnotes]

Adjusting to the 'new normal' for research

- How to collect and record data when face to face interviews no longer possible?
 - Loss of/challenges of visual research data opportunities?
 - Use of Zoom/other video platforms and telephone for interviews – implications? Practical, ethical, intellectual, epistemological...
- *Researcher fieldnotes – pilot interviews:*
 - *“Via Zoom (audio not video), used digital recorder (picked up my voice well, the interviewees voice is quite quiet, despite our volumes being on maximum) – hopefully good enough for transcriber (but I took notes at same time). Worked well, seemed informal. She advised a lot of people find zoom very stressful and telephone interviews should be offered”*
 - *“Mode: Zoom, with video. I used a recording app on my phone to record the interview. The app has a passcode enabled on it, and my phone has face recognition enabled. Files can quickly and easily be moved to my computer, then deleted from the app on my phone. The recording picked-up my voice well, the interviewee is quieter but can still be heard well enough to transcribe”*

Adjusting to the 'new normal' for research

- Benefits for participants of 'talking' during lockdown [rather than completing a questionnaire]?
- [Much] harder to develop rapport via phone/video interview than in person
 - Lack of visual cues
 - No opportunity for participant/observation
 - Household 'flow'; 'hold the baby'
 - Having to ask [rather than observe] the 'bleeding obvious'
 - Even via video call the participant isn't in a typical/natural situation
- Fewer fieldnotes to write/make use of
- Researcher entry/exit to the field different / impersonal




Thoughts about adjusting to the ‘new normal’ for research and lived experience

- Use PPI contributors as co-researchers, to collect data
- Make short, personal ‘talking head’ films to send to participants prior to data collection [or use PPI contributors to develop ‘intro’ films’
- Participate in online meetings organisations are holding to publicise research
- Surveys might sometimes work better!
 - Do phone interviews become another assessment/judgement about people and their lives...
“it’s like an assessment interview for Universal Credit”
- Get technology to participants who don’t have access to enable video interview?
- Outdoor interviews?
- Mobile research pod?



Final thoughts

- Real threat that research during social distancing and other restrictions may create further inequalities
 - Lived experience of those with the most chaotic lives may be missed
 - Lived experience of those unable to participate via current methods may also be missed
- Funders / teams must allow longer to recruit participants and undertake the research – we must fit in with participants, not the other way around
- Thanks to the UH/ARC EoE food/covid research team – Elspeth Mathie, Claire Thompson, Angela Dickinson, Sam Rogers, Roz Fallaize, Laura Hamilton for input
- **Thanks for listening, please get in touch:**
- **Email: covid19foodstudy@Herts.ac.uk / w.j.wills@Herts.ac.uk**
-  **Wendy_J_Wills**
- **Study website: <https://arc-eoe.nihr.ac.uk/covid-19-projects-innovations-and-information/prevention-and-early-detection-health-and-social-care/>**



Thanks to the PIRG and other PPI contributors for input into the design/conduct of the study