

**ARC North West Coast (ARC NWC) Equitable Place-based Health  
and Care (EPHC)**

**Title: Piloting diary methods to capture local community  
experiences of COVID19**

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## **Background and introduction**

Commencing October 2019, the Applied Research Collaboration North West Coast (ARC NWC) is an evolution of CLAHRC NWC, with a broadened consortium including Public Advisers, Local Authorities, NHS organisations and the Third Sector. The ARC NWC structure consists of three research themes reflecting local needs. These are: 'Person Centred Complex Care', 'Improving Population Health' and 'Equitable Place-based Health and Care'. Crosscutting themes also provide expertise and guidance to support research theme activity. The central focus of ARC NWC across all its work is on health inequalities.

ARC NWC's Equitable Place-based Health and Care (EPHC) theme aims to build on the Neighbourhood Resilience Programme (NRP), previously delivered under the public health theme of CLAHRC NWC in ten Neighbourhoods for Learning (2014-2019). The EPHC theme has a commitment to co-production with the public and practitioners, as well as a focus on actions to improve social determinants of health. Since the coronavirus pandemic emerged in the UK, ARC NWC's EPHC team has been reviewing how it can mobilise its capacity to respond to the current situation, with a particular focus on considering community experiences and needs. The project outlined in this application forms one component of this work.

## **Aim**

The coronavirus (COVID-19) is impacting the lives of many communities and individuals in the UK. There is limited understanding about how these impacts are affecting communities, and how best to capture this information particularly when traditional research methods may not be practical in the current environment. This study aims to test out a diary method approach as a tool for collecting public insights and experiences of how the coronavirus is affecting daily life in local communities.

## **Methodology**

### Recruitment

The sample will comprise members of the public who live in the geography of the North West Coast Applied Research Collaboration (ARC\_NWC): For this pilot, participants will be members of the public who are registered as public advisors within the ARC\_NWC. Advisors are recruited to ARC because of lived experience of a particular health situation or because they are resident in a locality where research is taking place. Members of the public range with respect to age, gender and ethnicity. All are over the age of 18 years old with capacity to consent. Up to 20 participants will be recruited from this network. Initially an email will be sent to potential participants explaining the purpose of the project. Where potential participants express interest, they will be provided with a research information sheet and consent form in advance of their participation commencing in the pilot. Members of the EPHC team will be available (by telephone or email) to answer any questions about what taking part may involve.

### Informed consent processes

Written consent will be sought from participants who agree to participate. The written consent form will cover all stages of participation outlined below. The participant will be provided with the information sheet at least 24 hours before an induction session takes place, giving them time to consider their involvement, and discuss the research with a researcher, and answer any questions they may have. However, we will treat consent as an ongoing process, with participants reminded of their rights at the start of each weekly contact. Alongside the consent process, participants will also be asked to complete a monitoring form so that we can understand the characteristics of individuals who take part in our research (e.g. their age group and gender). The form will be sent to participants as an anonymous electronic link via Qualtrics and the research team will not be able to identify who has completed the form. Access will be restricted to designated persons within Lancaster University and destroyed by the end of September 2020.

### Data generation

Diary methods have been used in a range of contexts including the foot and mouth epidemic<sup>1</sup> and flooding crisis (Hull)<sup>2</sup> and to gather carer experiences<sup>3</sup>. Other studies have explored everyday risk perceptions<sup>4</sup> as well as health and wellbeing amongst older people.<sup>5</sup> These studies have used multiple methods alongside diaries, including pre and post diary interviews and focus groups, quarterly group discussions, observation, and researcher contact notes. Combined methods have been found to provide more detailed understandings of experiences but also help interpretation where participants may show differing responses or approaches to completing diaries.

#### *i. Induction session*

An initial induction meeting will be convened with participants. This will take place with EPHC staff by arranging individual telephone calls or a group meeting(s) via Microsoft Teams or telephone. The session will last no longer than 45 minutes. The session will not be treated as research data but will explain what taking part involves and discuss the practicalities of recording diaries and taking part in weekly contacts.

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<sup>1</sup> Mort, Maggie, Ian Convery, Josephine Baxter, and Cathy Bailey. "Psychosocial effects of the 2001 UK foot and mouth disease epidemic in a rural population: qualitative diary based study." *BMJ* 331, no. 7527 (2005): 1234.

<sup>2</sup> Medd, W. ; Deeming, H. ; Walker, G. ; Whittle, R. ; Mort, M. ; Twigger-Ross, C. ; Walker, M. ; Watson, N. ; Kashefi, E. The flood recovery gap: a real-time study of local recovery following the floods of June 2007 in Hull, North East England. *Journal of Flood Risk Management*, December 2015, Vol.8(4), pp.315-328

<sup>3</sup> Herron R, Dansereau L, Wrathall M et al 2018. Using a flexible Diary Method rigorously and sensitively with family carers. *Qualitative Health Research*

<sup>4</sup> Hawkes G, Houghton J and Rowe G. Risk and worry in everyday life: Comparing diaries and interviews as tools in risk perception research. *Health Risk and Society* Volume 11 2009 issue 3

<sup>5</sup> Milligan, Christine, Amanda Bingley, and Anthony Gatrell. "Digging deep: Using diary techniques to explore the place of health and well-being amongst older people." *Social Science & Medicine* 61, no. 9 (2005): 1882-1892

The session will also remind people that they can end their participation in the research at any stage.

*ii. Diary keeping*

An online tool for diary keeping has been designed using the electronic survey software Qualtrics, recommended by Lancaster University. A survey link will be sent to the participant on a weekly basis over an 8 week period inviting them to complete their entry for that week. Where participants prefer to complete the diary 'off-line' we will provide a word version of the diary tool to complete.

The proforma has been developed drawing on questions/prompts used in previous diary studies referenced above. It provides written instructions/prompts to support completion but also allows the participant to write from their own perspective with free text space for participants to write about what is important to them. The proforma includes closed and open questions in relation to the following topics:

- (i) questions about how participants have been feeling over the last week, including their health/wellbeing, quality of life and relationships, using a scale ranging from 'very poor' to 'very good'
- (ii) free text space to record events or feelings on particular days of the week
- (iii) free space to record what is important to the participant and what they have observed going about their daily life.

*iii. Weekly contacts*

Weekly contacts will take the form of an assigned EPHC staff member contacting the individual participant at an agreed time, using the participants' preferred method of contact. To protect anonymity, the EPHC team member will not read the individual participants' diary entry or refer to this directly during the call. Alternatively, participants will be asked if they wish to reflect more generally on any notable events/developments that they wish to discuss further. The call will also discuss the participants' diary keeping and if they are experiencing any difficulties in completing it. The conversation will be considered to be research data, with notes recorded by the researcher. The call (or equivalent) will last no longer than 30 minutes. Finally, the weekly contact will also provide an opportunity to check in with participants, to ensure they are happy to continue their participation, or discuss if they need to withdraw, either temporarily or permanently because of coronavirus related pressures.

*iv. Post-group discussion:* Up to two focus groups (depending on number of participants involved) will be held at the end of the project. The focus group(s) will gather perspectives on participants' experience of taking part personally, and how the methods/process could be improved should the study be extended beyond the pilot. This will be convened virtually as an online group discussion, lasting up to 90 minutes. The EPHC team administrator has developed guidance for members of the public about using Microsoft Teams and will be on hand to provide technical assistance. Where individual participants prefer to debrief on a one to one basis or

are unable to participate in the group session, a member of the EPHC team will organise a telephone call as an alternative.

### Analysis

Diary entries and group discussions will be transcribed. Where a professional transcriber is used, the transcriber will be asked to sign a transcription protocol. Researchers will take fieldnotes of weekly contacts. All personal identifiable information will be removed from the material, and replaced with an anonymised code. We have developed a system to enable record linkage and within person analysis of the diary entries and weekly contacts, whereby participants will be assigned a personal unique identifier.

Data analysis methods are being developed but are likely to combine thematic and/or narrative analysis of the data. Data will be uploaded to NVIVO 12 for analysis. Initially researchers will analysis a small number of diary transcripts to compare emerging themes. The project team will also be encouraged to maintain their own reflexive notes about their experiences of the process. Preliminary findings / themes emerging from the analysis with the public advisers will be discussed, as part of sense checking and validating findings.

### **Planned outputs**

A written summary will be produced.

Presentations of findings to the EPHC theme management group, public advisers forum and ARC NWC's quarterly events will be undertaken.

More widely, the findings will be disseminated as part of future research and engagement activities including the ARC newsletter and website, social media as well as forming part of outputs such as conference presentations and journal papers.

### **Public involvement**

Two members of the public sit on the EPHC's management group and advise on our research. This pilot project also is recruiting members of the public who are advisers to research across the ARC-NWC. The intention of this study is to involve members of the public in testing out the development of recommendations for the future design and conduct of research.

### **Ethical approval**

Ethical approval for this study was granted from Lancaster University Faculty of Health and Medicine's Ethics Committee in April 2020.