

ARCBITE



Brokering Innovation Through Evidence

What's in a method? Using diary methods to research public experiences

Authors: Koser Khan (ARC NWC Equitable Place Based Health and Care (EPHC) theme, Lancaster University) and Hillary Garrett (ARC NWC Public Adviser) **September 2020.**

Background

COVID-19 is impacting the lives of communities and individuals across the world. We wanted to understand how individuals and communities in the NW Coast were affected and how best to capture this information in real time when traditional research methods were not practical. Our study aimed to test out a diary method to collect public insights and experiences of how the coronavirus was affecting daily life in local communities. The study design drew on previous diary projects used in a range of contexts such as flooding, the foot and mouth pandemic and everyday risk perceptions as well understanding experiences of specific groups such as carers and older people.

How did we involve people?

The Applied Research Collaboration North West Coast (ARC-NWC) is a partnership between organisations including universities, NHS, local authorities etc. and the public, undertaking applied research to improve health, wellbeing, quality of care and reduce health inequalities across the region. Public Advisers are recruited to ARC-NWC because of lived experience of a particular health situation or because they are resident in a locality where research is taking place.

All ARC-NWC Public Advisers were contacted to see if they would like to take part in the Diary Project. Fifteen Advisers (referred to here as 'diarists') signed up and all completed our Diary Project.

What did we do?

Each participant was teamed up with an EPHC theme researcher. They took part in an introductory telephone or video call session and then completed an on-line diary for 8 weeks from 20th April to 14th June 2020. Participants also had a weekly catch-up call with an assigned researcher. At the end of the 8 weeks, participants were invited to take part in an on-line focus group to explore their experience of theproject. In total 115 diary entries were completed and 114 weekly contacts took place during the 8-week period.

Information from the diaries and weekly calls was analysed using NVIVO12 (data analysis software) using thematic and narrative analysisii. Participants then took part in an online workshop to discuss emerging themes in August 2020. A reflective session was also conducted with the researchers at the end of the study. Ethical approval for this study was granted from Lancaster University Faculty of Health and Medicine's Ethics Committee in April 2020.

Four main themes have been identified from the findings which have been produced as a series of 'Research Bites' (i) the diary process (ii) mental health and wellbeing (iii) lockdown rules and regulations and (iv) the use of technology.

This Bite reports on the findings in relation to the use of the diary method using information collected from the diary focus group with participants, reflective discussion with research leads and information collected through weekly follow up contacts.

Study design:

- Online Diary (using Qualtrics) including short quality of life survey, free text space in addition to daily diary entries. Word template option provided for uploading responses
- Written guidance for completing diaries and 'how to' Microsoft Teams guide
- Participant inductions with assigned researchers
- Weekly links emailed to diary participants
- Weekly prearranged 30 minute call with assigned researcher using feedback template.
 Conducted through Teams or phone
- Online participant focus group
- Researcher debriefing session with external counsellor
- Administration support built in to administer the survey and provide technical support to participants
- End of study researcher reflective session
- Online data validation workshop with participants

Qualtrics is the name of an online tool for creating forms and carrying out surveys and analysing responses

What did we find?

Using diaries as a research method not only provides a unique data collection tool but also has the potential to have positive impacts on research participants. Participants in our study talked about the 'sense of purpose' that was provided through having 'something to focus on' during lockdown. Some described how they found writing down their experiences 'therapeutic' and the weekly catch up calls providing an 'emotional release' where they were able to talk through the highs and lows of lockdown and its impacts. Taking part in the project also enabled participants to document their experiences of lockdown and was described as capturing a piece of 'social history' that could be used and shared with others.

Summary of other benefits as described by research participants.

Diary writing:

- Space and time to reflect on experiences compared to other traditional research methods
- Provided a written account of their experiences during lockdown- a significant point in history
- Well-being impacts through contact with researchers, talking and writing about experiences

Weekly follow up calls:

- Enabled further reflections on experiences as well as diary content
- Opportunity to talk through experiences and provide more detail or add in missed accounts
- Helped build relationship and trust with researchers
- Support participation for those who find it easier to talk than write about experiences

"I wonder how much doing this diary has made me stop and think about things? I think I would maybe have just carried on being busy with busy work and not taken the time to reflect. I think it's also given me a bit of an outlet for my anger, sadness and fear." (Diary 8 Week 6)

"I thought it was very therapeutic and it was. It was enjoyable... It got me through the eight weeks what we did. I thought it was great." (Diary participant -focus group)

"I think this project should not be underestimated in its value as a piece of social history and history in general." (Diary participantfocus group)

"I think I enjoyed probably more than anything. Was the chat with 'researcher' on the Monday." (Diary participant focus group) Using both verbal and written methods to capture information had advantages for both the researchers and research participants. Making use of online methods enabled researchers to conduct research remotely and access data over time on the experiences of the pandemic in real time. Diary methods also produced detailed day to day accounts compared to more traditional methods such as one-off interviews or surveys. The combined approach of diary recording and weekly follow up calls also enabled more richer insights into the experiences of research participants and understanding of diary entries.

Weekly calls supported participation in the study with researchers encouraging diary writing and checking-in with participants. Participants talked positively about the researcher contact and how for some it provided a connection with 'another voice' during lockdown restrictions. Participants were also able to report back any concerns directly to researchers or through the team administrator.

Building in support was also important. Researchers participated in a de-briefing session on how to deal with sensitive situations and respond to issues arising as well as raise any concerns about individual participants.

How can diary methods be used for further research and public involvement?

Recognising the value and power of documented experiences participants felt that the diary method was a useful approach that could be used to collect the experiences of different groups of interest such as carers, patients discharged from hospital, those diagnosed with new conditions to better understand their experiences and identify unmet needs.

"Imagine if you get a whole load of carers to write about their experiences of being a family carer and the stresses and worries...! think that would be powerful" (Diary participant)

It was also considered to be an 'educational tool' that can be used to identify training needs, where diary writing is used to focus on how someone is getting on in a particular role, for example trainee doctors or children in school. The method provides an alternative approach to data collection that can capture insights and experiences over a period of time.



What to consider when using diary methods?

The methodology used in the study generally worked well and the overall experiences of participation were positive both for participants and researchers; however, we would like to share some points for consideration when thinking about using these approaches.

- The diary entries in this study were dependent on internet access and required participants to upload their responses or complete online. Issues with broadband connections impacted diary submissions causing frustration for some participants losing entries and having to rewrite and resubmit. This could be a barrier for some groups who may have limited access to the internet
- In addition to internet access participants were also required to have access to equipment such as laptops, tablets or smartphones to participate in the study. For some this came as an additional cost with participants in the study purchasing new equipment. Again, this may exclude or deter some individuals from participating in studies using online approaches.
- Literacy levels also need to be considered as some individuals are more comfortable writing and others talking. Using combined data collection approaches can be more inclusive and also provide more detailed insights.
- Using a more open approach to diary entries came with advantages and disadvantages. It enabled participants to write about what was important and relevant to them but also left some participants unsure of what aspects of lockdown they should focus on. Considering relevant prompts during the diary recording duration may support participants to focus their thoughts and write diary content.





- The importance of building trust with participants and assuring confidentially was highlighted by participants. Diary writing is likely to involve very personal accounts and include information that may make individuals identifiable to others. As with any research study, having clear processes in place helps to reassure participants.
- Another factor to consider is the time commitment required to participate.
 Although participants found it hard to quantify the amount of time spent writing dairies it was highlighted by some that they spent considerable amount of time reflecting and writing about their experiences and observations.
- It is also important to bear in mind when researching events as they
 unfold it can be a stressful time for participants and participation may not
 always be easy or as enjoyable for everyone. Supporting participation
 requires a flexible approach and sensitivity to individual circumstances.

We would like to thank the advisers who participated in the diary study for sharing their insights and experiences of lockdown with us. For more information about the research, please visit the Equitable Place Based Health and Care Theme's webpages or contact the EPHC theme at ephcenquiries@lancaster.ac.uk

Disclaimer: This project is funded by the National Institute for Health Research (NIHR) [ARC North west Coast]. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.