

# Online community engagement in response to COVID-19 pandemic

Community participatory research is a method of active engagement between community members to develop interventions that catalyse social change and improve health outcomes.<sup>1</sup> Increasingly, particularly in low-middle-income countries (LMICs), participatory research is used to co-develop low-cost community interventions. UK health policy and providers are also placing increasing emphasis on strengthening community services to equitably optimize health outcomes. South-to-north translation of community-based participatory interventions provides enormous potential to address these aims. In this article, we provide two examples of interventions which have been successfully implemented in LMICs<sup>2-4</sup> and are currently undergoing adaptation and testing in the UK, driven by the emphasis of NHS policy shifting towards community strengthening.<sup>5</sup> The first is community mobilization through participatory learning and action (PLA) cycles with women's groups and the second community-based parent group programme for children with complex neurodisability (Ubuntu).<sup>6,7</sup> Here we describe how these programmes are being further adapted to run partially or fully online in response to COVID-19, and lessons can be learnt from these two examples, which have accelerated digital innovation in the delivery of health services to enable non-contact approaches.

Women's groups PLA cycle is a WHO-recommended intervention to produce sustained improvements in maternal and newborn outcomes in rural LMICs. PLA cycles are iterative processes led by community facilitators (CFs) guiding participants through four-stage cycles of identifying and prioritizing contextual health issues, designing strategies to address these issues and evaluating post-implementation. The Nurture Early for Optimal Nutrition (NEON) programme<sup>9</sup> aims to co-adapt PLA from LMIC to the UK to improve infant feeding, care and dental hygiene practices for South Asian infants <2 years in East London.

Ubuntu family of programmes provides community-based parent/carer programmes using participatory approaches. These programmes were developed in LMIC to support carers of children at risk or with a diagnosis of complex neurodisability. These are, for cerebral palsy: the Getting to Know Cerebral Palsy (G2KCP) programme, for young children with developmental disability: the

ABAaNA Early Intervention Programme (ABAaNA: Uganda/Rwanda) and for children with congenital Zika syndrome (Juntos: Brazil).<sup>10</sup> This approach is being adapted in the UK for families of children with complex neurodisability, such as cerebral palsy to address an expressed, unmet need by parents for such an intervention.<sup>2</sup>

Due to COVID-19, the UK government enforced isolation measures, including social distancing.<sup>11</sup> This affected community engagement studies that relied on face-to-face meetings such as NEON and community groups for complex neurodisability. Despite evidence of increasing health uptake and engagement, little is known about the feasibility of undertaking online community engagement and research, especially during a pandemic.<sup>12</sup>

Salmons (2016) introduced an e-research framework that facilitates a holistic approach to undertake community engagement and qualitative research online.<sup>13</sup> Furthermore, social media platforms have been found to be valid tools to engage with communities during times of crises.<sup>13-15</sup> Consequently, the NEON team decided to adapt the intervention such that community engagement, delivery and evaluation occurred virtually, utilizing the software Zoom. CFs received a robust group and 1:1 training from the NEON team on how to use Zoom, to facilitate the NEON intervention meetings. Despite the varying digital literacy, all the CFs successfully used the online platform for the meetings. Similarly, the community parent/carer group intervention team have adapted their qualitative research methodology and workshops to online platforms.

Reflecting on our experiences, online engagement has several benefits over face-to-face; (a) CFs do not have to commute to meetings nor bear travel costs, and (b) participants have flexibility in terms of meeting dates and times. These factors helped in the conduct of meetings during holiday times and encouraged participation by reducing mobility barriers for physically disabled individuals and carers of infants. Meetings could also be recorded with the participants' permission and accessed later to reflect on specific points and/or for those who missed meetings.

Since COVID-19, there has been an increase in anxiety, depression and other mental health morbidity, which may have impacted on CF's proactiveness to participate online. Participation promotion techniques, for example inviting participants by name to speak in turn, splitting the group into smaller discussion groups,

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were used to mitigate these issues. We recognize that community engagement is difficult during crises due to changing lifestyles and commitments with some CFs volunteering to deliver necessities in their community. Whilst not observed, participants may be reluctant to attend online meetings if they feel they lack privacy in their home setting. Whilst not always practically possible, we encouraged CFs to undertake meetings in a private room in their house. Other limitations and/or risks of virtual meetings include: (a) loss of body language and non-verbal cues, particularly if individuals switch off their cameras and (b) risk worsening health inequities by reliance on digital methods as the highest risk, hardest to reach populations are likely those who experience greater digital poverty.<sup>16</sup>

After conducting online parent/carer workshops to gather feedback around the COVID-19 experience, the G2KCP project team is undertaking qualitative focus group discussions (FGD) and semi-structured interviews online. The team have incorporated solutions on how to conduct online qualitative research from Tuttas et al (2014) such as reducing FGDs sizes so that they are more manageable online.<sup>17</sup> In addition, they are exploring the feasibility of digital implementation of the programme. Collaborators in Rwanda and Uganda are similarly currently exploring the digital adaptation of the ABaANA programme. To advance patient and public involvement and community engagement, an online Facebook group is being set up as a virtual support group for East London parents during the pandemic. Furthermore, this virtual community can act as a space to disseminate information and promote shared learning.

NEON and community parent groups for neurodisability represent two exemplar community participatory research projects adapting to COVID-19 by implementing online research, meetings and intervention implementation as a successful alternative to face-to-face meetings. There may still be inevitable digital divide in the community, and evaluation of these is planned and required to ascertain impact on equity and efficacy. We hope that many generalizable lessons will be learned from our experiences that may be applied to the conduct of participatory and qualitative research and to the implementation of community-based interventions in the UK and beyond.

## KEYWORDS

children, community engagement, community-based intervention, infant, online interventions

## CONFLICT OF INTERESTS

No conflict of interests to declare.

## FUNDING INFORMATION

Dr Oulton is a National Institute for Health Research (NIHR) Senior Nurse and Midwife Research Leader. The views expressed in this article are those of the author(s) and not necessarily those of the NIHR, or the Department of Health and Social Care

## DATA SHARING AND AVAILABILITY STATEMENT

The data of this study are available from the corresponding author upon reasonable request.

## AUTHOR CONTRIBUTIONS

ML, LM, MH, NB, CL, AH and SA conceived the original concept of the study and designed the research methodology. SA carried out the ID meetings, workshops, co-development of the intervention toolkit and wrote the paper. LM, ML, SA, NB, CL, AH, KO, CM, CT, HK, YBK, EW, JG, KWM, CI and CE validated the study and revised the manuscript critically for important intellectual content. OZ and ICD were involved in drafting materials for the NEON meetings and workshops of the Intervention Development Phase. OZ, ICD and SaA contributed to the manuscript writing, edited the final manuscript and prepared it for submission. LM and SA had primary responsibility for the final content. All authors read and contributed to reviewing the study data, the designing of the manuscript and the approval of the final manuscript.

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### REFERENCES

- Hick S Participatory research. *Journal of Progressive Human Services*. 1997;8(2):63-78.
- ICfEi D. Getting to Know Cerebral Palsy: Working with parent groups—a training resource for facilitators, parents, caregivers, and persons with cerebral palsy. Modified from Hambisela. 2011.
- Lakhanpaul M, Benton L, Lloyd-Houldey O, et al. Nurture Early for Optimal Nutrition (NEON) programme: Qualitative study of drivers of infant feeding and care practices in a British-Bangladeshi population. *BMJ Open*. 2020;10(6):e035347.
- Prost A, Colbourn T, Seward N, et al. Women's groups practising participatory learning and action to improve maternal and newborn health in low-resource settings: A systematic review and meta-analysis. *Lancet*. 2013;381(9879):1736-1746.
- The NHS Long Term Plan. NHS; 2019. Available from: <https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/>
- Zuurmond M, O'Banion D, Gladstone M, et al. Evaluating the impact of a community-based parent training programme for children with cerebral palsy in Ghana. *PLoS One*. 2018;13(9):e0202096
- Heys M, Gram L, Wade A, et al. Long-term impact of community-based participatory women's groups on child and maternal mortality and child disability: follow-up of a cluster randomised trial in rural Nepal. *BMJ Glob Health*. 2018;3(6):e001024.
- WHO. WHO recommendation on facilitated participatory learning and action cycles with women's groups during pregnancy: The WHO Reproductive Health Library 2018. Available from: <https://extranet.who.int/rhl/topics/improving-health-system-performance/implementation-strategies/who-recommendation-facilitate-participatory-learning-and-action-cycles-womens-groups-during-pregnancy>
- Nurture Early for Optimal Nutrition (NEON) study: Aceso Global Health Consultants Ltd 2019. Available at: <https://www.acesogh.com/neon>
- Nampijja M, Webb E, Nanyunja C, et al. Randomised controlled pilot feasibility trial of an early intervention programme for young infants with neurodevelopmental impairment in Uganda: a study protocol. *BMJ open*. 2019;9(10):e032705.
- UK Government. Department of Health and Social Care, Coronavirus action plan. [Available at: <https://www.gov.uk/government/publications/coronavirus-action-plan>]
- Lupton D (ed). Doing fieldwork in a pandemic (crowd-sourced document); 2020. [Available at: <https://docs.google.com/document/d/1cIGjGABB2h2qbduTgfqribHmog9B6P0NvMgVuiHZCl8/edit?ts=5e88ae0a#>]
- Salmons J. *Doing qualitative research online*. London, England: SAGE; 2016.
- Marcolino M, Oliveira J, D'Agostino M, Ribeiro A, Alkmim M, Novillo-Ortiz D. The impact of mHealth interventions: systematic review of systematic reviews. *JMIR mHealth uHealth*. 2018;6(1):23.
- Marston HR, Musselwhite C, Hadley RA. COVID-19 vs Social isolation: The impact technology can have on communities, social connections and citizens. *The British Society of Gerontology*; 2020.
- Timmermans S, Kaufman R. Technologies and health inequities. *Ann Rev Sociol*. 2020;46(1):583-602.
- Tuttas CA. Lessons learned using web conference technology for online focus group interviews. *Qual Health Res*. 2014;25(1):122-133.

**How to cite this article:** Manikam L, Allaham S, Zakieh O, et al. Online community engagement in response to COVID-19 pandemic. *Health Expect*. 2021;00:1-3. <https://doi.org/10.1111/hex.13194>