# Research for All



#### Practice case study

# Community engagement in population-level research in the context of Covid-19 in rural Bangladesh

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## Abstract

Globally, researchers have been struggling with the ethical and practical questions of implementing community-based population-level research interventions during the Covid-19 pandemic. The safety of researchers and participants while implementing the interventions, and the need to avoid overburdening a health system already under pressure, are priorities, but it is also important to understand community perspectives on research. This article analyses community opinions about restarting a population-level community-based intervention for the prevention and control of type 2 diabetes in rural Bangladesh in a population of 120,000. We used qualitative phone interviews, discussions with key stakeholders and consultation with a trial steering committee. Community members were able and interested to attend intervention group meetings, but Covid-19 preventative measures were not being implemented routinely. People with diabetes did not perceive themselves to be at particular risk from Covid-19. Community members were meeting in groups and felt safe among friends and neighbours, but they did not feel safe among 'outsiders'. As a result of our community engagement, we restarted the intervention but controlled the size of the groups and screened group

members and group facilitators for Covid-19 symptoms. Community engagement enabled community members to contribute to decisions about how to restart the intervention.

**Keywords** community engagement; Bangladesh; Covid-19; participatory learning and action; diabetes; non-communicable disease; community participation

#### Key messages

- Qualitative phone interviews were a useful way to engage communities to inform decision making about restarting a community-based group intervention to prevent type 2 diabetes in rural Bangladesh.
- Community engagement informed the development of the intervention and delivery mechanisms by: (1) integrating promotion of Covid-19 preventative measures and increasing awareness of risk particularly among people with diabetes; (2) limiting the size and membership of community groups; and (3) ensuring that group facilitators and group members were known in the community and regularly screened.
- Community engagement is a key component of ethical public health research, and can help researchers make decisions about restarting interventions in a Covid-19 context.

# Introduction

The public health emergency of the Covid-19 pandemic disrupted public health research (Pai, 2020). Globally, researchers struggled with the ethical and practical questions of implementing communitybased population-level research interventions during this emergency. The safety of researchers and participants while implementing the interventions, and the need to avoid overburdening a health system already under pressure, were priorities, but it was also important to understand community perspectives on stopping and restarting research during this time. We describe a community engagement approach which informed decision making about restarting population-based research in rural Alfadanga Upazilla, Faridpur, Bangladesh following a Covid-19 national lockdown (Figure 1). Our research shows how community engagement can enable locally acceptable, ethical research in the context of a public health emergency, such as Covid-19.

#### **Community engagement**

Community engagement is a key component of most public health ethics frameworks (Childress et al., 2002). It can be defined as an interactive relationship between researchers and communities which can help to identify and manage non-obvious risks, extend respect for autonomy beyond the individual to the interests of the participant community, and develop the legitimacy of the research through ensuring local relevance (King et al., 2014). Engagement can happen through different levels of community participation, from receiving information, to consultation, collaboration and control (Boote et al., 2002). Consultation is often facilitated through advisory committees, but this can be problematic (Pratt et al., 2015). Unequal power relations, lack of capacity development and limited decision-making domains mean that advisory committees may find it difficult to represent the range of community interests (Lwin et al., 2013). They may also be conflicted as to whether they should advance the research or protect the interests of the community (Reddy et al., 2010).

#### The population-based intervention to address type 2 diabetes

Our collaboration between the Diabetic Association of Bangladesh (BADAS) and the UCL Institute for Global Health, UK was conducting a population-based participatory learning and action intervention



Figure 1. Project area of Alfadanga Upazila, as indicated by dotted red line. Source: Google Maps, 2023

in rural Bangladesh which was suspended at the peak of the Covid-19 pandemic. The intervention employed local facilitators to convene monthly men's and women's groups to work with their communities to address the barriers to prevention and control of type 2 diabetes in rural Bangladesh (King et al., 2021). Groups were open to anyone living in the community, and participants from any age group could attend. There were around 30 participants in each group, and facilitators travelled between villages and visited homes to facilitate groups and mobilise communities. Groups had begun discussing the causes and consequences of type 2 diabetes, barriers to care seeking for diabetes, the barriers to healthy eating and exercise, tobacco use and stress. As part of the participatory learning and action intervention, a community planning meeting was planned where it was estimated that around 300 people would discuss strategies to address the causes of type 2 diabetes.

Previous implementation of the same intervention in a similar rural Bangladesh context showed that common strategies of group exercise, kitchen gardening, home visiting, local blood glucose testing, and engaging with gender barriers to exercise might be implemented (Morrison et al., 2019). Our previous cluster randomised controlled trial of the intervention showed a 64 per cent relative reduction in the

combined prevalence of diabetes and intermediate hyperglycaemia (raised blood sugar) in intervention areas when compared with control (Fottrell et al., 2019). The intervention also significantly increased knowledge about the causes, symptoms and complications of diabetes. Our plans to implement and evaluate this intervention on a larger scale (King et al., 2021) were interrupted by the Covid-19 pandemic.

## **Covid-19 in Bangladesh**

The first confirmed Covid-19 case in Bangladesh was reported on 8 March 2020 (WHO, 2020), and we suspended field activities immediately. Infection rates remained low until the end of March, but a steep rise in cases followed in April 2020, with cases doubling every two days (Nabi and Shovon, 2020). By the end of March 2020, a nationwide lockdown had been implemented (Mamun, 2020). The lockdown restricted movement for all but essential tasks, such as food shopping and care seeking for illness. This lockdown lasted until the end of May 2020, when the government felt that it was economically unsustainable for population-wide movement restrictions to be maintained (Shawon, 2020). As evidence emerged that atrisk groups for diabetes were also those at highest risk of death and severe illness from Covid-19, it was apparent that the benefit of our intervention to these groups was an important consideration to balance against the harms of restarting. By September 2020, case rates were low, and senior members of the BADAS team had discussions with key stakeholders in Faridpur, and the process evaluation officer implemented a qualitative study with community members to discuss key issues related to the intervention.

## Consulting with communities

We used qualitative research to consult with communities. We describe the data collection and analysis methods of our qualitative research, before presenting the findings and implications of that research. We had ethical approval from the UCL and BADAS ethics committees to collect phone numbers during our population-based baseline survey to describe diabetes prevalence and risk factors. The survey ran between January and March 2020. We used these phone numbers to contact six men and two women with diabetes, four men and three women without diabetes, and two health workers. We also conducted two group interviews with men who usually interacted with each other, and one with women without diabetes. Participants were from four different villages. We called participants, took verbal consent, and provided additional information via text message. Most participants were familiar with BADAS, and the research study. The phone interviews and discussions were conducted by a trained qualitative researcher working as a process evaluation officer at BADAS (RH), and they were recorded. We asked how Covid-19 and the national response had affected participants, probing specifically around care seeking and diabetes riskreducing behaviours, such as physical activity, and fruit and vegetable consumption. Thereafter, we asked participants about community gatherings, and their feelings about moving around the community and interacting in groups with others. RH made notes of the recordings of the phone interviews in English, and JM and RH used descriptive content analysis (Green and Thorogood, 2005) to code data under identified themes. Interviews were around 30 minutes in duration.

In addition, we consulted with the Civil Surgeon (the district health administrator and superintendent of the district hospital), two local politicians and our community advisory committee. We also reviewed data on Covid-19 testing and prevalence with the Civil Surgeon and with our group facilitators. AK and TN met with the Civil Surgeon, facilitators and the community advisory committee, and made a report of their discussions in English. These reports were used to triangulate qualitative data from community members, and to inform our recommendations for community re-entry.

#### Diet during lockdown

A national lockdown was strictly enforced by the army and police, although some farmers in rural areas still worked in the fields as normal: 'Most people are farmers here. [During lockdown] they left home

in the morning alone and worked in their field' (369 Man). The market was only open for a few hours, and going to the market was perceived to be risky. In some places, vendors visited villages, and most people said that access to fruit and vegetables was not limited during lockdown. Despite this, their loss of income and financial insecurity meant that they were not able to eat normally: 'During lockdown, we faced a huge money crisis. We borrowed money from relatives and neighbours. We ate less food than we normally do' (1046 Woman). The price of food increased because of the effect of lockdown on supply chains. Economically poor participants worried about how they would feed their families, and took loans or donations from relatives, richer friends or workplace associations. Many discussed the fact that government aid was sparse and not distributed fairly.

## Physical activity in the context of high Covid-19 prevalence

Most participants reported that those who regularly walked in the morning were still able to walk, even during lockdown. But there were some whose physical activity had been affected. Of these, more women with diabetes than men with diabetes reported that lockdown and fear of Covid-19 prevented physical activity: 'I usually walk more than one kilometre every morning. During the lockdown, I walked regularly, but not like before Covid. I just walked around my house, and it is less than one kilometre' (1046 Woman). Health workers reported that physical activity among people with diabetes had decreased.

## Care seeking in the context of high Covid-19 prevalence

Most people with diabetes reported that lockdown had not affected their access to care, either because they did not seek care regularly, or because they went to their local medicine shop to check their blood glucose. Medicine shops remained open during lockdown. Participants with diabetes went to the medicine shop because this was usual for them, or because they were afraid of catching Covid-19 while travelling and while in crowded government health facilities. Some did not go to government health facilities because they heard that government staff were not regularly attending health facilities:

During lockdown and Covid times, I did not visit the hospital, because I heard that doctors are not regular at the hospital. That's why we just followed the previous prescription. Also I was worried about getting infected with Covid in the town area, that's why I did not visit the hospital. (369 Man)

Health workers reported seeing fewer patients than normal, and believed that the lack of transport and the worry about getting Covid-19 had kept patients away. One man and one woman with diabetes had stopped taking their medication because of financial worry:

Nowadays, I do not have enough money to buy medicine. I've stopped taking medicine. When I had money, I spent 8–10 taka per day. My younger son is a bus driver, and because of Covid, his earnings were getting lower day by day, so he did not give money at that time. My daughter also did not give money as her income decreased. (787 Man)

Some complained about the price fluctuation of medicine in private clinics. Consultations with the Civil Surgeon and visits to the community revealed that community clinics and family welfare centres were not providing services related to Covid-19, and that they were able to cope with the number of patients.

## Awareness of Covid-19 prevention

There was some awareness about how to prevent Covid-19, and many had heard public health messages on television. Hand washing, wearing a mask, changing clothing after travelling outside the village, and not interacting face-to-face with other relatives, neighbours and friends were all discussed: 'During the lockdown, I did not visit any of our relatives' houses, I called them instead. I avoided meeting with the neighbour frequently. It wasn't necessary to meet with them, so I didn't' (1046 Woman). No one described how they thought Covid-19 was transmitted, and several participants took measures such as drinking hot water with spices, and Malta (a drink) to prevent being infected.

#### Perceptions of risk and reassurance

During lockdown, most people felt at risk and were worried about Covid-19 affecting their family or village. Participants were aware of restrictions, and were supportive of them as they were deemed reasonable: 'To maintain the rules is easy. The government developed those rules for people's well-being' (52 Man). Communities, and particularly women, were worried about getting ill, and the restrictions on movement and the Covid-19 public awareness campaign made them feel reassured: 'We maintained all the rules, so we did not worry about Covid' (689 Man). Most respondents said that Covid-19 had not come to their village, and they felt safe in their village. Many felt that Allah was protecting them: 'For the help of almighty Allah, in our village and surroundings of our village, there are no Covid-19 cases here. We are safe from Covid-19' (787 Man). Several participants felt that if you got Covid-19, it was Allah's will. Many thought that people who smoked or who had flu were more likely to get Covid-19. Those with diabetes were not more worried than others about getting Covid-19, and only a few individuals without diabetes thought that old people and people with diabetes were at increased risk: 'All of the organs of the body are affected in a person with diabetes, so it is worrying for them if they are infected by Covid-19' (114 Man). Politicians, the Civil Surgeon, and advisory committee members suggested that the group intervention should restart, and that it could also be useful in raising awareness about prevention of Covid-19. Some community members, particularly those with diabetes, had asked about when the groups were restarting.

#### Trust in 'outsiders' after lockdown

During lockdown, many avoided interacting with those outside their household, but as lockdown lifted, participants felt comfortable among community members and friends; however, they remained uncomfortable around 'outsiders' (people from outside their village, or people they did not know):

We know there is no one with Covid-19 in this village or the villages around. So, we are not worried if we are with people from here. But if we meet someone we don't know, we must maintain three feet distance from them and wear a mask ... If necessary, then we would talk with them, otherwise we would avoid them. We don't know them and we don't know who carries the virus, so it's better to avoid them. (910 Man)

A few reported that an 'outsider' came to their village with Covid-19, but then got better. The immediate environment felt safe to participants, and, perhaps as a result, only a few people were wearing masks in villages.

Two people who were comfortable interacting with 'outsiders' were interacting with the public through their work. One was an auto driver (a motorised version of the pulled rickshaw or cycle rickshaw) who needed to earn money to feed his family, and another owned a shop: 'During the lockdown, I stopped meeting with those from outside the village, but now I meet with other people ...' (52 Man). He was fatalistic about being infected, believing that it depended on Allah. These respondents said that 'no one follows the rules' now.

At the time of data collection, interactions between friends and acquaintances had resumed in teashops: 'People gather at the tea stall just like before, like normal days. Around 10 to 15 people gather at the tea stall every day' (893 Man). These were not perceived to be high-risk interactions, but large gatherings were still perceived to be risky. Most said that they avoided crowds because they could interact with unfamiliar people who might have Covid-19: 'In a crowded place or a group meeting of 20 people, we don't know who has Covid-19, so there is a risk that it spreads' (811 Woman). One man said: 'Yes, from a group it's possible for Covid-19 to spread. Maybe people from the village don't have the virus, and village people aren't able to spread the virus, but someone from the town may be able to spread the virus' (893 Man). Participants were also wary of travelling by public transport: 'Now, I don't feel good to move around my village and use public transport like the bus. On the bus it's very difficult to maintain distance from others' (787 Man).

## Limitations

Focus group discussions might have been a better method to use than interviews to understand community norms, but it was not possible to collect data in person. We tried to stimulate some discussion of norms through group interviews, but we found that participants took turns answering the researcher over the phone, and using the loudspeaker on the phone was not effective. Despite this, interviews were useful in gaining some understanding of community context. Given that the research was conducted by BADAS, participants may have been reluctant to reveal suboptimal behaviours (such as non-adherence to preventative interventions such as mask wearing, and not meeting in large groups). We felt that this bias was acceptable, as this could lead us to more conservative conclusions.

## Integrating community perspectives in decision making

Our community engagement informed our decision making about restarting the intervention through consideration of the risks, benefits and feasibility of intervention mechanisms in the post-lockdown Covid-19 context.

#### Consideration of risks to participants

Qualitative research showed that participants perceived that Covid-19 risk was low if they were interacting with people from their village, and from their social circle. We understood from this that communities would be comfortable participating in a group-based intervention of small groups of people who were likely to know each other. In our previous intervention, groups had around 30 members, and so we decided to run two separate groups per village instead of one group. Groups were split geographically, so that it was more likely that participants would know and feel comfortable with each other. Previously the intervention was open to all, but we restricted group membership to those who had come to the first few meetings prior to lockdown. Facilitators screened group members for Covid-19 symptoms over the phone before they attended meetings.

## **Potential benefits**

Community members were reassured by preventative measures such as mask wearing and hand washing during lockdown, but enthusiasm for protective measures was waning, and we found that mask wearing and social distancing were not being routinely implemented when people interacted with those from the same village. There was also limited awareness of increased risk among people with diabetes. The group intervention provided an opportunity to encourage preventative behaviours which could also reassure community members who were concerned about Covid-19 risk in groups. Therefore, we integrated discussion about Covid-19 into our intervention, and implemented preventative measures at group meetings, such as social distancing, mask wearing and hand washing.

#### Feasibility of the intervention

We found that physical activity, consumption of fruit and vegetables and care seeking for diabetes had not been adversely affected by Covid-19. Our intervention seeks to stimulate community action to prevent and control type 2 diabetes, and we were encouraged to hear that community members could still take action to address diabetes risk factors, despite Covid-19 control measures and fear of risk. We felt that it was feasible to run a successful intervention in the post-lockdown Covid-19 context.

Community members were suspicious of 'outsiders'. Community facilitators who ran the groups were locally recruited, but they may not have been considered local to every village where they worked. We made additional efforts to coordinate with community leaders in introducing facilitators to the community and encouraging people to attend meetings. Facilitators also tested regularly for Covid-19, and they carried their test certificates when visiting villages. The reputation of BADAS as a health-promoting organisation was a strength that we built on in implementing the intervention.

#### Feeding community engagement data into trial steering committee discussions

We presented a summary of findings from community engagement and our recommendations to our trial steering committee (TSC), and discussed draft standard operating procedures for the intervention. The standard operating procedures contained safety precautions for the intervention, and trial stopping and starting rules. The TSC noted that we should align with local regulations, and commented on the standard operating procedures. The community engagement data were an important source of information for the TSC to consider the feasibility and ethical implications of restarting the intervention. The TSC also recommended that we initiate a data safety monitoring board to monitor adverse outcomes, which we proceeded to do.

# Conclusion

To make ethical decisions on the appropriateness of interventions and research procedures in population-based research, it is important to engage with communities. Ethics frameworks recommend early and ongoing engagement of affected communities to help researchers understand locally appropriate parameters of burdens, harms, benefits and fairness. Engagement has been made more challenging by public health emergencies, such as the Covid-19 pandemic, but we have demonstrated that it is possible and necessary. We evaluated potential benefits, risks and perceptions of risks through discussions in communities and with advisory committees. We found that by engaging with community members and those with diabetes, we were able to prepare and re-enter the community in informed consideration of the changed Covid-19 context. Community engagement is necessary to inform ethical decision making, particularly during public health emergencies, and researchers need to ensure that recommendations from engagement are centred on decision making about research

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# Declarations and conflicts of interest

#### **Research ethics statement**

The authors declare that research ethics approval for this article was provided by the UCL Research Ethics Committee (ref: 4199/007) and the Ethical Review Committee of the Diabetic Association of Bangladesh (ref: BADAS-ERC/E/19/00276).

### Consent for publication statement

The authors declare that research participants' informed consent to publication of findings – including photos, videos and any personal or identifiable information – was secured prior to publication.

## **Conflicts of interest statement**

The authors declare no conflicts of interest with this work. All efforts to sufficiently anonymise the authors during peer review of this article have been made. The authors declare no further conflicts with this article.

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