

COVID-19 and the ‘Ethics of Disruption’: Current Dilemmas Facing Longitudinal Research in Low- and Middle-Income Countries

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ABSTRACT In this paper, we draw on recent experiences from the Young Lives study to discuss some of the ethical and practical challenges facing longitudinal cohort studies in low- and middle-income countries in the time of coronavirus. We argue that COVID-19 has instigated an ‘ethics of disruption’ for social researchers across the world, and for longitudinal cohort studies like Young Lives, this requires navigating three core considerations: first, managing research relationships and reciprocity within an observational study design; second, maintaining methodological continuity and consistency across time; and third, balancing an immediate short-term response to COVID-19 against the longer-term perspective. We refer to the study’s plan to implement a new COVID-19 phone survey to illustrate how the team are navigating this altered ethical terrain.

Keywords: research ethics; longitudinal methodology; youth; phone survey; COVID-19; low- and middle-income countries

Introduction

The coronavirus pandemic raises several complicated ethical and practical issues for conducting longitudinal cohort studies, particularly in low- and middle-income countries where health systems and research infrastructure are generally weak, and the scale and impact of the virus continues to evolve. The threat of COVID-19 has disrupted social research across the world and required researchers to evaluate whether and how to continue their active studies. Maintaining scientific rigour and high ethical standards while also generating timely and useful evidence directly related to COVID-19 are combined challenges. It feels as though we have entered a new ethical landscape, one that is compelling social researchers to re-examine previously held assumptions about what is appropriate, possible, valuable and relevant for their research, and the nature of ethical responsibilities to all those enmeshed in the research relationship during this time (Dawson et al 2020:1).

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33 In this piece, we draw on recent experiences from the Young Lives study to discuss
34 these challenges within an emerging ‘ethics of disruption’ caused by the current Covid-19
35 crises, that is destabilising ‘business as usual’ for ongoing longitudinal cohort studies. Young
36 Lives’ decision to undertake a new rapid phone survey during the pandemic precipitated the
37 need to think through several of these ethical concerns, requiring inputs from across our
38 international team so that local expertise and contextual knowledge inform mitigating
39 strategies.

40

41 **Young Lives**

42 It is 18 years since the Young Lives study of childhood poverty began following the life
43 trajectories of 12,000 girls and boys in two birth cohorts growing up in over 100 communities
44 across Ethiopia, India (Andhra Pradesh and Telangana states), Peru and Vietnam, core funded
45 by the UK’s Department for International Development (DFID). This multi-disciplinary,
46 mixed-method study is coordinated by a small team based in the University of Oxford and is
47 implemented collaboratively with long-standing research partners located in the four study
48 countries.

49 The two cohorts of young participants at the core of this study are now aged 19 and 26
50 years. They are part of the largest demographic cohort of youth ever and their generation stands
51 to be especially affected by the global economic fallout caused by the pandemic, which means
52 that competition for jobs, particularly decent jobs, is likely to be fierce. We do not yet know
53 what the impacts will be from prolonged school and work closures; reduced access to modern
54 contraception; vulnerability to gender based violence; increased care burdens; and the forced
55 return of young migrants and of family members to their homes and associated job and
56 remittance loss. There are widespread concerns that the pandemic will exacerbate existing
57 social and economic inequalities, including among the world’s youth.

58 Young Lives is familiar with the many challenges that come with conducting long-term
59 research with vulnerable populations among whom hunger, economic struggle, illness and
60 premature death were common threats well before the coronavirus pandemic. Indeed, the study
61 has documented a plethora of ‘disruptions’ at differing scales affecting Young Lives families
62 and communities (for instance, interrupted school trajectories, unintended adolescent
63 pregnancies, droughts and economic shocks). However, the threat of COVID-19 has greatly

64 altered our usual ways of conducting research and has affected the family and working lives of
65 everyone involved in the study.

66 Coronavirus reached our four study countries at different times and the numbers of
67 reported COVID-19 cases currently differ markedly; for example, as of June 9th, Ethiopia²
68 recorded 2,156 confirmed cases in the country, in contrast to the 199,696 confirmed cases in
69 Peru (118,036 in Lima³ alone). Like social researchers everywhere, we have had to quickly
70 reassess the viability of our research, addressing the realities of remote working, probable
71 delays to fieldwork, pauses, cancellations, and protracted uncertainties. By late March, the
72 University of Oxford required staff and students to ‘pause or postpone ongoing or planned non-
73 essential University research involving face-to-face interactions with human
74 participants (unless arrangements can be made for the research to be conducted remotely or
75 online),’ with the exception of research related to COVID-19 and clinical research.

76 Crucially, at the time the pandemic was declared, the Young Lives household survey
77 team were finalising plans to undertake our Round 6 survey with the full sample of participants,
78 having secured new funding from DFID to support two survey rounds over the next five years
79 as part of the ‘Young Lives at Work’ research programme. Our most pressing decision was
80 therefore what to do about the upcoming household survey for which much of the tracking had
81 been completed but face-to-face survey administration would no longer be possible. The team
82 considered delaying the survey by six months, but this raised concerns about seasonality
83 effects, and whether lockdown orders would be lifted by that time. Delaying any later would
84 affect the potential for inter-cohort comparison, since the survey is timed to ask the younger
85 cohort (age 19) the same questions that the older cohort were asked (7 years earlier) at the same
86 age.

87 Following an intense consultation, the survey team agreed a two-pronged plan: (1) to
88 delay the Round 6 survey by one year (thus retaining consistency in seasonality and continuity
89 in the research instrument); and (2) to conduct a new phone survey, beginning in June 2020,
90 using an adapted scaled-down version of the Round 6 survey with additional questions to
91 directly assess the impact of COVID-19, thus retaining the potential for inter-cohort
92 comparison of key outcomes (e.g. work, education, marriage and fertility). The threat of
93 COVID-19 has required that all the survey development is conducted remotely, including the

² <https://coronavirus.jhu.edu/map.html> (accessed 09 June 2020)

³ https://covid19.minsa.gob.pe/sala_situacional.asp (accessed 09 June 2020)

94 drafting of instruments, field guides and ethical and safeguarding protocols, programming for
95 Computer-Assisted Personal Interviewing (CAPI), training of enumerators, pre-piloting and
96 piloting⁴, survey administration, research reciprocity⁵, data management, and stakeholder
97 engagement.

98

99 **Weighing practical and ethical risks**

100 The huge potential added value of data collection during a pandemic must be weighed against
101 related practical and ethical risks, including safeguarding the health and wellbeing of Young
102 Lives respondents and staff. Maintaining data quality and high ethical standards is still
103 paramount when conducting social research in a climate of emergency, and just because new
104 data collection is possible does not make it justified.⁶ Indeed, whether we should request people
105 in low- and middle-income countries to engage in research at all during this kind of crisis is an
106 important ethical dilemma.

107 We reasoned that Young Lives is in a unique position to inform policy makers in both our
108 study countries and globally about the effects of the pandemic on young people's lives and
109 wellbeing, and to do so relatively quickly. The fact that significant progress had already been
110 made in designing and preparing for the Round 6 survey meant the team were poised to rapidly
111 respond to the current situation; this included up-to-date contact information for the majority
112 of over 11,000 families, with tracking of current locations already completed in three out of
113 four of our study countries.

⁴ The phone survey is pre-piloted and piloted remotely in the four study countries with youth from outside the Young Lives sample who are the same age and from similar communities as their Young Lives counterparts. The pre-pilot gauges the time required to administer the survey, tests the feasibility, sensitivity, and strength of specific questions, and informs development of the CAPI program. Enumerators then pilot the survey to familiarise themselves with the instrument and protocols, re-test questions, and conduct a final check of the CAPI program.

⁵ Research reciprocity requires researchers to consider what they take from research participants as well as what they offer them in return. Young Lives country teams lead on the reciprocity strategies in their contexts, focusing on fairness and consistency. Reciprocity within research relationships is nevertheless frequently imbalanced and expectations change over time; it is therefore an aspect of research ethics practice that warrants frequent review by longitudinal researchers working with vulnerable populations.

⁶ See 'Guidance for Research in Response to Humanitarian Emergencies' by Mormina M, Horn R, Hallowell N, Musesengwa R, Lingou S, and Nguyen J. (2020) of the Oxford Wellcome Centre for Ethics and Humanities. <https://researchsupport.admin.ox.ac.uk/files/guidanceforresearchinresponsetopublichealthorhumanitarianemergenciespdf> (accessed 02 June 2020).

114 Weighing up and mitigating the risks of continuing longitudinal research at this time is
115 central to what we mean by the ethics of disruption, and in Young Lives, this has required
116 addressing several core considerations underpinning its study design and principles:

- 117 • Managing research relationships and reciprocity within an observational study design
- 118 • Maintaining methodological continuity and consistency across time
- 119 • Balancing immediate response against the longer-term perspective

120

121 *Reciprocating within the constraints of an observational study*

122 Longitudinal cohort studies rely heavily on the quality of the relationships between researchers
123 and respondents to underpin research vitality and longevity. Preserving the cohort for future
124 data rounds and taking steps to minimise respondent attrition and respondent fatigue over long
125 periods of time is a methodological priority. Research reciprocity is a core value within Young
126 Lives and a key strategy to reduce attrition, but it is complicated by unequal power relations,
127 the realities of poverty and human suffering and the study's observational research design. The
128 decision to move to a phone-based survey sought to minimise, if not eliminate, physical and
129 health risks for both research participants and survey enumerators. But the projects' ethical
130 commitments are multi-layered and even in a global health crisis are not limited to health
131 concerns.

132 Trust, for example, is crucial to long-term research relationships yet can be difficult to
133 manage in emergency situations (Dawson et al 2020:5). And although mobile phones are now
134 widely used in the four study countries, the phone is not the most user-friendly mechanism for
135 eliciting potentially sensitive information and it is impossible to read body language. For this
136 reason, certain topics of policy interest, such as individual experiences of domestic violence
137 during lockdown, have purposefully been excluded from the phone survey. One advantage of
138 a longitudinal study is that a level of trust already exists, and some enumerators have been
139 recruited because they have interviewed the families before. However, there is a risk of the
140 phone survey inadvertently taking advantage of this long-term engagement with the families,
141 rendering informed consent ever more important.

142 Managing expectations within the long-term research relationship during these difficult
143 times is indeed a challenge. We recognize that many respondents who agree to the phone survey
144 are likely to be living in very stressful and precarious circumstances. The phone survey is

145 purposefully short (any one call should be no more than 30 minutes) to reduce respondent
146 burden, and only experienced enumerators that have worked previously on data collection for
147 Young Lives will be hired.

148 Young Lives families are already feeling the economic repercussions of the pandemic.
149 We know of two families that emailed one of the country teams to ask for financial help,
150 compelling the team to agree to develop a country protocol. One researcher queried what a
151 ‘compassionate response’ to these pleas might look like in the current circumstances,
152 ‘remembering that we are human and so are our cohort members.’ In these very initial cases, a
153 few members of the team who were familiar with the families collated a modest donation out
154 of their own pockets and agreed a carefully worded script to explain (over the phone) to the
155 families that these were personal one-off donations, not from the project, aware that they might
156 be setting a precedent.

157 The need to develop well-defined protocols for responding to respondents’ requests in
158 the time of COVID-19 have quickly become apparent. Such protocols need to: promote equity
159 by equipping survey enumerators with guidance to treat respondents equitably; help avoid
160 creating false expectations, particularly in relation to the next data collection round; protect the
161 psychological wellbeing of enumerators by reducing the burden of responsibility to make
162 difficult decisions themselves; and provide research teams with a systematic way of recording
163 cases of concern.

164 In the past, country teams intervened in individual cases of emergency health crisis, for
165 example, facilitating transportation to a hospital, but avoided other types of intervention (e.g.
166 paying school fees). They determine how best to thank participating families and to compensate
167 them for potential lost wages for the time taken up by the interviews, usually a small amount
168 of cash or a gift (e.g. child’s backpack, mini radio) and photos, such approaches agreed and
169 consistently applied at country-level. Other than this, researchers remind participants that they
170 will not personally benefit by participating in the study.

171 It is not possible for researchers to physically hand over thank-you gifts to respondents
172 of the upcoming phone survey. Instead, the project will offer phone credit or an equivalent
173 bank transfer as a token of thanks to those who respond to the survey. The amount of phone
174 credit is considerably higher than what would normally have been provided owing to the
175 exceptional circumstances. Additionally, a resource leaflet containing information about
176 COVID-19 and the details for country-specific services, including for emotional support, will

177 be sent via messenger or email to all participants and posted on the international and country
178 Young Lives websites. Many communities are poorly resourced when it comes to services for
179 youth in difficulty.

180 COVID-19 is challenging our understanding of vulnerability within the team, as well,
181 particularly with respect to the survey enumerators since they are the ‘frontline’ workers in
182 direct conversation with the study’s youth and families. As data collection progresses, they
183 might find some of their conversations stressful or feel a sense of isolation if they are used to
184 working as part of a face-to-face field team. It is important that enumerators can access
185 emotional support, even under lockdown conditions, whether through peer debriefings or
186 professional counselling when needed. Indeed, some of the enumerators trained to undertake
187 the phone survey have had to deal with confirmed cases of coronavirus within their families or
188 have themselves had to self-isolate with suspected symptoms and stop work. There is not a
189 protocol for how to support enumerators affected by the virus during the period of data
190 collection, but the local teams are trying to devise a consistent response and reduce financial-
191 and work-related pressures on these individuals.

192 We acknowledge that introducing changes presents risks to the research but are
193 nonetheless appropriate responses within an ethics of disruption. For example, increasing the
194 amount of compensation has potential to bias answers and might raise families’ expectations
195 in future survey rounds post-COVID-19. Also, this monetary compensation, however modest,
196 and the information provided in the leaflet might impact on behaviours, and thus, be an
197 intervention, potentially affecting outcomes and research findings. Navigating an ethics of
198 disruption has meant weighing up these risks against new demands on research reciprocity in
199 the current crisis.

200

201 *Maintaining continuity and consistency*

202 Responding to the pandemic obviously requires research flexibility and adaptation, but some
203 changes may threaten to dilute the strength of the longitudinal study design particularly in
204 relation to data consistency and cohort continuity across many years. Administering both the
205 new phone survey and the delayed Round 6 survey requires careful planning, for example,
206 around seasonality (returning to communities at the same time of year) and age (same timing
207 for older and younger cohorts); the order in which survey questions are asked; using the same

208 wording for questions; and handling of the data (use of consistent identifiers and security
209 protocols).

210 Our new phone survey introduces some new targeted questions that will elicit sensitive
211 information about illness and death to understand how many young people have been affected
212 directly or indirectly by COVID-19. The new data will be linked to individual, household,
213 community and school-level data collected in previous rounds, so that the new data are
214 integrated in a consistent manner within the wider corpus of data.

215 Recent successes using phone-based tracking (pre-pandemic) in preparation for the
216 Round 6 survey suggest this is a suitable communication method for contacting Young Lives
217 families; however, it is unclear what impact this new data collection method (phone survey) or
218 a new line of questioning (about coronavirus) might have on future survey rounds and funders'
219 and participants' expectations. It might be that certain changes will stick over the longer-term
220 and be adopted for future survey rounds, such as a greater reliance on remote data collection
221 techniques. Such decisions will need to be revisited in the course of future research planning.

222

223 *Responding quickly with an eye to the future*

224 Longitudinal cohort researchers responding to COVID-19 are managing multiple, sometimes
225 competing short-term and long-term research demands. There is understandably a sense of
226 urgency; donors want to fund research that can provide rapid answers to how to best address
227 COVID-19 and inform related policy responses, including adapting existing funded projects.⁷
228 Yet longitudinal researchers must maintain an eye on the longer-term even as they attempt to
229 respond quickly to the immediate emergency and humanitarian crisis. For example, they must
230 balance the imperative to archive new data as soon as possible for wider public use with the
231 need to maintain the high quality of the panel data set and ethical commitments, and to not
232 jeopardize the potential for future post-pandemic data collection.⁸

233 An incredible amount of work goes into preparing Young Lives survey data sets for
234 public archiving; normally, survey researchers within the project have priority access to use
235 the data for up to one year after the end of data collection before it is placed in the public

⁷ Reflecting this sense of urgency, some journals are using their pre-print servers to publish papers on COVID-19 prior to peer-review so that findings are immediately available.

⁸ See Rob Davies' 'COVID-19: a defining moment for longitudinal research?' <https://www.closer.ac.uk/news-opinion/blog/covid-19-defining-moment-longitudinal-research/> (accessed 11 June 2020).

236 domain. The period of data embargo is made in agreement with the funder to acknowledge the
237 time and intellectual input of the Young Lives staff and to support capacity building. In the
238 case of the new COVID-19 phone survey, both the funder and international team of researchers
239 agreed to prioritise rapid sharing of the data over academic exclusivity, on the understanding
240 that early release of new data must in no way jeopardise our legal and moral obligation to
241 protect the anonymity of research participants and the places where they live.

242

243 **Concluding thoughts**

244 There is a distinct sense among many social researchers that COVID-19 has transformed our
245 familiar ethical and practical landscapes for conducting research. In this short piece, we
246 described some of the ways in which the Young Lives longitudinal cohort study has navigated
247 this altered terrain, or ‘ethics of disruption’. However, many of the ethical and practical issues
248 we highlight are not unique to either longitudinal cohort studies nor to research conducted in
249 low- and middle-income countries. On one hand, concerns around research integrity,
250 reciprocity and safeguarding are necessarily shared across distant geographies and different
251 study designs. On the other hand, each study has its unique history and constellation of
252 relationships, resources, and constraints. Perhaps it is the way considerations of temporality,
253 vulnerability and relationship combine in longitudinal cohort studies in low- and middle-
254 income countries that creates their challenges and opportunities in the time of COVID. In our
255 experience, what feels different this time, is that the global pandemic affects and connects us
256 all, albeit differently, and foments a renewed sense of solidarity with and ethical responsibility
257 to the study’s young people and families for whom the effects of the crisis will be long-lasting.

258

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267

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