

# Ethical Considerations for Evidence Generation Involving Children on the COVID-19 Pandemic

Gabrielle Berman

Office of Research - Innocenti Discussion Paper  
DP 2020-01 | April 2020

## THE UNICEF OFFICE OF RESEARCH – INNOCENTI

The UNICEF Office of Research – Innocenti is UNICEF's dedicated research centre. It undertakes research on current and emerging issues in order to inform the strategic direction, policies and programmes of UNICEF and its partners, shape global debates on child rights and development, and inform the global research and policy agenda for all children, and particularly for the most vulnerable.

Office of Research – Innocenti publications are contributions to a global debate on children and may not necessarily reflect UNICEF policies or approaches.

This publication has not been edited to official publications standards and UNICEF accepts no responsibility for errors.

The Office of Research – Innocenti receives financial support from the Government of Italy, while funding for specific projects is also provided by other governments, international institutions and private sources, including UNICEF National Committees.

For further information and to download or order this and other publications, please visit the website at: [www.unicef-irc.org](http://www.unicef-irc.org).

## INNOCENTI DISCUSSION PAPERS

UNICEF Innocenti Discussion Papers are signed pieces by experts and researchers on current topics in social and economic policy and the realization of children's rights. The aim is to encourage reflection and stimulate wide-ranging discussion.

This is a peer reviewed series.

Extracts from this discussion paper may be freely reproduced with due acknowledgement. Requests to utilize larger portions or the full publication should be addressed to the Communications Unit at: [florence@unicef.org](mailto:florence@unicef.org).

For readers wishing to cite this document we suggest the following form: Berman, G. Ethical Considerations for Evidence Generation Involving Children on the COVID-19 Pandemic. Innocenti

Discussion Paper 2020-01. UNICEF Office of Research – Innocenti, Florence, 2020.

### **Correspondence should be addressed to:**

UNICEF Office of Research – Innocenti

Via degli Alfani, 58

50121 Florence

ITALY

Tel: (+39) 055 20 330

Fax: (+39) 055 2033 220

[florence@unicef.org](mailto:florence@unicef.org)

[www.unicef-irc.org](http://www.unicef-irc.org)

twitter: @UNICEFInnocenti

[facebook.com/UnicefInnocenti](https://facebook.com/UnicefInnocenti)

## CONTENTS

### ETHICAL CONSIDERATIONS FOR EVIDENCE GENERATION INVOLVING CHILDREN ON THE COVID-19 PANDEMIC..... 4

#### Why ethical considerations specifically for evidence generation in COVID-19? ..... 4

What makes COVID-19 different?..... 4

Vulnerable cohorts of children ..... 6

Considering context ..... 7

When should you consider ethics? ..... 7

Why is this ethical guidance necessary?..... 7

#### Key ethical considerations for undertaking evidence generation involving children during COVID-19 (emergency and immediate recovery phase) ..... 8

I. Duty of care: weighing harms and benefits. Should the evidence generation take place? ..... 9

II. Ensuring privacy and confidentiality and consent..... 10

III. Ensuring appropriate communication of findings ..... 11

#### TABLE 1: ETHICAL CONSIDERATIONS FOR UNDERTAKING EVIDENCE GENERATION ON COVID-19 INVOLVING CHILDREN (EMERGENCY AND RECOVERY PHASE)..... 12

#### Key ethical considerations for undertaking evidence generation involving children post-COVID-19 containment and lifting of restrictions (post-emergency)..... 13

I. Institutional capacity to ethically involve children in research..... 13

II. Understanding power relations ..... 14

III. Harms and benefits ..... 14

IV. Informed consent and capacities of participants ..... 15

V. Privacy and confidentiality ..... 15

VI. Payment, compensation and reciprocity ..... 15

VII. Communication of findings ..... 16

#### TABLE 2: ETHICAL CONSIDERATIONS FOR UNDERTAKING EVIDENCE GENERATION ON COVID-19 INVOLVING CHILDREN (POST-EMERGENCY PHASE) ..... 17

## ETHICAL CONSIDERATIONS FOR EVIDENCE GENERATION INVOLVING CHILDREN ON THE COVID-19 PANDEMIC

### Why ethical considerations specifically for evidence generation in COVID-19?

*UNICEFs Procedure for Ethical Standards in Research, Evaluations and Data Collection* (2015) articulates the organization's position that it is the process of data collection, analysis and communication that raises ethical issues and not the nature of the evidence generation (e.g. research or evaluations). This approach recognizes that ethical conduct in evidence generation is an imperative to uphold the rights of those involved, to mitigate against potential harms and to pursue positive outcomes for children during and after this unprecedented outbreak. Hence all data collection, analysis and communication during and after COVID-19 requires ethical reflection and a strong focus on doing no harm.

This document identifies key ethical considerations (a) when undertaking evidence generation involving children during the mitigation stage of the pandemic (emergency phase) and (b) on subject matter relating to COVID-19 once the pandemic has been contained and containment policy measures, including lockdowns, have been lifted (post-emergency phase).

### What makes COVID-19 different?

While the COVID-19 pandemic is undoubtedly a global crisis, with evidence generation activities raising critical ethical issues that have been captured in the literature and relevant guidelines,<sup>1</sup> there are specificities relating to this emergency that need to be taken into account in unpacking potential ethical issues. Hence while ethical issues pertaining to evidence generation involving children in emergencies and humanitarian contexts are relevant and should be considered, there are a number of factors that define this 'special case' that must be considered from the outset and that will inform the core ethical considerations that will need to be taken into account. These are:

1. The spread of COVID-19 has been a protracted process and containment has been difficult. This has resulted in mandatory lockdowns and the potential for extended isolation of families.
2. In a number of countries these lockdowns occur in contexts of overcrowding, inadequate sanitation and health infrastructure, and where incomes are earned on a daily basis. These conditions are leading, or are likely to lead, to greater social and economic strain in the poorest contexts.

Taking into account the differing distribution of impacts within child populations (discussed further in the section on vulnerable children below), the following impacts and experiences during and after the COVID-19 pandemic need to be considered when undertaking ethical evidence generation:

<sup>1</sup> Berman, Gabrielle; Powell, James; Garcia Herranz, Manuel (2018). Ethical Considerations When Using Social Media for Evidence Generation, *Innocenti Discussion Papers no. 2018-01*, UNICEF Office of Research – Innocenti, Florence; Humanitarian Accountability Partnership (2014). The Core Humanitarian Standard on Quality and Accountability. <http://www.corehumanitarianstandard.org/the-standard>; Mann, G. and Tolfree, D. (2003). Children's Participation in Research: Reflections from the care and protection of separated children in emergencies project, Save the Children Sweden, Stockholm; O'Mathuna, D. P. (2010). Conducting Research in the Aftermath of Disasters: Ethical considerations, *Journal of Evidence-Based Medicine*, 3 (2), pp. 65–75; Sumathipala, A., Jafarey, A., De Castro, L., Ahmad, A., Marcer, D., Srinivasan, S., Kumar, N.K., Sutaryo, S., Bhan, A., Wadeyaratne, D., Beneragama, S., Jayasekera, C., Edirisingha, S., Siriwardhana, C. and Siribaddana, S. (2007). The Draft Statement/Guidelines for Disaster Research, Working Group on Disaster Research and Ethics. <https://globalhealthtrials.tghn.org/articles/draft-statementguidelines-disaster-research/>;



### Direct impacts

3. In light of the potential for extended isolation within home/institutional settings, children may be subjected to direct, indirect and possibly prolonged exposure to violence, including physical, sexual and verbal abuse and ongoing and repeated exposure to risky behaviours such as drug taking. In environments where violence is already occurring, this may be exacerbated by any lockdown in place. In certain contexts children may be at risk of not only experiencing personal violence but also heightened exposure to violence against other family members.
4. Children may be exposed to greater violence and surveillance outside the home resulting from enforcement of social distancing and lockdown and potential social unrest arising from restricted capacities for people to earn livelihoods.
5. Children may experience high levels of stress, frustration consequent to restrictions relating to movement outside the home, and limited social interactions.
6. Children's privacy in lockdown may be severely limited.
7. Children may or may not have processed any of the above, or indeed sought or received any psychosocial supports. It is possible that children and their families may not even be aware of internalized trauma and impacts.
8. Children's increased engagement with digital interfaces for schooling and socialization may expose them to an increased risk of harassment, abuse and other negative impacts.
9. Child safeguarding and other relevant child services and supports may not be possible to deliver remotely, may be overburdened resulting in significant delays, or may not be considered 'critical' and therefore may not be available. This in turn will impact the capacity to appropriately refer children identified to be at risk during evidence generation. Where these services are available online, for reasons noted above they may not be accessible to certain children, further reinforcing inequities in contexts where children's access to technologies is limited or where privacy is difficult to secure.

### Indirect impacts

10. Children are likely to have been directly exposed to the social, economic and health-related anxieties of carers and guardians. This will undoubtedly be more pronounced in contexts where employment is more precarious.
11. Children may have had to deal with the grief and anxiety attached to illnesses or ultimately death within families while unable to provide support as a result of physical distancing.

From the above it should be clear that children and their families are exposed to specific, heightened risks during the COVID-19 pandemic. This is particularly true for vulnerable cohorts that may be exposed to greater risks. These cohorts may also be more difficult to reach and hence, without considered approaches and reflection, are more likely to be marginalized in child-focused evidence generation programmes. It should also be noted that these risks and impacts may continue long after many of the restrictions are removed as the medium- to longer-term social, economic and psychological impacts and effects of COVID-19 are felt.

## Vulnerable cohorts of children

As noted previously, during and after the COVID-19 pandemic, the impacts of the virus itself and the government responses, particularly isolation, may differ across households/individuals within the same geographies. Particular families, cohorts, individuals and children are likely to be more vulnerable than others, particularly in contexts and households where multiple vulnerabilities exist. Those children that may directly or indirectly be more vulnerable include<sup>2</sup>:

- **Children living in poverty, those from households in low socio-economic groups or children of low socio-economic status (SES) in child-headed households.** Children and families living in poverty/low SES families and those in other non-familial living arrangements with low/subsistence incomes will have less resources and are likely to inhabit more confined/overcrowded places. Consequently, children in these contexts may experience greater restrictions and deprivations including less access to virtual communications tools, and by virtue of lack of space, potentially less privacy. These children may not have absolute or sufficient access to resources to meet basic needs, to ensure adequate hygiene and to protect themselves and their families/co-inhabitants from COVID-19 with personal protective equipment, or engage with education provided online. In light of the potentially greater exposure of these households to economic downturns and, in certain contexts, daily income subsistence, they are also more likely to be vulnerable to exploitation both online and offline. Further, their voices may be more likely to be excluded when online evidence generation is undertaken, resulting in further marginalization.
- **Children in intergenerational households.** These children are more likely to experience anxiety and potential trauma related to the greater risk of infection of older, more vulnerable members of the household.
- **Children with disabilities or in households with persons with disabilities.** In these instances, the child/person with a disability may be more vulnerable to the contagion, less able to understand or manage the restrictions or lack of services, and/or may struggle to fulfil basic needs such as shopping.
- **Children who are primary carers.** In these circumstances the person that the child cares for may be at greater risk, creating anxiety and stress not only about providing care but also the fear of contracting and passing on the virus.
- **Children who have mental health issues or living with people who have mental health issues** may be at heightened risk in isolation as the traditional routines and strategies of the individual with mental health issues are not accessible and/or the restrictions serve to exacerbate conditions.
- **Children on the move** (migrants, refugees/asylum seekers and internally displaced), particularly those that are unaccompanied and separated, may not be easily able to access the asylum/migration systems and resettlement procedures and supports. Further, reunification services and processes may be delayed, risking exposure of children to trafficking, abuse and exploitation.
- **Children on the streets.** Where children are living on the street, they are more likely not to have access to information regarding protective measures, resources or access to any communal resources (soap, clean running water, gloves). They are also more likely to be visible within less crowded streets and therefore at greater risk of violence and exploitation, and more susceptible to lack of opportunities to earn money, thereby reinforcing their vulnerability to exploitation or, more generally, deprivation. These vulnerabilities will likely continue as the economic impacts of COVID-19 are felt.

<sup>2</sup> This list is not exhaustive and traditionally marginalized cohorts such as street children, children from marginalized communities including those from indigenous and ethnic minority communities may be included within these categories or be at the intersection of these categories.

## Considering context

It should be emphasized that some of the above issues may not apply to all contexts given that the spread and impacts of the virus across geographies will vary, as will the responses by governments. To this end the following guidance, like all guidance pertaining to ethics in evidence generation, needs to be contextualized and should be considered primarily as a starting point for ethical reflection.

## When should you consider ethics?

As noted above, ethical issues may arise in relation to data collection, analysis and dissemination of information. Consequently, in order to safeguard the best interests of the child, UNICEF requires that all evidence generation involve ethical reflection. This includes:

- Studies
- Surveys (including Household Surveys, U-Report)
- Polls
- Research
- Evaluations
- Online and offline forums

This approach demands that the primary interests of the child be the focus of ethical considerations, not the output, as previously noted above. Subsequently the reflection, consultation, planning and strategies for addressing ethical issues should be applied even in the context of data collection and analysis activities that have not traditionally been the domain of ethics.

## Why is this ethical guidance necessary?

As noted above, the COVID-19 pandemic is a unique emergency situation in which the ethical issues arising from relevant contexts are defined by local realities but also, and importantly, the specificities of the virus itself and government responses to the outbreak. These issues include the scale, reach, social physical distancing measures, economic policies and complications relating to the virus, including limitations in testing capacities, lack of precise knowledge of transmission and asymptomatic infection. These factors have led to unprecedented and protracted public responses that require explicit consideration in the planning of, and indeed throughout, evidence generation programmes.

Without appropriate ethical considerations a number of negative outcomes may result from evidence generation involving children, including<sup>3</sup>:

1. Significant exposure to risk of traumatization or re-traumatization of children due to inappropriate questions and timing and an inability to determine where they may be within trauma and healing cycles. Difficulties responding to and ensuring an appropriate duty of care during the emergency

<sup>3</sup> Berman, G., Hart, J., O'Mathúna, D., Mattellone, E., Potts, A., O'Kane, C., Shusterman, J., and Tanner, T. (2016). *What We Know about Ethical Research Involving Children in Humanitarian Settings: An overview of principles, the literature and case studies*, Innocenti Working Paper No. 2016-18, UNICEF Office of Research, Florence.

stage and immediately post if observation or disclosure of abuse occurs and/or if significant psychological/physical needs are evidenced. This may occur given that (a) access to services may be limited and/or overstretched resulting in protracted delays (b) referral for psychosocial or physical care may simply not be possible because services are not available or unable to provide relevant supports (c) referrals may jeopardize the safety of child in context.

2. Difficulties responding to and ensuring an appropriate duty of care during the emergency stage and immediately post-emergency if observation or disclosure of abuse occurs and/or if significant psychological/physical needs are evidenced. This may occur given that (a) access to services may be limited and/or overstretched resulting in protracted delays, (b) referral for psychosocial or physical care may simply not be possible because services are not available or are unable to provide relevant supports, (c) referrals may jeopardize the safety of the child in context.
3. Perceived and actual privacy and confidentiality violations and data collection in excess of requirements and without appropriate and truly informed consent impacting both the child and resulting in the erosion of trust from children and their communities.
4. Data obtained for one purpose, such as contact tracing, being misused for political surveillance or social shaming.
5. Potential reprisals against child participation or even consequent attempts at recruitment in evidence generation, heightened during the mitigation stage of the outbreak in contexts where children are in lockdown.
6. Poorly designed evidence generation that produces unreliable or inaccurate data including:
  - ▶ poorly designed instruments that make incorrect assumptions relating to impacts, needs experiences, and heterogeneity of children and their experiences, and
  - ▶ using technologies that may not be accessible to disadvantaged children, resulting in poor representation, further marginalization of disadvantaged groups and inappropriate or inaccurate findings.

These in turn will result in poorly informed policies, programming and future risk mitigation strategies in outbreaks that fail to equitably meet children's needs and long-term development in the present and in consequent future outbreaks.

7. Missed opportunities to obtain children's perspectives and insights on a wide range of issues post-emergency, not just those considered to be 'children's issues', and/or prioritizing subject matter that fails to take into account children's priorities in relation to needs, experiences and supports during COVID-19 and other future outbreaks.



## KEY ETHICAL CONSIDERATIONS FOR UNDERTAKING EVIDENCE GENERATION INVOLVING CHILDREN DURING COVID-19 (EMERGENCY AND IMMEDIATE RECOVERY PHASE)

The following are key ethical issues in relation to undertaking ethical evidence generation involving children during the COVID-19 emergency and immediately post-emergency.

- Duty of care: weighing harms and benefits. Should the evidence generation take place?
- Ensuring privacy, confidentiality and consent
- Ensuring appropriate communication of findings

### I. Duty of care: weighing harms and benefits. Should the evidence generation take place?

#### I-A When evidence generation should not take place, or should be very carefully considered:

The following are instances where evidence generation should not take place, or where stopping or not proceeding should be very seriously considered. In these cases clear justifications for the urgency and necessity of the evidence generation during this period are required and a clearly articulated harm versus risk analysis should be undertaken. In these instances the principle of 'do no harm' should be of primary importance:

- To ensure the safety of children, their communities and data collectors, serious consideration should be given and action taken to **cease all face-to-face primary data collection** even in contexts where cases are currently low and no social distancing measures are in place.
- Recognizing the moral imperative to 'do no harm' and that:
  - Many children may be in contexts where their freedoms are significantly restricted
  - Children may be experiencing trauma by virtue of restrictions
  - Those collecting data may not be doing so for immediate therapeutic purposes
  - Children experiencing trauma may not have appropriately processed the trauma, or may be at various stages in the trauma cycle
  - Access to services may be limited, involve significant delays and/or may jeopardize the child in context.

**Online/mobile evidence generation for the sake of data collection should be avoided for the reasons mentioned above. Where it is undertaken, the purpose, nature and value of any direct data collection to participants should be clear and appropriate and adequate support services should be provided.**

**However, as a rule of thumb, data collection pertaining to needs and experiences during the COVID-19 pandemic should be delayed, specifically when lockdowns and restrictions are in place. Alternatively, such data collection should be clearly justified in terms of direct benefits and programming outcomes (see Box 1).** This delay should be considered until such time as privacy is more likely to be feasible, appropriate routine has been restored to children's lives and services

are accessible and able to function (to the greatest extent possible given local conditions) such that referrals for health and psychosocial services are possible and/or other relevant supports can be put in place. It should be noted that this can be similarly argued on data quality grounds, as processing of needs and experiences may take time.

### 1-B When/how evidence generation may be undertaken during COVID-19:

The following are the limited instances in which evidence generation may be required during the pandemic and immediately afterwards. In these instances the principle of 'do no harm' still applies by virtue of its importance when reflecting on the methods and risk mitigation strategies to be adopted.

- **Where evidence generation is integral to the delivery of emergency services** and critical supports, including those related to containment of the virus. These activities may include baseline surveys, rapid assessments, programme monitoring, or a formative evaluation of the response. However, these exceptions should be narrowly tailored to include only vital information that cannot be sourced via alternative, safer methods.
  - ▶ Where evidence generation is integral to the delivery of emergency services and critical supports/programming, ensure that the data are sufficiently disaggregated at minimum by sex and age, and capture the needs and experiences of marginalized or hard-to-reach populations such as children with disabilities, children working as labourers, children on the move, etc., to ensure that there is a good understanding of the specific needs of these populations and that they are not further marginalized within the context of the pandemic.
- **If evidence activities are to be undertaken in these exceptional cases**, all the other mitigation measures should be applied to the greatest extent possible. These include:
  - ▶ maximizing the use of secondary data sources and minimizing face-to-face approaches in favour of phone or virtual interactions, etc.
  - ▶ ensuring enumerators are protected and in turn will protect the persons contacted. This may require personal protective equipment, enhanced training, more on-site supervision, and symptom monitoring
  - ▶ maintaining traditional standards of data privacy including necessity (collecting only critical data), use limitations, limitations on access to raw data, data security, etc.
  - ▶ ensuring that questions are appropriately sensitive for age and context and that they do not traumatize or re-traumatize children.

## BOX 1

### Can't interviewing and asking questions sometimes be good for children?

In considering arguments about the potential psychosocial benefits of data collection for children during emergency situations, it should be noted that data collection with children in and of itself is not a therapeutic intervention. **During emergencies, data collection should not be the primary purpose of programmes.** Programmes involving children should be primarily designed and focused on intervention outcomes, with appropriate supports and appropriately qualified professionals and personnel and considered safeguards.

## II. Ensuring privacy and confidentiality and consent

During and after the pandemic, when gathering evidence relating to COVID-19 **collected from children through the passive use of third-party big data sets**, the following key issues relating to privacy, confidentiality and consent should be taken into account.

- Legislation pertaining to children's data
- What children should reasonably expect in terms of privacy and confidentiality when using the technology (for example when data are collected from specific child forums, etc.) and ensuring that any data received are in de-identified form
- Understanding the limitations of the data including issues related to representation on the platform, bias, contextual integrity, etc.<sup>4</sup>
- Be aware that in certain contexts children may have broken lockdown or curfews. Consider the legal implications of this.

## III. Ensuring appropriate communication of findings

After undertaking evidence generation during the COVID-19 pandemic, either directly or through third-party big data sets, the following should be considered:

- When **collecting information necessary to inform emergency service delivery** consider limiting the sharing of findings to relevant service provider personnel, being cognizant of the potential for stigma and discrimination if the information is disseminated more broadly.
- Where data fail to capture marginalized or hard-to-reach populations explicitly, note this in findings and be clear on the implications for these cohorts and for programming and policy. Use the findings to advocate for specific resources to ensure that these data are collected as soon as possible.
- Should **evidence be generated using big data sets comprising children's data**, consider:
  - ▶ privacy measures such as aggregation of findings and non-inclusion of identifying quotes
  - ▶ the potential for stigma and subsequent discrimination, and mitigation strategies (including increased aggregation in reporting findings)
  - ▶ limitations of both the data and the findings and the need to clearly identify and note these in the final report.
- That findings are used to support the well-being of children. In the contexts of delivery of emergency services and critical supports the data should be used explicitly and exclusively for this purpose.

<sup>4</sup> For further information relating to use of third-party social media data see: Berman, Gabrielle; Powell, James; Garcia Herranz, Manuel (2018). Ethical Considerations When Using Social Media for Evidence Generation, *Innocenti Research Briefs no. 2018-20*, UNICEF Office of Research – Innocenti, Florence

**TABLE 1: ETHICAL CONSIDERATIONS FOR UNDERTAKING EVIDENCE GENERATION ON COVID-19 INVOLVING CHILDREN (EMERGENCY AND RECOVERY PHASE)**

TYPES OF EVIDENCE GENERATION	HARMS AND BENEFITS	PRIVACY, CONFIDENTIALITY AND CONSENT	COMMUNICATION OF FINDINGS
<b>FACE-TO-FACE</b>	<b>DO NOT PROCEED</b>	<b>DO NOT PROCEED</b>	<b>DO NOT PROCEED</b>
<b>General</b>	The potential to spread the virus		
<b>ONLINE</b>  <b>Asking about experiences and needs during COVID-19 as data collection exercise</b>	<b>PROCEED WITH EXTREME CAUTION</b> <b>CONSIDER:</b> <ul style="list-style-type: none"> <li>▶ the potential to re-traumatize children</li> <li>▶ that access to services may be limited, involve significant delays and/or may jeopardize the child in context</li> <li>▶ those collecting data are frequently not doing so exclusively for therapeutic purposes</li> <li>▶ that children may be experiencing trauma, and may not have appropriately processed the trauma, or may be at various stages in the trauma cycle.</li> </ul> <p>The exception may be where the evidence generation is a product of a programme with direct benefits derived by participants. In these cases avoid sensitive questions and ensure appropriate online supports. Acknowledge evidence gaps if using findings. Adhere to appropriate privacy standards.</p>	<b>PROCEED WITH EXTREME CAUTION</b>  Be aware that in certain contexts children may have broken lockdown or curfews. Consider the legal implications of this.	<b>PROCEED WITH EXTREME CAUTION</b>  Be clear on the limitations and representation of the data. Clearly articulate any potential missing groups of children. Flag warnings that policy or programmes based on these data may exclude the most vulnerable and therefore policy or programmes need to explicitly take into account services and responses for these groups.
<b>FACE-TO-FACE</b>  <b>Evidence informing critical emergency response and programming</b>	<b>PROCEED WITH EXTREME CAUTION</b> <b>LIMIT THE HARMS BY:</b> <ul style="list-style-type: none"> <li>▶ maximizing the use of secondary data sources and minimizing face-to-face approaches in favour of phone or virtual interactions, etc.</li> <li>▶ ensuring enumerators are protected and in turn will take all measures to protect the persons contacted. This may require personal protective equipment, enhanced training, more on-site supervision, and symptom monitoring.</li> <li>▶ maintaining traditional standards of data privacy including use limitations, limitations on access to raw data, data security, etc.</li> </ul>	<b>LIMIT THE HARMS BY:</b>  Ensuring data confidentiality and security during <ul style="list-style-type: none"> <li>▶ collection</li> <li>▶ transfer</li> <li>▶ sharing</li> <li>▶ storage</li> <li>▶ communication</li> </ul> Ensuring that data are used exclusively and solely for emergency purposes.	<b>LIMIT THE HARMS BY ENSURING:</b> <ul style="list-style-type: none"> <li>▶ that data and findings are limited only to those that need the information for service delivery</li> <li>▶ that findings are used to inform emergency/critical interventions.</li> </ul>
<b>USING THIRD-PARTY BIG DATA</b>	<b>PROCEED WITH CAUTION</b> <b>LIMIT THE HARMS BY CONSIDERING:</b> <ul style="list-style-type: none"> <li>▶ children's expectations of privacy</li> <li>▶ categorical and individual data protection and anonymization</li> <li>▶ potential for stigma and discrimination in light of categorical findings.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Adhere to legislation pertaining to children's data collection and processing.</li> <li>▶ Understand children's expectations of privacy and confidentiality and ensure that any data received are in de-identified form.</li> </ul>	<b>LIMIT THE HARMS BY ENSURING:</b> <ul style="list-style-type: none"> <li>▶ that identifying quotes are removed from any report</li> <li>▶ that the potential for stigma and subsequent discrimination are considered alongside strategies such as increased aggregation in the reporting of findings</li> <li>▶ that the limitations are identified and noted in the report both in relation to the data and the findings.*</li> </ul>

\*For further information on ethical considerations and mitigation strategies when using third-party big data sets and analysis see: Berman, Gabrielle; Powell, James; Garcia Herranz, Manuel (2018). Ethical Considerations When Using Social Media for Evidence Generation, *Innocenti Discussion Papers no. 2018-01*, UNICEF Office of Research – Innocenti, Florence.

## KEY ETHICAL CONSIDERATIONS FOR UNDERTAKING EVIDENCE GENERATION INVOLVING CHILDREN POST-COVID-19 CONTAINMENT AND LIFTING OF RESTRICTIONS (POST-EMERGENCY)

Below is a summary of the critical ethical issues to be considered and accounted for in the design of any evidence generation project relating to COVID-19 involving children after the emergency phase of the pandemic. It should be noted that, unless there is a clear and well-justified need for urgency, projects should be postponed until services are restored and children's lives have largely returned to pre-COVID-19 routines prior to data collection. It should be noted that the following section does not go into significant detail for each issue given that, as noted above, COVID-19 is a specific case of an emergency context and detailed information relating to involving children in emergency contexts ethically can be found in other sources such as [Berman et al. \(2015\)](#). The information given here is just a summary of the critical considerations, adapted to address the specifics of the COVID-19 context.

The key issues that should be considered in this context include:

- Institutional capacity to involve children in research ethically
- Understanding power relations
- Weighing harms and benefits
- Informed consent (in appropriate form and language) and capacities of participants
- Privacy and confidentiality
- Payment, compensation, ancillary services and reciprocity
- Appropriate communication of findings

### I. Institutional capacity to ethically involve children in research

#### Key issues to consider

- Vetting and training of staff to work respectfully with children and their communities
- Clear protection protocols relating to:
  - Protecting children from re-traumatization
  - Identifying and referring those needing psychosocial or health support
  - Protecting staff if necessary
  - Complaints mechanism
- Considering the implications of mandatory reporting of child abuse, if abuse is observed or reported by the child or caregivers, the processes that will need to be put in place and any potential negative impacts on children and their families
- Avoiding tokenism: ensuring institutional will to listen to children's priorities or acknowledging limitations to doing so.



## II. Understanding power relations

It is important to consider power differentials and dynamics, and reflect on ways to minimize or manage them in context.

### Key issues to consider

- Perceptions of children and childhood and relationships within families and communities and the likely impacts on issues such as willingness to let children participate and privacy provided to children during any data collection.
- Researchers' relationship with children and potential actions to reduce power differentials to the greatest extent possible in terms of location, seating arrangements, tone and language.
- Relationships between different children (particularly important in the composition of focus groups when ensuring that all participants are able to have a voice and air differences in experiences across gender, SES, etc.)
- Understanding the politics, power dynamics and relationship between data collectors, the instigating organization and children's communities, necessitating reflection on means and ways to engage with the community prior to providing support and ways to address any concerns.

## III. Harms and benefits

### Key issues to consider

- Potential psychological, social, financial and physical risks and benefits to the children in context, their communities and children more broadly. There is a need to consider impacts across different cohorts, particularly marginalized groups.
- The potential risks for data collectors.
- When to include children in research in these contexts, considering safety and where they may be within the trauma cycle.
- Engaging children to understand, inform and reflect on risks.
- The need for child-friendly and contextually appropriate methods and implementation approaches.
- Other potential sources of data to avoid over-researching and unnecessary data collection.
- Legal implications if it is reported that children and their families did not adhere to lockdown or curfew requirements.

## IV. Informed consent and capacities of participants

### Key issues to consider

- Determining whether informed consent is legally required, or culturally expected of a guardian/parent; and who to seek consent from in cases of child-headed households or children in institutions.

- If the evidence generation involves questions related to experiences of violence in the home/institution,
  - ▶ seeking an exemption from parental/guardian consent from ethics review boards,
  - ▶ considering alternative guardians, and/or
  - ▶ taking into account the age and competencies of the children to be interviewed, determining whether they can provide informed consent in this context (which will need to be approved by an ethics review board).
- Ensuring that consent is in a form and language that reflects the competency of the child.

## V. Privacy and confidentiality

### Key issues to consider

- Culture, age and context-appropriate approaches to privacy and potential barriers to privacy.
- Data confidentiality and security including:
  - collection
  - transfer
  - storage
  - communication.

## VI. Payment, compensation and reciprocity

### Key issues to consider

- Meeting need versus payment and compensation.
- Whether or not you can provide ancillary services should they be needed or whether there are appropriate and accessible local services available through which support can be provided for children through a referral process.
- Opportunity cost of children's participation (when and where it is appropriate to undertake the evidence generation).
- Equity and impacts of providing payment or compensation to some members of the community and not others.
- Avoiding coercion.
- Reciprocity: Considering how you can 'give back' to those who have participated, or to their communities, including providing feedback to the communities in a form that is appropriate and accessible.

## VII. Communication of findings

### Key issues to consider

- Reviewing reports prior to dissemination.
- Triangulation from and feedback into communities.
- Using evidence for real change.
- Clear articulation of the limitations of the findings and whether or not they are representative. (to avoid poor policy and programming or marginalization of excluded groups).

**TABLE 2: KEY ETHICAL CONSIDERATIONS FOR UNDERTAKING EVIDENCE GENERATION INVOLVING CHILDREN DURING COVID-19 (EMERGENCY AND IMMEDIATE RECOVERY PHASE)**

INSTITUTIONAL CAPACITY	POWER RELATIONS	HARMS AND BENEFITS	INFORMED CONSENT	PRIVACY AND CONFIDENTIALITY	PAYMENT, COMPENSATION AND ANCILLARY SERVICES	COMMUNICATION OF FINDINGS
Avoiding tokenism: ensuring institutional will to listen to children's priorities or to acknowledge limitations to doing so.	The politics, power dynamics and relationship between data collectors and children's communities	Evaluating risks and benefits	Determining whether informed consent is required of guardian/parent	Culture-, age- and context-appropriate approaches to privacy	Meeting need versus payment and compensation	Reviewing reports prior to dissemination Ensure privacy and reflect on potential for stigma, etc.
Vetting and training of staff to work respectfully with children and their communities, and particularly those that have been potentially traumatized or victimized.	Relationships between different children (particularly for focus groups) and differences in experiences	When to Include children in research in these contexts considering safety and where they may be within the trauma cycle	Ensuring consent is in a form that reflects the competency of the child	Data confidentiality and security ► collection ► transfer ► storage ► communication	Opportunity costs of children's participation  (when and where it is appropriate to undertake the evidence generation)	Triangulation and feedback into communities
Clear protection protocols relating to: ► protecting children from re-traumatization ► identifying and referring those needing psychosocial or health support ► protecting staff if necessary ► complaints mechanisms.	Perceptions of children and childhood and relationships within families, communities and settings.	Engaging children to understand, inform and reflect on risks.			Equity in any payments or compensation, avoiding coercion.	
Considering the Implications of mandatory reporting of abuse if abuse is observed or reported by the child or caregivers.	Researchers' relationship with children and actions to mitigate power differentials.	Child-appropriate methods and implementation. Child-appropriate methods and implementation.			Reciprocity: considering how you can 'give back' to those who have participated, or to their communities.	Clear articulation of the limitations of the findings and whether or not they are representative. (to avoid poor policy and programming or marginalization of excluded groups).

Based on: Berman, Gabrielle; Hart, Jason; O'Mathúna, Dónal; Mattellone, Erica; Potts, Alina; O'Kane, Clare; Shusterman, Jeremy; Tanner, Thomas (2016). What We Know about Ethical Research Involving Children in Humanitarian Settings: An overview of principles, the literature and case studies, *Innocenti Working Papers no. 2016-18*, UNICEF Office of Research – Innocenti, Florence

**for every child, answers**