

Prioritising child participation in infectious disease outbreaks



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We acknowledge that during the COVID-19 pandemic, children from diverse backgrounds across the globe repeatedly called for more opportunities to engage with decision-makers to ensure that efforts to prepare for, respond to and recover from current and future outbreaks comprehensively address children's needs and the risks affecting them. We hope that by providing practitioner-oriented guidance regarding why and how to prioritise child participation before, during and after outbreaks in humanitarian settings, this Mini-Guide can help realise children's right to be heard, ensuring child-centred and, consequently, more effective outbreak management.

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Who is this mini-guide for & how should it be used?



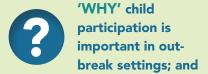
In humanitarian contexts, children typically represent a substantial proportion of affected populations and are both directly and indirectly impacted by outbreaks.² Children have also played an important role in preparedness, response and recovery efforts during past epidemics and pandemics,³ demonstrating both their capacity and willingness to act as viable and valuable partners in outbreak management. In the aftermath of the COVID-19 pandemic, children in humanitarian settings and humanitarian response actors acknowledged that centring children's voices is critical to ensuring that interventions meet the

needs of children and their caregivers. However, children are rarely consulted or substantively involved in the design, implementation, monitoring and evaluation of research, advocacy and programming in humanitarian settings. Recognition of their power, agency and influence still lacks appropriate attention, value, status and resourcing across all sectors involved in outbreak management.

Providing opportunities for diverse children to participate in the decisions that affect them, including in outbreak settings, is a shared responsibility across all humanitarian sectors and is not solely the remit of the protection sector. This Mini-Guide is therefore designed to be used by personnel from all sectors involved in preparing for and responding to infectious disease outbreaks in humanitarian settings. It may also be used by government and civil society counterparts, members of the social service workforce and teachers, among others, who have an obligation to uphold children's right to participate. Practitioners who specialise in working with children - such as those in child protection or education sectors – can help to facilitate this process, strengthening skills across sectors.

THIS MINI-GUIDE SETS OUT:







It also offers practical guidance to ensure that child participation is safe, meaningful and inclusive and that children are consulted at all stages of outbreak management (preparedness, response and recovery). This Mini-Guide aims to support children's agency and amplify their voices, ultimately improving the overall quality and effectiveness of subsequent interventions.

Principle 3 of the Minimum Standards for Child Protection in Humanitarian Action (CPMS):

"Humanitarian workers must provide children with the time and space to meaningfully participate in all decisions that affect children, including during emergency preparedness and response." 1

What do we mean by child participation in outbreaks?

The United Nations Convention on the Rights of the Child (UNCRC)⁵ identifies participation as one of four General Principles. Article 12 obliges States to (i) give children the right to freely express their views on any matter that directly or indirectly impacts them and (ii) to ensure that their views are taken into account by decision-makers. Articles 13 to 17 provide further details regarding how to put participation into practice. According to the UN Committee on the Rights of the Child, this right should be enjoyed by children both individually and collectively.8

Although governments are legally allowed to limit certain individual rights and freedoms to achieve legitimate public health goals during outbreaks, International Health Regulations² dictate that these decisions must be guided by the principles of necessity, proportionality and non-discrimination. The rights enshrined in the UNCRC, including the right to participation, must continue to be fulfilled, even during outbreaks.¹⁰

Indeed, children's agency is critical to outbreak preparedness, response and recovery. Children bring invaluable insights and expertise and have a unique ability to navigate the direct and indirect impacts of an outbreak, offering perspectives that the humanitarian sector can learn from. In the absence of formal structures, resourcing and external support, children play an important role in addressing escalating needs amongst their family members, peers and other community members. Outbreaks exacerbate existing vulnerabilities, discrimination and violations of children's rights, thus demanding a more strategic, proactive and strengthened child participation strategy – along with other accountability mechanisms - that are firmly embedded in collaborative and cross-sectoral humanitarian actions.

Child participation before, during and after outbreaks may be understood as...

- ...a **principle** of rights-based programming that is universally applicable across all sectors and settings.
- ...a way of working that helps realise children's right to be listened to and taken seriously as well as helping them to more effectively access and secure other rights, including their rights to health, protection and education.
- ...a goal to achieve more effective outbreak management and better outcomes for both children and their communities. 11

THE NINE BASIC REQUIREMENTS FOR EFFECTIVE AND ETHICAL PARTICIPATION. 12

According to the United Nations Committee on the Rights of the Child, ¹³ child participation must be:

Transparent

Voluntary

Respectful

Relevant

Child-friendly

Inclusive

Supported by training

Accountable to risk

The information shared throughout this Mini-Guide aims to meet or exceed these basic requirements.

WHY IS CHILD PARTICIPATION IN OUTBREAKS IMPORTANT?

Large-scale infectious disease outbreaks are on the rise ...¹⁵

While the COVID-19 pandemic is the most significant outbreak in recent memory, it is only one of many large-scale outbreaks so far this century. 16 Experts predict that infectious disease outbreaks will continue to rise, caused in part by the intensification of agricultural and livestock practices, increased urbanisation and the climate crisis. 17

Owing to compounding factors, such as

protracted conflict, political instability, forced displacement, infrastructural destruction and weakened public health structures, humanitarian settings present unique opportunities for the emergence, spread and recurrence of infectious diseases. ¹⁸
For example, recent years have witnessed a resurgence of cholera worldwide, including in areas where the disease had been absent

for decades. 19

The rapid and resurgent spread of COVID-19 exposed the global lack of preparedness to effectively contain, control and mitigate such risks and highlighted a 'collective failure' to prioritise outbreak prevention, response and recovery.²⁰

...and children are disproportionately affected...

Child-dominated demographics are common to many of the humanitarian settings in which outbreaks occur.²¹

Not only do children constitute a major population cohort but they are also the most likely to already be impacted by humanitarian crises.²² Children (depending on the intersectionality of their age, gender and other factors) may be required to assume a substantial share of household responsibilities, including cleaning, fetching water, caring for younger siblings or sick family members and generating income – especially if faced with the death or illness of

a primary caregiver.²³

Because of their socio-behavioural and biological characteristics – as well as their degree of agency and autonomy – children are particularly vulnerable during outbreaks. Children may be more susceptible to infection, in part due to lower immunological defences, higher rates of malnutrition or exposure to unique infection pathways, such as breast milk. Age-appropriate information about infection prevention and control (IPC) measures may be lacking. Younger children or children with certain disabilities may not adhere

to recommendations due to their physical proximity to or dependence on caregivers.

Children are also often highly affected by the indirect impacts of outbreaks which can disrupt the environments in which they live, learn and develop.²⁴ Public health and social measures, such as movement restrictions and school closures,²⁵ can trigger both immediate and long-term negative consequences for children's physical, psychosocial, educational and economic outcomes.²⁶

...and they are powerful agents of change.

During the COVID pandemic, despite unprecedented levels of disruption to their daily lives in almost every country worldwide, children found ways to swiftly adapt and contribute meaningfully to collective efforts to contain and control COVID-19. Children were highly motivated, quick to mobilise and innovate. They often combined their creativity and evolving capacities with available <u>technology</u> to circulate

information, prevent infection and provide practical support to peers, caregivers and other community members.²⁷ Some children successfully advocated directly with decision-makers, such as governments and donors.²⁸ In contexts characterised by seasonally occurring outbreaks (such as cholera), children have built community preparedness through awareness-raising, health clubs and other child-led activities in schools and

communities.²⁹

It is thus necessary to re-conceptualise children's role as powerful agents of change rather than passive bystanders or dependents. If children's agency as rightsholders during outbreaks is recognised and respected, children can become strategic and valuable partners in outbreak management.

Prioritising child participation during outbreak preparedness, response and recovery...

Children are experts in their own lives.

They are effective advocates, mediators and communicators – especially among their peers. They are also uniquely positioned to offer insight into the challenges and opportunities in their lives, informing decision-making around service provision as well as public health and social measures during outbreaks. With appropriate supports

in place, child participation can and should be prioritised before, during and after outbreaks.

Prioritising child participation now can capitalise on the current "window of opportunity" to prepare for the next major disease outbreak. This will entail changing mindsets, shifting norms, strengthening competencies, securing funds

and providing opportunities to engage with a diverse cohort of children across multiple sectors at the local, national, regional and global levels. It also means ensuring that culturally sensitive and appropriate measures are in place to ensure children's safe, inclusive and meaningful participation.

...can increase the quality of interventions,³¹ prevent harm and increase resilience amongst affected populations.

Children's participation in outbreaks to date has demonstrated how their engagement provides decision-makers with timely information that can drive evidence-based interventions across all areas of outbreak management. Children's participation can:

- Expand and improve the quality of disease surveillance.
- Improve the awareness, adherence, and child-friendly adaptations of IPC

measures.

- Provide targeted child-centred, child-led and/or peer-to-peer risk communication and community engagement (RCCE).³²
- Introduce child-friendly considerations in the design and implementation of services, including isolation and treatment centres.³³
- Boost vaccination uptake. 34

 Integrate child protection considerations into outbreak preparedness, response and recovery plans.

Children can also provide early warning of any adverse or unintended consequences of public health and social measures and recommend effective ways to mitigate their impact. The protective benefits of children's participation also encompass their own mental health and well-being.³⁵



How can we make child participation safe?

Children's participation must be guided by the overriding principles of 'do no harm' and the 'best interests of the child'. In outbreak settings, this must encompass:

- safeguarding measures to prevent harm (abuse, violence, neglect, or exploitation) when engaging children both virtually and face-to-face.
- public health and social measures put into place for outbreak management that may require adaptation of participation modalities.
- IPC measures to keep children safe from infection during face-to-face interactions.³⁶

TOP TIPS

Undertake a thorough risk assessment before engaging children^{3Z} to identify potential safeguarding, security and/or health-related risks as well as develop a risk management plan with mitigation measures designed to keep children safe during participation.

 Generally engaging children in outbreak preparedness and recovery does not carry the same level of risk (that is, potential exposure to infection) as is present during an active outbreak and should therefore be prioritised as a matter of good practice. However, child participation during outbreaks is equally important and can be achieved with adequate risk management.

CASE STUDY

CHILDREN AS AGENTS OF CHANGE IN OUTBREAKS³⁸

The first case of COVID-19 in Afghanistan was recorded in the rural western province of Herat. It is here that five adolescent girls, aged 14 to 17, members of an all-girl robotics team named the Afghan Dreamers, were given a seemingly impossible challenge: they were tasked with designing a mechanised ventilator that could be easily replicated and rapidly mass produced. In a country with only 200 ventilators to serve a population of over 35 million and faced with a likely shortfall of health workers who could operate manual ventilation options at the onset of the COVID-19 pandemic, the work was a matter of life or death.

The Afghan Dreamers had to overcome supply issues fuelled by lockdowns and shop closures to realise their dream, in addition to negotiating personal adversity as members of their own team fell ill with COVID-19. Nonetheless, the team persevered to successfully build and test a prototype ventilator, which they presented to the Ministry of Public Health. In the absence of other options, the girls had found an innovative solution. They used readily available and relatively low-cost car parts – from an old Toyota Corolla – to create a ventilator intended for emergency use (in the event that standard ventilators were not accessible or were already all in use). Their invention cost 100 times less than a typical fully automated ventilator. The Afghan Dreamers' success is a testament to children's potential to act as agents of change in outbreaks.

- Given that both risks and mitigation measures may change as an outbreak evolves, it is important to regularly update risk assessments and management plans based on the perspectives of diverse stakeholders.
- Risk assessments and management plans in the context of outbreaks must be guided by a holistic approach that considers children's physical and psychological well-being, in recognition of the increasing evidence for the mental health benefits of meaningful participation.³⁹

Continue to uphold standard safeguarding measures through advance planning and timely reporting.

• Allow for remote adaptations to obtain informed consent/ assent from caregivers and children, when necessary (for example, providing consent online), sharing information about the safeguarding, health and safety measures that will be put in place in addition to

- emphasising that participation is entirely **voluntary**. In certain circumstances, participation may also be **anonymous**. No child should feel coerced or forced to engage, nor should they fear any negative consequences should they choose not to participate. In all cases, an **enabling environment** in which children feel **respected** should be fostered.
- Even in rapid onset outbreaks in which recruitment processes may be accelerated, it is essential to ensure that any staff/volunteers who have direct access to children have been properly vetted and prepared, with reference checks, signed Codes of Conduct and provision of adequate training and access to resources.
- Ensure that age-appropriate and accessible reporting and referral pathways are in place and that the children are familiar with these. All children particularly those living in areas prone to

- endemic outbreaks⁴⁰ should be made aware of how to keep themselves safe and seek help when necessary.
- Enhance privacy and data security measures, given that adults may be working from home and/or using remote modalities.

Adapt existing child participation strategies, methodologies, and tools to ensure their physical and psychological safety in outbreak settings.

- Face-to-face activities should follow all recommended public health and social measures as well as IPC measures in place. These recommendations will change depending on the infectious disease in question, but may include limiting group sizes; conducting activities outdoors with physical distancing; using personal protective equipment (PPE), such as masks; and increasing hygiene and sanitation practices, such as frequent handwashing or disinfection of shared materials.
- If face-to-face engagement is

not possible and/or deemed unsafe, child participation can also be achieved remotely through various internet, radio and telephone-based options, including online meetings and surveys, interactive voice response (IVR) surveys, WhatsApp groups and radio competitions etc.41 In contexts where access to technology is limited and/or to achieve greater accessibility, participatory materials (for example, activities with instructions) may be safely delivered for completion and later collected for further analysis and action.42

Anticipate and address
 children's concerns about
 their participation, including
 questions about their health
 and safety during face-to-face
 interactions or frustrations linked
 to remote adaptations that may
 seem limiting relative to in person activities, for example.

How can we make child participation meaningful?

Participation can take a variety of forms, from consultative to collaborative to child-led, each with its own merits. 43

Consultative participation

- Adults seek children's views to better understand their perspectives and experiences
- Recognises children's expertise in their own lives
- Potential to share decisionmaking power

Collaborative participation

- Greater degree of partnership between adults and children
- Likely to be adult-initiated, but may allow for enhanced child-led action over time
- Enables children's involvement in and influence over both processes and outcomes

Child-led participation 44

- Children control both focus and process, with adults serving as facilitators to provide information, advice, training and/ or support
- May include individual as well as collective actions

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KEY OPPORTUNITIES TO PRIORITISE CHILD PARTICIPATION BEFORE, DURING AND AFTER OUTBREAKS

- Quantitative or qualitative data collection targeting child participants (individually or in groups) during needs assessments or situational analyses
- Formal or informal conversations, dialogue, or consultations with children to develop child-centred RCCE activities⁴⁵ or ensure the integration of child protection considerations in multisectoral and/or inter-agency outbreak preparedness, response and recovery plans⁴⁶

- Children's engagement in the design and implementation of isolation and treatment centres⁴⁷ or provision of child-friendly vaccination campaigns⁴⁸
- Children's involvement in the development and dissemination of child-friendly public health messages⁴⁹
- Children's representation

 in sectoral or multisectoral
 coordination committees with
 specific roles and responsibilities

- Individual children utilise an existing complaints mechanism to report concerns
- Child-led inventions and innovations to mitigate risks of infection and/or improve health outcomes⁵⁰
- Child-led and/or peer-to-peer
 RCCE activities in schools and the wider community on relevant issue areas (as identified by children)⁵¹
- Children elect peer representatives for a Children's Advisory Group

Whether it is consultative, collaborative or child-led (or a combination), for children's participation to be meaningful, they must have both the necessary opportunities and information to voice their perspectives to a relevant audience that will give children's views due weight and serious consideration. 52 The type of participation will depend on various considerations, such as the current outbreak phase, the needs and wishes of the children involved (which may be influenced by age, gender, disability and other factors) and the availability of staff expertise and budget.

Child participation has often been absent, insufficient or unstructured, even in non-outbreak settings. Adults may feel unprepared or unwilling to effectively partner with children in decision-making, risking tokenistic or manipulative engagement. They may be dismissive towards children's feelings and perspectives. In addition to strategic investments aimed at strengthening staff confidence and competency, children's participation may require a shift in norms to overcome attitudinal barriers, internal biases and beliefs about children's capacities that limit their role in outbreak management. This may be achieved through open dialogue and discussion among staff and volunteers as well as with faith-based and local leaders. Children should never feel that they have been engaged purely so that information may be extracted from them. Targeted advocacy may be necessary to create a culture of participation and accountability to children.

In recognition of the multitude of social, economic, and educational challenges already facing children in outbreaks, participation must have tangible benefits for children.⁵³ For example, it should:



Strengthen their life skills, such as public-speaking, advocacy, leadership, research, budgeting and project management as well as enhancing their use of internet and technology through training, coaching and mentorship.



Provide education through formal and informal learning, course accreditations and other opportunities.



Foster social connections through virtual and face-to-face engagement with peers, supportive adults or mentors and the wider community.



Share information to ensure children are aware of their rights, potential risks and reporting pathways, complaints mechanisms, information about the infectious disease and how they can best protect themselves from its direct and indirect impacts as well as any opportunities available to them.



Provide access to services, such as child-friendly spaces with provisions for their basic needs, including clean drinking water, nutritious snacks and menstrual hygiene products; routine childhood wellness checks and immunisations; and referral to mental health and psychosocial support (MHPSS) or sexual and reproductive health (SRH) services.



Compensate children for their time and expertise, where appropriate and aligned with organisational policy and practice. Depending on the circumstances, compensation may be financial (for example, transport allowance) and/or in-kind (for example, provision of school stationery or access to additional training opportunities/resources).

WHAT DOES ACCOUNTABILITY TO CHILDREN LOOK LIKE IN PRACTICE?

Accountability to children and communities is among the core commitments in humanitarian action.58 Children must be aware of the results of their participation. While expectations should be managed at the outset and realistic benchmarks, goals or outcomes discussed, children should – at a minimum – receive timely and transparent feedback about how their views, voices, images and other contributions were used and what immediate or long-term policy and programmatic changes may have resulted. Children also understand that their participation today may not always result in direct changes to their own lives but may impact the lives of future generations of children. Our accountability to children assures them that their participation will be both valued and respected and that we will not abuse our positions of power and trust. We can do this by ensuring that:

- Child participation is culturally sensitive and context-specific and builds on or strengthens existing processes, children's groups, networks and platforms.
- Children have access to ongoing opportunities for engagement (such as through monitoring and evaluation processes, advocacy or research).
- Children receive appropriate, honest and transparent responses to

their questions or concerns in a **timely** manner.

- Accessible channels of communication are established between children and key stakeholders, encompassing all children (not just those selected to participate in research, consultations or advocacy events) and allowing them to ask questions, share concerns and/or provide feedback.
- Children who have had the opportunity to participate are supported to **share feedback with their peers**, particularly if they were nominated as representatives.
- Follow up mechanisms are well defined, including co-created monitoring, evaluation and learning processes, child-friendly complaints and feedback mechanisms as well as child-friendly and accessible versions of reports. 52

CASE STUDY

CHILD PARTICIPATION IN OUTBREAK RECOVERY

In the absence of other formal mechanisms to gather the perspectives of children affected by the 2014/15 Ebola epidemic in West Africa, a Children's Ebola Recovery Assessment (CERA) was launched in Sierra Leone. During face-to-face focus group discussions using child-friendly participatory tools, over one thousand children shared their experiences and priorities for recovery. Key concerns raised included:

- The adverse impact of more than nine months of school closures and their desire to return to education.
- The many and varied impacts of Ebola on their day-to-day lives, including bereavement, fear and anxiety.
- The limited access to healthcare for routine issues.
- The wider economic impact of Ebola on their families and communities. 61

The CERA highlighted that children can clearly articulate their needs, wishes and expectations to key decision-makers in the aftermath of an outbreak.

Participation is a process, not a momentary act. 60

- UNITED NATIONS COMMITTEE ON THE RIGHTS OF THE CHILD

How can we make child participation inclusive?

Children are not a homogeneous group. Individually and collectively, they have different experiences and perspectives based on a diversity of factors. In addition to age, gender, sexual orientation and disability, children's ethnic, cultural, religious, educational and economic backgrounds may differ. They may be unaccompanied or separated from their families, possibly due to forced displacement, movement restrictions or the illness and death of loved ones. They may be asylum seekers, refugees, internally displaced or stateless individuals. They may be married and/or caregivers themselves. They may have been infected by the disease; may have a caregiver who was/is infected; and/or may have been orphaned or had a caregiver die as a result of the disease outbreak. These different individual-level characteristics may intersect with one another and impact children's resilience, access to protective factors, and vulnerability to risks.

Outbreaks can create conditions that further exacerbate existing inequalities, barriers to access, and social marginalisation. Actors who wish to engage children may be hindered by public health and social measures, including movement restrictions, service suspensions and school closures. **Inclusion requires intentionality, particularly in outbreak settings.**



TOP TIPS

Together with local leaders, child-focused actors and a diverse cohort of children, assess which children are most often excluded and have fewer opportunities for engagement in each setting – whether historically or because of the outbreak.

 Work closely with actors specialising in disability rights and issues relating to sexual orientation, gender identity and expression or sex characteristics (SOGIESC) as well as those working with children in displacement, detention, alternative care or street-connected children, among others. These may include community-level organisations, national and international non-governmental organisations (NGOs) and/ or dedicated focal points in national and local governmental structures. They can help (i) identify child representatives to engage in consultations; (ii) develop culturally sensitive participatory methodologies; (iii) identify appropriate locations to hold consultations; (iv) develop suitable ways to run consultations; (v) select and train enumerators with essential skills and behaviours: and (vi) determine the most impactful methods of compensating children for their expertise.

Develop context-specific strategies for representative engagement.

 Use a variety of channels and platforms to communicate and consult with children, including accessible modalities that promote equal access and do not necessarily rely on school attendance, access to the internet or other technology or knowledge of other languages. Any face-to-face activities should be held in **easily accessible locations.**

- Allow for culturally sensitive topics to be explored in age and gender-disaggregated groups with same-gender facilitators, when necessary.
- Create safe spaces to successfully engage with children of diverse SOGIESC.⁶²
- Consider the specific needs
 of younger children (who
 are often excluded from
 consultations), as they may
 require shorter, more dynamic
 sessions with play-based
 methodologies and materials
 that do not require literacy
 skills.
- Budget for the provision of individual accommodations or adaptations for children with different types of disabilities, including interpreters, assistive devices and additional modifications.
- Ensure that opportunities for engagement take children's existing commitments (which may have increased as a result of the outbreak) into account

and are scheduled, located and compensated accordingly.

• Liaise with existing structures, such as Children's Parliaments or Youth Advisory Groups, but avoid over-reliance on a single child or small group of children by ensuring that opportunities for engagement are equitably shared (for example, presentation at high-profile events or participation in international meetings).

Develop and disseminate communication materials that are age-appropriate, accessible and

available in local languages. 63

- Depending on the type of communication and target audience, consider using pictures and diagrams, sign language interpretation, closed captioning, audio descriptions, screen-reader-friendly online formats or large print and Braille hard copies. Avoid the use of complicated technical language or jargon, acronyms and abbreviations.
- Promote child-led, peer-topeer communication whenever possible.

Train staff/volunteers to have the necessary awareness, skills and capacity as well as adequate age-disaggregated guidance to safely and meaningfully engage children at different developmental phases as well as children from diverse backgrounds. 64

Collect, analyse and report sex, age and disability disaggregated data to better monitor the experiences of diverse children and respond to their intersectional needs.



CHILD PARTICIPATION ON A GLOBAL SCALE

The #COVIDunder19 survey ("Life Under Coronavirus") was the largest ever global survey of children's rights during times of crisis.

- The survey was co-designed with children for children.
 - Findings captured the experiences of 26,258 children aged 8–17 from 137 countries worldwide during the first six months of the COVID-19 pandemic.⁶⁵
 - Findings were analysed and interpreted by children from a wide variety of countries who engaged with data sets and adult counterparts remotely and at different times.

The survey could not provide a truly representative sample of the global child population. However, efforts were made to disseminate paper and online formats to marginalised groups of children, including children with disabilities, children of diverse sexual orientation, children in detention, children in displacement and street-connected children. The #COVIDunder19 survey demonstrated the incredible potential for child-led participation and partnership, even at the height of an outbreak.

ENDNOTES

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ENDNOTES

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