



USAID
FROM THE AMERICAN PEOPLE

READY

GLOBAL READINESS FOR
MAJOR DISEASE OUTBREAK RESPONSE

Photo credit: Sonali Chakma / Save the Children

CONFIDENTIALITY GUIDANCE NOTE: ADVICE FOR HEALTH ACTORS ON HANDLING CHILD PROTECTION CONCERNS DURING INFECTIOUS DISEASE OUTBREAKS



JUNE 2023

Introduction

During infectious disease outbreaks, the regular functions of child protection work and health facilities may be disrupted. However, health workers may encounter children who are difficult for child protection actors to access because of outbreak restrictions.

This might be because children are:

- Seeking treatment for infection;
- With adults seeking treatment for infection;
- Being placed in isolation or quarantine;
- With adults being placed in isolation or quarantine;
- Receiving guidance on containment, control, and mitigation measures; and/or
- Receiving additional vaccinations.

Under the pressures of an outbreak, children may be exposed to higher rates of violence, abuse or to deteriorating mental health.¹ The response to the outbreak and other public health measures imposed by governing bodies can mean that health workers might encounter children:

- (i) Whom child protection actors are finding it difficult to contact or reach directly, and/or
- (ii) Who are less frequently in contact with others who can respond to child protection needs. This includes, for example, teachers, extended family, and community actors.

It is therefore essential that health workers collaborate with child protection actors to appropriately and confidentially refer any child protection concerns disclosed and/or detected.

The following explains what confidentiality means, why it is important, how to maintain confidentiality, and best practice for confidentially sharing information when it is in the best interests of the child.

Key guiding principles in all cases:

- Any onward referral of child protection cases should happen with the informed consent/assent from the child and relevant caregivers. See guidance in [Annex 1: Procedures for seeking informed consent or assent](#) and [Annex 2: Confidentiality sample scripts](#).
- Maintaining confidentiality needs to be balanced against the best interests of the child. See the section below for further details on how to do this.

Key terms

Health actors are any individuals or organizations that provide and/or support health services. They may be paid, voluntary, temporary and/or permanent. They include those who provide medical assistance and those who perform support functions (i.e., administration, accounting, security, and logistics). They include community-level associations, government agencies, non-governmental organizations (NGOs), interagency or coordination groups, and relevant United Nations (UN) agencies.

Child protection is the prevention of and response to harm to children. This includes abuse, neglect, and exploitation of children; violence against children; and mental health and psychosocial concerns.

A child protection concern may be a suspicion or report of a child protection incident that has yet to be proven by evidence to be true.

Confidentiality is a set of conditions under which information revealed by an individual in a relationship of trust will not be disclosed to others.

Identifying information is detail about a person or case that can help you work out the identity of an individual. It can include names; age; a physical description; location of work, home or school; date of visit; details of a case; names of relatives; etc.

A child is any person under the age of 18. Children are of diverse ages, gender identities, and backgrounds and may live with disabilities.

Informed consent is the voluntary agreement of an individual—an adult or, in some settings, an adolescent—who has the legal and developmental capacity to take a decision, understands what they are being asked to agree to, and exercises free choice.

Informed assent is the process when an individual, adult or child, expresses a willingness to participate in services.

¹ See Nidhi Kapur (2022), "Child Protection in Outbreaks: Advocating for the centrality of children and their protection in infectious disease outbreaks," The Alliance for Child Protection in Humanitarian Action, [DOWNLOAD PDF HERE](#).

Why do health actors need to maintain the confidentiality of child protection cases?

Although usual ways of working may be disrupted during outbreaks, policies and standards relating to confidentiality must be maintained or even strengthened. Confidentiality breaches may have negative effects on the lives of children, their families, the community, and/or other people involved in the process.

Why is confidentiality important?

Confidentiality is in the best interest of the child at the center of the case because it prevents the intentional or unintentional misuse of information about them. An information leak can lead to further exploitation, stigmatization, and/or abuse.

Witnesses, friends, and family members may be harassed by the accused perpetrator or face threats of retaliation.

A wrongly or falsely accused perpetrator could become a target of hate or slander.

The following are examples of possible negative effects due to inappropriate information-sharing:

1 During a large interagency meeting, someone seeks advice. A girl has reported to their camp child protection focal point that due to school closure and economic insecurity, her parents have identified a husband for her. Her old school is named in the meeting. Later, the interagency group works together to sensitize communities about (i) the need to return to schools when closures end and (ii) negative effects of child marriage. They start the sensitization campaign in the named school. The girl's friends suspect the campaign is because of what happened to her and they start to bully her.

2 An email is sent about a child whose caregiver has been placed in isolation due to infection. The child has been tested for the virus and is not infected. The village the child is from and their name is given. Child protection staff have traced next of kin and will take the child back to her village. The email is forwarded to logistics staff who are organizing a vehicle for the child and a case worker. The driver receiving the email is from the child's community and knows the child's family. The driver mentions the child's situation to his own family. The child and her family are then stigmatized.

3 A child is taken to a health facility to help treat injuries sustained from abuse. The NGO's vehicle is a large pick-up truck with the NGO's logo. The vehicle must pass through a checkpoint to control the spread of an ongoing outbreak. The NGO staff members (i) give the names of everyone in the vehicle at the checkpoint and (ii) explain why they are traveling. An NGO staff member shares details about the child's abuse while the vehicle is inspected. Someone working at the checkpoint is from the same community and reveals what happened to the child to other community members. The child's safety and well-being are now at risk because the abuser may seek retaliation.

4 A child protection staff member is talking to a health sector colleague in a tea shop. The child protection staff member is explaining the increased number of cases of child labor they are seeing as schools are closed. They have seen the children working at a construction site in the refugee camps. The staff member mentions the many signs of abuse and injury they are seeing among these children. The staff member names the company that is engaging child labor. Others in the teashop can hear them talking. The company hears that there have been complaints about their treatment of the children, and they beat the children and threaten them.

How do health actors ensure the best interests of the child and maintain confidentiality?

The best interests principle states that “in all actions concerning children, ... the best interests of the child shall be a primary consideration.”²

As a health actor, you should not carry out a formal best interests assessment for a child. Only mandated agencies and organizations can do so. However, all service providers must consider the positive and negative consequences of their actions. The least harmful course of action is always preferable.

At times, when there is a need to protect a child’s physical and emotional safety and provide urgent assistance, the best interests principle may lead a service provider to make a choice against a child’s wishes. When there may be a risk of harm to the child or someone else, you must prioritize the best interests principle.

This can override a child’s wishes or the principle of confidentiality. This includes when there is ongoing risk of violence or the child expresses suicidal thoughts. For example, a child may wish to keep an incident of sexual violence secret, but (i) there may be a need to seek urgent medical assistance that would require referral to health service providers, (ii) the child may need to be placed in alternative care to prevent further abuse, and/or (ii) another child may still be living with the abuser.

Stringent safeguards and controls must be in place to ensure that a decision to breach confidentiality will secure the survival and overall well-being of the child. It must bring greater benefit than harm, in accordance with the best interests principle.

The limits to confidentiality relating to the best interests principle must be explained clearly to children and their caregivers.

How do health actors secure informed consent or assent from children?

When talking to a child, we should use child-friendly, inclusive communication methods to confirm that they agree to:

- (i) Continue discussing an incident or child protection concern;
- (ii) Have information about themselves recorded and potentially shared with other service providers; and
- (iii) The services they wish to access and be referred to.

This confirmation process is known as “seeking informed consent/assent.”

For guidance on child-friendly communication during infectious disease outbreaks, including how to seek informed consent/assent in child-friendly ways, see: [Mini Guide #4: Child Protection in Outbreaks: Communicating with children in infectious disease outbreaks.](#)

Parents and caregivers are typically responsible for giving consent for their child to receive services until the child reaches the age of 18. In some settings, older adolescents are also legally able to provide consent instead of, or in addition to, their parents or caregivers.

For younger children who, by definition, are too young to give informed consent but are old enough to understand and agree to participate in services, we ask for the child’s informed assent.

Consent should be recorded in writing and signed by a witness. Where individuals are not able to write, a thumb print is sufficient. Where consent forms show a name of an individual, a case code should be written on the document and the medical file, and the consent form should be stored separately. This keeps the full case file confidential.

² UN General Assembly, Convention on the Rights of the Child, 20 November 1989, United Nations, Treaty Series, vol. 1577, p. 3, <https://www.refworld.org/docid/3ae6b38f0.html> [accessed March 24th, 2021]

Sometimes, during outbreaks, a child needs assistance and their usual caregiver is not present to provide informed consent. For example, a child may be separated from their usual caregiver as their caregiver has been taken into isolation, is under treatment, or is unconscious.

In some instances, it is not in the best interests of the child to involve their caregiver in the informed consent process. For example, due to fear of disease or virus control measures, a caregiver's mental health may deteriorate, or they may start to neglect or become violent with their child.

A health worker then needs to identify whether there is another trusted adult in the child's life who can provide consent. If there is no other trusted adult to provide consent, the caseworker alone needs to determine the child's decisions and/or continue with a best interests determination process.



A trusted adult

will be an adult, known to the child, whom the child has chosen to confide in or accompany them for assistance. This may be a teacher, nurse, community worker, sports coach, or others. If no caregiver or such a trusted adult is present, the service provider (health worker, case worker, child protection worker, etc.) may need to provide consent asupport their health and well-being.

What skills and knowledge do health actors need to maintain confidentiality?

During outbreaks, there may be a need to rapidly establish new health facilities, such as isolation units and treatment centers. Despite the urgency, all personnel working in these sites must continue to adhere to confidentiality and referral protocols.

Include obligations to maintain data protection protocols and ensure confidentiality in staff employment contracts and codes of conduct, even if they are rapidly recruited for outbreak response.

Training on the following subjects should be mandatory. Even a short session on response to child protection concerns and ensuring confidentiality is better than nothing.

- Recognizing child protection concerns;
- Referral pathways that are in place and how to use them;
- The importance of confidentiality; and
- Communicating with diverse children, including administering psychological first aid where possible.

See [Annex 1: Procedures for seeking informed consent/assent](#) and [Annex 2: Confidentiality sample scripts](#), which includes guidance on how to seek consent when a caregiver is absent.

- Share guidelines and procedures for collecting, storing, using, and destroying confidential information with all staff joining your organization.
- Run and provide refresher training sessions for existing personnel.
- Prepare short briefs, job aids, and posters for all staff and volunteers.

How do we store information in a confidential way?

Develop clear guidelines and procedures for collecting, storing, using, and destroying confidential information.

Agree with other service providers how you will maintain confidentiality and manage confidential information sharing so as to provide necessary services to children who are at risk or who have experienced child protection concerns.

Adhere to the interagency agreed information sharing protocols for the Cox's Bazar response.

Store any notes and records of any discussions separately from the names or any other identifying details of individual participants.

Remove pages containing personal information, such as names and addresses, from notebooks.

Substitute names and identifying information with case codes. You may have a case coding system for your medical files; you can use this system instead of names or other identifying information. If you don't have a medical case coding system, speak to your nearest child protection focal point for advice. They may be able to (i) guide you on developing a coding system or (ii) provide you with codes used in their child protection information management system (e.g., CPIMS+).

In those rare instances when it is necessary to record identifying information, it should be stored in a lockable filing cabinet, drawer or room, and the keys kept with the person responsible for the information.

Restrict access to all rooms containing paper or electronic information to authorized personnel only.

Password-protect all electronic information on those who have experienced abuse, exploitation, or violence, and change the passwords on a regular basis.

Destroy computer printouts, written notes, extra photocopies, reports and other records that are not needed.

Where facilities have been rapidly established and therefore have no lockable space, cabinets, or rooms available, the following is advised:

- Staff with access to and responsible for the files keep the files in the room where they work at all times.
- The files should be placed in sealed envelopes.
- The envelopes should be placed in storage boxes with lids, until lockable cabinets are available.
- Where a health facility is open 24 hours, a staff member responsible for looking after the files should be designated during each shift.
- Where the health facility is only open for a few hours each day and the space cannot be locked, the staff member should transport the documents securely to the nearest office with secure lockable cabinets. This may be another office run by your organization or the office of a partner agency. This has to be done with approval, as part of a pre-agreed, controlled authorized process, and should only be done if the files are stored in a sealed envelope when in transit.

When can you share information?

Information that could jeopardize the confidentiality or well-being of the survivor must never be shared.

Children and their caregivers are the ones who can declare who can have information, when, and how. They should be given the opportunity to highlight any information that they do not want any particular person to know. For example, children may not want their caregiver or other members of their family to be told personal details about themselves that they would rather communicate face-to-face.

Sharing of information that could identify a survivor, an individual involved in a case, or an alleged perpetrator should be purely on a “need to know” basis. It should only be shared with other personnel or agencies who will do something to provide direct support to the survivor or who will action something as requested by the survivor (e.g., not every child protection actor needs to be informed of the details of every child protection incident).

You must still adhere to best practice on information sharing, even when outbreak investigation teams and treatment facilities put pressure on you to share information. For instance, details of a child protection incident or suspicion do not need to be revealed to health workers who are carrying out contact tracing.

How do you share information?

Information sharing protocols set out in standard operating procedures (SOPs) must be adapted to the specific challenges faced during major disease outbreaks.

Train all staff on the standard operating procedures during the preparedness phase. In particular, training should cover information sharing, referrals, and data protection.

At all times—even during outbreak response—all agencies must follow procedures as set out in interagency agreed standard operating procedures that contain information sharing protocols (ISPs).

Maintain confidentiality when transferring information through any medium: verbally, through the postal system, electronically, etc.

- **Electronic information sharing**, e.g., through e-mail, a shared database, or sharing a link to online stored data, is the preferred method for data transfer during outbreaks, allowing you to adhere to public health measures and reducing the chance of transmission of any disease. It must be done with great care. Any data shared by email should be transferred in an encrypted or password-protected format. Any database or online data storage system must be safe from hacking.
- **In-person electronic information sharing.** Where memory sticks are used, the data should be encrypted or password protected. Memory stick should be passed by hand between people responsible for the information and the file erased immediately after transfer. Depending on the disease this may require the provision of personal protective equipment (PPE)—including gloves and masks—and hand sanitizer or handwashing facilities.
- **Paper files. Where containment measures allow**, files may be transferred by hand between people responsible for the information. During the transfer itself, files should be stored in a sealed box or envelope. Additional safeguards can be established for when files are handed over, such as signing a confidentiality agreement form. PPE, including gloves/masks and hand sanitizer or handwashing facilities, should be provided to facilitate this physical contact, in line with government guidance. The file must be stored in a lockable cabinet and/or secure room as soon as possible after the transfer is complete.
- **When verbally sharing information**, ensure it happens one-on-one (not in a group), in a private space where you cannot be overheard. The private space should be chosen based on the ability to retain privacy while maintaining recommended social distancing and disease transmission precautions, such as, ventilation.
- **Online conference calls/videoconferencing.** First, confirm that the platform you are using is secure. Check for the latest information on preventing your call from being hacked. Before sharing any details of a case, confirm that the person with whom you are speaking is alone in hearing the information you are sharing. Use a headset so that only you can hear the conversation.

Information should be passed only to a person designated to receive it for clearly defined reasons. This may include a line manager or a medical, protection, mental health, or legal professional who will be taking action to help the child.

Keep the number of people informed of the case to an absolute minimum. The fewer people involved, the easier it is to ensure confidentiality for the child.

How do you maintain confidentiality when having direct contact with children and their families in the community?

Immediately refer any child needing help to service providers who can give medical, psychosocial assistance and ensure their safety. Referral must be done in ways that maintain the confidentiality and safety of the child and any parent, caregiver, family member, or trusted adult they are with. Child protection focal points can assist you in the referral process.

[Click here for details of the child protection focal point in your area.](#)

You should always:

Conduct discussions in private settings. This means that discussions with children, their families, or with other service providers must happen where no others can overhear. You must, however, be visible, so that people know that you are not harming the child in any way. Be conscious of not talking about confidential information, even in front of your own organization's drivers, administrative staff, extended family members, etc., as they may not be trained in confidentiality.

Try not to attract unnecessary attention to yourselves and those participating in a discussion. Be aware if people know that your organization works with a specific category of children, for example, survivors of sexual violence or those associated with armed forces or groups. Try to reduce the possibility that the children you are seen with will be assumed to fall into this group. For example, when it is safe to do so, avoid wearing a t-shirt with your organization's branding when conducting a home visit, and avoid arriving at community meetings in a vehicle with your organization's logo.

Request that child protection teams identify, brief, and/or train security services, community leaders, community health workers, checkpoint staff, security staff on patrol, and those working at camp entry points. They should have brief practical training on:

- (i) what confidentiality means
- (ii) why confidentiality is important, and
- (iii) how to maintain confidentiality.

Staff need to know that when children are seen accessing services, this is sensitive information that must not be shared.

To help in the process, health workers can provide child protection staff with information on:

- Frequent routes taken to access health facilities, and
- Where health worker site visits take place.

Annex 1: Procedures for seeking informed consent/assent

- Informed assent is sought from children who, by nature or law, are too young to give consent but are old enough to understand and agree to participate in services.
- Informed consent is generally only sought from children over 15 years old.
- When obtaining informed consent/assent from a child, use a child-friendly manner to share information on (i) services available, (ii) potential risks and benefits, (iii) personal information to be collected and how it will be used, and (iv) confidentiality and its limits.

PROCEDURES FOR SEEKING INFORMED CONSENT / ASSENT					
AGE	CHILD'S ABILITY TO MAKE DECISIONS	ROLE OF CHILD	ROLE OF CAREGIVER	IF NO CAREGIVER IS PRESENT OR NOT IN CHILD'S BEST INTEREST	HOW SHOULD THEY GIVE CONSENT
0-5	Should have things explained to them.	N/A	Informed consent	Other trusted adult's or caseworker's informed consent.	Adult's written consent
6-11	Right to give their opinion and be heard. May be able to participate in decision-making to a degree. Caution advised to avoid burdening them with decisions beyond their ability to understand.	Informed assent	Informed consent	Other trusted adult's or case worker's informed consent.	Child's oral assent, Adult's written consent
12-14	Presumed to be mature enough to make a major contribution to decisions.	Informed assent	Informed consent	Other trusted adult's or child's informed assent. Sufficient level of maturity (of child) can take due weight.	Child's written assent, Adult's written consent
15-17	Mature enough to make their own decisions.	Informed consent	Obtain informed consent with child's permission	Child's informed consent and sufficient level of maturity takes due weight.	Child's written consent, can be documented by case worker.

For children with disabilities: Recognize that children with disabilities have the right to provide informed consent or assent. Assess each individual child's ability to understand the situation and provide informed assent or consent. Use an approach to securing informed consent or assent that respects and supports the child's right to be involved in all decisions that affect them.

Annex 2: Confidentiality sample scripts

Below are sample scripts for confidentiality, safety, informed consent/assent, and best interest.

CONFIDENTIALITY

"What we discuss now, I will keep between us, unless:

You want me to talk to someone else about what we discuss

OR

You tell me something that makes me think you or someone else may get hurt. In which case, I have to act to keep you and/or someone else safe."

INFORMED CONSENT/ASSENT

"Are you happy to keep talking to me?"

"Do you still want to keep talking now?"

"Do you want time to think about these things before we keep talking?"

"We can bring you to meet [insert name of a case worker, mental health worker] they will help you by talking to you in ways that can make you feel better. Would you like to do this?"

BEST INTERESTS

"If I am worried about your safety, I may need to talk to someone about what you have told me, that would only be someone who can help you."

"If we need to get you more help in order to check any injuries you may have or to talk to someone who can help keep you safe, we will talk together about that other person, and decide together what we should tell them about what happened to you."

"My job is to try and make sure that you are not hurt anymore, so we may need to also get help from other people in order to keep you safe and healthy. Does this sound okay with you?"

"Sometimes, I may not be able to keep all the information you give me to myself. The times I would need to share the information you have given me is:"

1 "If I find out that you are in very serious danger, I would have to tell [insert appropriate agency here] about it."

OR

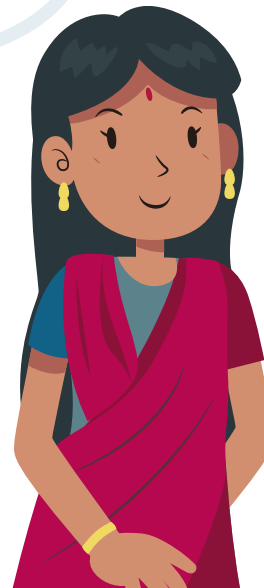
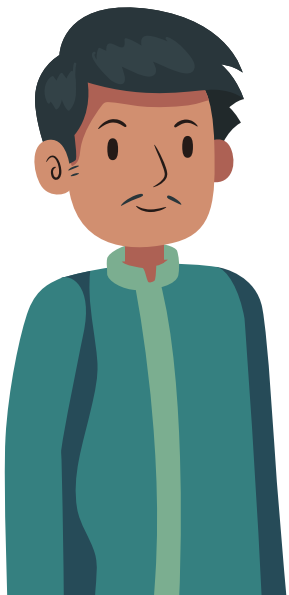
2 "If you tell me you have made plans to seriously hurt yourself, I would have to tell your parents or another trusted adult."

3 "If you tell me you have made a plan to seriously hurt someone else, I would have to report that.

"I would not be able to keep these problems just between you and me."

[Explain mandatory reporting requirements as they apply in your local setting].

[Add any other exceptions to confidentiality. For example, in cases of UN or NGO workers perpetrating sexual abuse and exploitation].





Acknowledgements

This checklist was created by Hannah Thompson at the request of the **READY** initiative. Nidhi Kapur and Dr Ayesha Kadir provided technical inputs. Lauren Murray reviewed the material and oversaw the development of the guidance. The content is based on the experiences of colleagues addressing the COVID-19 pandemic in the context of the Rohingya Response in Cox's Bazar Bangladesh. We would like to thank all the members of the Health Sector and Child Protection and Gender-Based Violence sub-sectors; and MHPSS specialists for engaging in the process for strengthening collaboration between health and child protection actors in Cox's Bazar. In particular we have valued the views and guidance of Krissie Hayes, Samrawit Assefa Melles, Taslima Begum, Ayesha Akter Monni, Dr Egmond Evers, Dr Francis Tabu, Patrick Halton, Melissa Bencik, and Parmita Sarkar.

This checklist is made possible by the generous support of the American people through the United States Agency for International Development (USAID). The contents are the responsibility of READY and do not necessarily reflect the views of USAID or the United States Government. Led by Save the Children, the READY initiative is implemented in partnership with the Johns Hopkins Center for Humanitarian Health, the Johns Hopkins Center for Communication Programs, UK-Med, and the Humanitarian Leadership Academy. READY is augmenting global capacity for non-governmental organizations to respond to large-scale infectious disease outbreaks. For more information, visit our website at <http://www.ready-initiative.org>.