Protection-Related Data Sharing Consent Guidance and Example Script

Instructions: This suggested script is meant for the service provider responsible for getting the individual's consent as part of the case management process. Note that this guidance and script may not be appropriate for use in non-case management activities; however, sections of the script may be adapted and used. Highlighted parts should be customized.

Introduction

Protection case management is an approach for addressing the needs of an individual who is at risk of harm, or has been harmed. It is designed to assist individuals through tailored, holistic, and coordinated support. When an individual enters into a case management relationship, the case worker/social worker is obligated to provide the information necessary for the individual to determine if they choose to share information by their informed consent.

When children are the individuals receiving support, their caregivers are often involved in the decision making process for sharing information. Case workers should seek informed assent from younger children; alongside informed consent from a safe caregiver.²

Who is this guidance for?

It is the responsibility of case workers/social workers to empower individuals along the case management process and to ensure there is ongoing consent. However, many case workers find the conversation about consent (or assent with children) challenging; especially related to information sharing. This Guidance and script is meant to aid case workers in these conversations, as well as their supervisors who can help tailor the conversation to the context.

How to use this guidance

The document below presents suggested guidance on how to ask for consent to share various protection-related information. Asking for consent to share data begins during a first intake session with an individual. The primary goal of the consent process is for the individual to drive the decisions that are being made throughout the process. This includes participation in services that are available at the time, and the information that the individual would like shared as they engage in those services. The primary goal of the consent process is to receive consent for the service being provided to the individual at that moment. While getting consent for information is essential, it should not take the place of or overshadow the informed consent process for receiving the service. For example, you might choose to sequence over the first few sessions the requests for consent for different types of information, so that the individual is not overwhelmed³.

This script is not meant to be printed and read, but rather presented here as a suggestion, so casework staff can see an example of how to have these discussions with the people accessing services. Please note, the case worker will need to customize aspects of this script according to the service being provided and your context. This customization could

¹ To ensure that modifications made to this script are in line with global best practices, the Global Case Management Forms for Child Protection or the Inter-Agency GBV Case Management Guidelines should be followed

² See the Interagency Guidelines for Case Management and Child Protection

³ With regard to Gender Based Violence: Refer to Step 1 of the <u>Inter-Agency Gender-Based Violence Case Management Guidelines</u> for more guidance.

include discussions with staff, UNHCR, partners, and focus group discussions with people from the individual group and depends on the circumstances of the individual.

Though not described in detail, it is important to outline the process for obtaining informed consent. Broadly, the steps for informed consent for protection-related information sharing are below.

- Prepare for your interview; make sure you have an interpreter if necessary, you
 are a in a quiet, secure and confidential location, and that you have sufficient time.
 Consider who you will speak to (child? Caregiver?) and whether you will interview
 together or separately. Anticipate their questions and concerns.
- Introduce yourself and the services being offered.
- Discuss confidentiality and the limitations of confidentiality(for example, where an individual plans to harm themselves or someone else)
- Discuss the rights the individual/child has throughout the process.
- Once the individual has determined what services they would like a referral to, ask
 the individual to explain their understanding of your statement in their own words
 what they think they are agreeing to, what the risks might be, and what would
 happen if they refuse. This can be a long or short conversation. This will allow the
 service provider to assess the individual's understanding of each issue, and if
 necessary, reinforce anything that was not clearly understood and correct any
 misunderstanding.
- Discuss information sharing for additional purposes (as detailed below)
- Document their decision on a consent form and electronically where appropriate/required⁴.

Because the consent for information sharing will happen in the process of case management, it could be construed that individuals/children are required to share information in order to receive the service. However, they can continue receiving services, even if they do not consent to information sharing.

SCRIPT

Purpose

Hello, my name is XXX

How are you feeling today? Thank you for coming to meet with me. I would like to explain some important informationWe see many [women, children, people] every day who are experiencing troubles in their lives. I am very glad that you came here today and I hope that we can work together to get you help if you decide you need it. My job is to listen to you, help keep you safe, and discuss with you what help you may want and how to get it. Before we start talking about what brought you here today, there are a few things I'd like to explain to you, so that you know what services [organization name] can offer to help you. I do this with everyone who comes here, so that we are both clear before we start.

Today, we can talk about what has happened to you, how it has affected you, and what support you feel might be useful. For example, we can talk about whether medical/health services might be helpful useful for you or how to help you improve your safety. We can

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⁴ See the associated consent form.

identify together what support you need urgently at the moment. You are also welcome to come back and talk with me regularly and I will continue to be available to help. My job is to support you while you figure out what comes next, and to help connect you the services you need and want, including ones that we do not provide. I will work with you as you make decisions about what will be best for you. Do you have any questions about this?

I want you to know that I will keep what you tell me confidential. This means that I will not share with anyone what you tell me, unless you ask me to or it is information that I need to share because you are in danger. All your information belongs to you and it's very important that you know that you are in control of it.

There may be times where you may decide that it is okay for me to share some information with someone else. As we talk, we might find that there may be other services that you could benefit from that [organization name] does not provide or there are other people or agencies that might be useful to you and who might be able to provide specific support. In that case, I can refer you to receive help with services such as safety, health, psychosocial, legal and/or protection. If that happens, we can talk about what information you want me to share with them before you go, and what they don't need to know. This can be helpful as you won't need to explain everything over and over again. For example, if you have been injured and would like medical care, I can share with the medical professional what injuries you have and how they happened. I will not share your information with other service providers unless you give me permission.

There are some times when I have to tell other people about what we discuss together, and I would like to be clear about that before we start. Then you can decide what you want to talk about and how much you want to tell me. When I have to tell someone else about your situation, it will be the smallest amount of information they need to know in order to serve you better and it will be in order to help protect you.

If you tell me that you may hurt yourself, I would need to tell my supervisor or others who could help keep you safe. If you tell me that you plan to hurt someone else, I would have to tell [relevant protection authorities] so we could prevent that action. If a UN or humanitarian worker has hurt you, I would need to tell my supervisor and report what this person has done, so he/she cannot hurt anyone else. Although I would keep your identity confidential if you would like me to. If... [Explain mandatory reporting requirements as they apply in your local setting]. Sharing information during these times is meant to keep you safe and get you the best help and care you need. Other than these times, I will never share information without your permission.

[COMPLETE ASSESSMENT STEP]

[Instructions: For all information sharing purposes that are applicable in your context, the following scripts should].

Referral Data Sharing Procedures	
Script	Notes

Based on our conversation, my understanding is that you are worried about [insert concerns]. Is this right, or is there anything we need to add?

From our discussion it sounds like seeing [referral org name or sector] might be helpful for you. The organization/agency that provides that service is [name of organization]. Would you like me to share some information with [name of specific person at that org, if possible], a [title] who is trained to work with [women, children, individuals] in similar situations? For example, this could include details about the [violence, concern, incident, issue] so they know what [type of service] services you may need. Your do not have to consent to information sharing in order to receive information about available services. Would you like me to share information with them?

[Refer to the associate consent form and document their response].

This is for immediate, available referrals. This consent script for referrals should be the same for any provider.

Referral to UNHCR for protection or assistance services based on UNHCR criteria for immediate or future access

Script Notes

There are also other services that UNHCR may provide that we do not know all the details about. They sometimes provide protection or assistance services based on information shared with them. For example, if an individual meets certain criteria, they can access a service or be added to or prioritized for an intervention. These potential services could be [list potential protection and assistance services that can be accessed or are likely to be accessed in the future in a particular operation]. If you would like me to share [list type of information] with them, it is possible they will contact you via [list all possible methods of contact]. This does not mean you will immediately or in the future receive a specialized service, it means there is a *possibility* of that. If the possibility exists, you will be able to make a decision about whether or not you want the service at the time of contact. Are you comfortable with this?

[Refer to the associate consent form and document their response].

This is for UNHCR services exclusively.

If this is for GBV, you need to specify that they will not be visited at their home with reference to their experience of GBV claim.

A discussion should also take place regarding safe mechanisms for contacting the individual.

In terms of Best Interest Procedures, care arrangements

information is
needed for
unaccompanied
minors to ensure
registration group
(responsible party
for the minor)
information is
updated.

Aggregate Information Sharing					
Script	Notes				
As part of our work - particularly for making changes to improve services for [women, children, individuals] -it is valuable and important for us to keep track of information about [violence, protection concerns, issues] being reported to us. Some of the ways this information may help us/overall response could be to increase the number of caseworkers like me if there is a need or to suggest improving lighting in particular areas that are unsafe. No information we collect will be specific to you or to any violence/concern/issues you report. There will be no way for anyone to identify you based on the information that is shared because it will be grouped together with all of the other reports we have received. It does not include names or any specific personally identifiable information about you. [Show monthly stats report/other aggregate statistic sample to individual as visual]. Do you have any questions about this based on what we have previously discussed? Are you okay if we use this information to improve services? [Refer to the associate consent form and document their response].	This is a good practice from the GBV sector, although recommended for other sectors as well.				

Permission to Proceed

We filled in the consent forms for the information that you would like me to share with [REFERRAL ORG/UNHCR] and we agreed what information I can tell each of them.

[COMPLETE ACTION PLAN STEP/REFERRAL PLANNING]

Feedback on referrals (to service providers or UNHCR) **Script Notes** Details to be shared As you know you were referred here by name of could include: organization. To let them know we provided the service, we service type, status can share feedback on this referral for their own records and (ongoing, completed case management processes. The type of information we etc.), date. Refer to would provide would be basic [insert details] about the type the technical note of service we provided. Are you okay with us sharing back for more details. this information with the organization that referred you to our

[COMPLETE CASE CLOSURE]

services?

Sharing closed	cases wit	h future	needs	with	UNHCR	and	UNHCR
archiving							

archiving	HCK and UNHCK
Script	Notes
I know we are just starting this process, but I want to talk with you about what would happen with your data if programs were closed here or if you close your case. As you may know, UNHCR stays in the country for the duration of there being refugees present. If lorg name were to close, would you like us to transfer your case file to UNHCR?	This is for UNHCR services exclusively. The contact information will need to be updated in each context.
If we do this, it can be helpful in case you would like to reference it in the future. It also allows UNHCR to ensure that a person receives the relevant services by having a complete picture of previous actions and assistance. The information that we would share would be the final version of your file describing the services you received. If in the future you would like to ask UNHCR about your information that they have, you can contact [enter contact details here].	In contexts where case management is a one-time occurrence, this can be done in an initial meeting. Otherwise, this should be done at case closure.
As a United Nations Organization, UNHCR keeps archives, or keeps a record of all cases shared with them, even the really, really old ones. If we share your information with UNHCR, it will be kept indefinitely as part of their records. UNHCR's archives are kept at their global office/headquarters for the purposes of historical research, as well as for personal access should you want to access your case file in the future. This means they would have a record of your case in their files for future reference, even in ten or	UNHCR will not share closed cases externally without the consent of the individual.

twenty years. In the past, individuals have been able to get their

records to support family tracing, to support judicial processes and claims for compensation for violations, and for personal information. You do not have to make a decision about this now. We will discuss it again later as we go through this process together. ⁵	
[Refer to the associate consent form and document their response].	

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 $^{^{5}}$ In contexts where case management is a one-time occurrence, this can be done in an initial meeting.