

## Topic Guide: MHM, PERSON WITH A DISABILITY

**Overview:** Menstruation is a vital sign of health, but it is shrouded in taboo. Water, sanitation and hygiene is vital for good menstrual hygiene management. In this research we need to understand what the experiences of menstruating women and girls are so that World Vision can develop programmes to better respond to these requirements.

**Objective:** to explore the MHM related experiences of a person with a disability. In particular, to investigate:

- Traditional norms, practices and cultural beliefs
- Water and sanitation facilities including for solid waste management
- Availability of affordable, usable and culturally appropriate sanitary protection materials
- Person with a disability's relationships with others (carer, family, peers, wider community, teachers, healthcare providers)
- Knowledge and information provision on MHM
- Skills in coping and support required
- Intensity of menstruation (pain) and implications on behaviour

These questions should be used to guide discussion but do not have to be used in the sequence listed below. The interviewer should follow up on any additional issues that may arise and seem important in relation to the issues above. Under most questions there are reasons why we are asking them in *italics*. If a participant asks you why you are asking specific questions, use this text to guide your answers. Do not volunteer it if the participant does not ask for it.

**Inclusion criteria:** person with a disability who menstruates.

**Materials needed:** information and consent sheet, voice recorder, spare batteries, notebook and pen, refreshments, menstrual hygiene products gathered through the market survey, bark and leaves.



**Introduction**

Good morning and thank you for your time. I am (Interviewer’s name) from.....  
Remind them of the issue of confidentiality and anonymity which is fully explained in the information and consent form that they completed. Reiterate that we will be asking questions about how they manage menstruation.

We are asking these questions because your experiences will help us understand the issues that people face when menstruating. These issues relate to water, sanitation and hygiene. World Vision want to understand these so that we can develop water, sanitation and hygiene programmes that better support people when they are menstruating. The only way we can do that, is ask people like you, personal questions about how you manage menstruation. What you tell us about your experiences will be invaluable. These questions may be difficult to answer. If they don’t want to answer any of them, they don’t have to – that’s ok.

Check if they have any questions from the information and consent form about the research. Remind them that they are free to decline to answer any of the questions or stop the interview at any time.

<i>Interview Date and time</i>	
<i>Interview venue and location</i>	
<i>Rural or urban</i>	
<i>Interviewer</i>	
<i>Participant’s name</i>	
<i>Participant’s code</i>	
<i>Age</i>	
<i>Gender</i>	
<i>Disability / no disability</i>	
<i>Functional domain: seeing, hearing, remembering/ concentrating, self-care, understanding/communication</i>	
<i>General observations: anything which might impact how the interview is conducted. E.g. a person interrupting the interview, if you feel that the participant is pressed for time, if they are uncomfortable answering the questions, if the interview is not conducted in private, levels of rapport you have with the participant.</i>	

**INSTRUCTIONS: INTERVIEWER TURN ON THE TAPE RECORDER AND SAY CLEARLY THE DATE, TIME, LOCATION, AND THE INTERVIEWER’S NAME**

QUESTIONS

<b>Opening/ rapport building questions</b>	
1	<p><b>Who do you live with? Siblings, parents / grandparents? Do you have friends nearby? Do you go to school or work? Tell me a bit about that.</b></p>
<p><i>Reason for the next questions: to understand if support is required, the level of that and who provides it</i></p>	
2	<p><b>Does someone in your family help you with daily activities, like washing and eating?</b></p> <ul style="list-style-type: none"> <li>• Who supports you?</li> <li>• What support do they give you?</li> </ul>
<b>First experience of menstruating</b>	
<p><i>Reason for the next questions: to warm participants up to talking about menstruation. Also to explore how open people are to talking about menstruation in their everyday lives.</i></p>	
3	<p><b>Now we are going to move on to our discussion about menstruation.</b></p> <p><b>What are words that girls and women use to talk about menstruation?</b></p> <ul style="list-style-type: none"> <li>• What words are used with friends?</li> <li>• What do they mean?</li> <li>• Are ‘secret’ words used so nobody else will know what is discussed?</li> </ul>
<p><i>Reason for the next questions: to understand the first experiences of menstruation, what information they had about it, how they managed etc. This will help build a picture about the levels of taboos around menstruation and disability, participant’s understanding/ knowledge about menstruation at that time, what products they used and who supported them and how all of this made them feel. Getting people to tell a story about their own experiences at the start of an interview can help people open up.</i></p>	
4	<p><b>Can you tell me about the first time you menstruated?</b></p> <p><i>Context:</i></p> <ul style="list-style-type: none"> <li>• How old were you?</li> <li>• Did you know what to do?</li> </ul> <p><i>Attitudes/emotions:</i></p> <ul style="list-style-type: none"> <li>• Can you remember how you felt at that time?</li> </ul> <p><i>Knowledge:</i></p>

		<ul style="list-style-type: none"> <li>• Did you know what it was when you got it? How?</li> <li>• Who told you about it (family, friends, teachers, health worker)?</li> <li>• What did they tell you?</li> </ul> <p><i>Resources/management/practices:</i></p> <ul style="list-style-type: none"> <li>• What did you use (pads, cloth, tissues, etc.)?</li> <li>• Who/where did you get materials from?</li> </ul> <p><i>Support:</i></p> <ul style="list-style-type: none"> <li>• Did you tell anyone? Please explain.</li> <li>• If yes, who did you talk with? Why?</li> <li>• Did you try to hide it or keep it a secret? Why?</li> <li>• What did you talk about?</li> </ul>
<b>Last experience of menstruating</b>		
<i>Reasons for questions: to track any changes in terms of ability to cope, levels of understanding and support received from the first menstrual cycle to the most recent.</i>		
5	<b>Can you tell me about the most recent time you menstruated?</b>	<ul style="list-style-type: none"> <li>• Where were you?</li> </ul>
6	<b>How did you feel (pleased, scared, worried, no negative or positive feelings at all)? Why?</b>	
7	<b>Did someone support you manage your menstruation (a carer / family member)? Who?</b>	<ul style="list-style-type: none"> <li>• Can you tell me how they help you?</li> </ul>
<b>Personal hygiene</b>		
<i>Reasons for the next questions: exploring accessibility, privacy and safety of the place that they change their menstrual product. This will help us understand if any of these topics are an issue for people, and therefore a priority for action.</i>		
8	<b>Where do you change your menstrual product?</b>	<ul style="list-style-type: none"> <li>• Can anyone see you there?</li> <li>• Can anyone walk in? Is it private?</li> </ul>
9	<b>Where did you go to clean yourself when you are menstruating?</b>	
10	<b>Do you feel safe in the place you clean yourself?</b>	

11	<b>How often do you clean yourself when you are menstruating?</b>	<ul style="list-style-type: none"> <li>• How often do you clean yourself when you are not menstruating?</li> <li>• Are you able to clean yourself as often as you'd like to when you are menstruating?</li> </ul>
Menstrual discomfort		
<i>Reason for the next questions: understanding ability to manage menstrual discomfort is important. If not managed, it can affect a person's ability to function.</i>		
12	<b>Do you have menstrual pain?</b>	
13	<b>How do you manage the pain (e.g. massage, warm cloth, paracetamol)?</b>	<ul style="list-style-type: none"> <li>• Does someone give you pain relief? Who? What do they give you?</li> <li>• Does this help?</li> </ul>
Preparing for menstruation		
<i>Reason for the next questions: to understand if / how people track their menstrual cycle, and if / how they prepare for it. Knowing when menstruation is coming helps ensure you're not 'caught out', identify if there is a problem with your menstrual cycle or if you are pregnant.</i>		
14	<b>Do you know when your menstruation is coming? How?</b>	<ul style="list-style-type: none"> <li>• Do you prepare for your menstruation? How?</li> <li>• Do you know when it has started and finished? How?</li> </ul>
15	<b>When you are menstruating now, who do you talk to about it (if anyone)?</b>	<ul style="list-style-type: none"> <li>• Friends/family/teacher/boyfriend?</li> <li>• Why do you talk to this person?</li> <li>• Why not others?</li> </ul>
Menstrual restrictions		
<i>Reason for questions: to understand menstrual taboos, beliefs and restrictions, and if / how this differs for people with and without a disability.</i>		
16	<b>Is there anywhere you're not allowed to go when you are menstruating?</b>	<ul style="list-style-type: none"> <li>• Are there restrictions placed on you? Mobility? Cooking? Eating? Religious? Why?</li> <li>• Are there things you prefer not to do?</li> <li>• Do you leave the house? Where do you go (work, school, friends)?</li> </ul>
17	<b>Are these restrictions different for you to females who do not have disability? How?</b>	<ul style="list-style-type: none"> <li>• If yes, how do they treat you differently?</li> <li>• Who treats you differently?</li> </ul>
18	<b>Are there any advantages to menstruating? Please explain.</b>	

Menstruation and incontinence		
<i>Reasons for the next questions: to understand if it is more difficult to manage incontinence during menstruation and how the participant copes.</i>		
19	<b>Now I'm going to ask you a few questions about incontinence. Are you happy for me to continue?</b>	<b>YES: ask next question.</b> <b>NO: skip to 'menstrual products used'</b>
20	<b>Are you able to hold onto your urine and faeces?</b>	<b>No:</b> <ul style="list-style-type: none"> <li>• How do you deal with that?</li> <li>• What are the challenges (i.e. getting to the toilet, washing, cleaning clothes / bedding, going out of the house)?</li> <li>• Do you use products (i.e. cloth, pad, nappy)? What are these? Where do you get them?</li> <li>• In relation to incontinence management, do you do anything differently when you are menstruating?</li> <li>• What do you do differently? Why?</li> <li>• How does that make you feel?</li> </ul> <b>YES: skip to the next question.</b>
Menstrual products used		
<i>Reasons for the next questions: to understand what products are being used, what is available, what participants do / don't like using and why, how affordable they are, how effective they are. Also to understand if they are disposed of in a hygienic or unhygienic way; if there is enough soap and water to wash reusable products as often as required and if they are dried in a hygienic way.</i>		
21	<b>I have some menstrual products people in this area use. I'd like to talk to you about which you use, your thoughts on them and the other materials.</b>	<i>Lay out all the menstrual products in front of the participant. Encourage her to pick any of them up. Answer any questions she has on them.</i>
22	<b>Do you use any of these? Ask about each item displayed: State which product are being discussed into the audio voice recorder. Discuss one item at a time.</b>	<ul style="list-style-type: none"> <li>• <b>YES:</b> ask next question</li> <li>• <b>NO:</b> What do you use (ie underwear, clothes, leaves, bark)? Then move to the next question.</li> </ul>
23	<b>When do you use this product (i.e. at night, day, when you have lot of</b>	

	bleeding, or a little bit of bleeding, at home / outside the home)?	
24	How easy / hard is it to change your menstrual product?	<ul style="list-style-type: none"> <li>Do you need support? Who helps you? What do they do?</li> </ul>
25	Where do you store this product when you are not using it?	
26	Why do you use this product?	<ul style="list-style-type: none"> <li>What do you like about it?</li> <li>What do you dislike about using it?</li> </ul>
27	Does your carer/someone who supports you help you use it?	<ul style="list-style-type: none"> <li>How do they help you?</li> <li>How often do they change it?</li> </ul>
28	Do you use it once, or can you use it again and again?	<p><b>ONCE: how do you / carer dispose of it?</b></p> <ul style="list-style-type: none"> <li>Where do you dispose of it?</li> <li>Can you tell me about that place please? (i.e. how far from the home is it? Is it near a water source? Is it buried?)</li> </ul> <p><b>REUSABLE: how do you / your carer clean it?</b></p> <ul style="list-style-type: none"> <li>How often is it washed?</li> <li>What do you use to wash it?</li> <li>Is this easy / difficult? Why? (e.g. availability of soap and water, privacy)</li> <li>How do you dry it?</li> <li>Do you face any issues in drying it?</li> </ul>
29	Where did you get this product?	<ul style="list-style-type: none"> <li>How easy is it for you to get them?</li> <li>Did someone recommend you used it?</li> <li>Have you always used it?</li> <li>What do you think about the cost?</li> <li>How often do you need to replace it or buy it?</li> <li>Who buys / gets it for you?</li> </ul>

*Reasons for the next questions: we want to hear from people themselves what assistance they would like to receive. All recommendations given by participants will be assessed to understand their priorities and if World Vision can integrate them in their policy influencing and programme work.*

30	<p><b>Introduce other products that are available on the local market (obtained through the market survey). Ask the participant if they have ever used any of the products? <i>State what these are into the audio voice recorder.</i></b></p>	
31	<p><b>Lay all the products available on the local market in front of the participant. Ask the participant what they feel about each product. <i>State which product are being discussed into the audio voice recorder. Go through one product at a time.</i></b></p>	<ul style="list-style-type: none"> <li>• Would you be willing to pay the price of this? Show the costs of each product (displayed on the bottom of the packaging)?</li> <li>• Which would you most like to use? Why? (Probe into physical accessibility, acceptability, affordability, appropriateness and quality)?</li> <li>• What would other people (ie carer, family members, community members) think of these products?</li> <li>• Could you use, wash and dispose of these products independently and privately? If not, why not?</li> </ul>
32	<p><b>Lay the shop bought products and the product/s currently used to the participant in a line front of the participant. <i>State what these are into the audio voice recorder. Ask the participant to:</i></b></p>	<ul style="list-style-type: none"> <li>• Reorder the products in preference order. Left being the least preferred option. Right being the most preferred option</li> <li>• Ask the participant why they have ordered them in that way?</li> <li>• Take a photo of the product line and say the order for the voice recorder.</li> </ul>
<p><b>Recommendations</b></p>		
33	<p><b>What could parents/families/careers do to support their girls with disability when they are menstruating?</b></p>	
34	<p><b>We are going to come up with recommendations for organisations that could help improve menstrual hygiene management for people have a disability. What advice would you like us to pass along to them that you think would make things better for you when you are menstruating?</b></p>	
35	<p><b>Thank you very much for your thoughts and for answering all my questions. Before we finish is there anything else you want to tell me? Is there anything you would like to ask me?</b></p>	



***If the participant has time, ask to see the water point, handwashing, bathing area and toilet that the participant uses.***

## ACCESSIBILITY AND SAFETY AUDIT<sup>1</sup>

Use this checklist to review the latrine, bathing area, water point. Make a note of any features that might make it difficult to use. Write these up after the interview. Take photos of the facilities. Add the jpeg number to the participant spreadsheet. The photos will be used by Jane to understand the situation. They will not be used in any reports.

**Switch on the voice recorder and explain what you see.**

Type of facility (i.e. latrine, wash room, behind a bush/tree, water point):	<u>Latrine:</u>  <u>Wash room:</u>  <u>Water point:</u>
Location:	
General description of the facility:	
Getting there:	
<b>Checklist</b> <ul style="list-style-type: none"> <li>• Distance from house to facility.</li> <li>• Is the path wide enough for the primary participant?</li> <li>• Is the path level and firm, with nothing to trip up?</li> <li>• Is the path surface slippery when either dry or wet?</li> <li>• Are there obstacles that block the path, or make it easy to trip especially for visually impaired people?</li> <li>• Are slopes too steep?</li> <li>• If used at night, is the path lit?</li> <li>• Are there any parts of the path which make people feel unsafe when using it? If so why?</li> </ul>	
Getting in/on/out:	
<b>Checklist</b> <u>Steps:</u>	

<sup>1</sup> Adapted from WEDC and WaterAid (nd.), *Accessibility and safety audit*. Available at <https://wedc-knowledge.lboro.ac.uk/collections/equity-inclusion/>

<ul style="list-style-type: none"> <li>• Are they even or uneven, firm or broken, non-slip or slippery?</li> <li>• Is there a handrail for support?</li> </ul> <p><u>Entrance:</u></p> <ul style="list-style-type: none"> <li>• Is it wide enough for the user to enter?</li> <li>• Is the door easy to open?</li> <li>• Is the door easy to lock and unlock?</li> <li>• If someone faced harassment or other safety risks when using the facility would they be able to safely get away from the facility?</li> </ul>	
Safety of use (ask the participant)	
<p><i>Checklist</i></p> <ul style="list-style-type: none"> <li>• Do you feel safe when using the facility?</li> <li>• Are there any particular times of day or night when you feel less safe?</li> <li>• Is there any way that anyone can easily see inside the facility?</li> </ul>	
Inside:	
<p><i>Checklist</i></p> <ul style="list-style-type: none"> <li>• Is there enough space inside for a participant and her Carer (if she needs support) to move around easily?</li> <li>• When the door is closed is there enough light to see?</li> <li>• Do the roof / window (if applicable) provide adequate privacy for user/s?</li> </ul>	
Water (observe and ask the participant)	
<p><i>Checklist</i></p> <ul style="list-style-type: none"> <li>• Is there an internal water point? Describe.</li> <li>• Can the water be used to wash the body and the menstrual / incontinence product?</li> <li>• Is soap or ash available?</li> <li>• Can the water and soap be easily reached by all users?</li> </ul>	
Disposal: Is there a place where washed reusable menstrual / incontinence product be dried, or where it can be thrown away (observe / ask the participant)?	
<p><b>Checklist</b></p> <ul style="list-style-type: none"> <li>• Can the product be hung up?</li> <li>• Is it in sunlight to dry the product?</li> </ul>	



<ul style="list-style-type: none"><li>• Is there a bin with a lid for disposal?</li><li>• Is there a safe location for the final disposal of the sanitary waste (i.e. incinerator, a place to bury it or disposal into municipal waste collection systems)?</li></ul>	
Any additional information or comments	