



## Topic Guide: MHM - PROXY

**Objective:** to explore how people with and without a disability who menstruates through a proxy (carer). In particular to investigate:

- Caring support required and provided
- Access to healthcare services for menstrual related issues
- Menstrual products used and experiences of using these
- Any additional challenges faced by people who menstruate and suffer from incontinence
- Personal hygiene
- Levels of participation and relationships with others

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.

**Inclusion criteria:** A carer of a person with an intellectual or communication impairment who menstruates, but is unable to fully understand the consent process.

**Materials needed:** information and consent sheet, voice recorder, spare batteries, notebook and pen, camera (charged), menstrual and incontinence materials, refreshments.

### 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. 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>Code</i>	
<i>Interview Date and time</i>	
<i>Interview venue and location</i>	
<i>Interviewer</i>	
<i>Participant’s name</i>	
<i>General observations (anything which might impact how the interview is conducted)</i>	

## GUIDING QUESTIONS

<b>OPENING / RAPPORT BUILDING QUESTIONS</b>	
<ul style="list-style-type: none"> <li>• Can you tell me a bit about yourself? Do you live here with others? Tell me about them.</li> <li>• What is the name of the person you care for?</li> <li>• What do you enjoy doing together?</li> </ul>	
1	<p><b>Do you help [name] with daily activities, like washing and eating?</b></p> <ul style="list-style-type: none"> <li>• What support do they give you?</li> </ul>
<b>UNDERSTANDING DISABILITY</b>	
2	<p><b>Can you tell me about [name's] disability?</b></p> <ul style="list-style-type: none"> <li>• What functional limitations does she have?</li> <li>• How long has she had her disability?</li> </ul>
<b>WATER, SANITATION AND HYGIENE</b>	
3	<p><b>Where does [name] get your water from?</b></p> <ul style="list-style-type: none"> <li>• How long does it take to collect water?</li> <li>• Is it easy for [name] to collect water herself? If not, why not? (e.g. too far, inaccessible)</li> <li>• Do you help [name] collect water?</li> <li>• Do you pay for water? Probe into if it is metered or a flat rate is paid. How much is it?</li> </ul>
4	<p><b>Has anything been done to make your water point (tank, tap stand, handpump) easier for [name] to use / more accessible? E.g. water brought nearer the home, ramp to the water point, handrails next to the waterpoint etc</b></p> <ul style="list-style-type: none"> <li>• How does she find using it? <i>Explore ease of use and any related barriers faced</i></li> </ul>
5	<p><b>Has anything been done to make the handwashing and bathing facilities more accessible for [name]? E.g. seat placed in the bathing area, water inside the bathing area, water placed on a table, handrails etc</b></p> <ul style="list-style-type: none"> <li>• How does she find using it?</li> <li>• Can other people see her bathing?</li> <li>• <i>Explore ease of use and any related barriers faced</i></li> </ul>
6	<p><b>Does [name] use the same toilet as the rest of the family? What sort of toilet is it?</b></p>
	<p><b>YES:</b> Has anything been done to make your toilet easier to use / more accessible? E.g. built nearer the home, ramp to the</p> <ul style="list-style-type: none"> <li>• How does [name] find using it?</li> <li>• Can other people see her going to the toilet?</li> <li>• <i>Explore ease of use and any related barriers faced</i></li> </ul>

	toilet, handrails outside, handrails inside, raised toilet seat, movable toilet seat, more space inside, etc	
	<b>NO:</b> Why doesn't [name] use the same toilet as your family?	<ul style="list-style-type: none"> <li>What does she use instead? Please tell me the reasons for that?</li> </ul>
<p><b>Ask to see the water point, bathing / handwashing area, toilet after the interview (if the participant has time).</b></p>		
<p><b>FIRST EXPERIENCE OF MENSTRUATING</b></p>		
7	<p>Now we are going to move on to our discussion about menstruation. <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>
8	<p><b>Can you tell me about the first time [name] menstruated?</b></p>	<p><i>Context:</i></p> <ul style="list-style-type: none"> <li>How old was she?</li> <li>Did she know what to do?</li> </ul> <p><i>Attitudes/emotions:</i></p> <ul style="list-style-type: none"> <li>Can you remember how she felt at that time?</li> </ul> <p><i>Knowledge:</i></p> <ul style="list-style-type: none"> <li>Did she know what it was when she got it? How?</li> <li>Who told her about it (family, friends, teachers, health worker)?</li> <li>What did they tell her?</li> </ul> <p><i>Resources/management/practices:</i></p> <ul style="list-style-type: none"> <li>What did she use (pads, cloth, tissues, etc.)?</li> <li>Who/where did she get materials from?</li> </ul> <p><i>Support:</i></p> <ul style="list-style-type: none"> <li>Did [name] tell anyone? Please explain.</li> <li>If yes, who did she talk with? Why?</li> <li>What did she talk about?</li> <li>Did she try to hide it or keep it a secret? Why?</li> </ul>
<p><b>LAST EXPERIENCE OF MENSTRUATING</b></p>		

9	Can you tell me about the most recent time [name] menstruated?	<ul style="list-style-type: none"> <li>Where was she?</li> <li>Under 'last experience of menstruating', cover: context, attitudes / emotions, knowledge and support as set out above (under 'first experience of menstruating')</li> </ul>
10	How did she feel (pleased, scared, worried, no negative or positive feelings at all)? Why?	
11	Did you support her manage your menstruation?	<ul style="list-style-type: none"> <li>How did you help?</li> <li>What did you do?</li> <li>How did she react?</li> </ul>
<b>PERSONAL HYGIENE</b>		
12	Where do you change [name's] menstrual product?	<ul style="list-style-type: none"> <li>Can anyone see her there?</li> <li>Can anyone walk in? Is it private?</li> </ul>
13	Where does [name] go to clean herself when menstruating?	
14	Does she feel safe in that place?	
15	How often does she clean herself when menstruating?	<ul style="list-style-type: none"> <li>How often does she clean yourself when she is not menstruating?</li> </ul>
<b>MENSTRUAL DISCOMFORT</b>		
16	Does [name] have menstrual pain?	
17	How does she / do you manage the pain (e.g. massage, warm cloth, paracetamol)?	<ul style="list-style-type: none"> <li>Does she have pain relief? Who? What do they give you?</li> <li>Does this help?</li> <li><b>NO:</b> how does she behave when she has menstrual cramps?</li> </ul>
<b>PREPARING FOR MENSTRUATION</b>		
18	Does [name] know when her menstruation is coming / do you know when her menstruation is coming? How?	<ul style="list-style-type: none"> <li>Does she / you prepare for the menstruation? How?</li> <li>Does she / you know when it has started and finished? How?</li> </ul>
19	When [name] is menstruating now, who does she talk to about it (if anyone)?	<ul style="list-style-type: none"> <li>Friends/family/teacher/boyfriend?</li> <li>Why does she talk to this person?</li> <li>Why not others?</li> </ul>
<b>MENSTRUAL RESTRICTIONS</b>		

20	Is there anywhere [name] is not allowed to go when she is menstruating?	<ul style="list-style-type: none"> <li>• Are there restrictions placed her? Mobility? Cooking? Eating? Religious? Why?</li> <li>• Are there things she prefers not to do?</li> <li>• Does she leave the house? Where does she go (work, school, friends)?</li> </ul>
21	Are these restrictions different for you to females who do not have disability? How?	<ul style="list-style-type: none"> <li>• If yes, how do they treat [name] differently?</li> <li>• Who treats her differently?</li> </ul>
22	Are there any advantages to menstruating? Please explain.	
<b>MENSTRUATION AND INCONTINENCE</b>		
23	Now I'm going to ask you a few questions about [name's] toileting. Are you happy for me to continue?	<p><b>YES: ask next question.</b></p> <p><b>NO: skip to 'menstrual products used'</b></p>
24	Is [name] able to hold onto her urine and faeces?	<p><b>No:</b></p> <ul style="list-style-type: none"> <li>• How does she / 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>• Does she use products (i.e. cloth, pad, nappy)? What are these? Where do you get them?</li> <li>• In relation to incontinence management, does she you do anything differently when she is menstruating? Do you?</li> <li>• Related to water, toileting and keeping yourself clean, what do you do differently? Why?</li> <li>• What does she / you do differently? Why?</li> <li>• How does that make her feel?</li> </ul> <p><b>YES: skip to the next question.</b></p>
<b>MENSTRUAL PRODUCT USED</b>		

25	I have some menstrual products people in this area use. I'd like to talk to you about which [name] uses	<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>
26	Does [name] use any of these?	<p><i>Ask about each item displayed: <u>State which product are being discussed into the audio voice recorder.</u> Discuss one item at a time.</i></p> <p><b>YES:</b> ask next question</p> <p><b>NO:</b> What does she use (ie underwear, clothes, leaves, bark)? Then move to the next question.</p>
27	<b>When does she use this product (i.e. at night, day, when you have lot of bleeding, or a little bit of bleeding, at home / outside the home)?</b>	
28	<b>How easy / hard is it for [name] to change her menstrual product?</b>	<ul style="list-style-type: none"> <li>• Does she need support? Do you provide that? What do you do?</li> </ul>
29	<b>Where does she store this product when it is not being used?</b>	
30	<b>Why does [name] use this product?</b>	<ul style="list-style-type: none"> <li>• What does she like about it?</li> <li>• What does she dislike about using it?</li> </ul>
31	<b>Do you help her use it? <i>This may have been answered previously</i></b>	<ul style="list-style-type: none"> <li>• How do you help you?</li> <li>• How often do you change it?</li> </ul>
32	<b>Does [name] use it once, or can it be used again and again?</b>	<p><b>ONCE: how does she / you dispose of it?</b></p> <ul style="list-style-type: none"> <li>• Where?</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 does she / you clean it?</b></p> <ul style="list-style-type: none"> <li>• How often is it washed?</li> <li>• What do you / she 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 / she face any issues in drying it?</li> </ul>

33	<b>Where did you get this product?</b>	<ul style="list-style-type: none"> <li>• How easy is it for you / her to get them?</li> <li>• Did someone recommend it to you / her?</li> <li>• Has she 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?</li> </ul>
34	<b>Introduce other products that are available on the local market (obtained through the market survey). Ask the participant if [name] has ever used any of the products?</b>	<ul style="list-style-type: none"> <li>• <i>State what these are into the audio voice recorder.</i></li> </ul>
35	<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>	<ul style="list-style-type: none"> <li>• Would she/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 [name] most like to use? Why? (Probe into physical accessibility, acceptability, affordability, appropriateness and quality)?</li> <li>• What would other people (ie you, family members, community members) think of these products?</li> <li>• Could [name] use, wash and dispose of these products independently and privately? If not, why not? <i>This may have been answered previously</i></li> </ul>
36	<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.</i> Ask the participant to:</b>	<ul style="list-style-type: none"> <li>• Reorder the products in [name's] preference order. Left being the least preferred option. Right being the most preferred option</li> <li>• Why are they ordered in that way?</li> <li>• Take a photo of the product line and say the order for the voice recorder.</li> </ul>
<b>RECOMMENDATIONS</b>		
37	<b>In your opinion, what do you think could be done to help [name] manage her menstruation better?</b>	
38	<b>Thank you very much for talking to me about your experiences. Before we finish is there anything else you want to tell me? Is there anything you would like to ask me?</b>	

Complete the accessibility and safety audit, detailed under previous guiding questions.