

## Topic Guide: Caregiver

Washington Group Short Set Questions (circle the answer)

I'm now going to ask you a few questions about any difficulties the person you care for has (circle the answers)

**Table S1. Washington Group Short Set Questions**

	Functional domain	No difficulty	Some difficulty	A lot of difficulty	Cannot do it at all
A	Does [name] have difficulty seeing, even if they are wearing glasses?	1	2	3	4
B	Does [name] have difficulty hearing, even if they are using a hearing aid?	1	2	3	4
C	Does [name] have difficulty walking or climbing steps?	1	2	3	4
D	Does [name] have difficulty remembering or concentrating?	1	2	3	4
E	Does [name] have difficulty with self-care such as washing all over or dressing?	1	2	3	4
F	Using your usual (customary) language, does [name] have difficulty communicating, (for example understanding or being understood by others)?	1	2	3	4

## GUIDING QUESTIONS

OPENING / RAPPORT BUILDING QUESTIONS		
1	Can you tell me a bit about yourself? Do you live here with others? Tell me about them.	<ul style="list-style-type: none"> <li>Do you work / go to school? What work do you do / where do you go to school?</li> </ul>
2	What is your relationship to <name of person with a disability>	<ul style="list-style-type: none"> <li>How long have you been supporting her?</li> </ul>
3	Do you help <name> with daily activities, like washing and eating?	<ul style="list-style-type: none"> <li>Explore WASH related issues [e.g. collecting water, self-care, including bathing, MHM, going to the toilet]?</li> </ul>
UNDERSTANDING DISABILITY		
4	How old is <name>?	<ul style="list-style-type: none"> <li>Can you tell me about her disability?</li> <li>How long has she had her disability?</li> </ul>
HUMANITARIAN CONTEXT		
5	Were you affected by <Cyclone Pam, Ambae evacuation, Cyclone Harold / other humanitarian crisis>	<ul style="list-style-type: none"> <li>Can you <u>briefly</u> tell me what happened please?</li> <li>Probe: if they were internally displaced, where they lived during that time, how long they were living somewhere other than home</li> </ul>
5a	AMBAE EVACUEES:	<ul style="list-style-type: none"> <li>How long were you in the evacuation centres during the Ambae evacuation?</li> <li>Did you have a choice in staying at the evacuation centre</li> <li>Were you and [name] able to stay together?</li> </ul>
5b	AMBAE & CYCLONE HARLOD EVACUEES:	<ul style="list-style-type: none"> <li>How long were you in the evacuation centres during the Ambae evacuation?</li> <li>How long were you in the evacuation centres during Cyclone Harold?</li> </ul>
MENSTRUATION		
<p>Now we are going to move on to our discussion about menstruation. This will focus on [name's] experiences, and your experiences of supporting her to manage menstruation. First, I'm going to ask you about what it was like before [humanitarian crisis], and then we will talk about what it was like during and after the [humanitarian crisis] so that I can understand how the situation compares.</p>		

6	What are words that girls and women use to talk about menstruation?	<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>
7	Can you tell me what happened when <name> menstruated <b><u>BEFORE</u></b> the <humanitarian crisis>?	You may need to skip around the topic guide here and probe into the following specific areas: <ul style="list-style-type: none"><li>• Knowledge and understanding (Q9)</li><li>• Behaviour (Q12)</li><li>• Menstrual materials (Q14)</li><li>• Changing menstrual materials (Q19)</li><li>• Disposal / reuse (Q23)</li><li>• Washing the body (Q25)</li><li>• Menstrual pain (Q28)</li><li>• Preparing for menstruation (Q30)</li><li>• Support / guidance (Q32)</li><li>• Menstrual restrictions (Q34)</li></ul>
8	What was it like when <name> menstruated <b><u>DURING/AFTER</u></b> the <humanitarian crisis>?	
KNOWLEDGE AND UNDERSTANDING		
9	Does <name> know what menstruation is? How?	<ul style="list-style-type: none"><li>• Who told her about it (family, friends, teachers, health worker)?</li><li>• What did they tell her?</li><li>• Do you need to remind her what it happening every time she menstruates?</li></ul>
10	<b><u>BEFORE</u></b> the <crisis> did <name> tell anyone when she was menstruating?	<ul style="list-style-type: none"><li>• If yes, who did she talk with? Why? What did she talk about? Did she try to hide it or keep it a secret? Why?</li><li>• If no, how did you know when she was menstruating?</li></ul>
11	Did this change <b><u>DURING/AFTER</u></b> the <crisis>?	<ul style="list-style-type: none"><li>• Who did she speak to? Why do you think that was?</li><li>• What did this mean for you?</li><li>• How did you respond?</li></ul>
BEHAVIOUR		
12	<b><u>BEFORE</u></b> the <crisis>, did <name's> behaviour change before or during menstruation?	<ul style="list-style-type: none"><li>• Why do you think this happens?</li><li>• What does this mean for you?</li><li>• How do you respond?</li><li>• Probe into any management solutions the participant mentions (e.g. cuddle her, let her rest, provides pain relief)</li></ul>
13	Did this pattern change <b><u>DURING/AFTER</u></b> the <crisis>?	
MENSTRUAL MATERIALS		
14	<b><u>BEFORE</u></b> the <crisis>, what menstrual material did she use (pads, cloth, tissues, underwear, nothing)?	<ul style="list-style-type: none"><li>• Who/where did she/you get materials from?</li></ul>

15	<b>Who/where did she/you get the materials from?</b>	<ul style="list-style-type: none"> <li>Where did she/you hear about that?</li> </ul>
16	<b><u>DURING/AFTER</u> the &lt;crisis&gt;, did she continue using the same menstrual materials?</b>	
16a	<b>YES:</b> Skip to question 17	
16b	<b>NO:</b> Why did she use a different material?	<ul style="list-style-type: none"> <li>How did [name] react to using the different menstrual material? Why?</li> <li>Which material does <u>she</u> prefer using? Why?</li> <li>Which material do <u>you</u> prefer she uses? Why?</li> </ul>
17	<b><u>DURING/AFTER</u> the &lt;crisis&gt;, were you given a hygiene kit and/or menstrual materials?</b>  <b>NO:</b> skip to next question	<ul style="list-style-type: none"> <li>Who/where did you get the hygiene kit from?</li> <li>What did the hygiene kit include?</li> <li>Were the menstrual materials suitable?</li> <li>Was there anything else you would have liked included in the hygiene kit?</li> <li>Where did she/you hear about the hygiene kit?</li> <li>Did you pay for them? Did you find this affordable?</li> </ul>
18	<b>Has &lt;name&gt; ever taken off her menstrual material in front of other people?</b>	<ul style="list-style-type: none"> <li>YES: this can be quite common. Can you tell me about what happens please? Probe into other people's reactions and what the caregiver does to manage.</li> <li>NO: skip to next question</li> </ul>
<b>CHANGING MENSTRUAL MATERIALS</b>		
19	<b><u>BEFORE</u> the &lt;crisis&gt; where did she / you change her menstrual material?</b>	<ul style="list-style-type: none"> <li>Could anyone see you/her?</li> <li>Was there a door with a lock on it?</li> </ul>
20	<b>Did &lt;name&gt; face any physical difficulties using this place?</b>	
20a	<b>YES:</b> What kind of difficulties does she have?	<ul style="list-style-type: none"> <li>Has anything been done to make it easier to use (e.g. handrail, movable seat etc)?</li> </ul>
20b	<b>NO:</b> SKIP to question 20	
21	<b>Could anyone see you/her in the place where you/she changes her menstrual material?</b>	<ul style="list-style-type: none"> <li>Was there a door with a lock on it?</li> <li>What did she/you find good or difficult about the place she changes her menstrual product?</li> </ul>
22	<b><u>DURING/AFTER</u> the &lt;crisis&gt;: repeat questions 19-21 (changing menstrual materials)</b>	

22a	AMBAE & CYCLONE HAROLD EVACUEES	<ul style="list-style-type: none"> <li>• Were there any differences between where she/you changed her menstrual materials during the Ambae and Cyclone Harold evacuations? Please explain</li> <li>• Probe into accessibility, privacy and safety</li> </ul>
<b>DISPOSAL / REUSE</b>		
23	<b><u>BEFORE</u> the &lt;crisis&gt; where / how did she dispose of the used menstrual material?</b>  OR <b><u>BEFORE</u> the &lt;crisis&gt; where / how did she / you wash and dry the used menstrual material?</b>	<ul style="list-style-type: none"> <li>• Why did she/you dispose of the materials there?</li> <li>• What did she/you find good or difficult about this?</li> </ul> OR <ul style="list-style-type: none"> <li>• Why did she/you wash and dry her menstrual materials there?</li> <li>• What did she/you find good or difficult about this?</li> </ul>
24	<b><u>DURING/AFTER</u> the &lt;crisis&gt;: repeat question 23 (disposal / reuse)</b>	
24a	AMBAE & CYCLONE HAROLD EVACUEES	<ul style="list-style-type: none"> <li>• Were there any differences between where you / she disposed of, or washed and dried the materials during the Ambae and Cyclone Harold evacuations? Please explain</li> </ul>
<b>WASHING THE BODY</b>		
25	<b><u>BEFORE</u> the &lt;crisis&gt;, where did she / you wash her body when she was menstruating?</b>	<ul style="list-style-type: none"> <li>• Can [name] collect water herself?</li> </ul>
25a	YES: What kind of difficulties does she have?	<ul style="list-style-type: none"> <li>• Has anything been done to make it easier to use (e.g. water bought nearer the home or inside the bathing shelter, handrail, movable seat etc)?</li> </ul>
25b	NO: SKIP to question 25	
26	<b>Did she/ you find anything good or difficult about the place she washes?</b>	<ul style="list-style-type: none"> <li>• Please explain</li> </ul>
27	<b><u>DURING/AFTER</u> the &lt;crisis&gt;: repeat questions 25-26 (washing the body)</b>	
27a	AMBAE & CYCLONE HAROLD EVACUEES	<ul style="list-style-type: none"> <li>• Were there any differences between your experiences during the Ambae and Cyclone Harold evacuations? Please explain</li> </ul>
<b>MENSTRUAL PAIN</b>		
28	<b><u>BEFORE</u> the &lt;crisis&gt; did &lt;name&gt; have menstrual discomfort?</b>	
28a	YES: How did she / do you manage the pain (e.g. massage, warm cloth, paracetamol)?	<ul style="list-style-type: none"> <li>• Did she have pain relief? Who? What do they give you?</li> </ul>

		<ul style="list-style-type: none"> <li>• <i>Did this help? If not, how does she behave when she has menstrual discomfort?</i></li> </ul>
28b	<i>NO: SKIP to next question</i>	
29	<b><u>DURING/AFTER</u> the &lt;crisis&gt;, did &lt;name's&gt; menstrual cramps get worse?</b>	<ul style="list-style-type: none"> <li>• Did you talk to anyone about this / seek help about this?</li> <li>• How did she/you manage the discomfort?</li> </ul>
29a	<i>NO: SKIP to next question</i>	
<b>PREPARING FOR MENSTRUATION</b>		
30	<b>Does &lt;name&gt; know when her menstruation is coming OR Do you know when her menstruation is coming? How?</b>	<ul style="list-style-type: none"> <li>• Does she / you prepare for the menstruation? How? Does she / you know when it has started and finished? How?</li> </ul>
31	<b><u>DURING/AFTER</u> the &lt;crisis&gt;, were you able to prepare for her menstruation?</b>	<ul style="list-style-type: none"> <li>• NO: why and what made it difficult?</li> <li>• YES: Did the way / she prepare for menstruation change?</li> <li>• How and why?</li> </ul>
<b>SUPPORT / GUIDANCE</b>		
32	<b><u>BEFORE</u> the &lt;crisis&gt;, did you ever talk to anyone about how to manage [name's] menstruation?</b>	<ul style="list-style-type: none"> <li>• Why did you talk to that person?</li> <li>• What did they say?</li> <li>• Did they give you any support or guidance? Was this helpful?</li> </ul>
32a	<i>YES: Who and why did you speak to them?</i>	<ul style="list-style-type: none"> <li>• <i>What support / guidance did you get?</i></li> <li>• <i>Who provided this?</i></li> <li>• <i>Did you find it helpful or not?</i></li> <li>• <i>Did you do anything differently after you had that information?</i></li> </ul>
32b	<i>NO: have you ever spoken to anyone else about managing [name's] menstruation?</i>	<ul style="list-style-type: none"> <li>• <i>Who have you spoken to?</i></li> <li>• <i>What did they say?</i></li> <li>• <i>Have you ever considered talking to a pharmacist, nurse, doctor?</i></li> <li>• <i>What information or support would you like to have?</i></li> </ul>
33	<b><u>DURING/AFTER</u> the &lt;crisis&gt;: repeat questions 32-32b (support/guidance)</b>	
33a	<b>AMBAE &amp; CYCLONE HAROLD EVACUEES</b>	<ul style="list-style-type: none"> <li>• Were there any differences between your experiences during the Ambae and Cyclone Harold evacuations? Please explain</li> </ul>
<b>MENSTRUAL RESTRICTIONS</b>		
34	<b>Is there anywhere [name] is not allowed to go when she is menstruating?</b>	<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> </ul>

		<ul style="list-style-type: none"> <li>Does she leave the house? Where does she go (work, school, friends)?</li> </ul>
35	Has this changed <b><u>DURING/AFTER</u></b> the <crisis>?	<ul style="list-style-type: none"> <li>How, what why?</li> <li>How have you / she responded to those changes?</li> </ul>
<b>MENSTRUATION AND INCONTINENCE</b>		
36	Now I'm going to ask you a few questions about <name's> toileting. Are you happy for me to continue?	<ul style="list-style-type: none"> <li>YES: ask next question.</li> <li>NO: skip to Biggest Challenges, Q39</li> </ul>
37	Is <name> able to hold onto her urine and faeces?	<ul style="list-style-type: none"> <li>YES: ask next question.</li> <li>NO: skip to Biggest Challenges, Q39</li> </ul>
38	<b><u>BEFORE</u></b> the <crisis>, how did she / you manage that?	
39	Has this changed <b><u>DURING/AFTER</u></b> the <crisis>?	<ul style="list-style-type: none"> <li>How, what why?</li> <li>How have you / she responded to those changes?</li> </ul>
39a	AMBAE & CYCLONE HAROLD EVACUEES	<ul style="list-style-type: none"> <li>Were there any differences between your experiences during the Ambae and Cyclone Harold evacuations? Please explain</li> </ul>
<b>BIGGEST CHALLENGES</b>		
40	<b><u>BEFORE</u></b> the <crisis>, what did you feel was the biggest challenge when <name> menstruated?	<ul style="list-style-type: none"> <li>Why is that the biggest challenge?</li> </ul>
41	<b><u>DURING/AFTER</u></b> the <humanitarian crisis>, what did you / <name> find most challenging when she was menstruating?	<ul style="list-style-type: none"> <li>Why is that the biggest challenge?</li> <li>Did you speak to anyone about this, or seek support anywhere?</li> </ul>
41a	AMBAE & CYCLONE HAROLD EVACUEES: ask question x and sub questions separately	<ul style="list-style-type: none"> <li>i.e. What did you / &lt;name&gt; find most challenging when she was menstruating during the Ambae evacuation? Why?</li> </ul>
42	<b><u>DURING/AFTER</u></b> the <humanitarian crisis>, was there anything, related to menstruation, that was better?	<ul style="list-style-type: none"> <li>Why was this?</li> </ul>
<b>RECOMMENDATIONS</b>		
43	In your opinion, <b><u>DURING/AFTER</u></b> the <crisis>, what do you think could be done to:	<ol style="list-style-type: none"> <li>Help &lt;name&gt; manage her menstruation better</li> <li>Help you support &lt;name&gt; during her menstruation</li> </ol>
44	Thank you very much for talking to me about your experiences. I have a few more short questions for you, but before I ask those, is there anything else you want to tell me? Is there anything you would like to ask me?	