

# Disabling Menstrual Barriers

*Identifying and addressing the barriers to menstrual hygiene that adolescents and young people with disabilities face in Nepal*



## Learning note

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### Introduction

The Disabling Menstrual Barriers research aims to investigate and address the barriers to menstrual hygiene management (MHM) that adolescents and young people with disabilities face in the Kavre district in Nepal. It is a collaboration between WaterAid and the LSHTM, with funding from the Bill and Melinda Gates Foundation.

During September 2017, qualitative data was collected using participatory methods, including PhotoVoice. This learning note presents the research questions, timeline, data collection methods and ethics. It also captures the preliminary findings from PhotoVoice and highlights the emerging research themes from this.

### The crisis

- Globally over 1 billion people have an impairment (WHO/World Bank, 2011)
- Menstruation is a taboo in many countries. Menstruating women and girls are often perceived to be polluting, dirty and face barriers and restrictions that prevent them from participating fully in daily life (House et al, 2012)
- It is likely that women and girls with disabilities face additional barriers to menstrual hygiene management, but there is limited evidence (Unicef, 2016; House et al, 2012)
- Without understanding the barriers that disabled women and girls face, menstrual hygiene management interventions may leave them behind

### Menstrual hygiene definition

Women and adolescent girls are using a clean menstrual management material to absorb or collect menstrual blood, that can be changed in privacy as often as necessary for the duration of a menstrual period, using soap and water for washing the body as required, and having access to safe, convenient [and accessible] facilities to dispose of used menstrual management materials. They understand the basic facts linked to the menstrual cycle and how to manage it with dignity and without discomfort or fear (JMP, 2012).

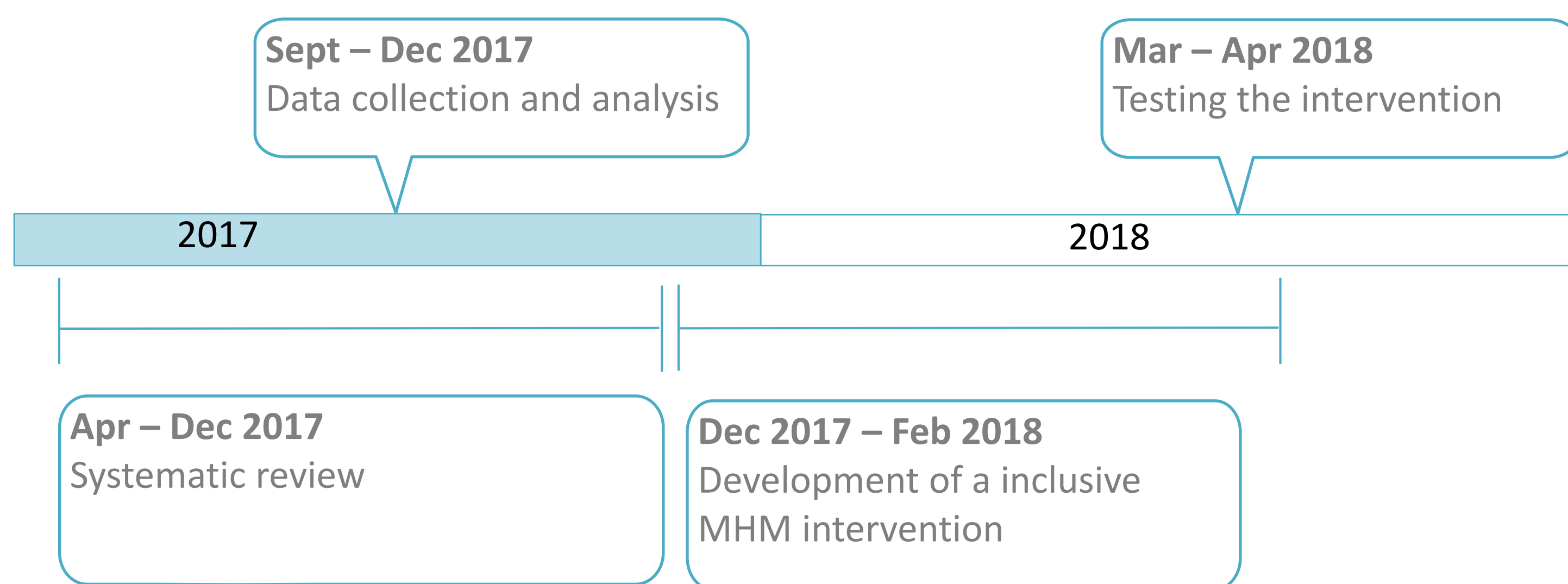


## Research questions

The Disabling Menstrual Barriers research aims to answer these questions:

1. What are the MHM requirements of people with disabilities and those that care for them (**systematic review**)?
2. What are the specific menstrual hygiene management requirements of:
  - adolescents and young people with disabilities living in the Kavre district, Nepal (**qualitative data collection**)?
  - parents / carers who support these adolescents and young people with disabilities during their menstrual cycle (**qualitative data collection**)?
3. What intervention could feasibility meet these requirements (**develop and test intervention**)?

## Timeline



## Data collection methods

Method	Respondents	Sample
In-depth interviews	<ul style="list-style-type: none"> <li>• Primary participants</li> </ul>	<ul style="list-style-type: none"> <li>• 20 females with a disability, aged 15-24 years living in rural and urban settings</li> </ul>
Accessibility and safety audits of the menstrual hygiene facility	<ul style="list-style-type: none"> <li>• Carers</li> </ul>	<ul style="list-style-type: none"> <li>• 10-20 carers of the adolescent and young females with a disability</li> </ul>
Market survey and product attribute assessment		
PhotoVoice	<ul style="list-style-type: none"> <li>• Primary participants</li> <li>• Carers</li> </ul>	<ul style="list-style-type: none"> <li>• 4-5 selected from the above sample</li> </ul>
In-depth interviews	<ul style="list-style-type: none"> <li>• Policy makers and implementers</li> </ul>	<ul style="list-style-type: none"> <li>• 5-10 policy makers and implementers, who focus on disability, sexual reproductive rights, and / or water, sanitation and hygiene at the national and district levels in Nepal</li> </ul>

## What is PhotoVoice?

PhotoVoice aims to equip participants with photography skills. Using photos, participants can share their personal perspectives and experiences of the barriers to MHM they face and how these affect them.

PhotoVoice was applied in this research because it is particularly useful when exploring topics that are private or difficult to talk about, such as MHM. It also allows the research participants to express themselves in a visual medium rather than through words, which is helpful for people who have difficulty communicating.

During meetings with the participants, the researcher:

- Explained how photos can tell a story; how to use a camera and compose shots
- Explained the task: take 5 photos that represent their feelings about menstruation and how they manage it
- Returned to the participant with their printed photos
- Carried out a short interview with the participant to understand what the photos capture and the story behind them
- Asked the participant to rank the photos from the most (number 1) to least important issue (number 5), and explored reasons for the order

The research ethics are very important due to the participants' age, disability and the nature of the topics explored. Full ethics approval was granted from the Nepal Health Research Council and the LSHTM.

The ethics and consent process of PhotoVoice was very thorough to ensure that the participants understood the purpose of the activity and what they are agreeing to. Written consent was sought at the start of the process. The researcher explained how participants could take photos without showing their face and how to represent MHM issues in a dignified way.

Secondary written consent was sought after the photos were printed. This consent related to how the photos could be used and if the photographer wanted to be credited by her real name or a pseudonym. This is done after the photos were taken, the interview conducted and the photo ranking so the participant could make a better judgement about how they wish them to be used.

All of the PhotoVoice participants agreed to be credited for their photographs, using their real names. Everyone also agreed that WaterAid and the LSHTM could use the photos, their names and content from their interviews in their work.

## Ethics and permission

# Results

Sharmila Tamang is 24 years old and has a physical disability.



*Caption: Water issue is also there, I would have to carry water, which is difficult.*

*Credit: Sharmila Tamang*

*Photo ranking: 2/4 (only 4 photos taken)*

“

That's my crutches and water tank. I need to use crutches to walk thus can't carry water. It's either me carrying my two legs or water. We don't have water in the tank now, it's all way in the bottom. [When we don't have water] I do nothing, I can't wash clothes either. I just keep the [menstrual] cloth and wait for water. I keep it under my bed when I can't wash it, and wash it when I get water. I have problem during menstruation when there is no water.

Tulasa Karki is 22 years old. She has physical disability, which makes self-care activities, such as washing her body and changing her clothes difficult.



*Caption: When I have to go to the toilet, I need someone else to help with the latch otherwise I can't do it myself.*

*Credit: Tulasa Karki*

*Photo ranking: 3/4 (only 4 photos taken)*



When I have to use the toilet or take shower, I need someone else to help with the latch otherwise I can't do it myself. People would tell me to close [the door] while using it but I can't use the latch.

When I have to change my pad, people might just open it. Whoever is helping me to change the pad might also forget to use the latch. My sister had taken me to the toilet and came inside and took a nap. My brother opened the door and yelled at me for not closing the toilet door properly.

Sharmila Tamang is 24 years old and has a physical disability.



*Caption: It is difficult to go to toilet.*

*Credit: Sharmila Tamang*

*Photo ranking: 1/4 (only 4 photos taken)*

“

This is photo of our toilet. It is difficult to go to toilet because the way to the toilet is slope. Specially when it rains, it is difficult. It is very difficult because the crutches might slip.

Even today, I fell down two-three times because yesterday it rained. I feel like crying when I have to use the toilet when it is muddy outside. [Then] I would use *kopra* [a potty] inside the house. [My parents] scold me, but I tell them I can't go to the toilet.

[I] need to wash menstrual cloth in [the] toilet. There is no water in the toilet. I sometime ask my mother, or aunty or others. When there is no one to help me carry water to toilet, I have to carry water in a bucket while also managing the crutches. It is very difficult, specially in the mornings. Earlier, I would have to crawl to toilet but now I learnt how to use crutches.

*For the purposes of this document, this quote is reordered and condensed.*

Babita Thapa is 20 years old. She has a physical disability and is currently staying in the Spinal Cord Rehabilitation Centre in Kavre.



*Caption: It is not only easier to use this type of toilet for those with spinal cord injury but it is a necessity. So even in villages, these types of toilets should be built for people as not everyone can live in the cities. During your period, also it is difficult to stand to change pads, so this kind is easier to use.*

*Credit: Babita Thapa*

Photo ranking: 1/5

Bishnu Maiya Sapkota is 38 years old. She cares for her 17 year old daughter who has an intellectual disability.



*Caption: I take care of my daughter and wash her menstrual cloth during her period as well as the other times.*

*Credit: Bishnu Maiya Sapkota*

Photo ranking: 1/5

“

Everything is washed in [this] toilet, even menstrual cloth. During [her] period, I wash her cloth, clean her. I don't feel anything. I think this is my faith so don't feel much. I don't mind.

For her, it is only her period that is difficult. If she could get training on self-care, cooking, washing and other skills, maybe she could do all the work herself. She would herself be able to do her own work. Probably other people will find it a relief. As a mother I have to do it but in future I might not be able to take care of her. And I am not sure who would help her. So if something can teach her to do her work on her own.



# Emerging themes

The participants change and wash the menstrual cloth in the toilet. **Barriers in accessing and using the toilet** include:

- Steep and slippery path, making getting to the toilet difficult
- Small fixtures and fittings on the toilet door
- A lack of seat inside the toilet that a person can sit on to change her menstrual product

Interviews with the PhotoVoice participants demonstrate that these barriers negatively affect their **safety, security and dignity**.

Babita was the only participant who uses **accessible WASH services** at the Spinal Cord Rehabilitation Centre. She ranked an accessible toilet as the most important issue. She finds the raised seat more comfortable than a pit latrine and sits on it to change her menstrual product. Babita stated that this accessible design could benefit other people with disabilities in Nepal, so it should be promoted more widely.

**Water availability, quantity and ability to collect it independently** are significant issues for Sharmila. Not having a suitable water-carrying device that can be used with her crutches means she is reliant on others. Without water, Sharmila stores her unwashed menstrual cloth under her bed until water is available.

Bishnu highlighted that her **caring tasks relate to WASH**. Though she sees this care as her duty as a mother, she worries about who will continue to provide that for her daughter in the future. She highlights the need to provide **appropriate training on self-care for people with intellectual disabilities**, which might improve their levels of independence.

1. Complete the systematic review
2. Analyse the qualitative data collection
3. Collaboratively develop an MHM intervention with key stakeholders in Nepal to address the key barriers
4. Test the MHM intervention with up to five original research participants

Longer term plans include conducting participatory feasibility and acceptability studies in different settings in Nepal to iteratively test and develop the intervention further. This will provide a strong foundation for scaling up the intervention within WaterAid's existing MHM programming and influencing other actors to do the same. This is dependent on securing further funding.

Next steps

World Bank (2012) *World development report – Gender equality and development*. <http://bit.ly/Jaj1vl>

House, S., Mahon, T., Cavill, S. (2012), *Menstrual Hygiene Matters*. [www.wateraid/mhm](http://www.wateraid/mhm)

UNICEF (2016) *Supporting the Rights of Girls and Women through Menstrual Hygiene Management in the East Asia and Pacific Region; Realities, Progress and Opportunities*. <http://menstrualhygieneday.org/supporting-rights-girls-women-menstrual-hygiene-management-mhm-east-asia-pacific-region/>

JMP, editor. Meeting Report of JMP post-2015 Global Monitoring Working Group on hygiene. Washington, DC: WHO/UNICEF Joint Monitoring Programme, Post-2015 Working Group on Hygiene; 2012.

Map image: Wikipedia