WaterAid

ASSESSING THE WATER, SANITATION AND HYGIENE NEEDS OF PEOPLE LIVING WITH HIV AND AIDS IN PAPUA NEW GUINEA

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Anglicare PNG

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ABBREVIATIONS

ARV	Antiretroviral treatment
HBC	Home-based care
HWWS	Hand washing with soap
IEC	Information, Education and Communication
MDG	Millennium Development Goal
NGO	Non-Government Organisation
OD	Open defecation
OI	Opportunistic infection
PNG	Papua New Guinea
PPTCT	Prevention of parent to child transmission
WASH	Water, sanitation and hygiene

EXECUTIVE SUMMARY

In 2010, 32,000 people were living with HIV in Papua New Guinea (PNG), a number that has been predicted to increase over the coming years (National AIDS Council Papua New Guinea, 2011) (UNAIDS, 2012).

However, comprehensive care and support, treatment and preventative services are improving across PNG, resulting in people living with HIV leading longer and healthier lives.

Owing to weakened immune systems, people living with HIV are at risk of many life threatening opportunistic infections, many of which are caused by exposure to unsafe drinking water, inadequate sanitation and poor hygiene (World Health Organization, 2010). Chief among them is diarrhoea which is experienced by more than 90% of people living with HIV in developing countries (Thom and Forest, 2006). This increased prevalence may also increase the risk of diarrhoea among children living in the same household. Diarrhoea can also interrupt the absorption of ARV medication and cause deficiency in essential nutrients, leading to malnutrition and further exacerbating the consequences of HIV and AIDS (Bushen et al, 2004).Children born to mothers living with HIV (Keusch et al, 1992), children who are HIV positive themselves (Thea et al, 1993) or children with a mother living with HIV who has experienced diarrhoea in the last seven days (Peletz et al, 2011) are all at increased risk of diarrhoea – which is the second largest killer of children under five globally (CHERG, 2012). Practices such as replacement feeding with infant formula milk, complementary feeding and weaning require water for breast-milk substitute, food and drink preparation. Thus, these practices may increase the risk of exposure to unsafe water and consequent diarrhoea (Peletz et al, 2011; Arvelo et al, 2010).

This risk of diarrhoeal disease can be mitigated by access to safe water, adequate sanitation and hygiene (WASH). When behaviours such as treatment and safe storage of drinking water, safe disposal of excreta and hand washing are practised together, deaths from diarrhoeal diseases can be reduced by 65% (Bateman et al, 2002). However in PNG, access to safe water and adequate sanitation is low: only 40% of the population has access to safe water and 45% to improved sanitation. As in many countries, these national figures conceal a discrepancy between coverage of water and sanitation in rural (33% and 13%, respectively) and urban areas (88% and 56% respectively) (JMP, 2014).

Anglicare, one of the largest non-government organisations working on HIV and AIDS in PNG, and WaterAid, recognise the poor WASH coverage in PNG and the pressing need to introduce WASH practices into HIV programming. Therefore, this research was designed in partnership to elucidate the specific WASH needs of people living with HIV in PNG to inform future Anglicare initiatives and programming for people living with HIV.

The objectives of the research were:

- Gather baseline information on people living with HIV's access to water and sanitation, and identify factors which may contribute to vulnerability to accessing WASH facilities among people living with HIV
- Investigate people living with HIV's experiences with stigma and discrimination as they relate to accessing water and sanitation facilities and services
- Investigate people living with HIV's health knowledge and health seeking behaviours regarding the causes of WASH-related illnesses, particularly diarrhoea
- Investigate the vulnerability of children living in HIV-affected households, and the specific WASH needs of mothers living with HIV
- Identify opportunities and provide recommendations for integrating WASH messaging and programming into existing HIV support and care, treatment and preventative services.

Methodology

A survey with close-ended questions (see Annex) was developed to investigate the WASH knowledge, perceptions and practices of people living with HIV in PNG, and was administered by Anglicare staff in four sites in PNG between October-November 2012.

Results

Ninety three surveys were collected across four sites. The majority of respondents were female (74%) and from urban areas (67%). Respondents typically lived in large households, with 36% living with more than eight people.

1. HIV Status

On average, respondents had lived with HIV for 7.3 years and 90% were receiving ARV treatment for an average length of time of 5.2 years. Fifty seven percent of respondents had at least one family member who was also HIV positive. Almost two-thirds (60%) of respondents described their current health as 'healthy' or 'very healthy'.

2. Water access and use

Over half of the respondents had access to an improved water source via a piped connection. Forty percent of respondents accessed water through an unimproved source including 30% from a lake, river or spring and 10% via an unprotected well or uncovered drum. Rural respondents were more likely to use unimproved sources than urban respondents. Knowledge and practices regarding water treatment were low. The majority expressed a need for additional water since becoming HIV positive, mainly for drinking (90%) and bathing (76%).

3. Sanitation access and use

Improved pit latrines were most commonly used (37%), followed by unimproved pit latrines (31%) and flush toilets (25%). Only 6.5% of respondents reported practising open defecation. Travel time to a toilet varied from one minute to forty minutes and on average people shared a toilet with at least ten people.

4. Hygiene practices

Almost all respondents (94%) acknowledged the increased importance of hygiene for people living with HIV. Self-reported rates of hand washing were high among the group, with over 60% washing their hands after using the toilet, but with only 44% reported washing hands before eating. 27% washed their hands after changing their child's nappy, and only 6% did not wash their hands at all.

5. Health knowledge and health seeking behaviours

Diarrhoea was cited by 90% of respondents as the most common opportunistic infection faced by people living with HIV. Over half the respondents had been ill in the last two months, the majority with coughs/colds (35%) and one quarter had experienced diarrhoea in the last two weeks. Increased fluid intake was the main treatment practice for diarrhoea among respondents (75%).

6. Stigma and discrimination

Forty one percent of respondents had experienced stigma and discrimination because of their HIV status from their family and 36% from their community. In 18% of cases respondents were prevented from collecting water because of their HIV status, while another 18% reported that members of their family had been prevented from collecting water in the past.

7. Vulnerability of HIV-exposed children

Fifty three percent of respondents in the study had children, of whom 39% were under the age of 5. Almost one quarter (23%) of these children were HIV positive. Knowledge and available information about the safe preparation of formula were limited as only 36% of respondents received information through an HIV setting, Government clinic or hospital, community health worker or family member.

Discussion

Overall, respondents demonstrated a good knowledge of the importance of WASH and the health benefits. However, this study highlighted several WASH needs for people living with HIV that must be acknowledged and addressed for programming, as well as the particular WASH needs of parents living with HIV in regard to caring for their children.

Recommendations

Specific areas highlighted in this research that require addressing include:

- Provide comprehensive guidance on the self-treatment of diarrhoea to people living with HIV, and their carers
- Prioritise latrine construction in communities where there is low sanitation facility coverage and a known high HIV prevalence (taking care not to disclose any member of the community's HIV status)
- Develop education and guidelines regarding the safe treatment and storage of water, to be integrated within existing health promotion activities for people living with HIV, in order to address the needs people living with HIV expressed for additional water
- Provide education around the transmission of HIV to overcome stigma which may be preventing people living with HIV from accessing WASH facilities
- This education material should be tightly integrated into all programming designed for people living with HIV
- Further assess the specific needs and care practices of families living with HIV, and their children.

Conclusion

The research revealed that people living with HIV in PNG have increased needs for WASH, and that these needs are not being adequately met. Stigma and discrimination were found to be barriers to access to WASH for respondents and their families. In addition, this study identified priority areas for service providers to direct future activities and best integrate WASH into programming for people living with HIV. Priority areas include hygiene education, safe treatment and storage of water, self-treatment for diarrhoea, latrine construction, and education around the transmission of HIV.

1. INTRODUCTION

In 2012, WaterAid Australia and WaterAid PNG undertook research to understand how water, sanitation and hygiene (WASH) affect the lives of people living with HIV and AIDS (people living with HIV) and their families in Papua New Guinea.

This research was conducted in partnership with Anglicare, a national non-government organization (NGO) providing HIV services in Papua New Guinea, to test the hypothesis that in relation to WASH, people living with HIV *have increased need, increased vulnerability and decreased access* (WaterAid, 2009). As discussed in the literature review, access to safe water, adequate sanitation and hygiene is crucial to safeguarding the health of people living with HIV and their families, particularly in regard to reducing their vulnerability to opportunistic infections (OI) such as diarrhoeal disease.

This research highlighted the WASH-related knowledge and practices of people living with HIV and their families in PNG, as well as explored their experiences with stigma and discrimination and how this impacted on access to water and sanitation. By identifying gaps and highlighting needs, it is hoped that this research will provide a platform to allow Anglicare and other HIV service providers to integrate WASH into existing HIV activities, inform the WASH and HIV sectors on how to identify and better address the WASH needs of people living with HIV, as well as more broadly making the case for the crucial role WASH plays in promoting health, particularly among the vulnerable and most marginalised.

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2. LITERATURE REVIEW

People living with HIV have weakened immune systems and are susceptible to illness and opportunistic infections. Many life-threatening opportunistic infections are caused by exposure to unsafe drinking water, inadequate sanitation and poor hygiene.

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Chief among them is diarrhoea, which is experienced by over 90% of people living with AIDS (Thom et al, 2006). This susceptibility decreases as a person commences ARV therapy, yet 40% of people living with HIV on treatment will still experience at least one diarrhoeal episode per year (Knox et al, 2000). Diarrhoea can also interrupt the absorption of ARV medication and cause deficiency in essential nutrients, leading to malnutrition, and further exacerbating the consequences of HIV and AIDS (Bushen et al, 2004).

Access to safe water, adequate sanitation and hygiene behaviours can mitigate a person's risk of diarrhoeal disease. For example, treatment and safe storage of water can reduce diarrhoea by up to 40% (USAID, 2004); safe disposal and handling of faeces can reduce risk of diarrhoea by at least 30% (Fewtrell et al, 2005), and hand-washing with soap can reduce risk by up to 44% (Curtis, 2003). These interventions are most efficacious when practised together, and have been found to reduce deaths from diarrhoeal diseases by an average of 65 per cent (Bateman et al, 2002).

Diarrhoeal illness can also affect a household by contributing to a reduction in productivity and a consequent loss in household earnings. In countries where people pay a high cost for water this decreased income and increased need for water can put a strain on household income and detract from expenditure on other essential items. In countries where prohibitive costs for WASH services exist, this increased strain may also act as a barrier to safe WASH practices and lead people to turn to unsafe options, such as using unprotected water sources that may lead to ill health (WSP, 2007).

The World Bank Water and Sanitation Program (WSP) found, in India, that HIV-affected households require more than 20 litres of water per person per day, of which 1.5 litres of clean water is for drinking with antiretroviral (ARV) medicines (WSP, 2007). Furthermore, a recent study conducted by WaterAid Nepal revealed that 52% of people living with HIV expressed an increased need for water for drinking, bathing and sanitation. This increased need for water may exacerbate the burden of care a family or carer provides to people living with HIV during periods of illness (WaterAid, 2010). Therefore, critical to the care and health of people living with HIV, is the provision of adequate WASH tailored to their specific needs.

Increased illness among people living with HIV may also increase the household's vulnerability to illness, especially among children living in HIV-affected households. Research has shown that children born to mothers living with HIV are 3.5 times more at risk of diarrhoeal disease compared to children born to mothers without HIV (Keusch et al, 1992). Furthermore, Peletz et al (2011) found that HIV-exposed children were six times more likely to have diarrhoea if their mother had diarrhoea in the last seven days. Children who are themselves HIV-positive are 11 times more likely to die from diarrhoeal disease than a HIV negative child (Thea et al, 1993). As diarrhoea is the second leading cause of death among children under-five globally (CHERG, 2012), this increased vulnerability among HIV-exposed children is a serious public health issue that warrants attention.

Replacement feeding and/or weaning of children by mothers living with HIV is one way of reducing risk of potential vertical transmission of HIV through breast milk. However, these practices increase a child's potential exposure to unsafe water, which may lead to diarrhoeal disease. Several studies have shown the risk of diarrhoea associated with weaning: Arvelo et al (2010) found that children of mothers living with HIV presenting with diarrhoea were less likely to be currently breast-fed, and their parents were likely to report storing household drinking water, which increased the potential for contamination. Similarly, Peletz et al (2011) found that practices including giving water and feeding solids such as porridge were associated with an increased risk of diarrhoea among HIV-exposed infants under two.

Adoption of targeted WASH behaviours, such as hand washing at critical times, safe disposal of excreta, and safe storage and treatment of drinking water, may be impeded by a lack of knowledge around the importance of WASH among people living with HIV. Various studies suggest that levels of knowledge on ideal WASH behaviours, and the importance of these behaviours in promoting health and wellbeing among people living with HIV vary across locations. For example, in India, people living with HIV demonstrated higher knowledge of target WASH behaviours than the general population (WSP, 2007) while in Uganda, WASH knowledge among people living with HIV was generally poor (Mugabe et al, 2012). A recent WaterAid study in Nepal found that knowledge of the importance of WASH among people living with HIV was high, with 94% acknowledging that people living with HIV had an increased need for better hygiene, and 71% identifying unsafe water as the cause of diarrhoea (WaterAid, 2010). This highlights the need to assess prevailing attitudes and levels of knowledge in order to develop programs and activities that address specific needs particular to the context and location.

Stigma and discrimination may also preclude people living with HIV from accessing WASH services and facilities as communities may hold misconceptions about the ways in which HIV is transmitted, evidenced by documented cases of discrimination against people living with HIV by private vendors who refuse to serve people with HIV and AIDS out of fear of transmitting infections or of losing business (WaterAid, 2010). In 2010, WaterAid conducted similar research on the WASH needs of people living with HIV in Nepal which found that 18% of people living with HIV had experienced stigma and discrimination from their families and 45% from their communities. In some cases, this stigma and discrimination also prevented people living with HIV and their families from accessing WASH facilities (WaterAid, 2010).

2.1 THE NATIONAL CONTEXT OF HIV AND AIDS AND WASH IN PAPUA NEW GUINEA

In 2010, approximately 32,000 people were living with HIV in Papua New Guinea (PNG), equivalent to 0.9% of the general population, and 4,200 people were newly infected. Rates have continued to rise and are expected to reach 1% by 2015 (National AIDS Council Papua New Guinea, 2011).

Access to safe drinking water and basic sanitation in PNG is generally low. Nationally, only 40% of the population has access to safe drinking water and 19% to basic sanitation. However, national figures do not reflect the discrepancy between rural and urban coverage; urban PNG has higher access to safe water and sanitation, at 88% and 56% respectively, compared to access in rural population, at 33% and 13%, respectively (JMP, 2014). These figures have remained largely unchanged over the last ten years, and fall short of both national targets and the Millennium Development Goal, which is approximately 70% coverage for both water and sanitation.

PNG has one of the highest rates of under-five child mortality in the Pacific region. Figures in 2010 show an under-five mortality rate of 61 deaths per 1,000 live births. While this is an improvement from the 1990 figure of 90 per 1,000 it is still insufficient to meet the Millennium Development Goal (MDG) goal by 2015.

3. BACKGROUND AND RATIONALE

Thirty four million people are currently living with HIV (UNAIDS, 2012). As access to antiretroviral (ARV) treatment increases worldwide, more people are living longer with HIV and AIDS. Comprehensive care and support, treatment and preventative services are now required more than ever to help people living with HIV live longer and healthier lives. International public health literature increasingly acknowledges the role water, sanitation and hygiene play in safeguarding the health and wellbeing of people living with HIV and their families, particularly in regard to protecting people living with HIV against opportunistic infections such as diarrhoeal disease (for example, WHO, 2012; CRS, 2010; USAID, 2009). Reflecting this trend, a number of organisations providing services to people living with HIV have begun to mainstream WASH activities and messages into a range of HIV and AIDS programs and activities.

Anglicare, one of the largest NGOs working in HIV and AIDS in PNG, and WaterAid, recognise the poor WASH coverage in PNG and the pressing need to introduce WASH practices into HIV programming. The impetus for research into the WASH needs of people living with HIV developed from a long-standing partnership between WaterAid PNG and a local NGO, AT Projects. ATProjects has developed a 'Living with Dignity Kit' based on the expressed needs of carers and people with end-stage AIDS. This kit provides pragmatic tools and items, such as a portable toilet and shower which enables carers to better tend to the hygiene and sanitation needs of the chronically ill. Wanting to investigate this further, WaterAid commissioned the Burnet Institute for Global Health to undertake a scoping study in 2011, which identified several possible entry points for further exploring the relationship between WASH and HIV and AIDS in PNG.

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In early 2012, it was decided that Anglicare would be a well-placed partner to further investigate the WASH needs of people living with HIV in PNG, and an exploratory research project would enable the organisation to introduce WASH into its existing programs. The partnership drew on WaterAid's experience in water, sanitation and hygiene and Anglicare's long standing experience in HIV and established relationships and presence in various communities across PNG.

Anglicare has three branches – in Port Moresby (HQ), Mt Hagen and Popondetta, and two offices in Wabag and Lae that provide services to six main provinces (National Capital District (NCD) and Central, Oro, Moreobe, Western Highlands and Enga Provinces). Anglicare provides a range of counselling, testing, treatment, care and support services, such as the provision of quality ARV support services, treatment and management of OIs, home-based care services, and an on-site program for people living with HIV for social, physical and emotional well-being.

WaterAid has an interest in building evidence which demonstrates the fundamental role WASH plays in health and development, reflected by Aim 3 of WaterAid's Global Strategy: *advocate for the essential role of WASH in human development.* It is hoped that this research will demonstrate how WASH can improve the health of people living with HIV as well as strengthening the case for integration of WASH and health both in practice and policy.

Moreover, this focus on people living with HIV reflects WaterAid's focus on equity and inclusion, which recognises that particular groups in society may be more vulnerable and marginalised than others (see WaterAid reports *Equity and Inclusion: A rights-based approach, (2010) and Towards Inclusive WASH (2011)* for further information). While universal access to water and sanitation is the ultimate goal, factors such as gender, disability, or HIV status may preclude people from accessing WASH, thereby increasing their vulnerability. For many of these groups, the consequences of limited access are likely to be greater than that of the general population (WaterAid, 2010). This is particularly the case for people living with HIV, who rely on clean water, adequate sanitation and hygiene to prevent opportunistic infections, safeguard their health and help them to live longer lives. Therefore, this research aimed to gather information on the specific WASH needs of people living with HIV and AIDS, so that these needs may be properly addressed and incorporated into future activities.

4. RESEARCH AIM, OBJECTIVES AND METHODOLOGY

The existing literature clearly acknowledges the importance of WASH for people living with HIV, yet knowledge and practices surrounding WASH are highly variable and context specific.

Therefore, this research aimed to gather country-specific information on the WASH needs of people living with HIV in PNG to identify the major gaps in knowledge and practices among this population, to contribute to the evidence base, and inform efforts to mainstream WASH into existing HIV programs.

4.1 AIMS AND OBJECTIVES

Aim

To assess current WASH knowledge, perceptions and practices of people living with HIV in PNG in order to identify gaps, and recommend ways in which WASH can be mainstreamed into HIV services.

Objectives

1. Gather baseline information on people living with HIV's access to water and sanitation by location and identify factors which may contribute to vulnerability among people living with HIV
2. Investigate people living with HIV's experiences with stigma and discrimination as they relate to accessing water and sanitation facilities and services
3. Investigate people living with HIV's health knowledge and health seeking behaviours regarding the causes of WASH-related illnesses, particularly diarrhoea
4. Investigate the vulnerability of children living in HIV-affected households, and the specific WASH needs of mothers living with HIV
5. Identify opportunities and provide recommendations for integrating WASH messaging and programming into existing HIV care, treatment and support services

4.2 METHODOLOGY

This research was conducted in two phases:

Phase 1

- Key informant interviews (KII) with Anglicare staff across various urban, peri-urban and rural locations
- Reading of relevant WASH/HIV literature and guidance to triangulate with KII data
- Development of closed-ended survey tool
- Pilot test of tool by staff in Port Moresby and Mount Hagen.

Key Informant Interviews

During the first phase of the study, field trips were taken to various Anglicare project sites to hold informal key informant interviews (KII) with various Anglicare staff involved in HIV prevention, care and support, and treatment activities, including clinic workers, outreach program staff and home-based care workers. The KIIs were designed to gather professional input and opinions regarding the WASH needs of the people living with HIV in the community, and to gauge staff comprehension regarding the importance of WASH and their capacity to promote it within their current activities.

Interviews were centered on the following three discussion points:

1. What are the main health problems faced by the people living with HIV you work with?
2. What role do you think water, sanitation and hygiene has in mitigating the health problems of people living with HIV in your community?
3. What resources and information do you provide to people living with HIV on preventing these health problems? Are there any gaps where better information could be provided?

Findings from these interviews were fed into the development of the survey tool. In summary:

- *Respiratory infections, including tuberculosis, and diarrhoea* were the main health issues of people living with HIV as observed by Anglicare staff
- Knowledge of the role of WASH in reducing risk of diarrhoea and respiratory infections varied among staff. Staff working in rural areas had observed an increased rate of diarrhoea during the dry season, when wells dry up and people resort to collecting water from rivers and lakes. Many staff also commented on the significant amount of animal waste in rural communities, and questioned if this had any impact on the health of communities. No staff explicitly mentioned the role of hand washing in reducing the risk of diarrhoea and respiratory infection, but general personal hygiene was mentioned often as a way to keep healthy.
- *The available resources and information given to people living with HIV varied across location and program*. There was no standardized information or resources available to Anglicare staff to provide to people living with HIV which promoted the importance of WASH for health. Clinic staff had a small number of posters on the walls on personal hygiene, but no form of health promotion resources to give to individual patients. There was only one manual on home-based care which provided information to HBC staff on the promotion of hygiene among people living with HIV, but less on sanitation and safe water. In the rural outreach programs, hygiene and cleanliness (especially of village) were addressed on an ad-hoc basis in the community. Community health workers (while not employees of Anglicare, they work closely with Anglicare staff members in the community) often promoted personal hygiene during encounters with people living with HIV and promoted the use of toilets instead of open defecation, but expressed difficulty in taking a systematic approach to hygiene promotion without resources.

The KIIs revealed that knowledge of WASH and its relevance for people living with HIV was variable among Anglicare staff, and several gaps were identified. For example, hand washing and clean water were mentioned often as key behaviours promoted to people living with HIV to avoid diarrheoa, but there was little mention of the role of sanitation. For this reason, an introductory session on WASH was developed and delivered in conjunction with the data collection training.

These concerns were incorporated into the development of the survey tool, which was based on an existing tool used by WaterAid Nepal to investigate the WASH needs of people living with HIV in Nepal in 2010. Feedback from the KII was triangulated with the existing literature on WASH/HIV integration, and with information on the local WASH and HIV context in PNG (e.g. NAC 2011; JMP 2012) in order to develop a survey tool which was relevant to the context in PNG and reflected the main WASH and HIV related issues.

A draft questionnaire was created and shared with relevant stakeholders and partners for feedback. The final survey tool (see Annex) addressed the following areas:

- People living with HIV's access to, and practices around water supply
- People living with HIV's access to, and practices around sanitation
- People living with HIV's hygiene practices
- Experiences with stigma and discrimination and how these impact on people living with HIV's access to WASH facilities and services
- Levels of health knowledge and health seeking behaviour regarding WASH related illness
- The vulnerability to diarrhoea of children living in HIV-affected households

PHASE 2

- Identification of Anglicare staff to assist with data collection
- Selection of study sites
- Roll out of training workshop to Anglicare staff
- Data collection and analysis

Selection of staff and study sites

Discussions were held with the management team from Anglicare to identify the most appropriate survey sites and staff to collect data. As the needs of people living in rural, peri-urban (urban settlements) and urban areas may differ, sites representing each of these regions were selected to provide an analysis of PLHIV's WASH needs across urban and rural areas in PNG. Areas that had a higher prevalence of HIV and/or disadvantage were also prioritised. Finally, sites were chosen to allow surveys to be administered via a range of channels, for example, through home-based care activities, clinic visits etc. (see Table 1).

Figure 1 Map of study locations in PNG

It was decided that surveys would be conducted at four Anglicare program locations: Begabari Clinic in Port Moresby, Anglicare Popondetta in the Oro Province, Anglicare Wabag in Enga Province and Anglicare Mt Hagen in Western Highlands (Figure 1).

Training

Following the selection of staff and study locations, a training workshop was developed by WaterAid. This workshop was held in each of the study sites during Phase 2 and aimed to introduce Anglicare staff to the aims and objectives of the research project, as well as provide them with an introduction to WASH. The workshop also provided an opportunity to introduce Anglicare staff to the survey tool and provide instruction on how to administer the survey.

Data collection

A priority was to avoid singling out PLHIV in an environment or setting which would make identification as HIV-positive possible. Therefore, staff were to collect survey data during the regular course of their work. Therefore, a purposive sampling method was adopted for this study.

This study investigated culturally sensitive issues and concepts, including HIV status, experience with stigma and discrimination, and behaviours regarding hygiene and sanitation. Some of these topics may be considered taboo, or are confronting to respondents. Care was taken to prepare culturally appropriate and comprehensible explanations about the study to enable informed consent, which was discussed in detail with study participants at the commencement of the survey, with a particular emphasis on the participants' right to withdraw from participation at any time. Verbal consent was sought from all participants prior to undertaking the survey. Identities of participants were not recorded.

4.3 LIMITATIONS

- This study was intended to be small, and due to the number and location of respondents, was not designed to draw conclusions on the entire PLHIV population in PNG. Given the small sample size and sampling method of this research, only descriptive statistics were presented.
- The findings of this study may not reflect the situation of other people living with HIV in PNG. As respondents were reached through Anglicare services, they may be in a more privileged position vis-à-vis those who do not have regular contact with service providers.
- Among respondents, 64% came from urban areas, 27% from rural and ten percent from peri-urban (urban settlement) areas. A significant number of surveys were collected from people attending the Anglicare clinic at Port Moresby. These respondents were labelled as 'urban' respondents to reflect the location of the clinic, rather than the location of the respondent's dwelling. As Port Moresby is surrounded by a number of urban settlements it is likely that numbers on urban and peri-urban location are distorted.
- There were some inconsistencies in the way data were recorded across the different sites which diluted some of the findings. For example, a number of the survey questions were intended to yield only one response, but in some cases, multiple responses were recorded instead. In these cases, the questions were analysed and presented as multiple response questions across all surveys.

Table 1 Selected Anglicare project sites

Province	Location type	Type of facility and project location	Type of HIV activities / services offered
National Capital District (NCD) (HIV Prevalence 1.17%*)	Urban / peri urban	Begbari Clinic, Anglicare Port Moresby	OI management and treatment / clinical services Home based care Drop in center (Psycho-social support)
Oro (0.9%)	Rural	Anglicare Popendetta outreach activities	Home based care
Enga (1.02%)	Rural	Anglicare Wabag	Home based care Clinical services
Western Highlands (0.9%)	Urban/peri urban	Anglicare Mount Hagen outreach activities	Home based care

*Source: NAC, 2011

5. RESULTS

The following section presents the major findings under each of the survey headings.

5.1 DEMOGRAPHIC DATA

Sixteen Anglicare staff collected ninety-three surveys across four sites over a four week period from October to November 2012. Twenty seven percent (n=25) of respondents were male, and 74% (n=68) were female. In terms of location, 67% of respondents were from urban communities, 27% were from rural and 10% were from peri-urban areas.

Respondents were reached through a variety of channels across the four study sites, with one third of surveys collected during home-based care visits, and another 23% collected at the on-site clinic in Port Moresby (Figure 2).

Figure 2 Mode of reaching survey respondents

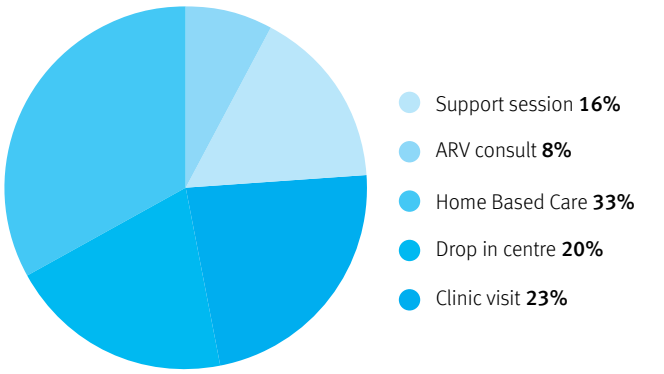


Table 2 Demographic factors of respondents by location (%)

		Location type		
		Urban (%)	Rural (%)	Peri-urban (%)
Age of respondent	‹15	66	33	0
	16-25	65	20	15
	26-35	68	24	9
	36-45	63	28	9
	46-55	25	75	0
	56›	1	0	0
Gender	Male	75	25	0
	Female	63	27	10
Years of education	1-5 years	33	39	28
	6-8 years	65	32	3
	9-12 years	83	13	3
	University	67	33	0
	None	50	25	25
Means of financial support	Employed	100	0	0
	Grow/sell vegetables	36	63	0
	Family support	61	21	18
	Market trader	68	15	16
	Other	100	0	0

Demographic characteristics were categorized by location which reflected differences in socio-economic status, such as a higher level of education and formal employment among urban respondents vis-à-vis those from rural or peri-urban areas (Table 2).

Respondents typically lived in large households, with 36% of respondents living with eight or more people, while only 13% shared a house with one to three people.

5.2 HIV AND AIDS STATUS

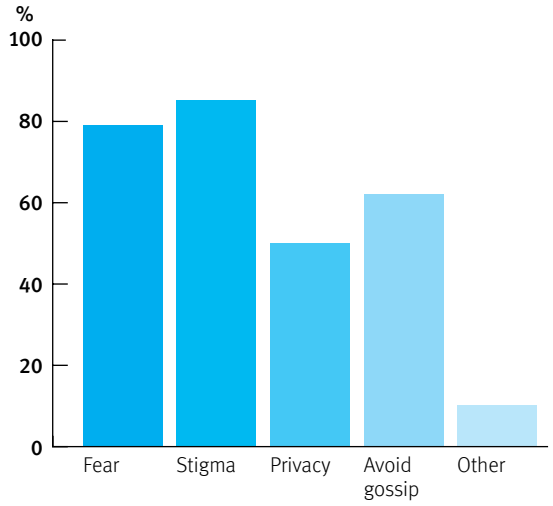
On average, respondents had been living with (defined as length of time since diagnosis) HIV for 7.3 years. Ninety percent of respondents were receiving ARVs and the average length of time on ARV treatment was 5.2 years. 57% also reported having other family members living with HIV.

Overall, respondents described their current state of health in positive terms: 60% of respondents described themselves as 'healthy', 23% as 'very healthy', while only 13% described themselves as 'sick/very sick'.

5.3 STIGMA AND DISCRIMINATION

Respondents were asked about the main reasons for not disclosing their HIV status (Figure 3). 'Stigma' was the most commonly cited reason for non-disclosal, followed by 'fear'. This highlights the highly stigmatized nature of HIV in PNG, which was corroborated by the finding that 41% of respondents had experienced stigma and discrimination from their family because of their HIV status, while 36% had experienced this from their community.

Figure 3 Main reasons for non-disclosure of HIV status



As discussed in the literature review, stigma and discrimination have been known to prevent people living with HIV and their families from accessing communal water facilities. Among the respondents, 18% indicated that they had been prevented from collecting water because of their HIV status, while 18% reported that members of their family had been prevented from collecting water in the past (Table 3). While the difference is small, respondents who reported facing discrimination from the community were more likely to report being prevented from collecting water.

Table 3 Relationship between stigma and discrimination and access to water facilities

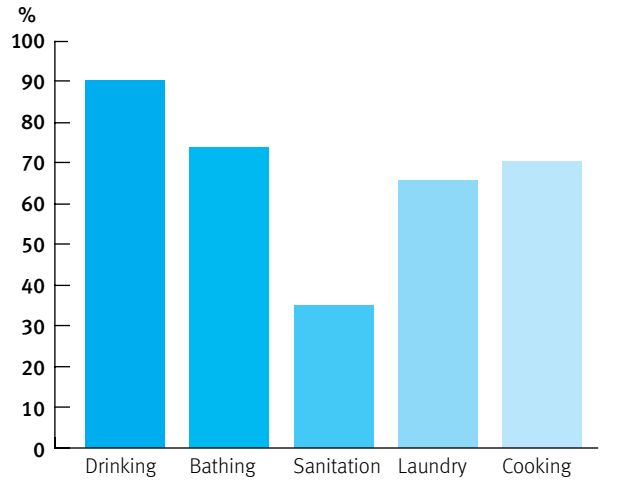
		Respondent prevented from collecting water (%)		Respondent's family prevented from collecting water (%)	
		Yes	No	Yes	No
Experienced discrimination from community (%)	Yes	17	15	16	15
	No	0	38	0	36

5.4 WATER USE AND ACCESS

Fifty two percent of respondents accessed water from piped sources, while 32% collected water from an unprotected source (lake, river or spring). Around ten percent of respondents relied on unprotected wells or uncovered rain water storage drums for water. Respondents from rural areas were more likely to rely on unprotected sources, such as uncovered wells and unprotected water bodies than those from urban or urban settlement areas. Eighty three percent of those who were using piped water were from urban areas, while 63% of those using unprotected sources were from rural locations. This finding is in line with national data that show that rural populations have lower access to safe water (33%) compared to urban areas (87%) (JMP, 2012).

Overall, most respondents (64%) accessed water via a public source, while 36% had access to a private water source. Almost all of the respondents (95%) reported an increased need for water since becoming HIV positive. The most commonly reported use of this additional water was for drinking (90%), followed by bathing (76%) and cooking (72%) (Figure 4).

Figure 4 Uses of additional water among respondents PLHA (%)



In regard to storage and treatment of water, 60% of respondents reporting storing water in bottles, 32% reported using a covered vessel, and 8% used an uncovered vessel. Around 85% of respondents did not treat water, with the majority citing that they felt that it was not necessary. 'Cost' and 'time' were also expressed as barriers to water treatment. Among those who did treat water, chlorination and leaving water in the sun (SODIS) were the most common means of treatment, although the frequency of this varied from 'every day' to 'once every two weeks'. Overall, knowledge and practices regarding treatment were low.

5.5 SANITATION USE AND ACCESS

Improved pit latrines were used by 37% of respondents, while 31% used basic pit latrines and 25% used flush toilet. Only 7% of respondents reported open defecation. Travel time to a toilet varied from one minute to forty minutes, with respondents from rural areas traveling further than their urban counterparts who had the highest coverage of flush toilets and improved pit latrines. Respondents from rural areas were more likely to use basic pit latrines.

Respondents were asked about the cleanliness of their toilets and latrines and the number of people sharing the facility. Fifty four percent described the cleanliness of their toilets and latrines as 'good', while 19% said 'fair' and 22% reported it as poor. Respondents shared a toilet or latrine with an average of ten other people.

5.6 HYGIENE, HEALTH KNOWLEDGE AND HEALTH SEEKING BEHAVIOURS

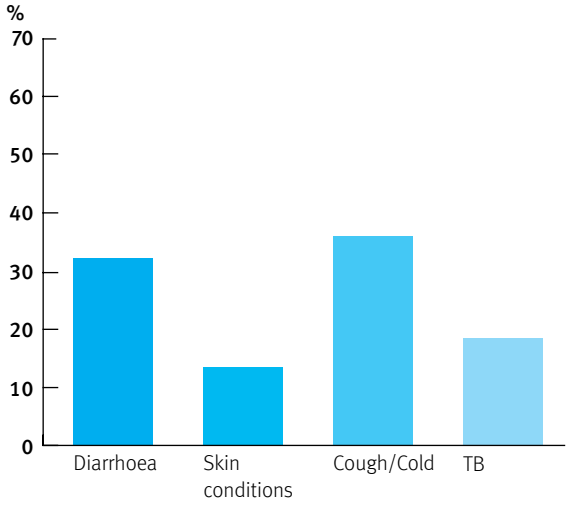
Ninety five percent of respondents said they had experienced a significant change in their health since becoming HIV positive.

When asked about their experiences with illness over the last two months, over 50% reported being ill, with 35% experiencing coughs and colds (Figure 5).

Additionally, a quarter of respondents had experienced a bout of diarrhoea in the previous two weeks.

The majority of respondents (94%) acknowledged that hygiene was more important for people living with HIV. Sixty four percent said this was because people living with HIV were more likely to get sick; 67% said because it helped people living with HIV to live longer, and 62% said because hygiene was important to keep people living with HIV healthy.

Figure 5 Types of illness experienced by respondents in last two months



5.7 HAND WASHING

The survey found high rates of self-reported hand washing. Over 60% reported hand washing after using the toilet, but only 44% reported washing hands before eating, and 27% reported washing their hands after changing their child's nappy. Six percent reported not washing their hands at all.

In terms of risk-increasing variables, having a place to wash hands with soap in the home was not found to be related to having diarrhoea in the last two weeks. However, hand washing at critical times was also compared against diarrhoea in the last two weeks

and revealed that respondents who did not report hand washing after changing nappies were more likely to report having diarrhoea in last two weeks (70%) compared to those who did wash their hands at this time (41%). These respondents were also more likely to report being ill with diarrhoea in the last two months (72%) compared to those who did wash their hands at this time (27%). While these sample sizes are small and cannot be considered statistically significant, the data suggest a potential area of risk for people living with HIV who may not be aware of the risk involved in handling child faeces.

5.8 HEALTH KNOWLEDGE

Diarrhoea was cited by 90% of respondents as the most common opportunistic infection faced by people living with HIV. Other responses included skin conditions (68%), tuberculosis (51%) and eye infections/trachoma (44%).

Most respondents were able to correctly identify at least one of the major causes of diarrhoea. Eighty eight percent cited dirty water, 87% cited dirty hands, 68% cited uncooked food and 63% cited poor sanitation.

Knowledge of diarrhoea prevention was high overall, with more than 80% of respondents citing clean water, food safety and personal hygiene respectively as the main ways to prevent diarrhoea. Two-thirds (67%) of respondents listed sanitation and safe disposal of waste.

5.9 HEALTH SEEKING BEHAVIOURS

Treatment practices for diarrhoea among respondents were investigated and it was found that 75% of those surveyed reported increasing their intake of water, 50% reported seeking treatment, and a quarter reported seeking traditional therapies and treatments.

Respondents were also asked about the sources of health and hygiene information. Eighty percent of respondents had received hygiene health messages within the past 12 months: the main sources of this information were government health centres (58%), and NGO centres (56%), while only 25% had received hygiene information through HIV-specific services/centres.

5.10 VULNERABILITY OF CHILDREN LIVING WITH PEOPLE LIVING WITH HIV

Fifty three percent of respondents had children, of whom 39% of were under five years old. Fifty percent of parents had between one and two children, 44% had between three and four, and eight percent had more than four children.

Twenty three percent of parents reported having children who were living with HIV. Among respondents who reported formula feeding their children, only 36% had received information on the safe preparation of formula. Among those who received information, 41% reported receiving this information through an HIV setting, 25% through a community health worker, 16% through government clinic or hospital, and 16% through family members.

Respondents with children were asked about their practices regarding treatment of diarrhoea in children. Sixty percent reported increased water intake as the main treatment practice, while around a third of respondents reported turning to traditional treatments (Table 4).

Table 4 Treatment practices for diarrhoea in children (%)

Increase water intake	60
Seek medical treatment	58
Eat starchy foods	47
Seek traditional treatment	32
No treatment	2

As mentioned in the literature review, recent evidence has suggested an increased vulnerability of HIV-affected children to diarrhoea, which was also explored in this study. Although the sample was small, and the periods referenced in the question slightly different, the data suggest a relationship between diarrhoea in respondents and their children (Table 5). Of those who reported that their child had experienced diarrhoea in the last two weeks, Of those parents that reported they had experienced diarrhoea in the previous month, 85% of their children had also experienced diarrhoea, while for parents who reported they had not experienced diarrhoea in the last month 40% of their children had.

Table 5 Comparison of diarrhoea in respondents and their children

	Parent experienced diarrhoea in last two weeks (%)	
	Yes	No
Child experienced diarrhoea in past month (%)	85	40

6. DISCUSSION

Overall, the findings demonstrated a good knowledge of the importance of WASH among respondents as well as an awareness of the role WASH plays in promoting and safeguarding the health of people living with HIV.

However, the research also highlighted gaps and clear priorities in relation to the WASH needs of people living with HIV.

The findings are discussed below in relation to the objectives of the study:

1. *Gather baseline information on people living with HIV's access to sanitation and water supply, and identify factors which may contribute to vulnerability among people living with HIV*

Access to adequate sanitation and improved water sources differed between the urban and rural respondents. Those from rural areas were more likely to use unprotected water sources and more likely to share a toilet with a large number of people. The majority of respondents expressed an increased need for drinking water, and for those who are using unprotected sources and those using poor storage and handling practices, this also increases their risk of diarrhoeal illness from contaminated water.

Knowledge and practices of water treatment were poor among respondents. This finding is similar to Gautam et al's (2011) study on the WASH needs of PLHIV in Nepal. Gautam et al's (2011) found that rural respondents had low rates of appropriate water treatment in Nepal. Both the current study and the Nepal research highlight that people living with HIV have increased needs for water since diagnosis. Given the effects of diarrhoea on absorption of nutrients and of medication, it is important that people living with HIV are aware of the dangers associated with unprotected water sources, and are equipped with knowledge about safe storage and treatment of water. This is particularly pertinent during times of illness.

A quarter of respondents stated they had experienced diarrhoea in the last two weeks, and the majority acknowledged that increased water intake was important during diarrhoeal treatment. These data suggest that comprehensive guidance on self-treatment of diarrhoea for people living with HIV, including the safe treatment and storage of water, could play an important role in promoting good health. This is an area that could be systematically incorporated into existing services such as home-based care, clinical services and Prevention of Parent to Child Transmission (PPTCT), as a way to promote this behaviour among people living with HIV. The comprehensive guidance on self-treatment of diarrhoea should focus on those from rural communities, who were more likely to access water from unprotected source. It must be noted that most respondents in this survey were from urban areas and therefore did not represent the rural-urban spread in PNG. Nevertheless, the survey revealed a disparity of WASH access between urban and rural respondents, replicating trends present in national statistics for the general population (JMP, 2012) and indicating that the WASH requirements of people living with HIV in rural areas need to be prioritised for programming.

2. *Investigate people living with HIV's experiences with stigma and discrimination as they relate to accessing water and sanitation facilities*

Despite accessing care and treatment services, this study found that respondents face substantial rates of stigma and discrimination from their family and community, and that this stigma impacts on their access to WASH facilities. Stigma and discrimination were experienced by several respondents from both their families and their community. A subset of those respondents who had experienced stigma and discrimination indicated they and/or their families had been prevented from collecting water in the past due to their HIV status. This suggests that there may be erroneous views in the community about the way HIV is transmitted, leading to people living with HIV being excluded from communal water sources. Therefore, continued education on the transmission of HIV to all in the community is critical to alleviate common misconceptions about the nature of HIV transmission. This could be incorporated into existing health promotion and community based awareness raising activities.

3. *Investigate people living with HIV's health knowledge and health seeking behaviours regarding the causes of WASH-related illnesses, particularly diarrhoea*

Knowledge of the causes of diarrhoea among respondents was high overall. However, the research supports the need to improve the health literacy of people living with HIV particularly in relation to the role of sanitation in preventing diarrhoea. Knowledge of the importance of hand washing after changing a baby's nappy was also low, which suggests that safe handling and disposal of faeces needs to be promoted as a key WASH behaviour. It needs to be addressed systematically through clear guidance and incorporated into existing IEC materials and health promotion activities.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Most respondents shared a toilet with at least ten people. In the WASH sector there are concerns that shared facilities are unacceptable in terms of cleanliness (JMP, 2012). As people living with HIV are more likely to experience diarrhoea and are at greater risk of opportunistic infections, programming should aim to encourage households to construct and maintain latrines in communities where toilet coverage is low. However, the promotion and construction of latrines alone will not address all sanitation needs for people living with HIV. They should be combined with improved health literacy about the role of sanitation in preventing diarrhoea and appropriate guidance on how to properly manage, as well as avoid, diarrhoea.

Coughs/colds and diarrhoea were the main health conditions experienced by respondents over the previous two months. While the survey did not attempt to evaluate respondents' knowledge about the causes of all opportunistic infections, there may be some benefit in incorporating information on the role that hand washing can play in preventing colds and coughs, as respiratory infections remain a major cause of morbidity and mortality of PLHIV (Davis et al, 2008).

4. *Investigate the vulnerability of children living in HIV-affected households and the specific WASH needs of mothers living with HIV*

Though the differences were small, the findings of this research support recent studies (e.g. Peletz, 2012; Xue, 2010) which found that children of mothers living with HIV were more likely to experience diarrhoea if the mother had recently been ill. As rates of access to ARV rise globally, people living with HIV are more likely to give birth to children without transmitting HIV, thereby increasing the number of children worldwide who are HIV-negative but living in HIV-affected households. Based on the emerging evidence, these children are at increased risk of diarrhoea, which is currently the second leading cause of under-five mortality globally (CHERG, 2012). Therefore, this growing at-risk cohort is likely to have a significant public health impact and warrants further research and targeted programming.

The low levels of hand washing after coming into contact with child faeces found among respondents may contribute to transmission of illness between child and mother, and may lead to subsequent contamination of water and food. Increasing water intake was the most common practice for the management of diarrhoea in children. Therefore people living with HIV (particularly those in rural areas who are more likely to access their water through unimproved sources) should be supported and encouraged to treat water and practise hand washing with soap following contact with child waste. This will avoid contamination of household drinking water.

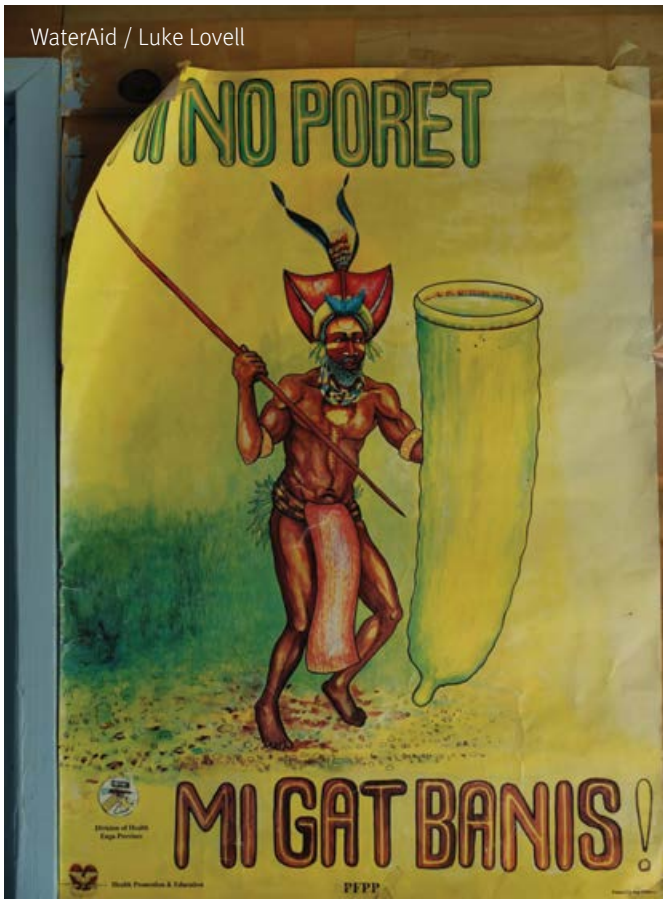
The safe preparation of formula should also be incorporated into HIV health promotion activities, home-based care and Prevention of Parent to Child Transmission (PPTCT) activities and promoted as a key WASH behaviour. Respondents were only asked about formula feeding, but as in other countries, replacement feeding may be another key means of exposing children to pathogens if contaminated water is used in food preparation or if proper food safety precautions are not followed. This warrants further investigation.

7. RECOMMENDATIONS

Based on the findings from this study a number of responses for actors in the WASH and HIV and AIDS sectors in PNG are outlined below.

WASH actors

- Prioritise latrine construction in communities where there is low sanitation facility coverage and a known high HIV prevalence (taking care not to disclose any member of the community's HIV status).
- Develop targeted education tools and guidelines for households regarding the safe treatment and storage of water. This can be integrated into existing health promotion activities for people living with HIV.
- Further assess the specific WASH needs and care practices of families living with HIV and their children. Strengthening the evidence and knowledge of these needs and practices in PNG will help inform future program design addressing WASH-related family care practices and needs for people living with HIV.



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HIV service providers

- Review existing IEC materials and where necessary, amend to promote consistent WASH messages across a range of activities targeting people living with HIV. Specifically, in response to this research, these messages should include -
  - Reinforcing hand washing with soap at critical times
  - Safe water treatment and storage
  - Safe disposal of children's faeces
  - Safe preparation of formula.
- Provide comprehensive guidance on the self-treatment of diarrhoea to people living with HIV and their carers.
- Provide and/or reinforce education around the transmission of HIV. This education should be integrated into all programming for people living with HIV, particularly as stigma can prevent people living with HIV, their families and carers accessing WASH facilities essential for their health and wellbeing.
- Support staff to undergo training and develop their knowledge of WASH in order to build their capacity to promote key WASH behaviour among people living with HIV, particularly in regard to sanitation and safe water treatment and handling practices.

In order for both the HIV and WASH sectors to work towards implementing these recommendations, it is key for the WASH sector to establish partnerships with a wide range of HIV actors, and support the development of WASH capacity within these organizations. This could include developing resources and training workshops to enable HIV partners to obtain a solid grounding in WASH, and how access to WASH influences the lives of people living with HIV. Furthermore, WASH and HIV actors should use examples of good practice and success at the local level to advocate for increased collaboration between WASH and HIV at higher policy levels.

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ANNEX

Identifying the WASH-related needs for PLHIV in PNG

A) ANGLICARE CLIENT INTERVIEW

Confidential – Information for research purposes only. Not to be distributed/shared.

Instructions to interviewer:

1. Please complete the following box
2. Please read the Informed Consent section aloud to the respondent
3. Please read questions as they appear. Only prompt respondent when indicated on question. Follow all instructions carefully.
4. If the respondent does not know an answer, please circle I don't know. If they do not wish to respond, please circle No Response

Name of interviewer:	Location name and date:

Facility/setting type (please circle):	HBC Visit	1
	ARV consult	2
	General clinic visit	3
	PLHIV support session	4
	Other (please specify)	
Location type (please circle):	Urban	1
	Rural	2
	Urban settlement	3

Informed Consent

Please read the following text aloud to the Participant

Hello. My name is .....
I have been asked to assist in a research project on water and sanitation and people living with HIV. This research is being conducted by Anglicare, with an organisation WaterAid in Papua New Guinea. We would like to include you in this survey. The purpose of this study is to learn about your access to water and sanitation and how this impacts you in daily life. I will be asking you a range of questions, and some are about personal information. You do not have to participate in this survey. If you want to participate, you are free to skip any questions which make you feel uncomfortable. The survey will take about 20 minutes. All information you provide will be confidential and will not be used or shared with anyone except those involved in the study. This survey is completely anonymous. We will not collect any information that could be used to identify you. Do you have any questions?

Do you consent to the interview?

☐ **YES** Thank you. I will start by collecting some general information.

☐ **NO** That's fine. Thank you for your time.

B) SECTION 1: RESPONDENT'S BACKGROUND

Q. #	Question	Responses	Codes	GO TO Q.
101	How old are you?	Under 15	1	
		16 - 25	2	
		26- 35	3	
		36-45	4	
		46-55	5	
		56 and above	6	
		I don't know	88	
		No response	99	
102	Sex of respondent	Male	1	
		Female	2	
103	What is your marital status?	Married	1	
		Never married	2	
		Widow/ Widower	3	
		Divorced/ Separated	4	
		No response	99	
104	What is the highest grade of education you have completed?	None	0	
		1-3	1	
		4-6	2	
		7-8	3	
		9-10	4	
		11 – 12	5	
		University	6	
		I don't know	88	
		No response	99	
105	What is your current occupation?	Unemployed	0	⇢ 107
		Student	1	⇢ 107
		Agriculture	2	
		Skilled Labour/Tradesperson	3	
		Unskilled Labour	4	
		Office/professional worker	5	
		Other (specify) _____	6	
		I don't know	88	
		No response	99	
106	What ways do you support yourself financially?	Employed	1	
		Grow and sell vegetables	2	
		Family provides for me	3	
		Trade at markets	4	
		Other (specify) _____	5	
		I don't know	88	
		No response	99	
107	How many other people currently live in the same house as you?	1-3	1	
		4-5	2	
		6-7	3	
		8 or more	4	

C) SECTION 2: HIV / AIDS STATUS

Q. #	Question	Responses	Codes	GO TO Q.
201	How long have you known that you are HIV positive?	_____Years _____Months		
		I don't know	88	
		No response	99	
202	Are any of your family members HIV positive?	Yes	1	
		No	2	⇢ 204
		I don't know	88	⇢ 204
		No response	99	⇢ 204
203	Which members of your family are positive? [Circle all that apply]	Partner	1	
		Children	2	
		Parent	3	
		Others (specify) _____	4	
		I don't know	88	
		No response	99	
204	Are you on ARV?	Yes	1	
		No	2	⇢ 206
		I don't know	88	⇢ 206
		No response	99	⇢ 206
205	How long have you been on ARV?	_____Years _____Months		
		I don't know	88	
		No response	99	
206	On a scale of 1 – 5 where '1' is very sick and '5' is very healthy, how would you rate your current level of health?	One	1	
		Two	2	
		Three	3	
		Four	4	
		Five	5	
		I don't know	88	
		No response	99	
207	Who is your main care taker when you are sick?	Partner	1	
		Children	2	
		Brother/sister	3	
		Parent	4	
		Others (specify) _____	5	
		I don't know	88	
		No response	99	

D) SECTION 3: STIGMA AND DISCRIMINATION

Q. #	Question	Responses	Codes	GO TO Q.
301	Do people in your family know about your HIV positive status?	Yes	1	
		No	2	
		I don't know	88	
		No response	99	
302	Do people in your community know about your HIV positive status?	Yes	1	
		No	2	
		I don't know	88	
		No response	99	
303	What are the reasons why people do not disclose their HIV status? [Circle all that apply]	Fear	1	
		Stigma	2	
		Discrimination	3	
		Privacy	4	
		To avoid gossip	5	
		Other (specify) _____	6	
		I don't know	88	
		No response	99	
304	Have people in your family ever said bad things or talk behind your back because of your HIV status?	Yes	1	
		No	2	
		I don't know	88	
		No response	99	
305	Have people in your community ever said bad things or talk behind your back because of your HIV status?	Yes	1	
		No	2	
		I don't know	88	
		No response	99	

E) SECTION 4: ACCESS TO WATER SUPPLY

Q. #	Question	Responses	Codes	GO TO Q.
401	What is the main source of drinking water used by your household? [select answer that best represents respondent's answer]	Piped water/tap	1	
		Pump	2	
		Protected well	3	
		Unprotected well	4	
		Lake/River etc	5	
		Rainwater tank	6	
		Uncovered drum	7	
		I don't know	88	⇢ 403
		No response	99	⇢ 403
402	Is the water point private or public?	Private	1	
		Public	2	
403	Where is this water source located? [select answer that best represents respondent's answer]	In my own house	1	⇢ 412
		In my yard/plot	2	
		In neighbour's yard/plot	3	
		In my village	4	
		At an institution (school, church etc.)	5	
		Other (specify)	6	
		I don't know	88	
		No response	99	
404	What do you use to store your drinking water in the home? [prompt for description if necessary]	Covered bucket/pot	1	
		Uncovered bucket/pot	2	
		Bottles/containers	3	
405	Do you have to pay for the water?	Yes	1	
		No	2	⇢ 407
406	a) How much do you pay per container b) How many of those containers would you collect in a day?	a) Kina _____ b) Number of containers_____		
407	Who collects the water for your home **most often?**	Myself	1	
		My husband	2	⇢ 410
		My wife	3	⇢ 410
		My child	4	⇢ 410
		My brother/sister/cousin.	5	⇢ 410
		Other (specify)_____	6	

E) SECTION 4: ACCESS TO WATER SUPPLY (cont.)

Q. #	Question	Responses	Codes	GO TO Q.
408	How long does it take to travel from your home to this place, fetch water and come back – during: F) Rainy season G) Dry season?	A) Rainy season: Hours_____ Minutes_____ B) Dry season: Hours_____ Minutes_____ I don't know No response	 88 99	 ⇢ 410 ⇢ 410
409	Do you think that the time taken to collect water is reasonable or too long?	Reasonable Too long I don't know No response	1 2 88 99	
410	On average how many buckets of water does your household use every day in total?	_____ buckets I don't know No response	 88 99	
411	On average how many buckets of water do you use every day in total?	_____ buckets I don't know No response	 88 99	
412	Has your need for water changed after you became HIV positive?	Yes No I don't know No response	1 2 88 99	 ⇢ 415 ⇢ 415
413	Do you need water more or less?	More Less I don't know No response	1 2 88 99	 ⇢ 415 ⇢ 415 ⇢ 415
414	What do you use the extra water for? [Circle all that apply]	Drinking Toilet/ sanitation Bathing Washing clothes Cooking Other (specify)_____ I don't know No response	1 2 3 4 5 6 88 99	

E) SECTION 4: ACCESS TO WATER SUPPLY (cont.)

Q. #	Question	Responses	Codes	GO TO Q.
415	Do you do anything to your water before you drink it to make it better?	Yes	1	
		No	2	⇢ 418
		I don't know	88	⇢ 418
		No response	99	⇢ 418
416	What do you do to make it better to drink? [Circle all that apply]	Boil	1	
		Filter	2	
		Leave it in the sun	3	
		Chlorination/Treatment	4	
		Other (specify)_____	5	
		I don't know	88	
		No response	99	
417	How often do you do this to the water?	Every day	1	⇢ 419
		Every other day	2	⇢ 419
		Once a week	3	⇢ 419
		Less than once a week	4	⇢ 419
		I don't know	88	⇢ 419
		No response	99	⇢ 419
418	What is the main reason you don't treat your water? [Circle the main reason if respondent gives more than one]	Already treated/does not need treating	1	
		Do not like treated water	2	
		Takes too long	3	
		Requires money	4	
		Other (specify)_____	5	
		I don't know	88	
		No response	99	
419	Have you ever been prevented from collecting water because you are HIV positive?	Yes	1	
		No	2	
		I don't know	88	
		No response	99	
420	Have your family members ever been prevented from collecting water because you are HIV positive?	Yes	1	
		No	2	
		I don't know	88	
		No response	99	

F) SECTION 5: SANITATION

Q. #	Question	Responses	Codes	GO TO Q.
501	What do you use when you need to go to the toilet?	Flush toilet	1	⇢ 502
		Closed Pit latrine	2	⇢ 502
		Open Pit latrine	3	⇢ 502
		Go in the Bush/field	4	⇢ 506
		I don't know	88	⇢ 506
		No response	99	⇢ 506
502	Is the toilet located within your residence?	Yes	1	⇢ 507
		No	2	
		I don't know	88	
		No response	99	
503	Is the facility private or shared?	Private	1	⇢ 507
		Shared	2	
504	How many households use this facility?	Households _____		
	How many people?	People_____		
506	How long does it take to travel from your home to toilet and back?	Minutes_____		
		I don't know	88	
		No response	99	
507	How would you describe the facility in terms of cleanliness?	Good	1	
		Fair	2	
		Poor	3	
		I don't know	88	
		No response	99	
508	Is there soap in the toilet you use?	Yes	1	
		No	2	
		I don't know	88	
		No response	99	

F) SECTION 5: SANITATION (cont.)

Q. #	Question	Responses	Codes	GO TO Q.
509	On what occasions do you wash your hands?	Before eating	1	
		After eating	2	
	[Do not prompt. Circle all responses given]	Before feeding baby	3	
		After going to the toilet	4	
		After cleaning child's bottom	5	
		Before taking medicines	6	
		Other (specify)_____	7	
		Not at all	88	
		No response	99	
510	What do you use to wash your hands?	Water only	1	
		Water and soap	2	
		Ash and water	3	
		Mud and water	4	
		Other (specify)_____	5	
511	Have you ever received hygiene related information and education?	Yes	1	
		No	2	
		I don't know	88	
		No response	99	
512	Where did you receive the information from?	Family members	1	
		Support Group	2	
		Health post/ hospital	3	
		VCT/ART/PMTCT/Rehab centre	4	
		Radio/TV	5	
		Newspaper/ Magazine	6	
		Other (specify)_____	7	
		I don't know	88	
		No response	99	

G) SECTION 6: HEALTH KNOWLEDGE AND HEALTH SEEKING BEHAVIOURS

Q. #	Question	Responses	Codes	GO TO Q.
601	Do you think HIV positive people have increased need for better hygiene behaviour?	Yes	1	
		No	2	⇢ 603
		I don't know	88	⇢ 603
		No response	99	⇢ 603
602	Why do you think they have increased need?	They are more prone to illness	1	
		To prevent AIDS	2	
		Other (specify)_____	3	
		I don't know	88	
		No response	99	
603	What are the frequent illnesses that HIV positive people suffer from? [Circle all that apply]	Diarrhoea	1	
		Skin conditions	2	
		Trachoma/Eye problems	3	
		Coughs/Colds	4	
		Tuberculosis	5	
		Other (specify)_____	6	
		I don't know	88	
		No response	99	
604	What do you think are the causes of diarrhoea? [Circle all that apply]	Dirty water	1	
		Uncooked food	2	
		Dirty hands	3	
		Unclean surrounding	4	
		Improper toilet use	5	
		Eating market food	6	
		Other (specify)_____	7	
		I don't know	88	
		No response	99	
605	How do you think people can prevent diarrhoea? [Circle all that apply]	Drinking safe water	1	
		Eating clean food	2	
		Maintaining good hygiene	3	
		Keeping surrounding clean	4	
		Faeces management	5	
		Other (specify)_____	6	
		I don't know	88	
		No response	99	

G) SECTION 6: HEALTH KNOWLEDGE AND HEALTH SEEKING BEHAVIOURS (cont.)

Q. #	Question	Responses	Codes	GO TO Q.
606	Has there been any change in your health since you became HIV positive?	Yes	1	
		No	2	
		I don't know	88	
		No response	99	
607	Have you been ill in last two months?	Yes	1	
		No	2	⇢ 609
		I don't know	88	⇢ 609
		No response	99	⇢ 609
608	What were you ill with? [Circle all that apply]	Diarrhoea	1	
		Skin related disease	2	
		Trachoma/Eye problems	4	
		Cough/cold	5	
		Tuberculosis	6	
		Other (specify)_____	7	
		I don't know	88	
		No response	99	
609	Have you had a bout of diarrhoea in the last 2 weeks?	Yes	1	
		No	2	
610	What do you do when you are sick with diarrhoea? [Circle all that apply]	Nothing	1	
		Drink more water	2	
		Eat starchy foods (like sweet potato)	3	
		Seek treatment	4	
		Traditional remedies	5	
		Other (specify)_____	6	
		I don't know	88	
		No response	99	
611	If you needed treatment for diarrhoea, where would you go?	At home only	1	
		Government Health Post/ Hospital	2	⇢ 612
		Private health facility	3	⇢ 612
		NGO facility	4	⇢ 612
		Medical shops	5	
		Faith-healers	6	
		Other (specify)_____	7	
		I don't know	88	
		No response	99	
612	When seeking treatment for diarrhoea, were you ever given you information on clean water, sanitation and hygiene by the service provider?	Yes	1	
		No	2	
		I don't know	88	
		No response	99	

H) SECTION 7: VULNERABILITY OF CHILDREN LIVING IN HIV-AFFECTED HOUSEHOLDS

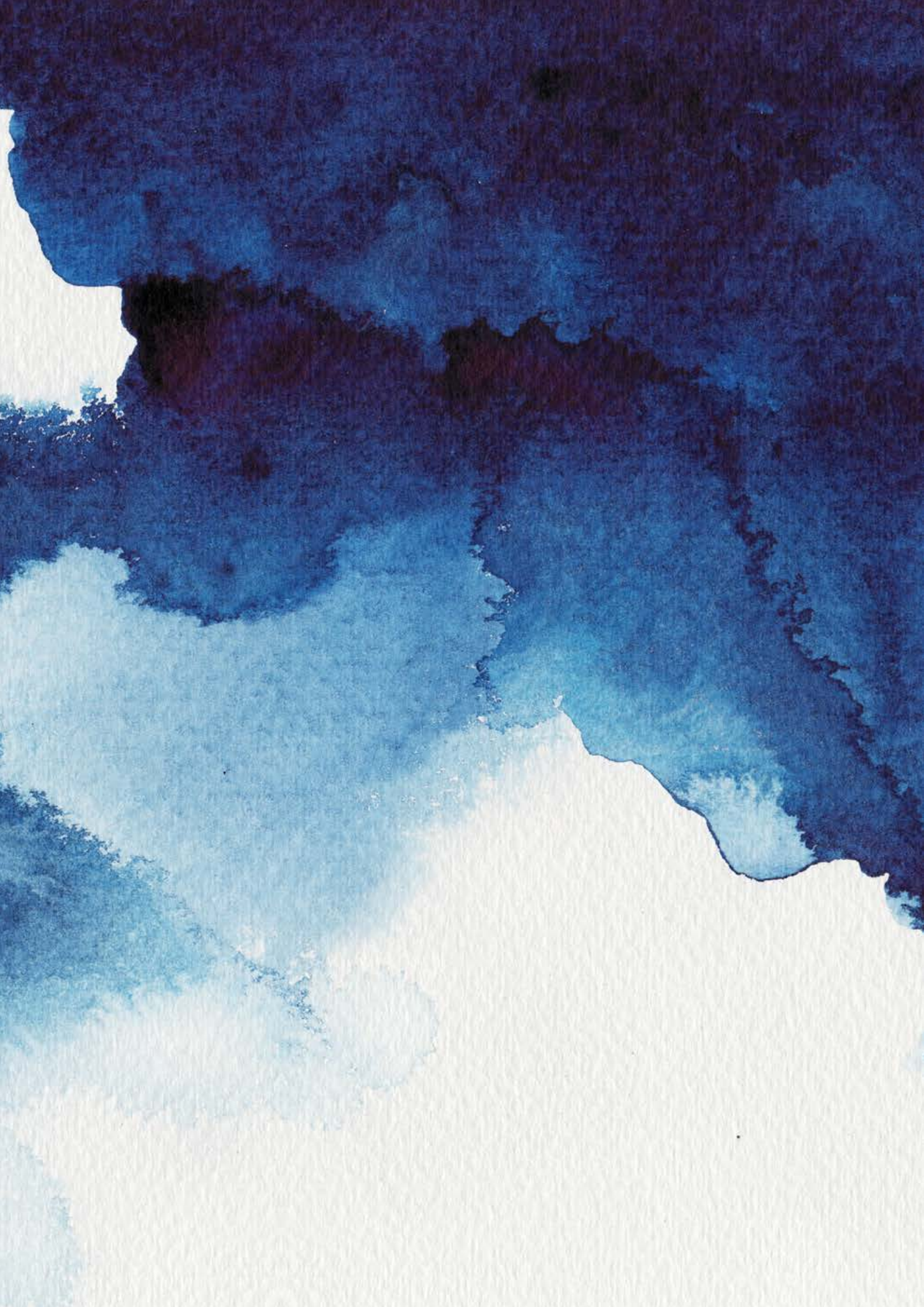
Q. #	Question	Responses	Codes	GO TO Q.
701	Do you have any children?	Yes	1	
		No	2	⇢ END
702	How many children do you have?	One	1	
		Two	2	
		Three	3	
		Four	4	
		More than four	5	
703	Are any of your children currently under 5?	Yes	1	
		No	2	
704	Are any of your children HIV positive?	Yes	1	
		No	2	
705	Have you had any children since learning about your HIV status?	Yes	1	
		No	2	⇢ 809
706	What age was your baby when you stopped breastfeeding?	Age in months (specify)_____		
707	Did you ever use formula to feed your baby?	Yes	1	
		No	2	⇢ 809
708	Were you given any information about how to prepare your baby's formula safely?	Yes	1	
		No	2	⇢ 809
709	Who provided this information to you?	Family member	1	
		Community health worker	2	
		Government hospital/clinic	3	
		NGO	4	
		Church	5	
		Through HIV clinic/setting	6	
		I don't know	88	
		No response	99	
710	In the last two weeks, how many times has your child/children had diarrhoea? [For each child, record age and number of times with diarrhoea separately)	Child 1: (age)_____ (times)_____ Child 2: (age)_____ (times)_____ Child 3: (age)_____ (times)_____ Child 4: (age)_____ (times)_____ Child 5: (age)_____ (times)_____		

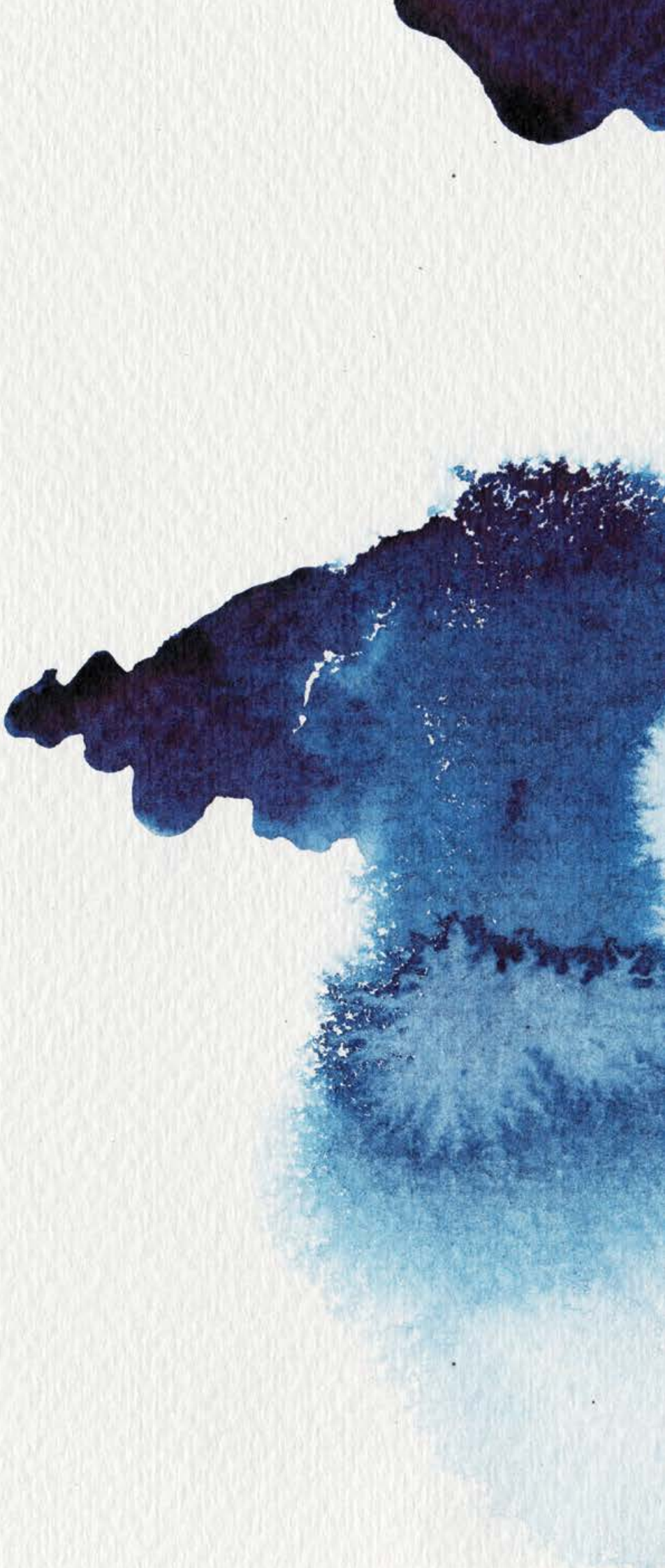
H) SECTION 7: VULNERABILITY OF CHILDREN LIVING IN HIV-AFFECTED HOUSEHOLDS (cont.)

Q. #	Question	Responses	Codes	GO TO Q.
711	What do you do when your children are sick with diarrhoea?	Nothing	1	
		Drink more water	2	
		Eat starchy foods	3	
		(like sweet potato)	4	
		Seek treatment	5	
		Traditional remedies	6	
		Other (specify)_____	88	
		I don't know	99	
		No response		
712	If you needed to seek treatment for your child's diarrhoea, where would you go?	Government Health Post/Hospital	1	⇢ 812
		Private health facility	3	⇢ 812
		NGO facility	4	⇢ 812
		Medical shops	5	⇢ 812
		Faith-healers	6	
		Other (specify)_____	7	
		I don't know	88	
		No response	99	
713	When taking your child for treatment of diarrhoea, were you ever given you information on clean water, sanitation and hygiene by the service provider?	Yes	1	
		No	2	
		I don't know	88	
		No response	99	
714	Is there any information you would like to add? [Write down main points]			

Read to the respondent:

We have now completed the survey.
Thank you very much for your participation.





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Our mission is to transform lives by improving access to safe water, hygiene and sanitation in the world's poorest communities.

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