



# Stories of Change

## Reflections from SHARE Phase I

Emily Balls  
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# Building knowledge. Improving the WASH sector.

Photos on front cover:

1. Mothers and Babies in Mali | WaterAid/Tara Todras Whitehill ©
2. Food hygiene in Malawi | WaterAid/Kate Holt ©
3. Participants in the 'Undoing Inequity' project | WaterAid/Robert Priscilla ©

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## Acronyms

ACF: Action Against Hunger

APO: Adverse Pregnancy Outcomes

BRAC: Bangladesh Rural Advancement Committee

CLTS: Community Led Total Sanitation

CRPD: Convention on the Rights of Persons with Disabilities

DFAT: Australian Department of Foreign Affairs and Trade

DFID: Department for International Development (UK)

ECHO: EU Humanitarian Aid

FAARM: Food and Agricultural Approaches to Reducing Malnutrition

FHI: Family Health International

GLUK: Great Lakes University of Kisumu

GTO: German Toilets Organisation

HACCP: Hazard Analysis Critical Control Point

HCAIs: Healthcare Associated Infections

HCF: Health Care Facility

ICDDR.B: International Centre for Diarrhoeal Disease Research, Bangladesh

IDSC: International Development Select Committee

IIED: International Institute for Environment and Development

IIPH: Institute of Indian Public Health

IIPHG: Institute of Indian Public Health Gujarat

Immpact: Initiative for maternal mortality programme assessment

INTRAC: International NGO Training and Research Centre

IPC: Infection Prevention Control

JMP: Joint Monitoring Programme

LMIC: Low and Middle Income Countries

LSHTM: London School of Hygiene and Tropical Medicine

MDGs: Millennium Development Goals

MEIRU: Malawi Epidemiology and Intervention Research Unit

MNH: Maternal and Newborn Health

MoH: Ministry of Health

M&E: Monitoring and Evaluation

MSC: Most Significant Change

NGO: Non-governmental Organisation

PI: Principal Investigator

RCT: Randomised Controlled Trial

RINEW: Research on Integration of Nutrition Early Childhood Development WASH

SDGs: Sustainable Development Goals

SDI: Shack/Slum Dwellers International

SHARE: Sanitation and Hygiene Applied Research for Equity

SHINE: Sanitation Hygiene Infant Nutrition Efficacy

SoC: Stories of Change

TEDDO: - Teso Diocese Planning and Development Office

UI: Undoing Inequity

UNICEF: United Nations International Children's Emergency Fund

USAID: United States Agency for International Development

VfM: Value for Money

WASH: Water Sanitation and Hygiene

WEDC: Water, Engineering and Development Centre at Loughborough University

WHO: World Health Organization

WSP: Water and Sanitation Program (World Bank)

WSSCC: Water Supply and Sanitation Collaborative Council

WVI: World Vision International

## Introduction

These Stories of Change (SoC) seek to capture and better understand impacts from Phase I of the SHARE consortium, and also include some related work conducted in Phase II. In Phase I, SHARE worked with five main partners: London School of Hygiene and Tropical Medicine (LSHTM), International Centre for Diarrhoeal Disease Research, Bangladesh (ICDDR,B), International Institute for Environment and Development (IIED)/ Shack/Slum Dwellers International (SDI), and WaterAid.

Working closely with national sector partners to define research priorities, SHARE generated rigorous and relevant applied research, and enhanced the uptake of new and existing research. In Phase I, SHARE focused its activities in four countries - India, Bangladesh, Malawi, and Tanzania. SHARE also supported specific research projects in over a dozen other countries including Uganda, Zambia, Zimbabwe, Kenya, Nepal and Ghana.

## Approach

The Stories of Change approach was decided in SHARE's 2016 Impact paper which defined impact for SHARE and analysed possible approaches to measure SHARE's outcome level impact (Balls, 2016). Stories of Change investigate how an intervention contributes to specific outcomes through looking at the pathways of expected or unexpected change. This process is usually precipitated by a success or failure gathered through qualitative Monitoring and Evaluation (M&E) data. The approach includes gathering evidence and then writing a narrative story about the change (Young et al, 2014).

While Stories of Change have been used by other organisations, calculating indirect beneficiaries is a less common practice. This is particularly challenging for programmes such as SHARE that do not deliver direct services but work in less tangible spheres such as policy, research uptake and advocacy. The International NGO Training and Research Centre (INTRAC) note that it is possible to give examples about how policy changes are filtering down to beneficiaries but caution that 'these cases remain illustrations, and it is rarely possible to perform any sensible degree of aggregation at beneficiary level' (Simister, 2016). Further details on the rationale and challenges relating to developing this approach are captured in SHARE's Impact Paper (Balls, 2016). The SoC approach has been used by SHARE between August - December 2016 and this document features three Stories of Change.

The SHARE Monitoring and Evaluation Officer reviewed previous documentation including annual reports and conducted interviews with Phase I Principal Investigators (PIs) and SHARE colleagues to develop the SoC. The process also involved interviewing staff outside of SHARE with expertise in the topic to ensure that the role of other contributors was accurately represented. SHARE SoC have built significantly upon the success stories published in previous annual reports but have sought to take a systematic approach, to integrate learning and to quantify change.

Key principles have informed the estimated indirect beneficiary figures included in this document. These include the use of robust data from credible data sources (such as the World Health Organization), conservative estimates where several options are available, clear assumptions and transparency about any calculations made. It is important to communicate these figures with the assumptions attached, and ideally as part of the entire Story of Change.

## **Structure**

The Stories of Change begin by describing the thematic issue around the projects that SHARE has funded. SoC include lessons learnt and seek to define the factors which led to success as well as transferable lessons that may be useful for others; they then highlight policy and practice changes at the national and global level, and seek to define SHARE's contribution to this complex change, as well as the important role of other actors. Each SoC estimates the potential reach of the thematic areas and includes Value for Money analyses.

## **Next steps**

In total the three Stories of Change featured in this report cover £590,706 of Phase I's £10 million budget, approximately 6% of the total budget. They illustrate that small strategically-made investments can have far reaching global effects. SHARE hopes to write Stories of Change to represent a total £2 million of its portfolio, in order to generate a clearer picture of the ongoing impacts from SHARE projects.

## Stories of Change

### Putting WASH and Nutrition on the global agenda

#### Background

Water, Sanitation and Hygiene (WASH), diarrhoea, food hygiene and nutrition intersect in multiple ways. Research demonstrates that keeping food free from faecal contamination plays an essential role in reducing disease transmission through faecal-oral pathways (Curtis et al., 2011). One study estimates that practicing adequate food hygiene behaviours can reduce the risk of diarrhoea by 33% (Sheth et al., 2000). WASH can also play a crucial role in reducing diarrhoeal disease through promoting hand-washing and other sanitation behaviours such as the de-contamination of household items (for example cooking equipment and utensils) and use of clean water for washing utensils.

Undernutrition affects at least 159 million children through stunting and 16 million children through wasting (WHO, 2015). Wasted and stunted children are more vulnerable to infectious diseases and mortality, accounting for around 45% of the global disease burden. Many factors contribute towards undernutrition and WASH plays an important role. Research suggests that WASH may be linked to undernutrition through diarrhoeal diseases, nematode infections and environmental enteropathy (Checkley et al., 2008; Moore et al., 2001; World Bank, 2006). One study suggests that around 860,000 child deaths from undernutrition could be preventable with improved WASH (Prüss-Üstün et al., 2008).

Nutrition-sensitive interventions, for which WASH is integral, are a key part of the solution to undernutrition. Research estimates that half of all undernutrition may be accounted for by environmental factors such as no access to water and sanitation and poor hygiene practices (Prüss-Üstün and Corvalán 2006; Victora et al., 2008).

In 2012, around 1.5 million people died from diarrhoeal disease and it was estimated that 58% of the total diarrhoeal disease burden was caused by inadequate WASH (Prüss-Ustün et al., 2014). For children under the age of five it was suggested that adequate WASH could prevent 361,000 deaths representing 5.5% of deaths in this age group (Prüss-Ustün et al., 2014).

*A different estimate indicates appropriate targeting and scale up of WASH interventions (as part of a package of interventions including exclusive breastfeeding and oral rehydration solutions) could prevent 95% of diarrhoeal deaths in children under the age of five by 2025 (Bhutta et al., 2013).*

WASH links closely with food hygiene, especially in relation to complementary feeding of young children. Until recently, efforts to reduce the diarrhoea burden in low and middle income countries (LMIC) focused primarily on improving hand hygiene and water quality and did not include food hygiene. However, research shows that diarrhoeal disease is higher in children after complementary food is introduced and actually peaks as the child's intake of complementary food increases (Barrell and Rowland, 1979). In some low-income settings, the level of contamination in complementary foods can be higher than that in unclean drinking water (Esrey et al., 1985; Lanata, 2003). Supplementing breast milk with complementary foods is important from six months on, yet poor complementary food hygiene and the use of unsafe drinking water to prepare food may account for a significant proportion of diarrhoeal diseases among infants and young children in low-income countries (Islam et al., 2013).

## SHARE's Role

In 2010, SHARE identified childhood undernutrition - as a consequence of poor sanitation and hygiene - as a priority area following consultation with a number of global and national stakeholders. SHARE funded a systematic review of the evidence on the effect of sanitation, hygiene and water on childhood nutrition (SHARE, 2011).

Recognising the importance of food hygiene in the prevention and control of faecal-oral transmitted diseases and the need to build a stronger evidence base, SHARE funded a series of studies to contribute towards the broader body of knowledge in Bangladesh, Nepal and The Gambia.

## Weaning foods in Mali

In a study funded by the Government of Mali, SHARE's Research Director, Professor Sandy Cairncross was the PhD supervisor of its Principal Investigator. The project, conducted in peri-urban Bamako, Mali, built upon an experiment in which the Hazard Analysis Critical Control Point (HACCP) approach was applied to the preparation of two common weaning foods (moni [a porridge made by cooking flour from various local grains with water] and fish soup). The Mali research developed

a small-scale hygiene intervention comprising of simple hygiene measures for mothers to take in preparing and serving foods to their children.

The intervention was highly effective in reducing the prevalence and intensity of faecal contamination - the latter by several orders of magnitude - and in achieving behaviour change (Toure et al., 2011, Touré et al., 2013). The HACCP approach was also found to be effective in identifying the specific behaviour changes that brought about such reductions. This piece of research had a significant influence on SHARE.

## Food hygiene and nutrition in Bangladesh

Following the success of the Mali study, in 2010 SHARE funded a food hygiene intervention study in rural Matlab, Bangladesh, to investigate whether the intervention could be replicated in a different setting and still be effective in reducing weaning food contamination. The same protocol (HACCP) was adopted and implemented allowing for different local foods, and the results showed that the hygiene intervention significantly reduced food contamination (Islam et al., 2013).

In 2010 SHARE also funded a nutrition study in Bangladesh. This research compared markers of environmental enteropathy, parasite burden, and growth in 119 children across rural Bangladesh. It found results that were consistent with the hypothesis that environmental contamination causes growth faltering mediated through environmental enteropathy (Islam et al., 2013, Lin et al, 2013).

## Cochrane Review on WASH and undernutrition

SHARE engaged Dr Alan Dangour, an eminent academic on nutrition at LSHTM to lead a Cochrane Review on the links between WASH and undernutrition. Dr Dangour later became a scientific advisor to the Department for International Development (DFID) on nutrition. This fostered greater engagement with the nutrition sector and was the first Cochrane Review on this relationship. The review found evidence suggesting a small benefit from WASH interventions on growth in children under five. It highlighted the need for greater evidence and higher quality interventions in order to further explore the connection between WASH and undernutrition (Dangour et al., 2013).

## Food hygiene at district scale in Nepal

Building on the Mali and Bangladesh findings, SHARE funded a PhD student, Om Prasad Gautam, to design, deliver and evaluate an intervention to change the food hygiene behaviours of mothers at district scale in rural Nepal. This consisted of a motivational package targeting five key food hygiene behaviours using emotional drivers rather than cognitive appeals.

The research found a high uptake of targeted hygienic behaviours and a 99% reduction in food contamination levels. Additionally, the research kept the cost of the intervention low (US \$17) per

participating mother/child pair, despite using a considerable portfolio of campaign stationery, such as badges, leaflets and bunting which was used to indicate a division between the kitchen area and where the animals were allowed.

The results therefore suggest that it is possible to substantially improve food hygiene behaviour and reduce the risk of food contamination through scalable community level interventions. The work in Nepal was the first comprehensive food hygiene intervention in a communal setting and can also be seen as breaking the silence on this topic which wasn't previously discussed in communities.

### Scaling up food hygiene in the Gambia

SHARE also funded a new study on food hygiene in The Gambia to roll out the approach tested in Nepal at district level with the support of the Gambian Ministry of Health (MoH). This study was co-funded by UNICEF. This cluster randomised control trial in rural Gambia (Central River Region) substantiates the findings of the Nepal study through adaptation of the intervention to a different, more resource-constrained context.

The results have not yet been subject to peer-review, but initial findings suggest the study was large enough to detect a reduction in diarrhoea incidence in the community. The findings of this trial are being followed by the UNICEF office in Banjul, and they are interested in scaling up nationally if further evidence suggests the intervention is successful.

### Safe Start; investigating WASH and nutrition in early childhood in Kenya

In 2014, SHARE-funded the Great Lakes University of Kisumu (GLUK) conducted the first phase of a study called Safe Start. Phase I of Safe Start involved conducting formative research on WASH and related social processes in informal settlements in Kisumu. The project sought to discover how social, economic and environmental factors correlate to WASH behaviours and conditions and how these factors affect children's exposure to enteric pathogens at both the household and community level. Phase I involved a combination of focus group discussions, key informant interviews and participatory Geographic Information Systems (GIS) mapping. Publications on major findings are forthcoming.

## National Change

### Nutrition and food hygiene research in Bangladesh

**Food and Agricultural Approaches to Reducing Malnutrition (FAARM)** is a cluster randomised trial led by Heidelberg University that is currently taking place in rural Bangladesh. It aims to evaluate the potential of reducing young child undernutrition in low-income countries through an integrated programme that trains women's groups in agriculture, nutrition, child care and hygiene. Dr Om Prasad Gautam, a former SHARE PhD student, provided guidance on the trial design and the importance of including food hygiene. The

trial replicates the Nepal approach mentioned above and scales up through targeting 46 clusters with 35,000 adults in total.

SHARE has also contributed towards building capacity in Bangladesh around WASH and food hygiene. ICDDR,B, a SHARE partner since Phase I, is now leading on a \$2.5 million Bill and Melinda Gates Foundation funded research project - **Research on Integration of Nutrition Early Childhood Development WASH (RINEW)**- on the integration of nutrition, early childhood development and WASH. This work began in September 2016. One of SHARE's former PhD students, Dr Tarique Md. Nurul Huda, is a co-investigator on this project. RINEW aims to optimise growth and development of children living in impoverished communities by empowering community health promoters to deliver an integrated cost-effective package of interventions.

## Global Change

### Integrating food hygiene into UNICEF's definition of hygiene in new WASH strategy

The UNICEF 2006 - 2015 strategy has one reference to food hygiene, where it discusses household practices and highlights “washing hands with soap after defecation and before handling food, and the safe disposal of children’s faeces” as a way to prevent diarrhoea (UNICEF, 2006).

In contrast, the 2016 - 2030 WASH strategy specifically mentions food hygiene in its definition of hygiene, and notes the importance of going beyond WASH interventions and integrating with health and nutrition interventions (UNICEF, 2016). The paper specifically references eight SHARE funded publications including SHARE's evidence paper (Esteves Mills and Cumming, 2016).

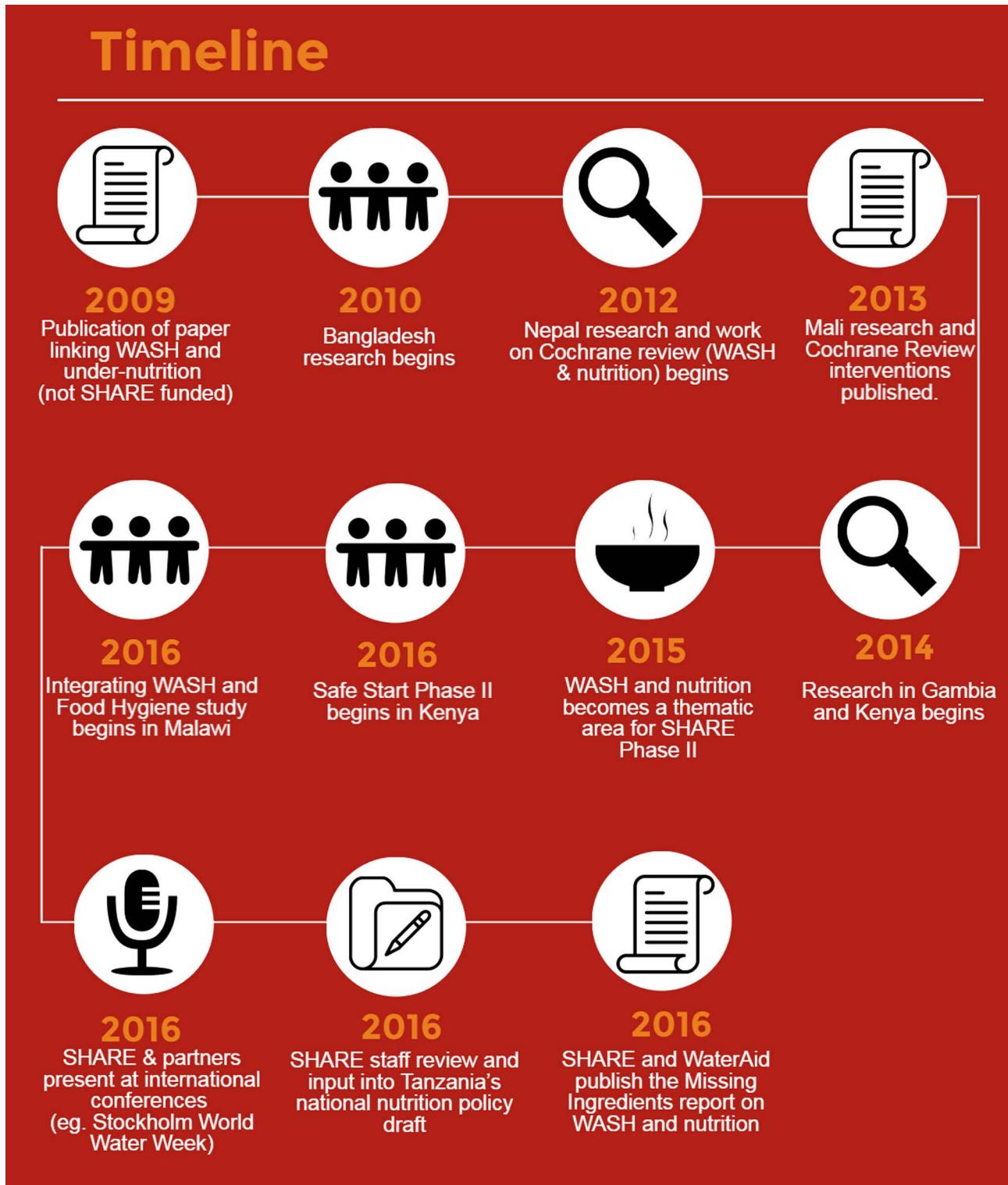


Figure 1: WASH and Nutrition timeline

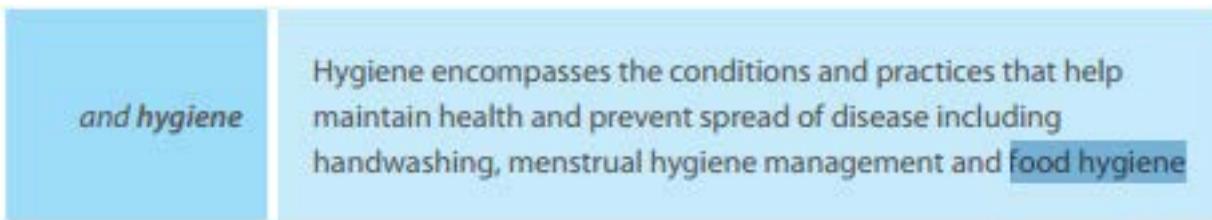


Figure 2: Food hygiene in the UNICEF WASH strategy

### Putting food hygiene on WaterAid's agenda

On completing his doctorate with SHARE, Om Prasad Gautam took up the position of Technical Support Manager for Hygiene at WaterAid UK. Prior to Dr Om Prasad Gautam's appointment, WaterAid did not have dedicated posts on hygiene which was seen as an optional add-on to water and sanitation projects. As the dedicated manager on hygiene, he provides programmatic support globally, leads on WaterAid's technical positioning, supports country partners to integrate hygiene, builds global capacity, provides technical training and develops behaviour change resources.

Hygiene is one of the four global aims in WaterAid's new strategy and has been institutionalised in their work. It is now a component of all their WASH projects as well as vertically integrated into specific projects such as the Pakistan National Sanitation Campaign and the Nepal Vaccination Campaign. In addition to Dr Om Prasad Gautam's technical lead on hygiene, WaterAid now has two policy staff who include hygiene as part of their portfolio.

WaterAid has focused strongly on nutrition at a global level by including WASH and nutrition as one of their two Global Advocacy priorities 2015 - 2018. They are also developing internal guidelines on nutrition sensitive WASH programming. WaterAid UK and SHARE worked together to produce the [Missing Ingredients report](#) which analyses WASH and nutrition policies in 13 countries. This report highlights why WASH is essential for nutrition and recommends where and how improvements should be made (WaterAid, 2016). It was launched to align with the [Nutrition for Growth 2016 Summit](#) and was also presented at [European Development Days 2016](#) and [Stockholm World Water Week 2016](#).

### Contribution to Change

SHARE has been a critical actor in putting WASH and nutrition on the global agenda. Importantly, this work has been in partnership with other institutions and individuals, including WaterAid as a SHARE partner institution as well as influential individuals from academia.

SHARE played a key role in engaging individuals from the nutrition sector including leading academics and DFID staff; the Cochrane Review launch was introduced by a member of DFID's nutrition team. SHARE worked strategically with other actors and took opportunities to present research findings widely to agencies, governments and NGOs. Research dissemination/uptake events were generally in partnership with academic colleagues or WaterAid

staff and used an insider track approach to advocacy.

SHARE's research projects built upon previous studies (such as the Mali work mentioned) to strengthen the evidence base on WASH and food hygiene, and tested the approaches in different contexts and at different scales. SHARE's work also introduced key ideas such as the focus on weaning foods and the HACCP process. Funding projects in different geographical locations may also have helped to strengthen the evidence base and better demonstrate the effect of food hygiene interventions.

Each SHARE project on WASH and food hygiene influenced later projects. SHARE's work has also influenced research projects and trials led by others, for example, former SHARE PhD Student Om Prasad Gautam advised the FAARM trial in Bangladesh on their project design.

The partnership between WaterAid and SHARE, through co-funding as well as ongoing relationships and interactions was essential in influencing these global and national changes. WaterAid was a key actor through buying into food hygiene and behaviour change, co-funding Om's PhD and committing to rolling out the approach internationally through evidence-based training. As noted previously, WaterAid has also included nutrition in their Global Advocacy priorities 2015 - 2018 and seek to roll out WASH and nutrition systematically across their work through this approach.

Funding key research on this topic at critical moments influenced agencies such as UNICEF to broaden and reconsider their definition of hygiene, critically incorporating food hygiene into their new strategy. The multiple references to SHARE-funded papers in UNICEF's new strategy, as well as specific reference to SHARE's evidence paper, demonstrates the important role of SHARE on generating evidence to support UNICEF's strategy and planning (UNICEF, 2016).

## Other advocacy contributors

The German Toilet Organisation (GTO) played a key role in **convening the first Bonn WASH and Nutrition Forum in November 2015**. This event brought together stakeholders from the WASH and nutrition sectors using an innovative conference format of 'mirror sessions'; this approach encouraged attendees to think about parallels between their sectors.

**SHARE presented a session** on the growing scientific evidence base for forging closer relationships between the two sectors, particularly through policy development. This event can be seen as one of the first WASH and nutrition specific events, bringing the topic to over 100 delegates and 300 web attendees including academia, governments and policy makers, donors, civil society and practitioners.

Other key actors include Action Against Hunger (ACF) who

have invested in operational research to broaden the evidence base as well as engaging in advocacy, UNICEF and EU Humanitarian Aid (ECHO) have played a key role in driving forward the agenda, including working with ACF and others on an operational manual containing practical guidance on WASH and nutrition. [World Vision International \(WVI\)](#) has also worked on the topic, particularly through collaborating with WaterAid on [BabyWASH](#).

NGOs more generally are now considering the links between WASH and nutrition; for instance [Concern Worldwide's 2016 Global Hunger Index](#) recognises the links between WASH and undernutrition and recommends coordination across key sectors including WASH in order to reach zero hunger (ConcernWorldwide, 2016).

### Other academic contributors

The Lancet paper published in 2009 by Jean Humphrey made a significant contribution to the discourse on WASH and nutrition, effectively opening up academic discussion on the topic (Humphrey, 2009). Other universities and academic groups have made key contributions to this topic over the duration of SHARE, including the [University of California \(Berkeley\)'s work on WASH Benefits](#) and Family Health International's (FHI) 360's work on [WASH Plus](#), funded respectively by the Bill and Melinda Gates Foundation and the United States Agency for International Development (USAID). The [Sanitation, Hygiene and Infant Nutrition Efficacy Trial \(SHINE\)](#) has also led on generating a strong evidence base.

It is likely that this ongoing momentum around WASH and nutrition in the academic sector has helped to foster a supportive environment for SHARE to influence key policy makers and practitioners. Published results of these trials are expected in the near future (including SHARE's Phase I work) and may have an impact on the advocacy environment, providing a stronger evidence base to influence policy and practice.

## Lessons Learnt

1

### Secure mutual investment for sustainability and longer term engagement

Dr Om Prasad Gautam's PhD was co-funded by SHARE and WaterAid. The additional funding allowed for a more rigorous methodology for the trial which strengthened the quality of evidence. It also meant that WaterAid were invested in the results from the very beginning and had an interest in advocating for food hygiene in the longer term. Similarly, SHARE's study in the Gambia was co-funded by UNICEF with support from the Ministry of Health.

2

### Build on global momentum to influence change

LSHTM have been at the forefront of researching behaviour change and have pioneered the **Behaviour Centred Design approach**. In 2013, LSHTM drafted a global positioning paper for development of the SDGs which focused on three key areas, one of which was food hygiene. The momentum of developing SDGs enabled existing networks to work together to put hygiene on the global agenda. Hygiene is now reflected in the target for SDG 6.2 which shows significant progress from the MDGs.

3

### Engage with the private sector for expertise

Dr Om Prasad Gautam noted that the concept of service provision is not always enough to change social norms and behaviours; working with the private sector in Nepal enabled the trial to draw on their experience in developing products and to apply marketing as a science.

4

### Engage outside the WASH sector

The 2012 SHARE Annual Report identified the need and opportunity to work with partners beyond the WASH sector to mainstream evidence on sanitation and hygiene (SHARE 2012). This was embodied through SHARE's cross-sectoral work on WASH and nutrition. The SHARE team found that engaging with experts outside the WASH sectors helped to foster stronger engagement. Working with established specialists in nutrition meant that WASH was taken more seriously by those working in nutrition and health. It also created opportunities for uptake and research dissemination outside the WASH sector.

5

### Integrate food hygiene at a sectoral level

The Nepal trial identified food hygiene as a major component in implementing WASH, nutrition and health programmes and the PI highlighted that ongoing food hygiene activities can fit into any of these sectors. Integration of hygiene can be used to advocate for greater uptake of hygiene activities. For example, food hygiene can be considered as part of the life cycle in the health sector and practitioners can advocate for integrating food hygiene in interventions such as complementary feeding, exclusive breast feeding, weaning foods and growth faltering.

## Value for Money and Estimated Reach

SHARE invested £295,431 into WASH and nutrition, with the majority of that funding going on research. This was **2.95% of the total SHARE Phase I budget** and does not include Phase II funding into the ongoing studies in Kenya and Malawi.

Table 1 suggests the reach of SHARE's work on WASH and nutrition; this is indicative and represents complex social change which SHARE's work may have contributed towards. It only includes global or national changes where enough data was available to make assumptions.

If SHARE's interventions prove to be successful and are replicable across other contexts, then there is the possibility for many more people to benefit in future.

Table 1: Estimated reach of WASH and Nutrition work

Uptake	Direct Beneficiaries	Indirect Beneficiaries	Practitioners /donors	Assumptions
Food hygiene research in Nepal	239 households (120 control households, 119 intervention households) with child aged 6-59 months  This is approximately 1,166 people.			Assumption that the intervention has now been rolled out to the control households, that a food hygiene intervention has benefits for everyone in a household and that census data on average household size (4.88) is accurate (Government of Nepal 2011).
WASH and nutrition intervention in Kenya: Safe Start Phase I	This intervention targets 800 households, focusing on health outcomes in 1 child in each household but seeking behaviour change from the primary caregiver.  This is approximately 1,600 people including the caregiver and child in each household			Assumption that the intervention has reached the caregiver and child in each household.  Phase II seeks to target 14,000 households but its actual reach will be confirmed after the intervention has taken place.

Uptake	Direct Beneficiaries	Indirect Beneficiaries	Practitioners /donors	Assumptions
Food hygiene in UNICEF's strategy			600 WASH staff in over 100 countries (UNICEF, 2016)	Assumption that the strategy will be read and taken up by all UNICEF WASH staff (potentially reaching more indirect beneficiaries through their programmes)
Food hygiene and nutrition research in Bangladesh - FAARM		35,000 people in the FAARM RCT.		Assumption that the trial will take on board learnings from SHARE research and that it will reach all of its planned research participants including control group.
WASH and nutrition knowledge sharing events			833 attendees at SHARE knowledge sharing and capacity building events on WASH and nutrition/ food hygiene between 2010 - November 2016.	This figure is based on the average number of attendees per SHARE event multiplied by the number of actual events on this theme (18), as detailed attendance data is not available for each event.
Totals	2,766 direct beneficiaries	35,000 potential indirect beneficiaries	1,433 donors and practitioners	

## Next Steps

WASH and nutrition is a continuing focus for Phase II of SHARE with specific projects taking place in Kenya and Malawi. In Malawi, [Malawi Epidemiology and Intervention Research Unit \(MEIRU\)](#) are leading on a project which aims to determine the relative effectiveness of food hygiene and WASH interventions in preventing diarrhoeal disease in children under five in Chikwawa District, Southern Malawi. It will seek to identify sources and causes of diarrhoeal disease and will then identify the most appropriate points of intervention and test food hygiene community based interventions.

In Kenya, [Great Lakes University of Kisumu \(GLUK\)](#) are building on their Phase I work to conduct [Safe Start Phase II](#): a cluster randomised controlled trial to design, implement and evaluate the impact of a novel early childhood hygiene intervention targeting caregivers of children at three months of age on enteric infections and growth faltering in low-income settlements of Kisumu, Kenya. This project seeks to address the challenge of undernutrition by designing and testing a child hygiene intervention in collaboration with community members, the health extension system and local government. The intervention will target children's caregivers with the aim of changing key hygiene behaviours.

## WASH in health care facilities; a story of change

### Background

Progress towards attaining Millennium Development Goal 5 - reducing maternal mortality by three quarters between 1990 and 2015 - was geographically and socio-economically uneven. With 289,000 maternal deaths still occurring every year across the globe (WHO, 2014), it is clear that traditional maternal health interventions alone have not been sufficient to adequately address this issue. Similarly, 748,000 newborn babies die each year from preventable causes and in 2015 a child was 500 times more likely to die on the first day of life than at one month of age (UNICEF, 2015). WASH links closely with maternal and newborn health with the connection between the handwashing of birth attendants and infection at childbirth established as early as 1795 (Gordon, 1795, Semmelweis, 1983).

WASH has been prioritised in the sustainable development agenda through the Sustainable Development Goal (SDG) 6, which seeks to achieve universal and equitable access to WASH by 2030. In contrast to the Millennium Development Goal targets for water and sanitation, SDG 6 considers access to WASH beyond the household which would include schools, the work place, prisons and health care facilities (HCFs).

In line with this, the WHO/UNICEF Joint Monitoring Programme, officially tasked with reporting on progress for SDG 6, has been reporting global coverage figures for WASH in health care facilities since 2015 (WHO and UNICEF, 2015). In addition, the United Nations Special Rapporteur on the Human Right to Safe Drinking Water and Sanitation identified the provision of WASH outside the household, as key to advancing human rights including the right to water and sanitation but also the right to health (Ohchr, 2012).

An adequate quantity and quality of drinking water, facilities for safely managing excreta and healthcare waste, and the application of hygienic practices such as hand hygiene and environmental cleaning, are essential to the functioning of any HCF (WHO and UNICEF, 2015). They are a prerequisite for the delivery of most infection prevention and control (IPC) practices and important for improving quality of care. Until recently very little was known about the coverage of WASH in HCFs in low and middle income countries and the potential impact this is having on health outcomes such as maternal and neonatal mortality.

In 2010 SHARE made a strategic decision to study the relationship between WASH and maternal and newborn health (MNH) in order to advance our understanding of this area and put WASH on the MNH global agenda.

### SHARE's Role

Prior to SHARE's systematic review (Benova et al., 2014a), there

was very little interest in the impact of water and sanitation on maternal mortality. This association was not seen as a priority given that cause of death statistics for maternal mortality focused on medical issues such as haemorrhage and pre-eclampsia. Any relationship between WASH and MNH was inferred and there was not a coherent methodical approach in place to understand the multiple, complex and often overlapping pathways of association. Furthermore, much of the evidence about these pathways was weak, based on observational studies and anecdotal evidence.

Since 2010, SHARE has sought to address the evidence gap by funding five studies on the relationship between WASH and MNH. This work has covered three important areas:

- The links between maternal and newborn health and WASH.
- WASH coverage in HCFs and the impacts of limited WASH coverage on health.
- Health care associated infections and WASH in HCFs.

Links between sanitation, hygiene, and maternal health were identified early on as a priority by SHARE consortium members - WaterAid and LSHTM - as well as external stakeholders. Some initial scoping work was done by SHARE in this area in 2010 and in 2012. SHARE's annual report specified a strategy to mobilise research and evidence around the topic (SHARE, 2012). An analytical approach to plug some of the knowledge gaps was developed by SHARE in partnership with leading LSHTM academics including Dr Lenka Benova and Professor Oona Campbell.

## Systematic review on water, sanitation and maternal mortality

In 2012, SHARE funded Dr Lenka Benova to lead the [first systematic review on the association between water, sanitation and maternal mortality](#) (Benova et al., 2014a). The review sought to assess whether the lack of access to water or sanitation facilities in either the home or in health facilities is associated with an increased risk of maternal mortality and to quantify the effect sizes. The review showed evidence of association between poor sanitation and increased maternal mortality, and between poor water and increased maternal mortality. Both associations were found to be of substantial magnitude and were maintained after adjusting for confounders (Benova et al., 2014a). The review highlighted the need for more rigorous research on the topic.

## Conceptual framework and call to action

Professor Oona Campbell led this study to explore the linkages between WASH and MNH via a conceptual approach and a scoping review. It used three lenses - the Bradley classification, a gender lens and a life-course lens - to produce the first methodical documentation and conceptual framework of the WASH risk factors potentially linked to MNH.

The **conceptual framework** showed that WASH affects the risk of adverse MNH outcomes (Campbell et al., 2015). The framework identified 77 potential chemical, biological and behavioural mechanisms linking WASH to MNH, and showed that these exposures are multiple and overlapping and may be distant (in time) from the immediate health outcome. Since this publication, the authors have led other studies (including country specific and prevalence studies) which contribute to the growing body of evidence on the causal nature of the link between WASH and MNH.

SHARE, WaterAid, UNICEF, WHO and LSHTM built upon this work to author a **call to action paper** which featured in PLOS Medicine (Velleman et al., 2014). This paper advocated for greater attention to MNH and WASH, given the existing evidence base. It recommended reflecting WASH in national and global efforts to reduce maternal and newborn mortality, and highlighted the opportunity represented by the post MDG development goals. The paper called for embedding WASH targets in MNH indicators and for further implementation research to identify effective interventions to improve WASH in HCFs.

This body of work also inspired follow-on research by LSHTM staff who used existing data to further investigate the link between poor WASH and maternal mortality in Afghanistan (Gon et al., 2014), Pakistan and Bangladesh (forthcoming). The Afghanistan paper found that women living in households with access to an unimproved water source had a higher risk factor for pregnancy related mortality than those with an improved water source. It also found a non-statistically significant association between unimproved toilet facilities and maternal mortality.

## **WASH in Tanzanian Birth Settings**

SHARE additionally funded Professor Oona Campbell to lead a study to assess WASH coverage in home and facility birth settings in Tanzania. This drew on existing data sources including the Tanzania 2010 Demographic Health Survey and the 2006 Service Provision Assessment. One paper that came out of this research estimated that less than a third (30.5%) of all births in Tanzania take place in a setting with safe water and sanitation; this is an important finding given the high maternal mortality burden in Tanzania (Benova et al., 2014b).

## **Infection Prevention Control and WASH in Maternity Units in India, Bangladesh and Zanzibar**

SHARE partnered with the Water Supply and Sanitation Collaborative Council (WSSCC) to fund WASH & CLEAN, a study on WASH in labour wards in India and Bangladesh. The Indian Institute of Public Health Gujarat (IIPHG), Bangladesh Rural Advancement Committee (BRAC), Initiative for Maternal Mortality Programme Assessment (Immpact), University of Aberdeen, and the Soapbox Collaborative worked together to develop and pilot a suite of tools that could be used to objectively capture levels of cleanliness and the determinants, processes and outcomes of cleaning on the labour ward. The tools

were piloted via a ‘situation analysis’ and a ‘needs assessment’ of the state of maternity units’ WASH and infection prevention and control practices in Gujarat, India.

The study revealed WASH conditions to be sub-optimal and provided greater depth on WASH coverage, status and use than previous research (Afsana, 2014). To provide a cross-cultural comparison, the WASH & CLEAN study was extended to Dhaka, Bangladesh through leveraged funding from the Soapbox Collaborative.

Tools were also adapted to conduct an in-depth needs assessment exploring WASH and IPC conditions in maternity units in Zanzibar in 2013. This work was undertaken by [The Soapbox Collaborative](#), [WaterAid](#) and the [Pemba Health Laboratory Ivo de Carneri](#). An associated [WASH & CLEAN toolkit](#) was launched in 2014, in order to make the WASH & CLEAN tools publicly available for global use. The tools are flexible and can be used as part of an internal audit process; as part of a continuous improvement cycle, or as part of a wider research study.

## Sanitation and Adverse Pregnancy Outcomes

SHARE funded the Asian Institute of Public Health to lead this population-based cohort study in Odisha, India. The study assessed the effect of poor sanitation during pregnancy on adverse pregnancy outcomes (APO).

It found that poor sanitation in general, and open defecation in particular, were strongly associated with APO after adjusting for a broad range of biological and socio-economic factors (Padhi et al., 2015). This is the first rigorous epidemiological study to demonstrate this relationship and the results have potentially important implications for maternal and newborn health policy in high burden settings.

## Systematic Review on Health Care Associated Infections and WASH

SHARE, in partnership with UNICEF and WHO, will follow on from this work in 2016/2017 by undertaking a systematic review on health care associated infections and WASH. It is expected that this will further inform global research on WASH in health care facilities.

## National Change

### Case study 1: India

Learnings from WASH & CLEAN have been taken up at state level in Gujarat, resulting in a move to improve WASH and IPC on maternity units and the wider facility context. The Government of Gujarat has asked the Institute of Indian Public Health (IIPH) to modify the WASH & CLEAN tool for outpatient departments, broadening its focus from the labour ward. The IIPH are also pioneering and testing draft Joint Monitoring Programme (JMP) indicators on WASH in HCFs. These indicators cover areas such as hand hygiene, waste management and sanitation and water - this trial is expected to inform final decisions on JMP indicators which will be rolled out globally in the future.

Findings from the WASH & CLEAN study have also fed into WHO's broader global planning processes, including a presentation by SHARE partner IIPHG at the WHO-led global WASH in health care facilities meeting in Geneva in March 2015.

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### Case study 2: Zanzibar

In Zanzibar, following completion of the research described above, an interpretation workshop was held with key stakeholders, including the Ministry of Health, where action plans were developed that drew on findings. The MoH have now developed an implementation plan for WASH in HCF in Zanzibar and a draft WASH in HCFs toolkit. The action plan included training for health care workers on waste management and the cleaning and maintenance of equipment. The Zanzibar MoH curriculum is now being rolled out in mainland Tanzania.

SHARE's investment in the topic has helped demonstrate that there is sufficient evidence of the effect on WASH on MNH to justify global action. Through international dissemination events, engagement of key actors and capacity building, SHARE and its partners have supported evidence-based policy and practice in this area.

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## Capacity Development

SHARE has invested resources in delivering capacity development activities to key stakeholders, aiming to ensure appropriate understanding and use of the research findings on this topic.

WASH and MNH linkages were included in many events including the following:

- The 2015 and 2016 ‘evidence-based policy and practice’ webinar series for UNICEF (which draws on SHARE-funded publications)
- Webinars for UNICEF South Asia and UNICEF HQ
- Lunchtime learning sessions at WaterAid UK and webinars for WaterAid America and WaterAid Australia
- Training course for UNICEF Kyrgyzstan.
- Webinars for NGOs including Plan International, Plan US and World Vision
- Face to face/virtual presentations to the DFID Health team in London, the South East Asia DFID Research Hub and DFID India.

## Global Change

### Informing WHO strategy

SHARE’s research on WASH and MNH informed a call to action paper published in PLOS Medicine and authored collaboratively by WASH and MNH experts, including SHARE researchers (Velleman, 2014). The paper offered tangible recommendations for immediate action and was launched in London in December 2014 by SHARE, with broad attendance from both sectors as well as participation from senior DFID and WHO representatives.

This work influenced the 2015 WHO & UNICEF Water, sanitation and hygiene in health care facilities: status in low- and- middle-income countries and way forward report, which provides strong recommendations for moving forward and has had huge reach globally (WHO and UNICEF, 2015). This was the first WHO report to recognise the significant of WASH in HCFs.

SHARE has been closely involved in the WHO-led development of an action plan to tackle inadequate WASH in health facilities, most recently hosting a meeting in London in March 2016. This plan has four task teams of which SHARE is involved with three of them: Monitoring; Evidence and Operational Research; and Policies, Standards and Facility-based Improvements. Most recently, SHARE has helped to draft JMP monitoring indicators which as noted earlier are now being tested in India by SHARE Phase I partner IIPH.

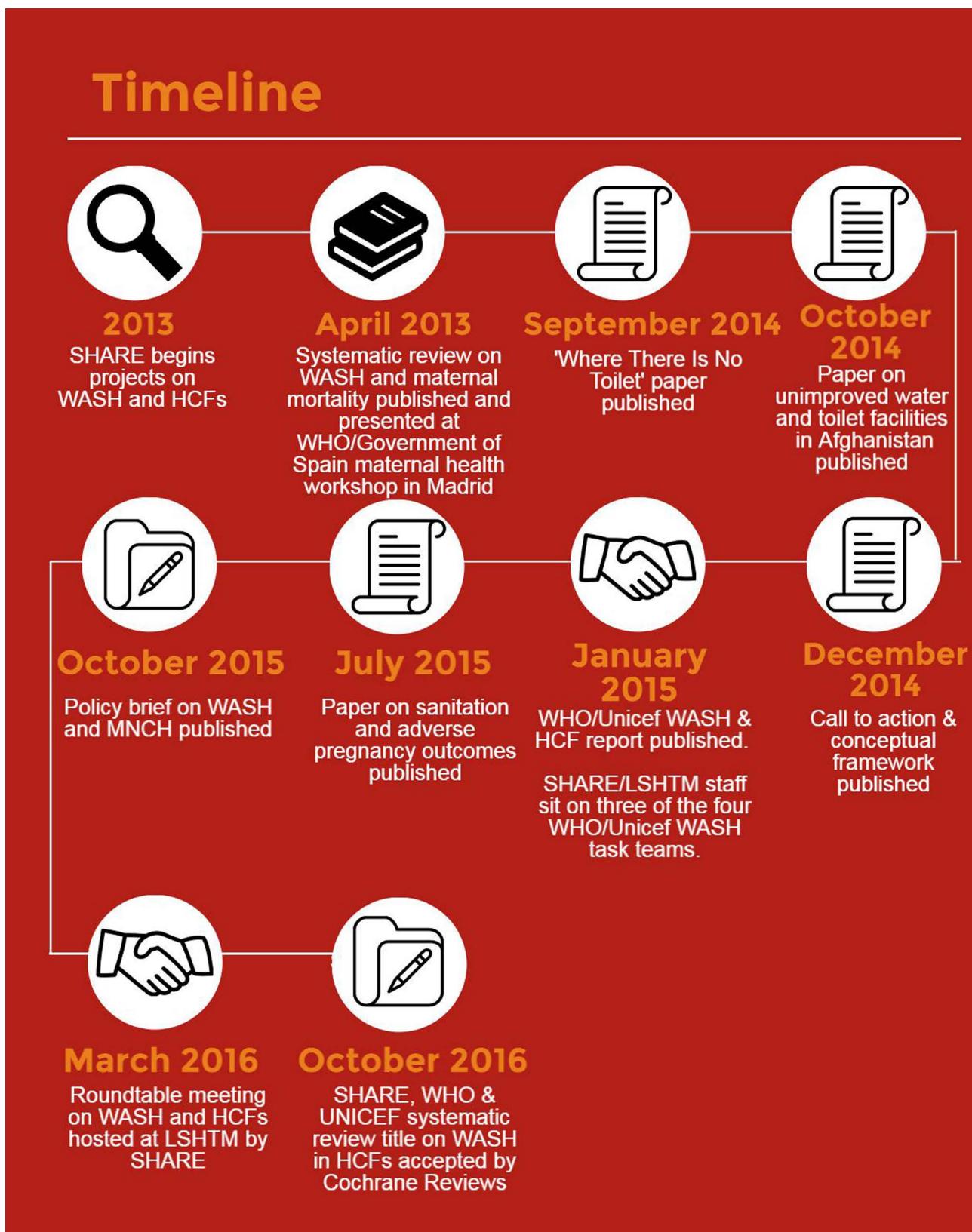


Figure 3: WASH in health care facilities timeline

## Contribution to Change

SHARE has been part of a small group of individuals and institutions who have been working on this issue and pushing the agenda forward. This includes researchers at LSHTM (Dr Lenka Benova, Professor Oona Campbell) and the Soapbox Collaborative (particularly Professor Wendy Graham and Georgia Gon), agencies including WHO and UNICEF, and donors such as USAID.

SHARE engaged LSHTM researchers who were working on maternal health but not on WASH, and sought to create links across these sectors and types of work. SHARE also sought to make WASH visible at international conferences on maternal health; for example SHARE was the only organisation representing WASH at the Global Maternal Health Conference in Arusha in 2013. Participation in this meeting led to the opportunity to publish a call to action paper in PLOS Medicine (Velleman et al., 2014).

As noted earlier in the Global Change section, SHARE has played a very direct role in influencing WHO's work on WASH and HCFs. This includes sitting on the task force for this topic, presenting at meetings and hosting strategic meetings.

## Other contributors

Others also worked on the issue separately; for instance, University of North Caroline at Chapel Hill (UNC) academics carried out research on facilities and coverage which has helped to fill other knowledge gaps on the theme. USAID played a key role in building momentum by announcing that they would be incorporating WASH into their maternal health strategy and referencing SHARE's systematic review in relation to this decision (SHARE, 2014).

There has also been leadership from regional governments who want to prioritise and address these issues such as the Government of Zanzibar and the Government of Gujarat. This has helped to build global momentum.

## Lessons Learnt

1

### Build on global momentum to influence key actors.

Part of the success of SHARE's work on WASH and HCFs has been due to SHARE building momentum around the topic and taking advantage of increasing interest from key actors. SHARE's call to action paper was co-authored by WHO and UNICEF helping to influence their report on WASH coverage on HCFs, which has since prompted an increase in studies in LMIC for WASH in HCFs.

2

### Use the SDGs process to get the topic on the global agenda.

SHARE's WASH in HCFs work aligned well with the launch of the SDGs which focus on universal and equitable access. The SDGs also highlight the differentiated needs of women and girls, which links closely to topics around M NH. As well as linking to the SDG goals around WASH, the topic links to SDG 3 and the attainment of Universal Health Coverage, as well as other global schemes such as WHO's 'Clean Care is Safer Care' Programme.

3

### Capitalise on a compelling and engaging topic.

Part of the momentum and increased interest may be the compelling topic - while women around the world are being encouraged to give birth in health care facilities, evidence suggests that these facilities may be unhygienic and may actually put women at risk. The concept that health facilities may be high-risk settings for spreading infections is worrying and has repercussions for attitudes towards facilities and health-care

4

### Use flexible management to seize opportunities.

Flexible management from the SHARE consortium also helped; SHARE made the decision to contribute the funding at an opportune moment using some of its flexible research uptake money. SHARE has continued this approach into Phase II in order to remain agile and reactive to opportunities. Other consortia could choose to keep funding aside for kick-starting small pieces of work or taking advantage of arising opportunities.

## Value for Money and Estimated Reach

SHARE invested £175,865 into WASH and HCFs, with the majority funding research activities. This was just **1.76% of the total SHARE Phase I budget** but contributed to complex national and global changes. Research into use funding included attending key events such as the maternal health conference in Arusha in 2013. Phase II work mentioned in the timeline has not been included in this budget.

LSHTM and its partners have built upon the success of SHARE's work in this area to access additional funding for follow on work:

- LSHTM have received £149,000 from the Medical Research Council to investigate handwashing of birth attendants in Zanzibar.
- LSHTM has received around \$20,000 from WHO and UNICEF to co-fund a systematic review on the effect of WASH on healthcare associated infections in LMIC.
- The University of Aberdeen have acquired funding from UNOPS/ WSSCC to further investigate WASH & CLEAN on the labour ward.
- Upon request from the Government of India, IIPH are seeking co-funding from SHARE Phase II, WHO India and UNICEF India to build upon WASH & CLEAN to produce a broader toolkit that looks beyond the delivery suite at health care facilities in general.

Table 2 suggests the reach of SHARE's work on WASH in HCFs; this is indicative and represents complex social change which SHARE's work may have contributed towards. It only includes global or national changes where enough data was available to make assumptions.

If SHARE's interventions prove to be successful and are replicable across other contexts, then there is the possibility for many more people to benefit in future.

Table 2: Estimated reach of WASH in HCF work

Uptake	Direct Beneficiaries	Indirect Beneficiaries	Practitioners /donors	Assumptions
Uptake in India	The original research covered 7 maternity units in Gujarat.	There is a potential indirect reach to approximately 1,071,840 women and babies annually.		<p>Gujarat has a population of 66 million people (IndiaCensus, 2016) and a crude birth rate of 20.3 per 1000 people. (Government of India, 2013). This means the approximate mean annual number of births in Gujarat is 1,339,800.</p> <p>Accounting for the fact that approximately 40% of births in India take place in HCFs (Balarajan et al., 2011), this means that approximately 535,920 births in HCFs per year take place in Gujarat.</p> <p>Potential beneficiaries are therefore 1,071,840 women and children each year (assuming births are one child).</p> <p>This figure assumes that all of these women have access to HCFs and that the findings have been taken up systematically across Gujarat.</p>

Uptake	Direct Beneficiaries	Indirect Beneficiaries	Practitioners /donors	Assumptions
Uptake in Zanzibar	The original research covered all 37 maternity units in Zanzibar which in total assist with 2,942 deliveries per month.	There is a potential indirect reach to approximately <b>47,867</b> women and babies annually		Zanzibar has a population of 1,303,569 (National Bureau of Statistics, 2013). The crude birth rate for Tanzania is 36 per 1000 people (Index Mundi, 2016). This means the approximate mean annual number of births in Zanzibar is 46,928. Accounting for the fact that approximately 50% of births in Zanzibar take place in HCFs, this means that approximately 23,923 births in HCFs per year take place in Zanzibar (UNICEF 2014).
Informing UN strategy			The UN Global Strategy on MNH aims to reduce global maternal mortality to less than 70 per 100,000 live births and to reduce global new-born mortality to 12 per 1000 live births.	SHARE's research found a significant association between WASH in HCFs and MNH; we assume that improving WASH in HCFs will contribute to the UN Global Strategy's ambitious goals.

Uptake	Direct Beneficiaries	Indirect Beneficiaries	Practitioners /donors	Assumptions
Informing WHO strategy			WHO has ambitious goals aiming to embed WASH in HCFs as a key component of quality Universal Health Coverage, maternal and new-born health targets, infection prevention and control activities and, outbreak prevention and response.	While WHO do not capture the number of beneficiaries reached, we assume that WHO's global influence, role as a donor and partnership with governments and NGOs around the world will lead to significant impact.
WASH and HCFs knowledge sharing events			1,110 attendees at SHARE knowledge sharing and capacity building events on WASH and maternal health, or WASH and HCFs since 2010.	This figure is based on the average number of attendees per SHARE event multiplied by the number of actual events on this theme (24). Detailed event attendance data is not available for each event.
Capacity Development			There were 62 attendees on the UNICEF course in 2015 and 75 in 2016. Attendees for the 2016 course represent 39 UNICEF duty stations across Africa, Middle East, Asia and the Pacific.	UNICEF staff who attend the course are likely to apply their learnings to their daily work and to share learning within their teams and offices, potentially reaching many more indirect beneficiaries across 39 countries.
Totals		1,119,707 potential indirect beneficiaries.	1,237 practitioners and donors.	

## Next Steps

WASH in HCFs is very much a live area of work for the SHARE consortium with ongoing plans still taking place in Phase II. In order to further drive the research agenda, SHARE, UNICEF and WHO are co-funding a systematic review on the effect of WASH on healthcare associated infections in LMIC - where WASH coverage rates in HCFs remains very low. Better understanding this relationship will contribute towards setting a research agenda for this important area of public health as well as enhancing existing plans and actions to reduce HCAI globally. SHARE will also continue to work closely with WHO and UNICEF as a member of three tasks teams, including testing and finalising the new JMP indicators.

By funding well-conceived, pioneering research in the area of WASH and HCFs, and leading or supporting research uptake and capacity development activities that assist in the understanding and use of findings by key stakeholders to improve policy and practice in this area, SHARE and its partners aim to continue to contribute to improved WASH provision beyond the household.

## Addressing WASH and Inequalities; a story of change

### Background

WASH and inequality is an important issue, and has been prioritised under the Sustainable Development Goals (SDGs) commitment to 'leaving no-one behind'. Marginalised groups and individuals often include older people, minority groups and people with disabilities. Disability has a disproportionate effect on those in low income countries, and on the poorest people within those contexts - it is estimated that 15% of the world's population are disabled and that 80% of these people live in LMIC (WHO, 2011). This suggests that disability has a wide reaching effect on families and communities in low-income contexts (Jones et al., 2002).

In 2011 the Australian government estimated that only 3%-4% of people with a disability actually benefit from international development programmes (AusAid, 2011). Additionally, there is evidence to suggest that individuals with an impairment, aged over 60 or suffering from chronic illnesses are at a disproportionately greater risk of not having adequate access to water and sanitation facilities (OHCHR, 2011), (WHO, 2011).

The Convention on the Rights of Persons with Disabilities (CRPD) protects the rights of those with disabilities specifically through the rights to accessibility (Article 9) and the right to an adequate standard of living and to social protection (Article 28) (UN, 2007). This commitment has been made explicit in the sixth SDG with targets that address equitable, inclusive and safe access to sanitation and water, especially for persons in vulnerable situations (UN, 2015). While equality is reflected across these documents, conventions and goals, in reality there are continued barriers globally which prevent those with disabilities from claiming their rights and participating equally in society (Devandas-Aguilar, 2015). These barriers can be understood as environmental, institutional or attitudinal (Jones et al., 2002).

In the WASH sector these can include limited access to accessible and appropriate WASH facilities, limited access to an improved water supply or sanitation, and increased vulnerability to diseases caused by faecal-oral contamination. Despite the disproportionate amount of people living with disabilities in low-income contexts, there is a small but growing body of evidence about the human and economic impact of poor WASH on those with a disability in these settings (Jones et al., 2002). Meeting international goals such as the MDGs - and now SDGs - around WASH is likely to be impossible unless the needs of people with disabilities are considered and addressed (Groce et al., 2011).

## SHARE's Role

SHARE has prioritised equity across all of its work and in Phase I strategically invested in research on inequalities. As a starting point a round table meeting was called by SHARE in 2011 to better understand why major development actors were not mainstreaming inclusive WASH in their work. This included key stakeholders such as DFID, UNICEF and IIED. The **discussions highlighted an evidence gap** on the issue of inclusive WASH and a lack of cross-country qualitative and quantitative evidence on the barriers that disabled people face, the extra costs of making WASH inclusive and on appropriate solutions.

SHARE, Leonard Cheshire Disability, the Water, Engineering and Development Centre at Loughborough University (WEDC) and WaterAid responded to this newly identified evidence gap through the Undoing Inequity (UI) project, which aimed to design and test an 'inclusive WASH' approach to better understand and address the barriers that disabled, older and chronically ill people face when accessing WASH across several districts in Uganda and Zambia.

Conducted by SHARE partner **WaterAid**, WEDC and **Leonard Cheshire Disability**, the **Undoing Inequity project** (2011 - 2016) investigated the environmental, attitudinal and institutional barriers that disabled, older and chronically ill people face when accessing WASH, and engaged communities to design and test cost-effective and inclusive WASH solutions.

The **baseline** offered an insight into the daily challenges faced by disabled, older and chronically ill people in Uganda and Zambia, a topic that had not been researched previously (Wilbur, 2014). Key findings included the following:

- Non-inclusive WASH facilities sometimes force people with physical impairments to crawl on the floor to use a toilet or defecate in the open.
- 40% of vulnerable household members (from 169 vulnerable households) had to wait for help to use the toilet and sometimes soiled themselves waiting for assistance.
- Vulnerable household members would sometimes reduce their consumption of food and drink in order to reduce the need to relieve themselves.
- Disability was associated with being dirty or contagious which sometimes stopped disabled people accessing water.

The UI intervention sought to address these issues. The initial findings of the project, documented in two mid-term reviews (**Uganda** and **Zambia**), and an accompanying process review, revealed that the 'inclusive WASH' approach improved access to water and reduced open defecation in the intervention sites for people marginalised by disability or age (Wilbur and Danquah, 2015). It also appeared to have conferred the additional benefits of increasing the self-esteem of marginalised people and fostering social inclusion, and to have positively impacted on stigma and discrimination. However, some barriers still remained, with older

people continuing to face disproportionate levels of discrimination due to decreased mobility and ill health.

Despite being based on a small sample size, and thus only being able to indicate trends, the findings offer salient insights for policy makers and practitioners wishing to mainstream disability and ensure greater equity in WASH programmes globally. Contrary to many people's assumptions, the infrastructural changes required to make WASH facilities inclusive within households are not expensive. Simple adaptations using local materials are often all that is needed - these have been compiled for practitioners in a [compendium](#). When communities, including people who tend to be excluded, have accessible information on low cost and low tech inclusive design options, and are fully involved in the programme, they can drive their own change, making WASH facilities accessible to all at a minimum cost.

Many of the insights from this project have been captured in the '[Frontiers of CLTS: Innovations and Insights](#)'. publication, which features software-related lessons learnt from the 'inclusive WASH' approach employed, and in the '[Compendium of Accessible WASH Technologies](#)', which specifically responds to calls from practitioners for simple guidelines on how household WASH facilities can be made more accessible. As well as documenting examples of low-cost technologies which families can adapt to suit their specific needs and budgets, the compendium is also [accompanied by online resources](#) - photos and a DVD - that fieldworkers can use when discussing options with communities. The resource was made available in English, French and Portuguese to ensure the widest possible uptake.

## Case study - Most Significant Change

The Most Significant Change (MSC) technique is a form of participatory monitoring and evaluation. In 2013, disabled and older persons and people with a chronic illness were asked to tell their own stories about what has changed in their life since the start of the Undoing Inequity project (Wilbur, 2013). The informants were encouraged to speak around the topic and were not guided into any specific direction; One MSC story came from Marina in Zambia, a 76 year old women with limited mobility due to old age.



WaterAid/Jane Wilbur ©

*We were happy that this toilet was constructed. It is unfortunate that my husband who was also a beneficiary of the toilet who was disabled passed away.*



Marina's inclusively designed toilet with a handwashing facility outside the toilet

*In 2012 we got involved in this project; we were called to go to Cecelia's place where we were told about the project. I used to go to meetings, contribute to the discussions and decide what can be done to help us have these toilets.*

*The toilet design was constructed in such a way that even my late husband could easily use it. With my old age it was difficult to carry him to the toilet., but it is also for me as I am old. Look at me, my knees are weak. I cannot squat down to use the toilet, but with the support base on the toilet, immediately I sit I can easily use the toilet with no problem.*

*We did not pay money to have the toilet done but my only son who looks after me, had to look for grass and sticks to the thatch the toilet roof.*

*The greatest change the facility has brought is that we are no longer going to the bush to answer the call of nature. We were in trouble then but things are much better now. We have a toilet within our premises which is very pleasing. With the toilet nearby I do not waste time and have more time for my other day to day chores.*

*We have water nearby at the water point though it is quite a distance. We have a cleaning rota, when it is my turn I go to clean the water point. If you go there you will see it is clean and swept.*

*All I can say is that I am very thankful to these children of God; we had huge challenges without water now we are better off. (Wilbur, 2013)*

## National Change

### Uptake in Nepal

The Compendium of Accessible WASH Technologies was in high demand following the 2015 earthquakes in Nepal; copies were distributed to the Global WASH Cluster, with UNICEF being particularly appreciative. WaterAid Nepal used the compendium to inform their design of temporary toilets for displaced persons with disabilities as well as using it for a disability campaign in Kathmandu to lobby for accessible toilet construction after the earthquake. World Vision is using it with HelpAge in Nepal and Tearfund staff have also used it.

### Government uptake in India

WaterAid India has developed a version of the compendium specific to the Indian context on the request of the Government of India; these **accessible household sanitation guidelines** were signed off and endorsed by the government in 2016. All districts in India have been tasked with implementing the guidelines.

### National uptake in Uganda

The Church of Uganda, Teso Diocese Planning and Development Office (TEDDO), one of the implementing organisations in the Undoing Inequity project, has scaled it up to integrate an inclusive way of working into their food security work. The Appropriate Technology Centre, also an implementing partner is continuing to work with WaterAid Uganda on lobbying others to mainstream inclusive services at national and district level. In addition, inclusivity is now part of the WaterAid Uganda country strategy.

## Global Change

### Open access tools

Undoing Inequity produced 17 open access transferable tools for data collection and for process monitoring. These have since been used by WorldVision in Papua New Guinea as well as shared with academic colleagues and DFID. More recently the study findings have been used to write a chapter in a new and important resource for the sector '**Sustainable Sanitation for All: Experiences, Challenges, and Innovations**', which is freely available to download online.

### DFID's Disability Framework

'Undoing Inequity' contributed towards the **International Development Select Committee's (IDSC) recommendations on mainstreaming disability in development**. WaterAid UK gave written evidence that drew on Undoing Equity as well as oral evidence, and shared the compendium as an example of what is needed on the ground (Wilbur, 2015). The **IDSC report** cited statistics from Undoing Inequity. The recommendations from the IDSC report have since been taken up by DFID, who published a **Disability Framework** in

December 2014 (DFID, 2015). This framework demonstrates DFID's commitment to mainstreaming disability in its work and specifically mentions WASH as a workstream.

This framework commits to holding implementing partners to account for disability sensitive programmes in the WASH sector; including making partner governments aware of their responsibility to deliver on their United Nations Convention on the Rights of People with Disabilities (CRPD) commitments and advocating for programme delivery partners to either develop a disability policy or to follow through on their commitments within an existing policy.

### Broad practical uptake in WASH sector

The Compendium was launched on the International Day of Persons with Disabilities in 2014, with initial responses from the WASH sector being extremely positive. The compendium has been shared with key WASH sector actors including [ADD International](#), the [Catholic Agency for Overseas Development \(CAFOD\)](#), [International Institute for Environment and Development \(IIED\)](#), [Leonard Cheshire Disability](#), [Plan International](#), the [Rural Water and Supply Network](#), [Save the Children](#), [Sightsavers](#), [UNICEF](#), [WASH United](#), [Water and Sanitation Program \(WSP\)](#), and [Water Supply and Sanitation Collaborative Council \(WSSCC\)](#).

The compendium has since been used in both development and humanitarian settings and has contributed to providing practical guidance for health workers, community volunteers and WASH practitioners working directly with disabled and older people and their families. It has also been a useful resource to inform qualitative research by academic institutions such as LSHTM.

### Strategic uptake at WaterAid

WaterAid's global strategy (developed in 2015) now has reducing inequalities at its core with equality as one of its four strategic aims (WaterAid, 2015b). Findings and approaches from the UI project were used to internally lobby for this strategic shift. WaterAid has also secured 120,000 USD from the Bill and Melinda Gates Foundation to work directly with LSHTM to develop formative research methods for the WASH sector which ensure the needs of people with disabilities are captured and considered in programme designs.

### Moving towards leaving nobody behind

The advent of the SDGs and move towards a rights based agenda which leaves nobody behind has presented new opportunities to integrate disability. In 2016 WaterAid UK drew upon the Undoing Equity findings to collaborate on the Big Lottery's new strategy; sharing experiences around mainstreaming quality and inclusivity across their work.

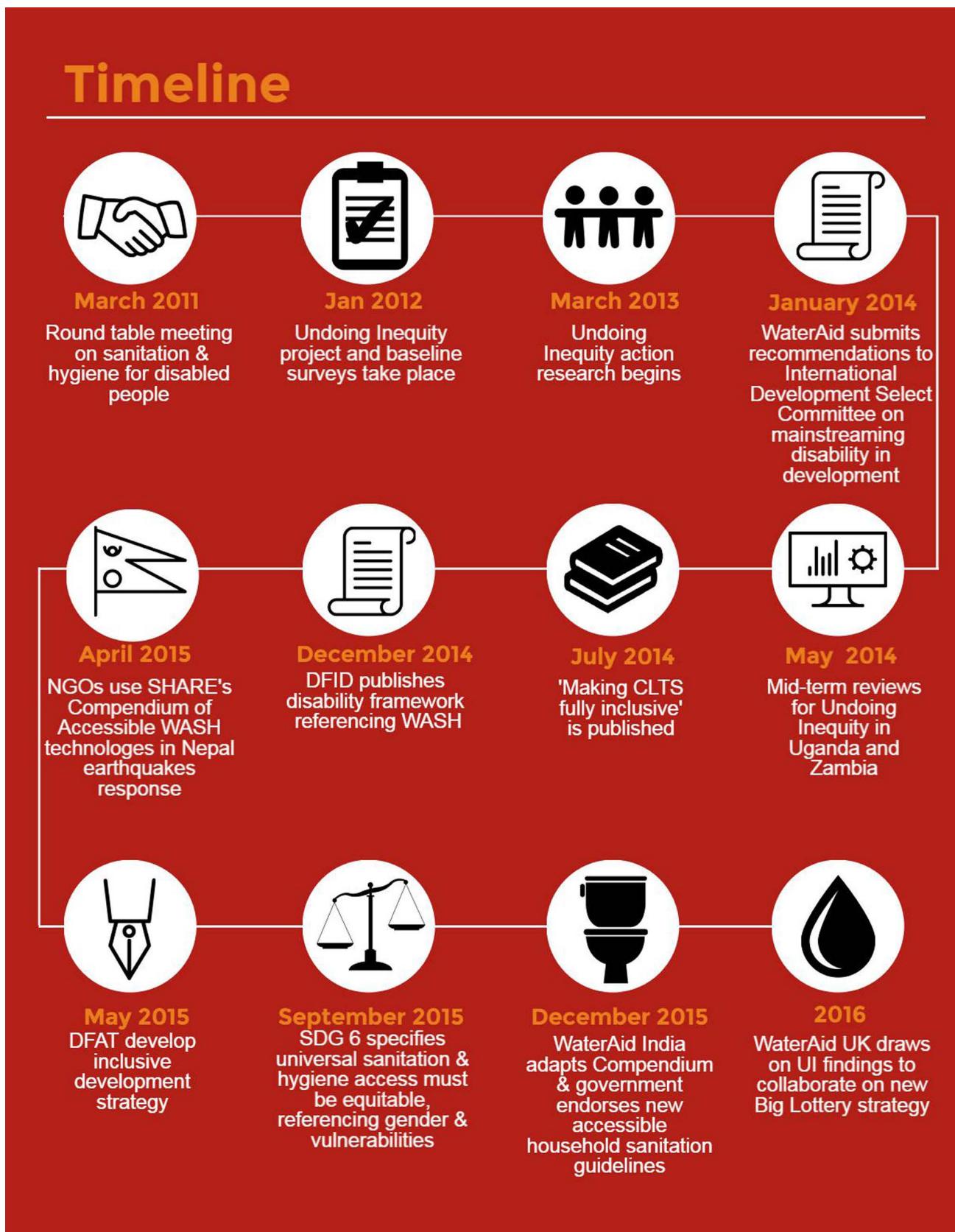


Figure 4: WASH and inequalities

## Contribution to Change

SHARE, in partnership with WaterAid, played a strong role in contributing towards the national and global changes detailed here. SHARE funded the Undoing Inequity project which produced several key outputs - the compendium, open access tools, online resources - these resources have since had wide ranging reach in Nepal, India and Uganda. SHARE's partner WaterAid played an important role in ensuring uptake at the national level through advocacy work as well as working with other implementing partners on the ground. Uptake in India can be linked very closely to the original SHARE funded work in Zambia and Uganda as the compendium resource was later adapted for the Indian context; SHARE's partner WaterAid worked closely with the Government of India to adapt this resource.

Undoing Inequity was also a key source of evidence for WaterAid's contribution to the IDSC recommendations to DFID, with statistics cited in the [final report](#). The fact that WASH was specifically included in DFID's Disability Framework demonstrates the extent to which our research influenced DFID: it will be of interest to see how this translates into DFID's operations globally and we look forward to future DFID publications on the implementation of their disability framework.

## Other contributions

SHARE contributed to the specific changes mentioned above but there are also other broader developments relating to WASH and inequalities which SHARE was not involved in. These may have helped enable a supportive environment which allowed SHARE to make progress and to influence others.

One key contributor to this positive environment is the development of Sustainable Development Goal 6 and the SDG focus on leaving nobody behind. Donors have an increasing interest in this topic (for instance AusAid has developed an inclusive development strategy and funded an inclusive WASH learning portal as well as several projects); most likely in part due to the development of the SDGs. WaterAid has played a leadership role on this topic but other NGOs have also shown an increasing focus on diversity and have been seeking to mainstream vulnerabilities such as gender and disability prior to the SDGs (WaterAid, 2012).

## Embedding and Sharing Learning

Undoing Inequity asked staff to 'do things differently' from the outset and to monitor what was done differently and what this meant in terms of additional time or human resources. This approach sought to capture and disseminate learning throughout the project. The process review captures recommendations for inclusive WASH and learning points for other organisations who are trying to mainstream a new inclusive approach (Wapling, 2014).

The design of the compendium aimed to mirror the inclusive approach and principles of the project itself in order to be transferable, relevant and have a global reach. The compendium can be used independently in multiple contexts without explanation or training and it seeks to foster learning through providing how-to guidance on simple tools including accessibility and safety audits, power analysis and barrier analysis.

Another useful output for learning was the development of the Mainstreaming Continuum tool which can also be applied to other parameters of inequalities, including those based on gender, caste, religion and health conditions (Jones, 2013). This continuum is a useful way for organisations to conceptualise the stages along the journey to mainstream equality and inclusion. It can be used to plan, resource and monitor progress. It has since been taken up in various ways including feeding into a [UK NGO workshop](#), and being applied in a World Vision India evaluation, as well as global WaterAid Equity and Inclusion reviews.

Learning from the project has also been shared at a variety of formal and informal fora; most notably at the SHARE-convened '[Addressing Equity in the Water, Sanitation and Hygiene sector](#)' session at Stockholm World Water Week (September 2014), a lunchtime capacity development seminar at WaterAid (February 2015), the 2015 European Development Days conference (June 2015), at the 38th WEDC International Conference (July 2015), and at a brownbag event for DFID's Disability and WASH teams.

## Lessons Learnt

1

### Dedicate funding and human resource in order to innovate

Undoing Inequity provided an opportunity to delve deeply into understanding barriers for disabled people. Dedicated funding and resources for innovation allowed the project to be responsive and to generate learning. For example, repackaging of evidence in different ways to suit the needs of diverse audiences - from WaterAid Uganda using the findings in policy and advocacy campaigns to featuring the findings in the *Guardian* newspaper and on Twitter.

Being able to fund a launch event was also an important contributor towards the compendium's success and broad uptake; launching the compendium at a workshop on mainstreaming disability created a space for sharing learning, asking questions and exchanging experiences

2

### Ensure there are sufficient resources dedicated to capacity development

The Undoing Inequity process review noted the challenges around transferring principles relating to rights, inclusion and vulnerability into practice. Non-discrimination and disability awareness can be a completely new way of thinking for people to adopt and understand, sometimes requiring people to question their own assumptions and pre-conceptions before they can effectively encourage others to be more inclusive.

Building greater confidence in national staff through training and the provision of local language materials before the research began could have given the project a stronger starting point and enabled national staff to feel more confident about sharing their experiences and evidence with stakeholders throughout the study.

3

### Understand the problem before you find the solution

The project team noted that it would have been difficult to avoid the issues around capacity development given that Undoing Inequity was primarily a learning project to understand these gaps. This meant that setting clear guidance on how to put principles into practice at project inception would have been challenging due to a limited initial understanding of national attitudes and knowledge about disability and inclusion.

The project PI noted that:

*You can't understand the solution before you understand the problem, you need to go through a process to get there.*

## Value for Money and Estimated Reach

SHARE invested £119,410 into WASH and inequalities, with the majority of that funding going on research. Capacity development funding included an initial kick off meeting to develop the proposal and a technical training course on equitable access to WASH. While this was just 1.19% of the total SHARE Phase I budget, there is a high estimated reach of indirect beneficiaries (Table 3) and the work contributed to complex national and global changes.

It is also important to note that an increasing consideration in Value for Money (VfM) analyses is equity; this should be considered as important as effectiveness, economy and efficiency (Bond, 2012). Equity is enshrined in the SDGs commitment to leave nobody behind. The Undoing Inequity project intentionally targets people with disabilities and puts equity at the forefront of its work. Bond note that equity is a core component of VfM and is necessary to maximise intervention effectiveness through including those who are most marginalised (Bond, 2016).

Table 3 suggests the reach of SHARE's work on WASH and inequalities; this is indicative and represents complex social change which SHARE's work may have contributed towards. It only includes global or national changes where enough data was available to make assumptions.

If SHARE's interventions prove to be successful and are replicable across other contexts, then there is the possibility for many more people to benefit in future.

Table 3: Estimated reach of Undoing Inequity

Uptake	Direct Beneficiaries	Indirect Beneficiaries	Practitioners /donors	Assumptions
WASH and inequalities knowledge sharing events			324 attendees at SHARE knowledge sharing and capacity building events on WASH and inequalities since 2010.	This figure is based on the average number of attendees per SHARE event multiplied by the number of actual events on this theme (7), as detailed event attendance data is not available for each event.
Project level in Uganda and Zambia	<p>UI involved 372 households (203 controls, 169 cases) with an average household size of 5.8 (approximately 2,159 people) across Uganda and Zambia.</p> <p>This included 169 disabled, chronically ill and older household members.</p>	<p>WaterAid reached 288,000 people with sanitation in Zambia and Uganda between 2012 - 2014 (WaterAid, 2015a)</p>		<p>In Zambia, WaterAid reached 57,000 people in 2013-2014 and 42,000 people in 2012-2013 with sanitation (WaterAid, 2015a).</p> <p>In Uganda WaterAid reached 87,000 people in 2013-2014 with sanitation and 102,000 people in 2012-2013 (WaterAid, 2015a).</p> <p>We assume that WaterAid's sanitation work in Zambia and Uganda continues to incorporate learnings from Undoing Inequity and is inclusive of those people with disabilities.</p>

Uptake	Direct Beneficiaries	Indirect Beneficiaries	Practitioners /donors	Assumptions
Uptake in DFID disability framework	DFID's integration of disability and WASH across its portfolio had a potential reach of 1.88 million people in 2015.	Between 2011 - 2015, DFID reached 62.9 million people with WASH (ICAI, 2016).	Approximately 15% of the world's population experience some form of disability and prevalence of disabilities is generally higher in developing countries (WorldBank, 2016).	12.58 million represents the number of people DFID reached with WASH in 2015 (assuming that DFID reached a similar number of people each year).  15% of this number is 1.88 million people. This is a conservative estimate that does not account for potentially higher prevalence of disabilities in developing countries.  We also make the assumption that disability considerations were integrated across DFID's WASH programmes globally in 2015 (the Disability Framework came into use in late 2014).

Uptake	Direct Beneficiaries	Indirect Beneficiaries	Practitioners /donors	Assumptions
Uptake of compendium in India		Wide potential reach but given the early stages of the work it is too soon to know the breadth of uptake.		<p>21 million people in India were identified as having some type of disability in the 2001 census and this number has likely grown since then given India's population growth (IndiaCensus, 2001).</p> <p>Implementation of the household sanitation guidelines has the potential to reach this group in future.</p> <p>We assume that census data is representative and that the guidelines will be implemented in future.</p>
Total	2,159 direct beneficiaries	2.16 million potential indirect beneficiaries	324 practitioners and donors	

## Next Steps

WASH and disabilities is a growing area of research and this is now being continued beyond the SHARE consortium. For example, researchers at LSHTM are collaborating with other partners with **WEDC, Mzuzu University** and the **Centre for Social Research, University of Malawi** on an **Australian Department of Foreign Affairs and Trade (DFAT)** funded study. This study aims to establish the prevalence of WASH access problems among people with disabilities in Malawi through a large scale quantitative survey. Through qualitative and quantitative analysis, the study explores what kind of barriers (e.g. environmental, institutional and attitudinal) prevent current WASH access.

The research found over 50 barriers which differed from person to person according to gender, level of education and whether participants lived in an urban or rural area (White et al., 2016). The findings from the baseline quantitative survey and the qualitative research will now contribute to the development of a specialised training for Community-Led Total Sanitation (CLTS) implementers. The effectiveness of this approach for inclusive CLTS programming has been evaluated through a randomised controlled trial in Northern Malawi and results/publications are expected by 2017.

**LSHTM's Disability Centre** is currently analysing survey data from four countries (Bangladesh, Cameroon, India and Malawi) to better understand the prevalence and nature of WASH access for people with disabilities, with findings expected in 2017. This will add to the work done by SHARE in Uganda and Zambia, and will help to expand the body of evidence to other contexts.

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## Building knowledge. Improving the WASH sector.

The Sanitation and Hygiene Applied Research for Equity (SHARE) consortium seeks to contribute to achieving universal access to effective, sustainable and equitable sanitation and hygiene by generating, synthesising and translating evidence to improve policy and practice worldwide. Working with partners in sub-Saharan Africa and Asia, two regions with historically low levels of sanitation, SHARE conducts high-quality and rigorous research and places great emphasis on capacity development and research uptake.

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 @SHAREresearch

SHARE Consortium  
London School of Hygiene & Tropical Medicine  
Keppel Street  
London  
WC1E 7HT, UK.

Tel: +44 (0)20 7927 2301  
Email: [contactshare@lshtm.ac.uk](mailto:contactshare@lshtm.ac.uk)

### Partners



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