

The challenges of translating the women's group Participatory Learning and Action Cycle from multiple low-income countries to the UK NHS context, using nutrition in infants of Bangladeshi origin in Tower Hamlets as an exemplar.

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I, Jennifer Shona Martin confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Jennifer S. Martin, November 2020

The views expressed are those of the authors and not necessarily those of the NHS, the NIHR CLAHRC, the Department of Health or the UCL Great Ormond Street Institute of Child Health.

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For Val.

I dedicate this PhD thesis to Professor Val Curtis, Director of the Environmental Health Group at London School of Hygiene and Tropical Medicine who sadly passed away on the 19th of October 2020. Professor Curtis was my Supervisor and Mentor during my master's at the London School of Hygiene and Tropical Medicine. Without her, I would not have explored health behaviours and women's empowerment, I would not have travelled to Zimbabwe, and I would not have pursued a PhD.

Thanks, Val.

Abstract

Background

There is a need for cost-effective and adaptable health interventions to address complex issues within the UK National Health Service (NHS). Reverse innovation in public health is the process of adapting health interventions developed in low-income countries (LICs) and implementing them in high-income contexts (HICs) (1). This process is gaining traction in global health as a means of offers knowledge sharing between the global south and the global north.

The adaptation of interventions from one context to another is ubiquitous and necessary, but the process is often unrecorded. There is a tension between fidelity to the intervention and adaptation to the specific needs of the target context and a heterogeneous population. In the UK, ethnic minority groups in particular experience disproportionate levels of obesity, type 2 diabetes, cardiovascular disease and micronutrient deficiencies compared with the majority White European-origin population (2), and current NHS services are unable to address the increasing rates of nutrition-related ill-health in these populations. Furthermore, there are inconsistencies in the effectiveness of NHS interventions in minority ethnic groups and there is a risk of intervention generated inequalities.

Adapting interventions that have been subject to reverse innovation could increase intervention effectiveness in their new context. The aim of this thesis is to present a framework that supports the theoretical adaptation of one such intervention, the women's group Participatory Learning and Action cycle (PLA cycle) (3) using the Nurture Early for Infant Nutrition (NEON) study (4) in the Bangladeshi population of Tower Hamlets as an exemplar. The framework is intended for multiple policy, practice and research benefits. Failing to follow a framework for implementation could lead to an unsuccessful intervention (5).

Methods

This thesis employed a qualitative research design across two studies:

1. The principles of how the women's group PLA cycle was adapted in practice were captured through Study 1. This study explored the process of adaptation to the women's group PLA cycle across the original seven cluster randomised controlled trials (RCTs) in Bangladesh, India, Nepal and Malawi through 14 key informant interviews.
2. Study 2 determined the specific contextual adaptations that could address the acceptability and feasibility to the women's group PLA cycle through focus group discussions (FGDs) with individuals of Bangladeshi-origin from Tower Hamlets.

All data were subject to the Braun and Clarke (2006) guidelines to thematic analysis (6).

Results

The key informant interviews generated data that resulted in an outline of a generic theoretical adaptation framework. The framework includes components requiring fidelity and those requiring subtle adaptations. The four-stage framework detailed a preparation phase, the process of adaptations and highlighted a specific set of micro-adaptations that can be adjusted to emulate local context.

The FGDs aimed to address the micro-adaptations that were suggested by the key informants. They showed a paradoxical relationship between the participants' Bangladeshi heritage and their lived environment. There were specific differences between individuals who had been in the country for less than three years, those that had been in the country for more than three years, and those that had been born in the UK but whose parents were from Bangladesh.

Discussion

The women's group PLA theoretical adaptation framework is the first attempt to create a formal adaptation structure for the PLA cycle which is also relevant to other participatory intervention paradigms. The framework was developed in the context of a wider study about reverse innovation of the women's group PLA cycle model but would also be relevant to any situation where a participatory intervention is being adapted. Relatively few studies have previously considered the macro policy and political context as a influencers on adaptation processes for health interventions, although this is well characterised in implementation literature (7).

Recognising the inherent differences within the Bangladeshi population of Tower Hamlets could allow the women's group PLA cycle to be adapted appropriately by the NEON study. I believe it is important to adjust the micro-adaptations to encompass both areas of the population's identity - heritage and environment. This has implications for other interventions that are looking to culturally adapt their interventions for minority populations in the UK.

Conclusion

The theoretical adaptation framework for the women's group PLA cycle is new to the innovation literature, because they outline areas to consider when an intervention developed in a LIC is undergoing reverse

innovation. Strength lies in the homogeneity of experience of the key informants, meaning that data had less ‘noise’ in terms of the actual intervention itself. This thesis has constructed a theoretical framework that could potentially assist other researchers with the adaptation of the model into their HIC context.

Impact Statement

This research has implications for the way we inform intervention design by demonstrating that, with adequate adaptation, evidence-based interventions developed in LICs. have the potential to be implemented in HICs. My PhD research has made a contribution to the adaptation from LIC to HIC by providing a robust framework. Specific adaptations have yet to be tested using this tool by the NEON project. This framework will allow others to adapt the women's group PLA cycle using a formulaic approach so that adaptations to the intervention do not affect the fidelity of the evidence-based model. Furthermore, it highlights the need for formative research to inform adaptations so that the social nuances and cultural stipulations of the target population are fully captured in the adaptations. Heterogeneity exists in most populations; however, there are still commonalities that bind them. Understanding these aspects can help us determine how and why to adapt interventions. Incorporating adaptations that recognise differences in the culture and/or environmental facets should increase the uptake, retention, sustainability and continuity of adapted interventions.

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Patient and public involvement

Data were collected directly from professionals and the public. This PhD research focused on the adaptation and implementation of the model from the perspective of professionals and hypothetical context specific adaptations with the target population. Both the NEON study steering group and the NEON study community facilitators workshop had public involvement.

Ethics

No NHS Research and Development ethics were required as this PhD research did not recruit through the NHS. Institutional ethical approval at University College London was mandatory. Approval for key informant interviews carried out during study 1 (section: 5) was granted by the chair of the University College London Research Ethics Committee on the 23rd of September 2016, application number 9619/001. Approvals for the focus group discussions (section: 7) were granted on 11th April 2017 by the full University College London research ethics committee, application number 10653/001. Participants signed a consent form before interviews and agreed for these to be recorded, transcribed and anonymised. Some participants gave online consent before completing their interview via Skype.

Acronyms

APPS – African Partnerships for Patient Safety

BADAS – Diabetic Association of Bangladesh

BEACHes – Birmingham Healthy Eating and Active lifestyle for Children Study

C-BIRD – Community-Based Integrated Rural Development

CCG – Clinical Commissioning Group

CHW – Community Health Worker

CLAHRC – Collaboration for Leadership in Applied Health Research and Care

GE – General Electric

HBM – Health Belief Model

HICs – High- Income Countries

LEAN – London East AIDS Network

LICs – Low- Income Countries

MDGs – Millennium Development Goals

MIRA – Mother and Infant Research Activities

MMR – Maternal Mortality Ratio

NAFAS – Social Action for Health and the Bangladeshi Drug Rehabilitation Project

NCDs – Non-Communicable Disease

NEON – Nurture Early for Optimal Nutrition

NGO – Non-Government Organisation

NHS – National Health Service

NIHR – National Institute of Health Research

NMR – Neonatal Mortality Ratio

OR – Odds Ratio

PAR – Participatory Action Research

PLA – Participatory Learning and Action Cycle

PMTCT – Prevention of Mother to Child Transmission

PPI – Patient Public Involvement

PRA – Participatory Rural Appraisal

RRA – Rapid Rural Appraisal

SDGs – Sustainable Development Goals

UHC – Universal Health Coverage

UK – United Kingdom

UN – United Nations

VDCs – Village Development Committee

WCF – Women & Children First

WHO –World Health Organisation

Professional Biography

My background is non-clinical public health. I obtained my bachelor's degree in Human Biology, Sociology and Psychology in 2012. My dissertation specialised in health behaviours using the exemplar of malaria in sub-Saharan Africa. During the entirety of my undergraduate period, I was a part-time intern with Greater Glasgow and Clyde Public Health team. I arranged this internship independently and managed rotations around Health Protection Scotland, the Regional Virology Lab, the tuberculous (TB) community nurse, the disability team, and shadowing the Director of Public Health.

After graduation, I spent two years working in the private sector assisting with transformation projects in NHS clinical commissioning groups in London. I then obtained a position with the Health Research and Social Development Forum in Kathmandu, Nepal. I worked closely with the Urban Health team and the policy team, delivering projects such as the piloting of the World Health Organisation's TB Gene X-pert, the review of the Government of Nepal Ministry of Health and Population's health insurance scheme, and the urban health outreach programme that targeted vulnerable populations in the slums around the Kathmandu Valley.

I pursued a masters at the London School of Hygiene and Tropical Medicine, where I specialised in health behaviour and designing interventions based on behavioural drivers. My thesis was supported by Dr Val Curtis and included secondment to Zimbabwe, where I designed and implemented a creative hand hygiene intervention in a paediatric and maternity unit in a government funded hospital in central Harare.

During my time in Zimbabwe, I realised that I wanted to continue in academia to further refine my research skills and support my development as a public health professional. I pursued this PhD opportunity because it was in applied health research at a prestigious institution. I wanted to learn about design and adaptation of interventions, and I wanted to continue to work with vulnerable communities. I wanted to gain particular skills in racial and ethnic minority groups research, in non-communicable disease prevention, and in the UK NHS context. I wanted to further my experience working in multidisciplinary teams with academics, public health professionals and community members, and I wanted to increase my exposure to public health and global health through an academic lens.

During my time as a PhD student at UCL, I have fully engaged with the academic community: teaching on master's courses, presenting at conferences, writing grant applications, contributing to other teams in my programme. I have overcome many challenges, the greatest of which was my own lack of self-belief. This has been my greatest achievement as an academic (so far).

Motivation

There were several factors that influenced my motivation to pursue a PhD research project:

Drive for research: I wanted a chance to focus on a problem that was influencing negative health outcomes in a vulnerable population and apply cutting-edge research techniques to address this problem. I wanted to contribute to advancing knowledge in the area of intervention transferability and generalizability, public health, and adapting potential NHS interventions for ethnic minority groups in the UK.

Enjoying the academic environment: I wanted to work and learn in a world-leading research institute while working in an internationally recognized, integrated child health team within a multidisciplinary team. I wanted to learn from professionals who are leading the field in public health and implementation science. I also wanted to work in applied health research so that I would gain implementation skills as well as further my academic abilities.

Developing important transferrable skills: I wanted to develop my technical and computational skills in the following areas: problem solving and conducting rigorous research; how to work independently and as a member of a team; how to communicate (by writing, by giving oral and poster presentations, by speaking in public); how to meet deadlines; how to manage my time effectively and how to prioritize activities.

Personal motivations: I wanted to prove to myself that I could overcome my own self-doubt about my academic ability and could grow as professional, and I wanted to learn from other professionals who are leading the field.

The Nurture Early for Optimal Nutrition Study (NEON)

My PhD research was embedded within the NEON study. The NEON study was funded by the CLAHRC North Thames and aimed to explore the optimal and sub-optimal infant feeding practices in the Bangladeshi population of the London borough of Tower Hamlets (4). My part in the NEON study was to explore how to adapt the women's group PLA cycle for the Bangladeshi population of Tower Hamlets.

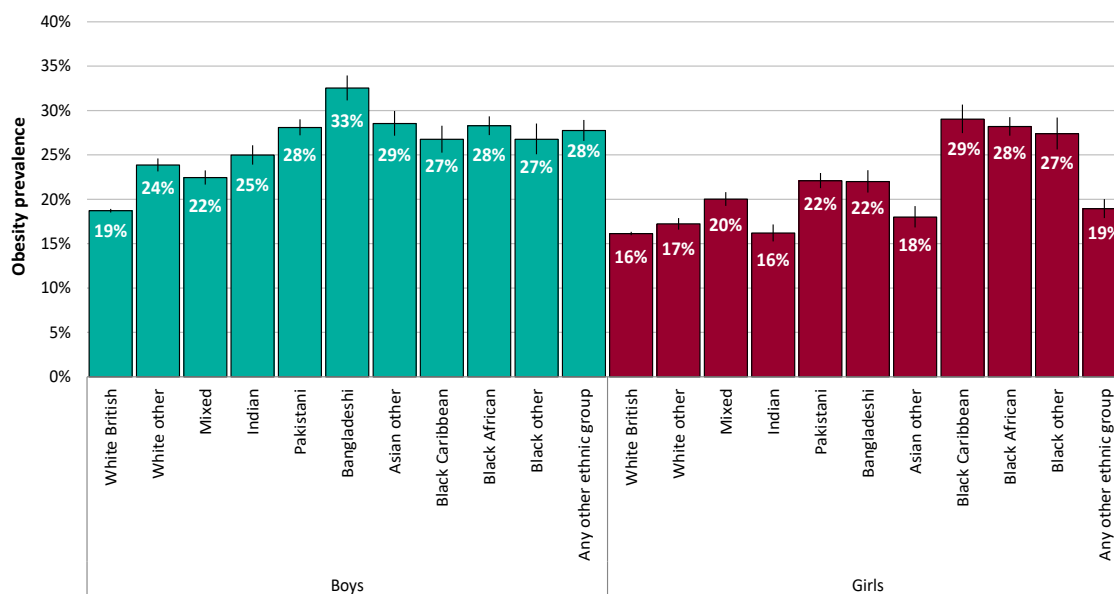


Figure 1: Public Health England Nutrition trends in childhood obesity 2016

The NEON study is divided into five phases (4):

1. Phase 1 involved four systematic reviews that explored infant feeding practices in Bangladeshi, Indian and Pakistani populations.
2. Phase 2 involved discussing infant feeding practices via FGDs with Bangladeshi population of Tower Hamlets and key informant interviews (Imams, heads of nurseries, child health services, child health ambassador, children's centre care practitioners and Mosque women's events managers).
3. Phase 3 involved key informant interviews about infant feeding practices in Tower Hamlets with community children's nurse, general practitioners (GPs), health visitors, pharmacists, midwives and public health professionals.

4. Phase 4 involved key informant interviews with the parents and grandparents of Bangladeshi origin who had an infant below two years old.
5. Phase 5 is to explore adaptations to the women's group PLA Cycle for the Bangladeshi population of Tower Hamlets.

In Tower Hamlets, individuals who identify as Bangladeshi origin constitute 32% of the population (8). The Bangladeshi population of Tower Hamlets has high rates of non-communicable diseases (NCDs) that relate to over nutrition (9) (see Figure 1: Public Health England Nutrition trends in childhood obesity 2016). These NCDs are also increasing among the children of Bangladeshi origin (see Figure 1: Public Health England Nutrition trends in childhood obesity 2016) (9).

Participatory models (like the women's group PLA cycle) involve their target population in the design or delivery of health interventions to ensure that, they are contextually relevant (10). Collaboration, mutual education and acting on the results devolved from the research are the key features of participatory models (11). Mutually respectful partnerships between researcher and the population of interest are important in participatory models (11). This intervention was chosen partly because it had demonstrated success in other settings (section: 4), but also because other participatory models have already shown that they can successfully engage the Bangladeshi population of Tower Hamlets (12). For example, Beck et al., (2005) aimed to develop recommendations for the users and commissioners of sexual health services for the Bangladeshi population in Tower Hamlets (12). They utilised community participation techniques to explore the cultural and contextual taboos around the access to services (12). They assembled a steering group optimising community interests within the project. They demonstrated that, community ownership was optimised by using an iterative approach to data collection which allowed the project to address key issues around the access to sexual health services by the target population (13). With these attributes in mind, the NEON study team appointed a steering panel, recruited community facilitators and employed a co-design method of intervention adaptation and eventual, implementation.

My PhD research was carried out concurrently with phases 2-4 of the NEON study. The insights from my research suggested theoretical adaptations (section 9.2) to the intervention that will be tested during NEON study 2.

1 Introduction

The value of reverse innovation is emphasised in both global health and local community engagement. The benefits of this bidirectional learning partnership have the potential to overcome some of the resource constraints faced by health providers, planners and health systems. Interventions developed in LICs could offer a new and cost-effective approach to current models of care in HICs. To optimise the effectiveness of these interventions, an adoption process should be taken place, which is standardised through the intervention lifecycle (from conception to implementation). This research will explore the concept of reverse innovation in the context of health intervention adaptation. The intervention, which will be adapted, is the evidence-based women's group PLA cycle model (14-20).

The case exemplar for the research is infant nutrition in infants of the ethnic minority Bangladeshi origin population in the London borough of Tower Hamlets. This population was chosen because of their increasingly high rates of cardiovascular disease, obesity and type 2 diabetes (7, 21). The rising rates of nutrition-related ill-health within this population indicate that they may not be responding to current NHS interventions or that they are unable to access culturally appropriate interventions. As the UK becomes more diverse and disease patterns change, there could be greater demand on existing services to provide culturally appropriate interventions to address rising rates of nutrition-related ill-health.

1.1 New approaches are needed to tackle resource constraints and changing disease patterns

Modern global health challenges are complex, multi-faceted and consume large amounts of resources (22). They require an interdisciplinary approach, which considers the whole systems rather than individual problems (22). Worldwide increasing demands for healthcare are transforming the way that health system designers maintain existing services and develop new programmes (23). Consumers of healthcare are petitioning for better quality, evidence-based, affordable and accessible care (24, 25). Global health advisors like the WHO and the UN are encouraging the countries to provide universal health coverage by strengthening current services, re-structuring health governance, improving accountability and legislation, and regulating health services from the private and public sector (25-27). These demands provide increasing pressure on healthcare providers to look further afield for solutions.

Global disease patterns are in transition from high rates of communicable disease to higher rates of non-communicable diseases and this is presenting a contemporary challenge to health systems (28). The growing burden of non-communicable disease includes cardiovascular disease, respiratory disease, obesity, type 2 diabetes and some cancers (29). Nutrition is engaged in a battle against two extremes: under-nutrition affects those that are deficient in calories, and over nutrition occurs when an individual is consuming too many calories leading to obesity (30). Both are classified as malnutrition. Malnutrition is an imbalance in the nutrients, which are being consumed and being utilised by the body (30). All the countries are experiencing a growing epidemic of non-communicable diseases linked to malnutrition (31), and changing economic landscapes and demographic variations mean that, the demand for services is transforming the way health providers address these diseases.

In 2015 the WHO stated that worldwide 39% of over 18 year olds were overweight (32). Between 1980 and 2014, the prevalence of obesity has more than doubled, with 15% of women and 11% of men being diagnosed as obese (32). Obesity is a risk factor for type 2 diabetes and cardiovascular disease, and often has co-morbidities such as micronutrient deficiencies and dental caries (33). Additionally, individuals suffering from these nutrition-related illnesses are getting younger, with 41 million children under five being diagnosed as overweight or obese in 2014 (32). These changes in disease patterns have prompted healthcare providers to adapt to meet new demands on services (3) and look for new models to fill gaps in existing medical professional-led health promotion interventions. Ethnic minority groups in HICs are at higher risk of developing these morbidities than their Caucasian European counterparts, therefore, they are a population of interest for health commissioners (34, 35). Crisp (2015) highlights that, HIC's health systems have the ability to treat nutrition-related ill-health, but they are generally not good at managing chronic illness and have not developed sufficient preventative mechanisms (36).

In global policy, universal health coverage (UHC) is part of the Sustainable Development Goal 3 *Health* (part 8). UHC is currently driving the global health agenda: as of 2018, the United Nations (UN) have dedicated an official UN UHC day (12th December) and UHC is achieved, when each member of the population can access all the domains of healthcare (health promotion, preventative, curative, rehabilitative and palliative services) of sufficient quality to be effective, while preventing the risk of financial hardship to the procurer of the service (37). In order to provide equal access to services the NHS should consider new approaches and/or adapt current approaches to address inequalities in health. With the landscape of health rapidly transforming, however, it is becoming increasingly difficult to provide accessible services to the whole population

Reducing health inequalities is a declared national priority in many economically developed countries (2). The resources needed to address such inequalities in health require adequate finance, structure, and collaboration between many health system actors. Over the next five years the NHS will continue to move into the community care by strengthening primary health care services and supporting allied-health professionals and communities to lead on preventive interventions (38). This is in response to an interest in social prescribing and working with social assets and the third sector (38). In order to optimise the relevance of preventative approaches that are closer to home, we must consider alternatives to the current health professional-led interventions. Community-based interventions have proven a viable alternative in low-income settings; however, the process of implementing such interventions within a trusted universal healthcare system is uncharted. Understanding the future challenges faced by current services helps unravel the contextual influences on health behaviours, barriers to accessing healthcare and limitations of health care providers, which could affect implementation in the UK.

Clinicians and nurses are equipped with skills that allow them to practice medicine universally. The *Brain Drain effect* is an economic theory whereby professionals who possess heterogeneous skills move from one country to another for higher social or economic capital (39, 40). This can either be beneficial or detrimental to an economy depending on the migration patterns of the professionals (39). In health and healthcare, health workers traditionally moved from LICs to HICs, presenting a problem for LICs who were financing the training of these health workers and then losing them to health systems that could offer stronger financial gains (41). Now, with changes to the NHS working policies for junior doctors and the impending Brexit restrictions to European mobility, the migration of health professionals is going to be compromised, with more professionals opting to leave the UK NHS (42, 43).

It is apparent that, the UK will face challenges relating to the provision of healthcare. Crisp et al., (2014) stated – “*health and healthcare are no longer the sole preserve of traditional professionals and health systems*” (44). In LICs the shortages of trained medical staff are prompting not-for-profit organisations and partnerships to explore creative means by using existing pools of knowledge and community resources to address these gaps in services (45-50). The majority of the literature in this area has focused on health worker shortages in LICs, especially in sub-Saharan Africa (51, 52). In the UK NHS, there are severe shortages of health professionals, particularly in primary care (53). The Nuffield Trust report (2014) emphasised that, there are not enough general practitioners (GPs) being trained, more trainees now work part-time, and the existing pool of GPs is under-resourced (53). This

problem is not unique to the GPs or the NHS; other HICs are experiencing staffing shortages, particularly in rural areas as health services become centralised (54-57).

1.2 Health inequalities in ethnic minority groups

In the UK, demands for NHS services are increasing and there is growing awareness of longstanding unmet health needs such as health equity for ethnic minority groups (38). Furthermore, NHS planners are looking forward to redesign healthcare so that the people can get optimal healthcare that is tailored to their needs when they need it (38). Ethnic minority groups in the UK experience disproportionate levels of nutrition-related ill-health as compared to their White European-origin counterparts. Differences in the rates of these morbidities have been reported by the majority of HICs (35). In terms of nutrition-related ill-health such as obesity or cardiovascular disease, the main preventable risk factors are amenable behaviours including physical inactivity and poor dietary choices. Addressing these behaviours therefore represents the focus of most preventative interventions.

The rates of ill-health related to nutrition vary globally based on environmental factors and, theoretically, on genetic ones (58). Migratory populations can be at a higher risk of developing their morbidities due to new environments, genetic predispositions and lack of engagement with health systems (58). Failure to engage these populations in health services poses a risk of inter-generational acquisition of behaviours, which contribute to nutrition-related ill-health (35). This could subsequently create complex disease patterns within the countries of migration (35). Addressing inequalities in ethnic minorities could help countries adjusting to new patterns of disease (58).

There is no specific nomenclature to describe what traits constitute an ethnic minority group in the literature. Villarroel (2018) highlighted the differences in the conceptualisation of ethnicity across Europe and consider this to be a barrier to identifying ethnic inequalities in health (59). Kulatai et al., (2016) suggested that, the constructs of ethnicity are interchangeable based on an individual's personal relationship with their environment and their heritage (60). Both facets can be influenced by culture (60). Challenges in the terminology lie in inequality and racism, so encapsulating the population of interest without including any negative connotations or terminology, which is challenging. Demographic information regarding ethnicity will vary between countries (59).

Country-level policies that group individuals by ethnicity could further contribute how ethnicity or race is conceptualised within a context. In the UK, Bhopal (2009) considers the White population as the ‘majority’ and then differentiates between minority populations based on their country of origin, e.g. Bangladeshi (35), which is challenging because, White is a category of race, not necessarily ethnicity. Ethnicity and race can often be used interchangeably, which can further complicate how ethnicity documented, leading to misconceptions about social norms and values, which could influence health service design.

Sproston and Mindell (2006) described the ‘general population’ as the whole population of England, regardless of minority ethnic group, which fails to distinguish the seven minority ethnic groups on whom the report focuses (61). Fixating on some of the larger ethnic minority populations and collating the smaller minorities into a single group- ‘Other’ (60), may further exacerbate issues relating to designing health services that are tailored to the needs of individuals. The terms ‘Other’ suggests that, the policymakers recognise larger ethnic groups, but not smaller groups, and there is not always an option for mixed race/ ethnic groups. Without nuances related to ethnicity, it may be challenging to design appropriate policy and health services to cater the needs of a population, which is changing and the disease patterns that are also changing as a result.

Individual ideologies relating to ethnicity could also influence how it is embodied within the population. Bhopal (2009) agreed that, ethnic group, country of birth and name are proxy indicators of ethnicity (62), but this may only be relevant to first generation migrants as second or third generation migrants may begin to identify with their environment. This suggests that ethnicity could be fluid and open to interpretation by the individual or the community in which the individual resides. This raises questions about which traits should be accounted for during adaptation and how they should be stratified. For the purpose of this PhD research, an individual, who belongs to an ethnic minority, is considered to be someone, who does not identify with the majority population in the UK.

1.3 PhD Research Aims & Objectives

My approach to this research was built on the assumption that, an efficacious evidence-based intervention which has proven successful in reducing neonatal mortality across multiple cluster-RCTs (3) could undergo theoretical adaptation to produce a set of insights that would allow it to address health disparities in an ethnic minority group in a HIC. I believed that to understand the facets of adapting an evidence-based intervention between two contexts I needed to explore three areas in my

narrative review. In the following section I will present the aim and objectives of this research and how each chapter will address each objective:

1.3.1 Aim

To determine how to theoretically adapt the women's group PLA cycle from multiple LICs to the UK NHS context, using the exemplar of infant nutrition in the Bangladeshi population of Tower Hamlets, London.

1.3.2 Objectives

1. To appraise the term reverse innovation and examine the potential challenges relating to the concept.
2. To determine the theoretical frameworks that support health intervention adaptation in the context of reverse innovation
3. To identify the components of the women's group PLA Cycle that need to be preserved and those that can be adapted to promote contextual fit, and potentially facilitate reverse innovation.
4. To explore how the principles of adaptation were applied during the seven women's group PLA cycle randomised control trials in Bangladesh, India, Nepal and Malawi.
5. To determine how the intervention could be adapted to be acceptable and feasible within the UK NHS context and the Bangladeshi population of Tower Hamlets.
6. To create a generic framework that details the theoretical adaptation process.

1.4 Outline of chapters in relation to the objectives of this PhD research

The following section will describe how and why I chose the areas of exploration for each chapter. This will begin with the narrative reviews, then the qualitative studies, and the synthesis of all primary and secondary data within Chapter 9: Discussion. Objectives 1-4 will be addressed in the narrative literature reviews of chapters 2-4. In these chapters I searched the literature using the criteria from the Identification, Screening and Eligibility phases of the PRIMSA flow diagram. I then critically reviewed and interpreted the literature of the three areas: reverse innovation (Chapter 2); health intervention adaptation (Chapter 3); and the women's group PLA cycle intervention (Chapter 4). The

rationale for the selection of these topics and how they address each objective is explained in the following section.

Chapter 2: Reverse Innovation (section 2) related to objective 1. I chose the concept of reverse innovation because to me it represents a collection of ideas, which highlight the challenges related to the inter-country adaptation of interventions, specifically between LICs and HICs. I decided to conduct a narrative review on the current evidence surrounding the concept of reverse innovation to determine the origins of the term, existing evidence and to help me understand the complexities of the process. I also wanted to consider the challenges to the process, which goes beyond the initial assumption that it is only about moving intervention from LIC to HIC contexts. I thought, it might help me to pre-empt and address some potential cognitive biases from health providers, participants and health systems. I hoped to include these in my theoretical adaptation framework.

Chapter 3: Health Intervention Adaptation in the Context of Reverse Innovation related to objective 2 (determining the theoretical frameworks that support adaptation of health interventions). I explored the literature that supports health intervention adaptation to assess the current theories including adaptation theory and to validate my own assumption, adapting a reverse innovation for context could facilitate its acceptability and feasibility in the new setting. I also believe that context can influence culture, and I wanted to determine if there were any models, which considered the context and culture, particularly for ethnic minority groups. I also wanted to explore how an intervention can be adapted to fit a new context without compromising previously successful intervention outcomes.

Chapter 4: The Women's Group PLA Cycle related to objective 3 (identifying the components of the Women's Group PLA Cycle that need to be preserved, and that can be adapted to promote contextual fit). I started by reviewing current women's group PLA literature to understand which components of the interventions I could adapt, and which must remain un-adapted to maintain the fidelity of the intervention. I also wanted to determine how adaptation had been approached in previous trial contexts, including how adaptation was informed and how it was implemented, and subsequently, how it was recorded. I felt like this would help me to formulate a basic understanding of the units of the theoretical adaptation framework for the intervention that I could build on through study 1 and study 2.

Chapter 5: Study 1 will detail the methods relating to the key informant interviews that will address objective 4 (Explore how the principles of adaptation were applied during the seven women's group

PLA cycle randomised control trials in Bangladesh, India, Nepal and Malawi). I will explore the areas where adaptation occurred in previous trials through in-depth semi-structured interviews with specifically selected researchers, who had experience of developing, delivering and evaluating the adapted intervention for a previous trial context in Bangladesh, India, Malawi and Nepal.

Chapter 6: Study 1 will record the results of the key informant interviews. All of the major themes, which emerged from the data, will be presented in this chapter. These results will be synthesised into a generic framework for the adaptation of the women's group PLA cycle, which will be used to inform the topic guide for the FGDs in Study 2.

Chapter 7: Study 2: Focus group discussions with the Bangladeshi population of Tower Hamlets were related to objective 5 (determining how the intervention could be adapted to be acceptable and feasible within the UK NHS context and the Bangladeshi population of Tower Hamlets). Assisted by the community facilitator from the NEON study, I conducted FGDs with members of the population of Tower Hamlets that identified as being of Bangladeshi origin. This helped me to explore the contextually and culturally appropriate adaptation that need to be applied to the women's group PLA cycle. I then synthesised the results of the three FGDs (2x female participants and 1x male participants) to produce a list of theoretical adaptations to the model for making it appropriate and feasible within this specific context.

Chapter 8: Study 2 will record the results of the FGDs with the Bangladeshi population of Tower Hamlets. The results will be presented in the same format as the Study 1 results in Chapter 6.

Chapter 9: Discussion related to objective 6 (creating a formulaic framework that details the theoretical adaptation process). This chapter of my PhD thesis allowed me to synthesise the concepts from chapters 2-4 and the qualitative studies 1 and 2 to create a theoretical adaptation framework for the women's group PLA cycle intervention. I appreciate that, these adaptations are theoretical in nature, and therefore highlight that, the feasibility and acceptability of the adaptations will be reviewed in the NEON study team meeting and via the NEON study pre-pilot.

The following chapter will explore the concept of reverse innovation in a bid to understand how and why this concept is important to public health during a time, where resources are ever constrained and the challenges in health provision are increasing. With challenges such as global warming and

changing disease patterns, it is potentially time to challenge where innovation emerges and how it is shared around the globe.

2 Reverse Innovation

The underrepresentation of LICs in global health knowledge exchange and leadership means that global health systems could lose perspectives, knowledge and expertise that these contexts could offer (63). In turn, it further limits the ability of HICs health systems to combat changing disease patterns with increasing resource shortages. This lack of representation limits the ability of HICs healthcare providers to deliver for communities and healthcare workers. When the talent, expertise and experiences of LICs are excluded, global, country-level and community-level health programmes could become weaker. In this chapter of my PhD thesis, I represent the concept of reverse innovation in the public health through a narrative review. Through a critical lens, the chapter examines how reverse innovation may be relevant to the individuals, institutions and information and the challenges each might present. I have tried to identify the processes within the reverse innovation literature that could support the adaptation of the women's group PLA cycle and I have also attempted to highlight the gaps in the literature where further research is required.

Chapter aims:

1. To explore the evolution of the concept of reverse innovation
2. To illustrate current examples of reverse innovation and critical assumptions relating to the process of reverse innovation.
3. To highlight the challenges of reverse innovation relating to the individuals, institutions and information.

2.1 The Evolution of Reverse Innovation

Recent years have seen a shift away from the traditional one-way innovation flow from HICs to LICs in global health. These innovations do not always arise from a lack of funding; they can be a result of ingenuity from leadership, management or research teams (12(64, 65)). As population demographics and disease patterns change, there is increasing support for an integrated approach to public health and a demand for equity in global health leadership (66), which involves HICs and LICs learning from one and other. Reverse innovation is the term utilised to describe an innovation, which has been developed in a LIC being implemented in a HIC. Crisp (2015) supported HICs adopting interventions developed in LICs, as he believed that, their community and asset-based approaches offer a different

approach to the NHS health service design (26), which could be beneficial if the NHS are looking to move towards community-led interventions.

This paradigm shift did not emerge from global health; the antecedents of reverse innovation emerged from business management. Immelt et al. (2009) from American multinational corporation General Electric was first to describe a method of learning from LIC product design and engineering sectors (3). It was then popularised by Govindarajan and Trimble in their 2010 book *Reverse Innovation: create far from home, win everywhere*, where they defined it as ‘any innovation that is adopted first in the developing world’ (4). Govindarajan and Trimble described reverse innovation as “revolutionary.” In their notion, they suggest a commercial strategy, which develops the products in LICs at a lower cost and distributes these products in HICs. This strategy of breaking into and developing new economies and disrupting (sometimes known as Disruptive Innovation 2.1.1) could be viewed as a neo-colonial ideology, which further suggests that the only advantage that LICs can offer is low-cost interventions, when they actually could potentially offer new perspectives on existing resource problems (67).

The emergence of the concept of reverse innovation has initiated a discussion about the benefits of mutual accountability and knowledge exchange in global health, one that supports collaboration between HICs and LICs (68, 69). Although this approach may be supported in principle, it does not always translate into practice. In the UK, for example, a mixed method study surveying 14 UK-based leads of the 114 Tropical Health Education Trust (THET)- supported International Health Partnerships stated that 70% of the 34 replies strongly agreed that the sole aim of the HIC-LIC partnership was to support LICs, whereas only 13% strongly agreed that the aim of the partnership was mutual learning(68). This suggests that HICs are still driving the global health agenda through a belief that they alone are leading innovation and supporting LICs. Instead, they could engage in a bidirectional process, which offered mutual learning for both the parties. Nonetheless, confusion could also be ascribed to the inconsistent use of the term reverse innovation in the literature and the way the process is described.

In *Turning the World Upside Down* (5) Lord Crisp suggested that, the NHS should look beyond the UK for health system design inspiration and advocated reverse innovation as a cost-effective means of addressing some of the NHS’s resource constraints. The term *Turning the World Upside Down* also suggests that innovations flows from the global north to the global south in a unilateral pattern (70). This unilateral movement and assumptions that innovation flows in one direction is confusing,

because by Crisp's (2014) definition, the global north includes countries in different hemispheres such as parts of Europe, parts of America, Australia and New Zealand (44). Furthermore, as new economic powers like India and China emerge, and their health and social care infrastructure potentially changes due to increased investment, it will be even more challenging to define if reverse innovation is occurring or not based on the innovation's country of origin.

Since 2014, Crisp has changed his stance on the term reverse innovation and *Turning the World Upside Down*, suggesting that the word 'reverse' makes the concept sound patronising (5). He now supports the idea that innovations can emerge from non-traditional settings and suggests that 'global sourcing of innovation' is a more appropriate term to describe the flow (23). However, the word non-traditional still implies that traditionally innovation would emerge from a HIC and it could be argued that the connotations of 'global sourcing of innovation' are similar to reverse innovation. The challenges of defining this concept could potentially be rooted in traditional power dynamics in global health, whereby HICs harbour the money and therefore, often drive the global health agenda. This will be discussed later in this chapter.

To help my understanding the concept of reverse innovation, I explore some of the concepts that have contributed to its evolution, including a short study on the term's disruptive innovation and frugal innovation.

2.1.1 Disruptive innovation (2003)

Disruptive innovation and frugal innovation often feature alongside the term reverse innovation in the literature (9-19). Clayton et al. (2015) described disruptive innovation as the process, where smaller companies with fewer resources are able to challenge larger incumbent companies by producing quality products, which further address that gap in the market with higher functionality and at a lower price (18), but it is also used to describe new products or processes, which are introduced into a market and cause rapid change.

Disruptive innovation was developed by private sector engineers and product designers as a strategy to break into emerging markets (14). These emerging markets offer new opportunities due to their large size, growing demands and their abundant source of research and development aptitude (10).

The term disruptive innovation is often utilised to describe a company which destabilised previously successful strategies, technologies or designs in industry by introducing new products (16, 18, 19).

Disruptive innovation champions accessibility, affordability and responsiveness, and optimises capacity (17, 18). An example of the application of disruptive innovation is the promotion of a paradigm shift in the delivery of education in school in the United States by Christensen et al. (2008) (17, 20). Christensen et al. (2008) reported that, in America, the education system is underfunded, outdated and in need of reform (17). It has presented a need to make education more intrinsically by engaging but also affordable. Christensen et al. (2008) suggested that, the use of information technology in the American school system could update the current school system, 'disrupting' the current system. This is an example of where a new 'product' was added to change the market, in this case delivery of education.

Although a little dated, the Christensen et al., (2008) example demonstrated how new technology can disrupt old systems of education delivery (71). This process, however, is not straightforward, as different innovations required different strategies for introducing it into different markets (18, 19) and this adds further confusion to the concept and makes it challenging to define what the process of disruptive innovation.

It demonstrates how there can be resistance to change, but ultimately disruptive innovation has the potential to be adopted by a wider system. Reflecting on this example twelve years on when most people and schools, at least in the global north, have access to technology, and it demonstrates that, innovation can be adopted, integrated and accepted by the wider system. This innovation was adopted by the education system in the U.S which potentially offers some evidence that formal HICs systems, that are resistant to change, can adopt innovations if implemented effectively.

2.1.2 Frugal Innovation (2010)

Frugal innovation, like disruptive innovation, is sometimes considered the predecessor to reverse innovation, and this can cause confusion between the two terms. Harris et al. (2016) suggested that, in health circles, reverse innovation is synonymous with frugal innovation, co-development and trickle-up innovation (12). The literature often described the process of frugal innovation as LICs manufacturing designs from HICs for less money exporting them to HICs (9-14, 26,(72)). Bhatti

and Ventresca (2012) expand on that description by suggesting that, frugal innovation is a broad term encompassing a group of activities, which lead to effective and functional solutions to common problems encountered by ‘the many’ with a minimal use of resources but with no description of the context in question (11).

Although frugal innovation and reverse innovation are entirely different concepts, the two terms can be used interchangeably. The two concepts are interconnected because an innovation that is subject to reverse innovation could first be created as a frugal innovation, Frugal innovation, however, do not just emerge from LICs, they can emerge from any context that is experiencing resource shortages (72). There are similarities, as both are trying to optimise resources in resource constrained settings. According to Brem and Ivens (2013), frugal innovation and reverse innovation have the potential to markets to improve both their sustainability performance and their market performance through promotion of cost-effective product development (73). However, Agarwal and Brem (2012) reviewed frugal innovation as designing solutions specifically for low-income market segments, whereas reverse innovation involves new products developed in emerging markets undergoing modification for sale in developed countries (10). Questions arise as to whether products designed in and for a LIC could effectively transition into HIC markets and if they would be accepted by consumers in HICs.

Packaging a product of a programme as ‘frugal’ could indicate cost effectiveness and Bhatti et al. (2017) suggested that ‘frugal’ can make it more appealing to health commissioners who are looking to provide health programmes on a reduced budget (22). Bhatti et al. (2017) suggested that, more efforts are needed to rise funding, particularly for frugal innovation. Their article demonstrates the strengths of frugal innovation including increased inspiration and relevance of these innovations to the context, but these are frugal innovations developed for the context in which they are developed. It could leverage reverse innovations by using the term frugal innovation within the NHS context where high-quality traditional health professional-led healthcare, although paid through taxes, is free at point of delivery anyway.

The limitations of the terminology relating to reverse innovation are complex because there are so many interchangeable terms used to describe the process (74). For example, reverse innovation can be described as disruptive (75), but disruptive innovation differs from reverse innovation in that it promotes a modification of unpopular programmes that already exist to maximise the potential of the system, product or technology (21). There is no flow of knowledge in or between different contexts in disruptive innovation. However, conceptually, reverse innovation and disruptive innovation promote

introducing innovations into systems to address resource shortages. Yet there are other concepts, which further describe knowledge exchange and learning between countries, for example, bidirectional learning. Bidirectional learning is described as a mutual learning process between HICs and LICs (23(76)). In the literature in relation to academic programming, this process primarily focused on academic institutional partnerships and models of learning for the classroom (71). Creating a formal taxonomy or more detailed typology could help overcome challenges that may have confused the debate (77).

For the purpose of this thesis, the term reverse innovation, based on the evidence, it was the most frequently cited term in the literature (10, 12, 25, 28, 31, 32, 37-44), but the term also highlights the inequities within global health, not just in how innovation flows, but also in who is leading it. It captures the perception and certainty that innovation always flows from the global north to the global south. This is another example of the power differential between HICs and LICs in global health. It demonstrates that there is still a power imbalance between HICs and LICs when it comes to who leads and controls global health. Until this power imbalance is addressed, the term reverse innovation will serve as a reminder that we need to work within individuals, institutions and information services to overcome preconceptions about who is leading the field. Furthermore, the use of the term ‘innovation’, which is often synonymous with a new or expensive product, can cause confusion, because the interventions that are subject to the process are evidence-based interventions that may be already be embedded within a LICs (74). It raises the question if this term is solely for HICs, as the innovation may be new to them, but not new to those that have implemented it within the LIC context.

The potential benefits of reverse innovation have caught the attention of actors within global health, particularly those that are interested in global knowledge exchange. Unlike the concept described by Immelt (2009) (78), in global health it refers to the process of HICs learning from policies, practices and programmes that have been developed in LICs (79). This process can be adopted by all of those within the global health community including governments, multilateral organisations, academic institutions and individuals (70).

There is scope for reverse innovation to be successful because it could offer the best of both contexts; HICs have cutting edge science and technology, as well as the resources to implement clinical trials and monitor and evaluate RCTs; and LICs have a large market size and fewer restrictions, allowing these markets to leapfrog innovations because they do not need to be integrated into the current system (6).

2.2 Examples of reverse innovation

The UK provides UHC to the population through the NHS, and users are accustomed to receiving what they believe is the most appropriate care through traditional NHS programmes. The NHS is unsustainable and needs to explore alternatives if services are going to continue to deliver the quality of care that its users have grown accustomed to (41). LICs innovate due to necessity, whereas in the UK the term innovation is often linked to cutting edge technology. Despite there being different cultures, health systems and contextual drives, LICs could still offer viable alternatives for the NHS setting.

Several papers have identified specific interventions that show potential for implementation in HICs (3, 24, 28, 34, 41). The following section describes two innovations, which have been identified for reverse innovation into the NHS context. The two innovations focus on social support and are community-led and health professional supported interventions that have emerged from LICs. One is a surgical tool that is being trialled as an alternative to costly implements. All three are cost-effective alternatives to current NHS models.

2.2.1 Brazilian Community Health Worker Model

The Family Health Strategy in Brazil employs Community Health Workers (CHW) to deliver free point-of-care healthcare to around 54% of Brazil's population (41). Since its implementation in 1994, the Family Health Strategy has been shown to significantly reduce infant mortality (45), improve screening uptakes, breastfeeding practices and antenatal care attendance, and lessen reported mental health problems (46). It has reduced the late presentation of illness at tertiary care facilities due to availability of primary care (47). Inequalities are further exacerbated by the uneven distribution of the health services between low-income and high-income localities (41). The programme aimed to switch the provision of healthcare focus from curative and reactive services to proactive, personalised, household/community-based health promotion (41). The model demonstrated improved health equity and also decreased the deficit between low-income and high-income households in the Brazilian context (48).

In a descriptive study, Johnson et al. (2013) suggested that, the CHW primary care strategy could undergo reverse innovation and be applied to a community in North Wales (41). Johnson et al. selected North Wales as a potential recipient of the Brazilian CHW model because there are notable health inequities in this region of the country and the strategy had already demonstrated that it could work across traditional boundaries of healthcare, it had proven scalability, and it could be a potential alternative to current fragmented vertical NHS health programmes (41, 49).

The Brazilian CHW North Wales model did not receive further funding and was not piloted in Wales. Johnson et al. suggested that this was due in part to remaining scepticism around the feasibility and acceptability of the model from funders and health providers around implementing health interventions developed in LICs in HICs (41). Whilst efficacy is necessary, it only demonstrates intervention success in trial settings (50). This further suggests that the value of translating interventions between LICs and HICs might not be recognised at a funder level, constituting a problematic barrier in the development cycle. This particular case study recommends how to make innovations ripe for adoption and demonstrated that reservations could occur at the individual, population, health facility and policy level. Johnson et al. continue to say that novel opportunities must be created to test the feasibility of interventions from LICs to the UK context so the NHS can achieve similar success (41).

2.2.2 The Arbutus Drill Cover System

In the UK, there is a need for affordable surgical instruments to address morbidities relating to an increasing burden of chronic disease(80). The rates of musculoskeletal disease and a need for orthopaedic care, for example, are on the rise in the UK, and it is a leading cause of clinical and economic burdens on the NHS (52). Additionally, the surgical power tools that are needed to perform orthopaedic surgery are expensive and, given the resource shortage within the NHS, would benefit from the introduction of a low-cost alternative (52).

The Institute of Global Health and Innovation collected innovations from LICs that have the potential to be integrated within health systems in HICs (81). They then narrowed it down to specifically focus on which innovations could exercise ‘frugality’ (acceptability, affordability and adaptability) for the UK NHS (82). They identified the Arbutus Drill Cover System as a potentially viable and cost-effective innovation that could be piloted in the NHS.

Originally from Malawi, Arbutus medical is a company that focuses on creating low-cost, sterile, effective and globally available surgical instruments. Their drill cover system uses a sterile cover to adapt commercially available power drills for use in a surgical environment. In 2014, the company was awarded funding by Grand Challenges Canada for the research and development of various products including their sterile drill cover. The company's products have enabled surgeons to treat an estimated 36,000 patients in 32 countries and it has a goal to reach 50,000 patients in 2019 (52).

In an exploratory study, Prime et al. (2018) developed insights that would indicate whether or not the Arbutus Drill Cover System would be a viable alternative to current NHS surgical power tool systems (82). The research team conducted key informant interviews via telephone and face-to-face with the founders of Arbutus Medical to unpick the innovation process. The team also analysed information relating to the testing of the drill cover system, feedback loops and iterations of the product. They also examined the regulatory approval process and visited three hospitals where the system was in use in Uganda and Kenya. Their insights suggested that the Arbutus Drill Cover System could be a cheaper alternative to current surgical drills being used in the NHS with savings of up to 94% - with current surgical power drills costing over £115million, the Arbutus Drill Cover System could reduce those costs to £7.5million (52). They suggested that the cover system was easy to use - easy to apply to the drill and easily to sterilise post-use. It was therefore easier to adapt drills from commercial use for the surgical environment, saving costs and improving efficiency (82).

The limitations of this innovation were reported to lie in supply chain and procurement (52). For example, it was suggested that, companies that act as a broker between the manufacturer and the NHS may be less inclined to supply lower cost innovations because this will negatively impact their profit margin (82). The only way to overcome this would be to disrupt the process of innovation procurement, cut out the middleman and deal directly with the manufacturers. In my opinion, this could also impact challenges relating to acceptability of a 'frugal' innovation in a HIC health environment, for both health providers and procurers of healthcare (52). If the broker has the choice between selling the most expensive system versus the inexpensive system, they could potentially leverage biases against 'frugal' innovations developed in LICs to encourage a purchase of the expensive product manufactured in a HIC. There is also the potential for there to be variance in the quality of power drill that the Arbutus Drill Cover System is being used on. This may require further testing and regulation to optimise effectiveness and usability in a surgical environment.

Arbutus Medical is working with the Institute of Global Health and Innovation to pilot this system in London hospitals. The drills they are providing are covered by a two-year warranty and the drill covers come with a one-year warranty. They suggest that it needs to be replaced after 75 cycles but didn't indicate how long a standard NHS surgical drill last. There was no indication on how this system would be introduced to the health professionals or the patients. In terms of acceptability, Prime et al. (2018) indicated that, it would be accepted by the regulatory bodies but did not explore how the health professionals may react to what they could view as the NHS trying to cut costs (82). A study into the attitudes of healthcare workers – orthopaedic surgeons and theatres nurses etc - could illuminate any potential challenge to adoption and acceptability of this system with the NHS.

Both of the innovations described have the potential to offer a cost-effective alternative to current NHS interventions, but they could face a number of challenges including getting buy-in from funders, health systems, health and allied health professionals, patients and the public.

2.3 Potential challenges that could influence reverse innovation

Already, reverse innovation has been shown to face particular challenges relating to the inconsistent terminology, the lack of nomenclature, and an innovation's ability or inability to fit into the new context, but there may also be biases relating to traditional views of how information is formed and propagated. In the UK, the usual routes for the piloting and adoption of new innovations are through national bodies, research institutions, local commissioning, special commissioning and professional councils. Therefore, there could also be explicit biases from individuals and institutions when reviewing the research and evaluating programmes, policy or practices flowing from LICs.

These challenges could be considered when the women's group PLA cycle undergoes reverse innovation into the UK context, and give some insight into whether it will be accepted by the Bangladeshi population of Tower Hamlets and what could be done to increase the successful implementation. Further details on each of challenges will be discussed in terms of information, individuals and institutions below:

2.3.1 Information

Information is an intangible asset in global health and provides a comparative advantage to those who possess it. Information exchange in global health is challenging to track because of the heterogeneity of the actors, the composite governance structures and the decision-making relating to the funding. Information in terms of knowledge exchange is an important factor when considering if and how an intervention could be subject to reverse innovation. Understanding the traditional process by which information is generated and disseminated within global health could give insights into some of the challenges that could be faced by reverse innovation.

In a meta review of 64 articles, Asrar-ul-Haq and Anwar (2016) examined knowledge exchange in organisations and suggested that knowledge is an integral part of ensuring continued success of innovation (83). They identified several barriers that could prevent knowledge sharing within an organisation including: lack of trust, interpersonal distrust and intra-organisational knowledge sharing, motivations and reward (83). These barriers can be affected by individual or institutional characteristics, the details of which will be described in section 2.3.3. Additionally, inherent inequalities which can be predetermined by the organisation sharing the knowledge can hamper the flow of knowledge within and out with organisations by encouraging biases about the source of the information.

Understanding the normative flows of information, of which knowledge transfer is one paradigm, could offer some insight into how reverse innovation could be received, viewed and categorised by HICs. Making innovations visible to the global health community is frequently recommended in the literature as a way to support knowledge exchange between HIC and LICs (24, 32, 33, 42, 43, 54), but arguably visibility is not the only hurdle that could be faced by these innovations as they break into HICs (44).

If we consider scientific knowledge as a form of information, the lack of mutual respect and recognition for the strengths and weaknesses of LICs and HICs could be a reason that information is not frequently shared between countries as readily as it could be (84). Yousefi-Nooraie et al., (2006) conducted a study that divided 50 manuscripts into four groups based on their World Bank income criteria (85). They found that manuscripts from LICs were more likely to be subject to manuscript selection bias which they believed was either a product of editorial bias towards LIC research or more stringent application of the guidelines in an attempt to increase the quality of research emerging from

LICs (85). This ideology was further explored by Harris et al., (2015) who suggested that the country where academic research emerges could be a precursor to its quality (86), they suggested masking the country or origin (79). However, this does not address the underlying bias that favours HICs as knowledge brokers and LICs are receivers and it does not account for articles published in non-English languages (87). There is a need to elevate examples of innovative academic research that is emerging from LICs, beyond making space for co-authors in journal articles or in research design.

As global health is such a complex system that includes various disciplines that often work in silos, this attitude could potentially stem beyond academia, to implementation teams or regulatory bodies. Skoptec et al. (2019) highlighted that, each innovation will face its own challenges when it comes to adoption, and that a regulatory body is required to assist with overcoming potential regulatory and community barriers (88). This could be because the individual or committee do not recognise a particular approach or method in the innovation. Arguably, this is not limited to reverse innovations, but could be a barrier for any new approach. It raises the questions around who should be responsible for innovation dissemination or a lack thereof.

The task may lie with academia as they are considered knowledge brokers, but innovation dissemination would value from a bottom-up and top-down approach whereby individuals could be given the information they need by global knowledge brokers to make informed choices about the innovations that are emerging from LICs (84). Knowledge brokers could support this process throughout the system and encourage cross-sectoral learning from different disciplines as well as from different contexts (89, 90).

Potentially, the next step to address the complex interconnected research agenda is to develop a standardised method for reporting the flow of health system benefits from developing to developed countries. Synthesising global knowledge pools and developing a standardised system for reporting the flow of health system benefits from LICs could support reverse innovation of information (29, 32, and 43). A monitoring system for innovation could promote the process; however, it may be biased to HICs, who have better access to technology (23). HICs could focus on improving the acceptance and value of different forms of knowledge from different countries by addressing cognitive biases in individuals and biases perpetuated by institutions where research is conducted and towards the context in which the information on innovation is emerging (40).

2.3.2 Individuals

Individuals can have bias towards the country where an intervention has been developed - akin to the *country-of-origin effect (COO)*. The COO suggests that consumers may judge the quality of a product based on the brand, the design or where it was developed (56, 57). Consumers may consider products that were developed in their country to be more reliable or of a higher quality (58) and may consider HIC or LIC product origins as markers for quality and risk (57). This attitude towards products developed in LICs could limit an intervention's acceptability and adoption by a specific group (91). Negative attitudes towards interventions, research or knowledge that has emerged from LICs could make the process more complex because it is challenging to change values or motivations that are entrenched in multiple individuals (83, 91). Changing the rhetoric around global health leadership could require unpicking the drivers that have descended from colonial rule - values that are still perpetuated by the HIC donors providing funding to individuals from HICs to conduct research or implement programmes in LICs (69).

The term reverse innovation and the mind-set that HICs are the leading health systems, clinical practice and research could be a barrier to the success of reverse innovation in global health (91). Harris et al. (2016), through a qualitative study with US experts in comparative policy analysis, leaders in reverse innovation, and key informants from health and social policy, suggested that the connotations attached to the term 'reverse innovation' could have a negative influence on how the intervention is perceived by these actors (92). They suggested that, this could be down to 'cultural arrogance' and a belief that, the innovations from LICs are being created in health systems that are weaker and less advanced than their US health system (92). Addressing a superficial characteristic like a term is not going to address the power structures which allow HICs to dictate the global health agenda or address these individual cognitive biases demonstrated by the participants in Harris et al's (2016) study (92). Bhatti et al. (2017) highlighted the complex nature of the process of reverse innovation in terms of integrating them into the health system (22) and how this will require acceptance from individuals and address the innate biases that create a dichotomous vision of how knowledge in global health is perpetuated (8).

The term reverse innovation raises potential concerns around ethnocentrism from individuals (8). In the long term, this could be problematic as academics from developing or emerging countries start to study the phenomenon in greater depth. It might be tempting to judge reverse innovation as a nonsensical business term and to use a more positive term to refer to it (35, 59), but that is not addressing the elitist attitudes of some individuals from HICs (92).

2.3.3 Institutions

Institutions could play a large role in setting agendas, disseminating ideas and steering funding. For example, there are many organisations involved in dissemination of reverse innovation via peer-reviewed publications, academic and non-academic research and social media (1, 42, 54, 61), but there is no single institution in charge of the dissemination of innovation. These institutions extend beyond governments and universities to national bodies (e.g., NHS Scotland), non-government public bodies (e.g., National Institute for Health and Care Excellence), disease-specific charities (e.g., Jo's Cervical Cancer Trust), federations (e.g., the World Obesity Federation), movements (e.g., Women in Global Health) and associations (e.g., the Nursing and Midwifery Council). Each of these institutions has a different role in enabling reverse innovation by sharing knowledge from between different contexts, but some of these knowledge sharing activities are potentially underused.

Although there is involvement of these actors at a national level, promulgation of health knowledge is primarily led by international governance bodies such as the UN and its affiliates, and it is sometimes criticised for being too bureaucratic (60). The UN has 193 member states which come together for an annual two-week conference called the UN General Assembly (UNGA) in September. This could be an opportunity to mobilise actors in each member state and utilise the momentum from UNGA to generate interest around reverse innovation. However, there appear to be two challenges that would impede this process:

1. This potential disconnect between the national and global health agendas could present a challenge for reverse innovation as it could reaffirm beliefs that HICs providers should provide for HICs and LICs should provide for LICs.
2. Although reverse innovation is known in management and academic literature, it is not as widely recognised as a potential global health solution; therefore, if federations, movements and NGOs could generate interest around this concept, it may be possible to get it onto the agenda of global events like UNGA.

The UN or an affiliate like the WHO is, by definition, multilateral and can be focused on LICs as it is part of their remit. They could create focal points (e.g., Grand Challenges) where reverse innovation could be brought into the discussion, but they still do not have a statutory role where they could

elevate LICs. If it is on the agenda of high-level global health discussions, it may become more widely recognised, but there still needs to be someone to oversee and guide the process. Berwick (2003) and Depasse and Lee (2013) suggested that, innovation should be managed by a central body that can oversee the ethical spread and implementation of innovation, but they did not suggest who should govern this process.

Universities can be a great source of knowledge exchange both through research and teaching which fosters reverse innovation and intercultural understanding through schemes such as Erasmus and multiparty research endeavours. Basu et al. (2017) also suggested that, HICs need to create trust and mutually respected relationships and develop structures to support peer learning (33), but they do not discuss how to develop these relationships or how they could ensure that, they are not enforcing a colonial knowledge exchange whereby students spend a short time in a LIC and publish a paper on the challenges they faced (93).

Academic institution partnerships can support knowledge sharing between HIC and LIC contexts, furthering global health bidirectional learning. Basu et al. (2017) described how the African Partnerships for Patient Safety (APPS), an affiliation between Johns Hopkins Medicine and hospitals in Uganda, Liberia and South Sudan, is promoting international knowledge sharing partnerships (33). Their secondary scheme, the APPS Community Engagement Approach from Uganda, details a series of seven steps describing the APPS stakeholder strategy (34). This strategy for stakeholder engagement was applied to a setting in Baltimore in the US (62), but it was not clear if this partnership was mutually beneficial. Subjecting an intervention to reverse innovation technically does support the global innovation flow, but it still implies that, HICs are benefiting from LICs adopting their innovations. Arguably, raising the visibility of innovations through increased publications and kudos may not be enough to incentivise the process. These incentives may drive knowledge dissemination in HICs, but the process in LICs may need to be incentivised through a different method.

Busse et al. (2014) illustrated another example of global knowledge sharing in their paper about the Ethiopian emergency medicine twinning partnership between diaspora networks and academic institutions from Canada, South Africa and the US (44). Their paper describes how reverse innovation can facilitate the global flow of knowledge but did not suggest a strategy to facilitate this process (33).

Redko et al. (2017) suggested creating developed-developing country partnerships and also enhancing bi-directional learning in academic research (76). This may seem a simple solution, but in practice it could be challenging as, when countries' economies grow and develop, it could be a challenge to determine which institution is deemed as 'developing.' Furthermore, classifying countries into developed and developing could further perpetuate the negative connotations relating to the Global North-South partnerships.

Academic institutions do not currently play a role in measuring this process of information exchange and they do not offer insight into a universal model that could be used to modularise and, therefore, credit learning programmes between LIC and HIC countries. Researchers could act as knowledge mobilisers and think tanks like the World Bank could lead or track the process. Unfortunately, the challenge lies in not only getting reverse innovation onto the agenda of these institutions through providing an evidence base but also requires creation of demand.

On a national level, innovations are vulnerable to political change. Supporting long-term change in political agendas requires commitment by the governments to examine the country constitutions and implement innovations to preserve change. For example, the earlier cited Family Health Strategy in Brazil resulted in social reform throughout the entire healthcare sector (63). It promoted an ethos that ensured each citizen's human right to access to health care, which shifted away from the former policies in place during the dictatorship until 1988 (63).

Delivering health services is challenging within all contexts. Each context has various stakeholders that influence the design, integration and implementation of health programmes, such as research regulatory bodies like the Care Quality Commission, health professional registers like the General Medical Council and national innovation regulators like NHS Improvement. These various actors and the context in which innovations emerge are integral, when understanding if and how an innovation could be subject to reverse innovation.

Bhatti et al. (2017) conducted a study that identified five evidence-based and scaled innovations within their contexts (63). They then considered how these innovations could be translated to the US and integrated within the health system. They were able to identify that promoting lower cost innovations within the US's fee-paying services could be problematic because integrating them within the current model could reduce demand for services (63). However, highlighting the value of innovations in reducing the overall cost of healthcare to US healthcare providers may be more

persuasive (63). Similarly, Harris et al. (2017) suggested that, if a cost analysis can demonstrate that the selected innovations would be financially viable, this could generate buy-in from health commissioners (55).

Strengthening health systems through sustainable programmes could support universal health coverage (94). Globally, health systems vary in terms of the services they provide, the way they are financed, the actors that manage the service and the services they provide. For example, Directly Observed Therapy short-term is an intervention, which was developed in Uganda and is available globally for the treatment of tuberculosis (TB) (32). It is widely used in many LICs that have a high burden of tuberculosis but the programme available in the NHS is smaller because the UK's burden of TB is less, therefore, the scale is slightly different and there are fewer resources needed to deliver the programme. Nonetheless, Syed et al. (2012) suggested that, there are emergent South-to-North lessons that could minimise the waste in healthcare and help to build sustainable and environmentally conscious hospitals and health systems (33, 53).

Finding the innovation is not the problem, it is thinking about the degree of fit to the HIC health system. In deteriorating and/or underdeveloped health systems, new interventions can be implemented quickly because there are less stringent regulatory frameworks and there are gaps in current services (10, 11, 14). Due to regulations and a need to optimise patient safety and preserve quality of care, it can take 17 years for an innovation to be developed and scaled within the NHS (7). These interventions can be cheaper to develop, implement and run, but they will require testing to determine if they are effective and safe for use in the NHS (64). These aspects could play an important role in determining whether an innovation can be translated into a HIC's health system (10). Additionally, cultural and contextual factors may vary between countries. For example, Hayhoe et al. (2018) suggested that, a scaled community health worker workforce integrated into NHS primary care may be a valuable policy alternative to the current health professional-led model (65), but they have not considered the cultural and environment adaptations that would be needed. Further pilot studies are required to be established if this model would be feasible and if it could demonstrate impact in NHS primary care. Patients using health professional-led NHS services may struggle to accept models from LICs that may potentially be community-led or allied health professional-led models. They may also challenge the change in the status quo because they are being asked to adjust their expectations of how healthcare is delivered in the UK.

The NHS could benefit from scalable interventions that are effective in real-time settings (51). Without funding pilots and implementing piloted intervention in HICs, interventions developed in LICs cannot make the leap from being efficacious to effective. Furthermore, when interventions are brought to scale, they require more funding and human resources for implementation. Implementation can take time and requires scrupulous adaptations and monitoring and evaluation. Implementing an intervention that utilises existing community structures and repurposes resources rather than requiring additional resources could overcome some funding barriers.

Our understanding of innovation diffusion between LICs and HICs is fragile and the existing literature on this reverse innovation hypothesises about its benefits to HICs health systems. Reverse innovation could challenge and reinvent the traditional knowledge flow within global systems. The literature did promote reverse innovation by bias reduction strategies (33, 41) and partnership building (44), but it did not outline how to adapt or implement an intervention developed in a LIC into a HIC health system. Global knowledge combined with on-the-ground innovations from LICs would undoubtedly transform future modes of international cooperation and any benefits accrued, however, innovations will need to be adapted for the health system and biases also required to be addressed.

2.4 Overcoming challenges

Working towards better global health could be supported by the dissemination of information on innovations (33) but overcoming these challenges relating to reverse innovation will require a multifaceted approach that addresses the value proposition that could increase the acceptability of these innovations for institutions and individuals in HICs. All health systems are complex. There is not a consistent reverse innovation process; therefore, there is a need for research to support the principles of reverse innovation and to optimise adaptation of health interventions so they can be translated to HICs.

Global health could benefit from a shift in ideology centring internalism towards greater openness. Negative attitudes from implementers, academics and consumers of healthcare towards LICs continue to compromise global health leadership, learning and partnerships (1). In section 1.3, it was identified that, on a macro-level, global health needs to address biases in the perceptions of where innovation emerges; suggesting that innovation, knowledge and learning that can emerge from anywhere (66). Building on this, the next section will describe some strategies from the literature to overcome some of these challenges.

Not all innovations will be appropriate or needed by HICs. Harris et al. (2017) suggested that, we need to design a process that would assist countries identify innovations which are appropriate for adoption (55). This process could help HICs and LICs to share knowledge about innovative policies, practices or programmes, which could help them to reach the universal health coverage (55). Harris et al. (2017) suggested that a mechanism to identify innovations that could be translated into HICs (55). Adapting and scaling innovations is also important, and Harris et al. (2017) point out those innovations should be classified based on their ‘affordability, adaptability and accessibility,’ but these differ between contexts. What Harris et al. (2017) do not suggest is how this process could become more routine and even how it could potentially be value blind. Whether an intervention is affordable or not is an extremely complex question. E.g., in Germany complementary therapies such as homeopathy are included in state healthcare but not in the UK because we hold different ideas about the necessity of maintaining wellbeing. Furthermore, prescriptions are included in Scottish state healthcare but not in England and Wales, demonstrating that even within the UK affordability could be dependent on the locality in which the intervention is being implemented.

Reverse innovation needs to be supported by those that are going to use the innovation or those that will deliver the innovation for example Kulasabanathan et al. (2017) suggested that, sending healthcare workers from HICs to work in LIC health systems could help support their belief in innovation, understanding of said innovation and also promote leadership in innovation. These new skills could develop leadership capacity in reverse innovation for the health systems in HICs (69).

By demonstrating that an intervention developed in a LIC could be led by an individual trained in its use in a LIC as well as demonstrating that it could be effective within a HIC’s healthcare system could help addressing some of the misconceptions from healthcare professionals, patients and the public. Sharing successful examples could help change public opinion and deconstruct some traditional ideologies surrounding global health leadership, management and knowledge dissemination.

Commitment from institutions including health system, academic and government could support the flow, equitable sharing and integration of innovations that could promote long-lasting change. Zedtwitz et al. (8) believed that, the flow of innovation was linear, and also suggested that innovation flowed between many countries concurrently, and that this process should be explored further (8), whereas Redko et al. (2016) considered reverse innovation to be a highly complex and fragmented

process, which requires collaboration and communication between all the stakeholders and beneficiaries (23). Encouraging policy makers to globally source innovations is challenging enough without a global body to oversee and record innovation. The flow of innovation could be supported by collaboration between the actors and governed by a global health body such as the World Health Organisation that recognises best practices regardless of their origin (5, 30, 67). Charting the flow of innovations could be an appropriate way of tracking where innovations emerge and the frequency with which they are implemented in a new context. This could help monitor and evaluate the flow of innovation which could support learning across both HICs and LICs. National Pilot schemes that seed fund innovation, e.g., Integrated Care Pilots, are a good example of where we learn a lot from the natural ecology of freely developed interventions within the same remit.

Another model for innovation diffusion was presented by Berwick (2003) who proposed that innovation diffusion is encouraged by three clusters of influence: (1) the perceptions of the innovation, (2) the characteristics of the individuals who may adopt the change, and (3) contextual and managerial factors within the organisation that may adopt the innovation (70). Some of the characteristics of innovation adopters were covered in the Depasse and Lee (2013) model (37), including contextual influences within innovation being part of the implementation process. Some of these factors were recognised by Greenhalgh (2004) who described three traits, which would make an innovation attractive to HICs (1) if the innovation has potential to be reinvented, (2) if it is uncomplicated, and (3) if it is able to emulate the norms of the adopting context (72). This highlights three important traits that need to be considered, when applying the concept of reverse innovation to an intervention.

Based on Roger's Diffusion Theory (2004) (95), Depasse and Lee (2013) have created the reverse innovation healthcare framework, which attempts to outline the process theory (37). It samples reverse innovation business theory (4) and diffusion of innovation theory (68) to create a pathway, which demonstrates the global innovation dissemination in health systems (37). The framework (see Figure 3: Depasse & Lee (2013) A model of reverse innovation in healthcare) includes four key steps: (1) identifying a common issue experienced in HICs and LICs, (2) charting the path of innovation flow within LICs, (3) recognising the point where innovation crosses over from LICs to HICs, and (4) charting innovation and the spread of innovation in HICs (37).

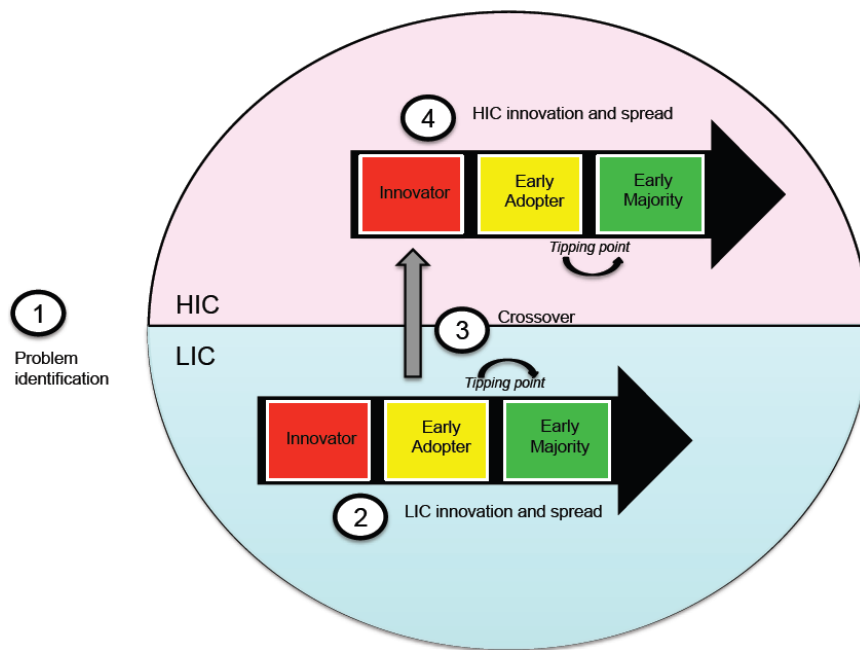


Figure 3: Depasse & Lee (2013) A model of reverse innovation in healthcare (37)

There are critics of diffusion theory, but it still remains a dominant theory in the field. In this case, diffusion theory contributes to the four steps outlined with the five crucial populations that represent the spread of innovation (37). These populations are:

Innovators- constituting 2.5% of the population, they will often have a high socioeconomic status which allows them to have high risk-tolerance, financial liquidity and will have exposure to other innovators. This group has a high level of innovation failures, but their high socioeconomic status allows them to absorb any losses.

Early Adopters- constituting around 13.5% of the population, they will usually be the second group to adopt the innovation along with the innovation pathway. They have similar traits to the innovators including high socioeconomic status and financial liquidity, but they are more discrete about their choices of innovation adoption and often more led by opinions within their peer groups.

Early Majority- constituting 34% of the population, this group is made up of individuals, who follow the innovation adoption patterns of the early adopters.

Late Majority and *Laggards* are the last groups to adopt innovation.

Along the pathway, there are two crucial points called *tipping points*, which could determine if an innovation could be adopted by the rest of the health system (69). *Tipping points* occur when 15-20% of a population have adopted the innovation and this increases the likelihood of the intervention being adopted by the remaining population (69). Innovations can spread further if *cross-over* occurs between LICs and HIC early adopters (37). This could be achieved by promoting interventions developed in LICs to early adopters in HIC markets. Berwick (2003) suggested that, innovations will spread, if early adopters in HICs are visible (70), but Depasse and Lee (2013) opined that, HIC innovators need to be susceptible to research and ideas from LICs. A potential change of this model is that it requires some level of in-person or virtual facilitation via research at conferences or via peer-reviewed journals, for example panels need to have geographical diversity, ensuring that there is equal representation from academics from LICs and HICs (37). Increasing the visibility of experts from LICs could, in the eyes of HIC researchers, academics and commissioners of health, help legitimise the research and address some of the colonial legacy, that is still reflected in global health leadership, management and practice.

Application of the Depasse and Lee (2013) framework includes measuring innovation spread from LICs to HICs, tracking the movement of innovations along the innovation pathway and identifying points where global health stakeholders could facilitate the uptake of innovation (37), but it does not indicate how this could be achieved. These global health stakeholders include policy makers, advocates, influencers, entrepreneurs and health system leaders, who will utilise different channels such as learning collaborative, conferences and online resources to create realistic dissemination tools for reverse innovation (37, 71). Nonetheless, this framework offers a flow of knowledge which shows how LICs move their innovations into HIC markets (37). The Depasse and Lee framework appeals for all global health stakeholders to disseminate innovations and take dual accountability for innovation dissemination (37). Without a central governing body, however, it could be difficult to monitor the flow of innovation dissemination (12).

To conclude, Depasse and Lee suggest recommendations to facilitate the global innovation flow including (37):

1. Identifying innovations that could address common problems between LICs and HICs.
2. Persuading global policy makers such as the WHO to encourage innovation dissemination.

3. Forming an international innovation database that can be accessed by potential consumers in HICs and LICs.
4. Encouraging funders to finance innovations from LICs to HICs to facilitate the *crossover* on the reverse innovation pathway by encouraging donors to invest in piloting and promoting integration of interventions from LICs in HICs health systems.
5. Creating opportunities to share innovation such as learning collaborative between HICs and LICs.
6. Measuring innovation activity to encourage the uptake of interventions and to track *LIC innovation and spread* and *crossover* to HICs.

Some of these recommendations, such as promoting the diffusion of innovation through ‘spannable social channels’, may seem achievable (37), however, Harris et al. (2016) argued that, encouraging uptake of innovations is much more complex (12). They suggest that the process would include persuading both health providers and individuals accessing healthcare to adopt a new intervention, which may have a different approach than current NHS programmes (12).

Building on Berwick’s (2003) suggestion to make innovations visible in HICs could assist acceptance and adoption of innovations from LICs. (70). Furthermore, Harris et al. (2017) suggested that, counter-stereotyping techniques and decision-making tools could help address some biases expressed towards research that has emerged from LICs (40). They advise the researchers to be mindful, when disclosing the sources of data (58). While this may overcome the initial biases expressed towards innovations that emerge from LICs, this is not addressing the root of the cognitive biases experienced by the concept. Peterson et al. (1995) suggested that consumer characteristics such as cultural orientations, level of education and ethnocentrism can influence the likelihood of an intervention being accepted within a context (56). This has implications for reverse innovation of the women’s group PLA cycle for the UK NHS context, because it suggests that the intervention may be adopted more readily by a population that has originated from the country in which it was developed; Bangladesh was one of the countries, where the intervention was developed, but it did not make any suggestions of how to make the intervention more culturally of contextually appropriate. This suggests that further research into how to make interventions undergoing reverse innovation contextually relevant could facilitate the process.

2.5 Gaps in the literature

Reverse innovation is an emerging field and, although the facets of the concept are beginning to solidify, there were still several gaps in the literature relating to the lack of consistent nomenclature, lack of a clear and universally recognised process from supporting the innovation flow between LICs and HICs, and a lack of evidence on how to appropriately prepare an intervention to be implemented in a HIC's context.

Reverse innovation could be viewed as a paradigm shift away from a post-colonial health professional-led didactic method of health intervention design and delivery towards an iterative exchange of knowledge between LICs and HICs. However, a lack of definitional precision and conceptual clarity could add to increasing confusion surrounding the aims of reverse innovation as the concept should elevate innovations from LICs, but the use of the term 'reverse' simultaneously reinforces the idea that HICs are the traditional leaders of the field (92). Basu et al. (2017) argued that, we need to stop thinking about the process as reverse innovation because it should not matter, where the innovation has been developed (96). They indicate that, efforts need to support the global innovation flow (33). Offering a framework that could potentially unpick the innovation flow may support knowledge exchange between LICs and HICs.

Reverse innovation can be applied to an intervention as well as to process, policies, practices and programmes in global health (2). Much of the literature has focused on the definition of the concept of reverse innovation and the identification of potential innovations (5, 24-32) and not necessarily the implementation process. Harris et al. (2015) suggested that, a definitive model is required to differentiate between where innovation comes from and the direction it is flowing (97). This could help classify innovations and measure their appropriateness to undergo the process. This model may be subjective – based on the type of innovation, which is being translated into a new country - and it could be contextual – based on the adaptations needed to make it culturally appropriate.

The literature does not recognise the nuances between different countries, categorising all LICs and HICs in the same way (37). This lack of diversity in approaches to reverse innovation could impact negatively on the successful implementation of innovation in HICs as it is not considering factors such as health system design and delivery. For example, the United States of America (USA) and the UK are both considered as HICs, yet the USA has private health insurance and public health coverage through schemes such as Medicare and Medicaid while the UK, though it does have private

healthcare, has mainly a government-sponsored universal healthcare system. Additionally, in the USA, there are several healthcare providers, which utilise different patient record systems making it challenging to universally introduce new technologies across health providers, whereas in the UK, the NHS has the Electronic Patient Record system. Also, the UK population is smaller than the USA's, and the UK has four national governments that regulate regional NHS bodies. These are some of the factors that are not taken into consideration in this model.

Even within each of these contexts there is heterogeneity in how healthcare is delivered and the health behaviours of the patients. The current literature does not consider the process of contextual and cultural adaptation which should occur when an innovation is being implemented within a new country. Finally, this model suggests that, the process is linear, that innovation only flows in one direction and only illustrates one innovation flowing at any one time (36). A more representative visual would show several innovation undertakings this process at once, repetitions in certain stages and may demonstrate a clearer timeline of when and how an innovation moves through the model (37)

2.6 Conclusion

Unsustainable healthcare expenditure (98), changing disease patterns and population demographics are encouraging HICs to look further afield for healthcare solutions. There is a potential need for HICs to address the biases, which are leading to the adoption and propagation of LIC innovations (69). This literature review has highlighted that, there is still insufficient emphasis on the benefits of learning from LICs and that more attention should be spent for addressing the inherent cognitive bias that places HICs in the driving seat of global health innovation. Drawing on this literature, this review has offered some evidence of the challenges faced by the individuals and institutions, as they try to address their cognitive biases. Different countries are affected by resource limitations in different ways, nevertheless there are many commonalities. Integrating an innovation into a healthcare system can be challenging, because there are various actors and regulations that need to be considered.

Not all interventions developed in LICs will be appropriate for the NHS, and each should be assessed based on feasibility, acceptability and potential cost savings (7). Additional work on contextualizing the interventions, including repurposing existing community structures where resources are limited, could release resources from other parts of the system if needed. For the women's group PLA cycle this review highlights the following key points:

- Acceptability, feasibility and attractiveness will need to be tested within the new context to optimise implementation.
- There may be some resistance from the NHS and the target population, acknowledging the needs and addressing any concerns about the efficacy of the intervention within the context prior to implementation may encourage further adoption (attendance at the women's groups).
- Applying reverse innovation to the women's group PLA cycle could offer an opportunity to strengthen partnerships between the HIC implementation institution (in this case UCL) and their overseas partners.

I believe that the next step in the process of reverse innovation for the women's group PLA cycle intervention is to determine how it has been previously adapted and set out some explicit objectives for its reverse innovation process based on the previous adaptations and exploration into the UK context. Exploring health intervention adaptation models could offer some insight into how the women's group PLA cycle model could be effectively translated between the two contexts, preserving intervention outcomes. It could also help in addressing some of the gaps in the reverse innovation literature, which do not recognise how LIC's innovation could be readied for implementation within a HIC.

3 Health Intervention Adaptation in the context of Reverse Innovation

While oftentimes sourcing the appropriate articles for reverse innovation was challenging due to the various terms that are used interchangeably to describe the process (section: 2.1) it helped me to appreciate the novelty of the concept and how it is not yet fully understood within the global health literature. This encouraged me to read management literature, diffusion theory, and implementation science and health intervention adaptation. I decided to conduct a narrative review of the health intervention adaptation literature, because I believed that, understanding how and why health interventions are adapted could help me address the gaps between the reverse innovation literature (section: Gaps in the literature) about implementation and attempting to deal with cognitive biases in the new context. I will do this through three aims:

Chapter aims:

4. To present a rationale for health intervention adaptation to support reverse innovation of the women's group PLA cycle.
5. To illustrate the different areas of health intervention adaptation.
6. To highlight the challenges of health intervention adaptation in relation to culture and context.

3.1 Rationalising the application of health intervention adaptation to support reverse innovation

For the first time the women's group PLA cycle is undergoing reverse innovation, and if it is going to be implemented by the NEON study, possibly it should undergo adaptation. I thought that understanding health intervention adaptation in particular could help me theoretically for adapting the women's group PLA cycle effectively for Tower Hamlets. Exploring the literature on the different areas of adaptation could help me to increase its acceptability and appropriateness for the Bangladeshi population that we will be targeting through the NEON study. Given the potential contentious dynamics between culture, context and health behaviours, the effectiveness of the intervention could be improved by incorporating features through a tested adaptation framework.

Unfortunately, diving into the complexities of health and health systems is beyond the realms of this research, but for the purpose of this thesis, I will indicate that, health interventions comprise various

different interventions, policies, programmes and practices in public health and health services research, which aim to reduce risk of exposure to development of disease. These can include interventions for the individuals or for groups that are preventative, curative or palliative in nature (99). Examples are interventions delivered to whole populations (e.g. regulatory restrictions on tobacco sales) and interventions targeting specific groups in the population based on ethnicity, socioeconomic status or age or specific groups with increased levels of risk (e.g. smoking cessation services or exercise on prescription for obesity) (2). Increasingly, health interventions are seen as interacting with complex systems into which they are integrated (100). From a systems perspective, all health interventions could be considered as complex as they operate through a series of active environmental interactions, and they are often influenced by or can influence mechanisms in the whole system (101). Highlighting the complexity of health interventions and the nuances between health systems should begin to support the case for health intervention adaptation.

Health intervention adaptation is not a new concept. Adaptation often occurs when a health intervention moves from policy to theory to implementation (101). Defining this process, however, can be challenging because often it is not recorded. McKelroy et al. (2006) defined adaptation as the process of changing an intervention without compromising or contradicting its core components or internal logic (102). In a field as complex as health, this high-level definition lacks granularity, nuance and contextual responsiveness, for which in this next section I will explore the nuances of adaptation and why we will use it.

Adapting an evidence-informed intervention for a new context could save the time and resources that are required to develop a new intervention. From a policy perspective, adapting interventions could support UHC by increasing accessibility of healthcare and reducing the costs associated with developing a new intervention (103). However, adapting an evidence-informed intervention that has been developed in a specific system to a new context that has a different health system, social norms and values and resources, without evidence on how it should be integrated into that new context could lead to an unsuccessful intervention. There are some case studies, which show the successful adaptation of health intervention between contexts (104, 105), but there have also been examples of unsuccessful intervention (106, 107). Hypothetical reasons for the inability of these interventions to be successfully adapted in new contexts could be that they are not contextually responsive because the adaptations have not been based on evidence. This could lead to lack of adaptation of the key components of the intervention, or differences in the monitoring and evaluation methods used by the implementation teams (108).

3.2 Health intervention adaptation frameworks that could support reverse innovation

An adaptation framework is an evidence-based means of adapting interventions for different contexts, exemplars or populations. Adaptation requires formative research to inform specific adaptations, but it also requires a formulaic method of implementing these adaptations. There are a limited numbers of health intervention adaptation frameworks that offer a systematic process to assist with adaptation (109). In the following section I will represent some of those frameworks.

Translating interventions between contexts could be assisted by a standardised approach, which facilitates the adaptation process by maintaining the core components of the intervention and adapting the non-core components in response to the implementation context (110). An element of successful implementation and scaling of adapted interventions could lie in the ability of the implementation teams to replicate the adaptation model to respond to variances in healthcare systems and also adapt the intervention to nuanced differences in various environments and within different target populations. Adapting health interventions in response to poor intervention outcomes is recognised, but not always recorded, way of improving the performance of health interventions (111), but this adaptation may occur after implementation instead of before, where it could be more effective.

From a policy perspective, adapting interventions could support UHC by increasing accessibility of healthcare and reducing the costs associated with developing a new intervention (103). Through a critical lens, the following section will detail some of the most frequently cited adaptation frameworks from the literature.

3.2.1 Adapting to maintain the fidelity of the intervention, whilst adapting to fit the context

Health interventions should be adapted to fit the target population, whilst maintaining the fidelity of the intervention (112). This theory was first presented by Castro et al.(2004) and it is one of the fundamental frameworks, which begin to unpick what is meant by culture and what it means to culturally adapt an intervention (110). They do so by examining the fidelity-adaption tension (112) which has two parts: to develop universal preventive health interventions and implement them with fidelity, and to design interventions so they emulate the cultural needs of the whole community (110).

The core components maintain the fidelity of the intervention and should not be adapted (110). Campbell et al. (2000) suggested that, design is the first core component of fidelity (113). They split design into three parts: the framework of an intervention which is comprised of elements essential to the experimental evaluation of impact as well as elements needed to evaluate or replicate the study (114); the programme model which is a well-defined set of interventions and procedures to help individuals achieve the desired goal (115); and the population dynamics which are cultural, social, and personal characteristics of the target population (116). Gearing et al. (2011) constructed a framework for fidelity of psycho-social, social and behavioural interventions that offers an essential guide to the core components that maintain fidelity of an intervention (117). Their review identified four components of an intervention that can be monitored to assess fidelity: intervention design and protocols; intervention training; monitoring of intervention delivery; and monitoring of intervention receipt (117). Identifying the core components of an intervention can preserve the intervention outcomes and potentially promote sustainability of an adapted intervention in a new context, but neither Gearing et al. (2011) or Castro et al. (2004) were able to determine how you monitor adherence to the adaptation framework and the preservation of the core components during implementation (110, 117). Without guidelines on how to pragmatically apply this framework during implementation, it is purely theoretical. This could make it challenging to translate into a practical implementation context, where teams may not have the time or capacity to spend money or the time to interpret the adaptation framework.

Adapting a health intervention should be a measured process that considers the context but does not inhibit the intervention's trial efficacy or real-time effectiveness. From a research and practical perspective, perhaps the main reason for adapting a successful evidence-based intervention is to replicate that success in another context. Therefore, it could be important to determine which areas of the interventions are core to that success (110). Castro et al. (2004) suggested that, programmes can be "*culturally mismatched*" which will impact on programme efficacy even if it is implemented correctly (110). There are three main areas which can cause the mismatch effect: programme delivery staff, group characteristics and administration and/or community factors (110). If these are not relevant to the target population, then the participants may not attend all sessions/appointments linked to the intervention; and this would compromise continuity and decrease the impact of the intervention on health outcomes in the target population (110).

Castro et al. (2004) further argued that, interventions, which are adjusted for culture, may be appealing to minority groups, however, if the adjustments are not based on evidence, effectiveness cannot be guaranteed (110). They advise that adaptation should be designed in response to cultural

needs and should occur to enhance programme outcomes, but should not compromise these outcomes (110). Therefore, it is essential to determine which areas of the programme are essential and which can be adapted for context. Castro et al. (2004) also suggested that, the essential components (core components) of the interventions had to remain the same, but the non-essential components could be adapted to improve fit (110). The programme theory is what can be adapted for fit, but the theory of change must remain same to maintain fidelity (110). A program theory (theory of action) can include several theories of change, which makes it slightly convoluted and difficult to translate into an implementation context. It requires several indicators to monitor and evaluate adaptation. This may be appropriate for a cluster-RCT setting, but could be challenging, when taking the adapted intervention is fully implemented and scaled because it could be too complicated and resource heavy.

3.2.2 Adapting a health intervention so it is selective and directive

In a narrative review, Lau (2006) pinpointed some of these critical areas that could raise the issue of lack of adaptation, including engagement (118). Lau proposed that, cultural adaptation should be “selective and directed”, and not indiscriminately made across evidence-based interventions (119). These adaptations should occur when there are issues between the fidelity of an intervention and the fit in the new cultural group (118). Adaptations that are made indiscriminately can lead to lack of adaptation (110). Lau (2006) highlighted that engagement and outcomes of an intervention could be compromised if social nuances within populations were not accounted for in the adaptation of an intervention (118). An exploration into the social nuances of cultural groups could indicate how an intervention could be adapted to increase engagement. Lau (2006) suggested that, interventions need to be adapted if a specific population group is demonstrating specific clinical outcomes, or if an intervention is not having a significant effect on the clinical outcomes of certain cultural groups (118). This theory supports the argument that in reality there is a substantial gap in services which reinforces inequalities in health outcomes amongst ethnic minorities (2). Lau’s (2006) suggestions require strong public health surveillance systems to be able to identify specific clinical outcomes. This could be appropriate for the UK, but like all health interventions, which rely on the quantitative data, it would be reactive rather than proactive, which could affect the interventions ability to be contextually responsive.

Building on Lau’s framework is Barrera’s (2006) *Heuristic Framework* for culturally adapting interventions, which discusses how using different language and evaluating comparability within a context assists with the adaptation process (120). Like Lau, they suggest that adaptation should be

selective, and cultural equivalence should be measured (118). They also suggest that, one challenge is to conduct appropriate formative research that collects data that is representative of the target population and, therefore, can inform cultural adaptation to optimise reliability, language/content, validity and structure of an adapted intervention(120). What they did not consider is how to account for heterogeneity within a target population and how this could influence engagement with the adapted intervention. Poor engagement procedures could prevent the uptake of an intervention by the target population.

Both Lau (2006) and Barrera and Castro (2006) acknowledged that, culture is complex but do not offer solutions to address this complexity. Their theoretical adaptation processes are principally aimed at treatment for individuals within cultural groups, not whole cultural groups, and they are centred on psychological therapy, not participatory models (118, 120), but understanding the complexities of culture and building a framework that responds to both culture and context could be challenging as it would require iterative evaluation to respond the changes in the environment and monitor effectiveness.

3.2.3 Adapting a health intervention for an ethnic minority group

Adapting for ethnic minority groups could be supported by a framework which further helps researchers and implementation teams identify an appropriate intervention for the target population and then adapt it according to their cultural needs. The RESET is presented by Liu et al. (2012) as a decision-making tool that facilitates an evidence-based process for identifying which areas of an intervention should or should not be adapted(2). It can be used alone, but Liu et al. suggest that it is accompanied with their Typology of Adaptation which contains 46 traits that could be adapted and the *Programme Theory of Adapted Health Promotion Interventions* which is an eight intervention cycle (2). This could potentially help support the identification and subsequent adaptation of health promotion intervention for ethnic minority groups in the UK.

The RESET suggests those health promotion interventions should be assessed on their appropriateness for ethnic minority groups based on the following questions:

Relevance

- Is this health promotion topic relevant to the target population?

- Is the topic of enough concern that action is required?
- Are there competing priorities for this population that would lessen their engagement with this intervention?

Evidence base

- What is the best intervention to address this health topic within this population?
- Is there evidence of intervention effect within the general population?
- Is there evidence of intervention effect within the target population?

Stage of intervention

- What stage(s) of the intervention programme theory should be adapted?
- What stages need adaptation for this population? (Adaptation may not be needed at every stage, e.g., English is appropriate as the language of intervention delivery for African Americans)
- What stages can be adapted in this intervention? (There may not be resources available to undertake all the desired adaptations and therefore adaptations require prioritisation)

Ethnicity

- What elements of ethnicity are most important to consider for this population?
- What are the conventional elements that are important to consider in adaptation? (e.g., religion, language, culture, physical features, ancestry, age, gender and socioeconomic status)
- What are the contextual elements that are important to consider in adaptation? (social environments, physical space, past exposures to health research and services, and diverse life experiences including stress)
- What degree of heterogeneity is present within the target population and is it possible to assess heterogeneity (i.e., measure ethnic identity, cultural affiliation or acculturation) and adapt the intervention appropriately at a subgroup level?

Trends

- What are the shifting trends within this population?
- Are there shifting patterns and trends in behaviours within this population?

- Can we monitor the patterns and trends in population characteristics, preferences and contexts and revise the adaptation(s) to maintain relevance over time?

Each of the five areas of this tool attempts to respond to the different areas that are relevant to adaptation of a health intervention, for example *Relevance* lists questions that would allow a research professional to determine if they understood their target population, and *Evidence base* prompts the research professional to assess whether this type of intervention is the best intervention to address this health outcome within the selected target population, supporting Castro's theory (2004) that suggests adapting to fit a population (section 3.2.1) (112). This stage of the intervention helps the research professional decide at what stage the programme theory should be adapted. A programme theory can include several theories of change. Ethnicity (interestingly not referred to as 'culture') helps decipher which areas of an individual's ethnicity should be encompassed in the intervention. It can help the research team account for trends such as assimilation, acculturation and biculturalism within the target population. Liu et al. (2012) concluded that, the conventional ideologies around ethnicity and how we adjust interventions for ethnicity need to consider contextual variation about assumed stereotypes (121).

A limitation of the RESET tool is that it generalises ethnic minority groups by using the categories outlined in the Scottish census 2008 (South Asian, Chinese other and Black African and Caribbean). This fails to recognise not just the nuances between the country of origin, but also differences between first or second migrants, geographical location (rural or urban), and population density (which can contribute to cultural collectivism). All these factors can influence how a health intervention can be adapted. Using the tool for individual ethnicities within each of those groups, e.g., Bangladeshi, could improve the specificity of the tool. There are, however, innate challenges that influence the tension between adaptation for context and adaptation for culture.

Merely grouping individuals or communities based on perceived ethnicity could be potentially challenging as there could be additional social determinants of health that could be influencing these behaviours, for example, socioeconomic status. In a narrative review, Szczepura (2005) suggested that, all programmes exploring cultural sensitivity must control for socioeconomic status (122). This was demonstrated by a qualitative study which interviewed women from low-socioeconomic status households attending prenatal clinics in Glasgow (123). In Scotland, a third of 11 year old children are overweight or obese, with higher rates among children from disadvantaged backgrounds (124). In disadvantaged areas around Glasgow, high rates of early onset obesity, type 2 diabetes and

cardiovascular disease are observed (125). Easterhouse, for example, is an extremely socio-economically disadvantaged housing estate in north eastern Glasgow where breastfeeding rates are at just 15% at seven days postpartum (123).

Increasing breastfeeding in communities like the one in Easterhouse could be an important part of protecting children from infectious disease, prevent obesity, reduce healthcare burden, and promote healthy cognitive and physical development into adulthood. Dungy et al. (2008) investigated the influence of social networks on breastfeeding initiation and continuation and on infant weaning practices in Caucasian women from low socioeconomic status (123). Their research team approached women who attended an NHS prenatal care facility in Easterhouse. They noted that breastfeeding and weaning practices were influenced by the direct peer group, mother and/or spouse (123).

This is a largely White British population on a council estate in Glasgow reporting infant feeding practices and rates of early onset nutrition-related ill-health similar to those in the Bangladeshi population of Tower Hamlets (9, 123). Like the British Bangladeshi population, the population in Easterhouse is socioeconomically deprived. This was recognised within the Dungy et al. study, where the barriers such as low literacy levels and low socioeconomic status were affecting childrearing practices (123). Poverty is a confounder for obesity. Low education rates, deprivation and lack of access to health facilities could be influencing the choices of the Easterhouse population and the Bangladeshi population of Tower Hamlets. Their environment is having a stronger impact on their childrearing practices and health outcomes than their heritage. If two communities from different ethnicities, nationalities and localities can present with similar practices, it is possible that socioeconomic status and accessibility of interventions is the issue, not culture or ethnicity.

The fluid nature of migration, disease patterns and increasing acculturation and mixed, inconclusive evidence of adapted interventions highlight the complexities in this field of study. There is a distinct lack of comparative studies and evidence of adapted research that has been translated into action. Inconsistencies in the reporting of the adaptation process, assumptions about identity and cultural adaptation have highlighted the need for guidelines for health intervention adaptation. Adapting an intervention to replicate traits of a target population is complex and requires exploration into the irreducible social nuances, beliefs and practices within the context.

While adapting for intersectional social determinants of health such as socioeconomic status, culture, geography and ethnicity could support stronger adaptation despite existing principles of adaptation,

there is currently a lack of evidence on whether adapted interventions are effective in practice for changing health behaviours and improving health outcomes of ethnic minority populations. To overcome the lack of evidence, exploring contextual influences while recognising biculturalism could be a more appropriate means of adapting health interventions. As Davis et al. (1999) suggested that, biculturalism is changing traditional perceptions around health in minority ethnic groups (126), but not everyone in these groups is identifying as bicultural. This poses difficulties in determining how a minority population has been influenced by the majority population (acculturation) (127) and recognising that adapting interventions for environmental influences may be more appropriate for ethnic minority groups. Barrera et al. (2017) suggested that, further research into local adaptation of interventions and participant engagement could improve the sustainability of adapted interventions for ethnic minority groups (128).

3.2.4 Evaluating health interventions to unpick previous adaptation

Exploring the evaluation of public health interventions could help unpick some of these challenges and add value to the evolving women's group PLA cycle theoretical intervention adaptation framework. One of the most popular frameworks for the planning and evaluation of public health interventions was RE-AIM (over 423 citations) (129). The RE-AIM tool (130) is a framework for measuring the effectiveness of public health interventions. It consists of five measurements, which are scored out of 100: reach, effectiveness, adoption, implementation, maintenance (130). Each of these measurements is briefly described below:

- **Reach:** The proportion of the target population that participated in the intervention. This can be measured using social validation techniques such as qualitative focus groups, or by collecting quantitative data on attendance.
- **Efficacy:** Success rate if implemented as in the research protocol. This can be determined by comparing the number of positive and negative outcomes.
- **Adoption:** Proportion of settings, stakeholders and plans that will adopt the intervention.
- **Implementation:** Extent to which the intervention is implemented as intended in the real world.
- **Maintenance:** Extent to which continuity and sustainability of a programme are preserved.

Applying the RE-AIM tool to health promotion intervention, Glasgow et al. (1999) hypothesised that interventions were efficacious whilst being tested in a controlled environment, but that intervention

outcomes were compromised when they were translated into an active programme (130). They also highlighted that the setting of a public health intervention is an equally important area that should influence design and delivery methods (130). Strengths of the RE-AIM model lie in its acknowledgment of the multiple levels of contextual influence (129), but acknowledging these many levels of culture could lead to mistakes in adaptation as the intervention is adapted for each of the cultural nuances. It would be useful to have inclusion and exclusion criteria through a list of micro-adaptations. This could help in determining the levels of culture and the extent of the adaptation.

Although the model champions quantitative methods to identify patterns in the data (129), it could use qualitative techniques to contextualise the results. Integrating qualitative and quantitative methods into the tool could make the process of adaptation more rigorous, although the results could not be extrapolated to the wider population due to the nature of qualitative research.

Furthermore, the responsibility of the adaptation lies chiefly with the research team and the implementation partners. This could mean that the process requires a lot of resources, making it time-consuming and expensive. Although the UK is classified as a HIC, the health system still has resource shortages. The NHS should provide accessible healthcare for all of residents in the UK. Yet some groups are still unable to appropriately engage with health services. In some areas of the UK, ethnic minority groups' populations are presenting higher rates of nutrition-related ill-health than their White British counterparts (131, 132). A potentially fundamental justification for undertaking adaptation of NHS interventions is that health research in the UK has been based primarily on data from the European Caucasian population, with insufficient research on ethnic minorities (2). Therefore, it could be inferred from the literature that aspects of some current NHS interventions may be inappropriate for ethnic minority groups as they have not been designed with these communities in mind (2, 110, 133).

The previous adaptation or health intervention evaluation frameworks that I have presented outline specific issues that should be considered when adapting health interventions for ethnic minority groups, whereas the RE-AIM tool concentrates on identifying population level disparities, and the RESET tool aims to understand why these disparities are occurring. All recognise culture as a fundamental attribute that can influence the uptake of health interventions, but they fail to account for environmental shifts. Exploring the individual aspects of culture and coupling these with environmental influences could create a more comprehensive strategy for adapting health

interventions, particularly for ethnic minority groups that are living in HICs. This could potentially support the reverse innovation theoretical adaptation of the women's group PLA cycle.

3.3 Challenges relating to health intervention adaptation

Often, context and its influence on health intervention adaptation are overlooked. Adapting interventions to increase access to health service, to improve the quality of the health system and to promote health-enhancing behaviours within implementation context is an important part of the adaptation process (134). The body of literature around adapting interventions for contexts shows that failure to engage with the context can lead to unsuccessful intervention (135). Interventions that have been effective in their primary implementation context are not transferring their positive outcomes into new settings. Like culture, context is fluid, and it changes overtime or between implementation settings, recognising context is could be an important part of the adaptation process.

Adaptation for initial context often occurs during the design and development of health intervention, however, the process is not always recorded, which makes it difficult for others to replicate when the intervention is being translated into a new context. The body of literature supporting the need to adapt health interventions suggests that careful consideration of contextual factors can enhance planning, engagement, implementation and retention of participants with the intervention (121, 135). This adaptation can occur on three levels: at the systems level (Macro), at the organisation level (Meso) or on the individual or team level (Micro) (135) and should be reviewed regularly and adapted further in response to changes within the context.

Ethnic minority groups, like most populations, have high levels of heterogeneity; basing intervention adaptations on the physical or biological similarities of some population without recognising the effect on environmental influences could compromise intervention outcomes. An example of the interplay between contextual and cultural adaption was demonstrated by Pallan et al. (2012) in the Birmingham Healthy Eating and Active lifestyle for Children Study (BEACHes) which involved members of the South Asian community in the design of an intervention to prevent childhood obesity (132). They interviewed parents, children, schools and other stakeholders about their perceived causes of childhood obesity (132). They recognised that, assumptions are often made about these communities, based on their identity that it must be traditional practices or genetics, which are influencing obesity rates (132). The participants, however, rebuffed these assumptions and indicated that, it was food marketing, sedentary lifestyles and the availability of local fast food outlets that were

affecting obesity rates (132). Within the immediate family the parents indicated that, it was work commitments that prevented them from preparing healthy meals (132). Interestingly the study found that if there was a “*first generation immigrant*” within the family unit (mother, father, grandmother or grandfather), they were more likely to encourage overfeeding among the children. This demonstrates the heterogeneity and the importance of understanding identity within a population. Furthermore, it highlights the benefit of unpicking the population’s understanding of their behaviours and what they think influences their decisions.

Pallan et al. (2012) concluded that, there were several contextual and cultural factors that influenced the practices contributing to nutrition-related ill-health in the South Asian community in Birmingham (132). They suggested that, many different communities had similar causal effects on childhood obesity and that culture played a presiding role (132). Pallan et al. stated that, understanding cultural context is important in the designing of childhood obesity interventions, but it is also difficult to define, as culture can change between religious groupings, neighbourhoods/localities, and within the family unit (132). Reconceptualising *community* within the Bangladeshi population of Tower Hamlets and recognising the intervention traits that need to be adapted to encapsulate this new community could prevent any assumptions and lack of adaptation.

Pallan et al. (2012) and Dungy et al. (2008) have demonstrated that, health beliefs and behaviours can be influenced by environment and exposure to different casual mechanisms that can vary across different environments (123, 132). These studies also demonstrated the large degree of heterogeneity in populations and exemplified, why it could be important to use local knowledge in intervention adaptation processes. Adapting interventions to increase their appropriateness for ethnic minorities should be a systematic process set out with specific methods and guidelines (136). This has ramifications for the adaptation of the women’s group PLA cycle intervention because the Bangladeshi population of Tower Hamlets is an ethnic minority, living in inner-city London and it demonstrates high levels of heterogeneity in terms of the languages spoken, the number of years spent in the UK, education levels and health literacy. All these factors could potentially influence engagement with the adapted intervention.

3.4 Overcoming challenge related to health intervention adaptation

In the literature, it was evident that adaptation should be supported by an adaptation framework, and that it could occur in response to two influential areas: (1) cultural adaptations which emulate social

nuances, practices and beliefs in the context relating to the target population; (2) environmental conditions which consider infrastructure, logistics, resources, policy and government, which effect, but are not directly related to, the target population. There were indications, however, that both needed a formulaic process to support evidence-informed adaptation.

Currently, no universal adaptation framework can be applied to all health interventions and for all contexts. In addition to choosing to follow a framework that could be applicable to the context, implementers must also focus on capacity building in adaptation methods and collaboration with the local stakeholders to implement optimal guidelines for the local context. Capacity building in adaptation methods could help in achieving the full potential of the frameworks. This could potentially be done by collaboration between major international guideline developers and local stakeholders, and training of implementers and policymakers in the methods of following a health intervention adaptation framework to support adaptation. Potentially, with a better understanding of the adaptation framework, the local adaptors could expedite the process of adaptation.

3.4.1 Adapting interventions based on the cultural preferences of the target population

The complexity of culture, our understanding of culture and the individual and societal differences of what we perceive as culture exemplify the intricacies of the field of cultural adaptation. This raises questions about how we differentiate between the indigenous British population and the non-indigenous population. In the literature I identified studies that were predominately based in the United States and focused on adaptations for health interventions for African American and Hispanic populations. Most of these studies focused on the adaptation of mental health services (137-142) and of substance abuse (139, 143, 144). More recently there has been a shift towards adapting health promotion interventions such as healthy eating, smoking cessation and exercise on prescription for ethnic minority populations (121, 133, 145, 146). These studies championed adaptation from a race perspective, not a cultural perspective. They also focused on low-income households in deprived areas. It is possible that, racial segregation is more prominent in the USA and that segregation confounds access to healthcare through systemic inequalities.

Adapting for culture is a popular concept in the literature. It includes using existing community knowledge to design and deliver interventions that are appropriate for the target population (120). There are several terms in the literature that were used interchangeably to describe adapting for culture. These include ‘culturally appropriate’ (147, 148), ‘culturally sensitive’ (149), ‘culturally

tailored' (150, 151), 'culturally directed' (118), 'culturally targeted' and 'culturally competent' (152). More specific sub-terms such as 'religiously tailored' (150) 'faith-based' (153) and 'adjusting for race' (120) are also present in the literature. The adaptation process can be called adjusting, modifying, translation, targeting or tailoring (110). Each term implies a change to an intervention of a conscious and planned nature (154). I recognise that, ethnicity can influence health, through aspects other than culture. In addition, terms such as 'targeted'(155) and 'tailored'(155) are also sometimes used to convey the aim of increasing appropriateness. Definitions have been proposed to clearly differentiate between these two terms. Kreuter (2003) described 'targeted' interventions as "*defined for a population subgroup that takes into account characteristics shared by the subgroup's members*", and 'tailored' as "*intended to reach one specific person, based on their individual characteristics*" (156). As I am to adapt an intervention for a community rather than an individual, the term 'tailored' is not appropriate.

Health in HICs must respond to the growing cultural diversity and acknowledge that ethnic minority groups in HICs are presenting disproportionately high rates of chronic disease related to malnutrition (2, 157, 158). Exploring the impact that culture has on behaviour could help adapt interventions appropriately. Most of the literature around adapting health interventions is focused on adapting for culture (13, 110, 120, 139, 144, 145, 159-161). The aim of cultural adaptation is to generate culturally appropriate modifications to an evidence-based intervention (110) while maintaining the efficacy of an intervention. The literature demonstrates that culture is in fact an umbrella term that includes ethnicity (162), religion (150, 163), local community (128) and ethno-cultural groups (164).

The term *cultural adaptation* which was the most frequently used throughout the literature seems to be an amalgamation of several areas that were attributed to individual or community beliefs, values and customs that influence their health seeking behaviours. A key aspect of adaptation for ethnic minorities is to ascertain how the group identifies and how their identity could influence adaptation (165). Exploring how new contexts influence beliefs and practices (126), and whether acculturation is affecting traditional ideologies around health, body image and diet (126) could lead to the appropriate adaptation of the intervention.

Re-conceptualising culture in this way could help pinpoint which sub-cultural differences should be the focus of adaptation, in a bid to facilitate better implementation outcomes (164), considering that within these sub-cultural groups, there is potential heterogeneity and being aware that people can identify with their cultural influences in different ways. Some ethnic minorities in HICs are

experiencing assimilation, acculturation and cultural change (110), making it more difficult to adapt interventions for the group. Variations of salience or effectiveness of interventions could affect outcomes of an intervention according to levels of ethnic identity and other contextual effects (age, gender, geography).

Adapting interventions to include different levels of culture could encourage long-term behaviour change (166). Culture is not unilateral; it influences different populations in different ways. Adapting health interventions to echo cultural norms and values beyond language and clothing could encourage engagement with these interventions (167). One of the original theories to recognise the importance of the layers of culture is presented by Resnicow et al. (1999) (149). Their aim was to delineate a framework for designing culturally appropriate public health interventions that consider the variations in culture and ethnicity in populations (149). Resnicow et al. further suggested that, cultural adaptations should occur on two levels: *surface structures* and *deep structures*: (1) *surface structures* are areas that are adapted to embody the language, music, food, locality and clothing of the target population; and (2) *deep structures* include religion, spiritualism, expression, preferred form of communication e.g. verbal, ancestry and historical influences, and the role of family and community (149). Limitations of this model exist in that the distinction between *surface* and *deep structure* modifications was theoretical, and no framework that could guide the application of such a classification.

Resnicow et al. hypothesised that; adapting these areas should increase receptivity and acceptance of the health intervention by the target population. Understanding how individuals and communities perpetuate their culture can assist with cultural adaptation of a health intervention. Resnicow et al. stated that, the degree to which an intervention adaptation is determined culturally sensitive is measured by “*the extent to which ethnic/cultural characteristics, experiences, norms, values, behavioural patterns and beliefs of a target population as well as relevant historical, environmental and social forces are incorporated in the design, delivery, and evaluation of targeted health promotion materials and programme*” (149).

The Resnicow framework (1999) was developed for African American and Hispanic/Latino Americans (149). This two-tiered structure does not account for bi-culturalism, acculturation and/or multicultural populations. Resnicow et al. (1999) suggested that, however, that the relevance of ethnicity should be measured so group differences can be identified and considered in the adaptation process. They concluded that even programmes that are directed explicitly towards certain minority

populations could potentially be culturally insensitive because these populations are diverse. Resnicow et al (1999) stated that, implementing a culturally sensitive intervention without adequate formative research cannot guarantee uptake of intervention (149). They did not suggest, however, a set of measurable outcomes for culturally sensitive interventions, but they did suggest further research is required to explore the effectiveness of culturally sensitive programmes. This framework is over 20 years old now, and without mentioning a set of measurable outcomes that could potentially help it be adapted to respond to today's multicultural society, it might not be appropriate for the reverse innovation of the women's group PLA cycle.

Building on the Resnicow framework, Davis et al. (1999) used structures within the African American culture to design an intervention for addressing overweight and obesity in young women (126). They identified structures that they believed to be cultural strengths such as resilience towards racism, sexism and the stigma relating to overweight or obesity. They developed an "*Afrocentric*" framework, which promoted developing a relationship with the patient, treating the patient as an expert, taking personal histories, tapping into social networks and acknowledging the potential benefit of these environments. This is slightly similar to Resnicow et al. who further suggested utilising health communication theories and social marketing to target specific groups (149).

Davis et al. recorded that, in the male and female members of the African American community a larger body was not viewed negatively, therefore they concluded that, framing weight loss interventions around aesthetics would be inappropriate for this population (126). They also recognised the importance of family, which included the members outside of a typical western nuclear family such as aunties, cousins and grandparents. They also made recommendations for oral communication above written information, which makes food diaries inappropriate. It has been concluded that, a behaviour-based or an action-orientated approach would be more appropriate for this population. Perhaps the most important and relevant recommendation that Davis et al. implied was that, members of the African American community related to their identity in different ways and with varying degrees of strength (126). This could be true of the Bangladeshi population of Tower Hamlets as some members were born in Bangladesh and now live in the UK. Exploring how their culture and environment are influencing social norms could help to inform adaptation of the intervention.

3.4.2 Adaptation could be supported by multilateral organisations in the future.

In Chapter 2, I suggested that multilateral organisations like the WHO should manage and support the global exchange of innovation (section: 2.3.3). Arguably, a part of that process involves adapting and integrating an intervention into the new setting. Therefore, it may be appropriate for the multilateral organisation to include the local adaptation framework in the process, which could potentially help overcome any challenges relating to lack of knowledge or resources around adaptation.

There was a limited amount of evidence demonstrating how to adapt health intervention for low-income countries, and there was no evidence to support the adaptation of health interventions between LICs and HICs. More research is required to guide adaptation between LICs and HICs, to determine the unique challenges that could be faced by an intervention in each new context. Adaptation frameworks could offer a more efficient means of implementing interventions in a new context, but they could also make it more challenging. Developing the adaptation's guidelines could be costly and challenging, and not all contexts will have the specialised resources required to create these guidelines. Therefore, it may be more appropriate if adaptations frameworks or guidelines were created by a multilateral organisation such as the UN, who could partner with local stakeholders to create evidence-based local guidelines. This does not, however, account for adaptation between countries, only within specific contexts.

Different countries have different regulations for health interventions, and this could impact the adaptation process. More in-country independent tests could be used to evaluate the usability of some of the adaptation frameworks and these could also help assess effectiveness of adaptation frameworks in improving the implementation process and potentially supporting the adapted intervention in a new context. Building a monitoring and evaluation system into the adaptation process that allows for the adaptation to be constantly reviewed and improved could also help reduce the resources and the time needed.

Producing an adaption framework with guidelines that outline recommendations for adaptation for local context with evidence to explain how far the implementation team can modify the intervention could reduce the number of resources require. There should also be an evaluation component so that the degree of adaptation can be recorded. This could increase the efficiency of the adaptation process by making it easier for implementation teams to follow an adaptation process.

3.5 Conclusion

In this review, I presented and compared some of the health intervention adaptation frameworks that are available in the literature in an attempt to draw out some of the facets of adaptation that could benefit the reverse innovation of the women's group PLA cycle. Although adaptation occurs during most implementation processes, it is often not recognised as adaptation, and therefore it is not well recorded. Establishing a generic health intervention adaptation framework could help the implementation where the teams can adapt interventions appropriately and it could help them record the process for future implementation teams.

I believe that the women's group PLA cycle intervention could benefit from the creation of a generic theoretical adaptation framework, which could support the reverse innovation of this intervention to the UK NHS context. The health intervention adaptation frameworks that I have presented in this review indicate that adaptation should occur through a phased approach and each of these phases should contain several processes that should be evidence-based. From the frameworks that I have presented, I have deduced that health intervention adaptation frameworks should have a basic four-phase model:

1. Exploration phase – this phase could include using quantitative data to identify a target population, then scoping the literature, contextual mapping, initial stakeholder engagement and the establishment of a steering group and a needs assessment.
2. Preparation phase – mobilise existing community resources, select an appropriate intervention for adaptation, then establish an implementation partner, conduct qualitative research to explore cultural and contextual adaptation, pilot these adaptations. Create indicators for the intervention adaptation framework.
3. Implementation – working with an implementation partner to implement the adapted intervention. Recording the indicators for the adaptation framework.
4. Evaluation – using the indicators to monitor adherence to the adaptation framework during implementation. Making further adaptations based on results and training implementation partner.

Before creating a theoretical adaptation framework to support with the implementation of adaptations, the literature suggested that an exploration phase should be conducted to not only conduct needs assessments for the population, but also to establish a rapport with the target population and the actors in the context.

3.5.1 Research should be conducted to inform evidence-based adaptation

I believe that community-based health intervention adaptation requires input by two methods: bottom-up (target population) and top-down (research professional/ institutional guidance) (168). These adaptations can be explored through various engagement activities with stakeholders and needs assessments which can allow for data to be collected via co-design leading to the implementation of contextually adapted, responsive intervention (5, 164). Recognising existing resources within a context and adapting interventions to utilise these resources could support the contextual adaptation process. McInnes et al. (2001) demonstrated this by assessing if social networks, including spouses, could influence a woman's attitude towards infant feeding in women from low-socioeconomic status in Scotland (section: 3.2.3) (169). These networks are user-friendly, free and readily available, a resource that could be adapted and integrated into the intervention for the Bangladeshi population of Tower Hamlets.

3.5.2 Conceptualise context as a group of potentially changing characteristics

The literature indicates that adaptation frameworks have generally been linear, but I think that, adaptation should be an iterative process, whereby changes can be made by the implementers to respond the different contextual demands. However, I do recognise that, it could be challenging to demonstrate attribution if the process is iterative or has more than one phase running concurrently. By conceptualising context as a group of characteristics that consist of fluid and unique components that interact with each other resulting in continuous change suggests that an adaptation framework should be able to respond to continuous adaptation. If an intervention is to be successfully adapted and integrated within a new system, it should be able to respond the changes within that system. Intervention effects are generated through establishing new pathways of working within existing contexts (170). Therefore, when adapting an intervention between countries and implementing it within a new context, adaptation and re-evaluation should be required to optimise the effectiveness of the intervention in the new system. Also recognising the value of using existing evidence-based interventions for health intervention adaptation has increased interest in the area.

Most of the literature discusses how to adapt a successful intervention for a different population within the same context, not how to adapt interventions between contexts. Adapting an already successful intervention is part of optimising the transferability of this intervention into different contexts (2). Certain aspects in the intervention can be modified to make it appropriate for the target

population to enhance social capital and increase engagement (34). Adapting programmes for minority populations could potentially reduce inequity of healthcare provision to these groups and hypothetically reduce the burden of morbidity in these groups (34).

3.6 Components for the evolving theoretical adaptation framework for the women's group PLA cycle model.

The following lists the components that I have deduced from the literature and will add to the women's group PLA cycle theoretical adaptation framework. Each of these components was added because I felt like it responded to environmental or cultural adaptation of potentially participatory intervention, like the women's group PLA cycle model:

1. Adaptation can be methodical and evidence-based; this could help promote rigour, which could lead to preservation of the intervention outcomes. Clearly laid out steps of adaptation frameworks should provide a structure to the process. This could increase the transparency of the adaptation process and make it easier to evaluate and replicate in the future.
2. The core components of the intervention should be maintained to preserve the fidelity of the intervention while the other components could be adaptable (section: 3.2.1) (110).
3. It should be based on context and the culture within the society, even if the society is largely heterogeneous. Offering a framework that demonstrates how to adapt the intervention for context and culture through a unique set of micro-adaptations could overcome some of the challenges in acceptability in a heterogeneous community. In the context of cultural adaptation, Resnicow et al. (1999) recommendations could be used to distinguish between *surface* and *deep structure modifications* (167). These features could be added to the micro-adaptations to account for culture (section: 3.2.3)
4. Offering upfront needs assessment of the context could help identify what resources are available and how they may influence/facilitate the adaptation process.
5. As most of the adaptation frameworks were developed in HICs, further research is required to unpick the challenges of adapting the interventions between LICs and HICs. There may need to be an additional step, for example addressing the cognitive biases exhibited by HICs towards interventions developed in LICs that which were discussed in Chapter 2.
6. Proper evaluation is required to optimise the effectiveness of the intervention in the new context and to prevent the issue of lack of adaptation, which could lead to an unsuccessful

intervention. This could be assisted by conducting capacity building with local stakeholders and in partnership with a local organisation to demonstrate what can be adapted and what cannot along the life cycle of the intervention.

7. There should be governance from a central body which can provide guidance on adaptations, as some countries may not have the capacity or the resources to test and evaluate the adaptation frameworks they generate.

Adaption is not only part of the implementation process; it can occur during the pre-implementation, planning and piloting stages, so that it can reduce the resources required to address avoidable unsuccessful outcomes. In this chapter, I have attempted to demonstrate why adaptation is potentially could facilitate the reverse innovation of the women's group PLA cycle. Although I identified elements that could assist reverse innovation, I did not find a health intervention adaptation framework that I believed could be applied to the women's group PLA cycle. Instead of refining the current frameworks that are available, I decided to use the components highlighted earlier in this section to further build the emerging theoretical adaptation framework for the intervention.

I propose that the intervention should undergo an adaptation process to facilitate implementation, so that it is not only contextually specific, but also culturally competent. Exploring how previous women's group PLA cycle interventions were adapted by key informants from each of the trials could illuminate the previous adaptation processes (section: 5), help identify the core components of the intervention and help compile a list of micro-adaptations. It could also help me gain insight into what happened when the intervention was not adapted efficiently and how was this fixed. All these factors could benefit the reverse innovation of the intervention to the UK NHS context.

4 The Women's Group PLA cycle

In this Chapter I will explore the previous applications of the evidence-based intervention that has been selected as a potential candidate for theoretical reverse innovation. I will provide an overview of the women's group PLA cycle as a narrative review. I chose not to conduct a systematic review as there was already one written by Prost et al. (2013) (3).

This narrative review has four aims:

1. To define the components of the Women's Group PLA Cycle operation model
2. To explore the concepts that informed the foundation of the women's group PLA cycle intervention
3. To explore the similarities and differences between the seven women's group PLA cycle cluster-RCTs
4. To identify potential areas of adaptation to the women's group PLA cycle that could support the reverse innovation of the intervention from multiple LICs to the UK.

4.1 The evolution of the Women's Group PLA Cycle

The women's group PLA cycle intervention was created in response to a study by Bolam et al. (1998) which demonstrated that didactic postnatal education for mothers on neonatal care practices failed to significantly improve breastfeeding practices and uptake of immunisations in Nepal (171). The individual RCT trial was conducted by UCL and local partner MIRA between November 1994 and May 1996 in the government-funded Prasuti Griho hospital in Kathmandu, Nepal (171). The intervention included four groups: (1) Group A— health education immediately after birth and an additional session three months postpartum; (2) Group B— health education at birth only; (3) Group C— health education at three months only; (4) Group D— no health education. Five hundred and forty mothers were randomly allocated to one of the four groups. The intervention included two twenty-minute one-on-one information sessions with postpartum women from low-income households. The study selected midwives and community health workers as health educators who they believed could establish a rapport with the mothers to deliver the information sessions (171). The primary outcome measures related to the participants' knowledge of infant care and uptake of postnatal family planning.

After failing to demonstrate a significant difference between study arms, Bolam et al. (1998) highlighted four key facts: (1) health education is widely promoted in primary care, but there have been few rigorous evaluations of its impact, especially in low-income countries; (2) the Bolam et al. (1998) trial tried to change behaviour with a maximum of only two contacts: the efficacy of health education interventions that rely solely on giving people information over short periods of time to bring about a change in health behaviour is unproved; (3) interventions should be evaluated before being implemented on a large scale; (4) the Bolam et al. (1998) trial only captured participants that had selected a health facility based birth: alternative strategies for health promotion in LICs are required to engage communities that may not access health services. (171).

Bolam et al. (1998) demonstrated that future interventions needed to include an alternative method of health information delivery over a sustained period with several contacts that could offer potential scalability (171). This prompted Anthony Costello (principal investigator) to explore alternative interventions to address neonatal care practices in Nepal. Understanding the context that drove the research team to explore new methods of health message delivery will facilitate the adaptation process as it will demonstrate which components of the women's group PLA cycle are integral parts of the intervention and which can be adapted.

Three main areas informed the foundations of the women's group PLA cycle Nepali trial:

1. The protocol was derived from the Bolivian Warmi Project (172)
2. The philosophical principles encapsulated those of Brazilian Paolo Freire's *critical conscientiousness* (173-175)
3. The tools were inspired by Robert Chambers Participatory Rural Appraisal (PRA) (176).

In the following section I will present the details of each of the aforementioned areas and illustrate how the MIRA Makwanpur team created the women's group PLA cycle and how they followed research study design recommendations from the Bolam et al. Nepali RCT (171).

4.1.1 The Warmi Project

The Warmi Project used women's groups to improve maternal and child health outcomes in a population of 15,000 in rural Bolivia (177). This study did not have a control, and it was led by Lisa

Howard-Grabman in partnership with Save the Children Bolivia and the USAID MotherCare Project (172). The study was implemented in a remote area of Bolivia which had limited access to conventional health services. The intervention offered a bottom-up method of education that encouraged communities to advocate change in their contexts (177). The project established 50 women's groups in the province and was viewed as being potentially scalable across Bolivia (177). The study explored perinatal mortality rates and obstetric behaviour in women through 409 cross-sectional interviews and 179 questionnaires that captured the demographic characteristics, obstetric history and details of the most recent childbirth before and after the study (2). Criticisms could lie in the fact that this study was not an RCT and this could raise questions around rigour and how the study was controlled to address potential biases. The Warmi Project claimed to successfully reduced neonatal mortality from 117 per 1000 live births to 43.8 per 1000 live births in fifty communities in Inquisivi Province (177). Nonetheless, without a stringent monitoring and evaluation process and with no randomisation, there are questions about the validity of the results from the Warmi project.

The Warmi project based the design of its intervention protocol on an established and proven methodology from Save the Children Indonesia's Community-Based Integrated Rural Development (C-BIRD) which utilised community capacity to identify local needs and plan projects using existing resources (178). The C-BIRD project aimed to involve residents in rural low-income households in Indonesia in their village decision-making and planning processes. It did this by exploring three key areas: the evolution of village community development committees; the application of an open management style at both local project and area program management levels; and the development of informal relationships between Save the Children staff and villages, and between staff and government officials. The results of the C-BIRD project suggested that training through community committees could increase awareness of village management practices by community members from low-income households which in turn could increase the number of independent projects that were developed by the communities. This demonstrated Freire's philosophy of promoting collective action through education by encouraging communities to critically examine their environment (section: 4.1.2) (179).

The C-BIRD project was an exercise in community-wide participation and management activities. The Warmi project built on this methodology by adding an "*auto-diagnosis*" cycle within a women's group structure, which offered a continuum of peer-led sessions for women across the whole community and a focus on maternal and child health (177). See Figure 2: The Warmi Project Meeting Cycle.

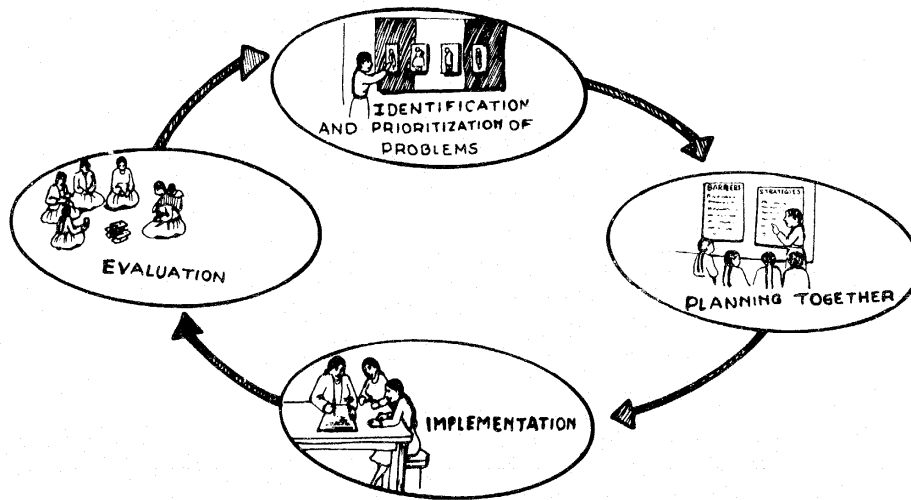


Figure 2: The Warmi Project Meeting Cycle (172)

Like the PLA cycle, the Warmi project moved through four stages: auto-diagnosis of issues relating to neonatal mortality; planning of strategies to address these issues; implementation; and a post-implementation evaluation (172, 180). At a glance, the Warmi project cycle looked identical to the PLA cycle, however, the post-implementation evaluation process differs significantly (172). It also provided supply-side strengthening by training of traditional birth attendants (177).

The Warmi project used similar participatory evaluation techniques, but instead of the groups conducting this evaluation they had a specific team conduct the final evaluation (172). Nine female community representatives participated in the evaluation with six external evaluators. The Warmi project manual was not piloted, but changes were made during implementation. This led to some adaptations to the stages of the cycle such as the suggestion that new or existing issues should be identified and prioritised by the group when they had ‘solved’ another issue, this gave way to the cycle-like approach (172). The Warmi project demonstrated that structured action cycles propagated via women’s groups can affect maternal and child health, however, the components of the intervention that facilitated behaviour change were not understood (177).

The Warmi project inspired principal investigator Anthony Costello to incorporate a community based, female volunteer led, iterative intervention in Nepal (172). This was seen as a new alternative method of health promotion that was cost-effective and potentially scalable (in line with the

recommendations of Bolam et al.) (171). The Warimi project recommended that further research needed to be conducted to assess the transferability of the intervention into different contexts (177). This methodology was adapted by the MIRA Makwanpur team in the Nepali trial (section: 4.3.1), which was the first to test their version of the participation action cycle in a cluster RCT (18).

4.1.2 The principles of Critical Consciousness – Paolo Freire

The Warimi Project encouraged their group participants to critically examine their environment to promote social cohesion (172) and the women's group PLA cycle (18). Knowledge of the environment and the channels which can instigate change in that environment are an integral part of gaining democratic control over the political, economic and social structures in a society (175). Paolo Freire's *Pedagogy of the Oppressed* suggests that social change can be initiated through encouraging individuals in a low-income community to question their context (175, 181). Status, power, and domination of the oppressor are not possible without the existence of the oppressed (174). This form of research is referred to as "*activist participatory research*" (179).

Encouraging underprivileged communities to question their environments and embark on campaigns that challenge political parties was part of Freire's plan to address inequalities faced by communities and oppressors. Freire (1969) defined oppressors as "*those who deny personal autonomy of others by imposing a worldview paradigm onto the oppressed that denies them the power to direct their own lives*" (181). According to Freire, this process of oppression has two scenarios. Scenario one involves the oppressed conducting a situational analysis which results in the realisation that they are suffering oppression (181), and, through the process of reflection and identification of common issues, they are able to form collective action (181). In the second scenario, which evolves from the first stage, the oppressed become liberated and the oppressors become powerless (175, 181).

Freire (1973) believed that many health problems are rooted in powerlessness and promoting collective action via creation of a common goal or purpose could encourage the development of critical consciousness (173). He encouraged the participants in his adult education programmes in rural Mexico to learn via critical analysis of their context (174). He believed that education was the key to the liberation of the oppressed who were usually governed by a member of the bourgeoisie (174). The oppressed cannot switch places with their oppressors to achieve social change and they cannot become oppressors at a macro level (181). The most inalienable solution is for the oppressed to evaluate their own position in the social hierarchy; then they can gain equal rights and lobby for a

civic voice so that they can become less dependent on their oppressors and become autonomous (181).

The Warmi Project (177) and the MIRA Makwanpur trial design (175) used these philosophical principles to underpin the cyclical examination of context in the trials. In terms of the women's group PLA cycle, the philosophical principles of Paolo Freire can be interpreted to mean more than the disempowerment of an oppressive individual in government. Across the women's group PLA cycle seven trial contexts, there were several factors that were oppressing individuals which were identified as a problem by the groups in all seven trials (14, 15, 17-20, 182). The intervention encouraged participants to question their environment and why certain practices resulted in adverse health outcomes. It disseminated health information via a dialogue led by a volunteer local female facilitator who had received some training in stillbirths and neonatal deaths and care but was not a health professional. The problem and identification stage of the cycle was the component that galvanised the participants in the group by demonstrating that there were common issues relating to neonatal morality (180). This allowed the participants of the groups to address issues on the micro level (self, family, and neighbours), meso level (community, locality, and village) and to lobby for change at a macro level (government, national policy).

The women's group PLA cycle applied Freire's principles by using volunteer peer-led women's groups to propagate the cycle. The groups were peer led, and this allowed them to examine common issues within their context and to design strategies to address them as most participants had the same literacy levels and were of similar socio-economic status.

4.1.3 Critiques and challenges of Freire's Critical Consciousness

Freirean pedagogies have been subject to some challenges relating to both the theoretical and practical applications. I will present some of these challenges which I believe could relate to the reverse innovation of the women's group PLA cycle in this section.

First, Freire indicates that populations are dichotomous (oppressed versus oppressor) and this could be viewed by an over simplified understanding of class struggles. It does not explore the intersectionality or heterogeneity that contributes to inequalities within a context. It also suggests that dialogue should be used as a tool to overcome oppression and that this should occur in group setting. This could be

problematic if the social determinants of health such as socioeconomic status (SES), ethnicity or age are not factored into the group participant selection. This could reinforce some of the inequalities within the group and prevent a continuous dialogue involving all participants.

There is also the potential that those that are acting in the facilitator or educator capacity take advantage of their position of power and use it to manipulate their group. There was an assumption by Freire that dialogue can result in liberation, and that a group acknowledging their collective inequalities could set aside their potential differences and advocate for democracy. However, there is the possibility that agenda could be influenced or potentially commandeered by those in positions of power.

Through this critique, I recognized that Freire's perspective on human nature foregrounded cognitive rationality, which presented itself as a limitation when considering my ontological beliefs and the focus of my research; and focused on the 'collective' rather than individuals, which is a shortcoming in relation to person-centred research that acknowledges the uniqueness of participants.

Acknowledging these limitations enabled me to draw upon wider philosophical perspectives around embodiment and person-centredness to develop more complete theoretical principles to underpin the development of my research methodology and methods. These will inform the ways in which I work with nurses, as participants and co-researchers, to explore the concept of muchness in nursing; the factors that enable their subjective experiences of well-being; and how muchness contributes to the development of person-centred cultures.

Yet despite these criticisms, Freire's work continues to be debated and this ideology continue to inform programmes that support community development across the world. Whilst I accept the criticisms outlined above, and recognise that these create limitations in Freire's thinking, I still believe that they are sufficiently coherent and robust to inform the method of learning in the women's group PLA cycle model.

4.1.4 Participatory Rural Appraisal – Robert Chambers

The women's group PLA cycle used a group of unique tools inspired by a collection of approaches known as Participatory Rural Appraisal (PRA) to deliver health messages and encourage collective action within each group (183). PRA includes a variety of techniques that encourage individuals

residing in rural areas to analyse and enhance their environment (176). PRA uses approaches from activist participatory research (179), agroecosystem analysis (184), applied anthropology (185), field research on farming systems (186), and rapid rural appraisal (RRA) (187). Robert Chambers at the University of Sussex, then Institute of Development Studies, first developed PRA in the 1970s (183). Prior to the 1970s, international development used didactic approaches to extract data from rural communities using survey questionnaires in a top-down manner (RRA) (183). Although PRA is influenced by participatory techniques, it was chiefly derived from RRA. A comparison of the two approaches is available in

Table 1 below. Major differences lie in ownership: RRA differs from PRA, because in RRA the information is elicited and obtained by researchers, whereas in PRA the information is obtained and shared by the target population, thus encouraging them to take ownership of any outcomes (183).

Table 1: Rapid rural appraisal (RRA) technique comparison to Participatory rural appraisal (PRA) technique (183, 187)

	Rapid Rural Appraisal	Participatory Rural Appraisal
Period of major development	Late 1970s, 1980s	Late 1980s, 1990s
Major innovators based in	Universities	NGOs
Main users	Aid agencies Universities	NGOs Government field organisations
Key resource earlier overlooked	Local people's knowledge	Local people's capacities
Main innovation	Methods	Behaviour
Predominant mode	Elicited, extractive	Facilitating, participatory
Ideal objectives	Learning by outsiders	Empowerment of local people
Longer-term outcomes	Plans, projects, publications	Sustainable local action & institutions

PRA encourages local people to use dialogue, discussion and creative ways of critically examining their environment. Researchers should maintain a relaxed attitude and avoid rushing the participants, show respect and be self-critically aware. Visual aids are used to facilitate an iterative process of investigating and analysing findings, either through groups or comparisons. Target populations conduct most of the initial formative research such as: community mapping and/or modelling;

conducting transect walks and reporting observations; investigating and interviewing potential recipients or stakeholders; leading on the analysis; disseminating findings; and planning interventions based on these activities (183). Strengths of this approach lie in the innovation continuum, knowledge sharing and exchange within and between communities.

PRA research operates on the following six principles:

1. **Target population knowledge and capabilities**- the target population have a greater capacity to map, model, quantify and estimate, rank, score and diagram their environment than any outside researcher.
2. **Relaxed rapport**- establishing a relaxed working relationship between the research team and the target population early in the process can facilitate the participatory process by reiterating that the target population are the brokers of the knowledge, not the research team.
3. **Diagramming and visual sharing**- these methods are popular with target populations because the groups can map, model or use diagrams to illustrate their information, leaving it open for discussion, manipulation and appraisal. Physical objects can be used in interactive sessions to encourage participation in the groups.
4. **Sequences**- relates to an iterative process of constructing and reviewing ideas which become successively more detailed and useful, or which include complementary information. This section relates to mapping exercises.
5. **Training and reorientation for outsiders**- these elements can be reduced because the target population should largely lead on the discussions, planning and implementation of their strategies. The researcher may only be there to observe and/or guide the group back to the topic (if there is a set agenda).
6. **Sharing and spread**- the three pillars of PRA are methods, behaviour and attitudes, and sharing experiences and learning from them is a fundamental attribute of the PRA technique. In this way, innovations can be continuously stimulated

PRA techniques offer alternatives to formalised methods of data collection, however, due to their qualitative nature, the data cannot be extrapolated to the wider population. Although they can generate a wealth of context-specific data, they do not have the statistical power of quantitative techniques.

They are approaches that encourage target populations to address the issues within their context that they consider important and they are generally not confined to the research priorities of outsiders.

PRA techniques encapsulate the alternative to top-down health message delivery that Bolam et al. (1998) were searching for after the failure of their original trial in Nepal (171). The participatory element generates diversity; target populations can play a part in interpreting, applying, and occasionally inventing methods of data collection, delivery and dissemination (176, 188). The women's group PLA cycle employed PRA principles, particularly around: the informal nature of the groups; using visual methods to empower underprivileged populations; presenting a topic for analysis, but not leading the conversation; using qualitative techniques to ascertain issues within context over quantitative questionnaires; and using iterative methods of information generation over classic anthropological information extraction methods.

The women's group PLA cycle is marginally more structured than straightforward PRA methods because of the addition of the four-stage action cycle and the availability of a formal and optional PRA-inspired toolbox. PRA principles encourage groups to be inventive and they are encouraged to improvise, whereas the women's group PLA cycle groups have a preordained agenda and aims, and objectives set out for each group. Although how much the group deviates from the agenda are at the discretion of the group facilitator. They are also encouraged to have a strong group with strong natural leaders will take discussions in new direction. The group facilitators try to adhere to the designed programme to a large extent, but also encourage iterative discussions through the Freire (1972) critical consciousness method of learning (179).

PRA techniques were applied to the women's group PLA cycle to encourage the target population to flow through a continuum of learning, sharing and reviewing their context. They could facilitate innovation by encouraging communities to constantly question their environment, but they currently only focus on rural contexts and not urban contexts. When adapting the women's group PLA cycle model for Tower Hamlets, some additional adaptation may need to occur to optimise the application of these tools to the urban context.

The PRA methods are not a panacea, they are a means of encouraging target populations to take ownership of the research and produce contextually specific strategies to address issues. Combined with the Warwi project protocol (172) and the principles of Freire (179), the PRA techniques provide a means of designing a participatory intervention.

The Warmi project demonstrated that target populations were amenable to community-led women's groups, Freire (1972) demonstrated that populations in rural regions with low literacy could be empowered through education to advocate for change on an individual, local and intuitional level (179), and the PRA techniques of Chambers (183) offered a range of tools and methods to optimise information delivery. Each of the three areas has contributed to the foundations of the women's group PLA cycle.

4.2 Components of the Women's Group PLA Cycle operation model

The women's group PLA cycle is a community-based female facilitator-led participatory model that seeks to address adverse maternal and neonatal health outcomes and has been proven efficacious across multiple RCTs in Bangladesh (14, 15), India (17, 20), Malawi (182, 189) and Nepal (18). The aim of the intervention is to increase appropriate care-seeking behaviour and increase the adoption of home prevention and care practices for mothers and newborn infants in low-income, rural settings with high maternal and neonatal mortality and low access to services (3), with a particular focus on women of reproductive age, particularly pregnant women and new mothers, as the primary beneficiaries. The PLA cycle groups are women-centred; however, the actions of these groups can benefit the surrounding community. The groups aim to capture women of reproductive age (15-49 years) but were open to women of all ages (14, 17, 18, 20) and sometimes men (16, 189).

The intervention centres around the creation of women's groups that deliver the Participatory Learning and Action Cycle (PLA Cycle) (18). This four stage cycle includes an iterative process of problem identification, solution design, implementation and post-implementation evaluation (3) (16) (see Figure 3: The Participatory Learning Action Cycle). Women's groups exist in every context, but not all groups follow a structured action plan. It is the inclusion of the PLA Cycle that makes this intervention different to other women's groups (190).

4.2.1 The four components of the Participatory Learning and Action Cycle

Figure 3: The Participatory Learning Action Cycle illustrates the four-stage action cycle that was propagated during the groups. Within each of the four stages there is an average of three meetings. Each meeting has a specific set of objectives which guided the groups through the process. Each

meeting involved activities facilitated by tools to initiate discussion around subjects relating to maternal and neonatal health. Some of these sessions would involve the group facilitator disseminating health information. Examples of the adapted cycles from the subsequent six trial can be viewed in Figure 5: Makwanpur PLA cycle , Figure 6: Ekjut PLA cycle , Figure 7: The BADAS PLA cycle , Figure 8: The seven phase Mumbai trial adapted cycle, Figure 10: The MaiKhanda women's group PLA cycle, and Figure 9: MaiMwana women's group PLA cycle (204).

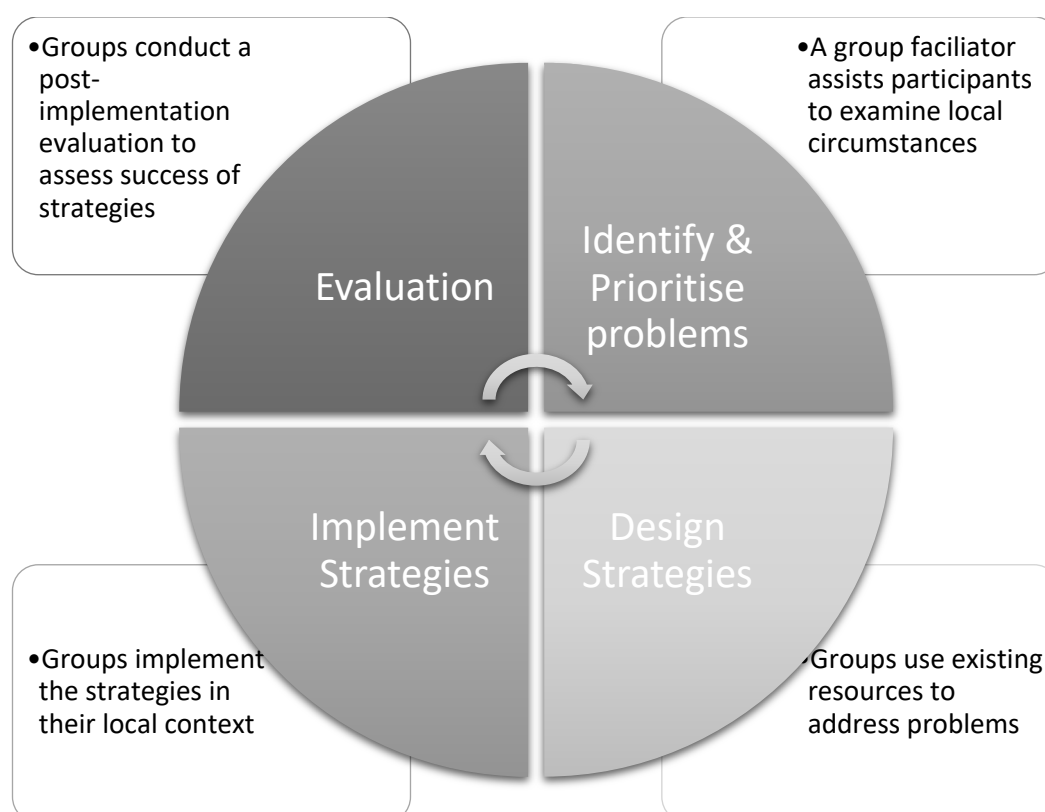


Figure 3: The Participatory Learning Action Cycle

The inclusion of the four-stage PLA cycle is what makes the intervention unique. Without this cycle the women's groups are unstructured. As previously discussed, the cycle was designed based on theories from a variety of sources (3) using evidence from tested programmes. It is the cycle that allows the group to identify commonalities in practices, beliefs and resource shortages in their communities, and to work together to address those barriers and limitations in care.

The PLA cycle moves through several meetings at each stage, and this is the area that could be adapted for each context. Also, the contents, materials and logistics of each meeting should be

adapted to emulate local circumstances. All seven trials adapted these qualities to encompass cultural stipulations and social nuances within their trial context (14, 15, 19, 20, 182). There is evidence in the literature to indicate the contents in these tools was changed for each context, for examples, the Jharkhand and Orissa trial team added nutrition modules to the standard contents in response to the local environment (191, 192), however, they did not detail the process of adaptation, how the content was informed, or how the new materials were designed and implemented.

The groups were led by female facilitators who guided the groups through the four-stage cycle. The facilitators were married women from the locality who would typically be literate, but, as demonstrated by the Nepal trial, literate women were not always available in remote rural areas (18). Not all of the facilitators were volunteers, whereas in Bangladesh they were salaried employees. Subsequently, other trial have explored options of using incentivised facilitators but this was not used in either Bangladesh trial (14), and in Malawi they were given bicycles to travel between their groups (19). Each trial team recruited facilitators via a systematic recruitment process (19, 182) or if they had been nominated by village headmen or chief (14, 18). Manandhar et al. (2004) indicated that it was important to have a facilitator rather than a teacher as this could create community ownership and sustain participation (18). These women were given training that lasted between 5-7 days and refresher training at six months (3). These sessions included training in participatory communication techniques, basic perinatal health issues training and some knowledge of potential interventions/strategies to combat neonatal health issues so they could act as brokers of information and catalysts for change (18).

In six of the seven trials, the group facilitators convened an average of 10.9 groups per month (range 9-18) (16, 18, 19, 189, 193). Six of the seven trials conducted monthly meetings (14, 15, 18, 19, 182) and the only urban RCT in Mumbai conducted fortnightly meetings (17).

The group facilitator manual detailed the specific learning objectives for each meeting and was available in the lingua franca in each region: Nepal – *Nepali*, India – *Hindi*, Bangladesh – *Bengali*, Malawi – *Chichewa*. In some settings there are several local languages spoken in the RCT implementation clusters, for example individuals in some clusters in the Mumbai trial practiced Islam and spoke *Urdu* (17), so group facilitators were responsible for translating the material in the manual into these languages if needed.

Trained supervisors oversaw the facilitators and groups. Trained managers were selected by the trial teams to manage the PLA cycle programmes. **Error! Reference source not found.** The facilitators, supervisors and managers were trained on how to deliver the specific manual and how to facilitate focus groups.

4.2.2 The role of the female group facilitator

The MIRA Makwanpur stressed the importance that the intervention should be community-led so that the community can take ownership of the strategies they formulate (190). The criteria for the female group facilitator were typically a local married women who was respected in the community and was literate (14, 15, 18, 20), however, MIRA Makwanpur had to review the literacy aspect when they were unable to recruit enough literate women who had the time to deliver the groups (18). The role of the group facilitator included guiding each group through the four-stage cycle.

4.2.3 Community entry process

Each of the seven trials used a local NGO partner to implement the trial while UCL led the monitoring and evaluation. This included a facilitated community entry process (190). It appeared that each NGO had existing links with UCL and previous experience working in the area where the trial was implemented (180). They were then able to use their contacts within the communities to gain access. For example, SNEHA was working with the Municipal Corporation of Greater Mumbai to deliver the 'City Initiative on Newborn Care'. The team were able to piggyback the trial onto this initiative and gain support from the government facilities (17).

Although each trial had a community entry process, the procedure varied depending on the local circumstances. The study teams utilised their existing relationships within each context to build links with the target population. This demonstrated that working with different local partner along the intervention development and implementation life cycle could facilitate a more efficient process of intervention integration in the context.

4.2.4 Community group rather than women's group

It could be argued that the term ‘women’s group’ is out of date as the role of men became stronger every time the intervention was implemented in a new context. Several of the RCTs had men within their groups (14, 15), there were also men’s groups set up in Malawi (182), and throughout the other PLA cycles men were encouraged to attend certain meetings and dissemination events (190). This potentially shows that the community group is the core component of the women’s group PLA intervention and not the composition of the groups. It is the manner of bringing the community together and promoting cohesion that is important.

The cluster-RCTS demonstrated through rigorous evaluation methods that women’s group PLA cycle can be successful in reducing neonatal mortality if a third of all pregnant women in the clusters attend the meetings and if there is significant population coverage (50).

4.3 Previous applications of the Women’s Group PLA Cycle

Exploring the differences between the women’s group PLA cycle cluster RCTs will assist with the identification of components that can be adapted and those that cannot. The seven trials of the women’s group PLA cycle took place in rural settings in Nepal (18), Bangladesh (14, 15), India (191) and Malawi (19, 182), and there was one urban trial in India (17). The first women’s group PLA cycle trial was conducted in a rural district of Nepal (190), subsequently there were four trials conducted across three rural contexts (14, 15, 20) and one urban (17) context in Asia. To test the transferability of the intervention, two trials occurred in rural Malawi (19, 182).

Each of the seven trials had seven qualities that indicated that they were part of the women’s group PLA cycle trial group. These qualities are listed below:

1. All seven original trials included women’s groups that propagated the PLA cycle
2. The principal investigator for all seven trials was Professor Anthony Costello of the UCL Institute for Global Health
3. All seven trials aimed to involve women of reproductive age (15-49 years)
4. All seven trials study outcomes included neonatal mortality as a primary outcome, and maternal mortality and stillbirths as a primary or secondary outcome
5. All seven trials were cluster randomised-controlled trials
6. All the seven trials offered supply-side strengthening in both control and intervention clusters

7. All seven trials were implemented by local partners.

4.3.1 Nepali trial- The Operational model

The first trial from which all subsequent trials were adapted was implemented in Makwanpur district in rural Nepal (190). Existing research had indicated that a new approach was needed to address adverse neonatal and maternal health outcomes in Nepal (171). The women's group PLA cycle was rolled out in Makwanpur district in a central region of Nepal, a rural culturally diverse, middle-hill society (180). The trial team consisted of members of the local NGO MIRA Nepal, and research professionals from UCL's Institute for Global Health. This team engaged with external stakeholders – the Makwanpur District Public Health Office, the Ministry for Health and Population, the Nepal Nutrition Project, *Saralhi*, members of the local geo-political administrative units called Village Development Committees (VDCs) and several other local health professionals and social care professionals (190). Forty two VDCs in Makwanpur were used as clusters (18). There was one community facilitator per cluster, and each community facilitator was nominated by a local community leader or recruited by the trial team to do house to house data collection on pregnant women (190). Twelve supervisors who were based locally worked in the intervention area, each responsible for a population cluster covering 60 km² and an average population of 7000 (194).



Figure 4: Women's groups using the PLA cycle in Makwanpur District, Nepal (credit – Thomas Kelly, Save the Children)

The women's groups were facilitated by a local woman who was married. Literacy was preferred for practical reasons but not always possible. The group facilitators guided the groups through the action cycle. In the MIRA Makwanpur trial, there were a total of ten meetings (see Figure 5: Makwanpur PLA cycle (180)).

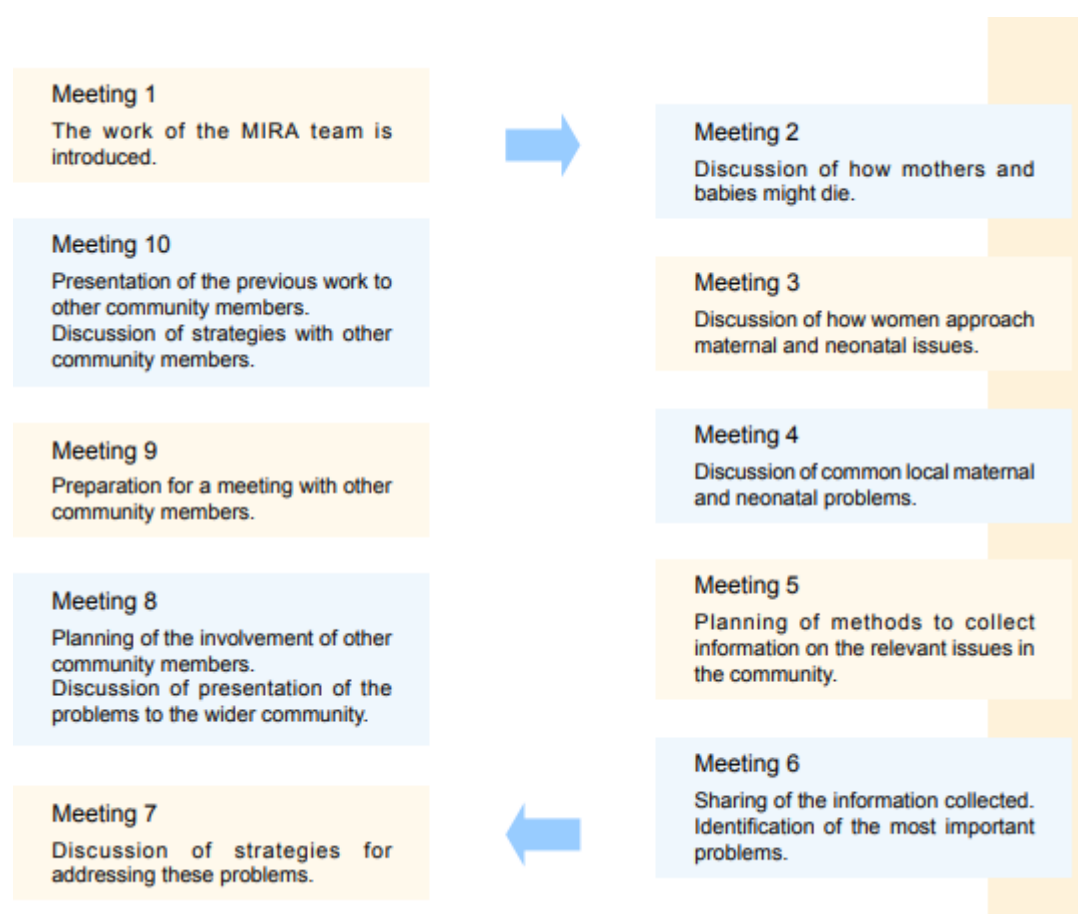


Figure 5: Makwanpur PLA cycle (180)

The MIRA Makwanpur trial design used existing community structures to piggy-back the women's group PLA cycle trial including engaging local NGOs to support implementation. The MIRA NGOs were able to lead on implementation and advice on which adaptations should be made to the Warmi manual for the facilitators, the trial protocol, the tools (depicting local circumstances and in the local language). They had trained and experienced staff who knew the trial context, had access to a local

illustrator who could help design the tools and activities for the group and had existing links with the government of Nepal and the Ministry of Health and Population (190).

The groups were aimed at pregnant women, but older women and teenage girls below 15 were also encouraged to attend. An example of one of the groups can be seen in Figure 4: Women's groups using the PLA cycle in Makwanpur District, Nepal (credit – Thomas Kelly, Save the Children) – the women are meeting in an outdoor community space during the day, after they had completed their morning tasks and before their husbands returned from work.

4.3.1.1 Health service strengthening activities in Makwanpur

A baseline service audit was conducted to review all antenatal health services in Makwanpur district (18, 195). Health service strengthening happened in both control and intervention areas for ethical reasons, and also to test the true effect of the women's group PLA cycle (18). Health service strengthening activities included equipping all health posts and sub-health posts with open incubators, phototherapy units, warm cots, and neonatal resuscitation equipment (18). The MIRA Makwanpur team also prevented drug stock-outs by providing essential neonatal drugs at the start of the trial, and then worked with local health-service managers to design a strategy for future drug procurement (18). In partnership with the District Public Health Office, the MIRA Makwanpur trial team offered training in essential neonatal care for all government health staff, female group facilitators and traditional birth attendants (190). The primary health care workers who were based in the community received a basic neonatal care kit which contained rubber bulb for suction, tube-and-mask for assisted respiration, iodine, gauze, a baby wrapping cloth, and a pictorial manual (18).

4.3.1.2 Monitoring and Evaluation

The team used a surveillance system which monitored births, deaths and pregnancies (196). It was based on the Nepal Nutrition Intervention Project (197). The system utilised local female 'ward enumerators' to monitor pregnancy status of women in each cluster (196). Consent was obtained by 44 ward enumerators, who visited potential members of the cohort in their homes (180).

After a pregnancy was identified, a MIRA community facilitator local to each VDC interviewed the mother at 7 months gestation and then at one year post-partum (196). Potential outcomes were

reflected at each of the stages. Measuring outcomes and categorizing cause of neonatal death by questionnaire was locally adapted from existing questionnaires used by MIRA.

4.3.1.3 *Results*

During the trial period (November 2001 – October 2003), the neonatal mortality rate was 26.2 per 1000 live births (76 deaths in 2899 live births) in intervention clusters compared with 36.9 per 1000 live births (119 deaths in 3226 live births) in controls (adjusted odds ratio 0.70 [95% CI 0.53–0.94]) (18). Stillbirth rates were similar in both intervention and cluster groups (18). The maternal mortality ratio was 0.69 per 1000 live births (2 deaths in 2899 live births) in intervention clusters compared with 3.41 per 1000 live births (11 deaths per 3226 live births) in control clusters (0.22 [95% CI 0.05–0.90]) (190). Women in intervention clusters were more likely to have antenatal care, institutional delivery, trained birth attendance, and hygienic care than were controls (18).

4.3.1.4 *Cost-effectiveness*

Borghi et al. (2005) conducted an economic assessment of the Nepal intervention concurrently with the Makwanpur trial (194). They estimated that the women's group PLA intervention cost an average of US\$ 0.75 per person per year (US\$ 90 with additional health service strengthening activities) in a population of 86,704 (194). The incremental cost per life-year saved (LYS) was US\$211 (US\$251), and scaling up the intervention could rationalize on initial costs and technical assistance, reducing the cost per LYS to US\$138 (US\$179) (194). They concluded that the women's group PLA cycle intervention could provide a cost-effective way of reducing neonatal mortality (194).

The MIRA Makwanpur trial demonstrated that the women's group PLA cycle could assist rural low-income populations with the reduction of neonatal mortality through an iterative health education process and with the promotion of collective action (190). It had managed to develop and maintain a community mobilisation programme where previous programmes using outreach workers had failed (194). It also demonstrated a reduction in maternal mortality. It was viewed as a cost-effective and potentially scalable intervention which could be applied to similar settings (18).

4.4 Replicating the model

The Makwanpur, Nepal trial served as the operational model from which all the subsequent trials have been adapted (198). In the following section I will provide an overview of each of the subsequent six women's group PLA cycle trials.

4.4.1 Rural India trial

Trials in the largely tribal areas of Jharkhand and Orissa states in rural eastern India also recorded similar successful reductions in neonatal mortality (20). Implemented by the NGO Ekjut, the trial conducted 20 monthly meetings led by a group facilitator who was married, could travel to the meetings and could speak the local language (20). The group facilitators were volunteers who were trained for seven days, conducted 12-14 meetings per month and were responsible for a population of 500 (20). Each group was facilitated through the four stage PLA cycle (see Figure 6: Ekjut PLA cycle). The community was encouraged to enter a discussion about perinatal care practices, although the intervention primarily targeted pregnant women and new mothers. An adaptation to the Ekjut intervention was the addition of home visits conducted by the group facilitators to encourage pregnant women and new mothers to attend PLA group meetings.

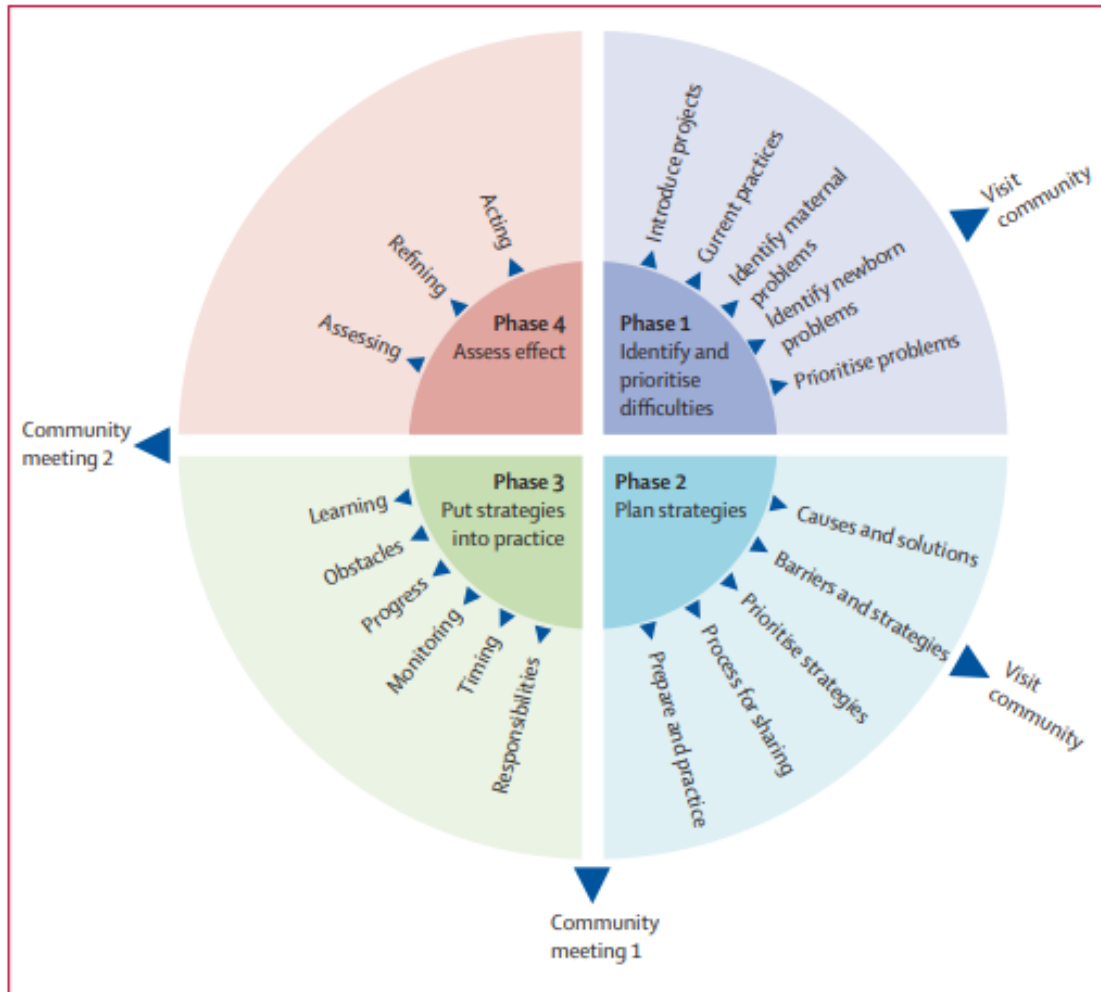


Figure 6: Ekjut PLA cycle (20)

The Ekjut trial was more cost-effective than the Makwanpur trial because of lower operating costs and greater effect of the intervention – a 45% reduction in neonatal mortality over the last two years (20). The trial concluded that the women’s group PLA cycle’s use of critical consciousness (179) supported collective action in the rural and underprivileged communities and this was an integral part of the success of the intervention (20).

4.4.2 Rural Bangladesh trials

There were two Bangladeshi trials: the first trial (February 2005- December 2007) (15) and the second trial (January 2009- July 2011) (14). Both cluster RCTs were implemented and managed by the Diabetic Association of Bangladesh (BADAS) in three rural districts (Bogra, Faridpur and Moulvibazar) of Bangladesh and evaluated by UCL. The same nine intervention and nine control

areas were used across both trials. The first trial established 162 groups across the intervention clusters (14). The second intervention supplemented the 162 original groups with 648 new groups and 36 new facilitators to run the groups (15). The intervention targeted women of reproductive age (18-49 years) who were permanently residing in the intervention clusters with a primary focus on newly married or pregnant women (199). Men could participate, but rarely attended.

The groups were guided through the four stage PLA cycle (see Figure 7: The BADAS PLA cycle) by a paid group facilitator in 19 monthly meetings, with two visits to the community and two community meetings. The group facilitator used PRA tools like picture cards and flip charts to incite discussion around perinatal care in the groups.



Figure 7: The BADAS PLA cycle (199)

The initial Bangladeshi trial showed no evidence of an effect on neonatal mortality (14). Azad et al. (2010) suggested that this could be due to three factors that relate to group facilitators population coverage and their ability to engage women of reproductive age:

1. The group population coverage of this trial (February 2005- December 2007) was approximately 1 per 1400 of the population (15), compared to the 1 per 700 of the Ekjut trial in India (20). This is crucial, because it demonstrated the optimum population coverage needed to significantly reduce neonatal mortality.
2. The female group facilitators were not always local women and there was one facilitator for every 18 groups (14) instead of one facilitator for every 9 groups like the Makwanpur trial (18). This meant that they had to travel long distances to get to their groups. During the trial period, there was flooding that prevented the facilitators attending the groups, therefore, some groups fell behind. The female group facilitators were not already for the refresher training at the same time and some missed the training as a consequence.
3. Increased workload of group facilitators meant that some facilitators were unable travel between groups and sometimes sessions were made shorter as a result. The trial team changed the group facilitators' allocation of groups from 1 per 9 in the MIRA Makwanpur Nepal trial (18) to 1 per 18 (14).

The second trial (2009-2011) did demonstrate a significant decrease in NMR of 20% (15). This intervention was adapted, and the adaptation was described by Houweling et al. (2011) in a bid to increase participation of pregnant women in the women's groups. Pregnant women in the community were now identified by facilitators, traditional birth attendants (TBAs), community health workers and women's group members, and were encouraged to attend the groups. Facilitators visited pregnant women and their families to explain the benefits of attending the women's groups and they kept a record of the number of pregnant women attending the groups (199).

These two trials were conducted in the same areas with the same trial team, the same PLA cycle and the same study design. They show why coverage is an essential component of the women's group PLA cycle. They also demonstrate how adaptations that are not based on evidence can have a detrimental effect on trial outcomes.

4.4.3 Mumbai, urban India trial

The purpose of the Mumbai trial was to improve neonatal mortality and to test if the women's group PLA cycle could be adapted for an urban context (200). The trial was part of the 'City Initiative' which was a public health agenda managed by the Municipal Cooperation of Greater Mumbai. Like the previous trials conducted in rural regions of Bangladesh (14), India (20) and Nepal (18), the

Mumbai trial included supply-side and demand-side strengthening. There was an abundance of government healthcare, private healthcare and unregulated providers around Dharavi, Mumbai (201, 202). The focus was quality improvement in government health facilities by introducing clinical protocols for maternal and neonatal services, improving cross-institutional and communication channels and linkages for patient referrals, and via the promotion of community mobilisation activities (14, 15, 191, 192, 199, 200, 203).

Five of the seven women's group PLA trials significantly reduced neonatal mortality (3, 14, 18, 189, 193, 204). The Mumbai trial did not produce evidence to suggest that it had significantly reduced neonatal mortality (3) and it could be argued that this renders the intervention inappropriate for the urban context (200). The availability and convenience of local health services in cities can make health seeking behaviours stronger, mortality rates lower and the delay in accessing health care shorter, rendering a community-based intervention less attractive to an urban population. Basing this conclusion on the outcome of one trial, however, may not be scientifically sound. Just because the women's group PLA cycle intervention did not significantly reduce NMR in Mumbai does not mean that it will not be efficacious in other urban settings. Understanding the process of adaptation should help unpick which components were acceptable within this setting and which were not. This should help implementation teams in the future understand how to adapt the intervention for their context.

Within the Dharavi locality, known as the Dharavi slum in Mumbai there is a diverse social heterogeneity (200). This social heterogeneity can impede collective action as the population competes for resources such as water and space. Six of the seven trials occurred in rural villages which were divided into clusters based on their geography or their administrative division, for examples the Nepal trial team based clusters on the Village Development Committees Nepal (180). Also, there were no outdoor community spaces for the women to gather, so the groups would be in cramped, small houses in the slum. This meant less women could attend and often meant that some groups would miss a meeting as not enough participants were present (17).

The Mumbai trial highlights the need to adequately explore contextual factors through formative research as it demonstrated that the baseline neonatal mortality rate was lower in this context than in the other six, and there were more accessible health services and stronger health seeking behaviours, especially since most of the pregnant women had travelled to Mumbai to give birth at a health facility (17, 200). Although access to healthcare is not limited by distance to health facility, it occurs through unavailability of affordable and quality health services (205). There was no significant difference

between the rates of stillbirths in the intervention and control arms (odds ratio 0.86, 95% CI 0.60-1.22), and the neonatal mortality rate was actually higher in the intervention arm (1.48, 95% CI 1.06-2.08) (3).

Success could be measured beyond the primary and secondary outcomes set out in the trial protocol and facilitator manual. The Mumbai trial did demonstrate that collective action could improve agency of individuals living in a high-density urban environment, however, the some urban women could be more isolated and this could make them reluctant to initiate change through group action, so the groups needed to be smaller (200). It did report behaviour change in certain clusters, but no visible population level effects (200). The groups could be built into programmes that target the most vulnerable populations that do not have access to the available services, and this could be combined with an initiative to support quality improvement in these health facilities.

The results of the trial prompted the SNEHA team to examine how they could adapt the model to fit the urban slum context. Participatory methods with seven phases (see Figure 8: The seven phase Mumbai trial adapted cycle) instead of four and based on the principles of appreciative inquiry were used in the meetings (200). This cycle had a total of 37 meetings across the four-stage cycle. It covered all of the stages of the PLA cycle, distilled them into individual phases rather than a group of meetings, e.g., discovery (phase 1), perception (phase 2), and energy (phase 3) stages are all components of phase one identify and prioritisation in the PLA cycle.

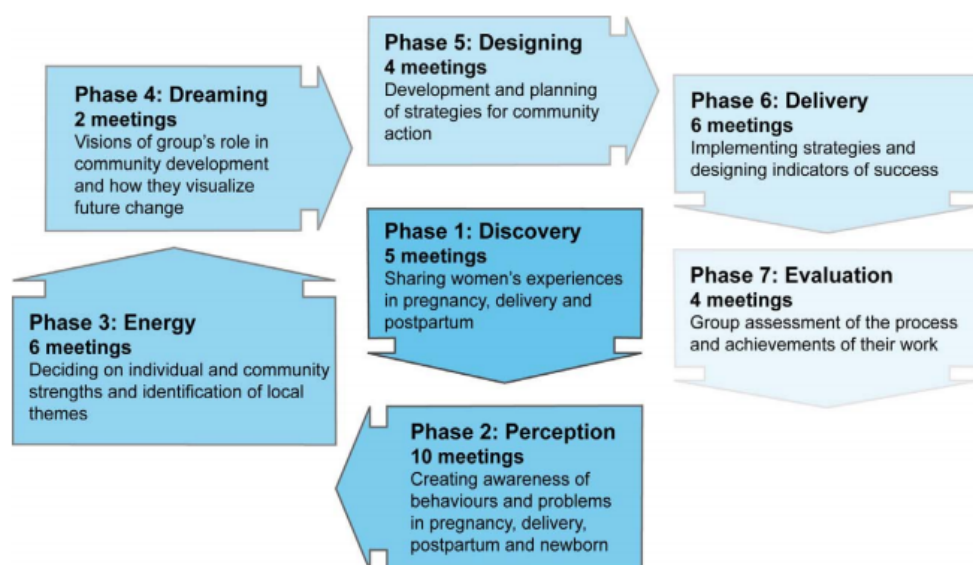


Figure 8: The seven phase Mumbai trial adapted cycle (200)

Adapting the PLA cycle by splitting it into seven stages and changing the form of inquiry compromises the fidelity of the intervention, thus arguably rendering the More et al. (2012) trial not a true women's group PLA cycle intervention (200).

4.4.4 Malawi trials

Testing whether an intervention is efficacious in different contexts is part of the intervention development process. Previously, the women's group PLA cycle had been tested in multiple different south Asian contexts. Translating the model into an African context that displayed similarly high rates of neonatal mortality with limited access to obstetric care was considered important. There were two trials in Malawi: the MaiMwana (189) project and the MaiKhanda trust (19). Both projects worked with local stakeholders in the health systems, government, chieftains and the local population. Both projects were supported by PACHI NGO. Both projects were set up specifically to conduct the women's group PLA cycle trials.

4.4.4.1 MaiMwana Project

The MaiMwana project ran a women's group PLA cycle as a factorial cluster RCT in the rural Mchinji district, Malawi (204). Two interventions were implemented by the project team concurrently, assisted by NGO Women and Children First: (1) the women's groups PLA cycle led by a female volunteer; and (2) volunteer infant feeding and care counsellors to promote perinatal health practices (189). The project partnered with the district health board on a range of health service supporting and strengthening activities such as male championship and community maternal death reviews. Women of reproductive age (10-49 years) were targeted primarily, mostly farmers (56.8%) and students (30.5%) (189).

Each group was led through the PLA cycle by a volunteer group facilitator. The PLA cycle was derived from the MIRA Makwanpur model (18). The four-phase cycle (see Figure 9: MaiMwana

women's group PLA cycle (204)) was delivered over a 20-month period. This cycle had considerably more meetings than the original Makwanpur trial cycle (18), with up to eight meetings in each phase. The rationale for increasing the number of meetings was not described in the literature. Participatory tools such as body mapping were used to identify and prioritise issues (phase 1) and picture cards were used to prompt discussions around key aspects of maternal and perinatal health.



Figure 9: MaiMwana women's group PLA cycle (204)

The women's group PLA cycle intervention successfully reduced NMR by 41% (in the intervention areas). Like all the interventions, the MaiMwana project team did not provide any additional resources to the groups, therefore, the groups had to devise plans to fund some of their phase 3 strategies.

Rosato et al. (2006) did say that the original women's group PLA cycle had been adapted for the Malawian context by the MaiMwana project team (204), however, they did not state the rationale for all of the adaptations. One adaptation that was mentioned was the illustrations on the picture cards. As

93.6% of the population in the Mchinji district identified as being Christian (189), the depictions on the materials were less graphic with no illustrations that showed women giving birth or reproductive organs. Another adaptation that was recorded but not recognised in the paper as an adaptation was adapting the content to encompass perinatal health care and maternal health care practices that were prevalent in Malawi. This would have been informed by the formative research conducted prior to implementation which would have included specific content on the main causes that influenced maternal and infant death in these regions of Malawi - haemorrhage, sepsis, ruptured uterus and eclampsia - and the main indirect causes - HIV, malaria and anaemia. The MaiKhanda trial also made adaptations to the target population of the intervention by excluding women who had lived in the vicinity of a good quality emergency obstetrics facility (19).

Women's groups in the intervention clusters implemented a wide range of strategies, with the most frequent being health education, voluntary testing and counselling for HIV/AIDS, village savings and loans, bed-nets to prevent vector-borne illnesses, vegetable gardens and bicycle ambulances (182). Both trials added a module that addressed the prevention of mother to child transmission of HIV since Malawi was in the midst of a HIV epidemic (19, 204).

4.4.4.2 MaiKhanda Trust Trial

The MaiKhanda team implemented and managed the application of the women's group PLA cycle across three rural districts in peri-rural Malawi (Kasungu, Lilongwe and Salima). This cluster RCT involved both the women's group PLA cycle intervention and health facility strengthening in a combined intervention. MaiKhanda ran 729 women's group, which were facilitated by 81 volunteer group facilitators supported by 9 staff (182). This trial utilised a factorial design which allowed the trial team to evaluate two interventions running in parallel, which saved some cost and time. The two trials were split into four arms; (1) health facility strengthening activities including provision of obstetric care training; (2) women's group PLA cycle; (3) combined health facility strengthening activities and women's group PLA cycle; and (4) control group (182). The intervention arm was unique because it addressed both the health facility supply side and the demand side; together they reduced neonatal mortality by 22% (182). The two trials that ran in parallel supported health service strengthening activities in all health facilities across the three districts.

The women's groups moved through the action cycle (see Figure 10: The MaiKhanda women's group PLA cycle), which had four meetings per stage instead of two; it also included a meeting (5) where

men were invited and two meetings (7 and 8) to involve the wider community in the planning of strategies to address prioritised issues.

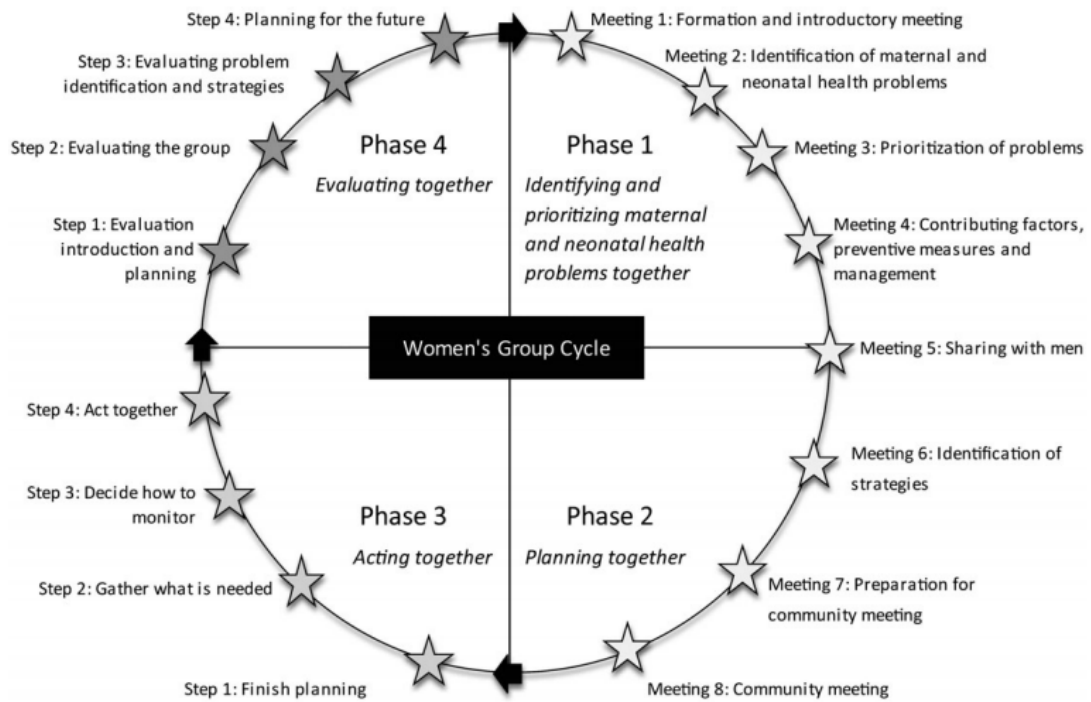


Figure 10: The MaiKhanda women's group PLA cycle (19)

First author & year	Setting	Study population	Length of intervention (months)	Intervention details	Control group	Frequency	Coverage	Reduction in neonatal mortality relative to control
Manandhar et al., 2004 (18)	Makwanpur district, Nepal	24 clusters; population 7000 per cluster Married women aged 15-49 living in Makwanpur district; pregnancies registered between Nov 1, 2001-Oct 31, 2003 were included	24 months	12 clusters (2972 births) Each cluster had a female facilitator who had brief training in perinatal health issues	Health service strengthening and training of traditional birth attendants	Monthly groups	1 group per 765 population 1 group facilitator per 7000 9 groups each 9 groups each	30% reduction
Tripathy et al., 2010 (20)	Three rural districts of Jharkhand and Orissa, India	36 clusters; mean population 6338 per cluster Women living in rural areas between the ages of 15-49 years, who gave birth between July 31, 2005- July 30, 2008	26 months	18 clusters (9770 births) A local woman facilitated 20 meetings after 7 days of training; groups moved through the four phase PLA cycle; groups were open to the whole community but primarily targeting pregnant women and new mothers	Health service strengthening	Monthly groups	13 groups per facilitator	32% reduction

Azad et al., 2010 (14)	Three rural districts in Bangladesh	18 clusters; mean population 27953 per cluster Women aged 15-49 living in the three rural districts of Bangladesh who gave birth between Feb 1, 2005, and Dec 31 2007	14 months	9 clusters (15 695 births) A local woman facilitated the groups that propagated the PLA cycle after 5 days of training; she visited every 10 th household in the intervention clusters and invited married women of reproductive age to join the groups; mother-in-law, adolescent girls, and later, other women. 162 groups set up.	Health service strengthening and training of traditional birth attendants	Monthly groups– some groups missed because of coverage by group facilitators (1 per 18 groups)	1 group per 1414 population 1 group facilitator per (2-5) x 7000 18 groups each	No significant reduction
More et al., 2012 (200)	Dharavi slum, Mumbai	48 clusters; population 5865 per cluster. Women recruited between Oct 1, 2006, and Sept 30, 2009. Women from transient	36 months	24 clusters (9155 births) The PLA cycle groups were facilitated by a local woman with secondary level education and leadership skills. The facilitator met		Fortnightly	10 groups per 1000 households	No significant reduction

		<p>communities were excluded</p> <p>Total population coverage- 283,000</p>		<p>other facilitators and a supervisor weekly. The groups followed a 36-meeting cycle and were open to all women. Participatory methods with 7 phases, based on the principles of appreciative inquiry were used in the meetings.</p>				
Lewycka et al., 2013 (19)	Mchinju district, rural Malawi	<p>48 clusters; mean population 3958 per cluster.</p> <p>Women aged 10-49, who delivered a child between Feb 1, 2006, and Jan 31, 2009</p>	36 months	<p>24 clusters (9374 births, n 379 births per cluster) in the factorial analysis, 12 clusters (3129 births) in the stratified analysis. Women's group led by a female facilitator through the PLA cycle over 20 meetings. Facilitators were local, literate women (20-49 years); they received 11</p>	Health service strengthening in the control group	Monthly		41% reduction

				days training, with refreshers every 4 months, 1 supervisor for 6 facilitators.				
Colbourn et al., 2013 (182)	Kasungu, Lilongwe and Salima, rural districts of peri-Malawi	62 clusters; mean population of 3934 per cluster. Open cohort of pregnant women between Oct 1, 2008, and Dec 31, 2010. Women were excluded if they had access to comprehensive obstetric care.	27 months	Two factorial design with four different combinations: (1) women's group PLA cycle intervention combined with health service strengthening activities; (2) health facility strengthening; (3) women's group PLA cycle; (4) control 15 clusters (10 329 births); 81 volunteer facilitators supported by nine MaiKhanda trial team members, each formed a women's	Quality improvement	Monthly	1 group facilitator had 9 groups	20% reduction in combination clusters

				group that propagated the PLA cycle.				
Fottrell et al., 2013 (15)	Three rural districts in Bangladesh	18 clusters; women who were permanent residents of the union in which their delivery was identified between Jan 2009, to June 2011.	18 months	9 clusters (9106 births) Set up 648 groups with new facilitators, adding to Azad et al., (2010) 162 groups (14)– increasing population coverage; from Jan, 2009, the new groups moved through the PLA cycle focusing on maternal and newborn health	Health service strengthening	Monthly	1 group per 300 population 9 group facilitators plus recruitment of 36 new CF 18 groups each	38% reduction

Table 2: Characteristics of the seven original women's group PLA cycle trials (3, 14-16, 19, 49, 189, 191, 192, 199, 203, 204, 206)

4.5 Summary of the features that led to successful implementation in the original seven contexts

A summary of the key features of each of the seven original trials is detailed in Table 2. The MIRA Makwanpur trial reported success by reducing neonatal mortality from 117 to 44 per 1000 live births over three years (section 4.3.1) (18). The Ekjut trial in Odisha and Jharkhand, a rural India trial, recorded similar success by reducing neonatal mortality rate of 58 to 36 per 1000 live births (section: 4.4.1) (20). As the original Bangladeshi trial did not record a significant decrease in neonatal mortality (section: 4.4.2) (14), population coverage was increased to approximately 1 group per 700 population which facilitated intervention success (15).

Each of the papers published on the original seven trials listed specifics for community facilitator criteria, length of cycle, frequency of groups, number of clusters control, outcomes, study population and setting (14, 16, 17, 47, 190). The traits of these seven trials are tabulated in Table 2.

Commonalities included the inclusion of the women's group format and the propagation of an action cycle by a female volunteer. In the More et al. (2012) trial, however, the cycle was adapted to include appreciative inquiry and a seven stage action cycle (section 4.4.3) (200). Furthermore, due to the transient nature of the environment, not all women were included, and the meetings were held fortnightly, so the groups could move through the cycle more quickly.

The groups aimed at women of reproductive age (15-49 years), although other members of the community were allowed to attend the groups (20) and the trials chose to include adolescents (14, 19). Lewycka et al. (2013) said that they originally restricted the groups to women but opened them up to men at a later stage (section: 4.4.4.2)(19). All the trials used a female facilitator to guide the groups through the PLA cycle; all facilitators received incentives. In the MaiKhanda trial the facilitators were given bicycles (section: 4.4.4.1)(189). All the facilitators were trained in group facilitation and basic perinatal health. All the trials selected local women who were married as facilitators. More et al. also wanted these women to display leadership skills and they were happy to train them in PLA cycle delivery (section: 4.4.3) (200).

It could be argued that some of the women's groups remained 'women only' so the participants could speak more freely within the groups, although presence of the mothers-in-law, who were also often seen in the groups, could negatively influence a woman's participation within the group. The cluster RCTs aimed to target women of reproductive age (15-49 years): some of these women would be pregnant and require their mother-in-law to chaperone them to the groups (18, 20). This could change the dynamics of the groups. Pragmatically, if a group is being held in a visible community space it is very difficult to prevent people from attending (180).

4.6 Gaps in the literature for the original seven trials

In the women's group PLA cycle trials, the success was based on reduction in the NMR, but attribution and the mechanisms of action were not recorded. This has implications for the adaptation of the intervention for the UK NHS context because without understanding with mechanisms behaviour change are attributed to, we could be at risk of changing a core component of the intervention that is critical to its success (section: 3.2.1). Besides from the cluster-RCTs that was used to monitor and evaluate the outcomes women's group PLA cycle, the actual process from conception to implementation was not as well recorded. There were implementation manuals, but they did not demonstrate all of the pragmatic adaptations that were made along the intervention life cycle and why they were made.

The women's group PLA cycle literature demonstrated that it can be difficult to report cultural values and beliefs that must be considered when adapting the model to address local standards (34). The Mumbai trial (section: 4.4.3) in particular, demonstrates that contextual factors can impact intervention outcomes (206). It also emphasises the importance of a formative research stage that unpicks the cultural and contextual factors that could influence the design and delivery of an intervention. Women's groups using the PLA cycle is an evidence-based method of community mobilisation that improves NMR in populations from low socio-economic households with limited access to formal and affordable healthcare (16). It is evident from the literature that the women's group PLA cycle was subject to adaptation in each trial context (18, 189, 191, 207, 208). The process of adaptation will be examined later in the thesis (Study 1: Key informant interviews with professionals who have adapted the women's group PLA cycle for their overseas contexts).

Adaptation of a health intervention involves changing specific elements to encompass social and environmental circumstances without compromising the fidelity of the intervention (section: 3.2.1) (112). Programme designers and implementation teams may adapt community-based participatory interventions for a number of reasons, but the former may focus more on the contexts, whereas the later may focus more on adapting for the target population (112). Neither process was described in the literature, and this encouraged me to approach key informants from the original seven implementation contexts to unpick how and why the women's group PLA cycle has been previously adapted.

4.7 Additional adaptations of the Women's Group PLA Cycle

In this section I will describe two examples of how the women's group PLA cycle was adapted after the seven original trials. The first example is an adaptation to the Ekjut trial in rural India (section 4.4.1), and the second example is an adaption to the BADAS trial (section: 4.4.2)

Tripathy et al. (2016) believed that the women's group PLA cycle could be used to address problems beyond neonatal health and indicated that further research is needed to adapt the intervention to improve health across the life course (192). The details of how these adaptations were informed and implemented were not detailed. Nair et al. (2017) have added modules to their women's group PLA cycle intervention that cover nutrition and growth within the first 1000 days of life in Jharkhand and Orissa, India (209). The children's linear growth in rural eastern India (CARING) trial, as it is known, served 120 clusters based in some of the most socioeconomically rural communities within these districts (209). The adapted module included a local female volunteer that: (1) attended monthly home visits for growth monitoring, breastfeeding promotion and support and infection control and childrearing; and (2) conducted monthly women's groups to propagate the PLA cycle (209).

The Diabetes Magic (D-Magic) trial adapted the PLA cycle to create men's and women's groups, supplemented with mobile health messaging, to improve diabetic outcomes in men and women aged >30 living in four rural upazillas in Bangladesh (administrative regions in Bangladesh) (210, 211). The three-arm cluster RCT (June 2015- June 2018) involved 18 monthly group meetings and twice-weekly voice messaging over 14 months that issued information on type 2 diabetes as part of a health behaviour change strategy (211). The primary outcomes combined prevalence of type 2 diabetes and intermediate hyperglycaemia in the population, which was measured at the end of intervention implementation, and a two-year cumulative incidence of type 2 diabetes in a cohort with intermediate hyperglycaemia at baseline. The D-Magic trial demonstrated a significant reduction in both outcomes in the PLA intervention group compared to the control group (adjusted odds ratio 0.36, 0.27–0.48), with an absolute reduction of 20.7% (95% CI 14.6–26.7) (211). How and why the adaptations were made within this trial were not explicitly recoded and neither was the adaptation process.

4.8 Emerging adaption framework for the Women's Group PLA Cycle

Increasing acculturation and ethnic diversity in the UK requires new approaches to eliminate complex health disparities (34). There are substantial ethnic variations in health, particularly in chronic conditions, e.g., coronary heart disease and type 2 diabetes (131, 132, 212, 213). These complex health disparities have prompted a call for culturally informed, preventative and responsive programmes that deliver the best practice while catering for local needs (2, 214). Calls from ethnic minorities to be included in provision of health care have also encouraged health service designers to assess accessibility and appropriateness of current services (215). Fundamentally, participatory health intervention could be an illustrious method of encouraging enrichment of communities and self by creating a sense of fellowship in a potentially fragmented population (216). From a political and public perspective, it may require agency from institutions in the public and private sectors to encourage and nurture its development (217). Implementing participatory models within the NHS context could help address some of the challenges that lie in providing healthcare services for heterogeneous populations. As healthcare providers in the UK increasingly target the management of chronic illness, there is a need for sustainable preventative solutions. Combining community-centred approaches could have the potential to support long-term health behaviour change (11). Collaborative methods of service design could increase capacity of current services in HICs and address increasingly heterogeneous population demands (218).

In order to optimise potential successful integration of the women's group PLA cycle in the NHS, the intervention should undergo adaptation. The following section outlines an emerging adaptation framework for the women's group PLA cycle which will be translated from multiple LICs to the UK NHS context to sub-optimal infant feeding practices in the Bangladeshi population of Tower Hamlets.

4.8.1 Contributions from Chapter 2: Reverse Innovation – establishing a clear reverse innovation pathway by creating an adaptation process.

In Chapter 2, I decided to explore reverse innovation as I believed that translating an intervention from a LIC to a HIC would be challenging and I hypothesised that understanding the literature could help me overcome some of these challenges. One challenge that appeared described how intervention uptake could be negatively impacted due to cognitive biases around country of origin. It suggested that highlighting the frugality of intervention developed in LICs and demonstrating that the intervention meets regulatory guidelines in the new context could help overcome this challenge (section: 2.3.2). I assumed that this could have implications for the Women's Group PLA cycle because, although it has been rigorously tested across

multiple cluster-RCTs in LICs, it has not been tested in the UK, and this could be an issue for healthcare providers and potential participants alike.

The literature also demonstrated that, although the concept of reverse innovation was gaining traction in global health, further research was required to explore the nuances that differentiate HICs, for example their different healthcare systems. Further research on how to integrate an intervention that has undergone reverse innovation in the new context is needed in the reverse innovation literature and this is one reason that I decided to explore health intervention adaptation.

In an attempt to overcome these cognitive biases and to prevent potential mis-adaptation, I decided to generate a staged adaptation framework. The NEON study will then test this framework through an exploratory study. The adaptations suggested in the framework should be piloted by the NEON study so that UK regulatory standards can be met.

4.8.2 Contributions from Chapter 3: Health Intervention Adaption in the Context of Reverse Innovation – adding a group of micro-adaptations to support contextual fit of the reverse innovation

In Chapter 3: Health Intervention Adaptation in the context of Reverse Innovation (section: 3) in the context of reverse innovation, I explored the principles of adaptation, particularly around cultural adaptation. I decided to explore cultural adaptation in more detail because the Bangladeshi population of Tower Hamlets is a British minority population that is not engaging with current NHS interventions that focus on infant feeding practices. Therefore, I assumed that the current NHS interventions may be missing the cultural nuances that would support uptake. In order to explore how cultural nuances could be acknowledged, I decided to conduct a review of the literature on the previous seven women's group PLA cycle cluster RCTs.

Chapter 3: Health Intervention Adaptation in the context of Reverse Innovation (section: 3), indicated some examples that I could pull on to facilitate a theoretical and structured adaptation process. For example Castro et al. (2008) suggested that interventions must be adapted to fit the context where they are being implemented, but that their fidelity must be preserved, or this could compromise intervention outcomes (section: 3.2.1) (110). They suggested identifying the core components and the adaptable components of the intervention to try to prevent mis-adaptation. However, this dichotomy suggests that an intervention component can be adapted, or it cannot be adapted, which also requires a certain level of technical expertise to know how and when to adapt the intervention. This could be challenging for the women's group PLA

cycle that is facilitated by trained volunteers, but principally led by the participants. Furthermore, I assumed that this format of adaptation could be potentially challenging in a field like public health where interventions are traditionally designed based on quantitative data and impact is measured using statistics, as we would potentially need to use qualitative methods to inform an iterative and holistic adaptation process that can respond to changes with the context (section: 3.5.1).

I also assumed that the environment in Tower Hamlets and the NHS could change and that the Tower Hamlets and the Bangladeshi populations could become increasingly diverse, and this may make designing interventions based on statistics challenging because they might be missing the cultural nuance at the community level (section 3.5.2). Therefore, I think there should be elements within the adaptation process that allow for individuals to adapt them based on their culture or context, and that adaptation should be continuous. I suggest that a set of micro-adaptions that can respond to culture and context should be included in the adaptation framework. A deeper understanding of what these micro-adaptations should include will be explored using focus group discussions with the Bangladeshi population of Tower Hamlets in Study 2.

4.8.3 Contributions from Chapter 4: The Women's Group PLA Cycle – Identifying the core components and adaptable components to perverse fidelity of the intervention

The Alma Ata declaration (1978) suggested that primary health care is the key to the provision of universal health and healthcare (219). It came in response to the UNICEF/WHO study of 'Alternative Approaches to Meeting B'. One of the principles of the Alma Ata declaration states that *"the people have a right and duty to participate individually and collectively in the planning and implementation of their health care"*.

Involving the community in the design, delivery and evaluation of NHS interventions could increase uptake, promote sustainability and ensure the provision of contextually specific programmes. The women's group PLA cycle was chosen for adaptation by the NEON for the Bangladeshi population of Tower Hamlets because it has reported significant reductions in neonatal mortality across six trials in rural contexts in India (section: 4.4.1 and 4.4.3), Nepal (section: 4.3.1), Malawi (section: 4.4.4) and Bangladesh (4.4.2) (14, 17, 189, 192). It is also a community-led participatory model, but also because it included the target population in a participatory intervention format that had not been previously applied in Tower Hamlets.

In Chapter 4 (section: 4), I explored the facets of the women's group PLA cycle through the literature published on the seven cluster-RCTs and also by examining how the women' group PLA cycle has been adapted in trials since the original seven were implemented (section: 4.3) . Cluster-RCTs are quantitative by design and measure impact based on statistics. They are the gold standard method of testing the effect on an

intervention and require a rigorous evaluation process. Each of the seven cluster-RCTs that tested the women's group PLA cycle intervention employed a UCL monitoring and evaluation team to assess the process from end to end. Although this was helpful to determine the true impact of the intervention on neonatal and maternal mortality, there may be relatively limited evidence to demonstrate how or why they had been adapted. They did, however, suggest that there were three core components to the intervention that should be maintained to preserve the fidelity of the intervention:

1. The PLA cycle – this could be in four stages or more, but the action-orientated cycle that moved from problem identification and prioritisation, solution design, solution delivery and post-implementation evaluation should be preserved (section 4.2.1)
2. Peer-led facilitation – the groups should be led by a trained facilitator from the community (section: 4.2.2). This facilitator should be someone that is respected by the participants. Further research into the qualities that earn respect within the Bangladeshi population of Tower Hamlets will be conducted in Study 2 (section: 7)
3. Participatory toolkit – this toolkit consisted of activities that could be used by the facilitator to guide the group through the stages of the PLA cycle. They were based the philosophical principles of critical consciousness (section: 4.1.2) (173) and PRA tools (section: 4.1.4) (188). Further research into how these tools can be made contextually and culturally specific will be carried out in Study 2 (section: 7).

The women's group PLA cycle should be to be a fully integrated health system. Like the Mumbai trial context, Tower Hamlets offers a high-density, largely heterogeneous, UK HIC setting which has access to free quality healthcare. The challenge will be if the Bangladeshi population of Tower Hamlets will favour a community-based intervention over current NHS interventions. It will be the first time it has been applied to a HIC context. I believe that the next step is to understand the process and the rationale for adaptation of the women's group PLA cycle model for each of the seven original trial contexts. Although some of the adaptations are recorded in the literature, there was not a coherent framework to support adaptation between contexts. Understanding how and why adaptations were made in each context could help me discover a pathway for the theoretical adaptations.

5 Study 1 Methods

The narrative review on reverse innovation highlighted some of the main challenges that an intervention could face when undergoing this process. In particular it suggested that cognitive biases (86, 220-222) and regulations in the new setting (223, 224) could impact the ability of the intervention to successfully undergo reverse innovation. To address these challenges, I explored the health intervention adaptation literature in a bid to understand the theoretical process of health intervention adaptation so that I could use this evidence base to inform the theoretical adaptation of the women's group PLA cycle for the UK. This is where I decided that adaptation should be systematic and based on evidence (120), and that culture and context can impact an intervention success rate in a new setting (110, 161). This led me to explore the women's group PLA cycle literature in more detail, specifically looking at how the model evolved, how it changed between settings and how it was adapted for each cluster-RCT (3). Although there was evidence of adaptation, this adaptation was not always recorded.

The outcomes of the narrative reviews led me to split my research from one study to two. The reason I chose to do this was because I believed that I needed to understand through key informant interviews how and why the women's group PLA cycle had been adapted in previous trials so that I could create a theoretical adaptation framework to potentially prevent any mis-adaptation that could lead to an unsuccessful intervention (110). This idea informed the participant selection and topic guide focus on previous adaptation for study 1.

In this chapter, I will present the methodology study 1. Study 1 will use a qualitative research design that involves interviews with key informants who have experience applying the model in their resource-limited setting to explore previous adaptation to the women's group PLA cycle. Establishing the process of adaptation across previous trials will assist with the adaptation of the model for the UK NHS context. The following methods section will detail the key informant interview process including recruitment, consent and the interview process.

5.1 Aim

To explore previous adaptations to the women's group PLA cycle across 7 trial contexts.

5.2 Objectives

1. Determine how the women's group PLA cycle was previously adapted by interviewing key informants who have experience applying the model in a resource-limited setting.
2. Explore why it was adapted by examining the experiences of key informants who have applied the women's group PLA cycle in a resource-limited context.
3. Identify the essential components that maintained the fidelity of the intervention.
4. Identify the modifiable components that could be adapted to emulate the context.

5.3 Ethics

Ethical approval was obtained from the UCL Research Ethics Committee Application number 9619/001. The UCL Research Ethics Chair approved the application on the 23rd of September 2016.

5.4 Theoretical Framework

Epistemological traditions or paradigms are used to interpret the actions or thought processes of individuals or populations. Mertens (2007) believes that methodological decisions are a consequence of basic beliefs that are influenced by a paradigm of overarching frameworks (225). All research professionals should have a theoretical underpinning that guides their work. This thesis will employ the philosophical underpinnings of the interpretivist paradigm. The interpretivist paradigm is often seen as an umbrella that has many sub-paradigms within the framework (226). It is a theoretical perspective that attempts to demonstrate social phenomena from an actor's perspective and examines how the actor experiences their surrounding environment (227). It aims to discover subjective meanings of social action, and how these meanings are context dependent. Instead of hypothesising, this framework aims to understand how and why action unfolds (228).

Epistemology	Assumptions	Values of Quality	Example techniques
Interpretivist	Single reality does not exist, knowledge is constructed and/or interpreted through researcher's values	Comprehensive; reflexive, transparent, systematic	Explore multiple perspectives; reflexive diary

Figure 11: Breakdown of the Interpretivist Paradigm (229)

Human beings are complex, erratic and reflect on their own behaviour. Instead of attempting to explain individuals and populations, research should aim to define human behaviour and how human interaction with the environment contributes to these behaviours (230). The interpretivist paradigm outlines the individual's ability to construct meaning relating to their behaviour and environment.

This research attempts to fit the tenets of the interpretivist paradigm, and the research questions were designed based on its principles. Green and Britten (1998) argue that qualitative research methods are able to gather information that quantitative methods cannot (231). This thesis aims to explore how and why a model must be adapted for a specific population, rather than measuring how much it should be adapted. The theoretical adaptations to the model should be context specific, therefore the subjective nature of qualitative research complements the method of inquiry.

5.5 Limitations of this the Interpretivist Paradigm

Interpretive research does not employ scientific procedures to determine results, so outcomes cannot be extrapolated to the wider population (232). Therefore, positivists often challenge the principles of the paradigm. Even though interpretive research is not generalisable, it can be converted into action for a specific population (233). It can purposely intervene in the target setting to achieve change or improvement. Interpretative research employs inductive research methods where the results inform the research (232). This objective stance allows researchers to hypothesise which environmental conditions lead to specific behaviours rather than the researchers own preconceptions. The most prominent criticism of the interpretative paradigm is the absence of concern for ideological and political influences on social reality (234). Positivist research aims to explain social phenomena and interpretivism aims to understand such

phenomena, but there is an absence of a research paradigm that encourages change or challenges social phenomena (234).

5.6 Method of Inquiry

Qualitative research concentrates on an individual's perceptions and experiences, and facilitates the interpretation of detailed textual accounts of these perceptions or experiences (230). Unlike quantitative research, qualitative can offer a rich source of information that can highlight the orientations of participants (230). A qualitative methodology is generally concerned with answering questions about the 'how', 'what' and 'why' of a phenomenon as opposed to the 'how much' and 'how many' (235).

This method of data collection attempts to offer insight into the beliefs, opinions, emotions, relationship and contradictory behaviours of participants (236). However, these opinions can sometimes be subject to bias or recall error (237). These issues in data collection will be discussed later in the limitations section. A strength of qualitative research is its ability to consider intangible factors, such as socioeconomic status, gender roles, social norms and religion (235), areas that are important to consider in this thesis due to the nature of the context and the target population. Qualitative methods can illustrate the complex reality of a situation and also the implications of quantitative data (235).

5.7 Limitations of Qualitative Research

Despite a growing interest in cross-disciplinary methods in health research and increasing acceptance of qualitative research as a tool to address questions surrounding the process, there are still sceptics that would argue it is unscientific or anecdotal (229). One limitation of the qualitative approach is that it has a smaller sample size, but the data collected from this sample can cover multiple topics (231). A large sample size in a qualitative study does not optimise the quality of the research because one occurrence of a code is all that is required to warrant its inclusion in the analysis framework (238). Understanding the process behind the topic may only require one mention of a code; therefore, frequency is rarely important in qualitative research. Theory generation instead of theory confirmation is the aim of qualitative research (238). Experts often condemn qualitative research for lacking structure or for its inability to produce quantifiable statistics, but, without an empathetic understanding of why populations behave as they do, researchers are unlikely to identify areas that could catalyse behaviour change (230).

Qualitative research is a pragmatic method of devolving patient experience of services (231). Green and Britten (1998) argue that this method of research adds to the evidence base as it can gather data on information that experimental methods cannot, such as social processes that may lead to service misuse (231).

5.8 Study setting

This study explored adaptations made to the women's group PLA cycle model in seven trials. These trials were conducted in India, Nepal, Bangladesh (south Asia) and Malawi (Africa) (3). Five trials were conducted in the south Asian countries and two in an African country. Six trials were conducted in rural contexts and one in an urban context in Mumbai.

5.9 Study design

An exploratory qualitative study design was applied to this study. Key informant interviews were chosen because they are a means of gathering information on experiences, opinions and knowledge that researchers want to study and offer an exclusive understanding of a specific phenomenon from an inside perspective (231). Interviews can explore subjective opinions, responses and beliefs (231), perspectives that can be masked in other data extraction techniques.

One-on-one semi-structured interviews were used to meet the qualitative research objectives in this study. I used semi-structured interviews to gather the experiences of key informants from all seven trials across four countries: Bangladesh, Nepal, India, and Malawi. Two interviews were conducted in the office of local NGO Society of Nutrition, Education and Health Action (SNEHA) in central Mumbai on the 27th of September 2016.

5.9.1 Sampling approach

Convenience sampling was used to recruit a purposive sample of individuals who fitted the study criteria (inclusion and exclusion criteria can be found in Study 1 Methods Eligibility criteria & Exclusion criteria). I aimed to contact 15-20 key informants for interviews. It was agreed by the PhD supervision team that 12-14 key informants would be sufficient to offer diversity of responses (limitations of sampling approach, section:

9.4.4). I primarily identified potential key informants by reading the authors who were listed on each of the publications for each of the seven RCTs. When the initial pool of key informants was contacted, they were asked to nominate other potential key informants (snowball sampling) who were involved in the trials.

I identified 20 potential key informants. One was unsuitable due to conflict of interest. Nineteen potential key informants were contacted via email. After the follow up email, sent two weeks after the initial email, 14 replied, four failed to respond, and one was contacted via an alternative social media channel (Twitter).

The majority of key informants were living overseas, therefore a variety of interview channels were made available, i.e., face-to-face, via telephone, via Skype call and calls via the mobile application, WhatsApp.

5.9.2 Eligibility criteria

The final eligibility criteria were confirmed as:

- Potential key informants must have been involved in the design, delivery or evaluation process of the PLA Cycle in India, Bangladesh, Malawi or Nepal.

5.9.3 Exclusion criteria

- Potential key informants were excluded if they were involved in the NEON project.

5.9.4 Recruitment specifics

Recruitment involved identifying eligible participants, adequately explaining the study to the potential participants, recruiting an adequate sample based on study goals and design, obtaining informed consent and maintaining ethical standards, and retaining participants until study completion. The initial contact email was used to establish a rapport with the potential key informant. Efforts were made to create a platform where the potential key informant would feel comfortable to express their views and opinions. The principal investigator of the NEON study, Professor Monica Lakhanpaul, facilitated the introductions, as she is familiar with the organisation SNEHA in India. The secondary supervisor of this PhD, Dr Fottrell, facilitated introductions to other potential participants in Bangladesh and Malawi.

Key informants were sent an email on the 12th September 2016 and given one month to reply as most were based overseas. After one month those who did not reply were sent a follow up email with a copy of the information sheet attached. They were then given a further two weeks to reply. One key informant who was considered an integral part of the design of all seven trials received an additional email and was finally contacted via social media platform Twitter.

5.9.5 Expression of interest timeframe

The process of approaching the potential key informants began with an introductory email, which was facilitated by a senior research professional, and member of the PhD supervisor team.

The response time frame will be:

- 1-month weeks to reply to first email, followed by reminder email.
- 1-2 weeks to reply to reminder email.
- 2 weeks to respond to interview request.
- Interview will be scheduled as soon as acceptance is confirmed.
- Interview will occur as soon as signed consent form is received and processed.

5.10 Data collection

Data collection occurred in the UK and in Mumbai in India, where it was facilitated by local NGO the Society for Nutrition, Education and Health Action (SNEHA). Interviews were conducted on Skype, on WhatsApp call and face-to-face. Due to location of the international key informants, these channels of communication were identified as the most convenient option and least time intensive.

I gave the key informants the option of conducting the interview in English or in their preferred language. The interviews were conducted in English because each of the key informants was able to speak conversational English. An interpreter could be provided if they chose to conduct the interviews in a language other than English. The topic guide and information sheets were developed and available in English only.

The interviews with the key informants explored their experience of applying the PLA cycle to their specific context. This included the rationale behind their decision to use the PLA cycle for their target population, the process of implementation, if and why they adapted the model for the context, and their personal opinion regarding the success of the model in context. They were asked specifically about any challenges implementing the PLA cycle in their contexts and how they involved the local population in the process.

5.10.1 Information sheet

An information sheet (see Appendix 4) explaining the purpose of the study was sent by email to the key informant prior to the interview. All potential participants were allowed sufficient time to consider participation and ask questions. In the face-to-face interviews, hard copies of the information sheet were issued at the start of the key informant interview before consent was obtained. In the online interviews, each key informant was asked if they had read the information sheet and if they had questions before the interview started. My contact details were printed on the information sheet should those approached wish to request more information.

5.10.2 Consent

Written copies of the consent form (see Appendix 5: Study 1 Consent Form) were sent via email to each of the potential key informants. Verbal consent was also available, although not used. Any questions concerning the study details such as the time/date/venue for the agreed interview were discussed during via email or telephone call, and permission to send out a reminder email/text message 24 hours prior to interview was obtained.

Prior to the start of the interview, informed consent was confirmed, and key informants were told that they could opt out of the process at any stage.

Each key informant was assigned a unique ID number at the time of consent. Written consent forms were stored in a secure filing cabinet in a locked UCL office and a copy was stored on an encrypted UCL desktop computer.

5.10.3 Data Storage

The key informant interviews were recorded on a Dictaphone and the files were stored on an encrypted file on a UCL computer. The interview recordings were sent to a UCL approved transcription service. The completed transcripts were stored in encrypted file on a UCL computer.

5.10.4 Topic guide development

To gain a better understanding of the entire process of adaptations, I conducted key informant interviews with professionals who have experience adapting the women's group PLA cycle for their trial context. I derived ten questions from the literature:

1. Beyond neonatal mortality, what existing issues were present in the target population?
2. How did the trial team enter the target population?
3. How did the trial team map the context?
4. Prior to the role out of the trial, whom did the team engage within the context?
5. Did the trial have any partners other than UCL or the appointed NGO?
6. How were the tools and materials designed?
7. Was there a process for adapting elements of the intervention?
8. How were contextual or cultural differences supported in the trial?
9. How was accessibility supported in the trial (linguistic accessibility, location, time, frequency)?
10. What was piloted?

These questions will be condensed for the topic guide for study 1 (section: 11.6). I developed it using the Green and Thorogood (2018) qualitative best practice guide (239). Five questions were designed to explore the respondents' experience and opinions regarding adaptation to the model for their specific context. The probes were used to clarify the answer given by the key informant, to get more detail on the information they had provided, to steer the interview after digression and to ask about variations. There were no tools to supplement the topic guide. The following section offers a breakdown of the topic guide and the rationale for each question:

5.10.4.1 *Question 1*

Tell me about the decision to start this intervention?

- Where did you hear about it?
- Needs locally?
- Previously tried anything similar.

The first question in the topic guide aimed to explore the drivers behind the decision to use the women's group PLA cycle model in the context. I did have some preconceived ideas about the potential drivers that I deduced from the literature. These included examining personal research interests, contextual demands and other influential institutions.

5.10.4.2 Question 2

How did you go about setting it up?

- Any conversations locally?
- Piloting?

This question was added to the topic guide to help me unpick the community entry process and the stakeholders who facilitated that process within each trial. The literature demonstrated each trial team included monitoring and evaluation activities from UCL, and the in-situ adaptation and implementation were carried out by a local NGO. Understanding the dynamics of this relationship in more detail could assist with the adaptation of the model in the future.

5.10.4.3 Question 3

To what extent did you adapt the model to fit the context/setting?

If Yes:

- Why?
- How did you decide?
- Process of adaptation?

If not at all:

- How did the cycle fit?
- Any issues?

Question 3 encouraged the key informant to explain how they made adaptations to the process before the model was implemented in the context and post-implementation. The formative research stage was part of the exploratory phase that may or may not inform adaptations to the women's group PLA cycle model. The implementation stage refers to the trial teams implementing their adapted model into the chosen context. During each process more adaptations may or may not have been made. This question was added because the literature indicated that adaptations had been made to the contents and logistics of the trial, but the process was not recorded. Recording the process could help understand the rationale for adaptation.

5.10.4.4 Question 4

How well did the intervention work in practice?

- Any ideas?
- Any further changes?
- Further reflections?

It was evident from the literature presented in chapter 4 (section: 4) that six out of the seven trials recorded significant reductions in neonatal mortality (3). Nonetheless, understanding unforeseen outcomes is valuable to the adaptation process because recording reflections from the key informants could assist with defining a generic process of adaptation.

5.10.4.5 Question 5

Is there anything we've missed?

This question allowed for the key informants to voice any other opinions or experiences that had not been uncovered within the previous four questions. It is deliberately vague to encourage the key informants to address a wider range of topics in their response.

5.10.5 Quality Assurance

To optimise the quality of the data collection process, the topic guide was standardised, and the questions were cross-checked by Dr Georgia Black, a qualitative researcher from the UCL Institute of Epidemiology and Health. The topic guide and interview technique were piloted via a face-to-face interview with a member of UCL staff who had experience adapting the women's group PLA cycle in one of the trials (section: 4.4.2). This interview was held in a meeting room in the UCL Institute of Child Health. The pilot was recorded, and the sound file was sent to the supervisor team for assessment of topic guide delivery. A member of the

supervisor team provided feedback in relation to the interview technique and, therefore, the approach was modified but the topic guide remained unchanged.

5.10.6 Further Data Collection

Gaps in the data were identified post-key informant interviews. The gaps included why specific partners were chosen for each trial and why the key informants felt it was necessary to adapt the women's group PLA cycle for the context. To fill these gaps an email was sent to all 14 key informants with the following two questions:

1. Why was the particular local NGO chosen for this trial?
2. Why did the trial decide to adapt the women's group PLA cycle in situ?

A response deadline of two weeks was set (01.08.2017-15.08.2017). Respondents received a follow up email on 08.08.2017. From the 14 emails that were sent, 10 key informants responded. The responses were collated into a word document and the corresponding participant number was applied to each response. The word document was stored on an encrypted UCL computer.

6 Study 1 Results

The aim of this study was to understand how and why the women's group PLA cycle was adapted across the seven previous trials. First, I will present the demographic information from the key informant interviews with professionals who have applied the women's group Participatory Learning in Action Cycle (PLA cycle) in a resource-limited context. Second, I will present the thematic structure and framework for adaptation that emerged from the data collected from the interviews. Finally, I will detail each theme and sub-theme and their corresponding description, supported by a verbatim quote.

Initially I invited 20 participants to be part of the study using convenience sampling (four potential participants did not respond to the initial email, one opted out due to conflict of interest and another opted out as they were unavailable over the interview period). The participant who opted out due to conflict of interest was a member of the PhD supervisor team. I therefore conducted 14 semi-structured interviews with researchers who had experience in the design, delivery or evaluation of one or more of the women's group PLA cycle RCTs. Interviews lasted between 31 and 68 minutes. Significant variation in the length of interview occurred as two of the key informants reported on multiple women's group PLA cycle trials (one on three trials and one on two trials).

6.1 Demographic information

Across the seven trials, key informants were recruited that had a variety of occupations, different roles in design, implementation, monitoring and/or evaluation of the women's group PLA cycle (section: 5.9.3) (Table 3: Demographic information for all potential participants from Study 1.). Demographic information sheets were not issued to the key informants to preserve anonymity.

I travelled to Mumbai on the 26th of September 2016 and conducted the interviews in the Urban Health Centre in Dharavi on the 28th of September 2016. One interview was conducted at the offices of Women and Children First in London, and four were conducted at the UCL Institute of Child Health in London. The remaining interviews were conducted on a computer or via telephone in a UCL private office. One participant was involved in both the original MIRA Makwanpur trial and subsequently, the SNEHA Mumbai trial.

Table 3: Demographic information for all potential participants from Study 1.

Position	Study	Stage
Monitoring & Evaluation	Nepal	Interviewed
Monitoring & Evaluation	Nepal	Interviewed
Monitoring & Evaluation	Bangladesh	Conflict of interest
Implementation	Bangladesh	Interviewed
Implementation	Malawi	Interviewed
Implementation, & M&E	Jharkhand, India	Interviewed
Implementations, & M&E	Rural India	Interviewed
Monitoring & Evaluation	Mumbai & Nepal	Interviewed
Monitoring & Evaluation	Malawi	Interviewed
Monitoring & Evaluation	Malawi	Interviewed
Monitoring & Evaluation	Malawi	PILOT
Monitoring & Evaluation	Nepal	Opted out
Monitoring & Evaluation	Malawi	Interviewed
Monitoring & Evaluation	Malawi	Opted out
Implementation	Mumbai, India	Interviewed
Implementation	Mumbai, India	Interviewed
Implementation	Jharkhand, India	Interviewed
Implementation	Malawi	Opted out
Implementation	Bangladesh	Interviewed

Monitoring & evaluation – the key informant was part of the team that carried out the monitoring and evaluation process during and after each trial

Implementation – the key informant was involved in the operational adaptation and subsequent implementation of the women’s group PLA cycle model in each context

M&E– abbreviation for monitoring and evaluation

Table 4: Demographics of sample – specific details of trials were removed to preserve anonymity

Sex	Region
Female – n = 9	Bangladesh – 2
Male – n = 5	India rural – 2
	India urban – 3
	Malawi rural – 2
	Malawi peri-urban – 2
	Nepal – 3
Position	
Practical – n = 11	Advisory – n = 3
<p>Practical – refers to their involvement in the collection and analysis of the formative research or the implementation of the women’s group PLA cycle in context.</p> <p>Advisory – refers to the involvement of the key informant in the strategic management of the project. This mainly consisted managing the monitoring and evaluation process.</p>	

6.2 Analysis

The key informant interviews were transcribed by a UCL approved transcription provider (Essential Secretary). The provider sent the documents in the form of a Microsoft Word document via encrypted email. They were then imported on computer assisted qualitative data analysis (CAQDAS) software NVivo version 10 which allowed the data to be ordered. Although inductive, the data analysis was guided by the gaps in the women's group PLA cycle (section: 4) and the health intervention adaptation in the context of reverse innovation (section: 3) narrative reviews. This also informed the development of the topic guide and influenced the subsequent themes that were generated. A member of the supervisory team throughout the analytical process validated the coding structure and themes. This supervisor crosschecked the initial themes that the data generated before the final thematic framework was constructed. This maintains should maintain the integrity of the research analysis.

6.2.1 Analysis steps

The transcribed data from the key informant interviews were subject to Braun and Clarke guidelines to thematic analysis (2006) (6). Analysis occurred in six stages explained in more detail below:

1. I started with initial immersion and familiarisation where I listened to the interviews several times and made notes of emerging themes. I then read through the transcripts and recorded some initial ideas. I discussed these initial themes with a member of the NEON team before continuing analysis
2. I recorded interesting features of the data and established a coding framework.
3. I grouped codes into themes within the CAQDAS which facilitated the development of a thematic tree.
4. I checked the relevance of themes in relation to the data extracts and the overall data set.
5. I continued to review and adjust the themes as I formulated the results, including defining the themes and their titles. Two members of the supervisor team reviewed themes before they were finalised.
6. I reported the results in a clear and concise manner which will be presented in the following section.

I started with initial immersion and familiarisation where I listened to the interviews several times and made notes of emerging themes. I then read through the transcripts and recorded some initial ideas. I discussed these initial themes with a member of the NEON team before continuing analysis

6.3 Overview of results

In this section I will elaborate on the results from the key informant interview. Each theme will be described in detail and the descriptions will be illustrated with verbatim quotes.

The data generated four main themes:

Theme 1: Setting up your intervention

Theme 2: Context Influencing Adaptation

Theme 4: Micro adaptations

Theme 1 *Setting up your intervention* describes the factors that you need to consider before you think about adapting the model for the trial context. Theme 2 *Context Influencing Adaptation* is the next stage in the process; it indicates the external and internal factors that would influence adaptation of the model. Theme 3 *Process of Adaptation* indicates different methods which the trial teams employed to explore specific adaptations. Theme 4 *Micro-Adaptations* are a set of adaptations that can be made to the women's group PLA cycle to make it contextually specific whilst preserving the fidelity of the original model.

A detailed account of the findings on each of these main themes are presented in the following sections in which each is elaborated and discussed in turn by illustrating a constitutive organisation structure with main theme, organisational themes, then the sub-themes.

A schematic diagram follows each main theme and outlines the hierarchical and associated relationships between the main themes, organisational themes and sub-themes. These will be supplemented with quotes (verbatim), which will further demonstrate and support the four main themes. In the following sections the term *key informant* (the key informant will be identified by their participant number) is used to refer to the participants of this study, and the term *participants* to refer to those for whom the trial was delivered, not the individuals that were interviewed.

6.4 Theme 1: Setting up your intervention

Setting up your intervention is the first step in the intervention adaptation process. It outlines the initial factors that need to be considered when adapting the women's group PLA cycle intervention for each trial context and also suggests which factors should not be adapted.

It consists of two organisational themes: *community entry process* and essential components. Within those two organisational themes there are five sub-themes: engage with local stakeholders, conduct/use existing quantitative data to identify issue in context. See

Table 5: Theme 1 .

Table 5: Theme 1 structure

Theme Morphology		
Main theme	Setting up your intervention	
Organisational theme	Community Entry Process	Choosing an exemplar
Sub-Themes	<i>Engage with local stakeholders</i>	<i>Identify existing issue in the context</i> <i>Conduct needs assessment</i>

6.4.1.1 Community Entry Process

All of the key informants described elements of their trial's community entry process. The community entry process could be defined as a set of activities that were carried out prior to the roll-out of the women's group PLA cycle in each of the trial contexts. The key informants all reported different experiences with the community entry process. Although they did not directly say that the process was adapted for the context, it was evident from their answers that each trial approached the community entry process in a way that considered the specific stakeholders, issues and resource shortages in the area.

6.4.2 Sub theme: Engage with local stakeholders

All of the key informants reported engaging local stakeholders to support the community entry process. Stakeholders were involved at two levels:

1. Partnerships – refers to the involvement of the stakeholders in the adaptations and the implementation of the each of the trials
2. Consultancy – these stakeholders were involved in informing adaptation, but were not involved in the running of the trials

6.4.2.1 Partnerships

All of the key informants suggested working with multiple partners including local NGOs, to facilitate implementation. Most key informants suggested that the local NGOs in all trials were chosen primarily for their leadership and potential for conducting a thorough randomised control trial. The NGO MIRA was the local partner in the original operational trial in Makwanpur District in Nepal in 2001. A senior member of monitoring and evaluation team in this trial had a strong existing relationship with MIRA. This influenced their decision to choose MIRA as their local partner in Nepal. MIRA also had a history of conducting thorough research, was embedded within the trial context and could provide the technical support that the trial needed in-situ.

All of the key informants indicated that it was important to use an organisation with local knowledge of the context in each trial. The sites of the trials were selected based on where the trial team had existing experience and a working relationship with a local NGO, apart from in Malawi. Six of the trials employed a local NGO partner, but in one of the Malawi trials the team set up the NGO MaiMwana specifically as there was no alternative.

Researcher: You say you used local people to garner knowledge about the target population, but without a local NGO to facilitate the community entry of the project. How did you pragmatically embed the project?

Key informant 014: We established a new local NGO, in partnership with the Malawi MoH (Ministry of Health).

Why the team was unable to partner with an appropriate NGO was not discussed in the interviews but was mentioned in the follow up email from the research professional to the key informant. The key informant suggested that at the time of the trial, Malawi was experiencing a HIV/AIDS epidemic and there were staff shortages as a result.

6.4.2.2 Consultation

The entire pool of key informants described the many community stakeholders that they consulted prior to adapting the intervention. These stakeholders included religious leaders, community leaders

such as chiefs, community elders, health professionals and allied-health professionals, and local and central government. These stakeholders varied across different levels with the Macro stakeholder operating at the government and health service level (municipal corporations, health commissioners and policy makers), the Meso stakeholders being members of the wider community (religious leaders, chiefs etc.), and at the Micro level including extended family and close friends (grandmothers, grandfathers, mothers-in-law etc.)

The key informants all mentioned that an important step in the community entry process was to conduct an orientation activity which would introduce the trial team to the target population. This typically occurred at cluster level, although sometimes it would occur in each individual village. This process is described below:

Key Informant 12: and also, we organised the orientation meeting, in this meeting, orientation meeting, in this meeting, local leaders any person at the community people – spoke all the grandmothers, and Imams... they're very bold, I put a bit up with them, it's not a lot to put up with them, and motivated, motivated local leaders to support the intervention.

6.4.2.3 Choosing an exemplar

Most of the key informants discussed how they chose their exemplar for each trial. Furthermore, a few suggested that it was important to have an exemplar which the target population and stakeholders considered important within the context as this could create buy-in.

All of the key informants described using a number of techniques to identify the issue within each context. This included ethnography, quantitative data that was provided from the government or nongovernment organisation (national or state level), and previous work within the trial context.

6.4.3 Sub-theme: Identify existing issue in the context

A few key informants stated that there were many factors that caused ill health in their trial context, but they focused on neonatal mortality because they believed that even incremental changes could make an impact in areas where health service provision was poor/non-existent. Some of the key informants suggested that initial discussions with the target populations, sometimes during the

orientation activities, helped them establish that there was an issue with neonatal mortality within the context. Below, key informant 001 describes the process by why they decided to focus on neonatal mortality in their context:

Key informant 001: Yeah, so there were very high levels of both maternal and neonatal mortality that was clear from sort of national level data and state level data in where we work. And the first meetings of the PLA cycle there is lots of dialogue with community members about what they feel are the most important problems related to pregnancy, childbirth in the postnatal period. And quite rapidly it became clear that there were lots of maternal deaths...

So, I guess both from academia and logical data and from the early discussions with community members, especially women in TBAs who knew that there was ... that there were lots of problems related to the peri-natal period.

6.4.4 Sub-theme: Conduct needs assessment

All of the trials conducted a needs assessment prior to adapting the women's group PLA cycle model. All of the key informants' described resource limitations and barriers to care that caused poor health outcomes in each context:

Limitations included lack of trained health professionals or allied health professionals to deliver obstetric care, lack of sterile birth equipment, neonatal drug stock outs, broken/out-dated or lack of neonatal equipment such as incubators, and lack of delivery facilities.

Barriers included lack of transport to hospital/health post/sub-health post/clinic, lack of money for travel, access to clean water.

They described how these observations led to them addressing neonatal mortality in each trial context.

Participant 010: Now neonatal mortality stagnated because of bad obstetric conditions. So labour is not very, most of the deliveries, more than 70% of deliveries still happen at home in not the best of circumstances. So, the babies are asphyxiated at birth because delivery is not done on time. And this also leads to problems in the mother because labour is delayed, and labour is prolonged.

The other issue with mother is if she bleeds then she's in a problem. So, most of maternal deaths are happening because of postpartum haemorrhage. So, these two, in my domain, I'm not an adult physician but in my kind of domain these are the two main areas crying out for attention.

In the above quote one of the key informant's describes why they decided to address maternal and neonatal health and some of the resource limitations within each their trial context.

6.5 Theme 2: Context Influencing Adaptation

The *Context Influencing Adaptations* dictates how the trial team applied adaptations to the model. The *Process of Adaptation* theme describes the methods that informed the adaptations to the model in each trial context. Two series of actions were taken, first of which was based on pragmatic factors (cost, resources and time), and the second involved evidenced-based methods to inform adaptation (formative research, exploratory phase, previous trials).

Theme 1 *Context Influencing Adaptation* presents some of the drivers behind some key trial decisions including site selection and rationale for using the specific women's group PLA cycle. All of the key informant's reported poor health outcomes and healthcare shortages in each context similar to those reported in the narrative review (section 4), however, the drivers behind site selection and intervention selection were only discussed by a few key informants.

Under the theme *Context Influencing Adaptation* there were two organisational themes – *drivers behind context selection* and *drivers behind PLA cycle selection*, with five sub-themes *site opportunism, government priorities, population need, clinical research funding guidelines* and *a new approach was needed* (see Table 6: Theme 2 structure)

Table 6: Theme 2 structure

Theme Morphology		
Main theme	Context Influencing Adaptation	
Organisational theme	Drivers behind context selection	Drivers behind women's group PLA cycle intervention
Sub-Themes	<i>Government priorities</i> <i>Site opportunism</i> <i>Population need</i>	<i>A new approach was needed</i> <i>Offering a structured process</i> <i>Using a female volunteer</i>

Context influencing adaptation refers to the factors within each trial environment that influenced adaptation. It was clear from the key informant responses that each trial team made adaptations to encompass the social nuances, cultural beliefs, and logistics and/or health system in each trial setting. All key informants indicated that the trial teams utilised existing resources and relationships to inform the adaptation of the model for the context. This included the selection of local partners, the selection of the trial site and the selection of the community facilitator supervisors. Other factors such as international and national health priorities and funding research agendas also influenced aspects of adaptation in each trial. This was not structured process, but an acknowledgement by the trial teams that considering health priorities could optimise buy-in from crucial government or policy partners.

6.5.1 Sub-theme: Government priorities

Some key informants reported that they aligned their research priorities with those on the international or national health or social care agenda. Most of the key informants reported that maternal and child health is high on the agenda for many of the host country governments and the research teams therefore prioritised it over other issues that they could have addressed.

All key informants across the seven trials reported programme gaps in neonatal services including absence of neonatal units at health facilities, health facilities that did not have the proper neonatal equipment or drugs, lack or absence of neonatal programmes or initiatives and/or insufficient trained health professionals that could assist with antenatal, perinatal or post-natal care. Key informant 007 from the Mumbai trial team described the lack of programmes for neonates in their local and national

contexts. This quote illustrates that there was a gap in the current national policy relating to child health.

Key informant 007: Organisations that work on health did not focus on newborn health, they focused on general health of women and children and mostly older children. So, we didn't find anything either in Mumbai or in urban India, except I think in North India, Bombladish. I think there were couple of places where people had tried...

Some of the key informants mentioned the WHO Extended Programme of Immunisation (EPI), which offers infant vaccination operated in India, Nepal, Malawi and Bangladesh. They suggested this programme had had a significant impact on neonatal mortality, but that neonatal mortality had not decreased further since the initial reduction after the introduction of the programme. They hypothesised that an additional non-biomedical intervention that addressed maternal behaviours was needed. Key informant 009 described some of the different interventions that the local NGO (SNEHA) had tried before the women's group PLA cycle was trialled in Mumbai.

Key informant 009: SNEHA wanted to do a quite ambitious thing which was at that time called the City Initiative which they wanted to do institutional supply sites strengthening, so working with the municipal cooperation health providers and also the communities. So, I became involved pretty much more in the community side of it, which were the women's groups because that was the model.

6.5.2 Sub-theme: Population need

All of the key informants recognised that the population needed sound neonatal education and care within each trial context. Each context had different resource limitations, cultural beliefs and social nuances. This led each trial team to adapt the women's group PLA cycle in response to the contextual demands. All of the key informants suggested that the initial exploratory phase showed that the target population did view neonatal and maternal mortality as a problem in their context. Key informant 003 described the magnitude of this public health problem in Africa and Asia in the following quote:

Key informant 003: First, in Asia, neonatal deaths account for 75% of under-5 deaths. In Africa neonatal deaths account for 25% of under-5 deaths. The Ministry of Health context is fundamentally different in terms of problems and causes so needs to be carefully understood.

The sub-theme of *Population Need* describes the absence of vital, appropriate and high-quality programmes, policies, health personnel or health providers in each trial context. The key informant believed that current interventions were unable to address the factors that contributed to these rates and referred to poor obstetric resources contributing to this burden. The key informant demonstrated the lack of quality resources below:

Key informant 012: *Now neonatal mortality stagnated because of bad obstetric conditions...most of the deliveries, more than 70 per cent of deliveries still happen at home in not the best of circumstances...*

Several of the key informants reported the presence of informally or partially trained health or community workers within each context. These community health workers were not trained in behaviour change techniques or had no formal medical training. The failure or absence of existing services or trained personnel influenced each key informant's decision to implement the women's group PLA cycle in each context. The availability of resources was the driver that led them to adapt the model. Some key informants indicated that a new and innovative intervention was required to address the behaviours that were influencing neonatal and maternal mortality in each trial context.

Key informant 012: *...neonatal mortality had become stagnant we were desperate to try out any means and this ... Nepal has the same kind of health status as Bangladesh, so we wanted to try it out here...*

With each trial setting demonstrating high rates of maternal and neonatal mortality and a lack of programme or policy in place to address these high rates, the trial teams believed that the population immediately needed an intervention. Some key informants reported that the need for any intervention affected the process of adaptation. Most key informants reported that adaptation was not always based on formative research and tested via piloting. Some key informants highlighted that piloting was time-consuming and not always appropriate for this type of intervention, as the results from the pilot could not be extrapolated to the wider target population. Key informant 002 describes why they believed piloting was not appropriate for their context in the following excerpt from the data:

Key informant 002: *And then, on the basis of that meeting we drafted I think three meetings and so we did like a pilot, we didn't do actually many pilots in Nepal because I'm not sure if they really work, if you're doing a participatory intervention then a pilot tells you that it worked in those places with those people, but it might respond completely differently.*

The key informant indicated that the trial team had to make adaptations to the procedure of intervention implementation due the nature of the intervention. They suggested that each sub-population will engage with an intervention in a different way and that it is difficult to measure success based on one group's experience.

6.5.3 Sub- theme: Site Opportunism

The sub-theme *setting site opportunism* refers specifically to the country and locality selection for each trial. All key informants reported that each trial site was selected because the leading academic institution had existing links with an NGO that had experience implementing public health interventions in the context. Thirteen of the key informants had existing links with UCL which precluded their credibility. This can be demonstrated by the following quote from the data, which describes a chance encounter with the trial Principal Investigator at an international public health conference.

Researcher: *Why was the particular local NGO chosen for this trial?*

Key informant 007: *We had initiated work on securing the buy-in of multiple stakeholders. We were already in discussion with the funder who in turn was in discussion with ***** for rigorous evaluation of their partner agency work. Coincidentally ***** met ***** around the same time in an international conference. He visited us in Mumbai and subsequently funded a baseline survey in Dharavi, which formed the basis of the City Initiative for New-born Health (CINH).*

Once the women's group PLA cycle had been trialled across multiple south Asian contexts (Nepal, India and Bangladesh), it was reported by a small number of key informants that the academic institution decided to run a trial in an African context to demonstrate the generalizability of the model. One key informant described the academic motivation for this decision.

Researcher: *Firstly, why did you apply it to a community in Malawi?*

Key Informant 014: *I think the team thought you have to have an African and Asian proof of concept, so that was purely it. It was, we proved in Asia, despite Asia being obviously incredibly diverse, let's prove it in Africa and again one country in Africa is not Africa...*

Malawi was chosen as it had high rate of neonatal and maternal mortality and as the monitoring and evaluation team had previously conducted research in the country. The trial team identified it as an appropriate site for an African context RCT.

6.5.3.1 Drivers behind women's group PLA Cycle selection

All of the key informants reported acutely high rates of maternal and neonatal mortality in each trial context and this was seen as a research priority. All of the key informants indicated that there was limited access to affordable and regulated health services in their trial contexts. Patterns of resource limitations were similar in each context, but not the exactly the same. Most of the key informants reported that it was these contextual differences that led to the adaptation of the model.

6.5.4 Sub-theme: A new approach was needed

Some of the key informants reported that interventions that used didactic approaches were unable to impact adverse neonatal health outcomes in their contexts, thus a new approach was needed. Key informant 008 reports the previous efforts by the NGO MIRA in Nepal to reduce neonatal and maternal mortality. In this excerpt from the data the key informant describes a trial which tried direct information giving intervention with mothers in the perinatal period.

Key informant 008 *...we did a little trial in Kathmandu of using a more formal health education approach to women after birth, where we gave them two 45-minute interviews, one in the hospital, one in the home, and we showed no impact (in neonatal mortality) from that trial*

A few key informants suggested that it was the failure of this trial that prompted the trial team to explore alternative intervention approaches. They described this process in the following excerpt from the data:

Key informant 014: *And I was talking to the social scientists, *****and others, down in Sussex and she alerted me, she said, “Well, there is a women’s group approach that is being used in Bolivia”,*

Not all of the key informants indicated if a participatory model was needed or just that there needed to be an alternative to current interventions. The decision to use a women’s group PLA model intervention was motivated by the research priorities of the trial teams. All of the key informants described how the Principal Investigators’ encounters with other research professionals and trials influenced the decision to prioritise the women’s group PLA cycle intervention. The following excerpt from the data describes why the trial team decided to use a women’s group participatory model and indicates why they considered testing it in an RCT as a research priority.

Key informant 009: *... in the late 1990s because we were working with our colleagues at MIRA in Nepal and ***** became aware of a piece of work done by a group ... in Bolivia which did this kind of process, this action research cycle with women’s groups, with Amara women in rural Bolivia to reduce perinatal mortality. We thought that this was an interesting model; an interesting approach and their work appeared to show that there was potential for this process...*

Some key informants indicated that it was the participatory and innovative approach of the women’s group PLA that made it favourable to governments. Below, key informant 012 explains why the women’s group PLA cycle intervention seemed attractive and appropriate for the Bangladeshi context with reference to the trial in rural east India and the original trial in Makwanpur Nepal.

Key informant 012...*we wanted to do this in Bangladesh and he also did the same in India...because the government are very strapped for cash and resources in Bangladesh and neonatal mortality had become very stagnant. Over time mortality had gone down, neonatal mortality was not going down. So, we were thinking of trying out innovative approaches...Nepal has the same kind of health status as Bangladesh, so we wanted to try it out here.*

In this quote the key informant demonstrates the monetary limitations experienced by Bangladesh. They indicate that they were looking for a cost-effective alternative to current interventions. The key informant also stressed failure of current interventions to address the high rates of neonatal mortality in Bangladesh. They continued to draw parallels between these rates and the rates in India and Nepal.

6.5.5 Sub-theme: Offering a structured process

Most of the key informants recognised that there were women's groups already operating within their trial contexts. A few of the key informants indicated that the women's groups were known methods of disseminating health information or for the promotion of collective action within a target population. However, all of this key informant highlighted that the term *women's group* is used universally to describe the meeting of women. The term does not dictate the frequency of the meeting, the objectives or the structure.

Key informant 002: *And that's the important distinction, because you'll go around the world and lots of people will say, "Oh, yeah, we have women's groups", but there are women's groups and women's groups. And it's all right to have an official coming together of women once in a blue moon, it's quite another to have a more formal structured facilitated process.*

Another important distinction made by most of the key informants was the presence of the four-stage action cycle. This formal process was considered a mechanism for promoting collective action and keeping the participant's in each group engaged. In the quote below, a key informant described why women's groups that propagate the PLA cycle are different to other women's groups:

Key Informant 008: *When we started, of course, we knew that there were some women's groups and officially every Female Community Health Volunteer ran a women's group...actually that simply meant that once a year they'd come together for the national immunisation day, or for a vitamin A distribution, there was no formal participatory learning and action cycle being practised.*

Some of the key informants suggested that although these women's groups were not as structured as the PLA cycle women's groups, these established groups could be used to embed the PLA cycle within the population. They needed to consider how to adapt the model so it could be incorporated into existing groups in the context. Some of the key informant's indicated that it was the availability

of this pre-existing structure that encouraged them to explore using women's groups as tool development and subsequent propagation of the women's group PLA cycle.

6.5.6 Sub-theme: Using a female facilitator

All of the key informants reported that there were government initiatives that aimed to tackle the absence of trained medical professionals and allied health professionals in the locality by training local women to act as community outreach officers or community health workers. Each of the key informants reported utilising existing female facilitators in their intervention, whether it was to facilitate the groups, for data collection, or for recruitment of participants. They all reported adapted roles of the female volunteer for their own context. Furthermore, they reported working with existing female volunteers to either initiate or enable the process. These existing female volunteers included Accredited Social Health Activists (ASHAs) in India and female community health volunteers in Nepal. Most of the key informants reported the presence of trained health volunteers influenced the adaptations that were made to the recruitment process for the groups and the delivery of the intervention. A key informant from the Mumbai trial demonstrated their understanding of the responsibilities of female community health workers below:

Key informant 009: *...their big thing was that they trained community women to become health workers effectively who could do some interventions, I mean some biomedical interventions as well as other things for the baby and so it was a distributed community health worker type model which was quite different from our model.*

The key informant suggested that they used local women for outreach and engagement because these women were accepted by the communities and could potentially be adapted for the women's group PLA cycle trials. The presence of this model allowed the team to engage and learn from local women who already had training in community outreach.

6.6 Theme 3: Process of Adaptation

The *Process of Adaptation* refers to methods that were used to inform the adaptations that were made to the model. There was a widespread consensus amongst the key informants that adaptation was

conducive with the intervention life-cycle process and that failure to adapt the model for the context would be both unethical and research malpractice.

The sub-themes were organised into two groups: (1) *Using local sources to assist with the formative research stage to inform adaptations* (sub-themes: *Using stakeholders as sources of information, understanding the context, optimising data collection by utilising local volunteers*) (2) and *using own experience to assist with adaptation process* (sub-themes: *Making pragmatic adaptations based on previous experience*). This is tabulated in see Table 7: Theme 3 structure.

Table 7: Theme 3 structure

Theme Morphology		
Main theme	Process of Adaptation	
Organisational theme	Using local sources to assist with the formative research stage to inform adaptations	Using own experience to assist with adaptation process
Sub-Themes	<i>Using stakeholders as sources of information</i> <i>Understanding the context</i> <i>Optimising data collection by utilising local volunteers</i>	<i>Making pragmatic adaptations based on previous experience</i>

All of the key informants described different processes that informed adaptation to the women's group PLA cycle in each trial context. Some of the key informants suggested that adaptations were made before, during or after the trial. A few of the key informants indicated that they recognised what adaptations should be made based on experiences from previous women's group PLA cycle trials. They also suggested that they used a wide variety of research tools to explore adaptation within their context. Below is a quote that illustrates the research tools and methods of learning used to explore adaptation:

Key informant 005: *So, we had information from previous trials about what had worked in the Participatory Learning and Action Cycle, so we used that as our basis, but then we adapted it to the local situation by conducting formative research, qualitative research, mainly doing focus groups to find out about indigenous care practices.*

6.6.1.1 Using local sources to assist with the formative research to inform adaptations

All of the key informants described the value of local sources when adapting an intervention for a trial context. A few of the key informants stated that the intervention should be participatory from its

conception and this can be optimised by utilising local sources of knowledge from the outset. Furthermore, a few of the key informants suggested that involving health systems, governments and communities in the adaptation of an intervention can increase the appropriateness of the model for the context and encourage the community to take ownership.

Two of the most common approaches to formative research in the trials were stakeholder consultation (focus group discussions and/or in-depth interviews) and context mapping. These methods are effective for gaining insight into what motivates individuals and communities to behave a certain way and how they view the world or the community around them. Both employ qualitative techniques to reveal additional insight into existing quantitative data, such as NMR or MMR in each context.

6.6.2 Sub-theme: Using stakeholders as sources of information

All of the key informants described the process of gathering information that would inform the adaptations that were going to be made to the women's group PLA cycle for their trial context. This always included accessing information rich sources in each context, which included a consultative process involving a wide range of stakeholders. All of the key informants described using local stakeholder consultations to gather information that could help them adapt the model for their trial context. They also used local stakeholders to coordinate actions, to collect information on the specific needs at designated facilities and to choose sites for the intervention. Key informant 002 describes how their trial team involved different stakeholders (community and health system) to facilitate this process below:

Key informant 002: Formative research which was absolutely the discussion of the community members and community leaders and everyone who could have a stake, then also interrogation of the data, just working out what are the mortality rates, what are the skill attendance rates does that differ across different health facilities, so we know where to place groups.

A few key informants suggested that it was the process of engaging local stakeholders that helped them to gather a wide range of information that could inform potential adaptation. Some key informants said that the process would help them engage with those that had a vested interest in maternal and neonatal health within each context (including the national and regional health authorities, civil society organisations and the target population). Furthermore, they thought that this

process optimised a continuous communication and coordination between institutions and was structured around the following activities.

6.6.3 Sub-theme: Understanding the context

Most of the key informants stated that they needed to understand what the barriers and limitations were within each context so they could adapt the intervention for each context. They all described using observational techniques to study the environment and the population. A quote from key informant 003 illustrates how they used the information they had gathered to adapt the manual for the field coordinators:

Key informant 003: So, we assessed what the traditional birth practices and the traditional care practices were during pregnancy, delivery and immediately post-partum. And then having identified what some of the problem areas were, we then studied ... preparing a pictorial manual in simple Nepali for the Field Co-ordinators to then train our group facilitators to use.

Some key informants stated that they used local volunteers to help understand the context through mapping. Mapping the context was seen as a way to inform the adaptations that need to be made to the logistics of the women's group PLA cycle intervention. Key informant 002 describes how they used this process to determine the location of the groups so they could optimise dosage in each intervention cluster:

Key informant 002: Mapping the community so that we know the population numbers, so we can have one per 500 populations, so all of that kind of formative research fed into the design of the logistics, the approach.

6.6.4 Sub-theme: Optimising data collection by utilising local volunteers

All of the key informants used local volunteers to collect data that informed adaptations to the model for each trial context. Some of the key informants said that using local volunteers was cost-effective and faster. They suggested that using individuals that were recognised in the local area would help embed the intervention within the context. Furthermore, a few of the key informants stated that some

of the trial contexts were mountainous and/or remote and using a local person that knew the context was more efficient timewise.

Most of the key informants explained the requirements for volunteers and their specific role. They suggested that volunteers would typically be school leavers and that each cadre would be trained in research methods. A statement from key informant 005 describes how they used volunteers to assist with formative research data collection below:

Key informant 005: We recruited a cadre of Supervisors called 'Co-ordinators', these were women with a school leaving certificate or maybe even a bachelor's degree level pass, intermediate level pass anyway, so above your standard school leaving level of education. We recruited them and we trained them all about the principles of participatory learning, adult learning and we also trained them in collection of qualitative data.

A few of the key informants mentioned that the introduction of structured funding body specifications necessitated a comprehensive formative research stage which often entailed a context mapping, needs assessments and evidence of stakeholder engagement.

Additionally, all of the key informants mentioned that they obtained baseline data from routine channels such as local, regional, national and international level. One key informant explained that information could be accessed from the National Government in the form of census data, or from the Ministry of Health such as regional or national maternal mortality ratio or neonatal mortality ratio.

6.6.5 Using own experience to assist with adaptation process

Some of the key informants mentioned that not all adaptations needed to be based on evidence and that some were made based on existing knowledge of the context. One key informant referred to this form of adaptation as “*common sense adaptations*”.

A few key informants included factors that seemed “*obvious*” to them to adapt. Most of the key informants demarcated between practical adaptations that occurred in the initial stages of intervention and the adaptations that were based on formative research. A few key informants suggested that this method of adaptation was not based on previous formative research or routine statistics. All of the key

informants reported that pragmatic adaptations were applied in response to imminent environmental/local needs. Some of the key informant's referred to these adaptations as "*sensible*" and/or "*realistic*".

Several of the key informants mentioned that these adaptations were based on sensible decisions made by team members who were familiar with the anthropological features or philosophical connotations of the context. Some of the key informants indicated that the research team was experienced and was able to make judgements on when to adapt the model and when not to adapt the model based on their previous experiences.

Key informant 009: *I mean, yes, obviously the manual was translated into Nepali*

A few key informants suggested that adaptations were made pragmatically because the trial team knew enough information about the context to make an informed decision on which aspects of the women's group PLA cycle to adapt without conducting formative research.

According to a few of the key informants the MIRA Makwanpur had more pragmatic adaptations than evidence-based adaptations. The key informants from that study suggested that this was because the trial was informed by the protocol from the Warmi project (section: 4.1.1) and also from the team's previous trial experience in the context. Surprisingly, they also suggested that funding guidelines were less stringent at the time of this trial and this allowed them to do less formative research. Key informant 008 describes the emergence of formative research and how this became popular post-MIRA Makwanpur trial:

Key informant 008: *So, round about 2005 I am guessing people started talking about this thing called formative research and then maybe round about after 2010 people started talking about complex intervention development and I think that is good, but we just blundered in.*

6.7 Theme 4: Micro adaptations

All key informants reported adapting components of the intervention for their trial contexts. These adaptations that were made can be referred to as *micro-adaptations*. A micro-adaptation is a feature

that can be altered in the model to make it more appropriate for the context. The *Micro-Adaptations* theme presents some of the components that were adapted to make the women's group PLA cycle intervention contextually appropriate.

This theme was divided into three organisational themes: *Delivery* (method of delivery, accessibility, incentives, encourages collective action and considers gender dynamics and group composition); *Materials* (adjusted for ethnicity, context and culture); *Content* (that used ethnically and culturally appropriate message, echoes local culture, and addresses mistrust in health system and discrimination); and nine sub-themes (see Table 8: Theme 4 structure)

Table 8: Theme 4 structure

Theme Morphology			
Main theme	Micro-adaptations		
Organisational theme	Delivery	Materials	Contents
Sub-Themes	<i>The hook helps get the stakeholders interested</i> <i>Methods of delivering the information</i> <i>Changes to the delivery approach</i> <i>Involving the health system in delivery</i>	<i>Materials that can be understood by everyone</i> <i>Using a local artist to create relevant depictions</i>	<i>Listening to the target population</i> <i>Adapt for the salient social identity</i> <i>Testing the content</i>

Micro-adaptations were considered by most of the key informants not to be an essential component of the intervention, but one that can be adapted to emulate social, cultural or environmental factors within each trial setting. All of the key informants stated their trial teams adapted the materials, contents or delivery of the women's group PLA cycle for their trial context. Some of the key informants suggested that it would be unethical not to adapt the materials.

6.7.1.1 Delivery

Various methods of delivery were utilised across the seven trials. All seven trials used the women's group format to propagate the participatory learning and action cycle. All seven trials used materials to disseminate health messages or introduce concepts. Within each trial there were components that were adapted to make the intervention purposeful, practical, feasible and ethical within the context. Adjustments were made to consider confines of resources, time and political context. The *Delivery* sub-theme refers to the method by which the content of the model was delivered. It includes logistical factors, linguistic accessibility and adapting for culture and geographical morphology. It also includes the mode of delivering sessions and alternatives to disseminating health information.

6.7.2 Sub-theme: The hook helps to get the stakeholders interested

All of the key informants described how they reframed the outcomes of the target population and any significant key stakeholders. This method was considered to improve the delivery of health information in each trial context. Key informant 001 described how the trial team in rural India used information gathered from earlier stages in the PLA cycle to create a contextually relevant, relatable and illustrative story that exemplified issues relating to neonatal and maternal health in the context. This demonstrates how the delivery methods can be adapted to optimise engagement of the target population.

Key informant 001: *...and the story was supposed to weave in all of the underlying causes for the postpartum haemorrhage, both medical and social so we might weave in the fact that the mother didn't have an antenatal care check-up because she didn't have support from her family to take her to the antenatal care check-up. So, all kinds of different layers of causation, and so the groups would listen to that story, discuss the story; discuss whether they thought it was plausible whether they faced similar cases.*

All of the key informants described different issues relating to neonatal mortality in each of their trial contexts. They suggested that interventions like the women's group PLA cycle benefit from adapting their *hook* to fit the context. The key informants stated that the *hook* can act as a driver that encourages the target population to take ownership of the intervention.

6.7.3 Sub-theme: Methods of delivering the information

The methods that were used to deliver the information were mentioned by all of the key informants. These included the composition of the groups, the length of the cycle and the participatory toolkit.

6.7.3.1 *Women's groups*

The composition of the groups was only discussed by a few of the key informants who suggested that the term *women's group* is slightly misleading. They stated that the groups consisted of men, women, adolescents and children. Although the men were not always actively involved in all meetings, there were some that they were able to participate in. This was mainly because the groups were held at times when the men were at work. The key informants from the Mumbai trial suggested that large groups of women were not compatible in an urban transient context. Key informant 008 described some of the barriers to hosting women's groups in Mumbai below:

Key informant 009: *Well, I mean it is probably best if I do not talk too much about this because someone like **** knows a lot more but my understanding is that people are a little bit territorial about that so they know those people in the next alley they are not our people can happen.*

The key informant then went on to suggest that, although the Mumbai trial did not significantly reduce neonatal mortality, it cannot be blamed on the mode of delivery (women's groups). They suggested that women's groups may not be appropriate for these outcomes but may be useful for other exemplars:

Key informant 008: *...I do not think we can conclude that women's groups do not work in this sort of context, we can only conclude that they do not make much difference for these outcomes if enacted in the way it was enacted, but that unfortunately does not really answer very many questions.*

6.7.3.2 *Participatory Toolkit*

Some of the key informants reported referencing the MIRA Makwanpur model's toolkit to help the group facilitators move the women's groups through the cycle. Not all of the trials found the tools

developed in Nepal useful. Key informant 014 from the Malawian trial described how the tools had to be adjusted for their context.

Key informant 014: ...a lot of the tools that they're using in India and Nepal weren't very, we trialled them, we kind of tested things out like problem tree, body mapping, we'd use body mapping to begin with which is very common and popular in Bangladesh. It wasn't just as visually appealing to people in Malawi just within their cultural language, their official language, it wasn't something they often did whereas the timeline was much easier, we used problem tree for example, which is how a problem grows from the roots into the trunk and you have the effects.

Some of the key informants suggested that there were certain aspects of the groups that needed to be adapted to capture employment situations and to emulate circumstances within each trial locality. One of the areas that was adapted was the frequency of the groups. The frequency of groups refers to how often the groups were held. A few of the key informants stated that within some of their trial contexts participants may be formally employed and this may impact on the time they have available to attend the groups. Furthermore, a few of the key informants suggested that some of the participants were only living in the locality temporarily, and this encouraged them to shorten the delivery of the PLA cycle from monthly to every two weeks. Some indicated that it was the regularity of the women's group PLA cycle that contributed to the success of each trial. Most of the key informants mentioned frequency of the groups as important factor in the retention of participants.

6.7.4 Sub-theme: Changes to the delivery approach

All of the key informants used the PLA cycle to deliver action research in the initial trial. Six out of the seven trials went forth to continue to use the PLA cycle. The key informants from the Mumbai trial suggested that this mode of delivery was failing to significantly reduce neonatal mortality. They thought that a problem-centred approach was not appropriate for their urban context and adapted the PLA from four stages to seven stages. They also changed the mode of inquiry to an appreciative inquiry. Key informant 007 describes why they decided to adapt the mode of delivery below:

Key informant 007: So, we did get an orientation to the process and what we realised is the women context in Mumbai being very different and we did know that groups are very difficult to run in the urban context. So, we realised that this problem-solving approach may not be very attractive, and we decided to bring in appreciative enquiry.

The key informants recognised that this adaptation was necessary to make their model contextually viable, but also noted that with a significant change like this, the model was no longer considered PLA cycle and they renamed it *Micro-Planning*.

6.7.4.1 *Involving the health system in delivery*

All of the key informants mentioned that it was important to involve the health system and associated personnel in the women's group PLA cycle process, but it was equally important to market the groups as a *community initiative* that was managed by local women and addressed local health needs. The entire sample reported different degrees of participation by the health system and health workers. Some of the key informants described consulting health workers during the content development stage, and some key informants suggested that *health system strengthening* was a trial objective. Key informant 008 described why they believe it is important to have a relationship with the health system below.

Key informant 008: *Yeah, we always do that because our view is, although we're not having a health worker run the group, we should liaise closely with the health system, whether it's a community health volunteer or a mother and child health worker or even a midwife in certain circumstances.*

Some of the key informants suggested that involving the health system in the delivery of the groups could support the embedding of the intervention within the population. They said that, although this intervention is participatory, you could not increase the demand for health services and not support service strengthening. Furthermore, they recognised health information should be consistent, providing training for some health professionals could optimise this process.

6.7.5 Sub-theme: Disrupting the daily routine

All of the key informants mentioned adaptations that were made to their women's group PLA cycle intervention to address issues around accessibility. The most commonly mentioned issues included emotional and structural barriers and limitations to participation, group dynamics and/or group composition. These were all considered to disrupt the daily routine of participants.

Some key informants reported that emotional and structural barriers and limitations disproportionately affected the female participants. This was because the groups were held during the day when their husbands were at work and when they were meant to be cleaning, cooking, shopping or looking after the children. Some of the key informants presented this as a barrier to participation. Key informant 010 described their experience with *disrupting the daily routine* below:

Key informant 010: *...initially we had quite a bit of problem with women attending the meetings because it meant a chunk of the time taken away from housework. About one to two hours taken away and that would create some tension between the mother-in-law and the daughter-in-law you see...*

Most of the key informants stated that financial incentives were unsustainable and that giving financial incentives would detract from the participatory nature of the women's group PLA cycle intervention. One of the key informants described how important it was to involve the grandparents in their groups to bolster motivation and prevent any resistance in the family below:

Key informant 010: *So, I mean we wanted them (grandparents) to join so that they knew what was going on and how it would benefit the whole family.*

6.7.5.1 Materials

All of the key informants reported that the materials (video, tools, booklet, skits, hand-outs, games) were adapted for their target population and their context. All of the key informants recognised that adjusting materials could increase the impact of the trial's/programme's health messages. All of the key informants suggested that adapting the materials to depict scenes relating to neonatal health would create buy-in from most of the stakeholders and evidence related to the importance of addressing contextually specific problems.

6.7.6 Sub-theme: Materials that can be understood by everyone

A few of the key informants described the materials as instruments that were used to convey information. Some of the key informants stated that materials had to be designed to engage large

numbers of “community members” and other stakeholders to help form vast coalition. The materials were adapted so the team and the participants could relate to the depictions, testimonials or health information that was being disseminated.

A few key informants noted that they tried to adapt the materials for a variety of different audiences including the trial team, the community facilitators and the participants, therefore, it was important that each party could comprehend and relate to them. They suggested that the most valuable aspect of the intervention was having a toolkit of materials that could be adapted for different audiences. Furthermore, they suggested that materials were adapted for salient language, vocabulary and the level of literacy in the target population. Key informant 008 described how they assessed literacy levels in their groups before adapting the materials accordingly:

Key informant 008: *Well, in terms of education, there wasn't as much heterogeneity as you think...I would have thought at that time two-thirds were illiterate or barely literate. We had questions like, 'Can you read or write?' 'Read and write your own name?' or, 'Educated?'. So, most women were not educated, even from higher castes. So, it was more about getting the group to work, sharing a lot of pictorial material and doing everything by the oral tradition... repeated messages...*

A few of the key informants also stressed the importance of keeping the messages clear and simple so they could be memorised by the target population. Some of these key informants said that the maternal and neonatal health information provided by the government was sometimes too complicated for the target population. They suggested that this information was for medical professionals. Below, key informant 012 explains how the materials should be adapted to embody simple messages:

Key informant 012: *...we make it a simple message. How we make it the, so we give them, so many people a picture card, and all this thing, delivered to our government, and they remember.*

6.7.7 Sub-theme: Using a local artist to create relevant depictions

All of the key informants described working with the target population and a local artist to design contextually appropriate materials. All of the trials designed their own pictures cards, although several

of the key informants said that the MIRA Makwanpur picture cards were used as a template. Below, key informant 011 states that they designed and tested their picture cards in their context:

Key informant 011: Yes, all the cards were designed locally based on that problem and also fully tested before, yes.

The key informants said that they used a local artist to illustrate the picture cards for their trial because they did not have access to a camera or facilitating for printing the photographs they needed. They also suggested that the target population may feel more comfortable with illustrations because some of the images were quite graphic. In the Bangladeshi trials, the illustrations were exaggerated and, therefore, more comical. A key informant from the Malawian trials said that their picture cards were more conservative because of the predominately Christian beliefs in the context. They did not have any graphic images of childbirth or antimony, and all the women were wearing skirts below the knee in the illustrations.

6.7.7.1 Content

The content refers to the messages or health information that was being presented to the participants either by the group facilitator or by a guest facilitator in each trial.

Key informant 007 indicated that the target population wanted the content of the health messages in the Mumbai trial to embody more than direct causes of neonatal and maternal mortality. In this trial further information on hygiene, sanitation, nutrition and seasonal illnesses supplemented the original programme content.

Key informant 007: The women in the slums wanted information on say seasonal illnesses or how to keep water clean or diarrhoea or nutritious food.

All of the key informants described adapting the content for each of their contexts. Most of the key informants adapted content that was already available from the MIRA Makwanpaur trial. The MIRA Makwanpur trial key informants described adapting content from the Warmi project and from other sources such as the WHO.

6.7.8 Sub-theme: Listening to the target population

All of the key informants stated that they were addressing neonatal mortality but needed to explore barrier and behaviours in the context so they could design appropriate content. Some of the key informants' used accounts from members of the target population to inform the adaptation of the contents, and some incorporated specific content that the target population had requested, along with their own health messages. Using participant preferences were described by key informant 007 below:

Key informant 007: The women in the slums wanted information on say seasonal illnesses or how to keep water clean or diarrhoea or nutritious food.

A few of the key informants discussed how content was then added to reflect issues that were arising within the context. Key informant 001 from the rural India trial describes using formative research to inform the content of the materials. In the quote from the data, the key informant described part of the process that was used to explore local practices in pregnancy childbirth and new-born care.

Key informant 001: Then we had a second meeting which was about understanding current local practices... we developed some picture cards using the problems that the mothers had brought up during the meeting, as well as conditions that we knew were prevalent in the area and just generally in South Asia for mothers and new-borns... we turned all of these into picture cards that were appropriate for that context...

Key informant 006 described how further modules on gender-based violence and nutrition were added to their trial below:

Key informant 006: And we also did a lot of adaptation, so the first time when we did all the PLA technique and implementation, the next time we adapted it to violence, the next time we adapted it to nutrition, so I think really ethnic understanding and adapted all we do that that we want PLA...

A few of the key informants used the group facilitators to assist with the design or adaptation of the materials in each trial. These included picture cards, testimonials, storytelling or role-play content.

Key informant 001 described how their trial team used existing community knowledge to inform contextually specific adaptations of their materials content:

Key informant 001: *And we also got the facilitators to develop the stories as part of their training. So, it was a way to kind of draw in on local experience and themes and stories that the facilitators knew because they were local.*

A few of the key informants stated that utilising existing knowledge within the context could make the contents of the intervention more engaging and more relevant to the target population. They stressed that participatory research methods should be employed throughout to help with the design or adaptation of contents.

6.7.9 Sub-theme: Adapt for the salient social identity

Some of the key informants admitted that it would be difficult to adapt the contents for every culture, religion or language within each of the trial contexts. They suggested that this could be overcome by adapting the contents to echo social nuances, context specific issues and the salient social identity. The salient social identity embodied the most widely spoken language, practices, religion and culture within each context. Several of the key informants suggested that in Nepal, rural India and Bangladesh trials this was a relatively straightforward task, however, in Mumbai the materials were translated into Hindi and Urdu, the salient local language. The team deemed that Marathi, the local language of Maharashtra State, was not an appropriate language to be used in the materials because it was not widely spoken within the Dharavi slum where the trial was being conducted. The key informants overcame this barrier by having group facilitators that spoke the Hindi or Urdu, along with the local language favoured by their group. Key informant 007 demonstrated this below:

Key informant 007: *Having the manual in Hindi seemed right. Some of the Sukhe's (facilitators) could speak Marathi and Urdu; they could translate (for the group participants)*

The key informant suggested that the trial was being conducted in an area with residents from across India who spoke a plethora of languages. They explained that it was a transient environment with many travelling for seasonal work. Hindi was the salient local language and spoken by the majority across central and northern India and that is why the trial team decided to have the manual in Hindi.

In this quote, the key informant states that their facilitators could speak other languages, so they were able to make the adaptations and translations that were needed to make intervention accessible to all in the context.

The key informants from Malawi had a similar problem. The materials were translated into several languages, as reported by key informant 014 below:

Key informant 014: *...we had a very diverse and dispersed community...we're working in MaiMwana we had to translate it into Chinese, Burmese and English on the cards because they can understand each of the languages*

All of the key informants expressed barriers to providing universally culturally appropriate materials because of the heterogeneity in each context. They suggested making adaptations at the micro (group or cluster) level to account for this heterogeneity.

All of the key informants reported working with the health system to design materials or contents, but only a few mentioned that their populations distrusted the health facilities that were available. A few of the key informants suggested that this was because of discrimination, poor care or concerns about being overcharged. They suggested that local traditional healers were often favoured over formal health facilities. One key informant said that addressing this preference was difficult because of the varying cultural beliefs and practices in their trial contexts. This is illustrated in a quote from key informant 008 below:

Key informant 008: *Yeah, and they varied because Nepal is a mix of many castes, so you had Tamangs, who were Buddhists, who had two kinds of ... they had Lamas, who were their priests, and Bombos, who were their healers. But then you had the Hindu castes, who would use so-called Dhami-Jhankris and even our quite educated staff would use both, go to a health worker but also to a healer.*

6.7.10 Sub-theme: Testing the content

Most of the key informants described how the content was formally piloted in each context. This included working with stakeholders such as health professionals, allied-health professionals,

community workers, the local NGO and the government. Three of the key informants stated that they did not pilot the content for each meeting.

Researcher: *And did you pilot the groups at all?*

Key informant 010: *[Pause]. We didn't have any pilots.*

They did not elaborate on why they did not pilot the content, but they did suggest another means of testing out each meeting. This included a feedback system between the group facilitators where one would hold the meeting and reflect on the success or failure of certain parts of the meeting with other group facilitators at a later stage. Key informant 007 below reported this:

Key informant 007: *We had around two forty-four groups and, so the ones who were a step ahead would try out the new meeting, come back and share, then the others would try it out, come back and share and then the dialogues, the actual questions that the Sukhe's (facilitator) had to use to facilitate the group meetings were developed, that's how I manual developed.*

The above quote demonstrates how the trial team used available resources to test their materials. As some of the key informants said that there was no time for piloting materials, they used other methods to test out each meeting.

7 Study 2 Methods

Study 2's design was based on the evidence in support of contextual and cultural adaptation from the health intervention adaptation literature (2, 34, 149, 159, 239). In particular, Liu et al. (2012) who suggested that a 46-component Typology for Adaptation could appropriately adapt health promotion interventions for ethnic minority groups (section: 3.2) (2). They also suggested that further research should be conducted to examine the nuances within these groups and that researchers should avoid making assumptions based on pre-existing biases (2, 34). The health intervention adaptation literature also suggested that phenomena like biculturalism and acculturation could affect the validity of an adapted intervention (127, 240). This helped inform my participant selection which led to me approaching individuals that had been living in the UK over various periods of time, were first- or second-generation migrants, and men or women of reproductive age. The literature also indicated that adaptation should be a continuum which led me to build prompts about context, heritage, culture and change into the topic guide for study 2. The results of study 1 (section: 6) also fed into the design of the topic guide for study 2, with a particular focus on the areas that had been previously adapted (section: , case study of the tools, delivery and location of the groups).

In this chapter I will present the methods for the second of the two studies in this thesis. Study 2 is a qualitative focus group discussion (FGD) study with members of the Bangladeshi population of Tower Hamlets.

7.1 Aim

To explore how the women's group PLA cycle model can be adapted Bangladeshi population of Tower Hamlets.

7.2 Objectives

1. Explore how the contents of the women's group PLA cycle intervention can be adapted to encourage engagement
2. Determine the logistics of applying the PLA cycle intervention to the Tower Hamlets context
3. Establish which materials involved in the intervention need to be adapted and how
4. Devise alternative method design tools and materials based on available resources e.g., media

7.3 Ethics

Ethical approval was obtained from the UCL Research Ethics Committee Application number 10653/001. The UCL Research Ethics Chair approved the application on the 11th April 2017.

7.4 Study setting

The London borough of Tower Hamlets is a congested urban area that is located at the edge of Zone 1 in east London (Figure 16). It has an estimated population of 297,800 (241) and is considered a relatively deprived locality.



Figure 12: Map of London with the borough of Tower Hamlets highlighted

According to Simpson's Diversity Index, Tower Hamlets is the 16th most ethnically diverse locality in the UK, with 55% of its residents qualifying as black or ethnic minorities (BME) (Figure 16) Figure 13: Breakdown of ethnic groups according to the 2011 census in the London Borough of Tower Hamlets (8) (8, 241). It is home to 81,377 people who identify as of Bangladeshi origin, making it host to the largest Bangladeshi origin population in England (8).

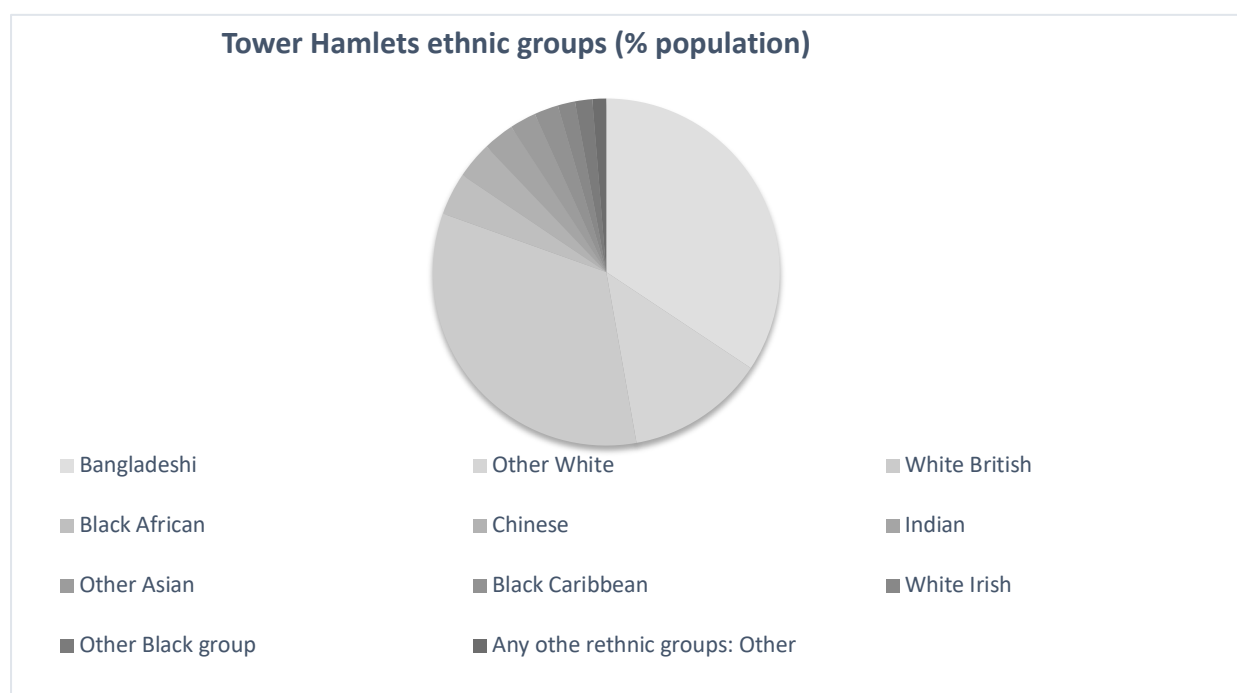


Figure 13: Breakdown of ethnic groups according to the 2011 census in the London Borough of Tower Hamlets (8)

The Bangladeshi population in Tower Hamlets experiences high levels of deprivation and overcrowded housing, and are likely to have low school and university attendance, which subsequently leads to high levels of unemployment (242, 243), see Table 9: Population facts in Tower Hamlets in comparison to wider London & the UK (183). Residents of the area historically worked in low paid roles at the docks at Wapping or in the garment industry (243). Currently, the majority of Bangladeshis living in Tower Hamlets are employed in the catering industry or in the garment making industry, with some owning small businesses such as newsagents (243).

Table 9: Population facts in Tower Hamlets in comparison to wider London & the UK (183)

Facts	Tower Hamlets, 2012	London, ONS, 2011	UK, ONS, 2011
Population	263,000	8,170,000	63,182,000
Population density (residents per km ²)	13,296 (2nd highest in London)	13,467	406
Age structure (ONS, 2012):			
<3 years olds (% of total population)	6.2	6.0	6.2
0-19 years old (% of total population)	24.3	24.5	23.9
Religion (%)			
Christianity	27.1	48.4	59.4
Muslim	34.5	12.4	5
Hindu	1.7	5.0	1.5
Buddhist	1.1	1.0	0.5
Ethnicities (ONS, 2011)			
White British (%)	31	45	87
Asian or Asian British Bangladeshi (%)	33	2.7	0.71
Child poverty (%)	42 (highest in the country)	40	27

7.5 Study design

This research will employ a qualitative study design to explore the perspectives on how culture and context might affect adaptation of the model. It will do this by FGD with a select sample of the Bangladeshi population of Tower Hamlets. Eakin et al (2002) believed that an understanding of the

barriers that impeded ethnic minorities' access to health care could help providers develop more culturally appropriate models of service (244). Additionally, it is important not to make assumptions about the target population and to guarantee that all changes made to the original model are evidenced based.

7.5.1 Sampling approach

Convenience sampling was used to recruit a purposive sample of individuals who fitted the study criteria (inclusion and exclusion criteria can be found in section: 7.5.2). Sampling aimed to recruit 27-30 participants for three focus groups, based on the recommendation of 8-10 participants per FGD by Green and Thorogood (2013)(230).

I primarily wanted to sample female participants who identified as being Bangladeshi origin and were living in the London Borough of Tower Hamlets. I based this on the idea that, although men were able to attend groups in previous trials, they were not actively involved in all of the meetings. Therefore, the groups in Tower Hamlets could be predominately be directed towards women. Nonetheless, due to the participatory nature of the model it was agreed that men should be included. The supervisory team also thought that it would be unethical not to have the men's perspective on the model, as the men may be involved in more of the meetings in the UK NHS context.

Like all contexts, the UK NHS context is complex because of urban environment, universal healthcare coverage and the heterogeneous population. There are several differences between the UK NHS context and previous trial contexts that must be considered in adaptation e.g., a woman only model was appropriate for previous trial contexts but may not be appropriate for the UK because the nuclear family structure and gender norms within the British context may be different from previous contexts. Including men may encourage engagement of the whole Bangladeshi community in Tower Hamlets, not only the female element. It is also useful to understand gender dynamics within this population, which may or may not differ from the dynamics reported in previous trials. It was agreed by the supervisory team and I that the men's perspective should also be obtained. As composition of the groups is an area for exploration within study 2, it was agreed that men should be involved in the adaptation process.

The community facilitators (CFs) from the NEON project were recruited from the various maternal and child health care groups working under the Department of Public Health in Tower Hamlets and

the voluntary community organisations associated to these groups. They were recognised and respected members of the Bangladeshi population of Tower Hamlets because they had previous experience of conducting community engagement work. The CFs from the NEON project are embedded within the Bangladeshi population. They have experience working in similar public health research and in community outreach programmes. They have facilitated FGDs as part of phases 2-4 of the NEON project.

To optimise maximum variation sample, three forms of recruitment took place. First, members of the Bangladeshi population of Tower Hamlets who took part in phase 2-4 of the NEON study and had signed a disclaimer that allowed them to be contacted for further research were contacted. Second, participants were encouraged to recommend individuals for the FGDs (snowball sampling - described in study 1, sampling strategies). Finally, the CFs from the NEON project were asked to recruit members of the population for the FGDs (purposive sampling - described in study 1, sampling strategies).

Initially the groups were targeted at primary care givers (mothers, fathers, grandmothers and grandfathers, mothers-in-law), who identified as Bangladeshi and resided within the London borough of Tower Hamlets. Older women within the family are a key influence on women's infant feeding choices, hence why this study will include mothers-in-law and grandmothers (245). In practice the group participants with different roles, countries of birth, occupations and genders were approached for interviews with the explicit aim of capturing a range of opinions and perspectives.

7.5.2 Eligibility criteria

- Participants must identify as being Bangladeshi origin
- Participants must be a male or female parent or grandparent
- Participants must be over the age of 18
- Participants must be living within the London borough of Tower Hamlets

7.5.3 Recruitment specifics

There were three recruitment waves that corresponded with different sample requirements for each FGD. This is because each FGD group was looking for a different sub-sample. The details of each sub-sample are recorded below:

1. FGD 1 targeted mothers and grandmothers of Bangladeshi origin who were living in Tower Hamlets to discuss micro-adaptations to the model including, but not limited to, the use of '*the Hook*' (the topic that will encourage attendance). Aesthetics, logistics and the use of media. A female NEON CF recruited these women. None of the women had been previously involved in the NEON study.
2. The second group was fathers and grandfathers of Bangladeshi origin who were living in Tower Hamlets. They were recruited by a male NEON community facilitator.
3. The third FGD was with mothers and grandmothers of Bangladeshi origin who lived in Tower Hamlets. The same female NEON community facilitator recruited this group as the first FGD. This group discussed the tools that would be used in the groups, how the participants would like to receive information about the groups, and the composition of the potential groups.

I decided to conduct FGDs with these individuals because the intervention was directed towards women of reproductive age in the previous trials and the NEON study was also planning to engage mothers with infants from six- twenty-four months, therefore it seemed appropriate to invite mothers. I also made the assumption that men of Bangladeshi origin in Tower Hamlets may be more involved in child-rearing because some families live alone, therefore, I wanted to engage the fathers. Unfortunately, I was unable to recruit mothers and fathers from the same family, because logistically, it was very challenging to procure space for the groups and secure an appropriate time for all of the participants.

7.6 Data collection

I used FGDs to collect data from a select number of the target population. The FGDs involved 8-10 individuals based on the guidelines by Green and Thorogood (2013) and lasted about 45 minutes (230). The demographics of the groups varied, and, like the NEON study, the men and women were in separate groups, so they felt comfortable expressing their opinions and also because the different groups had availability at different times; the men's FGD was held in the evening and the women's FGDs were held during the day after the morning school run.

7.6.1 Information packs

We considered sending out electronic copies of the packs, but not all of the potential participants had access to a computer. To save time and cost, the information packs were delivered by the CFs to each potential participant at their homes or workplaces.

Hard copies of the information sheet were issued at the start of the focus group before consent was obtained. As the CFs had prior knowledge and experience working with the NEON study, they were able to inform participants of the aims and objectives of the NEON project. They were briefed on the aims and objectives of this study during the initial meeting. They then issued the potential participant with an information sheet (see Appendix 7: Study 2 Information Sheet). The information sheet explaining the purpose of the study was supplied in Bengali and English through the NEON community facilitator. All potential participants were allowed sufficient time to consider participation and ask questions. My contact details were printed on the information sheet should those approached wish to request more information, and also contact details for Patient Information and Liaison Service at UCL were provided in case a participant wanted to report a problem.

7.6.2 Expression of interest timeframe

The protocol suggested that an expression of interest form would be issued to potential participants. However, a more pragmatic approach was later employed whereby a date was set for the FGD and the CF recruited 8-10 participants that were available on that date. It proved a more efficient and effective method of recruitment. This process may have been more efficient because the NEON project was currently operating in the context and, therefore:

- The team had existing relationships with the target population which nurtured trust and visibility of the project.
- The team had built on existing population structure by employing CFs from the target population.
- The team had collected data and issued forms that allowed past participants to be contacted for future research opportunities.

To optimise the reliability and the validity of the information delivered by the CFs to potential participants, these three activities were carried out:

1. I met with the CFs individually at the Flower and Dean Community Centre in Tower Hamlets on the 23rd of June 2017. We read through the information sheets, consent forms and demographic information sheet and spent 30 minutes addressing the topic guide and protocol for the FGDs. At this point each of the CFs were asked to voice any concerns or questions relating to understanding of the relevant documents and if they had any ethical concerns around the protocol or method of data collection.
2. I observed each of the CFs deliver information on the study to members of the Bangladeshi population of Tower Hamlets who were potential participants. I then issued verbal feedback.
3. If the NEON CFs had any queries about the study, they were able to contact me via email and via WhatsApp messenger. If they required further explanation regarding the recruitment process a phone call was arranged.

A verbal agreement between the potential participant and the NEON CF was considered as a formal expression of interest. This was followed by a telephone call from the NEON CF to confirm. Any questions concerning the study details such as the time/date/venue for focus group/interview were discussed during this call/message, and permission to send out a reminder text/telephone call 24 hours prior to meeting taken. The time and date of the group was based on the availability of the participants, the researcher and the CF. The location was decided based on the NEON CFs existing links with community centres in Tower Hamlets. They also considered holding groups in areas that were accessible for the participants.

7.6.3 Consent

Informed consent was obtained from each participant prior to the start of the FGD. Individuals who were invited to participate in the discussions were asked to arrive 20 minutes early so consent could be obtained. A written copy of the participant demographic information (see Appendix 9: Study 2 Participant Demographic Information Sheet) and consent form (see Appendix 8: Study 2 Consent Form) outlining the research aims and objectives was available in English and/or Bengali. The CF was also available to explain any information that the participant did not understand in English, Bengali or their chosen dialect.

If verbal consent has been needed, I would have asked each participant to state their name, the date and the time of giving their consent. A copy of the audio-recorded consent was available at the participants' request, but during this study it was only written consent that was used.

The NEON community facilitators and I explained informed consent to each group. Participants were asked to bring their signed consent form to the focus group and reminded that participation was voluntary and that they could withdraw from the process at any time. Some did not bring a signed copy of the consent form because they forgot, or they did not have access to a printer. I brought spare copies of the form in case anyone needed one.

Each participant was assigned a unique ID number at the time of consent. Written consent forms are kept in a secure filing cabinet in a locked UCL office.

7.6.4 Format of the groups

I opened each group with a short presentation that outlined the details of the women's group PLA cycle model. I tried to keep the conversation in the groups continuous and interactive, and as genuine/upfront/explicit as possible. I used semi-structured questions with prompts and tools to facilitate the discussion. A creative means of initiating conversations was required to extract the information regarding the relevant adaptations to the model because of the hypothetical nature of the questions that were being asked. I decided to use hard copies of picture cards depicting visual representations of the logistical characteristics that the group can discuss or certain PLA aspects like games.

I conducted data collection in English, and the CF facilitated the groups in Bengali or a chosen dialect. Focus group discussions should be conducted in the preferred language chosen by the participant (230). In Tower Hamlets, the two most common languages spoken are English (66%) and Bengali, which includes *Sylheti* and *Chatgaya* (18%) (246). The language barrier was overcome by using the NEON CF (who was fluent in *Bengali* or dialects of *Bengali*) to lead each of the groups. They were then available to translate data into English if needed. The full format of the FGDs can be found in Appendix 11: Study 2 Running Order.

7.6.5 Group composition

The men and women were divided into separate groups and a facilitator of the same sex facilitated their groups. This was based on advice from other members of the NEON team who had conducted previous FGDs with this population. The population indicated that they were more comfortable with

single sex groups. They expanded this by mentioning that they would feel comfortable discussing information in front of their own husbands, but not other women's husbands. Additionally, as the female facilitator recruited females and the male facilitator recruited males, it was more convenient to have them facilitate the groups with the participants they had recruited.

7.6.6 Topic guide development

The topic guides were developed based on a qualitative methodology (239). The questions were designed to explore the respondent's experience and opinions regarding certain theoretical contextual adaptations of the women's group PLA cycle. Two topic guides were developed: Topic guide A for FGDs 1 and 2 (see Appendix 12: Study2 Topic Guide A) and topic guide B for FGD 3 (see Appendix 13: Study 2 Topic Guide).

Topic guide A was the first to be developed. The questions were informed by the results from study 1 which highlighted potential areas of the model which needed to be adapted to emulate the context. Topic guide A contained questions about how to adapt the model in the domains of: *The Hook*, logistics, aesthetics and the use of media. Topic guide B was developed in response to gaps in the data from FGD 1 and FGD 2. Topic guide B contained questions on the tools that could be used to facilitate the groups through the cycle and also the composition of the groups. The following section will run through the questions from topic guides A and B individually.

7.6.7 Topic guide A

First the women's group PLA cycle model was introduced to the groups along with a diagram showing the PLA cycle.

Questions 1 and 2

1. What do you think of the women's group PLA cycle model?
2. What are some of the not so good things about this model?

Question 1 and 2 were general questions about the model. The FGD participants were asked firstly to determine if the group understood the concept of the women's group PLA cycle intervention, and secondly, to see if they could identify any potential areas for adaptations before being asked directly

about adaptation. This question was designed to explore the idea of participatory groups and problem-focused solutions, and what the target population thought of this approach.

Question 3

What would make you come to the groups?

Question 3 was designed to explore what topic would encourage the participants to engage with the intervention. This was referred to as *the Hook*. Study 1 demonstrated that the trial outcomes may be the same but the way in which the topic is framed can be context specific. The adaptation framework for the women's group PLA cycle that was created from the results of Study 1 highlights *the Hook* as *delivery* related micro-adaptation. In this question, I asked the participants how they would like to re-frame infant nutrition and complementary feeding practices, so they were relevant to the context.

Question 4

What do you think of this picture?

*The group are shown a photograph from a group in a rural setting in one of the previous trials (Figure 18).

Prompts covered the following areas:

- Location of the groups
- Transport to and from the groups
- Day of the week that the groups will be held
- Time of day the sessions will be held
- Number of individuals in each group
- Number of children allowed in each group
- Group attendees/ composition of the groups

*Presents a photograph of group in Bangladesh



Figure 14: Women's group using the PLA cycle in Bangladesh (picture Women & Children First)

This question was designed to determine the logistical adaptations. Previously, trials were in rural or urban areas in resource-limited settings. In this study the groups would be held in an urban high-income setting. These areas cover the *accessibility* area within the study 1 framework under the *delivery* sub-theme. Therefore, I asked the focus group how we could make the group accessible by showing them a picture of a group in Bangladesh.

Question 5

We use materials to help deliver information. What do you think of this picture?

* The group are shown a picture card with breastfeeding mother and baby from Bangladesh trial (Figure 15: The two cards that were used for the FGD 1 & 2 from the BADAS-PCP Bangladesh trial)

Prompts-

- Clothes

- Illustration – cartoon, use of photographs



Figure 15: The two cards that were used for the FGD 1 & 2 from the BADAS-PCP Bangladesh trial

This question was designed to evaluate the aesthetic appeal of the tools. Previously trials have used a variety of activities to facilitate discussions within the women's group to help identify and prioritise issues and to disseminate key health messages. The activities were inspired by Robert Chambers participatory rural appraisals tool box (188). The data from study 1 indicated that picture cards were a material used by all seven trials. Therefore, it was assumed that pictures cards might be used for a similar purpose with the Bangladeshi population of Tower Hamlets. During FGD 1 and 2, I used two examples of picture cards (see Figure 15: The two cards that were used for the FGD 1 & 2 from the BADAS-PCP Bangladesh trial) from the BADAS Bangladeshi trial to generate information on the following areas:

- Materials for facilitating discussion - are picture cards an appropriate tool?
- Design of illustrations on material to facilitate discussion - are these illustrations aesthetically appropriate for the Bangladeshi population of Tower Hamlets?

Question 6

How would you otherwise receive information about your health?

Prompts

- Mobile phone applications
- Fliers
- Posters
- Via medical professionals (GP, midwife or health visitor etc)
- Via allied-health professionals (pharmacist etc)
- Family or friends
- Other sources

Question 7

How could we disseminate information from the groups?

Question 6 and 7 were designed to explore alternative methods to disseminate information. Under the micro-adaptation area in the study 1 framework there is a section that relates to the *method of delivery*. One of the trials noted using mobile health messaging as a method of disseminating key information (247). This was a micro-adaptation to the original model. I presumed that as we are targeting a population within a high-income context there would be alternative methods of disseminating information about the groups or content from the groups. Therefore, these questions related to how the NEON project could utilise available media resources for information dissemination purposes.

7.6.8 Topic Guide B

After FGDs 1 and 2, there was a meeting with the NEON project team and Women and Children First (WCF) on the 25th of September 2017. Women and Children First is an NGO who have experience running the women's group PLA cycle in resource-limited settings. They were contracted by the NEON project to assist with the design and the delivery of the pre-pilot. During this meeting I presented my provisional observations from FGD 1 and 2. It was decided that another FGD should be conducted to determine if tools and materials are required to facilitate the groups through the PLA cycle. These tools would primarily be used in stage 1 (identify and prioritise issues in the population).

They can also be used to disseminate key health messages. WCF assumed that a discussion would be adequate for the context and did not believe that tools were necessary.

Topic guide B was developed for FGD 3, and it was used to determine if tools were required in the intervention and how they could be adapted for the exemplar. The questions also examined how we could use existing resources to make information and materials more accessible to the target population. Additionally, gaps in the data from the NEON project were identified and a further question around group composition was added. Unlike topic guide A, topic guide B is not split into domains. This is because it is filling in the gaps in previously conducted research. Each question is explained in further detail below:

Question 1

Do you need any activities to help you move through the PLA cycle?

Prompts

- Games, activities?
- Materials

Question one specifically relates to the tools. The term *tools* were substituted for activities in this question, as it requires less explanation to the participants. As in the previous FGDs, the intervention was presented, and a diagram of the PLA cycle was issued.

The topic guide then diverged into two sections. The question that was asked depended on the response from the group.

Question 2

If yes

1. What (tools) would you like?

Prompts

- Picture cards- *are picture cards an appropriate for this context and what format would you like them in e.g., illustrations or photographs?*

If no

Why not?

(Why do you think tools are not appropriate?)

Prompts

- Alternatives? *To tools to facilitate the groups through the PLA cycle.*

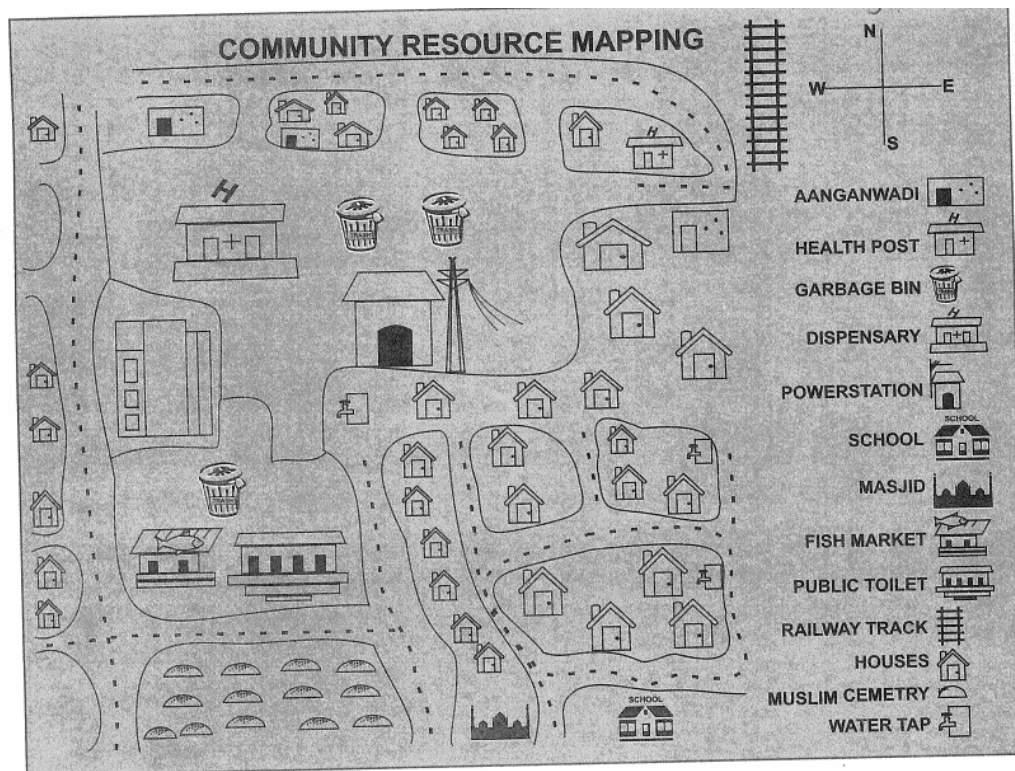


Figure 16: The context map, women's group PLA cycle tool to help groups identify and prioritize issues in their context. SNEHA, Mumbai example

Question 3

What do you think of context mapping as an activity?

Prompts

- Like
- Dislike
- Is there an alternative?

Question 3 was designed as a case study of the context-mapping tool that was used in several of the RCTs. The groups were issued with a copy of the map from the SNEHA Mumbai, India trial (See

Figure 16: The context map, women's group PLA cycle tool to help groups identify and prioritize issues in their context. SNEHA, Mumbai example). This map depicted an area of the *Dharavi* slum in central Mumbai. This map was chosen in particular because it details an urban setting and is from the only trial that was conducted in an urban context. The concept of contextual mapping was explained to the group and a discussion ensued.

Question 4

How would you like to receive key messages?

- Power Point?
- Mobile phone applications?

Question 4 addressed one of the key gaps in the data that emerged from the NEON project and from my earlier FGDs: how we can use different types of media to convey information about the groups or to share content? Previous trials have adapted to encompass available resources. In the UK NHS context, we also have consistent access to internet connection from mobile networks, home networks or via free Wi-Fi connections. This presents the opportunity to disseminate messages via these portals. Format of the messages can be altered, and a senior member of the NEON project suggested using PowerPoint to engage participants during the groups and to disseminate information post-groups.

A member of the NEON team highlighted that they wanted further evidentiary support for who should be invited to attend the groups. This was covered in FGDs 1 and 2, but they felt they needed further detail as there was a mixed response.

Question 5

Who should come to our groups?

Prompt

- Men's presence?

7.6.9 Quality Assurance

To assure the quality of the FGDs' process, I formulated a standardised presentation and topic guide for the facilitator to use in each group. The NEON facilitators who enabled the groups received training on FGDs facilitation by Dr Georgia Black (UCL) and Dr Lorna Benton (UCL). They received further training on the content of this study's presentation and the relevant topic guide from me.

7.6.10 Recording and transcribing

Brief observation notes were drafted immediately after each of the FGDs so that initial themes could be fed back to the NEON project quickly. As the data from study 2 directly informs the NEON pilot, it was essential to share information immediately so it could inform the design of the pre-pilot protocol. Any additional themes that emerged from the thematic analysis were shared with the NEON team in a presentation of the results at a NEON team meeting.

The FGDs were recorded on a Dictaphone and the files were stored on an encrypted file on a UCL computer. The completed transcripts were stored in encrypted file on a UCL computer.

8 Study 2 Results

The aim of this study was to understand how the women's group PLA cycle could be adapted for the Bangladeshi population of Tower Hamlets. First, I will present the demographic information from the three FGDs. Second, I will present the thematic structure and framework for adaptation that emerged from the data collected from the FGDs. Finally, I will detail each theme and sub-theme and their corresponding description, supported by a verbatim quote.

The NEON community facilitators were embedded in the Bangladeshi population of Tower Hamlets and have been working in partnership with the NEON study from the outset. I elicited their support to recruit participants for the adaption study due to their strong links with the community. Previously the women's group PLA cycle had been led by community facilitators; this enabled groups to be mixed because these community facilitators could speak the lingua franca and the local languages/dialects (3). Like the previous contexts Tower Hamlets has a mix of languages, therefore the groups were not restricted by language as the NEON community facilitators were able to translate into Bengali and other languages spoken by the participants.

A total of three FGDs were conducted between the 23rd of June and the 17th of November 2017. Initially I asked the CFs to invite 12 people per FGD; FGDs 1 and 3 had 10 women of reproductive age (15-49 years), and FGD 2 consisted of 8 men (10 were invited) of reproductive age. It was decided to have a mix of men and women so I could compare and contrast their experiences and adapt the intervention accordingly.

All the participants were born in Bangladesh and lived in Tower Hamlets. They had each spent between 9 and 45 years in the UK. The age range was 23-44 years in the women and 28-56 years in the men. All the FGD participants identified as being parents. The men were all-in full-time employment, and the women were full-time mothers, apart from two who worked part-time. The demographic sheet indicated that all the participants were of Bangladeshi origin and they all lived in Tower Hamlets at the time of the study.

The NIHR Involve Principles were followed to optimise the ethnicity of the public involvement in this PhD research (248). The FGDs were held in accessible community centres in Tower Hamlets. All of the groups received the same presentation containing the research rationale and the objectives of the

FGDs. Each participant was issued with an information sheet, signed a consent form and received a £10 voucher to thank them for their participation. The sessions lasted between 42 and 72 minutes and were transcribed verbatim.

8.1 Analysis

All of the data from the FGDs were transcribed and saved as Microsoft Office documents. They were then imported onto computer assisted qualitative data analysis (CAQDAS) software NVivo version 10 which allowed the data to be ordered. Data analysis was guided by the previous literature reviews as well as the results from Study 1. Although the data analysis was inductive, the gaps in the literature assisted with the development of the topic guide and, therefore, influenced the data and the subsequent themes that were generated. A similar process of checking validity of the themes for Study 1 was employed in Study 2. This included working with a member of the supervisory team throughout the analytical process. This supervisor cross checked the initial themes that the data generated before the final thematic framework was constructed. This maintained the integrity of the research and the validity of the results.

8.1.1 Analytical steps

The transcribed data from the FGDs were subject to Braun and Clarke guidelines to thematic analysis (2006) (6). Analysis occurred in six stages:

1. I started with initial immersion and familiarisation where I listened to the interviews several times and made notes of emerging themes. I then read through the transcripts and recorded some initial ideas.
2. I discussed these initial ideas with a member of the NEON team before continuing analysis.
3. I recorded interesting features of the data and established a coding framework. I grouped codes into themes within the CAQDAS which facilitated the development of a thematic tree
4. I checked the relevance of themes in relation to the data extracts and the overall data set
5. I continued to review and adjust the themes as I formulated the results, including defining the themes and their titles. The NEON team reviewed the final themes during a meeting and some changes were made to the thematic structure. The changes principally included the addition of the group of sub-themes that surrounded specific adaptations to the model for the Bangladeshi population of Tower Hamlets

6. I reported the results in a clear and concise manner which will be presented in the following section.

8.2 Overview of results

The results of this study facilitate our understanding of how the participants characterise their environment. They help us to unpick the factors that could influence behaviour and in turn this will provide us with sufficient evidence to adapt the materials, contents, logistics and delivery of the intervention for this population. Themes 1 and 3 suggested how social structures like family and community could influence behaviour. They also indicated that cultural practices could influence food habits and childrearing. These factors can assist with the development of appropriate contents and materials for the adapted model. Theme 2 demonstrated the logistical differences between contexts and how that impacted on childrearing, health guidance and family dynamics. Theme 4 showed that their social circumstances and cultural influences may limit the delivery of the intervention with regards to the sustained and long-term participation of mothers and other family members.

The results from the data are illustrated in themes and sub-themes with a supplementary verbatim quote from the text in italics. A schematic diagram and a table will illustrate the structure of each individual theme.

Theme number and title:

1. *The family around the child – constructing the ‘typical’ Bangladeshi family in Tower Hamlets and feeding habits*
2. *Place, space and health – how people come together*
3. *Getting advice from a respectable individual*
4. *The social implications of sharing health information in a community group*

Theme 1 *the family around the child – constructing the “typical” Bangladeshi family in Tower Hamlets and feeding habits* describes the reported interplay between the influence of the British Tower Hamlets context and Bangladeshi heritage. Theme 2 *place, space and health – how people come together* discusses the radical differences between the previous trial contexts and Tower Hamlets. Theme 3 *getting advice from a respectable individual* describes who the participants would ask for help or advice regarding health information. Theme 4 *the social implications of sharing health*

information in a community group highlights some of the potential areas that might affect the success of the women's group PLA cycle within the Bangladeshi population of Tower Hamlets

8.3 Theme 1: The family around the child – constructing the 'typical' Bangladeshi family in Tower Hamlets and feeding habits

This theme was split into two organisational themes: *Deep structural differences between the Bangladesh and the UK context* and *The Modern British Bangladeshi Family*, and seven sub-themes. The structure of the theme is tabulated in table 10.

Table 10: Theme 1 structure

Theme Morphology		
Main theme	The family around the child – constructing the ‘typical’ Bangladeshi family in Tower Hamlets and feeding habits	
Organisational theme	Deep structural differences between the Bangladesh and the UK context	The Modern British Bangladeshi Family
Sub-Themes	<i>Nuclear family structure</i> <i>Generational clash</i> <i>Working parents have less time in urban HIC environments</i>	<i>The modern British Bangladeshi family does not act like this</i> <i>Differences between old Bangladeshi and new Bangladeshi</i> <i>The Bangladeshi population of Tower Hamlets is not a traditional “community”</i> <i>There are still some traditional practices within this community</i>

The data from the FGDs demonstrated that the participants recognised there was heterogeneity within the Bangladeshi population of Tower Hamlets. Some of the participants indicated that they interacted with their British environment to a greater degree than their parents and were beginning to identify less with their Bangladeshi heritage. The participants interacted with their British context by engaging with other non-Bangladeshi members of the Tower Hamlets population, accessing goods and services that they considered “*British*”, dressing in a less traditional fashion (wearing trousers instead of saris), and speaking English. This was further reflected in the FGDs where the majority of the participants indicated that they would consider themselves *British Bangladeshi*. The participants recognised a number of ways that their heritage and their lived environment influenced their behaviour. Behaviours such as dietary selection, eating habits, clothing, education levels and social activities possessed stark differences between what was viewed as *traditional Bangladeshi* and what the participants thought was *British Bangladeshi*.

Some of the participants suggested that traditional families would include grandparents, aunts, uncles, cousins and the nuclear family unit, but this was not always the case in Tower Hamlets as

some family members would be in Bangladesh or elsewhere. Furthermore, they suggested that, although most women were full-time mothers, some women worked. This was because of financial demands of living in Tower Hamlets, but also because some women *wanted* to work. The younger male participants also articulated that they were more “*hands-on*” with their wife’s pregnancy and with the care of the child. Both of these examples could demonstrate a shift in the parental roles within the Bangladeshi population of Tower Hamlets and how the family dynamics may have been affected by the Tower Hamlets context.

8.3.1 Deep structural differences between Bangladesh and the UK context

This theme describes the innate trait that the participants’ thoughts were an integral part of their collective social identity. It suggests that areas that could be influenced by heritage and home factors were religion, language, culture, ancestry and physical features. Some of the participants implied that it was the deep structures that made them Bangladeshi. Resnicow et al (1999) suggested that health intervention adaptation is dichotomous: superficial structure adaptations can be made to language, depictions or literacy levels, whereas deep structure adaptations can be made to emulate environment, culture or spirituality (149). The participants in the FGDs did recognise that they had adopted some British customs (changes to superficial structures), but still held some of their cultural beliefs such as religion (unchanged deep structures). It was these deep structures, the participants suggested, that they reported as making them Bangladeshi.

The following organisational theme – *deep structural differences between Bangladesh and the UK context* demonstrates the characteristics that the participants reported as being entrenched in their “Bangladeshi life” but were different in the UK context. It represents the more intrinsic differences within the Bangladeshi population in Tower Hamlets. This theme has three sub-themes:

1. Nuclear family structure – the traditional family unit versus the British Bangladeshi family unit
2. Generational clash – traditional advisors, conflicting advice from grandparents
3. Parents have less time in urban HIC environments – mothers and fathers working in the British traditional sense

8.3.2 Sub-theme: The Nuclear Family Structure

All the focus groups identified distinct differences between the Bangladeshi community of Tower Hamlets and Bangladeshis living in Bangladesh. All the participants stated that their mother and father still lived in Bangladesh. This opened up a discussion about the differences between families living in Tower Hamlets and families living in Bangladesh. All the focus groups discussed the family unit in Tower Hamlets. The composition of families related to the number of individuals living in the family home and their relationship to one another. Traditionally, grandparents may live in the household and, therefore, become part of the Bangladeshi nuclear family unit. However, as demonstrated by the next quote, in Tower Hamlets, if the grandparents are living in the UK they often live in a separate house. A female participant from FGD1 said that her mother lived in a separate house in the UK, which is contrary to the Bangladeshi norm of grandparents living with their children. She describes below a situation where she was trying to get her children to eat healthily and her mother was giving them sweets:

FGD 1, female participant 1: *where it is one rule in my house and when my children go to my mother in law's house...*

This situation was described by many of the participants. They refer to the single nuclear family unit as “single parent/s”, meaning that they did not have grandparental support (rather than the common meaning of a mother or father raising a child alone).

All the focus groups mentioned that family dynamics in Tower Hamlets were different from those in Bangladesh. They referenced the preconception that the mother-in-law would typically influence the feeding patterns and care of the children. When asked about who was responsible for the care of the infants, the groups replied:

FGD2, male participant 6: *That sometime happens, that our mum gives us advice from back home, the situation there and here is not the same.*

FGD2, male participant 5: *Yes, and other thing is back home in the family there are lots of people to help for household activities but here there's only me or my wife, we have to do everything.*

The above excerpts from the data demonstrate the differences in families living in Bangladesh and those families of Bangladeshi origin in Tower Hamlets as reported by focus group participants. Both the men's and women's focus groups identified that the lack of help from family members made infant care more challenging. However, they suggested that it was easier to make their own informed choices about feeding and care without feeling pressured from grandmother or grandfather to carry out traditional practices.

8.3.3 Sub-theme: Generational clash

All of the focus groups discussed the conflicting childrearing practices between generations. The participants said that "*traditional advisors*" were typically grandparents or mother-in-law. A community elder could be a mother-in-law/grandmother, father-in-law/grandfather or a "*community leader*." A community leader could be an older friend or relative of a friend. Most of the female participants challenged the conceived Bangladeshi paradigm that would see them seeking advice from "*traditional advisors*." The following quote demonstrates a difference in approach between a female participant and her mother-in-law. In this example the mother-in-law could be viewed as a community elder.

FGD1, female participant 1: *It is not just the mothers you need to educate to be honest. With nutrition where I had a problem is, I was educated enough to read up what is good for the baby and what is not. My mother in law on the other hand was totally different and it was like we used to clash because I would actually steam my child's food and blend it and make it whereas she has been taught, her children were brought up in Bangladesh where they were born and straight away they used to give banana, because he was breast fed my son so you can imagine I couldn't put him down and obviously she is like – Oh you should do it this way and it was her way and she tried to feed him banana and he just went blue in the face and she just gave up after that and she got frightened as well. So, it is not just educating the mothers; you need to actually reach out to the elderly people who give this advice to the younger mothers because obviously there are a lot of people who come up to me and say – Why are we feeding children of six months? We had this debate whereas before my eldest is seventeen, three to four months but there can be kidney problems, a lot of people don't know this. Sometimes you know like, a child like my youngest who is four, but I didn't wait six months; he was ready by five months. He was ready, I knew he was ready.*

This quote demonstrates a shift in knowledge acquisition away from the traditional means of consulting a community elder such as a mother/mother-in-law. This pattern of knowledge acquisition shows that the participants are becoming more confident and independent enough to make their own decisions about infant care and not always seeking advice from a grandparent. In the past, the participants suggested, they would access information from community elders who often gave advice that conflicted with the advice available on the NHS.

8.3.4 Sub-theme: Parents have less time in an urban HIC environment

The sub-theme *parents have less time in an urban HIC environment* refers to the work commitments of mothers and fathers. This concept could be related to theme 1, sub-theme 2 –*conceptualisation of urban space*. Most of the participants were concerned about the time and cost associated with travelling long distances in London. The majority of the male participants said that they could not attend because they had to work. Most of the female participants said that travelling with multiple dependent children in London was stressful, difficult and costly. These barriers could prevent them from attending regular groups.

The majority of the male participants said that their wives should attend the groups, but they should not because traditionally and culturally “*South Asian*” women were seen as the carers within the household while the men were seen as the financial providers for the family.

FGD2, participant 5: *Because of the social circumstances here, one thing is in India, Bangladesh or the other countries if you work from these people from here to there, and you’ve got everybody there. If you give one message to one person, if you give this message to one person it passes to everyone. It is very easy to pass the messages, but here you cannot go to door to door to knock, so here it is very difficult you cannot go to door to door to knock that we are going to hold a meeting and the other thing is that sometimes mums they work, the fathers they work. Back home culturally the mums, well most of them all I would say sometimes the majority of them don’t work, so you can pass a message easily to them.*

In the above quote some participants in FGD 2 drew parallels between traditional Bangladeshi family norms and the norms of British Bangladeshis in Tower Hamlets. It is not apparent if the British Bangladeshi norms are influenced by the idea of being British and that British women work or if it is

because the context demands that women work. Some of the female participants suggested that their time was already taken up with household activities or childrearing.

FGD2, male participant 5: *Yes, and other thing is back home in the family there are lots of people to help for household activities but here there's only me or my wife, we have to do everything. If I'm working my wife has to look after the family, cooking, washing, dressing, everything so it is difficult to manage time even.*

The women in the focus group also observed that when in Tower Hamlets their duties were sometimes compromised. They considered their duties as a wife and mother to be cooking, cleaning or playing with their children. They suggested that a lack of support from extended family members and time constraints had impact on family activities such as cooking and childcare.

The participant did not fully articulate why their time was compromised in this quote, but this quote was part of a conversation around family life in busy Tower Hamlets. Like all parents, the participants felt they only had a limited amount of free time. This could have implications for group attendance as it may be difficult to persuade them to attend regular PLA groups.

FGD2, male participant 4: *If I'm working my wife has to look after the family, cooking, washing, dressing, everything so it is difficult to manage time...*

The majority of participants in the focus groups stated that men in the Bangladeshi community in Tower Hamlets supported their families by working, therefore, they may not have the time to attend the groups. Additionally, the mothers' time was typically dedicated to family responsibilities and this could make it difficult to attend groups and some of the female participants said they worked, though it was generally part-time. Some of the participants suggested that, even if they worked, there was still an expectation from their husbands that they would primarily care for the family. This has implications for the timing of the adapted women's group PLA cycle and the frequency of the groups.

8.3.4.1 The Modern British Bangladeshi Family

This organisational theme describes some of the differences and similarities between what the FGD participants described as typical modern British Bangladeshi families living in Tower Hamlets and families living in Bangladesh. This organisational theme has 2 sub-themes:

The Bangladeshi population of Tower Hamlets is not a traditional “community”.

There are still some traditional practices within this community.

8.3.5 Sub-theme: Dressing differently, eating differently, being different

The FGD participants were shown cards from the Bangladeshi trial (see Figure 15: The two cards that were used for the FGD 1 & 2 from the BADAS-PCP Bangladesh trial). All of the participants agreed that the setting of the picture card looked basic. They recognised that it was a depiction of a rural family. Everyone reported that they did not sit on the floor to eat their meals in Tower Hamlets. They mentioned that families would sit at a table and use a knife and fork. They also suggested that if there were no space for a table, sometimes families would sit on a bed, but not the floor. One of the women from FGD1 voiced her contempt for the setting below:

FGD 1, female participant 3: *I am assuming the majority of us eat on the table with plates...*

When discussing the clothing of the women illustrated on the picture cards, most of the female participants in the focus groups said that women do not wear saris every day in Tower Hamlets as it is not practical. All of the female participants acknowledged the presence of the mother-in-law in the picture and said that traditionally she would always be present at mealtimes in Bangladesh. In the UK, however, the mother-in-law may not live with the nuclear family unit, either because she lived in her own home or in Bangladesh. When asked how the Bangladeshi picture cards could be adapted for the Tower Hamlets context, members of FGD 1 suggested that the women could wear conservative western clothing and the family could sit around a table when they were eating. A few of the participants also suggested that photographs would be better than illustrations.

FGD 1 conversation:

Female participant 2: *First of all, everyone wears trousers (in the UK); everyone is ready to go out. They are all busy; busy... it is a different time, different foods...*

Female participant 1: *It is very, very traditional*

Female participant 4: *You could have like if you had a family, they could be wearing different clothing, someone with sari or trousers on. Make it natural...*

Female participant 3: *A proper photo maybe and to see everything properly: the food and the people rather than a drawing.*

The men's focus group also acknowledged the differences between current practices in Tower Hamlets and traditional practices in Bangladesh. The following quote for FGD 2 was taken from a response to the picture card that was shown to the group:

FGD 2, male participant: 2: *My grandfather when he was alive, we used to eat like this, all the family members when I was with them in the village, we have to have our breakfast, lunch and dinner...*

Most of the participants in the women's focus groups discussed food preferences and cooking. This topic was not discussed in the same depth in the men's focus group where they mentioned that the cooking was the "*the job of the wife*". The women in the groups reported that, as well as cooking traditional Bangladeshi staples such as rice and curry; they also like to cook "*British*" or "*English*" food.

FGD 1, female participant 2: *You know we said about rice and curry? In my house I am sorry, but no one ate only rice and curry because it is ... my children like English food: Lasagne you know, chicken & mushroom pie. It is just my mother-in-law every few days she has rice and curry, but things are changing constantly, you can't keep up.*

The above quote also demonstrates how some of the participants' food preferences were influenced by their British context. The grandmother was opting for traditional Bangladeshi foods and the mother and children wanting to cook "*English food*." This demonstrates that people who are delivering interventions should not make assumptions about the way the community live or eat. In particular, health professionals need to tailor their messages once they know what sort of foods, etc the family eat.

FGD 1, female participant 4: *we have different clothing, different food, pictures...for example maybe the rice and curry or lasagne, pasta, shepherd's pie so at least when you discuss you can say – Look at those two people for example, what do you think? It is more of a traditional family. The classics, you have got the rice there the curry there and the mum with the sari maybe or the daughter.*

The above quote demonstrates that the participants of the focus group did acknowledge that there were changes happening within their community as a result of their British context, but still observed their traditional heritage and practices. Although the purpose of this work was to reflect on current practices in the Bangladeshi population of Tower Hamlets, it is important to acknowledge how these practices can inform the adaptation of the tools from previous women's group PLA cycle trials.

8.3.6 Sub-theme: The Bangladeshi population of Tower Hamlets is not a traditional “community”

This sub-theme exemplifies the participant's view of population diversity within their context. It signifies many factors that influence the participant's view of what their “community” encompasses and their relationship with different individuals in their context. It suggests that interpersonal similarities in the population may not be enough to call them a “community”. Although similarity can breed connection, it could be viewed as presumptuous to assume that they all have the same characteristics. Previously, the women's group PLA cycle has been implemented within rural communities that demonstrated homogenous traits such as similar language, country of origin, level of education and locality.

The theme of *community diversity in Tower Hamlets* demonstrates that Bangladeshi population in Tower Hamlets may not provide a cohesive network similar to the rural villages that previously received the women's group PLA cycle intervention in India, Nepal, Malawi and Bangladesh. Therefore, the intervention for the UK NHS would need to reconceptualise community and, by doing so, they would need to create a new community that has a particular interest in infant nutrition in Tower Hamlets.

8.3.7 Sub-theme: There are still some traditional practices within this community

Some of the participants suggested that the Bangladeshi population of Tower Hamlets was a “community” in the traditional sense. These described a “traditional community” as a group of

individuals that live in the same locality and were acquainted. They indicated that they would recognise someone as being similar to themselves and it made them feel more relaxed and confident. This juxtaposes the belief that individuals in a high-density urban part of London may not have the social cohesion and community structure that the women's group PLA cycle uses to promote change. When talking about the format of the groups and the delivery method, a female participant felt that the Bangladeshi population in Tower Hamlets was a "*community*." This is demonstrated in a quote from a female participant below:

FGD 1, female participant 4: *it is because in the Asian community, which is the majority in Tower Hamlets, we are so close knitted as an extended family...*

In this quote the participant refers to the Bangladeshi population as an "*Asian community*." It is unclear if she is basing this on physical features, religious salience, language or all of these.

8.4 Theme 2: Place, space and health – how people come together

This theme does not have any organisational themes but is instead split into three sub-themes: *conceptualisation of urban space, access to reliable and free healthcare, and difficulty creating relationships in an urban environment.*

Table 11: Theme 2 structure

Theme Morphology	
Main theme	Place, space and health – how people come together
Sub-Themes	<i>Conceptualisation of urban space</i> <i>Access to reliable and free healthcare</i> <i>Difficulty creating relationships in an urban environment</i>

Most of the participants from the FGDs identified several areas where they felt that living in Tower Hamlets had influenced their situation including their living situation, access to support and the roles and responsibilities they believed a parent should assume. They suggested factors such as availability of space in the family home and outside, building relationships within an alien environment and a

recognition that urban Tower Hamlets is a considerably different context to urban or rural Bangladesh. It is not apparent, however, if this was unique to Tower Hamlets, or if similar populations would experience it in other HIC urban localities. The availability of space is an important consideration for adaptation of the women's group PLA cycle because the groups in LIC are large and need a lot of space and this will need to be adapted to reflect the limited available space within the Tower Hamlets context.

8.4.1 Sub theme: Conceptualisation of urban space

There are distinct differences between previous trial contexts where the women's group PLA cycle was applied and the Tower Hamlets NHS context. The FGD discussion participants identified these when they were shown a photograph of a group in rural Bangladesh. The participants in the FGDs suggested that the Bangladeshi population in Tower Hamlets was not the same as populations in Bangladesh. They suggested that structural barriers like availability of venues for social gathering, time to gather and travel prevented them from getting to know their neighbours.

Most of the FGD participants recognised that Tower Hamlets differs from previous trial contexts because it is a high-density urban environment in a HIC. They commented that the rural communities where the model had previously been implemented might have pre-existing relationships because of family ties or lack of opportunities for families to move out with their village. The clusters in previous trials typically involved whole villages where people were acquainted, and generations of families remained in the same area. The existing community structures were utilised to piggyback the women's group PLA cycle intervention. These structures need to be mapped in the Bangladeshi population of Tower Hamlets so that the adapted intervention can utilise them in a similar way to previous trials.

Most of the FGD participants acknowledged that the group location was not appropriate for Tower Hamlets because it was outdoors. Some of the participants suggest outdoor areas around Tower Hamlets that could be used, but they agreed that they would need shelter in the winter months, which is not unusual considering the UK climate. The participants did, however, recognise that there was a limited number of venues around Tower Hamlets where groups could be held. In previous trials the groups have met in outdoor public space, and an equivalent space that is indoors and has childcare facilities would need to be procured around Tower Hamlets.

An extract from the discussion about the photograph of the Bangladeshi women's group PLA cycle shows the appreciation that there are differences between the urban UK context and a rural Bangladeshi context below:

FGD1, female participant 1: *but that is rural, they could probably do that in a park and they probably don't have centres and facilities like what we would have in a city area...*

A female participant from FGD1 made the distinction between the two contexts and suggested using indoor facilities to hold the Tower Hamlets groups. Available outdoor space was not the only reservation of the groups, all the groups pointed out that the weather in the UK was not predictable, and that they did not want to sit outdoors in the cold and the rain.

Additionally, most of the participants said in Tower Hamlets the mothers were still the main carers for the children, but some worked part-time. They suggested that the group venues should provide childcare, should be accessible for prams and pushchairs and the groups should be held during school hours.

FGD 1, female participant 8: *The best way would be if mothers had to drop off their kids to school and they have got a baby if you do a session and tell them something like – Bring your baby along and we will you know ... have babysitting for your children as well where you can discuss any concerns that you have got. You know like mums with new babies they are very isolated because babies do take a lot of time and they are busy. Usually, we don't make the effort ... usually I just left my babies with my mother-in-law and just go out wherever I wanted because it was too much getting them ready and taking them with me.*

The female participants suggested that holding smaller groups throughout Tower Hamlets might encourage them to attend. This has implications for where the groups should be held and who should attend the groups. It raises questions about the need to have a men's group if the women are sole carers for the children.

FGD 1

Researcher: *Where would you like to have it and in what borough, where is easy for everybody to get to?*

Female participant 1: *I don't think you should have it in one setting.*

Female participant 3: *Yes, I think you should be smaller groups.*

Female participant 1: *so, you encourage them to go to different places, different centres.*

By running more groups with fewer participants at different venues throughout the borough, the groups could be more accessible and then tap into pre-existing social circles instead of bringing together strangers.

8.4.2 The sub-theme: Access to reliable and free healthcare

All the focus groups indicated that living in a UK context had increased their expectations of health and healthcare in relation to the NHS. The participants indicated that they were used to having health professional-led information and seemed sceptical about peer-led/community-led interventions. Some of the FGD participants recognised this to be a difference between Bangladesh and the UK. They questioned how successful a voluntary group would be within the Tower Hamlets context because they had access to the NHS. A few felt that they would accept a casual gathering in Bangladesh because there was not an alternative, but not in the UK:

FGD1, participant 2: *It sounds really bad, but I think we accustomed to more. I know that sounds really bad to say. I don't see anybody in Tower Hamlets just sitting in the park and accepting that.*

This quote shows that there is a differentiation between health intervention expectations in the UK and in Bangladesh. The participants questioned the role of the female facilitator and how she would be able to lead a group of her contemporaries. They were concerned about the lack of direction from the NHS and the ethos of the participatory action cycle. They also suggested that the women's group PLA cycle would be more successful in a context that did not have access to healthcare as there would be no alternative. A male participant from FGD 2 talked about the availability of information from the

internet and trained health professionals, and why they would choose to access information through those sources because it was convenient and less time-consuming than attending groups:

FGD 2, male participant 3: *yes, this type of thing is good for people that have time and don't have the advice we have here (Tower Hamlets) ... maybe they would ask a neighbour, but I would ask my GP*

Asides from location, the groups suggested that the format of the group was also something that they might struggle to adhere to on a regular basis as they felt they would gain more knowledge from “hands-on” experience over sitting “chatting”.

8.4.3 Sub-theme: Difficulty creating relationships in an urban environment

The FGD participants described some of the barriers within Tower Hamlets that inhibited their ability to build relationships with their neighbours. Contrary to the previous assumptions that a large and condensed population of Bangladeshis live within Tower Hamlets, this theme describes the participants' views of diversity, autonomy and isolation of individuals and families. This has important implications for the adaptation of the women's group PLA cycle intervention with regards to language, cultural relevance and health-seeking behaviours. Some of the participants suggested that a lack of space for them to gather socially, the time it took to travel to these spaces and also their restricted time for socialising because of family or work commitments prevented them from nurturing relationships. They also suggested that they experienced an urban paradox: they had higher literacy levels and ability to advocate for change but felt less empowered to make changes in their urban environment. The following quote illustrates the living situation of one of the female participants:

FGD1, female participant 5: *My house is small. I have lots of kids. There is no space for friends!*

The male participants suggested that they would often meet at the mosque, but that there was no room for women at the local mosques.

The FGD participants suggested that similarities in country of origin, ethnicity or physical characteristics in the Bangladeshi population might not be enough to call them a ‘community’. A few of the FGD participants said they could identify individuals of Bangladeshi origin in Tower Hamlets based on their physical appearance. Some of the female participants said, “*You just know*” [that they are Bangladeshi]. When probed they suggested that clothing and accent were telling signs of

Bangladeshi origin. They could also tell who had been born in Bangladesh, who had been born in the UK and the length of time in the UK based on their accent. They mentioned that “*British [Bangladeshi] women don’t wear saris*”, but they still remain covered.

8.4.4 Sub-theme: Different needs

It is important to acknowledge that both the British context and previous trial contexts have resource limitations which have both facilitated and inhibited the women’s group PLA cycle intervention. Within the Tower Hamlets context, the FGDs noticed that they have better access to healthcare, the internet and travel. Some recognised this to be a potential problem for the women’s group PLA cycle because they suggested that they would use the internet or ask the GP if they had any health questions. The male participants in particular said that they did not need an intervention “*like this*” because they had the GP.

FGD 3, female participant 5: *yeah, I ask other mothers, but I know them. It is easy to know who you can trust...*

The FGD participants suggested that universal healthcare may prevent the participants from attending the groups, especially within an urban environment where there is public transport, but it might be expensive and take longer because of the heavy traffic in Tower Hamlets.

Internet access was not available in previous trials, but it is available in Tower Hamlets and the participants indicated that they did utilise this resource. This could be an alternative means of engaging individuals in the intervention or disseminating information to those that have missed a session as the participants suggested that most people have access either in the house, public space or on a smart phone.

The male participants suggested using photographs and YouTube as tools to disseminate health information or to initiate discussion in the groups. The female participants said that they would like to use a variety of tools such as photographs and WhatsApp messaging and PowerPoint presentations, because not everyone, especially the older generation, would be able to use PowerPoint on a laptop or desktop computer.

FGD3

Researcher: *So, to have some training to use PowerPoint, so maybe paper would be easier?*

Female participant 4: *Paper, yeah.*

Female participant 1: *Paper is better.*

Female participant 2: *And the PowerPoint is good as well, it depends on the parent basically.*

Researcher: *So, to have variety?*

Female participant 2: *So, if you have, you know, there could be a lot of options you know, the paper, and the PowerPoint and displays and this and that, that helps that more, because obviously one parent would talk and then it's going down there, and they'd see around as well so this is like better for the community as well.*

Female participant 4: *Also, the posters, the posters and stuff...*

One of the participants said that her son used PowerPoint for university, and she had to pay to download Microsoft Office. She said that not everyone would be able to afford it for the sole purpose of reading materials from the groups. She also said that not everyone had desktop or laptop computers. The FGD participants then suggested that, although there was the potential to access many resources in the context, not everyone could afford them.

8.5 Theme 3: Getting advice from a respectable individual

This theme is divided into three sub-themes: *healthcare professionals and institutions, religious leaders and grandparents*. The structure of the theme is tabulated below:

Table 12: Theme 3 structure

Theme Morphology	
Main theme	Getting advice from a respectable individual

Sub-Themes	<i>Healthcare professionals and institutions</i>	<i>Religious leaders</i>	<i>Grandparents</i>
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This is important because the results of study 1 suggested the target population should respect group and community facilitators. All the participants agreed that they would seek advice from a *respected* individual. Being *respectable* was an attribute that they all considered very important. They wanted to seek advice from a *respectable* individual, and they wanted to be seen as *respected* so others would seek advice from them. This theme explores the characteristics that constitute a respectable person for the FGD participants.

All the participants discussed different interpretations of respected individuals. There was a variety of responses from the groups, but the most prominent characteristics were someone who had significant knowledge or experience with the exemplar.

FGD 2, male participant 6: *It should be like some people with experience...*

Experience differed from education. Some of the female participants agreed that having an education did not make you experienced, and it was experience with the subject that would make them respect an individual enough to ask for advice. Most of the female participants suggested they like a member of the community who had some life experience to lead the delivery of the workshops.

FGD 3, female participant 6: *I think the point here sorry, if you see the people here, they're not educated, but they have experience, you don't have to be educated, life experience that is very important.*

There was the general consensus amongst the FGD participants that a respected individual could be a community elder, a religious leader or a member of the NHS. This has implications for the delivery of the intervention as the Bangladeshi population have alluded to exploring internet interfaces (women), and seeking medical help, particularly from GPs (men).

8.5.1 Sub-theme: Healthcare professionals and institutions

Most of the participants' respected the advice from healthcare professionals. There were, however, some differences between the responses from the male and female FGDs. Furthermore, there were different responses from mothers who had one child and mothers who had several children. The men were more likely to visit their GP for advice and the women expected to get advice from the health visitor. Both men and women believed that it was the job of the healthcare professionals to teach them how to feed and wean their infants. The male participants favoured the GPs because of their medical knowledge and experience.

FGD 2, male participant 2: *I think a group discussion is good, but people should be more educated because if it's just a group discussion and someone told me you can't do this, you can't do that, I should go to the GP first for experience.*

The men also recognised GP surgeries as places where they could access information about local health initiatives:

FGD 2, male participant 7: *The best solution is the GP centre I think with the cooperation with the social people, those who are related to the GP services. I saw so many notices about yoga, diabetes and other things; they have notices in the surgery, so some people choose to do this...*

Finally, the men thought that recruitment should occur through GP surgeries.

FGD 2, male participant 5: *But it has to be started from GP I feel, any problem people are going to the GP first. If they had to take the responsibility first, then to refer them, like you know in your body you need it, you might get diabetic or something like that you have to go there. They have to refer first.*

Unlike the male participants, the women did not want to seek advice from a medical professional, particularly the health visitors. The female participants in the FGDs suggested that they did not trust their health visitor because of inconsistent information.

8.5.2 Sub-theme: Religious leaders

All the FGD participants said they practiced Islam. The men all considered the Mosque a large part of their life outside their family. A few mentioned that they would consider asking their imam for advice. They stated that this advice was not health advice but mainly religious council. The men suggested that imams could be a means of disseminating information about the groups because they had the platform to do so. The men described their commitment to “*their Mosque*”, their admiration for “*their imam*” and how they could rely on each in times of hardship.

A few of the male participants’ recalled speeches that had been given to the congregation at their mosque about health during the busy Friday prayer session. An example of this is illustrated in the quote below:

FGD2, male participant 2: *We did some diabetic sessions in Tower Hamlets, so the main focus was going to the mosque, but when you go to the mosque and talk with the Iman or talk with other people they’re invited on the Friday to the mosque and all of the people are coming there.*

The female participants did not suggest a religious leader as someone that they would ask for advice.

8.5.3 Sub-theme Grandparents

Some participants considered asking for advice from grandparents based on their capacity to provide information based on “wisdom” and experience. Some of the FGD participants reported that they would still ask their mothers or mothers-in-law for advice, but they reported that the more experienced they got with parenting, the more confident they felt to challenge the advice that they received. Most of the participants’ parents were still living in Bangladesh and they recognised this as a limitation in their ability to give up to date advice.

FGD 2, male participant 6: *my mother is living back home (Bangladesh) she tries to help, but it is hard when she is there, and I am here. We can talk, but sometimes I need her to show me and also her ways (infant rearing practices) are not what we are told to do here (the UK) ...*

A few voiced that it was not disrespectful to disagree with a grandparent; their ability to disagree with the information on childrearing given by their parents was merely based on conflicting information between the British and the Bangladeshi contexts. The male and female participants would seek advice from their mothers and mothers-in-law when they had their first child, however, if the mother/mother-in-law was from Bangladesh then they would listen to their advice but not always practice it as they felt it was “*old fashioned.*”

FGD 2, male participant 4: *Yes, of course. I am learning a lot staying at home watching YouTube and all the other information. The thing is you see things practically like before we were thinking about taking the baby last week... Me and my wife we are not that much supported because if we go back home we will still have parents who don't know about the babies so it is about controlling yourself, we'll try next year, and next year and when you have the baby and now you think you should do it before because the experience of doing it practically which is a lot, rather than reading books or watching television those kind of things, they're very important for doing practically yourself.*

The unwillingness of participants to ask for advice from grandparents has implications for the process of adaptation of the women's group PLA cycle model for the wider Bangladeshi population as it challenges the retention of knowledge that is being passed inter-generationally within the Bangladeshi population of Tower Hamlets. Previous generations may have asked for advice about infant care from their parents, but participants in the FGDs described using other means to find this information such as the internet. Some of the participants demonstrated that they were computer literate and felt confident accessing their own information, but they did say that the variety of information available sometimes made it difficult to know what practices to follow. Some of the other participants, however, said that they were not sure where to access information.

FGD 1, female participant 4: *I just think you know, the information provided is not ... it is not clear because I have just heard what you guys are saying about first-time mums or breastfeeding help, my friend just recently had a child. I don't remember and I have got two children and my friend recently, she has got no support, she is at home and she keeps saying – Is there any meetings, I said there is one, but it is quite far from your house. It is new to her husband as well and she has just recently lost her mother-in-law, so she is really like ... everyone is giving all this advice, so it is just finding the information, how do you find it? We didn't get anything, and we asked – Can you help us, but they were so busy.*

Potentially, it would be beneficial to include the grandparents in the adapted women's group PLA cycle intervention, but not in the primary group. They could be engaged during the dissemination of strategies by the primary participants.

8.6 Theme 4: The social implications of sharing health information in a community group

The following theme has four sub-themes: *other people's husbands*, *concerns about neighbour's opinions*, *concerns about sharing experiences within "strangers"*, and *concerns about being viewed as a bad mother*. The structure of the theme is tabulated below:

Table 13: Theme 4 structure

Theme Morphology				
Main theme	The social implications of sharing health information in a community group			
Sub-Themes	<i>Other people's husbands</i>	<i>Concerns about neighbour's opinions</i>	<i>Concerns about sharing experiences with "strangers"</i>	<i>Concerns about being viewed as a bad mother</i>

All the FGD participants mentioned that they would have problems sharing experiences in a group setting. The theme of apprehension about sharing experiences with unfamiliar faces describes the participant's reservations about the group format of the women's group PLA cycle. All the participants raised the problems with the group format. The female participants were the most nervous. When shown the photograph of the rural Bangladeshi women's group, the female participants pointed out that the women in that picture would know most people in the group. They also suggested that the women in the picture probably had more support from friends and family as relatives would live in the same area. They identified that those women's problems were most visible due to the nature of the rural context and that it would be easier to empathise with each other if you recognised that you had similar difficulties. The male and female participants voiced some of the

drivers that would make them nervous about sharing their experiences in public. These are captured in the four sub-themes:

1. Other people's husbands
2. Concerns about neighbours' opinions
3. Concerns about sharing experiences with "*strangers*"
4. Concerns about being viewed as a bad mother

8.6.1 Sub-theme: Other people's husbands

This discussion was a product of whether men should be allowed to attend the women's group PLA cycle intervention along with their wives or other relatives. All the groups talked about the traditional role of men and women in the household and in the community. The men indicated that in rural Bangladesh women would typically be segregated from the men and that their wives would have female friends. The women in the groups talked less about structural segregation, but more about the psychological impact that not having exposure to "*strange men*" had on their confidence around the opposite sex. There was a lot of contradictory data around whether or not the men would attend, and also, whether or not the women would feel comfortable articulating their experiences in the presence of men.

The female participants suggested that they were comfortable discussing problems in the presence of their own husbands or husbands of friends, but they were not sure if they would be able to discuss problems with men they did not know. They also suggested that men might not be interested in attending the groups because they were discussing childrearing and that was considered 'the job' of women. An example of this attitude is framed in the sample from FGD3 below:

FGD 3:

Female participant 2: *But then again sometimes some women, they might not want to open up in front of men because sometimes the men are troublemakers, oh you don't do it this way, yeah, yeah. It's the truth though isn't it? They do, do it. It's better if...*

Female participant 1: *Yeah, you can introduce parents, as I've said, I went to this session, it was called MEN, M-E-N*

Female participant 3: *One for the father, one for the men...*

Female participant 1: *The father doesn't know...*

Female participant 2: *There were two Father's Day...*

Female participant 5: *Maybe men, maybe not men, maybe sometimes.*

Female participant 2: *Maybe separate.*

Female participant 1: *I think the best way is separate because women do open up when the men are not around*

Female participant 4: *Men will never have time to go the session, a lot of men are not interested in it.*

Female participant 2: *Men aren't really bothered; they know the wife does that.*

This insecurity in the presence of men was discussed in both the women's and men's groups. All groups suggested that segregation between men and women was traditionally how social gatherings were conducted. The men said traditionally men and women would pray separately and that some of the smaller local mosques in Tower Hamlets did not have accommodation for women. This is important when considering the location of the women's group PLA cycle, as it means that mosques could not be the only venue for the women's groups.

8.6.2 Sub-theme: Concerns about neighbour's opinions

The participants reported that the high-density urban context of Tower Hamlets made it difficult to build relationships with other people living in the area. This often prevented them from asking for help or advice from their neighbours. It also induced an anxiety circulating their neighbour's opinions about their parenting, particularly in the female participants. Although the participants claimed not to have a relationship with their neighbours, they did not want to be perceived in a negative way. When shown the photograph of the women sitting in a circle in rural Bangladesh, one participant said:

FGD1, female participant 9: *Well, groups like that are good if you know someone, but I don't know anyone in my street. If I had a problem with my son, it would not be my neighbour that I asked. I would feel bad...*

The above quote demonstrates an apprehension that resonated with most of the participants. There is an apparent reservation about asking neighbours for help. They reported reservations based on a variety of factors including not wanting to inconvenience a neighbour, feeling embarrassed about problems and/or a lack of awareness that individuals in the population could be experiencing similar issues. All of these factors influenced the participants' inability to share their experiences with people in their surrounding area and the cohesion within the Bangladeshi population of Tower Hamlets.

8.6.3 Sub-theme: Concerns about sharing experiences with “strangers”

Initially, when the idea of the women's group PLA was introduced, the female participants in the focus groups seemed sceptical about the potential benefits. It was also apparent from the interactions that the female participants felt unsure about sharing their experiences with “strangers.” The groups suggested that health should be a private family matter and not discussed openly with members outside the nuclear family unit. When asked about the format of the women's group, one female participant responded:

FGD 3, female participant 3: *It's family health, why are we debating on somebody else's health?*

The above quote was taken from a conversation about sharing experiences around infant feeding and care. This rhetoric went beyond the realms of infant feeding and care practice. The more experienced mothers seemed more willing to share their health problems in the focus group. All the focus groups recorded a concern about discussing problems in “public” for fear of being judged by their peers. Some participants considered this to be a product of the isolation of families in Tower Hamlets. The participants reported some Bangladeshi families in Tower Hamlets usually lived as “single parent” families. They suggested that living in this way increased their autonomy and their need for privacy when it comes to their infants' health and care.

Some of the female participants indicated that they believed other members of the population would be disinterested in their problems. The following quote was taken from a discussion about the format of the women's group.

FGD 3, female participant 5: *my mother is always asking me what is happening with my son, she is in Bangladesh... she always wants to know what is happening with him and she can be demanding, and she is my mother! I don't know if someone else would care...*

The above quote suggests that the participant accepts that her mother will share an interest in the care of her infant, but not potential members of the women's group. A few of the female participants expressed concerns about sharing their problems issues as they did not want to be judged.

8.6.4 Sub-theme: Concerns about being viewed as a bad mother

All the focus groups indicated that they would only discuss "*family health*" within their close friends and family. The women were concerned about being labelled a bad mother if they had problems with their child. This included being judged by their neighbours and also being judged by NHS health professionals. The participants who had several children and considered themselves experienced mothers were less concerned with being labelled a bad mother because they had confidence in their own knowledge. Nonetheless, all the female participants agreed that, at some point, they had feelings of anxiety or embarrassment about their inability to care for their children. A discussion around accessing advice from a health professional prompted this statement from a female participant below:

FDG 3, female participant 3: *Some mothers didn't want to go to professional people, they find it embarrassing or whatever. Maybe something would help like that, there's a thing that you want to and talk to someone, an experienced mother and speak to like other people, and maybe they might find it comfortable.*

The female participants did find it difficult to ask for professional help. They indicated that they would prefer peer-led support groups who might be a more acceptable and less daunting vehicle to access information for the less experienced mothers. This is an important consideration for the adaptation of the women's group PLA cycle group as the less experienced mothers feel vulnerable and nervous about sharing their problems. An extra support system could be added to help these mothers express their problems in a safe environment.

8.7 Evidence for the adaptation of the women's group PLA cycle

The following section is a collection of notable sub-themes that have been recognised as significant for the adaptation of the model for the Bangladeshi population in Tower Hamlets.

They are not considered collectively as themes because they are answering different questions around context specific adaptation. The sum of these sub-themes answers the objectives from study 2 by addressing questions about the adaptations to the materials, contents and the delivery of the intervention. Twelve sub-themes are included in this section. Each has been titled with a question that study 2 objectives looked to address. These questions are listed below:

1. Who would benefit most from the women's group PLA cycle intervention?
2. Can we use visual aids?
3. What tools can we use to engage the men?
4. Should the groups be incentivised?
5. Who should deliver the session?
6. What format should the groups be in?
7. The Hook
8. Delivering consistent information is paramount!
9. How can we make the women's group PLA cycle groups more accessible in Tower Hamlets?
10. Is a mosque-based intervention an option in Tower Hamlets?
11. What are potential ways to recruit participants to the groups in Tower Hamlets?
12. How do we create Linguistic accessibility?

8.7.1 Who would benefit most from the women's group PLA cycle intervention?

8.7.1.1 *First time mothers*

All the participants discussed how to engage families and individuals that would benefit the most from the women's group PLA cycle intervention. They signified that first-time mothers could benefit most from the PLA cycle groups, but that experienced mothers could come for a “*refresher*” or to share their own experiences.

The female and male participants had different ideas regarding how to engage with these groups. The female participants indicated that they would prefer not to have a referral from health professionals. Male participants ‘suggested positive ways to engage new mothers may be through GPs, health visitors and antenatal clinics at hospitals. Both the male and female participants recognised that new mothers were often isolated and alone during the first few month’s post-partum. A female participant sympathised with this feeling and described a situation in the quote below:

FGD 3, female participant 6: *it is hard, you are alone with a baby and you have no support during the day. Some new mums are tired and isolated*

The above quote exemplifies the understanding that being a new mother in Tower Hamlets can be difficult and lonely. Some of the female participants indicated that they had felt alone during the first months of the post-partum period because their husbands were at work and their mothers or mother-in-law were in Bangladesh. The younger male participants also recognised that new mothers had a difficult time in Tower Hamlets. In the following quote, one of the younger male participants described his concern for his wife when she had problems during her first pregnancy and then problems with breastfeeding:

FGD2, male participant 9: *I was involved from the beginning, because my wife had problems. She was bleeding. It was just me and her, our family was in Bangladesh... when she started to feed, she had more problems and her mother was trying to give advice from Bangladesh, and she felt worried because she was far away...*

The above quote demonstrates difficulties experienced by mothers during pregnancy and with infant feeding. It also shows that this participant’s wife felt most comfortable asking her mother for advice, even though she was in Bangladesh. He recognised that communication between his wife and her mother was important, but it was difficult to get advice and support when his mother was in Bangladesh. Some of the female participants suggested making the PLA cycle groups “mothers support groups”, so that new mothers, particularly those with no familial support, could ask for help and advice from other mothers.

8.7.1.2 “Single parents”

All the FGDs mentioned the term ‘single parent’, which in a western context describes a mother or father raising a child on their own. However, the participants used this term to describe a nuclear family. A nuclear family is a basic social unit that includes a mother and father and their dependent children. When discussing who the women’s group PLA cycle intervention should target, one female participant suggested targeting “single parents.”

FGD 1, female participant 2: *A lot of parents are single parents they don’t have that extra family so if you aimed it towards them it would be really beneficial*

The female and the male participants suggested that extra support should be given to single parents who did not have the immediate support from their extended family. Extended family members included grandparents who were living outside of Tower Hamlets. All the participants had been born in Bangladesh, however, some of them had family in other boroughs across London (particularly Newham) and some had family in other areas in the UK (Leicester and Birmingham). One participant did have a sister that lived in Tower Hamlets, but she said that her sister was preoccupied with her own children:

FGD 3, female participant 5: *My sister lives nearby, but she has a baby and a toddler. She does not have time to look after my children as well. Also, it is too much and too far away... she is in Tower Hamlets, but it is still a long walk with two kids for me! So, my husband and I, we manage!*

This quote demonstrates two important factors that need to be considered in the adaptation of the women’s group PLA cycle for the Bangladeshi setting. First, that “single parents” do need support and that they may benefit most from the groups. Second, this participant highlighted that Tower Hamlets is a large borough and there needs to be multiple groups around the borough, so that the participants do not need to travel far, saving time and money.

8.7.1.3 Refresher for experienced mothers

Although all the participants suggested that new mothers would benefit the most from the intervention, they also agreed that it could be advantageous to include more experienced mothers in the groups. Most of the experienced mothers amongst the female participants reported feeling

“*confident*” enough to make their own decisions about how to look after their infants. They suggested that having several children had given them “*practice*.” There was a lot of discussion about changing guidelines regarding infant weaning practices and conflicting advice from the health visitor. One female participant said that she was able to decide when her infant was ready to wean based on her experience from previous children:

FGD 1, female participant 2: *my youngest who is four now, but I didn't wait till six months; he was ready by five months. He was ready, I knew he was ready...*

The experienced mothers in the focus groups seemed confident enough to challenge the advice from their mother-in-law. This counters the assumption that a mother-in-law may be an influential figure in family decisions. Many of the female participants reported that they were technologically astute enough to access advice or health information online. This is demonstrated in a quote from an experienced mother and female participant below:

FGD 1, female participant 2: *With nutrition where I had a problem is, I was educated enough to read up what is good for the baby and what is not.*

8.7.1.4 *The whole community*

All the participants acknowledged the value of the potential education that the women's group PLA cycle could provide. All the participants suggested that this education should be extended to their wider family and the wider Bangladeshi population in Tower Hamlets. The male participants believed that education made them more confident in their decisions in everyday life. The female participants believed that educating their family members would help them to feel safer and more relaxed leaving their infant. It was the female participants that felt the most strongly about including “*everybody*” in the intervention because this would give a wide diversity of views, knowledge and experiences which could help change individual, family and, potentially, community perceptions. This is demonstrated in two quotes from the same focus group below:

FGD 1:

Female participant 5: *Why are we targeting mothers?*

Female participant 3: *But you need to educate people as well, it is not just ... I don't know, it is not just the mothers; it is the fathers, the grandparents, the neighbours ... everybody.*

This exchange shows that the participants recognised that their family and friends were influential figures in infant care. The entirety of participants agreed that the intervention should target the whole Bangladeshi population through different types of media. The female participants said that they would feel comfortable with female participants and the men said that they were unsure if they had the time to attend the groups. Therefore, the intervention may need to involve other platforms to disseminate information.

8.7.2 Can we get the men along?

The male participants' responses about their involvement in "*family life*" varied between older and younger fathers. The younger fathers reported being more involved in the care of their infant by attending antenatal classes with their pregnant wives. The older fathers voiced that they did not have time to attend classes as they are working and in their spare time they like to be "*social*". Most of the men described "*social*" activities as mosque-related such as praying or seeing friends at the mosque. This is illustrated in an exchange between the male participants' in FGD 2 below:

FGD 2:

Male participant 2: *If it is a fixed issue like diabetes or a mum problem then the doctor can help, but if it is not a fixed issue, not an issue then you can go to the mosque or the community centre is the better policy. The mosque you can discuss with everyone.*

Male participant 9: *It's more social.*

Male participant 2: *It's a social place.*

Male participant 5: *I want to mention one thing for men especially here, they have not interested that much to come because they are more interested about social things and economic things.*

The men's focus group said that they would be interested in attending the group but felt like they had too many "*social or economic commitments*" that prevented them from being able to commit to a monthly meeting. This indicates that some men still occupy the traditional view of a husband. It also suggests that women and men may need to be separated as they will not be able to attend a group at the same time. All the participants in the men's focus group stated that they would rather have information delivered at the mosque because they did not have time to attend regular meetings.

In this discussion about engaging men, it was apparent that it might be difficult as they favoured economic ("*business and work*") and social engagements. The older men in the focus group suggested that infant and care practices were for their wives.

FGD 2:

Male participant 9: *How can we make this a social thing, what would make men come?*

Male participant 3: *If it is an economic thing?*

Male participant 6: *Yeah, they are there for the job, for business for other things and they leave the rest, the family things on the wives, the child issue and everything mostly they don't want to know that much.*

The above quote demonstrates some of the older men's beliefs around family care. The younger men definitely appeared to be more involved in the care of their children and seemed more enthusiastic about the intervention. There may need to be multiple strategies to engage men. This will be explained further in the sub-theme: *what tools could we use to engage men?*

The participants suggested that financial restrictions are the reasons why some of the Bangladeshi mothers had to work.

Alternatively, it is simply demarcating the beliefs and practices between the older and younger generations. These differences would be seen in British Caucasian populations as well as other groups

across the UK. The participants suggested that the younger fathers were more involved in the care of their children whereas the older fathers believed it was “*a wife’s job*” to look after the children. Traditional views of fathers being the *breadwinners* (249) have long faded and the contemporary view of fathers as co-parents is now popular in western countries (250). Cabrera et al (2003) thought that trends such as increased migration and the increase of women in the workforce have contributed to the reconceptualization of fatherhood in western countries (250). This adoption of western ideals of fatherhood could be an example of how the Bangladeshi population of Tower Hamlets is responding to their British context and exemplifies the need for adaptation.

8.7.2.1 *What tools could we use to engage the men?*

The male participants indicated that they were happy to get information from the internet. The male participants did mention that health information is accessible via the internet. They discussed using YouTube and accessing National Institute of Health and Care Excellence (NICE) guidelines.

The male participants expressed a view that it was easy for them to motivate themselves to access information but thought it might be difficult to motivate lots of men to attend the groups. This is demonstrated in a discussion from the male participants about how to get men to attend the intervention in Tower Hamlets:

FGD 2:

Male participant 4: *Things like motivating yourself, you have to do it yourself. These kinds of things no one can push you*

Male participant 6: *It is very difficult to do it with a group*

Male participant 4: *With a group, within a group...er it’s not even our culture... but in a family, like me and my wife, we think we’re going to do it, we can do it because we’re together*

The above discussion illustrates that male participants do not like being told what to do and may not respond to egalitarian recruitment measures, however, the last sentence from participant 4 suggests that wives may be able to influence attendance. This is because participant 4 suggested that he and his

wife do things together. Participant 4 suggested that sharing information in a group is not part of his “culture,” but he challenged the gender dynamics that are typically associated with this population suggesting that he and his wife work as a team.

8.7.3 Can we use visual aids?

Using tools to disseminate health messages was an integral part of the former women’s group PLA cycle trials. Exploring whether similar tools can be used to disseminate health messages with the Bangladeshi population of Tower Hamlets and how they can be adapted is an important part of the adaptation process.

All the participants suggested that adapting the tools to emulate social nuances, beliefs, behaviours and maybe actions of the Bangladeshi population of Tower Hamlets could increase engagement within the groups. When asked about tools to disseminate health information or initiate conversations in groups, the focus groups mentioned that visual aids were a good means of communicating information to individuals who could not read or write in either English or Bengali. A segment from the FGD 1 (women) supported this statement below:

FGD1, female participant 1: *I like the picture card idea. I think we use it a lot in study that we do you know where communities lack or have certain language barriers. I think a picture says a lot to help us... I will translate or I will be like –No, you will be fine. So, when it comes to something like this you have live visuals.*

All the participants concluded that the picture cards were the best tool to inspire a discussion in the groups. They also agreed that they were a good way of demonstrating optimal practices. They suggested changing the scenarios that were depicted so that they captured the Tower Hamlets context.

The groups were each shown a picture card with an illustration and most of the participants agreed that visual aids were an appropriate way of communicating health messages in Tower Hamlets. (see Figure 15: The two cards that were used for the FGD 1 & 2 from the BADAS-PCP Bangladesh trial). The discussion that ensued surrounded the differences in practices between the perceived context of the picture cards and the Bangladeshi population in Tower Hamlets. All the participants agreed that there should be changes to the aesthetics of the picture cards. These included the clothes that the

characters wore, the food they were eating, the way they were eating their meal and the median that was used to illustrate the picture. They considered the cards to be “*old fashioned*” and suggested that they looked like they were from an “*old Bangladeshi story book*”. A segment from the text demonstrates this attitude below:

FGD1, female participant 1: *I would say this picture is like very old like you know back in Bangla-book...*

Some of the participants wanted the content to truly represent the “British Bangladeshi”. This included adjusting the clothing of the characters to represent their British environment. The female participants indicated that most women wore a hijab, but they modernised to echo fashion trends in their British environment. They suggested wearing jeans and long sleeve tops with fashion scarves that they got from the market. A few of the women said that they did not wear hijabs, especially in the summer when it was too warm. When shown the picture card illustration, most of the participants’ agreed that not everyone wore the traditional sari.

FGD 1, female participant 4: *Different clothing, different food, pictures. So, you have got the traditional for example maybe the rice and curry or lasagne, pasta, shepherd’s pie so at least when you discuss you can say – Look at those two people for example, what do you think? It is more of a traditional family. The classics, you have got the rice there the curry there and the mum with the sari maybe or the daughter. In the other one you could say okay more of the working parents maybe, do you know? It builds up and that is where they will do discussion and say – Actually I find it hard to cook every day. And someone will say I cook once a week and I put it in the fridge. You get stories and say actually is that nutrients enough, is that healthy enough? It is a quick snack.*

The female FGDs wanted to have more food choices that represent both Bangladesh and Britain included in the materials. They highlighted that they could not always get the foods they would eat in Bangladesh in Tower Hamlets, and that they sometimes had to substitute certain ingredients with British alternatives. Most of the female participants also suggested that they did enjoy traditional Bangladeshi cooking, but it was time consuming and needed a lot of kitchen space. Some of the participants also suggested that their children were requesting British food, so they wanted information on how to prepare healthy British and Bangladeshi recipes.

All the participants' indicated that tools were needed to stimulate discussion and encourage engagement with the participant in the groups. Additionally, the female participants said they wanted interactive sessions on cooking, infant feeding, infant care, physical activity and healthy eating. The men did not discuss food or activities to the same degree.

8.7.4 Should the groups be incentivised?

Unpicking the complexities that inform the expectations around incentives will help us understand the drivers around attendance. Two of the focus groups discussed using incentives to encourage group attendance. They suggested that if participants were to attend the group, they should receive a token to thank them for attending. The FGDs did not demonstrate familiarity with women's group concept, most of the participants suggesting that they would prefer a more formalised health intervention. However, they did discuss using practical sessions to encourage attendance. So, although physical incentives are not sustainable, sessions that delivered information in an alternative format would encourage attendance.

FGD 1:

Female participant 1: *So, I am just thinking about for people to come, I would be interested if you had like a practice session where you show how to blend foods in and stuff like that where people can get involved as well and you give out goody bags as well...*

Female participant 2: *We have said already; people want gift, people want this and that.*

This sub-theme suggests ways of motivating the target population to attend the groups. It was mentioned by all the focus groups. The women, in particular, wanted the groups to be incentivised, whereas the men said they wanted alternative methods of accessing information. All the participants said they wanted incentives: if not monetary, then some form of new knowledge or skill such as how to prepare food for baby weaning.

8.7.5 Who should deliver the sessions?

All the focus groups stated that they would like the information in women's group PLA cycle to be delivered via practical sessions and lectures. Most male participants wanted these sessions to give them health information to be delivered by a health professional. Most of the female participants said that they wanted the sessions to be peer-led by someone who had "*life experience*" with infant feeding and care.

8.7.6 What format should the groups be in?

The men's group stated that they would prefer to use online resources because they did not have time to attend regular groups. The women's groups indicated that they would enjoy the causal gathering format of the groups, but that the contents would need to offer information on child growth and development if they were to attend past their first child. The female participants also suggested that they wanted a safe, secure, casual and welcoming environment. They did not want to be chastised for problems or inadequate practices. The female participants suggested that they would feel more comfortable exploring "*good*" rather than "*not so good*" practices. One female participant thought that people would be more likely to attend the groups and keep attending the groups if the delivery was more positive:

FGD 3, female participant 4: *Mum's don't want to be in trouble, the health visitor sometimes says you're doing it wrong. I think, if we said – this is how you do it, instead of – no! That is wrong, it would be better, and people wouldn't be scared...*

This is an interesting shift from the messages being framed around sub-optimal practices in previous applications of the women's group PLA cycle in low-income contexts to framing the messages around optimal practices in the Tower Hamlets' context.

8.7.7 How do we get people to encourage attendance?

The *Hook* is the overall topic that will be addressed by the women's group PLA cycle in the Tower Hamlets context. It describes different topics that could encourage members of the Bangladeshi population to attend the groups. The female participants agreed that infant weaning was too narrow and only applicable to new mothers. All the female and male participants agreed that they would attend groups that discussed "*infant growth and development*". The men were particularly interested

in cognitive development and the female participants were more interested in physical development. The female participants wanted people that could advise them on infant feeding and care and did not have a preference on who delivered the sessions. The male participants indicated that they would prefer a health professional to lead the sessions as they “*trusted their knowledge*”. Creating an interesting and relevant syllabus was considered paramount in the adaptation of the women’s group PLA cycle contents agenda.

8.7.8 Delivering consistent information is paramount

All the participants mentioned confusion around inconsistencies in the information that they received from health visitors, NHS guidelines and past experiences. This caused a lot of mistrust in the health professionals that were providing the information. The female participants reported disagreeing with the health visitor and voiced discontent at the assumptions that the health visitor made about their own knowledge. An exchange between the female participants of FGD 3 demonstrates their contempt for the health visitor:

FGD 3:

Female participant 1: *Sometimes the doctors give you wrong advice as well...*

Female participant 2: *It’s stupid yeah.*

Female participant 2: *I went to the midwife and said look I’ve read the leaflet for Canesten cream for thrush, why did she give that for my head, my baby’s head or my ear or whatever and she goes, she’s stupid the doctor, I don’t know what’s going on.*

Two factors suggest that information should be accessible to the Bangladeshi population of Tower Hamlets outside of the NHS. A few of the female participants and most of the male participants believed that it was the responsibility of health professionals to make recommendations on infant care, including feeding. This was because they themselves were inexperienced and potentially isolated. They suggested that they were upset that the health professionals did not always have time to give them the level of support that they required and also mentioned that changing recommendations from Public Health England made making decisions about infant feeding difficult. The more experienced mothers mentioned that they felt confident in their own ability to look after their infant and felt that

they were responsible for their health. One of the more experienced mothers articulated her ability to make decisions that challenged the health visitor's advice:

FGD 3, female participant 3: *Even the day I went to the midwife she goes, she's not even my first baby obviously and she goes you're feeding her too much, I said excuse me, I've got six children, I know what I'm feeding her on.*

There was a conflict of opinions between the experienced and less experienced mothers in the groups. The less experienced mothers wanted more help from the health visitor and the more experienced mothers wanted less help. This could be because they had received poor advice in the past and exemplifies that the women's group PLA cycle should have an accurate and up to date syllabus to instil trust in experienced and less experienced mothers.

8.7.9 How can we make the women PLA cycle groups more accessible in Tower Hamlets?

All the participants in the women's focus groups said that to make the women's group PLA cycle intervention more accessible, childcare would need to be provided at each session. They indicated that new mothers can sometimes feel isolated and allowing them to bring their infant to the groups could make the groups more attractive. One of the participants suggested allowing mothers to bring their children to the groups so they did not need to arrange childcare:

FGD 3, female participant 4: *The best way would be if mothers had to drop off their kids to school and they have got a baby... tell them something like... bring your baby along and we will have babysitting for your children as well where you can discuss your concerns*

An alternative would be to hold the groups in a facility that could offer childcare. The female participants proposed holding the groups in unused classrooms at schools and in children's centres. They were particularly interested in the latter option because a lot of the female participants frequently attended the children's centres for other activities.

All the focus groups suggested that the women's group PLA cycle intervention should be held during "school hours". This included morning school run or before collection at the end of the day. The

women said this would be easier as they were already out the house and would not need to entertain older children if they were at school. They also wanted these sessions to be delivered within an hour. They mentioned that any longer than an hour and people would be disengaged. One of the female participant's demonstrated why she would find it difficult to attend a group for more than an hour:

FGD 3, female participant 5: *You see there are lots of distractions, phones, children, husbands. One hour is plenty, otherwise we will get bored!*

This is an adaptation from the previous women's group PLA cycle session length of three hours to a more condensed session of only an hour. The female participants illustrated the demands that they are faced with in their Tower Hamlets context. They said that women have more time to "*sit around chatting in Bangladesh*" but that in the UK they have to consider school runs, transportation to and from the group, childcare and travel costs.

8.7.10 Is a mosque-based intervention an option in Tower Hamlets?

The male participants stated that women were not permitted to use the mosque facilities therefore it cannot be a solely mosque-based intervention. The following quote came from a discussion about potential locations of the groups:

FGD 2, male participant 4: *No, sometimes it is difficult in the mosque; they don't have accommodation for females.*

The men suggested that segregation was "*respectful*" and "*conventional*", whereas the women indicated that they felt less confident in the presence of men. The men indicated they would always try to attend Friday prayer at the Mosque.

All the participants discussed different ways of engaging the Bangladeshi population of Tower Hamlets. All the groups suggested that a good way of accessing potential group participants would be through primary healthcare services. The women in FGD 1 also suggested social workers, health visitors, maternity mates, walking groups and coffee mornings. It was obvious from the different responses between male and female participants that a variety of strategies were needed to recruit to

the women's group PLA cycle intervention in Tower Hamlets. Three of the most commonly mentioned strategies are explained in the following section.

Male and female participants suggested recruiting through NHS services. The younger men said that they attended antenatal groups with their wife, and they felt that would be a good point to advertise the groups. The female participants suggested catching potential participants in hospital waiting rooms. Some of the participants said they would pick up a leaflet, but most said that they would rather that someone was there to speak to them about the benefits of the groups. A quote from a couple of female participants lists a few recruitment personnel suggestions:

FGD 1:

Female participant 2: *I think through surgeries and doctors and hospitals*

Female participant 1: *Social workers and health visitors*

All the men wanted to be referred from a GP. They said that if they had any “*problems*” they would go to the GP. They thought it should be their responsibility to refer people to the groups. The discussion about the role of the GP was very detailed and all the men believed that “*he*” should handle health. They insisted on having “*his*” involvement. This attitude is described below:

FGD 2, male participant 5: *But it has to be started from the GP I feel, any problem people are going to the GP first, then to refer them...*

The men were asked if they would be more or less likely to attend a group that was NHS led. They answered more likely, but also made the distinction that they did not have time to attend groups on a regular basis. The men said that they would go if the doctor ordered. This is important for the adaptation of the women's group PLA cycle when thinking how the groups could be facilitated for men. This is demonstrated by the quote from focus group 2 (men) below:

FGD 2:

Researcher: *And how would we reach them?*

Male participant 1: *I think through surgeries and doctors and hospitals.*

Male participant 1: *Social workers and health visitors, GP*

Male participant 2: *Even schools because parents have got babies so coffee mornings that would be quite nice ... nurseries, we have got nurseries in the borough*

All the FGDs suggested that the intervention could access participants through secondary care facilities like hospitals. The female participants thought accessibility could be maximised by targeting women when they were in hospital for antenatal care and during their post-natal stay. The male participants suggested accessing participants through antenatal classes. Interestingly there was a clear division between the responses of the older and younger men in the group. The older men said they would not attend the antenatal classes but maintained that they were involved in infant care, whereas the younger men were actively involved in antenatal classes and infant care.

Most of the participants suggested accessing potential participants via nurseries, schools and children's centres. Participant three from FGD 1 suggests why children's centres could be a useful way to access the Bangladeshi population:

FGD 1, female participant 3: *... a lot happens with children's centres now obviously I want to differentiate between children's centres and community centres as well. Sometimes children's centres are ... the have selected days that we attend, they have short programme, they are fully booked...I am just trying to think maybe having flexibility of having ... especially if you are trying to reach out to the community there would be like translators...*

This sub-theme has demonstrated a range of recruitment strategies recommended by the participants. Male participants favoured a health professional led recruitment strategy and the female participants said that they would prefer recruitment through schools or children's centres. Also, the female participants agreed that they would recruit friends and family members.

8.7.11 How to create linguistic accessibility

Most of the participants mentioned that certain individuals in their population experienced a language barrier when receiving health information from a health professional or allied health professional, or seeking information online, through a health facility or through other health outlets such as pharmacists. This language barrier extended beyond actual spoken language to understanding the information that was being disseminated. This is important for the women's group PLA cycle intervention because it could be adapted to facilitate linguistic accessibility. Linguistic accessibility includes comprehension of language including literacy; speech and understanding. The participants mentioned that the structure of Bengali is different to English and that sometimes messages do not translate properly.

Most of the group members could speak Bengali and they suggested that being able to speak Bengali was important to their identity as a Bangladeshi. However, they also suggested that it was practical to speak English in Tower Hamlets, because "*everyone speaks English*". They suggested that only speaking Bengali could affect their confidence and ability to ask for help. All the participants mentioned that having a Bengali translator could be beneficial. They identified that the families that cannot speak English may need more help with infant weaning than those that can speak English. This is illustrated in the following quote:

FGD 1, female participant 1: *if you were trying to reach out to the community there would be like translators or like you know trying to engage those who probably don't understand the importance of weaning...*

The participants suggested that even if the materials and the information that the NHS provides is in Bengali, they could not always understand the information. This was down to two factors: the English to Bengali translation was not always correct, and many participants said that, although they had been raised to speak Bengali as their first language, their Bengali vocabulary had become more basic as they were not using the language as often.

FGD 2, male participant 8: *it is hard, you see, we don't all speak the same Bengali... some are from a different city or town. Bangladesh... it is big!*

The above quote shows the diversity of the Bangladeshi friends and family of a male participant. He said that linguistic differences exist in this population. Some of the participants also claimed that their friends and family who had not been born in Bangladesh could not read or speak fluent Bengali. Furthermore, individuals spoke different dialects such as Sylheti, which cannot be written.

8.7.12 Providing a new approach to infant care

This sub-theme demonstrates why the women's group PLA cycle format could potentially be a novel way of delivering health messages about infant nutrition in Tower Hamlets. Most of the FGD participants wanted reliable information from a credible source to be delivered in an engaging manner. Some of the female participants suggested that it would be difficult to attend a cycle of sessions because they were already very busy. A few of the female participants mentioned that they would like to attend the groups, however, they wanted sessions on new and interesting child health and care topics that were not already available to them. A participant from FGD 1 articulates these points below:

FGD 1, female participant 2: *The thing about activities like you said, having workshops or whatever, everyone is so busy nowadays it is making the time so if today like somebody said to me, we are having something about healthy eating, can you come along, I would probably say no because I am dragging three children ... I can just do that on the internet ... healthy eating, what is healthy eating? So, you actually need to provide something more for people out there for them to come to you. If you say to me – I am going to teach you how to make pot noodle, I will know that and I am not going to come to you, do you understand what I mean? You have to give the option like goody bags ... fresh ... or activities for the older children if you have to bring your children along to keep them engaged to keep them quiet you know? You have to think of the children as well.*

A few of the participants wanted sessions that would offer a mix of learning, discussions and activities. They did not want to sit in lectures, and they did not want to be taught solely about nutrition.

Some of the female participants said that bringing the community together in groups was a positive way to engage with mothers at a critical period when they may be feeling isolated and lonely.

FGD 1, female participant 5: *I think if you start early like, this is to do with nutrition as well we introduce these things, if you introduce some things like programmes and activities then you get all the communities coming together it is quite nice; that engagement. That time some people do stay home and maybe I will just look after my child in my own home. They need to go out and talk to other mothers and that and get a bit of excited feeling you know – What has she done, what have I done, what other leaflets saying ... what other nutritional benefits you know, all these things it is quite important.*

Furthermore, a few of the participants said that they would benefit from hearing other mothers' experiences and being able to voice their own concerns. Nonetheless, they said that they still wanted literature to support the discussions in the groups.

Some participants wanted the sessions to be delivered quickly in 60 minutes or less and they wanted them to be held in quick succession. Some stated that they would not be interested in attending monthly groups for a year.

FGD 1, female participant 3: *If we had some sort of aim or goal and it might be a personal thing or a group thing, but I think you should ask each individual what they wanted out of it. I don't think it should be too long a session like a week or something but just a couple of sessions to make sure that they have achieved the goal that they started out with because if you are aiming towards something you are more likely to go to that.*

Researcher: *So, would you prefer it to be you know, quite quick?*

FGD 1, female participant 2: *I wouldn't say quick, but I wouldn't want it to be ... I don't know, eight to nine weeks. I would hate it; just make it two or three weeks. Has a goal section, an information section and your evaluation and say – Did you get what you wanted to get out of it or why, what is it that you are missing?*

8.8 Summary of Study 2 Results

In summary the data from the FGDs generated themes relating to the participants' perceptions of how the Bangladeshi population interacted with their environment and with their heritage, and how both of these areas affected family dynamics, social circumstances, childrearing, dietary choices and finances in Tower Hamlets. These themes have implications for the adaptation of the women's group PLA cycle for the Bangladeshi population of Tower Hamlets because they indicate distinct differences at the individual, interpersonal and community levels.

The differences on the micro level relate to Bangladeshi families in Tower Hamlets having the help and support that they need from extended members when raising their children. This would impact their ability to attend the groups because they had less free time because they had more household tasks, and some had to work. This encouraged them to become more independent and search for the information they needed from alternative sources which improved their computer literacy.

There was a clear dichotomy in responses between male and female participants. Table 14: Differences in responses between the male and female participants lists some of the key adaptations and the differences in responses between the male and female participants.

Table 14: Differences in responses between the male and female participants

Topic	Male participants	Female participants
Facilitation	Health professional-led	Peer-led
Content of intervention	Health information	Infant feeding & care
Incentives	Monetary incentives	Skills, goodie bags, money, childcare, new information
Location of groups	The Mosque	Children's centres, schools
Barriers to attendance	Social & economic priorities	Family, traditional views of wife, economic

Information delivery	Through online resources (YouTube, NHS) or health professional	By health professional, mothers-in-law, grandmothers, aunties, peers
Time of day/ day of the week	Weekends	After the school run in the morning or before the school run in the evening
Frequency	One off session	Multiple sessions in a block
Technology/mobile applications/social media	Use phones, Twitter and WhatsApp	WhatsApp and Facebook

These responses stratified by gender are important considerations for how the women's group PLA cycle could be adapted for men and women within the Bangladeshi population of Tower Hamlets.

The differences on the meso level related to interactions within the community. Whereas in rural communities everyone may know their neighbours personally, the participants felt they were isolated. They also suggested that the urban context influenced their ability to build relationships and to identify common issues, compromised them logistically, and incurred financial demands such as travel expenses that might not be experienced in LIC rural contexts.

The differences on the macro level related to the Tower Hamlets environment and their ability to change their environment. As Tower Hamlets is an inner-city high-density HIC context, the participants felt less able to make changes to the NHS or to legislation. They discussed inconsistencies in health information, challenges of accessing information from health professionals and the lack of services available for to them. However, they felt less empowered to advocate for change at this level.

9 Discussion

The aim of this thesis is to provide insight into the adaptations required to theoretically successfully adapt the women's group PLA cycle from multiple low-income contexts in the UK for using nutrition in infants of Bangladeshi origin as an example. In this chapter, I will present the main findings from study 1 and study 2. I will then contrast these findings in relation to the overall objectives of the project. Finally, I will represent the strengths and limitations of this research.

9.1 Summary of Main Findings

The findings of study 1 and study 2 are used as further evidence to support the adaptations that emerged from the narrative reviews. They also highlighted additional areas that could be included to the theoretical framework, particularly the micro-adaptations, where they suggested how to contextually adapt the intervention for the Bangladeshi population of Tower Hamlets. The following section will outline the main findings of each of the studies in more detail.

The results of study 1 (section: 8) generated four themes relating to previous adaptation of the intervention across seven trial contexts. These themes allowed me to confirm my preconceived theories that the intervention had been adapted in response to the context, specifically that adaptation occurred systematically to preserve the fidelity of the core components of the intervention (110). Castro et al. (2004) suggested that, it was important to adapt the intervention for the local context (110). In the literature from the women's group PLA cycle intervention, it was evident that, some adaptations had occurred to the number of community facilitators delivering the trials, to the frequency of the group sessions, to the length of the cycle period, and then to the micro-adaptations (language, creative work, content) (section: 4.4), but it was not obvious how these adaptations were tested, implemented or evaluated. The key informants from study 1 suggested that, adaptations were based on evidence but could also be made pragmatically by the implementation team and by the community facilitators, who were delivering the intervention (section: 6.6). They confirmed that adaptations could be made to a set of components, but the participatory delivery of the intervention, peer-led facilitation, the PLA cycle, and the number of sessions that the peer facilitator is delivering in a rural context should be preserved.

The main lessons that can be added to the theoretical adaptation framework for the intervention from study 1 are suggestions around the nature of the adaptation process, the core components and the micro-adaptations. The results of study 1 indicated that, adaptation can occur in two forms: evidence-based adaptation and pragmatic adaptation. The second reiterated the core components including the PLA cycle, the peer-led facilitation and the participatory tools. The number of sessions a facilitator should deliver within a rural context was excluded from the core components in this case, because it is not applicable as the intervention is being implemented in an urban context. This renders session frequency as an adaptable component in this instance.

The final lesson from study 1 suggests that, we should include a set of micro-adaptations and that these micro-adaptations should include the design of the contents, delivery, logistics and materials. Logistics and delivery should also be adapted to emulate context, with specific adaptations made to the location of the groups, frequency of groups, length of the cycle and the size of the groups when working in an urban context. Within an urban context, there is also the need to pay attention to the elevated levels of heterogeneity and the potentially transient nature of the target population, and to adapt the materials, contents, delivery and logistics (micro-adaptations) for responding to these variations. Furthermore, the women's group PLA cycle literature indicated that, local partners could potentially facilitate the adaptation process by assisting with the contextualising of the micro-adaptations, so that they can be tested, further adapted and implemented as appropriately and efficiently as possible (14, 15, 49, 191, 199).

The results of study 2 (section: 8) generated evidence to support the literature which further encourages careful consideration of the heterogeneity in minority ethnic group populations and the influence of disparate environments and potentially the effect of acculturation on socio-cultural practices (251, 252). It also supported the literature that challenged whether the Bangladeshi population would be receptive to a community-led intervention that was targeted solely at *Bangladeshis*, based on the UK census ethnicity data, because they considered themselves bicultural (British and Bangladeshi) (127). This has implications for the theoretical micro-adaptations, specifically around the group composition, linguistic accessibility, delivery, contents and materials adaptation, because it indicates that, the population may have varying degrees of acculturation and those facets will need to be adapted accordingly.

The main lessons that can be extracted from study 2 could form the theoretical micro-adaptations of the intervention. The results indicated heterogeneity within the Bangladeshi population of Tower

Hamlets and the barriers and limitations that could occur in the urban inner-city context. They suggested that the population are influenced both by their Bangladeshi heritage and their lived environment. This could have critical implications for their socio-cultural preferences in relation to social mixing, food, language, family structure, employment situations and religious beliefs. It also suggested that we should consider how long the participants have been living in the UK, as some may have migrated to the UK recently, some have spent several years in the UK and some were born in the UK. Each facet could have a different preference regarding the aforementioned socio-cultural preferences.

It was also suggested that we should recognise the inherent differences between LIC rural contexts and HIC urban context, particularly regarding the availability of space to hold the groups, transport to and from the groups, the influence that the structural barriers have on the population sense of community, and the ability of the groups to facilitate behavioural changes in the presence of free and good quality healthcare. The data also demonstrated that, male participants may prefer a medical professional-led intervention, whereas female participants may opt for a peer-led intervention. Moreover, it was suggested that a mosque-based intervention may not be appropriate because not all mosques in Tower Hamlets accommodate women.

Finally, the participants indicated that, they felt uneasy in expressing their negative experiences in front of the strangers, particularly male strangers. This further suggests that there should be more relationship-building activities at the start of the cycle and that groups should be smaller and more intimate. Furthermore, the contents and materials should include both negative and positive experiences and messages; so that the participants feel comfortable expressing their views in a group environment once they have been reassured that their challenges are experienced by other families in their context.

9.1.1 Determining how the women's group PLA cycle was previously adapted by interviewing key informants who have experience applying the theoretical model in a resource-limited setting

The data from the key informant interviews has attempted to demonstrate that, the intervention was adapted for each trial context; however, theoretical adaptation was not always recorded or evaluated. The MIRA Makwanpur trial was the original operational model from which all subsequent trials were adapted. Micro-adaptations had to be made to materials, contents, logistics and delivery in this trial to make the model relevant to the context. Each trial team emulated these adaptations for their context.

This supported the evidence on adaptation from the literature around the frequency of groups (17), number of groups led by each group facilitator (15), using a local artist to draw culturally and contextually appropriate materials (16, 18, 207) and making adaptations to the contents (50, 191). What the literature did not describe was the details of this adaptation and processes and how they were informed. Therefore, the topic guide in study 1 (5.10.4) was designed to explore previous adaptations with a particular focus on identifying the context, the process of adaptations, and the cultural and contextual adaptations.

The results of study 1, theme 3 *the process of adaptation* described two ways that adaptations were implemented in the previous women's group PLA cycle trials (section 9.1). This decision by the key informants not to pilot certain adaptations was neither intentional nor unintentional; instead, the key informants viewed these pragmatic adaptations as “*obvious*” areas of adaptation that would occur along the life course of the intervention development process. They suggested that it is “common sense” to adapt certain areas of the women's group PLA cycle to echo the context, for example adapting to the local language, and this did not require new evidentiary support.

The key informants also indicated that the pragmatic adaptations were made by advisory and evaluation team from UCL or the implementation partners who had previously implemented cluster-RCTs in the each context (Bangladesh (section: 4.4.2)(14), India (sections: 4.4.3 and 4.4.1)(17, 192) and Nepal (section:4.3.1) (18) (171). The team were already familiar with the context prior to adaptation and were able to make educated decisions on the delivery, language and logistics for the intervention. Therefore, their prior knowledge of the intervention development and implementation process allowed them to make evidence-based decisions on adaptations without needing to conduct formal research. Most trials, however, it has been started off by applying formal research to conduct a needs assessment, but then continued to adapt the intervention through development and implementation, which suggests that theoretical adaptation must be a continuous process.

9.1.2 Exploring why it was adapted by examining the experiences of key informants who have applied the women's group PLA cycle in a resource-limited context

Arguably, the model was implemented in response to contextual demands and pre-ordained research agendas, set by international donors or governments and this was supported by the results of study 1. For example, the key informants from the Nepali trial suggested that, interventions that use didactic methods to provide health information had failed to reduce neonatal and perinatal mortality; therefore

a new method of delivery was required (171). This spans across both the external and internal factors, because the government and international agendas at the time of the MIRA Makwanpur trial focused on a reduction in neonatal mortality, but the research team had to reassess how they could deliver the intervention in a way that would have an impact on neonatal mortality in their context (190). The theme of *context that influences adaptation* demonstrates that there are many factors, which can influence the theoretical adaptation and that external factors may address *what* you do while internal factors address *how* you do it. This has implications for the adaptation process, because it illustrates that, the research agenda should address NHS and local priorities; by addressing both of these areas, there will be good support from NHS providers and population buy-in.

9.1.3 Identifying the modifiable components that could be adapted to emulate the context

The modifiable components were identified in Study 1, theme 5 *the micro-adaptations and on-going adaptations* are the areas of the women's group PLA cycle framework, which encompass contextual adaptation. These adaptable components were grouped into a set of *micro-adaptations*, the set of adaptable components that allows the model to be adjusted specifically for the context. Only some of the key informants reported population heterogeneity in their context. This finding is curious because, although most of the clusters had a largely homogenous population, there was a lot of heterogeneity between the clusters in terms of the local languages spoken, education levels, socioeconomic status and ethnic groups. The levels of heterogeneity were not fully explored in the literature, however, differences in ethnic groups were described by Manandhar et al. (2004) (190) and More et al. (2008) (17) in terms of ethnicity, literacy levels, linguistic and culture. This further demonstrates that, the heterogeneity of the population had less influence on the design of the contents, materials and delivery because a lot of the health messages being disseminated focused on generic practices around health service delivery, hygiene, pregnancy, home deliveries and antenatal care (3). These care practices offer the same advice for all the participants in the cluster area; however, infant feeding practices in a non-indigenous population in an urban setting are more complex. This adaptation requires an understanding of how the context has influenced behaviour and practices.

9.1.4 Alternative methods to co-design adaptable components based on available resources

In study 2, the FGD participants were asked, where they accessed their health information. The participants said, they used the Internet and social media channels for this purpose. The male participants used more formal websites like NICE guidelines and NHS online, whereas the female

participants would consult their peers on Facebook or WhatsApp as a first option, and then they are asked about their GDP as a second option. All of the participants agreed that they would benefit from having the information from the groups available online in the event that they missed a session, or they wanted to share the information with friends and family who were in Tower Hamlets, in other areas of the UK or located overseas. They said this information could be available in a PDF or on a website, but they felt that, a PowerPoint presentation would not be suitable. They did not think that many people would have access to PowerPoint in their community and that they did not have the digital literacy to use it effectively. They also suggested that mobile phone penetration, particularly availability of smart phones, was not high in this population. Women in particular would often use a family phone or their husband's phone and it was often monitored by another family member.

The previous section has indicated some further suggestions for that will be added to the theoretical adaptation framework. In the next section, I will present the theoretical adaptation framework for the reverse innovation of the intervention.

9.2 Theoretical adaptation framework for the reverse innovation of the Women's Group PLA Cycle

This research aims to add to the existing knowledge of adaptation literature by presenting a theoretical framework for the reverse innovation of the women's group PLA cycle based on the narrative reviews of the literature, the experiences of professionals who have previously adapted the model for their context and based on insights from the target population for the UK context. By listening to the reflections of the key informants in study 1, I was able to understand the process of adaptation and how each trial team used local sources and existing data to inform these adaptations. Drawing on the literature, I was able to identify the core components of the interventions, where some theoretical adaptations have occurred, and how they have been implemented (15-18, 20, 21, 51, 121). I will now present a four-step sequential process which illustrates factors that need to be considered, when adapting the intervention with so, it can undergo reverse innovation into the UK context.

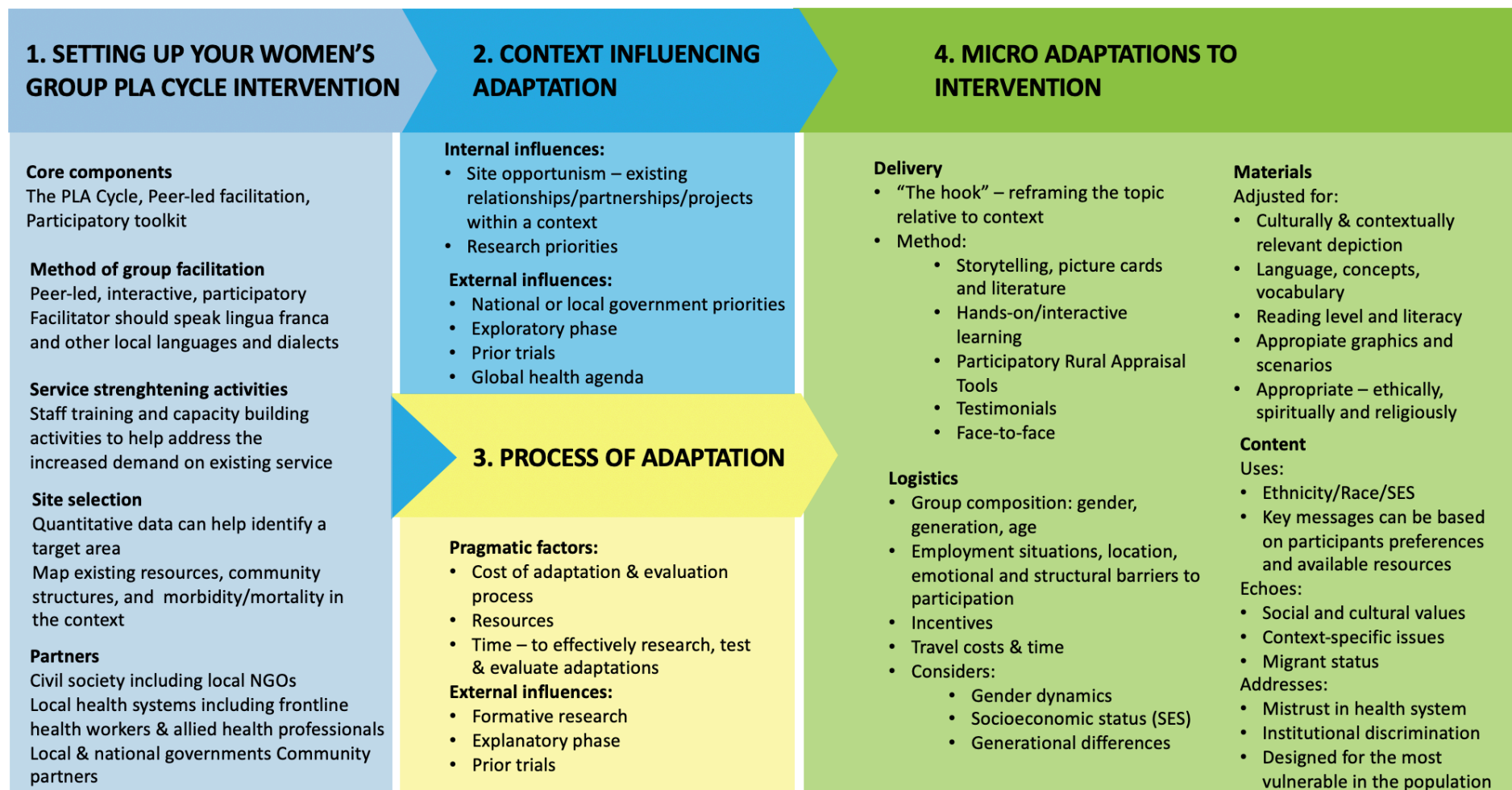


Figure 17: Theoretical adaptation framework for the reverse innovation of the Women's Group PLA Cycle

9.2.1 Unique and salient features of Theoretical adaptation framework for the reverse innovation of the Women's Group PLA Cycle

The following section will outline the theoretical adaptation framework for the women's group PLA cycle (Figure 17), which should assist with the reverse innovation of the intervention from multiple LICs to the UK context using nutrition in infants of Bangladeshi origin as an exemplar. Although there are other adaptation frameworks available within the literature (6, 181, 195-197), the framework for the adaptation of the women's group PLA cycle has multiple unique and salient features that should be distinguished. Specifically, throughout the theoretical adaptation process, this framework aims to:

1. Utilising existing knowledge within the context in the form of stakeholders from government, members of the target population, representatives from the health sector, and local NGOs
2. Highlighting the necessity of utilising routinely available national and international health statistics (census data and/or existing health data), qualitative data collection (interviews and FGDs) and ethnography to understand the extent of the issue in each context
3. Recognising that some theoretical adaptations can be made efficiently through pragmatic adaptation (based on existing knowledge of the context) and some require piloting (through pretesting methodologies)
4. Outlining the core and adaptable components to promote a balance between fidelity and fit
5. Suggesting the adaptation that should be an iterative process and occur throughout the intervention life cycle
6. Indicating the domains that can be adapted to emulate local context (materials, contents, delivery and logistics) and suggests how these can be adapted
7. Demonstrating a sequential and systematic adaptation process that facilitates the adaptation of the model between context and exemplars.

The following section will outline each step of the adaptation framework and how it was informed by the results of the narrative literature review, study 1 and study 2:

9.2.2 Step 1: Setting up your intervention

Step 1 of the theoretical framework outlines areas that need to be considered, when setting up the intervention. This includes the core components, methods of group facilitation, systems strengthening, site selection, and engaging several local partners, the community and local services (section. These areas were all considered across all the seven women's group PLA cycle cluster RCTs and should be considered when translating the intervention across incongruent geographical contexts. Each will be explained in the following section.

9.2.2.1 The core components

Core components maintain the fidelity of the intervention (7, 197). This PhD research demonstrates that, the women's group PLA cycle has three core components. The examples, listed below, demonstrate how the women's group PLA cycle was initially designed and the following section shows how these design features informed the core components of the intervention:

1. The theoretical underpinnings of the PLA cycle embody the philosophical principles of Brazilian Paulo Freire's Critical Conscientiousness, which asserts that, through reflection and action, an individual can develop an awareness of their social reality (section: 4.1.3) (91).
2. The Warmi Project, which inspired the women's group PLA cycle format, was led by American Lisa Howard-Grabman and implemented by a local team in Bolivia (section: 4.1.1) (84).
3. Robert Chambers' PRA toolkit, a creative and iterative means to assess the issues in one's surroundings (100, 198): and these tools offered creative methods of conducting research that could be led by the community (section: 4.1.4)(100).

The key informants considered these components as essential influences in the design of the women's group PLA cycle. Based on this, I assumed that these were the core components of the women's group PLA cycle intervention:

1. The PLA cycle – inspired by the Warmi Project (minus the post-implementation evaluation stage) (84)
2. The participatory toolkit – inspired by Robert Chambers (100)
3. Community-led facilitation – inspired by Robert Chambers (100) and utilised in the Warmi Project (84)
4. Encouraging change by a critical examination of lived environment (Paulo Freire) (91)

Each of these elements is recorded in theme 1: setting up your intervention in the theoretical adaptation framework. Other factors mentioned by the key informants that were considered essential parts of the implementation process, but not essential parts of women's group PLA cycle core components were:

- Engaging with a local NGO, the community and local services
- Framing the topic to create buy-in from government, health services and the target population

The remaining components of the intervention can be adapted to emulate the context. The context specific adaptation will be addressed in 4. Micro-Adaptations.

9.2.2.2 Method of group facilitation

The key informants described using local respected women to facilitate their women's groups through the PLA cycle. Some reported that, although a literate facilitator is more practical, they are not always available, and that further training and assistance could help to illiterate facilitator and manage each group successfully. The group facilitator should be fully trained and remunerated for their time. It is important to deliver rigorous training, observe their first few sessions and conduct refresher training every six months to optimise their ability to deliver the intervention in each group. Sub-optimal training can lead to the group facilitators offering their own advice or interpreting the facilitator manual incorrectly, therefore compromising delivery of the intervention.

9.2.2.3 Systems strengthening

The women's group PLA cycle contributed not only to strengthening health system but also wider "system" strengthening including provision of healthcare, availability of health facilities (particularly in rural contexts), food accessibility/ availability (rural India) and availability of information of not only neonatal health outcomes but hygiene, nutrition, and sexual and reproductive health (section: 4.3.1.1).

Previously, the intervention successfully reduced neonatal and perinatal morality in multiple LICs (15, 18, 20, 102, 104, 111, 121) through a two-pronged approach that offered participatory learning rather than didactic health information delivery (19). It also addressed problems at the in the community, from the demand and in healthcare facilities, at the supply-side (92). Nevertheless, five out of the seven previous trials conducted an antenatal, delivery and new-born care service audit and then provided health service strengthening in intervention and control areas (15, 16, 19-21).

9.2.2.4 Site Selection

The key informants all suggested that they used routinely available quantitative data to help them identifying a prominent health problem within each context. They also suggested that, collecting information on prevalence and incidence of the chosen problem could help with the monitoring and evaluation of the trial. For acute problems such as neonatal mortality this is easier than collecting data on chronic illness reduction or general behaviour change. They used routine channels to collect information and they selected a site. Site selection was influenced by the local NGO's experience conducting research in the specific locality.

Previous trials reported health systems strengthening as part of their intervention (15, 16, 18, 20, 21, 94, 102). Prost et al. (2013) reported that, service strengthening activities were conducted in all seven trials but differed across each context (2). The key informants from study 1 further implied that, these activities did take place in both the intervention and the control clusters but did not report a standard set of health strengthening activities. This is an important finding because it demonstrates that service strengthening should occur within the limitations of the project and also in response to the context. Interestingly More et al. (2008) reported that, community mobilisation through women's groups was successful in areas where there were high neonatal mortality rates, and that areas with low rates of neonatal mortality should focus on health service strengthening (18).

9.2.2.5 Engaging a with implementation partners through a local NGO, the community and local services

In previous women's group PLA cycle trials, the UCL team worked in collaboration with multiple local partners to facilitate the adaptation and implementation process. These included NGOs, local government, ministries of health and influential figures within the target population, community

health workers, health professionals and applied health professionals. The purpose of the local partner was to advise on adaptation and implementation and to assist with the community entry process and formative research stage.

The key informants described the value of local partners' existing knowledge of the context, ability to facilitate the community entry process and their ability to navigate local and national policy. Using local partners was a strategy also used by Wingwood et al. (2008) in the ADAPT ITT-model for the inter-contextual adaptation of effective HIV interventions (195). Regarding implementation, most of the key informants described engaging with a local NGO who assisted with the formative research, and the adaptation, implementation and management of the trial. UCL were partners, but mainly managed the monitoring and evaluation. The local partners led the data collection, management of groups, training of the ground facilitators and the initial exploratory phase. They were instrumental in the implementation of the intervention, where they took a lead role in coordinating human resources and quality control.

The NEON project has engaged several local partners; some had a working understanding of Tower Hamlets and were able to recruit community facilitators, others were familiar with the intervention and were able to offer advice on the intervention design. It may be that the UK NHS adapted the model that does not require the same level of input from the local partner because the Bangladeshi population of Tower Hamlets is potentially more accessible than the rural villages in six of the cluster-RCTs. The Bangladeshi population of Tower Hamlets can also access information about the NEON project and their partner NGO on the Internet, and this offers credibility. Additionally, UCL is recognised as a credible institution within the UK and was considered respectable by the community facilitators. This raises the question of whether or not a local partner is needed to advise on the adaptation and implementation of the women's group PLA cycle intervention in the UK context or whether it would be better to use them for the community entry process alone.

9.2.3 Step 2: Context that influences adaptation

Step 2 describes different factors that influence the adaptation process. These included internal and external factors that may change a research team's aims and objectives. These are important to consider when designing the intervention from both the (1) stakeholder and (2) target population perspective. The aims and objectives should align with national and international health agendas to encourage support from stakeholders at these levels. The target population could identify the

exemplar as an issue within their context to increase engagement with the intervention, encourage ownership, and improve sustainability of the intervention within the trial context.

Apart from the physical context where the women's group PLA cycle is being implemented, I wanted to consider the research context and how it has evolved over the last twenty years in terms of donor requirements and compliance, regulatory bodies and ethics committees.

The first women's group PLA cycle trial was conducted before the publication of the MRC's guidelines for developing and evaluating complex interventions (253), and a few of the key informants mentioned that before these guidelines were published projects could be funded without formative research. Furthermore, they suggested that it was possible to make adaptations to a model without a stringent piloting phase. This could be the reason that, the previous women's group PLA cycle trials did not have a universal adaptation process. Castro et al. (2006) suggested that, an intervention can be adapted for culture, but it must maintain its fidelity by preserving the core components (110). If the previous trial teams were making some adaptations based on their personal experience, they cannot assume that others will have the same experience. Therefore, it is possible that the women's group PLA cycle's fidelity could be compromised, because there are variations in the implementation process, and this supports the need for a consistent adaptation process.

A generic framework for theoretical adaptation could facilitate pragmatic adaptations which could potentially save time and money, but it does need to respond to changing in the research landscape as well and this could occur in relation to funding, additional health systems/government/local restrictions and differences in ethnics committees' requirements or individual committee members preferences. For example, the NEON study had to submit NHS ethics on three occasions before it was finally accepted, and the study team decided to change which NHS ethics committee region where they submitted the application, because they recognised that the other region had experience in participatory intervention processes and therefore, may be understand the requirements of the study. Understanding the research context and responding accordingly could be an important area to consider for future applications of the intervention as well, if they are going to be implemented in HICs that may have stricter regulatory bodies.

9.2.4 Step 3: Process of Adaptation

Adapting programme materials, tools and approaches that are culturally and geographically appropriate is a critical part of the design and delivery of interventions. Formative research is an activity conducted at the beginning of the intervention design process and it could facilitate the appropriate adaptation of the intervention. It is the systematic collection of information about the activities and characteristics of a target population or context that can improve the trial/programme/intervention and allow the trial team to make judgements about the potential of the trial/programme/intervention effectiveness, and/or inform decisions about future design, development or implementation. It is used to gain insight into the health issue or behaviour the intervention intends to address; relevant characteristics of the target population; communication access, habits and preferences; and the main drivers of behaviour.

Methods of formative research that were used in the women's group PLA trials included a wide range of quantitative and qualitative methods depending on what research teams needed to know to design an effective intervention. Quantitative methods generate numeric data and are often designed to produce information that is statistically representative of the intended audience. Qualitative methods collect verbal, descriptive information that is often rich in detail but cannot be generalised to an entire population or intended audience. These methods could help the research teams to discover and explore themes or processes, generate illuminating and illustrative personal narratives, and uncover attitudes or ideas that are common among members of a population, but they cannot be used to determine the proportion of people in an intended audience who think or act in a particular way. Qualitative methods may be used, when the research teams have limited resources, lack formal training to collect and analyse quantitative data analysis or do not need to estimate the proportion of an attribute in the population. However, using them properly still requires particular skills and sensibilities.

9.2.5 Step 4: Micro-adaptations

Steps 4 suggests a set of micro-adaptations which attempt to demonstrate the complex interplay between environment and heritage and how this can affect adaptation. They are specific to the women's group PLA cycle intervention but could potentially be applied to similar participatory models.

9.2.5.1 Considering cultural and context to support the adaptation of the micro-adaptations

Manipulating the micro-adaptions to echo local or national characteristics could assist in optimal adaptation, integration and uptake of the intervention across different settings. The results from study 1 and study 2 confirmed some of the theories that I had around the adaptation process including Resnicow's (1998) model for adaptation, which suggested that interventions should be culturally sensitive and this could happen by adapting for surface (matching intervention components to visible characteristics) and deep structures (emulating social, psychological, environmental or historical factors) (149). An example of how I applied this theory to my research was illustrated by study 2, which further suggested that interventions should be adapted for context and culture, and that this process should be continuous because the populations are changing in response to environmental changes. It also influenced some decisions around how the women's group PLA cycle should be adapted for that population from study 1. For example, the contents and facilitation should be in Bengali and English, and that the groups should not occur on a Friday because of Friday prayer at the mosque. The groups should be held in a public space but should not be associated with the mosque, because not all mosques allow women to enter. The groups should be smaller and local, so the women who are living in the overcrowded urban environment can reach them without paying for travel expenses or in time. All of these features will be fed into the NEON study so they can test the validity of these theoretical suggestions.

Cultural stipulations like the example described above, emerged in Chapter 3 (section 3.4.1) on various occasions, but the literature presented no definition of culture or how to measure it within a population. Perhaps, you cannot succinctly define or measure culture, because it is not a constant. It is influenced by contextual influences, popular influences and heritage. The idea of defining an individual or population so that you may design for them appropriately is perhaps an illustration of where the traditional objectivist public health research paradigm clashes with the subjectivist social sciences participatory research paradigm. In Chapter 3, I introduced the concept of cultural adaptation (section: 3.3) , culture in this sense being synonymous with ethnicity. I suggested that, culture extends beyond ethnicity to include creed, colour, lived environment, ancestry and country of origin. It could be important to detail a target population, but it raises the question if research teams need to pigeonhole target populations based on their ethnicity, culture or race.

This is exemplified by Liu et al. (2012), who described a 46 typology for the adaptation of health promotion interventions for ethnic minority groups in the UK (section: 3.2.3) (200), but they failed to

account for the differences between each sub-population. For example, they grouped all south Asian populations together and did not describe the differences between each sub-population. The closest adaptation framework to this list of micro-adaptations was published by Liu et al. (2012) (1). They suggested that the research into adapting the interventions should be led by a principal investigator of the same ethnicity (1). This could be problematic in populations that identify as bicultural. Presuming that the population would identify more with their ethnic minority status above their context may be appropriate for first generation migrants, but it might not be appropriate for those that were born in the UK, especially as the FGD participants indicated they consider themselves British Bangladeshi.

The participants of the FGDs described this shift in cultural beliefs and practices when they discussed how the intervention could be adapted for their population. The data demonstrated a paradoxical relationship between Bangladeshi heritage and their Tower Hamlets context. This indicated the process of acculturation whereby the individual or sub-population can change based on their exposure to different environmental stimuli (127). The data from the FGDs demonstrates the heterogeneity within the Bangladeshi population and exemplifies why interventions cannot be adapted to encompass only ethnicity. Liu et al. (2012) described how to culturally adapt health promotion interventions in the UK NHS context (2). They stratified ethnic minorities into three broad categories, including grouping all south Asian populations. The recommendations of Liu et al. stressed that further research was required to determine adaptations to sub-groups (2). Liu et al., also suggested adapting for salient language, ethnicity, religion and culture but did not offer means of capturing those who may have been born in the UK, but identify as bicultural (121).

Berry (2003) believed that, there were four models of acculturation that can occur– integration, assimilation, separation and marginalisation (254). Tower Hamlets has a large and concentrated population of British Bangladeshis, which could indicate that they might be receptive to participatory models that piggy-back from existing community structures, however, the FGD participants suggested considered themselves to be British Bangladeshi and that interactions with their environment had changed their expectations for health provision, their eating habits and their language and customs. Alecar and Deuze (2017) stated that, acculturation rates were dependent on the environment or socioeconomic status of the individuals (255).

The FGD participants had all been born in Bangladesh. The older men were more conservative, whereas the younger men were more involved in the care of their children. This could be a generational difference rather than a cultural difference. Measuring rates of acculturation within

Tower Hamlets could be challenging due to the diversity of the population, the intergenerational shift in wealth, culture and also due to the inter-cultural acquisition of information between the indigenous population and the Bangladeshi population in Tower Hamlets (255). However, as the study 2 sample was small and employed a qualitative design, these results cannot be extrapolated to the wider Bangladeshi population of Tower Hamlets. Instead, they can be used to indicate to the NEON study that there could be a change in cultural norms and values, and this should be considered in the trial design. Resource restrictions may make it difficult for any trial team to continuously adapt and/or fully understand the degree of acculturation within this population, but there should be room for the model to respond to these changes.

Applying social identity theory could help unpick the dynamics of social identities in the Bangladeshi population, which has demonstrated a conflict between cultural heritage and lived environment. The social identity theory is a socio-psychological approach, which aims to understand the interplay between self-perceptions, associated cognitive processes and social beliefs in group processes and intergroup relations (256). It suggests that, a specific social group can display specific collective behaviour, encourage social mobilisation and protest, have different leadership within and between groups, have social influence, and demonstrate generic groups norms (256). Adapting for collective social identity could be a new and proactive means of adjusting interventions to emulate the increasing acculturation and assimilation of migrant population in the UK. Equally, as the Bangladeshi population of Tower Hamlets includes individuals that were born in the UK, it raises questions about the suitability of the terms such as acculturation and assimilation because these individuals are not migrants. Being born into British culture and a British environment could affect their individual and collective identity.

Social identity theory suggests that there is a salient identity hierarchy, where an individual's commitment to delivering the behaviours associated with that identity affects the relationships within their social group (256). This could be further explained by the loyalty that an individual feels towards a certain part of their identity (257), such as their nuclear family unit. Adapting for the salient social identity in the Bangladeshi population of Tower Hamlets could be an appropriate means of adapting the women's group PLA cycle for this population as the results from Study 2 demonstrated that context and heritage both contribute to their behaviour. However, difficulties lie in measuring acculturation within this population and the NEON study team should be mindful of the high levels of heterogeneity within this population and potentially avoid making any assumptions about behaviours based on their ethnicity, religion or migrant status.

9.2.5.2 *Delivery of the model within Tower Hamlets*

There was a framework of norms, behaviours, and artefacts within the FGD sample illustrated the relationship between past and present experiences, and how these contributed to the participants' cultural identity that could benefit the design of the NEON study (258). Schein (2010) theorised that, culture is a multidimensional entity with many layers (259), but they did not consider that it could shift in response to contextual stimuli. The data from Study 2 strengthened this by outlining the paradoxical relationship between Bangladeshi heritage and British context, and how both influenced behaviours. This has implications for adaptation of the delivery of the women's group PLA cycle for the Bangladeshi population of Tower Hamlets because it demonstrates the heterogeneity within the population. Heterogeneity was identified in Study 1 as a potential limitation. The key informants did identify that adaptations cannot be made to echo every social nuance in a population; therefore, the micro-adaptations cannot be made to each facet of the social identity of the target population. To overcome this challenge the group facilitator must have full comprehension of the facilitator manual and be able to converse in the salient language and other dialectics/languages spoken by their specific group. Within Tower Hamlets, the facilitators would need to speak English, and potentially Bengali with an understanding of *Sylheti* and other dialects.

Previous trials operated in contexts that had heterogeneity between the clusters, but the key informants suggested that the composition of participants within each cluster was largely homogenous. This was because the clusters were assigned, generally by village or by administrative division. Participants within each village would at least be familiar with one another and there were a lot of extended family members living in the same village. This was not the case in the Mumbai trial which was conducted in the transient and high-density slum of *Dharavi*. The key informants from this trial reported that, women would often visit the slum to access health services to give birth in the local areas.

9.2.5.3 *Language*

Adapting the model for the UK NHS context and a different exemplar means that the NEON study team are not translating materials or contents that have been used in previous trials contexts. Resnicow et al. (1999) suggested that an intervention should be adapted from *surface* and *deep* structure (149). They indicated that, one of the *surface* structures was language (section: 3.2.3). Adapting language was supported by the results from Study 2, which demonstrated that, the

population in Tower Hamlets speak Bengali and English, and the contents and materials will need to be available in both the languages. There is the potential for these to be mistranslated or for the terminology to be misinterpreted because the structure of Bengali and English are different. Addressing differences in terminology has been recognised as a potential barrier internationally to the success of interventions, which are being translated (260, 261). Sussman et al. (2018) suggested using forward and backward translating is effective to overcome potential problems. As previous trials have adapted the model iteratively, it may be that the components which need to be translated can be tested and terminology can be discussed to optimise the translation and preserve fidelity of the health information being delivered.

There are limitations associated with translating materials in a locality where several languages are spoken. Kleinman et al. (1978) suggested that, the process of translating an intervention into the language spoken within the context can be difficult, when there are differences in cultural understandings with respect to idioms and explanatory models, which are aimed at initiate a discussion around health or behaviour change (262), but did not suggest how to overcome language barriers. The FGD participants suggested speaking Bengali, English and other Bengali dialects, but not everyone was able to read each language. The key informants suggested using a well-trained group facilitator who could speak the salient local language and other languages/dialects to deliver the intervention. This is a cost-effective and practical means of overcoming translation issues.

Sussman et al. (2018) stressed the importance of translating the intervention into the appropriate language, literacy level and terminology when translating interventions between nations (252), but did not consider multi-lingual populations and how to make materials appropriate for those that can speak, but cannot read a language. Linguistic accessibility includes adjusting for language, which includes adapting written or spoken information so that it is comprehensible to participants with different cognitive abilities. This can include simplification of scientific language, focusing on main areas only, using a simple oral or written structure so that the disseminated information is clear, focused and accessible. The data from Study 1 demonstrated that, it was beneficial to disseminate information to the groups using a variety of techniques that are preferred by the target population. This could reflect the target population's preferred method of communication: storytelling, poetry, and literature; hands-on/interactive learning; testimonials; face-to-face. They also suggested that they did not want to sit around talking; they wanted activities, demonstrations or games to initiate discussions in the groups.

Factors such as literacy levels and comprehension of health information delivered by an intervention was described by Sussman et al. (2018) (252), but they only referred to these obstacles at a national level and mainly focused on LICs. The women's group PLA cycle intervention does not necessarily need the participants to be literate to participate, but written materials may be issued at the end of each session. All the FGD participants were literate but did suggest that, they knew people in their community who were not. Levels of education can vary within each context, and this can affect the comprehension of health messages (252). Appreciating that the education levels within the UK NHS context may vary and that some participants may need pictorial tools as well as written information is a key adaptation for the context.

9.2.5.4 *Creating a Community*

Providing a cohesive network similar to the rural villages that previously received the women's group PLA cycle intervention in India, Nepal, Malawi and Bangladesh could assist with the embedding of the intervention within the Bangladeshi population of Tower Hamlets. Therefore, the intervention for the Tower Hamlets would need to reconceptualise a community in this context. This could be done by designing a value proposition, which appeals to the target group (Bangladeshi population, who have an infant between 0-2 years, which are living in Tower Hamlets). Establishing the drivers that are causing these individuals to practice sub-optimal feeding practices and reframing them to reflect what they value could help form a new community around the intervention.

This research has demonstrated that community is potentially a critical component that facilitates the success of the women's group PLA cycle. One of the core components of the women's group PLA cycle intervention are the philosophical principles of Paolo Freire's *critical conscientious* (1972), which encourage participants to critically examine their environment together as a group (section: 4.1.2) (175). Arguably, Tower Hamlets is not a traditional community because of the urban context, autonomy of individuals and the transient nature of the context. Nonetheless, it still boasts a large and concentrated population of British Bangladeshis. Rotheram Borus et al., (2012) also suggested that, targeting minority populations within their locality with appropriate marketing, making the intervention culturally appropriate and providing incentives could be a way to increase participation in interventions (263). In Tower Hamlets, it is not the visibility of the Bangladeshi population that is problematic, but understanding how to engage them in health services and how to encourage them to question their environment to promote the Freire model of change (179).

The participants described Tower Hamlets as a radically different context, where they felt less capable of making changes. They also suggested that people within the Tower Hamlets context had higher standards and they were unsure if the participatory action approach would be attractive to people who could visit the doctor instead. This raises questions about the possibility of bringing the target population together to encourage collective action within an urban environment where they have less ability to encourage institutional change.

Parallels can be drawn between the situation in the Mumbai trial context *Dharavi* (17) and that in the Bangladeshi population of Tower Hamlets. The population of Tower Hamlets exudes similar features through their Bangladeshi heritage, and the FGD participants did recognise these as traits, that bonded individuals within their context. They suggested that they could tell if someone was Bangladeshi by their physical features such as hair and skin colour, and practices such as their religion. Nonetheless, physical features and faith are not the only defining attributes of a community. A community could be based around the people with similar socioeconomic status or similar interests. For the purpose of creating a community for Tower Hamlets, it may be better to base this around a group of people with similar interests such as child health. This was supported by the results of Study 2, where the female FGD participants articulated that they would be interested in attending groups that centred on infant growth and development. They also suggested that this was enough to encourage attendance of new and experienced mothers as it was not confined to complementary feeding practices. The participants in Study 2 reported feeling unable to share their problems with their neighbours in Tower Hamlets. There was unease amongst the participants at the thought of sharing their problems in public. The male participants did voice concern, but it was the female participants that were particularly anxious about the women's group format.

9.2.6 Community-led versus health professional-led health intervention delivery

The previous women's group PLA cycle interventions utilised a variety of methods to disseminate information regarding neonatal mortality in each groups (3). The NEON study team should consider input from health professionals and the target population, when they design their tools. Local women could be trained as group facilitators to assist the groups through the PLA cycle. With the support of trained supervisors, who could oversee the groups, monitor the learning objectives for each session and suggest activities that could be used as strategies to combat neonatal mortality in each context.

The key informants suggested that group facilitators were local mothers who were respected within their community. They suggested that literacy was not an absolute necessity, although it was more practical to have a literate facilitator. The important trait was the individual's credibility within the group. The FGD participants agreed that, they would seek advice from a respected individual. Being respectable was an attribute that they all considered very important. They wanted to seek advice from a respectable individual, and they wanted to be seen as respected so others would seek advice from them.

The male and female participants respected different people in their community. The male participants considered a medical professional to be a respectable person and the females said that, they would consider an experienced Bangladeshi mother from Tower Hamlets to be respectable.

The men also suggested that, they should be referred by their GP to the adapted women's group PLA cycle intervention. Although this could be an adaptation to the intervention that needs to occur in Tower Hamlets, and it challenges the participatory nature of the process. It is possible that, the intervention will need to become less participatory if it is to be embedded within the formal NHS services within Tower Hamlets. Populations in previous trial contexts did not have the same access to or trust in health facilities as they do in Tower Hamlets, therefore a health professional-led model is not appropriate.

The female participants considered different people to be respectable. First time mothers would seek advice from their mothers and mothers-in-law when they had their first child and more experienced mothers considered experienced mothers to be respectable as they were able to give advice on infant care. If the mother/mother-in-law was from Bangladesh, then they would listen to their advice, but not always practice it as they felt it was "*old fashioned*". Unlike the male participants, the females did not want to seek advice from a medical professional, particularly the health visitors, for two reasons: they thought that they might be viewed as a bad parent and they often received conflicting advice.

The women's group PLA cycle literature suggested that the '*respected*' peer-led facilitation was a core component (50). This could have implications for the delivery of the adapted women's group PLA intervention because it demonstrates that, men and women respect different individuals or institutions in the Tower Hamlets. The male community facilitators indicated that they wanted to be linked to the NEON project. They suggested that people would trust them if they knew that they were

“*working*” for UCL. The female community facilitators were not as concerned with being associated with UCL.

The male community facilitators found it challenging to recruit men for the FGD in Study 2. The male participants suggested that they did not have time to attend the groups because they had “*other social and economic commitments*.” Hypothetically, the male community facilitators may have found that, recruiting men would be easier; if he was attached to a familiar institution and that an identification card would help them in demonstrating their position. The female participants were recruiting females, and they did not suggest that they required the support of the institution to do so. Potentially this is because the women in this setting were recruited by someone they trusted, which made them feel comfortable attending informal groups.

The response from the female participants is consistent with the literature around cultural adaptation, particularly Falicov (2009) who suggested that interventions should be run by staff of the same ethnicity as the target population (264) and Liu et al. (2012) also believed that, the principal investigator in each intervention should be of similar ethnicity to the target population (121). However, neither of them considered that additional factors such as socioeconomic status or gender may influence an individual’s or a group’s ability to interact with an intervention. By considering intersectionality, we may be able to adapt for differences between male and female participants, individuals that consider themselves bicultural and those that do not, and other phenomena such as migrant populations beginning to engage with their new environment.

9.2.7 Framing the Topic to encourage buy-in in Tower Hamlets

In the reverse innovation literature, Depasse and Lee (2013) advocate for an emphasis on innovation crossover, when innovations pass from LICs to early adopters of innovations in HICs (section: 2.4) (265). Harris et al. (2015) suggested that, emphasising the frugality of the intervention could make it more appealing to HIC health systems (222), but neither of them have addressed how to support uptake of the intervention when it is implemented within the context. Unpicking what makes an intervention attractive to the community it is targeting could encourage buy-in.

One-way to support buy-in could be possible to create a values position for the intervention that recognises the main challenges in the implementation context. In the initial seven trials, the key

informants suggested that neonatal and perinatal mortality were chosen as exemplars in previous trial contexts for three reasons:

1. They are a global health priority as identified by the WHO
2. They are considered a health priority by national governments and ministries of health
3. There is demonstrable evidence to suggest that neonatal and perinatal mortality was a problem within each community in the context

Each of these areas helped to boost support for the intervention, which allowed it to become embedded within the community and accepted by healthcare providers. However, previous trial contexts often had little to no healthcare provision; therefore, any incremental changes would have an impact on trial outcomes. Where previous trial participants may have seen rapid decreases in the outcomes, it may take longer to show an impact on nutrition-related health in the Tower Hamlets Bangladeshi population.

Chronic illness prevention requires a sustained long-term behaviour change and there is no *quick fix*. Addressing chronic illnesses rather than acute illness could require long-term behavioural change and this could affect the longevity, contents and delivery of the intervention further. There will need to be a variety of topics to keep the participants engaged over the length of time that is required to show an impact on obesity rates. This raises questions about engagement, retention and sustainability of an intervention that is using a participatory approach to address chronic illness. This could require specific short-term outcomes so that behaviour is being reinforced regularly (166).

Framing the topic to create buy-in from the target population is only one part of supporting innovation dissemination. Harris et al. (2016) believed that, the process of reverse innovation is complex, with both the HIC consumers and the commissioners of healthcare requiring persuasion to adopt innovations from LICs (220). Framing this intervention as an alternative to current health services could promote buy-in from the health sector. Harris et al. (2016) suggested promoting interventions from LICs as a frugal alternative to current services in a bid to increase adoption by HIC health systems (220). Both are the methods of increasing support for the adapted women's group PLA cycle within the Tower Hamlets context.

Tower Hamlets is a densely populated and heterogeneous environment, where not everyone is aware of their neighbour's issues. One challenge that could influence buy-in and uptake of the groups was addressed in theme 3 *apprehension about sharing experiences with unfamiliar faces*. This theme highlighted worries expressed by some of the female participants about being judged by their neighbours, strangers or other people's husbands. This was a similar concern in the Mumbai trial in *Dharavi*. Pregnant women would visit *Dharavi* to access maternity services. The women and their families were visiting from across India; they would not always speak the same language, share the same customs or be the same religion as their neighbours. This created barriers to accessing pregnant women because of the length of the duration of their stay in *Dharavi* and also created barriers to share experiences because of insecurities about being judged by strangers.

The women's group PLA cycle has previously been implemented in contexts with little to no access to healthcare. In areas where healthcare was available, it may be costly, unregulated or limited by resources such as drug stock-outs and out-dated equipment. Therefore, any incremental change that was made by the groups in these contexts would have an impact on the outcomes of the trial. In Tower Hamlets, there is health care that is regulated, free and accessible. On a local level, having access to good quality health care that is managed by a central body and is standardised across the UK that could make it difficult to advocate for change at this level. This raises questions about the ability of the women's group PLA cycle to encourage social change through collective action in the Tower Hamlets context. Potentially, the social change at a local level may be challenging but changing family or personal habits of groups of locals may be more feasible. Equally, if the provision of health care in Tower Hamlets is remaining constant and the rates of nutrition-related ill health are increasing, then it could be that a preventative intervention that operates out with the realms of the NHS could be successful. Other factors that could prohibit collective action could be the lack of prominent and singular community structure within Tower Hamlets which could be utilised to piggy-back the intervention.

9.3 Theoretical and Conceptual Strengths of this research

9.3.1 Data collection techniques

This research project involved both key informants who had adapted the intervention for their specific contexts and members of the Bangladeshi population of Tower Hamlets who suggested how they would like the intervention adapted for their context. As such, it provides a balanced view of how the

intervention could be successfully adapted for the UK NHS context and the Bangladeshi population of Tower Hamlets. This provides health policy makers, commissioners of health and health service designers (international and local) with a framework that can support the translation of the women's group PLA cycle intervention between LICs and HICs.

Secondly, the topic guides in both Study 1 and Study 2 offered questions that further allowed the participants to demonstrate their attitudes and beliefs surrounding adaptation. For the key informants specifically, the topic guide was designed with prompts to encourage them for examining their experience of adaptation. This facilitated a richer account that was able to build on the adaptations that had been described in the literature.

The participants in the FGDs were prompted using visual aids to encourage a more engaging conversation around adaptation. The visual aids sparked conversations around delivery methods, logistics, materials and contents of the intervention. This strengthened the methodology because it made the session more interactive which made the participants feel more relax. It also increased engagement, as the groups could discuss each picture with the researcher and the group facilitator. Strength in this methodology was the presence of the group facilitator who could speak English, Bengali and Sylheti, who had received training from the researcher on the session, training on how to facilitate FGDs and was familiar with the NEON project. This was strength within the project, as it means that, the FGDs were managed well and that everyone could access the information.

9.3.2 Strengths in relation to Policy

This thesis not only highlights the need for generic adaptation frameworks so that interventions can be translated within contexts, it highlights how this could be effective by going further to demonstrate how the framework could be applied to a population, context and exemplar (Bangladeshi population of Tower Hamlets targeting infant nutrition). Developing a generic framework for the adaptation of an intervention could assist with the global translation of the intervention and, thus, support the bi-directional flow of knowledge, interventions and learning from LICs to HICs (224). This would potentially save policymakers the cost of carrying out feasibility studies to provide future frameworks for adaptation of participatory interventions that are being translated between LICs and HICs.

This thesis shows how potential policy makers could encourage interventions to move through the innovation pathway. Depasse and Lee's (2013) (265) *a model for reverse innovation in healthcare* described a unique pathway where innovations spread from LICs to HICs. The framework considered their recommendations of encouraging the stakeholders to endorse innovations by including external influences in a *context that Influences Adaptation*. Adapting the intervention to adopt a national government's priorities could create buy-in from macro stakeholders and also could facilitate the adoption of interventions from LICs by HIC adopters. This was also demonstrated in the data from the key informant interviews, where most key informants described targeting neonatal mortality because it was a priority for governments and for global policy makers.

Specifically within the Tower Hamlets context, this thesis demonstrates that barriers and limitations highlighted in the literature (acculturation, assimilation and biculturalism (240) are affecting the Bangladeshi population of Tower Hamlets. The population is being influenced by both their cultural Bangladeshi heritage and their Tower Hamlets lived environment. This has implications for policy makers because it suggests that materials, contents and delivery need to encompass both domains for their *British Bangladeshi* identity, which includes, for example, offering nutritional advice for infants that includes *European* and *South Asian* options and hosting groups in English but having a facilitator that can speak Bengali and any relevant dialects. This is a new perspective on cultural adaptation and goes beyond the recommendations of Liu et al. (2012) *adapting health promotion interventions for ethnic minority groups* by exploring the interplay between the two influential domains of heritage and environment (2). It could assist the policy makers to design future campaigns legislation and provide recommendations for British minority ethnic groups

9.4 Theoretical and Conceptual Limitations of this research

Steps were built into the methodology of this project (see Study 1 Methods and Study 2 Methods) to optimise the credibility, auditability and fittingness of the results. Despite these efforts, some limitations still existed in the theory and conceptualisation of the thesis, the research strategy and data quality. The following section will discuss some of the limitations of this thesis.

9.4.1 Concept of reverse innovation

The tenets of reverse innovation are still poorly defined. The literature demonstrated that HICs and

LICs could benefit from the global acquisition of knowledge, but it did not offer a framework to demonstrate how an intervention could be moved between LICs to HICs. It also did not offer insights into how an intervention can be successfully integrated within a new context. This thesis has attempted to create the first theoretical framework for the reverse innovation of a participatory intervention. This framework has yet to be tested and the intervention has yet to be implemented within the UK NHS context and, therefore, it remains theoretical. This means that, although the intervention has theoretically been subjected to reverse innovation, it still needs to be piloted within the UK NHS context. It however, demonstrates that, this intervention could potentially be subject to reverse innovation. Therefore, further research is required to pilot and implement the intervention within the context to examine the real-time barriers and limitations of adapting an intervention developed in a LIC into the UK NHS context. There could be potential barriers and limitations that have perhaps not been identified in the literature due to the novel nature of the field of reverse innovation.

9.4.2 Concept of health intervention adaptation

There were several theoretical frameworks that suggest how to adapt interventions in the health intervention adaptation literature, but none expressed specifically how to adapt an intervention between HIC and LIC contexts (120, 161). This thesis sampled frameworks from cultural adaptation (112), adapting for ethnic minorities (2, 34) and implementation science (2) to inform a base for the adaptation framework for the women's group PLA cycle. This base was then supplemented with data from the key informant interview (Study 1).

Measuring whether an intervention has been sufficiently culturally adapted can be problematic because the target population may be different from the members that were used to input on adaptation of the curriculum, materials, graphics, films etc. Healey et al., (2017) questioned the ability to determine whether observed results were pertinent to effective adaptation or whether it was another aspect of an intervention unless the control and intervention groups were identical (266). An additional barrier is the cost of designing and evaluating culturally adapted interventions to determine if they are effective in the wider target population. The Bangladeshi population of Tower Hamlets has high levels of heterogeneity; they may differ in their cultural norms and practices. The qualitative data that was collected during this project cannot be extrapolated to the wider population because of the nature of qualitative research.

9.4.3 Research Design

Ideally, this project should have included piloting of the adapted women's group PLA cycle intervention. This could have allowed for a practical, rather than hypothetical, assessment of whether the adaptations made to the intervention were feasible in the context. Although a stakeholder panel that included medical professionals and NHS managers were engaged throughout the process, piloting the full PLA cycle was beyond the realms of this project. Presenting the fully adapted model to a stakeholder panel would have given more strength to the study in the context of embedding within the NHS. Certain parts of the adapted intervention did, however, undergo pre-piloting to assess the acceptability and appropriateness of the adapted content, delivery and materials within the Tower Hamlets context.

Meetings 2-4 were tested in a pre-pilot phase which brought together women from the Bangladeshi population of Tower Hamlets and were facilitated by a female group facilitator who had been trained by the NEON team. It was recognised during this phase that the female group facilitator would need more training, so that they were able to adequately deliver the intervention without compromising the core components.

9.4.4 Sampling: Key Informants

In Study 1 there were three areas that had the potential to incur bias. First, the key informants were selected purposely: this has the possibility of introducing selection bias into the results generated. Second, although I tried to have equal representation from the entire seven Women's Group PLA Cycle cluster-RCTs, some trials had a higher representation than others. This was due to my ability to engage potential key informants and to the availability of potential key informants over the data collection period. Finally, the majority of the key informants occupied senior positions within the trial team: this meant that their experience of adapting the model was from a strategic rather than an operational stance. Advising on research strategy (monitoring and evaluation) is important, particularly when there are time constraints, however, discussing the programmatic and operational issues that affected the implementation where the teams may have given a more comprehensive overview of adaptation at site level. Exploring the experiences of the implementation team could have illuminated the specific ontological principles of that process and how they overcame barriers and limitations in context. It also could have widened the number of perspectives and availability of participants.

Another limitation that affected this the sampling methods in study 1 is the way I decided on the number key informants that I would select. As I was not using Grounded Theory to analyse my data, which would involve interviewing until I reached saturation of themes, I used Braun and Clarke (2006) Thematic Analysis (6). Therefore, I did not consider at the time the potential limitations of not underpinning my sampling based on the analytical framework that I was going on use, or vice versa. To strengthen the research, the sampling approach should have been based interviewing until saturation of themes occurred and not just convenience.

9.4.5 Sampling: Focus Group Discussions

A limitation in the FGD sampling was based on the recycling of participants from earlier phases in the NEON study. Most of the female participants were involved in earlier research with the NEON study. This gave them a wider understanding of women's group PLA cycle intervention, which allowed them to make more specific suggestions. The FGDs were all conducted in English by a facilitator who could speak English and Bengali. The information sheet and the consent form were available in English and Bengali, but there were no participants that spoke solely in Bengali. All the participants had originated from Bangladesh with time in the UK ranging from 9-45 years. This is a limitation because the data does not include the adaptations for individuals who have newly arrived in the UK (<3 years) or for individuals who do not speak fluent English.

9.4.6 The challenges of taking a multidisciplinary approach

This research was funded by the Collaboration in Leadership for Allied Health Research and Care (CLAHRC), there for it was conducted to feed into an actual intervention that was going to be physically implemented in Tower Hamlets. This made working within a multidisciplinary team potentially more challenging than normal because there was a tension exploring the theoretical adaptation and thinking long-term about the practical implementation of the adapted intervention.

I want to highlight some of the personal challenges working at the intersection of several disciplines including health behaviour, public health, anthropology, psychology, sociology and epidemiology.

9.4.6.1 The challenges of conducting a project with a multidisciplinary supervisor team

My supervisors had different ideas about how my thesis should be structured and the key themes that I should address. Initially, it took many iterative conversations to align our research priorities. From the outset, I wanted to focus on the process of reverse innovation because I had identified the unique nature of translating an intervention developed in a LIC into a HIC's health system, but some members of my supervisor team were very focused on the terminology which is still interchangeable in the reverse innovation literature. For this context, my supervisor team consisted of three supervisors from different disciplines:

- Clinical Professor of Integrated Community Child Health – Great Ormond Street Institute of Child Health
- Principal Research Fellow– Department of Applied Health Research
- Senior Lecturer in Epidemiology–Institute for Global Health

It was evident to me that the challenges lay in our understanding of each other's thematic knowledge and technical expertise. The clinician wanted me to focus on the sub-optimal feeding practices and high-levels of nutrition-related ill-health in the Bangladeshi population, which I later realised that it could inform the cultural and contextual adaptation of the women's group PLA cycle intervention. This supervisor was very cautious about allowing me to begin community data collection. The Principal Research Fellow, however, wanted me to focus on qualitative research methodology, which they believed would optimise my research design. They encouraged me to conduct a community mapping exercise community data collection, so I could get insights into the contextual factors that were influencing health behaviours. Unfortunately, I was unable to conduct a community mapping exercise because I had been advised not to go into Tower Hamlets until my second year.

My supervisors and I found it challenging to align the aims and objectives of this thesis because we were trying to balance the objectivist clinical and epidemiological views of traditional public health research with some of the subjectivist views of cultural adaptation and reverse innovation that were required to theoretically adapt this intervention. The epidemiologist wanted me to focus on the women's group PLA cycle trial and encouraged me to go overseas to collect data in India so that I could better understand previous trial contexts.

Another challenge occurred, when I wanted to conduct a three-part literature review, each part I believed to be critical to the reverse innovation of the women's group PLA cycle. I believed that, a literature review on reverse innovation would help me in identifying the challenges faced in terminology (which I had experienced myself). The literature review on health intervention adaptation could give me grounding on the principles of adaptation and also fill in the gaps from the reverse innovation literature around how to adapt and implement an intervention in a new context. The final part of the literature review gave me the theoretical overview of the previous applications of the women's group PLA cycle intervention and how it had been adapted for previous trial contexts. Some of my supervisors found this a logical pathway, but others did not understand why I needed the three-part literature review, as they believed I just required focusing on the results of the previous cluster-RCTs. This is where I found a tension between those that favoured the objectivist and those that favoured the subjectivist approach to research. The supervisor that supported the subjectivist view accepted my choice to explore context and culture through reverse innovation and the women's group PLA cycle, and how to overcome any challenges by considering health intervention adaptation, and also encouraged me to explore qualitative methodology.

Additionally, I decided to split this thesis into two studies, because I recognised from the literature that, to understand how to adapt the intervention for the new context, I required in determining how and why it had been adapted in previous trial contexts. Initially, there was resistance from the quantitative supervisors because they felt that the literature was sufficient to tell me whether it had been adequately adapted. I also wanted to understand the adaptation process that led to a successful trial.

Ultimately, I believed that a multidisciplinary approach would support research rigour and offer a balance between subjectivist and objectivist approaches, because it can bring the best of both paradigms. It just takes a several conversations in the research design phase to align aims and objectives. In the end, I strongly favoured using a qualitative methodology throughout my thesis, because I wanted to capture the nuances around a population's interaction with context. I would explore the published literature on the cluster RCTs and supplement it with my own qualitative research that addressed previous adaptation and qualities for theoretical future adaptation

9.4.6.2 Challenges in integrating the concept of reverse innovation and health intervention adaptation in public health.

The core principles of public health are based on policy development, assessment and assurance (267). Arguably, public health is a predominately objectivist field that applies quantitative data collection methods to generate statistics, which can help to monitor the diseases within a population, but in diverse populations it could be challenging to control disease and support wellness if the health services are not tailored for the populations they are serving. Therefore, there could be a need for qualitative information to help adapt health services and tailor them towards the patient's needs. For example, for policy development it is challenging to base a new policy solely on quantitative data. Data can help you in identifying an area that may need extra resources, but it cannot provide insights into the culture or context that are driving the issue. It is similar for assurance: quantitative data can monitor who is adhering to the policies and can help evaluate effectiveness and accessibility but cannot explain why a policy is not effective.

This chapter has attempted to present evidence for supporting the tension existing between the need to adequately theoretically adapt the intervention and compromised adaptation processes due to research restraints (time, funding, personnel and documentation of previous adaptation process). It has tried to demonstrate that, adaptation was occurring, but that it was not always recognised as a formal part of the trial life cycle.

I have presented some well-documented challenges, which are related to international translation of interventions particularly around when to involve a diverse target population (268), working with local stakeholders (268) and working towards a common goal (269). Sussman et al. (2008) documented that, the process of translating interventions between contexts can be compromised due to lack of control over the adaptation process (261), but they did not consider that a framework for adaptation which could facilitate this process controlled adaptation. They suggested that, programme developers needed to culturally adapt the intervention (261), but did not consider which components could be adapted and which could not.

The purpose of this research was to supply evidence that could potentially support future uptake of the intervention when it is piloted, and this is what led me to attempt to create a theoretical adaptation framework that can be used to assist the NEON study team to adapt and evaluate the intervention for Tower Hamlets. The women's group PLA cycle had evidence to support that, it was efficacious

within a trial setting (3), however, it did not have the evidence to support implementation in Tower Hamlets and there was no evidence to optimise its uptake by the Bangladeshi population. The theoretical generic adaptation framework for the reverse innovation of the women's group PLA cycle could facilitate this process.

10 Conclusion

As a potential reverse innovation, the women's group PLA cycle, if adequately adapted, could potentially offer a cost-effective alternative to current health-professional led models, which are operating within the Bangladeshi population of Tower Hamlets. Further research by the NEON study team needs to be conducted to test the feasibility of the theoretical adaptation process in the new context. If the model is to generate cost-savings, it could prove efficacious in a trial setting and effective within a real-time setting.

This research has contributed to knowledge and practice in five ways. First, I have explored the process of reverse innovation and the challenges specifically relating to the individuals, institutions and information that could potentially be experienced by the women's group PLA cycle model. Second, I examined health intervention adaptation and presented examples of how cultural and contextual adaptation has been informed and implemented. This has offered a theoretical understanding of where adaptation to the women's group PLA cycle could support the reverse innovation process. Third, I have explored the evolution of the women's group PLA cycle and its previous applications in a bid to understand how it has previously been implemented in the trial contexts. Fourth, I conducted interviews with key informants that were involved in the implementation or monitoring and evaluation of the RCTs. This helped me to further explore adaptation to the model before, during and after implementation. It also helped me to determine the difference between pragmatic and evidence-based adaptation. This further allowed me to form a potential understanding around where and how the model had previously been adapted and use this to inform the topic guide for the FGDs with the Bangladeshi population of Tower Hamlets. Fifth, through an iterative dialogue during these FGDs, I was able to gather information that could assist with the theoretical adaptation of the women's group PLA cycle model so that it could potentially undergo reverse innovation into this context.

10.1 Final reflections

Globalisation and changing populations are putting new demands on existing health systems. In an increasingly diverse UK NHS context, health care planners could consider the needs of these populations and how these can be supported. They could optimise inclusion within the health systems by supporting services that can cater to the needs of a diverse population. This may require alternative approaches to optimise engagement of ethnic minority populations within the health system. Adapting a peer-led participatory intervention that has proven efficacious across seven trial contexts could offer such an alternative to the current health professional-led NHS models. This could encourage uptake and continuous engagement in health services.

This thesis has attempted to demonstrate that there are innate complexities in translating an intervention between LICs and HIC. This research has implications for future policy because it suggests that interventions could be translated from LICs to the UK NHS if they undergo a systematic adaptation process. It also suggests that participatory models in the presence of a UHC may find it harder to recruit and retain the participants. Therefore, the values proposition needs to be carefully curated based on insights from the target population. It highlights the need for consistent and appropriate information generation, analysis and integration within a model, so that it can respond to environmental changes. Finally, it demonstrates that, minority populations in the UK may identify with both their cultural heritage and their lived environment and this has implication for adapting interventions in the future as the populations see themselves more embedded within their environment and their culture was fluid and has the potential to change.

My PhD research experience made me capable of reflecting on some of my own biases towards where knowledge emerges. Personally, I would have always considered myself to be open-minded and willing to try new approaches. Upon reflecting on whether or not I would opt for a reverse innovation in place of current NHS interventions, I think I would have had some concerns about the validity of that intervention. After completing the narrative review on Reverse Innovation, I realised that, innovation is a continuum, not only in terms of its evolution, but also in terms of how it travels through the world and changes along the way. This thesis allowed me to understand why it is important to elevate knowledge and expertise from LICs and to think about why we need to decolonise global health if we want to provide stronger and equitable health for all. Moving forward, I would like to use my knowledge and revised outlook to work in partnership with individuals from other contexts so that we can develop innovation that will improve the lives of the most vulnerable.

Previously, I would have advocated for health professional-led initiatives because of my experience in public health and my own interactions with the NHS. Working with community facilitators from the Bangladeshi population of Tower Hamlets, I was able to gain insights into how peers could leverage their existing community status to gain the trust of the participants and how they were able to lead groups of men and women in their community. The men and women were also extremely candid about their own issues, often commenting on how current affairs such as Brexit were going to lead to increased racial discrimination towards their community. It made me realise the value of working in partnership with the community and promoting self-efficacy within these communities. It also made me think that a participatory model could potentially be viable in the UK and, if adequately trained; peers could mobilise and deliver specific health information straight to the communities. These communities know what their problems are and may just need some additional support to elevate their confidence and help them integrate within the current health system.

I lived in Tower Hamlets on Halcrow Street for one year from 2012 to 2013. I remember the white British market vendors on Whitechapel High Street shouting in Bengali to the Bangladeshi vendors. It seemed like a diverse and prospering community in the midst of a chaotic central London location. Working on this thesis, I was able to build relationships with individuals that, though they lived in the same areas as me during that period, I would probably never even have spoken to, and that has added immense value to my experience. Drinking tea and eating biscuits in the Flower and Dean Community Centre in Tower Hamlets and speaking to mothers, aunties, uncles, fathers, grandmothers and grandfathers, I was able to get a glimpse of what life was like for the Bangladeshi community of Tower Hamlets. I am very grateful for the opportunity and for the lessons that I have learned and will carry with me throughout the rest of my career.

I will end this thesis with an Islamic Proverb which is one of the NEON study community facilitators that told me when we were talking about the importance, brilliance and special nature of cross-cultural partnerships:

الكثير من الزهور المختلفة تصنع باقة. المثل الاسلامي

(A lot of different flowers make a bouquet.)

11 Appendices

11.1 Appendix 1: Reverse innovation narrative review search strategy

The literature was searched was conducted in January 2016, and re-run in March 2018 using Medline (Ovid interface), as well as some grey literature, using the following MeSH terms:

(Bidirectional learning or knowledge sharing or (frugal adj innovation) or (reverse adj innovation)).mp.
[mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] or “diffusion of innovation”/

AND

Developing Countries/ or Global Health/ or exp Internationality/

AND

(low income countr* or middle income countr* or LIC* or MIC*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

Subject headings were exploded to amplify the search scope. Forward snowballing was used to identify studies, which had been cited in other papers. No language or date restrictions were applied to the searches at the time they were run. All abstracts found were read to determine their importance to this study and relevant studies were read in full and cited in this study.

The search generated 927 articles. I screened the titles of all 927 articles and read the abstracts of 94, selected 24 papers to read and included 18 in the review. I then searched the references of the final 24 papers and added a further two papers.

11.2 Appendix 2: Health intervention adaptation in the context of reverse innovation - narrative review search strategy

The literature was searched initially in April 2016, and re-run in May 2019 Medline (Ovid interface), as well as some grey literature, using the following MeSH terms:

((cultur* or ethnic*) adj3 (adapt* or adjust* or appropriate or sensitive)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

AND

exp Health Promotion/

AND

(Implement* or translate*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

No language or date restrictions were applied to the search. Subject headings were exploded to amplify the searches scope. Forward snowballing was used to identify studies, which had been cited in other papers. All abstracts found were read to determine their importance to this study and relevant studies were read in full and cited in this study.

The search generated 183 articles, 134 were removed after screening title, and I read 49 abstracts. In total 21 papers were included in the health intervention adaptation review. I then searched the references of each of the 21 papers.

11.3 Appendix 3: The Women's Group PLA Cycle narrative review search strategy

The literature was searched between December 2015 and re-run in June 2018 on Medline (Ovid Interface), as well as some grey literature, using the following MeSH terms.

Community Participation/

OR

((participatory action adj2 learning) or ((participatory learning adj2 action) and cycle) or (PLA and cycle)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

AND

nepal* or india* or bangladesh* or malawi*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

in other papers. All abstracts found were read to determine their importance to this study and relevant studies were read in full and cited in this study.

The search generated 432 articles, which subsequently had their titles screened, from which 44 abstracts were screened, and 18 articles were selected for the final review. I then searched the references of the 18 papers that were selected.



UCL

Information Sheet for data collection stage of: Adapting the women's group

Participatory Learning Action Cycle to optimise its transferability from resource limited settings to the UK, NHS context using nutrition in infants of Bangladeshi origin as an exemplar

Researcher name: Jennifer S. Martin, Doctoral Researcher

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Supervisor's name: Professor Monica Lakhanpaul

I would like to invite [insert participant's name] to participate in this research project

Details of Study:

Research aims

The principle aim of this research is to establish the adaptations required to make the Women's Groups Participatory Learning Action Cycle an appropriate tool to address infant nutrition in the Bangladeshi community of the London Borough of Tower Hamlets.

How the research will be carried out

1. Professionals who have utilised the approach overseas will be interviewed regarding their personal experiences in adapting the model for their target group.
2. Members of the Bangladeshi community from the London Borough of Tower Hamlets will be interviewed to establish their ideas of how the intervention could be adapted for their community.

What the benefits of value of the research will be?

The results from this formative research stage will assist the development of a framework for adapting the Women's Groups Participatory Learning Action Cycle for ethnic minorities in the UK, National Health Service context.

Role of the participant

Who is being recruited?

1. We are recruiting professionals who have used the Women's Groups Participatory Learning Action Cycle overseas.
2. We are recruiting members of the Bangladeshi community from the London Borough of Tower Hamlets.

What they will need to do?

Each participant must be available for an interview either face-to-face, via Skype or via telephone.

How the data will be collected?

All interviews will be recorded with a Dictaphone and all voice files will be saved on an encrypted file on a UCL computer to preserve participant confidentiality. Each participant will be issued with a number. No personal information will be displayed on any written or voice files.

Benefits: You may request a copy of the transcript of their interview, or a report of the findings.

Please discuss the information above with others if you wish or ask us if there is anything that is not clear or if you would like more information.

It is up to you to decide whether to take part or not; choosing not to take part will not disadvantage you in any way. If you do decide to take part, you are still free to withdraw at any time and without giving a reason.

If you would like to take part in the study or for any further information, please contact **Jennifer Martin** via email: **Jennifer.Martin.15@ucl.ac.uk**

All data will be collected and stored in accordance with the Data Protection Act 1998.



Collaboration for Leadership in
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North Thames



Consent form: Professional Interviews (Version 1.0 July 2016)

Title of Project: *Optimising transferability of the Participatory Learning Action Cycle from resource limited settings to the UK, NHS context using nutrition in the Bangladeshi community of Tower Hamlets as an exemplar.*

Participant identification number for this study:

Name of Researcher: Jennifer Martin

Principal Investigator: Professor Monica Lakhanpaul

Please read the following statements and mark the boxes to show you agree

1. I confirm that I have read and understand the information sheet (Version 1.0 July 2016) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights or employment status being affected.
3. I understand that my participation in these discussions will be audio recorded and stored anonymously.
4. I understand that relevant sections of my anonymised data collected during the study may be looked at by members of the research team. I give permission for these individuals to have access to this data. I understand that this information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.
5. I understand that data and quotations I provide may be used (anonymised fully) in future publication of this research.
6. I understand that, in the event of my withdrawal from the study, data I provide prior to my withdrawal will be retained (anonymised fully) for analysis and publication.
7. I agree to take part in the above study.

Name of participant

Date

Signature

Name of person taking consent

Date

Signature



Collaboration for Leadership in
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North Thames

11.6 Appendix 6: Study 1 Topic Guide



1. Tell me about decision to start this intervention?

- Where did you hear about it?
- Needs locally?
- Previously tried anything similar.

2. How did you go about setting it up?

- Any conversations locally?
- Piloting?

3. To what extent did you adapt the model to fit the context/setting?

If Yes:

- Why?
- How did you decide?
- Process of adaptation?

If not at all:

- How did the cycle fit?
- Any issues etc?

4. How well did the intervention work in practice?

- Any ideas?
- Any further changes?
- Further reflections?

5. Is there anything we've missed



Information Sheet for data collection stage of: *Adapting the women's group Participatory Learning Action Cycle to optimise its transferability from resource limited settings to the UK, NHS context using nutrition in infants of Bangladeshi origin as an exemplar*

Before we invite you to take part, we would like to share some important information about the project, why we are collecting information, and what we would like to learn from you.

Meet the team:

Jennifer S. Martin, 2nd year PhD student at the Population Policy & Practice, UCL Great Ormond Street Institute of Child Health

Supervisor's name: Professor Monica Lakhanpaul

Approvals: This study has been approved by the University College London Research Ethics Committee (Project ID number): _____

Why are we doing this research?

The Bangladeshi population of Tower Hamlets have identified that action must be taken against the high rates of obesity, type 2 diabetes, cardiovascular disease and dental caries in their community. We aim to develop a community-based model in partnership with you to focus on infant feeding practices linked to healthy growth and development to prevent these problems.

Why me?

We would like to speak to you because we think you will be able to help us in creating this new model. We want to hear about the changes you would make to the model we plan to use, and what materials would help you learn about infant feeding practices.

What will I be asked to do?

You will be asked to take part in a focus group discussion with 6-8 other people from the Bangladeshi population of Tower Hamlets which will last 1 hour and 15 minutes. The groups will be split into women and men and will be led by someone from the community itself (community facilitator) without support.

Do I have to take part?

No, you do not have to take part. If you change your mind at any stage, you can withdraw from the process. You can keep this paper and all forms that you are issued and have signed.

Incentive for participating

In addition to the travel expenses being paid to participants, mothers and their families will be given supermarket vouchers for participating in interviews and workshops.

- You will be given a £10 voucher /family

What are the possible good or bad things if I take part?

Taking part will take up your time, but it will also help us develop an intervention that will benefit you, your family and other community members. We want to make sure our intervention is suitable for the Bangladeshi population of Tower Hamlets, and you can help us do that by giving us your opinions on the design. Also, you will get the opportunity to have a voice, get involved with the community in a participatory approach, to engage in a discussion around a topic that is important in the long-term health consequences and therefore improve health.

What happens at the end of the project?

Once the model is developed with your input, we hope to test it out in the community. The results will be written up in Jennifer Martin's PhD thesis, in other academic papers, and may be presented at other meetings.

What happens to the recordings?

We would like to keep the recording of your discussion to draw out main points and the quotes. We think that these could be very useful in understanding various modifications that we need to make to our model. For this we may want to use some anonymous quotes in presentations, publications, reports, papers or in the media. The recordings will be safely kept on an encrypted computer or a very

secure system called the 'Data Safe Haven', which only the lead researcher will have access to. We shall contact you in the future if we want to use them. If you do not interview stored, just say no on the consent form and we will destroy the recording after the study has ended and won't contact you about this.

What will happen to my personal details?

It's your choice! We can destroy them after this project has finished, or you can give us permission to keep them in a locked cabinet in a locked office in a secure building at the University College London. Just let us know of your decision in the consent form. We'd like to keep them for two reasons:

1. So, we can contact you to ask about using the interviews for teaching and training – see the above section for details.
2. Once this study has finished, we may want to contact you for your help in studies that follow on from this one or to contact you when we want to spread the messages from the study to other people. Even if we have your details you can always say not to being involved at any stage.

Will my taking part and collected information be kept private?

Yes, we will not inform anyone else that you have taken part. No individuals who have taken part in the interviews will be identifiable in any reports, publication or website. If you come to the workshop, the other people there will know that you are part of the study. At the start of each focus group each member will agree that the discussion must remain confidential. Participants are reminded to only share information that they are comfortable sharing.

All data will be collected, stored and treated in accordance with the provisions of the Data Protection Act 1998. All participants will be provided with copies of study information sheet, consent form and final report.

HOWEVER: We have a responsibility to support each child's wellbeing and safety. It may be necessary to break confidentiality if we believe there is an issue that threatens a child in this way.

For example: If a child is severely malnourished that they are in danger, then we will need to share our concerns, including the names and details of child, with other professionals. We will always tell parents if we are doing this.

What if I change my mind about being in the project?

You can withdraw from the project at any time, without giving any reason. If you do withdraw, we will not contact you to talk about the later parts of the project and we will destroy your contact details if you tell us. We will keep any recordings we're already made (if you have already taken part in an interview) just to analyse them as part of the study, although if you specifically ask us not to use your recording, we will not.

What if I have a problem with the project?

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions. To contact please use the contact details of Jennifer Martin or Professor Lakhanpaul at the end of this information sheet. If you would like to speak to someone outside of the research team, please contact the Patient information and Liaison Service (PALS) at:

PALS

Ground Floor Atrium

University College London Hospital

235 Euston Road

London NW1 2BU

Or email at PALS@uclh.nhs.uk

Who is doing this and paying for the research?

The study is being sponsored by the University College London (UCL), in partnership with NIHR CLAHRC (National Institute for Health Research and Collaboration for Leadership in Applied Health Research and Care) who is paying for it.

Who has reviewed the study?

This study has been reviewed by the University College London Research Ethics Committee

Please discuss the information above with others if you wish or ask us if there is anything that is not clear or if you would like more information.

It is up to you to decide whether to take part or not; choosing not to take part will not disadvantage you in any way. If you do decide to take part, you are still free to withdraw at any time and without giving a reason.

If you would like to take part in the study or for any further information, please contact **Jennifer Martin via email: Jennifer.Martin.15@ucl.ac.uk**

All data will be collected and stored in accordance with the Data Protection Act 1998.



Collaboration for Leadership in
Applied Health Research and Care

North Thames



Consent form: Focus group discussion with the Bangladeshi population of Tower Hamlets

(Version 1.0 February 2017)

Title of Project: *Adapting the women's group Participatory Learning Action Cycle to optimise its transferability from resource limited settings to the UK, NHS context using nutrition in infants of Bangladeshi origin as an exemplar*

Participant identification number for this study:

Name of Researcher: Jennifer Martin

Principal Investigator: Professor Monica Lakhanpaul

Please read the following statements and mark the boxes to show you agree

8. I confirm that I have read and understand the information sheet (Version 1.0 February 2017) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
9. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights or employment status being affected.
10. I understand that my participation in these focus group discussions will be audio recorded and stored anonymously.
11. I understand that relevant sections of my anonymised data collected during the study may be looked at by members of the research team. I give permission for these individuals to have access to this data. I understand that this information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.
12. I understand that data and quotations I provide may be used (anonymised fully) in future publication of this research.
13. I understand that, in the event of my withdrawal from the study, data I provide prior to my withdrawal will be retained (anonymised fully) for analysis and publication.
14. I agree to take part in the above study.

Name of participant

Date

Signature

*Initial of participant upon receipt of
£10 voucher*_____

Name of person taking consent

Date

Signature



Collaboration for Leadership in
Applied Health Research and Care
_____ North Thames

11.9 Appendix 9: Study 2 Participant Demographic Information Sheet



Demographic Information Sheet for data collection stage of: *Adapting the women's group Participatory Learning Action Cycle to optimise its transferability from resource limited settings to the UK, NHS context using nutrition in infants of Bangladeshi origin as an exemplar*

Before we invite you to take part, we would like to share some important information about the project, why we are collecting information, and what we would like to learn from you.

Meet the team:

Jennifer S. Martin, 3rd year PhD student at the Population Policy & Practice, UCL Great Ormond Street Institute of Child Health

Supervisor's name: Professor Monica Lakhanpaul

Approvals: This study has been approved by the University College London Research Ethics Committee (Project ID number): **10653/001**

If you would like to take part in the study or for any further information, please contact **Jennifer Martin via email: Jennifer.Martin.15@ucl.ac.uk**

All data will be collected and stored in accordance with the Data Protection Act 1998.

Please select the boxes information that describes **you** from the following options:

Gender

Male

Female

Age

18-29 years

30-49 years

50-54 years

65+ years

What is your religious preference?

Country of birth	Bangladesh	UK	Other
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If 'other' is selected, please note which country here:

How many years have you been in the UK?

Highest level of education

Some high school

High school graduate

Some college

Trade/technical/vocational training

College graduate

Some postgraduate

Post graduate degree

11.10 Appendix 10: Study 2 Extended Rationale for using focus group discussions

Focus groups discussion (FGDs) are an effective method of exploring topics that are difficult to observe such as decision making processes, opinions or attitudes (230). They can produce a large amount of data to ascertain perspectives on a specific topic, particularly from marginalised groups (230). However, the opinions of individuals could be influenced by other members of the group, making the information from the groups an inaccurate representation of the topic (270).

FGDs can generate rich and detailed accounts, and have the added advantage of *producing data on group meanings, group processes of meaning generation, and group norms* (230). FGDs enable the researcher to explore perceptions and how these perceptions and social nuances are influenced by different contexts (230). Understanding how group dynamics could influence the interpretation of materials, information and behaviours is essential to understanding the process that drives behaviours within a specific context (230). Unlike one-on-one interviews, FGDs can provide an insight into the interactions between participants, and thus some insight into how social knowledge is conceived (230). FGDs were selected over opportunistic naturally-occurring groups as they can be organised specifically to discuss the research topic and, logistically, are less time-consuming (230). FGDs were selected as this study required a broad range of ideas on an open-ended topic. The urban context also facilitates a formal, controlled pre-arranged time and place for these groups.

FGDs also have the advantage of providing a secure and relaxing environment for the participants to disclose opinions on sensitive topics (230), however, the ability of participants to disclose sensitive information can depend on local cultural values, and the group dynamics. The Bangladeshi population in Tower Hamlets is relatively conservative patriarchal society with strong religious values, this could prohibit truthful responses from the participants, particularly young women (271).

11.11 Appendix 11: Study 2 Running Order

Check that everyone has signed consent forms

Welcome, including introductions

1. Welcome

Introductions

Review the following:

- Who we are and what we're trying to do?
- What will be done with this information
- Why we asked you to participate
- If you are a supervisor, we would like to excuse you at this time

2. Explanation of the process

Ask the group if anyone has participated in a focus group before. Explain that focus groups are being used more and more often in health and human services research.

About focus groups

- We learn from you (positive and negative)
- Not trying to achieve consensus, we're gathering information
- No virtue in long lists: we're looking for priorities

Logistics

- Focus group will last about 45 minutes
- Feel free to move around the room
- Where is the bathroom? Exit?
- Help yourself to refreshments

3. Ground Rules

Ask the group to suggest some ground rules. After they brainstorm some, make a list of agreed ground rules.

- Everyone should participate in the discussion
- Information provided in the focus group discussions must be kept confidential
- Stay with the group and please don't have side conversations
- Turn off cell phones if possible

- Have fun
4. Turn on Dictaphone
 5. Ask the group if there are any questions before we begin and address those questions.
 6. Group Introductions
 7. Women's group using the Participatory Learning Action Cycle presentation discussion with topic guide A (Group 1 & 2) or Topic Guide B (Group 3).
 8. Questions



Topic Guide A

Topic guide for population-based focus group discussions

10-minute Presentation introducing the women's groups PLA cycle model to the group

Questions:

2. What do you think of the women's group PLA cycle model?
3. What are some of the not so good things about this model?

The Hook

4. What would make you come to the groups?

Logistics

5. What do you think of this picture? *show picture of group in India

Prompts: Time, space, location, indoor versus outdoor, men, women, children. Length of group, travel and travel expenses

Aesthetics

6. We use materials to help deliver information. What do you think of this picture *show card with breastfeeding mother and baby from Bangladesh trial?

Prompts- clothes, cartoon, use of photographs

Media

7. How would you otherwise receive information about health?

Probes: information- mHealth, fliers, posters, via GP or other health outlet

Respect/recognition from others in population

8. How could we disseminate information out the groups?

That concludes our focus group. Thank you so much for coming and sharing your thoughts and opinions with us. Pads & Pencils for each participant.



Topic Guide Focus Group 3

16.11.2017

1. Do you need any activities to help you move through the PLA cycle?

- Games?
- Material?
- Prompts?

If yes:

2. What would you like?

- Picture cards?

If no

3. Why not?

- Alternatives?

4. What do you think of context mapping as an activity?

- Like
- Dislike
- Alternative

5. How would you like to receive key messages?

- Power Point?
- mHealth

6. Who should come to our groups?

Men's presence

11.14 Appendix 14: Adaptation Insights for the NEON Study

11.14.1 Insight 1: Maintain the fidelity of the model by preserving the four stage PLA cycle, the use of the participatory tools & the volunteer-led group facilitation

The literature review (chapter 5) and the data from the key informant interviews demonstrated that there were three key components that maintained the fidelity of the women's group PLA cycle intervention. Preserving these components was an integral part of the adaptation process because they demonstrate which components must not be adapted and which elements can be adapted.

The four-stage PLA cycle: Do not change the PLA cycle. This component of the intervention preserves the principles of Paulo Freire (1979) by encouraging the participants to critically assess their environment. It is this structured process that makes the intervention unique to other women's groups.

The use of participatory tools: A principle of this intervention to avoid didactic methods of information delivery. Use the participatory tools. These components facilitate the groups through the cycle and assist with identifying issues within their context. They should be adapted at an individual level, but their use is an essential to preserve the participatory nature of the intervention ***addressed in recommendation 4**

The peer-led group facilitation: Optimise participation by using peer facilitation. This intervention was considered an alternative to the current top-down health programmes in previous trial contexts. Part of reiterating that narrative was to make the groups as participatory as possible. The groups required facilitation as the meeting structure was complex; the key informants suggested that trained volunteers are a method of overcoming this barrier to participation. The traits of these facilitators are ***addressed in recommendation 4**

Preserving the core components (listed above) could be an integral part of the adaptation process adequate method of facilitating the groups in meetings for the Bangladeshi population of Tower Hamlets; however, they have not been fully piloted and may not be applicable in latter stages of the PLA cycle. Furthermore, the NEON pre-pilot highlighted that volunteer-led group facilitators require comprehensive training to optimise their delivery of the aims and objectives of each groups. Some groups were conducted in Bengali which made it difficult to monitor how the volunteer group facilitator adhered to the manual. A formal method of assessing the capacity of volunteer group facilitators may be needed in the intervention.

11.14.2 Insight 2: Align aims, objectives and outcomes with international & national health and research agendas, target population priorities & stakeholder expectations

The data from the key informant interviews and evidence from the literature indicated that aligning your trial aims, objectives and outcomes with the international and national research agenda, population priorities and stakeholder expectation could facilitate engagement and enhance participation in the intervention. In order to define specific agendas and priorities, it could help to understand the barriers and facilitators in the context and assess the feasibility and acceptability of adapting the intervention with these in mind. It is also important to understand these aspects to help design relevant outcomes which could optimise monitoring and evaluation processes.

International & national health & research agendas: Use an exemplar that is recognised as a public health problem on the global platform. This can open up areas for collaboration, knowledge sharing activities and funding opportunities. National health agendas can create buy-in from senior health care managers, commissioners and health and allied-health professionals.

Target population priorities: Have a clear understanding of the health, social and economic issues in the context and work with the target population to identify a relevant exemplar that they consider to be a major issue. This will create a value proposition which could support community buy-in and help embed the intervention and encourage the target population to take ownership.

Stakeholder expectations: Consult allied health professionals, health professionals, community workers and local government on relevant outcomes; optimise relevance of outcome by assessing feasibility and whether they are measurable; be clear as to the role of these stakeholders and how they can assist with outcome development.

The FGD data suggested that only focusing on complementary feeding practices in infants of Bangladeshi origin in Tower Hamlets was too narrow. The participants wanted something that encompassed cognitive growth and development. This aligns with the NHS agenda and international health agendas that are focusing on childhood obesity.

11.14.3 Insight 3: Determine which adaptations will require formative research and which can be made pragmatically

The key informants reported that adaptations were made pragmatically, and some adaptations were evidence-based. They reported that some adaptations could be made pragmatically because their local

partners had knowledge of the context. Some adaptations, however, required an exploration into the contextual barriers, facilitators and limitations, so that that the intervention could be adapted accordingly.

Pragmatic: Ask local partners to advise on the best way to engage the target population, which language to translate the materials, protocol and facilitator manual, about the religion, ethnicity, and spiritualism within each context. Their knowledge of the context should be able to inform these preliminary steps to adaptation that occur before the piloting stage of the trial.

Formative research: Use formative research techniques such as community mapping, resource mapping, transect walk, key informant interviews, workshops and community meetings to get feedback on materials, contents, delivery and logistics. This can be conducted in a formalised pilot stage or in a rapid feedback assessment. This formative research stage occurs when there are items to test before the preliminary development of the aforementioned adaptable components.

The FGDs demonstrated that the Bangladeshi population of Tower Hamlets is experiencing acculturation and therefore requires formative research to explore the extent of this. They also demonstrated high levels of heterogeneity, which suggests that assumptions cannot be made as to the language that is spoken, the literacy level, the practices or beliefs, or the culture within this population. The NEON study should develop the facilitator manual, materials, contents and protocol in English because that is the salient language that is spoken by the team, but further research is required to test whether it can be appropriately translated into Bengali without compromising the health messages.

11.14.4 Insight 4: Adapt the materials, content, delivery & logistics to reflect the cultural and contextual norms and values.

This recommendation is again based on the key informant interviews and evidence from the literature that demonstrated that there was a set of components that could be adapted to embody the social nuances and cultural practices of the target population and the local context. It could be important to adapt these components so that the materials, content, delivery and logistics are relevant, accessible, attractive and feasible within each context and to each member of the target population.

Materials: Consider relevant depiction; salient language(s); concepts, vocabulary; reading level and literacy; appropriate graphics and scenarios - appropriate ethically, spiritually & religiously.

Content: Uses ethnic/contextually specific data or messages based on participant preferences and available resources; echoes social and cultural values/context-specific issues; addresses mistrust in health system/ health professionals/allied-health professionals and/ or discrimination.

Delivery: Explore a topic that would attract the target audience - *the hook* - reframing the topic relative to context; use methods such as storytelling, picture cards and literature, hands-on/interactive learning, participatory tools, testimonials or face-to-face discussion.

Logistics: Accessibility – consider the group composition, employment situations, location, emotional and structural barriers to participation; explore different types of incentives (facilitator’s time should be incentivised; encourage collective action, using participatory tools to facilitate discussion.

The data from the FGDs suggested that most of the Bangladeshi population of Tower Hamlets relate to their British context and their Bangladeshi heritage, therefore, they wanted materials and contents that reflected each culture. They thought that the materials should be photographs and not illustrations and they wanted a more structured form of delivery, because they felt they were accustomed to “more.” They wanted the groups to be smaller and held somewhere near their homes. They also wanted the groups to be after the morning school run or before the afternoon pick up. The women also wanted childcare and a peer-led group, and the men wanted a health professional-led group.

As the Bangladeshi population of Tower Hamlets are considered migrants and/or an ethnic minority, appreciating that some mothers may not have the support structures in place to help them raise their children could be important when considering venues for the groups. Additionally, when adapting an intervention for an ethnic minority population, it could be important to consider institutional racism that could inhibit their access to healthcare. Further research to understand the depths of parents’ perceptions and/or fears within the Bangladeshi population of Tower Hamlets could help to inform the content of the adapted women’s group PLA cycle intervention for this population.

11.14.5 Insight 5: Engage with local partners to facilitate community entry process & formative research stage

Key informant interview findings described how each of the previous projects engaged with multiple different local partners to assist with the community entry process and the formative research stage. Local partners were able to give insight into the context, demonstrate knowledge of the target population, and were recognised and trusted by the target population. This made them able to access the target population and assist in the formative research that led to some of the adaptations.

Community entry process: Use a local NGO and engage local leaders such as religious leaders, chiefs or village elders can facilitate the community entry process. Once they have been recruited, they can assist with the organisation of a community initiation/project kick-off meeting to disseminate information about the trial to the target population. On a health systems level, engaging with ministry of health and local and/or central government can assist with raising awareness of the intervention for health and allied-health professionals.

Formative research stage: Engage a local NGO to assist with the appointment of community-based data collectors. Engage with the national health system to help identify any routine data that is available and could be used to measure outcomes and/or assess the magnitude of the issue at a national or local level. This routine data could also help identify a trial site that has a significant problem relating to the exemplar.

Currently, the NEON study engages the international NGO Women & Children First who had experience implementing the intervention overseas, but local partners could facilitate the adaption process. They should engage multiple stakeholders within Tower Hamlets including the clinical commissioning group, the public health team, local government, health professionals (GPs, health visitors), allied-health professionals (dietitians, pharmacists) and existing community groups. The FGDs suggested that attaching the PLA cycle to existing meetings or groups (coffee mornings or through children's centres) would help embed the intervention within the community. The men in the FGD said that they would not mind a Mosque-based intervention, but some Mosques did not have rooms for women. They also suggested that they wanted it to be promoted by their GP surgery.

11.14.6 Insight 6: Utilise existing knowledge to inform the adaptation of the micro-adaptations outlined in recommendation 3

This recommendation was developed with the data from the key informant interviews and evidence from the literature that demonstrated that each trial team had accessed different resources to inform their intervention adaptation. Furthermore, this recommendation supports the National Health Service advisory group's suggestion that the public should be involved in health and social care research.

Patient & Public Involvement: Use the target population to inform adaptations by involving them in the formative research stage or having them as representatives in the steering group. Try to involve them throughout the adaptations process and offer them the opportunity to comment on the trial design throughout.

Current literature: Inform adaptation based on current best practice, published work and current guidelines.

Professional input: Engage health professionals, allied-health professionals, government representatives, academics, and development professionals to give input to the adaptations. Local and national professionals from the health sector and central and local government can advise on current interventions and programmes in context, legislation and navigating political context, and how to disseminate results both nationally and locally. Engaging with academics and development professionals could assist with adaptation from a programme or intervention development perspective.

Representatives from the Bangladeshi population were involved in the data collection steering group and contributed to the design of the contents and materials for the NEON study pre-pilot. The FGDs also asked the participants to suggest games and activities that could be used as materials to facilitate the groups through the cycle. They suggested picture cards and community mapping exercises. The NEON study also engaged professionals via a steering group which met every six months. When designing the contents of the picture cards, a paediatric dietician and a health and wellbeing expert from BARTS were engaged.

11.14.7 Insight 7: Consider recruiting respected individuals who speak the salient language & local dialects for group facilitation & community outreach

The data from the key informant interviews suggested that it is recruiting *respected* team members and volunteers that speak the salient local language which is beneficial to the intervention. Although the women's group PLA cycle suggests that there should not be a hierarchy within each group, employing respected individuals and equipping them with a title of group facilitator, data collector or community facilitator constructs a chain of command. Practically, having an individual who speaks

the salient language and can translate into local dialects makes it easier to adapt the manual and contents. Nonetheless, caution is advised when this adaptation cannot be fully monitored, and comprehensive training on how to deliver the intervention, including what can and cannot be adapted could be potentially prevent mis-adaptation.

Respected: Assess who the target population consider to be influential members of their community. The key informants considered a influential or “respected” individual to be someone who had sufficient relevant experience with the exemplar to enable them to contribute to the group. Under the neonatal mortality exemplar in previous contexts, this was seen as a married woman who had given birth. The FGD data complimented this view of the respected individual by suggesting that they would listen to a medical professional (men) or another mother (women).

Salient language & local dialects: Determine the salient local language. Within each context there is a salient language that is spoken, e.g. *Hindi* in the Indian trials, but the key informants reported that within each sub-context individuals spoke a variety of languages. It would be extremely resource intensive for each trial team to adapt their manual, contents and materials into each individual language, some dialects cannot be written, e.g. *Sylheti*, and some individuals cannot read. To overcome this barrier, each trial employed group facilitators and community facilitators who could speak the salient language and the local dialects.

This PhD research aimed to demonstrate which parts of the women’s group PLA cycle should be preserved to maintain the fidelity of the intervention, and which components can be adapted for the context. The feasibility and accessibility of these adaptations recommended in the previous section on insights were assessed in the NEON study pre-pilot.

The results of FGD data from the NEON study pre-pilot confirmed the insights that were suggested from the PhD research. For example, some individuals of Bangladeshi origin could speak English or Bengali, not were not able to read in these languages. Also, some of the group facilitators could not read Bengali but they could speak it and they preferred to have their manual, contents and materials in English. This also has implications for the translation as English and *Bengali* do not translate directly; caution must be applied when translating.

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