Know Your Bugs: A collaborative evaluation of a community health education module that aims to be accessible to adults with learning disabilities

Rebecca Owens

School of Health, Wellbeing and Social Care

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Abstract

The right to health should be a fundamental right of everyone. However, despite initiatives to improve the health of adults with learning disabilities, concerns about poorer health and health inequalities remain, and have been exacerbated by the COVID-19 pandemic. Accessible health promotion can help to overcome barriers to healthy behaviour but the effectiveness of health education in infection prevention and self-care is unknown. This research aimed to understand the health education experiences of adults with learning disabilities regarding a module designed to improve knowledge about self-care, infection prevention and antibiotic use.

Beginning with a scoping review of ‘what works’, this research involved observation of the learning context in two locations and semi-structured interviews with 18 course participants to explore health knowledge and behaviour change in the short, medium and longer term. Data were analysed iteratively, addressing the realist concept of context/mechanism/outcome configurations.

Participants had a positive learning experience and gained knowledge about microbes, hand hygiene, self-care, and antibiotic use. Some participants reported behaviour change regarding handwashing and self-care. The contexts that influenced learning were personal, social, physical, active, and external. Mechanisms that interacted with these contexts to trigger learning included: accessible teaching methods, interactive resources, relaxed and effective participant interactions, facilitation of independent thinking and planning, appropriate involvement of supporters, and an inclusive and engaging educator style.

Knowledge gain and changed behaviour intentions were achieved through an engaging, interactive, and focused learning environment, underpinned by a complex and changing combination of interactions. However, further research is needed to understand effective ways of communicating health information in an education context, to understand the impact of education on behaviour change, and to identify ways in which the longer-term retention of learning can be achieved. The research proposes a draft model that can guide effective community health education provision.
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Declaration of authorship

I declare that this thesis has been composed solely by myself and that it has not been submitted, either in whole or in part, in any previous application for a degree. Except where otherwise acknowledged, the work presented is entirely my own.

References to relevant works:

Journal articles:


Conference presentations and national meetings:

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List of abbreviations and a note on terminology

BtB    Beat the Bugs
CMO    Context/Mechanism/Outcome
CMOC   Context/Mechanism/Outcome Configuration
KYB    Know Your Bugs
LSA    Learning Support Assistant
MRT    Middle Range Theory
MYI    Managing Your Infection (leaflet)
OHID   Office for Health Improvement and Disparities
PCIU   Primary Care and Interventions Unit
PHE    Public Health England*
PS     Personal Supporter
RDG    Research Development Group
UK HSA  UK Health Security Agency
VARK   Visual Audio Kinetic (Learning)
WHO    World Health Organization
* Until 1st October 2021, Public Health England (PHE) was an executive agency of the Department of Health and Social Care in England. On 1st October 2021, Public Health England was replaced by UK Health Security Agency and the Office for Health Improvement and Disparities. Throughout this thesis I refer to the organisation as PHE because this was its name during the research period.

**A note on terminology: the term ‘learning disability’**

Terminology in the context of learning disability is often contested and there are local, national and international differences in use of language, perspective and definition. For the purposes of this thesis, I have chosen to use the label ‘learning disability’ to represent the many millions of people who experience global health inequalities and have cognitive impairments. I decided to use this term because it was preferred by most of the participants and organisations involved in my research.
Chapter 1. Introduction

The right to health should be a fundamental right of every human being (World Health Organization, 2017; Office of the United Nations High Commissioner for Human Rights, 2008). Incorporated within the World Health Organization’s 1946 Constitution (World Health Organization, 2006), the right to health is one of a set of internationally agreed human rights standards that include freedom to control one’s own body and health, entitlement to health protection and equal opportunity to enjoy the highest attainable level of health. It is not a right to be healthy but an entitlement to these standards. A rights-based approach to health means that it should be experienced without discrimination, that healthcare should be timely, acceptable and affordable, and that there should be provision for the underlying determinants of health such as sanitation, housing, health-related information and education, (World Health Organization, 2012, 2017).

The right to health applies equally to adults with learning disabilities as it does the rest of the population, and these underlying determinants are crucial in supporting everyone in fulfilling this entitlement. However, there are considerable disparities between the health-related entitlements all people have globally, and the extent to which they can access them (Ooms et al., 2019; Rumbold et al., 2017). This thesis focuses on the important role of health education in this respect, particularly in the context of infection prevention, self-care and the health of adults with learning disabilities which have come to the fore since the emergence of the COVID-19 pandemic.

Many of us are living longer, healthier lives. In the UK for example, average life expectancy increased by seventeen years between 1946, when the World Health Organization’s Constitution was written, and 2020 (Statista, 2020). Many previously fatal diseases are now controlled through immunisation and treatment, and frequent new developments in science and medicine improve healthcare and increase longevity. However, people with learning disabilities experience poorer health and greater health inequalities than the rest of the global population and have done so for a long time. The right to health can provide a context for addressing issues of discrimination, exclusion, and power imbalance, directing focus onto issues of equity (Rumbold et al., 2017), and it
is in this context that my research addresses adults with learning disabilities’ experiences of a specific community health education module, Know Your Bugs. Know Your Bugs addresses learning about infection prevention, self-care, and the use of medicines, and aims to enable participants to practise self-care and make decisions about their health.

The international literature on the health of adults with learning disabilities consistently describes poorer health and greater co-morbidities than the general population (Taggart et al., 2021; Totsika et al., 2021; Doherty et al., 2020b, 2020a; Bauer et al., 2019; Robertson et al., 2019; Melville et al., 2018; Emerson et al., 2016; Emerson and Hatton, 2013). They are, for example, two to three times more likely to have diabetes (Taggart et al., 2015), and have a higher prevalence of obesity, tending to become obese at an earlier age than the general population (Taggart et al., 2021; Melville et al., 2018; Bhaumik et al., 2008). Adults with learning disabilities are also more likely to live with complex and varying health concerns, and are at higher risk of associated health conditions such as dementia and mental health issues (Hussain et al., 2020; National Institute for Health Research, 2020; Reppermund et al., 2020; World Health Organization, 2008). Older people with a learning disability, for example, have more prevalent and combined health problems than people of a similar age in the general population (Bauer et al., 2019).

Although people with learning disabilities in England are living longer than previously, they nevertheless die on average at a much younger age than the rest of the population. Data suggest that in 2018/2019 this disparity was 23 years for males and 27 years for females in England, and proportionately far fewer people with learning disabilities live beyond the age of 65 years (LeDeR, 2021). Compared to the rest of the population, data suggest that people with learning disabilities are also more than three times as likely to die from an avoidable medical cause of death (LeDeR, 2021). Furthermore, although data on the health status of people with learning disabilities from minority groups is limited, research indicates even poorer morbidity and mortality, suggesting people with learning disabilities from minority ethnic groups are dying at a disproportionately young age (MENCAP, 2020; Robertson et al., 2019).

These statistics present a concerning situation. However, researchers estimate that these issues in fact affect many more people with learning disabilities in the UK than the public statistics show (House et al., 2018; Hatton, 2016; Emerson, 2011). Official figures suggest
that there are about 1.2 million people with learning disabilities in England, over half of which live at home (Public Health England, 2016). However, the literature also suggests that there is a ‘hidden majority’ of approximately 700,000 people with learning disabilities in England (Hatton, 2016; Emerson, 2011). These are those that are not formally identified as such. They are less likely to access health services including health promotion and health education, and more likely to be exposed to social determinants of poorer health (Taggart et al., 2021; Hatton, 2016; Allerton and Emerson, 2012; Emerson, 2011).

These health disparities were exacerbated by the emergence of the COVID-19 pandemic during 2020. COVID-19 is an infectious disease caused by a newly discovered coronavirus that was first identified in China in 2019, and rapidly spread across the world during 2020. The disease has had a huge impact on life and death globally; 3.9 million people died between January 2020 and June 2021 (John Hopkins University, 2021).

However, in England COVID-19 has affected proportionately far more people with learning disabilities. People with learning disabilities had considerably higher risk of hospital admission and death due to COVID-19 (Courtenay and Cooper, 2021; Williamson et al., 2021). It was in fact the leading condition-specific cause of death for people with learning disabilities in 2020 (LeDeR, 2021), and it is estimated that the COVID-19 death rate amongst people with learning disabilities during 2020 was 3.6 times the rate in the general population (Public Health England, 2020a). Studies have shown that adults with learning disabilities were more likely than the general population to be infected with COVID-19. They also had worse outcomes once infected, particularly those under 65 years with higher mortality and fatality than those who did not have a learning disability (Henderson et al., 2021; LeDeR, 2021; Totsika et al., 2021).

Many factors contributed to the disproportionate number of deaths of people with a learning disability during the COVID-19 pandemic (Henderson et al., 2021; LeDeR, 2021; MENCAP, 2020). Amongst people with learning disabilities there is a high prevalence of comorbidities such as heart disease, respiratory disease, hypertension and diabetes for example, (Dunn et al., 2018; Glover et al., 2017; Cooper et al., 2015) which have been linked with poorer outcomes from COVID-19. However, there were also many concerns
about the treatment of people with learning disabilities during the pandemic, and their access to appropriate healthcare. These concerns span the whole health experience including provision of accessible public health information, COVID-19 testing and diagnosis, and inpatient care (LeDeR, 2021). There were reports of failures to implement reasonable adjustments such as ensuring availability of support from specialist learning disability services, the inaccessibility of the NHS 111 service (and the appropriateness of its assessments), and concerns about diagnostic overshadowing and the quality of care provided in, and on journeys to, hospital (LeDeR, 2021; MENCAP, 2020; Public Health England, 2020b).

In England, during the first wave of the pandemic in the winter and spring of 2020, there were concerns about the treatment of adults with learning disabilities in healthcare settings (Care Quality Commission, 2021; Courtenay and Perera, 2020; Hassiotis et al., 2020; MENCAP, 2020). At the onset of this first wave, the National Institute for Health and Care Excellence (2020) published guidance on the treatment of patients in critical care. This suggested that staff graded patients using a Clinical Frailty Scale and use this grade to make decisions about eligibility for critical care. This disadvantaged people with learning disabilities because the scale included assessment of ability to undertake activities with which people with learning disabilities might need support (MENCAP, 2020). They were therefore often not deemed eligible for critical care support. This led to concerns about widespread and inappropriate use of ‘Do Not Attempt Cardio-Pulmonary Resuscitation’ (DNACPR) during the first wave of COVID (LeDeR, 2021; MENCAP, 2020) and, although the guideline was changed, clarifying that it should not be used with people with learning disabilities, it was too late for some. In fact, several reviewers of COVID-19 deaths for the LeDeR programme1 (NHS, n.d.) noted that some DNACPR decision making processes had not adhered to the Mental Capacity Act (LeDeR, 2021; UK Public General Acts, 2005). Of the people with learning disabilities who died from COVID-19 in 2020 and were reviewed by LeDer (LeDeR, 2021), 81% (385 people) had had DNACPR on their record.

1 The Learning Disability Mortality Review (LeDeR) Programme was established in 2017 to provide a central point for the notification of all deaths of people with learning disabilities.
The pandemic has thus further highlighted the existing barriers in access to healthcare which have contributed to this disproportionately high number of deaths (Care Quality Commission, 2021; House of Commons, 2021; Ijezie et al., 2021; LeDeR, 2021; Office for National Statistics, 2021; Amor et al., 2021; Totsika et al., 2021; Courtenay, 2020; Hassiotis et al., 2020; Jeste et al., 2020; United Nations, 2020a). In England, these have included insufficient and inadequate information, lack of communication, increased isolation at home and in hospital, and lack of availability of support from specialist learning disability services (LeDeR, 2021; MENCAP, 2020).

So, where does this leave people with learning disabilities? They appear to be experiencing considerable difficulties in exercising a right to health, and the poorer health and health inequalities they experience is substantial and well documented in the literature (McMahon and Hatton, 2021; Taggart et al., 2021; Reppermund et al., 2020; Doherty et al., 2020a; Heutmers et al., 2019; Northway, 2017; Hatton, 2016; Public Health England, 2016; Krahn and Fox, 2014; Emerson and Hatton, 2013; Emerson et al., 2012; Emerson and Baines, 2011; Turner, 2011). These authors and others (Scott and Havercamp, 2016; Naaldenberg et al., 2013; Allerton and Emerson, 2012) report that poor health and health inequalities in the UK are also compounded by disparities in preventative care, and in engagement with healthy behaviours such as good oral hygiene, diet and physical exercise.

Research also suggests that these health inequalities are a result of the social and economic determinants of health rather than learning disability per se, and impact considerably on the lives of people with learning disabilities (Bauer et al., 2019; Bollard et al., 2018; Emerson et al., 2016; Krahn and Fox, 2014). In this respect, accessible health communication, effective health promotion and education as well as access to housing, employment and social support networks can affect health and potential health behaviours (Cytowska and Zierkiewicz, 2020; MacLeod and MacLure, 2020; Chinn, 2017; Tracy and McDonald, 2015; Emerson and Hatton, 2013).

International and national initiatives are attempting to overcome some of these health inequalities, and I describe some of these in Chapter 2. However, the evidence in the UK
suggests that there is a long way to go before people with learning disabilities can fully exercise a right to health.

Often overlooked in this context is the role of health education. As a tool for health promotion and one of the crucial underlying determinants of health outlined by the World Health Organisation (2017), health education aims to inform about the ways in which people can take care of their own and other people’s health, and thus influence positively health knowledge, attitudes and behaviours. Health education is thus critical for improving health (European Centre for Disease Prevention and Control, 2021; World Health Organization, 2012). Effective health promotion and health education have been shown to have a positive impact on health knowledge, health decision making and the health behaviour of adults with learning disabilities (Vlot-van Anrooij et al., 2020; An et al., 2018; O’Leary, Taggart, et al., 2018; Bollard, 2017; Kuijken et al., 2016; Scott and Havercamp, 2016; Taggart and Cousins, 2014; Naaldenberg et al., 2013; Hanna et al., 2011).

In the context of the problems I have described, effective health education could provide a framework for individual decision making, enabling behaviour change, and thereby supporting improvements in health. However, it still receives insufficient attention. Although it does not address all of the problems I have raised, health education is a crucial underlying determinant in the poorer health and health inequalities of adults with learning disabilities because it can enable them to have and utilise knowledge to make informed decisions and ask questions about their health.

This thesis describes my collaborative research to explore the role of health education in enabling adults with learning disabilities to make informed health decisions with specific reference to a module called Know Your Bugs. Know Your Bugs is an interactive community health education module that aims to educate about infection prevention, self-care and antibiotic use. As such it is the final of six modules that constitute a broader course called Beat the Bugs and is described in further detail in Chapter 2, section 2.4. Know Your Bugs is particularly important in addressing the issues people with learning disabilities experience in exercising a right to health, particularly in the light of the COVID-19 pandemic. This is because it focuses on hygiene, infection prevention and antibiotic
use; on health communication, and aims to support understanding and impart the skills to self-care, to spot the signs of serious illness, and clarify when and how to access advice and support.

The research questions that I aimed to answer in conducting this research were:

- How does the learning environment influence learning and behaviour change regarding self-care and the management of good health of adults with learning disabilities?

- How does the Know Your Bugs module equip adults with learning disabilities with knowledge and confidence to self-care and manage common infection?

- How does collaborative working with adults with learning disabilities on public health evaluation enhance research outcomes?

To answer these questions I conducted a collaborative realist evaluation (Emmel et al., 2018; Pawson and Tilley, 1997). Realist evaluations examine what works, for whom, in what circumstances and how, thus enabling the researcher to understand the reasons why an intervention is or is not effective. In the context of my research, this enabled me to explore the learning environment and how this influenced participant outcomes from the Know Your Bugs session.

In Chapter 2, I discuss the background and wider context in accessing good health, healthcare and health promotion for adults with learning disabilities. Chapter 3 reviews the specific literature that evaluates community health education programmes for adults with learning disabilities. This presents findings from the scoping review I conducted as a foundation to the realist evaluation. Chapter 3 concludes by proposing components of effective education in the form of the contexts and mechanisms that interact to generate effective outcomes. This provides a basis for developing the initial middle range theory to be explored in the realist evaluation. Chapter 4 provides an overview of the theoretical
underpinnings of my research, and thus provides context for Chapter 5, Methodology. Chapter 6 provides a detailed description and analysis of my findings, and it is here that I propose a revised middle range theory that encapsulates an effective Know Your Bugs module.

In Chapter 7 I discuss the implications of my findings in the context of health rights and education. I review the strengths and limitations of my research design, including review of my proposed participatory approach with a collaborative group of adults with learning disabilities. In conclusion, Chapter 8 summarises key findings from the evaluation in the context of participants’ learning experiences and suggests practical adaptations and reasonable adjustments that should be made to ensure the module is accessible to adults with learning disabilities. Finally, I describe the need for further research to support the development of better self-care education and appropriate inclusive evaluation models and propose a model for accessible community health education in the context of learning disability.
Chapter 2. Background: The context for Know Your Bugs

This chapter describes the background to the concerns raised in my introduction and introduces the important concept of researching collaboratively with people with learning disabilities. It aims to provide context to my research by outlining some of the significant policy and legislative responses to health inequalities. The chapter concludes by introducing Know Your Bugs in this context as a means of addressing health promotion and health education that aims to be accessible to adults with learning disabilities.

2.1 The wider context: Policy and legislative responses to health inequalities of adults with learning disabilities

Internationally, the United Nations has taken steps to address the inequalities experienced by disabled people, including people with learning disabilities, and to provide a framework for improvement. The United Nations Convention on the Rights of Persons with Disabilities and its Optional Protocol (United Nations, 2006) was adopted in 2006, and is supported by the United Nations Disability Inclusion Strategy (United Nations, 2020b). These require nations to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms, including a right to health. Article 25 (United Nations, 2006) further recognises the ‘right to enjoyment of the highest attainable standard of health without discrimination’ for disabled people, and presents measures that should be taken to ensure this right. Core components of these measures include availability, accessibility, acceptability and quality, and including access to additional support if needed.

More recently, in response to the COVID-19 pandemic, the United Nations issued an additional brief (United Nations, 2020a), setting out further areas for action, applicable to all nations, in order to ensure the needs of disabled people were addressed in relation to the pandemic. This included ensuring accessibility of information, facilities and programmes, and meaningful consultation with, and active participation of disabled people in the COVID-19 response. As I have outlined in Chapter 1, emerging international
research in response to the COVID-19 pandemic suggests that these measures are not being addressed however, and statistics have shown a disproportionately higher number of deaths from the disease (Amor et al., 2021; Ijezie et al., 2021; LeDeR, 2021; Office for National Statistics, 2021; Courtenay, 2020; Hassiotis et al., 2020; Jeste et al., 2020; United Nations, 2020a).

Many policy and legislative developments have aimed to address concerns about the health and health inequalities faced by adults with learning disabilities, and as such to support them in enjoying a right to health. In 2001 the UK Government published the White Paper *Valuing People: A new strategy for learning disability for the 21st Century* (Department of Health, 2001), advocating a more inclusive approach to supporting people with learning disabilities, based on greater choice and control. Subsequent to this, legislation such as the Equality Act 2010 (UK Public General Acts, 2010) and the Mental Capacity Act 2005 (UK Public General Acts, 2005) aimed to give people who have been marginalised equitable status and greater choice in making decisions about their lives.

In 2012, NHS England introduced the Transforming Care Programme (Department of Health, 2012a) which aimed to reduce the number of people with a learning disability who were placed in inpatient services. Focusing on people moving out of inpatient facilities, the programme intended to improve community health and care services so that more people with learning disabilities could live in the community with appropriate and accessible support.

To improve care, reduce health inequalities and prevent people with a learning disability dying sooner than the rest of the population, the Learning Disabilities Mortality Review Programme (LeDeR) was established in 2017. The programme provided a central point for the notification of all deaths of people with learning disabilities, national reporting on these deaths, and the completion of additional focused projects addressing premature deaths and health inequalities. Despite the encouraging picture of an overall reduction in the proportion of preventable, treatable and avoidable medical causes of death of people with learning disabilities between 2018 to 2020, the most recent LeDeR report presents concerning information about the experiences and deaths of adults with learning disabilities regarding the COVID-19 pandemic (LeDeR, 2021). I have addressed the COVID-
pandemic in Chapter 1 and will return to it throughout my thesis as it had a significant bearing on my research.

The Government’s Mandate to the NHS 2018-19 (Department of Health and Social Care, 2018) set an objective for the NHS to close the health gap between people with mental health problems, learning disabilities and autism and the population as a whole. In response, the NHS Long Term Plan 2019 (National Health Service, 2019) included learning disability and autism as one of the top five priorities for action, and set out intentions to improve the general health of people with learning disabilities. This included promoting health checks and, later, health passports.

In 2018, the National Institute for Health and Care Excellence (NICE) published a guideline on support for people with learning disabilities and behaviour that challenges (NICE 2018). This guideline aimed to promote a lifelong approach to supporting people with learning disabilities. Following the policy shift to support people with learning disabilities in moving out of inpatient establishments (Department of Health, 2012a) there has been a greater need for interventions that support self-care and independence. However, in the context of research described earlier on poor health outcomes, inadequate health education and health inequalities, it seems there is still a need for further progress in both a research and policy context.

National and local initiatives have aimed to address this need from a support and education perspective. The NICE Guideline 63 (National Institute for Health and Care Excellence, 2017) aimed to change public behaviour in the context of infection prevention and antibiotic use. In a commentary on the Guideline, Eley and McNulty (2018) stressed that everyone has a responsibility to help prevent infections by teaching through example and public education about hygiene and vaccination. Public initiatives have included health promotion and education interventions focusing on good self-care, hygiene and infection prevention behaviours and their consequences (Hayes et al., 2021; Eley et al., 2018; Kesten et al., 2017; National Institute for Health and Care Excellence, 2017), more recently also associated with the spread of infections such as COVID-19 (Alexander et al., 2020). However, none of these programmes have specifically addressed the needs of adults with learning disabilities.
Nationally in England, sustained and new public health initiatives have intended to improve the public’s health decision making, and include updated immunisation campaigns to prevent the spread of infection (Public Health England, 2021a), obesity and lifestyle programmes (Taggart et al., 2021), and self-care education and information, most recently in the light of the COVID-19 pandemic for example (NHS England, 2020). However, apart from lifestyle, dental and obesity programmes and developments there are relatively few specific health education initiatives directly aimed at adults with learning disabilities, especially regarding infection prevention, self-care, and antibiotic use.

Therefore, despite some developments, adults with learning disabilities in the UK still experience greater health inequalities, have more co-morbidities, and die younger than the rest of the population (LeDeR, 2021; McMahon and Hatton, 2021; Totsika et al., 2021; Doherty et al., 2020b; Robertson et al., 2019; Dunn et al., 2018). I have already referred to the evidence on mortality, but the underlying problems are still profound, and provide concerning indicators. For example, almost half (46%) of adults with learning disabilities who died between 2018 and 2020 had 7 to 10 long-term health conditions when they died (LeDeR, 2021). Younger people (aged 18-24) were less likely to have received a health check in the last year, a variable associated with the likelihood of dying at a relatively young age.

2.2 The role of health promotion and health education

The World Health Organization defines health promotion as ‘the process of enabling people to increase control over, and to improve, their health.’ (World Health Organization, 2012, p. 13). Within this context, it describes health education as a tool for health promotion, a means of increasing knowledge about personal health behaviour and developing skills to make effective decisions in attaining good personal health.

In exploring the role of health promotion in the context of learning disability, Roll (2018) identified four key conceptual areas as being important components of effective health programmes: supporting a healthy lifestyle, providing health education, involving supporters and being person-centred. Roll (2018) and others (Taggart et al., 2021; Kuijken
et al., 2016; Scott and Havercamp, 2016) suggested that, if such concepts were appropriately addressed in developing and implementing health promotion and education programmes, these programmes were more likely to support effective outcomes such as empowerment, enhanced quality of life, informed and healthier lifestyle choices and, potentially, reduced health disparities. In exploring perceived barriers to healthy living and solutions, (Doherty et al., 2020b), for example, identified a need for clearer accessible information, peer support and the need for further research into the wider socio-economic barriers that affect health.

These components of effective health promotion are in fact often cited in the literature addressing learning disability (St. John et al., 2021; Taggart et al., 2021; Melville et al., 2018; Roll, 2018; Willems et al., 2017; Williamson et al., 2017; Scott and Havercamp, 2016; Bergström et al., 2013; Doody and Doody, 2012). However, they are often not achieved by programmes that aim to address specific issues such as diet, obesity or lifestyle (Taggart et al., 2021; Scott and Havercamp, 2016; Bergström et al., 2013, 2014; Hagströmer et al., 2011). In these contexts, people with learning disabilities often face barriers to accessing effective health promotion, including use of appropriate and accessible language, health provider knowledge and understanding of people’s needs, and availability of appropriate community and personal resources (St. John et al., 2021; Williamson et al., 2017; Scott and Havercamp, 2016). Although recognised as a growing area of research and intervention development, authors conclude that a holistic perspective of health and understanding of health experiences should inform the development and implementation of appropriate health promotion programmes if they are to be accessible to people with learning disabilities (St. John et al., 2021; Scott and Havercamp, 2016; Bergström et al., 2014). In order to achieve this, evidence suggests a need for further research.

Barriers to healthy behaviour identified in the literature include lack of: accessible health promotion and education, accessible transport and links, appropriate identification of learning and behavioural support needs, health professional understanding of the implications of learning disability, joint working between different care providers; and inadequate aftercare or follow-up support (Taggart et al., 2011; Emerson, 2012; Taggart and Cousins, 2014; Scott and Havercamp, 2016; Mencap, 2018; St John et al., 2021).
These barriers correspond to the concepts described by Roll (2018), representing what could happen if the components suggested by the author were not in place.

Some studies have found that proposed strategies for overcoming health concerns are often reactive rather than proactive, and that accessible health promotion in a learning disability context has been insufficiently prioritised within provider organisations (Taggart et al., 2021; Doherty et al., 2020b; O’Leary, Cooper, et al., 2018; Bollard, 2017). Although Taggart et al., (2021) reported concerns over the applicability of complex behaviour change techniques in lifestyle programmes developed for adults with learning disabilities (Willems et al., 2017), they also identified organisational and individual barriers to accessible information exchange and knowledge acquisition. These included a failure to make reasonable adjustments to ensure clear, accessible information and training on healthy lifestyles, and a concern that many lifestyle programmes had not been optimally adapted for this population. This is a feature of much of the literature on this topic (Taggart et al., 2021; Doherty et al., 2020a; Bauer et al., 2019) although there are examples of good practice: Steels and Rodgers (2016) used creative methods such as drama, dance and art to educate participants about health, and Liu et al. (2021) found that a board game was effective in teaching about oral hygiene. These researchers found that creative methods of teaching public health could support change in planned health behaviours for people with learning disabilities, specifically around self-care and the understanding of complex subjects.

Kuijken et al. (2016) concluded that although some people with learning disabilities may understand what healthy living entails, many may have difficulty translating this into healthy behaviours. The authors suggested that, as people with learning disabilities face difficulties in trying to live healthily, health promotion should be tailored to individual needs, and focus on actively supporting appropriate behaviours. In this context, effective self-management of health potentially increases choice and empowerment (Taggart et al., 2021; Friedman et al., 2019), and its impact can be wide ranging in terms of positive health implications (Bollard, 2017). Using a proactive approach to health promotion, Vlot-van Anrooij et al. (2020) utilised an ‘asset-based’ method to identify aspects of the environment that, from the perspective of people with learning disabilities, supported
healthy living. These included social networks; places and environments; and healthcare and prevention.

Individual participant contexts are also identified in the literature as key components of effective learning about health (Taggart et al., 2021; Dixon-Ibarra et al., 2018; Witton et al., 2017; Scott and Havercamp, 2016; Bergström et al., 2014), particularly learner motivations and accessibility of the supporting context. In a study of barriers and facilitators in health education for adults with learning disabilities for example, Bergström, et al. (2014) found that support from within and outside the formal learning environment was important. The authors stressed the importance of an individualised supportive context, although acknowledged that this raised potential feasibility challenges.

The role of health literacy and health communication has been identified as pivotal in supporting healthy behaviours of adults with learning disabilities (Cytowska and Zierkiewicz, 2020; MacLeod and MacLure, 2020; Chinn, 2017; Fish et al., 2017; Ryan et al., 2017; Tracy and McDonald, 2015). However, research suggests that adults with learning disabilities often find it difficult to process new information, recall simple information, and ascertain which skills are needed to maintain daily life (Blair, 2012). The use of medication provides a good example in this respect. Fish et al. (2017) found that people with learning disabilities often struggled to read leaflets and remember verbal information. MacLeod and MacLure (2020) reported that studies showed issues of health literacy, reliance on personal supporters, difficulties with memory and perception of time, and health professional communication as underlying a need for greater focus on health communication. The authors also stressed a need for further research into people with learning disabilities’ lived experience of medication.

Blair (2012) reported little evidence of education regarding medication requirements or of holding appropriate discussions about medication use. Some studies (Smith et al., 2019) also reported that people with learning disabilities did not understand the purpose nor usage instructions of their prescription medication and concluded that there was a need for more accessible information and communication in this context. Fish et al. (2017) and others (Cytowska and Zierkiewicz, 2020; Ervin et al., 2014; Friedman et al.,
2014) also found that health services often failed to communicate in an accessible way, often focusing health discussions on carers or support workers rather than involving the patient directly. Chinn (2020) suggested that Easy Read health information could support understanding and health decision making in this context, although Chinn’s research suggests a need for clarity on how such resources are best utilised. In all these contexts, lack of knowledge and understanding is disempowering, leading to fewer opportunities for understanding and self-managing health, and potentially poorer management of long-term health conditions (Cooper et al., 2018).

Many advocate that there should be greater focus on a reduction in disparities and a subsequent development of opportunities for self-management through education, support and self-advocacy so that people with learning disabilities can manage their health (National Institute for Health Research, 2020; Friedman et al., 2019). With a shift to more people living in the community and shrinking care packages in the UK (Public Health England, 2016), there is potentially an increased need for adults with learning disabilities to take greater responsibility for hygiene, self-care and use of medicines such as antibiotics. Research suggests the role of support should also be considered in this context (Doherty et al., 2020a; Friedman et al., 2019; House et al., 2018; Willems et al., 2018; Bergström et al., 2014; Hagströmer et al., 2011), and I will discuss this further throughout my thesis.

2.3 The need for more research

The broad topic of my doctoral research, evaluation of an aspect of Beat the Bugs, was initially suggested by Public Health England (PHE) and planned as a collaboration with the Grand Union Doctoral Training Partnership (GUDTP) and the Open University. Having worked in disability research previously, and more recently in public health intervention evaluation at PHE, I was familiar with some of the policy, research and practical issues that were pertinent to the topic. I had a particular interest in applying the social model of disability in public health research and was inspired by the potential to add to knowledge in this area.
Despite the policy initiatives described previously, it seemed that there were still many gaps in knowledge relating to how adults with learning disabilities self-care (with or without support) and manage their health, particularly in the context of infection prevention, health communication and information use. There are limitations within the literature in terms of both quantity and quality of evidence. First, Krahn and Fox (2014) and Robertson et al. (2015) report methodological shortcomings with earlier research on health inequalities. Much of the earlier work was not based on true population data and used convenience samples that were often unsatisfactory. They report that findings were therefore often not awarded attention by policy makers. However, there have been subsequent moves to improve the quality of research data in this area including expanding health services research, developing inclusive research, improving health indicators, enhancing health surveillance and utilising mixed-methods approaches to research (Taggart et al., 2021; Doherty et al., 2020a; National Institute for Health Research, 2020; Frankena et al., 2019; Bollard et al., 2018).

2.3.1 Evaluation of health education aimed at adults with learning disabilities

There is still only limited research addressing the health learning and information needs of adults with learning disabilities, and the effectiveness of initiatives that aim to address these needs (Bollard, 2017; Bergström et al., 2014; Naaldenberg et al., 2013). In a structured literature review Naaldenberg et al. (2013) concluded that, despite the recognised importance of health promotion, there was insufficient focus on its effectiveness in the context of learning disability. There are global research priorities that aim to address the need for further research to improve awareness, prevention and promotive interventions (Tomlinson et al., 2014). However, in a review of systematic reviews concerning the health of people with learning disabilities, Robertson et al. (2015) identified gaps in evidence and methodological issues in research covered by the study. The authors also reported that people with learning disabilities were largely excluded from mainstream health research and existing datasets rarely identified learning disability appropriately.

A limitation of the evaluation literature is that many studies do not address the longer-term effectiveness of interventions aiming to support improvements in healthcare of
adults with learning disabilities (Taggart et al., 2021; Hanlon et al., 2018). This is important because adults with learning disabilities often have difficulty retaining knowledge and skills. Although longer term studies are emerging, there is still a need for a more comprehensive understanding of longer-term effectiveness of programmes that aim to educate about self-care (National Institute for Health Research, 2020). Additionally, although not solely focussed on health education, Taggart et al. (2021) found that limitations within the literature with few theoretically-based programmes that explored the personal and environmental issues influencing outcomes, thus potentially failing to address the underlying reasons behind programme effectiveness in healthy lifestyle and obesity programmes. I discuss and evidence this further in Chapter 3, section 1.1.

2.3.2 Inclusive, participatory and collaborative research

In recent years, there has been increasing recognition of the value of inclusive and participatory research methods in the context of learning disability and health research (Salmón and Pernia, 2021; Chalachanová et al., 2020; Frankena et al., 2019; Walmsley et al., 2018; Seale et al., 2014, 2015; Nind and Vinha, 2012a). A key principle here is that those affected by research are best placed to design and deliver it because they have life experience that shapes meaningful study (St John et al., 2018; Walmsley et al., 2018; Frankena et al., 2015; Nind, 2014; Seale et al., 2014). On commencing my doctoral research, I was interested to explore this further in the context of the literature on health evaluation. Whilst inclusive and collaborative methods have become more prominent in social research during the last two decades, they have developed more slowly within public health research (Frankena et al., 2015, 2019; Nind, 2014). I aspired to address this in my research, and therefore began by including an assessment of participatory methods used by the studies. This was included in a scoping review of the literature, published in the Journal of Applied Research in Intellectual Disabilities (Owens et al., 2020) and findings are presented in Chapter 3, section 3.3.
2.3.3 Research addressing the general public’s attitudes and behaviours regarding self-care, infection prevention and antibiotic use

The inappropriate use of antibiotics and corresponding spread of antibiotic resistance is an international health concern (World Health Organization, 2020) and a key priority for Public Health England (Public Health England, 2019). Research suggests continued misunderstanding of the subject (Hayes et al., 2021; McNulty et al., 2019) despite health promotion and education programmes aimed at the public.

Several national and local initiatives have aimed to address this concern and educate about purpose, behaviour, and consequence (Hayes et al., 2021; Eley and McNulty, 2017; Kesten et al., 2017; National Institute for Health and Care Excellence, 2017), more recently also associated with the spread of infections such as COVID-19 (Alexander et al., 2020). However, whilst there are evaluations in a broad context (Eley et al., 2018; Lecky et al., 2010), there is very little that specifically examines the impact of these initiatives on the decision making of adults with learning disabilities.

Some health concepts are difficult to convey to the general public and potentially even more so to people with cognitive impairments (Feldman et al., 2012). The concept of antibiotic resistance, for example, is challenging (Pinder et al., 2015). As research suggests, adults with learning disabilities bring different levels of understanding, abilities and motivations to a learning environment, and effective education needs to account for this (Scott and Havercamp, 2016; Bergström et al., 2014). However, previous systematic reviews of the literature on this topic suggest that studies are diverse, that they explore a range of health issues, and many have methodological weaknesses (Scott and Havercamp, 2016; Frankena et al., 2015; Gerber, 2012).

In a literature review and behavioural analysis of behaviour change and antibiotic use in healthcare settings, Pinder et al. (2015) stated that public understanding of appropriate antibiotic use was variable, and there was often a misunderstanding of antimicrobial resistance at the conceptual level. The authors’ behavioural analysis suggested that some people may therefore not possess adequate skills to cope appropriately with illnesses such as respiratory tract infections, common colds and urinary tract infections. For people
with reduced intellectual capacity, this may be even more difficult to conceptualise and to subsequently manage.

Although there is a growing body of literature that addresses the health status of, and support for people with learning disabilities, relatively little is known about their attitudes and health behaviours regarding self-care, infection prevention and antibiotic use. Recent literature addresses response to the COVID-19 pandemic (Amor et al., 2021; Alexander et al., 2020; Jeste et al., 2020), although studies focus on issues such as access to services, support and mortality rather than individual management or prevention of the disease.

Whilst there is little research that addresses the specific area of my study, there are some studies that focus on specific aspects of self-care such as oral hygiene, and there is a larger body of obesity and lifestyle studies that research broader health issues. Research into oral hygiene and access to dental services suggests that people with learning disabilities have more untreated decay and poorer oral care than the rest of the population. There is also evidence of poor access to oral healthcare services along with the existence of issues that inhibit access such as fear, ignorance and inappropriate health promotion and education (Ward et al., 2019; Wilson et al., 2019; Chadwick et al., 2018; Hartwig et al., 2017; Bernal, 2005). However, aside from Eley et al.’s (2018) pilot study and broader healthy lifestyle studies (Taggart et al., 2021; Owens et al., 2020; O’Leary, Taggart, et al., 2018; Scott and Havercamp, 2016; Robertson et al., 2015), to my knowledge there is no further evidence that specifically addresses learning about self-care, infection prevention and antibiotic use regarding adults with learning disabilities.

In 2018 Public Health England re-launched a campaign, *Keep Antibiotics Working*, to address public understanding about antibiotic use and the management of self-limiting infections. The campaign was aimed at adults, particularly those that are more likely to need, or are responsible for people who need, antibiotics. However, it is unclear whether the campaign promotion is accessible to people with learning disabilities.

Key concepts relating to self-care, infection prevention and antibiotic use are addressed by a community education programme entitled Beat the Bugs (Public Health England, n.d.) Beat the Bugs was launched in 2017 and is aimed at community members including
adults with learning disabilities. In an evaluation of this project, Eley et al. (2018) found an overall improvement in participant knowledge and behaviour change, including increased handwashing, teeth brushing and visits to the dentist. However, the pilot study was very small and did not address ways in which the course might have changed knowledge and/or behaviour nor did it generate detailed understanding of what was effective for course participants and how. The Public Health England Primary Care and Interventions Unit (PHE PCIU) decided to co-fund the present study in the expectation that it would address the identified gaps in knowledge about such interventions and, at the same time, support a doctoral researcher in achieving a PhD.

2.4 Educating adults with learning disabilities about infection prevention, self-care and antibiotic use: Beat the Bugs and Know Your Bugs

Know Your Bugs (KYB) is the final module of Beat the Bugs (https://e-bug.eu/beat-the-bugs/), a community health education course developed by Public Health England (PHE) and Kingfisher Treasure Seekers, an organisation supporting disadvantaged people in Gloucester. The course aims to increase awareness and change behaviour about self-care, infection prevention and antibiotic use. It was originally designed for community groups and disadvantaged adults, including people with learning disabilities. Beat the Bugs comprises six modules that can be delivered as a set or as standalone sessions. These are Meet the Bugs, Spreading Bugs, Food Bugs, Mouth Bugs, Bug Busters and Know Your Bugs. I provide further detail on course content in Appendix 2 and a description of the theoretical development of the course in Chapter 4.

After discussion with Public Health England Primary Care and Interventions Unit and my supervisory team, we agreed that my research would focus on the KYB module. There were several reasons for this. First, the module appeared to be particularly relevant in addressing the global concerns about poorer health and health inequalities experienced by learning disabled people; in this context it addressed how to self-care but also where to go for advice, what to ask and, how to access and utilise various healthcare resources. Secondly, as the last of the six modules, KYB aims to summarise learning throughout the course and look ahead to planning self-care strategies and understanding information sources. Due to time constraints of the PhD, it would not have been possible for me to
evaluate the whole course, and I therefore felt this would be an appropriate and useful reflection of a key aspect of Beat the Bugs in the light of my analysis of the literature and policy developments.

Figure 2.1 below provides an overview of the components of the development and delivery of the KYB component of the course in the context of my doctoral research.

Figure 2.1 Development and delivery overview of KYB in the context of this doctoral research

KYB aims to educate the public about using information to self-care at home and making effective health decisions, addressing important issues about health management and serious illness prevention. In particular, these include the role of effective health education in reducing health inequalities and supporting a need to take greater responsibility for hygiene, self-care and the use of medicines such as antibiotics.
The Beat the Bugs course guide outlines a range of activities that can be undertaken to achieve the overall KYB learning outcomes. KYB is usually the last of the six sessions and delivered in one half-day session, although it can be longer or shorter depending on the participant group. The suggested activities, along with intended learning outcomes, are outlined in Table 2.1

**Table 2.1 Know Your Bugs - suggested activities**

<table>
<thead>
<tr>
<th>Theme</th>
<th>Activity</th>
<th>Intended learning outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>Self-care at home/when and how to contact GP</td>
<td>Understand how to self-care at home when ill and when to go to the doctor</td>
</tr>
<tr>
<td>Activity 1</td>
<td>How to take antibiotics correctly</td>
<td>Understand how to use antibiotics appropriately</td>
</tr>
<tr>
<td>Activity 2</td>
<td>Accessing health information online</td>
<td>Understand where to access health information</td>
</tr>
<tr>
<td>Activity 3</td>
<td>Health information leaflets</td>
<td>Understand what information can be gained from healthcare leaflets and where to find them</td>
</tr>
<tr>
<td>Discussion</td>
<td>Discussion about health information</td>
<td>Understand how to access health information, and its advantages and potential problems</td>
</tr>
<tr>
<td>Antibiotics scenarios</td>
<td>Discussion-based scenario activity</td>
<td>Understand how to use antibiotics properly</td>
</tr>
<tr>
<td>Further discussion</td>
<td>Discussion about antibiotic use</td>
<td>Understand how to use antibiotics properly</td>
</tr>
</tbody>
</table>

Educators are not necessarily expected to cover everything in the guide; the guide suggests that activities should be selected, planned and adapted to meet the needs and abilities of individual participants and be delivered at a pace that suits them.
2.5 Chapter summary

Despite some initiatives to improve the health of adults with learning disabilities, there remain concerns about poor health and health inequalities, and these have been highlighted by the COVID-19 pandemic. There are still barriers to accessing effective health promotion, particularly in the context of education regarding self-care and infection prevention. These barriers are important because they can be gateways to further and more serious illnesses, and a starting point for learning about healthy behaviours.

Despite the continued difficulties experienced by adults with learning disabilities in enjoying a right to health and accessing public health support, there are some programmes that aim to enable them to live healthily. In the following chapter I review the research relating to these programmes, including the ways in which this research is conducted in collaboration with disabled people, with a view to understanding what might be effective in a health education context.
Chapter 3. What works in health education for adults with learning disabilities: A scoping review of the literature

In this chapter I review in depth the evaluation literature addressing community health education programmes aimed at adults with learning disabilities. My aim in conducting this review was to clarify what, according to the literature, were the components of an effective intervention in this context, and thereby provide further clarity and depth to my evaluation planning.

I chose a scoping review because it is typically more appropriate than a literature or systematic review in identifying key characteristics relating to a theme, establishing knowledge gaps or clarifying concepts (Munn et al., 2018; Peters et al., 2015; Levac et al., 2010). Due to time and resource constraints and questions about the quality of this literature I felt that a systematic review was not appropriate.

Research suggests that there is insufficient good quality information regarding the effectiveness of health education interventions (Taggart et al., 2021; Bergström et al., 2014; Naaldenberg et al., 2013). Earlier reviews of the literature have suggested that studies are diverse and many have methodological weaknesses (Scott and Havercamp, 2016; Frankena et al., 2015; Gerber, 2012). I anticipated that, by scoping this and the more recent literature in depth, I could clarify the concept of effectiveness in the context of my proposed research as well as identify useful characteristics and gaps relating to this body of literature.

Published in the Journal of Applied Research in Intellectual Disabilities (Owens et al., 2020), the scoping review addressed the following research questions:

- What are the components of effective community health education for adults with learning disabilities particularly in relation to self-care, infection prevention and the ongoing management of good health?
• What do we know about the effectiveness of inclusive and participatory research methods in evaluations of health education for adults with learning disabilities?

### 3.1 Review method

I used the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) extension for Scoping Reviews (Tricco et al., 2018) to guide this review. An initial review of the literature suggested that the papers relevant to the research topic were dispersed in terms of database location, methods and results. The search strategy (applied in February 2019) therefore involved searching 11 different bibliographic databases and sources of grey literature, citation tracking, and a manual search of reference lists from included articles.

A search of the Cochrane Database of Systematic Reviews and the Database of Abstracts of Reviews confirmed that there was no published systematic review of education/training evaluations for people with learning disabilities. Naaldenberg et al. (2013) focuses on health promotion but does not explore in depth the process of improving knowledge and behaviour. This is fundamental to the questions of the current review.

I selected the following databases for relevancy and scope: MEDLINE, PubMed, Social Care Online, Social Sciences Citation Index, Scopus, CINAHL, Cochrane Central Register of Randomised Controlled Trials (CENTRAL), TRIP (Turning Research into Practice) and PsychINFO. Additionally, a search of OpenGrey, EThos and Google provided links to unpublished studies, reports and national guidelines.

Keywords included the Boolean search terms: “learning disabilit*” OR “intellectual disabilit*” OR “developmental disabilit*” OR “mental retardation” AND “health” AND “training” OR “education” OR “promotion” AND “evaluation” OR “effectiveness” OR “intervention”. Figure 3.1 shows an example of a search.
Citation tracking and manual searching of reference lists enabled a search for additional papers that were excluded in the bibliographic search results. I included studies in the search if they:

- evaluated a health education, training or health promotion intervention for adults with learning disabilities aged 16+ that aimed to address a change in health behaviour;
- appeared as peer reviewed articles in academic databases published in the English language between database inception and January 2019. International studies were included if they were published in English; and
- included people with mild, moderate or profound learning disabilities. I also included papers with an additional focus on learning difficulties such as dyslexia, autism, and Asperger’s syndrome to ensure full coverage of potential components of effective health education.

Studies were excluded if they:

- focused on children (under 16 years);
- focused solely on caregivers, supporters or staff; or
• only used physical outcome measures.

A meta-analysis is often used for reviewing groups of intervention studies (Higgins and Green, 2011) and usually includes randomised controlled trials. The body of literature on health education relating to learning disability is not developed enough to conduct this type of analysis. This review therefore included non-randomised studies and, by using narrative synthesis, evaluated the evidence for each intervention individually.

Figure 3.2 Flow diagram of literature search
3.1.1 Data extraction and analysis

Figure 3.2 illustrates the search and selection process. Having identified appropriate articles for inclusion, I imported all included papers into QSR NVivo 11 for narrative synthesis of the literature (Popay et al., 2006). The research questions formed the basis of the analysis, and I analysed the whole of each paper. First, I identified text that addressed the research questions and therefore related to the delivery, experience and outcomes of the interventions undergoing evaluation. Secondly, I identified themes in this text inductively by reviewing findings in the studies that were relevant to the research questions. I conducted ongoing review and refinement of the analytic framework to ensure that earlier papers were further analysed in the light of new themes arising from subsequent articles. This thematic analysis enabled me to gain insight into the educational experience of participants as reported by the authors, and review in detail the context of the intervention and of the study results.

I also summarised data in a Microsoft Excel spreadsheet so that I could analyse the following: general study characteristics and evaluation results; intervention characteristics; quality assessment scores; and evaluation findings. I present this data in Table 3.1.

I repeated the searches in 2021, identifying a further 99 records. On reviewing eight potentially eligible articles, I excluded all because they did not meet my inclusion criteria.

3.1.2 Quality assessment

Scoping reviews are not required to include an element of critical appraisal (Munn et al., 2018; Peters et al., 2015; Levac et al., 2010). However, I chose to conduct a quality assessment of the studies I reviewed for several reasons: I thought it would provide a further element of objectivity to the review; I anticipated it would provide further insight into the characteristics of the studies I had included, and, as a researcher new to this method, I was keen to gain experience of critical appraisal in this context.
The Cochrane Centre acknowledges the difficulty in assessing the quality of public health and health promotion studies (Higgins and Green, 2011). This is largely due to the range of designs used and the complexity of appraising qualitative studies that often form part of such evaluations. As Higgins and Green (2011) suggest, appraisal criteria will depend on the type of study undergoing review. Since different types of study were included in this review, I used three methods of quality assessment:

**Eight criteria of quality assessment developed by Naaldenberg et al.** (2013) Using this method, I scored studies according to the following characteristics: clear description of aim(s) and research question(s); description and discussion of rationale for sample size chosen, research population, attrition rate and measurements used; discussion of study limitations; and description of intervention development and content. It is possible to assign a maximum of 16 points to each paper; two points per criteria if information was provided and elaborated, one point if marginal information was provided and discussion or elaboration was lacking, and zero points if no information was provided.

**The Quality Assessment Tool for Quantitative Studies** (Effective Public Health Practice Project, 2007). This tool was developed to appraise any quantitative study design and involves assessment of the following: question formulation; literature search and retrieval; identification of relevance criteria; assessment of literature for relevance and quality; data extraction and synthesis; peer review; and dissemination.

**Quality assessment of inclusive research methods using the questions posed by Nind and Vinha** (Nind and Vinha, 2012b). This includes 13 question areas including: Does the research involve people with learning disabilities in a meaningful and active way? Is the research communicated in a way that people with learning disabilities can understand and respond to? Are the research questions the kind that inclusive research can best answer? Were the ways of working carefully thought through and adapted in response to needs?
3.2 Results

3.2.1 Main study characteristics

Table 3.1 outlines the main characteristics of the 22 papers included in the review. The studies addressed a range of health areas including physical activity and diet; general health and health advocacy; women’s health; hygiene, infection prevention and oral health; and diabetes. Studies covered a range of different geographical areas: nine were conducted in the USA, seven in the UK, and the remainder geographically dispersed across the world. Programme participants represented a wide range of demographic characteristics.

Studies either used precise measurements to define learning disability (specifically IQ levels or performance on assessments), or they used broader inclusion criteria asserting that participants should be able to understand basic concepts around health and self-care to participate in the programme.

Sample sizes ranged from five to 198 participants. Eleven studies selected a sample of between 11 and 50 participants, four of between 51 and 100, and a further four studies had a sample size of over 100. One article did not specify the sample size. The differences in sample size reflect the diverse set of studies in this review.

Two papers about the same study authored by Dixon-Ibarra et al. (2017, 2018), two by Feldman et al. (2012, 2016) and two by Bergström et al. (2013, 2014) were included in the review because they presented different but relevant study characteristics, measures and findings.

Eleven programmes focused specifically on health education. The remainder included a health education component as part of a wider programme which also included behaviour change techniques. Sixteen papers described community settings, four a group home environment and two educational establishments. Most were small group interventions, although one programme (Wells et al., 2012) was delivered in one-to-one instructional sessions. Two programmes (Sandjojo et al., 2019; Feldman et al., 2016)
offered one-to-one additional support or booster sessions alongside group activity. Five of the interventions also included specific components for caregivers (Taggart et al., 2018; Dunkley et al., 2017; Hartwig et al., 2017; Witton et al., 2017; Bergström et al., 2013). One programme (Witton et al., 2017) used a peer-led approach, and another (Heller et al., 2004) involved one peer trainer working alongside other trainers.

Fourteen papers describe the application of learning or behavioural theory in the development of the programme. Theories included social cognitive theory, goal setting and diffusion theory, the transtheoretical model or a combination of several theories. Eight studies did not mention the use of theory in programme development and only three (Eley et al., 2018; Dixon-Ibarra et al., 2017; Marks et al., 2013) referred to theoretical underpinning in their analysis, albeit briefly.
### Table 3.1 Scoping review: Main study characteristics

<table>
<thead>
<tr>
<th>Authors</th>
<th>Study topic</th>
<th>Methodology</th>
<th>Sample size</th>
<th>Measurement of effectiveness</th>
<th>What worked</th>
<th>Quality assessment**</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical activity (PA) and nutrition studies:</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Bergström et al. (2013)</td>
<td>Diet and PA in group home setting. HE and BC*.</td>
<td>Cluster RCT; pre-, post- and follow-up.</td>
<td>139</td>
<td>Pre-, post and follow-up assessments - dietary quality (photos), physical measures, life satisfaction.</td>
<td>Positive effect on PA, work routines and waist circumference.</td>
<td>15</td>
</tr>
<tr>
<td>Bergström et al. (2014)</td>
<td>Diet and PA in group home setting. HE and BC*.</td>
<td>Qualitative component of above study.</td>
<td>83</td>
<td>Thematic identification of barriers and facilitators of effectiveness.</td>
<td>Created an individualised supporting context.</td>
<td>16</td>
</tr>
<tr>
<td>Dixon-Ibarra et al. (2017)</td>
<td>PA in group home setting. HE and BC*.</td>
<td>Formative and process evaluation; one month follow-up,</td>
<td>54</td>
<td>PA knowledge via questionnaire, PA via activity sheets, BMI and pedometer, use of training tools, behaviour risk questionnaire for staff.</td>
<td>Staff learned about delivery of the programme and how to motivate residents to enjoy PA.</td>
<td>12</td>
</tr>
<tr>
<td>Dixon-Ibarra et al. (2018)</td>
<td>PA in group home setting. HE and BC*.</td>
<td>Qualitative component of above study.</td>
<td>12</td>
<td>Thematic analysis of programme training, implementation, physical activity, barriers and facilitators.</td>
<td>Use of positive prompting or encouragement to facilitate enjoyment of PA. Ability to make choices and have materials.</td>
<td>16</td>
</tr>
<tr>
<td>Bodde et al. (2012)</td>
<td>Community PA scheme with education component. HE and BC*.</td>
<td>Formative &amp; process evaluation; short follow-up.</td>
<td>42</td>
<td>Assessment of knowledge gain. PA effectiveness assessed using accelerometer.</td>
<td>Knowledge gain and some PA.</td>
<td>15</td>
</tr>
<tr>
<td>Melville et al. (2015)</td>
<td>Community walking programme with education component. HE and BC*.</td>
<td>Cluster RCT; pre-, post- and follow-up.</td>
<td>102</td>
<td>Standardised assessment tools and measurements - physical, QoL, self-efficacy. Accelerometer to assess PA and questionnaire to assess self-reported PA.</td>
<td>Although feasible, programme was difficult to adapt and effectively implement. Importance of social support and need for further research. Programme provided choice, good self-esteem and confidence as well as physical health gains.</td>
<td>15</td>
</tr>
<tr>
<td>Authors</td>
<td>Study topic/setting</td>
<td>Methodology</td>
<td>Sample size</td>
<td>Measurement of effectiveness</td>
<td>What worked</td>
<td>Quality assessment**</td>
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<tr>
<td>Heller et al. (2004)</td>
<td>Community fitness and HE programme. HE and BC*</td>
<td>RCT; pre-, post- and follow up.</td>
<td>53</td>
<td>Scales of activity, cognitive-emotional barriers, exercise perceptions, community integration, depression, life satisfaction.</td>
<td>Programme developed more positive perception of the benefits of exercise.</td>
<td>16       Weak</td>
</tr>
<tr>
<td>Marks et al. (2013)</td>
<td>Community health programme. BC*</td>
<td>RCT; pre-, post- and follow up.</td>
<td>67</td>
<td>Standardised measures of psychosocial and physiological health status; knowledge and skills; and fitness level.</td>
<td>Improvements in knowledge and some fitness. Removed barriers by developing goals and targeting specific behaviours.</td>
<td>15       Weak</td>
</tr>
<tr>
<td></td>
<td><strong>General health and health advocacy studies:</strong></td>
<td></td>
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<tr>
<td>Sandjojo et al. (2019)</td>
<td>Community self-management. BC*</td>
<td>Cohort; pre-, post and follow-up.</td>
<td>17</td>
<td>Assessments of goal attainment, social functioning, work support needs and quality of life.</td>
<td>Intervention led to attainment of goals and decrease in support needs.</td>
<td>14       Strong</td>
</tr>
<tr>
<td>Feldman et al. (2016)</td>
<td>Health self-advocacy training. HE*</td>
<td>RCT; pre-, post and follow-up.</td>
<td>31</td>
<td>Scenario assessments, satisfaction questionnaire and health interview.</td>
<td>People with learning disabilities can learn generalised self-advocacy skills, training group outperformed control group.</td>
<td>15       Moderate</td>
</tr>
<tr>
<td>Feldman et al. (2012)</td>
<td>Health knowledge training programme. HE*</td>
<td>RCT; pre-, post and follow-up.</td>
<td>22</td>
<td>Health interview, satisfaction questionnaire.</td>
<td>Knowledge gain and retention.</td>
<td>15       Moderate</td>
</tr>
<tr>
<td>Codling (2015)</td>
<td>Community health knowledge and management programme. HE*</td>
<td>Unclear.</td>
<td>12</td>
<td>Assessment of knowledge gain.</td>
<td>Linking health to feelings enables people to better understand their health.</td>
<td>7        N/A</td>
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<tr>
<td></td>
<td><strong>Hygiene, infection prevention and oral health studies:</strong></td>
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<tr>
<td>Hartwig et al. (2017)</td>
<td>Oral health programme. Rehabilitation centre setting. HE and BC*</td>
<td>Quasi experimental with follow-up.</td>
<td>61</td>
<td>Gingivitis and debris measurement.</td>
<td>Dental debris and gingivitis scores reduced significantly within a short period.</td>
<td>15       Weak</td>
</tr>
<tr>
<td>Eley et al. (2018)</td>
<td>Community hygiene and self-care course. HE and BC*</td>
<td>Cohort; pre-, post- and follow-up.</td>
<td>7-9</td>
<td>Knowledge change, reported behaviour change and trainer views.</td>
<td>Increase in knowledge and some behavioural change (handwashing, teeth brushing).</td>
<td>14       Weak</td>
</tr>
<tr>
<td>Authors</td>
<td>Study topic</td>
<td>Methodology</td>
<td>Sample size</td>
<td>Measurement of effectiveness</td>
<td>What worked</td>
<td>Quality assessment**</td>
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<tr>
<td>Witton et al. (2017)</td>
<td>Peer dental ambassador programme. Community setting. HE and BC*</td>
<td>Cohort study; interviews. No follow-up.</td>
<td>Not specified.</td>
<td>Qualitative interviews and knowledge quiz.</td>
<td>Good acquisition of skills and knowledge. High levels of engagement due to positive course context.</td>
<td>7</td>
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<td></td>
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<td>N/A</td>
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<tr>
<td>Women's health studies:</td>
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<tr>
<td>Swaine et al. (2014)</td>
<td>Education on cervical and breast cancer screening. Community setting. HE*</td>
<td>RCT with follow-up.</td>
<td>198</td>
<td>Validated assessments via computer assisted interviews including National Core Indicators and the Socio-Sexual Knowledge and Assessment Tool-Revised. Both measures have been tested with adults with LD.</td>
<td>Positive response to the programme. Promoted independence and self-care.</td>
<td>16</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td>Moderate</td>
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<tr>
<td>Lunksy et al. (2003)</td>
<td>Women's health programme. University setting. HE and BC*</td>
<td>Cohort; pre-, post- and follow-up.</td>
<td>22</td>
<td>Results of interview addressing women's health knowledge, healthy behaviour beliefs, problem-solving and coping strategies regarding medical procedures.</td>
<td>Significant gains in health knowledge, gains in health beliefs and coping strategies.</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Weak</td>
</tr>
<tr>
<td>Parish et al. (2012)</td>
<td>Breast and cancer screening info programme. Community establishment setting. HE*</td>
<td>RCT; pre-post and follow-up.</td>
<td>170</td>
<td>Questions from various established instruments used to measure knowledge. Tested and refined standardised tools with two women with learning disabilities.</td>
<td>Moderate knowledge gain.</td>
<td>16</td>
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<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>Moderate</td>
</tr>
<tr>
<td>Authors</td>
<td>Study topic</td>
<td>Methodology</td>
<td>Sample size</td>
<td>Measurement of effectiveness</td>
<td>What worked</td>
<td>Quality assessment**</td>
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<tr>
<td><strong>Diabetes studies:</strong></td>
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<tr>
<td>Taggart et al. (2018)</td>
<td>Diabetes education programme. Community setting. HE*.</td>
<td>Pilot RCT with pre- and follow up. Also process evaluation</td>
<td>39</td>
<td>Standardised questionnaires administered by interview, focus groups. Educator reflection after each session</td>
<td>Reduced HbA1c, positive response to programme by participants and educators.</td>
<td>16 Weak</td>
</tr>
<tr>
<td>Dunkley et al. (2017)</td>
<td>Diabetes screening and education programme. Community setting. HE*.</td>
<td>Qualitative – two phases.</td>
<td>11</td>
<td>Qualitative themes.</td>
<td>Programme led to sense of understanding and achievement.</td>
<td>16 N/A</td>
</tr>
<tr>
<td><strong>Other studies:</strong></td>
<td></td>
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<td></td>
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<tr>
<td>Wells et al. (2012)</td>
<td>Computer education programme. Academic setting. HE*.</td>
<td>Quasi-experimental design; pre- and post- assessments but no follow-up.</td>
<td>46</td>
<td>Qualitative interviews and computerised assessments. Survey for staff.</td>
<td>Knowledge gain.</td>
<td>15 Weak</td>
</tr>
<tr>
<td>Clark et al. (2001)</td>
<td>Epilepsy education programme. Training centre setting. HE*.</td>
<td>Experimental design; pre-, post-, and follow-up.</td>
<td>18</td>
<td>Results of knowledge questionnaire (learning disability), EY-Checklist, evaluation questionnaire.</td>
<td>Knowledge gain.</td>
<td>12 Weak</td>
</tr>
</tbody>
</table>

* HE = health education; BC = behaviour change.
** Qualitative score: Naaldenberg et al. (2013). Quantitative score: EPHPP (2007)
Thirteen studies adopted an experimental design, and 10 of these conducted a randomised controlled trial. Two papers focused on a qualitative component of a wider experimental study. The remaining nine studies adopted various cohort designs, most of which included a pre-/post-/follow-up approach.

Five studies did not report a follow-up measurement of outcomes. The follow-up period of the remaining 17 studies varied considerably: five studies assessed outcomes up to one month after completion of the programme, and a further five contacted participants between one and six months after completion. Two studies contacted participants 12 months after completion of the programme.

The methods used to measure outcome within the studies included in this review are outlined briefly in Table 3.1. Most researchers used more than one outcome measure and a combination of standardised and specifically developed tools. One paper did not specify how it measured outcome. Measures used include knowledge gain, quality of life, psychosocial, reported behaviour change and measures specific to the topic of study, for example physical outcomes for physical activity studies.

These measures provided insight into the outcomes of the programmes evaluated. The quality assessment indicated that most outcome measurement tools were valid and reliable. However, sample sizes were small, and several researchers commented that further research was needed with larger samples. Most of these measures do not reflect the learning experience of the participant nor the ways in which the education was effective. For example, (Heller et al., 2004) found that a centre-based programme provided an appropriate learning context, changed attitudes towards exercise resulting in increased self-efficacy and improved life satisfaction. However, studies lacked detail on participants’ experience of the learning environment (internal and external to the programme) and the extent to which this influenced a change in behaviours.
3.2.2 Research quality

Overall, the quality of the research was mixed. The table presented in Appendix 1 entitled *Quality assessment of studies selected for scoping review* summarises the outcome of my quality assessment, and shows that only two studies rated as ‘strong’ on the The Quality Assessment Tool for Quantitative Studies (Effective Public Health Practice Project, 2007). Seven were ‘moderate’ and eight ‘weak’. Five studies were not appropriate for this measure because they used qualitative methods or did not provide sufficient information to assess adequately. Those that rated as moderate or weak often did not provide sufficient information relating to key assessment criteria and therefore scored as ‘can’t tell’ which equated to a weak rating. Studies that are not randomised controlled trials (RCTs) are also at a disadvantage on this assessment tool because they automatically score less due to the study design. A RCT is not always appropriate for evaluations with people with learning disabilities (Mulhall et al., 2018; Oliver et al., 2002) and assessment results should therefore be interpreted with caution.

Naaldenberg et al.’s (2013) assessment approach supports a more qualitative assessment of studies. Most performed well on this assessment; the average score was 13.9 out of a total of 16. Seven studies scored the maximum 16. The lowest score was seven.

No studies were excluded on the basis of quality. There are two reasons for this. First, even those that rated as weak on the quality assessment displayed some interesting methodological issues or relevant intervention development. Secondly, some papers performed well on Naaldenberg et al.’s (2013) assessment but not so well on the quantitative tool. These studies are included because of the qualitative component.

Many of the authors described limitations in their research, notably small sample sizes (Sandjojo et al., 2019; Dixon-Ibarra et al., 2017; Hartwig et al., 2017; Swaine et
Convenience samples were also often listed as a limitation of the studies included in this review because they could not guarantee generalisability. Several of the studies were feasibility or pilot studies (Eley et al., 2018; Taggart et al., 2018; Dunkley et al., 2017) and authors had plans to extend the scope of the evaluations. The issue of convenience sampling is also a strength of many studies because it enables us to establish what works for whom in what circumstances. This is particularly important with a potentially diverse group of people such as those that are learning disabled and may have different preferred learning styles and abilities.

A limitation of many studies in this review is the lack of long-term follow-up. Evidence suggests that people with learning disabilities learn best through continued reinforcement and repetition (Dunkley et al., 2017). None of the studies followed-up participants beyond a year and therefore evidence of longer-term effectiveness is not available. There is also little evidence in the papers about the process and experience of education from perspectives of the participants. I address this further in section 3.3 of this chapter.

Few of the studies included in this review involved people with learning disabilities in the research process. Involving the public in intervention design and evaluation helps to ensure validity, accuracy and appropriateness (INVOLVE, 2018; Walmsley et al., 2018). Taggart et al. (2018) developed a reference group of adults with learning disabilities with Type 2 diabetes. The group commented on the scales used for data collection and these were amended during the process to include pictures and symbols. Feldman et al. (2016) worked with a group of five self-advocates who reviewed initial research ideas and together agreed on the focus of the evaluation. The researchers adopted a ‘rights-based’ approach to the implementation of the programme although little further detail is provided regarding participation of people with learning disabilities on the evaluation.
3.2.3 The components of effective health education for adults with learning disabilities

All the studies reported some effectiveness, although the extent of this varied considerably. Reported outcomes of effective programmes included:

- Knowledge and skills gain
- Healthier behaviours (handwashing, toothbrushing, exercise, nutrition)
- Enjoyment of healthier behaviours
- Acquisition and application of skills to manage health more independently
- Reduction in specific support needs
- Better health (healthier teeth, healthier weight, increased fitness, general health)
- Feelings of self-efficacy and life satisfaction
- Development and use of coping strategies to address health issues

A purpose of this review is to generate an understanding of what works well in health education for adults with learning disabilities, particularly the ways in which health concepts are effectively conveyed and healthy behaviours subsequently adopted. Most of the studies in this review provided data on learning outcomes without reflecting on the process of education and learning that produced this outcome. It is therefore difficult to fully evaluate the education and its outcomes. However, the studies do provide some interesting information regarding components of effective health education. I grouped these into the realist concepts of mechanisms for education delivery, and the preferred contexts that accompany these mechanisms. This enabled me to incorporate the findings from this review within the realist evaluation framework that I describe in Chapter 5.

Table 3.2 presents the mechanisms which are divided into education planning and development, education delivery, and education follow up.
Table 3.2 Mechanisms of effective health education accessible to adults with learning disabilities

<table>
<thead>
<tr>
<th>Mechanism</th>
<th>Why/how it facilitates effective health education for adults with learning disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Education planning and development:</strong></td>
<td></td>
</tr>
<tr>
<td>Appropriate theoretical basis</td>
<td>Creates a sound basis for education programme development.</td>
</tr>
<tr>
<td>Built-in flexibility and adaptability of course</td>
<td>Support meeting of individual needs.</td>
</tr>
<tr>
<td>Participatory methods in course development</td>
<td>Ensure the education is appropriate and most likely to succeed.</td>
</tr>
<tr>
<td>Combination of accessible resources and techniques</td>
<td>Facilitate understanding, involvement and learning.</td>
</tr>
<tr>
<td>Goal setting and action planning</td>
<td>Are motivational and reinforce learning.</td>
</tr>
<tr>
<td>Integrated reinforcement and repetition</td>
<td>Embed learning and behaviour change.</td>
</tr>
<tr>
<td><strong>Education delivery:</strong></td>
<td></td>
</tr>
<tr>
<td>Involvement of supporters, caregivers and staff</td>
<td>Supports learning through motivation, reinforcement and practical input.</td>
</tr>
<tr>
<td>Motivational, sensitive and perceptive delivery</td>
<td>Participants enjoy learning and get the best out of it.</td>
</tr>
<tr>
<td>Appropriate methods and techniques of delivery</td>
<td>Support positive individual learning outcomes.</td>
</tr>
<tr>
<td>Course fidelity (but a need for flexibility too)</td>
<td>Ensures programme is delivered as planned.</td>
</tr>
<tr>
<td>Visual and interactive mechanisms (including tools to take away)</td>
<td>Generate interest, motivate and illustrate learning concepts. Opportunity to practice what is learnt.</td>
</tr>
<tr>
<td>Small group learning or one-to-one</td>
<td>Enable achievement of learning goals and reinforcement of behaviour change steps.</td>
</tr>
<tr>
<td><strong>Education follow-up:</strong></td>
<td></td>
</tr>
<tr>
<td>Long-term need to reinforce after learning sessions</td>
<td>Embeds learning and behaviour change.</td>
</tr>
</tbody>
</table>
The studies also highlighted the importance of achieving the right context for effective health education to encourage and reinforce learning. Table 3.3 illustrates the important components here which include a social and supportive learning environment, contextual adaptation appropriate to the course and participants, and opportunities for post learning support.

Table 3.3 Components of an effective learning context for adults with learning disabilities

<table>
<thead>
<tr>
<th>Context</th>
<th>Why/how context supports effective health education</th>
</tr>
</thead>
<tbody>
<tr>
<td>A positive physical environment – comfortable and opportunities for refreshment breaks.</td>
<td>Encourages a good frame of mind and physical comfort for learning.</td>
</tr>
<tr>
<td>A social and supportive learning environment.</td>
<td>Encourages a good frame of mind and mutual support for learning, sharing ideas and asking questions.</td>
</tr>
<tr>
<td>Opportunity to practice autonomy but also access appropriate levels of support.</td>
<td>Meets the needs of individuals.</td>
</tr>
<tr>
<td>Participatory and interactive ethos but not intimidating.</td>
<td>Enhances learning by encouraging debate and input of ideas.</td>
</tr>
<tr>
<td>Contextual adaptation appropriate to the course and to the participants – understanding of each participant’s personal context and learning needs.</td>
<td>Enhances learning at an individual level.</td>
</tr>
<tr>
<td>Accessibility (physically, mentally and in terms of resources and materials).</td>
<td>Ensures physical needs are met, supports well-being and appropriate learning.</td>
</tr>
<tr>
<td>Opportunities for post-learning support and reinforcement of learning.</td>
<td>Embeds learning and behaviour change.</td>
</tr>
</tbody>
</table>
3.3 What works well in community health education for adults with learning disabilities

To recap, this review aimed to address two key questions in relation to community health education for adults with learning disabilities:

- What are the components of effective community health education for adults with learning disabilities particularly in relation to self-care, infection prevention and the ongoing management of good health?

- What do we know about the effectiveness of inclusive and participatory research methods in evaluations of health education for adults with learning disabilities?

Here I answer these questions by describing the effective components identified within the literature in terms of mechanisms, contexts and middle range theory. I do so in order to provide a foundation for my doctoral realist evaluation by using realist terminology and concepts to describe the initial middle range theory of the module. As I will discuss later in this thesis, particularly in Chapter 5, section 5.8.3, there is much debate in the literature about defining mechanisms, contexts and middle range theory. There are no widely agreed definitions as such, although I was guided by methodological and review papers (Emmel et al., 2018; The RAMESES II Project, 2017a; Dalkin et al., 2015; Lacouture et al., 2015; Pawson, 2013; Byng et al., 2005). I adapted suggestions in this literature to form the following concepts as a guide:

- *Context* = actors or factors that are external to the intervention

- *Mechanism* = reasoning and reactions of human agents; behaviour and interrelationships; responses to an event within the system that are responsible for change
• Middle range theory = a realist evaluation concept that broadly describes the ways in which programmes are, or are not, effective, and is described in further depth in Chapter 4, section 4.1.4.

3.3.1 Mechanisms for effective health education accessible to adults with learning disabilities

Table 3.2 outlines the mechanisms that I identified in the literature as generating outcomes for study participants within specified contexts. There were 13 mechanisms in total, and I grouped these into those that operated within education planning and development, education delivery, and education follow-up.

3.3.1.1 Education planning and development

Cognitive models are recognised as being important for education and behaviour change interventions (Naaldenberg et al., 2013). Many of the health education programmes in this review were developed using learning or cognitive development theories. However, most authors did not refer to theoretical underpinnings in the analysis of results, and it is therefore difficult to determine the role of theory in the evaluation of these studies. It is possible to make some inferences, however. For example, the activity programme in Heller et al. (2004), was based on a social learning model. Group activities were reported to be enjoyable. Relating health to participants’ feelings led to better understanding of their health conditions and the implication was that a social model could support health learning in this context.

The literature suggests that an effective health education programme for adults with learning disabilities needs to be either specifically developed or carefully adapted to meet learning needs (Taggart et al., 2018; Witton et al., 2017; Heller et al., 2004). Most of the programmes were specifically developed to address the needs of adults with learning disabilities although some were adapted from existing
programmes aimed at a wider population. Adaptations included accessible resources such as easy read materials, videos and scenario-based role playing.

Flexibility is also required in terms of both the learning and the support environment. Witton, Potterton and Smith (2017) and Taggart et al. (2018) identified the importance of delivery and timing of sessions to meet individual concentration levels and learning needs. In these programmes the adaptation of resources, structure, curriculum, length of sessions and use of health action plans were effective. The health self-management training programme evaluated by Sandjojo et al. (2019) focussed on addressing individual needs through flexible support regarding the transfer of learned skills to daily life. This was a relatively intensive programme that involved on average two trainers guiding four participants. However, it was effective in decreasing support needs and attaining self-management goals. In fact adaptation helped to illustrate reasons why the ‘Walk Well’ programme (Melville et al., 2015) was not effective; challenges in adapting complex behaviour change interventions for adults with learning disabilities partially explained the lack of effectiveness of the programme.

Several papers referred to the importance of working with people with learning disabilities on the development and adaptation of the educational intervention (Taggart et al., 2018; Dixon-Ibarra et al., 2017; Dunkley et al., 2017; Bergström et al., 2013; Bodde et al., 2012; Feldman et al., 2012). In this context participatory methods can facilitate the development of accessible and appropriate resources.

Dixon-Ibarra et al. (2017) described stakeholder involvement in the development and implementation of the programme but to a lesser extent in the evaluation. The researchers worked with an advisory group to obtain community feedback regarding barriers, facilitators and critical feedback for the programme design. In Bodde et al. (2012), people with learning disabilities met twice, piloted two lessons and commented on the readability of visual materials. They were involved in the second draft of curriculum development and developing the process measures for the evaluation. Staff in Bergström et al. (2013) also tried to involve participants in
planning content although the success of this varied. Codling (2015) briefly described working with a steering group of eight people to discuss course development, including one with learning disabilities and one carer.

3.3.1.2 Education delivery

Goal setting enabled participants to remove or remediate barriers such as lack of support, motivation, and access. Witton et al. (2017), Eley et al. (2018), Taggart et al. (2018) and Sandjojo et al. (2019) found that setting, monitoring and reporting on goals could be motivational and could enhance learning. For example, Eley et al. (2018) reported that action planning to pledge behaviour change supported an increase in appropriate health behaviours such as handwashing and tooth-brushing behaviour. Sandjojo et al. (2019) reported that conducting goal setting alongside training contributed to attainment of goals regarding self-management. However, the participants in Melville et al.’s (2015) study experienced difficulties conceptualising and adhering to self-monitoring and goal setting. The authors suggested this was partially because the behaviour change techniques that were used did not support these activities.

Learning reinforcement mechanisms such as certificates of attendance or completion (Eley et al., 2018; Dunkley et al., 2017), action planning and goal setting (Sandjojo et al., 2019; Eley et al., 2018; Dunkley et al., 2017), self-monitoring opportunities and activities such as diary-keeping (Dunkley et al., 2017) were effective in supporting knowledge retention and behaviour change. Use of repetition and recapping on sessions was also effectively applied (Eley et al., 2018; Dunkley et al., 2017; Feldman et al., 2016). Hartwig et al. (2017) maintained weekly motivation to ensure oral hygiene was part of daily routines in four sequential sessions. Witton et al. (2017) found that regular demonstration and repetition enabled people with learning disabilities to brush their own teeth appropriately and therefore supported independent oral hygiene practice.
Effective means of delivery included small group sessions, one-to-one support, a computer assisted learning approach, and various combinations of taught sessions with additional individual support. The programme evaluated by Wells et al. (2012) used a computer programme to teach about HIV/AIDS concepts. The authors concluded that teaching HIV/AIDS concepts via interactive technology was effective because it was not dependent on literacy levels and could be undertaken in different locations and environments. After this programme, participants’ knowledge and avoidance skills improved. Feldman et al.’s (2016) sample learned health self-advocacy skills through small group training that used PowerPoint slides, interactive videos and games. Dixon-Ibarra et al. (2017) found that visual and interactive mechanisms such as video games, pictures, and role play in small group learning sessions (three to four people) with optional one-to-one support was effective. Tools to take away, including diaries and homework, were also effective in embedding learning because they provided the opportunity to practise what was learnt.

Some health topics may need a more specific approach. Whilst role play worked well for participants in Lunsky et al.’s (2003) study of a women’s health education programme, Swaine et al. (2014) found that some concepts taught in education of breast and cervical cancer screening were not appropriate for role play. Instead, a ‘Building Skills’ activity worked better which involved scenario-based questioning. Lunksy et al. (2003) suggested that role play would not suit women with profound and multiple disabilities and staff intervention combined with small group or individual therapy would be more appropriate.

Many of the papers in this review illustrated that a combination of resources such as videos, pictorial instructions, worksheets, role-play, games and other interactive activities could increase health knowledge gain (Sandjojo et al., 2019; Dunkley et al., 2017; Feldman et al., 2016; Swaine et al., 2014; Bodde et al., 2012). Dunkley et al. (2017) used multiple practical and participatory methods including models, images, visual memory aids, bingo and story-telling along with regular breaks. The educators also used materials developed by the participants themselves to support
behavioural and lifestyle changes. They found these effective although also established that it was important not to overwhelm with too many resources.

The literature suggests that a motivational educator, interactive sessions, and a comfortable and safe learning environment can lead to high levels of engagement and enjoyment and contribute to good acquisition of skill and knowledge. The programme evaluated by Dixon-Ibarra et al. (2017) included a focus on personal choice and enabled participants to develop and use their own materials. In this context, motivational learning/interviewing was effective both in terms of an educational technique and utilising a good educator who engaged well with participants. In Dunkley et al.’s (2017) programme, educators identified challenges and motivated participants to make behavioural changes.

In the programme studied by Sandjojo et al. (2019) facilitators ensured that each participant’s training was tailored to their abilities and preferences. They achieved this by continuously consulting with participants about how they would like to be trained. For example, if a participant was unable to read, the training was presented more orally or visually with demonstrations, role-play or video material.

Heller et al. (2004) and Witton et al. (2017) included a peer approach to learning in their programmes. Peers were considered effective because participants could relate to them. In this context, Witton et al. (2017) described high levels of engagement and enjoyment and good acquisition of skills and knowledge.

The extent to which caregivers and supporters are effective facilitators in health education for people with learning disabilities can vary considerably. Some studies reported they had a positive effect on acquiring and embedding learning (Sandjojo et al., 2019; Dunkley et al., 2017; Hartwig et al., 2017; Bergström et al., 2013). Dunkley et al. (2017) found that care workers had a key role in helping to motivate and support participants to make and sustain changes to their diet and physical activity. Hartwig et al. (2017) reported that targeting caregivers could be a successful strategy to improve oral health.
However, supporters can also impede progress. Course leaders in Bergström et al. (2013) suggested that a course without caregivers’ presence provided an opportunity for the participants to increase autonomy. The authors identified several instances where caregivers did not support participants in the programme. They suggested that more frequent communication about how best to support participants would have improved this. Bergström et al. (2013) also suggested that good collaboration with caregivers was important however. This is also illustrated by findings in Dixon-Ibarra et al. (2017). Here the authors refer to the importance of obtaining ‘buy-in’ from staff and caregivers and suggested this was critical for behaviour change in the context of the programme they evaluated. Achieving this is often difficult, however. Lunsky et al. (2003) found that support workers offered an opportunity to support and embed learning but there were often challenges regarding regular staff turnover and shift work.

It appears that with commitment, good communication and an appropriate programme it is possible to achieve a good balance between participant support and autonomy. For example, Marks et al. (2013) reported on the unique role of staff in a train the trainer model to improve health and health behaviours of people with learning disabilities. Trained staff worked closely with participants to support them in developing goals, targeting specific behaviours and improving knowledge, skills and fitness. The evaluation showed significant improvements in psychosocial and physiological health status and an increase in healthy behaviours.

Fidelity is the extent to which a course is delivered as planned and adheres to its theory. In the context of health education, it is important because it enables consistent delivery as well as understanding of the causal mechanisms regarding behaviour change. Several of the studies identified fidelity as important in supporting a consistent and effective programme (Taggart et al., 2018; Dixon-Ibarra et al., 2017; Hartwig et al., 2017; Feldman et al., 2016; Marks et al., 2013; Bodde et al., 2012; Parish et al., 2012).
3.3.1.3 Education follow-up

Educational follow-up can provide an opportunity for longer term reinforcement and embedding of learning (Taggart et al., 2018; Dunkley et al., 2017). Most of the interventions evaluated within this review only included follow-up for research purposes and there was little evidence of longer-term educational follow-up.

3.3.2 Contexts for effective health education accessible to adults with learning disabilities

The contexts within which the identified mechanisms operated were more succinct and provided a framework within which the mechanisms could operate. Outlined in Table 3.3, there were fewer contexts than mechanisms although they were important in showing the circumstances in which mechanisms operate. Contexts incorporated personal, social, collaborative, physical and external components. The literature showed that a participant’s personal context affects the knowledge, experience and motivation they bring to a learning environment (Bergström et al., 2014). Additionally, the learning environment provides context that influences participants’ experience (Bergström et al., 2014; Bodde et al., 2012). In a study of barriers and facilitators in health education for adults with learning disabilities, Bergström et al. (2014) found that support from within and outside the formal learning environment was important, and supportive post education context was subsequently crucial in embedding learning. In this respect, context can also support the reinforcement of learning and behaviour change.

Individual motivations and abilities are another important contextual component of successful learning, and this is reflected in learning theory used by some of the programmes in this review. Several studies suggested that the motivations, abilities and interests of participants can all affect learning outcomes (Dixon-Ibarra et al., 2017, 2018; Witton et al., 2017; Bergström et al., 2013). In a review of a dental ambassador programme, Witton et al. (2017) concluded that it was critical to
design a programme that was realistic about the abilities and skills of the participants and could account for diverse needs.

Heller et al. (2004) and Witton et al. (2017) described the importance of a comfortable and safe learning environment, an ethos of participation, collaborative working and enjoyment as important components of health education for people with learning disabilities. These generated high levels of engagement and subsequent acquisition of knowledge and skills. Additionally, familiarity and consistency was found to support effective learning (Dunkley et al., 2017). Dunkley et al. (2017) found that combining use of the same venue with a core group of educators ensured continuity and developed rapport. The authors suggested that educators should also gain an understanding of each participant prior to starting a course. This enables familiarisation and development of plans to meet individual needs. It also enables the establishment of mutually agreed guidelines to support group functioning.

3.3.3 The extent and effectiveness of inclusive or participatory methods in evaluations of health education for adults with learning disabilities

Few of the studies included in this review involved adults with learning disabilities in the research process. Those that did, tended to use a group approach to shared participation. Taggart et al. (2018) developed a reference group of adults with learning disabilities with Type 2 diabetes. The group commented on the scales used for data collection and these were amended during the process to include pictures and symbols. Feldman et al. (2016) worked with a group of five self-advocates who reviewed initial research ideas and together agreed on the focus of the evaluation.

Dixon-Ibarra et al. (2017) worked with an advisory group to obtain community feedback regarding barriers, facilitators and critical feedback for the programme design. In Bodde et al.’s (2012) study, adults with learning disabilities met twice, piloted two lessons and commented on the readability of visual materials. They
were involved in the second draft of curriculum development and developing the process measures for the evaluation.

There is limited evidence however of inclusive or participatory approaches in these studies. Those that have used such approaches have done so in only specific aspects of their research and did not reflect extensively on this process.

### 3.4 Chapter summary

Although the range of studies in this review is broad, authors made similar conclusions regarding the components of effective health education. Important components included fidelity alongside flexibility of delivery, accessibility of materials, and a supportive and motivational learning context. The means of measuring the effectiveness of these components varied considerably however, and the focus tended to be on outcome evaluation. Whilst the studies included in this review described some components of effectiveness, few explored engagement with the learning experience of participants and the effect this had on outcomes. I concluded that further research was needed to understand the learning context as experienced by people with learning disabilities, particularly the education environment, the personal context of course participants and how this relates to their learning outcomes and potential behaviour change.

In this review, only Eley et al.’s (2018) pilot study addressed the substantive issues of self-care, infection prevention and antibiotic use. In order to ensure adults with learning disabilities can understand and address these concepts more evidence is needed on the effectiveness of health education in improving knowledge and behaviour in this respect. This includes evidence on whether such programmes work in the short, medium, and longer term and on the development of appropriate outcome measures.

There are many approaches to evaluating health education and training. In conducting this scoping review, I have explored the models and findings of those in
the literature that are most relevant to my doctoral research. This review has identified three key gaps in the literature that address a need for further research to enhance understanding of community health education that is accessible to adults with learning disabilities. These include a need for better understanding of:

- **the community learning experience of adults with learning disabilities.** Whilst the studies included in this review described some components of effectiveness and outcomes, none really engaged with the learning experience of participants. This review has thus identified a gap in knowledge in the effectiveness of the learning context as experienced by adults with learning disabilities, particularly the education environment, the personal context of course participants and how this relates to their learning outcomes and behaviour change. In addressing this gap, it would be possible to understand more effectively what it is about people and programmes that enable effective outcomes, and thus to develop appropriate means of supporting good management of health.

- **the effectiveness of infection prevention education programmes in the context of learning disability and how to measure it.** In order to ensure adults with learning disabilities can understand and address the concepts of self-care, infection prevention and antibiotic use, more evidence is needed on the effectiveness of health education in improving knowledge and behaviour in this respect. This includes evidence on whether such programmes work in the short, medium and longer term and on the development of appropriate outcome measures.

- **how collaborative, inclusive or participatory research methods with adults with learning disabilities can shape good quality health education evaluation.** Inclusive and participatory research methods are used more frequently in public health studies. However, there is little detailed evaluation of what is effective in this context.
This scoping review has enabled me to identify some important components of effective community health education in the context of learning disability that are present in the literature, and to understand the limitations of existing evidence. In doing so, this led me to the next stage of my research; the development of initial middle range theory, clarification of research questions and subsequent development of research methodology. I describe and justify my approach to achieving this in depth in chapters 4 and 5. However, in concluding my scoping review, I felt it was useful to present here the initial middle range theory (RAMESES II Project, 2017; Pawson and Tilley, 1997) that emerged from this review.

Described in more depth with programme theory in Chapter 4, section 4.1.4, middle range theory is one of the fundamental underlying components of a realist evaluation. As such, it is an abstraction of programme theory, and provides a broad description of the components of an effective programme and the ways in which they interact. The design of realist evaluations often begins with the development of a programme theory and initial middle range theory to form a basis for empirical investigation of the programme. Middle range theory is understood as the theory of the programme (Pawson and Tilley, 1997) and, regarding my research, represents an initial theory of the components of an effective module.

My initial middle range theory, illustrated in Figure 3.3 and referred to as MRT1, suggests that effective outcomes would be generated by a positive social learning environment that was flexible and aligned accessibly with individual needs. The components that support this include personal, social, environment, collaborative and active contexts, and the following mechanisms that interact with these contexts to trigger positive learning outcomes: visual and interactive mechanisms, accessible teaching methods and techniques, an effective educator, small group or one-to-one learning, course fidelity alongside flexibility, and appropriate involvement of supporters.
In the following chapter I explore the practical, methodological, and theoretical issues I considered in progressing from this middle range theory to developing a comprehensive realist evaluation framework in the context of Know Your Bugs.
Chapter 4. Perspectives on evaluation methodology

This chapter describes and discusses the theoretical and practical approaches to evaluation that I considered were relevant to the development of my research design. As such, it sets the methodological context for my research and provides relevant background to the realist evaluation which is presented in depth in Chapter 5.

At the outset, as a lone researcher with a potentially broad brief, I was conscious of the potential challenges in ensuring that my research was appropriate, achievable and matched the aspirations of my funders and myself. I therefore made many methodological considerations. These included considerations about the type of evaluation I would undertake, about ethical and methodological issues in researching with adults with learning disabilities, and practical considerations about what was feasible within the resource constraints of a PhD.

In this chapter I discuss these considerations. I begin by presenting the theoretical perspectives that are relevant to my chosen philosophy; realism and explore the other theoretical frameworks that are relevant to KYB. In this context, there are several components to theory: the theories that informed the development of KYB; and the theoretical frameworks relevant to the evaluation. I will describe each individually, subsequently summarising how they fit together, and influenced my research design.

4.1 Theoretical perspectives

The term ‘theory’ can have different meanings in the context of intervention evaluation. The RAMESES Project II (RAMESES II Project, 2017) succinctly summarises four different aspects of theory that can be relevant to programme development and evaluation: philosophical theory; formal theory relating to a discipline, programme theory; and evaluation theory. I found it useful to adapt this summary in the context of KYB, and Figure 4.1 illustrates the four different ‘types’ of theory in the construction, delivery and evaluation of the module.
4.1.1 **Formal theory: The complex theoretical underpinnings of Know Your Bugs**

The design of Beat the Bugs, and therefore KYB, was informed by learning and behavioural theories, and subsequent development and testing of methods of course delivery. In the context of health, learning and behavioural theories provide a framework for understanding behaviours, and designing, implementing, and evaluating interventions (Astbury, 2018; Michie et al., 2018; Taggart et al., 2021). By relating evaluation findings to the theoretical basis of an intervention it is possible to refine and improve theory objectively and better understand the ways in which an intervention can work. Here I briefly describe the theories that I will later explore in my analysis of KYB outcomes.

Several theories underpinned the development of KYB, including social learning theories (Fleming and Mills, 1992; Kolb and Fry, 1975; Pask, 1975) and behaviour change theories (University of Southampton, 2020; Kesten et al., 2017; Ajzen, 1991). It is important to consider these theories within the evaluation to understand their influence on the
intervention, and potentially make conclusions about appropriateness and further theoretical development. As I have discussed in Chapter 3, many evaluations have not addressed this, and this represents an important gap in knowledge about the theoretical development of health education programmes. Realist evaluation offers an effective approach in this context because it supports explanatory theoretical development, incorporating as many relevant explanatory theories as considered appropriate.

People approach learning in different ways and there are many theories of learning (Kearsley, 2010). Preferred learning styles may also change as learners develop and are not mutually exclusive (Lecky et al., 2011). Discussions with the course developers and review of Beat the Bugs course and published literature, clarified that the development of Beat the Bugs was thus informed by the following different learning theories:

- **Conversation theory** (Pask, 1975) - lesson plans were developed in accordance with Pask theory of conversation learning (Lecky et al., 2011); that learning occurs through topic discussion, and topics should be presented in a structured manner (learning objectives, introduction, plenary).

- **Visual, Audio and Kinaesthetic learning** (Fleming and Mills, 1992) - Visual, Audio and Kinaesthetic Learning (VAK or VARK - [www.vark-learn.com](http://www.vark-learn.com)) focuses on three broad styles of learning: visual, auditory and kinaesthetic. People usually favour at least one of these styles although the authors agree that learning styles are not mutually exclusive and can change over time. Beat the Bugs incorporates VARK learning in all its design (Lecky et al., 2011) through the use of posters, videos, visual and interactive activities.

- **Kolb and Fry’s learning styles** (Kolb and Fry, 1975) - the learning theory of Kolb and Fry (1975) advocates that learning styles are those of observers, thinkers, deciders and doers (Lecky et al., 2011). Beat the Bugs incorporates this in its design by enabling learners to observe, consider, and participate in activities.
The design of Beat the Bugs activities also incorporated behaviour change components. Use of action planning and health behavioural pledges regarding hand hygiene and antibiotic use including Germ Defence (University of Southampton, 2020) and Antibiotic Guardian (Kesten et al., 2017) have shown to increase knowledge and influence behaviour. These were included in Beat the Bugs to address a potential intention-behaviour gap regarding hygiene, self-care and antibiotic use by supporting individuals to translate their health intentions into behavioural action. Additionally, The Managing Your Infection (MYI) leaflet, a key resource in KYB, was developed using the Theory of Planned Behaviour constructs (Ajzen, 1991) which were applied in the following ways (Eley et al., 2018):

- **Behaviour attitude** - by providing the public with an understanding of how to self-care without using antibiotics the leaflet aims to change attitudes towards using self-care now and in the future.

- **Subjective norms** - by understanding usual illness durations the public should gain an appreciation of what they can expect from their own illness.

- **Perceived behavioural control** - educating the public on which serious symptoms to look out for, when to re-consult and where to get further help, aims to reduce any perceived barriers, and enable learners to have a sense of autonomy over their illness.

The Behavioural Change Technique Taxonomy (Michie et al., 2013) and the EAST Framework (Service et al., 2014) were also used to develop a checklist and instructions for behaviour change regarding the Managing Your Infection (MYI) leaflet. The Behavioural Change Technique Taxonomy (Michie et al., 2013) comprises 93 hierarchically clustered behaviour change techniques that can be used to support the development and analysis of interventions. The EAST Framework (Service et al., 2014) proposes four principles for applying behavioural insights, stipulating that they should be: easy, attractive, social and timely. The four main behavioural steps that were consequently incorporated into the leaflet are: how to help make yourself better; check how long your symptoms last; look out for serious symptoms; and where to get help (Eley et al., 2018).
The Public Health England Primary Care and Interventions Unit (PHE PCIU) subsequently used COM-B (Michie et al., 2013) to identify areas where capability, opportunity and motivation may influence behaviours reinforced through learning during the course. COM-B is a model that is frequently used to explore behaviour in contexts such as these and I describe it in further detail in this chapter, section 4.1.3.3. In using this model in unpublished work (Public Health England PCIU, 2019), the PHE PCIU concluded that the course could equip participants with capability to gain knowledge and skills regarding microbes, self-care and infection; could promote opportunity to learn and practise appropriate behaviours; and could enhance motivation to enact desired behaviours and retain knowledge.

4.1.2 Philosophy: Realism ontology and epistemology

Different schools of philosophy have different perspectives about the nature of the world (ontology) and an understanding of knowledge in relation to it (epistemology). In this context, realism is a methodological orientation grounded in the philosophy of science and social science (Bhaskar, 1975), and suggests a logic of investigation that broadly sits between positivism and constructivism (The RAMESES II Project, 2017b).

Realism suggests that there is a world within which people interact and construct meaning. Whilst theories, concepts and perspectives may generate a valid understanding of phenomena, they cannot and do not exhaust it. This is because knowledge is contextual and partial, and there is always a possibility of the existence of alternative explanations. For example, people experience health differently; they address different health issues and utilise different support systems in doing so (such as health professionals, family, and friends, and/or local sources of information). They therefore potentially have different health education needs and bring different experiences to an education environment. Thus, a theory of effective health education will generate an understanding of the subject, but it will not be definitive because contextual experience is diverse.

Consequently, realist ontology views human action and understanding as non-linear. It is understood in terms of its location within different layers of social reality and attempts to
understand this by focusing on causation. Realism thus encapsulates a number of different stances; it advocates that knowledge of the world is always relative to who we are and that an objective reality can be explained by the concept of agency (“the how”) (Pawson, 2002).

In realism ontology, reality is stratified into three levels: the empirical (the realm of events as we experience them); the actual (where there is no filter of human experience); and the real (where causal structures exist). Realism aims to explain social events through reference to these causal mechanisms and, in doing so, develop recommendations for action. There are broadly two strands of realism; critical realism (Bhaskar, 1975); and empirical or scientific realism (Pawson, 2006). The difference between the two relates to their explanatory perceptions of open systems. Critical realism assumes that there will always be an excess of explanatory possibilities but that some are likely to be mistaken. Scientific realism also assumes that there are many explanatory possibilities. However, it advocates that a researcher should aim to decide between alternative explanations of causation and accept that there may be additional explanations that are not identified. In doing so, it is therefore necessary to undertake clear critical comparisons of potential explanations and patterns. It is this that underpins realist evaluation.

Epistemologically, realism focuses on causation. It stipulates that what can be known about a programme is not definitive, although acknowledges that both the material and the social worlds are ‘real’ and can have ‘real’ effects. For example, with respect to healthcare evaluation, there could be many reasons why an education programme leads to enhanced and retained knowledge; these might include the influence of pre-existing personal contexts of an individual, their preferred approaches to learning, and the opportunities that enable them to utilise their knowledge afterwards. In the context of evaluation, there may be many variations of these contexts that are not present in the evaluation environment.

Realism thus advocates that both the natural and social worlds are independent of, and interdependent with, our understanding of them. For realists, natural and social systems exist and exert their own powers, although people interact with them differently and make different judgements and decisions in relation to them. Therefore, people can
affect and be affected by them. Relevant enquiry and observations are therefore shaped by the human brain and there is no such thing as ultimate truth or knowledge. Instead, empirical research aims to explore and explain the different aspects of causation within a system, accepting that there may always be alternative explanations addressing how a programme may be effective.

Realism recognises all social systems as open systems with flexible boundaries (Brousselle and Buregeya, 2018; Pawson, 2013). In this sense, resources can interchange and move across these boundaries, and different social systems can interact and influence each other. Any outcome observed will be result of interactions within and across those systems, but evaluation will only ever be able to show that a programme or policy contributed to an outcome in that setting. Therefore, realism epistemology focuses on understanding the nature of contexts that support the generation of mechanisms that together generate an outcome.

4.1.3 Evaluation theory

Evaluation is the systematic collection, analysis and reporting of information relating to an activity in order to understand its effectiveness. Effective evaluation can achieve many things. It can explore what works and in which ways; it can support understanding and assess the impact of resource allocation; and it can provide contextual information about the effectiveness of an activity including causal effects and prevalence of issues (Shaw et al., 2006). Theory-based evaluation is usually based on an explicit theory of change (Astbury, 2018; Brousselle and Buregeya, 2018; De Silva et al., 2014; Pawson and Tilley, 1997), and is used to enable an effective understanding of complex programmes. My doctoral research aimed to use theory-based evaluation to understand the learning environment of a community health education module, Know Your Bugs (KYB), and the ways in which it influenced outcomes for participants.

There are different approaches to theory-based evaluation (Qian, 2018; The RAMESES II Project, 2017b; Moore et al., 2015; De Silva et al., 2014; Oliver et al., 2002; Pawson and Tilley, 1997). Authors often cite logic analysis, contribution analysis and realist evaluation as examples (Brousselle and Buregeya, 2018), and some researchers have used, or
suggest using, a combination of these approaches depending on the research question (Taggart et al., 2021; Westhorp, 2008). The diversity within the evaluation literature addressing community education and learning disability is described in Chapter 3, and Table 3.1 provides examples of the range of studies and strengths of some different methods. Potential approaches included impact/outcome evaluation, process evaluation, economic evaluation, experimental evaluation, and realist evaluation. Some designs also include combinations of these approaches. These approaches are underpinned by different philosophical and theoretical perspectives, and an analysis of the evaluation literature and consideration of the aims and scope of the research led me to choose a realist approach to this evaluation. I felt this would best answer my research questions and address some of the gaps in knowledge about interactions within a learning environment such as KYB.

4.1.3.1 Realist evaluation

As a logic of investigation that is grounded in philosophy of science with its own specific set of assumptions (Westhorp, 2018), realism offers a comprehensive philosophy of science that underpins realist evaluation. It can inform a general methodological framework for research but is not associated with any specific set of methods (Marchal et al., 2018; Astbury, 2013; Pawson and Tilley, 1997).

Realist evaluation is not just a type of evaluation. It is a type of applied realism that is underpinned by an understanding of the nature of the world and of knowledge. In this respect, realist evaluation focuses on the ways in which programmes work by identifying the mechanisms of delivery, exploring the context, and combining these to identify and analyse measures of outcome (Pawson and Tilley, 1997). It is often referred to as a form of theory driven evaluation that looks at ‘the now’; the principles of causation and their effect on how things work (Pawson, 2013). To achieve this, realist evaluation examines what works, for whom, in which contexts and how.

Fletcher et al. (2016) suggest that using a realist approach to evaluation can be particularly effective at considering effects on different social groups and addressing inequalities in health and other outcomes. They suggest that public health researchers
have often under-theorised and under-researched how interventions are intended to engage with their social contexts to enact change (Fletcher et al., 2016), potentially affecting knowledge of effectiveness in the context of groups that experience inequalities in health. I decided to undertake a realist evaluation because I had hoped it would enable in-depth exploration of KYB at the ‘real’ level – in other words, its implementation, and outcomes. This approach could incorporate some of processes that are used in impact, and process evaluations but would also enable me to explore KYB as an open system, identifying how the relationships between mechanisms and context affect outcomes. Beat the Bugs is delivered through a series of interactive sessions, and I anticipated that context and mechanisms would be particularly important components of the implementation of the course. Realist evaluation would enable me to explore these in depth and understand the learning environment.

(Pawson and Tilley, 1997) suggest that realist evaluation enables us to use a theoretical approach to address ‘messiness’. This is particularly important in the context of the present study. Adults with learning disabilities can bring different experiences, knowledge and expectations to a session such as KYB. The context of the learning environment is important for everyone, and particularly for people with learning disabilities because they often need an individual supporting context for learning, and a chance to embed their learning (Bergström et al., 2014). I anticipated that realist evaluation would enable me to explore the differences within and externally to the course context that impact upon participant learning and behaviour outcomes.

However, realist evaluation is complex and time consuming; it requires the detailed identification, analysis and re-analysis of ‘hidden’ causal relationships for example (Punton et al., 2020; Dalkin et al., 2015; Pawson and Tilley, 1997). On reading the literature it was clear to me that there was relatively scant methodological guidance and transparency in conducting realist evaluation (Emmel et al., 2018; Fletcher et al., 2016; Astbury, 2013; Byng et al., 2005), for example on the process of identifying mechanisms and context, developing alternative explanations and overall ensuring rigour in the retroductive approach to analysis (Jagosh, 2020). Correspondingly, there is also criticism in the literature about how researchers have conducted realist evaluation. Pawson and Manzano-Santaella (2012), for example assert that researchers often do not address the
concept of ‘mechanism’ appropriately. I was aware of the extent of my challenge but was
confident that adopting a realist approach to my research would be most appropriate in
addressing my research questions. I could conceptualise KYB as a social system for
example with human interactions at different levels as described in section, 4.1.3.3. I was
clear about these methodological challenges I needed to address and developed my
research planning with this in mind.

4.1.3.2 Other approaches to evaluation

After reviewing the literature, I discounted other more traditional approaches to
evaluation, including randomised controlled trials (RCTs), process evaluation, intervention
logic models, some models of impact evaluation, and a combined model approach. Some
of these typically look at context and mechanisms but not how they interact with each
other (Fletcher et al., 2016; Moore et al., 2015), and can therefore fail to address the
underlying mechanisms of programme delivery and to enable full understanding of all
factors affecting causation (Bonell et al., 2012; Pawson and Tilley, 1997). In the context of
KYB this might therefore exclude focus on the experience of training (from a trainer and
participant perspective) for example, and therefore fail to fully understand the impact of
the intervention for different stakeholders.

Although the randomised controlled trial is still often considered the gold standard of
evaluation, (Mulhall et al., 2018) there are concerns in the literature relating to the
validity, reliability and ethics of conducting such studies with adults with learning
disabilities. Mulhall et al. (2018) and Oliver et al., (2002) discuss issues in
implementing a RCT with people with learning disabilities. Whilst arguing that the RCT is a
strong basis for a rigorous knowledge base, the authors encountered ethical,
methodological and service capacity difficulties in its implementation in a learning
disability context. There are also often ethical issues in withholding treatments or
intervention to people as part of a trial (Willis et al., 2018; Westhorp, 2014), especially
people that might need support with decision making. Some researchers (Jamal et al.,
2015; Bonell et al., 2012) suggest conducting a realist RCT. However, this approach is
criticised in the literature (Van Belle et al., 2016; Marchal et al., 2013) because it is using
contradictory theoretical approaches.
I also anticipated that it would neither be feasible nor appropriate to conduct a RCT within the duration of this doctoral research project. It was not appropriate because my priority was to understand the complex causal relationships that existed within the implementation of the course. It was not feasible because I had limited resource as a sole researcher including time, financial and personnel constraints.

I concluded that other approaches to evaluation presented similar limitations. Whilst a process evaluation would have enabled me to explore the module’s fidelity to design, as well as resource use, contexts, mechanisms, and outcomes, it would not have focused on the interactions of these components within the learning environment in the same depth as a realist evaluation. These interactions were key to my research questions. I considered conducting a combined process evaluation and realist model, but I was concerned this might compromise the realist evaluation theoretically, and again, as a sole researcher I felt that mixing approaches in this way would compromise the quality of the research.

Many of the evaluations I identified during my review of the literature explored the impact of a community health education intervention, doing so through a pre- and post-intervention analysis of knowledge or behaviour change (Sandjojo et al., 2019; Melville et al., 2018; Bergström et al., 2013; Marks et al., 2013). Impact evaluation focuses on the effect brought about by an intervention (Westhorp, 2014). Traditionally, this often involves an experimental design and a pre-post-analysis. If conducted alone, one major limitation of impact evaluation is that it can fail to address the underlying mechanisms of programme delivery and therefore doesn’t provide an understanding of the full range of factors affecting outcomes (Bonell et al., 2012; Pawson and Tilley, 1997). In the context of KYB, conducting solely an impact evaluation could risk excluding the true experience of training, and therefore potentially failing to fully understand the impact on outcomes for different stakeholders.

4.1.3.3 Theory-based tools to support the evaluation: Complexity theory and COM-B

In order to address the issue of transferability of findings, and to ensure that I had not overlooked any key issues, I was also particularly interested in Westhorp’s (2013) approach to using complexity theory alongside realist evaluation as a means of explaining
complex processes of change in community settings. I hoped this might help me to further address the criticism that realist evaluation has limited generalisability (Befani et al., 2007) as it would enable me to look beyond the middle range theory. In fact, ‘generalisation’ is not a term that is considered appropriate in scientific realism. This is because the epistemology assumes that there are many potential explanations for an outcome. Instead, transferability is a more acceptable conception. I discuss this further in Chapter 4, section 4.1.5.

Complexity theories help to understand programmes by addressing reality as comprising layers of open systems. Theories can be organised within a hierarchy to reflect and explain these different layers. I felt that it was certainly appropriate to view KYB as part of a complex social system: it is a system within a system (a session that is part of a course attended by people who function outside the course environment), it comprises multiple components including fixed and flexible elements and relations, and it has hierarchical structures that are also non-linear (people, fixed resources, internal and external environments).

Both complexity theory and realist philosophy understand reality as comprising multiple nested open systems in which change is generative and time irreversible (Westhorp, 2008). Byng et al. (2005) and Marchal et al. (2010) posited that a realist approach is particularly appropriate for evaluation in complex systems and demonstrated its use in complicated or complex programmes. Additionally, using a complex systems analysis in a realist evaluation can enable deeper insight into the components of a system and the ways in which they interact. Using different formal theories to understand different levels of systems can assist in conceptualising and thus managing analysis of the multiple processes of causation.

Pawson (2013) proposes ways in which complexity can be addressed, suggesting that programmes have always been complex interventions that are introduced into complex systems. Pawson characterises ‘complexity’ from a realist perspective, addressing it in the form of seven principles: theory, abstraction, reusable conceptual platforms, model building, adjudication, trust and organised scepticism (Pawson, 2013). I agreed with Astbury (2013) that this appeared unduly complex. However, rather than looking for
further theories to explain KYB, I intended that the concept of complexity theory would help me to understand the ways in which the prior theories (those that informed the development of Beat the Bugs) worked together within the levels of the session. I explain how I conducted this in Chapter 5, section 5.7.

COM-B (Michie et al., 2011, 2013, 2018) is a behaviour change model developed from existing theories of behaviour change. It proposes that, to understand the determinants of health behaviour, one should consider the interactions between capability (C), opportunity (O) and motivation (M), where individual, group and environmental determinants are equally considered in controlling behaviours (B). The COM-B framework is particularly well-suited to supporting a CMO analysis because it focuses on the links between behaviour change techniques and mechanisms of action. I provide further description on how I used this theory-based tool in Chapter 5, section 5.8.5.

4.1.4 Programme theory and middle range theory

In the context of realist evaluation, programme theory is the description of the intended outcomes of a programme (a theory of action) and the ways in which it aims to achieve these (a theory of change) (RAMESES II Project, 2017). There are many different models of programme theory (Funnell and Rogers, 2011), although for realists programme theory should explain how and why different outcomes of an intervention are generated in different contexts (Punton et al., 2020). Programme theory is an explanatory theory and is often the methodological starting point for a realist evaluation because it provides a broad description of information about the programme and thus background to support decisions about the data that needs to be collected. In Chapter 5, section 5.3.1, I describe how I developed programme theory during the evaluation of KYB.

Middle range theory is a broader abstraction of programme theory, describing the social and environmental structures and triggers that are likely to enable a programme to be effective. The concept of middle range theory was developed by Merton (1968) who defined it as a ‘theory that lies between the minor but necessary working hypotheses ... and the all-inclusive systematic efforts to develop a unified theory that will explain all the observed uniformities of social behaviour, social organization and social change’ (Merton,
In the context of KYB, middle range theory represents an overview of the key interactions that enable a programme to be effective. Middle range theory can have many uses within realist evaluation: it can summarise findings, be a point of reference and initially provide a starting point from which to develop an understanding of ‘what works’.

Middle range theory is usually expressed in terms of Context/Mechanism/Outcome (CMO) configurations and evolves through one or more iterations during the course of a study to refine its explanatory accuracy. As Pawson and Tilley suggest (Pawson and Tilley, 1997), it is often difficult, inappropriate even, to try to summarise middle range theory in a sentence because it potentially encompasses a broad range of components that represent the theory of a programme or intervention. In the context of my research, a key purpose of data collection and subsequent analysis was to develop a further iteration of the initial middle range theory (MRT1), an empirically based revision that aimed to represent a clearer understanding of KYB, the ways in which it was effective and how the learning environment influenced this.

4.1.5 A comment on ‘generalisation’

Some researchers argue that realist evaluation has limited effectiveness on policy and practice because it has limited generalisation (Bonell et al., 2012; Ledermann, 2012; Befani et al., 2007). They state that because the focus of the evaluation is on causality at the point of intervention delivery (the middle range) it is difficult to make assumptions about effectiveness outside of the research setting.

Views on generalisation vary according to philosophical or theoretical perspectives. Whereas experimental evaluators often aim to address external validity, qualitative researchers often prefer to talk about transferability and naturalistic generalisation (Astbury, 2018, p. 4). Most qualitative research studies intend to study a specific issue in a certain population and locality, and generalisability has often not been an expected attribute. However, with the emergence of larger qualitative studies and meta-syntheses, evaluation of generalisability has become more pertinent (Astbury, 2018; Leung, 2015; Befani, 2013; Befani et al., 2007).
Astbury (2018) refers to generalisation in terms of using explanation to explore causal validity, a key component of realist evaluation. He concurs with Pawson and Tilley (1997) that, in understanding how and why an intervention works, realist evaluation is actually effective at identifying causal validity through its process of abstraction. In this respect, realist evaluation addresses plausibility rather than probability and transferability rather than generalisability (Marchal et al., 2010). By testing and further refining understanding about the ways and contexts in which an intervention works, it is therefore possible to make inferences about how it could work at another level of abstraction. Westhorp (2012), Jagosh (2015) and Fletcher (2016) elaborate further, explaining that realist evaluation can examine aspects of programmes as middle range theories, abstractions, or patterns of decision making relating to the main ideas about how outcomes will be generated. These theories help us to become closer to reality, developing and testing ideas that make inferences about programme policy and development.

By exploring the process of abstraction in relation to the contexts in which an intervention operates, rather than a closed environment such as a contrived research setting, realist evaluators and policy makers can therefore consider situations in which the intervention is likely to be effective. Astbury (2018) suggests that it is often then useful to take realist evaluation to a further level of abstraction and develop further research to address hypotheses identified through the context/mechanism/outcome (CMO) identification process. I address further research priorities in Chapter 8, section 8.2.

### 4.2 Developing inclusive research with adults with learning disabilities

Involving the public appropriately in programme design and evaluation helps to ensure validity, accuracy and appropriateness (INVOLVE, 2018). In this context, inclusive research is research that includes or involves people with learning disabilities as more than just objects of research (Walmsley and Johnson, 2003). This can include as research designers, interviewers, analysts, authors, and users of research. For example, Beighton et al. (2017) described how working with people with learning disabilities on health research strengthened the quality of their research by offering realistic perspectives, changing questions and developing new outcome measures. At the outset, I aspired to develop an
inclusive research project; one in which I worked with adults with learning disabilities as co-researchers. I had anticipated that a co-produced study would produce more meaningful and valid findings.

In the context of learning disability, a fully inclusive study is one in which people with learning disabilities are involved at the outset and through all stages of the research process (Ellis, 2018; Walmsley et al., 2018; Nind, 2014; Walmsley and Johnson, 2003). It is not always possible to achieve this however; the very nature of doctoral research requires individual responsibilities that can render a fully inclusive study difficult (Ellis, 2018; Björnsdóttir and Svensdóttir, 2008). I felt that I therefore had to be pragmatic about what I could achieve (Ellis, 2018; Frankena et al., 2016; Nind, 2014), specifically in terms of balancing involvement of people with learning disabilities in my research and meeting funder expectations. The broad research topic for example was developed by Public Health England, prior to my appointment and to any discussion about inclusive or collaborative research with adults with learning disabilities.

I therefore decided to adopt a collaborative model (Salmón and Pernia, 2021; Bigby et al., 2014) whereby I engaged with a group of adults with learning disabilities in active discussion on the design, implementation and outcomes of the research. Literature scoping identified this as a growing area within public health research but one about which we still needed to know more (Sandjojo et al., 2019; Beighton et al., 2017). I describe in detail in Chapter 5, how I achieved this.

Recently, more participatory studies have emerged in health research with people with learning disabilities (Burke et al., 2021; Salmón and Pernia, 2021; Vlot-van Anrooij et al., 2020; An et al., 2018; St. John et al., 2018; Vlot-Van Anrooij et al., 2018; Ryan et al., 2017; Stack and McDonald, 2014). Recent examples of health research that aims to include people with learning disabilities include Burke et al.’s study (2021) to develop, refine and validate resources to deliver health education to adults with learning disabilities, Vlot-Van Anrooij et al.’s study (2020) of health promotion in group residential settings, Watchman et al.’s study (2021) of psychosocial interventions with people who have learning disability and dementia, House et al.’s case finding study and RCT (2018) of people with
diabetes, and Beighton et al.’s research (2017) into involvement in a study of the effectiveness of NHS health checks.

These studies added value to research by enhancing its validity, its meaning, ethics, and relevance. I hoped that by working with adults with learning disabilities in a collaborative way my study would incorporate some active involvement of people with learning disabilities that was achievable within the resource constraints of the PhD. It would also add to this growing body of knowledge about working collaboratively in a health evaluation context.

I drew on the growing literature addressing inclusive research to consider the important decisions I needed to make in designing my research and discussed these with my supervisory team and the organisation that hosted Research Development Group members. These considerations included practical issues such as team building, ethical issues such as consent and potential power imbalances, and the question of what training to provide Group members (Strnadová et al., 2014, 2016; Seale et al., 2015; Nind and Vinha, 2013). I discuss these further in presenting my research design in Chapter 5, section 5.2 and, later, reflect on the effectiveness of this in Chapter 7, section 7.6.1.

4.3 Ethical considerations

Research with adults with learning disabilities raises many important ethical issues (Hamilton et al., 2017; Goldsmith and Skirton, 2015; McDonald and Kidney, 2012; Walmsley and Johnson, 2003). As a part ESRC-funded studentship, this research adopted the principles of the ESRC Framework for Research Ethics (ESRC, 2015) thus maximising benefit to research participants, respecting rights and dignity, researching with integrity, defining lines of accountability and maintaining independence. I discuss in further detail the important ethical considerations I made in Chapter 5, section 5.1.

This research was granted ethical approval twice from the Open University Human Research Ethics Committee; once for the Research Development Group (HREC/3286/Owens) and once for the main study (HREC/3385/Owens).
4.4 Chapter summary

In this chapter I have discussed the important theoretical perspectives and broad considerations that influenced my decision making in relation to my research design. These included the theoretical, methodological, and ethical issues that provided an important stage to my research planning. In the following chapter I present my research methodology, demonstrating how I used these considerations to develop my research.
Chapter 5. Methodology: A collaborative realist evaluation of Know Your Bugs

This chapter describes the methodology I adopted in carrying out my research and provides rationale for the methods I used. To recap and provide context for this, my research questions were:

• How does the learning environment influence learning and behaviour change regarding self-care and the management of good health of adults with learning disabilities?

• How does the Know Your Bugs module equip adults with learning disabilities with knowledge and confidence to self-care and manage common infection?

• How does collaborative working with adults with learning disabilities on public health evaluation enhance research outcomes?

My research design was based on realist evaluation principles with an added analytic component addressing reported or potential self-care behaviours. The evaluation was conducted and reported in line with the RAMESES II reporting standards for realist evaluations (Wong et al., 2016). It was supported with advice from members of a Research Development Group, a group of adults with learning disabilities that I had convened. The Group had an important role in my study design and data collection, and thus my study findings. I therefore begin this part of the chapter by outlining the rationale for the Group and describing the process of collaboration.

5.1 Ethical considerations

As I have stated in the previous chapter, research with adults with learning disabilities presents important ethical issues. These include ensuring that consent is understood, voluntary and remains so for the duration of the research; that it is compliant with the legislative framework (UK Public General Acts, 2005), and there is an appropriate balance between safeguarding and ensuring that voices are heard; that any
potential power imbalances are considered fairly; that communication and information are appropriate; and that any participant concerns are understood and addressed appropriately (Hamilton et al., 2017; Jepson, 2015; McDonald and Kidney, 2012).

McDonald and Kidney (2012) outline some key ethical challenges regarding the fair and appropriate participation of adults with learning disabilities in research. These include promoting understanding through appropriate communication and relationship-building, ensuring a balance between protection and empowerment, and ensuring ethical accountability. Many of these issues relate to the ways in which researchers engage with research participants and I aimed to address these important points by adopting person-centred strategies such as relationship-building, discussion, time, adapted materials and proxy support if appropriate (Hamilton et al., 2017; Jepson, 2015; McDonald and Kidney, 2012). Other specific steps to ensure my research was conducted ethically included:

**Accessibility.** I considered practical issues of accessibility in developing appropriate research and information materials and using comfortable physical environments; through dialogue, individual needs were assessed and addressed. The Research Development Group provided support in developing accessible and flexible materials.

**Ongoing support.** All research participants could read and were given an easy-read information sheet that showed access to information and support on the issues covered during the session. This aimed to support participants should they feel uncomfortable or concerned about any of the issues that were addressed. One participant voiced concerns relating to some of the subject matter, although not about the research itself. This was Fiona who had enrolled on the course largely because she was very anxious about becoming ill with a virus and wanted to learn about the spread of infection. She was supported by staff and supporters in her concerns throughout the course and, even during interviews, Fiona sought reassurance. Her concerns were exacerbated by the growth of the COVID-19 pandemic, and she needed verbal support in rationalising some of her thinking.
Acknowledging contributions. I offered a form of ‘payment in kind’ to members of the Research Development Group for their contribution. This was in the form of training and support in the subject nature of the project and the practical application of research methods. As intended, this was an informal session which initially took place once a month and covered issues such as microbes and infection, self-care, and dental hygiene. I also offered a £10 gift voucher as recompense for their work. Whilst there could have been concerns that this approach was coercive, I felt it was important to acknowledge the contributions of the group.

Researcher safety. To address my own safety whilst conducting fieldwork I had developed a risk assessment of lone working in line with the principles of the Lone Worker Standard (BS 8484, 2016) and University guidance. I developed an action plan that incorporated informing supervisors and family members of my weekly whereabouts and when they could expect to see me, ensuring that I was contactable, and overall being prepared and mindful about risks. Fieldwork was conducted either at the course venue or later over the telephone from my home.

I also made additional ethical considerations during the research process, specifically in relation to individual components of the study. I address these in Chapter 5, as they arose during my research.

5.2 Conducting collaborative research with adults with learning disabilities: The Research Development Group

The purpose of the Research Development Group was to ensure that people with learning disabilities had a role in shaping the research as it developed. Recruitment to the group was conducted with the help of a local organisation in Norfolk that supported adults with learning disabilities. I chose Norfolk because it corresponded to the empirical component of the study and was local to me so that we could conduct pre-meetings and meetings with only minimal travel on my part. The local connection also meant that I had some shared knowledge and experiences with group members which was helpful in relationship building.
Potential group members were regular attendees at one of the organisation’s community hubs in Norfolk. I chose this approach because members of the group would know each other and were accustomed to working together. They were also very familiar to staff who were instrumental in the recruitment process; staff knew potential members well and could support me in ascertaining whether they would be appropriate for the group, and whether they would also enjoy the experience.

Research suggests it is important to start building research relationships as early as possible (Ellis, 2018; Bigby et al., 2014; Nind, 2014), and I began by visiting potential group members early in the first year of my doctoral research. I attended several regular lunchtime ‘forum’ meetings at the organisation’s venue to develop a relationship with potential participants and engage in conversations about the research. I also introduced some of the Beat the Bugs activities to participants so that they became familiar with the course and had an opportunity to be involved in it.

Adults with learning disabilities who attended this organisation were referred to by staff as ‘customers’. The organisation invited all customers to attend a regular ‘forum’ meeting by putting up posters in the building a week before the meeting. I attended this meeting in an introductory capacity, presented the study, and discussed the information sheet with forum participants if they wanted. I explained that I would return the following week to follow-up and discuss this further with those who were interested in joining the group. At the second meeting I assessed capacity to consent by asking simple questions about the group and the project. Those that wished to participate signed a consent form.

Inclusion criteria for the group were broad as I did not want to be prescriptive about impairment, age or gender. There were just two specific inclusion criteria; that members could understand basic concepts of healthcare, and that they were able to contribute in a group environment. I did however aspire to including at least two female and two male group members and a range of ages. Seven adults with learning disabilities joined the group. Two participants were female, and ages ranged from mid-20s to 72 years.

I had intended to meet with the Group four times during the research: on introduction, prior to data collection, after analysis and on completion of drafting my thesis. I had also
hoped that members of the Group would work with me on an accessible summary of findings. In practice, I had two research meetings with the group, and several other informal meetings and email contact.

Prior to the COVID-19 pandemic, meetings took place in a community building that was visited regularly by group members. This worked well; the venue was familiar to members them and fit in well with transport and other accessibility issues. Training was informal and involved verbal briefings and discussion about the research and about the group’s role, using basic terminology and illustrative concepts. During introductory meetings, I described the proposed research and explained what would be involved in being a member of the group. At the beginning of each meeting, we discussed our expectations and conducted a Beat the Bugs activity. We also discussed the methodological nature of the specific meeting; for example, interviewing when discussing the questions I should ask, and analysis when addressing outcomes from the data collection.

Meetings were structured around a broad agenda. The Beat the Bugs activity we conducted at the beginning of the meeting helped group participants to familiarise with the course, thereby providing information that they could use as a basis for evaluation ideas. The meetings and their scope are outlined in Table 5.1. It was also important to me that participants had a role in directing the meetings, deciding on content and identifying outcomes. We therefore spent time at the beginning of each meeting discussing what we could do during the session, and at the end discussing what we would address next time.

After the emergence of the COVID-19 pandemic it was difficult to meet; most of the participants did not have personal access to the internet and many were self-isolating. It was difficult to maintain contact and therefore collaborate as planned. Instead, I engaged in telephone conversations with those I was able to contact. I had engaged with three participants in this way and was hoping to hold a Zoom meeting in July 2021 to collaborate on a summary of findings. However, although initially keen to do this, just one member of the Group felt able to engage with me at this stage. This was disappointing. However, it highlighted the difficulties in engaging with people during this time, and in fact enabled me to develop a positive collaboration with a single individual, and thus experience a different way of working collaboratively.
I refer to the Group member who volunteered to work with me on the accessible summary of findings as Lucie. I met with Lucie on a one-to-one basis on two occasions and spoke several times over the telephone. Initially I drafted a proposed summary of findings which we discussed face-to-face in a café. This meeting took place shortly after some, but not all, pandemic restrictions were lifted and at that time it was only possible to meet in a public place. We chose somewhere that was convenient and familiar to Lucie, and safe for both of us. After discussion, and on Lucie’s suggestion, I changed the summary substantially. We also agreed it was better as a PowerPoint presentation. The presentation progressed through a second iteration of development which involved Lucie making comments and editing before we agreed on a final version. I aim to present this, with Lucie if she would like, to the research participants during Autumn 2021. I include a copy of the presentation at Appendix 20.

**Table 5.1 Research Development Group meetings**

<table>
<thead>
<tr>
<th>Meeting</th>
<th>Purpose</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meeting 1, September 2019</td>
<td>Introductory, inform development of research.</td>
<td>Research discussion, microbes activity (‘Meet the bugs’), summary.</td>
</tr>
<tr>
<td>(1 hour)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meeting 2, January 2020</td>
<td>Inform data collection.</td>
<td>Introduction, microbes activities (‘spreading bugs’, hand hygiene), what is research, what research questions shall we ask?</td>
</tr>
<tr>
<td>(10am to 3pm)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Further engagement by telephone</td>
<td>Discuss and agree research findings.</td>
<td>Discussion of key points and quotes raised by me.</td>
</tr>
<tr>
<td>June – September 2020</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(three members)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meeting with Lucie, July 2021</td>
<td>Develop accessible summary of findings.</td>
<td>Discussion of printed document.</td>
</tr>
<tr>
<td>Meeting with Lucie, October 2021</td>
<td>Refine accessible PowerPoint summary of findings.</td>
<td>Discussion of PowerPoint presentation.</td>
</tr>
</tbody>
</table>

Although not an inclusive study, I decided to use the questions raised by Nind and Vinha (2012a) outlined in Figure 5.1 to review the effectiveness of my approach. I had used these questions to assess the perceived level of participatory involvement in the studies
included in my scoping review, and it had provided a robust basis for consideration. I discuss the outcome of this analysis in Chapter 7.

<table>
<thead>
<tr>
<th>Is the topic relevant to the lives of people with learning disabilities and interesting to them? Could it become relevant?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does the research involve people with learning disabilities in a meaningful and active way?</td>
</tr>
<tr>
<td>Are the participants in the research treated with respect?</td>
</tr>
<tr>
<td>Is the research communicated in a way people with learning disabilities can understand and respond to?</td>
</tr>
<tr>
<td>Is there honesty and transparency about everyone’s role and contribution?</td>
</tr>
<tr>
<td>Were the ways of working carefully thought through and adapted in response to needs?</td>
</tr>
<tr>
<td>Does the research create worthwhile knowledge?</td>
</tr>
<tr>
<td>Are there likely long-term wider benefits for the people involved e.g. new networks, skills, funds, roles, social inclusion?</td>
</tr>
<tr>
<td>Are the research questions the kind that inclusive research can best answer?</td>
</tr>
<tr>
<td>Does the research reach participants, communities and knowledge that other research could not reach?</td>
</tr>
<tr>
<td>Does the research use, and reflect on, the insider cultural knowledge of people with learning disabilities?</td>
</tr>
<tr>
<td>Is the research genuine and meaningful?</td>
</tr>
<tr>
<td>Will the research make impact that people with learning disabilities value?</td>
</tr>
</tbody>
</table>

(Nind and Vinha, 2012a, p. 60)

**Figure 5.1** What makes good inclusive research? Key questions against which an inclusive project can be judged

### 5.3 Research design

My research adopted a realist approach. As outlined in this chapter, this involved the identification of programme theory, development of a first iteration of middle range theory, and observation and a series of interviews with course participants over time to develop a second iteration of middle range theory which represented the ways in which the programme was, or was not, effective. I describe the constructs of programme theory
and middle range theory in Chapter 4, section 4.1.4, and the approach I adopted is presented in Figure 5.2.

![Figure 5.2 Research methods and timeline](image-url)

**Figure 5.2** Research methods and timeline
5.3.1 Development of programme theory and initial middle range theory

Having briefly reviewed the literature, held informal conversations with course developers at Public Health England and follow-up discussions with contacts made during external meetings and events, I developed three programme theories that aimed to describe KYB. As described in Chapter 4, section 4.1.4, programme theory development is often the first analytical step in realist evaluation as it aims to encapsulate what the programme sets out to do and how. As such, it usually forms the basis for initial investigation. To achieve this, I used The Rameses II Project (2017) eight step process to developing programme theory (Table 5.2); addressing key questions about the module including: What change does it intend to create? Who does it intend to address? What does it provide to enable a choice or behaviour? How might sub-groups respond to the resource? What features of context affect how people respond and in what ways?

Table 5.2 The Rameses II Project 8-step process to developing programme theory

<table>
<thead>
<tr>
<th>Realist assumption</th>
<th>Focus questions</th>
<th>Realist programme theory</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Programmes intend to cause a change.</td>
<td>What change (outcome) does it intend to create?</td>
<td>Identifies intended outcomes.</td>
</tr>
<tr>
<td>2. The programme intends someone to do something differently to cause the change.</td>
<td>Who does it intend to do what differently?</td>
<td>Identifies whose decision-making should be examined.</td>
</tr>
<tr>
<td>3. Programmes provide resources or opportunities or change environments to enable a different choice/behaviour.</td>
<td>What does it provide to enable that choice or behaviour?</td>
<td>Identifies the resource(s) in programme ‘reasoning and resources’.</td>
</tr>
<tr>
<td>4. Programme staff and participants make active choices and respond differently to resources.</td>
<td>How might different sub-groups respond to the resource?</td>
<td>Identifies various sets of ‘reasoning’. Contributes to identifying ‘for whom’ programmes may/may not work.</td>
</tr>
<tr>
<td>5. Participants’ choices depend on/are affected by context.</td>
<td>What features of context will affect how people respond to the resources? In what ways do those features affect responses?</td>
<td>Identifies what it is about context that matters. Also contributes to identifying ‘for whom’ programmes may/may not work.</td>
</tr>
<tr>
<td>6. Context affects more than participant outcomes.</td>
<td>Which other features of context will affect whether and how the programme ‘works’?</td>
<td>Identifies features of implementation, organisation, capacity, history that affect whether or not programmes work.</td>
</tr>
<tr>
<td>7. The choices that participants make lead to different outcomes.</td>
<td>What outcomes would be generated by different decisions?</td>
<td>Identifies a wider range of potential outcomes (also can be negative).</td>
</tr>
</tbody>
</table>
To evaluate programmes, collect information about context, mechanism and outcome. What information will be needed and could be collected about contexts, mechanisms and outcomes? Identifies the data necessary to test the programme theory.

Adapted from: ‘Theory in realist evaluation’ (RAMESES II Project, 2017, p. 2)

I participated in five meetings with course developers at PHE and Kingfisher Treasure Seekers; three in person and two over the telephone. I did not transcribe meetings or conversations with programme developers at this stage. This early stage of my PhD focused on development work regarding understanding of the module and the literature, and I did not have ethical approval at that time. However, I made detailed notes of meetings and discussions and research diary entries, and am confident that these reflected the conversations that were held about the module. I imported my notes into QSR NVivo 11 (later updated to version 12) and analysed thematically (Braun and Clarke, 2013). I present further detail on my analysis in this chapter, section 5.8.

The three programme theories that I developed during this early stage of my research provided a clear outline of initial programme expectations, and the intended delivery and effect of KYB. These were:

- Incorporating several learning and behavioural theories within the development and delivery of KYB supports learning for diverse groups of people.
- KYB as a summary session enables participants to recap and reinforce previous learning.
- Interactive and engaging resources motivate course participants to enjoy learning and acquire knowledge.

These programme theories were useful in two respects; they provided a clear outline of programme expectations; and they informed the more in-depth scoping review of the literature described in Chapter 3. The scoping review subsequently enabled me to develop a first iteration of initial middle range theory; a broader abstraction describing the social and environmental structures and triggers that are likely to enable the
programme to work. I outline how I developed the components of the initial middle range theory in Chapter 3.

The initial middle range theory (MRT1) is illustrated in Chapter 3, Figure 3.3. I discussed this with programme developers at Public Health England, my supervisory team and with staff at Kingfisher Treasure Seekers, a social enterprise in Gloucester that was involved in developing the module. We agreed that MRT1 formed a valid, reliable, and interesting foundation from which to further develop the research. A key purpose of the fieldwork and subsequent analysis was to develop a second iteration of middle range theory; an empirically based revision that aimed to represent a clearer understanding of KYB, the ways in which it was effective and how these were influenced by the learning environment.

5.4 The study group

5.4.1 Training organisations

On commencing my research, Beat the Bugs was a relatively new course and implementation was still in its infancy. Aside from at the Kingfisher Treasure Seekers, a collaborator in developing Beat the Bugs, the course had not been delivered nationally in a learning disability context as far as I was aware. I therefore needed to identify and recruit organisations that would deliver the course so that I could evaluate the KYB component of it. I chose as my sampling frame all organisations in Norfolk, England that worked with adults with learning disabilities, and were listed on a county database of health and social care providers. I chose Norfolk for pragmatic reasons; it was my home county and therefore a practical location in which to travel and make follow-up visits. It was also an area of the country that had relatively high antibiotic prescribing practice (Public Health England, 2021b) and I considered would benefit from further educational initiatives.
5.4.2 Course participants

My study group comprised two KYB cohorts, each including nine participants. Eight individuals in Group 1 and three in Group 2 were female. All considered themselves to be White British. The mean age was 34.8 in Group 1 and 36.6 years in Group 2 although ages ranged from between 22 and 68 years in Group 1, and 24 and 48 years in Group 2.

Seventeen of the participants in my research were connected to learning disability support services because they had at some stage in their lives been identified as being learning disabled. Defining learning disability is complex and terminology is often contested (Walmsley et al., 2018). The term ‘learning disability’ is in fact one of many labels that may be used to describe a person, and definitions and terminology can differ widely (Bates and Mafuba, 2016; Strnadova et al., 2016).

MENCAP defines learning disability as: ‘... a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life.’ (MENCAP, n.d.). The label ‘learning disability’ should not be viewed in isolation and, when considering support needs, the emphasis should always be on the person’s rights, dignity and individuality (Cluley et al., 2020; Werner and Abergel, 2018). For the purposes of health, social and educational support however, definitions can be useful and are often used to assist in determining support needs. They can also be used in research for determining the focus and methodology of a study.

Seventeen of the participants did identify with having a mild to moderate learning disability; one had mental health issues and was attending the course to build confidence. Often used in a needs assessment context, the International Statistical Classification of Diseases and Related Health Problems (World Health Organization, n.d.) suggests that people with a moderate learning disability have an IQ of between 35 and 50, and are likely to have some language and communication skills.

This is of course a medical perspective on disability but is often used to determine support needs. Some people with learning disabilities may need more support caring for themselves, but many will be able to carry out day to day tasks. People with a mild
learning disability often have an IQ of between 50 and 70 and are usually able to hold a conversation and communicate most of their needs and wishes. They may need some support to understand abstract or complex ideas. I did not explore the medical history of potential participants nor the concept of any clinical diagnosis because it was not strictly relevant to me or the course providers. As is commonplace, educators did not know participants’ clinical diagnosis; entry criteria to the course addressed individual need in terms of independent living and was based on informal assessment. Participants had been accepted onto the course because they were deemed eligible and at an initial information day educators felt that the course was suitable for and accessible to them.

Figure 5.3 shows that five participants from Group 1 and two from Group 2 had attended a mainstream school, and most had attended other community education since leaving school, often in literacy and IT. Five participants in Group 1 and four in Group 2 were receiving formal support. The nature of this support varied, and included group residential living, a formal foster arrangement, or support for specific activities such as cooking, cleaning and shopping. One participant commented that they were entitled to support but found it difficult to access. Another said that they were unable to access the statutory support to which they were entitled and paid privately instead. Five participants reported that they were supported informally by their families, and three commented that they no longer had access to support. Four participants (one in Group 1 and three in Group 2) were accompanied by personal supporter during the KYB session, someone who supported the individual in a daily living context.

The participants’ lifestyles varied. Some attended a range of activities or courses at organised venues; others worked voluntarily. Three had paid jobs; one worked in a café, one for the local authority and one for a local community organisation. One Group 1 participant and four Group 2 participants led relatively unstructured lives and did not work, volunteer or attend classes. I include in Appendix 21 further detail on participants’ backgrounds in the form of individualised pen portraits.
18 participants; 9 in each group
17 self-identified as having ‘mild to moderate learning disability’

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Group 1</th>
<th>Group 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age</td>
<td>Group 1: 34.8 years (range 22 – 68 years)</td>
<td>Group 2: 36.6 years (range 24 – 48 years)</td>
</tr>
<tr>
<td>Gender</td>
<td>Group 1: eight female, one male</td>
<td>Group 2: three female, six male</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>Both groups: all white British</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>Group 1: five mainstream, four specialist</td>
<td>Group 2: two mainstream, five specialist</td>
</tr>
<tr>
<td>Support</td>
<td>Group 1: five received formal support</td>
<td>Group 2: four received formal support</td>
</tr>
<tr>
<td>Lifestyle</td>
<td>Range of structured activity (volunteering, paid work, clubs) and unstructured lifestyle</td>
<td></td>
</tr>
</tbody>
</table>

**Figure 5.3 Course participants - summary of background characteristics**

### 5.4.3 Supporters

Each tutor was supported by two Learning Support Assistants (LSAs) who had been present throughout the course. Personal supporters were also present during the session; one in Group 1 and three in Group 2, although only one personal supporter actively participated in the session (Group 1). The role of personal supporters can be important in the context of learning disability and learning. Some studies have reported a positive supporter effect on acquiring and embedding learning (Sandjojo et al., 2019; Dunkley et al., 2017; Hartwig et al., 2017; Bergström et al., 2013). For others, supporters have been found to negatively impact upon their ability to manage health care and sometimes impeded the research process (Dixon-Ibarra et al., 2018; Chadwick et al., 2018). Although the focus of my research was adults with learning disabilities, I felt it was important to consider the role and influence of personal supporters, especially as they were also employed by the course providers in order to facilitate positive learning outcomes.
5.5 Recruitment

Figure 5.4 illustrates the process of recruiting organisations to deliver the module and the participants that undertook it. I approached 19 local providers by email. Four of these indicated an interest in delivering the course, and, after a further follow-up reminder, no further organisations expressed an interest. The organisations that expressed an interest in participating were a local authority department that provides training in independent living skills across the county, a social enterprise, a local self-advocacy group and a day service provider. On viewing the course materials, members of the self-advocacy group felt that they would be unable to deliver the course because the materials were inaccessible to them. I address the issue of accessibility in Chapter 6, section 6.8.2 and discuss further in Chapters 7 and 8.

The day service provider was eventually unable to commit to training within the necessary timescale and therefore did not proceed. Educators from within the two remaining organisations attended a training session provided by the Public Health England Primary Care and Interventions Unit to ensure they were equipped with the knowledge and techniques required to deliver the course. After these sessions, the social enterprise withdrew from the research without wishing to provide a reason why. Although just one organisation was therefore willing and able to deliver the course within the required timeframe, it had many different outlets across the county.

Prior to commencing data collection in January 2020, I attended a Beat the Bugs trainer training session in April 2019 with the educators of the module that is subject of this evaluation. This was a morning session delivered by PHE staff to a range of educators from across Norfolk and aimed to provide an outline of the course and train in how it would best be delivered. Educators enjoyed this session. They informally fed back to me after the session that they liked the course and thought aspects of it could be adapted to their learners with learning disabilities.

Subsequent to this, programme managers in this organisation designed a 10-week course called ‘Living healthily’ that combined Beat the Bugs with a healthy eating course entitled ‘Joy of Food’. This was part of a 30-week programme of independent livings skills
education conducted over three academic terms between September 2019 and June 2020. The other components of this programme were ‘Living positively’ and ‘Living creatively’ which were undertaken by the same group of people during different terms of the academic year. The overall programme was designed so that educators could select and deliver from a range of components to suit the needs of their learners.

Twenty-five educators linked to this organisation were trained to deliver Beat the Bugs. Two of these educators were able to deliver the course in time to comply with my PhD timelines. Both developed individual session plans based on the re-designed course, and agreed to participate in the evaluation.
Organising the course and module delivery took time. Twelve months passed between making initial contact with potential course providers and actual delivery of the sessions. For the course providers, competing service priorities, availability of resources and the time needed to recruit to and set up the course were all considerations that had to be made during this period, alongside dealing with many other organisational constraints and priorities. This raises implications for others in setting up a course such as Beat the
Bugs; discussions about time, funding and personnel should be held in advance of committing to delivering a course.

The education providers led the recruitment of participants. With support from the Independent Living Skills Co-ordinator at the local authority I made contact with two educators, referred to as tutors within the organisation, who agreed to deliver the course as part of an Independent Living Skills programme. Potential participants were identified by the training organisations using their normal recruitment practices. These included circulation of publicity about courses through circulars to organisations, individuals and at ‘roadshows’. I chose this approach because it aligned with the organisations’ regular recruitment procedures and the staff were best placed to identify, understand and ultimately select participants. Potential participants then applied to register on the course. The sample included adults with a mild to moderate learning disability that were able to understand the basic concepts of the course, had expressed an interest in attending and had the capacity to consent to research as assessed by me.

5.6 Obtaining consent

I adopted careful strategies in addressing consent with potential participants. Participants' capacity to consent to participate was assessed by myself in line with the Mental Capacity Act (MCA) 2005 requirements. I began by discussing my plans with training organisations and, with their advice where appropriate, adopted a suitable personalised approach for each participant. I discussed the research with individual participants at a consent interview, asking a series of questions to ascertain whether they could understand and retain the information presented (Appendix 3). This enabled me to assess their capacity to consent. Prior to meeting potential participants, training organisation staff also had such discussions with them so that they had early introduction to the research.

I discussed preferred means of communication with training organisers, participants and supporters if appropriate. Once capacity to consent had been confirmed, potential participants were given an accessible information sheet which I also explained verbally (Appendix 7). Although I had planned contingencies for if participants were unable to
provide written consent, all were in fact able to do so. Consent was also reconfirmed immediately prior to each data collection and at the end of final data collection. I am confident that the process was fair and robust, whilst honouring the MCA principle of 'presuming capacity' as a starting point.

Although I had planned contingencies in case of non-consent, all invited participants agreed to participate in the research and consented to the recording of sessions and interviews.

5.7 Data collection

Data collection encompassed the following four stages, each with a different but complementary thematic focus:

- Stage 1: Introductory (interviews)
- Stage 2: The learning context (observation)
- Stage 3: Health behaviour change in people’s lives (interviews)
- Stage 4: Recall and retention (interviews)

These stages are illustrated in Figure 5.5 along with an outline of the broad timelines for data collection.
Figure 5.5 Data collection methods

Stage 1: Introductory semi-structured interviews with course participants prior to the KYB session

Dunkley et al. (2017) found that an introductory meeting assisted in gaining confidence of participants and establishing a positive research relationship. I began by doing the same. The purpose of this short introductory interview was twofold: first to follow-on from the consent interview and further introduce myself and the study, begin to establish rapport and enable the participant to ask any questions about the evaluation; and secondly to obtain contextual data that was relevant to the research.

Organising and conducting interviews with adults with learning disabilities can be challenging; concerns about power imbalances, acquiescence bias, and ensuring appropriate accessibility and time for participants can involve complex planning and often conflicting considerations. Llewellyn and Northway (2008) chose not to interview for example due to concerns that the interviewer could be in an authoritative position. Nind and Vinha (2012b) used Freire’s (2000) ideas around using dialogue to listen, reflect and transform during focus groups. Interview design requires extra
attention compared with focus groups due to the development of accessible materials and ensuring comprehension (Abma and Broerse, 2010; Boyden et al., 2009).

A further consideration I had regarding interviews was that of acquiescence bias. This is often cited as an issue in research with adults with learning disabilities although Ellis (2018) describes this issue as problem of inappropriate question semantics rather than acquiescence per se. Despite these shortcomings, I thought that interviews remained the most appropriate method for this stage of the research because they could be personalised; an important component of a realist evaluation. Interviews enabled me and participants to establish a rapport and begin to feel comfortable with each other for example.

An effective realist interview is underpinned by a specific approach and organisation. Realist interviews are often described as theory-gleaning interviews with the purpose of engaging with participants in eliciting views on an initial programme theory, exploring these through conversations, and thereby enabling refinement of that programme theory (Mukumbang et al., 2018, 2020; Manzano, 2016; Pawson and Manzano-Santaella, 2012). This interview is based on a process of conceptual focusing (Pawson and Tilley, 1997) whereby interviewees, as participants in realist theory generation, are encouraged to provide their viewpoints in relation to their own thinking and decision making processes in the context of the interviewer’s own theory. Mukumbung et al. (2020) demonstrated how they achieved this by adopting the three stages suggested by Manzano (2016) of theory gleaning, theory refining and theory consolidation, and by engaging the teacher/learner function advocated by Pawson and others (Pawson and Manzano-Santaella, 2012; Pawson and Tilley, 1997).

The teacher/learner concept is an important component of the realist interview; it is based on an understanding that the interviewer is expert in their knowledge of the proposed programme theory. Correspondingly, the interviewee adopts the role of the learner regarding this theory; learning about it, and subsequently expressing their views, thoughts and motivations in relation to the programme under study. However, this expertise is not static, and can transfer from interviewer and interviewee at different stages of the interview (The RAMESES II Project, 2017c; Pawson, 1996). At the outset I
was aware that the concept of expertise had different connotations in the context of inclusive research with adults with learning disabilities, and I spent much time considering and clarifying my thinking to ensure that my approach was appropriate both methodologically and ethically.

In this context, my underlying philosophy was one of ‘shared expertise’ and began with The Research Development Group who supported me in designing interview questions. Group members and interview participants were experts by experience in many different contexts: in their lived experience of learning disability, their management of their health and, regarding session participants, their decision making in relation to the course. My expertise was as a researcher and developer of realist programme theory in relation to KYB. I intended that our shared conversations during interviews would enable exploration of participant experiences and reasoning that addressed my programme theory. As a ‘teacher’ in the realist interview sense, it can in practice be difficult to present programme theory effectively to interviewees (Mukumbang et al., 2020; Manzano, 2016; Pawson and Tilley, 1997; Pawson, 1996), and I had anticipated that this would be the case with the participants in my study. The concept and content of my initial programme theory was complex and the research participants were not experienced in working with theory in this context.

To address this, and to ethically and usefully engage participants, I adopted an approach suggested by Pawson and Tilley (1997) and utilised by Mukumbung et al. (2020), engaging in conversations that addressed micro-elements of the initial programme theory. I did this through my questioning, exploring how participants made decisions and choices in relation to KYB and its intended outcomes. I initially prepared and tested questions and concepts with the Research Development Group using discussion and explanation. By conducting follow-up interviews several times in the post-module period, I was able to further test, consolidate, potentially expand and strengthen my initial programme theory using the three-stage process (Manzano, 2016) of theory gleaning (during introductory interviews), theory refinement (during post-module, six-week and five-month follow-up interviews) and theory consolidation (during six-week and five-month follow-up interviews).
Face-to-face interviews were conducted at the course venue during a lunch break and lasted from between 10 and 23 minutes in length. They were supported by the semi-structured interview guide presented in Appendix 12 that I had developed with guidance from the Research Development Group and using the components of the initial middle range theory. Questions focussed on micro aspects of the session that were relevant to each participant, and the ways in which it was experienced by them. Questions also addressed participants’ background circumstances, motivations for attending the course and their existing knowledge. This interview included the pre-module knowledge assessment questions presented in Appendix 13, aiming to gain insight into participants’ knowledge of hygiene, infection prevention and antibiotic use prior to starting the session. With permission, I audio recorded all interviews and transcribed them verbatim, checking transcripts against the audio recordings.

**Stage 2: Observation of course sessions and interviews immediately afterwards**

I conducted non-participant observation of each session, focusing on the learning context. My aim in doing so was to gain an understanding of the course environment and an impression of participant response, course leader variability, and mechanism and context influences. I present further detail on the observation and my findings in Chapter 6, section 6.1.

Observation is often an effective method in realist evaluation (Willis et al., 2018; Oakes et al., 2016; Wilson et al., 2015). It has the advantage of directly accessing ‘the lived experience’ of research participants and avoids some of the filters and potential for acquiescence bias that may occur during interviews (Mansell, 2011). I sat with participants around the table and made observation notes regarding movements within the session, participant contributions, observed responses and interactions. I also recorded my thoughts and impressions on my observations. With permission, both sessions were audio recorded; I had decided against video recording sessions because I felt it would be an intrusion and may hinder personal health discussions. With hindsight these discussions were open and relaxed, and I think video recording would have been acceptable. Instead however, I made fieldnotes immediately after each session in order to
supplement my recorded data and ensure I had an accurate record of the content. Along with audio recordings these provided rich data on the content of the session.

To minimise potential researcher impact I re-introduced myself at the beginning of sessions, reconfirmed consent, and intended otherwise to be non-participant. However, in practice I was occasionally involved in session conversations through tutor questioning.

**Photo-elicitation to support subsequent interviews.** With permission, participants were invited to take photographs of the environment and activities during sessions. Research shows that photo-elicitation can lead to an increase in participant-led dialogue producing rich data (Copes et al., 2018; Meo, 2010). It can create opportunities for appropriate inclusion in the research process and empowerment of the participant, therefore readdressing the power imbalance between the researcher and the researched (Bates et al., 2017). It can also be an effective method of supporting recall; a memory aid to support reflection. In this context, photo-elicitation aimed to serve as a memory aid for participants about the session during subsequent interviews.

While photo-elicitation interviews can be used as an independent method of obtaining data, they work best when used alongside other interview methods to provide additional depth to participant responses (Padgett et al., 2013). In this case, I used these alongside the earlier observation and semi-structured questioning to generate rich dialogue about the session, aiming to keep interviews stimulating and structured (Bates et al., 2017).

The consenting process addressed the use of photography. I ensured that participants understood that the photographs would only be used as a memory aid to stimulate recall and discussion for interviews; they would not constitute data, be published or seen outside of each respective group. I provided disposable cameras for all participants and explained how to use them. Seven participants in each group engaged with the photography. They did this at the end of the session so as not to influence the session itself. They were all positive about this activity although viewed it in different ways. Group 1 participants initially saw this as an opportunity to record their own presence in the course and were keen to take ‘team photographs’ of themselves. On suggestion
however, they also photographed the course setting. Group 2 participants focused on photographing the course setting and two participants interpreted the activity as integral to the course. They spent time taking photographs of items that they thought might host microbes, akin to the Magazine Microbes activity. In this respect, the photography potentially served to further embed learning about microbes and reinforced enjoyment of the session. I was aware of this during subsequent interviews and considered it possible that the photography may have reinforced two participants’ learning about microbes and influenced some participants’ enjoyment of the session. I reflect on this further in Chapter 7.

I held individual participant interviews immediately after each session with all nine participants. These were audio recorded and ranged from between 12 and 20 minutes in length. The interviews explored qualitatively the reasons behind participants’ experiences of the session and the ways in which these were influenced by the learning environment. I also conducted a short knowledge assessment interview; a repeat of the questions asked at the pre-module stage. The post-module knowledge assessment is presented in Appendix 14 and the broader interview guide at Appendix 15.

Educator interviews (two interviews in total) took place on completion of each session. A semi-structured interview schedule enabled me to collect data on educator impressions of the course, experiences of delivering it and views on the context. Both educators were important mechanisms in KYB and had a role in setting course context. Audio recorded and subsequently transcribed, these interviews were therefore integral to the realist evaluation.

**Stage 3: Interviews six weeks after completion of the session**

Semi-structured interviews with participants took place six weeks after completion of the session during a lunch break at the course venue. These interviews ranged in length from nine to 25 minutes, were audio recorded and subsequently transcribed. The thematic focus of these interviews was reported behaviour change in participants’ lives and questions focused on health management in the intervening period; the role and suitability of health information; and any other relevant issues that have been important
since attending the course. These interviews also included the post-module knowledge assessment questions asked immediately after the session. Interviews were guided by a semi-structured guide (Appendix 16) that I had developed using the components of the initial middle range theory with guidance from the Research Development Group, and subsequently revised after analysis of pre- and post-module interviews. The photographs and a selection of course materials also supported interviews to elicit explanation of ways in which the mechanisms and context of the course had or hadn’t supported a change in planned or perceived behaviour.

Stage 4: Telephone interviews five months after session

Due to limitations on personal contact instigated by the COVID-19 pandemic, it was not possible to interview face-to-face at the five-month stage as initially intended. After discussions with participants and staff, it was agreed that telephone interviews would be most practical; many participants did not have internet access or skills and support to use internet-based methods (Seale, 2020). Interviews were conducted using the semi-structured interview guide presented at Appendix 17 and aimed to address longer term recall of the learning environment. The interview guide also incorporated the pre- and post-module knowledge assessment questions. Interviews lasted from between 20 and 45 minutes, and all were audio recorded. I had offered to post participants a selection of visual recall aids prior to interviews such as the photographs and course materials. However, they felt this was not necessary and could all recall the session.

5.8 Analysis

Analysis in a realist evaluation is largely focused on a process of retroduction, the identification, development and refinement of context/mechanism/outcome configurations, also often referred to as CMOC development (Jagosh, 2020; The RAMESES II Project, 2017d; Jagosh et al., 2015; Pawson and Tilley, 1997). As such, analysing realist evaluation data is a lengthy and complex process of refinement, often progressing through many iterations of CMOCs and searching for alternative explanations to ensure reliability of findings (Fletcher et al., 2016; Marchal et al., 2010; Byng et al., 2005; Pawson and Tilley, 1997). There is much diversity in the literature regarding how researchers
address the process of analysing realist evaluation data (Hoddy, 2019; Marchal et al., 2010; Westhorp, 2008; Byng et al., 2005). Few share their approach in detail but, as I will describe, my analysis methodology was guided by the literature and my own ideas about how I could approach the data robustly and comprehensively.

My dataset comprised interview transcripts, a written transcription of each KYB session, fieldnotes and a research diary of thoughts and impressions recorded throughout my research. Interview and observational data was imported into QSR NVivo 12 and prepared for analysis by establishing files, notes and data characteristics. Separate to this, I compiled a spreadsheet of participant characteristics and answers to questions about their understanding of hygiene, infection prevention and antibiotic use, thus developing an overview of their substantive understanding at the key interview stages. This was a useful way of building up a summary record for each individual and their CMOCs as I analysed the data. Figure 5.6 illustrates the steps in my analysis.

Figure 5.6 Stages of analysis
5.8.1 Stage 1: Thematic coding and analysis of interviews and observation

I initially coded all interview and observation transcripts inductively, identifying, recording and refining codes as I read through the data, a process informed by Braun and Clarke (2013). Although not a traditional first step in realist analysis, I wanted to ensure that I approached the data with as open a mind as possible and was not outwardly led by the individual components of the initial middle range theory I had developed after reviewing the literature. Although, as explained in Chapter 4, section 4.1.4, middle range theory is a key component of realist evaluation analysis and had already informed my data collection, I wanted to begin analysis by stepping back from the middle range theory, as a means of considering potential alternative explanations for the underlying theory of KYB effectiveness. I aimed to mitigate against the potential impact of the initial middle range theory on this thinking by focusing solely on the data, although acknowledging that it had influenced the generation of data at the outset. I would revisit this later once I had a more comprehensive grasp of the themes, experiences, and outcomes of research participants. The result was a clear picture of participant understanding, experience, and reactions to the session in the immediate and longer term. Table 5.3 shows the codes that I developed.
Table 5.3 Thematic codes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-theme (Level 1)</th>
<th>Sub-theme (Level 2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Course atmosphere</td>
<td>Enjoyment</td>
<td>Accessibility (linked to motivation and inspiration)</td>
</tr>
<tr>
<td>Learning and understanding</td>
<td>Activities and resources</td>
<td>Understanding (right or wrong)</td>
</tr>
<tr>
<td></td>
<td>Antibiotics</td>
<td>Style</td>
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<td></td>
<td>Educator</td>
<td>Views</td>
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<td></td>
<td>Keeping well and self-care</td>
<td>Impact on self-care</td>
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<td></td>
<td></td>
<td>Medication and antidotes</td>
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<td></td>
<td></td>
<td>Seek advice</td>
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<td></td>
<td></td>
<td>Serious signs</td>
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<tr>
<td></td>
<td></td>
<td>Using information</td>
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<tr>
<td>Learning from each other</td>
<td>Learning support</td>
<td>Good microbes</td>
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<td></td>
<td>Microbes</td>
<td>Handwashing</td>
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<td></td>
<td></td>
<td>Spreading microbes</td>
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<td></td>
<td>Motivation and inspiration</td>
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<td>Prior knowledge</td>
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<td>Venue and group size</td>
<td>Impressions</td>
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5.8.2 Stage 2: Identification of participant learning outcomes and development of pen portraits

Having thematically coded the data, I developed individual pen portraits for each participant summarising their background, describing their outcomes, and exploring how and why these occurred. ‘Outcomes’ in fact became a theme in my initial analysis, comprising different thematic strands which later would form the basis for the CMO
5.8.3 Stage 3: Identify context/mechanism/outcome (CMO) configurations at participant level for each stage of fieldwork

This step in my analysis involved returning to the focus of explanation (Jolly and Jolly, 2014) and identifying the CMO configurations at each stage of data collection: during the session, immediately afterwards, and six weeks and five months later.

There is much debate in the literature about difficulties in defining contexts, mechanisms and outcomes (Dalkin et al., 2015; Lacouture et al., 2015; Salter and Kothari, 2014; Jackson and Kolla, 2012; Marchal et al., 2010; Befani et al., 2007; Byng et al., 2005), and this is often a lengthy and complex process. In terms of methodological guidance, Pawson and Tilley (1997) are relatively unclear about the process of defining mechanisms in particular. Mechanisms are acknowledged to be particularly difficult to identify because of their hidden nature and the lack of clear definition and illustration in original and subsequent literature on realist evaluation (The RAMESES II Project, 2017a; Dalkin et al., 2015; Pawson and Tilley, 1997). This lack of guidance in Pawson and Tilley (1997) also creates difficulties and potential inconsistencies in interpretation which can lead to concerns about reliability of the CMO C development process, and therefore the end result.

Whilst I appreciate the reasons for lack of prescription (realist evaluation is a philosophy rather than a methodology), it does mean that the application of realist principles is challenging in this respect (Dalkin et al., 2015; Lacouture et al., 2015; Salter and Kothari, 2014; Marchal et al., 2010). For example, there is often debate about whether components of a programme could be constituted as mechanisms. Traditionally in realist evaluation, mechanisms are hidden in nature and therefore would not usually be represented by a fixed programme component (The RAMESES II Project, 2017a). However, I agreed with the researchers who suggest that programme components that could be applied differently should be included as a mechanism (Dalkin et al., 2015). The use and application of KYB resources was such an important component that I thought
was integral to the CMOC process, and I therefore decided to include the application of programme components as mechanisms.

After reviewing the literature, I adapted existing definitions and methodologies for CMOC development and analysis. A criticism of published realist evaluations is that accounts often lack detail on the methods used to define CMOs and subsequently develop middle range theory (Jamal et al., 2015; Marchal et al., 2012; Byng et al., 2008). There is some detail in the literature although most researchers address this only briefly. Byng et al. (2005) and Dalkin et al. (2015) provided useful accounts that I used as a basis for developing my own definitions of context, mechanism and outcome. These are shown in Figure 5.7.

In using definitions such as those I adapted, researchers such as myself are reliant on the literature and persistent scrutiny of the data in developing and validating their own approach. I was concerned about methodological rigour in this respect as two people may approach the same work differently and identify different findings. As a lone PhD student, I did not have the opportunity to share and refine this process with another researcher, and there was therefore potential for ambiguity in interpretation and definition. I overcame these potential issues by adopting an approach similar to Byng et al. (2005) and Marchal et al. (2010) by first grouping multiple CMOs into ‘bundles’ (2010) and then into levels (in my case, the individual, group and external). I discussed these with the RDG, supervisors and peers, and presented to the PHE team.
I then conducted frequent plausibility checks to ensure the accuracy and validity of my causal explanations, looking for alternatives, and verifying or disproving potential CMO interactions. This process is known in realist analysis as retroduction (Jagosh, 2020). It included analysis and re-analysis of data, consideration of potential counter arguments for my potential conjectures, further review of the literature, and discussions with supervisors. These strategies enabled me to address potential oversights, and support accuracy and validity of my findings.

I had considered using Lemire et al.’s (2012) Relevant Explanation Finder (REF) to support me in this process. The REF aims to provide a framework for identifying and examining influencing factors and alternative explanations. The framework consists of a table enabling assessment of the degree of influence of a potential causal explanation by noting its perceived certainty, robustness, range, prevalence, and theoretical grounding. In this context the REF could provide a structure for supporting objective decision-making regarding which influencing factors should be the focus of analysis. However, I discounted this framework as I felt it was relatively untested and thought it might constrain rather than guide my thinking.
For every participant, I worked through the transcripts and fieldnotes, identifying outcomes and looking for contextual and mechanistic components that appeared to be involved in generating that outcome. For example, Alan appeared to have learnt that antibiotics have a role with bacteria (although he couldn’t define this role precisely); he did not know this prior to the session but afterwards suggested this when asked if he knew what antibiotics did. This I therefore recorded as an outcome and then explored the transcripts for reasons behind that outcome or data that refuted this.

I recorded this information in the spreadsheet along with data on participant characteristics and circumstances, prior experience, expressed attitudes, prior learning and answers to specific questions about hand hygiene, self-care and antibiotic use. This way I could include all patterns of combinations for each outcome and each individual, and it was more feasible to summarise at the next stage.

The process was one of refinement rather than rejection; I rejected none of my initial CMOC thoughts, and instead refined them as I progressed through analysis and as the KYB session developed. I did not find competing theories as such, more different perspectives on an outcome – for example, most participants understood and valued the Managing Your Infection leaflet and could see how it could support them in making self-care decisions. This outcome was generated in a reflective way for some participants (who took it home and reviewed it themselves) but in an active immediate sense for others (who were enthusiastic and vocal about it during the session). Both were proactive responses.

I began analysis as soon as I had transcribed the first interview. Subsequent data were analysed concurrently, and previous data re-analysed in the light of new findings. This iterative process aimed to ensure that all relevant issues within the data were considered. This stage of the analysis was complete when I was confident that I had identified all outcomes and the reasons behind them.
5.8.4 Stage 4: Summarise CMO configurations at group level and revise initial middle range theory

To recap, and as described in Chapter 4, section 4.1.4, middle range theory is a broad abstraction of the theory of how a programme is, or is not, effective (programme theory). In this respect, middle range theory describes the components of a framework that are observable in the data as being effective (or not), and the reasoning behind the observed effect. Middle range theory is not an addition to programme theory but a more abstract way of presenting it, and thus provides a broader and more transferable description of the programme. A criticism of published realist evaluations is that they often lack clarity on how middle range theory is developed. As with mechanisms, there is little clear guidance in Pawson and Tilley (1997) and in the broader literature on how to develop middle range theory, essentially because specific rules would go against the grain of the open nature of realist evaluation. Specifically, there is still insufficient methodological evidence showing how researchers have progressed from CMOC analysis to actual middle range theory development (De Weger et al., 2020; Mukumbang et al., 2020; Marchal et al., 2010; Byng et al., 2008). Marchal et al. (2010) suggest that to overcome these limitations in the literature, presentation of analysis should include the combinations of attributes required for an intervention to be effective, the various alternative explanations that were considered, and the potential transferability of findings by showing the links with existing knowledge. I attempted this in the following ways:

- On commencing this stage of analysis, I had identified 51 contexts, 71 mechanisms, and 109 outcomes. There were only very subtle differences between some of the components, and to synthesise them into a more manageable and meaningful dataset set I explored the data in the spreadsheet visually, consolidating outcomes into thematic groups and further subgroups that summarised them. For example, the outcome ‘learning that antibiotics influence bacteria’ initially had 12 CMO configurations but was synthesised into the structure in Figure 5.8. I began developing a matrix of CMOCs as part of the analytic process (Astbury, 2013; Westhorp, 2008), conscious of some criticisms that these can be too linear in trying to address realist evaluation data. In fact, I found this matrix too cumbersome and difficult to navigate; my
spreadsheet was more effective in recording and analysing the full range of combinations.

Figure 5.8 CMO configuration summary: Learning that antibiotics have influence on bacteria

- I then conducted visual comparison of the CMOC themes and configurations that were in the spreadsheet with those that were identified during analysis of the structured literature review. The purpose of this stage of the analysis was to compare previously identified CMO configurations with those arising from the interviews and observation and suggest a refined CMO configuration that represented the evaluation outcomes and the reasons behind them. This was the revised middle range theory, referred to as MRT2.

5.8.5 Stage 5: Analysis of reported behaviour, complex systems and final refinement of MRT

Formal theory can have an important role in refining programme theory (Astbury, 2018; RAMESES II Project, 2017; Jolly and Jolly, 2014). As I had identified the integration of several formal theories in the development of KYB (outlined in Chapter 4, section 4.1) I
also felt that I needed additional tools to help address the complex theoretical construction of the course and to support understanding of the potentially complex layers of reality that were reflected in the session and afterwards. For this I used complexity theory and COM-B as previously discussed in Chapter 4, section 4.1.3.3 to guide me in my analysis. I had identified early on in my research that the KYB learning environment was potentially a complex social system. It had many parts including elements and relations that were nonlinear and potentially hierarchical but also connected. In the context of KYB these parts included three groups of components:

- Elements and relations: KYB educators, learners, activities, materials, behaviours.
- Non-linear components: interactions, attitudes and beliefs, understanding, connections inside and outside the formal learning environment.
- A hierarchical structure: different levels of KYB session delivery (teaching, learning, conversation, activities), different levels of learning (formal and informal learning environments, individual, group and wider community).

Conceptualising Know Your Bugs as a complex system thus enabled me to explore the learning environment in further depth and understand the many parts that ultimately connected within the system to form an outcome. Having identified the learning theories that were initially used in the development of KYB, I explored the data for instances in which these theories were evident and recorded their role in the CMO interaction. This was not intended to be an in-depth complex systems analysis; only a starting point for identifying the ways in which these theories played out in the implementation of the module.

As discussed already in Chapter 4, section 4.1.3.3, I chose to support the CMO analysis with use of the COM-B theoretical framework (Michie et al., 2013). Michie et al. (2009) found that behaviour change interventions could be applied in disadvantaged groups, and there is growing evidence in favour of these in the context of programmes aiming to support people with learning disabilities. Whilst some question the appropriateness of applying complex behaviour change approaches in this context (Taggart et al., 2021), others claim to have used techniques effectively (Overwijk et al., 2020; Waninge et al., 2018; Willems et al., 2017, 2018). I decided to remain open minded about this; I was not
developing a programme, simply complementing my broader analysis with a behavioural component. I achieved this by identifying and coding text and context that related to the capability, opportunity, and motivations of course participants, thus relating to the theories of behaviour that underpin KYB.

5.8.6 Stage 6: Reflective analysis of the collaborative research process

An important aspect of my doctoral research related to process; the process of conducting a collaborative study of public health education that aims to be accessible to adults with learning disabilities. My analysis therefore also included reflection on the research process and methods used. To achieve this, I imported detailed field notes and recordings of Research Development Group meetings, my research experiences, and impressions into QSR NVivo 12 for inductive analysis. I explored and coded text thematically for comments and phrases that related to the experience and efficacy of research activities and used this to understand what did and did not work regarding the research process, the application of realist evaluation methodology and the collaborative nature of the research.

5.8.7 Consolidating analytic outcomes

Although there was an incremental element to the six stages of analysis that are illustrated in Figure 5.7, each stage was also independently important. On completion of all stages of analysis I consolidated analytic outcomes by summarising in a chart the key themes and explanations identified at each stage.

5.9 Chapter summary

In this chapter I have described in depth the research methodology I developed, illustrating how I conducted the realist evaluation. This has included description of the retroductive process of identifying the components of causation and the strategies I undertook to overcome potential biases and oversights. In the following chapter I present and discuss findings that emanated from this research process.
Chapter 6.   Findings: How the learning environment influenced outcomes

In this chapter I begin by outlining descriptive findings in relation to the sessions I observed. I progress to explore how the context/mechanism/outcome (CMO) configurations identified during my analysis influenced the learning experience and outcomes for research participants.

6.1  Know Your Bugs in practice: Observation of the learning environment

The two sessions I observed during data collection were part of a broader course; a ‘Living healthily’ component of an independent living skills programme. Each programme was overseen by a different educator, referred to by the host organisation as ‘tutor’ and I therefore use this term in my session description and analysis. The programme had begun three months previously; this was the second term of the academic year, and there were nine participants in each session.

The tutors each developed their own lesson plans by selecting content from the Beat the Bugs course guide. The two sessions were similar in aims, structure and ethos; they addressed the same topics; they were relaxed and informal; and they adopted a discussion-based approach. The sessions were however quite different from the suggested KYB module. They incorporated components from other Beat the Bugs activities, aiming to recap on some of the learning that had been addressed previously or to use resources from previous sessions to support new learning. As identified later in this chapter, section 6.8, repetition and reinforcement were important components in the delivery of the module, and as such enabled me to explore how the activities interacted incrementally.
The evaluation therefore addressed a broader topic than Know Your Bugs (KYB). However, I have chosen to refer to the session as KYB because it was the tutors’ preferred way of delivering the module.

**Group 1 (January 2020).** This session took place in a large church building in a city centre in which participants met once a week during term time. The tutor led the session interactively and largely remained standing in front of participants using a flipchart to demonstrate and record information. The nine participants communicated with each other in a very relaxed and familiar manner. Figure 6.1 shows the room layout.

![Figure 6.1 Layout of Group 1 session](image)

Participants sat across two tables, for the most part four participants on one and five on the other. They were accompanied by three supporters, two of which were
generic to the group (LSA1 and LSA2) and employed by the local authority, and the other was the personal supporter (PS) of a specific participant, Michelle.

The session was just over one hour long. It included a recap on microbes; a discussion of mild illnesses; learning about antibiotics; a focus on how to help recover and stay well; and KYB antibiotic scenario discussions.

**Group 2 (February 2020).** This session took place in an annex of a larger building belonging to a furniture recycling organisation, centrally located in a medium-sized town. Participants attended one day every week during term time. As with Group 1, participants appeared comfortable and interacted well with each other socially. Figure 6.2 shows the room layout.

![Figure 6.2 Layout of Group 2 session](image)

The nine participants sat together around one table as always. Sitting with them were the tutor and five supporters; two of these were generic to the group and
employed by the local authority (LSA1 and LSA 2), and three were personal supporters (PS) for specific participants.

The session lasted just over 90 minutes and comprised a range of activities. These included a verbal recap on microbes and how they spread, followed by the ‘Magazine Microbes’ and ‘Glitter Microbes’ activities, a short video, discussion about being ill and the role of antibiotics. The session culminated in further discussion of illnesses and how to self-care.

Both sessions were therefore considerably broader than KYB and followed an incremental sequence that was similar. They addressed aspects of the Meet the Bugs, Spreading Bugs and Bug Busters modules. The tutors engaged participants in slightly different activities, however. Figure 6.3 illustrates the content of each session and the time spent on different components.
Figure 6.3 Actual content of the Know Your Bugs sessions

Group 2 experienced a longer session. This group spent considerably more time and activity than Group 1 on microbes and the consequences of their spreading (57 minutes in Group 2 as opposed to 16 minutes in Group 1). Discussions with the tutor prior to the session indicated that Group 1 had already addressed this topic in more detail previously, although the tutor felt it was important to recap. Group 1 spent more time on antibiotics than Group 2; they undertook the ‘Antibiotics Scenarios’ as well as the ‘Antibiotics Right or Wrong’ activity which was also covered by Group 2.

Both sessions addressed several learning outcomes that extended beyond those of KYB. These included understanding about microbes and how they spread, about
getting mild infections, and about the purpose and use of antibiotics. Both sessions also addressed the KYB outcomes about how to self-care and use information. The intended learning outcomes that were addressed are listed in Figure 6.4. This shows that 16 learning outcomes were addressed by Group 1 and 21 by Group 2. Group 2 covered more outcomes because they experienced a longer ‘microbes’ and ‘spreading bugs’ session. In the duration of this chapter, I will explore the extent to, and ways in which, these learning outcomes were achieved.

Specific learning outcomes were addressed using discussion and different materials from the Beat the Bugs course guide, although the two groups addressed the learning outcomes differently. For example, the topic of microbes was taught in Group 1 using a flipchart and discussion; and in Group 2 using the ‘Magazine Microbes’ and ‘Glitter Microbes’ activities, a video and discussion. Several
opportunities were taken throughout each session to address in different contexts the hand hygiene and spreading bugs learning outcomes. For example, in Group 1 Anne suggested participants might be interested in the handwashing techniques she’d learnt in her volunteering role at the hospital. In Group 2, Fiona instigated discussion about handwashing and cleaning the taps as she was preparing to take a toilet break.

Antibiotics was addressed as a key topic during both sessions and learning outcomes were repeated during activities and conversations. Tutors also used the group setting to summarise learning from other activities. In Group 2 for example, the tutor summed up the antibiotics component using the ‘Bug Busters’ poster and finished with a swift round of relevant questions:

Tutor: So, antibiotics dos and don’ts. Let’s see what we remember.
Try and treat yourself is better than using antibiotics. Yeah?

Alan and Susan together: Yeah

Tutor: Do we take other people’s antibiotics?

Several together: No!

Tutor: Should we take the antibiotic exactly as they’re prescribed?

Alan and others together: Yes

Tutor: Should we only take antibiotics when we really need them?

Together: Yes.

Tutor: I think we’ve pretty much nailed antibiotics.

(Group 2 KYB session)
Participants appeared to enjoy short, focused exchanges such as this and, in sections 6.6.1 and 6.9.4, I will discuss the ways in which techniques such as these may succeed in embedding antibiotics learning.

Both sessions were interactive and integrated discussion with activity. During ‘Antibiotics Right or Wrong’ participants read and discussed eight different statements and were asked to conclude whether they thought the statement was right or wrong. Group 1 undertook this as two separate sub-groups, each led by the participants and with support if necessary. Group 2 conducted this as a whole group around the table.

Participants had a role in determining session content and ensuring personal relevance. Tutors frequently asked questions relating to participant experience which would lead to conversations and learning about relevant issues such as using medication or how to deal with urgent health matters. Some participants often offered information or asked questions without being invited. For example, when discussing self-care in Group 1, Sonya volunteered information about using a voice-controlled virtual assistant to remind her when she needed to take paracetamol. This reminded other participants that they had such a device and enabled them to consider using it in the same way.

Both tutors incorporated repetition into their session and utilised opportunities for reinforcement. Specific topics were repeated several times throughout each session using different examples and scenarios. This included hand hygiene (why, how and when) and antibiotics (fight bacteria, don’t work on coughs and colds).

Both sessions were also sociable in nature. The atmosphere was informal, and participants were free to make drinks, take toilet breaks and ask questions or describe relevant experiences when they wished. Participants appeared relaxed and familiar with each other, the tutors, and the venues, and they chatted informally during activities or breaks. Group 2 conversations were often lively and animated with banter between participants or between participants and the tutor or support
staff. For example, during ‘Glitter Microbes’ Group 2 participants held several informal but relevant conversations about hand hygiene and sneezing:

Tutor: Yeah and then wash your hands. If you haven’t got a tissue, what should you do?

Mary: Wipe it on your sleeve [sarcastic!]

All: [Laughing]

Tutor: If you want to sneeze ... into your elbow.

(Group 2, KYB session)

6.2 Tutors and supporters

Both tutors were approachable and relaxed. Participants appeared to like the tutors and conversed in a relaxed manner with them. Both tutors knew the participants well and had incorporated their knowledge of participants within session planning and delivery. They felt that this was important, particularly due to the individual health issues experienced by some of the participants and the potential seriousness of some course content:

I think you need to be aware of their previous knowledge. One of the most important things you have to be aware of is kind of not scaring them too much and kind of reigning them in a bit because a lot of the times they have lots of medical issues.

(Tutor, Group 1)

Group 1 and Group 2 tutors thought that it was important to deliver this session later in the overall course in order to allow time to familiarise with participants and enable effective session planning. Both were inclusive in their style of educating
and responsive to individual participant issues. They responded positively to participant accounts of health experiences for example by answering questions and enabling the group to engage in further relevant discussion. Tutors aimed to focus on enabling independence within the session and the course:

Because it’s in independent living I want them, I encourage them to make their own food, um take turns washing up – we do it on a rota.
Yeah, they’re learning life skills, so very important.

(Tutor Group 2)

Each tutor was supported by two Learning Support Assistants (LSAs) who had been present throughout the course and sat with participants during the session. The LSAs supported individuals in session activity, interacting informally with participants and identifying and addressing support needs by answering questions or stimulating discussion. Personal supporters were also present during the session although only one supporter actively participated in the session (Group 1). This personal supporter facilitated the smaller group ‘Antibiotics Right or Wrong’ discussion.

6.3 The venues

The two venues were very different from each other although both were geographically accessible to most participants. Group 1’s venue was large with plenty of space for physical activity and for breaking off into smaller group discussion. Participants could make refreshments at a table and bring snacks, which they did and shared. Although small, Group 2’s room was attached to a kitchen where participants could easily make refreshments. The kitchen was also used for storage and some activities such as watching the video or preparing for ‘Glitter Microbes’.
Some members of Group 1 commented to me that the room was a little large and echoey; it could be difficult to hear other people at times. Some Group 2 participants commented that their room was small, and they were a little cramped around the table. However overall, participants appeared to be comfortable in both venues.

6.4 The participants

I have described previously some of the participants’ background characteristics (Chapter 5, section 5.4.2). The present section explores the participants in more depth, analysing their personal contexts and motivations that are relevant to the realist evaluation. All participant names are pseudonyms.

Motivations for joining the course varied amongst the participants. Alice, Kevin, and Alan joined to get out and do something for themselves although they all also said that they were particularly interested in the subject matter. Fiona was concerned about illness, particularly viruses. She described herself as paranoid in this respect and hoped that the course would enable her to understand and potentially become more rational in considering her health. Others were motivated to undertake the course because they understood and valued its potential contribution to their independence. Several participants also mentioned that they really enjoyed learning; Lisa, Michelle, Alice, Kevin, and Alan all referred to their enjoyment of learning in a healthy living context. Lisa said:

Lisa: I just love to learn. That’s one thing I like.

Interviewer: Is there anything in particular that you like to learn?

Lisa: I learn healthy food and that ... like different things. I want to learn. I like it. I love learning.

(Lisa, Group 1, pre-module interview)
Lisa was an outgoing participant who enjoyed interactive learning and was particularly looking forward to using creative methods to learn about microbes and self-care. Fiona described herself as ‘artsy’ and enjoyed participating in practical ways of learning such as craft and conversation. Many other participants also reported they enjoyed learning through discussion and illustration.

Although most participants had undertaken previous community education, they had very different prior health knowledge and experience. Alice for example had recently had pleurisy and had taken antibiotics. She had self-cared in this context but also cared for her husband daily and was experienced in addressing many health issues. Alice had good prior knowledge relating to all aspects of the session. Anne, however, also had healthcare experience and was supported by her family, boyfriend, and personal assistant in dealing with these issues. She had good prior knowledge about hand hygiene but had not heard of antibiotics and was less experienced in self-care than Alice.

I asked participants a series of questions that aimed to explore their knowledge of hand hygiene, use of antibiotics and self-care, the core learning outcomes of the session. I asked these questions before the session, immediately after the session and five months later to ascertain knowledge change and retention. Their knowledge encompassed the following:

**Microbes** – most had some prior knowledge of microbes although some had more insight than others. Alice and Lisa for example knew that colds were caused by a virus, and Anne knew that foot infections were often related to fungi. Mary knew the different types of microbes. Paul and Sophie did not indicate prior knowledge of microbes.

**Hand hygiene** – all had prior knowledge of hand hygiene. They all knew why and how to wash hands although again, some had more insight than others. Mary knew
to sing the ‘birthday song’ twice to ensure she washed her hands for long enough although Alan did not. Alice was aware of the ‘catch it bin it kill it’ advice.

**Antibiotics** – prior knowledge of antibiotics varied considerably. Participants in Group 2 appeared to have a better initial understanding of antibiotics. Four Group 2 participants suggested antibiotics fought infection and three thought they made us better. Five Group 1 participants did not know what antibiotics were, two thought they were tablets and two suggested they fought bacteria/infection.

**Self-care** – most had good understanding of self-care and were in fact addressing various health conditions. Some were able to manage their health issues independently and knew what signs to look out for. Lisa, for example, was self-managing IBS, anxiety, recurring urinary tract infections and severe headaches. Others were supported by family or supporters in the context of self-care. Paul, for example, was supported by his mother in managing health issues that regularly needed medical attention such as severe stomach pain, foot, and hearing issues.

### 6.5 Identifying how Know Your Bugs influenced the learning environment

To recap briefly, my aim was to use realist evaluation to develop an understanding of the ways in which community education initiatives such as KYB are effective for adults with learning disabilities, and thereby identify the components of an effective intervention. As outlined in Chapter 5, section 5.3.1, I began in traditional realist form by identifying three programme theories that represented the planned action and change regarding the intentions of KYB. The three programme theories that enabled me to understand the intended delivery and effect of KYB were:

- Incorporating several learning and behavioural theories within the development and delivery of KYB supports learning for diverse groups of people.
KYB as a summary session enables participants to recap and reinforce previous learning.

Interactive and engaging resources motivate course participants to enjoy learning and acquire knowledge.

I extended these to a further level of abstraction by conducting a scoping review of the literature and developed an initial middle range theory that proposes the contexts and mechanisms that together would generate outcomes for KYB participants (the CMO configurations). This is encapsulated within MRT1 in Figure 6.5, and detailed in Chapter 3. Broadly, this proposes that effective outcomes can be generated by a positive social learning environment that is flexible and aligned accessibly with individual needs.

My interviews and observations confirmed this theory. Group interactions and accessible, active learning contributed to a positive learning experience for all participants. However, my empirical findings also indicated that there was a bigger picture; one in which additional mechanisms, personal contexts, shared experiences, and accessible, engaging resources worked together to support KYB in generating an effective learning experience. Throughout my analysis I explored the ways in which the configurations were apparent in my data and refined the causal components of MRT1 (Figure 6.5) to produce a clearer perspective of the session and participant outcomes over time. This perspective is represented by the revised middle range theory, MRT2, and is described diagrammatically in Figure 6.6.
Figure 6.5 Initial middle range theory (MRT1)

Figure 6.6 Revised middle range theory (MRT2)
As is usually the case in realist evaluation, it is not possible to summarise middle range theory in a single statement. There are too many CMO combinations to do this. To explain the components of my revised middle range theory and explore the ways in which these interacted within my data, I begin by outlining participant learning and personal context in Table 6.1 Participant prior knowledge and module learning. I then describe the session outcomes I identified during my analysis and explore the configurations that generated these outcomes.

### Table 6.1 Participant prior knowledge and module learning

<table>
<thead>
<tr>
<th>Alice (Group 1)</th>
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| Prior knowledge: | Importance of handwashing regarding hygiene.  
Antibiotics kill infections. Unsure of consequences of overuse.  
Several self-care strategies. |
| Knowledge gain: | Antibiotics – overuse can lead to resistance and antibiotics might therefore not work.  
Handwashing – more detailed understanding at post-module stage. |
| Mechanism of knowledge gain: | Discussion led by tutor on consequences of overuse. Recap discussion on hygiene. |
| Key personal contextual issues: | Already had good knowledge of self-care and using medication including antibiotics. |

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<thead>
<tr>
<th>Anne (Group 1)</th>
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| Prior knowledge: | Importance of handwashing regarding hygiene.  
Not heard of antibiotics.  
Some self-care strategies. |
| Knowledge gain: | Antibiotics – heard of them, become unwell if overuse.  
Self-care – new strategies if unwell but did not recall these in longer term.  
Handwashing can get rid of germs. |
| Mechanism of knowledge gain: | Group discussion including discussion about self-care using MYI leaflet and recap discussion on hygiene. |
| Key personal contextual issues: | Has experience of addressing a range of health issues.  
Has a wide support network (family, boyfriend and his father, PA). |
<table>
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<th>Carla (Group 1)</th>
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<tbody>
<tr>
<td><strong>Prior knowledge:</strong></td>
<td>Handwashing prevents spread of microbes. Antibiotics kill infections. They can become resistant and not work if we overuse. Several self-care strategies.</td>
</tr>
<tr>
<td><strong>Knowledge gain:</strong></td>
<td>None – knew already.</td>
</tr>
<tr>
<td><strong>Mechanism of knowledge gain:</strong></td>
<td>N/A</td>
</tr>
<tr>
<td><strong>Key personal contextual issues:</strong></td>
<td>Does not self-identify as having a learning disability. Prior to the session had already achieved the learning outcomes.</td>
</tr>
</tbody>
</table>

<table>
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<tr>
<th>Julie (Group 1)</th>
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<tbody>
<tr>
<td><strong>Prior knowledge:</strong></td>
<td>Importance of handwashing regarding hygiene. Understands antibiotics are medication. Unsure of consequences of overuse. Limited self-care strategies.</td>
</tr>
<tr>
<td><strong>Mechanism of knowledge gain:</strong></td>
<td>Discussion about self-care using MYI leaflet. Recap discussion on microbes. Discussion led by tutor on consequences of overuse.</td>
</tr>
<tr>
<td><strong>Key personal contextual issues:</strong></td>
<td>Likes to learn using discussion. Has guidance from her mother on self-care.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Lisa (Group 1)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Prior knowledge:</strong></td>
<td>Handwashing addresses spread of microbes. Heard of antibiotics but not sure what they do. Some self-care strategies.</td>
</tr>
<tr>
<td><strong>Knowledge gain:</strong></td>
<td>Antibiotics – can help us get better, overuse can make us ill, reinforcement that may need antibiotics for urine infection.</td>
</tr>
<tr>
<td><strong>Mechanism of knowledge gain:</strong></td>
<td>Discussion activities – Antibiotics Right or Wrong, Antibiotics Scenarios, general antibiotics discussion led by tutor.</td>
</tr>
<tr>
<td><strong>Key personal contextual issues:</strong></td>
<td>Already had good knowledge about self-care and is experienced in addressing several personal health issues.</td>
</tr>
<tr>
<td>Michelle (Group 1)</td>
<td>Handwashing addresses spread of microbes. Antibiotics are wipes. Unsure what they do but drug us up/make us wheezy if we overuse. Some self-care strategies.</td>
</tr>
<tr>
<td>-------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Mechanism of knowledge gain:</strong></td>
<td>All through discussion activities – Antibiotics Right or Wrong, Antibiotics Scenarios Discussion on hygiene.</td>
</tr>
<tr>
<td><strong>Key personal contextual issues:</strong></td>
<td>Has undertaken a lot of adult education. Understands her health issues and signs to look out for.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Paul (Group 1)</th>
<th>Handwashing prevents spread of microbes. Not heard of antibiotics. Some strategies for self-care.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Knowledge gain:</strong></td>
<td>Nothing new – reinforcement about handwashing and self-care.</td>
</tr>
<tr>
<td><strong>Mechanism of knowledge gain:</strong></td>
<td>Discussion activities.</td>
</tr>
<tr>
<td><strong>Key personal contextual issues:</strong></td>
<td>Has several health issues which he self-manages with medication and equipment. Enjoys active learning and discussion.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sonya (Group 1)</th>
<th>Handwashing prevents spread of microbes. Antibiotics are tablets. If overuse we might faint. Several self-care strategies including internet searching for further information.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Knowledge gain:</strong></td>
<td>Antibiotics – become unwell if overuse, not needed for headache and flu symptoms. Self-care – dial 111 if unsure of symptoms and need advice.</td>
</tr>
<tr>
<td><strong>Mechanism of knowledge gain:</strong></td>
<td>Discussion during Antibiotics Right or Wrong. Discussion about self-care using MYI leaflet.</td>
</tr>
<tr>
<td><strong>Key personal contextual issues:</strong></td>
<td>Already had good knowledge about self-care and strategies for addressing this.</td>
</tr>
<tr>
<td>Group</td>
<td>Prior knowledge</td>
</tr>
<tr>
<td>-------</td>
<td>----------------</td>
</tr>
<tr>
<td>Sophie (Group 1)</td>
<td>Handwashing prevents spread of microbes. Heard of antibiotics but not sure what they do. Limited self-care strategies.</td>
</tr>
<tr>
<td>Alan (Group 2)</td>
<td>Antibiotics make us better. We become addicted if we overuse them. Importance of handwashing regarding spread of microbes. Several self-care strategies including in more serious situations.</td>
</tr>
<tr>
<td>Colin (Group 2)</td>
<td>Use soap and water for handwashing. Did not indicate knowledge of antibiotics. Take paracetamol if unwell.</td>
</tr>
<tr>
<td>Fiona (Group 2)</td>
<td>Antibiotics make you better. Doesn’t know consequences of overuse. Handwashing prevents spread of microbes. Some self-care strategies but also preventative strategies.</td>
</tr>
<tr>
<td>Name</td>
<td>Group</td>
</tr>
<tr>
<td>--------------</td>
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</tr>
<tr>
<td>Giles (Group 2)</td>
<td></td>
</tr>
<tr>
<td>James (Group 2)</td>
<td></td>
</tr>
<tr>
<td>Kevin (Group 2)</td>
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</tbody>
</table>
6.6 Outcomes

Whilst many aspects of KYB had a positive impact on participants, individual learning outcomes varied considerably and related to personal context and prior knowledge. Some participants acquired new, or reinforced previous knowledge about microbes and hand hygiene. Most also acquired further strategies for self-care if they became ill with a common infection. Some participants also acquired knowledge about antibiotics. The areas of outcome for participants were:

- A positive learning experience;
- Specific learning outcomes (knowledge gain, reinforcement and retention about microbes, hand hygiene, self-care, and antibiotic use); and
- Healthy behaviours (some reported behaviour change regarding handwashing and self-care).
The data suggest that all of the participants in both groups had a positive learning experience. Although not emphasised widely in the literature on adult health education and learning disability, the concept of a positive learning experience is one that is enjoyable, perceived to be effective and/or equips participants with some knowledge or skills gain. It can also support confidence in learning and set participants up for future learning success (Bergström et al., 2013). This was important for KYB participants as many had previously encountered some negative learning experiences such as being unable to follow in classes, declined registration on courses or generally feeling uninspired by some classes.

KYB was very different in this respect. Most participants appeared to enjoy the session. They were relaxed and attentive, many chatted informally about the topic during the session, most engaged in the activities, and some supported each other with relevant ideas and shared experiences. When left alone, Group 2 participants chatted enthusiastically about bacteria for example. Group 1 participants embraced the ‘Antibiotics Right or Wrong’ activity with zeal and exhibited satisfaction that they were working through the exercise as a group, undertaking appropriate discussion and often answering correctly.

The positive learning experience provided an effective backdrop to participant achievement, consequently reinforcing the positive experience. Alice, Sophie, and Michelle expressed a sense of accomplishment for example. Alice particularly enjoyed the educational component; she had found it inspiring and had enjoyed learning:

It’s interesting to find out different things ... All about viruses. All about everything else. You know, a session that floods your brain with information.

(Alice, Group 1, post-module interview)
Sophie commented during her post-module interview that the session had really ‘got me thinking’ about antibiotics and about hygiene. For Michelle, a sense of achievement seemed to be particularly important. She regularly asked whether she had provided the correct answer to a question; she was proud when she did and frustrated when she did not. She felt that she had achieved this and frequently expressed satisfaction with what she had accomplished.

The positive learning experience also seemed to remain with participants in the longer term. For example, five months after KYB, Alan recalled it as a positive session and expressed a personal sense of achievement. He remembered learning about bugs and appropriate health behaviour. Alan appeared very satisfied and confident that he had also transferred his knowledge outside of the learning environment to his daughter:

Yeah, I loved it. Because it was one thing that I’ve always wanted to do – learn about bugs. It’s not just that, I’ve been teaching my daughter as well. When she sneeze, she sneeze into her hands and then I say no if you gonna sneeze you fold your arm up and you sneeze into the corner where your elbow is so you’re not passing the germs onto other people. And if you sneeze into your hands you don’t shake hands, you go and wash your hands and get all the bacteria off your hands.

(Alan, Group 2, five-month interview)

In line with the intended aims of the module, positive learning outcomes included knowledge gain, reinforcement and retention about microbes, hand hygiene, antibiotics, and self-care. Learning outcomes varied amongst the participants, rather than between groups; some participants acquired much new knowledge across the range of topics covered whereas others gained relatively small snippets of knowledge in specific areas. Figure 6.7 summarises the main positive KYB outcomes.
6.6.1 Learning about microbes, hand hygiene, self-care and antibiotics

There was much variability in knowledge acquisition. The extent of learning about microbes for example varied considerably. Alan was enthused by learning about the widespread existence of microbes. James said that he had learnt generally about microbes that cause illnesses, and Giles demonstrated new learning about infections. Kevin’s learning was relatively advanced as he was already knowledgeable, interested and adept at interpreting some of the concepts. For example, he learnt from the video and subsequent discussion that good microbes were important in addressing diseases such as diabetes.

*I’m like diabetic and I didn’t realise it was something to do with like the stuff or something inside of you. Your good bacteria, I weren’t having enough of that and that can lead to diabetes and other things or something.*

(Kevin, Group 2, post-module)
All the participants had some prior knowledge of hand hygiene. Prior to the session most understood that handwashing could eliminate germs. They all also knew to use soap and water or an antibacterial substance to keep hands clean. All participants appeared to understand that hand hygiene was an important basic principle in fighting and preventing the spread of infection and potential illness. This is illustrated by Alan when discussing handwashing when visiting hospital:

‘Cos you could go into the ward and shake somebody’s hand then the bacteria from your hand will get on their hands and then they’ll get poorly even more.

(Alan, Group 2, KYB session)

This prior knowledge provided a good basis from which to learn further about hand hygiene and, alongside providing reinforcement on the topic, it appears that the session gave participants new ideas and further strategies for handwashing. Alan learnt to sing Happy Birthday twice while washing hands, Colin learnt that hand hygiene was important in relation to bugs, and Anne learnt that handwashing could eliminate germs. They also appeared to have retained this knowledge in the longer term. Five months after the session, all recalled that handwashing was important to prevent the spread of microbes. Participants also reported behaviour change in relation to hand hygiene in the longer term; almost all commented that they had increased the extent to which they washed their hands and described additional situations in which they would do so such as cooking and after touching animals.

An important focus of the session for both groups was how to self-care and manage common infections such as coughs and colds, where to go for advice, and how to identify and address more serious signs of illness. Most participants seemed knowledgeable about self-care in this context before the session; during pre-module interviews they suggested strategies such as taking paracetamol or a cold and ‘flu remedy, resting at home, keeping warm, and drinking lots of fluids. Some of the Group 2 participants suggested they would seek advice first of all, often from their GP.
After the session however, participants talked more confidently about self-care strategies; they offered further ideas and appeared more comfortable when conversing about the topic. Paul and Giles, for example, had initially suggested they might contact their GP if they felt unwell. After the session they said they would stay at home and take medication first. Similarly, Julie, Alan, Sonya, Sophie and Colin provided further ideas regarding action they would take if they felt unwell such as keeping warm, drinking and taking analgesia.

Antibiotics learning outcomes were inconsistent within and across the two sessions and over time. This was a more complex part of the session and prior knowledge and understanding differed quite considerably amongst participants. At the pre-module interview, seven of the nine Group 1 participants and all nine participants from Group 2 said they had heard of antibiotics. After completing the session, some of the participants offered a different perception of the purpose of antibiotics and it appears that the session instigated some knowledge gain in this respect. In Group 1 only two participants, Michele and Lisa, appeared to understand better the purpose of antibiotics after the session whereas all Group 2 participants were clearer in this respect. In fact, Fiona’s description of antibiotics after Group 2’s session was very clear:

... *what do they do? Um they attack the bad bacteria inside and they fight it and... if the bad bacteria’s weak then antibiotics win them don’t they?*

(Fiona, Group 2, post-module interview)

Prior to the session Fiona had suggested antibiotics ‘make you better’ but wasn’t able to provide other detail.

The session addressed other areas of learning about antibiotics including the effect of antibiotics on a virus and consequences of overuse. Again, knowledge gain and retention varied, and participants were often unclear in their understanding. For example, when asked directly whether antibiotics worked on a virus, Group 2
correctly said ‘no’. However, when discussing the statements during ‘Antibiotics Right or Wrong’ they appeared to be confused and gave inconsistent answers to the three statements that addressed this.

Most of the participants did not grasp the concept of antibiotic resistance. When asked on completion of the module what they thought might happen if they overused antibiotics, opinions were diverse. They ranged from ‘make you wheezy’ (Michelle, Group 1) to ‘make you ill’ (Julie, Lisa and Sonya, Group 1) to ‘become resistant’ (Alice, Group 1; Kevin, Group 2). Five participants in Group 1 and two in Group 2 changed their views about the consequences of overusing antibiotics. James changed his view from ‘make you sneeze’ to ‘overdose’; and Fiona, who didn’t know prior to the session, subsequently suggested our bodies become immune if we over-use. In the longer term, few retained their changed knowledge in this respect at five months; just one participant out of five interviewed in Group 1 and one in Group 2 recalled their new antibiotics knowledge.

So, how did these outcomes materialise? Using realist evaluation methodology, I explain this by identifying the contexts and mechanisms that together interacted to generate the outcomes I have identified.

6.7 The contexts for Know Your Bugs outcomes

As outlined in Chapter 5, Figure 5.9, I defined contexts as the actors or factors that are external to the environment. In using this definition, I was able to remain open minded and consider all potential environmental issues that may constitute a context, and thus able to explore the ‘for whom and in what circumstances’ component of realist evaluation in depth. My observation and interviews enabled me to clarify, refine and build on the contexts relevant to the KYB session that I had outlined in MRT1. As with MRT1, in MRT2 these contexts were physical, social, collaborative, personal and external. However, they were also active and, as I will shortly explain, this was a key feature of the KYB context. Figure 6.8 shows the ways in which MRT2 expands upon the findings in the literature that composed MRT1.
The contexts that supported learning for KYB participants were:

- A social context where participants could discuss comfortably; a positive group atmosphere, engaging conversations. I defined social context as the interactive setting in which social communication took place. It could exist
within the other contexts; for example, the physical context of the KYB session or the external context when going for walks together.

- A personal context that incorporated motivation and enthusiasm to learn and prior knowledge and experience. I perceived personal context as connecting experience, circumstance, attitude and skill.

- A physical context that was comfortable, familiar, and accessible. I defined physical context as the material surroundings in which learning took place. This was largely the course setting itself, although also incorporated reported physical contexts outside of this such as participants’ home environments, and thus connected with external contexts.

- A collaborative context in which they could work together. A collaborative context encapsulated co-operative activity in relation to learning.

- An active context in which participants could be mobile and participate in activity. I defined an active context as one in which there was physical and/or interactive movement and interaction.

- An external context that provided opportunities to practise or remember learning. An external context constituted any environment external to the physical course. This could include at home, in health settings or in social situations.

These contexts were not mutually exclusive. Indeed, there were often blurred boundaries between them. However, they provided a framework for consistent thinking in my analysis and therefore opportunity for considering and reconsidering possible explanations for the ‘in what circumstances’ component of realist evaluation.

### 6.7.1 A social context for learning

The data suggest that the social context was particularly important in determining a good learning experience and supporting learning outcomes. Both sessions provided a positive social space in which participants could discuss the topic, offer thoughts and experiences, and ask questions. For Michelle, it provided opportunity
to socialise, be proactive, and learn at the same time. For Fiona it was a place to relax and get away from some of the stresses of everyday life:

*I suffer from absolute anxiety sort of thing so to come in here is relaxing to do something else.*

(Fiona, Group 1, post-module interview)

This worked well for those that were outgoing in a social context, particularly Michelle, Alice, and Alan because they could contribute to conversations, share their experiences, and thus personalise their learning. It also worked for those who were quieter during the session because they could absorb information were not under undue pressure to contribute. Giles, for example, a relatively quiet individual during sessions, suggested himself that aspects of the social context supported his learning; when asked if he thought the interactive style suited him, he replied insightfully:

*I think it does, yeah ... because you can interact with other people and see what they think as well.*

(Giles, Group 2, post-module interview)

When asked about the session many of the participants spoke positively about the social context. Group 1 participants often referred to the course as a means of establishing and maintaining friendships, and this was evident during the session. Sophie, Michelle, Lisa, Alice and Carla engaged actively with and supported each other both regarding the course and other personal issues. Later they also supported each other when they were living in isolation due to the COVID-19 pandemic.

This social context therefore set the scene for positive learning by being amicable, supportive and simultaneously remaining relevant to the topic. Participants appeared to be uninhibited about asking questions and open to sharing health
experiences. This enabled them to self-direct their learning as well, ensuring that it addressed issues that were realistic and personal to them. Lisa, for example, asked about the appropriateness of using antibiotics for a Urinary Tract Infection. Sophie was able to describe her experiences of using antibiotics for a chest infection. Both sessions were therefore meaningful to participants in different ways, and relaxed conversations supported a positive group experience.

6.7.2 Personal contexts

Individual participants brought different experiences, motivations, and knowledge to the sessions. My observations concurred with Bergström et al. (2013) finding that the motivations and experiences people with learning disabilities bring to a setting can exist as barriers or facilitators to effective learning, and are important in establishing whether the experience is effective. In this respect, I identified broad areas of personal context that influenced learning: motivations and preferences; and prior knowledge and experience. Personal contexts varied considerably and I illustrate the diversity of these characteristics amongst four participants in Figure 6.9. These contexts were in fact part of a wider pattern of interactions with mechanisms that I will discuss later in this chapter.

Most of the participants were motivated to learn and knew their preferred learning styles. Mary was motivated by learning itself; she said she loved to learn and aspired to develop personally through knowledge gain. When asked why she was motivated to attend the KYB session she said:

I just want to learn more, be more intelligent.

(Mary, Group 2, pre-module interview)

Kevin was particularly interested in science and nature, and motivated to ask complex questions. Fiona said she was ‘fascinated’ and at the same time ‘paranoid’ about microbes.
Most participants could relate the course to their aims to live independently in the context of health and wellbeing. Some participants appeared to be more outwardly motivated than others; Alan was keen to relate his learning to his life for example, and Carla was motivated to gain confidence in self-management. Ian was less motivated about the course content; he attended principally so that he could be with his girlfriend who was also a participant.

<table>
<thead>
<tr>
<th>Motivations for joining KYB</th>
<th>Preferred learning methods</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Kevin</strong></td>
<td>- Discussion and engagement</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Using pictures as illustrators</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Watching activity</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Using pictures as illustrators</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Using art and colouring</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Writing</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Through games and having fun</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Discussion and engagement</td>
<td></td>
</tr>
<tr>
<td><strong>Fiona</strong></td>
<td></td>
<td>- Positive learning experience</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Antibiotics kill bacteria; mutate if overused</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Microbes really are everywhere</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Dial 111 or contact pharmacist if need advice</td>
</tr>
<tr>
<td><strong>Lisa</strong></td>
<td></td>
<td>- Positive learning experience</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Reassurance on addressing infections</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Better understanding of antibiotics: do not share, always complete the course, consequences of overuse</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- New self-care strategies including use of MYI leaflet</td>
</tr>
<tr>
<td><strong>Sophie</strong></td>
<td></td>
<td>- Positive learning experience</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Antibiotics can help us get better, overuse can make us ill, reinforcement about when to use antibiotics</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- New self-care strategies</td>
</tr>
</tbody>
</table>

*Figure 6.9 Four personal contexts: Kevin, Fiona, Lisa and Sophie’s motivation,*
Whilst initial motivations inspired many participants to learn, the positive nature of their learning experiences also motivated them. Carla said:

*I’ve just needed to build my confidence and it’s been really helpful.*

*It’s going back to basics and that’s been really really good. And I feel a lot more positive and that now than obviously when I did and I think it’s because I’ve been coming to this every week and yeah.*

*(Carla, Group 1, pre-module interview)*

These personal motivations and preferences were an important context to individual learning, and the mechanisms that emerged during my analysis illustrated how KYB accommodated these preferences. However, they did not work alone; there were many complex interactions between context and mechanisms, and I will shortly discuss how these facilitated outcomes.

All participants had some prior knowledge and experience that formed a basis for their further learning. Prior knowledge varied considerably within each group however. It included knowledge about microbes, hygiene, self-care, and some antibiotics knowledge. Whilst knowledge about antibiotics was very variable, all had a good basic knowledge of hand hygiene and the essentials of self-care. It also seemed that everyone could relate to the experience of having mild infections such as coughs and colds.

All participants were experienced in addressing personal health issues and many were managing long term conditions; some with and some without support. In this respect there was a diverse range of knowledge and coping strategies within the group that would potentially impact their learning needs and the contributions they could make in a whole group setting. This was also important in realising personal learning and some were able to relate learning to their own experience and lifestyle. Alan, for example, was often able to offer experiences relating to a conversation topic such as urgent healthcare or educating his daughter about
bacteria. Michelle was able to relate use of honey, lemon, and paracetamol to when she had a cold. Importantly, most participants expressed an aspiration to manage their health independently as with other aspects of their lives. Anne for example often spoke about her aspiration to be more independent. For her this meant managing her health but also living with her boyfriend and having a paid job. She said:

*I’m trying to be independent, and I have a PA who comes in on Tuesdays to help me for my independence.*

(Anne, Group 1, pre-module interview)

### 6.7.3 Physical contexts

The venue, group size and participant combination provided an important physical context for a positive learning experience in both sessions. Participants in both groups appeared to be comfortable and content within the venue. It was geographically accessible to most of them, familiar, and supported independence by enabling them to freely make refreshments and use facilities. Each time I arrived, participants were very welcoming and appeared very comfortable physically and socially. Michelle in Group 1 offered to make me refreshments and show me around for example. In Group 2, participants would regularly pop to the kitchen to make refreshments.

Although Group 2’s room was a little small and Group 1’s large, participants did not appear to be uncomfortable. Lisa in Group 1 mentioned it was sometimes difficult to hear because the acoustics were not good in a large room, and Alan commented that the Group 2 venue was a little cramped. Their learning experience may have been improved with a more moderate size of room. However, although Lisa commented that the noisiness meant it was a little difficult to hear and focus at times, the other participants did not report that these physical limitations affected their learning.
6.7.4 A collaborative context

In the context of KYB, I have defined a collaborative context as one in which participants, educators, supporters, and participants work together to generate learning. This context was a feature of both groups. Sessions were planned and initially led by the tutors who were motivational, knowledgeable in the main and flexible in the context of KYB. They were responsive to participant needs and incorporated flexibility within their session planning (Note, this is also a mechanism that I will describe shortly).

At times participants were effective in managing each other. For example, Michelle asked Paul several times to read more loudly when they were involved in the ‘Antibiotics Right or Wrong’ activity. This was effective as Paul succeeded in reading out a statement in a way that the others could hear and understand, and Michelle was able to understand the antibiotic scenario that Paul was reading. Differences between participants did arise on occasion but these were well-managed by tutors.

Support staff, also part of this collaboration, were knowledgeable, intuitive and appropriate, adept at identifying where they were needed. Formally, support was provided by Learning Support Assistants (LSAs), personal support workers, tutors, and other participants but only when an individual appeared to need it. Participants also supported each other informally at times, such as when having discussions about antibiotics and about self-care. This support helped participants to gain a better learning experience because it addressed their individual needs in a sensitive manner. I did not observe any situation where support appeared unwelcome or ineffective.

Occasionally, this collaboration was not so effective. Kevin for example was relatively advanced in his knowledge and questions regarding bacteria. The complexity of the subject, lack of knowledge on the tutor’s part, and the absence of follow-up discussion led to lack of resolution for Kevin in this context.
6.7.5 External contexts

I defined an external context as one that was outside the KYB session. This included, domestic, work and leisure settings; important because they provided a framework for reinforcing, implementing and extending learning (Bergström et al., 2014). Previous external contexts, those that participants had experienced prior to the course and referred to them during discussions, were also important in this respect. They provided realistic examples of health scenarios to which participants could relate and therefore could attribute learning to situations in which they might have to make health decisions. A good example is provided by Group 2’s discussions about dealing with more serious signs of illness, specifically the listing of chest pains on the Managing Your Infection (MYI) leaflet. Participants suggested courses of action that involved engaging with external contexts such as going to the hospital, dialling 111 and thereby seeking telephone advice, or calling an ambulance. They held effective conversations about their experiences of doing this. This is illustrated in the following excerpt from the Group 2 session where Alan raises his experiences of being taken to hospital with chest pains by ambulance:

Alan: With err chest pains when I had them they get you on the phone they ask are you still breathing. Course I’m still breathing I say, I’m on the other end of the phone talking to you. Then all of a sudden they ask “where do you live, what’s your phone number, what’s your postcode? Stay on the line, we’re sending some help”. And then all of a sudden they’ve got the help and you’ve got to sit there and explain to the paramedic what’s the symptoms? Chest pains so they wire you all up to the machine and that lot. And to see if it’s quite bad, give us a number between nought to ten. And all of a sudden they said right we’ll take the bags out and we’ll come back for you. Well I got as far as the main gate. I couldn’t walk any more. They had to… they get their chair then lay on the bed.

Tutor: OK. And so were you admitted?
Alan: No they err sent me home that same night. They done more tests.

Tutor: Oh they sent you to hospital then.

Alan: Yeah and then a couple of days later I then got a phone call from the GP to go up and see him and then he was on the phone to the hospital “why didn’t you keep him in?”

Tutor: And did they find out what was wrong?

Alan: Yeah it was just sort of like chest pains and that lot.

(Group 2 KYB session)

After this exchange there followed a lively discussion about experiences in going to hospital and making decisions about urgent self-care, thus reinforcing participants’ learning about addressing such situations and enabling them to relate this to realistic situations.

The course context external to the session also helped to build a supportive learning experience and to enhance outcomes through positive activity and conversations about health. I did not observe these personally but recorded many instances during which participants talked about them. Group 2 participants went for a daily walk and had a weekly ‘weigh-in’. Group 1 participants undertook physical weekly activity together after the KYB session. Both activities had a health and social purpose, a role in underpinning the social and physical context of KYB, and supported preparedness to learn. Group 2 for example talked enthusiastically about their ‘weigh-ins’ and walks, relating them to healthy living.
6.7.6 An active context

In the context of KYB, an active context was one in which participants could discuss ideas and experiences, participate in designated activities, get up and move around regularly, and address their physical needs. This context was present in both groups. It provided a framework for participants to remain attentive and feel positive, not sitting still for too long. It also supported independence and therefore a positive learning environment because participants could attend to their physical needs and simultaneously contribute to the session.

Both sessions included good examples of how an active context supported learning. Paul in Group 1 discretely left the room voluntarily twice because he needed to sneeze and wanted to wash his hands afterwards. When he returned, he explained why he had left the room and what he had done. The active context enabled Paul to make decisions in relation to his knowledge gain and relate these to a real-life scenario. Another example is when Mary needed to use the bathroom. As she informed the group that she was doing so, the tutor used this as an opportunity to hold a reinforcement conversation about handwashing:

Mary: Just going to the toilet.

Tutor: OK, what do you need to do when you’re finished?

Mary: Wash your hands and sing Happy Birthday twice.

Alan: What? Happy Birthday twice?

Tutor: Yeah, well done. And do you just go like that? [simulating a quick wash of the hands]

Mary: No.

Tutor: What should you be using?
Ian: Soap.

Tutor: Just water? Cold water?

Mary: No, soap. Hot water, in’t it? [Getting up to go to the loo]

Tutor: Good.

Mary: Do you want to come and remind me?

[Everyone laughing]

(Group 2 KYB session)

6.7.7 The pandemic context

A new context emerged during the course of the fieldwork that is likely to have impacted upon learning, knowledge retention and behaviour change in relation to KYB; the COVID-19 pandemic. An infectious disease caused by a coronavirus that was discovered in 2019, COVID-19 spread rapidly during 2020, and was quickly defined as a pandemic. To help address the disease, England entered into a period of restrictions in March 2020 whereby the Government required the population to stay at home wherever possible and prohibited many public activities. Additionally, those who were classified as ‘vulnerable’ in a health context were required to shield at home, meaning they were not allowed to undertake activities such as shopping, meeting and physically attending appointments. This period was known as ‘lockdown’ and coincided within my data collection period, specifically during the time between the six-week and five-month post-module interviews.

During this time there was much publicity around handwashing and self-care as another means of addressing the virus. This gathered momentum as the pandemic spread and it is likely that this context reinforced understanding about hand hygiene and self-care amongst KYB participants. Each time I visited the groups they
talked about the pandemic more intensely. Certainly, at six weeks (March 2020) and five months (July 2020) after completing KYB, most participants reported that they had increased handwashing, and most were confident in suggesting strategies for self-care if they were ill with flu-like symptoms. Figure 6.10 shows a timeline of relevant COVID-19 events and how these coincided with my data collection.

**COVID-19 pandemic timelines**

**KYB data collection timelines**

**Figure 6.10 COVID-19 and data collection timeline**

The COVID-19 pandemic had not emerged at the time of my research planning, and as such was not originally intended to be a consideration in my research. However, as it emerged, the existence and spread of the pandemic became an important subject during my data collection. I had many conversations with participants about the disease and its implications for them, especially in relation to their concerns about addressing the disease and, later, their experiences of living during a period of social restrictions.

**Concerns about addressing the disease** – many participants expressed concern about COVID-19. They were aware of the disease from the outset, although their reactions varied. During post-module interviews with Group 2 in February 2020, Kevin was initially concerned about the virus but thought that it would not reach
him geographically. Fiona however was extremely anxious. Six weeks post module in March 2020, Kevin had become concerned about the wider health implications for himself as a diabetic who might become ill with COVID-19. At this stage, Fiona was even more stressed about the pandemic:

*It’s so terrible, I can’t bear this virus. It’s horrible. Loads of other people can’t either. I can’t even … I was so anxious about coming here this morning in case it weren’t on.*

(Fiona, Group 2, six-week interview)

Fiona felt reassured by coming to the sessions. The tutor supported Fiona and other participants with advice regarding their concerns, although was also concerned about how they would address these when they were in isolation.

**Living through ‘lockdown’** – the participants that I interviewed five months after completing the module had experienced life with UK ‘lockdown’ restrictions during which they predominantly had to stay at home. At the time of these interviews (June/July 2020), they were still living within a constrained social climate. None had been ill in the intervening period although some were feeling very despondent about the arrangements; isolated, and anxious to remain healthy and see family and friends. Alan said:

*It’s just a nightmare because with everything going on and that I can’t really do anything.*

(Alan, Group 2, five-month interview)

Others appeared to be positive about life in a period of social restrictions and showed resilience in addressing it; Julie had become accustomed to going out shopping with her mum wearing a mask, and Alice had begun to enjoy gardening during the ‘lockdown’ period.
I’ve got artificial grass and I’ve got pots and plants in the ground and I’ve got a herb garden. I’ve been doing gardening during shut down.

(Alice, Group 1, five-month interview)

All of the contexts I have identified were related and indeed often merged; personal contexts often merged with external contexts, and with active or collaborative contexts. For example, Fiona’s personal context included high anxiety about becoming ill with a virus and this motivated her to attend the course. The external context generated by COVID-19 introduced a new concern for Fiona (and others), heightened her anxiety about influencing her health, and intensified her attitude to learning. Later in this chapter, section 6.9.3, I show how the COVID-19 context and KYB interacted in a positive configuration to support participants in addressing the pandemic.

6.8 Interactions within the learning context that generated outcomes: the context/mechanism/outcome (CMO) configurations of a realist evaluation

The mechanisms, contexts and interactions identified in the initial middle range theory, MRT1, were indeed apparent during my observation and interviews. However, my research has exposed a more in-depth understanding of the ways in which the session did or didn’t work for participants by identifying further mechanisms and how they configured with contexts to make a difference to participants. Initially, I identified 39 detailed mechanisms. After further analysis I developed a second iteration, grouping items into 24 mechanisms within six different headings representing CMOC headings. Figure 6.11 displays these mechanisms and shows the change between them prior and post fieldwork.

My research confirmed that four of the mechanisms I had identified through analysis of the literature and displayed in MRT1 were instrumental in generating good outcomes during KYB. These were: ‘accessible teaching methods and
techniques’, ‘visual and interactive resources’, an ‘effective educator’ and ‘appropriate involvement of supporters’.

The other mechanisms in MRT1 were active during the session but they were re-grouped within overarching mechanisms that I redefined during the second iteration of analysis. As such, ‘course fidelity alongside flexibility’ was incorporated within ‘accessible teaching methods and techniques’, ‘visual and interactive resources’, and ‘effective educator’ in MRT2. The MRT1 mechanism ‘small group or 1:1 learning’ was incorporated within ‘effective educator’.

The additional mechanisms identified as part of MRT2 were: ‘facilitation of independent thinking and planning’ and ‘relaxed and effective participant interactions’. Most mechanisms interacted with each other and within the contexts described previously. I did not identify an instance where a single mechanism worked alone; in fact, most CMO configurations included all of the mechanisms I have identified. The remainder of this section briefly describes each mechanism and illustrates how it interacted with context to generate outcomes.
Figure 6.11 Mechanisms developed during Know Your Bugs evaluation

6.8.1 An effective educator

The previously described contexts of a positive social atmosphere and individual personal contexts supported tutor-participant engagement. Both tutors were engaging in the group context and, at the same time, responsive to individual needs. As the tutors had developed good relationships with the participants over time, were sensitive to their needs, and experienced in facilitation, they were able to adapt to address the needs of each individual. In this context, familiarity, sensitivity, experience, and adaptation were important components of an effective
educator. For example, the Group 2 tutor was adept at alleviating Fiona’s anxieties about illness and infection and enabling her to have a realistic perspective. This contributed to Fiona’s positive learning experience as well as supporting learning which she recalled with enthusiasm, although was still a little anxious about the COVID-19 pandemic:

Yeah ‘cos it’s really really really basic ‘cos I can’t take take two or even one thing at a time. If it’s artsy stuff like that, I can get absorbed with it and like um yeah it’s like fun stuff. Nothing fun about what’s going on now. A few weeks ago yeah it was fun but now, no.

(Fiona, Group 2, six-week interview)

Sessions were often lively, and tutors succeeded in instigating and managing relevant input from most of the participants; tutors’ choice of language was accessible and the material was presented in a way that participants understood and to which they could relate. Tutors tried to be inclusive and would subtly draw participants into conversations if they were inactive for a while. They achieved a good balance between remaining on topic and enabling participants to have a role in determining their learning through their conversations and questioning. This is illustrated when the Group 2 tutor and a LSA succeeded in bringing Susan into a conversation about identifying more serious signs:

Susan: I did that once, it’s not good [phoned emergency services].

Tutor: Did you faint?

Susan: Aha.

LSA1: It’s embarrassing isn’t it?

Tutor: Were you ok though?
Susan: Not really. Had to go to hospital.

Tutor: Did you? Did they find anything?

Susan: Yeah they said it was a seizure.

(KYB session, Group 2)

In this excerpt Susan, who was usually very quiet during sessions, volunteered information about an emergency experience. Both the tutor and the LSA supported Susan in further engagement and information sharing about the topic. This facilitated learning for the group and enabled Susan to make positive and relevant contributions about the topic.

Both tutors were liked by participants. The tutors were relaxed, friendly and responsive to participants’ needs. For example, Group 2’s tutor responded positively to challenging questions raised by Kevin. Although the tutor was unable to provide direct answers to some of his questions, she ensured that Kevin could talk through some of his questions. This also worked particularly well for Anne, Paul, Alan, Lisa and Fiona; they could ask questions, discuss answers and thereby learn about the topic. These interactions were an important mechanism in ensuring that individuals had a positive learning experience and worked well because the social context was engaging.

Tutors succeeded in maintaining enthusiastic engagement from most participants. Reflecting on both sessions in my fieldnotes I found that there was a genuine feeling of satisfaction at the end of both sessions, contributing to a positive atmosphere and learning experience. For example, engaging conversations about illness and self-care took place at both venues, and participants acquired different strategies to manage illness; Kevin that he could dial 111 if he needed advice; Paul to take tablets, stay at home and drink fluids if he felt unwell.
Tutors commented that it was at times challenging to be inclusive; despite tutors adopting an engaging and knowledgeable style, not everyone appeared to be engaged all the time. As with any group, individual personal contexts varied, and some participants were more easily engaged than others. To address this, the Group 2 tutor subtly asked questions as a strategy to include participants in discussion activities, and to monitor participant understanding and progress during the session. When asked how they engage and assess participants the Group 2 tutor said:

*By their questions. And by their yeah their general interaction I find um you can see who is still with us and who you know we’ve gone too far.*

(Group 2 tutor)

This worked well because the tutor knew the participants well and was insightful in their questioning and overall management of the session.

The tutors encouraged independent thinking and contributions, asking open questions such as ‘who can remember …’ when recapping on microbes (Group 1 tutor) or more closed questions when the topic became more complex: ‘Are all microbes bad?’ (Group 2 tutor). The Group 1 tutor encouraged input from participants by enthusiastically recording contributions on a flipchart in front of the group. These actions appeared to support participant engagement with learning by enthusing them and working well with activities and interactions. This also enabled tutors to monitor learning informally by assessing individual progress according to their contributions.

Although approached differently in the two sessions, the tutors’ management of groupwork within the group discussion social context was effective in several ways. It enabled students to discuss and explore the topics, relate them to their own experiences, share knowledge and thereby learn, personalise, and reinforce learning. Group 1 alternated between large and smaller groups; smaller groups for
focussed discussions and the large group for introductory learning or feedback. This approach appeared to work particularly well for Sophie, Julie, Sonya and Paul, quieter members of the group; it provided greater opportunity to participate in discussions in the smaller groups, followed by opportunity to listen and gain reinforcement in the larger group. This also was effective on an informal level in Group 2. Although not strictly divided into groups, by working around a big table on activities such as ‘Magazine Microbes’ participants tended to form informal smaller social groups, chatting about the topic while they worked within the large group context.

6.8.2 Accessible teaching methods and techniques

‘Accessible teaching methods and techniques’ incorporated several components: course fidelity and flexibility, incremental delivery, reinforcement and repetition, effective conversations, and working at an appropriate pace. The course guide formed the basis for fidelity and flexibility. Both tutors thought that it was an effective resource; it proposed many enjoyable and effective activities and was easy to follow. The Group 2 tutor commented:

The resources in the book I feel are fabulous. There are lots of ideas to choose from for each topic which I like as opposed to one. There is a variety to meet people’s needs.

(Group 2 tutor)

Although tutors used the guide as a basis for the session, both were flexible in their interpretation of activities and worked within their knowledge of participant personal contexts. The relaxed and effective participant interactions were also an important mechanism here, enabling participants to discuss and direct learning to suit their personal contexts. This worked well in supporting learning about microbes for example; Group 2 could participate in activities addressing new learning whereas Group 1 were subjected to a basic recap to re-address previous learning.
However, it was less effective regarding antibiotics learning; here, the additional mechanism ‘visual and interactive resources’ was not aligned with most participants’ personal contexts. As I discuss further in sections 6.8.2, 6.8.3, and 6.9.5, resources were not fully accessible and not fully understood by all participants.

The interactive nature of the session and the accessibility of the tutors’ styles enabled participants to be involved through undertaking activity, holding effective conversations, and asking questions. In doing so, participants influenced the pace and content of the session to ensure it suited them. An effective educator was also key in this as they assessed as they went along. Tutors monitored participant progress informally as the session progressed; when questioned about pace and how to monitor progress one tutor said:

"By their questions. And by their yeah their general interaction I find um you can see who is still with us and who you know we’ve gone too far."

(Group 2 tutor)

Many participants commented that they had understood everything (even though at times they hadn’t) and that they had found the sessions accessible. They also appeared to enjoy the session and achieved during it. In this respect, the mechanism ‘accessible teaching methods and techniques’ was an important component in generating another mechanism; the ‘positive learning experience’. Michelle for example, was not only able to keep up with discussions about self-care and antibiotics but contribute to them and interact, thus providing a sense of achievement. This was also effective for those who raised questions during the session such as Sonya, James and Giles in Group 2. Paul too (Group 1), with support, was also able to keep up and absorb information in some but not all topics.

Tutors planned the session so that it developed incrementally and logically. Participants moved on to a new component once one had been completed. Tutors decided when it was time to move on although this was often led by participants
indicating they had acquired the intended knowledge. Tutors assessed this informally through questions and responses to ascertain participant understanding of what had been addressed. This worked well within a social context of discussion such as this and with the physical layout and management of both groups. For example, Group 1’s recap of microbes was relatively quick but this was effective because they had already covered it in detail previously. It was short enough to retain interest and in fact was a lively part of the session; all participants engaged enthusiastically in exchanges about microbes and the illnesses they can cause. They appeared to enjoy this, and it was likely motivating for them to realise they had remembered what they had learned previously. In fact, the tutor was impressed at how much they recalled.

The incremental approach to delivery of the session also facilitated a positive learning experience because it developed in accordance with participants’ personal contexts, specifically their motivations, learning preferences and knowledge. For example, Michelle was able to receive regular affirmation that she was learning and contributing correct answers. It also offered participants enjoyable variety during the session, thus experiencing small achievements as they moved through the session.

Tutors used repetition and reinforcement throughout the session. Repetition is often cited as an effective means of reinforcing learning (Bergström et al., 2013). Both tutors approached this by repeating learning concepts and embedding them within a context of discussion and accessible resources. This was particularly beneficial for participants such as Lisa who liked active learning and was unable to concentrate for long. Tutors were effective at grasping opportunities to reinforce learning and engage individuals in conversations such as the example I cited in section 6.7.6 when Mary from Group 2 was going to use the bathroom. Another effective example was provided by Lisa when she provoked further learning about treating bacterial infections. In this situation the tutor responded to Lisa by moving the group on to a learning component about using antibiotics:
Lisa: How about a water infection?

Tutor: That is a bacterial infection so you may need antibiotics for that. So, we’ll look at that ... so antibiotics only work on bacterial infections. If you’ve got a cold or you’ve got a sore throat, then they’re not going to work. And you may develop something called antibiotic resistance, do you know what antibiotic resistance is? What is it? Do you know what it is? If you’re resistant to something, what does it mean?

Alice: They don’t work when you’re on them for a long time.

Tutor: Yes. Good. So, it means if you keep taking lots of antibiotics they stop working. So, if you really need them and you take them your body will say oh, I’m used to this now, it’s not going to work.

(Group 1 KYB session)

However, antibiotics discussions were not accessible to everyone. Paul, Anne, Sophie and Michelle did not understand some of the antibiotics discussion nor some of the resources. The excerpt here shows how quickly the tutor moved through this topic; it appears a little too quickly for some participants.

Group 2 used feedback to share knowledge about microbes, learn from others and to enable the tutor to monitor learning. This worked well during the ‘Magazine Microbes’ activity where participants were each asked to informally present their collage. Participants that had otherwise remained relatively quiet within the group showed that they had good knowledge and ideas regarding the topic. James for example presented a collage that included a baby’s changing mat; an item which has significant potential for spreading bacteria. The Group 1 tutor also encouraged individual contributions to support the session; here participants provided thoughts and ideas about types of microbes, the illnesses they can cause and what we can do about them.
6.8.3 Visual and interactive resources

The social, personal and physical contexts combined with accessible activity and resources enabled participants to engage with an interactive approach to learning. The activities were only partially a fixed component of KYB; they were fixed in that they were described in the course guide but the way in which they were adapted and delivered influenced the experience of participants. For most, the activities were enjoyable and relevant because they were visual, interactive, and accessibly illustrated learning. These also supported the positive learning experience. Mary said:

*Mary: I enjoyed all of it.*

*Interviewer: That’s good. Do you think it’s a good way to learn about these things?*

*Mary: Yes, it’s a brilliant way to learn about these things.*

(Mary, Group 2, six-week interview)

Lisa enjoyed taking part in the activities because she liked active learning; Fiona particularly enjoyed ‘Magazine Microbes’ and ‘Glitter Microbes’ because she felt she learnt well through creative activity. ‘Magazine Microbes’ was also very effective for Colin. Normally very quiet within the group, Colin made a sophisticated collage of items upon which microbes could be found. He presented this to the group therefore reinforcing his and others’ learning.

I categorised the KYB resources as an ‘implementation mechanism’; they were not hidden interactions as in the conventional realist mechanism, but they were fixed and important components of the session that underpinned the whole learning experience. Tutors and participants liked the resources; the tutors found them easy to work with and participants enjoyed using them.
There was scope for improvement in the accessibility of some resources; the video was not fully understood, not everyone learnt that there are also good microbes, and some statements on “Antibiotics Right or Wrong” were complex and confusing. The resources that underpinned antibiotics discussions were at times inaccessible for some participants and participants did therefore not always achieve the intended learning outcomes. Sophie, Lisa, Paul, Anne, James and Colin did not appear to have learnt that antibiotics fight bacteria. On questioning these participants after the session, it appears that they would have benefitted from some more basic discussion about what antibiotics are and how they differ from other medicines. This, along with some visual resources, might have provided a better platform for antibiotics learning. To maximise effectiveness, the antibiotics resources need further in-depth review.

6.8.4 Relaxed and effective participant interactions

The social and collaborative context of the session, individual personal contexts and the mechanism ‘effective educator’ enabled participants to have a role in shaping the session through their interactions so that it was personally suitable. In this respect, relaxed and effective participant interactions worked through:

- voluntarily sharing experiences, therefore personalising learning and relating it to real life situations;
- relaxed conversations that were instigated by the tutor and directly addressed the learning topic;
- informal conversations with each other often as an adjunct to the main topic of discussion; and
- tutors’ requests to formally feedback to the group.

In this context, the familiarity that participants had developed with each other was important in supporting mutual learning. Participants were able to hold informal conversations about topics such as self-care, microbes and antibiotics that supported their learning, thereby reinforcing some of the formal learning outcomes.
that were part of the course. This worked well for Alan and Group 2 participants in the context of discussions about bacteria and I have illustrated the sequence of causation in Figure 6.12. Here, Alan reinforced knowledge and enthusiasm within the group about the fact that bacteria is everywhere by sharing this information in an enthusiastic way. This instigated further discussion and apparent reinforcement of learning. In fact, this mechanism often worked interactively with all of the other mechanisms.

![Figure 6.12 Inspiring Alan's learning about microbes](image)

These relaxed interactions remained on topic throughout the session. They appeared to provoke a sense of achievement and give some participants confidence regarding their learning. I have cited already the example of Michelle who liked to learn via discussion and was very vocal within both the large and small group context of Group 1. Michelle described satisfaction with the session and a sense of accomplishment regarding her learning. In fact, participants such as Michelle, Alice,
Lisa, Alan, Kevin, Mary and Fiona appeared to thrive in this situation; they were able to direct conversations to meet their personal learning needs and preferences but also to learn from each other’s experiences. This was illustrated by Fiona asking what it feels like to have a temperature and later by Kevin asking what caused an earache.

It was enjoyable for some to actively participate in conversations but equally the quieter participants such as Paul in Group 1 and James and Giles in Group 2 commented that they enjoyed listening to conversations and digesting information. The group conversations and the MYI leaflet resource were mechanisms enabling Giles to learn about sources of advice such as ‘111’ or pharmacists for example.

6.8.5 Facilitation of independent thinking and planning

‘Facilitation of independent thinking and planning’ was a complex mechanism. It worked within all contexts and in conjunction with all other mechanisms, enabling participants to think about how the concepts illustrated during the session were relevant to themselves and how they would address them. This facilitation was achieved through the following strategies:

- tutors made statements and asked questions about them thus enabling participants to think independently
- participants asked questions, relayed experiences and discussed amongst themselves (with support if needed), thus introducing their own ideas and questions
- through large or small group discussions based on structured activity such as ‘Magazine Microbes’.

The following excerpt (Figure 6.13) from the Group 1 session shows how the tutor facilitated independent thinking and planning in self-care for coughs and colds. By asking questions, agreeing with answers, taking a steer from participants, and encouraging collaborative engagement the tutor successfully guided the group through mutual learning and reinforcement.
Figure 6.13 Using questioning, affirmation and discussions to facilitate independent thinking and planning

<table>
<thead>
<tr>
<th>Michelle suggested self-care strategy</th>
<th>Tutor used affirmation and questioning to expand upon Michelle's suggestion and facilitate participant thinking about self-care</th>
</tr>
</thead>
</table>
| Michelle: If I get a cold, yeah, I put the central heating on and let it sweat out of you. | Tutor: Yes, so keep warm, stay warm. Right, just talking about painkillers and paracetamol, what do you know about painkillers and paracetamol? [All giving answers simultaneously!]
| Tutor: Yes, every 4 hours. How many do you need to take? | Michelle: Every 4 hours
| Michelle: Two | Tutor: Two tablets every four hours. What do you need to be careful of with things like paracetamol, Lemsip and all those kinds of things?
| Alice shared useful knowledge | Tutor reinforced Alice’s response |
| Alice: Lemsip contain paracetamol… and no more than 8 in every 24 hours of paracetamol | Tutor: Yes, so either make sure you read the instructions or somebody else is reading the instructions, take the tablet or the Lemsip and then put it away so that you’re not doing it again. OK so you’re not accidentally taking it without keeping an eye on the time.
| Sonya offered an idea based on her experience; others learnt this | Tutor was supportive and reinforced Sonya’s strategy |
| Sonya: So I have an Alexa yeah and I say “Alexa in 4 hours time can you remind me a Lemsip”. | Tutor: Brilliant, that’s a really good idea, yeah, excellent.
| Anne relates to Sonya’s strategy | Anne: I’ve got Alexa as well |

6.8.6 Appropriate involvement of supporters

As described already, supporters were present during both sessions to facilitate learning. They were an effective component of the learning context but also a mechanism, instrumental in supporting generation of learning outcomes. Learning Support Assistants (LSAs) supported a positive learning environment because they interacted well with participants and supported them in understanding course concepts and working through the activities in a relaxed and person-centred manner. LSA2 in Group 2 for example was adept at allaying Fiona’s anxieties about viruses and supported her in thinking realistically about their impact. Personal supporters were also effective. Michelle’s personal supporter facilitated the smaller group discussion and guided them sensitively to correct answers. The personal
supporter knew Michelle and the group well and was effective at deciding when to get involved. The following excerpt shows how she supported a smaller group of individuals in getting to a correct interpretation of an ‘Antibiotics Right or Wrong’ statement.

Paul: My headache and flu symptoms are really getting me down. I think I need antibiotics.

Michelle: Symptoms … Yeah [meaning she thought this was a correct statement, although in fact it is not].

Personal Supporter: You think so? It’s like saying oh I’ve got such a headache; it’s getting me down I need antibiotics.

Lisa: You need painkillers.

Michelle: Yeah, you need painkillers.

Personal Supporter: Painkillers are very different from antibiotics.

Michelle: Yeah, so that’s a no [Michelle is now correct].

(Group 1 session)

If carried out effectively, the analysis of CMO configurations culminates in reflective explanations of the ways in which an intervention is effective (or not) for those involved in its delivery. In the context of my research, the CMO configurations replicated my findings in the literature, although I identified additional configurations such as using activity and discussion within an active context to facilitate independent thinking and planning. As I have outlined in Chapter 4, scientific realism advocates that there may be many explanations for an outcome, and I remained aware of this during my analysis. By scrutinising the data for
alternative explanations, I aimed to ensure that I had considered as many explanations as possible that were provided by the data. I discuss ways in which I achieved this in Chapter 7, section 7.2 using the example of Kevin and the question of whether the pace was appropriate for him.

6.9 Context/mechanism/outcome (CMO) illustrations

CMO configurations describe how context and mechanisms interacted to generate outcomes for KYB course participants. Having described the contexts and mechanisms in depth, I thought it would be useful to present five CMO examples in diagrammatic form: a positive learning experience, learning about self-care, addressing the COVID-19 pandemic, learning about antibiotics, and not learning about antibiotics.

6.9.1 A positive learning experience

I present the CMO configurations for a positive learning experience in Figure 6.14. This was an important outcome for KYB participants; it incorporated most of the mechanisms and contexts I identified during my analysis and in fact supported participants in achieving during their learning.
Kevin provides an interesting example of a positive learning experience CMO configuration. Kevin was an articulate participant with good prior knowledge, scientific interest, and a motivation to learn. He could listen, ask questions, and relate to relevant information. Kevin was also socially and physically comfortable within the group environment and confident in participating in conversations. These personal contexts along with social and physical contexts helped to set him up for a positive learning experience; Figure 6.15 shows the further context and detailed mechanisms behind this through the different stages of KYB. Kevin enjoyed the engagement of the session, it enabled him to ask questions relevant to his knowledge gaps, and he learnt and reinforced knowledge.

However, the session did not always work for Kevin. His scientific interest in nature was advanced and the tutor was at times unable to answer his questions. Therefore, in Kevin’s case the mechanism of ‘working at an appropriate and accessible pace’ was not instrumental in his positive learning experience and there
was unfulfilled potential for further learning. Kevin in fact appeared comfortable with the group’s pace. He did not display frustration. Nor did he try to change or accelerate the direction of conversations. The tutor was aware of Kevin’s extensive knowledge on the subject but had not anticipated the technical depth of some of his questioning. Thus, for Kevin, the mechanism was not delivered effectively at that point in time because the tutor had misjudged his pace.

![Diagram](image)

**Figure 6.15** Kevin’s positive learning experience

### 6.9.2 Learning about self-care

Figure 6.16 shows the contexts, mechanisms and outcomes that supported effective learning about self-care.
Personal contexts external to the course made a key difference in the ways in which the CMOs interacted with each other, and therefore participants’ acquisition of additional self-care strategies. As I have discussed earlier in this chapter (see section 6.4) participants had a diverse range of experience, attitudes and motivations that influenced their learning needs, and in this respect brought different prior knowledge and experience to this component of the session. In the main, tutors were effective at facilitating informed and productive conversations, often led by participant contributions. Resources addressing self-care were inspirational, accessible, and relevant. The Managing Your Infection (MYI) leaflet was particularly inspirational and accessible, and provided an effective basis for self-care discussions for everyone. I discuss further findings regarding self-care later in this chapter (see section 6.10) in relation to the COM-B model of behaviour, and the ways in which it works with CMOC analysis.
6.9.3 Addressing the COVID-19 pandemic

Figure 6.17 sets out the ways in which the COVID-19 pandemic provided context for further learning and planned behaviour change in relation to KYB.

![Figure 6.17 Context/mechanism/outcome configuration: The COVID-19 pandemic](image)

The pandemic provided participants with an opportunity to practise some of the skills they had learned regarding handwashing, and to prepare for self-care if they became ill. It therefore supported reinforcement of learning and planned behaviours by providing a real-world context within which participants could appreciate and act on the content of the module. Most participants recognised this; they appeared to feel positive and empowered that they could take action themselves in the context of the pandemic. For example, when Michelle was asked how she would help herself recover if she were ill with a virus she said:

*Michelle: Take tablets. Stay in bed … drink plenty of fluids.*

*Interviewer: And if you got a little bit worse and you weren’t getting better, what would you do then?*
Michelle: Go to the doctor’s.

Interviewer: And is there anywhere else you’d go for advice?

Michelle: Doctor’s, walk-in centre. See, I know everything don’t I!! Even though I got brain damage yeah I still know a lot about stuff.

(Michelle, Group 1, five-month interview)

An important focus of the session for both groups was how to self-care and manage common infections such as coughs, colds, and influenzas, where to go for advice, and how to identify and address more serious signs of illness. Tutors encouraged COVID-19 discussions about this and, after the session and in the longer term, most participants were able to talk more confidently and suggest further strategies such as keeping warm, drinking, and taking analgesia.

On commencing KYB, most participants had some prior knowledge of hand hygiene, and perceived it as an important basic principle in fighting and preventing the spread of infection and potential illness. This prior knowledge provided a good basis for further learning and COVID-19 discussions, providing reinforcement on the topic and a positive course of action. The pandemic also provided context that enabled participants to retain this knowledge in the longer term; five months after the session, all recalled that handwashing was important to prevent the spread of microbes and reported that they were doing so to prevent the spread of COVID-19.

Conversely for Anne however, the effect of living in more isolated circumstances appeared to have restricted her independence. Spending more time with family appears to have increased her dependence on advice with self-care. Although immediately on completion of the module Anne suggested she would utilise independent self-care strategies if she were ill, six weeks and five months later she suggested she would rely on family and close contacts for advice and support with self-care.
6.9.4 Learning that antibiotics fight bacteria

Figure 6.18 illustrates the broad CMO configuration for learning that antibiotics fight bacteria. As with other components of KYB, it appears that the extent of antibiotics learning related to participant personal context (their prior knowledge, motivation to learn and capacity to understand what was covered during the session). Group 2 participants were more knowledgeable than Group 1 in this respect and had a stronger knowledge base from which to build. The overall context for both groups was supported by the group environment; the accessible and motivational discussions that took place, and a supportive group context.

![Context/mechanism/outcome configuration: Learning that antibiotics fight bacteria](image)

The mechanisms that generated this learning included the tutors’ incremental development of the antibiotics sessions, pitching interactions at an accessible level and facilitating enjoyable, relevant conversations supported by accessible and engaging resources. By starting with the basics and gradually moving onto more complex concepts the tutor was able to assess and develop learning. This worked well during the session although the knowledge gained was often not retained five months later. By participating
in enjoyable, motivational and relevant conversations about antibiotics, participants enjoyed the session and appeared to find it conducive to learning. Overall, they were open minded about learning new facts but also contributed their own; this ethos continued throughout the antibiotics session. Even those who were quiet within the group appeared to have absorbed some new information about antibiotics.

Fiona provided a good example of how this CMO configuration worked. Prior to the session Fiona was unclear about antibiotics; when asked what antibiotics do she answered with a question, indicating that she was unsure:

**Interviewer:** Do you know what antibiotics do?

**Fiona:** That’s if you got a virus and antibiotics you get them from the doctor.

**Interviewer:** And do you know what they do?

**Fiona:** Um, make you better?

(Fiona, Group 2, pre-module interview)

Immediately after the session Fiona was significantly more confident and also very accurate in her recall of what had been covered during the session:

**Interviewer:** Do you know what antibiotics do?

**Fiona:** Um they attack the bad bacteria inside and they fight it and... Bad bacteria inside, then they fight it and if the bad bacteria’s weak then antibiotics win them don’t they?

(Fiona, Group 2, post-module interview)
Fiona’s learning about antibiotics developed within a positive learning environment where she felt able to ask questions when needed. Personally, she had some prior knowledge and capacity to understand which provided a good basis from which to acquire and reinforce new knowledge. The incremental development of learning was a particularly effective base-mechanism here because it provided relevant context to Fiona’s learning and enabled her (and the group) to gradually ‘step up’ between aspects of new knowledge. This is illustrated as follows:

- Basis: Microbes can be bad (and at times good)
- Step up to: Microbes can spread and cause infection
- Step up to: Antibiotics fight infection

### 6.9.5 Not learning that antibiotics fight bacteria

However, learning about antibiotics was mixed, apparently due in part to participants’ prior knowledge, the accessibility of resources and teaching techniques, and participants’ ability to grasp a complex concept such as antibiotic resistance. Some participants did not learn that antibiotics fight bacteria. The CMO configuration model Figure 6.19 shows that there were several reasons for this. For some participants, the resources and subsequent discussions were too complex although also shallow and therefore not addressing the gaps in individual knowledge.
Paul provides a good example of the CMO configurations for this outcome. He had participated in discussions about antibiotics but the basics were not addressed during the session in a way that was accessible to Paul. Paul had little prior understanding of antibiotics (he hadn’t heard of them prior to the session) and the group moved relatively quickly through this part of the topic. Despite some support from the Learning Support Assistant, it appears that the concept was not addressed in a way that enabled Paul to learn.

6.10 Know Your Bugs and reported behaviour change

One of the aims of this research was to understand whether the session had any behavioural impact on participants’ management of common infections. I did not have capacity to conduct a comprehensive study of behaviour change regarding KYB; my time was limited, and I did not spend time with participants outside of the education environment. It was therefore not possible to explore fully their behaviours subsequent to the session; instead I had chosen to focus on learning, and on proposed or reported behaviour change. It has however been possible to gain a perception of reported and
intended behaviours, and thereby begin to understand whether any components of KYB could be changed so that they are effective in generating plans for behaviour change.

Less than half of the participants were ill with a common infection during the data collection period, and therefore had little opportunity to change self-care behaviour in this respect. I can however report the following thematic findings:

- Those that had been ill suggested they had practised appropriate self-care;
- Most participants recalled the self-care strategies they had learnt during KYB and suggested they would then adopt them appropriately if they were ill;
- Some participants commented that they practised more preventative behaviours after the session including handwashing, sneezing into the elbow, and eating healthily; and
- Some participants displayed lack of confidence regarding self-care six weeks and five months after the session.

In the remainder of this chapter, I present these findings using the components of the COM-B model of behaviour (Michie, 2011); capability, opportunity and motivation. COM-B assumes that a particular behaviour will occur only when the person concerned has the capability and opportunity to engage in it and is more motivated to carry out that behaviour than any other behaviours (Michie et al, 2011). In this respect, capability and opportunity are perceived to influence the relationship between motivation and behaviour, rather than behaviour itself.

### 6.10.1 Capability (psychological and physical)

During and after the session most participants demonstrated psychological capability to identify signs of illness. The session also enabled some to address psychological and physical capability to identify and enact appropriate self-care strategies or, if necessary, to seek advice.

After the session and at subsequent follow-up stages, all participants had good recall of potential strategies for self-care and could describe what they planned to do if they were
ill. They often suggested a range of strategies including staying at home, keeping warm, drinking fluids and/or taking paracetamol or a cold and ‘flu remedy.

As I have described previously, many of the participants in fact already had good self-care knowledge prior to the session. Afterwards, they often remembered different aspects of the discussions. Table 6.2 shows that some recalled that they should take medication; others that they should drink fluids and rest; and some participants recalled both.

**Table 6.2 Proposed self-care strategies of six participants**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Pre-KYB session</th>
<th>Post-KYB session</th>
<th>5 months later</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anne (Group 1)</td>
<td>Rest and Lemsip</td>
<td>Rest, paracetamol, fluids</td>
<td>Tell mum/boyfriend, take Lemsip</td>
</tr>
<tr>
<td>Paul (Group 1)</td>
<td>See doctor, take tablets</td>
<td>Take tablets, stay at home, drink</td>
<td>N/A</td>
</tr>
<tr>
<td>Michelle (Group 1)</td>
<td>Rest, keep warm, request support</td>
<td>Ask nurses for medication, drink honey and lemon</td>
<td>Take medication, rest</td>
</tr>
<tr>
<td>Alan (Group 2)</td>
<td>Phone doctors or chemist, take medication</td>
<td>Take paracetamol, rest, fluids</td>
<td>Take paracetamol or Lemsip</td>
</tr>
<tr>
<td>Ian (Group 2)</td>
<td>Go to doctor, otherwise stay at home, take medication</td>
<td>Stay in bed, take hot drinks</td>
<td>Inform support staff</td>
</tr>
<tr>
<td>Kevin (Group 2)</td>
<td>Ask chemist</td>
<td>Take Nurofen</td>
<td>Phone NHS, take paracetamol</td>
</tr>
</tbody>
</table>

Table 6.2 shows that Anne and Ian did not appear to retain their knowledge gain in the longer term, or at least they offered a different perspective; rather than planning to take self-care action they both suggested they would refer to their supporters for advice. Both had complex underlying health conditions, and Ian lived in supported accommodation so
always had to request medication if he felt he needed it. Anne lived with her parents and had a strong support network of family and friends upon which she relied:

_Interviewer: So, if you got ill with a cough or a cold or a bit of a headache now, what would you do?_

_Anne: [Pauses] So if I have those things ... that means I have to let mum know. I would let my boyfriend know as well. So that’s what I would do._

_Interviewer: And would you do anything to look after yourself?_

_Anne: If I was being independent, I really don’t know [laughing apologetically]._

(Anne, Group 1, five-month interview)

Therefore, although this aspect of the session did not succeed in grounding self-care behaviours for these participants in the longer term, there were wider more complex issues relating to participant capability and opportunity that perhaps could be addressed on an individual basis. Anne and Ian were clear about what they needed to do if they felt ill with a common infection, they just needed support in executing the preferred behaviours.

Those who had initially suggested seeking advice if they were mildly ill demonstrated further psychological capability after the session. Alan, Kevin and Paul had initially suggested that, if they felt unwell, they would seek advice from a GP or pharmacist if they felt unwell and also conduct self-care. After the session (Alan, Kevin and Paul) and on follow-up (Alan and Kevin) they reported that they planned to self-care rather than initially seek professional advice.

Some participants also often suggested they were capable both psychologically and physically to deal with more serious symptoms if they arose. Michelle, for example, knew what to do if she had a persistent headache; she would seek advice immediately. Michelle has had a brain aneurysm and has been admitted to hospital with this in the past. She
knew that a headache could be a symptom of this and would therefore seek advice in this situation. Kevin was self-managing diabetes. He knew the more serious signs to look out for and would contact a diabetic nurse if these arose. Alan had been admitted to hospital with chest pains. Again, he would seek advice if they arose again. It seems these participants were able to identify the more serious signs and were motivated to address them as they had done so in the past. For some, these strategies appeared to be fuelled by their past experiences, whereas others learnt from listening to these experiences. The motivational and relevant discussions during the session appeared to have provoked thinking and therefore supported recall and capability to self-care.

Anne and Paul did not display as much psychological capability as the other participants in their planned self-care strategies and they appeared less confident in this respect. When asked what they would do if they were mildly unwell both appeared to have learnt a little during the session; Paul to stay at home and drink fluids; and Anne to take paracetamol and drink fluids. However, both also spoke about consulting with family or close supporters to help them make decisions about self-care. In the longer term, Anne suggested she would look to her family, boyfriend, or PA for advice if she were mildly unwell. It appears that she did not retain the knowledge she had initially gained about resting, taking paracetamol, or drinking fluids.

There appear to have been several reasons for lack of confidence in self-care. First, external to the course environment, both Anne and Paul lived with their parents and had a strong support network. In this context, it appeared that their supporters were their established first step if they had any health issues. At the five-month interview stage, Anne had been spending more time at home with her parents due to COVID-19 lockdown and further restrictions, and it appears she had become a lot more dependent on her family and boyfriend for support. Secondly, in terms of physical capability, both were managing with support several complex health conditions concurrently; Paul had issues with his ears, his stomach, and his feet. Anne was experiencing undiagnosed fainting episodes and was about to undergo investigations. Again, they manage these with close support. And finally, Anne and Paul appeared to find it more difficult to understand some of the concepts that were covered during the session such as the role of antibiotics.
Some participants reported that they had not actually changed any behaviour because of their learning on the course; they thought that they would have taken exactly the same course of action prior to undertaking the session. However, these participants inferred that the session had increased their psychological capability to self-care through leading them to think more about their health and practise healthy behaviours such as eating healthily, exercising, and looking after their mental health. Most participants referred to behaviour plans with a clear positive outlook and attitude of confidence. Alan for example, thought he had a clearer outlook on infection prevention and self-care since completing the session:

Yeah, I’d do a lot. Because one you’ve got to look after yourself. You’ve got to look after your body. It’s not worth sitting there and saying oh I ain’t gonna do this or I ain’t gonna do that where if you look at most of them [the symptoms on the Managing Your Infection leaflet] then you know what you gotta think.

(Alan, Group 2, six-week interview)

Regarding personal context, all participants could recall having had a cold and some were addressing other health issues. All already understood the basics of self-care if they had a cough or cold and had prior experience of this. Some also had prior experience in addressing more complex health issues as well; Lisa and Sonya, for example, were experienced and confident in self-care; Sonya could manage minor illness confidently and used her phone to search for information if she were unsure what to do. Lisa was experienced in managing several health conditions concurrently, including urinary tract infections, irritable bowel syndrome, and mental health issues.

6.10.2 Opportunity (physical and social)

According to the COM-B model (Michie et al., 2011), opportunity is the attribute of an environmental system that, together with capability, makes a behaviour possible or facilitates it. It is both physical and social. In the context of KYB, opportunity to acquire skills was provided by the contexts; the session, the external context, and personal contexts that influenced ability to learn. The social, personal and physical context of the
course was instrumental in providing opportunity for inspiring and embedding learning about self-care. The relaxed social context of both sessions enabled participants to use the MYI leaflet as a basis for discussing their self-care experiences and thoughts, thereby learning from each other, raising issues that were personally relevant and addressing questions. In this way, participants’ discussions about life experiences provided opportunity to acquire appropriate self-care and preventative behaviours.

Those who were ill potentially had the opportunity to practise appropriate self-care. Seven participants had been unwell within six weeks and one within five months of completing the session. Of those who had been unwell, seven had had a mild infection and one, Susan, had been more ill with a throat infection. Susan had attempted self-care by resting, drinking and taking paracetamol but eventually needed a course of antibiotics; in this respect it appears she was no longer able to self-care effectively but was motivated by her illness to seek medical advice. The remaining participants thought that they had managed their illness appropriately. Sonya and Julie for example had had a cold. They did not take medication but recalled going to bed early, drinking fluids and keeping warm. Giles and Susan had consulted the MYI leaflet to consider expected durations of a cough, cold or sore throat. The others that had had a cold took paracetamol and either stayed inside or ensured they were warm and comfortable. All said they had recovered within a relatively short time period.

The environment external to the course provided opportunity for some to practise self-care and for all to engage in preventative behaviours. Personal living circumstances varied amongst the participants and most had a support system in place. Ian, Mary, Michelle and Sophie, lived in supported accommodation where they had to ask if they needed medicines, and they would first notify their support staff if they felt unwell. Some were more reliant on support than others; Anne and Paul for example lived at home but appeared to be particularly dependent on support from either family or close contacts to help with self-care decision making. Others however, such as Lisa, Sonya, Fiona and Kevin, lived on their own. They made health decisions more independently, although Lisa and Sonya had family back-up if they needed it. It appears that those in supported living and those with close support networks had less opportunity to self-care independently.
although they still had to take initiative to raise with supporters if a health issue arose. I discuss this further in Chapter 7, section 7.7.

It is important to acknowledge again the potential impact of COVID-19 on participant opportunity and motivation to consider and practice self-care. The increased publicity and educational material in the public domain at this time is likely to have had an impact on participants’ understanding of what to do if they had a cough or flu-like symptoms as advice on self-care was publicised widely. It was also certainly emphasised during KYB and subsequent follow-up sessions and raised during many six week and five-month interviews. Sophie, Fiona and Kevin for example stressed that they did not want to catch the virus and had consequently increased their handwashing.

6.10.3 Motivation (reflective and automatic)

Regarding participant outcomes and KYB, ‘motivation’ encompassed different contexts. These included personal motivations to undertake the course, motivation by undertaking the KYB module and motivations incurred by the external environment.

Figure 6.9 provides an outline of some of the participant motivations to undertake the course, and the pen portraits presented in Appendix 21 provide further detail. Most participants were motivated by an aspiration to be healthy and to be more independent in managing their health. For many participants, their pre-existing health conditions were also a source of motivation in this respect. Kevin, for example, was diabetic. He was motivated to learn as much as he could about his disease and take appropriate action to prevent illness. Many participants took their health conditions very seriously and as such this formed an important part of their motivation to live healthily and independently.

The KYB context was motivating for individuals. The learning environment appeared to inspire thinking by hosting engaging discussions and offering relevant information that was perceived to be important. Sophie, for example, recounted how the course had inspired her health plans, Fiona was able to address her health anxieties, and James to understand appropriate strategies for self-care.
The tutors were also a motivating component of the self-care aspect of KYB. Trusted by participants, they both had an engaging style, were generally able to provide advice and answer questions, and facilitated positive discussions about how to address more serious signs of illness. Although sessions were relaxed and there was light discussion and banter, the tutors conveyed the seriousness of the topic in a motivational manner, ensuring participants could relate the discussions to their day-to-day lives without being too daunted by the subject matter.

Although participants were familiar with some appropriate self-care strategies prior to the session, the session appears to have reinforced this through relevant interesting and motivational discussions based on a trusted and accessible resource such as the Managing Your Infection (MYI) leaflet. The MYI leaflet was liked by everyone; it was clear, easy to understand and contained useful information. In this respect it appeared to be a credible means of conveying messages about appropriate self-care behaviour. It also served as a source of further information. Kevin and Fiona liked the concept of estimated durations for example; they found this a useful way of monitoring when they should change their behaviour and seek advice.

Motivation to be healthy was a component of the whole course. Some participants spoke enthusiastically about the health behaviours they had learned during the whole course. Alan (Group 2) mentioned several times that, since joining the group, he was thinking more about his health behaviour and trying to ensure he had a healthy diet and exercise routine. Kevin too spoke about diet and walking as a form of exercise. Carla in Group 1 reported that she had gained confidence from the course in how to manage a healthy lifestyle; she explained that this had given her confidence that she could self-care and look after her mental health.

Participants were often motivated by session content, could understand its relevance and were able to physically address it by handwashing and sneezing appropriately. They appeared inspired to do what they could to minimise the risk of catching a mild infection; they were motivated by discussions during the session because they were engaging and relevant and helped to embed the importance of living healthily. The importance of healthy behaviours was fundamental to the whole course and many of the participants
were able to see how this would benefit them. Some of the course material was directly relevant to the COVID-19 pandemic and replicated guidance in the public domain. It appears this connection motivated participants because they could understand its importance. It also reinforced knowledge about self-care in the context of viral infections (thus showing psychological capability) and further endorsed participants’ trust in the information. Alice, for example mentioned the ‘Catch it bin it kill it’ strategy as one that was important to her and that she implemented.

Most of the participants reported increased handwashing six weeks and five months after the session. As I have suggested already, it is difficult to determine whether the session had an impact on this or whether it was a result of a national drive to improve hand hygiene in helping to address the COVID-19 pandemic, or indeed both! There were certainly many references to handwashing during the session although there was concurrently much guidance on this in the external environment. It is likely that the emphasis on hand hygiene in both contexts raised awareness and motivation and encouraged participants to practise good hygiene in this respect.

It appears therefore that KYB motivated participants to use appropriate self-care and preventative behaviours and, to a slightly lesser extent, supported their capability and enabled opportunity in this respect. However, as participants’ circumstances and capabilities were diverse, further education tailored to address individual circumstances might have enhanced the opportunities and capabilities of some.

Exploring intended behaviour is not however a reliable method of understanding how individuals would actually behave if they were ill. Although some studies do indicate that intentions predict behaviour (Sheeran and Webb, 2016), there is a known intention-behaviour gap in behavioural science (Faries, 2016; Sheeran and Webb, 2016) whereby many people do not follow through their intention. It is therefore unwise to make assumptions. Interview data in the present study provide some insight into participants thinking and strategy recall in addressing mild illness. Further research into actual behaviours regarding illness and self-care would provide a realistic perspective on the longer-term effectiveness of the session in influencing behaviours.
To summarise, there was considerable diversity in participants’ apparent capability, opportunity and motivation to self-care. This presents a potentially complex situation when considering the wider transferability of my findings, raising difficult policy and practical questions regarding expectations, roles, and responsibilities of adults with learning disabilities and their supporters. I discuss this further in Chapter 7, section 7.7.

6.11 Chapter summary

My findings have shown that the learning environment comprised changing combinations of contexts and mechanisms that generated different outcomes for different individuals. The detail of what was important to participants varied throughout. However, I identified two particularly important components of the learning environment; the role of the educator in adapting and facilitating delivery of the session to address individual needs, and the prevailing relaxed social atmosphere of each session in providing context for learning.

KYB was in fact broadly effective for all participants in many respects. It provided them with a positive learning experience and enabled them to understand better how to self-care when they were ill. It supported a better appreciation of how microbes spread and the consequences of this. Regarding antibiotics learning, the session was less effective. Some participants learnt a little more about what antibiotics aim to do and issues to consider if we have to take them. However, the extent of this learning varied considerably amongst the two groups and retention of new knowledge was relatively poor. Whilst some learning about antibiotics and bacteria was achieved, the more complex concept of antibiotic resistance remained unfamiliar to many. There was also variable learning about the realities of sharing antibiotics and finishing the course, apparently because the pace of learning was too fast and the conversations and resources inaccessible for embedding knowledge. In the following chapter I will discuss these findings in relation to the changing middle range theory, and the transitioning of contexts, mechanisms and outcomes.
Chapter 7. Discussion

In this chapter I discuss the development of the revised middle range theory and its relationship with other theories that underpinned the development of KYB. I discuss how and why the contexts, mechanisms and outcomes appeared to transition during my research, and how this related to the learning environment experienced by participants. I conclude this chapter by reflecting on the research process I undertook from both a theoretical and practical perspective, and on the ways in which I worked collaboratively to enhance research outcomes.

7.1 Exploring middle range theory: Transitioning contexts, mechanisms and outcomes

The middle range theory provided a useful framework for understanding how and why KYB worked (or did not work) for the participants in my research. Good outcomes for participants identified by MRT2 included a positive learning experience; knowledge gain, reinforcement and retention about microbes and antibiotics; better understanding of self-care regarding common infections; and some reported behaviour change regarding handwashing and self-care.

The contexts that provided background for these outcomes were personal, social, physical and external to the session. The mechanisms that generated them included an effective tutor, positive group interactions that addressed the topic, provision of appropriate support where needed, accessible, engaging and relevant course materials, and using repetition and a combination of activities to embed learning.

As is usually the case with realist evaluations, these context/mechanism/outcome (CMO) configurations were closely linked, and often several contexts and mechanisms worked together to generate an outcome. Effective CMO configurations varied for participants at different stages of the session. They also came into force at the onset of different activities or conversations. For Kevin these configurations changed at each activity for example as illustrated in Chapter 6, Figure 6.15. Even within activities, the outcome
aspect of the CMO configuration often varied quite considerably. Learning about antibiotics provides a good illustration of this; the engaging resources and conversations, an effective educator and personal knowledge and experience led some to learn that antibiotics fight bacteria. However, others appeared unable to relate to the detail of these activities and did not acquire new knowledge about antibiotics.

These configurations also changed frequently; contexts at times transitioned into mechanisms and some outcomes developed into contexts. I found many instances of an overlap between context and mechanisms, including situations where a component was both a mechanism and context, and others where an outcome became a context and/or a mechanism for another outcome. So, although they were established components of KYB, the CMO configurations interacted in a way that was far from static and were instrumental in influencing the learning environment as well as its outcomes.

For example, ‘interactive learning’, initially identified as a mechanism, became a context for all learning and social outcomes, particularly part of the interactive and accessible social context. ‘Accessible teaching methods and techniques’, also initially a mechanism, became a context at times, for example during ‘Antibiotics Right or Wrong’ when these set the context for discussions. ‘Appropriate involvement of supporters and caregivers’ was initially identified as a mechanism for some participants including Paul and Michelle in Group 1 and Fiona and Colin in Group 2. As both sessions developed, it became clear that supporters were also an important part of the whole group context. They had a key role in the supportive learning context but also acted as a mechanism in delivering aspects of the session by responding to questions, facilitating activities and identifying and responding to participant support needs.

Some of the outcomes were connected to, and often influenced each other. For example, knowledge about hand hygiene appeared to have influenced reported behaviour change (increased handwashing), and knowledge about healthy living was linked to plans for self-care. These connections occurred several times during the session and were often retained during subsequent interviews with me. They were often referred to directly by participants; Alan (Group 2) and Paul (Group 1) for example spoke enthusiastically about
how they could maintain good health by handwashing, self-care and adopting a healthy diet and exercise routine.

Some of the CMO configurations identified during my evaluation were also negative in nature. In the case of antibiotics learning these did not work as effectively for most participants as intended: the groups were too large, the conversations too complex and some of the resources confusing. From a research and development perspective however, this is useful because it suggests what might happen if personal contexts are not considered when developing and delivering this component of the session.

As is often the case in realist evaluations, the boundaries between mechanisms and contexts became blurred at times (De Weger et al., 2020; Dalkin et al., 2015; Lacouture et al., 2015). I endeavoured to adhere to the definitions set out in Chapter 5, Figure 5.9 and reviewed my analysis several times to check for consistency in my application of definitions. My analysis indicated an effect similar to Jagosh et al.’s (2015) ‘ripple effect’ and Byng et al. (2005) ‘feedback loops’ whereby an outcome, or components of an outcome, often transitioned to become the context or mechanism for another outcome. I also identified ‘spin-off’ activities (Jagosh et al., 2015); those that were unplanned but have value and often sustainability; for example when participants introduce their personal health experiences and thereby direct discussions and instigate new learning for others.

The effect I identified was in fact cyclical in nature and is highlighted in the following example of the outcome ‘positive learning experience’. For KYB participants, a positive learning experience, and the mechanisms that generated it, became the context and mechanisms for learning outcomes. These learning outcomes then further generated a positive learning experience. This process was supported by the incremental and social nature of the module and again shows how learning developed gradually through social conversations and gradual topic change.
Michelle’s experience provides an effective illustration of this cyclical process. Michelle had a positive learning experience. She learnt that antibiotics “kill germs”, she acquired further strategies for dealing with common illness, and experienced reinforcement and further detail on hand hygiene. Five months after KYB, Michelle retained self-care and hand hygiene knowledge, she still had a limited understanding of antibiotics although with prompting could recall they kill bacteria, and she reported increased handwashing generally. The positive learning experience was important to Michelle. As an outgoing and chatty participant, Michelle was very engaged with the session. Her positive experience enabled her to feel optimistic about her learning and gave her confidence to ask questions and participate in discussions. In this context, the positive learning experience became a mechanism, along with others, that generated Michelle’s learning about microbes and self-care. This learning consequently reinforced Michelle’s positive experience of the session and provided a sense of achievement and confidence about learning.
7.2 Reflecting on contexts, mechanisms and outcomes

In Chapter 5, section 5.8.3 I have presented some of the complexities in defining contexts, mechanisms and outcomes, and the corresponding discussions in the literature (De Weger et al., 2020; Dalkin et al., 2015; Lacouture et al., 2015; Jolly and Jolly, 2014; Salter and Kothari, 2014; Marchal et al., 2010; Byng et al., 2005, 2008). After reviewing the literature, I had developed my own definition and methodology for CMO development and analysis as described in Chapter 5. However, I acknowledged that as a lone PhD student I did not have a research team with which to share and refine this process and there was therefore potential for ambiguity in interpretation and definition. I remained aware of this throughout my analysis and frequently conducted plausibility checks to address the issue. These included analysis and re-analysis of data, considering potential counter arguments for my potential conjectures, further review of the literature and discussions with supervisors. I feel that these strategies enabled me to address potential oversights and ensure validity and accuracy of my data.

I found that the definitions I had developed were robust. They enabled me to explore and categorise the data in a meaningful way and provided a framework within which I could re-consider my proposed explanations. This was a necessarily lengthy process however, due in part to the complexity of the data, and in part to my need to ensure rigour.

A criticism of realist evaluation is the potential existence of a gap between the CMO configurations and the middle range theories (Byng et al., 2005). Again, as there is little clear methodological guidance on the extrapolation of CMO configurations into an overall explanatory outcome, some argue that generating the middle range theory is methodologically problematic (Brousselle and Buregeya, 2018; Emmel et al., 2018; Befani, 2013). As Marchal et al. (2010) suggested, in order to be useful for decision making, this synthesis should consider the combinations of attributes required for an intervention to be effective, the various alternative explanations, and the potential transferability by demonstrating links with existing knowledge.

In doing so, researchers such as myself are reliant on the literature and persistent scrutiny of the data in developing and validating their own approach. I was concerned about
methodological rigour in this respect as two people may approach the same work differently and produce different results. I overcame these potential issues by adopting an approach similar to Byng et al. (2005) and Marchal et al. (2010) by first grouping multiple CMOs into ‘bundles’ (Marchal, 2010) and then into levels (in my case, the individual, group and external). By then reviewing the literature a second time, and my initial MRT, I further grouped these statements into an overall summary which became the revised middle range theories.

It can be difficult to assess the exact CMO contribution to change. However, in revisiting the data to conduct regular plausibility checks, applying the COM-B framework, and rigorously considering potential explanations for an outcome, I was able to pragmatically consider alternative causal reasonings and thereby refine the MRT. However, in line with scientific realist thinking outlined in Chapter 4, section 4.1.2, I must accept that there may well be other causal explanations for outcomes, potentially those that were not apparent in my data and which I am therefore unable to identify. Kevin provides a good example here. I described in Chapter 6, section 6.9.1, how the pace of the group appeared to be misaligned with his learning during some components of the session. He indicated by his questioning that he was able to acquire further knowledge at a faster pace than most other participants, and the tutor was occasionally unable to answer his questions. In attempting to identify explanations for this outcome, I made many causal considerations and asked questions of the data. In doing so I concluded that:

- It appeared that most other participants within the group needed to work at a slower pace to achieve KYB learning outcomes. They did not always grasp concepts first time and detailed discussion was often needed to reinforce these concepts. In order to ensure others achieved these intended outcomes, the tutor maintained this slower pace and focus on basic detail whilst simultaneously trying to address Kevin’s questions.

- Kevin’s knowledge needs exceeded the intended learning outcomes of the session. The tutor focused on the more basic needs of some other participants in line with the KYB intended learning outcomes. In interviewing the tutor after the session, they clarified that Kevin’s knowledge needs were advanced in some
respects and potentially outside the scope of learning of some other participants. The tutor felt it was more appropriate to steer the session in line with the needs of the rest of the group.

- Other participants did not display the same depth of knowledge as Kevin, nor it seems the interest, motivation or capability to explore the learning concepts in the same depth (personal contexts). However, this does not mean participants did not have these attributes, just that the attributes were not apparent in the data I had collected. I addressed this in subsequent interviews by asking about knowledge and motivation but did not glean any further information to suggest an alternative explanation.

- The tutor lacked the knowledge required to address Kevin’s questions.

There may well therefore be other explanations as to why the pace and depth of the session appeared to not fully meet Kevin’s needs in specific areas. I had considered for example whether the lack of evaluation of KYB led to insufficient understanding of participants’ potential needs during the session. This may well be a feasible additional explanation. However, it is not apparent in the data, and I felt I could not include this as a causal explanation.

As Marchal et al. (2010) suggest, describing implementation context in this way can in fact improve external validity as well as support identification of the active components of change. It does not really matter whether attributes are defined as context, mechanism or outcome; more important is that the process enabled me to identify the causal pathways that improved my understanding of the session.

I approached the CMO analysis flexibly. Although I viewed KYB as a social system, the ways in which the contexts and mechanisms interacted with the fixed components of the course such as resources and activities were also important. I defined these components as ‘implementation mechanisms’; although they were not ‘hidden’ in a conventional Pawson and Tilley (1997) sense, they were instrumental in generating change in an
interactive manner. Including these in my CMO configurations provided me with a more comprehensive explanation of causality.

This perception of mechanism does not detract from the social basis of the CMO analysis; in fact, it adds to it. Contexts, mechanisms and outcomes can be shaped by environments that are enabling or disabling, and by each other (Wong et al., 2012). Although not usually inherent to the intervention, these ‘implementation mechanisms’ in KYB interacted with participants, within the contexts described and with other mechanisms to generate outcomes such as understanding potential illness durations, sources of advice and self-care strategies using the MYI leaflet. As Wong et al. (2012) report, an intervention itself doesn’t change its participants; it is the participants’ reactions to the opportunities provided by the programme that trigger change – in this respect the enthusiasm generated by the resources and the discussions interacted with participants’ personal contexts and a range of mechanisms to provoke different reactions in different learners. Alan in Group 2 for example was vocal and involved, taking new knowledge home to his family. James was quiet and more passive within the group, but he also referred to using his new knowledge at home. In this respect their outcomes were similar but the interactions within the course environment different.

In accordance with much of the literature, my research has therefore shown that it is not one single or combination of mechanisms that facilitate outcomes but the interactions of mechanisms with the contexts identified (Willis et al., 2018; Lacouture et al., 2015; Wong et al., 2012). These interactions can be difficult to identify but my research design, with a staged data collection and analysis, enabled me to review and further explore this several times and thereby refine and validate my findings. My design enabled me to explore and validate these concepts by using the literature as a starting point, reviewing data regularly for emerging CMOs and re-visiting these during interviews at each stage of data collection.

However, my work did not explore actual behaviour change. This remains a gap in knowledge about the self-care and infection prevention component of the session and warrants further research.
7.3 Learning content: what worked for whom in what circumstances

As I have shown, the session enabled participants to achieve most of the intended learning outcomes. The interactive nature of the session, the educational resources, the educators, and the people contributed to an enjoyable and productive learning session.

However, there were components of the session that were less effective in terms of participant learning, particularly in relation to antibiotics. Public understanding about antibiotics is known to be often inaccurate; appropriate antibiotic use can be difficult to understand and translate into behaviours due to scientific complexity (Hayes et al., 2021; Pinder et al., 2015). Within each of the groups I observed there was certainly a diverse range of prior knowledge, learning and interpretation of fact regarding antibiotics. In subsequent interviews, participants’ recall also varied considerably.

The Beat the Bugs antibiotics resources require change if they are to be effective for all participants with learning disabilities. It is difficult to decide what would be appropriate content in a course such as this, especially for larger groups with a range of prior health knowledge and understanding amongst members. My observations and interviews confirm that learning about antibiotics through resource-focused discussion can be difficult. The KYB learning environment certainly provided a framework for these discussions and participants were motivated by the resources. However, there was insufficient depth for many participants, particularly regarding the consequences of overusing antibiotics and the concept of antibiotic resistance. Perhaps it would be better to incorporate smaller incremental steps to the antibiotics learning, include an element of peer learning, and sub-divide large groups so that individual needs can be addressed. Some participants did not fully grasp the concept of the scenarios for example; when they were asked direct questions they could provide a correct answer but they could not in a scenario-based context.

Further research and development work would be necessary to achieve this. Such work could enable a better understanding of how people with learning disabilities can have effective conversations about antibiotics. This would usefully include identification of the
relative importance of detail on consequences of overuse, and what accessible resources could support this learning.

Important in the learning context is also the educator, and the ways in which they facilitate the session. Both sessions were planned and facilitated by non-disabled educators, although course participants were instrumental in developing the sessions through their questioning and conversations. One participant, Alice, mentioned that she had led a previous session addressing healthy eating, and that this had been enjoyable and education for her and the rest of the group. It is important to further explore the potential for delivery of the session, and indeed the entire course, by experts by experience in this respect. Having observed the ways in which participants supported each other, I can envisage that, with the right resources and support, this could work. I identified during my review of the literature that peer-led learning was an effective approach in some studies, and I subsequently held initial conversations with a local self-advocacy group on this issue. At the time the group felt that the resources needed further development before they were accessible and could therefore be used effectively. It is perhaps now time to revisit this and explore the feasibility of taking forward an initiative such as this.

The role of the external environment in learning about hygiene, self-care and infection prevention proved to be extremely important. This is where participants operationalise their learning but also where other forces might add influence. An effective example of this is the COVID-19 pandemic. Clearly, the pandemic was very relevant to my research; whilst participants were learning about viruses, hand hygiene and self-care in the course setting, COVID-19 was spreading and causing serious illness amongst the population. In this respect the pandemic reinforced the knowledge gained during KYB but also the course equipped participants with confidence to address concerns about the pandemic. It provided an additional opportunity for reinforcement and operationalising learning, an important ‘real-world’ scenario to which participants could relate. Fiona for example was able to face her considerable anxieties about the virus and gain support and confidence from staff and participants in planning avoidance and self-care strategies. It is highly likely therefore that the pandemic had an influence on my findings.
7.4 Theoretical perspectives

Using a realist ontology in evaluating KYB enabled me to identify causal pathways in terms of CMO configurations that explained how, why and for whom the session was effective. By understanding KYB in this way, I was able to identify conditions within which causation developed and the many contexts within which the module had impact. On reflection, I feel this was a more appropriate approach than I had envisaged at the outset. It enabled me to develop a realistic and clear framework with which to explore the learning environment and the connections between components that I identified as instigating a successful session. In viewing KYB as a social system in which social interaction had an integral role in personal learning and skills acquisition, I was able to explore the complex nature of the module and its wider system that incorporated other modules, internal and external networks, and places.

The common criticism of a realist evaluation’s focus on the ‘middle range’ (Ledermann, 2012; Befani et al., 2007) was a consideration I frequently reflected upon during my research. Realist research advocates address this by suggesting that the process of generalisation is in fact one of abstraction and the process of refining the CMO configurations can lead to conjecture about interventions and policies in the real world (Astbury, 2018; Jagosh et al., 2015; Marchal et al., 2012; Pawson and Tilley, 1997). I concur on this front. However, where does this take me? Is it acceptable to move beyond the middle range theory in evaluations of complex interventions such as KYB? Byng et al. (2005), Marchal et al. (2010) and Jagosh (2015) used realist evaluation successfully to make conclusions and subsequent policy recommendations about programmes. Indeed, Byng et al. (2005) and Marchal et al. (2010) argued that a realist approach is appropriate for evaluation in complex systems and demonstrated its used in complex programmes. I feel the same. Derived initially from the literature and then revised in the light of my analysis and further reflection of the literature, the components of my revised middle range theory provided effective explanations of how an intervention such as KYB could interact to generate learning and potential behaviour change for adults with learning disabilities.
However, some (Sanderson, 2002) suggest that trying to identify causal processes and mechanisms in complex systems is futile due to the existence of emergent interaction effects. My aim was in fact to understand such interaction effects, and in this respect, I feel that a realist approach was wholly appropriate. Realist evaluation assumes that an outcome will be a result of interactions that occur within and across systems (Westhorp, 2014). It also assumes that thinking and actions are socially and culturally conditioned; people may therefore respond differently to an initiative, certainly a finding of my research. Realist evaluation has therefore helped me to identify the context for and mechanisms of change for each of my participants at different stages of their learning and therefore understand why the module did or did not work. For example, I gained insight into the importance of the social context, setting the scene for interactions with the educator and appropriate materials in influencing the ways in which participants learnt from each other.

Identifying causation in complex systems is challenging, however. In order to address this and ensure that I had not overlooked any key issues I was particularly interested in Westhorp’s (2013) approach to using complexity theory alongside realist evaluation as a means of explaining complex processes of change in community settings. I wondered whether this might help me in considering the transferability of findings and therefore further address the criticism that realist evaluation has limited generalisability (Befani et al., 2007) as it would enable me to look beyond the middle range theory. Complexity theories help to understand programmes by addressing reality as comprising layers of open systems. Theories can be organised within a hierarchy to reflect and explain these different layers. As I have outlined in Chapter 4, section 4.1.3.3, it is appropriate to view KYB as part of a complex system. It is a system within a system (a session that is part of a course attended by people who function outside the course environment), it comprises multiple components including fixed and flexible elements and relations, and it has hierarchical structures that are also non-linear (people, fixed resources, internal and external environments).

However, rather than looking for further theories to explain KYB, the concept of complexity theory helped me to understand the ways in which the prior theories (those that informed the development of Beat the Bugs) interacted within the levels of the
session. This was a plausible first step in addressing the formal theoretical structures of KYB and understanding the wider implications of its implementation. Figure 7.2 shows that MRT2 in fact encapsulated most aspects of the formal theories that were applied in the initial development of the module.

<table>
<thead>
<tr>
<th>Theories of learning</th>
<th>How encapsulated by MRT2</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Revised Middle Range Theory (MRT2)</strong> – learning generated by a positive social learning environment that was flexible and aligned accessibly with individual needs</td>
<td><strong>Revised Middle Range Theory (MRT2)</strong> – learning generated by a positive social learning environment that was flexible and aligned accessibly with individual needs</td>
</tr>
<tr>
<td><strong>Conversation theory</strong> (Pask, 1975) - learning occurs through topic discussion</td>
<td>All contexts, ‘relaxed and effective participant interactions’, ‘appropriate involvement of supporters’, ‘facilitation of independent thinking and planning’, and ‘accessible teaching methods and techniques’.</td>
</tr>
<tr>
<td><strong>Visual, Audio and Kinaesthetic learning</strong> (Fleming and Mills, 1992) three broad styles of learning: visual, auditory and kinaesthetic.</td>
<td>All contexts, ‘visual and interactive mechanisms’, ‘accessible teaching methods and techniques’, ‘relaxed and effective participant interactions’ and an ‘effective educator’</td>
</tr>
<tr>
<td><strong>Kolb and Fry’s learning styles</strong> (Kolb and Fry, 1975) advocates that styles are those of observers, thinkers, deciders and doers (Lecky et al., 2010).</td>
<td>Personal contexts and all mechanisms</td>
</tr>
</tbody>
</table>

**Figure 7.2 Know Your Bugs: Mutual theories, contexts and mechanisms**

In this respect, MRT2 addressed the social and vocal components of conversation theory. It included each of the styles of VARK learning; visual through the video that was shown to Group 2 and the ‘MagazineMicrobes’ activity; auditory through conversations; and kinaesthetic through tactile activities such as ‘MagazineMicrobes’ and ‘GlitterMicrobes’. It was also closely aligned with the components of the COM-B framework as outlined in Chapter 6, section 6.10. However, the formal theoretical development of the course did
not address learning disability and due to resource constraints within the PhD I did not have the capacity to explore in depth the appropriateness and influence of these theories in a wider learning disability context. As outlined in Chapter 3, the literature addressing community learning and learning disability suggests that many of these components do have an important role in effective community learning for adults with learning disabilities.

### 7.5 Methodological discussion

As well as exploring the learning environment of KYB, my research aimed to address ethical and methodological issues that were pertinent to research with adults with learning disabilities. My research design was therefore relatively intricate; data collection and analysis involving several stages.

In setting up my research I had felt it was important to address the many potential ethical issues raised in my literature review. Previous research suggested that time spent with participants with learning disabilities in the preliminary stages of a study could yield more robust and ethical findings (Hamilton et al., 2017; McDonald and Kidney, 2012). I achieved this through several informal meetings and conversations before I started fieldwork, ensuring that participants were engaged with my study and all their questions were addressed. I was confident that the consenting process was ethical and comprehensive; I had assessed capacity to consent, given participants time to consider whether they wanted to be involved and re-addressed this each time we met. I felt that this facilitated a sense of ease with my questioning and deeper engagement with the research. For example, although during interviews we often spoke about personal health issues and, in some cases, anxieties, participants spoke to me with confidence and enthusiasm. They also did not appear to be perturbed by my presence during the session.

The follow-up interviews enabled me to address and validate points that had been raised previously and to focus on specific issues; initially knowledge gain, then reported behaviour change and finally longer-term retention and recall. With hindsight this approach also helped me to deal with the impact of the COVID-19 pandemic. Although I managed to conduct several stages of interviews before England went into ‘lockdown’,
the final follow-up interviews were carried out by telephone in July 2020 when face-to-face contact was still not possible. Restrictions on personal contact due to the COVID-19 pandemic meant that many people across the world had to find different ways of working and communicating. Research suggests this introduced further challenges to the lives of adults with learning disabilities (McCausland et al., 2021; Seale, 2020) but also opportunities for some. Seale et al. (2020), for example, identified barriers presented by ‘The Digital Divide’ and lack of in-home support. McCausland et al. (2021) found inconsistencies in use of technology but that it may have supported inclusion for some older adults with learning disabilities and exclusion for others. However, (Burke et al., 2021) found that online methods of research and course development worked well as the COVID-19 pandemic progressed and people with learning disabilities became more accustomed to working in a virtual context.

At the time of the interviews that took place five months after the session, many of the participants in my research still did not have access to, or support in using digital technology for communication. After discussion it was clear that using digital platforms was therefore going to be challenging and we agreed to conduct telephone interviews instead.

In fact, conducting these interviews by telephone worked well. Participants knew me well enough by then to remember me and feel comfortable talking over the telephone. I was also able to talk to them for longer than previously as when interviewed at the venue I was only able to fit interviews within breaks. These interviews enabled me to learn more about participants and their circumstances in the interim and they were uninhibited in telling their stories. All were finding the ‘lockdown’ restrictions challenging and most did not have access to online communication. Some had continued contact with friends they had made during the course whereas others were struggling with isolation. However, although interviews were productive, I was only able to make contact with five participants in each group. Whilst this resulted in fewer interviews, I am confident that the interviews I conducted provided robust and informative data.

Although I gained some insight into reported health behaviours, a limitation of my research was the lack of evidence on actual behaviour change. Within the resource
constraints of the PhD, it was not possible to explore this alongside the evaluation of learning. To fully understand the impact of KYB on self-care and preventative behaviours further research would invaluably address this gap and be particularly pertinent in the light of the COVID-19 pandemic. However, further research would be complex, and would present ethical, theoretical, and methodological challenges; ethical due to the intrusiveness of studying potentially vulnerable people when they are ill, theoretical because there are questions to be addressed about the appropriateness of behaviour change theories in relation to people with learning disabilities, and methodological because of challenges in identifying and engaging with participants in this capacity. It would nevertheless be important research in enabling a better understanding of how adults with learning disabilities address a right to health in this respect.

Although my interviews generated many hours of useful data, some may criticise my sample size of 18 participants as being small. Those that advocate a positivist approach to evaluation would perhaps criticise the scale of my work and question the extent to which the findings were generalisable. Initially, I had planned to supplement the qualitative work with a pre-/post-questionnaire phase in other KYB settings. However, due to the COVID-19 pandemic the educators did not deliver any other courses during the data collection phase. Whilst it would certainly have been interesting to explore the impact of the course in other settings, this approach would have provided just a snapshot of knowledge change at one point in time, and not fully addressed the concept of causation.

My choice of using relatively open questions during the realist interview to address knowledge change provided a different perspective than one which would have been gained from questionnaire completion but one that was equally, if not more, valid and appropriate. By asking participants to explain how/why we wash our hands or what they would do if they had a mild infection, I was able to ascertain in their own words what they knew. I often had to ask several questions to obtain information but found that as I became more familiar with individual participants, I could employ better probing strategies. I was able to thematically capture and compare knowledge change over time on a spreadsheet but at the same time obtain rich data that gave greater insight into participant knowledge and thinking. This also enabled me to verify the validity of participant response.
The use of photo-elicitation proved an interesting, albeit small, component to my methodology. The planned use of photography had two purposes: to further engage participants with the research, and to support elicitation of session recall during follow-up interviews (Copes et al., 2018; Meo, 2010). Most participants enjoyed the photography and some in fact perceived it as an activity that was integral to the session; Alan for example spent a long time photographing different items upon which he would expect to find microbes; and saw this as an extension of the Magazine Microbes activity. It was helpful for some to use the photographs as a basis for some conversations during interviews. However, the participants that preferred not to take or use photographs also recalled the session well.

Implementing a six-staged analysis plan enabled me to analyse my data thoroughly and re-visit and explore further potential thoughts and findings. It is not traditional in a realist evaluation to approach the data inductively as I did at the beginning; indeed, a realist approach involves re-describing data using theoretical concepts, and identifying causal mechanisms and associated contextual conditions. However, there is no prescription as such and there is some evidence of alternative robust approaches to analysis. Hoddy (2019) used a variant of grounded theory for example, Wiltshire (2021) describes a realist approach to thematic analysis and Westhorp (2008) used realist analytic induction, each demonstrating how an approach such as theirs may be appropriate for realist analysis. I agree. Beginning data analysis with a more inductive approach enabled me to explore the data with an open mind and ensure that I did not overlook anything that was not encompassed within the middle range theory. Developing the participant pen portraits and drawing out themes brought me closer to the data and enabled me to view it from a different perspective than if I had started with the initial middle range theory. Developing the pen portraits for example enabled me to consider ‘what worked’ for each individual relative to their personal circumstances and supported my recall of their characters and behaviours. In fact, the themes that I identified were closely aligned with the CMO configurations in the refined middle range theory.

I hope that my research makes a positive contribution to the invaluable and growing literature on conducting realist evaluation. Aspects of realist evaluation still lack explanation and can be interpreted flexibly, particularly regarding definition of contexts.
and mechanisms, and the revision of middle range theory (De Weger et al., 2020). There is experiential and methodological guidance on this (De Weger et al., 2020; Emmel et al., 2018; The RAMESES II Project, 2017d, 2017a; Wong et al., 2012, 2016). However, there are no specific rules, and researchers have often utilised methodological guidance differently. I chose to build upon my preferred existing methodologies in this respect such as Dalkin et al. (2015) work on defining mechanisms, and a focus on middle range theories rather programme theories (Jagosh et al., 2015). I aimed to be as open and descriptive as possible in my approach in order to contribute to wider knowledge.

7.6 Collaboration: Developing productive research relationships to enhance public health research outcomes

The development and management of productive research relationships was pivotal in ensuring that my research was effective. Collaboration was an important thread running throughout my PhD; I engaged regularly with different people and organisations, each adding their own value to the research. Figure 7.3 illustrates the collaborations and their contributions to the PhD.
Whilst challenging at times, these collaborations enhanced research outcomes and at times helped to ensure the research was seen as relevant amongst external stakeholders. They were thus often mutually beneficial and achieved this by:

- enabling accurate, reliable and valid insights into learning experiences during KYB;

- supporting the development of a feasible model for delivering a community health education course such as Beat the Bugs;

- identifying further research needs; and

- ensuring an enjoyable experience and positive attitudes to involvement in further research.

Figure 7.3 Research collaborations
7.6.1 The Research Development Group (RDG)

From the outset I aimed to ensure my research was robust, ethical, and appropriate by working with adults with learning disabilities on its design and execution. I had originally hoped to work more inclusively than I did and considered different approaches such as recruiting co-researcher(s) and working with a self-advocacy group. However, due to resource limitations and funder requirements regarding the evaluation this was not possible. In fact, the Group came together well, and was initially productive and enjoyable.

The collaborative approach I adopted added value to the research through working with an extended team of experts by experience within a space we had created and developed. Group members had lived experience of learning disability, community adult education and, in different respects, self-care. Consequently, they often offered ideas and perspectives that I had not considered within the space we had created. The Group provided insights that improved my data collection, interpretation of transcripts, and development of accessible dissemination material. With their advice I developed interview guides (Appendices 11-18) that enabled me to focus on topics addressing my research questions, and simultaneously enabled participants to provide accounts that were relevant to themselves.

The Group’s role in ensuring that the research was feasible, appropriate, and relevant was therefore crucial. After the first meeting, I realised that some of my expectations were unrealistic as my proposed questions and content were a little complex for some. Additionally, I had anticipated that asking the Group a direct question about how to research learning outcomes would not have been productive; members would have found this hard to conceptualise. However, by providing examples and delivering some of the KYB content during a RDG meeting I was able to ask what group members thought of it and how they might try to find out about others’ experiences. Together we were then able to discuss some questions for fieldwork. This resulted in good contextual data collection as I was better informed, and subsequent relevant, accurate and valid data.
There was a shift in activity and method of working of the RDG due to the COVID-19 pandemic. As the pandemic spread and in-person meeting restrictions persisted, contact became more difficult. This was because we could not meet physically, and some members did not have internet access. At this stage we became a smaller, more disparate group. Those that had internet access and support connected with me virtually. Most of those that did not, spoke on the telephone to me or unfortunately withdrew from the group. Although this was disappointing, I offered to reconnect with those that had withdrawn once we were allowed to meet in-person again. Working with Group members had enhanced research outcomes through elaboration of important and useful perspectives. The Group had supported me in reflecting on what was relevant and useful, and I hoped that we would be able to reconvene once meeting restrictions were over. Unfortunately, I was only able to collaborate with one member of the Group, Lucie, in the time that was available.

Meeting with Lucie on a one-to-one basis became a different type of collaboration. Although it was an extension of the Research Development Group, it was a more focused partnership as our aim was to develop and refine an accessible summary of findings. Lucie was a natural supporter and other group members had previously described to me how she often helped them in a range of activities. She was therefore accustomed to working with others. Lucie was committed to our work, had useful ideas and was confident in expressing them. Lucie’s contribution changed both the content and the format of the summary. We have yet to ascertain whether the summary is accessible as, at the time of completing my thesis, we had not presented it. However, in terms of a collaborative method of working it felt positive, was productive, and Lucie and I thought that we had produced an accessible and meaningful summary.

The application of Nind and Vinha’s (2012a) inclusive research assessment, enabled me to evaluate the work I undertook with the Research Development Group and later with Lucie. Broadly, this indicated a positive contribution to the overall research. The topic was perceived as relevant by group members and one to which they could relate, although they did not choose it themselves. They could however see the value of the topic in supporting independent healthy living and appeared to be committed to the concept of good health. I aimed to ensure that the research involved people with learning disabilities
in a meaningful and active way; meaningful in the context of a topic that was important and of key relevance to the group members; and active in the context of engaging collaboration. However, as I have discussed, the COVID-19 pandemic made this difficult at times and, although I tried to work around this, access to and support with technology inhibited some activity. Group members were all treated with respect, and I made effort to ensure that information about the research and the course was communicated in an accessible and open way. This included developing accessible documents, providing clarification, and prompting and responding to all questions. We also undertook some of the course activities together so that Group members could understand and visualise aspects of the KYB session.

I aimed to be honest and transparent throughout, and considerate of individual needs. We took regular breaks during meetings, and I provided refreshments. I was aware of potential power imbalances and tried to ensure that these did not occur; meetings were relaxed, and everyone had opportunity to consider and contribute. Some Group members were more engaged and interactive than others, and we remained sensitive to the needs of those who found verbal communication more challenging. We took our time in this respect and no one appeared to feel excluded. As Group members already knew each other well and were accustomed to group situations together, they already had an established rapport. During the first meeting there were times when one individual was becoming less engaged and appeared bored with a conversation about self-care. I therefore decided to switch activities and return to the self-care discussion later in a shorter component of the session.

I believe that the collaboration has been a productive and worthwhile experience for those that were involved. On reflection of the work undertaken, Group members were positive and engaging. Most were forthcoming about their enjoyment of the experience and expressed an aspiration to undertake further collaborative work. It provided change and a valued activity. Two Group members were less outwardly enthusiastic although I understand that they were generally quieter more reserved individuals who nevertheless liked to participate. Although at the time of writing my thesis I am still unable to meet in person with Group members, I plan to do so as soon as restrictions are lifted to discuss next steps.
I hope that this research creates worthwhile knowledge. It provides an authentic and unique analysis of adult community education experiences. It suggests ways in which a module such as KYB could be improved to address the health learning needs of adults with learning disabilities and suggests further research that is needed to provide a foundation from which to effectively address a right to health. Broadly, it proposes a model of community health education that aims to ensure learners needs are met, and that they achieve the best and most relevant outcomes possible, thus supporting pursuance of a right to health.

7.6.2 The research participants

All research participants (those attending the sessions, the tutors and the supporters) were also an important part of the overall collaboration. Course attendees were open and willing participants in the research, providing much useful data. Flexibility on my part was very important in this respect, and I found that communication and information flow became easier each time I returned. As I got to know participants better, I could adapt my style accordingly, resume where we had left off previously, and thereby build on my data. For example, Colin and James preferred to take their time in conversations and were comfortable with considered silences. Conversely, Alan and Michelle were outgoing socially; they often extended conversations proactively and disclosed further relevant detail.

I was keen to ensure that the research was a positive experience for the participants in my study. I achieved this through a relaxed style, several meetings and conveying enthusiasm about the research. Developing positive research relationships in this way supported the generation and validation of rich data about health knowledge and behaviour strategies.

Tutors and supporters facilitated the process and worked with me on any issues that arose. Together this helped to ensure that the research process was smooth, timely and enjoyable.
Finding and working with people who were prepared to deliver the session was at times challenging and setting this up took longer than anticipated; some groups chose not to be involved whereas others were very enthusiastic. However, once I established engagement, my collaborators were productive and engaging. The course tutors were invaluable in supporting me through the consenting, recruitment, and data collection process. They also helped me address challenges presented by the COVID-19 pandemic, thus ensuring that good quality research continued.

### 7.6.3 Collaborative organisations

The organisations that were involved in my doctoral collaborations had different but sometimes converging roles. Academically, the Open University provided supervisory input, training, and networking opportunities as well as peer support. The Grand Union Doctoral Training Partnership (GUDTP) provided access to further training, peer discussion and events. Public Health England and the local authority were also a source of information and advice. Together these enhanced research outcomes by helping me develop as a researcher and thereby evaluating all strands of the research. The process was also motivating and enjoyable for me, enabling me to reflect comprehensively and make the most of working relationships.

### 7.7 Managing self-care: Whose responsibility?

As I have described in Chapter 6, section 6.4, the participants formed a very diverse group with different health experiences and perspectives. Some were managing complex health conditions relatively independently whereas others looked to family, friends, personal supporters, or residential staff for advice and help with health decision making. Consequently, participants had different learning needs, and their proposed self-care strategies and reported behaviour varied considerably in relation to their learning. Michelle and Ian, who both lived in supported accommodation, were confident about when they needed to request medication for example, they understood the signs to consider, and thought that they knew how to interact with staff to address any health concerns. Paul and Anne on the other hand, who lived with their parents and were very
close to other family members, appeared to be much less confident about deciding and implementing self-care strategies, even more so as the COVID-19 pandemic progressed.

In this context, my research raises questions about expectations and responsibilities regarding illness identification and corresponding self-care in a range of health contexts. Although there has been a policy and legislative drive to give people with learning disabilities greater choice in making decisions about their lives (UK Public General Acts, 2005, 2010; Department of Health, 2001, 2009), it may be difficult for some people to take full responsibility for their health. People with learning disabilities often must address more complex health issues than the rest of the population which can render self-care challenging. Anne and Paul were unclear about how to self-care for example, despite having participated in self-care discussions during the session. Michelle was at times confident and other times confused about using antibiotics; stating that she knew not to share antibiotics but also saying that she shared them with her mother. At their five-month interviews, most participants were less clear than they were immediately after the session about which self-care strategies they should use if they were ill. This implies that they were unable to retain some of their learning. Due to PhD time constraints, I was unable to explore how long the KYB participants retained the knowledge they acquired on the course. However, my research suggests that this varies for each individual in the short to medium term.

Rather than expect course participants to retain the knowledge and skills they acquired during a session such as KYB, I suggest that further research is conducted to explore the appropriateness of including a personal planning session within the entire course. During this session participants could plan with assistance from course staff and include discussions about support outside the course setting and in the longer term. The aim here would be to enable either independent self-care or ensure that there is an effective health partnership in place so that a person has accessible, trusted, and informed support in the process of illness identification and self-care. This might involve linking with an advocate for example to help identify health concerns and make appropriate corresponding decisions.
This introduces the subject of the personal supporter’s role in supporting good management of health, and the potential role of the wider community in providing a supporting framework for self-care. The KYB session was geared towards adults with learning disabilities, not their advocates, although some KYB participants attended the session with personal supporters. This appears to be a potentially important oversight, particularly in the cases of people such as Paul and Anne who appeared to work better in partnership with their family on health decision making. It would be helpful in these situations that those who support them are informed about the learning outcomes of the module (and the entire course). The Beat the Bugs course was originally designed for ‘the community’, not specifically for adults with learning disabilities, and further consideration should be made to adapting the course for supporters.

In fact, research suggests that communities can have a multi-faceted role in individual health behaviours (Michie et al., 2021; Public Health England, 2020c; South et al., 2020). Individual knowledge, approach to risk and motivations are key but also important is the existence of socially shared understandings and co-ordinated efforts in preventing the spread of infection (Michie et al., 2021; South et al., 2020). In the context of learning disability, there needs to be further investigation of support in this context, and the ways in which it can help to address health inequalities and enable a right to health.

This reintroduces one of the questions raised in my introduction: who and where are adults with learning disabilities? An important consideration in supporting people with learning disabilities in a self-care context (either through education and/or personal support) is the existence of the ‘hidden majority’ of people with learning disabilities (Russell et al., 2017; Carey et al., 2016; Emerson et al., 2016; Hatton, 2016; Emerson, 2011); those who are not formally recognised as such. There still needs to be further discussion on identifying and potentially supporting people such as these who may not self-identify as having a learning disability or are not linked to formal support networks. I suggest this warrants further research and debate to explore ways of ensuring that everyone has access to enjoying a right to health. This is particularly important in the light of the COVID-19 pandemic which, as described in Chapter 1, has further highlighted the health inequalities and poorer health of people with learning disabilities.
7.8 The role of Know Your Bugs in supporting a right to health

In introducing my thesis, I presented the concerns raised in the literature about the health inequalities experienced by people with learning disabilities, and the role these have in exercising a right to health. As I described, the right to health includes freedom to control one’s own body and health, and entitlement to health protection and equal opportunity to enjoy the highest attainable level of health (World Health Organization, 2017; Office of the United Nations High Commissioner for Human Rights, 2008). Good health should therefore be experienced without discrimination, and healthcare should be timely, acceptable and affordable (World Health Organization, 2012, 2017). I suggested that the known health inequalities and the underlying determinants of them (for example, sanitation, housing, health information, health promotion and education) inhibit access to a right to health, and that there is potentially a considerably larger number of people affected by this than public statistics show (Emerson et al., 2016; Hatton, 2016; Emerson, 2011). This is particularly important given the considerable co-morbidities and early mortality that people with learning disabilities experience compared with the rest of the population.

In researching the important topic of health education in the light of this background, I found that a module such as Know Your Bugs (KYB) can support an improved understanding of health concepts and self-care if it is delivered interactively, flexibly and accessibly. This matters because without such initiatives to improve health knowledge and appropriate self-care behaviours I argue that this is a missed opportunity to support people with learning disabilities in exercising their right to health. The KYB module, of course, is short term and only addresses specific health issues. There is however arguably potential to educate about other aspects of health in the same way, as in the independent living skills programme compiled and delivered by the education provider in my research. Consideration should also be made to virtual formats of health education as suggested by Burke et al. (2021). The use of online technology has increased considerably since the COVID-19 pandemic, and although there are concerns about its accessibility to people with learning disabilities (Seale, 2020), emerging research suggests that there is potential for its use in a health education context (Burke et al., 2021; Jeste et al., 2020).
Education is of course also not the only underlying determinant of health inequalities. Adults with learning disabilities are known to experience multiple other disadvantages including socio-economic inequalities and life chances (McMahon and Hatton, 2021; Totsika et al., 2021; Hatton, 2016; Emerson, 2011). Education is however an effective starting point for health understanding because it can provide knowledge and comprehension that supports appropriate behaviours. However, as with all determinants of health inequalities, access is a concern frequently cited in the literature; many people with learning disabilities do not have access some of the components of a right to health such as appropriate and accessible education, information and the support to address these (Hatton, 2016; Emerson, 2011). A right to health advocates that good health should be accessible to all and practised with equal opportunity (World Health Organization, 2017).

As I have outlined in section 7.7, I feel there needs to be continuing debate on how to reach those who do not access support and on how to ensure that they are supported appropriately. This was raised recently in Courtenay and Cooper’s (2021) editorial on COVID-19 which reiterates the importance (and indeed legality) of making reasonable adjustments in a health context. The authors advocate taking steps such as the introduction of specialist learning disability doctors and training for health professionals in the needs of people with learning disabilities and the health inequalities they experience. The Know Your Bugs module has the potential to contribute to improving this wider context by educating and informing everyone; people with learning disabilities, their supporters, health professionals, educators and policy makers.

As I have also discussed in section 7.7, there are also more specific questions that need to be addressed regarding who, in the context of Know Your Bugs (and Beat the Bugs), should access health education. Although a right to health advocates having control over one’s body and health, some adults with learning disabilities may need support to enable this, particularly on a longer-term basis. It is thus possible that many adults with learning disabilities would be better placed to manage their health if their personal supporters were also educated.
KYB aims to impart health knowledge and improve health behaviour strategies through education, awareness-raising, activity, and positive discussions. In this respect it has the potential to improve understanding of, and access to health resources. It can enhance shared support and decision-making. It can also engender a positive feeling about addressing health, perceiving good health management as a whole approach that focuses on prevention, and management (if necessary), of health problems such as infection, obesity, and diseases such as diabetes. All of these can be important ingredients of a right to health.

However, to achieve this, specific components need to be in place in the short, medium and long-term, including accessible mechanisms for long-term reinforcement, appropriate support, and accessible, motivational resources. KYB has the potential to fulfil these some of these needs as it is part of a broader course that addresses these and other issues. A longer duration of the entire course (10 weeks) could support the reinforcement of learning concepts over time. However, I suspect that there is a need for longer term reinforcement as well. Due to PhD time constraints, I was unable to address this.

As I have discussed, my research did not explore in depth the course participants’ actual behaviour change, and specifically not sustained behaviour change which is cited in the literature as challenging in the context of COVID-19 preventative behaviours (Michie et al., 2021). Michie et al. (2021) have recently outlined potential approaches for achieving sustained behaviour change in this context. The authors suggest 30 distinct approaches to sustained behaviour change, including: maintaining education to maximise knowledge, providing instruction in action planning, providing tools and resources, and promoting behavioural goal planning. It is not clear whether these are wholly relevant to adults with learning disabilities, nor indeed whether there are other components that should be considered. However, many of the behaviour change approaches suggested by the authors are in fact addressed by KYB. In this context of health education, they may provide an important first step to practising appropriate preventative behaviours. As a first step in taking this forward, I propose a community model of health education which comprises the key components of an effective intervention that I have identified during my research. This model is illustrated in Figure 7.4.
This model represents one of several potential next steps in moving forward with Know Your Bugs, and it first needs wider discussion. However, there is also a need to explore the feasibility of wider delivery of the module and the course in terms of costs, human resources and timescale, linking this with local priorities.

Due to time constraints of the PhD, it was not possible nor appropriate to undertake this as a component of my realist evaluation. However, it is an important next step that warrants research. In setting up my research, I encountered reluctance from some other education providers to deliver the course. This was due to the other priorities within provider organisations and is a consideration that warrants attention. It might, for example, be appropriate to consider an online version of the course. Burke et al. (2021) found that using a digital platform to learn about health engendered confidence and a clear understanding of how to self-care.
7.9 Chapter summary

This realist evaluation has provided useful insight into causal pathways regarding learning in a session addressing hygiene, infection prevention and self-care. In combining a realist approach with analysis of pre-existing theory, I identified contexts, mechanisms and outcomes that transitioned and merged over time. The refined middle range theory that I developed, MRT2, provided a detailed illustration of a model that has potential applicability outside of the learning environments that I studied. My research outcomes contain very strong messages about the social context, the educator, and the interactive nature of the course as key players in the causal pathways for all participants.

There is certainly a need for further work to fully understand the delivery and impact of KYB. I did not evaluate set-up or cost-effectiveness of the module for example, nor did I explore actual behaviour change. However, my research enabled me to investigate and understand the complexity of the session that addressed the module, and to advance theoretical understanding of the components that need to be in place to ensure an effective session. In my final chapter, Conclusion, I conclude my thesis by summarising the components I feel should be in place to ensure positive outcomes for adults with learning disabilities participating in a course such as this and outline some next steps.
Chapter 8. Conclusion

On commencing my doctoral research, I had set out to provide insight into the community learning experiences of adults with learning disabilities in relation to a health education module called Know Your Bugs (KYB). I aimed to explore the immediate effectiveness of the KYB session, particularly the ways in which the learning environment influenced participants’ understanding of the concepts that were taught. I planned to explore the extent to which new knowledge was retained and could be recalled in the longer term. I aimed to gain a perception of behaviour change, although acknowledged that I did not have the resource to fully address this alongside my other aims. Finally, I aspired to gain insight beyond the literature into the experience of collaborative working with adults with learning disabilities on public health evaluation, specifically addressing how it was possible to engage productively on complex evaluations.

So, how did the learning environment influence learning and behaviour change in the context of my research? It did so in many ways as illustrated by the context/mechanism/outcome configurations identified during my analysis. Foremost, it influenced participants by providing a foundation for a positive learning experience. Led by engaging educators, the sessions provided a stimulating learning environment that enthused participants and was supported by motivational resources. By establishing familiarisation with participants during previous sessions, the educators achieved a positive balance between instruction, activity, and discussion, thus enabling participants to acquire knowledge in relation to microbes, self-care and, to a lesser extent, antibiotics.

The learning environment thus influenced learning and intended behaviour change through social, personal, and physical contexts that encouraged motivation and enthusiasm to learn, collaborative working and active learning that built on personal knowledge. For participants, the learning environment continued beyond the formal course context and into their personal lives. It influenced learning and reported behaviour change through providing opportunities to practise what they had learnt, particularly in relation to the COVID-19
pandemic. The messages conveyed in the formal learning environment echoed those that were conveyed externally about hand hygiene, keeping well and seeking advice if necessary.

The learning environment also influenced learning and intended behaviour change through important mechanisms of delivery. These included an effective educator, accessible teaching methods and techniques (including activity and interaction, reinforcement and repetition, and incremental development of the session), visual and interactive resources, relaxed and effective participant interactions, facilitation of independent thinking and planning, and the ways in which supporters engaged with participants.

The revised middle range theory explaining the KYB session succinctly encapsulated the original theoretical underpinnings of the course. It incorporated the styles of VARK learning and was closely aligned with the components of the COM-B framework. In developing, implementing, and refining programmes such as Beat the Bugs it is therefore important to consider and exploit the range of potential interactions thus maximising the benefit to the participants and forging good outcomes. For example, the educators were also integral to the success of KYB; planning according to participant needs, managing difficult conversations, and enabling flexibility to pick up on participant leads where appropriate.

How did the module equip adults with learning disabilities with knowledge and confidence to self-care and manage common infection? It did so through KYB activities and resources that were motivational and, in the main, supported achievement of the learning outcomes listed in the course guide. These included some learning about self-care, identifying signs and steps to take in the case of serious illness, and some learning about antibiotics. However, some resources and techniques need adaptation. These included the antibiotics resources which were too complex for many participants; corresponding discussions did not generate the intended learning outcomes. It is difficult to develop a course that is accessible to everyone. Participants had different prior knowledge, levels of understanding and preferred learning styles, and addressing these appropriately for everyone is challenging. However, adjustments need to be made to ensure the antibiotics resources and discussions
can be understood by everyone, and that key learning points are addressed throughout the course to support reinforcement and retention of learning.

To conclude my research, I have proposed a community health education model that aims to outline the delivery components necessary for a module such as KYB to work. This is illustrated in Chapter 7. This is a first draft of the model that brings together the context/mechanism/outcome configurations identified in the revised middle range theory. The model has been discussed with adults with learning disabilities and with the educators that participated in this study. It does however need wider discussion. It does not address the set-up process, resource needs or costs; these were not addressed during my evaluation.

How does collaborative working with adults with learning disabilities on public health evaluation enhance research outcomes? As a collaborative project, I had anticipated that my research would show how working with adults with learning disabilities on public health evaluation could enhance research outcomes. This approach added value to my research by enabling me to ask appropriate questions and bringing a more valid perspective to my data and conclusions. However, this approach was challenging in practice, first due to the complexity of my research methodology, and secondly in light of the COVID-19 pandemic which made it difficult to engage with those that did not have access to, or support in using online approaches to meeting. Despite published guidance on ways of working with adults with learning disabilities on health research, there is no recent synthesis on the effective ways of doing so, particularly regarding public health evaluations. Further research identifying what constitutes good inclusive evaluation practice and gaining reflections from people with learning disabilities and researchers on what is and is not effective would enable a better understanding of how public health evaluations can be enhanced by co-production approaches.

My research has clarified the role of appropriate, accessible, and inspirational education in supporting a right to health and addressing health inequalities. In this respect, education
such as Know Your Bugs can improve knowledge and provoke thinking about positive health behaviours; it can provide confidence and understanding about self-care in addressing personal health considerations positively, and can initiate access to sources of information, advice and further support. Education such as this therefore has the potential to open doors that were previously closed to many.

My research has also highlighted the importance of the longer-term learning context in reinforcing knowledge. It has shown how the external environment can enable reinforcement of, and opportunities to practise learning. However, knowledge was often forgotten in the longer term. To enable adults with learning disabilities to recall, reinforce and act on their learning, and thus engage with opportunities to have equal access to healthcare there is a need for education to continue in the medium and long term. Clearly, there is also a need for health services, including healthcare, diagnostics, information and advice to be accessible and appropriate.

My research has raised the question of support in this context and identified further questions about expectations and responsibilities in experiencing a right to health. For example, who and in what circumstances do adults with learning disabilities need support in managing good health; who are ‘supporters’ and what is their appropriate role in a health education and a healthcare context; in which situations would it be appropriate for those involved in supporting adults with learning disabilities to undertake such education?

8.1 Next steps

At the outset, PHE aspired to achieve widespread implementation of Beat the Bugs beyond my doctoral research; for adults with learning disabilities and for those who are not learning disabled. There certainly appears to be a need for the course, particularly in the light of the COVID-19 pandemic. However, it would be necessary to conduct further work to disseminate the aims and value of the course. My experience in engaging with potential course providers has implied that it would take time to engage, train and support
organisations that agree to deliver the course. I did not conduct a process or economic evaluation and therefore did not look at costs, time, personnel, and other issues in delivering Beat the Bugs. It would certainly be useful to do so now that I have illustrated what would constitute a good course. In this respect, further research would enable potential providers to assess whether they could deliver the course and on what basis they could do so.

Regarding the KYB resources, PHE has been acting on an evaluation summary suggesting interim changes to the content (Appendix 19). This includes further development of Beat the Bugs resources including updating the guidance on self-care, ensuring the resources give consistent messages, developing more accessible antibiotics resources and developing a programme for reinforcement of learning.

### 8.2 Further research priorities

To support development and implementation of the model and to improve the resources, further research is necessary, in addition to the needs I have already highlighted. First, there is a need to evaluate the whole Beat the Bugs course, and thus explore consolidation of learning across more than one module. Using a realist evaluation approach to doing so would enable a more in-depth understanding of ways in which the different components of the course are effective, and the contexts and mechanisms that do or do not generate acquisition and implementation of independent living skills.

Preliminary discussions with a self-advocacy group during the earlier stages of my research had shown considerable interest in and commitment to the nature of the course. However, the group agreed that they would not be able to deliver it because it was not accessible to them. Further research and development are needed to enable them and others to deliver Beat the Bugs. Changes suggested by the self-advocacy group included audio recording the course guide, updating some of the slides, and replacing some resources so that they are less child-like. In the KYB Group 2 session, the video was enjoyed by those who watched it.
although they did not understand some of the important concepts; it might be very useful to develop an accessible video about microbes, illness, and self-care for example.

The Beat the Bugs course was modelled on e-Bug, an educational resource originally developed for schools. It was subsequently adapted for delivery to the wider public, although not specifically adapted for adults with learning disabilities. There are areas that need improvement in this respect, such the antibiotics resources. To be in a position to make reasonable adjustments to the course, further research is necessary to understand adult learning needs in this context and optimal methods of addressing these, for example how to engage in productive communication about medication and self-care, and how to have effective conversations about issues such as antibiotic use. This also has a wider relevance in the context of effective health communication, an important determinant of a right to health.

The session incorporated an intended behaviour change component, aiming to change inactive behaviours regarding self-care and infection prevention. My work explored reported but not actual behaviour change in this context because I was limited by time and human resource during my doctoral research. To gain a more comprehensive understanding of behaviour change, further research should address this alongside longer-term recall and retention of knowledge gain. This would be particularly useful in the light of the COVID-19 pandemic and suggestions about supporting sustained preventative behaviours that minimise the risk of spreading infection (Michie et al., 2021). Such research would be challenging ethically and methodologically. However, it would be helpful in enabling adults with learning disabilities to develop self-care skills in preventing and managing illness, and in addressing their personal health effectively.

This research has addressed the learning experiences of adults with learning disabilities in relation to a community health education module. Although I have considered and analysed the role of supporters within the study, this was not a primary focus. The support provided to the participants in my research included one-to-one personal supporters (for four
participants) and course-based learning support assistants. Some participants also referred to support outside of the learning environment in assisting them to live healthily, and further research to explore the influence and effectiveness of supporters in self-care would enable a better understanding of how they can contribute to independent healthy living.

Participating in a module such as KYB can support adults with learning disabilities in addressing their right to health from an educational perspective by providing them with information and generating thinking and action. Further adaptation and accessible improvement to the whole Beat the Bugs course alongside accessible implementation nationally could provide a good foundation for addressing improvements in health inequalities.
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## Appendix 1 Quality assessment of studies for scoping review

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<th>Authors</th>
<th>Study topic</th>
<th>Methodology</th>
<th>Qualitative assessment (EPHPP, 2007)</th>
<th>Quantitative assessment score</th>
<th>Global score</th>
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<td>Parish et al. (2012)</td>
<td>Breast and cancer screening info programme. Community establishment setting. HE*.</td>
<td>RCT; pre-post and follow-up.</td>
<td>16</td>
<td>Moderate (2)</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Diabetes studies:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Taggart et al. (2018)</td>
<td>Diabetes education programme. Community setting. HE*.</td>
<td>Pilot RCT with pre- and follow up. Also process evaluation</td>
<td>16</td>
<td>Weak (3)</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Authors</td>
<td>Study topic</td>
<td>Methodology</td>
<td>Qualitative assessment (Naaldenberg et al., 2013)</td>
<td>Quantitative assessment score (EPHPP, 2007)</td>
<td>Component scores:</td>
<td></td>
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<tr>
<td>Dunkley et al.</td>
<td>Diabetes screening and education programme. Community setting. HE*.</td>
<td>Qualitative – two phases.</td>
<td>Qualitative – two phases.</td>
<td>Global score</td>
<td>A: Selection bias N/A  B: Study design N/A  C: Confounders N/A  D: Blinding N/A</td>
<td></td>
</tr>
<tr>
<td>(2017)</td>
<td></td>
<td></td>
<td>16</td>
<td>N/A - qualitative</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other studies:</td>
<td></td>
<td></td>
<td>15</td>
<td>Weak (3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wells et al.</td>
<td>Computer education programme. Academic setting. HE*.</td>
<td>Quasi-experimental design; pre- and post-assessments but no follow-up.</td>
<td>Weak (3)</td>
<td>3 2 3 3 2 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(2012)</td>
<td></td>
<td></td>
<td>12</td>
<td>Weak (3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clark et al.</td>
<td>Epilepsy education programme. Training centre setting. HE*.</td>
<td>Experimental design; pre-, post- and follow-up.</td>
<td>Weak (3)</td>
<td>3 1 3 3 3 3 3 3 3</td>
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<tr>
<td>(2001)</td>
<td></td>
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</tbody>
</table>

HE = Health Education, BC = Behaviour Change
### Appendix 2  Beat the Bugs course content

<table>
<thead>
<tr>
<th>Session</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meet the Bugs</td>
<td>Introduction to and overview of microbes. Participants are shown the world of microbes, firstly by exploring the different types and shapes of microbes and then by discussing different useful and harmful microbes. Begins with a poster entitled “Meet the bugs”. Suggested activities include: a yeast race, top trumps, magazine microbes.</td>
</tr>
<tr>
<td>Spreading Bugs</td>
<td>Focuses on hand and respiratory hygiene and gives an overview of the spread of infection. Includes how microbes are spread through sneezing and how proper hand washing with soap can break the chain of infection. Suggested activities include: the ‘Snot Gun’, ‘Horrid Hands’, 6 steps of hand washing.</td>
</tr>
<tr>
<td>Food Bugs</td>
<td>Participants learn how easily potentially harmful microbes on raw food can transfer to humans. Interactive quiz shows how to prepare food safely and the food labelling activity demonstrates how to interpret labels.</td>
</tr>
<tr>
<td>Mouth Bugs</td>
<td>Focuses on prevention of tooth decay by demonstrating the importance of limiting sugar intake and brushing teeth twice a day. Participants are requested to keep a diet diary for the week prior to this session. Suggested activities include: Healthy Diet (look at diet diary for sugar attacks), How much sugar?</td>
</tr>
<tr>
<td>Bug Busters</td>
<td>Introduces antibiotics, and when and how to take them correctly. Includes demonstration of antibiotic resistance and a participant activity to show how easily antibiotic resistant bacteria spread.</td>
</tr>
<tr>
<td>Know your Bugs</td>
<td>Participants learn how to self-care at home for common infections enabling them to make decisions on their own health. Suggested activities: How to take antibiotics correctly (worksheets with scenarios), Accessing health information online (discussion – websites, apps, info sources), Health information leaflets (talk through ‘Managing your infection’ and other leaflets).</td>
</tr>
</tbody>
</table>
Appendix 3  Assessing capacity to consent

Know Your Bugs Research Development Group

Assessing capacity to consent

*Run through information sheet and briefly recap on the course and the research.*

1. What do you think Beat the Bugs is?
2. What do you think the research project will do?
3. What do you think it will involve for you if you take part?
## Appendix 4  Expression of interest (RDG)

### Know Your Bugs Research Development Group
### Expression of interest

Would you like to be involved in a group to work with me on some research?

The group will meet 4 times over 2 years.

The research is looking at a course for adults with learning disabilities called Know Your Bugs

I would like to see how good the course is.

If you would like to take part, please tick these boxes

- [ ] I have read the information sheet about the group.
- [ ] I am happy for Rebecca to contact me about this group.

If you would like to take part please write your name and contact details here

- **Name:** ____________________________
- **Date:** ____________________________
- **Email:** ____________________________
- **Telephone number:** ________________

Please give this form to **(named member of staff)** or send it to Rebecca in the envelope provided.

If you have any questions please contact me, Rebecca Owens, either by email: Rebecca.owens@open.ac.uk or by phone: 07500 249448
## Appendix 5 Information sheet (RDG)

### Joining the Know Your Bugs Research – information sheet

<table>
<thead>
<tr>
<th>Image</th>
<th>Text</th>
</tr>
</thead>
</table>
| ![Person](image) | I am doing research to find out what people with learning disabilities think of a course about health.  
The course is called Know Your Bugs.  
I would like to know if it helps people look after themselves so they are less likely to get ill. |
| ![Group](image) | I would like to work with a group of people with learning disabilities on this research.  
The group will help me do the best research possible. |
| ![Meeting](image) | I would like to meet with this group 4 times to talk about the research.  
There will be between five and seven people on the group. |
| ![Magnifying Glass](image) | I hope the group will help me decide on questions to ask people who do the course.  
I also hope that the group will help me listen to what people say about the course and tell me what they think of it. |

4 meetings

Meetings will start at 11 o’clock and finish at 3 o’clock.

---

This project has been reviewed by, and received a favourable opinion from, the Open University Human Research Ethics Committee, reference HREC/3286/OWENS
## Appendix 6  Consent form (RDG)

### Know Your Bugs Consent form

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>![Image of people]</td>
<td>I would like to join the group</td>
<td></td>
</tr>
<tr>
<td>![Image with words]</td>
<td>It is OK to use my words in the report</td>
<td></td>
</tr>
<tr>
<td>![Image of meeting]</td>
<td>It is not OK to use my words in the report</td>
<td></td>
</tr>
<tr>
<td>![Image of phone]</td>
<td>It is OK to record the meetings</td>
<td></td>
</tr>
<tr>
<td>![Image of phone]</td>
<td>It is not OK to record the meetings</td>
<td></td>
</tr>
<tr>
<td>![Image of report]</td>
<td>I would like to have a summary of the report</td>
<td></td>
</tr>
<tr>
<td>![Image of person holding sign]</td>
<td>I don’t want a summary of the report</td>
<td></td>
</tr>
<tr>
<td>![Image of name sign]</td>
<td>It is OK to use my real name</td>
<td></td>
</tr>
<tr>
<td>![Image of name sign]</td>
<td>It is not OK to use my real name</td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td></td>
<td></td>
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<tr>
<td>------</td>
<td>--------------------------------</td>
<td></td>
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<tr>
<td>Email</td>
<td></td>
<td></td>
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<tr>
<td>Telephone</td>
<td></td>
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</tr>
</tbody>
</table>

Date ..................  

You can leave the group at any time and I will not use your words if you don’t want me to.

All the meeting reports will be put together in a computer programme after the last meeting and your words cannot be excluded after September 2021.

If you have any concerns or complaints about this research please contact:  
Sarah Earle  
The Open University  
sarah.earle@open.ac.uk
## Appendix 7  Information sheet (main study)

### Know Your Bugs research project - information

<table>
<thead>
<tr>
<th>I am Rebecca Owens, a researcher at the Open University.</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am doing research to find out what people with learning disabilities think of a course about health.</td>
</tr>
<tr>
<td>The course is called Know Your Bugs.</td>
</tr>
</tbody>
</table>

| I would like to know if it helps people look after themselves so they are less likely to get ill. |

<table>
<thead>
<tr>
<th>I would like to:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Watch what happens in the course while you are there</td>
</tr>
<tr>
<td>• Ask you some questions before and after you do the course</td>
</tr>
<tr>
<td>• Speak to you 6 weeks after you have done the course</td>
</tr>
<tr>
<td>• Speak to you 6 months after you have done the course</td>
</tr>
</tbody>
</table>
I will look at the information I collect
And use it to write a report
And show the report to other people
I will also write about it in academic journals, on websites and talk about it at conferences
I will use this to improve the course for people with learning disabilities

You don’t have to be part of the research if you don’t want to. That is not a problem.
If you join the research but then change your mind you can leave at any time by contacting me.
If you leave, I will not use your words in the report or in anything else if you don’t want me to.
I can remove your words any time until September 2021.

To find out more please contact me, Rebecca Owens by email at: Rebecca.owens@open.ac.uk
Or call me on: 07500 249448

If you have any concerns or complaints about this research please contact:
Sarah Earle
The Open University
sarah.earle@open.ac.uk

This project has been reviewed by, and received a favourable opinion from, the Open University Human Research Ethics Committee, reference HREC/3385/OWENS
## Appendix 8  Consent form (main study)

**Know Your Bugs Consent form**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1" alt="Image" /></td>
<td>I would like to be interviewed for this research</td>
</tr>
<tr>
<td><img src="image2" alt="Image" /></td>
<td>It is OK to use my words in the report</td>
</tr>
<tr>
<td><img src="image3" alt="Image" /></td>
<td>It is not OK to use my words in the report</td>
</tr>
<tr>
<td><img src="image4" alt="Image" /></td>
<td>It is OK to record the meetings</td>
</tr>
<tr>
<td><img src="image5" alt="Image" /></td>
<td>It is not OK to record the meetings</td>
</tr>
<tr>
<td><img src="image6" alt="Image" /></td>
<td>I would like to have a summary of the report</td>
</tr>
<tr>
<td><img src="image7" alt="Image" /></td>
<td>I don’t want a summary of the report</td>
</tr>
<tr>
<td><img src="image8" alt="Image" /></td>
<td>It is OK to use my real name</td>
</tr>
<tr>
<td><img src="image9" alt="Image" /></td>
<td>It is not OK to use my real name</td>
</tr>
</tbody>
</table>

*HREC/3280/01WENS*
Name ________________________________

Email ______________________________

Telephone ___________________________

Date .........................

If you have any concerns or complaints about this research please contact:
Sarah Earle
The Open University
sarah.earle@open.ac.uk

You can leave the group at any time and I will not use your words if you don’t want me to.

All the meeting reports will be put together in a computer programme after the last meeting and your words cannot be excluded after September 2021.
Appendix 9  Information sheet (educators)

Know Your Bugs evaluation

Participant Information Sheet – course leader/educator

Know Your Bugs is part of a wider health education course called Beat the Bugs that aims to educate people about self-care, hygiene and infection prevention with the overall goal of improving their health and wellbeing. It was developed by Public Health England (PHE) and a social enterprise called the Kingfisher Treasure Seekers.

I am a PhD student based at the Open University but also funded by Public Health England and the Economic and Social Research Council Doctoral Training Partnership to evaluate Know Your Bugs as part of a funded PhD. The evaluation will help us to understand the course better and to improve the design and implementation of such courses in the future.

I understand that you are delivering Know Your Bugs to adults with learning disabilities and I would value hearing your views on the module. I would like to sit in on a session of You’re your Bugs and interview you straight afterwards to ask what you think about it.

I’d like to make sure that you understand and are happy about the study before you agree to take part. Please read this sheet which I hope will answer some of the questions that you may have about the study and your part in it.

What is the purpose of the study?

The purpose of the study is to find out how effective Know Your Bugs is in helping people understand how to manage aspects of their health. By talking to people who have taken part in the programme we are aiming to understand these issues better.

Why have I been invited?
I would value your participation because you are delivering the course to adults with learning disabilities and I would like to understand know what you think about it. This will help us understand how to develop programmes better for the future.

**Do I have to take part?**

No. It is absolutely up to you whether you decide to take part or not. If you decide to take part, you are still free to withdraw at any time without giving a reason.

**What happens to me if I agree to take part in this study?**

There will be one observation session of the course in practice and one interview which will last up to one hour. The interview will take place after the session in a private space. After expressing your interest to participate in the study I will contact you with further details about it. Before we start the session you will be required to complete a consent form.

**What are the possible risks and disadvantages of taking part?**

I do not anticipate any disadvantages to you participating in the research, apart from the time taken to complete the interview which I appreciate.

**Will I benefit from participation in this study?**

As a thank you for your time I will give you a £10 voucher for your time.
How much time will I need to spend on the study

We anticipate the interview will take approximately one hour.

Confidentiality: will the information be kept confidential?

The session and the interview will be voice recorded and listened to by myself. It is being recorded so that I can listen without being distracted by taking detailed notes. You will have the opportunity to request a typed transcript of the interview and to ask for particular sections to be deleted should you wish to. Your name won’t be used at any stage in the analysis of the recordings or in any write up or published findings. Your views will be combined with those of others who are taking part in the research. The roles of everyone involved in this research will be described generally. I am likely to illustrate points of view with quotations, but all quotations will be anonymised and described as from a “research participant”. Detailed notes will be made based on the recording. These notes will only be seen by myself. They will be stored in a secure location at the Open University and destroyed ten years after the completion of the study. Please be assured that all information about you and that you provide will remain confidential.

What will happen if I don’t want to carry on with the study?

You are free to withdraw from the study at any point. If you do this you can ask me to remove your data from the study and it will be destroyed. The latest date I can remove your data is September 2021.

Who has reviewed the study?
The Open University has a Human Research Ethics Committee which reviews all studies undertaken at the university to ensure that the interests of the participants are protected. This study has been reviewed and approved by this committee.

**What will happen to the results of the study?**

The results will be written up and presented in a thesis. They may be published in scientific journals or presented at meetings and conferences. I may publish quotations or summary opinions but will not publish names. I would like to give you a summary of the study results after the research has been completed.

**Who do I contact if I have any concerns?**

Should you have any concerns, please contact myself, Rebecca Owens, at the Open University on Rebecca.owens@open.ac.uk, telephone 07500 249448. Should you have any concerns that cannot be answered by myself, please contact my lead supervisor, Sarah Earle at the Open University on sarah.earle@open.ac.uk

*Thank you for taking the time to read this information sheet.*

*Please keep this sheet so that you can refer to it in the future.*
Appendix 10  Consent form (educators)

Know Your Bugs evaluation – Educator consent form

If you would like to take part in an interview for the evaluation of Know Your Bugs please read and complete the following.

1  I confirm that I have read and understood the information sheet for the evaluation of Know Your Bugs

2  I agree for the interview to be audio recorded

3  I agree to the use of anonymised quotes

4  I understand that I am under no obligation to take part and can withdraw at any stage

5  I agree to take part in an interview for the evaluation of Know Your Bugs
Should you have any questions or concerns, please contact myself, Rebecca Owens, at the Open University on Rebecca.owens@open.ac.uk, telephone 07500 249448.

Should you have any concerns that cannot be answered by myself, please contact my lead supervisor, Sarah Earle at the Open University on sarah.earle@open.ac.uk
Appendix 11  Interview guide: introductory interview

[The purpose of this short informal interview is to begin to establish rapport with research participants and enable them to feel comfortable with the research.]

Before starting interview run through information sheet and check participant still consents to participation in the study.

Introduction

Hi - I am Rebecca Owens, a student at the Open University, and I am doing some research to find out what people think of a course called Beat the Bugs. I am doing this by watching the course and by asking people like yourself what they think of it. This is a first interview before you start the course and I hope you can tell me a little bit about who you are and why you’d like to do Beat the Bugs.

I have just a few short questions and if you have any questions yourself please ask me.

1. So could you tell me a little bit about yourself?
   Prompt for information about age, living and working circumstances

2. Why would you like to do Beat the Bugs?

3. What are you looking forward to about the course?

4. Do you have any questions about the research that I am doing?

5. Do you have any questions about Beat the Bugs?
Close – thank participant and remind them that I will be at the Know Your Bugs session and then would like to interview them twice after they have finished the course. Make sure participant has contact information about the study and knows where to go if they have questions.
Appendix 12  Pre-module interview guide

[The purpose of this short informal interview is to begin to establish rapport with research participants and enable them to feel comfortable with the research.] Before starting interview run through information sheet and check participant still consents to participation in the study [skip if introductory meeting took place on same day].

Introduction

Hi - I am Rebecca Owens, a student at the Open University, and I am doing some research to find out what people think of parts of a course called Beat the Bugs. I am doing this by watching one of the sessions and by asking people like yourself what they think of it. This is a first interview before you start the course and I hope you can tell me a little bit about who you are and why you’d like to do Beat the Bugs.

I have just a few short questions and if you have any questions yourself please ask me.

1. So, could you tell me a little bit about yourself?

Prompt for information about age, living and working circumstances

2. Why were you interested in doing Beat the Bugs?

What do you think you have learned on the course so far?

3. What are you looking forward to about the rest of the course?
4. Do you have any questions about the research I am doing?
5. Do you have any questions about Beat the Bugs?

Close – thank participant and remind them that I will be at the Know Your Bugs session and then would like to interview them twice after they have finished the course. Make sure participant has contact information about the study and knows where to go if they have questions.
Appendix 13  Pre-module knowledge assessment

[To be conducted at introductory interview]

1. Do you know why we should wash our hands?
   What would you use to wash your hands?

2. Have you heard of antibiotics?
   Do you know what they do?
   Do you know what can happen if we use antibiotics too much?

3. How would you try to get better if you had a cough or cold and a high temperature?
   (Prompt if unsure: take paracetamol, rest and stay at home, go to doctor, drink fluids)

4. Where would you get help from if you felt poorly?
   (Prompt if unsure: websites, leaflets, people)
Appendix 14  Post-module knowledge assessment

[To be conducted immediately after session - researcher individually ask participants. Then to be repeated at each subsequent interview/focus group with participants]

1. What did you think of the session?

2. Do you know why should we wash our hands?
   What would you use to wash your hands?

3. Have you heard of antibiotics?
   Do you know what they do?
   Do you know what can happen if we use antibiotics too much?

4. How would you try to get better if you had a cough or cold and a high temperature?
   (Prompt if unsure: take paracetamol, rest and stay at home, go to doctor, drink fluids)

5. Where would you get help from if you felt poorly?
   (Prompt if unsure: websites, leaflets, people)
Appendix 15  Post-module interview guide

[The purpose of this interview is to explore what participants thought of the session, ascertain what they learnt, and determine what contributed to this learning]

Before starting interview run through information sheet and check participant still consents to participation in the study.

Introduction

Hi [participant] – Explain purpose of interview.

1. The session – Know Your Bugs

So what did you think of the session

Probe a little: can you remember what you have done? What activities?

Mention specifics if they can’t remember to assist recall.

Can you remember what you liked about it?

Can you remember if you learnt anything from it?

If yes, probe for details

Repeat post–learning knowledge questionnaire
2. **Self-care at home**

Can you remember if you have been ill since we last met? If yes, probe a little for details:

Eg did you take medicines? If yes, how did you manage this? What did you do with them when you finished?)

What did you do – how did you deal with the illness?

Do you think you did anything differently because of what you learnt on the course? Probe for details

What would you do if you had a bad cold? And what if you had a bad headache and very cold skin that wasn’t getting any better?

Probe: How would you manage this? Would you ask for help (who?)?

Do you think there is anything you differently since doing the course if you feel unwell?

3. **Seeing a doctor**

Can you remember if you have seen a doctor this year? Have you seen the doctor since doing Beat the Bugs? If yes, probe for why (eg the course influence) and what was the outcome.

Do you know what are some of the serious signs to look out for if you are feeling unwell?

Probe for severe headache, very cold skin, trouble breathing, feeling confused, chest pain, problems swallowing, coughing blood
Have you had any of these signs? If yes, what did you do? Do you think that was the right thing to do? Has your view on this changed since doing the course?

Since doing Beat the Bugs have you changed your mind about when you would contact your doctor?

If yes how? If no, why not?

4. **Accessing and using health information**

Do you ever use information to help with your health (for example if you feel unwell or want to find out about something)?

Probe for details on sources (websites, people, printed information)

If yes, how has this helped you? (Did it cover everything you wanted? How easy was it to understand?)

Has your use of this sort of information changed since doing the course?

Have you used this leaflet (show Respiratory Tract Infection leaflet)?

What do you think of it?

What would you do if you wanted to find out how to deal with feeling unwell?

Probe: Where would they go for information? Has anything you learnt on the course helped with managing your illness?

5. **Anything else?**
Is there anything else you’d like to say about the course or managing your health?

Close – thank participant and remind them that I will be in touch for a focus group in a few months’ time. Make sure participant has contact information about the study and knows where to go if they have questions.
Appendix 16  Follow-up interview guide 1

(6-8 weeks after completing the module )

[The purpose of this interview is to follow up on participant knowledge and behaviour change 6-8 weeks after the course. During this interview the main focus is health behaviour and how the course has impacted on this]

Before starting interview run through information sheet and check participant still consents to participation in the study.

Introduction

Hi - I am Rebecca Owens, a student at the Open University, and I am doing some research to find out what people think of a course called Beat the Bugs. Do you remember meeting me when you did the course? Today I thought we could talk about the course again and what you thought of it. If possible this time I would like you to tell me about what you remember about the course and how you might have changed how you do certain things because of it.

6. The course – Beat the Bugs

What do you remember about the course?

Probe a little: can you remember what you did? What activities?

Mention specifics if they can’t remember to assist recall.

Can you remember what you liked about it?
Can you remember if you learnt anything from it?

If yes, probe for details

Repeat post-learning knowledge questionnaire

7. Self-care at home

Can you remember if you have been ill since you did the course? If yes, probe a little for details:

Eg did you take medicines? If yes, how did you manage this? What did you do with them when you finished?)

What did you do – how did you deal with the illness?

Do you think you did anything differently because of what you learnt on the course? Probe for details

What would you do if you had a bad cold? And what if you had a bad headache and very cold skin that wasn’t getting any better?

Probe: How would you manage this? Would you ask for help (who?)?

Do you think there is anything you differently since doing the course if you feel unwell?

8. Seeing a doctor

Can you remember if you have seen a doctor this year? Have you seen the doctor since doing Beat the Bugs? If yes, probe for why (eg the course influence) and what was the outcome.
Do you know what are some of the serious signs to look out for if you are feeling unwell?

Probe for severe headache, very cold skin, trouble breathing, feeling confused, chest pain, problems swallowing, coughing blood

Have you had any of these signs? If yes, what did you do? Do you think that was the right thing to do? Has your view on this changed since doing the course?

Since doing Beat the Bugs have you changed your mind about when you would contact you doctor?

If yes how? If no, why not?

9. Accessing and using health information

Do you ever use information to help with your health (for example if you feel unwell or want to find out about something)?

Probe for details on sources (websites, people, printed information)

If yes, how has this helped you? (Did it cover everything you wanted? How easy was it to understand?)

Has your use of this sort of information changed since doing the course?

Have you used this leaflet (show Respiratory Tract Infection leaflet)?

What do you think of it?

What would you do if you wanted to find out how to deal with feeling unwell?
Probe: Where would they go for information? Has anything you learnt on the course helped with managing your illness?

10. Anything else?

Is there anything else you’d like to say about the course or managing your health?

Close – thank participant and remind them that I will be in touch for a focus group in a few months’ time. Make sure participant has contact information about the study and knows where to go if they have questions.
Appendix 17  Follow-up interview guide 2

[5 months after completing the module]

[The purpose of this interview is to follow up on participant knowledge and behaviour change 5 months after the course. During this interview the main focus is knowledge in relation to the course and the retention of this.]

Before starting interview run through information sheet and check participants still consent to participation in the study.

Introduction

Hi - I am Rebecca Owens, a student at the Open University, and I am doing some research to find out what people think of a course called Beat the Bugs. Do you remember meeting me when you did the course and shortly afterwards? Today I thought we could talk about the course again and what you can remember about it.

1. The course – Beat the Bugs

What do you remember about the course?

Probe a little: can you remember what you did? What activities?

Mention specifics if they can’t remember to assist recall.

Can you remember what you liked about it?

Can you remember if you learnt anything from it?

If yes, probe for details
Take a few minutes to repeat post-learning knowledge questionnaire – facilitated by researcher

2. Self-care at home

Can you remember if you have been ill since you did the course? If yes, probe a little for details:

Eg did you take medicines? If yes, how did you manage this? What did you do with them when you finished?

What did you do – how did you deal with the illness?

Do you think you did anything differently because of what you learnt on the course? Probe for details

What would you do if you had a bad cold? And what if you had a bad headache and very cold skin that wasn’t getting any better?

Probe: How would you manage this? Would you ask for help (who)?

Do you think there is anything you differently since doing the course if you feel unwell?

3. Seeing a doctor

Can you remember if you have seen a doctor this year? Have you seen the doctor since doing Beat the Bugs? If yes, probe for why (eg the course influence) and what was the outcome.

Do you know what are some of the serious signs to look out for if you are feeling unwell?
Probe for severe headache, very cold skin, trouble breathing, feeling confused, chest pain, problems swallowing, coughing blood

Have you had any of these signs? If yes, what did you do? Do you think that was the right thing to do? Has your view on this changed since doing the course?

Since doing Beat the Bugs have you changed your mind about when you would contact your doctor?

If yes how? If no, why not?

4. Accessing and using health information

Do you ever use information to help with your health (for example if you feel unwell or want to find out about something)?

Probe for details on sources (websites, people, printed information)

If yes, how has this helped you? (Did it cover everything you wanted? How easy was it to understand?)

Has your use of this sort of information changed since doing the course?

Have you used this leaflet (show Respiratory Tract Infection leaflet)?

What do you think of it?

What would you do if you wanted to find out how to deal with feeling unwell?

Probe: Where would they go for information? Do they use the internet? Has anything they learnt on the course helped with managing any health issues?
5. Anything else

Is there anything else you would like to say about the course?

Close – thank participants and ask them if they would like to receive a report about the study. Ensure participants have contact information about the study and know where to go if they have questions.
Appendix 18  Educator interview guide

Interviewer notes:

The purpose of this interview is to gain educator views on the setting up and delivery of Know Your Bugs. It will take place immediately after delivery of the module. These are broad questions, but exact content will depend on the content of the module that is delivered (some educators may include different components and deliver differently).

Before starting interview run through information sheet and check research participant still consents to participation in the study.

Introduction

Hi - I am Rebecca Owens, a student at the Open University, and I am doing some research to find out whether Know Your Bugs helps people with learning disabilities manage their health when they become ill. It would be really helpful if you could tell me what you think of the module. Is it OK if we run through a few questions?

1. The course – Beat the Bugs and Know Your Bugs

What do you think are the important considerations in delivering a course like Beat the Bugs to adults with learning disabilities?

Prompt if necessary:

Mechanisms:

Flexibility and adaptability to meet individual needs
Accessible resources and techniques

Goal setting and action planning (did they do this?)

Involvement of caregivers, supporters and staff

**Context:**

Accessible environment

Participation/interaction

Group size

Contextual adaptation to meet individual learning needs

Opportunities to practice autonomy

2. **What do you think worked well today?**

   Probe

3. **What do you think could have gone better today?**

   Probe

4. **What do you think of the resources that were used today?**

   Were they appropriate for the participants – Why? How? How do you think they support learning in this respect?

5. **What do you think about the format of delivery?**
How well did the activities work? Which activities and how did they work well? What didn’t work?

How well suited is the delivery to the course participants?

6. As an educator, how easy did you feel it was to deliver a course such as this?

What were the issues for you?

7. To what extent do you think participants will remember learning points of the course?

What would help them – probe for post learning reinforcement and support

8. Overall, how well do you think the course design enables it to meet its learning outcomes of:

   - how to self-care at home
   - when to go to the doctor
   - where to access health information
   - what information can be gained from healthcare leaflets?

Close – thank participants and ask them if they would like to receive a report about the study. Ensure participants have contact information about the study and know where to go if they have questions.
Appendix 19 Summary of findings for PHE

- KYB activities and resources are motivational and, in the main, support achievement of learning outcomes

- Some resources and techniques need adaptation (antibiotics, discussions, self-care)

- Difficult to develop a course that is accessible to everyone (range of prior knowledge, levels of understanding and preferred learning styles)

- A positive social learning environment influences outcomes

- Tutor delivery style and familiarisation with participants prior to session enables adaptation to individual learning needs

- Longer term reinforcement and repetition is important in embedding learning

Next steps for Beat the Bugs resources

- Guidance for educators on combining resources with discussion (eg post video conversations, how to discuss antibiotics)

- Guidance on self-care to acknowledge existing conditions and the potential need for shared care (their health contexts are often complex)

- Ensure resources are giving consistent messages (eg illness durations)

- More guidance on antibiotics discussions – amount of time, appropriate content, sheets for recording discussions
• Further antibiotics resources accessible to people with learning disabilities

• Programme for reinforcement of learning (during and after the course)
Know Your Bugs
Research summary

Know Your Bugs is a course about keeping healthy
It teaches people how to help stop getting ill with a cough or a cold or ‘flu.

It also teaches them how to get better if they do get ill.

We did some research to find out what people think about the course.

They thought it was really good.
They learnt about the importance of washing hands

And about using medicines

After the course most people remembered what they had learned

They learnt about bugs

and about getting ill
People liked the course because they did lots of fun activities that helped them learn.

They also liked sharing ideas about keeping healthy.

But learning about antibiotics was hard.

That part of the course needs to be changed so it is easier to understand.

But first we need to find out how people with learning disabilities can learn about antibiotics.
For more information about this project please contact:

Rebecca Owens  
The Open University  
Rebecca.owens@open.ac.uk
Appendix 21 Course participant pen portraits

Group 1 - Carla

What worked for Carla and why?

Carla had a positive learning experience although she thought she did not learn anything new. Carla has been off work with depression and was motivated to attend the course to build her confidence. The course and the session achieved this for Carla. The session enabled her to go ‘back to basics’ in terms of independent living skills and to think more positively about herself and her potential. It is also likely that the courses further embedded her knowledge in this area.

Carla really liked the learning environment. She enjoyed the discussions and watching other participants learn. She also said that she liked to learn through discussion. Carla was motivated to overcome her mental health issues and felt that the positive context of the course had helped with her to achieve this.

What did not work for Carla and why?

Carla did not acquire substantive knowledge during the session; she was already knowledgeable about the subject matter.

Group 1 – Anne

Anne is 22 and lives at home with her parents. She is working towards living independently with her boyfriend. Anne has a personal supporter who supports with acquisition of independent living skills; she cooks for herself, shops, and does laundry. During the earlier stages of the research Anne was volunteering at the local hospital and at a dance class. She was applying for paid work and aspired to become a dance teacher. However, at the six-week interview Anne explained that she had been offered a job at a local hospital, passed the medical and was waiting to start.
At the time of undertaking the entire course, Anne was taking medication and having further tests for a heart condition.

Anne was looking forward to further learning during the course, particularly in relation to gaining skills for independent living. She enjoyed education and liked to learn using printed materials alongside discussion. Anne was having speech and language therapy currently and felt that her verbal skills and her learning were consequently improving.

At the time of her introductory interview, Anne remembered learning about handwashing and hygiene during the previous term. She understood why and how we should wash our hands; in fact she had also learnt about handwashing techniques in her role as a hospital volunteer. Prior to starting the Know Your Bugs module she hadn’t heard of antibiotics. After the session she said she had heard of antibiotics but didn’t know what they were. Anne said that if she became unwell with a cough or cold Anne would rest and drink a cold and ‘flu remedy. She would seek advice from her GP if she became more unwell.

**What worked for Anne and why?**

Anne had a positive learning experience. She had acquired knowledge during the session but was unable to be specific about her learning outcomes. Anne enjoyed having the opportunity to talk about her health issues and share information with others about journal keeping. Anne was able to think about handwashing and relate discussions on the course to hospital handwashing techniques. She was also able to share this with other participants.

Immediately after the session, Anne appeared to have learnt a little about antibiotics and acquired further strategies for self-care. However, she did not retain this knowledge in the longer term.

The course content supported Anne’s learning because it contained the correct messages and information, and most topics were presented and discussed in an accessible way. Anne was genuinely interested in learning about the subject, and open discussion enabled her to raise issues that were important to her (hospital handwashing, fungal foot infections, her episodes).
What did not work for Anne and why?

Anne did not retain her new knowledge in the longer term. This appears to be because she did not have opportunities for reinforcement and COVID-19 social restrictions led her to spend more time in isolation with her family.

**Group 1 - Sonya**

Sonya is 28 and lives on her own in supported accommodation. She thinks she went to a mainstream school and has since completed many training and adult education courses. Sonya does have help at home, supporting her with cooking and cleaning. Sonya has recently started working with a toddler group and volunteers at Brownies.

Sonya heard about the course from her parents. They had had seen promotional material and suggested she registered. So far, she has enjoyed the activities she has undertaken during the course but she cannot remember undertaking any of the Beat the Bugs components (they had done this about 4-6 weeks previously); Sonya remembered the healthy eating side of the course however, done at the same time.

Sonya had a good understanding of hygiene and self-care prior to the session and was proficient in using her phone to locate health advice and information. If she became ill with a cough or a cold, Sonya would take a ‘flue remedy and go to the doctor if she did not improve. Prior to starting Know Your Bugs, Sonya had heard of antibiotics, but she did not know what they were or did. She also didn’t understand the concept of antibiotic resistance.

What worked for Sonya and why?

Sonya had a positive learning experience; she enjoyed the group environment and the subject matter of the course. Sonya learnt a little more about antibiotics during the
session. Although she had some prior knowledge of antibiotics prior to the session, she did not understand what they aimed to do and thought that people would faint if they overused them. After the session Sonya had a slightly clearer perception of antibiotics and the consequences of overuse.

Sonya knew how to self-care if she were ill with a cough or a cold and was quite advanced in obtaining information – for example, she used her phone to search the internet for advice about toothache and used a digital assistive device to indicate when she could have her next paracetamol. Sonya had a cold at her six-week interview but she felt it was not severe enough as to warrant taking medication. She was knowledgeable and experienced enough to make this decision herself but thought that the session had reinforced her knowledge in this respect.

Sonya thrived within the group environment. The self-care discussions and information were accurate and motivational.

**What didn’t work for Sonya and why?**

Sonya did not learn a great deal as she was already relatively knowledgeable and had potential for further learning. More discussion and focus on the antibiotics side of things would have helped address her lack of knowledge gain in this respect.

**Group 1 - Lisa**

Lisa is 35 and lives in a flat on her own. She moved out of her family home approximately three months before starting KYB as she was having issues with her stepfather. Lisa went to a school for students with learning disabilities and has since completed several education and training courses. Lisa says that she loves to learn, and therefore chose to register for the Beat the Bugs course. Lisa particularly likes to learn through art and fun activities such as games. Lisa likes writing too.
Lisa enjoyed the Beat the Bugs course overall and could recall learning about healthy eating and food preparation. She could not specifically recall learning about microbes.

Lisa has several health issues and often takes medication for migraine. She has taken antibiotics for a urine infection and sinusitis and takes epilepsy medication. Lisa already had good prior knowledge of self-care and manages her health issues effectively. Prior to the session she understood that handwashing and hygiene were important in preventing the spread of infection.

At the beginning of the session Lisa showed relatively good understanding of antibiotics and would disagree with other participants when she knew she was correct – she knew a cold was a virus for example and that antibiotics did not work on viruses. If she became unwell with a cough or cold, she would drink hot lemon or hot blackcurrant, and call the doctor if she became more ill.

**What worked for Lisa and why?**

Lisa had a positive learning experience. She enjoyed the group environment and the course activities, and felt the style, delivery and content suited her learning needs. Lisa preferred to be divided into two groups as she struggled with noise levels at times in a larger group setting. She did however suggest it could be more fun by using games and activity; she really enjoys bingo for example. Lisa appeared to have acquired learning reinforcement during the session rather than new knowledge.

Lisa was able to talk a little more about antibiotics after the session. Whereas at the pre-module stage she had heard of antibiotics but didn’t know what they aimed to address, at post-module she understood that antibiotics could help recovery from an infection. She did not retain this knowledge in the long-term, however.

Lisa did not appear to have acquired further self-care knowledge during the session. She already knew what to do in the case of a cough or a cold and indeed in more advanced health scenarios.
Lisa’s questions and comments also served to inform others about real life scenarios and how to deal with them; for example, she explained how to treat a urine infection with antibiotics.

Lisa felt comfortable and enjoyed the group environment. The tutor provided realistic and helpful information that was accessible.

**What did not work for Lisa and why?**

Lisa struggled with focus at times and was asked to by the tutor to re-engage on a few occasions. She said she often finds the noise of the larger groups distracting.

Lisa already had a good knowledge of health and appropriate health behaviours and knew how to self-care in specific scenarios including most of those that were covered during the session. In this respect some of the course content was perhaps a little basic for her and she had potential for further learning.

**Group 1 – Paul**

Paul is 24 and lives with his parents. He went to a mainstream school and a local further education college. Paul enjoys learning and currently attends various courses locally including English, Maths and ICT. He likes to learn through activity and also enjoys a range of sporting activities. Paul likes to interact with participants and enjoys active learning. He particularly enjoyed the colouring aspect of the current course and is clearly comfortable in the physical and social environment. At his introductory interview, Paul was looking forward to everything about the rest of the course.

Prior to starting the module, Paul understood the concepts of hand hygiene and self-care. He did not know what antibiotics were, nor the implications of overusing them. Paul has some health issues and takes medication for stomach pain. Prior to starting the course he said he would consult with a doctor if he became ill with a cough or a cold.
What worked for Paul and why?

Paul had a positive learning experience. He enjoyed the session, particularly the resources and the discussions. Paul thought that he understood everything (although he did not). He appeared to gain reinforcement of his knowledge regarding handwashing. He had some prior knowledge of this and each time he sneezed; he left the room to wash his hands.

The social environment of the course suited Paul along with the familiarity of the learning environment, the tutor and the participants. He responded well to discussions and the overall active style of learning.

What did not work for Paul and why?

Paul did not appear to have learnt anything about antibiotics nor acquire any further knowledge regarding self-care and how to seek alternative sources of advice. The resources and discussion appear to have been too complex for Paul to grasp.

Group 1 - Julie

Julie is 26 and lives with her mum. She does not know if she receives support. Julie is attending an adult education course and likes to get out a lot during the week. She wanted to undertake Beat the Bugs because she likes to go out and make new friends. She has enjoyed the course so far and can remember learning about keeping clean and healthy.

Julie enjoys learning. She went to a school for students with learning disabilities and likes to use pictures and discussion to learn. She has also completed a number of other adult education courses.

Prior to the start of the module, Julie understood basic concepts about hygiene. She knew that antibiotics were medicines and thought that people could become ill if they used
them too much. If she became ill with a cough or a cold herself, she would take medicine such as paracetamol. If she became more ill and wasn’t sure what to do, she would talk to a doctor or a nurse.

What worked for Julie and why?

Julie enjoyed a positive learning experience. The group size worked well, especially dividing into two groups. The format of the session worked well for Julie; she liked turn-taking and engaged well with the activities.

Julie thought that after the session she understood the topic much better. There was a little change before and after the session in her proposed self-care strategies, and her antibiotics knowledge improved slightly. After six weeks and some probing, Julie understood that antibiotics could help recovery from illness and, with prompting, suggested that antibiotics eliminate germs.

At the time of her six-week interviews, Julie had had a cold since undertaking the session and had practised appropriate self-care – she rested, took warm drinks and fresh air. However, she did say she would have done this anyway and doing the course hadn’t made a difference.

What did not work for Julie and why?

Julie struggled with recall and was often unable to remember what she had learnt. She would have benefitted from further reinforcement in and outside the formal learning environment.

Group 1 - Alice

Alice is 68 and lives with her husband in supported accommodation. She is retired but is a full-time carer for her husband. They are paying for private care because they have been unable to access statutory support, although Alice thinks that they are entitled to this.
Alice has a learning disability, physical health issues including epilepsy, and has been ill with pleurisy recently. She is also registered blind. Alice was motivated to join the course because she was fed up with becoming ill. She also wanted some time for herself.

Alice went to a boarding school for adults with learning disabilities which she really enjoyed. She enjoys learning and has completed many adult education courses. She has achieved Level 4 learning, although she didn’t elaborate in what. Alice understands what antibiotics do and the implications of antibiotic resistance. She has addressed a lot of health issues during her life and is relatively experienced and knowledgeable in self-care. Alice says she is taking long term antibiotics and knows that this can be detrimental to health. However, she has had pleurisy recently and been seriously ill so agrees that antibiotics are necessary. Alice cares for her husband who also has many health issues, including pneumonia and other infections in the past.

At the time of her introductory interview, Alice had enjoyed the course so far. She had found it interesting to learn about viruses and it gave her a break from her role as a carer.

**What worked for Alice and why?**

Alice had a positive learning experience. Although she thought that she had not learnt anything new during the session, she did provide far more detailed answers to questions about self-care and antibiotics afterwards.

In fact, Alice provided more information in her answers to the pre- and post-module questions at post-module stage than she did at pre-module stage. Her prior knowledge and interest in the topic provided something upon which to build, and it appears that she was able to grasp some of the more complex concepts that were discussed such as overuse of antibiotics.

Alice’s contributions may have helped others in their learning. She often offered useful ideas such as replacing lost salts, how many paracetamol adults can take, and the fact that paracetamol is in some cold and ‘flu remedies.

**What did not work for Alice and why?**
Alice’s knowledge already met the learning outcomes of the course. She had potential for learning about more advanced issues such as antibiotics.

Group 1 – Sophie

Sophie lives in a shared living arrangement with a foster carer who supports her in day to day living and gaining independence. Sophie volunteers at an art class and coffee morning and attends a boxing class. On starting the module, she wasn’t in employment but aspired to having an evening job in a café.

Sophie chose to attend the Beat the Bugs course as it offered her something new to do. On starting KYB she was feeling very inspired about the course overall; learning about bugs was fascinating and the social aspect of the course was enjoyable. Sophie was also beginning a health research project for the first time; she was exploring views of an information booklet about epilepsy, designed for people with learning disabilities.

Sophie enjoys learning and likes to learn through discussion. She did go to school when she was younger, although cannot remember what sort of school this was. Sophie’s prior knowledge in relation to hygiene and infection prevention was good although she had limited understanding of self-care and antibiotics.

What worked for Sophie and why?

Sophie had a positive learning experience because she enjoyed the session and was motivated by the topic, the resources, and the social environment. She found the venue comfortable and conducive to learning.

Sophie appeared to have learnt about self-care and was inspired by the antibiotics’ discussions, although it does not appear that she learnt from these. She retained her self-care knowledge gain six weeks after the session and appeared confident in addressing potential illness.
At the six-week interview, Sophie appeared to be more aware of the role and importance of handwashing in preventing the spread of bacteria. This was likely to have been reinforced by the COVID-19 pandemic.

**What didn’t work for Sophie and why?**

Although she had experience of using antibiotics, Sophie found the antibiotics sessions difficult to understand. It is likely that further discussion and more accessible resources would have helped her to understand more during this component of the session.

**Group 1 – Michelle**

Michelle is 35 and lives in supported accommodation for people with learning disabilities. Michelle went to mainstream school and has completed a few adult education courses. She likes to learn using pictures and discussion, although she can read and write a little as well. Michelle has a personal supporter who helps her during education sessions.

Michelle used to work in a local shop but has been out of work since the shop closed. She is hoping to move out of the residential establishment as she does not like it and hopes the course will help her with independence.

Prior to the Know Your Bugs module, Michelle understood that handwashing was important to prevent the spreading of germs. She did not fully understand what antibiotics were; she has taken them in the past to treat illness, although she also thought that antibiotics were a wipe or a gel. If she felt unwell with a cough or a cold, Michelle would stay inside, keep warm and ask the nurses for a paracetamol. She might also take a cold and ‘flu remedy. If she wasn’t getting better and needed more help or advice she would go to the doctor or hospital.

**What worked for Michelle and why?**
Michelle had a positive learning experience. The social aspect of the course worked well for her, and she learnt from conversations about self-care. Michelle also experienced reinforcement of learning about bugs and hygiene. The session worked well for Michelle through providing opportunities to discuss, raise questions, make comments and generally be herself. She felt comfortable in the group setting, and the tutor and her personal supporter knew her well and could adapt to her needs.

**What did not work for Michelle and why?**

Michelle did not grasp lot of the antibiotics discussion – after the session she still initially described antibiotics as a wipe, although on probing she suggested they eliminate germs and could clear out our ‘system’ (sic). Michelle became quite confused when discussing some of the antibiotics right or wrong statements and displayed some frustration with herself if her answer to a question was wrong.

**Group 2 - Alan**

Alan is 48 and lives independently with his wife and disabled daughter in a maisonette. Alan’s wife is supported by a local mental health team and Alan has been allocated his own support worker, although he finds it difficult to contact her. Alan volunteers regularly for the YMCA and really enjoys this.

Alan began education at a mainstream school but was removed and went to a boarding school for students with learning disabilities. He has completed a range of adult education courses in the past, including English and Maths. He still wants to improve his literacy, however.

Alan joined Beat the Bugs to continue his learning. During his pre-module interview he said that had already learnt about different microbes and how they spread. He understood why handwashing was important and knew that antibiotics could make us better. Initially he thought if we used antibiotics too much, we might become addicted to
them. However, after completing the KYB session he subsequently thought that people’s bodies could get used to antibiotics if they over-used them.

Initially, Alan said that if he felt unwell with a cough, cold or a headache, he would call the doctor or visit a pharmacist as well as take paracetamol, aspirin or a cold and ‘flu remedy. On completion of KYB, he appeared to be more confident about looking after himself; he said that if he felt mildly unwell, he would take paracetamol, rest, drink plenty of fluids and eat healthily. On completion of the module, he did not mention seeking medical advice, although he knew to contact the GP or pharmacist if symptoms persisted or became worse. Alan has some health issues and has previously been admitted to hospital with chest pains. Consequently, he already understood some of the more serious signs to look out for in this respect and would contact a GP if he identified serious signs of illness.

**What worked for Alan and why?**

Alan had a positive learning experience. He enjoyed the session and liked the way it was set up. Alan engaged in reading and writing practice – this is something he felt he needed to work on when he joined the course and was able to do by reading and recording what he has achieved or assessing and monitoring. This appeared to also embed his learning further – during the afternoon after completing the KYB session they were asked to record on a form the important aspects of self-care.

Alan learnt about illness durations and appeared to have a slightly broader understanding of antibiotics immediately after completing the KYB session, learning that overuse has consequences. The engaging and motivational resources supported this learning.

His learning during the session (and during the course as a whole) stimulated further thinking and discussion. Alan was able to go home and engage with his daughter on the same issues. This is likely to have further embedded his learning, support his confidence as a learner, and enable him to educate others (in this case his daughter).

Alan had a positive impact on the rest of the group. He was very enthusiastic about learning and about the session overall; he set a good example by asking questions and
being sociable, helping to create a positive social context and potentially enhancing knowledge gain for the rest of the group.

Alan was a motivated, interactive, and positive participant who appeared to thrive in an engaging social context. He therefore responded well to the range of activities undertaken during the session. These were inspiring and enjoyable for Alan; they retained his attention throughout and embedded the messages. The knowledge (both social and topical) of the tutor and the incremental structure of the session helped to reinforce previous learning for Alan by recapping on what they had previously learned about microbes and moving onto related issues in a logical way. The tutor facilitated engaging discussion at the appropriate level for Alan supported by resources that were in the main accessible and motivational.

**What did not work for Alan and why?**

Alan did not fully grasp some aspects of the session, including the antibiotics components and the video. More focussed discussed and more accessible resources would likely have supported him in understanding some of these more complex issues. Alan also did not retain his knowledge gain in the longer term. He had little opportunity for direct reinforcement in this respect, although COVID-19 potentially might have supported some of this.

**Group 2 - James**

James is 25 and lives with his family. He works in a café. James is relatively healthy and has had coughs and colds but rarely anything more serious. At his introductory interview, he couldn’t remember why he wanted to undertake the course, but he had enjoyed it so far.

James went to a mainstream school and likes to learn using words and pictures. He also likes working in a group setting. James is quite quiet during group sessions, but his contributions are often accurate and correct. He already has a good knowledge base
regarding infection; he suggested for example that meat could contain salmonella and that a baby’s changing mat would be a source of bacteria. James also suggested that paracetamol could be bad for our kidneys.

Prior to starting Know Your Bugs James understood that hand washing was important in order to be clean and hygienic. He would use soap and water to wash his hands. James had heard of antibiotics but didn’t know what they were nor what might happen if we over-use them. If James felt unwell with a cough or a cold, he would use his inhaler if he needed it. He might also hold his head over a bowl of hot water containing Olbas Oil. After the KYB session, James said that he would sleep and eat fruit if he felt ill with a cough or a cold. If he felt worse, he would go to the doctor. James said he also used health information leaflets. Although he couldn’t remember what he used, he did say that the Managing Your Infection leaflet had been useful because it provided handwashing advice.

What worked for James and why?

James had a positive learning experience. He said that he had learnt about viruses and bacteria, although was unable to be specific about exactly what he had learned. He also appeared to have a slightly better understanding of antibiotics after the session, although he hadn’t fully grasped the concept of antibiotic resistance.

James thought that the sessions were easy to understand, the discussions were stimulating, and the group size was appropriate. It seems therefore that the learning environment was positive for him – the tutor had chosen activities that were easy to understand, and the sociable group setting enabled relaxed and focused conversations.

What did not work for James and why?

Six weeks after completing the module, James could not remember what he had done during the session. He didn’t recognise any of the serious symptoms that had been discussed and he wasn’t sure if he had changed anything he’d done as a result of undertaking the course. It is likely that James would have benefitted from more frequent
reinforcement or perhaps smaller group sizes so that content can be more closely geared towards his needs.

**Group 2 – Fiona**

Fiona is 48. She lives on her own and has access to support from local organisations. She has adult children. She doesn’t work but she attends some classes. Fiona wanted to undertake this course because she is particularly interested in viruses and the spread of infection. She described herself as paranoid in this respect and is very anxious about becoming ill with an infection. Fiona’s daughter has some health issues at the moment and Fiona decided to join the course also to ‘chill out’. She feels she has a lot to deal with in life and has anxiety.

Fiona went to a private school. She always struggled at school, and she feels it wasn’t until she was an adult that her learning difficulties were appropriately recognised. Fiona has a brain injury and Asperger’s Syndrome. She likes to learn by watching and enjoys working in a group. Fiona also likes creative activity and described herself as ‘artsy’ and has really enjoyed the course so far. Fiona will ask questions if she is unsure about anything; for example, she asked the tutor for elaboration about the symptoms of a severe infection and what this might feel like.

Fiona said that she lacks confidence in her learning, particularly recall, and needs to record what she has learnt otherwise she forgets quickly.

Prior to starting Know Your Bugs, Fiona understood that handwashing was important to stop the spread of germs. She knew that antibiotics could help people recover, although she also suggested that antibiotics were intended to address a virus. Fiona had also heard that antibiotics might not work sometimes. Fiona gets very anxious about becoming ill and avidly follows news events about spreading infection. At the time of her six-week interview, Fiona was very concerned about the spread of coronavirus (COVID-19) and was following the news intently.
Fiona tries to adopt a healthy lifestyle and take various supplements which she hopes will stop her becoming ill. She knew that a product such as Actimel could help restore good gut bacteria and she had been taking raw garlic to try and keep her immune system healthy. If she felt unwell with a cough or a cold Fiona would take a cold and ‘flu remedy and stay at home. She might wear a mask if she went out and if she became more unwell, she would ask friends and health professionals for advice.

**What worked for Fiona and why?**

Fiona had a positive learning experience. She thought that the course had helped her deal with coughs, colds and her health. She thought it was a good way to learn – it was ‘basic, easy and fun’ (six-week interview). Fiona said she enjoyed everything about the module, particularly the range of activities and the creative work (Magazine Microbes). With a little prompting, Fiona often remembered more than she thought she could. She commented several times that she generally forgot straight away any new facts. However, it appears that with prompting she was able to recall information she had learnt previously, such as the role of antibiotics.

Fiona acquired new knowledge about antibiotics during the KYB session. She did have some knowledge of antibiotics before she started the course; she knew that they help people to get better and that they are prescribed by a GP, although she did think that they were prescribed to address a virus. After the session she appeared to have a more accurate understanding of how antibiotics work and knew that they should not be shared.

Fiona saw value in the Managing Your Infection leaflet and said she would attach it to the fridge or wall at home. She thought that she would use it regarding the illness durations although said that time is often irrelevant to her. She thought it would be a useful way of monitoring illness and of reducing her anxiety.

It appears that the session provided Fiona with further self-care strategies and direction on where to go for advice. After the session, and in the longer term, she was able to talk more confidently about these topics. Overall, the session appeared to work for Fiona because she responded well to creative methods of learning, discussion, and the
opportunity to ask questions. Fiona was already very interested in and motivated by the subject, and it was pitched at an appropriate level for her.

**What did not work for Fiona and why?**

Fiona became confused at times about the intended learning outcomes of the activities. For example, she said she did not understand all of the video (although she did explain a fair bit of it). She also did not fully recall the reasoning behind the glitter hand shaking activity. Fiona is slightly contradictory at times, possibly because her anxiety takes over. Although she seemed confident in her answers to what would she do if she had a cough and a cold, later on during her post-module interview she said she would panic if she had a cough or a cold at this time, particularly now that COVID-19 was in the UK.

**Group 2 - Susan**

Susan lives at home with her father. She attends a local club once a week and a personal supporter helps her with cooking and other daily activities. Susan’s boyfriend, Ian, also attends the course. Susan attended a school for students with learning disabilities and joined the Beat the Bugs course because she thought it was good. She likes to learn by using pictures and having discussion. Prior to starting the module, Susan understood that handwashing could kill germs and would use soap and water to wash her hands.

Susan was quiet during sessions, but she often responded to a correct statement with an affirmative ‘yeah’.

Prior to starting KYB, Susan had heard of antibiotics and thought they were tablets that would help people recover if they were ill. She understood that there were potential consequences of over-using antibiotics and thought that people would become ill in such cases. If she became ill with a cough or a cold, Susan said she would stay at home, use tissues and drink water. If she became more unwell, she would ask her dad for support or maybe go to the GP. On completion of the module, Susan understood that antibiotics kill bacteria and, as before, she would stay at home if she was ill and seek advice from her
father or a doctor if she wasn’t sure what to do. In fact, Susan had been ill during the six weeks after completing KYB. She had stayed at home as she had said she would do if she became ill and, when she became worse, she consulted her GP and obtained antibiotics.

**What worked for Susan and why?**

Susan had a positive learning experience, and had enjoyed the KYB session and the course. She particularly liked the video and thought that it had helped her learn about microbes and how they spread. There was nothing about the module that she thought could be improved and she thought that she understood everything. Susan said the venue and the group size worked well for her as well.

Susan’s knowledge of antibiotics seemed to have improved slightly after the KYB session, and she was able to provide a clearer explanation of what they aim to do, and knew that overuse might lead to negative consequences. Susan liked the MYI leaflet; she took it home and said that she used it to help identify when she might need to go to the doctors.

At her six-week interview, Susan remembered much of the KYB session clearly, and had opportunity to apply her learning during becoming ill with a sore throat. She said that she had learnt to stay at home when ill and that she did when her throat became sore. In fact, her throat subsequently became worse, and she was eventually prescribed antibiotics. In this respect Susan did exactly what the course suggests she should do.

Overall, the session worked well for Susan because the discussion and visual methods suited her style of learning, the range of activities was diverse and interesting, she liked the venue and the group size, and she could relate the content of the session to her life.

**What did not work for Susan and why?**

I was unable to identify anything that did not work for Susan.

**Group 2 – Ian**
Ian is 28 and lives in supported accommodation. He used to volunteer in a charity shop but doesn’t any longer because the shop had too many volunteers and let him go. Instead, he visits his brother during the week or goes to the amusement arcades. Ian attended a school for people with learning disabilities and joined the Beat the Bugs course because it enabled him to get out and see his girlfriend (Ian’s girlfriend is Susan who also attends the course).

Ian likes to learn in groups and sometimes by using pictures and writing.

Immediately prior to commencing the KYB session, Ian said he had learnt how to keep himself clean, and understood that handwashing with soap and warm water would help to prevent himself becoming ill. He was looking forward to the rest of the course because it would give him something to do. At his pre-module interview, Ian said that he had heard of antibiotics and suggested that they fight ‘nasty diseases’. He thought that if antibiotics were overused they would not work and had learnt this from the ‘Keep antibiotics working’ video he had seen at home.

Prior to the module, Ian had good self-care knowledge. If he felt ill with a cough or a cold, he said he would go to the doctor and then stay at home. If his symptoms became more severe, he would go back to the doctor or to hospital. At his post-module interview, Ian’s thoughts changed a little; he said he would initially stay at home and take hot drinks if he felt unwell and consult with support staff or a GP if he didn’t get better.

What worked for Ian and why?

Ian had a positive learning experience and thought that he had learnt a lot during the session. Ian was chatty during the session; he made quips, asked questions, and provided answers throughout. He liked the range of activities that were offered, particularly the video, and creative work. Ian thought that he understood everything and thought that nothing about the module could have been better. Six weeks later Ian remembered much of what he had learnt during the session.
Although Ian already had a good understanding of antibiotics, he said that he learnt during the session that antibiotics can stop helping people. However, he also said this at his pre-module interview, and his answers were at times a little contradictory.

Although Ian did say that he had not learnt anything during the session that would lead him to do things differently, he did appear to have learnt about managing his health when unwell; whereas he initially said he would seek medical advice straight away if he had a cough or a cold, after the session he said he would try staying at home and self-managing first of all.

Ian’s knowledge about reasons for handwashing appear to have improved after the session. At his pre-module interview he knew that handwashing helps prevent us from becoming ill, although he did not mention germs or bacteria in relation to this. At his post-module interview however, he was more precise and suggested that handwashing stops bacteria spreading.

Overall, the session worked for Ian because he was motivated, and the activities and resources were accessible and enjoyable. He also had a good knowledge foundation upon which to build and was able to grasp some of the more complex concepts.

**What did not work for Ian and why?**

Ian’s learning about antibiotics was limited and there was scope for improvement. His knowledge of antibiotics was comparatively good; he knew that if we overuse antibiotics, they might not work but could not explain why. Ian knew not to share antibiotics but was a little unsure about whether it was OK to stop if he felt better after three days into a seven-day course. These issues were not covered in detail during the session and further discussion and reinforcement may well have supported Ian in embedding this information.
Group 2 – Colin

Colin is 28 and lives with his parents. He has some support with daily living but he was not able to say what that was. Colin was not able to convey why he originally wanted to undertake the course. However, he said he was enjoying it and had learnt about germs and handwashing. Prior to starting Know Your Bugs he knew to wash hands with soap and water. If he became ill with a cough or a cold, he said he would take paracetamol and if he became more ill he would contact the doctor.

Colin is not an active contributor to discussion. He remained relatively quiet during the session, and the tutor tried to engage with him occasionally and involve him in the discussions. This was often difficult to achieve, however.

What worked for Colin and why?

Colin seemed to have a positive learning experience in the main. He appeared to be content during the session, although engaged most with the ‘Magazine Microbes’ activity, where he made a detailed collage. Colin appeared to have acquired further knowledge about handwashing and its relationship with the spread of microbes.

Colin experienced reinforcement of self-care strategies such as taking paracetamol and acquired further ideas on where to go for advice if necessary. Colin could read the Managing Your Infection leaflet and appeared to be motivated by its content.

Immediately after the session Colin seemed to be familiar with the word ‘antibiotics’ and, when asked what they were, said that they were tablets. He did not answer these questions during his pre-module interview, so it is difficult to assess whether he had learnt anything further during the session.

Overall, the session worked for Colin because he engages well with creative activity, because the environment was relaxed and the resources inspiring, and because there were opportunities to learn from other participants’ discussions.

What did not work for Colin and why?
Colin sometimes found it difficult to focus his attention during discussions, and he would often talk to himself or make various noises. Better engagement during discussion or further creative activities might have resulted in further knowledge gain, and a much smaller group size might facilitate this.

**Group 2 – Mary**

Mary is 42 and lives in supported accommodation. She attended a mainstream school initially but was moved to a specialist school for students with learning disabilities. Mary enjoys working as a volunteer for a foodbank and in a charity shop. Mary has anxiety and takes anti-depressants. She also said she was taking long term antibiotics.

Mary registered to undertake the course because she enjoys learning and wants to learn more. She also finds the subject matter interesting. Mary is enthusiastic and motivated about learning generally. She contributes regularly during sessions and has a good knowledge base from which to learn about this topic. She often is able to takes things to a more advanced level; for example, she remembered something of the different types of microbe (she recalled ‘the twirly whirly one’ during the KYB session). Mary also already knew to sing happy birthday twice whilst washing hands.

Before starting the module Mary had some understanding of antibiotics and keeping well. For example, she knew to keep warm and take cold or ‘flu remedies if she had a cough or a cold. She also had a good understanding of what to do in more serious situations; she had called 999 for help with her grandmother who was subsequently admitted to hospital.

Mary had a basic understanding of antibiotics, and this seemed to be enhanced after completing the module; whereas before she’d said antibiotics killed germs, on completion of the module she said they killed bacteria (so was using more complex and appropriate terminology at this stage). Mary also appeared to have learnt a bit more about dealing with more serious illness; if she became ill with a cough or a cold she would initially self-care but if her symptoms became worse she would consult with a GP or dial 111.
Previously, she had said she would seek advice from her mum or a GP straight away. However, Mary did not appear to fully grasp the concept of antibiotic resistance and thought that overuse would lead to an overdose or becoming more poorly.

Six weeks after completing KYB Mary said that she had really enjoyed the whole course so far. She thought she had learnt a lot but could not remember what. When probed she said the course had helped her know when she did not need to contact a doctor and how to self-care instead.

**What worked for Mary and why?**

Mary had a positive learning experience. She was a keen and enthusiastic learner who was motivated to learn more. Mary also had good prior knowledge and ability from which to extend learning about the topics that were addressed during the session. For example, she already had some basic knowledge of handwashing and antibiotics. Mary was also able to apply appropriate strategies for dealing with an emergency situation with her grandmother.

Mary’s basic understanding of antibiotics appeared to be enhanced a little after completing the module; whereas she had initially said antibiotics killed germs, on completion of the module she said they killed bacteria (so was using more complex and appropriate terminology). She also learnt about dealing with more serious illness. Six weeks after completing KYB, Mary could recall the session with enthusiasm although she had not retained all of her knowledge gain.

Overall, the session worked well for Mary because it enabled her to build on her motivation to learn through a socially engaging session. Mary enjoyed the group setting, the mix of activities and the discussion – it appears that these motivated her further to learn, and created a positive environment in which to do so.

**What did not work for Mary and why?**

Mary said that she had difficulty remembering what they had undertaken during the session and what she had learnt. However, with probing she was often able to recall
elaborate. She had initially had a basic understanding of antibiotics although she did not appear to fully grasp the concept of antibiotic resistance. It appears that Mary had potential for extended learning, however.

Group 2 - Kevin

Kevin is 44 and lives in a flat on his own. He does not have support. Kevin enjoys learning and is particularly interested in wildlife and science; he can hold good conversations about these issues and asks probing questions. He also really enjoys activities such as going to museums; he recently found a museum about local history fascinating. Kevin wanted to undertake the course so that he could get out and do something. He likes to learn by using discussion and pictures.

Prior to starting Know Your Bugs, Kevin knew that handwashing was important to stop the spread of bacteria. He wasn’t too sure exactly what antibiotics could do but he thought that if people use them too much their bodies would get used to them and they would not work as well. On completion of the module Kevin knew that antibiotics fight bacteria. He also suggested that if antibiotics were over-used, bacteria can mutate, and the antibiotics might not work as well. Kevin has a very enquiring mind, is keen to ask questions and able to hold good conversations about antibiotics. He often offers science-based ideas and questions. For example, during his post-module interview he mentioned research with ants to develop new antibiotics.

Kevin has very good health knowledge and understanding. On starting the session he knew where to go for health advice, and had a good understanding of what symptoms feel like. He understood concepts such as a severe headache, reaction to flu vaccination, and breaking a finger). Kevin also seemed to retain knowledge well. Six weeks after the session he still knew that antibiotics should only be taken as prescribed, and that overuse may lead to them becoming less effective because the bacteria fight back.

Kevin often posed complex questions during the session and took issues to a more advanced level. For example, on reading the illnesses and durations on the MYI leaflet he
asks what causes an earache. Kevin is an intuitive thinker; when asked what he would do if cough or a cold symptoms became worse, he consulted the Managing Your Infection leaflet and he suggested he would seek advice.

**What worked for Kevin and why?**

Kevin had a positive learning experience. He learnt about microbes, antibiotics and illness durations and symptoms. He was able to ask questions and have stimulating conversations about the subject matter.

Kevin’s interactions within the group environment facilitated creation of a positive learning experience for other participants. Kevin was a motivated and knowledgeable member of the group who engaged in discussion and asked relevant, sometimes challenging, questions. He had a positive effect on the group, facilitating a good atmosphere, an effective learning environment and at times enhanced planned content by taking things a step further.

Kevin responded positively to the Managing Your Infection leaflet – he suggested recording dates on a calendar to monitor the duration of an illness and facilitate decision-making about what action to take. Discussion around the leaflet also stimulated further focused conversations and learning for Kevin about symptoms such as what causes an earache and reference to the NHS 111 number. This thus facilitated further knowledge gain.

Kevin appeared to acquire further knowledge about microbes during the session, learning through discussions that microbes are everywhere, and from the video that good bacteria is important. Kevin appeared to have acquired some further knowledge about antibiotics. Initially he said he wasn’t sure what antibiotics did. However, during his post-module and follow-up interviews he commented that antibiotics killed bacteria and could mutate if they were over-used.
What did not work for Kevin and why?

It appears that Kevin had unmet potential for further knowledge gain. There were occasions during the session when his questions were not fully answered, and the discussion did not address his questions. For example, he had heard that bacteria eating bones when humans die.

Group 2 – Giles

Giles is 38 and lives on his own. He has support from his parents and enjoys shopping and walking. Giles attended a mainstream school. He wanted to undertake the course because he had an interest in healthy foods. At his pre-module interview, he said he had learnt about eating healthily, about handwashing and spreading germs. He was looking forward to everything about the rest of the course. Giles is flexible in how he likes to learn; he can read and likes to use both words and pictures in learning.

Giles enjoyed the KYB session and the entire course. Prior to starting the module, Giles knew that it was important to wash hands to keep germs away. He had heard of antibiotics and understood that they could fight infection.

After completing the session, Giles stated that antibiotics killed bacteria, thus providing more detail than prior to the session. When asked what might happen if an individual overused antibiotics, Giles thought it might result in addiction. At his post-module interview, Giles said that if he became ill with a cough or a cold, he would take it easy and stay at home. He might take paracetamol and, if he felt worse, he would go to the doctor.

Giles occasionally uses online or paper-based health information, particularly diet sheets.
What worked for Giles and why?

Giles had a positive learning experience. He reported that his health behaviour had changed since undertaking the session because he was adopting a healthier and more hygienic lifestyle.

Giles appeared to have learnt a little more about antibiotics or at least gained some reinforcement as he was able to provide further detail after the session.

There was a slight change after the session and in the longer-term as to how Giles proposed to self-care. Each time he was asked, he said he would stay at home, take fluids and ask advice from a GP (pre-module interview) or pharmacist or GP (post-module interview) if he felt worse. Since undertaking the course Giles learnt that if symptoms were mild, he did not need to go straight to the doctor – it seems the course has taught him more about how to self-care and given him more confidence in this respect.

Giles learnt from the Managing Your Infection leaflet how long he could expect certain illnesses to last. He went on to use this leaflet at home; to consult it to see how long he could expect a cold to last.

Overall, the session worked well for Giles because it suited his preferred style of learning and offered variety of relevant activity. In this context, the range of activities was diverse and interesting, the group was relaxed and stimulating, and he had good basic prior knowledge and motivation upon which to build.

What did not work for Giles and why?

Although Giles enjoyed the session, he initially said that he had not learnt anything new. He did however say that he thought the session overall was very good at helping him to learn – either this is a contradiction or perhaps the session reinforced previous learning rather than embedding anything new. At his six-week interview however, he appeared to think he had learnt more (about infections from the video, and illness durations from the Managing Your Infection leaflet).
Giles thought that he had not learnt anything about antibiotics. He also did not appear to have grasped everything that was covered in the session, and there was potential for him to have learnt more regarding the consequences of overuse. Analysis of interviews and observation of the session suggests that the antibiotics discussions and resources were inaccessible; discussions did not address the basics clearly and the resources were complex.