Health literacy in the lives of young people (16-19 years) in England: a participatory study (2018)

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Health literacy in the lives of young people (16-19 years) in England: a participatory study.

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Health literacy in the lives of young people (16-19 years) in England: a participatory study.
Abstract

A range of recent research suggests that health literacy, characterised as ‘more than simply being able to ‘read pamphlets’, make appointments’ (WHO, 2015:1) underpins health knowledge and understanding (Rowlands et al, 2015) which, in turn, impacts on health behaviour and choices (Abel et al, 2014), health decision making and use of services (SCMI, 2014b). There is also evidence that being health illiterate is linked to the socio-demographic outcomes of health inequalities (Batterham et al, 2016) and of poorer life outcomes (Sentell et al, 2017, Rudd, 2015). Currently, there is limited knowledge about how young people become health literate (Roberts, 2015a, Warsh et al, 2014). This study addresses this gap in knowledge, offering recommendations for practice from the perspectives of young people.

The study was carried out with young people (aged 16-19 years) and used a participatory, co-produced research approach. Methods of data collection included the use of participatory meetings with a co-production group of young people, and a detailed online survey. The research was completed within a mainstream English secondary school which offered access to young people from a range of diverse backgrounds and with a variety of experiences. Findings from the study suggest that being health literate is a life skill which prepares and supports young people’s successful transition into adulthood. Young people’s contributions illustrate ways in which the prioritisation of health literacy would enhance their health knowledge, develop their confidence and skills to use their health knowledge, improve their health service use and tackle health outcome inequalities. The thesis concludes with evidence-based recommendations from young people to enhance the way health literacy as a life skill should be developed and taught within school by health experts.
Health literacy in the lives of young people 16-19 years in England: a participatory study.

1. Introduction

National and international literature on young people’s health has repeatedly shown that young people do not feel involved in their own health and health care (Rudd, 2015, Hope, 2015) and feel disenfranchised as a stakeholder at policy level (Schulz and Nakamoto, 2015, Frosch and Elwyn, 2014). These findings highlight risking a whole generation not interested or invested in their (or their society’s) health. Alongside the risk to health and wellbeing now and in the future, poor health outcomes are intrinsically linked to health and social inequalities (World Health Organisation (WHO), 2015, McCormack et al, 2017).

Kaufmann’s 1990 (cited Smith and Greene, 2015) notion of structural indifference that everyday life has become increasingly adapted to meet exclusively, the needs of adults, and seen within the arena of health literacy in that policy and strategy (Public Health England (PHE), 2016b, National Health Service (NHS), 2017) are beginning to address health literacy for adults but not yet for children and young people. However, the Association of Young People’s Health (AYPH, 2017), whilst recognising improvements in some areas of health for young people, acknowledge concerning upward trends in young people’s ill health in the United Kingdom (UK). Young people are not managing long term conditions and there is increasing prevalence of new substance misuse and health inequalities (AYPH, 2017:2). The AYPH recognise that good health is central to young people’s wellbeing and is a ‘bedrock’ for their later life (2017:2) as unmet health needs are a predictor for poor health in adulthood (2017:3).

Health literacy offers a contemporary view of health knowledge which is meaningful in enabling individuals and communities to take control of their health as an active partner rather than a passive recipient of health care. However, there is little understanding of how young people become health literate (Fairbrother et al, 2016, Rudd, 2015) and so this study seeks to contribute to this understanding.
1.1 Health literacy: an introduction

This study was designed to develop insights into how young people (aged 16-19) understand and become responsible for their own health, wellbeing and healthcare. Previous research has shown that young people are generally disengaged from their health (Schulz and Nakamoto, 2013) but simultaneously show a desire to understand and take control of this element of their lives (Roberts, 2015a, Hope, 2015, Fairbrother et al, 2016). Evidence suggests that existing health literature is not engaging for young people (Smith-Greenaway, 2015, Massey et al, 2012, Children’s Rights Alliance for England (CRAE), 2015), is too complex (Rowlands et al, 2015, Rudd, 2015) and does not address their needs (Hope, 2015, Roberts, 2015a). For the purposes of this research, the term health literacy is characterised as ‘more than simply being able to ‘read pamphlets’, make appointments’ (WHO, 2015:1). It is increasingly understood as a concept that moves towards health empowerment of people and their communities, and away from merely a form of health compliance (Batterham et al, 2016:3). In essence, it is valued as a social commodity (Carollo, 2015), enabling people, including young people, to maintain and improve their health by understanding and using health information, services and advice, and social capital. Health literacy is entwined with debates on health (in)equalities; existing research suggests that being health illiterate is correlated with poor health outcomes (Sentell et al, 2017, Roberts, 2015a) and associated with socio-economic inequalities such as poverty, low education, poor social capital and social issues (Harper, 2014, Batterham et al, 2016, WHO, 2015). These concepts are discussed further in chapter 2.

1.2 Research aims and approach

This study adds to the existing knowledge and generates new understanding about how young people become health literate, filling the gaps as identified by Fairbrother et al (2016) and offers recommendations to enhance practice.

The specific aims of this study were to:

- conceptualise the meaning of health literacy in the lives of young people;
- examine the link between being health illiterate and inequalities;
- explore how young people acquire, develop and use health literacy;
- produce recommendations for practitioners and policy makers concerned with improving the health outcomes of young people aged 16-19 years in England.
The study took place over two years in a large mainstream secondary school in England. A co-production group of nine 16-19 year olds was integral to the design and development of the study, working with the researcher to develop an online survey for peers of their age, and interpreting and evaluating the primary data. Members of the co-production group acted as peer researchers and consultants during its completion, ensuring an ongoing and productive discourse between the researcher and participants which enabled a collaborative understanding and construction of the participants’ lived experiences.

An online survey was designed through co-production and, following a pilot, completed by 53 young people aged 16-19. This survey collected quantitative and qualitative data about participants’ lived experiences in knowing and engaging with their health and health services. For this study, the focus was on young people aged 16-19 years, in order to allow comparisons with previous English studies about health for young people (Atkinson, 2013, Department Health (DH), 2013, PHE/AYPH, 2015).

1.3 Direction of study
This study starts with a review of the literature and research about health literacy in chapter 2, exploring the socio-economic aspects of this and seeking to understand how health literacy is acquired by young people to prepare them for adulthood. The chapter outlines how health literacy has many definitions; however, in introducing health literacy for this study the WHO (2015) definition is used to articulate the way in which people, communities and society understand, use and access information to promote and maintain good health.

Chapter 3 explains the study’s interpretivist paradigm aligned with co-production and how this placed young people as pivotal in the design, interpretation and suggested application of practice. The chapter describes the study context, explains the methodology and primary research within the phases of the study, including research ethics. There is discussion about the data analysis approach and actions undertaken for this with reflection on the outcomes.
Chapter 4 using interpretive co-production, the chapter evaluates the themes from the literature and study findings. This discussion then considers key themes identified from the primary research, which are services, advice and health information. These themes are considered within the context of health literacy in the lives of young people and are influenced by the findings from chapter 2.

Chapter 5 draws upon the young people’s interpretations of health literacy in finding solutions in enhancing health literacy for young people through a response to the study aims. There follows discussion of health literacy as a life skill correlated to tackling inequalities and reflects upon young people and their health. The study’s application to practice considers health literacy education and the interpretivist co-production participatory approach to research.
2. Literature review: contextualising young people and health literacy in England

2.1 Introduction

Chapter 2 provides a critical appraisal of existing literature which underpins this thesis, conceptualising health literacy in the lives of young people. It begins by examining the effects of health literacy and inequalities, asking how young people acquire health literacy. It then explores the practical application of health literacy in young peoples’ lives. The review is presented according to three main themes. Firstly, issues relating to defining health literacy within the arena of public health and health equality are considered. The chapter then scrutinises the literature about young people and their health, health knowledge acquisition and health research. Lastly the review examines health literacy in the lives of young people, providing the context for the study’s primary research and practical application.

2.2. Defining health literacy: public health and health equalities

Over the past 20 years health literacy has been used to describe the functional skills needed to read health information (Nutbeam, 2000, Institute of Medicine (IOM), 2004, AYPH, 2016). A widely-used definition comes from Ratzan and Parker:

‘the degree to which individuals have the capacity to obtain, process and understand basic health information and health services in order to make appropriate health decisions’ (2000:1).

This is a somewhat static description of health literacy and suggested health information as straight forward, easy to understand and digested by the intended population (Nutbeam, 2000). More recent notions of the term have moved from static definitions to a concept of how health information is understood and used. The WHO state health literacy is ‘more than simply being able to ‘read pamphlets’, make appointments’ (WHO, 2015:1), and is increasingly understood as a concept that moves from ‘improving (health) compliance to empowering individuals and communities’ (Batterham et al, 2016:3). However, Ormshaw et al (2013) found that for young people, there was insufficient evidence of what health literacy meant, as it cannot be
measured or tested because it is multi-dimensional and rooted in social, economic, educational, philosophical and health influences (Squiers et al, 2012, Camerini et al, 2012). This shift in paradigm suggests that health literacy is moving from being a passive, one-way consumeristic action to being an interactive and empowering activity, as evidenced within some strategic approaches to improve health literacy (Scottish Government (Scot Gov.). 2015, United States Department of Health and Human Services (USDHHS), 2010, WHO, 2015).

It is useful to understand how health literacy has moved from being a health-related information-sharing model to a multi-dimensional skill base that has meaning for society. Ratzan and Parker (2000) suggested that health literacy required a person to have proficient functional interaction and communication skills aligned with critical literacy (Nutbeam, 2000) drawn from health education. This inferred the ability to follow complex instruction and problem solve. The IOM (2004) noted the need for additional skills of numeracy and of having cultural and conceptual health knowledge. As literacy functionality has developed, particularly in using multi-medium platforms, Harper (2014), USDHHS (2010) and Sheridan et al (2011) have all updated these skill sets and suggested that comprehension, health numeracy, media literacy, digital literacy and internet information-seeking skills are also co-requirements of being health literate. Sheridan et al (2011) considered health literacy as,

‘a constellation of skills including the ability to interpret documents and read and write prose (print literacy), use quantitative information (numeracy), and speak and listen effectively (oral literacy)’ (2011: 31 citing IOM, 2004).

This inferred these groups of skills are transferable and assumed a level of concept mapping where assimilation of new concepts generated new understanding and knowledge (Novak and Canas, 2008).

Massey et al (2012) suggested health literacy as a derivative of numerical and literal health information designed for adult understanding, that enabled medical compliance and tackled illness. The inference being that lower functional numeracy and literacy skills resulted in less compliant patients who may not follow a prescribed treatment regime due to their lack of ability to understand the health information
(Nutbeam, 2000, Kickbusch et al, 2005). Thus, health promotion and educational activities are designed to meet the literacy and numeracy capacity of the audience (Massey et al, 2012). However, the impact of health literature does not show tangible change in health behaviour (Camerini et al, 2012, Altman, 2009), which suggests as stand-alone literature, it has been ineffective. Accepting that health information and health education has limited impact on health and well-being (Tannahill, 2009, Rowlands et al, 2015) this study explores health literacy, as an evidence-based approach, to develop sustained health knowledge for young people which prepares them for adulthood.

Sorenson et al (2012) suggested that being health literate allowed an individual to appreciate their own health and wellbeing in context, as well as their families’ and community health. This included taking responsibility, understanding and addressing the factors that influenced health (2012:1) with importantly, the emphasis on health promotion activities, rather than developing health literacy. However, this position on health literacy showed a fundamental gap in understanding and tackling the key issue that people do not understand health promotion (Massey et al, 2012, Ormshaw et al, 2013). Not understanding health information remains a risk in sustaining and improving people’s health and other life outcomes (Massey et al, 2012, IOM, 2004, Ormshaw et al, 2013). The ability to obtain and understand health information (Massey et al, 2012) and therefore, make informed decisions about health and health services, underpins the notion of health literacy. Parker and Ratzen (2010) suggested that it is the interplay of the skills and abilities (of the person) alongside health context and information that allows understanding (about health) to occur. It is this understanding of the nature and impact of the health issue which strengthened compliance and positive action (Tannahill, 2009, Raingruber, 2012). However, health knowledge, in and of itself, has been shown to be not enough for positive health behaviour change (Camerini et al, 2012, IOM, 2004).

Ormshaw et al (2013) viewed health literacy as a functional concept of applied health education in which educational functionality became a pre-requisite of health practice. This adds a political, socio- economic aspect to health literacy similarly seen within the educational arena. In turn, this suggested health literacy was not just an individual attribute but one which indicated individual, community and social
competence (Sorenson et al, 2012) in building healthy societies (WHO, 2015). Smith-Greenaway stated that key findings from the past 30 years show ‘education is a key determinant of individual’s health and survival’ (2015:124). Like educational attainment, health literacy has a place in tackling social, economic and health inequalities.

Being health literate develops other attributes such as agency, empowerment, motivation, intention and self-determination. Rather than this being the next step on from health promotion and health education, the concept of health literacy developed the whole person: for example, articulation and communication, cultural self-efficacy, self-worth and emotional intelligence (Massey et al, 2012, AYPH, 2016, Roberts, 2015a). Puntoni (2010) suggested that health literacy involves health decision-making, health advocacy and activism. This implied a degree of self-agency and confidence alongside knowledge of health and health systems which should be key aspects of developing independence in preparation for adulthood. However, Rowlands et al, in their report to the Royal College of General Practitioners noted health literacy as an ‘important determinate of health’ (2014:6) but stressed that being educated could not infer being health literate.

This is an important point that acknowledged that functional (and advanced) literacy and numeracy skills were not enough to measure, develop and evaluate health literacy. However, health staff continued to repeat health messages (Rowlands et al, 2014) albeit with improved presentation. Rowlands et al (2014) suggested that this light touch approach to health education was not enough and would continue to fail. In developing young people’s health literacy Fairbrother et al (2016) suggested that schools should re-frame children’s health knowledge and view this as fluid and interactive health education. Recently, the AYPH published a toolkit for School Nurses (2016) to develop young people’s health literacy. The toolkit is based upon health promotional models, and can be evaluated aligned with the critique of Rowlands et al (2014) that health promotional models are ineffective for their audience. Further the suggestion to; ‘use immunisation sessions to deliver health literacy messages’ (AYPH 2016:8) and that schools will buy extra school nurse time for this (2016) suggests this is an ill-thought strategy. Health literacy is much more than simply delivering a message, and further, these ‘messages’ on sex education, drug and alcohol use, are
not particularly effective as young people feel disengaged with them (Elliott et al, 2013). However, crucially, there is an acknowledgement that schools are not likely to buy in school nurses to support the development of health literacy because this is suggested as a socio-community role (Rudd, 2015) and not seen as an educational responsibility (Fairbrother et al, 2016).

There remains no agreed English national strategy to tackle health illiteracy. The NHS monitor small health literacy projects, for example teaching about health to those with chronic conditions, (Berry, 2016) and with PHE, remain wedded to a health promotional approach to improving and developing public knowledge of health; shown by Rowlands et al, (2014 and 2015), to be largely ineffective for its’ audience.

Seminally, the WHO (1986) defined health promotion, under the Ottawa Charter for Health Promotion as

‘the process of enabling people to increase control over, and to improve, their health. It moves beyond a focus on individual behaviour towards a wide range of social and environmental interventions’ (1986:1).

It is often explained and described as a ‘model’, something to be applied within a practice framework. Raingruber (2012) suggested these models fall broadly into 5 types: Behavioural / Change Theory, Intervention Based Models, Environmental / Ecological Models, Communication Theories and Planning Models. Widely used and adapted is Tannahill’s 1980 Health Promotion Model (cited Tannahill, 2009) which, in common with those listed above, encompass several psychological concepts such as behaviour, belief and motivation in health promotion activities. However, Tannahill (2009) suggested that the term ‘health promotion’ is now meaningless as there are so many definitions and iterations. He emphasised that his original model, whilst a medical model, was meant more as a conduit of health information; however, it seems health promotion has now become a byword for health based learning activities. Further Tannahill asserted that newer terminology such as ‘health improvement’ took something away from the purpose of prevention of poor health and enhancing positive health (2009: 398), which underpinned health promotion.
Another frequently used term in addressing health promotion is ‘health education’ (Bernhardt et al, 2013). The aim of health education is to change beliefs, attitudes, and behaviour in a manner which promotes positive health (Altman, 2009). Alongside disease prevention (Blair and Hall, 2006) health education tackled health promotion through disease prevention and health improvement strategies through health promotion campaigns. To be effective, this stance would also necessitate a socio-politico-economic approach in tackling wider issues such as housing, access to health care, education and employment (Blair and Hall, 2006).

Health knowledge is a key component of health promotion and health education (Raingruber, 2012). PHE acknowledged health knowledge as an essential component for public health empowerment (PHE, 2014), a way to improve health and reduce health inequalities using a model based upon the ‘power of information’ (2014:8). What is not really explored is how health knowledge is acquired, how the knowledge cycle is put into action and evaluated: it is inferred this happened through experiential learning, health education activities, social learning theory and life experiences, direct and vicarious. This study explores the real experiences of young people in developing their own health knowledge and health literacy and moves from inference to understanding.

Nguyen at al (2011) suggested that there are two main types of health knowledge: theoretical and applied. The differentiations are that theoretical health knowledge is a constructed concept of health understanding developed from the person’s learning and experiences of health; and that applied health knowledge is putting into practice that theoretical knowledge. This inferred that taking action (using that knowledge) as broadly the outcome of health promotion and health education. Kickbusch et al (2005) developed the nuance of health literacy from health knowledge activities such as health promotion and education as they suggested that health literacy should be empowering, enabling an individual to be proficient in information seeking and increased their responsibility about their health (2005:8).

Parker and Ratzan (2010) expanded on this definition, noting the influence of setting and context (of the health knowledge). This suggested health literacy as also steeped within the motivations and priorities of the individual concerned – a ‘need to know’
scenario, and placed health literacy as a socio-cultural concept rather than targeted health promotion. Camerini et al (2012) went further to suggest that health knowledge is, of itself, an ability to develop a sense of health empowerment. Through their evaluation, they found that health empowerment supported patient self-management of their health conditions. This appears to be something of a self-explanation notion of empowerment: little is explored in how health knowledge becomes empowering; rather this infers the common aphorism of knowledge is power. By contrast, this study has found from the literature cited, that health literacy is dynamic, inter-dependent and based upon self-agency. It is influenced by the relationships and capacities of the individual and would suggest that a broader, emancipatory approach to the development of health literacy enables self-efficacy in health.

The study focus of health literacy in the lives of young people is contextualised through empowerment and participation, and suggests that health literacy skills development start with the relationship the young person has with their health, wellbeing and health services. Thus, if a young person does not engage with their health and related health services there is no relationship to develop and disengagement with their health and health services puts a young person at high risk of poor (life) outcomes (Atkinson, 2013, Roberts, 2015a). Further, disengagement, disempowerment and powerlessness are commonly linked (Gill and Tranter, 2014) and reflect a society that places little value on individuals and their outcomes. Bergsma noted that;

‘Powerlessness is a significant health risk factor and conversely, opportunities to experience power and control in one’s life contributes to health and wellness’
(Bergsma 2004:152).

Squiers et al (2012) stressed that underneath the layers of socio-politico health, health literacy functions from the level of the individual (2012:30). Indeed, the IOM contest that it is the skilled interaction of individuals within social systems that transpire as health literacy (2004:3). Thus, this study has found that the need for individual agency to understand, engage and act (about health) is more than a public health concern of improved health outcomes and economic expediency, but one of worth, value and
equality. Hence, developing health literacy for young people demonstrates a sense of value society places upon young people’s worth and future life outcomes.

In being economically accountable, Rowlands et al’s (2015) comprehensive study of English health information materials found that through cognition and functional skills, the intended audience could not understand the materials produced (2015:380). This raises the question of the level of health literacy of the population but also questions the costliness and effectiveness of the health information materials. This was not only a waste of public health monies but highlighted missed opportunities for health education (Roberts, 2015a). Rowlands et al (2015) suggested more care be taken in developing health information materials, ‘particularly for more vulnerable groups’ (2015: 379). As Rowlands et al elaborated, ‘health texts are written at levels that exceed the average public reading skills’ (2015: 380). Thus, as literacy and numeracy is understood as levels and abilities so health literacy can be seen within functional-capacity levels (Roberts, 2015a). More specifically health literacy is ‘concerned with the capacities of people to meet the complex demands of health in a modern society’ (Sorensen et al, 2012:1) and those with limited health literacy potentially limit their life opportunities (Roberts, 2015a).

The turn from health promotion and health education to health literacy argues that conventional notions of health education and promotion tends towards a more restricted view of health, often confined within communication and behavioural structures (Rutten and Gelius, 2011, Naidoo and Wills, 2009). Whereas, Abel et al (2014) have taken Nutbeam’s original ideas further and argued that health literacy is an applied and context-specific set of skills. This is an important point; this would begin to suggest that simply knowing a person is literate and numerate to their expected cognitional stage cannot be the sole basis for assuming the person is also health literate (Rowlands et al, 2014, Rudd, 2015). Indeed, being health literate has individual and community socio-economic impacts as Rowlands et al (2015) found low health literacy led to increased use of health-related services, low interactions with preventative care, increased challenges managing long-term illness and generally reduced health outcomes.
Roberts (2015a) and Carollo (2015) argued that health literacy should both educate and empower people about their health and be valued as is a ‘social commodity’ (Carollo, 2015:538). Batterham et al’s (2016) research added to previous literature of linking low health literacy with poorer health outcomes (Sorensen et al, 2012, Harper, 2014, Roberts, 2015a, Rowlands et al, 2015, WHO, 2015) and modelled this as causal pathways of health literacy influencing health outcomes.

Figure 2.1. Batterham et al’s (2016:5) Causal pathways of health literacy and health outcomes.

Batterham et al concluded that lower levels of health literacy led to worse health outcomes compared with higher levels of health literacy (2016:5), however this was confined within a health context. This raises questions of how people and communities first understand and participate in health and health services. Access and utilisation of health requires knowledge of how to do this, and participation in health requires (some level of) knowledge and articulation (Roberts, 2015a).

Smith-Greenaway (2015) suggested that to be health literate, health salience is needed alongside educational competence. Rudd’s United States (US) research (2015) examined health information material from over a 30-year period and similarly with Rowlands et al (2015) and Roberts (2015a) UK research, found a strong link with the materials exceeding the populations’ reading levels; interestingly this was outside Batterham et al’s model (2016). Importantly, their conclusions shifted the paradigm from the ‘patients’ inability to understand health information by asking searching questions. Firstly, Rudd (2015) questioned the responsibility of the US education system aligning low functional educational skills with lower health outcome and highlights education as a conduit of functional literacy and numeracy. In England
Rowlands et al suggested that investment in education that raises literacy and numeracy levels will impact positively on health (2015:385).

Secondly, Rudd (2015) and Roberts (2015a) questioned if the responsibility of understanding health information was solely with the person or if responsibility was also held with the health care professional / health institutions in engaging purposefully with individuals and their health. This inferred the need for organisations and institutions to be health literate in their public approach to health.

Health literacy has consequently moved from being a method of health information exchange to an issue of social equality and justice. This is because research shows that poor health literacy, or being health illiterate, is strongly linked to poor health, increases health inequalities and has a negative impact on life outcomes for individuals, communities and societies (Batterham et al, 2016, Rudd, 2015, WHO, 2015, Rowlands et al, 2015, Roberts, 2015a, Sentell et al, 2017). More recently, the prominent thread of the social impact of health literacy has been raised through the publication of the WHO Mandate for Health Literacy (2015) re-defining health literacy as,

‘personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health’ (2015:1).

Sentell et al (2017) researched the social context of health literacy through their meta-analysis and came to three major findings. Firstly, that there is a common association of health literacy and social context, finding that poorer levels of health literacy were associated with poorer social capital and social engagement. This echoes Roberts’s (2015a) conclusion that limited health literacy led to limited social and life opportunities. Accepting this finding begs the question of equality for individuals and groups with poor social capital and poor social engagement; those who are marginalised, vulnerable or isolated. This has the impact of increasing already poorer outcomes (WHO, 2015, Harper, 2014, Roberts, 2015a) through health illiteracy and social isolation.
Secondly, Sentell et al (2017) suggested their findings demonstrated that being health literate implied a strong social context; that ‘people do not deal with health alone’ (2017:42). Roberts (2015a) concurred with this, and found health literacy linked to social circumstances, empowered self-management of health and improved social outcomes. This suggests that social context is used (as a method) in achieving good health outcomes. Sentell et al’s last finding was that health literacy was a shared commodity, an ‘aggregated property’ (2017:42). This, they suggested, is as a collective activity within a family, community or group. Aggregated property helped sustain health literacy and reduce health inequalities of that community through social cohesion, collective need and momentum pressure (Sentell et al, 2017). This finding has been further supported by Batterham et al (2016) and Roberts (2015a) who contended that health literacy, whilst an individual attribute, it is also collective within families and communities.

Within Britain, health inequalities have been explained by Graham (2009) as ‘systematic differences in the health of people occupying unequal positions in society’ (2009:12). This was emphasised by Atkinson (2012) who stated that, for young people, ‘inequality in health outcomes is closely related to socio-economic measures of a citizen’s status in society’ (2012:4). Health inequalities are often correlated against other determinants such as class, wealth and poverty (Roberts, 2015a). As factors such as (un)employment and poorer housing contribute to lower educational attainment (McNally, 2010, Raffe et al, 2006), what has become clearer is that low health literacy levels are an important indicator to low health outcomes (Sheridan et al, 2011, Atkinson, 2012. Roberts, 2015a). Poorer health literacy is also beginning to be associated with socio-economic factors such as age, ethnicity, race and education (Harper, 2014).

In areas of deprivation (in England) the take up of ‘(proven) prevention and protective health measures are low’ (Atkinson, 2012:5). Of note, most of the socio-economic factors discussed in being significant to health literacy levels are relatively static such as ethnicity, culture and social class; one factor which has potential for movement and thus to impact on health literacy levels is education.

The link between health outcomes and functional educational attainment has been acknowledged by a range of authors (Kickbusch 2001; Dyson et al, 2009; Kennedy,
2010) and some of the context of this research comes from accepting the notion that health literacy has an association to educational attainment. This aligns to the wider paradigm of the cycle of poor education, poverty and inequalities (Department of Work and Pensions (DWP)/ Department for Education (DE), 2011). Emerson and Baines (2010) and the Scottish Government (Scot. Gov.) / NHS (2014) similarity concluded that low health literacy was found to be prevalent in lower socio-economic and other minority groups, which culminated in lower health status, greater chance of hospitalisation, poor health decisions and self-management (Scot. Gov., 2014:4) and feeding into the cycle of deprivation (Joseph, 1972 in Welshman, 2006).

Health illiteracy, poor socio-economic status and poor educational attainment perpetuates the cycle of inequality (Roantree and Shaw, 2014; Roberts, 2015a). Further efforts made to narrow the educational attainment gaps linked to wealth and poverty should complement efforts to narrow health attainment gaps (Chief Medical Officer (CMO) Report, 2013). SCMI Associates (2014a) suggested that strengthening health literacy to address inequalities, and argued that health literacy can be an asset at both individual and community level, building social capital and ultimately enhancing empowerment (2014a). Thus, education plays a part as a determinant of health literacy, but this is not clear cut, as Harper (2014) found in assessing health literacy levels, and concluded that graduating US students could not be assumed to be health literate.

Discrimination also plays a part in contributing to health inequalities. Emerson and Baines (2010), in their study of people with learning disabilities, note that limited communication skills contributed to a significantly reduced capacity to express health needs – this led to reduced access to appropriate health advice and reduced use of health services which culminated in reduced health outcomes. Roberts (2015a) agreed that disadvantaged groups were at greater risk of health illiteracy and so caught within the cycle of health inequality. As a marginalised group, young people are further disadvantaged through adult-centric health provision (Massey et al, 2012) and this further perpetuated health and social inequalities and the cycle of poor life chances of already deprived young people (Atkinson, 2012, PHE / AYPH, 2014). This study will add to this body of knowledge, through considering health literacy in the lives of young people as a means to improve health and reduce inequalities.
It would, however, be short sighted to focus only on developing adult health literacy; health literacy needs to be a life developing skill from childhood. This would support and mitigate against current and emerging public health issues and can be a positive approach to tackling wider social issues of inequality and outcome (Ormshaw et al, 2013; IOM, 2004). There is increasing awareness of the need to ‘encourage health literacy’ (PHE / AYPH, 2015; AYPH, 2016) as part of the PHE framework in improving young people’s health and this moves health literacy forward from health promotion.

WHO (2015) and the United Nations Economic and Social Council (ECOSOC) (2009) called for development of action plans to improve health literacy because low health literacy levels contribute to poorer health and life outcomes (Rowlands et al, 2015, Harper, 2014). An increasing number of researchers within the UK concluded that poor health literacy has ‘substantial’ health consequences: that people with low health literacy present with worse physical and mental health, have a higher prevalence of co-morbidities, engage less with preventative services and have an increased use of emergency services (Putoni, 2010; Rowlands, 2014; Kramer, 2014; Roberts, 2015a). Whilst there appears no English agreed strategy of improving health literacy (Squiers et al, 2012, Massey et al, 2012, Roberts, 2015a) per se, America, Australia, Finland, Scotland and Wales lead the way in recognition of the need to up-skill their populations’ functional health literacy. The approach to health literacy in England could be considered passive, with no specific strategy (Roberts, 2015a, PHE, 2016a), however localised positive examples have been drawn from practice (Berry, 2016). The AYPH Toolkit for School Nurses: Improving Young People’s Health Literacy (2016) suggested health literacy increased young people’s independence, developed skills for life and helped young people access and use health services appropriately (2016:3). The AYPH argued that school nurses were uniquely placed to ‘deliver health literacy messages’ (2016:8) despite Elliott et al (2013) suggestions these approaches were not effective in reaching young people. A critique of AYPH toolkit is that it implies a piecemeal roll out of patchy health literacy messages rather than a robust strategy of health literacy education.
In planning ahead, the US Government published a ‘National Action Plan to Improve Health Literacy’ in 2010, while devolved Welsh and Scottish administrations have reported to their National Assemblies to develop population health literacy (Putoni, 2010, Kramer, 2014). Within the UK a growing body of evidence (Scot. Gov., 2014, Emerson and Baines, 2010, SCMI Associates, 2014b, Roberts, 2015a) have shown that being health illiterate widens the gaps of health and socio-economic inequalities. Wales has targeted development of health literacy as part of its strategy to overcome health inequalities (Wales Assembly Gov., (WA Gov.) 2011) and Scotland has launched a national action plan to improve population health literacy (Scot. Gov., 2015).

NHS England is developing towards improvements in national health literacy levels and has appointed a specialist advisor as part of a scooping health literacy project which has three identified objectives. Firstly, to develop a national strategy for health literacy through ‘arm’s-length bodies’ (Health Education England (HEE)/ PHE, 2017:1), although there is, as yet, little articulation about how this strategy is to be developed. Secondly NHS England (2016) have set up a collaborative health literacy resource base. This resource base includes information on testing health literacy levels, advice on developing health information and other measurement tools. It does not consider issues around health literacy that are outside of a health agenda. Interestingly, Batterham et al (2016) suggested that health literacy principles sit outside of the health education and health promotion arena, the inference being that health literacy has evolved from static behaviour and belief models (Tannahill, 2009). Instead, they suggested, the challenge is to ‘changing health educational culture’ (2016:7) and this has implications for the developing health literacy strategy which should consider education aligned with health salience as a key attribute (Smith-Greenaway, 2015).

Lastly, NHS England (2016) are setting up a health literacy ‘demonstrator’ (Berry, 2016: 1) to test out if being health literate enhances patient management of long term conditions, which was a finding of Roberts’ UK report (2015a). There is already much global evidence that being health literate does improve health and that being health illiterate is a risk to health (WHO, 2009, WHO, 2015, Batterham et al, 2016, Rowlands et al, 2015).

This study contributes to the body of evidence that health literacy needs to be a life-skill educational priority in order to promote health and address inequalities.
Research suggested that health illiteracy is most prevalent amongst disenfranchised groups (Sentell et al, 2017, Roberts, 2015a), including young people. Existing evidence has shown young people as disenfranchised and disempowered about their health and by health services (Atkinson 2013, Harper, 2014, Roberts 2015a, Sentell et al 2017) and has rarely explored young peoples’ own experiences and understanding of their health (Atkinson, 2013, Cha et al, 2014, Rowlands et al, 2015). This study will add to the body of knowledge of health literacy and young people.

2.3. Young people and their health

In thinking about young people and their health in England it is useful to consider how young people are valued within society. A range of critical literature suggests that Britain is currently in a socially stagnant and economically shrunken state (Gould, 2015, Harding, 2017) and this is having a particularly negative impact on young people (Milburn, 2017). Indeed, the Social Mobility Commission (2016) suggested that rather than improving, the situation for young people in this context is worsening. It is from this context that British politics defines its citizens through policymaking in terms of worth and social justice. Tronto’s notion of ‘privileged irresponsibility’, linked to moral theory, has shown how a privileged majority group hold and maintain power in many contemporary democratic societies, through institutional practice and epistemological ignorance (2013). Moral theory highlighted the significance of dependant relationships and how power relationships are used to maintain dependence in order to maintain privileged positions (Tronto, 2013). Furlong suggested youth as a socially constructed stage bridging childhood and adulthood (Furlong, 2013) with the inference that young people remained disempowered as dependant. This sits within the debate of structure and agency of young peoples’ experiences and opportunity; both of which are often defined more by constraint rather than through opportunity. Young people are both dependant agents to be nurtured into adulthood but also constrained through that same nurturing. Thus, is can be argued that in contemporary British society, young people are positioned as the dependant agent, valued as needing to be taken care of within a rigid framework (Milburn, 2017, Houghton, 2015). This view not only disempowered the agency of young people but demonstrated a profound disregard for the development of that agency (Spencer and Doull, 2015, Munford and Sanders, 2015). However, through participatory work
grounded in information, knowledge and partnership, young people can be valued as autonomous agents (Smith and McMenemy, 2016; Houghton, 2015).

Heinz’s (2009) life course theory contextualised agency as embedded in social networks and relationships that influenced emergent transition. This suggested a more positive and vibrant view of youth. Recent literature (McDonald et al, 2013, Smith and McMenemy, 2016) suggested that policy and media discourses commonly depicted youth as synonymous with popular culture, homogenising youth as a broader aspiration rather than an age-related stage. This challenged Wyn and Woodman’s definition (2014) of youth as generational, different in social dynamics and knowledge. Other theories of generation discussed the notions of social agency and change - old to young and young to old (Furlong, 2013). In contemporary Britain adults adopt youthfulness by assuming youth cultural symbols such as clothes and music (Smith and McMenemy, 2016). Through the sense of adult youthfulness, the dichotomy of identity politics may appear a shibboleth, to have self-resolved but it has not. Legal and social structures still dictate power bases and maintain the balance of power to ensure young people as a marginalised group. For example, adults sustain young people as outsiders through legislation such as, maintaining the voting age at 18, restrictions of choice and opportunity through policy, inequality and educational structure. Literature supports this stance, maintaining child focussed activities with rhetoric and action; the restriction of movement without an adult (Smith and McMenemy, 2016, Simmons et al, 2014) and the inability to seek health support without adult consent, (Hope, 2015). By not addressing the development of health literacy for young people, current educational and health institutional structures uphold the notion of young people as dependant bystanders. This disempowers young people and holds back their transition into productive adulthood (Rowlands et al, 2014, Roberts, 2015a, Rudd, 2015, AYPH, 2016).

An additional aspect of young people’s marginalisation in the UK comes from Simmons et al (2014) who note that the marginalisation is not related to social exclusion but more marginalisation of economics; that young people are ‘socially congested’ (2014:43), stuck within an impotent youthfulness that impedes social mobility. This has some resonance with MacDonald et al’s finding (2013) that young people have become trapped within constructed and actual dependency which hangs
on economic and capacity issues created within society and institutions such as the NHS. The impact of this marginalisation can be aligned to the nuances of Identity Politics (Jacobs and Potter, 1998). Jacobs and Potter (1998) described how marginalised individuals and groups were required to vie for recognition and support by competing to be the ‘most needy’, compounded by having poor social capital (Harper, 2014). As already discussed WHO (2015) and Roberts (2015a) identified marginalised groups with poor social capital and poor engagement at greater risk of poor health outcomes.

In the UK, it is widely noted that power within health services lies with Commissioners and Providers (Timmins, 2013). However, this position of power is contested via the Health and Social Care Act 2012 which fragmented the health arena through placing a statutory duty of public health to Local Authorities (Timmins, 2013). Within this structure, Commissioning Boards are required to ‘listen and respond’ to patient views (Wye et al, 2015, Timmins, 2013) but crucially, were not required to act. The reality of this is that patient representation was at a tokenistic level and this had not changed over time (Ocloo and Matthews 2016, Hart, 1992). Outside of specialist child health research, for children and young people, there have been few substantive attempts to gather their views and opinions about their health and health services (Children and Young People’s Health Outcome Forum (CYPHOF), 2012, Hagell and Coleman, 2014). This study carried out a local scoping exercise of Commissioners and Boards which showed a mixed localised picture. There was no structured or evaluated way of working in partnership with young people. Anecdotal responses described loose and casual consultation with young people on an ad hoc basis. Consequently, young people were lost within this structure and have no identified space to input into their own health needs. Yet, Hagell and Coleman (2014) eloquently start their AYPH update on young people noting adolescents face barriers to appropriate (health) care (2014:1).

Thus, it is argued that neglecting young people in planning and providing health services further disenfranchises them from their own health (CRAE, 2015). The consequences of this disenfranchisement are potentially catastrophic for future generations and risks producing unhealthy adults and the consequential social, economic and welfare impact this will have on an already austerity-steeped country.
Hannon and Tims (2010) and HM Government (HM Gov.) (2013), further supported the notion that the generational gap is that of economics which fed directly into increasing inequalities for young people. Hannon and Tims suggested the message to young people from UK society is: “I know who you are’ rather than ‘I know what you are feeling’” (2010:15). The inference being that whilst young people are not passive social agents they tend to be treated as such through adult-centric policies and generational inequalities. The reality of the generation gap was seen starkly in the UK’s Summer 2016 vote to leave the European Union. Curtice (2016) in the ESRC commissioned post-Brexit report, found ‘striking evidence’ of difference between voting preference and age groups (2016:5).

Milburn (2016) suggested that the European Referendum has reconfigured the political generation gap in the UK. The generational gap was seen starkly in the 2017 UK General Election with ‘age being the new key predictor’ for voting preference and young people’s voting based on inclusive social justice issues rather than economic ideology (Curtis, 2017). Thus, the generation gap differences appear to be shifting from softer notions of social culture to harder ideology of economy and politics (Milburn, 2016, Munford and Sanders, 2015) seen through identity politics and the potential for the growth of mobilisation of the ‘perceived disenfranchised’. As a consequence of identity politics in the UK, one group are positioned as more influential and powerful than another; one group (adult) is therefore more valued over another (young people). Thus, young people are treated as passive agents and feel disenfranchised; they become disengaged and are disenfranchised (Spencer and Doull, 2015, Munford and Sanders, 2015).

Research found that this widening economic gap is making it harder for young people in the UK to transition into adulthood (Simmons et al, 2014, MacDonald et al, 2013). This approach has become entrenched through legislative decisions which benefit adults and take a punitive approach to young people; for example, the introduction of the National Living Wage only to those over 25 years and the loss of housing benefits for 18-21 year olds. Thus, Hannon and Tims concluded that ‘British politics is failing to offer young people a vision for their future’ (2010:14), with Curtis (2017) suggesting
this is seen through young people’s voting patterns of recent elections through increased political engagement and participation of young people.

In their report, Positive for Youth, HM Gov. (2013) acknowledged the need for participation with young people, stating that they would ‘return power to young people, families and communities’ (2013:7) through consultation and listening to their views in order to improve their world. This Governmental report details several case studies but has little evidence of the consultation process, rather it appears tokenistic in reporting adult-centric generated case studies with little narrative of young people views. This is an important point to note; for young people their lived experience is a narrative. This narrative, collected through sound research methodology, should be acknowledged as evidence, so that young peoples’ lived experiences can influence Governmental consultation and decision making. It is the process of developing that narrative through maintaining truth and interpretation that gives narrative credibility (Mansuri and Rao, 2013, Furlong, 2013).

Currently, the UK Government is a signatory to the United Nations Convention for the Rights of the Child (UNCRC) 1989. Several articles to the Convention infer that participation in health is a right for young people;

- Article 4: ‘you have the right to have your rights made a reality by the government’;
- Article 12 ‘you have the right to an opinion and for it to be listened to and taken seriously;
- Article 23; ‘if you are disabled, either mentally or physically, you have the right to special care and education’;
- Article 24; ‘you have the right to the best health possible and to medical care and information’

In 2013, a Government report found that children and young people, who should be consulted and involved in development of services, were not (HM Gov. 2013). This built from Kennedy (2010) who suggested that children and young people’s health simply held a much lower priority than adult health and was side-lined, concluding that health guidelines, polices and reforms were written and planned for from an adult-centric perspective. Atkinson (2013) acknowledged some attempts were made in practice and policy development to include young people in developing their health
and health services but that this is often tokenistic, patchy and generally unrepresentative in the sampling of the young people. Further, Lambert et al (2014) and Moules and O’Brien (2012) noted difficulties recruiting children and young people as participants in health research and suggested this could be perceived as a barrier, preventing meaningful participation for children and young people. In their study of how young people view health and the implications for policy formation, Ott et al (2010) found that engaging young people with the process of policy writing and health information helped bridge unmet health and care gaps. Following the PHE / AYPH (2015) strategy the NHS has set up a consultative Youth Forum which recruited, via the British Youth Council (BYC), 25 representative young people. No reporting date was set for this consultation and there has been no formal reporting from this consultation.

The Department of Health (DH) in 2013 also recommended including the views of young people in health policy and planning. In 2015, the PHE / AYPH wrote their Framework for Improving Young People’s Health and Well-being’ which consulted with a ‘small number’ (2015:23) of young people invited to join with series of Twitter chats and a survey. A critique of the PHE framework, was that the recruitment process for the young people used adult-centric social media. Also in 2015, the CRAE research involved young peoples’ focus groups in 24 hours of data collection with 22 participants. In both studies, young people do not appear to have been asked about their health priorities but rather consulted on topic based issues; for example, mental health. However, there have been some generalised findings from research of young people which found that young people want their health care delivered by staff who are knowledgeable about young people rather than adults and that they are ‘listened to’ (CRAE, 2015:20, PHE/ AYPH, 2015, Hagell, 2015, AYPH, 2013). With some resonance to children and young people’s health research methodologies of Lambert et al (2014) and Moules and O’Brien (2012), designed, carried out, evaluated and co-produced by young people over a period of two years, this study undertook primary research to understand the lived experiences of young people about their health, health knowledge and health use.

In 1999, the Institute of Education found that health promotion was not effective for young people in the UK, particularly for those young people at risk of adverse health
and health behaviours (Harden et al, 1999). Close to 10 years later, Oliver et al (2008) also concluded that health promotion for young people did little to tackle their health problems and failed to mitigate issues of health inequalities. In 2013, Elliott et al found that health promotion had limited impact and value for young people, with only limited attempts to conceptualise and re-think why this disengagement with health happens. There are a myriad of reasons for this. One reason is that health promotion activities were not generally linked to health inequalities but were aimed at reducing national health targets (Elliott et al, 2013, PHE, 2015). Further, these health promotion activities were related to adult health choices and based upon behavioural and psychological models of health education, but had an unintentional consequence of disenfranchising young people (CRAE, 2015). Moreover, Fairbrother et al (2016) found that health advice continued to be ‘one-dimensional messages’ (2016: 476) which simply highlighted gaps in health knowledge and acted to ‘switch off’ for young people. However, two decades on from Harden et al (1999), there remains little evidence of health promotion working for young people with PHE reporting that ‘9.9 million young people have poorer health outcomes’ (2015:5) and that inequality continues to have a negative impact on their health (2015). However, educating young people about their health remains wedded to ineffective health promotional activities (Fairbrother et al 2016, Rowlands et al 2015, Rudd, 2015). Alongside this, if health services continue to fail to address the real, rather than adult perceived, needs of young people, young people will continue not to engage with health services and health activities (CRAE, 2015). For example, in reducing teenage alcohol consumption Seaman and Ikegwuonu, (2010) acknowledged the issues of disengagement with health promotion, young people did not identify alcohol problems as an issue for themselves (Elliott et al, 2013). Aligned with young people as the least likely group to attend outpatient follow-up appointments (Hope, 2015) this demonstrated a mismatch between health promotion, service provision and what young people want and will use.

Further evidence of this mismatch can be seen within young people’s mental health services. The Young People’s Health Forum (2013) found mental health to be an urgent problem with 1.2 – 1.3 million (10% of population) children and young people with a diagnosable condition by the age of 14. However only 25% needing treatment get the treatment they need (Young People’s Health Forum (YPHF), 2013). Other
studies suggested that this might be due to young people not being aware of what mental health is and what help was available (MHF, 2015); or that they and their parents see and respond to physical illness more readily than to mental health illnesses (MHF, 2015, PHE/AYPH, 2015). Other research suggested that additional barriers exist, for example, access to General Practitioners due to difficulty in making appointments, and the perception of the need for an adult to be present during consultation (Hope, 2015). Fergie et al (2015) found young people view seeking specialised treatment as difficult with additional steps in accessing these services, through a gatekeeper, usually the GP.

Furthermore, the ways in which young people use health services seem not to conform to adult presumptions; for example, Hargreaves et al (2012) found young people dissatisfied and disengaged with health services, partially because health services did not recognise their needs differed from adults (2012:528). Alongside young people’s non-engagement of adult-health services, the manner of engagement for young people is also changing. Hope (2015) found that 48% of 16-24 year olds had accessed a health app and 26% had looked up medical advice using the internet. From an adult perspective information provided on the internet is questionable for its accuracy, quality, robustness and reliability (Ofcom, 2014) as there are very few quality filters applied through the whole internet which crosses international boundaries and legislations. (Ofcom, 2014, 2016).

In 2015 Fergie et al found that young people wanting health support and advice used internet searching (referred to as ‘googling’) as their first, and often only, means of information. The importance of this study is that it recognises how the internet has moved from ‘gatekeeper’ of health-related services to being a key source of health provision. A second finding (Fergie et al, 2015) was that alongside googling their health, young people were using their social networks to gain health information as this was viewed as a trusted mechanism. Thus:

‘...[young people] actively and effortlessly negotiate between professionally produced content....user-generated content...draw on other people’s experiences of a similar illness and inform their own health management strategies’ (Fergie et al 2015:5).
Ofcom (2014) reported that 70% of UK 5-15 year olds have access to the internet via tablet devices whilst over 80% of all 12-15 year olds own a smart phone and now spend more time on the internet via their device, than watching the television. In developing services that do engage young people it seems multi-media must be a platform to this engagement, so a key challenge for practitioners is to understand how young people themselves understand their health and health services within this changing context.

2.4. Young people and health literacy

This study explores how young people learn about their health and use health services. It examines the need to engage and empower young people about their health, rather than be passive bystanders and receivers of health services. This study moves on from passive recipient ideas of health promotion and health education, incorporating health literacy for young people through an active participatory approach. This is underpinned by the concepts of empowerment, emancipation (of health) and participation in, and use of health services and decision making, in order to improve overall life outcomes for young people.

Health literacy plays a significant role in issues of health (AYPH, 2016) and social inequalities (WHO, 2015), and as such, is of importance to young people. In summarising the links of health inequality and health illiteracy the Scottish Government concluded in 2011 that ‘children born into poverty and deprivation are less likely to make healthier ‘choices’ (2011:3) and found that lower levels of numeracy and literacy were intrinsically linked to socio-economic factors such as educational attainment and employment chances and this is supported by the research of Rudd (2015), Harper (2014), Roantree and Shaw (2014) and Batterham et al (2016). Further, poorer health outcomes were compounded by the inability of the young person (and their families) to interact and access health services, follow health based instruction, engage with health promotional materials and take up of preventative programmes (Sentell et al, 2017, Ormshaw et al, 2013, WHO, 2015). Alongside Harper’s (2014) research which showed graduate students were not health literate, this raises the issue that despite reasonable levels of educational skills and attainment, young people may not have the capacity to bring these skills together to use and access health
support, advice and services. This concern is reflected within Smith-Greenaway’s study (2015) which noted that an assumption is often made that educational attainment can be an accurate approximation of health literacy. Whilst this assumption may be partially so, it does not answer the whole picture of health knowledge related to health outcomes for young people. Smith-Greenaway suggests that ‘health salience’ (2015: 131) is needed to support health literacy. These concerns emphasised the importance of this study’s aim, to understand how young people acquire, develop and use health literacy and produce recommendations for practitioners and policy makers concerned with improving the health outcomes of young people.

In taking Smith-Greenaway’s findings further, whilst health literacy broadly manifests itself as a functional interplay of applied education competence, health literacy is underpinned through developmental health and educational progress, not just educational attainment. For example, in contextualising health literacy Massey et al (2012) looked at measures of skills and competencies for young people within a healthcare setting and concluded these as:

‘i) navigating the system ii) rights and responsibilities iii) preventative care iv) information seeking v) patient-provider relationship’ (2012: 961).

These skills and competences implied the young person would need to be both informed and capable as a health-care user and consumer. This also assumes a relationship with the health care provider and the young person in providing information about, for example, the system to be navigated. In considering Massey et al’s (2012) arguments this study extends the findings to suggest that health literacy differs from the usual concept of health promotion and health information for young people. Massey et al (2012) and Smith-Greenaway (2015) suggested health literacy has a more complex relationship than simply user (health) and provider (of health services) but failed to conceptualise this or suggest an alternative. A suggestion could be that it is the interaction of the user with the provider in order to overcome barriers to healthiness such as interpersonal skills, functional skills, confidence and agency of both partners, within the context of health.
PHE / AYPH (2015) open their ‘Framework for Improving Young People’s Health and Well-being’ by stating that ‘treating different, specific health issues separately will not tackle the overall wellbeing of this generation of young people’ (2015:6). However, they found that currently, despite downward trends the UK still has:

- The highest European teenage birth and abortion rates;
- Child and teenage drinking well above the EU averages;
- One of the highest rates of alcohol abuse amongst 11-15 yr. olds. (PHE/AYPH, 2015).

In tackling young people’s health needs the PHE/AYPH carried out research, which was a meta-analysis of child / young people’s health and included a ‘short’ (2015: 22) survey of young people (n =51) and five twitter chats (n = not disclosed) which settled on six core principles:

1. Relationships: being with friends and family, a sense of belonging;
2. A positive focus on what makes young people feel well and able to cope;
3. Reduce health inequalities for those most in need by providing targeted services;
4. Integrated services that meet needs holistically and are centred on young people;
5. Understanding young people’s changing health needs as they develop;

These core principles were designed to be useful for commissioners and service providers (PHE/AYPH, 2015:6), but did not appear to consider how the core principles can be applied to young people. This effectively bypasses young people in service design, excluding young people from, what should be, their health services. More positively Gould (2015) argued that young people prefer to be collaborative and this is a response to adult-centric political institutions which disenfranchise young people. Young people, saw developing integrated and holistic services as meeting their changing needs (Gould, 2015).
Within England health education and promotion for young people is typically focused in school settings (AYPH, 2016) and generally refers to services provided by the School Nurse (RCN, 2016). There are two current toolkits for school nurses published through established professional bodies. Firstly, the Royal College of Nursing (RCN) Toolkit for School Nurses (RCN, 2014) explained the school nurse role as educating staff about the health needs of pupils, addressing targeted health needs of the (school) community such as healthy eating and delivering public health priorities, for example, smoking cessation. The outcome of this is that school nurses do not educate young people in developing health literacy but instead target adult knowledge to disseminate to young people. Secondly and in contrast, the AYPH (2016) toolkit directly suggested school nurses as the key professional to improve young people’s health literacy through health promotion. School nurses are commissioned through a plethora of funding streams which inevitably leads to a variety in the provision and quality of these services. A critique remains that these toolkits are based on outdated health promotional modes which do not effectively address the learning or self-defined health needs of the young people in developing their health literacy (Hope, 2015, Fergie et al, 2015).

The English national curriculum is set out by the Department for Education (DfE, 2013) as compulsory subjects taught in state run schools. All subjects are academic with only 2 subsidiary topics of religious education (RE) and sex education. Academies and other school settings must teach English, Mathematics, Science and RE (DfE, 2013). As a subject ‘Health’ is not identified by the National Curriculum and there is no compulsion for schools to spend time teaching health. Public Health England (PHE) do not have a specific role in health education for the public but instead advice national and local government and other organisations (PHE, 2016a: 4-6).

PHE priorities are aligned to schools’ health promotional activities linked to strategic national targets; for example, young people’s sexual health or reducing teenage pregnancies (PHE, 2016) rather than directly delivering health education (PHE, 2015a / 2015b). These health promotion sessions are delivered via the public health funding of the local authority, usually carried out by a school teacher (Pound et al, 2016, Hope, 2015). In their study, Pound et al (2016) found that sexual health was delivered in schools as if any other subject, leaving young people feeling vulnerable, anxious and
at risk of harassment. Further, due to blurred boundaries young people felt it was wrong that teachers delivered these sessions citing lack of anonymity and embarrassment (Hope, 2015, Pound et al, 2016). Whilst this may be indicative of poor preparation and training of the teachers, a result of this could be that poorly delivered health education puts young people at further risk. Young people might disengage with this education, developing their own health knowledge (through peers and the Internet) which may be incorrect and put them at risk of harm. Evidence suggests that involving young people in their health education would improve their participation in this (Hope, 2015, Gould, 2015).

Participation in health education can be seen within the context of patient participation, now a legislative requirement (HM Gov., 2006, HM Gov., 2012), with participatory activities commissioned as part of health care services. Everyday definitions of participation generally mean ‘to take part’ or ‘be involved’, Lansdown describes participation as ‘social engagement’ (2010:11). These definitions, however, do not set out any parameters of the ‘taking part’, ‘involvement’ or ‘social engagement’. Participation, as a continuum, could be as a light touch - just checking things out, or as total immersion (in the activity).

In health, there are no set parameters for this participation but conferring with patients regarding their wishes appeared to be common practice (Mansuri and Rao, 2013). Healthcare participation for children and young people occurs as part of a model of care or care-plan. Commonly it is ‘actively engaging with (the child)’ or ‘gaining engagement and co-operation’ (Schalkers et al, 2016:1038). Whilst this falls under the definition of participation it raises the question of the purpose for the participation; for example, is the participation a way in which to gain compliance. Hear by Right (Badham et al, 2010) is a standards framework for organisations seeking to achieve effective youth participation. The principles of the framework are that the participation is visible and resourced, valued, based on equal opportunities and supported by policy and systems. A briefing released jointly by the National Youth Agency (NYA), DH and AYPH (2010) suggest health services adopt the NYA (2009) standards of participation with young people. To date, there is no evaluation or reporting to show this has been the case. Rather the general participation approach within health remains as induced (Mansuri and Rao, 2013) and demonstrated a
bureaucratic response from health services to legislation such as The NHS Service Act 2006 (HM Gov. 2006) and Health and Social Care Act 2012 (HM Gov. 2012), which set out requirements that patients (young people) have a voice about their care and services. This raises the question of the purpose of healthcare participation: whether this is to validate the actions of the healthcare provider or professional or whether participation is a collaborative partnership. Participation, at its core, equally values the contribution of all stakeholders. This rests upon the definition of who the stakeholder is and raises questions of the allocation of power within this ‘participatory’ relationship. Participation, as a concept, raises the question of purpose. Lansdown (2010) suggested that participation is now widely accepted but the application of the participation needs to be addressed (Mansuri and Rao, 2013, Elsley and Tisdall, 2014).

Over the past 10 years participatory health research has developed to capture the views of health users in contributing to their own health and health services. More specifically, hearing and responding to the voices of children and young people in relation to their health has emerged from the field of children and young people’s health practice (O’Brien and Moules, 2007, Coad et al, 2008, Lambert et al, 2014). Moules (2009) argued that these methodologies should be underpinned by the belief that health and health services, informed by the experiences of children and young people, are vital to ensuring that their needs are met. These developments in children and young peoples’ health participation aligns with the paradigm shift of British health services in understanding user views, from passive consultation to active user participation, rather than viewing them as merely future adults or patients (NHS, 2017).

In 2008, Coad and Coad utilised a youth council in their hospital-design research which included young people being involved in planning the research tools and verifying findings. The young people were sourced and accessed via an adult Advisory Board, who then wanted to add their own understanding to the findings. Coad and Coad themselves comment that adults did not fully understand or were not able to, hand across power and decision making to the young people / youth council (2008). The inference here could be that the Advisory Board did not understand the premise of participation as equal but rather as taking part and tokenistic, or because there was a lack of trust in the outcomes of the young people. Reflecting on this further, Coad and
Coad (2008:23) noted the young people ‘verifying findings’ which suggested the outcomes as the researchers’ rather than from the young people. Other important methodological points emerged from this research; participatory research with children and young people is time consuming and requires the researchers to be flexible in their approach. An example of this flexible approach to research practice was the co-developed terms of reference with the youth council (2008). Terms of reference ensure roles and responsibilities were clear to allow the young people to be involved meaningfully (Coad et al, 2008).

Notably, for children and young people, health research participation often involved working with or through adults (parents or staff) as the gatekeepers to children and young people. In 2009, Moules noted an up-shift in the valuing of children and young people’s participation with their healthcare and in health research. However, Moules found that the level and quality of the participation remained dependant on the ‘interpretation those adults place on the term ‘participation’ (2009:17). This suggested that the participation was heavily influenced through an adult gatekeeping process and this aspect of understanding children and young people’s views has increasingly been seen as a barrier to meaningful participation (Coad and Coad, 2008, Lambert and Glacken, 2011) explained succinctly as ‘children’s voices...represented through adult proxies’ (Lambert et al, 2014:59).

The need for gatekeeping comes from the notion that children and young people are vulnerable (Lambert and Glacken, 2011) and this has been experienced as an over-cautious power obstacle to direct health research with children and young people (Coad, 2012, Lambert and Glacken, 2011). However, Coad (2012) emphasised that the principle of participatory research is to ‘give a voice.... to those being researched’ (2012:12) such that the relationship of power became part of the process of the knowledge generated and that the data collected is authentic and this moves the participation from tokenistic to meaningful. This is significant because children and young people say they want to be active participants in their health and health services, including health research (O’Brien and Moules, 2007).

Further, Lambert et al, (2014) and Moules and O’Brien (2012) acknowledge that power within a participatory research framework is variable and dynamic. It is through being reflexive to, and understanding this variability, that facilitates participation to be
authentically collaborative and shape the way in which the research participants learn about each other and the research subject (2012:399).

Many of the health researchers cited (Lambert and Glacken, 2011, Coad, 2012 Moules and O’Brien, 2012) have critiqued models of participation in their health focussed research with young people, and they recognise those models as somewhat restrictive and have settled upon bespoke methodologies which developed dialogue through consultation with children and young people (Moules and O’Brien, 2012, Lambert et al, 2014). Further, the studies discussed have engaged with a broadly purposive sample (Silverman, 2016) of children and young people; those engaged with health services (such as in hospitals), or recruited from a health focused source, such as a youth council based at a health setting. This study asked how young people acquired their health knowledge, and accessing young people directly from a health service had the potential to weight responses and so the study focused on young people from a neutral setting. The study took from health participation an understanding that it is acceptable for the power balance to be variable across participative research and that young people do want to be involved, valued and enabled about their health and health services.

Thus, explained above, health participation for children and young people is largely held upon the approach and attitude of the healthcare professional and parent (Simonelli and Guierreiro, 2010, Coyne, 2008). Gatekeeping, contradicts principles of participation, and to active and meaningful participation taking place. Frequent justifications for this gatekeeping are linked to the ideas of the child / young person, not just as vulnerable (Lambert and Glacken, 2011) but also incompetent, in need of protection, and lacking maturity (Coyne and Harder, 2011, Dedding et al, 2015, Schalkers et al, 2016). In addition, participation may not happen because of challenges experienced by the adults, for example lack of communication, expertise and skills, organisation, time or resource constraints (Schalkers et al, 2016). More interestingly there is a growing view that the power relationship of professional versus child / young person restrains some healthcare professionals from engaging in participation decision-making as this has the potential to require the professional to, at the very least, share the power with the child / young person (Schalkers et al, 2016, Massey et al, 2012, Coad and Coad, 2008, Lambert and Glacken, 2011). This reticence may be
rooted in the belief that the child / young person could not be considered the expert in their care, further it questioned the practice of the health care professional. Schalkers et al suggest two further reasons for this reticence. Firstly, that the professional / parent is concerned with the level of health risk and impact in shared decision-making. Secondly that the professional / parent related decision-making to age and cognition (2016:1041). Coyne and Harder (2011:316) recognised within this conundrum, the need for the child / young person ‘to have a say’. This would be a compromise to the balance of participation and protection, and could not be a truly participative relationship; rather this described a model of shared decision-making, but is a step towards developing health knowledge, self-agency and health literacy. This shared decision making can be seen within Dunscombe’s (2002) research of the political relationship of cultural power. Political relational power is culturally embedded into health services, however Dunscombe notes that ‘it is how it is used that matters’ (2002:2). If participation becomes a disempowering tool within health, for example it serves merely to tick a checkbox requirement, this would suggest participation is induced and tokenistic (Mansuri and Rao, 2012).

The reluctance to embrace participation within clinical practice appears to extend to young people’s healthcare consultation. It again raises the question of the purpose of health participation. In the case of participative research these are inductive types of participation and respond to Government legislation in gaining the opinions of the young people from a pre-designed perspective (CYPHOF, 2012; PHE / AYPH, 2015; CRAE, 2015). As cautioned by Mansuri and Rao (2013), a danger with induced participatory work is that small scale, snapshot findings can be viewed as a definitive outcome and used as a broad-brush approach that influences large scale policy. Over a period of two years this study undertook an in-depth survey designed by young people, alongside participatory co-production which captured young people’s views and experiences and generated genuine knowledge about young people and health. This approach avoided induced participation and snapshot findings and was representative of the young people being studied.

Another approach to participation is organic participation, which is driven through social movement to address issues (e.g. inequity), rather than respond to policy and codes of practice. Thus, organic participation creates greater democratic expression
by giving voices to those who may be deemed ‘underprivileged’ (Mansuri and Rao, 2013: 32). In the context of this study, this relates to young people. Commonly, social movement works to tackle disenfranchisement at its root and improve lives (Ruggiero and Montagna, 2008). This social justice stance fits the scope of this study and is within organic participatory parameters. This study aims to generate organic participation which seeks to be more immersive in its approach. Further organic participation would support the ownership of the issue for young people, nurturing a personal investment with the aim of becoming emancipatory, self-motivating and empowering.

Effective participation can be a hard thing to do, particularly if the participant joins an already established group with its own rules and regulations. The participant starts as an outsider, and this inevitably is a position of low power. Foucault famously argued that ‘knowledge is power’ (1988). This is the position of the young person as they encounter health services. The National Health Service is premised upon an altruistic notion of equal access to health care, of equal standards, to all, however it is currently challenged through austerity funding cuts (Stevens, 2014). In Britain, overwhelmingly, the NHS is the main commissioner, provider and hub of health services. The NHS system is, of itself, a cultural microcosm with its own systems, practices and language. It is an extremely complex body underpinned with competing bureaucracy and multitude ways of working, the NHS requires intimate knowledge of the its system in order to understand, navigate and access its’ outputs: it requires insider knowledge.

Increasingly complementing the NHS are other sector health services, for example, charities and third sector. National organisations like Cancer Research, Marie Curie, MIND and organisations such as The Lowdown (a local, free counselling service for young people) fit into the gaps and niches not universally covered by the NHS. This is because either the NHS cannot directly commission and fund these services or because a local or national need has developed. The framework of the UK health economy requires these organisations to buy into the closed shop approach of the NHS. Private and paid for health services are also compelled, to compete and work within the complex terms of reference of the NHS. For example, paid for health services are gatekeepered with NHS frameworks such as the National Institute for Health Care and Excellence (NIHCE, 2016). Thus, insider knowledge is needed in order
to navigate health services within the UK. By not disseminating this insider knowledge, through developing health literacy, ensures that the UK health system, including the NHS, remains a closed shop to outsiders, the public. It has become an exclusive club where club members need to know the rules to be part of and use the club facilities, as suggested by Rowlands et al (2015). NHS, free at the point of use does not equate to freely accessible at the time of need.

To be an active participant rather than a passive receiver of health care requires the user to be health literate. Therefore, developing a young person’s level of health literacy is a crucial tool in enabling health empowerment. However, raising health literacy levels does not correspondingly enable empowerment of a person’s health if the health provider retains a stranglehold on that health provision. Schulz and Nakamoto (2013) suggested that without empowerment being shared between the health user and health provider, the user remains dependant on the provider, whatever the user’s level of health literacy. This perpetuated the cycle of dependence on health providers and professionals. This dependence appears to be an entrenched paradigm of the NHS and health agenda of the UK. Conversely, Schulz and Nakamoto (2013) concluded that having high levels of empowerment without higher levels of health literacy has the potential to lead to risky or harmful health choices. Thus, there needs to be a balancing of equipping people to be empowered and health literate whilst developing real working partnerships that enable empowerment through health services and providers. Poor health literacy sustains an individual as lower status within the power-relationship of health services. Before these entrenched elements of the NHS can be improved, there is a need for timely research which incorporates the views of young people and underpins recommendations for change. Through its’ participatory approach this study contributes such research.

The NHS sustains insider health knowledge; through jargonisation, constant change and multi-complex set up. This maintains the closed shop culture and perpetuates the need for insider knowledge. In sustaining the insider knowledge culture the NHS holds the power of access to health and thus is able to dictate health outcomes of the general population. Currently, a user of health services (in the UK) is a passive agent and consumer of health services. Having poor health literacy is often seen as a ‘patient deficit’ (Frosch and Elwyn, 2014: 12), this suggested the deficiency as an issue with the
individual rather than a reflection of the health service. This way of framing the issue of poor health literacy reinforces the notion of institutional paternalism. This power relationship of institutional paternalism needs to be addressed if there is a real will to include young people as active participants in health. Health literacy is a necessity in increasing active participation (Protheroe et al, 2009) and to raise outcomes for individuals, community and society.

Further, the paternalistic power relationship can also be seen within the parent child relationship of how health services engage with young people. Sharif and Blank (2010:43) found that health literacy is freely assumed of adults. However, for a child and young person, there was an assumption that adults in their lives act as the health advocate and are regarded as the young person’s voice and key contact point (Bates and Freeman, 2014). Alongside these assumptions and common within health care practice, is that parents / guardians are the gatekeepers for children and young people’s health and use of health services (Hope, 2015). This is regardless of the age, cognition and understanding of the child or young person and places the adult as the powerbroker for the health of that child or young person (Hudson, 2012, Health et al, 2004). This may be an unhelpful relationship if the adult is health illiterate and remains a health outsider. Carroll et al’s (2015) work contributed to understanding the need for insider knowledge in finding that parents could understand health through an intense programme of education and familiarisation (of the health condition and service for their child). Importantly, they found this knowledge to be durable and parents used this with their subsequent children (Carroll et al, 2015). Another consideration within this picture of adult-led young people’s health is the reliance on the capacity for health literacy of the adult. DeWalt and Hink (2009) found a direct link with parental health literacy and the health outcomes for their child. The inference being that the poorer the health literacy levels of the adult, the poorer the health outcome for the child. Developing health literacy for young people would begin to mitigate this gap.

These notions are significant in setting out capacity and autonomy for young people in their health decision-making. The points of age and capability have been contested and judged, with examples such as Gillick (Competency) and Fraser (Guidelines) (NSPCC, 2012) holding upon the young person’s ability to know and judge the
potential outcomes of their health decisions. This requires the young person to be autonomously health literate. On health autonomy, Cha et al (2014) concluded that young people living at home with parents showed a lower level of overall health literacy than those living alone. A reason for this may be linked to the power and control relationship of parent and child in situations such as reliance on parental intervention to seek health support and advice, for example, in parents booking GP appointments (Hope, 2015). Whilst this was a normal situation, Hope (2015) suggested this as a gatekeeper role. This gatekeeping role then became a perceived norm, that young people could not access health services without parental permission (Cha et al, 2014, Hope, 2015). Crucially, the outcome of the normal role of the adult, acting as a conduit to health services, culminates in the young person not knowing how to book a GP appointment and perpetuates the cycle of health illiteracy. This is a critical point in young people’s health empowerment and in understanding how health literacy is acquired by young people, the focus for this study.

2.5 Context for the study
Empowerment as a positive attribute is premised upon three paradigms (Schulz and Nakamoto, 2013). Firstly, explained as ethical and right relationships, which develop personal autonomy. This has resonance with secondly, developing engagement, participation and responsibility as seen from Hart’s seminal work from 1992 – moving from tokenism to citizenship. Thirdly, Schulz and Nakamoto (2013) suggested empowerment as ‘advocated as improving health outcomes’ (2013: 4). However, as noted at the start of this review, Ormshaw et al (2013) concluded that there is insufficient evidence or description of what health literacy means for children and young people and that it cannot be measured or tested in terms of subject knowledge. The then Children’s Commissioner (2013) stated that ‘the foundations of good health and well-being are laid...in adolescence especially the teenage years’ (Atkinson, 2013:2). Added to this is that the transition into adolescence is a time when long-term health beliefs and behaviours are formed (Cha et al, 2014). Kennedy (2010), LaValle et al (2012), Atkinson (2013) continued to show that some young people, through inability and opportunity, failed to use health services. For example, they may not be able to read an appointment letter or text. Thus, in order to develop health engagement and improve health outcomes for these young people, health literacy needs to be developed.
Chase et al (2010) found that nurses are confronted by challenges when they seek to promote children, young people and family health in the school environment (2010), because schools failed to value and place health within the educational arena. This report further indicated that the emphasis of school nurse work has shifted from direct child / young person contact to more generic health support of schools, as an organisation (2010:11). This aligns with PHE (2015), AYPH (2016) and RCN (2014) reports which all highlighted a shift in direction of health support and the need to take an integrated approach with other services in engaging young people with their health.

Health literacy is seen in functional levels of literacy and numeracy (Nutbeam, 2000, Rudd, 2015), alongside the abilities and skills to seek, understand, communicate and evaluate health information (Ormshaw, 2013, Rowlands et al, 2015) and interpret them within their social, cultural and environmental context (Batterham et al, 2016, Rudd, 2015). A shift appears to be taking shape in moving health education and knowledge from a predominantly health model into socio-educational and community pedagogy.

The context of this research comes from accepting that health illiteracy has a strong causal attachment with poorer life outcomes. Poor health and lower education have been systematically linked into the cycle of poverty and inequalities (Joseph, 1972 in Welshman 2006, DWP/ DE, 2011). Squiers et al (2012) placed health literacy within the sphere of public health explaining the relationship health literacy has with educational and health systems and social and cultural systems (2012:30). Roantree and Shaw’s (2014) research demonstrated this relationship and concluded that health illiteracy and poor educational attainment perpetuated the cycle of inequality.

SMCI Associates, (2014b) called for a systematic approach to addressing health literacy as a priority in tackling health inequalities, improving health and addressing inequalities. In moving from insider knowledge to shared knowledge the health economy can support users to be more equal and active agents of their health and health outcomes. Young people’s perspective of health literacy has been that this happens through incidental life experiences (Abel et al, 2014, Hope, 2015) or learnt
from family members with insider health knowledge, and that families with little health insider knowledge or who are health illiterate, have not, in general, supported the development of health literacy for young people (Rowlands et al, 2015, Rudd, 2015). The study’s young people agreed that health literacy was not considered within their educational setting or other youth settings and this echoed findings of Abel et al (2014). Further young people felt that educational settings only supported their educational outcomes such as passing examinations (Young et al, 2014) and targeting their next educational steps, for example gaining a place at University. However, the young people felt that educational settings was the right place to develop their health literacy as part of their preparation for adult life, and this was supported by UK and global research (Rowlands et al, 2015, Batterham et al, 2016, Frosch and Elwyn, 2014). Building on this evidence, this study's premise is that developing health literacy in young people will support better general health, better engagement with health services and overall life outcomes. Further, health literacy is a participant life skill and people and communities need to be enabled to have health-related self-agency rather than being peripheral observers and recipients (Dennen, 2008). To empower young people, health literacy should be learnt from childhood as a necessary life skill and as part of the transition into a happy and productive adult life. In conjunction with young people who were co-producers and participants of this study, this thesis suggests tangible ways to improve health literacy appropriate to young people’s needs and preferences.
2.6 Summary

Within the arena of public health this review considered how health literacy has evolved from a functional skill to maintain health to a life skill that supports healthiness. This was demonstrated from an individual level through to community and societal outcomes of health emancipation. The review also raised questions about the association of educational competence in understanding health and being health literate but acknowledged the interplay of education and health in developing healthy societies. Further, the chapter has shown how being health literate plays a role in tackling health inequalities with links to similar determinants of social inequalities, such as poverty, low educational attainment, disenfranchised groups.

Chapter Two has highlighted that little is known about how young people acquire health literacy but that young people do want to take control of their health as part of transitioning into adult life. Being health literate would facilitate this for them.
3. Methodology: young people, interpretative participation and co-production

3.1. Introduction

The study was rooted in active participation which engaged young people in thinking about the issues, solutions, resources and interventions using mixed methodologies with co-production (Elsley and Tisdall, 2014, Bazeley and Kemp, 2012). Using this approach, young people contributed to the research design, evaluative discussions and analysis. This resulted in young people taking an active co-lead in the study’s methods, generated topics explored and developed data collection tools. Through interpretative co-production with young people, the study designed bespoke methodology to shape the data analysis, evaluation and outcomes. This approach ensured that active participation created knowledge that was innovative and genuine in responding to the lived experiences of the young people as co-producers and participants. This new knowledge will support practice, influence policy and improve health literacy for young people (Abel et al, 2014, Sorensen et al, 2012).

The study methods included an online survey developed through co-production and focussed co-production group discussions which developed themes to be interpreted and evaluated as the primary data. In analysing the meaning and recommendations of the study, the co-producers acted as consultant-readers and were pivotal in their commentary and responses used to validate the researcher and study interpretations. These methods ensured an ongoing and productive discourse between the researcher and participants which enabled a collaborative understanding and construction of the participants’ lived experiences.

This chapter explains the primary research undertaken in the study. Section 3.2 justifies co-production and participation as the study’s research methodology, before Section 3.3 discusses how the interpretivist paradigm aligns this methodology as interpretive co-production. Section 3.4 describes the context of the research, presenting an account and justification of the research setting. This leads to a dialogue on the methods and phases of the study, Section 3.5. Sections 3.6 and 3.7 evaluate the approach to data analysis and the ethical dilemmas associated with the study.
respectively with concluding remarks in Section 3.8. Research limitations and future opportunities are reflected within the conclusion of the study, Chapter 5.

3.2. Co-production and participation

This study drew predominantly from the reflexive hermeneutics approach of Ricoeur (1981) that something cannot be understood without first understanding the context of that something; for this study, that was recognising health literacy in the everyday lives of young people. Co-production offered ‘authenticity’ through capturing the lived experiences of young people in a way which encompassed their views, opinions and narratives (Elsley and Tisdall, 2014, Bragg et al, 2009). Participatory enquiry generated rich data that was fundamental to the premise of the study. Without this approach, the study would play into the participation critique of ‘doing to’ young people rather a genuine ‘doing with’ (Furlong, 2013). As a cyclical process, the lived experiences of the young people informed the development and outcomes of the study. The Nuffield Council on Bioethics (NCoB, 2015) suggested that researchers should involve children and parents specifically in ‘research and research tools’ development (NCoB, 2015xxxvii). Reflecting on this, the researcher, with a background as a health care professional working with young people, it was an alien concept not to consult and negotiate with the young person, through acknowledging their expertise about themselves. The NCoB report (2015) validated this stance from a quality and ethical perspective. Co-production and active participation was a way in which to put this into research practice.

As discussed in Chapter 2, health participation is often induced (Mansuri and Rao, 2013) with participation a requirement (NHS, 2017), or a task. This task is often tackled using a model of participation, for example Hart (1992) or Treseder (1997). The critique of this is that viewing participation as a task infers a ‘must do’ rather than a genuinely inclusive action (Lambert and Glacken, 2011, Moules and O’Brien, 2012). Further, use of a model of participation assumed that stages must be followed and completed within a structure. This constrained participation because of the need to follow these imposed models and turned participation from a meaningful activity into a bureaucratic task.
For this study, viewing participation as a requirement, task and model was counter-intuitive and would have demonstrated a false representation of young peoples’ lived experiences. In explaining this, the overriding critique of Hart’s model (1992) was that of hierarchy and the need to reach the top. The implication being that one idea, concept (or person), will be surpassed in order to move up the ladder. This fed into identity politics (Jacobs and Potter, 1998) and marginalisation; one group, view or idea, being side-lined in favour of another. This would have been a juxtaposition to the study ethos. Treseder’s model updated Hart’s work (Tisdall et al, 2014) to rearrange Hart’s ladder into a non-hierarchical circle of ‘degrees of participation’ (Treseder, 1997:10) but this circle maintained the starting point of induced participation (Mansuri and Rao, 2013) rather than authentic and organic participation.

Ali and Davies (2009) described young people’s participation as a continuum and suggested this could be as a one-off involvement. This could be in partnership with commissioning adults in strategic health structures, an opportunity for young people to shift the power balance and influence policy making (Ali and Davies, 2009). This demonstrated some determination for young people to influence their own lives through participation that impacts policy and services. However, counter to a continuum approach, Percy-Smith described health participation as ‘giving service users a voice.....extending rights of citizenship’ (2007:879). Ensuring that participation is more than tokenism (Hart, 1992), Percy-Smith acknowledged that organisational structures and processes created barriers to participation, suggesting alternative collaboration action research as a deeper participatory approach. This cycle embeds dialogue, reflection, social enquiry and learning (2007:880) via engagement. In concluding this work, Percy-Smith noted that the reflective element of the collaborate action required health professionals to (re)consider their assumptions, and the ways in which they work with children. Further, he signalled a need for them to include real experiences of young people in policy and research design (2007:891).

In framing the participative approach to the study, Shier (2001) offered a ‘pathway to participation’ (2001:11) that demonstrated how the young person is nurtured, through openings, opportunities and obligations towards shared power and decision making (appendix iii). Tisdall et al (2014) note that Shier’s pathway ‘requires stakeholders to assess the power relations and institutional barriers to each level of
participation’ (2014:12). This seemed a pragmatic and genuine approach to participation but lacked the participation being organic in structure and nature. Organic participation gives voice to those who have been marginalised (Mansuri and Rao, 2013), as it is a platform of equal engagement. This position reflected that of the purpose and meaning of participation for the researcher and balanced the philosophical ethos of the study. Thus, this study aimed to generate organic participation which sought to be immersive in its’ approach and compatible with its’ hermeneutic roots. Further, organic participation would support the ownership of the issue for the participant, embedding the issue as a personal investment and thus more likely to be emancipatory, self-motivating and empowering.

This is illustrated in Figure 3.1 using an adapted diagram of a hermeneutical spiral (Conroy, 2003). Conroy explains the hermeneutical spiral as working from the interpretations of individuals to development of principles and ideas. With adaption for the study, Figure 3.1 shows co-production within the spiral showing the organic development of ideas.
The nature and length of the study, over two years, combined with the innovative data collection and led by co-production, ensured authenticity in capturing the lived experiences of the participants and co-producers. Percy-Smith and Thomas suggested participation as a ‘manifestation of individual agency with a social context’ (2010:57) and this is how participation has been interpreted for this study. Co-production offered participation as authentic and organic, emphasising the free choice of the young person to get involved (Davies, 2005).
Reflecting upon the sticky issues of levels, stages and phases of participation led the researcher to think more about participation purpose. The researcher drew from theories of active and passive learning and considered this as active and passive participation: being a doer and being a watcher, for the study. Passive learning theory suggested a learner as taking on-board knowledge incidentally as a watcher or observer (Smith and Smith, 2014, Dennen, 2004, Sfard, 1998). Further, passive learning can be described as learning vicariously, through active learners within a learning community. For online learning, this has been termed ‘lurkers’ (Dennen, 2008:1626) where a learner can ‘lurk’ in the background of an online learning community, not be visibly active but still learn. Smith and Smith (2014) suggested this as still a good form of learning, that the learning was with ‘good intent’ (2014: 89) and the learner still engaged.

In this context, the researcher regarded passive learning theory as comparable to passive research participation: willingly the participant engaged, with ‘good intent’ but as a watcher. The crux of this is how the role of watcher came about. If being a watcher occurred due to the constraints and structure of the research, then the state of passive participation was not a useful one, rather it is one that just fits into the notion of induced participation (Mansuri and Rao, 2013), as a task. However, if the role of watcher was to absorb, learn (Smith and Smith, 2014, Conroy, 2003) and develop there was great value in this. An observant, watchful participant will have much to contribute to any research. Further, as with passive learning, the passive participant, should they wish, could switch their role to that of active participant, perhaps through the knowledge and confidence they developed as a watcher (Dennen, 2008, Jones, 2004). Further, passive participation was seen within the approach of the survey as capturing participants’ observations of their lives.

Active learning theory viewed the learner as a ‘seeker’ and a ‘doer’ (Jones, 2004) and as interactive with the teacher (Sfard, 1998, Dennen, 2008) or learning materials. For the active learner, this would ensure that the learning was not incidental. Smith and Smith (2014) explain active learners as becoming normalised within the culture of their learning community, learning the rules and language and being ‘encultured’ (2014:88). This more active stance of learning seemed, to the researcher, a richer, deeper and more meaningful learning experience in contributing to the learner’s
knowledge and as a route to sustained learning (Sfard, 1998, Jones, 2004). As with passive learning and participation, the researcher saw how active learning sat within participation paradigms with active research participation. The participant being embedded as part of the research community; encultured, equal, and valued. The researcher utilised co-production as a method of enculturing the participants with the study. As with passive learning, there was an acknowledgement that co-producers might swap between passive and active participation. This begged the question of why this swap might occur and questioned the constraints and structure of the research design. However, the co-production model was an agreed way of working that the co-producers and the researcher took ownership of. Participants, including the researcher, might seek periods of watchfulness and observation, and this was accepted and fostered as part of a session in allowing a space for thought and reflection. This was considered a strength, an indication that the culture of the research allowed the participants to feel comfortable enough to reflect. From this, participants tested out their ideas, deepened their knowledge, which in turn, contributed to the study. Alongside the notion of active participation, Shier pathway principles (2001) have been used for this study in which young people’s active and organic participation was the central premise of positive action to ensure the validity and currency of this study.

3.3. Interpretivist paradigm

The study was grounded by the epistemological perspective that knowledge is interrelated to reality and research (Guba, 1990) and that interpretivism seeks to understand multiple realities rather than ‘one reality of positivism’ (Chowdhury, 2014:433). Interpretivism is rooted through hermeneutics and phenomenology (Smith et al, 2012). Ricoeur’s theoretical approach to hermeneutics suggested a philosophical join between methods and methodology through a naturally seamlessness acknowledgement of lived experiences; the epistemological interpretations and understanding of those lived experiences (Ricoeur, 1981). This philosophical basis of interpretation of lived experiences brings clarity and rigour to, what can be considered, less tangible data, that begins with description. Geanellos (2000) suggested Ricoeur’s approach allowed the researcher to move from superficiality to
deeper understanding; from grasping parts of the texts to seeing the texts and its’ parts as whole, something he termed ‘intersubjective knowledge’ (2000: 112).

Hannoum (2005) explained hermeneutics as conceptualising specific and representative issues of the lived experience - in making it real: for this study, health literacy for young people. As a philosophical approach to the study of experience, phenomenology offered an opportunity to reflect upon lived experiences ‘that really matter to us’ (Smith et al, 2012:11) and was creative in examination and understanding lived experiences (Larkin et al, 2006). In being responsive to lived experiences, this study drew upon reflexivity, which acknowledged the person in a two-way process, through knowing their influence on the study and recognising the influence the study had on them (Mann, 2016). Reflexively, this study set out to understand the phenomenological narrative of health literacy in the everyday lives of young people. Thus, it drew predominantly from the reflexive hermeneutics approach (Ricoeur, 1981) that ‘something’ cannot be understood without first understanding the context of that ‘something’.

The interpretivist paradigm has been developed as a critique of positivism (Garfinkel, 1967, cited Silverman, 2016) to find a way to analyse everyday life by understanding how people made sense of their experiences. The interpretivist method is naturalistic and avoided ‘rigid structural frameworks’ (Carson et al, 2001 cited Bevir and Rhodes, 2015:90) often found in positivism or grounded theory. Boas’s (1995) anthropological perspective of interpretivism reflected human agency as an organic whole of values influencing lived experiences. The significance of this is that knowledge would be influenced by preconceptions. Thus, interpretivism sought to understand the context of knowledge as well as the knowledge itself. This was a benefit to the study as the researcher also sought to understand participant knowledge. Thus, the study required a genuinely reflexive, open and flexible research design and approach. Interpretivism gave significance to meaning and used multiple methods to capture and reflect multiple meanings (Bevir and Rhodes, 2015, Silverman, 2016). This allowed a reflexive approach that ‘captures meaning’ (Bevir and Rhodes, 2015: 61) and made sense of perceived reality. There is something of a double hermeneutic, the researcher sought to know the lived experiences of the young people as they also sought to understand this and interpretivism was a route to this. The consequence of this double
hermeneutic is that interpretative research methodology recognised knowledge as a social construct of human agency (Chowdhury, 2014, Silverman, 2016) through an epistemological perspective, that can be understood. Indeed Angen (2000) argued that interpretivism has an ethical role in ‘moving us beyond our present understanding….to some new, more generative understanding’ (2000:388).

An issue with interpretivism is that of researcher subjectiveness. In this study, to mitigate against this subjectiveness, the role of the co-production group came into its own. The co-producers were pivotal in interpreting and analysing the data and outcomes. This was supported through the completion of thematic analysis by the researcher, which offered an opportunity for comparison and further discussion (Heffron and Gil-Rodriguez, 2011, Silverman, 2016, Bazeley and Kemp, 2012) through interpretative analysis (Smith et al, 2012). The consequence of this innovative approach ensured the researcher’s understanding was clear and neutral as the co-production group made final comments and agreement to the findings.

For this study, and in positioning the researcher as a social actor valuing difference (Smith et al, 2012), interpretivism meant that the new knowledge generated by the participants facilitated the organic development of the study. Reflecting upon this approach demonstrated the stance of the researcher of meaningful participation rather than tokenism. In some ways, this showed a level of subjective choice, in that the study was not wedded to one methodology in order to not constrain understanding the lived experiences of the participants.

A further question of interpretivism are that lived experiences are socially constructed and contextualised, and so objectivity can be difficult to claim. Goldkuhl (2012) viewed the interpretative processes as ‘back-and-forth movement between the whole and its part’ (2012:138) as a robust progression, to ‘create a holistic understanding of the studied area; not only an understanding of its different parts’. (2012:138).

Thus, using interpretivism to understand many lived experiences of many participants would incrementally develop understanding of the subject and decrease the subjectively of the findings, as with this study. This increased the validity and application of the findings to a wider arena than the direct participants of the study. Further, the depth of the data generated, using an interpretivist approach, was associated with a high level of validity as the data tends to be honest and trustworthy.
(Smith et al, 2012, Bevir and Rhodes, 2015). The result of this position was that the study development was reflexive and responded to the emergent constructs of the participants rather than to a fixed methodology or framework.

Angen’s (2000) research approach recommended two principle strands, that of ethical validation and substantial validation that ensured rigour and robustness of interpretive research. Ethical validation entailed consideration of the framing of the research questions with persuasive development of the evaluation to ensure the validity of the research. The research sought to practically answer the ‘so what’ questions (2000:388) and became a moral position to be addressed throughout the research process. Substantive validation offered a more tangible aspect to interpretive research and Angen (2000) suggested the research undertaken should demonstrate ‘interpretative evidence and biases inherent’ in the research and be reflective to demonstrate the transformation of the research (2000: 391). This study utilised Angen’s suggestions to the study. The choice of methods, design of the study tools and contextualisation of co-production all sought to answer, ‘so what’ from a practice perspective. As did the collection of the interpretative evidence and acknowledgement and mitigation of inherent bias. Demonstrating transformative thinking and new knowledge has been highlighted through the application of the study and through the study evaluation and outcomes.

The research setting, research methods, study tools, data analysis, research ethics and limitations / lesson learnt are explained in the remainder of this chapter.
3.4. Research setting

The study took place over two years in a mainstream English secondary school. The parameters of study were to work with representative young people and the school offered the opportunity to involve young people with a variety of needs, and from a range of backgrounds similar to that of the cohort population (Ofsted, 2012). This included pupils with special educational and disability needs (SEND), pupils with additional health needs and pupils who were re-engaging with education. The use of youth groups and clubs was rejected, as, by nature of being a group or club, the cohort would have been exclusive rather than generalised. Further, a school setting captures an arguably English definition of ‘normal activity’ for young people and offered a large cohort of participants who fell within the personal protected attributes of a typical population (16 – 19 years) within England (HESA, 2012). All research activities took place during school time, on school premises or via school platforms.

3.5. Research methods

Mixed methodology in research was justified by Cresswell and Piano-Clarke (2007) as a way in which to bring together traditional paradigms of qualitative and quantitative research acceptable to the research community. Bazeley and Kemp (2012) gave a common-sense definition of mixed methods research that, with a shared purpose, mixed methods achieves more than using (either) method alone (2012:5).

This study sought to interconnect, through incremental progression, the methodological approach, data generation and interpretation as a whole rather than as separate research activities. Teddlie and Tashakkori (2009) suggested that data generated through mixed methodology would be described as multi-method, however this does not allow for differentiation of the research paradigms that underpin the research design and data generation. A fundamental difference of a mixed methodological approach and that which distinguished it from a multi-methodological approach was the ‘interdependence’ (Bazeley and Kemp, 2012:69) of the selected approaches; in this study that of active participation, co-production and interpretivism. Further, Bazeley and Kemp (2012:69) suggested mixed methodology as ‘including the analytical writing process’ (2012:69) of the research elements. Importantly, as suggested by Glogowska (2011) and Archibald et al (2015), as rigorous research behaviour for mixed methodology, this interdependence should be
demonstrated throughout rather than only at the analytical writing process. This interdependence of mixed methodologies allowed the study to be reflexive, for example, to minor changes in the co-production group from consultation to interpretation and in responding to tensions of consent design between the University Research Ethics Committee (REC) and the co-production group. The justification of integrated methods enriched the entirety of the study and allowed themes of the study to be explained and analysed as a whole rather than as a method (Bazeley and Kemp, 2012, Archibald et al, 2015). This study was designed as an incremental and cyclical process, drawing from the ideas of the co-producers, using thematic analysis and building on emergent findings. The study’s primary data collection started with an online survey, with co-production discussion groups over the course of 24 months which included subject debate, analysis and interpretation of findings and emergent outcomes. This flow of study phases reflected the underpinning organic and participatory approach of this study.

The chronological development of the study, used a mixed methodological approach (Onwneguzie et al, 2010) and was carried out reflexively using the principles of sensitivity to context, commitment and rigour, impact and importance, and transparency and coherence (Hefferon and Gil-Rodriguez, 2011). Aligned with this mixed methodological approach and underpinned with an interpretative narrative of hermeneutics, the study’s participative approach enabled participants to review the data collected at each stage to ensure that their contributions and evidence were accurately presented. These principles were pivotal in considering the ethical aspects of the study, including researcher positionality, and in seeking to interpret the study findings and recommendations. This was in keeping with active participatory research making real experiences the basis for the interpretative nature of the study (Angen, 2000, Bevir and Rhodes, 2015), whilst taking responsibility for the research methods and logistical aspects (Madison, 2012) of the study. Accordingly, the study utilised more than one method in being creative within a robust research structure, to meet its aims through descriptive statistical research, related qualitative data collection, narrative qualitative research, evaluative and interpretive data analysis and applied findings. This study was innovative through co-production with participants.
Reflectively, as a professional within this field, the researcher considered this a natural, reasonable and equitable way to understand the participants lived experiences. A fixed and inflexible approach, wedded to framework and structural methodological processes would have resulted in a researcher-led outcome with little or no influence of and from the participants: essentially an adult-centric research study.

3.5.1 The phases of the study

The study began with a review of the literature set out in the previous chapter (2). The literature review applied a thematic and evaluative methodology to synthesise the main arguments raised in the research (Hart, 1999, Boyne, 2009). The dialogical nature of the literature review (Silverman, 2013) supported fluid and responsive decision making across the phases of the study. The review theoretically conceptualised health literacy for young people, contributing to the study rationale and purpose. It also helped focus and shape the primary research tools and inform the co-producers in their discussions.

Figure 3.2: Diagram of key decision-making process using review of the literature
Of note was that much existing literature which focused on young people’s health literacy drew from adult-centric research (Sorensen et al, 2012, Rudd, 2015, Sentell et al, 2017). This study’s ethos and approach of active participation ensured young people were the central part of the study. Gathering the views of young people to understand the emergent health literacy of young people was a new approach and the key aspect in developing the study outcomes of this research and so this study offered something different from the literature reviewed.

3.5.2 Recruitment

To recruit the study participants an initial presentation session was held to introduce the researcher and explain the study. The presentation discussed participation in the survey and as a co-producer. The session set out the anticipated commitment from the participants, all of which were volunteers. Purposive sampling (Bryman, 2012, Cresswell, 2013) guided the age range of participants of 16 -19 years. It was anticipated that within this age range the young people may have some control of their health and health choices (outside of parents and guardians) which would enrich the data sought. Secondly, the inherent issues of consent and capacity in researching with children and young people, were considered by the school, to be more straightforward with this age range.

As reflected within Higham and Davies’s (2013) research on fathers’ roles (on their child’s unplanned hospitalisation), the male perspective of health and health care can be viewed within the parameters of perceived gender roles. These perceptions came from the male participants themselves as well as from the health care professionals. This echoed a more general finding for health and health services; Saewyc (2012) and Boyce et al (2012) suggested that health services have a dominant focus which is generally female, and further, that males access and use health services differently from females (Saewyc, 2012). With Cooper and Rixon (2017) cautioning that it is important to acknowledge issues of difference because ‘average measures.... only tell so much’ (2017:21) this study sought to capture views from young people that was diverse and also representative. The recruitment presentations took place in mixed gender sessions where males were afforded the same participant experiences as females.
The survey was distributed to all sixth form students and all survey participants self-selected to take part. All co-producers self-identified as volunteer participants. From these volunteer participants, all were suitable and recruited.

This resulted in a male participant rate of 30.6% for the survey and males making up one third of the co-production group. At the time of the study, the National Archives (TNA) reported 49.4% of male pupils in the school (TNA/DE, 2012). Of note, this value was taken from the whole school population rather than the smaller sixth form cohort. However, rates around 30% indicated a level of disenfranchisement of males with this study about health. This can be seen to validate Saewyc (2012) and Boyce et al (2012) findings of male disenfranchisement with health and health services. A reflection from the recruitment process of this study is to be targeted and creative in recruiting male participants.

To recruit participants, consent and permissions from parents / guardians were collated, on behalf of the researcher, using the school’s sixth form lead and this followed the school’s protocols. Parental consent was an opt-out method and normal practice of the school. This also acknowledged the sixth form participants’ capacity to give their own consent.

For the co-production group 9 young people were recruited and this was an optimal target number for interpretative study (Hefferon and Gil-Rodriguez, 2011). The co-producers went through consent expectations with the sixth form lead and the researcher. Consent was gained freely from all co-producers and copies of this were kept securely by the researcher. The co-production group were self-selected. The sixth form lead was on-hand to identify any student whose safety and well-being might have been compromised by taking part. The co-production group comprised of 9 young people plus the study researcher. The co-producers were 6 females and 3 males: 4 identified as non-white British and 5 identified as white British with 1 self-identified as having SEND. This was a broad representation of the school population (Ofsted, 2012). Further, it was entirely appropriate that young people were co-producers in research about themselves (Tisdall et al, 2014, Furlong, 2013, Bragg et al, 2009). The literature mostly focussed on young people rather than children (PHE/AYPH, 2015, Hope, 2015), unless the health literacy topic was condition specific (LaValle et al, 2012). The study approach was to avoid condition specific health, as this
was a potential issue that could skew the discussion of health literacy. In matching generic age ranges, the study has been able to closely scrutinise comparisons of previous research.

This research sought a less formal and structured approach in keeping with the principles of partnership and co-production (Tisdall et al, 2014, Furlong 2013) than a focus group but took some of the key elements of focus group methodology. These elements included group size (Krueger and Casey, 2009) and shared facilitation and management of the group (Wilkinson, 2004, Bryman, 2012) which required soft leadership and organisation. The dialogical approach encouraged participants to debate specific topics from the online survey, the findings of the literature review and the emergent themes from the discussions themselves, rather than a generalised discussion of a broader topic, as is common in focus groups (Willis et al, 2009, Silverman, 2013). Through this exploration, the co-production group gathered rich and new data (Cresswell, 2013, Silverman, 2016). This data was evaluated and analysed to ensure an accurate interpretation of the lived experiences of the participants (Bevir and Rhodes, 2015, Angen, 2000). The co-production group considered the outcomes of the study to generate new knowledge about health literacy for young people (seen in chapter 4 and 5).

The preparation of the co-producers took place at an initial meeting and developed terms of reference (Appendix 1). A discussion of the topics likely to be discussed was used to gauge common understandings which ensured the co-producers were representative in comparison with the reviewed literature. This further supported the development and rigour of the study by fine-tuning the presentations of the data collection tools (Bryman, 2012). This was an important stage in gaining the necessary permissions for this study in that the topics could not be written at the research proposal stage.
3.5.3 Data collection: design and reflection

The online survey recruited participants via an email sent by the school sixth form lead to all sixth-formers. This, again, was purposeful sampling (Bryman, 2012, Cresswell, 2013). The versatile nature of a survey was that it can be attractive and shaped to the lifestyles of the respondents (Sapsford, 2007). Dillman et al (2008) argued that ease of use and likely engagement should be suited to the lives of the participants. In selecting a data collection tool, a survey was identified by co-producers as a tried and tested method familiar to participants. Further, the co-producers argued that the survey be online as this was attractive and convenient to distribute, using secure school systems to the target participants. The choice to carry out the survey online was further influenced from the Ofcom (2012) findings of young people’s increasing engagement with online activities and supported the co-producers’ preferred choice. A survey allowed the study to appeal to a larger population (Cresswell, 2013), gain a more generalised response (Dillman et al, 2008) and assured confidentiality of the respondents in encouraging honest replies (Sapsford, 2007). There was a risk that the survey would be ‘spoilt’ or not completed seriously (Fowler, 2009). This can be mitigated against by seeking a larger respondent sample, for this study approximately 150 (Sapsford, 2007, Fowler, 2009). 150 invites to participate were sent out with 53 responses, a response rate of 35.3%. Response rates for online surveys average at 24.5%, which Nulty’s (2008) meta-review suggested, rates of 20-47% as evidentially acceptable. Amunsdsen and Lie (2013) noted overall lower response rates of young people (15-20 years) to surveys which suggested they were overwhelmed by this type of data collection and that results of less that 30% are made up of ‘good responders’, and this was reflected through this study. They suggested this as an international trend (Amunsdsen and Lie, 2013) and this can also be seen within some of the UK research noted by PHE (PHE/AYPH, 2015) and the Office of the Children’s Commissioner (CYPHOF, 2013). This survey, at 35.3%, was considered acceptable.

The introductory pages of the survey explained the research purpose and outlined ethical considerations and sought consent. Participants were required to agree to a statement about their consent and any that selected ‘non-consent’ were blocked from further engagement with the survey. Non-consent was not recorded by the online survey tool and so no data was collected for this. The survey aimed to examine trends
within the participant group about health knowledge, health literacy and understand their lived experiences of this. The survey collected descriptive statistical data and richer narrative qualitative data. This included questions about how health information is gained, how health information is accessed, what types of health information are used and which types of health information are trusted. In collaboration with the sixth form lead and the co-production group, a pilot online survey was run with sixth form leavers during an afternoon session. This was run by the researcher as a group activity and feedback was taken for the survey development. This sample of participants did not participate in the final survey. Responses from the pilot survey were used with the co-producers to refine and change aspects of the survey which included simplifying terminology, removing repetitive questions and shortening the introduction and explanation. Technical changes to functionality of the survey were made such as options to add comments or to be able to select more than one choice. The renewed survey was presented by the researcher to the co-producers for agreement prior to release. The survey remained open for 3 weeks across February and March 2015. A copy of the survey questions can be seen in appendix 2.

Reflecting on the research design and implementation

Reflecting upon the research design of the survey raised an issue of consent documentation between the University REC and the co-producers. The co-producers felt participants would understand that, by continuing to complete the survey, the participant had implied consent and this was normal practice in their everyday lives and for the school. The University REC insisted written consent was evidenced. A compromise was reached through inclusion of additional explanatory text about the study at the start of the survey. Participants were then asked to ‘opt in’ by ticking the consent box. The explanatory text was specific, as required by the University REC and included some complex terminology. The co-producers felt this wordy format would be off-putting to participants and this reached an impasse. As a solution, an explanation of the requirements of the University REC was discussed as part of a further presentation session. Anecdotal evidence from the co-producers was that this discussion did help mitigate this issue but they felt this demonstrated the influence of the University REC from an adult-centric perspective. Their point is further supported
by The Wellcome Trust (2017) who discussed the importance of making information about studies relate to the needs of participants.

**Researcher positionality**

Researcher positionality was considered throughout the study. An example of this was to acknowledge the power relationship that existed due to age and status of the researcher in comparison to the participants. Benwell and Hopkins (2017) suggested that power can be seen through the perspective of institutional and societal role structure. In this case, the institutional structure (the school) promotes age as positionally powerful and the employment status of the researcher (in this case as a university lecturer) is similarly viewed as powerful. Kelly (2014) further discussed roles related to power suggesting that shared positions of power can produce better qualitative research through the process of negotiation and mediation. The study took direct action to mitigate role power through setting out agreed terms of reference (Coad and Coad, 2008) for the study (Appendix 1) which outlined roles of the co-production group aligned with the research paradigm of participant interpretivism and the pivotal role of the co-producers through interpretation and understanding of the lived experiences of the participants.

Another view of positionality within research was that of the researcher being considered an ‘insider’ or ‘outsider’ (Denzin, 2016). Research methodology suggested either position can be useful in gaining narrative data if a robust research process was negotiated (Denzin, 2016, Kelly, 2014). For this study, the researcher was mostly an ‘outsider’; no longer a young person, but took an ‘insider’ role as part of the research group situated within the interpretative co-production methodology. Further, McGarry (2016), in her meta-analysis of youth research concluded that ‘research methods characterised by a variety of power dynamics can generate situated knowledges of youth experience’ (2016:339), within a framework of insider and outsider knowledge. As an expanded notion, this suggested a constant shifting of power through the research, which added to the depth of interpretation (Denzin, 2016, Smith et al, 2012) and helped to ensure parity of voice (Benwell and Hopkins, 2017). This study positioned the lived experiences of the participant young people as the fundamental influence of the research.
The co-production approach of this study also supported the mitigation of researcher positionality in relation to the hermeneutic approach of understanding the researcher’s own position of the topic (Turner, 2003, Kelly, 2014). The researcher’s position was that positive health outcomes underpin quality of life and this was drawn from lived experience, education, observed practice, knowledge and understanding (Benner, 1982, Smith et al, 2012, McGarry, 2016) and held upon the strong causal link of the choices young people make about their health. For the researcher, this raised a concern that being health illiterate sustained inequalities and saw health literacy as an issue of social justice. Setting out the researcher positon is part of being honest within research (Denzin, 2016, Benwell and Hopkins, 2016, Turner, 2003, Kelly, 2014) and this concern of social justice has been explored in chapters 1 and 2 of this study. Mitigating against bias of this positon was implemented through the rigorous research methodology and interpretivist participant co-production approach. The researcher held that interpretivism closed the link of the perceived and imagined understanding of the researcher, with that of the participants. Influencing this was the cultural position of the researcher which was understood as ‘cultural competence’ (Smith et al, 2012:195). They explained this as the researcher not needing to be a cultural insider but inferred that the researcher should prepare to understand the participants, though, for example, developing terms of reference (Smith et al, 2012, Coad and Coad, 2008). Further, through a maintained hermeneutic and contextual interpretivist approach, this largely mitigated subjective cultural otherness (Smith et al, 2012, Wilson and Cresswell, 2013). For this study, this was through the co-producers holding an influential and critical role in the interpretation of the study and in checking the interpretative understanding of the researcher.

3.5.4 Validity

Validity is concerned with reliability, consistency, and dependability of the data and findings (Bryman, 2012). Validity asks if the research is believable and true (Torrance, 2012) and if it sought to answer the research purpose (Glogowska, 2011). Silverman (2013) proposed that research is valid when the research outcomes are ‘credible and demonstrable….based on the data’. (2011:415). For subjective data such as narrative interpretivism it is not about replication of the data results (Bryman, 2012) but more about the ‘dependability and consistency’ of that data (Wilson and Cresswell, 2013:15). This dependability and consistency was based on the research design,
choices and rigour (Silverman, 2013). Wilson and Cresswell (2013) and Torrance (2012) highlighted that it was the integrated approaches of mixed methods that strengthened the validity of mixed methodological research. This was echoed by Glogowska (2011) and Archibald et al (2015) who asserted that the paradigm of a mixed methodology that was interdependent and consistent was rigorous and valid. Underlying this rigour is triangulation. Bryman (2012) explained triangulation as an important aspect of mixed methodological research that sought to validate research findings through the comparison of different data sets, as seen within this study.

For this research, the crucial aspect of the data was that of interpretivism. Torrance described this as ‘respondent validation’ (Torrance, 2012:113) and saw respondents as part of democratic research engagement that signified rigour and triangulation in research. This, Torrance suggested, contributed to the production of new social knowledge (2012). Wilson and Cresswell (2013) concluded that participant validation not only added to the rigour of mixed methodological research but often facilitated ‘new evidence coming to light ...through draft report being modified’ (2013: 113). For this research, validity in the co-production process was essential practice. This included consistent checking with the co-producers that the phases, ideas, findings and recommendations resonated with them as a true reflection of the research into their lived experiences. Guidelines and protocols for this work were set up and abided by to demonstrate clear researcher and participant parameters. (Appendix 1). At all phases, active participant interpretivism was critical to the validation and rigour of this study.

3.6. Data analysis
Mixed methodology underpinned the research position of this study. Quantitative data was subjected to SPSS cross—tabular descriptive statistical data analysis (Cresswell, 2013) which drew from coded thematic analysis (Hefferon and Gil-Rodriguez, 2011, Bazeley and Kemp, 2012). More in-depth discourse thematic and interpretative analysis (Smith et al, 2012, Silverman, 2016) supported the qualitative and evaluative methodology which was embedded in the study participatory approach, with interpretivism as a means of understanding participant lived experiences (Guest et al, 2012). Further the study applied a reflexive approach in understanding the data, through acknowledging the researcher positionality, in
reflecting on the multi-dimensional outcomes within the context of the study (Mann, 2016).

Common with a mixed methodological approach, this study utilised some descriptive statistical summaries (Cresswell, 2013, Bryman, 2012). Within the data analysis phase SPSS was used to categorise the responses and demonstrated ranking and choice. These tables were then set up to compare various data sets as more extensive cross-tabular descriptive statistics. The question sets were generated through coded thematic analysis which allowed deeper analytical comparison of the data aligned with the literature and outcomes of the co-production group work. The online survey collected descriptive statistical data and richer narrative qualitative data. The survey aimed to examine trends within the participant group about health knowledge and health literacy. Quantitative summarisation allowed patterns and common features to emerge from the data (Cresswell, 2013, Bryman, 2006). These descriptive statistical data summaries were generated from the survey tool as SPSS data and used within the co-production group as points for discussion. Onwneguzie et al note ‘tactical authenticity’ (2010:708) as another aspect and bonus of mixed methodological data analysis, this was explained as including participants as part of the data analysis which elevated their understanding and acted as an empowering force.

Thematic analysis ‘reflects reality,... and to unpick or unravel the surface of ‘reality’” (Braun and Clarke, 2006:10). Importantly, Braun and Clarke (2006) stressed the importance of thematic analysis being disciplined and rooted within a theoretical perspective, applied to this study, as active participation. These principles were significant and sought to understand, analyse and interpret the study findings and outcomes. Thematic analysis offered more than merely themising meaning; it took from other qualitative approaches such as discourse narrative, grounded theory and other interpretative approaches, rather than being wedded to the more constrained aspects of these processes of interpretative analysis (Archibald et al, 2015). This matched with the aims of the participatory philosophy of the study which gave the co-producers a voice and sense of investment in the study. Thematic analysis (Silverman, 2016, Cresswell, 2013) was a key component that complimented the development of the data collection tools and underpinned the data analysis as both ‘accessible and theoretical’ (Braun and Clarke, 2006:6, Guest et al, 2012). Fundamental to this study
was the ethos of understanding the lived experiences of young people about health literacy, such that health knowledge could be purposefully imparted. The co-production group discussed themes and trends on an incremental basis. Examining these aspects and using a narrative theme asked how a similar theme generated different interpretations and experiences for the participants and this was a key attribute of this study and is recognised as being a fundamental strength of thematic analysis (Guest et al, 2012) alongside the paradigm of interpretivism. Tan et al (2009) suggested that, with adaption, using a layered analytical approach, Ricoeur’s hermeneutic interpretation theory provided a rigorous tool in which to analyse phenomenological data collected. Further this provided a ‘rigorous foundation’ (2009:13) for human study and interpretation.

3.7. Research ethics

Codes and principles of ethical research were used to shape the ethical approach of the study from the British Educational Research Associate (BERA) (2011), British Psychological Society (BPS) (2010), and Economic and Social Research Council (ESRC) (2012). The study aligned these with guidelines of working and researching with young people notably Alderson and Morrow (2011), Elsley and Tisdall (2014), Nuffield Council of Bioethics (2015), Bragg et al (2009), and Christensen and Allison (2008). Lastly the University of Northampton Ethics Code and Procedures were strictly observed. The process of ethical consideration and action can be seen in tabular form in Appendix 3.

Some of the main areas noted from ethical guidelines are the avoidance of harm (BPS, 2010), and to maintain confidentiality, safety and protection (BERA, 2011). For these points, the research set out rigorous parameters and worked within agreed guidelines (BERA, 2011, ESRC, 2012). For example, within the consent and information letters (appendix 4) the research aims were explained including issues of confidentiality and protection (Alderson and Morrow, 2011, Christensen and Allison, 2008). In order to be clear this gave examples when this confidentially might be breached, such as in the case of a child protection issue being raised, or harmful / illegal events being disclosed (BERA, 2011, BPS, 2010). Other ethical practice was in gaining support with logistical arrangements and using policy correctly. For example, use of online survey tools.
within policies such as internet use (Elsley and Tisdall, 2014), safeguarding children and young people, and working with partners (Alderson and Morrow, 2011).

A reflection on the potential outcomes of the survey and co-production work was that the focus of the study was health. The researcher was very aware of the potential of asking questions about health and the risk of causing unintended harm. To mitigate these risks the researcher drew from evidence based practice and experience and put plans in place to prevent such harm and suggested support should this occur (BPS, 2010, Alderson and Morrow, 2011). The researcher created an information hyperlink within the survey and a memo-card for the co-production group which details of expert support and advice should they have any health questions. All these actions were considered as measured and essential aspects of ethical research and part of expected practice, not an additional task to do (Appendix 5).

Consent and the information letters informed participants and parents about their rights to freely withdraw, not to be coerced into the research or to expect rewards/payments (BERA, 2011, ESRC, 2012). It was noted that data/information was held securely and used appropriately for this research and dissemination (BERA, 2011). A risk assessment was carried out to appraise and address issues such as lone working, risk of harm, disclosure (BERA, 2011, BPS, 2010). Ethical approval for this study was granted via the University of Northampton’s REC in conjunction with the research setting.

3.8 Concluding remarks
The study sought to ‘understand health literacy in the lives of young people 16-19 years in England’ and collected primary data from young people using interpretivist participation and co-production via an online survey and co-production group work. The study was reflexive and points of learning were discussed with the co-production group which added authenticity to the research process. The study was innovative primary research with young people incorporating co-production and active participation. The study was comparable in size to other English research (PHE, 2014, Atkinson, 2014, Fairbrother et al, 2016), critically this study was robustly inclusive in its approach to participation and this generated rich data which supported the validity of the findings and conclusions. The robust research framework of the study, carried
out over a two-year period, strengthened the practice recommendations. Critically, the study recommendations came from the participants themselves, giving an authentic voice to their needs.

In the chapter which follows (Chapter 4) the findings and analysis of the study are presented and critically discussed. Chapter 4 therefore examines the link between being health illiterate and inequalities, and explores how young people acquire, develop and use health literacy, drawing from their own contributions. Ultimately, therefore, the chapter considers the meaning of health literacy in the lives of young people.
4. Data Analysis and Discussion: young people defining and experiencing health literacy

4.1 Introduction

As noted in Chapter 3, this study was rooted in participation (Mansuri and Rao, 2013, Tisdall et al, 2014) which engaged young people in thinking about solutions and interventions in understanding health literacy for young people. This chapter presents analyses of the participants’ experiences, explains the themes and evaluation from the online survey and co-production group work, drawing on previously considered literature, research, and policy.

The primary data analysis sought to:

- Explore how young people acquire, develop and use health literacy
- produce recommendations for practitioners and policy makers concerned with improving the health outcomes of young people aged 16-19 years in England.

The study aims to add knowledge to understanding how young people acquire health knowledge and develop health literacy, as critiqued within the literature review, as there is only a very limited understanding of this (Fairbrother, 2016).

Three key themes arose from the data, and these will be discussed throughout the remainder of this chapter. These are:

- **Services**: which services young people use and recognise as sources of health support, education and help.
- **Advice**: where and who young people turn to in order to get advice about their health.
- **Health Information**: what and how young people understand health information and how they get this information.

Each theme is presented and discussed, where possible using direct commentary to hear the voices of young people and give authenticity to the findings of the study. Survey qualitative commentary is signposted throughout as Survey Narrative: SN, and Co-Production Group critical analysis and discussion as CPG.
4. 2 General Information about participants.

Study participants.
Sixth form students (n = 150) were invited to take part in the online survey, 53 young people responded, a response rate of 35.5% which is considered an acceptable response (Nulty, 2008, Amunsden and Lie, 2013).

A full breakdown of demographic data for survey participants is offered in Table 4.1. Quantitative summarisation allowed patterns and common features to emerge from the data (Cresswell, 2013, Bryman, 2006). Protected characteristics data were sought from both the survey participants and co-production group to analyse responses related to those derived from the research for this study and from the setting’s use of HESA data analysis (2012). Characteristics of the survey participants are shown in Table 4.1.
### Table 4.1 Characteristics of Survey Participants

<table>
<thead>
<tr>
<th>Protected Characteristics</th>
<th>No. Respondents</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16-17</td>
<td>38</td>
<td>77.5</td>
</tr>
<tr>
<td>18-19</td>
<td>11</td>
<td>22.5</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>34</td>
<td>69.4</td>
</tr>
<tr>
<td>Male</td>
<td>15</td>
<td>30.6</td>
</tr>
<tr>
<td><strong>Socio-economic status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent employed</td>
<td>44</td>
<td>89.8</td>
</tr>
<tr>
<td>Parent unemployed</td>
<td>5</td>
<td>10.3</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>43</td>
<td>87.4</td>
</tr>
<tr>
<td>Black Caribbean</td>
<td>1</td>
<td>2.1</td>
</tr>
<tr>
<td>Other Black African</td>
<td>1</td>
<td>2.1</td>
</tr>
<tr>
<td>Asian</td>
<td>1</td>
<td>2.1</td>
</tr>
<tr>
<td>Indian</td>
<td>1</td>
<td>2.1</td>
</tr>
<tr>
<td>Pakistani</td>
<td>1</td>
<td>2.1</td>
</tr>
<tr>
<td>Prefer not to say</td>
<td>1</td>
<td>2.1</td>
</tr>
<tr>
<td><strong>Religion</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Christian</td>
<td>5</td>
<td>10.4</td>
</tr>
<tr>
<td>Catholic</td>
<td>5</td>
<td>10.4</td>
</tr>
<tr>
<td>United Reform</td>
<td>1</td>
<td>2.1</td>
</tr>
<tr>
<td>Muslim</td>
<td>1</td>
<td>2.1</td>
</tr>
<tr>
<td>No Religion</td>
<td>35</td>
<td>72.9</td>
</tr>
<tr>
<td><strong>Disability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Declared disabled (SEND)</td>
<td>8</td>
<td>16.3</td>
</tr>
<tr>
<td>Declared not disabled</td>
<td>41</td>
<td>83.7</td>
</tr>
</tbody>
</table>

**Characteristics of the co-production group.**

Nine young people, separate from the survey participants, were recruited as part of the discussion group: six females and three males. They declared themselves as white British (n= 5) and black African (n= 2), Asian (n= 1), Indian (n= 1) with 1 self-declared as disabled (SEND) (n 1). The characteristics of participants in the survey and discussion group broadly corresponded to the demographics of the school and surrounding area as noted by the last school Ofsted (2012) report and
Northamptonshire Analysis information (2016), albeit for male to females whom were under-represented at 30.6 - 33% against a whole school (rather than sixth form) rate of 49.4% male (TNA/DE, 2012). This did show a comparable cohort representative of young people locally. As Table 4.1 shows, by age, survey participants were aged 16-19 years and more than two-thirds of participants were female (mean = 68) with just under one-third male (mean = 31.9). In terms of social analytics of participants, very high numbers of parents / carers were in employment 89.5 (mean) with 10.7 (mean) not in employment. Few young people chose to answer the questions related to parental / carer employment status and so this information has been discounted in the analysis.

87.4% of survey participants (n=47) described themselves as White British with 6 participants selecting Asian, other Black African, Indian, Pakistani, White and Black Caribbean and ‘prefer not to say’ – representing 1 participant each. 14% of the participants described themselves as Black Minority Ethnic (BME). Most participants, 72.9% (n=35) self-identified as ‘no religion’ through response selection. Christianity (Catholic, Christian, United Reform) was the most self-identified religion with 22.9% (n= 11). Muslim was self-identified at 2.1% (n = 1) with prefer not to say also at 2.1% (n=1). Lastly, just over 4/5 of participants (83.7% n= 35) considered they did not have a disability with 16.3% (n=8) declaring a disability. Of those 8 participants declaring a disability the highest described disability was mental health with 50% (n=4) other selected disabilities included autism, literacy / numeracy, and 1 participant selecting prefer not to say. Significant differences in terms of age, gender, ethnicity or disability are reported as they arise in the sections discussed.
4.3 Data Analysis Strategy

Figure 4.1 shows how the analysis of data was developed across the study to generate the themes. This model was purposefully developed for this study but draws from interpretive paradigms (Hefferon and Gil-Rodriguez, 2011) and mixed methods research (Bazeley and Kemp, 2012). The model enabled the participative research to remain the primary driver in the study’s analysis and subsequent development of outcomes, essentially to ensure young people’s experiences and voices incrementally developed the study and outcomes.

Figure 4.1: Model of Data Analysis Outcomes used within study

The key themes, services, advice and health information, have been directly aligned with comments from the co-production group about young people’s health needs and wants. These young people felt strongly that their need for health information was not being addressed and this was reflected in other methods used throughout the study. This is a fundamental point and serves to highlight the importance of this study in contributing new knowledge and suggesting solutions generated from the young people themselves. The following extract from the co-production group illustrates one such discussion:
CPG: ‘adults should be patient, they should understand that we are human beings and have to learn’.

CPG: ‘we will make mistakes, so what, they (adults) did too. If we don’t learn (about health) then that’s it but give us the chance to do it’.

CPG: ‘I accept we don’t know what we don’t know – but we do know what they want to tell us (about health) – what we don’t know is what they won’t tell us – that makes us curious’.

CPG: ‘I have to grow up, they have to help me- I’ll just have a go anyway’.

The analytical evaluation of the themes is drawn from the survey and co-production data with reference to the reviewed literature. As part of the embedded participatory approach, interpretation of meaning was contemporaneously validated by the co-producers and researcher, for example within each discussion session. For accuracy, these interpretations were noted within transcripts and recorded (Figure 4.2) and within the report generated by the online survey (Figure 4.3). These interpretations have been utilised evidentially as part of this chapter and as narrative evidence.

Figure 4.2: Example of interpretation of meaning (in blue) of co-production group transcripts validated co-producers and researcher: narrative evidence
Figure 4.3: Example of narrative from co-production group on survey data: evidential interpretation.

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>(%)</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Internet</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>40</td>
<td>83.33%</td>
<td>83.33%</td>
</tr>
<tr>
<td>No</td>
<td>8</td>
<td>16.67%</td>
<td>16.67%</td>
</tr>
<tr>
<td>Total</td>
<td>48</td>
<td>100.00%</td>
<td>100.00%</td>
</tr>
<tr>
<td><strong>Twitter</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>3</td>
<td>6.25%</td>
<td>6.25%</td>
</tr>
<tr>
<td>No</td>
<td>45</td>
<td>93.75%</td>
<td>93.75%</td>
</tr>
<tr>
<td>Total</td>
<td>48</td>
<td>100.00%</td>
<td>100.00%</td>
</tr>
<tr>
<td><strong>Facebook</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>3</td>
<td>6.25%</td>
<td>6.25%</td>
</tr>
<tr>
<td>No</td>
<td>45</td>
<td>93.75%</td>
<td>93.75%</td>
</tr>
<tr>
<td>Total</td>
<td>48</td>
<td>100.00%</td>
<td>100.00%</td>
</tr>
</tbody>
</table>
4.4 Theme One: Services

Knowledge and awareness of health services

The survey asked participants to share their knowledge and use of health based services, and to comment qualitatively on their experiences. The co-production group identified a range of services which they felt young people should have heard of or know about. The researcher cross-matched these services to those provided within the local environment to develop a final list for inclusion into the survey. The list provided a basis of questions related to knowledge and awareness across a range of different services. Summary data relating to this question is provided in Table 4.2 which showed which health services young people were aware of and adds to the understanding of their acquired health knowledge.

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes % (n)</th>
<th>No % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you know how to register with a GP?</td>
<td>65.3 (n=32)</td>
<td>34.7 (n=17)</td>
</tr>
<tr>
<td>Do you know how to register with a dentist?</td>
<td>61.2 (n=30)</td>
<td>38.8 (n=19)</td>
</tr>
<tr>
<td>Do you know how to access a local health centre?</td>
<td>30.6 (n=15)</td>
<td>69.4 (n=34)</td>
</tr>
<tr>
<td>Do you know how to access a walk-in centre?</td>
<td>24.5 (n=12)</td>
<td>75.5 (n=37)</td>
</tr>
<tr>
<td>Do you know how to get an appointment with your GP?</td>
<td>93.3 (n=46)</td>
<td>6.1 (n=3)</td>
</tr>
<tr>
<td>Do you know how to get help from a Dentist?</td>
<td>77.6 (n=38)</td>
<td>22.4 (n=11)</td>
</tr>
<tr>
<td>Do you know how to get your eyes/hearing checked?</td>
<td>77.6 (n=38)</td>
<td>22.4 (n=11)</td>
</tr>
<tr>
<td>Do you know how to get general health advice (such as diet or exercise)?</td>
<td>55.1 (n=27)</td>
<td>44.9 (n=22)</td>
</tr>
</tbody>
</table>

Broadly, table 4.2 showed that just over half (55.1%) of young people felt they knew how to access general health advice however, the format of this advice was not specified; for example, this might be virtual or not involve any health service setting. Hope (2015) found that 48% of 16-24 year olds accessed health application (app). With Fergie et al (2015) finding that young people turned to ‘googling’ as their first (and often only) means of health information. Ofcom report (2014) that 70% of 5-15
and 80% of all 12-15 year olds own a device that is Internet enabled. This was re-enforced in more detail, as young people reported being highly aware of how to access high profile primary health services, GP, dental, eye and hearing check-ups.

The co-production discussions showed that whilst young people might claim to ‘know’ how to access actual health services, the reality was that they knew how to get information that was available online rather than through realised service provision. For example, they might seek potentially unsafe advice from peers on social media rather than obtain sound advice from a pharmacist or GP. This behaviour leaves young people at risk of harm and concurred with Roberts’s research (2015b). They also discussed young people’s reliance on others in obtaining access to these services and suggested this was mostly via their parents. This was explained through their experiences of attempting to access the services and being blocked by the service ‘gatekeeper’. Examples of this were an over complicated or intimidating booking system, not having specific information (such as knowing name of GP), and being turned away because they were not accompanied by an adult. This was echoed within the literature where Bates and Freeman (2014) found health services do not work flexibly enough in seeking provision within children and young people’s spaces. Examples of this was found in the co-production group narrative and interpretation:

CPG: ‘you need to tell me what’s wrong otherwise I can’t book you in’:
intimidating gatekeeping in accessing GP.

CPG: “where is your Mum, she needs to be here’: incorrect gatekeeping advice given to same young person.

CPG: ‘if you don’t know the name of your doctor I can’t help…’: unnecessary barrier given to prevent access to walk-in centre.

The use of primary services alone does not correspond to being health literate, it is the correct use of them that reflects this (Rowlands et al, 2014, Rudd, 2015, Roberts, 2015b). Higher levels of participant knowledge of dominant and visible primary health services (GP, dental, eyes / hearing) contrasted with much lower levels of knowledge of more generic services such as health centre (30.6%) and walk-in centre services.
(24.5%) which offer generalised advice, focus on health promotion and second level interventions, for example physiotherapy. Research from Kennedy (2010), LaValle et al (2012), Atkinson (2013) showed that some young people, through inability and opportunity, failed to use health services. This corresponded to Elliott et al (2013) findings about limited engagement and impact for young people with general health information and services. They argued that firstly, health information was not suitable or engaging through design, and secondly, the information was of limited interest to the young person (Elliott et al, 2013). It also supports the findings of Hope (2015) who found that having sought help, young people were then the least likely group to follow up health appointments and additionally, there was a perceived need for adult presence in seeking health advice. The co-production group explained the perceived need for an adult as a barrier, rather than a conduit, to access health services.

CPG: ‘my Mum can’t always come with me, and I don’t want that, I’m old enough, why can’t they understand that’.

CPG: ‘I wouldn’t have gone if I had to take her’ (mother).

In contrast, the eight survey participants who self-defined as having a disability signalled more general knowledge of health and how to access secondary health services. In a follow up discussion, the co-producers commented on this, suggesting that this reflected those who are more likely to need and use these services. This is an interesting point as young people with a disability are usually framed as more dependent than their peers, relying on the adults around them to make use of services on their behalf (Stokes et al, 2013, Smith, 2016). These findings begin to suggest that one of the tenants of health literacy, having awareness and knowledge about services, is something that these young people are knowledgeable of, although further research is needed to consider the extent to which they are enabled to act on this information:

SN: ‘the information I get is reliable face to face. The fact they have experience (parents) to help me’.
However, research by Allerton and Emerson (2012) suggested 40% of adults with disabilities have difficulties in accessing health services, facing similar barriers noted by Hope (2015). This indicates a high risk of those currently capable study participants becoming disenfranchised as they transition from child to adult services. Further, this shows that use of health services does not indicate health literacy but rather a more passive state of receivership (of health services) than knowledgeable engagement. Being health literate indicates an active and purposeful relationship with health services. Allerton and Emerson’s (2012) research suggested that, despite disabled young people having an enduring need for health services, this purposeful relationship declined into adulthood. This indicates health use rather than health literacy. Developing health literacy as a life skill would mitigate against this decline as the young person would be more autonomous about their health. Further, if young people are supported by adults who are health literate, there is some evidence from literature (Smith, 2016, Stokes et al, 2013) that they, like all young people, could become health literate. The survey and co-production group identified their own levels of health literacy were developed through learning from others (adults) who were health literate. In appraising this point of learning from adults, the study found those adults tended to be health professionals, closely related to health services or competent consumers of health.

As discussed in chapter two, section 2.4, there is little evidence of how young people learn to be health literate (Fairbrother, 2016) and so this study adds to this knowledge. This point is illustrated through the CPG discussion about knowledge of health and exercise. In terms of knowledge about specific health (exercise and diet) more males than females said they knew how to access and use services and get advice. There was some correlation to this from the Women’s Sport and Fitness Foundation (WSFF) (2012) whose research showed that approximately half the number of girls, compared to boys, engaged with sport at age 12, however this indicated engagement and did not test knowledge. Further, the WHO (2017) found only 15% of girls completed the minimum guidelines of physical activity at age 14 which declined with age and was much lower than rates related to boys. This, again, indicates doing rather than knowing. This was further seen as more males than
females had knowledge about gaining information about diet and was unexpected however the co-production group felt that:

_CPG: ‘boys are more pressurised now to look good’_

This sparked some discussion and was strongly felt by all members of the co-production group who also highlighted that engagement with sport was to look good rather than knowledge of health aligned to sport. However, in aspects of health where there was a high general awareness (such as accessing primary health services) there is less of a gender difference.

**Knowledge of urgent and emergency health**

The co-production group identified the key health services they felt would be most used by young people to stay healthy; emergency, urgent and dental health help, substance misuse, sexual and mental health issues, and non-emergency but urgent care. Therefore, the survey asked participants about their knowledge in seeking health support and advice from these services (see Table 4.3). As discussed in chapter 2, Hagell and Coleman (2014) have suggested that young people do face barriers in accessing health support, particularly if they sought this support independently. In terms of emergency or urgent health support this raises the issues of capacity to consent to treatment, treatment being a common consequence of emergency or urgent health support. Guidance from the GMC (2007) is very clear that,

> ‘capacity to consent depends more on the young person’s ability to understand and weigh up options than on age’ (2007: 14),

and would therefore support young people’s capacity to seek this health support.
Table 4.3 Knowledge of urgent and emergency health

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes % (n)</th>
<th>No % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you know how to get emergency medical help?</td>
<td>93.9 (%)</td>
<td>6.1 (%)</td>
</tr>
<tr>
<td>Do you know how to get emergency dental help?</td>
<td>46.9 (%)</td>
<td>53.1 (%)</td>
</tr>
<tr>
<td>Do you know how to get emergency help re. sexual health issues?</td>
<td>36.7 (%)</td>
<td>63.3 (%)</td>
</tr>
<tr>
<td>Do you know how to get emergency help re. mental health issues?</td>
<td>28.6 (%)</td>
<td>71.4 (%)</td>
</tr>
<tr>
<td>Do you know how to get emergency help re. substance misuse?</td>
<td>28.6 (%)</td>
<td>71.4 (%)</td>
</tr>
<tr>
<td>Do you know how to get urgent, but not emergency help (such as for a minor injury)?</td>
<td>69.4 (%)</td>
<td>30.6 (%)</td>
</tr>
</tbody>
</table>

There was a marked difference in participants’ knowledge of seeking general health support compared to specific urgent or emergency health support. 93.9% of participants felt that they knew how to access emergency medical support (GP / hospital) whereas only 46.9% said that they knew how to access emergency dental support. From the participant responses, in evaluating this, it appeared this knowledge came from experiential learning and information drawn from the media:

   CPG: ‘I saw, ‘24 hrs in A&E’ … (pause, giggles) yuk, so real, they like, just film it, learnt loads, more than school says and its funny’.

   CPG: ‘everyone knows A&E, you can just go, they have to see you’.

As highlighted in Table 4.2, participants commented upon being less knowledgeable about where to seek specific forms of health advice. The PHE / AYPH (2015) open their Framework for Improving Young People’s Health and Well-Being by stating that ‘treating different, specific health issues separately will not tackle the overall wellbeing of this generation of young people’ (2015:6). This inferred current health provision did this in an ad hoc manner and so fragmentation might be contributing to young people not knowing where to go to for more expert support. This fragmentation suggests the need for insider knowledge; knowing the local nuances of the local health provision. This fragmentation of services has been tackled through National Service Frameworks.
and currently the National Institute for Health and Care Excellence set out to standaridise health pathways (NIHCE, 2016). This is a new theme in developing health knowledge for young people and highlights a true gap in contemporary planning and provision of health for young people; they are neither aware of the services provided nor inclined to use them. This was borne out further in the current study with participants reporting less awareness for how to access more specialised emergency health services, for example, mental health (28.6%), sexual health (36.7%) and substance misuse (28.6%). Further, this showed a correspondence to the findings of Table 1.1 where young people reported knowing little about sources of specialist health advice. In addition, they perceived adult gatekeeping as a barrier to accessing services. However, in a new understanding from this study, for specific services, the GP was perceived as a gatekeeper or, as the co-production group suggested, the young person must find their way to an alternative service that may not be appropriate, convenient nor apparent:

CPG: ‘yeah I know, you know about it (CAMHS) cos … my friend ….it took too long and she has to miss out (school). No idea where she goes when she does’.

Specific health knowledge on mental health, substance misuse and sexual health aligned with key health targets set out by PHE (2015). This broke down as sexual health where between 77.7% and 100% of all ages of the participants knew how to get advice about sexual health; this may be aligned to compulsory PHSE which has sexual health as a must do component (DE, 2013). Emotional health showed some age differentiation and this was evaluated by the researcher and co-production group. 16 year olds (65%) were most confident in getting help with emotional issues, which was possibly related to adult support. Whereas the older age range (17-19 years) noted half (50%) were confident is seeking help, possibly as they now turned to trusted friends / peers / partners, rather than health services.
Issues of stigma and embarrassment were raised by the qualitative responses and narrative analysis of the participants about getting support for sexual and emotional health:

SN: ‘mental health issues – BIG stigma still attached’

SN: ‘without having the potential awkwardness of telling people your personal health...’

These findings suggested that stigma was a significant barrier in young people organising support for themselves for this. Further, evaluation narrative of participants indicated that learning about the more specific topics of their health and health services is something that came with experience:

SN: ‘you do not need specific health (lessons) as you pick up information as you get older’.

This point highlights new information from the study and is worrying as it assumes (health) knowledge ‘just happens’. This has the potential to lead to wrong knowledge being learnt, misuse of health services, as correct use has not been learnt, and risks to health as preventative knowledge is not known. This would encapsulate health illiteracy and echoed similar findings to Roberts (2015b) and Fairbrother et al (2016). Further narrative analysis referred to disinterest or disengagement with specific topics:

SN: ‘too much.....particularly about STIs and Alcohol because teenagers ...All people seem to talk about are these two topics’

These findings supported the idea that adult-centric decisions about specific health may not be reflective of young peoples’ perception of what they need in terms of access to health services (Hope, 2015, Eliott et al, 2013). This also closely corresponded to the policy briefing research of PHE / AYPH (2015) which identified adult-centric targets developed through statistical data outcomes, to improve young people’s health. It is these topics that will became aligned to strategic targets and
campaigns. The question raised is that of effectiveness and accountably in spending public monies on strategic targets that has largely not engaged with the target audience (Rowlands et al, 2015, Abel et al, 2014). This was further evidenced by the co-production group who re-iterated this very issue in the following terms:

CPG: ‘we don’t have the same ideas as adults – they think they know best but don’t. I want to know about stress and exams and stuff and they want me to know about smoking I DON’T SMOKE’.

4.5 Theme Two: Advice

Sources of advice about health issues

An aspect of being health literate is being able to navigate health advice and information in order to take responsibility for one’s own health (Sorensen et al, 2012). The survey asked participants about topics identified by the co-production group as being important to young people: puberty, sexual health, contraception, pregnancy, mental health, emotional health, relationships and substance misuse. These topics do have some similarities to those identified by PHE/ AYPH (2015), but there are still gaps and differences identified by the young people in this study. This highlights the need for contemporary evidence to be used in generating health advice.

Figure 4.4: Example from CPG of issues to be funneled into topics for the survey.
They also felt that being told, by a health care professional, to simply stop a behaviour, (for example not to smoke) was disempowering. This then created a situation where young people referred to each other for information. This was perceived as a more reasonable approach but highlighted the need for clear and safe information based on evidence rather than being anecdotal:

*CPG: ‘well, like, learn through ourselves. Like we share things (experiences), happens to us and our friends’*

Table 4.4 shows responses from participants in their ability to navigate health advice.

**Table 4.4 Sources of advice about health issues**

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes % (n)</th>
<th>No % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you know how to get advice about puberty?</td>
<td>71.4 (n= 35)</td>
<td>28.6 (n= 14)</td>
</tr>
<tr>
<td>Do you know how to get advice about sexual health issues?</td>
<td>85.7 (n=42)</td>
<td>14.3 (n=7)</td>
</tr>
<tr>
<td>Do you know how to get advice about contraception?</td>
<td>87.8 (n=43)</td>
<td>12.2 (n=6)</td>
</tr>
<tr>
<td>Do you know how to get advice about pregnancy?</td>
<td>83.7 (n=41)</td>
<td>16.3 (n=8)</td>
</tr>
<tr>
<td>Do you know how to get help and advice about mental health issues?</td>
<td>61.2 (n=30)</td>
<td>38.8 (n=19)</td>
</tr>
<tr>
<td>Do you know how to get help and advice about emotional issues?</td>
<td>57.1 (n=28)</td>
<td>42.9 (n = 21)</td>
</tr>
<tr>
<td>Do you know how to get advice about relationships?</td>
<td>51 (n=25)</td>
<td>49 (n=24)</td>
</tr>
<tr>
<td>Do you know how to get advice about substance use?</td>
<td>60.4 (n= 29)</td>
<td>39.6 (n=19)</td>
</tr>
</tbody>
</table>

Table 4.4 indicated that the topics that most young people felt able to source advice on were sexual and reproductive health (87.8% and 83.7% respectively). Some explanation of these high rates might be that sex education is taught within schools as part of the national curriculum (DE, 2013). This correlated to the Royal College of Paediatrics and Child Health (RCPCH)/ NHS Confederation (2012) and PHE/AYPH (2015) strategies of reducing teenage pregnancies resulting in a concentrated volume of health education to target to reduce this, which demonstrated some value to this.
As seen in Figure 4.2 sexual education continued to be identified by young people as an important issue, but that this is now well established and effective PHE/AYPH (2015). Interestingly, issues about mental health, substance use and emotional health were broadly known at 61.2%, 60.4% and 57.1%. Just over half of the participants felt that they knew how to get advice about relationships (51%). Relationship advice has now been targeted through recent policy initiatives (PHE / AYPH, 2015), and was identified as an important topic by members of the co-production group during their discussions.

Where would you seek health advice?
Massey et al (2012) identified ‘navigation of the system’ alongside ‘information seeking’ (2012:961) as components of young people’s health literacy, meaning that they should be able understand the system enough to enable them to locate advice. The survey asked participants where and who they would go to in order to obtain health advice. This topic also arose from discussion with the co-production group that health advice is often personal in nature but that the health education they had received was mostly in school and in large groups;

CPG: ‘...they do like assemblies and stuff, about, like being stressed, but that like, doesn’t help, it’s not really a help, you can’t like, like listen and ask’.

CPG: ‘yeah it’s like they are worried about what other people will think as well. It’s like it’s not just them’

This led to discussion about the role families and friends play in teaching health and the CPG had a mixed response to learning from families, raising issues of trust and embarrassment:

CPG: ‘I’d have thought like, families and friends, like would be more supportive (than school) about it....get things sorted’

The CPG then discussed other common sources of advice such health professionals and the internet and so generated a range of choices for the participants to select from, including family and school. Table 4.5 asked participants who they turn to for
health advice and looked to distinguish between their selections through gathering additional narrative explanation to understand these choices.

Table 4.5 Where would you seek health advice?

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes %   (n)</th>
<th>No %   (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would you ask parents / carers for health support and advice?</td>
<td>83.7 (n=41)</td>
<td>16.3 (n=8)</td>
</tr>
<tr>
<td>*Would you ask siblings for health support and advice?</td>
<td>30.6 (n=3)</td>
<td>63.3 (n=31)</td>
</tr>
<tr>
<td>Would you ask other family/relation for health support and advice?</td>
<td>36.7 (n=18)</td>
<td>63.3 (n=31)</td>
</tr>
<tr>
<td>Would you ask friends for health support and advice?</td>
<td>67.3 (n=33)</td>
<td>32.7 (n=16)</td>
</tr>
<tr>
<td>Would you ask teacher for health support and advice?</td>
<td>20.4 (n=10)</td>
<td>79.6 (n=39)</td>
</tr>
<tr>
<td>Would you ask school nurse for health support and advice?</td>
<td>38.8 (n=19)</td>
<td>61.2 (n=30)</td>
</tr>
<tr>
<td>Would you ask pharmacist/chemist for health support and advice?</td>
<td>53.1 (n=26)</td>
<td>46.9 (n=23)</td>
</tr>
<tr>
<td>Would you ask GP for health support and advice?</td>
<td>95.6 (n=47)</td>
<td>4.1 (n=2)</td>
</tr>
<tr>
<td>Would you ask health professional (hospital) for health support and advice?</td>
<td>85.7 (n=42)</td>
<td>14.3 (7)</td>
</tr>
<tr>
<td>Would you ask health professional (clinic/community- not GP) for health support and advice?</td>
<td>67.3 (=33)</td>
<td>32.7 (n=16)</td>
</tr>
<tr>
<td>Would you ask charity (such as The Lowdown, NSPCC) for health support and advice?</td>
<td>18.4 (n=9)</td>
<td>81.5 (n=40)</td>
</tr>
<tr>
<td>Would you search internet for health support and advice?</td>
<td>81.6 (n=40)</td>
<td>18.4 (n=9)</td>
</tr>
<tr>
<td>Would you ask Twitter for health support and advice?</td>
<td>6.1 (n=3)</td>
<td>93.9 (n=46)</td>
</tr>
<tr>
<td>Would you ask Facebook for health support and advice?</td>
<td>6.1 (n=3)</td>
<td>93.9 (n=46)</td>
</tr>
<tr>
<td>Would you watch YouTube for health support and advice?</td>
<td>18.4 (n=9)</td>
<td>81.6 (n=40)</td>
</tr>
<tr>
<td>Would you use Tumblr for health support and advice?</td>
<td>12.2 (n=6)</td>
<td>87.8 (n=43)</td>
</tr>
</tbody>
</table>

* 6.1% (n=3) did not have a sibling
The participant responses were thematically analysed (Hefferon and Gil-Rodriguez, 2011, Bazeley and Kemp, 2012) and three recurring themes have been identified; trust (not be judged, confidence in knowledge), confidentiality (intimate details treated with respect and shared only when critical) and the right to privacy (overcoming shyness).

SN: ‘I require confidentiality or anonymity to ask personal questions’

SN: ‘People I trust, such as qualified professionals’

SN: ‘I would rather talk to .....as I feel more comfortable’.

CPG: ‘If they make you feel stupid, what’s the point? Even if you know they know the right thing’

This study has found that whilst trust, confidentiality and right to privacy are seen within the literature of working with young people (Hope, 2015, PHE / AYPH, 2015, Atkinson, 2013), they have not been considered as an integrated whole in developing health knowledge, independence and health literacy. As an integrated whole, this results in understandable health knowledge (Rowlands et al, 2015), which incrementally develops health independence (AYPH, 2016) and health literacy (Rudd, 2015) and is illustrated in Figure 4.5 (below).
Fig 4.5: Incremental health literacy > health emancipation- identified by young people.

Table 4.5 ‘where would you seek health advice?’ showed that young people ranked GP’s (95.6%) as their key source of health advice. Existing research has shown a range of challenges for young people in trying to access a GP (Bates and Freeman, 2014), including the perceived need for an accompanying adult, appointment gatekeeping, timing and getting there. Another strand implicit of ‘where’ health advice was sought was who the person might be; their role, status, ability to help:

SN: ‘advice is reliable and trusted (e.g. GP) and private’

SN: ‘..it comes from a reliable source, GP, and they have lots of training.’

Coleman reported that young people wanted to see someone ‘more understanding of teenage issues’ (2011:2), and were ‘not aware of their rights of confidentiality’ (2011:2). The issue of confidentiality is interesting as the co-production group noted a general awareness of confidentiality from GP’s but that this issue of confidentiality was less certain from other professionals. This point was borne out with narrative analysis responses from the participants:
Young people rated hospital based health professionals (85.7%), parents (83.7%) and the Internet (81.6%) as other sources for health advice. These findings are contextualised by the rich narrative analysis data which brings the rationale of these choices back to the notions of trust, confidentiality and right to privacy.

As well as being highly scored by participants (81.6%) the Internet was identified frequently through their narrative and the analysis and was seen as an increasingly important and trusted tool within health and health services.

As discussed within chapter 2, Hope’s (2015) research found 48% of 16-24 year olds accessed a health app and 26% had looked up medical advice using the internet, given this research is already two years old it can be assumed that these figures are now much higher (Ofcom, 2016). Further, Fergie et al (2015) found that young people ‘googled’ their health queries as their first (and often only) means of information. This study considered the internet within the arena of health information for young people, and the analysis re-positioned the internet from a gatekeeper to being a primary source of health knowledge for some young people:

SN: ‘I’d do a quick google to check it out’....

SN: ‘often have to use the internet to clarify this info’
Participants would ask friends and community health professionals for health advice and ranked these both fairly high at 67.3%. This reflected a level of trust and privacy granted by young people to (trusted) friends and health professionals and sought in confidence (Bates and Freeman, 2014), without the (perceived) need for adult chaperone (Hope, 2015). In picking apart the contrast of friends from health professionals Coleman (2011) suggested young people avoided health services, as they wanted health advice from a source that is ‘understanding of teenage issues’ (2011:2), for example, their peers:

SN: ‘friends care enough to give good advice’

SN: ‘I talk to friends, sometimes in a private Facebook message’

From the participants’ narrative analysis, it is clarity that was the key aspect of health advice from professionals that was valued and distinguished this from advice from friends.

SN: ‘hearing it and having it explained by a professional’

SN: ‘the professional gave me the information and the emphasis behind what they were saying’.

A smaller number of survey participants stated that they would ask school nurses for advice (38.8%). This important narrative evaluation reflected a lower confidence in school nursing services, but is also worrying given the role of school nurses in the framework of health education (RCN, 2014, AYPH, 2016). Bates and Freeman’s (2014) report recommended that the profile of the school nurse team needed to be raised alongside tackling the stigma that exists from young people in using this team:

SN: ‘Not confident to get advice from school nurse’

There was also the underlying issue that school nurses are no longer a consistent and visible presence within schools with numbers having been cut by 16% since 2010.
(RCN, 2016) and roles of health education and promotion radically reduced due to ‘considerable proportions of their time being spent on safeguarding activities and administration’ (RCN, 2014:57). Thus, schools do not have an active schedule of health education (Bates and Freeman, 2014) and this was illustrated by the co-production group who were unable to say when they had last had contact with a school nurse for health education.

Siblings were ranked lower (30.6%) as a source of health advice:

   SN: would talk to parents and friends, but not little brothers…’.

Few participants stated that they would ask teachers for advice (20.4%). As discussed within the chapter 2, currently there is no compulsion for general health to be taught within schools (DE, 2013). Local authorities, through their public health responsibilities, deliver health promotional activities within schools (PHE, 2015) and this often falls to teachers to deliver. The outcome of this situation was that young people were left feeling vulnerable, anxious and at risk of harassment (Pound et al, 2016). The co-production group discussed the issue of teachers being sources of health advice and concluded that, they would not go to a teacher for health support as their teacher did not have expert knowledge and the conversation might not stay confidential. These evaluative comments reflected the study’s recurring themes of trust, confidentiality and right to privacy. Further, they agreed, it would be hard to re-build the teacher relationship / role after this event (Elliott et al, 2013):

   CPG: ‘I think loads of her, but how would she know about my health – she’s not my Mum or my doctor’

   CPG: ‘….but you might worry, like, what do they think of you?’

Exploring who should educate young people about their health is examined later in this chapter.
Charities were less frequently indicated as sources of health advice at 18.4% and this included a reference to a local, well-known charity as well as citing a National charity renowned for its’ work with children and young people. In terms of social media YouTube also scored lower at 18.4% as a source for seeking health advice with social media (combined 24.4%) broken down between commonly used platforms identified by the co-production group as Facebook, Tumblr, Twitter. Aligned to the literature, Fergie et al (2015) suggested young people were using their social networks to gain health information but there is a noticeable lack of filter or checking of the reliability or quality of the information gathered:

“They actively and effortlessly negotiate between professionally produced content….user-generated content…draw on other people’s experiences of a similar illness and inform their own health management strategies’ (Fergie et al, 2015:5).

The survey participants have not often cited social network platforms but have alluded to using the Internet as a go to place for information linked to private messaging or sharing. Ofcom (2016) note that 72% of 12 – 15 year olds have a social media profile.

SN: ‘I would not publicly ask anyone on the Internet just use Facebook to ask friends or google’.

SN: ‘would not use Twitter etc as in the public domain...’

Contrary to its’ low score YouTube itself was identified several times in the narrative as useful in terms of demonstration and explanation. Ofcom (2016) research shows that 87% of 12-15 year olds use YouTube:

SN: ‘I’d use YouTube to look for medical explanation / exercise for muscle pain’

In asking participants about seeking health advice from ‘The Internet’ and named social media sites, the survey may have skewed these results as social media and the internet are inter-reliant. This was seen within the qualitative data as references to the internet often cited other media points such as Google, NHS, Twitter.
Who do you trust to give you good health advice?

The theme of trust ran throughout the data from this study and the co-production group felt that questions around trust should be included in the survey. Analysis of the data suggested that trust, health knowledge and advice came together as an integrated whole as a key aspect of young people’s health emancipation cited in Figure 4.5 section 2.2. Table 4.6 drew deeper information from the participants about their notion of health and trust aligned with their justification for their choices.

Table 4.6 Who do you trust to give you good health advice?

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes %  (n)</th>
<th>No %  (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would you trust parents / carers to give you good health advice?</td>
<td>83.7  (n=41)</td>
<td>16.3  (n=8)</td>
</tr>
<tr>
<td>Would you trust siblings to give you good health advice?*</td>
<td>32.7  (n=16)</td>
<td>61.2  (n=30)</td>
</tr>
<tr>
<td>Would you trust friends to give you good health advice?</td>
<td>59.2  (n=29)</td>
<td>40.8  (n=20)</td>
</tr>
<tr>
<td>Would you trust teacher to give you good health advice?</td>
<td>44.9  (n=22)</td>
<td>55.1  (n=27)</td>
</tr>
<tr>
<td>Would you trust pharmacist / chemist to give you good health advice?</td>
<td>75.5  (n=37)</td>
<td>24.5  (n=12)</td>
</tr>
<tr>
<td>Would you trust GP to give you good health advice?</td>
<td>98  (n=48)</td>
<td>2  (n=1)</td>
</tr>
<tr>
<td>Would you trust health professional (hospital) to give you good health advice?</td>
<td>87.8  (n=43)</td>
<td>12.2  (n=6)</td>
</tr>
<tr>
<td>Would you trust health professional (clinic/community - not GP) to give you good health advice?</td>
<td>75.5  (n=37)</td>
<td>24.5  (n=12)</td>
</tr>
<tr>
<td>Would you trust charity (such as The Lowdown / NSPCC) to give you good health advice?</td>
<td>51  (n=25)</td>
<td>49  (n=24)</td>
</tr>
<tr>
<td>Would you trust the internet to give you good health advice?</td>
<td>42.9  (n=21)</td>
<td>57.1  (n=28)</td>
</tr>
<tr>
<td>Would you trust Twitter to give you good health advice?</td>
<td>6.1  (n=3)</td>
<td>93.9  (n=46)</td>
</tr>
<tr>
<td>Would you trust Facebook to give you good health advice?</td>
<td>4.1  (n=2)</td>
<td>95.9  (n=47)</td>
</tr>
<tr>
<td>Would you trust Youtube to give you good health advice?</td>
<td>10.2  (n=5)</td>
<td>89.8  (n=44)</td>
</tr>
<tr>
<td>Would you trust Tumblr to give you good health advice?</td>
<td>4.1  (n=2)</td>
<td>95.9  (n=47)</td>
</tr>
</tbody>
</table>

* 6.1% (n=3) did not have a sibling
Perhaps unsurprisingly there were marked similarities between where young people go for health advice and from whom that advice is sought. Trust in GP’s stayed similarly high at 98% and parents remained constant and equally trusted at 83.7%. Health professionals (hospital based) remained highly rated, increasing by 2.1%. These rises can be justified as,

SN: ‘trust any health professionals with a knowledge of medical issues’.

The co-production group discussed trust in great depth and concluded health care professionals (HCP) were trustworthy due to their commitment to their career with examples being positive contact of HCPs and others having HCPs within their families.

CPG: ‘I went with my friend when he needed to go to them (CAMHS) or he won’t. he really needed it .....’

CPG: ‘my auntie’s a health visitor and she always helps me when I ask, she’s great. She’s always busy and I know she loves her job, she’s always saying, but she tells me not to be one (HV) as its crap pay’.

This fed into social learning theories and scaffolded learning (Boyd, Bee 2013, Ritchie, 2017), learning by experience, doing and knowing. It does, however, beg the question of how this same learning can happen effectively for young people who have negative, little or no experiences of HCP, or who do not know anyone within health services. It has potential to lead into a cycle of health illiteracy and feeds into questions related to the insider knowledge needed to understand and navigate the health systems and services discussed in chapter 2.

There were marked differences between where young people go for health advice and from whom that advice is sought. Pharmacists were trusted highly at 75.5% but only ranked 53.1% as a source of health information. This could be explained related to the issue of trust in a recognised qualification as the participants repeatedly commented upon this point:
SN: ‘They’re trained in these things’

SN: ‘The fact that these people have spent a lot of time training’.

Teachers were ranked lower as a source (20.4%) but more than doubled this for trust at 44.9%. Within the co-production group teachers were mostly referred to with a sense of respect and some affection. Teachers were clearly identified as educators and a pivotal source of learning, however, as seen from 2.2, teachers were not considered suitable sources of more personal education despite the implicit trust placed in them. Pound et al (2016) research concluded that due to blurred boundaries young people felt it wrong that teachers delivered health sessions citing lack of anonymity and embarrassment.

The co-production group did identify the need for continuity in the person teaching them about their health to develop a trusting educational relationship, whomever this might be. This is illustrated in Fig 4.6.

Figure 4.6. Flip chart diagram identifying need for stability to foster trust.

Charities were a low source of information (18.4%) but rated higher (32.6%) for trust. There was little explanation from participants that supported this increase in trust, however narrative analysis showed that charity profiles helped develop knowingness:

SN: ‘campaigns that raise awareness’.

Populus, on behalf of the Charities Commission, found that public confidence in charities had fallen overall from 6.7 out of 10 in 2014, to 5.7 out of 10 in 2016 and suggested poor press coverage and scandal as a reason for this decrease (Populus,
However, the report still showed that 61% of people surveyed trusted charities. This information is a broad brush that indicates charities do hold relatively reasonable trusting status.

This study showed the Internet was a common source of health information for the participants. Trust in the internet dropped to 38.7% and Facebook and Twitter were lower in terms of sourcing health information and remained low for trust. YouTube and Tumblr, low for source, both rated less trustworthy by 8.1 % and 8.2 %. This was quite a reassuring finding given how difficult it can be to know the reliability and validity of information placed on the Internet. Internet information can be posted by anyone, can appear as something it is not or might contain false information (ICO, 2017). Participants were quite shrewd with this citing:

SN: ‘whereas information on the internet cannot necessarily be perceived as correct’

SN: ‘social media is unreliable on non-health issues let alone health issues’.

However, the Internet does have great potential to support the development of health literacy for young people. Ofcom (2016) research found that:

‘the qualitative research found that children were more likely to apply critical thinking skills when circumstances demanded it’ (2016:9).

From the literature, Ofcom (2016) information that 80% of UK 5-15 year olds have access to the internet whilst over 79% of all 12-15 year olds own a tablet or smartphone and now spend more time on the internet than watching the television demonstrates multi-media is a platform that engages young people.
There were smaller differences between where young people go for health advice and from whom that advice is sought. Other health professionals, whilst not an initial source of health information increased in terms of trust by 8.2% and narrative analysis related this to the trust the participants placed in them:

\[ \text{SN: ‘information from a health professional is accurate’}. \]

Friends were moderately less trusted for health advice by 8.1% but there was no real narrative to explain this decrease. Trust in siblings’ advice increased by 2.1% but remained as moderately rated. There were some interesting differences shown through the analysis of the participant data. For family and friends there was a clear delineation about who participants sought out for health advice. 83.7% of participants would seek advice from their parent or carer and 67.3% would ask friends for this advice, however this is somewhat reversed with 63.3% of participants who would not seek this advice from siblings.

GP’s were the most noted sources of health advice at 95.9% for the participants followed by other health professionals at 85.7%. School nurses were not generally seen as someone participants sought health advice form with 61.2% saying they would not ask them. Only 20.4% of participants would seek health advice from a teacher, therefore 79.6% would not. On the whole charities (national and local) were not considered as places the participants would go to for health advice with 81.6% not using these resources. The same high figure, 81.6% was recorded by participants as using the internet to seek health advice, however Facebook, Twitter and YouTube were rated between 81.6% and 93.9% as not used as sources of health advice by the participants – which begs the question, what internet sources were sought. The co-production group discussed these nuanced differences of seeking advice between family, friends, health professionals and the Internet and felt the three key aspects of trust, confidence and the right to privacy were pivotal in how or whether young people sought health advice. Figure 4.7 illustrates a mind map from the co-production group showing the Incremental health literacy aspects of confidentiality and right to privacy.
4.6 Theme 3: Health Information

Usefulness of health information

Knowing how to access health services and advice, is of course, only part of the picture for effective and sustainable healthiness. Health information completes this picture if it is effective, understandable and useable. At a basic level, understanding and utilising health services, advice and information is at the root of being health literate. The literature noted that having functional skills in order to understand and be compliant with health information helped tackle illness (Massey et al, 2012, Ormshaw et al, 2013) however their research did not suggest how this might be developed to prevent illness and sustain healthiness. What is apparent though, is not understanding health information was a significant risk in sustaining and improving health and life outcomes (Massey et al, 2012, IOM, 2004, Ormshaw et al, 2013). The co-production group discussed what being health literate meant to them. At the start of the study it was unsurprising that the group felt health literacy was not something they really knew about. Broken down, the components of health literacy are the skills needed to understand health information and apply that health knowledge (Sharif and Blank, 2010, Ormshaw, 2013),

CPG: ‘I found it massively hard to read the instructions on the packet (of medication), I had to ask my Auntie, she was shocked the doctor hadn’t told me how….’
These points were discussed and the co-production group concluded that becoming health literate needed to happen as they reached young adulthood. Developing health literacy was identified in the literature (AYPH, 2016, Roberts, 2015b) as part of becoming independent and transitioning into adulthood. The co-production group were unable to identify how or where this health literacy education happened,

**CPG:** ‘you need to sort yourself out, that’s what being health literate means, not rely on your Mum or mates, you know, be responsible for yourself (health)’

**CPG:** ‘oh my god, no, I’d never ask (teacher name), when we had lessons (on health) we were all together in assembly and it was useless. That’s all I’ve ever had’.

**CPG:** ‘I’ve just picked things up, like, watched my Mum when she gave me Calpol, seen how she reads stuff first, not let me have too much’.

Identifying these gaps in knowledge and education led to the inclusion of questions in the survey which asked participants about their understanding of health information, how useful this information was, the skills they thought they required to understand this information, who had taught them these skills and lastly, how they used this to understand health information. The survey asked about usefulness of information related to information format such as leaflet, posters, discussion and video with qualitative commentary capturing participants’ explanation for their choice. Table 4.7 illustrates participants’ responses about usefulness of health information and the additional narrative contributed to understanding how this information was consumed by participants.
Table 4.7 Usefulness of health information

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes % (n)</th>
<th>No % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you find health advice leaflets helpful?</td>
<td>53.1 (n=26)</td>
<td>46.9 (n=23)</td>
</tr>
<tr>
<td>Do you find health advice factsheets helpful?</td>
<td>38.8 (n=19)</td>
<td>61.2 (n=30)</td>
</tr>
<tr>
<td>Do you find written instructions (such as found in a tablet box) helpful?</td>
<td>73.5 (n=36)</td>
<td>26.5 (n=13)</td>
</tr>
<tr>
<td>Do you find illustrative instructions (such as a diagram) helpful?</td>
<td>44.9 (n=22)</td>
<td>55.1 (n=27)</td>
</tr>
<tr>
<td>Do you find interactive discussion (for example having a demonstration) helpful?</td>
<td>28.6 (n=14)</td>
<td>71.4 (n=35)</td>
</tr>
<tr>
<td>Do you find discussion of the health information (such as in class) helpful?</td>
<td>44.9 (n=22)</td>
<td>55.1 (n=27)</td>
</tr>
<tr>
<td>Do you find watching a video helpful?</td>
<td>44.9 (n=22)</td>
<td>55.1 (n=27)</td>
</tr>
<tr>
<td>Do you find webpages helpful?</td>
<td>51 (n=25)</td>
<td>49 (n=24)</td>
</tr>
<tr>
<td>Do you find media campaigns (such as Movember / Cancer UK Think Pink) helpful?</td>
<td>30.6 (n=15)</td>
<td>69.4 (n=34)</td>
</tr>
</tbody>
</table>

73.5% of survey participants felt that written instructions (for example those given within medication boxes) were a useful source of health information. The narrative analysis around written instructions (such as found in a tablet box) related to structure of written information and trust in the information.

SN: ‘It must easy to understand, for example use of bullet points’

SN: ‘things written by a professional’

SN: ‘diagrams / instructions / leaflets, short and simple’

SN: ‘…most recent research and developments...’
The co-production group (Figure 4.8) did not feel the high rating really reflected written information and felt that what was meant by ‘written’ could have been clearer despite the example used in the question. They suggested young people might find these instructions difficult to decipher due to medical terminology and frightening due to the (compulsory) warnings.

Fig 4.8. Annotated notes of co-production group from survey results 2016

The co-production group concluded that written information needed to be simple, clearly explained with a lack of jargon, and that use of diagram was very helpful. These same conclusions have been found in the literature (Rowlands et al, 2015, Rudd, 2015, Roberts, 2015b). Hence it was a surprising result that the participants ranked leaflets less than ‘written information’ which was as relatively useful at 53.1% and webpages just behind at 49%. An additional point about leaflets was made in that they offered confidentiality and privacy, both key findings throughout this data analysis:

**SN:** ‘leaflets that can be read later on when alone, so there is no embarrassment etc’.
Further there were comments about information within leaflets being adult centric or focussed on how adults think young people want to consume the information:

SN: ‘we need a crib sheet of typical examples that teenagers go through and ways to handle it ourselves as we don’t always like going to those with more authority’

This linked directly to Coleman’s assertion that young people wanted to see someone ‘more understanding of teenage issues’ (2011:2). Further, the interpretation of the co-production group drawn from these results, was that participants defined ‘written’ as items that needed to be read and as such leaflets, webpages and instructions may have been understood under this term by the participants. This explanation linked to the next set of questions which identified other information formats which were not written and so made a clear distinction. Illustrations and watching a video were rated slightly less useful than leaflets at 44.9%. An interesting point made by participants was that the source of these illustrations and videos was important to them and further supports Ofcom (2016) finding that young people are increasingly discerning users of multi-media:

SN: ‘online such as the nhs website’

SN: ‘found on reliable websites online’.

Media campaigns were found moderately useful at 30.6% and this was explained in the narrative analysis as linked to public visibility, trends and ease of access. However, there was little qualitative evidence of the effectiveness of the campaigns:

SN: ‘campaigns that raise awareness’

SN; ‘due to the fact the majority of Britons have access to the media, and can therefore be reached very easily in this way’.
Interactive discussion and having a demonstration was rated low in terms of usefulness at 28.6%. This was another surprising rating as the co-production group had highlighted discussion and demonstration as an effective learning approach about health and health services. Interestingly, participants’ narrative analysis suggested the low rating related to the right to privacy and confidentiality:

SN: ‘being told about it along with other people. I prefer it when it’s more private’.

This, again, raised the importance of confidentiality and the right to privacy for the participants, highlighted in these findings, and without this, young people were reluctant to engage with health education (Bates and Freeman, 2014, Coleman, 2011).

**Understanding health information**

Understanding health information is an essential aspect of health literacy and so the survey included questions about this. Table 4.8 summarises the responses of participants in relation to questions which asked whether they understood health information in various formats. A critical reflective point was that, whilst the question set for table 4.8 was considered carefully, the question cluster was framed as an unintended double negative. This was tested by the co-production group and they found they answered as the participants had: ‘no’ affirmed the statement and ‘yes’ rejected the statement.

Table 4.8 shows that nearly two-thirds of the participants said they *always* understood health information. This was in stark contrast to the rest of this data set showing high levels of confusion about health information and was a point that the co-production group challenged. The co-production group discussion centred around how the content was given by health information such the format, use of jargon, medicalisation, complex instruction, numerical information and the nature of the health warning notices. They felt health information was so steeped within health culture that they felt they were passive receivers of this information, powerless to ask questions if they did not understand. This narrative analysis is new information and suggests one reason why young people might not engage with health information. Figure 4.9 illustrates an example of the lengthy debate the co-production group held in interpreting the narrative from the survey.
Fig. 4.9. Co-production notes of discussion showing contesting the survey results of two-thirds of participants understanding health information.

This echoed the findings of Elliott et al (2013) that only limited (health information) work had attempted to re-engage young people in their health. Further, this fed into the notion, proposed by this study, of insider knowledge required to understand health information and reinforces the notion of NHS institutional paternalism alongside subtle disenfranchisement of ‘others’ (young people) of health services.
Table 4.8 Understanding health information

<table>
<thead>
<tr>
<th>Question</th>
<th>No % (n)</th>
<th>Yes % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don't understand health information because don't feel confident to follow the advice?</td>
<td>79.6 (n=39)</td>
<td>20.4 (n=10)</td>
</tr>
<tr>
<td>Don't understand health information because don't understand the words used in the information?</td>
<td>83.7 (n=41)</td>
<td>16.3 (n=8)</td>
</tr>
<tr>
<td>Don't understand health information because instructions are too difficult or complex?</td>
<td>93.9 (n=46)</td>
<td>6.1 (n=3)</td>
</tr>
<tr>
<td>Don't understand health information because don't understand the illustrations?</td>
<td>100 (n=49)</td>
<td>0 (n=0)</td>
</tr>
<tr>
<td>Don't understand health information because can't use or access the information?</td>
<td>89.8 (n=44)</td>
<td>10.2 (n=5)</td>
</tr>
<tr>
<td>Don't understand health information because given different advice and not sure which to follow?</td>
<td>79.6 (n=39)</td>
<td>20.4 (n=10)</td>
</tr>
</tbody>
</table>

The responses corresponded broadly to section 3.1 (Usefulness of health information). Of note all participants found health information via illustration understandable. This was supplemented throughout the narrative analysis as:

*SN: ‘lines of lines of information (not helpful). Laying it out in pictures or a special format makes it much easier to read, and appeals to a wider age range’.*

Health instruction was found to be very highly understandable at 93.9%,

*SN: ‘telling you, exactly, what to do’.*
The ability to obtain, process and understand health information (Massey et al, 2012) and thus make informed decisions about health underpins the notion of health literacy. These aspects were seen through the narrative and commentary of this section. This further highlighted the three recurring themes found within this study, of trust (not be judged, confidence in knowledge), confidentiality (intimate details treated with respect and shared only when critical) and the right to privacy (overcoming shyness) with an increasing emphasis on trust in the legitimacy and evidence of the health information.

The narrative asked participants to comment on ‘what kind of health information is NOT useful?’:

Theme trust: This was noted through two aspects: firstly, that the person imparting the information could be trusted to give advice objectively and secondly that young people trusted the knowledge of the person through education, experience and role.

SN: ‘..and teachers tend not to have a huge knowledge of health related issues anyway’

SN: ‘information given on websites such as Facebook because you don’t know what you trust’.

Theme confidentiality: This related to the need for the young person to have confidence in the person being able to deal discreetly with the health issue and share only when the need was critical.

SN: ‘...especially as I don’t want people knowing about my personal issues..’

Theme right to privacy: Having some resonance with confidentiality, the right to privacy related to the place and space of learning about health aligned with trust in the comprehensive nature of the health information which could then be taken and reused by the young person in a safe format (for example at home).

SN: ‘being told it along with other people. I prefer it when it’s more private’.
SN: ‘I want to be able to read it in my own time, but I like to have someone to ask if I don’t understand’.

Figure 4.10 shows examples of the narrative generated asking participants about helpfulness of health information.

Fig. 4.10: Example of survey narrative ‘what kind of health information is NOT useful?’

Class discussions can sometimes be useful, but not always. It’s often embarrassing to ask questions and often some classmates do not take it seriously. And teachers tend not to have a huge knowledge of health related issues anyway.

dependent on the sensitivity if the health information, but public and group discussions and information can make me feel intimidated, especially as I don’t want people knowing about any of my personal issues. I also find lots of unreliable websites and self diagnose sites negative and not useful as they give people a false diagnosis and often incorrect information.

Diagrams without instructions

Extreme stories about sex

Healthy eating/balanced diet.. WE KNOW!

Information given on websites such as facebook because you don’t know what you can trust.

Information that would scare me more than educate me.

Internet discussions quickly descend into fallacies and personal affronts - they are not helpful. Written instructions can be unclear.
One other new and notable message from the narrative analysis was the need for health information to be *balanced*. This is seen within the context of the knowledge being educational and information rather than developing a sense of unnecessary worry and fear.

**SN:** ‘*Information that would scare me more than educate me*’

**SN:** ‘*extreme stories about sex*’

Bates and Freeman’s (2014) found that young people did not conform to adult presumptions and this aligned with the CPG assertions and other literature (Kennedy, 2010, Coleman, 2011, Hope, 2015) that young people’s health was planned from an adult-centric viewpoint. Indeed, the survey narrative emphasised that young people’s traditionally targeted health messages are now having a negative impact:

**SN:** ‘*particularly about STI’s and alcohol because teenagers have other problems part from that. All people seem to talk to us about is those two topics*’

**SN:** ‘*Broadly stereotyping all teenagers and trying to help us with diet or sexual health....*’

**SN:** ‘*obvious information, like ‘chocolate is bad for you’.*’

As noted in the literature, Hargreaves et al (2012) argued that:

‘*Young people are often dissatisfied and do not engage with health services; however, we do not always understand how their health care priorities differ from those of older adults*’ (2012: 528).
This study adds to the knowledge of what young people’s health priorities are, significantly, this knowledge is generated from young people themselves. This crucially, redresses the imbalance of health priorities being adult-centric through its participatory interpretivist approach and is discussed in the final chapter as part of the proposed Health Literacy Education. Figure 4.11 summarises key topics suggested by the co-production group on incremental health literacy development.

Fig 4.11. Co-production group key topics for health literacy

Skills in understanding and using health information

In thinking more pragmatically about health literacy, young people and the potential implications for practice the study sought to establish what skills young people thought they needed in order to understand and take control of their health. Earlier literature (Nutbeam, 2000) suggested health literacy as essentially functional and the IOM (2004) added to these functional skills the need for cultural and conceptual knowledge, oral literacy, print literacy and numeracy. More contemporary research on health literacy suggested that complex communication skills, media literacy, digital literacy and internet information-seeking skills were also co-requirements of being health literate (Harper, 2014, Sheridan et al, 2011). Abel et al (2014) built on Nutbeam
(2000), and argued that health literacy was both applied and context-specific. This was an important point as it began to suggest that by simply knowing a person was literate and numerate it could not be assumed that the person was also health literate. What was clear was that functional skills underpin health literacy (Nutbeam, 2004, Roberts, 2015a).

The co-production group discussed what skills they thought were essential for health literacy and they concluded being able to seek out help was an essential skill for health literacy. This led to discussion about how actual and virtual communication facilitated young people’s use of health, specifically in understanding health issues. They concluded that being health literate was a life skill they needed as they prepared for young adulthood and this corresponded with recent literature (Roberts 2015a, AYPH, 2016).

The study sought to understand what skills participants thought they might need in understanding and using health information. Being mindful of the literature and the co-production group discussion, the survey sought to capture participants views of functional skills, such as following instruction, the survey also asked about more complex skills of confidence, complex communication styles and understanding health information. Table 4.9 shows participants’ responses about skills required in using and understanding health information.
### Table 4.9 Skills in understanding and using health information

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes % (n)</th>
<th>No % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being literate is key skill needed to understand health information?</td>
<td>85.7 (n=42)</td>
<td>14.3 (n=7)</td>
</tr>
<tr>
<td>Understanding maths / numbers is key skill needed to understand health information?</td>
<td>20.4 (n=10)</td>
<td>79.6 (n=39)</td>
</tr>
<tr>
<td>Understanding health language/terminology is key skill needed to understand health information?</td>
<td>53.1 (n=26)</td>
<td>46.9 (n=23)</td>
</tr>
<tr>
<td>Being able to follow easy instructions is key skill needed to understand health information?</td>
<td>85.7 (n=42)</td>
<td>14.3 (n=7)</td>
</tr>
<tr>
<td>Being able to follow complex instructions is key skill needed to understand health information?</td>
<td>26.5 (n=13)</td>
<td>73.5 (n=36)</td>
</tr>
<tr>
<td>Being able to talk to someone / ask for help is key skill needed to understand health information?</td>
<td>79.6 (n=39)</td>
<td>20.4 (n=10)</td>
</tr>
<tr>
<td>Being able to use the internet is key skill needed to understand health information?</td>
<td>53.1 (n=26)</td>
<td>46.9 (n=23)</td>
</tr>
<tr>
<td>Having confidence to seek out support is key skill needed to understand health information?</td>
<td>73.5 (n=36)</td>
<td>26.5 (n=13)</td>
</tr>
</tbody>
</table>

85.7% of survey participants felt that being literate and being able to follow easy instruction were both essential to understand health information and this was reflected in existing literature (Nutbeam, 2000, IOM, 2004). Following easy instruction was suggested by Nguyen et al (2011) as applied health literacy knowledge. Further the top participant selections were reflected by the co-production group analysis of skills being developed that would be durable and purposeful:

*SN: ‘being able to read – you often need to be able to read instructions’*
Talking and asking for help (in order to understand) was rated second highest by participants at 79.6% and directly correlated with the co-production group discourse. This issue was included in this survey but was not part of other young people’s health surveys (PHE / AYPH, 2015, Atkinson, 2013). This suggests new knowledge in supporting young people about their health and developing health literacy and is closely linked to another new aspect from participants, of having confidence to seek support, which at 73.5 %, was echoed by the co-production group. This acknowledgement of participants that talking and asking for help and needing confidence to do this reflected further the assertion of the study that young people need trust, confidentiality and the right to privacy in order to effectively engage with health services, advice and information – in becoming health literate:

CPG: ‘having confidence to seek support is important because otherwise you will end up suffering in silence’

SN: ‘confidence to seek out support because if you won’t ask for help then people might not know you need any help’

In contrast participants rated following complex instruction (26.5%) and numeracy (20.4%) as low skills required for understanding and using health information. The literature reflected this low rating and Rowlands’s (2014:7) research concluded that when health information was presented numerically 61% of working adults could not understand this – they were effectively health illiterate. The narrative analysis of the survey explained this from the participants point of view as:

SN: ‘….maths should not be involved as many people struggle’

This is an important issue as mathematics, even at a basic level, is very often part of health treatment, such as dosage and frequency of medication. Whilst the Internet was rated very highly (81.6% Table 4.4) as a source of health information, being internet capable is only identified moderately (53.1%) as a skill needed to understand
and use health information. There was also cross-over in the narrative in that participants linked the Internet with the ability to read, follow instruction, and need for confidence (to seek support) and confidentiality. These were all suggestive of the modest Internet ranking:

SN: ‘so you are able to utilise it, i.e., a YouTube video instructing you on how to do CPR’.

SN: ‘reading through instructions on the Internet’

SN: ‘easiest way to access information is online. Confidence is needed to ask for advice in person’.

SN: ‘online and not be embarrassed’.

Similarly understanding health terminology was rated moderately (53.1%), as a skill needed to understand and use health information, but participants identified this highly as a potential barrier in Table 4.8 at 83.7%. The narrative analysis suggested participants understood health terminology if it was presented within a useable context, often in multiple formats:

SN: ‘because the information can come in many forms, on the leaflet with diagrams- I can get that’

SN: ‘follow the packet and (instruction) from the doctor – then you understand what they said and meant’

As a summary, the study and the literature about understanding and using health information, found that, as a starting point health literacy, rested upon a functional skill-set that is required to become more complex and nuanced (Sheridan et al, 2011, Massey et al, 2012). Further that these skill-sets were transferable and sustainable (Sorenson et al, 2012). Across the course of the study the co-production group felt that taking control of their health was an essential aspect of emergent adulthood and this has been seen in the literature (Roberts, 2015a, AYPH, 2016). Indeed, this was
something of a driver for them in their commitment to volunteer for the study. The discourse of this section allowed the co-production group to articulate this value into a tangible outcome of incrementally learnt health knowledge to support health literacy, seen as Health Literacy Education (chapter 5).

**Who should teach you about your health?**
Reflecting upon the dissemination about health and health services, advice and information alongside the skills required to understand and use this, raises of the question of who should facilitate this dissemination. Smith-Greenaway suggested ‘*health salience*’ (2015:131) as part of an educational framework and attainment. Analysis of the literature showed that poorly taught health education risked disengaging young people (Hope, 2015) from developing their health literacy. Aligned with this, participatory theory suggested that involving young people (Schalker et al, 2016, Tisdall et al, 2014) would improve their engagement with this. As a start to this participatory approach the survey asked participants who they thought should teach them about their health, identifying those they might engage with for this. Table 4.10 asked participants who should teach them about their health.
### Table 4.10 Who should teach you about your health?

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes % (n)</th>
<th>No % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Should parents / carers teach you about your health?</td>
<td>83.7 (n=41)</td>
<td>16.3 (n=8)</td>
</tr>
<tr>
<td>Should family / relations teach you about your health?</td>
<td>34.7 (n=17)</td>
<td>65.3 (n=32)</td>
</tr>
<tr>
<td>Should school / teachers teach you about your health?</td>
<td>79.6 (n=39)</td>
<td>20.4 (n=10)</td>
</tr>
<tr>
<td>Should health professional (such as School Nurse) teach you about your health?</td>
<td>85.7 (n=42)</td>
<td>14.3 (n=7)</td>
</tr>
<tr>
<td>Should the Government / NHS (such as Change4Life) teach you about your health?</td>
<td>73.5 (n=36)</td>
<td>26.5 (n=13)</td>
</tr>
<tr>
<td>Should clubs and organisations (such as Youth Club) teach you about your health?</td>
<td>24.5 (n=12)</td>
<td>75.5 (n=37)</td>
</tr>
<tr>
<td>You have English and Maths lessons. Do you think you should have lessons that help to explain and understand your health?</td>
<td>59.2 (n=29)</td>
<td>40.8 (n=20)</td>
</tr>
</tbody>
</table>

85.7% of survey participants said that a health professional should teach them about their health. This matched with findings from Table 2.2 where participants said they would ask health professionals for health support and advice. However, there was also a contrasting response, seen in Table 2.2, with nearly two thirds (61.2%) of participants saying they would not ask a school nurse for health support or advice, but 85.7% said school nurses should teach them about their health. The nuance of the question is important, as being taught about health is quite a different and distinct relationship to seeking support and advice. The RCN (2014) set out the role of school nurses was to educate staff about health needs of pupils and address targeted health needs of the (school) community. The AYPH (2016) suggested school nurses should be bought in to improve the health literacy of pupils using a health promotion approach. Due to reduced numbers of school nurses (RCN, 2014) they are not available as students’ first point of call for health support and advice. Further the RCN (2014) found school nurses did not have a particularly visible presence in schools and
colleges. However, narrative analysis indicated the higher rating of health professionals for educational purpose linked closely to the element of trust, and confirm that HCP’s (school nurse) approach to health education would be trusted. The co-production group called this ‘a legitimacy in the information source’.

SN: ‘...NHS can trust but it needs to feel confidential to receive the information happily’

SN: ‘there should be classes where they teach you the basics of health and well being. Health prof (including nhs) should tell you’.

Trust in the quality, reliability and validity of the health support and advice came through strongly with ranked responses seen in Table 4.6 related to GPs, HCP and other health services, and the rich narrative of the responses replicated this for the educational aspect of health professionals’ roles:

SN: ‘would prefer if we were taught by a health professional who would be able to answer more complex questions and have a wider knowledge of health issues, like a nurse’.

Parents and carers were also highly rated as educators about health (83.7%) and much of the narrative analysis and co-production group discussions further strengthened the themes of trust, confidentiality and the right to privacy:

SN: ‘Family and parents should feel comfortable to talk about health and discussing it at home will make it more comfortable’

SN: ‘I was taught about health at home. It has given me advice I can trust’

SN: ‘you can open up to parents the most and they know you best’.

However, there were some contrary responses that indicated parents (and families) alone should not be the sole educators for young people about their health, and this is
a cautionary message in thinking about the responsibilities of developing young people’s health literacy:

CPG: ‘maybe some families are less supportive than other, maybe they are the problem’

CPG: ‘you should be independent, like, may do and ask things you don’t want parents knowing’

SN: ‘as you get older it’s better not with parents, it’s better to be told by a professional’.

This very point is supported in the literature; Cha et al (2014) found that young people living at home with parents, showed a lower level of overall health literacy than those living alone. Whilst not concluded within Cha et al’s research it is alluded that parents were unwilling to relinquish control of the health issue to their children, maintaining a state of disempowerment. Whereas, Schulz and Nakamoto suggested empowerment as a key aspect of ‘improving health outcomes’ (2013: 4).

Another contrasting finding is that 79.6% participants said they would not ask teachers for health advice / support (Table 4.5), however school and teachers were equally highly identified to teach about health 79.6%. The higher rate appeared to come from what participants indicated as their lived experience; being taught by teachers about health in school. A deeper critique of this situation is that this teaching was not steeped within the three aspects of trust, confidentiality and the right to privacy, found to be central from this study. As reflected already in section 3.2 narrative commentary included;

Trust, (not be judged, confidence in knowledge):
SN: ‘lots of people act stupidly in those classes and she (teacher) found it difficult to answer’

SN: ‘teachers tend not to have a huge knowledge of health anyway’

Confidentiality, (intimate details to be treated with respect and shared only when critical):

SN: ‘It’s patronising, it is in front of other people and peers (school)’

Right to privacy, (overcoming shyness):

SN: ‘Only health teaching was in assemblies – not private or anything’

The literature supported the study position that trust, confidentiality and right to privacy must underpin health learning as Pounds et als’ research (2016) found that young people felt it wrong that teachers delivered these sessions, citing lack of anonymity, embarrassment and blurred boundaries. Lastly, teacher education does not prepare or train them to deliver health education (HM Gov., 2016) and further because health is a supplementary subject to the national curriculum (DE, 2013) there is no compulsion for schools to spend time teaching about health. The co-production group discussed effective health learning and concluded that teachers were not best placed to educate young people about health.

However, they did see value in teachers’ introducing the fundamentals of health for primary aged children and built this into the study’s recommendation of Health Literacy Education (chapter 5). This can be seen in Figures 4.12 and 4.13 (below) that show the co-production group and researcher development of health literature development for young people.

Figure 4.12. Co-production group annotation on survey and discussion noting teachers not appropriate people to education around health
The co-production group and researcher concluded that the relationship and trust primary aged children had for their teacher was more sustained due to the stability of the role of ‘class teacher’ in primary school. Further, if the class teacher was...
supported by a school nurse (RCN, 2014, 2016) this seemed a reasonable approach to make for health teaching.

Participants rated Government / NHS sources fairly highly at 73.5%, to teach them about health. This contrasted with media campaigns found as broadly not useful at 30.6% (Table 4.7). Reflecting on this study's identification of key components of engaging young people with their health as trust, confidentiality and right to privacy, the Government and NHS have been clearly cited as trustworthy throughout the survey narrative analysis:

SN: 'learn through government campaigns'

SN: ‘use a trusted one, like, look up on NHS, change4life’

SN: ‘web pages not written by qualified medical professionals eg WebMD’

The question related to teaching, and analysis of this data suggested that participants were discerning (Ofcom, 2016) and proficient with their use of the Internet in gathering health information as a process of education. This format of education also overcame issues of confidentiality and right to privacy as this education happened discreetly. There was an issue of the quality of the education but the narrative analysis supports further the notion of discerning use (Ofcom, 2016):

SN: ‘I also find lots of websites and self diagnose negative and not useful...incorrect information.

Increasingly the Internet was found to be an essential tool for life with an acknowledgement that as children become older they became more expert in their life online (Tisdall et al, 2014) and this informed the study choice of the survey being hosted online.

About a quarter of survey participants felt that clubs and organisations have a part to play in teaching young people about their health (24.5%). Given that clubs are often staffed by volunteers and are not places that offer expert and trusted information
about health, neither do they offer confidential nor private spaces, thus this was not considered as an option in application to practice outcomes.

Lastly, above half (59.2%) of participants thought they should have lessons that explained and helped them understand their health and health services. That was important as young people recognised their need to know about their health and health services and acknowledged a gap in their education about this. The narrative analysis described participants experiences of some health teaching and how they have linked functional educational skills to skills needed for health:

\[ \text{SN: ‘general education should provide most people with the simple skills required to understand information’} \]

\[ \text{SN: ‘get taught to read in school which will enable them to read health leaflets} \]

There was also a thread of how being taught about health was not an exclusively school domain but was mostly recognised as being delivered within the school environment.

\[ \text{SN: ‘when the nurse came in (school) and talk to groups of them at a time’} \]

\[ \text{SN: ‘though school and everyday activities’} \]

\[ \text{SN: ‘through school assemblies, through observing parents while growing up, government information campaigns’} \]

These points were considered and built upon with the CPG in developing a potential framework for Health Literacy Education (chapter 5) for children and young people and can be seen in an early development of health literacy in schools (Figure 4.14).

\[ \text{Fig. 4.14: Work from co-production group towards creating model for health literacy in schools.} \]
4.7 Developing health literacy education.

In keeping with the ethos of organic participation and utilising the lived experiences of young people, the survey sought rich data from the participants about their views of empowerment, learning and education about health and health services. This data was thematically analysed (Silverman, 2016) through the co-production group process and raised topics from the participants which informed the study’s health literacy education for children and young people (chapter 5). The emergent topics from the participants were:

- Preferences, styles and effectiveness of educational styles
- Identified health learning and health learning needs
- Empowerment; self-responsibility and the importance attached to learning about health.

4.7.1 Preferences, styles and effectiveness of educational styles
Preferences, styles and effectiveness of educational styles falls into the health information theme of the collective data findings. The participants overwhelmingly cited integration and interaction as their preferred and most effective way of learning. This aligned with a participatory pedagogic teaching style (Ormrod, 2014) increasing seen as educationally empowering (UNESCO, 2014). This included use of varied teaching approaches, assemblies, class, group and individual work, use of expert knowledge and durable resources:

SN: ‘school environment could be a fun and less embarrassing way to learn with friends’

SN: ‘people coming into the school, giving talks and stuff, they listen to you and answer’

SN: ‘School talks from health professionals, videos, when they explain them, leaflets I can take away’

SN: ‘there should be school classes where they teach you the basics of health and wellbeing’.

From this commentary, the notion of trust came through strongly as did the wish of young people to be educated and not to be scared (see Section 3.2). There was also a strand of formalisation from participants, and this was explained in the narrative analysis to reflect the importance of the learning:

SN: ‘Being given information in the form of lessons means it is important to learn for exams and therefore you will absorb it better’.

SN: ‘general school and education – it’s part of that or it won’t happen’

SN: ‘school and school nurses have a duty to inform pupils of health-related issues and be there to support if students do not feel they can talk to their parents or family’
For the study focus, this would place health literacy education as a life skill and it would be considered as comparable to main curriculum subjects.

4.7.2 Identified health learning and health learning needs

Identified health learning and health learning needs adds to the three themes from the data findings of services, advice and health information. Participants narrated their health learning needs as a process and part of growing up, Further, their commentary referred to the level of experiential learning that happened around health. This is not without its risk, and places health literacy education as an empowering safeguarding skill:

SN: ‘anecdotal, as in, I’ve been through it’

SN: ‘Doing it’

SN: ‘Experience and guidance’.

Another aspect of health learning needs was that participants and the co-production group began to list gaps they felt they had in their knowledge of health and to topics they wanted to know more about. This demonstrated a close correlation in two phases of health knowledge, and knowledge and safety. These have been identified through frequency and analysed by the researcher and the co-production group. The learning needs have been clustered into ‘growing up’ and ‘staying healthy’. The first cluster, ‘growing up’ encompassed learning about growing older and transitions from child to adult life, development of resilience. More practical skills would include how to look after yourself and others, recognition of common illness, and dealing with illness - knowing what to do. This would incorporate using medicines and understanding medical instruction / health advice and information:

SN: ‘growing older and dealing with family illness, how to look after people’

SN: ‘what drugs are useful for which illness, for example when you have a cold...’
SN: ‘what the most common illnesses / diseases are for my age group / gender…minimise risk’

SN: ‘where to go if I do become ill’.

The second learning needs cluster was ‘staying healthy’ and some of the explanation choices came from the poor quality of teaching participants had already received; for example, teaching about sexual health, mental health, healthy eating and obesity. This implies that the health education for these topics needs to be reviewed. Whilst the participants have had health messages on these topics, they remained broadly health illiterate on these subjects:

SN: ‘mental health, …no-one (participants) knows or understands, which means not only people don’t know how to cope / where to get help, but people don’t know how to spot signs’

SN: ‘more on sex ed….or more useful sex ed’

Identified by the study participants, other topics that need new, more or renewed emphasis within staying healthily were relationships, stress, learning first aid and physical health. There was some correlation of the participants’ identified topics and the topics from the PHE/AYPH (2015) such as need to promote knowledge of mental health and improve sex education, understanding relationships and building children and young people’s resilience. However key targets from PHE/ AYPH (2015) and DE (2013) such as reducing alcohol intake, reducing teenage pregnancies did not feature from the participants. That should not mean these topics are disregarded, as noted by one participant, but indicates a greater need for the health message to be meaningful for the participants:

SN: I don’t know what I don’t know’,

Other topics have emerged through the literature such as emotional health (CRAE, 2015) and the study proposes a pragmatic approach in understanding issues, such as the development of resilience, as a transitional life skills.
4.7.3 Empowerment; self-responsibility and the importance attached to learning about health.

Empowerment; self-responsibility and the importance attached to learning about health was the last emergent topic from the participants’ discourse. This included participants’ considering and commenting upon maturity and age and the importance attached to this learning in taking control of their health. Participants were clear that health learning needed to be staged and linked to life stages such as independence. There was a strong acknowledgment that maturity happened differently and that aspects of health empowerment were linked to legalisation and safeguarding.

SN: ‘old enough (14) to have some responsibility, mature enough to take things seriously and intelligent enough to understand how to look after yourself’

SN: ‘it’s the time (16) when society puts most pressure on your to be an adult, in order to take more care of yourself’

SN: ‘old enough to understand the information, you should not rely on your parents anymore (12)’

SN: ‘you must know (about health). You start to become aware of dangers and how to fix them, stay safe, and you mature at this age (12)’.

Hence the study proposes a pragmatic approach to building Health Literacy Education through incrementally developed and themed health issues using a participatory pedagogic teaching approach. Aligned to this proposal (chapter 5) the co-production group considered topics from the survey and reflected upon their own health literacy development as part of the study work towards applied Health Literacy Education. This work formed the basis for applied Health Literacy Education presented as part of the study’s application to practice and recommendations.

4.8 Summary
Themes derived from the descriptive data findings which used cross-tabulation and thematic analysis were (health) Services, Advice and Health Information. Further interpretative analysis drawn from the survey and discourse of the co-production
groups identified Trust, Confidentiality, and the Right to Privacy as integral components of health use and knowledge for young people.

Ormshaw et al (2013) found insufficient evidence or description of what health literacy meant for young people, however this study proposes that health literacy is a life skill for young people and would lead to health emancipation. Further, individual agency (being health literate) mitigated against health inequalities. Lastly, development of young people’s health literacy should start from young children and be incremental, empowering, aiming to educate and not scare, supporting the transition into adolescence, when long-term health beliefs and behaviours are formed (Cha et al, 2014, Atkinson, 2013:2) and smooth the transition from dependant young person into independent young adulthood (Roberts, 2015a, AYPH, 2016).
5. Conclusions and application to practice

5.1 Introduction
Using interpretive co-production as an encultured methodology (Smith and Smith, 2014), this study has been rooted in young people’s thinking about the implications of health literacy and has engaged them in finding solutions in enhancing health literacy for young people. This thread underpins the discussion points in this chapter.

This chapter starts with a summary response to the study’s four aims followed by an integrated discussion of health literacy as a life skill – tackling inequalities, and young people and their health. The chapter then explains the study’s application to practice in two parts through interpretivist co-production participatory research with young people and proposing a pedagogical approach to Health Literacy Education. The study concludes with some reflections for future opportunities. Throughout this chapter new information generated from this study is highlighted.

5.2 Summary response to the study aims
• Conceptualise the meaning of health literacy in the lives of young people

This study has found that young people conceptualise health literacy as a vehicle in which to engage them with their health, as an issue of emancipation and equality, which would support their health-related decision-making, avoid misuse of health services and enable them to use health services appropriately. This was important new knowledge, generated by young people, which placed health literacy as a central strand in growing up. Comparable to the literature, young people from this study identified health literacy as a way to develop their independence, help their transition into adulthood and manage health conditions (AYPH, 2016, Roberts, 2015a, RCN, 2014).

Through research, this study has shown that, as a concept, learning to become health literate is an important aspect of young adulthood (Roberts, 2015a), and would enable emergent independence (AYPH, 2016), develop health autonomy (Camerini et al, 2012) and build individual and social agency (Sentell et al, 2017). Developing health literacy for young people would address inequalities (WHO, 2015, Sentell et al, 2017), ensure young people were empowered about their health (Schulz and Nakamoto, 2013) and prepare them for adulthood (Fairbrother et al, 2016, Roberts, 2015a, AYPH,
Lastly, this study has found that being health literate would facilitate young people’s individual and social empowerment (Camerini et al, 2012, Carollos, 2015).

- **Examine the link between being health illiterate and inequalities**

  This study has shown how young people understand health literacy as a life skill which would equip them for adulthood and is thus an issue of equality, with evidence that lower levels of health literacy is associated with social inequalities (WHO, 2015, Rudd, 2015, Roberts, 2015a, AYPH, 2016). Being health illiterate culminated in poor health outcomes (Rowlands et al, 2015), low social capital and health isolation (Harper, 2014, Sentell et al, 2017), misunderstanding and misuse of health services (Batterham et al, 2016, Rowlands et al, 2015), little engagement with health prevention (Roberts, 2015a, Sentell et al, 2017) and poor control of health conditions (Rowlands et al, 2015, Rudd, 2015). Having a health literate population would mitigate these issues through an informed populace (WHO, 2015), expedient use of health funds (Sentell et al, 2017), and social and health cohesion (Sentell et al, 2017). Individuals and communities would be better able to manage their health (Rowlands et al, 2015, Rudd, 2015), seek out and use health services (Batterham et al, 2016) and be more engaged with health (Rudd, 2015). Health literate institutions and organisations would be more effective in using their resources through a more open and honest joint understanding with their users (Rowlands et al, 2015, Sentell et al, 2017).

- **Explore how young people acquire, develop and use health literacy**

  The contributions of the young people in this study have shown that they had limited engagement with health learning activities and have learnt about health in an ad hoc way or simply incidentally. Current health promotional activities were not engaging young people (Smith-Greenaway, 2015, Massey et al, 2012, CRAE, 2015) and health information was too complex (Rowlands et al, 2015, Rudd, 2015), too adult-centric (Hargreaves et al, 2012, PHE, 2014, AYPH, 2016), and did not address young peoples’ needs (Schulz and Nakamoto, 2013, Hope, 2015, Roberts, 2015a). The study has evaluated young people and their health, and their engagement with health services and has shown that young people have been disenfranchised from health through lack of voice (Hope, 2015, Mansuri and Rao, 2015, Schulz and Nakamoto, 2013), services developed without due concern for their needs and wants (Massey et al, 2012, Fergie et al, 2015) and barriers to health services through misunderstood health processes
Young people expressed a desire to be supported to be health literate and research highlighted the value of this (Roberts, 2015a, Hope, 2015, Fairbrother et al, 2016).

- **Produce recommendations for practitioners and policy makers concerned with improving the health outcomes of young people aged 16-19 years in England**

  The young people in this study wanted to learn about and take control of their health. They understood this as an important transition into adulthood and literature supported these points (Roberts, 2015b, AYPH, 2016, Schalkers et al, 2016). Further, through taking control of their health (Schulz and Nakamoto, 2013, CRAE, 2015, Fairbrother et al, 2016) young people wanted to make their own decisions about this (Smith-Greenaway, 2015, Hagell, 2015) in order to facilitate their emergent independence (AYPH, 2016, Fergie et al, 2015). Whilst there is some evidence that greater levels of functional education indicate a greater likelihood of being health literate (Raingruber, 2012) this link is more complex (Roberts, 2015a). This study has found that being educated does not always equate to being health literate (Rudd, 2015, Batterham et al, 2016). Health literacy was influenced by other factors such as socio-economics (Harper, 2014, Roberts, 20015a), social agency and competence (Abel et al, 2014, Sentell et al, 2017), discrimination (Emerson and Baines, 2010) and poverty (Harper, 2014). To tackle these issues, PHE / AYPH (2015) recognised the need to ‘improve health literacy’ (2015:15).

  This study concurs with this view and recommends a tangible pedagogical approach to improving health literacy, Health Literacy Education for all school age children and young people. This is a significant recommendation which offers an innovative and original approach in developing health literacy for children and young people. This study has found that young people want Health Literacy Education to be taught in school and structured to teach them about health as they develop and mature. They want scaffolded health learning to match the changing agenda of growing up and suggested their incremental health autonomy be developed alongside their health knowledge. In practical terms, the young people felt Health Literacy Education would be directly with teachers and guest health educators in primary school with increased use of health experts and technology-based learning for older children and young people. A detailed proposal of how Health Literacy Education might look, can be seen...
in Appendix 6: Incremental Health Literacy Learning. This was a culmination of work by the researcher and CPG.

5.3. Health Literacy as a life skill: tackling inequalities

Health literacy is a life skill that is dynamic, inter-dependent and based upon self-agency (Camerini et al, 2012, Massey et al, 2012, Smith-Greenaway, 2015). It is influenced by the relationships and capacities of the individual (Schulz and Nakamoto, 2013, Massey et al, 2012) and organisations (Rowlands et al, 2015). This study suggests that a broader, emancipatory approach to the development of health literacy enables health self-efficacy. The benefits of self-efficacy in health for individuals, communities and society are significant in terms of better health (WHO, 2015, McCormack et al, 2017), socio-economics (Rowlands et al, 2015), social cohesion (Sentell et al, 2017) and contributing to social equality (Batterham et al, 2016).

Being health illiterate has a strong causal attachment with poverty (Sentell et al, 2017, Rowntree and Shaw, 2014), poorer life outcomes (WHO, 2015, Rudd, 2015), and health and social isolation (Harper, 2014). Roantree and Shaw’s (2014) research demonstrated this relationship and concluded that health illiteracy perpetuated social inequality.

It is important to acknowledge that being health literate is not only an individual attribute (Sentell et al, 2017) but is also a social, cultural and institutional issue (WHO, 2015, Rowlands et al, 2015). McCormack et al (2017) found that use of health services does not indicate health literacy. This study suggests this use as a passive state of receivership (of health services) rather than knowledgeable engagement. Being health literate moves individuals from a passive receiver to an active participant in their health and using health services. Squiers et al (2012:30) found health literacy to be embedded in health, social and cultural systems and placed health literacy as an issue of educational and public health.

As with other social inequalities issues such a low education attainment (CMO, 2013), poverty (Marmot, 2010), familial health illiteracy can be cyclical. This study found that young people learn about health from their family, however families who were health illiterate did not support the development of health literacy in young people (Rowlands et al, 2015, Rudd, 2015). This study proposes that through teaching young
people to be health literate, this cycle will be broken. Developing health literacy across cohorts of young people would tackle inequality individually and as a society. Thus, health literacy is an issue of social justice. Kickbush (2001) and Rudd (2015) suggested that schools have a role in empowering children about health decisions and it follows that teaching health literacy to pupils of all abilities and from all backgrounds would contribute to reducing health inequalities. This study, and the participant young people, recommend that health literacy should be taught to children and young people in schools to tackle inequalities and develop life skills.

5.4 Young people and their health

This study’s methodological approach has tested out an innovative approach to participative research with young people which has generated new knowledge in understanding young people’s views about health knowledge and emergent adulthood. Youth, as a pathway, infers it is a time-constrained phase (Furlong, 2013) and that phase remained adult-centric in terms of power and control (Smith and McMenemy, 2016). Tisdall et al (2014) found that ‘even within spaces that are (supposedly) critically reflexive about power inequalities’ (2014:14) young people were marginalised, particularly in decision making processes. This study addressed this marginalisation through its innovative methodology. Further, this study concluded that being health literate is empowering and should be nurtured and developed as young people transition into adulthood.

Checkoway, (2011) found that participation contributed to a democratic society through recognition of expertise. This study has assumed young people as experts about themselves, and acknowledged this through the influential position they have held through the co-production paradigm. Co-production has shaped the flow of the study, the nuance of the findings and generated new knowledge about their views on health and health knowledge.

Firstly, the study found that young people do not want to be paternalistically stereotyped as ‘childlike’ and dependant (Hudson, 2012, Schalkers et al, 2016) about health. The study concluded that young people are not simply passive recipients of (health) care (Smith-Greenaway, 2015, AYPH, 2016) but want to be empowered and
independent about their health which they see as part of their transition into adulthood. Echoing previous literature (Ocloo and Matthews, 2016), this study has found that young people consume health in different ways to adults. Their use of health flips between real and virtual health services and as competent (Ofcom, 2014) digital consumers (Bayne and Ross, 2011) young people were at ease with this. A key finding of the study has been to evidence how young people assumed they would learn about health once they became an adult, rather than as part of a growing up process. Conversely, the study found that young people want to learn about their health. Further, young people believe that health services are designed for and used by adults (Hudson, 2012, CRAE, 2015). These two points are of concern and suggest new reasons as to why young people disengage with health education and services.

The study found that there are myths about health held by young people that could be bridged through being health literate, for example, the need for a young person to be accompanied by an adult (for health and health services), effectively acting as a gatekeeper. As acknowledged by Hope (2015) and Coleman (2011) these beliefs have constituted a barrier to accessing health for young people, however this study has found that these beliefs are being sustained by adults (Coleman, 2011, CRAE, 2015) and institutions (Rowlands et al, 2015). Young people said they wanted to be educated and empowered about their health and this would challenge myths and barriers.

Despite public campaigns and health promotional activities, this study has found that young people are neither aware of health services provided nor inclined to use them. This particularly applied to specific services or if services were difficult to access (Bates and Freeman, 2014) and young people will seek alternative advice and services. This is a concern as the alternative advice / service may be unsafe and cause harm, be incorrect and escalate the problem. This point has some resonance with the conclusion that young people consume health differently from adults.

Significantly, as new practice knowledge and influencing the study’s outcomes, young people said they want to be educated about their health, not scared. They felt that fear was a common method to ensure their compliance of health treatments and behaviours. The study identified three components needed from health services and
professionals in order to engage young people in their health. This was trust (not be judged, confidence in knowledge), confidentiality, (intimate details treated with respect and shared only when critical) and the right to privacy (overcoming shyness). The young people acknowledged that health services often offered some of these components, but they felt all three aspects needed to come together for young people to engage meaningfully. These three components were seen within the literature on young people’s health services (Hope, 2015, PHE / AYPH, 2015), but not as an integral whole.

5.5 Application to Practice
This study contributes to practice through both its innovative methodological approach and by offering a new pedagogical approach for health literacy education: becoming health literate.

5.5.1 A pedagogical approach for health literacy education: becoming health literate
As noted by Fairbrother (2016) and Cha et al (2014), there was little knowledge of how young people learn to be health literate, however this study has shown that young people develop health literacy in an ad hoc way through incidental life experiences, or as echoed in the literature, learnt from family members (Schulz and Nakamoto, 2013, Abel et al, 2014). This left much to chance, and is neither a coherent nor strategic way to approach developing health literacy, tackling inequalities and improving health (WHO, 2015, Sentell et al, 2017). Further, learning about health through incidental experiences or health illiterate families, left young people unsupported and at risk of harm (Elliott et al, 2013) and caught in a cycle of familial health literacy (Rowlands et al, 2015, Rudd, 2015).

This study proposes that young people should be health literate. In order to re-frame health education for children and young people, this study recommends a pedagogical approach to Health Literacy Education which will incrementally develop health knowledge, as a reflexive, interactive and multi-dimensional (Fairbrother et al, 2016) pedagogy. Aligned with the co-production group process in understanding and being informed by young people, evidence from this study suggests Health Literacy Education should be balanced, educational and informative rather than foster compliance through unnecessary worry and fear. The Health Literacy Education will be
developed by health professionals who have expert and insider knowledge and be informed by young people’s views. Given the positon that schools educate for life (Freire, 2004, Robinson and Aronica, 2015) Health Literacy Education will be delivered in school.

Health Literacy Education design, content and delivery must reflect the components of trust, confidentiality and the right to privacy. The Health Literacy Education topics will be aligned with physical and emotional maturity allowing for incrementally built knowledge to be tailored as health issues might naturally arise, for example the onset of puberty. As noted previously, an extended aspect to the study which demonstrates the input of young people, the researcher and co-producers propose an outline of Health Literacy Education in Appendix 6: Incremental Health Literacy Learning: Researcher and Co-production Group 2016.

With the researcher, the co-producers generated a pedagogical framework of the Health Literacy Education which recognised the bespoke needs of schools in;

a) Preferences, styles and effectiveness of educational styles, seen as an effective pedagogical approach (Ormrod, 2014) and educationally empowering (UNESCO, 2014).

b) Identified health learning and health learning needs. This was identified in the study as ‘growing up’ and ‘staying healthy’ and will be designed by trusted health experts with educational knowledge.

c) Empowerment and being responsible about learning about health. The study aligned this to life phases and the strong acknowledgment that maturity happens differently – with aspects of health empowerment linked to safeguarding and legislation.

The specific justification for the HLE proposed related directly to the study findings as:

**Learning and pedagogy**

This study found that young people felt that health education was poor in schools. They did, however, feel that school was the right place to learn about health as part of their preparation for adult life and this is supported by research (Rowlands et al, 2015, Batterham et al, 2016, Frosch and Elwyn, 2014). Further, the study found that school was young peoples’ preferred choice.
In defining learning Kickbush (2001) saw learning as a way of understanding and experiencing. Further, knowledge that is both learnt and experienced creates more complex and powerful understanding (Freire, 2004, Richie, 2017) that allowed the learner to differentiate issues (Bruner, 1973 and Vygotsky, 1978 cited Bee and Boyd, 2013) and created better links of the knowledge (Robinson and Aronica, 2015). The study highlighted several new points that form part of the Health Literacy Education pedagogy. Participants emphasised that young people need to be enabled to talk about health. The prevailing emphasis on cessation of behaviours was disempowering and lastly, young people need to learn skills and confidence to seek (health) support. These aspects further reflect the assertion of the study that young people need trust, confidentiality and the right to privacy to effectively engage with health and health learning.

In relation to mediums of delivery this study has shown that young people are competent learners across a variety of teaching mediums and they expressed a preference for mixed approaches. They acknowledged the benefits of face to face teaching and engaging with debate, the privacy of online information through anonymity, the sustainability of reusable resources and so the findings of the study promote a blended learning approach (Tannehill, 2017, Price et al, 2011) to teaching practice for Health Literacy Education.

**Taught face-to-face by trusted facilitators**

Young people emphasised the importance of trust in the indicative content of the Health Literacy Education through two aspects: firstly, that the person imparting the information could be trusted to give advice objectively and secondly that young people trusted the knowledge of that person through qualification and experience.

This study recognised the need for a consistent and trusting educational relationship in Health Literacy Education. The study’s young people identified their need for face to face conversation with the health literacy educator and explained how hard resources are preferred and reusable, easy to follow and enable choice within a structured learning environment. Young people identified teachers as trusted and stable, particularly for primary aged children, but not suitable for personal health
topics and this was reflected from the research (Pounds et al, 2016). The study showed that school nurses were valued by young people for their expert knowledge and advice for young people and reflected the role they hold (RCN, 2014, AYPH, 2016). Further, Bates and Freeman (2014) suggested a raised and visible profile of the school nurse can help reduce the stigma of (young people) seeking help for their health. However, teachers’ education does not prepare them to deliver health education (HM Gov., 2016) and this would need to be addressed at national policy level. Other nations, such as the United States, Wales and Scotland are considering this (USDHHS, 2010, WAG, 2011, Scot Gov., 2015) and organisations such as PHE and AYPH could be mobilised to lobby for this.

**Teaching topics**
Alongside standard health topics identified by PHE / AYPH (2015) and Roberts (2015a) the study identified new topics such as being independent about health, using health smartly, and understanding health structures and systems (gaining insider knowledge) as important aspects to be taught within Health Literacy Education. A detailed diagram of this is proposed in Appendix 6.
This example has been aligned with health learning (RCN, 2014) and further developed by the researcher with the co-production group and recognised their identified health learning needs, reflecting on their past and current experiences of health education and gaps in this knowledge. The study clustered topics into ‘growing up’ for primary aged children (5-11 years) and ‘staying healthy’ for young people in key stage 3 – 5 (11-18 years). National strategic health targets, PHE/ AYPH (2015) and DE (2013) would fit seamlessly into these categories.

5.5.2 Interpreivist co-production participatory research with young people
This study engaged young people as co-producers as an encultured (Smith and Smith, 2014) interpretivist participative research methodology. From the starting point that young people’s participation was tokenistic within English health services (Ocloo and Matthews, 2016), this study challenged the generally adult-centric (Ocloo and Matthews, 2016) and paternalistic (CRAE, 2015) narrative about young people and health. Through engaging young people about their health, the study embraced the notion of young people as active health users (Fairbrother et al, 2016) with the potential to influence policy (Roberts, 2015a) and practice (PHE / AYPH, 2015). As
interpretivist participative research, participation, as a tool, opened the research process to hearing young people’s views (Shier, 2001). Aligned with co-production this facilitated organic participation (Mansuri and Rao, 2015) which shaped the co-producers’ agenda and issues as fluid and cyclical, rather than task focused. Percy-Smith (2007) suggested cyclical research gave a voice to young people and Smith and Smith (2014) noted this as creating richer and deeper understanding and knowledge. Introducing interpretivism into the co-production process added authenticity to this (Smith et al, 2012, Bevir and Rhodes, 2015).

This methodology captured the lived experiences of young people, told by young people and interpreted by young people which culminated in the study outcomes being pertinent to health literacy education and health practice applied to young people. The research methodology began with recruited participants who came together under agreed terms of reference as a co-production group. This challenged the traditional powerbase of the researcher as the director (Kelly, 2014) and the position of participants as passive receivers (Mansuri and Rao, 2015). The research design allowed the researcher to step back from directing the study and follow a socially pedagogic narrative which acknowledged the co-producers’ agency. Schulz and Nakamoto (2013) showed that empowerment reduced dependency and as capable research agents, the co-producers were able to shape the research as capable co-producers. Schalkers et al (2016) argued that health professionals must relinquish their powerbase to young people in order to have a meaningful partnership and this resonated with the study’s position. Finally, interpretivism added an authentic perspective to the research. The co-producers ensured the responses of the study participants retained meaning through their interpretation, rather than the (potential) subjective meaning of the researcher. This important step shaped the study and added genuine purpose to the study.
5.6 Limitations and comparisons

There were some limitations of the study which should be acknowledged and explained. In engaging participants, the study was carried out within a mainstream secondary school in order to capture a representative population of young people; the study was not able to capture the views of young people not engaged with education. Within the school there were some pupils who were acknowledged as ‘erratic attenders’ and these pupils will have been invited to participate with the online survey, however the study is unable to state if these pupils did engage. Carrying out similar research in alternative education provision would be beneficial as this might capture a population who have some of the social demographic profiles that might indicate health illiteracy and poor education and life outcomes. Comparisons to this study’s finding would enrich practice knowledge,

The online survey did not offer alternate versions. During development of the survey the school assured the researcher this was sufficient to reach all participants who have access to support / help for translation should they require this. For example, those participants who could not understand written English or required a spoken version. This was not requested from participants and it cannot be known if this aspect prevented any participation. Conducting the survey online had the potential to exclude participants who did not own a computer or required additional help to access online content. Again, the school were confident that participants would be able to access the survey on the school setting and seek help at the same time.

There was a limited response to the survey question about household employment status which was intended gather descriptive data to analyse of social class linked to employment. This could have been because participants were unsure of the meaning of the question, they did not know the household employment status or chose not to respond. This did not adversely impact the study as data from the school Ofsted (2012) report offered useful data in this area, however the survey was not able to show which respondents came from which employment class. A reflection on this is to consider the usefulness of this data and re-phrase the question if required
In comparison to previous studies explored in chapter 2, this study was larger and more in-depth than PHE (2014). The methodology and participation with young people is of greater depth compared to the report of the Children’s Commissioner (2014). With similarities in size, timespan and some data collection methods, there is also comparability with Fairbrother et al’s (2016) school based study of health literacy (Northern Ireland), however Fairbrother et al’s study was topic focussed (food knowledge) with younger children (9-10 years). Other comparative studies, seeking the viewpoints about health and including direct work and consultation with children and young people, have been carried out. One of the most influential studies has been the Public Health England jointly with the Association for Young People’s Health (2014) ‘Improving young people’s health and wellbeing: A framework for public health’. This report engaged with young people through a short survey of 9 questions and circulated through the AYPH Twitter accounts with re-tweets from the Office for the Children’s Commissioner, NHS England, Department of Health Strategic Partnerships and other voluntary organisations (2014:22). 5 Twitter chats were held with an unspecified ‘small number’ (2014: 23) of young people. The report did not comment in knowing how representative the respondents were. It would appear, however, that respondents will have an interest in health or links to voluntary organisations reflecting the recruitment platforms. With 53 respondents aged 16- 19 years taken from a secondary school that mirrors the demographics of the locality (Ofsted, 2012, NASASP, 2016), this study can claim to have scoped a representative sample of young people. The 2-year series of co-production group discussions with attendance ranging from 6 -9 for each session was substantial in generating depth and volume of data. Thus, this study can demonstrate a solid sample selection and engagement process that can conclude with robust findings.

5.7 Future opportunities and areas of research
The study considered examining the link of educational attainment aligned with health literacy. Whilst the literature associates educational capabilities to health literacy (WHO, 2015, Rudd, 2015), currently there is no established way to assess health literacy in young people (Abel et al, 2015, Sorenson et al, 2012). The study design and co-production work did not examine this link as part of the scope of primary data collection. Further, educational attainment data was limited and lastly, more recent literature appears ambiguous in this assertion (Roberts, 2015a,
A future recommendation would be to carry out research on these links to understand the interplay of educational attainment and health literacy levels so that this knowledge can definitively contribute to health literacy education.

Other elements do contribute to health literacy competence such as social capital (Sentell et al, 2017), familial health literacy (Schulz and Nakamoto, 2013, Abel et al, 2014) and insider knowledge. The primary data generated limited response to understanding the survey participants’ social status: exploring the social positioning of health literacy and young people would enhance the body of knowledge to improve health literacy in tackling inequalities.

The study was positioned in a mainstream secondary English school, this work could be replicated in primary schools and other specialised schools to gain a broader picture of understanding how young people acquire health knowledge, for example those with special educational needs and disability. Additionally, as noted within chapter 3, males were under-represented in the study and so a more targeted recruitment approach could be taken in future studies to readdress this. Lastly, the study acknowledges that the proposed HLE may not be situated correctly for harder to reach children and young people, for example those not in education. Additional research should be undertaken to improve their health literacy as they will remain more disadvantaged through lack of education and being health illiterate compounds inequalities. Comparisons to this study’s finding would enrich practice knowledge.
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7. Appendices

Appendix 1: Terms of Reference for co-production group

Aim
The group aim is to influence the research in order for the experiences and voices of young people to inform the research process, findings and recommendation for practice.

Members selection
1. Up to 10 co-producers will be selected thorough self-identification using the recruitment process of a presentation, email and information.
2. Co-producers will need to understand the time commitment across 2 school years and commit to being engaged in the process
3. Setting staff will be used to identify and avoid potential vulnerable participants.

Process
The group is formed from volunteer participants having understood and agreed to take part (via the presentation session and giving consent).
The group will meet (on school premises) and address the research tasks:
- developing the survey
- piloting the survey
- developing the focus of the group discussions
- contributing to the findings and assisting in interpretation
- contributing to the recommendations
- contributing to aspects of the research dissemination
Co-production organisation

The co-production group day-to-day organisation will be led by the researcher and communication routes will be identified from the start of the project. For example use of group communication forums.

- The terms of reference for the group will be introduced, discussed and agreed at the initial meeting. For example, confidentiality and safety, ability to participate, access to participate
- Schedule of meetings and tasks will be set out at the start of the process by all
- Co-production meetings will be facilitated by the researcher initially with implicit equality principles that allows all co-producers to lead meetings as they progress.
- Co-production meetings will be recorded for the purposes of accuracy and the researcher will be responsible for this.
- The transcriptions will be checked by the co-producers for true representation of meaning
- Co-producers and the researcher may be allocated tasks and will be responsible to the co-production team in meeting deadlines for this.
- In order to facilitate attendance and be mindful of academic commitments of the co-producers the co-production meetings will take place on school premises and will not last longer than 30 minutes. It is anticipated that there will be no more than 2 meetings per term.
Appendix 2: Copy of survey questions

Questions from online survey

1. Gender (choice)
2. Age (choice)
3. How would you describe your ethnicity (optional choice)
4. How would you describe any religious/belief? (optional choice)
5. How would you describe any religious/belief? (optional choice)
6. How would you describe your parent / carer / main family occupation? (choice)
7. Do you know how to access the following health (choice)
8. Do you know how to....? (choice: health appointments)
9. Do you know how to....? (choice: health advice)
10. Do you know how to...? (choice: emergency health)
11. Would you ASK each of the following for health support and advice? Please select all (choices)
12. Would you TRUST each of the following to give you good health advice? Please select all (choices)
13. How do you get health support and advice? Please select all that apply (choices + narrative)
14. Do you always understand health information given to you? (choice)
15. Please select reasons why you feel that you don’t always understand health information given to you? (choices)
16. Please give an example as to why you don't always understand the health information given (narrative)
17. What helps you feel confident to follow the health advice given to you? (narrative)
18. What kind of health advice helps you? (choices)
19. What kind of health information do you think is useful? Please explain why and give an example (choices and narrative)
20. What kind of health information is NOT useful? Please explain why and give an example (choices and narrative)
21. What skills do you think you need to understand health information? (choices)
22. Please explain why you have chosen the skills in the previous question and give examples (narrative)
23. How do you think young people learn the skills they need to understand health information? Please comment and give an example (narrative)

24. Who do you think should teach you about your health? Please select all that apply (choices)

25. Where do you think you should be taught about your health? (choices)

26. Please explain why you made these choices about who and where you should be taught about your health and give an example (narrative)

27. Please explain what type of learning has helped you with understanding your health and give an example (narrative)

28. Please explain what health learning you think you still need and give an example (narrative)

29. What age do you think you should start 'taking responsibility' for your own health? (select from 5 - 18 years)

30. Please explain why you chose that age of 'health responsibility'? (narrative)

31. Lastly, you have English and Maths lessons. Do you think you should have lessons that help to explain and understand your health? (narrative)
Appendix 3: Overview of Ethical Considerations: demonstrating ethical and substantive validation.

<table>
<thead>
<tr>
<th>Ethical Considerations and literature</th>
<th>Ethical Strategies and Procedures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Permissions</td>
<td>*Permission and consent obtained for the study to take place in a secondary school.</td>
</tr>
<tr>
<td></td>
<td>*Signed ethical approval was applied to the research. This was obtained from participants, and parent/guardians.</td>
</tr>
<tr>
<td></td>
<td>*The study was fully risk assessed including suitability of the setting, location, safety of participants and researcher</td>
</tr>
<tr>
<td>Participant selection</td>
<td>*Participants identified by the setting following consultation with the researcher: for example in avoiding participants who may be vulnerable</td>
</tr>
<tr>
<td></td>
<td>*Participants were invited to take part in the study with no coercion, bribe or compulsion to take part. Researcher worked with host staff in this aspect in the recruitment process</td>
</tr>
<tr>
<td></td>
<td>*Participants opt in to the research: as co-producers, as participants in the survey and prompted discussions</td>
</tr>
<tr>
<td>Information to relevant parties</td>
<td>*Participants, participant parents / guardians received information about the study aims and purpose, duration and commitment, assurances about safety and security as part of the selection and consent processes. This was in-line with University and School policies. The information was produced in several formats and matched to the recipients needs such as leaflet / email / letter</td>
</tr>
<tr>
<td></td>
<td>*Study Setting: Staff received information about the nature and purpose of the study. The support of the staff was an important aspect of the study running smoothly and professional relations were developed.</td>
</tr>
<tr>
<td></td>
<td>*Supervisory team: received copies of all documentation as required</td>
</tr>
<tr>
<td>Consent</td>
<td>*Study setting: written consent and study agreements agreed from the start of the study: A pro-forma was already in place at the setting. The study followed this which: it set out the School and Local Authority needs for Safeguarding, Confidentiality and Respect. The setting will required blank copies of the consent forms and information sheets as part of this.</td>
</tr>
<tr>
<td></td>
<td>*Participants: Participants were required to give written consent in the form of a signed consent form. This form detailed the study purpose, commitment to the study; their</td>
</tr>
</tbody>
</table>
| Confidentiality | *The anonymity of participants and the study setting was maintained throughout the whole study process and details of the strategies was explained to the participants and the setting.  

*Of note there might have been need to breach confidentiality should a child protection, disclosure of criminality or a harm situation arise (see note below).  

*Any contact details are to be destroyed at the end of the research unless permission has been obtained to retain them for further research.  

*Codes or pseudonyms were used when writing the thesis and names of places were changed or fictionalised to ensure anonymity.  

*Details for keeping the data and time scales were set out.  

*The Data Protection Act was adhered to |
| Avoiding harm and protecting well-being | *Strategies were in place for the researcher to report issues of child protection, criminality and potential harm. This included breach of confidentiality within restricted circumstances and parameters. This was clearly set out to the participants, setting and University (Strategy set out in Appendix 4).  

*Whilst the study did not seek personal health information there was a recognition this may come up. Strategies were developed and agreed (Appendix 4) to mitigate these instances. For example a system of signposting participants to further support. |
| Protecting participants | *The researcher held a current DBS and complied with the study setting policies for child welfare and protection.  

*Participants (including parents, guardians and staff) were informed and reminded throughout that any disclosure that raised concerns (child protection, criminality or potential harm) would need to be reported following child protection procedures (of the setting). |
| Risk Assessment | *Risk assessments were carried out in relation to the participants, researcher and setting. |
The research will follow all University and setting RA procedures and utilise relevant forms

<table>
<thead>
<tr>
<th>For example</th>
</tr>
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<tbody>
<tr>
<td>- health and safety requisites of the premises.</td>
</tr>
<tr>
<td>- accessibility (physical and other such as written word)</td>
</tr>
</tbody>
</table>

*Issues that will required RA included
- lone working: all research will take place on school premises
- researcher safety
- participant safety
- emergency procedures: i.e., fire evacuation
- child protection procedures
- how to access help and support whilst on site

NB: this list was not exhaustive and was reviewed as the research progressed

Data recording

| *Permission and consent was obtained from all participants for any data recording. Recording took place openly and without deception. |
| *Arrangements were made for participants who did not wish to be recorded but who wanted to share their experiences. |

Potential Harm

*The study took all steps to avoid any harm to any participant. This included sensitivity in developing the data collection tool; inclusion of participants at various stages of the study; support strategies should an issue arise

Data Storage

*All data and study information has been kept securely. This was in locked cabinet in the researcher’s office and also stored under password protected files on the researcher’s computer.

*Use of the University data management (for researchers) systems included abiding by guidelines and protocols.

Dissemination

*The co-producers have supported some aspects of the dissemination.

*All participants were invited to dissemination sessions at the end of the study. This was within the spirit of co-production and ownership

*Participants have been informed of the potential of the study to be used in other arenas such as publication, conference or policy impact
Appendix 4: Copy of Consent Letters and Information

i) For online survey (NB: Parental consent sought and collated by email by the School)

![Screen shot of online survey](image)

None of the questions ask you for any personal health information.

The survey is a mixture of short click answers and some where I'd like you to comment and give more detail.

---

i) For co-production (NB: Parental consent sought and collated by email by the School)

![Screen shot of co-production](image)
Co-production Information

Membership of co-production group: Research study led by Wendy Turner

Aim

The group aim is to influence the research in order for the experiences and voices of young people to be heard, inform the research process, findings and recommendation for practice.

Members selection

1. Co-producers will be selected thorough self-identification following information / presentation of study by sixth form Head.
2. Co-producers will need to commit to some time for the group (agreed at initial meeting). This time will form part of the hours required for volunteering.

Process

The group will meet on school premises and address the following research tasks:

- Develop and pilot the survey
- Develop and pilot the focus of the promoted discussions
- Contribute to the study findings
- Contribute to the study recommendations
- Contribute to aspects of the research dissemination

Co-production organisation

The co-production group day-to-day organisation will be led by the researcher and communication routes will be identified at the initial meeting.

- The terms of reference for the group will be introduced, discussed and agreed at the initial meeting. For example confidentiality, ability to participate, access to participate
- Schedule of meetings and tasks will be set out at the start of the process
- Co-production meetings will be facilitated by the researcher but all will ensure that all co-producers can take part.
- Co-production meetings will be recorded for the purposes of accuracy and the researcher will be responsible for this.
- The transcriptions will be checked by the co-producers for true representation of meaning
- Co-producers may be allocated tasks and will be responsible to the co-production team in meeting deadlines for this.
• In order to facilitate attendance and be mindful of academic commitments of the co-producers, the co-production meetings will take place on school premises and will not last longer than 45 minutes. It is anticipated that there will be no more than 2 meetings per term.

Consent Form: Participants

Project Title:
‘Exploring the acquisition and place of health literacy in the lives of young people (11-18 years)’.

Researcher Details:
Wendy Turner
Student: Professional Doctorate
School of Education / Health
University of Northampton
wendy.turner@northampton.ac.uk

1. I confirm that I have read and understand the Information sheet for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason.

3. I agree to take part in the above study as a co-producer and this work will be recorded.

4. I agree to take part in the above study and be part of the prompted discussion group that will be recorded.

5. I agree to the use of my anonymised quotes in publications.

_________________________________________  ___________________________  ___________________________
Name of Participant                        Date                                  Signature

_________________________________________  ___________________________  ___________________________
Name of Researcher                        Date                                  Signature
Appendix 5:
Strategy for dealing with health related enquiries and issues that might cause distress

i) Screen shot of support hyperlinks for survey

![Screen shot of support hyperlinks for survey](image)

i) Example of strategy for support for co-production group

Context:
The study asks young people about their engagement with health related materials and their use.
There is a recognition that this focus may raise (although it is not intended) enquiries about health or issues that might cause distress to the participants.

Strategy:
At the start of the research a person from the School will be allocated to the researcher as a contact point. This has already been discussed and agreed as good practice in safeguarding the participants, the researcher and the School. This is likely to be the School Pastoral Lead.

Dealing with distress
Prior to the research starting the study will have agreed procedures in place with School in dealing with distressed participant. *This will include working in partnership with the Pastoral Lead as the contact point.*
At the start of each session the researcher will remind participants of confidentiality parameters of the study and also the strategy in gaining extra support from School staff if needed.

1. The school will be aware of the research schedule: agreed dates / timings and rooms. The researcher will ‘sign in’ with the School and meet with the Pastoral Lead to ensure any issues are resolved prior to the start of each session (such as room changes).

2. Should a participant become distressed during the session the researcher will attempt to resolve this at the time. That participants are also informed that they can stop/pause/ withdraw from session at any point. If these actions are unsuccessful or the participant needs further support the researcher will stop the session and contact the identified school staff (Pastoral Lead) for immediate support.

3. Because the sessions are held on the School site within participant lunch time, it would be safe to allow the other participants to leave the session.

4. The researcher will inform the identified school staff (Pastoral Lead) that the session is ended and the participants have left the session.

**Dealing with health**

At the start of the research process the researcher will have a prepared a contact card with appropriate contact details of:

- Safeguarding co-ordinator at the School
- School nurse
- Local walk-in centre
- Key personnel in School: Pastoral lead / year co-ordinators

**Non-urgent enquiries**

The researcher will give the contact card to all participants at the start of the study.

5. Should a non-urgent health enquiry be raised the researcher will gently respond to the enquiry, by signposting to relevant information/ professional, and bring the focus back to the research point.

6. At the end of the session the researcher will remind the participants of the contact details in order to gain further support if needed / wanted.
Urgent enquiries

As a registered health care professional specialising in health for children and young people, the researcher is able to recognise an urgent health enquiry.

1. The researcher would gently remind the participants of the parameters of her role.
2. At the end of the session the researcher will give the contact card to the participant again
3. The research would explain to the participant the need to share information should the enquiry cause concern; for example child protection or serious threat to well-being or criminality.
4. If the information is serious enough to be shared (3) the researcher will follow the School / Local Authority procedure and policy in reporting concerns of child safety.

Emergency situation

The researcher will follow the School policy / procedure in seeking emergency help.
Appendix 6: Incremental Health Literacy Education: Researcher and Co-production
Group 2016

Reception

Key Stage 2 (i)
Key Stage 2 (ii)

- Mindfulness / other healthy MH
- Other emotional / MH issues: Introduce and understand mental and emotional health. Actual and virtual tailored access to information, support and help.
- Bullying
- Depression / being low: More severe issues: self harm / suicidal thought
- Anxiety and Stress

Key Stage 3

- Mental & emotional health: developing trust with F2F and key online support
- Physical health and exercise: learning about medicine
- Growing up & taking charge
- Graduated tailored learning: online / classroom: Off site visits and visitors
- Learning about safe internet use / trust
- Being sexually healthy: gender specific and mixed: use of specialist HCP
- Specific illness: cancers / health checks
- Family issues: divorce / death / DV
Key Stage 4

Growing up: physical health and exercise: managing illness: health app

Health promotion and campaigns / self checks / starter packs

Graduated tailored learning online / classroom: Off site visits and visitors

Emotional and mental health: taking charge: mindfulness

Stress: exam stress
Coping strategies / de-stress

Being sexually healthy: Being an adult: self-worth / real samples and demos

Emotional and mental health: taking charge: mindfullness

Being an adult: self-worth / esteem / roles / responsibilities

Key Stage 5

Taking charge / managing own health: understanding health of others

Being independant: emotional well-being: tackling bullying / tackling mental health

Confidence building / security / relationships

Graduated tailored learning online / classroom: Organise own activities Off site visits and visitors

Feelings and emotions: mindfullness / coping with stress / balancing life demands

Mentor / support 'growing up' for younger C&YP