

Addressing the weight management needs of underserved populations: a systems perspective

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# Addressing the weight management needs of underserved populations: a systems perspective

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Published works submitted in partial fulfilment of the requirements of Sheffield Hallam University for the degree of Doctor of Philosophy on the Basis of Published Work.

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### **Abstract**

**Background:** Nutritional inequality leads to poorer health and wellbeing outcomes, including acquisition of diseases such as obesity. Obesity is recognised in policy as a complex global health issue which continues to increase. Current practice is based on a conceptualisation of individualised responsibility for weight gain, and transactional behaviour-change interventions which rely on individual agency. These interventions are poorly engaged with, have high attrition rates, and likely contribute to further health inequality. These communities are often referred to as 'underserved' and are excluded from service or system design and delivery.

**Method:** A series of mixed-method design research papers using qualitative and quantitative research methodologies to explore nutritional inequalities (e.g., obesity, diabetes) in selected places, with selected people and the food environment in the context of underserved communities.

**Results:** Seldom heard and underserved communities provide valuable insight into their lived experience and can highlight failings in the current system and interventions, whilst suggesting alternative solutions which are likely to be more successful at reducing health and nutritional inequalities. The results of this research have contributed towards the development of NICE weight management guidelines, made recommendations for policy change and improving obesity management, developed a Theory of Change which highlights the impact of the seldom heard public voice in service design and development and food provision, and has extended the socioecological model of food choice for Muslim adolescents.

**Conclusion:** A re-conceptualisation of obesity management supports a more systemic approach and interventions that are more successful because they are coproduced with empowered underserved communities. By coproducing solutions *with*- rather than *for*-underserved communities, it is possible to overcome barriers and facilitate changes in policy and practice to elicit a healthier holistic environment for all which reduces nutritional inequalities.

### List of abbreviations

Al Appreciative Inquiry

BMI Body Mass Index

HCP Health Care Professional

HFSS High Fat, Salt and Sugar foods

ICS Integrated Care Systems

NHS National Health Service

OHID Office for Health Improvement and Disparities

PHE Public Health England

PPI Patient and Public Involvement

SES Socioeconomic Status

UK United Kingdom

VCSE Voluntary, Community and Social Enterprise

WHO World Health Organization

WSA Whole Systems Approach

### List of publications

Ref No	Full citation	Digital Object Identifier (Please use URL including DOI)
001	<b>Nield L</b> & Kelly S. (2016) Outcomes of a community-based weight management programme for morbidly obese populations. <i>J Hum Nutr Diet</i> . 29, 669–676	https://doi.org/10.1111/jhn.1239 2
002	Brown TJ, Todd A, O'Malley C, Moore HJ, Husband AK, Bambra C, Kasim A, Sniehotta FF, Steed L, Smith S, <b>Nield L</b> & Summerbell C. (2016) Community pharmacydelivered interventions for public health priorities: a systematic review of interventions for alcohol reduction, smoking cessation and weight management, including meta-analysis for smoking cessation.	https://doi:10.1136/bmjopen- 2015-009828
003	Stockton J & <b>Nield L</b> (2020) An antenatal wish list: A qualitative systematic review and thematic synthesis of UK dietary advice for weight management and food borne illness. <i>Midwifery</i> .	https://doi.org/10.1016/j.midw.20 19.102624
004	<b>Nield L</b> , Bhanbhro S, Steers H, Young A & Fowler Davis S (2023) Impact of Voluntary, Community and Social Enterprise (VCSE) organisations working with underserved communities with Type 2 diabetes mellitus in England. Healthcare, 11 (18).	http://doi.org/10.3390/healthcare 11182499
005	<b>Nield L</b> (2024) "I Prefer Eating Less Than Eating Healthy": Drivers of Food Choice in a Sample of Muslim Adolescents" <i>Adolescents</i> 4, no. 1: 41-61.	https://doi.org/10.3390/adolesce nts4010004
006	<b>Nield L</b> (2023) Empowering and including 'seldom heard' communities in systems thinking for weight management. Perspectives in Public Health. 2023;143(6):310-312.	http://doi.org/10.1177/17579139 231180732

### 1 Critical Appraisal of published works

### 1.1 Introduction

Obesity (defined as the accumulation of excess fat which is detrimental to health) is a chronic disease leading to multiple physical and mental health concerns for individuals (WHO, 2023a). The number of people living with obesity has grown rapidly in the UK and worldwide, leading to public health concern due to the financial, social and health implications of excess weight for individuals and society (Holmes, 2021). Globally, prevalence of obesity has tripled since 1975 (WHO, 2021). In England, overweight and obesity rates remain high with 59% of women, and 69% of men in the UK living with overweight or obesity, with women more likely to live with obesity (NHS Digital, 2022).

Research to address the challenges of obesity and healthy weight has been at the forefront of population health research for the past 50 years. UK government strategy and policy over the last 30 years has been developed to address the obesity epidemic and alleviate some of the aforementioned pressures, yet obesity levels and associated comorbidities continue to rise. Analysis suggests that UK obesity policies have failed due to reliance on less interventionist approaches, lack of opportunity for implementation, failure to learn from previous failures and the publication of policies which rely on individual behaviour change rather than changing the environment.

This means that policies, if implemented, are less likely to be effective or equitable (Theis & White, 2021). Whilst much of the resulting research and service delivery was well-intentioned, well-designed and well-managed, outcomes for weight loss remain poor, weight regain is common (Wadden, Butryn, & Byrne, 2004) and nutritional inequalities, including obesity, have increased.

The intersection of gender, deprivation, environmental, cultural and ethnic differences all impact on individuals' abilities to achieve and maintain a healthy weight (OHID, n.d.). Obesity is recognised as a disease that is acquired due to the intersection of these factors. In the most deprived areas of England, obesity and overweight prevalence is 9% higher than in the least deprived areas (House of Commons, 2023). When multiple sociodemographic risk factors are combined, the cumulative effect is greater, for example, around 40% of women from the most deprived quintile live with obesity compared to 22.4% in the least deprived. Over 70% of women living with obesity are from Asian Pakistani, Black African and Black Caribbean populations (OHID, n.d.). The distribution of people living with overweight and obesity in the UK highlights that obesity is a disease of inequality, resulting from systemic health inequality,

which disproportionally affects the most deprived and underserved communities, resulting in widening health inequalities (Marmot, 2020).

Obesity is a complex challenge which urgently needs addressing to identify what works and for whom (Salm et al., 2023). Fundamentally, there is a failure to recognise that the difficulty in sustaining healthy weights is a socioeconomic problem. The perpetuation of the idea that individual action alone will lead to nutritional equality and weight management is at the heart of the dilemma. Individuals recognised for being overweight are presented with individual solutions, but the impasse lies in the public health approach that sees obesity as a population health issue rather than a socioeconomic and cultural problem for the whole of society.

Typical UK weight management approaches are based on a 4-tier system. Tier 1 is general, preventative, population-health messages such as the 5-a-day campaign and physical activity guidelines; Tier 2 is mainly commercially available (e.g., Slimming World), Voluntary, Community and Social Enterprise (VCSE) sector or primary care led provision for those with overweight or lower severity of obesity. Tier 3 weight management services are for complex weight management issues with multiple comorbidities and serviced by a multidisciplinary group of healthcare specialists. Tier 4 weight management services provide bariatric surgery (NICE, 2014b).

Within Tier 2 and 3 services, weight management provision is delivered to individuals or small groups. Interventions are offered to those engaging with the referral, assessment and treatment pathways (NICE, 2014b). Recent evaluation of English tier 2 weight management services highlighted that 44% of all participants enrolled in services were from high-risk groups (defined as people who live in the most deprived 20% areas of England; from a Black, Asian or minority ethnic group; with a mental illness; or with a disability or learning disability) although these services were particularly focussed on recruitment from underserved groups (OHID, 2023).

These traditional, transactional weight management approaches may target 'at-risk' populations (e.g., those with raised body mass index (BMIs), family history of obesity, or obesity-related comorbidities) on an individual level, but fail to address the obesogenic environment in which people live, and the system-wide challenges which determine and drive levels of obesity and poor nutritional health within the population. It has been evidenced that individual-level interventions can exacerbate, rather than reduce, health inequalities and that these types of interventions fail to change the environments that people move and function within leading to unsuccessful or short-lived unsustainable outcomes (Adams, Mytton, White,

& Monsivais, 2016; Swinburn et al., 2011; Lorenc, Petticrew, Welch, & Tugwell, 2013). Despite this, weight management policy and provision has not adequately addressed multifaceted causes of obesity and continues to focus on individual behaviour change approaches putting the onus for weight loss on individuals, with success or failure dependent on their personal agency (Holt-White, 2019). Typically, these approaches omit the voices of those with lived experience and underserved populations, with provision designed 'for' rather than 'with' the target groups.

'Wider determinants of health' are recognised as the significant influence of sociocultural, economic, environmental and political factors on health and their interaction within a system, often driving and perpetuating inequalities (Dahlgren & Whitehead, 1991). It is accepted that inequalities are caused by a plethora of socioeconomic and environmental determinants. The Marmot review argued for change to prevent ill health and social injustice caused by inequality, thus protecting health and wellbeing of future generations. It described the complex interrelationships between the social determinants of health which drive inequalities across communities and clearly articulated the need for community empowerment to reduce health inequalities, arguing that having control over one's life is critical to individual health and wellbeing (Marmot, 2010). It is therefore recognised that addressing inequalities requires effective interventions, garnering insight from and examination of the socioeconomic and environmental conditions that impact and perpetuate inequalities (New Local, 2023).

### 1.1.1 Research Programme

The published works centre on the current management of weight in people living with obesity and related comorbidities. This published works recognises and critiques the failures of current weight management provision that relies on individual diet, physical activity and behaviour change approaches that have been largely unsuccessful in achieving improvements to population health, and how this can lead, unintentionally, to further health inequality.

Obesity is a disease, which correlates with deprivation, low household income and markers of marginalised communities such as ethnic minority groups (OHID, n.d.). The published works frame obesity, and related comorbidities, as diseases of inequality, due to an unequal and unjust system.

For the purpose of this thesis, 'seldom heard' groups refer to those most vulnerable and socially excluded by virtue of socioeconomic factors. The term 'underserved' is used to extend this phenomenon to identify those who are not only seldom heard in a research and policy context but have tended to be excluded from healthcare utilisation by virtue of the ways that services are delivered or unwitting de-prioritisation of minority interests. These groups,

communities and populations of people are considered 'underserved' due to being underrepresented in research, public health, consultation, and agenda-setting activities resulting from systemic, structural and procedural barriers which prevent their engagement (IRISS, 2011). Underserved communities such as those living with diabetes, adolescents living in deprived areas, and pregnant women included in this work, are subject to an unequal system which contributes to unequal outcomes and greater inequality of practice and policy.

Contemporary researchers describe population health issues such as obesity as outcomes of a complex adaptive system. Systems approaches have potential to reshape the environments that people interact with, live and work within, therefore influencing routine or automatic behaviours (Adams, Mytton, White, & Monsivais, 2016) and making health-promoting behaviours easier. Systems are highly adaptive, dynamic and responsive to different contexts, and can be tailored to different settings and demands of different groups. The published works are underpinned by systems-thinking building on the complexity highlighted in the Foresight Obesity Systems map (Foresight, 2007b).

The work in this thesis aligns systems and population health approaches, highlighting the benefits of working collaboratively with seldom heard communities. By understanding and giving voice to the lived realities of the communities and populations involved, and interrogating previously published data, this body of work argues for the voices of service users to be embedded throughout the design and implementation of health and weight management services and systems to improve efficacy and equality. It should embrace the lived experience as key to success by removing barriers for the most vulnerable. The work values the important and unique contribution of service users, or potential service users, highlighting the weaknesses in developing and delivering services within a health system which underrepresents diverse and seldom heard groups.

This thesis represents a strong commitment to the worth of augmenting the voices of underserved communities in the design and development of interventions to address inequalities. It provides an original contribution that relates to a whole systems approach (WSA) to tackling obesity and associated health inequalities by embedding the voices of underserved populations into service co-design and delivery. The empirical, conceptual and methodological contributions are provided in the publications presented, including a wish list for obesity interventions in pregnant women, a theory of change for integrated community management of diabetes and development of focussed ethnographical methodologies within deprived adolescent groups. The thesis acknowledges the limitations of current approaches to population weight management and suggests how a more systemic approach with the

involvement of those affected by obesity and excess weight may be important for change which realises the value of community empowerment in service and policy design and delivery.

The wraparound text highlights the need for a systems-focus which transforms the environment for individuals to ensure weight management is more effective and sustainable for reduction of obesity and crucially improving health equality (PHE, 2019).

#### 1.2 Aims

The aim of the published works is to generate new insights from seldom heard, and underserved populations while arguing for embedding the service user voice into sustainable, systems-based approaches to addressing diseases of nutritional inequality, including obesity, and improving the efficacy and equality of weight management solutions.

The objectives of these published works are to:

- Undertake a mixed-method exploration of the experiences, wants and needs of a selection of seldom heard populations in weight management service design and delivery.
- Understand and empower service user lived experience and advocate to embed their voices in service design and implementation.
- Synthesise the findings within a systems approach to make suggestions for policy and practice.

The six publications presented collectively provide an account of aspects of the obesity system experienced by different seldom heard populations. This research makes three unique contributions to knowledge, advancing existing understanding.

1. Nutritional inequalities, including obesity, can be managed more effectively by recognising the lived experience of, and empowering, seldom heard communities and individuals to contribute to solutions that reflect their sociocultural norms (Papers 3, 4 & 5).

Nutritional inequalities are more evident in some populations often leading to obesity and comorbidities within particular communities. This work provides examples of lived experience of groups trying to prioritise health within an unjust system which does not reflect their needs. This body of work demonstrates the impact of recognising and working with underserved and seldom heard populations such as pregnant women, adolescents, ethnically diverse groups and those living with severe and complex obesity. The research empowers individuals and communities to have their voices heard, and to identify the types of interventions with which

the groups can identify. The focus is on socioeconomic and environmental factors which contribute to nutritional inequality. This is a significant contribution to knowledge, demonstrating that marginalised populations want the opportunity to share what matters to them to shape services and interventions which are socio-culturally aligned to their lived experience.

# 2. Methodological contributions for working with and coproducing research in novel ways which benefit seldom heard populations and reduce health inequalities (Papers 4, 5 & 6)

The participatory methods highlight the importance of selecting and operationalising ways that facilitate and include the views of underserved populations. Coproduction amplifies the voices of those with lived experience for improved community empowerment and just outcomes. In this research, groups actively participated when they were recruited and engaged in an appropriate and accessible way. The use of community researchers (Paper 4) and novel participatory methodologies such as PhotoVoice (Paper 5) highlighted the importance of empowering and engaging with seldom heard communities to understand the nuances of their experience and its impact on particular health and nutrition behaviours. As a result, the theory of change (Paper 4) and the adaptation of socioecological model of food choice for adolescents (Paper 5) were developed. Paper 6 summarises the value of systems work and coproduction for improving the obesity system.

# 3. To further evidence the importance of systems-thinking in addressing policy and practice challenges for obesity management to reduce health and nutritional inequalities (Papers 1, 2 & 6)

The overarching focus of the thesis is to recognise the importance of, and critically engage with systemic challenges which perpetuate the consequences of nutritional inequality. The thesis challenges the individualised current behaviour change approach to management of such conditions and suggests a more systemic approach that addresses the social determinants of health as opposed to the focus on individual agency. The thesis calls for changes to public health practice and policy regarding obesity management, to understand the failures of transactional approaches to weight management (Paper 1 & 2). By underpinning obesity management in a broader context with systems-thinking, wider inequalities can be addressed.

### 1.3 Literature review/description of the research programme

The Covid-19 pandemic further highlighted the presence of structural inequalities in the UK and shone a spotlight on their impact on health and wellbeing outcomes (The Health Foundation, 2021). Structural inequalities in society impact every aspect of individuals' lives including education, welfare, socioeconomic status (SES), health and wellbeing. Structural inequality leads to health inequality. Individuals living in more deprived areas are more likely to experience poorer air quality, higher crime rates, less access to green social spaces, more exposure to poor-quality, fast-food provision, and poorer access to affordable, nutritious food (The Kings Fund, 2022). In turn these individuals have less ability to make healthy diet and lifestyle choices which lead to poorer health outcomes and diseases of nutritional inequality. Over time, the societal and environmental challenges for these individuals, plus the impact of their disease leads to further multimorbidity such as diabetes and mental ill health, perpetuating the broken system, and realising poorer quality of life and health outcomes for future generations.

The University College London (UCL) 'Structurally Unsound' report provides a definition of 'structural inequalities' which focussed on two components: persistence and intersectionality. Persistence is used to consider inequalities that are present at birth and continually reinforced during an individual's lifespan and intergenerationally. Intersectionality therefore refers to the relationships between these inequalities and the combined impact of experiencing multiple inequalities, recognising that each individual will experience inequality differently. The report reiterates that, "certain groups in UK society face greater inequalities with increased persistence, and these differences can be explained by specific social structures and institutions" (UCL & Resolution Foundation, 2019, p11-12).

#### 1.3.1 Health inequality and the social determinants of health

In 1948, the World Health Organization (WHO) defined health as "a complete state of physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 2023b). It recognised the complex and multifaceted concept of health, overriding the traditional biomedical view, which focussed on physical mechanisms and diseases, effectively reducing health to 'the absence of disease'. Health inequalities are defined as "avoidable, unfair and systematic differences in health between different groups of people" (The Kings Fund, 2022). Health inequalities are caused by several interrelated factors which are often divided into four categories for policy-related activity in England:

- socio-economic factors (e.g., household income)
- geography (e.g., rural vs urban)
- specific characteristics including those protected in law (e.g., sex, ethnicity or disability)

• socially excluded groups (e.g., people experiencing homelessness).

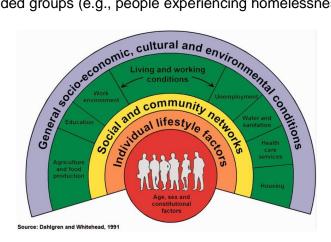


Figure 01: Social Determinants of Health Model (Dahlgren & Whitehead, 1991)

Health inequalities are well-recognised, complex in nature and are observed to be contributors to, and impacted by, wider societal inequality (Marmot, 2020). Advances in the literature, such as the Social Determinants of Health model (see Figure 01; Dahlgren & Whitehead, 1991) sought to explain the multiple factors which impact an individual's health, acknowledging that the individual's health outcome is determined by a complex raft of factors largely outside of the control of the individual. In addition, discussions regarding the Commercial Determinants of Health (CDoH) have also come to the fore. CDoH are a particular type of social determinant which refers to the activity of commercial actors within a system that affects health in a positive, negative or neutral way (WHO, 2023c). The activity of commercial actors is widespread within the system, shaping physical, social and digital environments. Different population groups are likely to be affected differently by different commercial activities, for example young people are particularly susceptible to fast-food advertising and celebrity endorsers (WHO, 2016; Molenaar et al., 2021). Thus, the CDoH are another contributor to widespread systemic health inequalities and have the potential to override individualised weight-management efforts.

Figure 02 provides a socioecological model of food choice that I adapted from Story et al (2008). Specifically, I extended the impact of individual and environmental factors to include social media and influences, based on data from lower SES adolescents (Nield, 2024). These socioecological models help to recognise the complexity of factors which may determine individual choice and the impact on health outcomes for different population groups (Story, Kaphingst, Robinson-O'Brien, & Glanz, 2008). They recognise the numerous factors determining food and lifestyle choices, and its impact on the health of individuals. There is a strong argument for a holistic approach which represents, includes and manipulates individual factors, social networks, physical environments and macro-level environments (i.e., socioeconomic and cultural) to produce a system conductive to health.

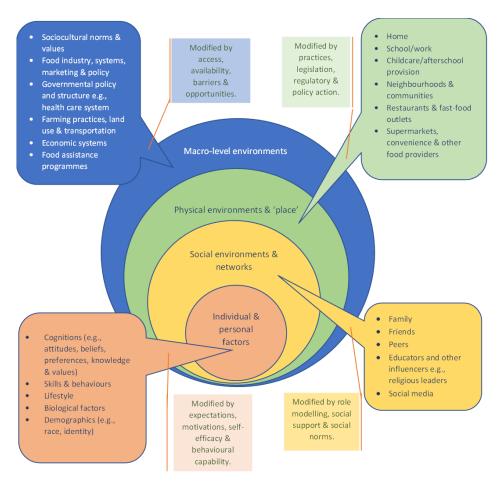


Figure 02: Socioecological model of food choice (Nield (2023) adapted from Story et al., (2008)

It is well established that traditional approaches to public health challenges, such as obesity, are failing to address key public health outcomes or reduce health inequalities. This leads to poorer health outcomes, life expectancy and healthy life expectancy which have a social, financial and health implication for the populations and individuals who are affected (McCartney, Douglas, Taulbut, Katikireddi, & McKee, 2021). Despite public health teams being well established for the past decade in English local governments, and best placed to address health inequalities, gaps in health inequalities have worsened, and deprived communities faced the brunt of funding cuts (Marmot, 2020). Radical change is required to address health inequalities and scale up interventions which are more effective (Stansfield, South, & Mapplethorpe, 2020).

Lessons from physical activity interventions (e.g., short-term education or the provision of physical activity interventions) have predominantly focused on individual agency and decision making to drive healthy behaviour change, putting the onus on individuals where success or failure is determined by individual grit, determination, or willpower, without manipulation or consideration of the social infrastructure. As a mechanism of change, individual behaviour change interventions have been consistently shown to worsen, rather than improve, health

inequalities and environments that people move, live, and work in rarely change (Adams, Mytton, White, & Monsivais, 2016; Swinburn et al., 2011; Lorenc, Petticrew, Welch, & Tugwell, 2013). Efforts should be focussed on alternative approaches requiring lower levels of individual agency, reach out to broader populations, address multifactorial influences, and reduce inequalities (Adams, Mytton, White, & Monsivais, 2016). However, these approaches are often less-favoured by local governments due to the cost of provision, small evidence base and political will, as well as perceptions that low-agency interventions limit free choice (Adams, Mytton, White, & Monsivais, 2016; Swinburn et al., 2011; Rutter et al., 2017; Frieden, 2010).

Knowing that access to, and engagement with healthcare varies with sociocultural and socioeconomic factors, it is important to recognise that participants who attend obesity interventions are unlikely to be truly representative of the diversity of the population it aims to serve. Recruitment and retention of participants in these services are notoriously challenging (Moroshko, Brennan, & O'Brien, 2011; Holzapfel et al., 2014). Barriers to engagement in interventions include perceived lack of time, social pressures, poor physical and mental health, socioeconomic constraints, perceived lack of knowledge and lack of enjoyment of exercise (Burgess, Hassmén, & Pumpa, 2017). Adherence to programmes is improved with early weight loss success, lower baseline BMI, better baseline mood, being male and older age (Burgess, Hassmén, & Pumpa, 2017). These factors indicate that current weight management interventions are inequitable in their engagement and retention activities, and even successful, multidisciplinary, 'best practice' models of weight management have limited success as demonstrated in Paper 1 (Nield & Kelly, 2016). Nevertheless, in March 2021, additional government funding was distributed across local authorities in England to support people living with excess weight and obesity as part of a place-based WSA to tackling obesity by supporting the expansion of adult tier 2 behavioural weight management services. Each local authority decided how best to spend this money, often focussing on an underserved community which had poor engagement with the standard service offer. Preliminary data, indicates that whilst uptake was poor (only 22% of referrals to the service between April 2021 and December 2022 completed 75% or more of their programme), targeted expansion of the service in a whole systems informed manner appeared to have more equity of engagement for underserved communities (OHID, 2023). However, standard provision is generally less suited to individuals from underserved and more deprived groups, who often have the most need. Consequently, lack of tailored engagement with these populations continues to drive health inequality and highlights the need to understand the barriers, wants and needs of underserved communities and to consider this in the design and development of weight management provision.

Place-based approaches work at a community, hyper-local level and provide an assessment of population need which can then be addressed with place-based interventions, defined as,

"any intervention, policy or programme, or action delivered at a local or regional level, excluding national level interventions" (McGowan et al., 2021) and have been suggested as suitable alternatives to individualistic behaviour change interventions which recognise the considerable contribution of 'place' - where one lives or works - on the experience of inequality (UCL & Resolution Foundation, 2019) and the importance of tackling issues at the right level.

As a result of increased awareness and emphasis on reduction of health inequalities, the NHS CORE20PLUS5 approach was launched in 2021 (NHS England, n.d.). The aim of the CORE20PLUS5 approach is to identify the most 'at risk' populations and target support and provision where it is most needed to reduce inequalities and 'level up' population health outcomes. Where wellbeing and healthcare provision fail to recognise and address inequality and diversity of the populations they are working with, outcomes are poor for individuals and the service. This is particularly evident when interventions are delivered which ignore the place-based nature and context of individuals targeted by the service (Pinto, McKay, & Escobar, 2008).

### 1.3.2 Recognising underserved communities and populations

The population groups targeted by the CORE20PLUS5 approach include ethnic minority communities; people with a learning disability and autistic people; people with multiple long-term health conditions; groups that share protected characteristics defined by the Equality Act 2010; groups experiencing social exclusion, people experiencing homelessness, drug and alcohol dependence, vulnerable migrants, Gypsy, Roma and Traveller communities, sex workers, people in contact with the justice system, victims of modern slavery and other socially excluded groups. By identifying and actively targeting these population groups, the approach aims to provide exceptional quality healthcare for all, ensuring equitable access, excellent experience and optimal outcomes, and addressing longstanding health inequalities (NHS England, n.d.).

The importance of including seldom heard groups in health and social care research is crucial on scientific, policy and ethical grounds (Bhopal & Sheikh, 2009). The under-representation of these groups in health research impacts the validity and generalisability of data (Oakley, Wiggins, Turner, Rajan, & Barker, 2003), the development of services and interventions that meet their needs (Hussain-Gambles et al., 2004), allocation and access to resources (McLean & Campbell, 2003) and can lead to the perpetuation of health inequalities, especially as some of these groups have more health problems and health needs (Redwood, Gale, & Greenfield, 2012; Herrera et al., 2010; Liljas et al., 2019).

Much literature describes inequality in health and health outcomes in patients from diverse sociocultural backgrounds, with members of ethnic minority groups often experiencing poorer

outcomes (Raleigh & Holmes, 2021). Cultural differences in health seeking behaviours are wide-ranging from knowledge and beliefs of disease causation, symptoms, curability, and consequences, to trust in medical professionals (Uskul, 2010).

Failures to address diversity and inequality in healthcare and weight management provision, only serve to compound inequalities within underserved and marginalised communities, leaving them vulnerable and with a larger health burden. It is of paramount importance that weaknesses in the current health system are identified and addressed, including the recognition of systemic, structural inequalities, and alternative, holistic approaches proposed.

Paper 4 demonstrates the current successes and failures of the diabetes management system for individuals from diverse and marginalised groups (Nield, Bhanbhro, Steers, Young, & Fowler Davis, 2023). It provides a theory of change which highlights the valuable impact of VCSE organisations in providing care which supports statutory care providers and tailoring advice and knowledge into culturally appropriate, personalised and nuanced information which is meaningful to the individuals and communities they serve. It demonstrates the importance of a holistic 'systems approach' which recognises the valuable contribution of all the community assets working together and integrating within the health system.

### 1.3.3 Justifying whole systems and holistic approaches to health and wellbeing

The latest Health Survey for England data (2021) shows that 26.5% of women, and 25.4% of men are living with obesity (OHID, n.d.) and in recognition of the widespread issue of obesity, Public Health England (PHE, 2018) advocates for a community approach to tackling excess weight, underpinned by the stance that obesity is not an individual but a societal problem. When the problem is so widespread in society (i.e., over 60% of individuals live with overweight and obesity in the UK), it is resultant from a broken wider system rather than individuals lacking capability. Sociologist C Wright Mills made this distinction in relation to the example of unemployment:

"When, in a city of 100,000, only one man is unemployed, that is his personal trouble, and for its relief we properly look to the character of the man, his skills, and his immediate opportunities. But when in a nation of 50 million employees, 15 million men are unemployed, that is an issue, and we may not hope to find its solution within the range of opportunities open to any one individual. The very structure of opportunities has collapsed." (Mills, 1959, p9).

As per Mills' example, obesity is not an individual issue with individual solutions, but one requiring *systemic* societal, economic and political solutions. This understanding is beginning to penetrate public health, where there is growing consensus that systems approaches can

help address many complex public health issues being faced, including obesity (Bagnall et al., 2019; Rutter & Glonti, 2016; Nobles et al., 2022).

A system is defined as "a set of inter-connected parts that have to function together to be effective" (WHO, 2007). Systems approaches are notoriously complex, and as such, they are bounded so that the complexity is manageable enabling adaptation and improvements within the system which will lead to a population benefit (Morris & Martin, 2019). Contemporary researchers are describing population health issues such as obesity, physical inactivity, homelessness, and smoking as outcomes of a complex adaptive system. Complex adaptive systems are ones which contain differing interacting elements, a combined effect which is greater than the sum of its parts and has long-lasting effects which adapt to changing circumstances (Luke & Stamatakis, 2012).

A systems approach aims to influence multiple parts of the system by capitalising on the expertise and resources of individuals, communities, organisations and sectors (Swinburn et al., 2011). Systems approaches have the potential to reshape the environments that people interact with, live and work within, therefore influencing routine or automatic behaviours (Adams, Mytton, White, & Monsivais, 2016) and making health-promoting behaviours easier. Systems are highly adaptive, dynamic and responsive to different contexts, and can therefore be tailored to reflect different settings and demands.

The Obesity Systems Map presented in the Foresight report describes the complexity of weight management and highlights the multifactorial drivers of obesity, and arguably other nutritional inequalities (Foresight, 2007a). In recognition of the complexity of factors, attention has turned to a WSA (Public Health England, 2019b). To address such complex issues, the Foresight report considered the social determinants of health and draws on the sociocultural and socioeconomic models for health with a lens on obesity. It highlights the complexity of obesity and weight management and the numerous interconnected factors which determine someone's chance of becoming overweight, challenging the simple 'energy in vs. energy out' rhetoric which describes a purely mathematical model of weight management based on reducing the calories consumed, and increasing the calories expended (Foresight, 2007a). The mapping highlights the complex system which drives weight changes in individuals and highlights challenges associated with living in an 'obesogenic' environment (an environment that encourages overweight and obesity in individuals and populations; Lake, Townshend, & Alvanides, 2010) and how obesity can be seen as a normal 'passive' biological response to the wider food and physical environment. Whilst it recognises that some adults and children are more susceptible to weight gain due to genetic, social or environmental factors, it is "unwise to blame individuals within a society for their poor health...when the most appropriate

response is to consider their environmental circumstances and their particular need for help" (Lake et al., 2010, p4).

Local government authorities have been supported to implement a WSA to obesity in England (Public Health England, 2019b) and internationally (Bagnall et al., 2019) with varying success. Whilst there is a consensus that working in a systems-thinking approach is beneficial, implementation is more challenging, and it is often not embedded into practice. Despite the increased focus on, and implementation of, systems approaches in public health there is a paucity of research evidence surrounding their evaluation (Bigland, Evans, Bolden, & Rae, 2020; Nobles et al., 2022). This is complicated by a lack of a consensus definition of WSAs, and poor fidelity to recognised frameworks (Bagnall et al., 2019).

Currently, there is no single agreed definition of whole systems obesity work; a practical definition provided by the Foresight team defines an obesity system as an emergent condition, being 'the sum of all the relevant factors and their interdependencies that determine the conditions of obesity for an individual or group of people' (Foresight, 2007b; Salm et al., 2023). A recent definition developed in collaboration with PHE, the Local Government Association, Association of Directors of Public Health and Leeds Beckett University, amongst others is:

"A local whole systems approach responds to complexity through an ongoing, dynamic and flexible way of working. It enables local stakeholders, including communities, to come together, share an understanding of the reality of the challenge, consider how the local system is operating and where there are the greatest opportunities for change. Stakeholders agree actions and decide as a network how to work together in an integrated way to bring about sustainable, long-term systems change" (Public Health England, 2019b).

Despite the recognised benefits of systems approaches, much of the focus of weight management interventions to date has led to the burden on the individual living with obesity, yet the causes of obesity are multifactorial encompassing biology and behaviours within a cultural, environment and social context (Foresight, 2007).

# 1.3.4 Opportunities and challenges in systems and place-based approaches

Population health is the driver of public health (Jarvis, Scott, El-Jardali, & Alvarez, 2020). Healthcare and public health are frequently described as separate systems, often with their own aims and functions, governance and financial systems, and service delivery models. The health system is therefore separate from but influenced by larger systems including political and social systems (Jarvis, Scott, El-Jardali, & Alvarez, 2020). Whilst public health and healthcare both endeavour to support the health of individuals within populations, integration,

the intersection of public health and healthcare, could provide a more seamless service delivery within the wider health system which better responds to the needs of both individuals and communities (White, 2015). However, there are arguments for and against integration of the systems and for this to be successful there would need to be an agreed definition, and broader vision of health across all systems. Rutter et al. (2017) argue that to date, many complex public health challenges have been tackled using clinical, linear, models of cause and effect which have been ineffective. Calls have been made for effective responses to be grounded in a complex systems model based on a wider set of approaches (Rutter et al., 2017).

Structural inequalities are pervasive in health and care systems and attempts to address these issues have resulted in the NHS England and NHS Improvement's Integrating Care paper (2020) which introduced Integrated Care Boards, demonstrating a commitment for greater collaboration of health and care partners and stakeholders, including the VCSE to address place-based health inequalities (NHS England and NHS Improvement, 2020). The Institute for Health Equity (IHE) report proposed a broad health system approach to improve and tackle health inequalities and advocated for a 'place-based' health system, which enables local solutions, and which focusses on prevention and treatment of ill health, understands local population health risks, collaborates across sectors, acts on social determinants of health and develops 'proportionate universalist' approaches (Allen, Goldblatt, Daly, Jabbal, & Marmot, 2018).

Other place-based initiatives have introduced the 'population intervention triangle' to illustrate the benefits of collaborative action at scale which meets the needs and addresses the context of populations (Public Health England, 2019a). This model embeds the proportionate universalism approach of Marmot et al. (2010) to target those specific population groups with most need (Marmot, 2010).

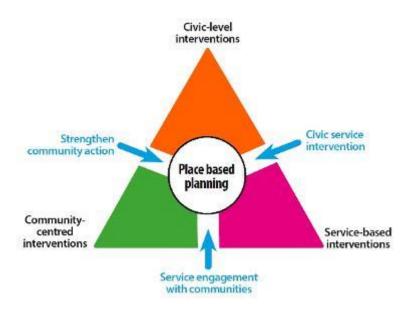


Figure 03: The Population Intervention Triangle model (PHE, 2019a)

A rapid review commissioned by What Works Wellbeing synthesised 27 place-based interventions which enabled community wellbeing and established several mechanisms for change that could lead to greater collective agency and control including the development of more neighbourhood connections, communities having a voice and decision-making influence to create a shared vision, and the recognition of community assets and capabilities (New Local, 2023).

Caution with place-based approaches alone should be exercised as they may result in the widening of inequalities between different social groups. The whole system context must be considered (McGowan et al., 2021). Consequently, interest has grown in embedding place-based approaches into wider systems thinking to recognise, understand and develop holistic solutions to address and improve nutritional inequality and help communities to live longer, happier, healthier lives at a healthy weight.

Embedding the voices of communities and stakeholders is of value, but it is not without its challenges and defining 'success' of an intervention is notoriously difficult. It is complicated, amongst other things, by the perception of different stakeholders (Baccarini, 1999; Davis, 2017; Thomas & Fernández, 2008). Defining success in terms of healthy weight is a complex and contested issue. On an individual level, success may be defined as the ability to tie one's shoelaces or improve self-esteem. For the service and commissioners, this may involve value-for-money, clinically significant weight loss, number of patients accessed and attrition rates (Public Health England, 2017); and for a system, success may be reliant upon whether individuals accessing weight management services are representative of the local population thus demonstrating equality of access, that it delivers a coordinated approach to weight management, and that it results in a healthier, happier population. It has therefore been argued

that the best way to judge the efficacy of a health system is by how well it can improve the health of individuals and populations (Sofaer, 1999). Similarly, the WHO Framework for Action (2007), states that "the best measure of a health system's performance is its impact on health outcomes". Health outcomes for weight management practice, at a basic level are focussed on percentage weight loss targets of individuals, and percentage of individuals within a service who achieve the stated targets (NICE, 2014a). Usually, these targets are based on clinical benefit of weight loss e.g. reduction in cardiovascular disease risk, or medication usage (NICE, 2014a; NICE, 2022) which drives individual, transactional approaches to management of these conditions. However, a more holistic approach, and perhaps an approach which is more patient-centred, would also incorporate quality of life, psychological measures, improvements in sleep, physical activity or diet quality; irrespective of weight loss (National Obesity Observatory, 2009; Public Health England, 2019b). There is recognition that systems are big, messy and 'wicked' which leads to resistance to implementing systems-based approaches due to the perceived complexity and expense of evaluating interventions, the lack of knowledge and skills within teams and the historical reliance on outcome metrics which are easier to measure and report (Boyle, Slay, & Stephens, 2010). Where systems approaches have been embedded in healthcare design and delivery, they have predominantly resulted in improvements to service and patient outcome. However, there are limitations due to the difficulties in generalising findings to other contexts or settings, and challenges of measuring impact (Komashie et al., 2021). Lack of progress in systems thinking, inequalities and public health has been critiqued and highlighted as a problem of 'lifestyle drift' where 'upstream' SDoH have been simplified into 'downstream' individual behaviour change solution where 'governments start with a commitment to dealing with the wider SDoH but end up instigating narrow lifestyle interventions on individual behaviours' (Hunter et al. 2010: 323), thus removing the systems approach and undermining the chances of policy success (Williams & Fullagar, 2019).

One way of envisaging the benefits of systems change is to develop logic models and theories of change which depict the evidence-based theoretical model of how an intervention is likely to translate into outcomes (Funnell & Rogers, 2011). Paper 4 presents a theory of change which describes how integration of VCSE services into mainstream diabetes management services could improve outcomes for marginalised communities (Nield, Bhanbhro, Steers, Young, & Fowler Davis, 2023). Success metrics have been proposed by the PHE logic model (see Figure 04) which describes short-, medium- and long-term outcomes including a reduction in health inequalities, reduction in child and adult obesity levels, effective use of community and other assets and an overall improvement in population health and wellbeing (Public Health England, 2019b).

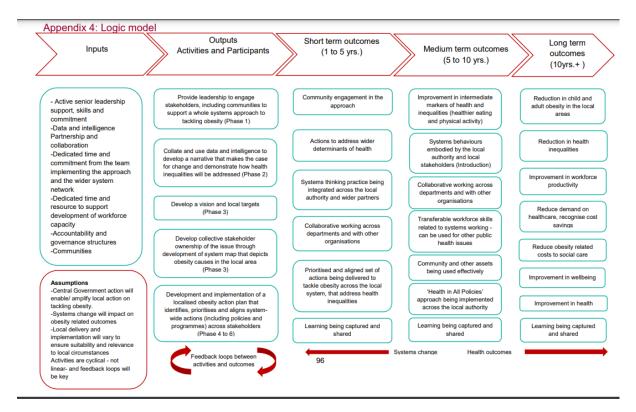


Figure 04: The PHE whole systems approach to obesity logic model

Whilst the move towards, and expansion of, systems thinking is encouraged, this model lacks patient-led outcomes and an understanding of 'what matters most' to populations involved in, and targeted by, weight management systems. Based on the literature presented in this thesis and building upon models and theories which have previously been proposed, it is argued that a healthy weight system will be less effective without tailoring services and the system to the service users, and embedding their wants and needs into service design and delivery.

# 1.3.5 The role of stakeholders, participatory methodologies and community engagement

The inclusion of stakeholder networks is pertinent to systems approaches (Savigny & Taghreed, 2009). PHE (2019) state that, "a whole systems approach can add value by providing the opportunity to engage stakeholders across the wider system to develop a shared vision, and include actions that address the causes of obesity outside the realms of public health" (Public Health England, 2019b), whilst Buck and colleagues (2018) see a WSA as "a dynamic way of working, that brings together stakeholders to develop a shared understanding of the challenge, and integrate action to bring about sustainable, long-term systems change" (Buck, Baylis, Dougal, & Robertson, 2018).

In the case of obesity, stakeholders are health care actors within the wider health and care system, and should also include users of, potential users of and beneficiaries of the system such as those living with, or at risk of obesity (IRISS, 2011). Each stakeholder may have a

different viewpoint which allows a broader perspective and new insights into how the system works, what the problems are and why, what can be improved or changed, and the impact of changes on other components in the system (Davis, 2017). It is important that stakeholders are representative of the community and populations targeted by weight management systems. A systematic review concluded that the most successful WSA weight management and public health projects included effective community involvement where participants identified the needs and actively participated in solutions at a local level (Bagnall et al., 2019).

The review showed that whole systems thinking is in its infancy and is not consistently embedded into the implementation or evaluation of interventions, with few published studies successfully targeting 'at risk' population groups (Bagnall et al., 2019). Not only does this restrict the usefulness of the findings, but it also demonstrates how systems thinking in weight management has not always been inclusive and has engaged minimally with some communities rendering them 'seldom heard' (Bagnall et al., 2019; IRISS, 2011).

As concluded in paper 6 (Nield, 2023), "It is therefore of paramount importance that future obesity approaches adopt a strong WSA that is inclusive of the voices of underserved communities and that actively recruits and engages people from seldom heard groups in the identification of issues, challenges and barriers, service design, delivery and development, implementation of actions for systems change and evaluation."

Participatory methodologies such as co-design and coproduction are at the heart of systems approaches: to understand the needs and demands of underserved groups in a considered rather than tokenistic way (Locock & Boaz, 2019) and to ensure that the system is built around the needs, experiences, and knowledge of its stakeholders (Griffiths et al., 2023). Coproduction is an approach that is used for decision-making and service design. It describes "a way of working where service providers and users work together to reach a collective outcome. The approach is value-driven and built on the principle that those who are affected by a service are best placed to help design it." (involve, 2023). As such, a transdisciplinary systems framework for obesity has been developed (see Figure 05) with coproduction at the heart of the model (Griffiths et al., 2023). It is based on the premises within this definition and model that coproduction is embedded within these published works.

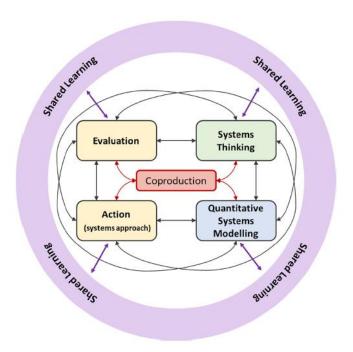


Figure 05: Complex systems framework for obesity (Griffiths et al., 2023)

Evidence from New Economics Foundation (NEF) and NESTA (2010) indicates that savings of six times the investment in coproduction approaches are elicited in addition to better outcomes for the public (Boyle, Slay, & Stephens, 2010). Case studies captured by NEF and NESTA report an array of successful uses of coproduction methodologies which serve to demonstrate the benefits of a new way of working and capture the creativity and determination of those working with and living in communities to deliver better services (Boyle, Slay, & Stephens, 2010).

Paper 5 (Nield, 2024) demonstrates the importance of coproduction with seldom heard groups. Adolescents have unique health care needs yet often fall between the gaps of child and adult service provision, and as such are a particularly underserved group (Neufeld et al., 2022; Aldiss et al., 2015). Adolescent voices often fall out of service design and development discussions, as evidenced by the PPI work which was carried out prior to this work, adolescents said, "why do you want to talk to us Miss, no-one has ever asked us". Working with a group of adolescents from a socially deprived area using PhotoVoice (an inclusive photo-elicitation focussed ethnographical methodology) enabled adolescents to discuss their food practices in a non-judgemental manner, allowing the researchers to work with the adolescent group to advocate for change in their school meal provision. This work is particularly valuable as it gives voice to these seldom-heard communities and highlights the value of their lived experience on finding solutions to a broken system, particularly in those of a younger age group where earlier systems changes can have more potential to make significant contributions to their health and wellbeing and for generations which follow.

"Co-production and co-development methodologies need to be embedded within WSA from the start, and effort needs to be made to ensure that the participants are truly representative of the target populations. Without capturing the voices of these communities, whole system approaches to the management of nutritional inequalities (including weight management provision) may inadvertently ignore the needs of those at high risk of obesity and perpetuate further health inequalities" (Nield, 2023).

This is not without its challenges. Coproduction needs translating into impactful implementation. The outcomes of coproduction activities can be difficult to evidence and hard for commissioners and funders to measure with current methods which rely heavily on strictly defined outputs and targets. As traditional evaluation methods are unable to capture the holistic benefits of using a coproduction approach, the public health sector requires a new range of analytical tools and evidence gathering approaches which overcomes this obstacle and helps to define success. Community engagement is a key principle of systems leadership. As previously described, what works for different types of people, and why, is variable and further work with segmented populations is warranted. By considering community members to be assets of the community and involving community expertise there is recognition that intervention efforts can be more effective (Public Health England, 2019b).

Therefore, whilst there are many strengths of coproduction for improving service design and delivery, and reducing health inequalities, there are additional considerations for it to be fully implementable in policy and practice. Co-production requires engagement with a variety of communities and stakeholders to ensure a diverse voice is included in the work, coined 'representative coproduction' (Eriksson, 2019). This takes time to build trust with organisations and individuals and building confidence and skills within the co-production participants to feel their voice is of equivalent worth to all others (Donetto, 2015). Therefore, coproduction is not particularly suitable for larger groups, which in turn may reduce the representation of the participants. There's also the challenge that we hear the same voices in every coproduction activity and at some point they stop being the naïve voices of the public, and become more like a researcher. Currently, there is no unified solution for doing co-production en masse which is a challenge for future research agendas. Additional tools are required which will help to scale up successful coproduction interventions for new people within new contexts or place. There is also a challenge to provide appropriate development and professional practice skills and knowledge to current and future professionals for them to engage and confidently work with coproduction approaches (Boyle, Slay, & Stephens, 2010).

### 1.4 Ontological and epistemological positioning

The research presented in the thesis takes a mixed methods approach which is underpinned by a critical realist philosophy. Critical realism proposes that a real and knowable world exists, but it can only be accessed through subjective and socially located knowledge (Madill, Jordan & Shirley, 2000). As such, the truth can only be known through the social world, culture and history (Clarke & Braun, 2013, p28) and qualitative methods, like interviews, can be used to access this subjective knowledge. Critical realism is not associated with individual research methodologies, making it compatible with a mixed methods approach (Fletcher, 2017).

Critical realism encompasses aspects of both realist and constructionist philosophy, allowing an explanation of social phenomena which is widely used in the field of social sciences (Bhaskar, 2008). The ontology of critical realism is that reality exists and is ordered. The epistemology of critical realism is that our ability to observe reality directly is limited by subjectivity (Bhaskar, 2008). Critical realism proposes that there are two stages to understanding the world 1) the feelings and events that we experience, and 2) the mental processing of the experience to understand the underlying reality which might have caused them. This second stage is 'retroduction', an explanation or reasoning to explain why data appear as they do and is a feature of critical realism (Olsen, 2007). Critical realists focus on providing an explanation or 'theory' for observable events by looking for the underpinning relationships, causes and mechanisms shaped by social structures in everyday life (Archer et al., 1998). Critical realists, use methodology to observe the world as best they can, using their findings to generate knowledge as theories (Danermark, Ekström, & Karlsson, 2019). Critical realism allows social science researchers to attempt to explain causal relationships and suggest solutions for social change (Fletcher, 2017).

The work presented in this thesis is set within a whole systems obesity context which draws on the critical realist philosophy. As such, the ontological framing of this work, is based on an understanding of relationships which are ever-changing within the health and wider environmental system, and a contextualist epistemological view which commits to the appreciation and recognition of multiple perspectives, "pluralistic and participatory nature of systemic knowledge as an evolutionary process of perception, interpretation, and creation of meaning, has nurtured the development of systems methodologies with an explicitly ethical commitment to inclusivity." (Hammond, 2017, p18). This research philosophy has been embedded in the work presented, using a number of specifically selected methodologies to understand the lived experience of different underserved communities from their perspective. By taking an understanding of the multiple perspectives of these different communities in the context of health and nutritional inequality, explanations of the wider system which they are experiencing, and inclusive solutions for change have been generated. Taking this approach

is important as 'top down' interventions are ineffective and perpetuate inequalities. Without addressing the wider systems issues pertaining to nutritional inequalities, and embedding the perspectives of underserved segmented population groups, challenges will remain. Less affluent communities will still be unable to purchase higher nutritional quality foods such as fruit and vegetables, and will continue to rely on cost-effective high fat, salt and sugar (HFSS) and convenience food which drive poorer health outcomes; engagement with transactional weight management approaches continue to be ineffective; and the communities continue to live in an obesogenic environment which perpetuates weight gain.

### 1.5 Methodological development during the research

As the work which contributes to this thesis has progressed, methodological perspectives have developed from empirical work evaluating traditional weight management services, to work which addresses wider sociocultural perspectives, embracing systems thinking and codevelopment work which is underpinned by a critical realist philosophy. This body of work reflects my journey as a researcher focussed on nutritional inequalities, within an evolving obesity research field. Within this work, I have designed and delivered mixed-method studies advancing my knowledge and skills from literature reviewing and research design to coproduction methods.

As a clinical dietitian by background, my initial research focussed on the benefits of evidence-based, 'best-practice' services on weight management outcomes for populations who access these services. This approach is evidenced in two papers- the service evaluation of a community weight management clinic (Paper 1; Nield & Kelly, 2016) and the role of community pharmacies in community weight management provision (Paper 2; Brown et al., 2016). This research contributed a novel understanding of the demographic and place-based factors which determined retention and weight loss in these services and highlights the populations who were underserved by traditional weight management approaches.

This empirical research approach, whilst valid and of benefit to understand and evaluate services is reflective of only a small part of the complexity of weight management systems and as such research has since developed to explore the wider context, to understand the factors which contribute to success or failure of weight management provision at place. It is well documented that weight management for individuals is difficult, often unsuccessful, has high attrition rates in clinical and community settings, and cements the feelings of failure, blame and stigma on those living with obesity (Wadden, Butryn, & Byrne, 2004; Nield & Kelly, 2016). After considering the underpinning systems failure with regards to population health, my research trajectory evolved to understand the lived experience of many populations, to ascertain their barriers to healthier lifestyles and to augment their voices to advocate for

change to support and maintain a healthy weight and lifestyle. This work is not about how individual behaviour change interventions are required, but about how we can disrupt an obesogenic system to provide sustainable systems change which facilitates healthier behaviours and weight management.

I have achieved this objective by using different methods which have evolved as my research focus has developed. Each method was chosen to answer the specific research question of each study and has provided a broad mixed-method exploration of underserved communities within different research contexts. The chosen qualitative methodologies elicit the lived experience of populations and were designed to work effectively with the specific population involved.

The qualitative thematic synthesis (Paper 3; Stockton & Nield, 2020) provided a recognised structure and process through which to interrogate existing qualitative data and elicit the wants and needs of pregnant women in a weight management context (Thomas & Harden, 2008). The methodology was robust, validated and provided an appropriate approach for answering the research question. The main weaknesses with this methodological approach, is the quality of the output is dependent on the quality of the inputs and the relative lack of high-quality research can be recognised as a weakness. This study consolidated an understanding of the breadth of underserved populations from both a research and public health context and developed my interest in working with underserved populations to amplify their voices and advocate for change.

After publishing research which addressed those living with very high BMIs and pregnant women (Papers 1-3), I undertook two pieces of research which were codesigned with individuals and stakeholders to develop research which addressed 'what matters most' to the underserved groups. The VAS diabetes project (Paper 4) uses a novel research recruitment design in which staff from local VCSE organisations were trained to recruit and interview their service users, to evaluate their service. An appreciative inquiry (AI) approach was used to understand what works currently for these deprived communities across the whole diabetes journey. AI is aligned with an asset-based approach (Finegold, Holland, & Lingham, 2002) where atypical populations are engaged, and more marginal views are sought (Locock & Boaz, 2019). Using this qualitative AI approach allowed an understanding of what was positive and successful in current diabetes service provision and provided an opportunity for individuals to consider their ideal service, identifying what is lacking from their lived experiences. The framework synthesis provided a structured methodology through which findings were synthesised into an initial theory of change (Breuer, Lee, De Silva, & Lund, 2016; Connell &

Kubisch, 1998) which demonstrates the role and potential impact of the VCSE sector in supporting underserved communities with improved health and wellbeing.

The PhotoVoice methodology used for the adolescents and food choice paper (paper 5) takes a focussed ethnographical approach which allowed a detailed insight into the food practices of Muslim adolescents from a deprived setting during cultural celebrations as well as understanding the day-to-day lived experiences of their food environment. Using a collaborative, coproduction approach with the adolescents ensured that the methodology and questions were age-appropriate and demonstrated how autonomy and power dynamics could be rebalanced 'at place' (i.e., the school setting). The resulting synthesis using framework analysis represented the adolescents' viewpoints consolidating understanding of their food environment and how this drives food choice.

Paper 6 consolidates the need for representation of underserved communities in codevelopment activities related to the food and obesity systems. If we are to truly 'level up' and tackle health and nutritional inequalities, then we need to augment the voice of those most underserved. This piece reflects the need of the research, public health and policy communities to come together and address structural, systemic inequalities to improve the health and wellbeing of everyone.

### 1.6 Ethics statement

All work published within this thesis has been reviewed and approved by the appropriate ethics committees. Publications have been peer-reviewed prior to publication.

### 2 Contribution to the field (significance and originality)

The work presented in this thesis contributes new knowledge and advances understanding in the field of nutritional inequalities. This cohesive body of work and resulting theoretical development guides the reader to understand the contribution of this work towards a bigger domain of influence. This research makes three unique contributions to knowledge, advancing existing understanding in the following areas.

- 1. Nutritional inequalities, including obesity, can be managed more effectively by recognising the lived experience of, and empowering, seldom heard communities and individuals to contribute to solutions that reflect their sociocultural norms (Papers 3, 4 & 5).
- 2. Methodological contributions for working with and coproducing research in novel ways which benefit seldom heard populations and reduce health inequalities (Papers 4, 5 & 6)
- 3. To further evidence the importance of systems-thinking in addressing policy and practice challenges for obesity management to reduce health and nutritional inequalities (Papers 1, 2 & 6)

	Full citation	My role	Contribution to knowledge
1	Nield L & Kelly S. (2016) Outcomes of a community-based weight management programme for morbidly obese populations. J Hum Nutr Diet. 29, 669–676 https://doi.org/10.1111/jhn.12392	Idea generation, study design, data collection, data management, data analysis, wrote draft manuscript, wrote final manuscript, submitted final manuscript.  Approximate contribution: 95%	3- To further evidence the importance of systems-thinking in addressing policy and practice challenges for obesity management to reduce health and nutritional inequalities
2	Brown TJ, Todd A, O'Malley C, Moore HJ, Husband AK, Bambra C, Kasim A, Sniehotta FF, Steed L, Smith S, <b>Nield L</b> & Summerbell C. (2016) Community pharmacy-delivered interventions for public health priorities: a systematic review of interventions for alcohol reduction, smoking cessation and weight management, including meta-analysis for smoking	Data collection and screening, cross- checking data was correctly entered, revision of manuscripts and sign-off of final manuscript.	3- To further evidence the importance of systems-thinking in addressing policy and practice challenges for obesity management to reduce health and nutritional inequalities

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	cessation. <i>BMJ Open</i> ;6:e009828. https://doi:10.1136/bmjopen-2015-009828	Approximate contribution: 5%	
	11ttps://doi.10.1130/binjopen-2013-003020	Approximate contribution: 5%	
3	Stockton J & <b>Nield L</b> (2020) An antenatal wish list: A qualitative systematic review and thematic synthesis of UK dietary advice for weight management and food borne illness. <i>Midwifery</i> . Volume 82, 102624. https://doi.org/10.1016/j.midw.2019.102624	Idea generation, screening of papers, quality assessment, data management and qualitative synthesis, editing of manuscript, sign off final manuscript.  Approximate contribution: 45%	1- Nutritional inequalities, including obesity, can be managed more effectively by recognising the lived experience of, and empowering, seldom heard communities and individuals to contribute to solutions that reflect their sociocultural norms.
4	Nield L, Bhanbhro S & Fowler Davis S (2023) Impact of Voluntary, Community and Social Enterprise organisations (VCSE) working with people living with type 2 diabetes mellitus in underserved communities: a complex evaluation.  Healthcare, 11 (18).  http://doi.org/10.3390/healthcare11182499	Consultancy and idea generation, study design, data collection, PPI, data collection, project management, data analysis, wrote sections of draft manuscript, wrote final manuscript, submitted final manuscript.  Approximate contribution: 55%	1- Nutritional inequalities, including obesity, can be managed more effectively by recognising the lived experience of, and empowering, seldom heard communities and individuals to contribute to solutions that reflect their sociocultural norms.  2- Methodological contributions for working with and coproducing research in novel ways which benefit seldom heard populations and reduce health inequalities.
5	Nield L (2024) "I Prefer Eating Less Than Eating Healthy": Drivers of Food Choice in a Sample of Muslim Adolescents"  Adolescents 4, no. 1: 41-61.  https://doi.org/10.3390/adolescents4010004	Idea generation, literature review, study design, participant recruitment, data collection, data management, data analysis, project management, wrote draft manuscript, wrote final manuscript, submitted final manuscript.  Approximate contribution: 100%	1- Nutritional inequalities, including obesity, can be managed more effectively by recognising the lived experience of, and empowering, seldom heard communities and individuals to contribute to solutions that reflect their sociocultural norms.  2- Methodological contributions for working with and coproducing research in novel ways which benefit seldom heard populations and reduce health inequalities

6	<b>Nield L</b> (2023) Empowering and including
	'seldom heard' communities in systems
	thinking for weight management.
	Perspectives in Public Health.
	2023;143(6):310-312.
	http://doi.org/10.1177/17579139231180732

Idea generation, literature review, wrote draft manuscript, wrote final manuscript, submitted final manuscript.

Approximate contribution: 100%

- 2- Methodological contributions for working with and coproducing research in novel ways which benefit seldom heard populations and reduce health inequalities
- 3- To further evidence the importance of systems-thinking in addressing policy and practice challenges for obesity management to reduce health and nutritional inequalities

# 2.1 Paper 1: Outcomes of a community-based weight management programme for morbidly obese populations

This paper describes a mixed-methods service evaluation of a multidisciplinary community weight management service for those with BMIs greater than 35kg/m². The service was designed and delivered in accordance with NICE and best practice guidelines for tier 3 weight management services (NICE, 2006). Data was collected routinely as part of the service and this study is based on prospective observational data. Data from this service evaluation were considered during the development of the new NICE Public Health guidelines (2014) and embedded into a recommendation which suggest that a 3% weight loss target is beneficial for this patient group and is a more realistic target for commissioners to be using in tenders (NICE, 2014a).

NICE guidelines describe a successful weight-loss intervention as one that achieves an average of 3% weight loss in all patients attending one or more sessions, with at least 30% of patients having lost ≥5% of their initial weight (NICE, 2014a). Whilst outcomes of this service were deemed 'successful' based on the recommendations and expected weight loss (in terms of % of cohort who lost weight and % weight loss), it describes the high rates of attrition which have been normalised in weight management services (59.7% by 6 months) and provides evidence of the poor acceptability of such service provision even in motivated population groups. A strength of this study was that the service was delivered from a main hub, with satellite clinics in areas of deprivation. The service was accessed equitably by patients from all deprivation quintiles, with 53% of attendees living in the two most deprived quintiles which demonstrates the impact of place-based working to engage underserved communities.

The paper highlights the importance of multidisciplinary weight management provision which is tailored to the patients' needs and showcases the benefits of holistic evaluation of services which does not focus solely on weight loss outcomes. The holistic evaluation includes physical activity, psychological and nutritional impacts, which is important because many individuals living with obesity report long-lasting effects of obesity-related stigma as a result of a perceived over-focus on weight which leaves them less likely to engage in health-promoting activities and health care services as well as poorer mental health (Emmer, Bosnjak, & Mata, 2020; Westbury, Oyebode, van Rens, & Barber, 2023). Such transactional services, may then, be more detrimental to health in the longer-term.







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#### WEIGHT AND HEALTH

## Outcomes of a community-based weight management programme for morbidly obese populations

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#### Keywords

morbid obesity, service evaluation, weight management.

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#### **Abstract**

Background: Morbid obesity is an ongoing concern worldwide. There is a paucity of research reporting primary care outcomes focussed on complex and morbidly obese populations. The National Institute for Health and Care Excellence (NICE) recommends a specialist, multidisciplinary weight management team for the successful management of such populations. This is the first service evaluation reporting both primary (weight change) and secondary [body mass index (BMI), waist circumference, physical activity levels, fruit and vegetable intake, Rosenberg self-esteem score] outcomes in these patients.

**Methods:** The present study comprised a prospective observational study of a cohort data set for patients (n = 288) attending their 3-month and 6-month (n = 115) assessment appointments at a specialist community weight management programme.

Results: Patients had a mean (SD) initial BMI of 45.5 (6.6) kg m<sup>-2</sup>; 66% were females. Over 80% of patients attending the service lost some weight by 3 months. Average absolute weight loss was 4.11 (4.95) kg at 3 months and 6.30 (8.41) kg at 6 months, equating to 3.28% (3.82%) and 4.90% (6.26%), respectively, demonstrating a statistically significant weight change at both time points (P < 0.001). This meets NICE best practice guidelines for the commissioning of services leading to a minimum of 3% average weight loss, with at least 30% of patients losing at  $\geq$ 5% of their initial weight. Waist measurement and BMI were reduced significantly at 3 months. Improvements were also seen in physical activity levels, fruit and vegetable consumption, and self-esteem levels (P < 0.001).

Conclusions: This service was successful in aiding weight loss in morbidly obese populations. The findings of the present study support the view that weight-loss targets of 3% are realistic.

#### Introduction

Overweight and obesity are both defined as an abnormal or excessive fat accumulation that presents a risk to health <sup>(1)</sup>. Morbid obesity [body mass index (BMI) ≥40 kg m<sup>-2</sup>] levels are rising in the UK; from 0.2% of men and 1.4% of women in 1993 to 1.6% and 3.9%, respectively, in 2013 <sup>(2-4)</sup>. The higher the BMI, the greater

the risk of developing obesity-associated conditions  $^{(1,5,6)}$ , resulting in higher total healthcare costs  $^{(7,8)}$ . Additionally, the psychological aspects of obesity have been well documented, with an established relationship between weight loss, better emotional well-being and health-related quality of life  $^{(9)}$ . For the purpose of the present study, 'complex obesity' is defined as a BMI  $\geq$ 35 kg m<sup>-2</sup> with at least one obesity-related comorbidity.

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There are very few published data evaluating UK National Health Service (NHS) weight management service provision for morbidly obese patients outside of a research context (10-12). NHS services are often set up quickly to provide evidence-based information and support for patient groups and, although the provision of useful service evaluation data is often not considered at the planning stages, and so data for rigorous evaluation are not available. The lack of published evidence for NHS services, in comparison to commercial slimming organisations (12-15), means that it is difficult to provide substantial evidence to support the value of the service when service providers are making decisions concerning the commissioning and decommissioning of services. This is particularly relevant in open tender situations for the provision of public health services, including weight manage-

In 2004, the UK government white paper Choosing health: making healthy choices easier (16) emphasised the role of primary care in obesity management and recognised primary care as a suitable setting in which to provide weight-loss services. Despite clinical guidelines for obesity management (4,17-20) and related disease (21), there is little research from primary care about treating morbid or complex obesity populations and, indeed, a recent systematic review found no interventions that reported data from solely morbidly obese individuals (22). Research from primary care on individuals with morbid obesity is limited to a single study: Logue et al. (2014) evaluated the NHS Glasgow and Clyde Weight Management Service (GCWMS). This service evaluation was based on a large cohort of 1838 obese patients (BMI ≥30 kg m<sup>-2</sup> with obesity-related comorbidities or BMI ≥35 kg m<sup>-2</sup>) who had a mean starting BMI of 43.3 kg m<sup>-2</sup> and reported only weight change data up to 12 months (23). It is well recognised that weight loss as a solitary outcome measure does not capture the protective benefits of increased fruit and vegetable intake (FVI), physical activity or self-esteem (24); all of which are important to the health of this population group. For example, in addition to aiding weight-loss maintenance, increased physical activity has been shown to benefit the blood lipid profile (25), insulin sensitivity (26), and all-cause and cardiovascular disease mortality (27).

The UK National Institute for Clinical Excellence (NICE) guidelines recommend that primary care physicians and healthcare professionals identify their obese patients and offer clinical management <sup>(4,18)</sup>. However, there are barriers to staff raising the issue of weight in primary care, including a lack of evidence of efficacy, time and training <sup>(28, 29)</sup>. Clinically significant weight loss has been defined as a loss of 5–10% of initial weight <sup>(4,30)</sup>, although the Scottish Intercollegiate Guidelines Network recommends a 15–20% reduction for those with a BMI

≥35 kg m<sup>-2</sup> (17). Evidence suggests that a 5–10% weight loss is associated with meaningful clinical improvements in health-related risk factors, such as serum lipids, glucose tolerance and blood pressure (31,32). Current NICE Public Health guidelines describe a successful weight-loss intervention as one that achieves an average of 3% weight loss in all patients attending one or more sessions, with at least 30% of patients having lost ≥5% of their initial weight (18).

The present study aimed to investigate the physical, psychological and dietary impact of a 12-week Specialist Community Weight Management Programme (SCWMP) on morbid and complex obesity patients.

#### Materials and methods

The service evaluation in the present study uses routinely captured data from patients, in a prospective cohort study. The SCWMP was established in August 2010 in accordance with NICE recommendations <sup>(4)</sup>. Patients were referred to the service by general practitioners or healthcare professionals. Patients were contacted if they were eligible to attend the service and met the inclusion criteria. Patients who did not meet the inclusion criteria were referred to an appropriate alternative service. The most common reasons for exclusion were: patients with a BMI <35 kg m<sup>-2</sup> (or 32.5 kg m<sup>-2</sup> for South Asians); patients presenting with other comorbidities that needed to be prioritised prior to weight loss; patients not motivated to lose weight; or patients currently engaged in successful weight-loss attempts elsewhere.

Eligible inclusion criteria for the service were: patients who were male or female, aged  $\geq$ 18 years; patients registered with an eligible general practitioner; patients who were motivated to make changes to their diet and lifestyle; patients who were not pregnant; patients with a BMI  $\geq$ 35 kg m<sup>-2</sup> with a comorbidity or a BMI  $\geq$ 40 kg m<sup>-2</sup> without a comorbidity ( $\geq$ 32.5 kg m<sup>-2</sup> with comorbidity, and  $\geq$ 37.5 kg m<sup>-2</sup>, respectively, for South Asian) <sup>(1)</sup>; and patients who had tried and failed previous Tier 1 services.

Each eligible patient had a 1-h initial appointment with a senior member of the multidisciplinary team (MDT; i.e. dietitian, physiotherapist, psychologist) where a holistic assessment of the patients' medical, physical, psychological and social history was collected and a tailored treatment plan was agreed between the patient and assessor. The intervention consisted of up to 12 contacts via telephone, e-mail, in groups or face-to-face (decided by the patient), over a 12-week intervention period. The contact appointments were delivered by dietitians, physiotherapists, psychologists, cognitive-behavioural therapists, nutritionists and/or physical activity guides. Staff received external training in motivational interviewing and

behaviour change techniques, which they embedded into their consultations. Evening and weekend appointments were provided for enhanced accessibility of the service. Patients had an assessment at the end of the 3 month treatment period ('interim'), followed by a further follow-up at 6 months ('final'). This analysis includes those who attended their interim assessment appointments.

#### Demographics and anthropometrics

A detailed multi-component assessment of the patient included anthropometric measures and questionnaires that were distributed to all patients at baseline, and at 3 and 6 months. The primary outcome was weight change. Secondary outcomes included physical activity levels, FVI, self-esteem score and BMI.

Anthropometric data were collected in a pre-determined standardised sequence by trained staff members. Patients were weighed (kg) on calibrated scales (BC-420MA, Tanita Corporation, Tokyo, Japan; Seca 665 high capacity, Seca GmbH & Co. KG, Hamburg, Germany). Height (m) was measured using a Seca Leicester stadiometer. If the patient was unable to stand, ulna length was measured, and height was calculated using British Association for Parenteral and Enteral Nutrition charts (33). BMI was calculated using weight (kg) divided by height (m) squared. Waist circumference was measured (cm) with a standard length, plastic coated tape measure in line with National Health and Nutrition Examination Survey III protocol guidelines (34). Waist circumference was not measured in patients who were wheelchair bound or unable to stand. The Rosenberg self-esteem scale, used as a measure of psychological well-being, is validated and widely used in the obese population (35,36). Scores range from 0 to 30, with a higher score indicating greater selfesteem. FVI was assessed as an indicator of dietary quality using self-reported consumption of 0, 1, 2, 3, 4 or 5+ portions per day. Seven-day physical activity recall was used to assess number of minutes of physical activity perceived to be at moderate-high intensity per week, as adapted from the Stanford 7-day recall (3). The British Index of Multiple Deprivation (https://www.gov.uk/ government/statistics/english-indices-of-deprivation-2010) was used to infer socio-economic status, and was provided as deprivation quintiles from the NHS data analysis team. This is a validated area-based measure of deprivation based upon the individuals' postcode of residence (37).

#### Statistical analysis

Data from the patient records were analysed using spss, version 18 (SPSS Inc., Chicago, IL, USA). Frequency data

describe the baseline data. Differences were measured between time points using parametric or nonparametric methods as appropriate.

Change in parametric data were analysed using paired t-tests. Nonparametric data (FVI and Rosenberg score) were analysed using a Wilcoxon signed ranks test. P < 0.05 was considered statistically significant. A regression analysis of change in BMI (kg and % as separate models) was completed using STATA, version 13.1 (Stata-Corp, College Station, TX, USA). Explanatory variables were age, sex, ethnicity, physical activity, fruit/vegetable intake, self-esteem, number of sessions attended and type of therapist used.

Variables were tested one at a time for inclusion in the model and then all statistically significant variables (P < 0.10) were entered into a multivariate model. The final model was reduced to only statistically significant variables (P < 0.05). Each nonsignificant variable was then checked by entering it into the final model one at a time.

Very little data were missing, although final numbers may vary slightly as a result of this. BMI and waist circumference were available at all time points.

Ethical approval was not sought because service evaluation in the UK is subject to different guidance in accordance with National Research Ethics Service (2009), thus exempting the work from the need for ethical approval <sup>(38)</sup>.

#### Results

Two hundred and eighty-eight participants began the present study and 115 were still enrolled at 6 months. Most patients who attended an initial assessment were aged 35–65 years. Thirty-four percent of patients accessing and 38% completing the service were male (Table 1).

Patients who attended seven or more of their booked appointments were considered to have engaged well with the service. The mean (SD) number of sessions attended was 9.3 (1.75), with 95 (33%) people completing 10 of 12 sessions. There was significant loss to follow-up (60%) between the 3- and 6-month appointments.

The service was accessed equitabally by patients from all deprivation quintiles, including the two most deprived quintiles who comprised 53% of attendees.

There were statistically significant declines (P < 0.001) in weight at the 3- and 6-month assessments; the mean (SD) weight loss at 3 months was -4.11 (4.95) kg [3.28% (3.82%)] from baseline. At 6 months, absolute weight loss was -6.30 (8.41) kg [4.90% (6.26%)] from baseline (Table 2). Overall, 82.0% of patients who attended their interim appointment lost some weight (>0.05 kg) at 12 weeks, with 79.5% having lost some weight at their 6-month final assessment.

Table 1 Characteristics of patients at baseline and final assessment

	Baseline (n = 288)	Final (n = 115)
Sex	n (%)	n (%)
Male	98 (34)	44 (38)
Female	190 (66)	71 (62)
Age range (years)		
19–24	9 (3.1)	1 (0.9)
25–34	31 (10.8)	14 (12.2)
35–44	67 (23.3)	29 (25.2)
45–54	73 (25.3)	27 (23.5)
55–64	71 (24.7)	32 (27.8)
65+	37 (12.8)	12 (10.4)
Ethnicity		
White British and Irish	259 (89.9)	100 (87.0)
Asian	18 (6.3)	11 (9.6)
Black African/Caribbean	11 (3.8)	4 (3.5)
Deprivation quintiles		
Most deprived	77 (27)	
2	75 (26)	
3	55 (19)	
4	40 (14)	
Least deprived	35 (12)	
Unknown	6 (2)	
	Mean (SD)	Mean (SD)
BMI (kg m <sup>-2</sup> )	45.5 (6.6)	43.5 (7.5)
Weight (kg)	126.9 (21.5)	120.3 (2.0)
Waist circumference (cm)	130.7 (14.6)	125.1 (1.4)
Physical activity (min week <sup>-1</sup> )	113.2 (233.2)	213.6 (248.1)
Fruit and vegetables (portions day <sup>-1</sup> )	2.6 (1.5)	4 (1.2)
Rosenberg self-esteem score	16.8 (6.1)	20.3 (6.2)
No of different therapists seen		
0	1 (0.3)	0
1	38 (13.2)	12 (10.4)
2	144 (50.0)	61 (53.0)
3 or more	105 (36.4)	42 (36.5)

Table 2 presents the data based on secondary research outcomes. Physical activity levels, FVI and Rosenberg self-esteem score all significantly increased from baseline to 3 months, and from baseline to 6 months (P < 0.001).

In regression models none of the variables (i.e. the number of sessions attended, clinician seen, consultation method (face-to-face, telephone etc.) were identified as being predictive of weight loss at 3 or 6 months, except for the change in physical activity level, which was positively associated with weight loss at 6 months (P=0.028).

#### Discussion

Data are presented for 288 complex and morbidly obese individuals who attended a multi-professional intervention. The analysis shows that the SCWMP is a successful way of aiding weight management and improving overall well-being. From the data presented, we conclude that, for those patients who attended their planned sessions, the prevention of weight gain is likely to be achieved by over 80% of patients, regardless of their age, ethnicity or sex.

At 3 months, 24.3% of patients actively participating in the programme had lost 5% or more of their initial weight, increasing to 45.4% by 6 months. Previous research has reported a variety of weight losses at 12 weeks (14,15,29,39). In a study by Stubbs et al. (2011), 8913 patients with a mean BMI of 45.4 (5.2) kg m<sup>-2</sup> were recruited into a 12-week Slimming World programme via primary care referral. Using last observation carried forward methodology, 35.8% of patients lost 5% or more of their initial weight, after attending an average of 8.9 (3.5) sessions (15). The Lighten Up study compared 740 obese or overweight patients who were allocated to one of eight different intervention arms, including commercial weightloss programmes, primary care and pharmacy interventions. Mean BMI at baseline was 33.06 (3.5) to 33.96 (3.9) kg m<sup>-2</sup>. Some 16% of general practice and 46% of Weight Watchers patients lost more than 5% weight at 12 weeks (14). The mean BMI for patients in the present study was 45.5 (6.6) kg m<sup>-2</sup>, which is considerably higher than previously published data sets, which ranged from 31.4 (2.6) kg m $^{-2}$  (13) to 39.7 (6.9) kg m $^{-2}$  (39) and similar to the group in the analysis by Stubbs et al. (15). A weight loss of 24.3% at 12 weeks is lower than some of the previously published data; however, in most cases, the mean

Table 2 Change in primary and secondary outcomes given as mean (SD) in patients between initial, interim and final assessments

	Change at 3 months	P value	Overall change at 6 months	P value
Weight (kg)	<b>−4.11 (4.95)</b> <i>n</i> = 287	<0.001	<b>−6.30 (8.41)</b> <i>n</i> = 115	<0.001
Body mass index (kg m <sup>-2</sup> )	<b>−1.46 (1.73)</b> <i>n</i> = 287	< 0.001	<b>−2.18 (2.84)</b> <i>n</i> = 115	< 0.001
Waist circumference (cm)	-4.08 (5.12) $n = 282$	< 0.001	<b>−5.64 (7.61)</b> <i>n</i> = 115	< 0.001
Physical activity (min week <sup>-1</sup> )	<b>123.2 (363.5)</b> <i>n</i> = 287	< 0.001	<b>107.4 (209.7)</b> <i>n</i> = 96	< 0.001
Fruit and vegetable intake (portions day <sup>-1</sup> )	<b>1.0 (1.3)</b> <i>n</i> = 286	< 0.001	<b>1.3 (1.4)</b> <i>n</i> = 97	< 0.001
Rosenberg self-esteem score	<b>3.1 (5.4)</b> <i>n</i> = 286	<0.001	<b>3.6 (5.6)</b> <i>n</i> = 97	< 0.001

n varies because of missing values.

initial BMI was higher. This highlights the need for caution when comparing studies because the percentage weight loss can mean significantly different absolute (kg) weight losses depending on the initial average BMI of the study populations. There is a stark similarity between the weight-loss results from this intervention and the NHS GCWMS service evaluated by Logue *et al.* (2014)  $^{(23)}$ . At 3 months, 25% of all completers had lost  $\geq$ 5% of their starting weight (compared to 24.3% in the present study) and, at 6 months, 44% of all completers had lost  $\geq$ 5% (compared to 45.4% in the present study). Based upon the limited evidence available on complex and morbidly obese populations, a 5% weight loss may only be possible in fewer than 50% of patients by 6 months. Further follow-up studies on complex obesity patients are needed.

By 3 months, 21.5% of patients reported that they did zero minutes of moderate-high physical activity per week, which improved slightly to 19.6% of patients by their final assessment. In 2010, 20% of respondents in the Health Survey for England reported that they took walks of at least 20 min 'less than once a year or never' (40), which is in line with the findings from the present study. However, regression modelling suggests that physical activity levels were the strongest predictor of weight loss at 6 months.

The increase in Rosenberg scores at interim and final assessment were significantly improved from baseline (P < 0.001), which is indicative of higher self-esteem. Evidence is lacking concerning whether an increased Rosenberg score impacts upon ability to lose weight; although the relationship between low self-esteem and obesity is well established in children <sup>(41)</sup>.

Fruit and vegetable intake increased throughout the intervention and follow-up period (Table 2) indicating that patients continue to make dietary changes even after the intensive intervention has finished. The Health Survey for England (2012) found that average FVI was 4.2 portions day<sup>-1</sup> for adults aged 19-64 years, and 4.4 portions day<sup>-1</sup> for older adults <sup>(40)</sup>. The data presented show that the present study population were consuming less than the UK average FVI at baseline, although consumption appeared to increase in line with the rest of the general population during the study period. This supports the conclusions of Carlson et al. (2012) (42) who reported that an increase in FVI may be one of the easiest healthpromoting behaviour changes to make. In the present study, the maximum number of portions of fruit and vegetables per day which could be recorded was 5. It would be reasonable to assume that some patients will eat more than five portions per day and therefore averages are based on a worst case scenario, although it is recognised that self-reported data are subject to reporting bias. Wang et al. (2014) (43) demonstrated a significant

correlation between increased FVI and reduced all-cause mortality, particularly cardiovascular mortality, with Tapsell *et al.* (2014) <sup>(44)</sup> reporting that increased vegetable consumption as part of a calorie-controlled diet results in greater weight loss, which appears to be sustainable.

The improvement across all measures demonstrates the benefits of the specialist MDT supporting a variety of patients' needs within a single service. The SCWMP was designed in line with NICE and Grace recommendations (4,20) and the inclusion of an MDT may have contributed to the holistic improvement of this patient group. Unlike many of the previously published studies, there were no statistically significant differences in weight change or secondary outcome measures by age, ethnicity, sex, attendance, therapist seen or continuity of same therapist. This may be a result of the thorough assessment of patients at their initial assessments and the flexibility of the programme, which ensures that patients are seen by the most appropriate clinician(s) at the most appropriate time or that the changes in weight reported are seen predominantly in those with a BMI <35 kg m<sup>-2</sup>.

The data presented in the present study are intended to help generate debate over realistic target weight losses for morbidly obese patients, and emphasise the importance of longer term multi-disciplinary specialist weight management programmes in helping patients achieve physical, social and psychological benefits; not with a pure focus on weight-loss targets. Many obese individuals report longlasting effects of obesity-related stigma as a result of a focus on weight, which leaves them less likely to engage in health-promoting activities and healthcare services (45,46), as well as experience stigma-related mental health issues such as depression, anxiety, low self-steem and psychological stress (47). This leads to debate as to whether body weight is a realistic or ethical target within public health interventions (48) and whether more holistic 'health promotion' services are indeed more beneficial than weight management, with the movement of the 'Health at Every Size' agenda (http://www.haescommunity.org/).

#### Strengths and limitations

The present study provides a 'real-life' insight as to how weight management interventions are attended in NHS settings, and highlights achievable outcomes for morbidly and complex obese populations. Data are lacking in this area, and it is well-recognised that attrition rates are high <sup>(49)</sup>. In addition, engagement with male patients and those of low socio-economic status has previously been reported to be poor <sup>(50,51)</sup>. However, in the present study, 38% of subjects who completed the 6-month intervention were males, and engagement with patients from low socio-economic groups was high (53% of attendees were

from lowest socioeconomic groups), which supports the findings of Moroshko, Brennan and O'Brien (2011) (49) who concluded that, although many factors have been suggested to correlate with attrition, no individual factor had been consistently identified. It is hypothesised that providing a holistic, multi-disciplinary assessment at baseline encouraged otherwise poor engagers to attend the service because it was tailored to the individuals' needs. The disadvantage of the multi-disciplinary approach is that it is difficult to identify the benefit of an individual component. However, we found no relationship between the type of therapist used by the patient and weight change and so it may be that the interaction of many components is the benefit.

These results are representative of only one city in the UK and further research is required from similar services, both nationally and internationally. Larger data sets with longer-term follow up are needed, with the data sets following patients from baseline through to completion at 12–24 months and beyond. However, attrition rates are notoriously high and participant engagement post-intervention period is low <sup>(52)</sup>. In future studies, the improvement of data collection would be valuable, including, for example, an improved fruit and vegetable scale and the addition of blood biochemistry.

## Implications for future practice and recommendations for service improvement

As a result of the nature and complexity of morbidly obese patients, a holistic service evaluation is necessary, and it is unhelpful to use weight change as a sole primary outcome for service evaluation. Data from this service evaluation were considered during the development of the new NICE Public Health guidelines (2014), which suggest that a 3% weight loss target is beneficial for this patient group, and is a more realistic target for commissioners to be using in tenders <sup>(18)</sup>. The impact of increased physical activity, self-esteem (alongside other measures of mental health status) and dietary quality should be recognised, and these attributes should be addressed within the service by specialist multi-disciplinary teams <sup>(17,18,20)</sup>.

Additional data from this population group are lacking, and provision should be made by commissioners for data collection and thorough service evaluation, with statistical support. Data collected by each service should be standardised to aid the ease of comparison, and can be collected using the NOO Standard Evaluation Framework (2009) <sup>(53)</sup>. It is crucial that these data are available in the public domain to improve the understanding of factors that are pertinent to effective services and to aid service development, design and commissioning in the future.

#### **Conclusions**

By 6 months, over 60% of patients who actively engaged with the SCWMP lost ≥3% body weight, demonstrating that this was an effective weight loss service for complex and morbidly obese populations. The results appear to be comparable to the existing literature, although it is recognised that larger data sets are required. NICE guidelines, along with the results of the present study, suggest that a 3% weight loss target should be used as a realistic aim for this complex population group. Longer-term interventions (e.g. 12–24-month programmes) are likely to be more appropriate for these patients, and further research should consider the optimal duration.

## Conflict of interests, source of funding and authorship

The authors declare that they have no conflict of interests. This service evaluation data were routinely collected and the manuscript has been developed and written in an academic capacity without the use of external funding sources.

LN lead the research and carried out the study, collated study data and drafted the research paper, prepared the literature review and carried out data analysis and interpretation, and critiqued the manuscript and prepared the paper for submission. SK provided support for data analysis, manuscript writing, editorial support and drafting of the paper and also critiqued the manuscript and prepared the paper for submission. Both authors critically reviewed the manuscript and approved the final version submitted for publication.

#### **Transparency declaration**

The lead author affirms that this manuscript is an honest, accurate and transparent account of the study being reported, that no important aspects of the study have been omitted and that any discrepancies from the study as planned have been explained.

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#### Supporting information

Additional Supporting Information may be found online in the supporting information tab for this article: **Table S1**. Percentage weight loss achieved by participants at interim and final assessments.

### 2.2 Paper 2: Community pharmacy-delivered interventions for public health priorities: a systematic review of interventions for alcohol reduction, smoking cessation and weight management, including meta-analysis for smoking cessation.

This paper is a systematic review and meta-analysis examining the suitability of pharmacy-based interventions for several health-promoting services related to deprivation, including weight management. It was the first to explore the capacity of pharmacies to deliver such interventions in comparison to other primary care and healthcare settings with the underpinning view that the provision of services to communities in a location which is convenient and known to them could provide an appropriate alternative for public health service provision. However, whilst the outcomes for weight loss in individuals appeared to be as effective as other primary care provision, longer-term weight loss maintenance was poor.

Of the 19 studies that were included, study quality was variable. Five studies were related to weight management and only two of these studies explored the impact of sociodemographic variables on weight loss. None of the studies considered the potential differential effect of socioeconomic variables on the output intervention and none of the weight management studies reported any collaboration or consultation with stakeholders in either the planning or delivery of the intervention.

The interventions are predominantly individual behaviour-change focussed with or without pharmacological agents such as Orlistat or low-calorie diet meal replacement products. This paper provides a snapshot of some of many costly interventions which are designed, delivered, and evaluated internationally and showcases the pitfalls of such interventions such as the 93% attrition rate in one of the studies. This paper highlights the systemic failures of individual-level weight management approaches and the importance of understanding the characteristics and demands of a population prior to design or delivery of a service to ensure it is tailored appropriately and can empower people to make effective change.

## BMJ Open Community pharmacy-delivered interventions for public health priorities: a systematic review of interventions for alcohol reduction, smoking cessation and weight management, including meta-analysis for smoking cessation

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#### **ABSTRACT**

**Objectives:** To systematically review the effectiveness of community pharmacy-delivered interventions for alcohol reduction, smoking cessation and weight management.

Design: Systematic review and meta-analyses. 10 electronic databases were searched from inception to May 2014.

Eligibility criteria for selecting studies: Study design: randomised and non-randomised controlled trials; controlled before/after studies, interrupted times series. Intervention: any relevant intervention set in a community pharmacy, delivered by the pharmacy team. No restrictions on duration, country, age, or language.

Results: 19 studies were included: 2 alcohol reduction, 12 smoking cessation and 5 weight management. Study quality rating: 6 'strong', 4 'moderate' and 9 'weak'. 8 studies were conducted in the UK, 4 in the USA, 2 in Australia, 1 each in 5 other countries. Evidence from 2 alcohol-reduction interventions was limited. Behavioural support and/or nicotine replacement therapy are effective and costeffective for smoking cessation: pooled OR was 2.56 (95% CI 1.45 to 4.53) for active intervention vs usual care. Pharmacy-based interventions produced similar weight loss compared with active interventions in other primary care settings; however, weight loss was not sustained longer term in a range of primary care and commercial settings compared with control. Pharmacybased weight management interventions have similar provider costs to those delivered in other primary care settings, which are greater than those delivered by commercial organisations. Very few studies explored if and how sociodemographic or socioeconomic variables moderated intervention effects. Insufficient information was available to examine relationships between effectiveness and behaviour change strategies,

#### Strengths and limitations of this study

- To the best of our knowledge, this is the first systematic review that combines evidence from community pharmacy-delivered alcohol, smoking and weight management interventions, and directly compares these findings with other primary care and community healthcare settings.
- This review provides healthcare commissioners with useful evidence on reach, effectiveness and costs when considering using community pharmacies to help deliver smoking cessation and weight management services.
- There was insufficient evidence to assess the effectiveness of community pharmacy-based interventions on health equity.
- The descriptions available did not allow for the coding of specific aspects of theory and behavioural content of the interventions.
- Insufficient information was available to examine the relationship between intervention effectiveness and behaviour change strategies and/or models used, implementation factors, or the organisation and delivery of interventions.

implementation factors, or organisation and delivery of interventions.

**Conclusions:** Community pharmacy-delivered interventions are effective for smoking cessation, and demonstrate that the pharmacy is a feasible option for weight management interventions. Given the potential reach, effectiveness and associated costs of these interventions, commissioners should consider using community pharmacies to help deliver public health services.



#### INTRODUCTION

A number of agencies and countries, including WHO, have set a clear strategy for the future of public health. This agenda is focused on improving the healthy life expectancy of the population and, where possible, reducing or removing threats to this aim. One strand within this agenda is to create accessible, multidisciplinary networks of public health professionals who work within communities and provide services to address key public health issues, health inequalities, and ultimately improve health and well-being. Worldwide, community pharmacies may be an important component of this agenda; WHO acknowledges that community pharmacies and their staff are easily accessible and, as such, could play a key role in delivering public health initiatives, especially in priority areas.<sup>2</sup> For example, in England, community pharmacies are more accessible than general practice (GP) services.<sup>3</sup> A recent study has also demonstrated that, in England, 89% of the population can walk to a community pharmacy within 20 min. Significantly, in areas of highest deprivation, this value increases to almost 100%—the so-called positive pharmacy care law.<sup>4</sup> Community pharmacies could, therefore, be a way of engaging with hard-to-reach populations.

In view of this, many community pharmacies in some countries, now offer smoking cessation services, and a few offer alcohol and weight reduction services.<sup>5</sup> These services are delivered by pharmacists, pharmacy technicians and/or medicine counter assistants, with a view to modifying health-related behaviours. The specific types of services are wide ranging and include two main approaches: pharmaceutical-related (eg, supplying nicotine replacement therapy (NRT), monitoring of biochemical markers) and non-pharmaceutical-related (eg, providing advice on behaviour change strategies), or a combination of both approaches. Funding arrangements for these services vary by country; in the UK, at present, many of these services are commissioned by the local authority according to local need, and delivered according to an agreed framework. Currently, six Local Pharmaceutical Committees (LPCs) have weight management services, 14 LPCs have alcohol reduction services, and there are 81 stop smoking services.<sup>6</sup>

In 2008, the Department of Health for England<sup>7</sup> stated it was important to develop 'a sound evidence base that demonstrates how pharmacy delivers effective, high quality and value for money services'. Reviews published since 2008 have attempted to summarise this evidence base, but the lack of relevant randomised controlled trials (RCTs) have limited their findings. However, a scoping search performed in 2013 revealed a number of relevant RCTs that had, or were about to report their findings; a number of relevant controlled trials were also identified, that could usefully inform the evidence base where there was a lack of evidence from RCTs. The primary objective of this review, therefore, was to systematically review the effectiveness of community pharmacy-delivered interventions for alcohol

reduction, smoking cessation and weight management. The secondary objectives were to explore if and how age, ethnicity, gender and socioeconomic status (SES), moderate intervention effects; and to describe how the interventions have been implemented, organised and delivered.

#### **METHODS**

The review was funded by the National Institute for Health Research Public Health Research Programme (project number 12/153/52). The review was carried out using the principles outlined in the Cochrane Handbook for Systematic Reviews of Interventions. 11 The protocol is published in BMC Systematic Reviews, 12 and is registered with the International Prospective Systematic Reviews Register of (PROSPERO CRD42013005943). A review advisory group comprising patients, pharmacists and researchers, helped to guide the research. The review is reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. 13 14

#### **Interventions**

The review included any type of community pharmacydelivered intervention aimed at alcohol reduction, smoking cessation, or weight management; of any duration, based in any country and of any age. The setting of interest was the community pharmacy, which was defined as a pharmacy set in the community, which is accessible to all and not based in a hospital, clinic or online. Where a pharmacy is referred to throughout this paper, we refer to a community pharmacy. There was no restriction on the type of comparator, which could be a non-active control, usual care, or another type of active intervention, set in or out of the community pharmacy. Participants could be recruited from outside of the community pharmacy as long as one of the intervention groups was delivered from the community pharmacy. The intervention had to be delivered by the community pharmacist, pharmacy technician or medicines counter assistant; however, the intervention could also include other deliverers as part of a multidisciplinary team.

#### Study design

A broad range of controlled study designs were included, using the Cochrane Effective Practice and Organisation of Care (EPOC) study design criteria. These included RCTs; non-RCTs (nRCT); controlled before/after studies (CBA); interrupted time series (ITS), and repeated measures studies. We included both fully powered and pilot studies; studies were graded lower on quality if they were insufficiently powered.

#### Search strategy

Ten electronic databases were searched: Applied Social Sciences Index and Abstracts, Cumulative Index to Nursing and Allied Health Literature, EMBASE,

International Bibliography of the Social Sciences, MEDLINE, NHS Economic Evaluation Database, PsycINFO, Social Science Citation Index, Scopus and the Sociological Abstracts; from inception to May 2014 (see online supplementary file 1). Supplementary searches to identify published, unpublished and ongoing studies included bibliographies, contacting experts, grey literature (OpenGrey, Social Care Online, Prevention Information & Evidence elibrary and Nexus UK), study registers (International Standard Registered Clinical/soCial sTudy Number registry and the National Research Register) and website (Google).

#### **Outcomes**

Interventions for alcohol reduction and smoking cessation had to report a relevant behavioural outcome, and interventions for weight had to report an anthropometric outcome. These outcomes were considered the primary outcomes, and could be measured or self-reported. Where studies reported if and how sociodemographic (age, ethnicity, gender) and/or SES (education, income, occupation, social class, deprivation or poverty) moderated intervention effects on the primary outcomes, this is reported in the review.

The review also describes how the interventions have been organised, implemented and delivered using the methodological tool for the assessment of the implementation of complex public health interventions in systematic reviews, developed by Egan *et al*<sup>16</sup> for the workplace, and adapted by Bambra *et al*<sup>17</sup> for obesity interventions. The Behaviour Change Wheel<sup>18</sup> and the Nuffield Intervention Ladder<sup>19</sup> were used to broadly describe the behavioural strategies, intervention functions and policy categories of the interventions.

#### Data extraction and quality appraisal

Three reviewers (CO, HM, SS) screened the titles and abstracts and two reviewers (CO, TB) screened the fulltext articles. Data extraction and quality assessment were conducted independently by TB and one other reviewer (from among AT, CO, CS, HM, LN, LS, SS). Study quality was appraised using the Effective Public Health Practice Project Quality Assessment Tool for Quantitative Studies,<sup>20</sup> which is recommended by the Cochrane Public Health Review Group.<sup>21</sup> Studies were assessed for quality using six criteria: selection bias, study design, confounders, blinding, data collection methods and withdrawals/dropouts. Each study was given an overall (global) rating based on the ratings for the six criteria: 'strong' (no 'weak' ratings), 'moderate' (one 'weak' rating) and 'weak' (two or more 'weak' ratings). Any discrepancies in the data extraction or quality assessment were resolved through discussion, or referred to a third reviewer (CS) for final assessment. Extraction of contextual data was conducted by one reviewer (CS) and checked by another (TB). Assessment of behaviour change strategies used was conducted by one reviewer (CS) and checked by two others (FS and LS).

#### **Analysis and synthesis**

Narrative synthesis was conducted for all the included interventions. Owing to the heterogeneity of the studies, it was only possible to conduct meta-analyses for the smoking cessation studies. The smoking data was analysed (AK) using binomial-normal random effect model (R package meta). In order to explain the observed heterogeneity between studies, four different meta-regression models were fitted, accounting for whether the comparator was an active control or usual care, duration of the intervention and the global quality assessment ratings. Q-statistics and the percentage of heterogeneity between studies were reported for each meta-regression model. The most optimal meta-regression model was chosen using a minimum Akaike Information criterion. Owing to the limited available data and lack of informative priors, subgroup analysis by demographic or SES was not considered. A funnel plot for the smoking cessation RCTs was carried out to indicate the possible presence of publication bias and other biases.

#### **RESULTS**

The electronic search identified over 19 000 records, of which 72 full-text articles were screened for eligibility; 19 studies (from 23 articles) were included, and 49 were excluded. Five excluded studies <sup>22–26</sup> (from six articles) were pharmacotherapy plus lifestyle advice interventions in participants with comorbidities. These studies were excluded because the primary focus was not alcohol, smoking or weight management; these interventions focused on self-management of a chronic condition. The process of inclusion and exclusion of studies are shown in figure 1.

#### **Study characteristics**

Tables 1-3 provide the main study characteristics for all 19 interventions (see online supplementary file 2) for detailed study characteristics, including sociodemographic and SES). There were 2 alcohol reduction interventions, <sup>27</sup> <sup>28</sup> 12 smoking cessation interventions <sup>29</sup>–40 and 5 weight management interventions. 41-45 There were 15 RCTs, 2 nRCTs<sup>25</sup> 33 44 and 2 CBAs.<sup>29</sup> 29 42 There were 17 published journal articles and two reports.<sup>28</sup> 42 Eight studies were conducted in the UK, 27-29 33 36 38 42 43 four in the USA, 30 35 41 44 two in Australia 31 39 and one Canada,<sup>32</sup> Denmark,<sup>40</sup> Japan,<sup>37</sup> Netherlands<sup>34</sup> and Thailand.<sup>45</sup> All studies were of adults. Fourteen studies reported on funding; types of funding sources included academic research health-related institutions, commercial organisations and pharmaceutical companies.

Three studies<sup>29</sup> 42<sup>2</sup>43 recruited participants from areas of high deprivation, and compared a pharmacy-based setting with other settings. Twelve studies recruited participants within the community pharmacy; other recruitment settings included hospital/primary care units, via telephone and a community health centre. Types of

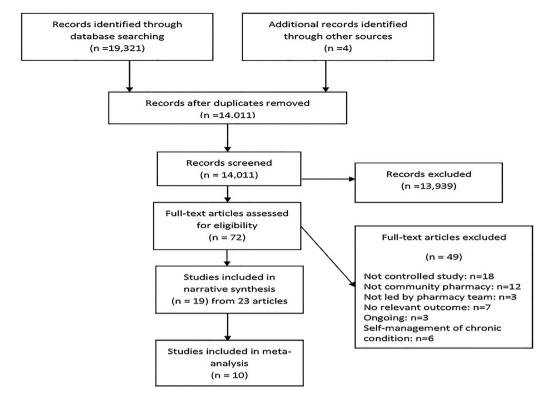


Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram.

pharmacies included single outlets, small chains and large chains; set in rural, urban and a combination of both geographical settings. The number of pharmacies included within each study ranged from one to over 200. Participant sample size ranged from 28 to around 7000, comprising approximately 13 500 service users in total. Mean age ranged from 24 to 60 years; there was a majority of females across all studies, particularly in the weight management studies. Duration of follow-up ranged from 5 to 56 weeks.

In terms of data analysis, only four studies assessed whether sociodemographic variables moderated the effect of interventions; four studies <sup>28</sup> <sup>38</sup> <sup>42</sup> <sup>43</sup> assessed any differential effects of gender, and one of these also assessed age. <sup>42</sup> No study assessed any differential effects of SES. Few studies used regression analysis to assess the influence of sociodemographic or socioeconomic variables on change from baseline, as potential predictors of outcomes within intervention groups, or to explain retention.

#### **Quality assessment**

The studies were assessed for quality using six criteria and assigned a global rating; six studies were rated 'strong', four studies 'moderate' and nine studies 'weak' (see online supplementary file 3). Participants were not obtained from a randomly selected sample in any of the studies. Five studies reported a low attrition rate, with follow-up of at least 80% of participants. Only five studies were sufficiently powered. Six studies conducted intention-to-treat analyses. Fifteen studies imputed data from baseline or last follow-up, or made assumptions

about dropouts (eg, assumed that dropouts had not stopped smoking/not lost weight). Six studies used hierarchical modelling techniques to adjust for potential pharmacy or pharmacist-level effects on individual participant outcomes. None of the studies reported details about whether the intervention was delivered as intended, for example, by observation of sessions, quality control audits, or staff and researcher records.

#### Implementation of the interventions

Very few studies reported any degree of consultation or collaboration, with stakeholders as part of the planning process, or during delivery of the intervention (see online supplementary file 4). Both the brief alcohol reduction interventions consulted with pharmacists during the planning stages.<sup>28</sup> The smoking cessation study by Hoving  $et at^{34}$  collaborated with a national charity on smoking and health, and together they developed the intervention. The smoking cessation study by Costello et al<sup>32</sup> was nested within a 'host' study called 'STOP', which collaborated with different community and regional partners in many different ways during the planning and delivery of the intervention. In the majority of interventions, regardless of their target behavioural or health outcome, pharmacists received reimbursement for providing the intervention; this appears important in order for the intervention to be sustainable.<sup>32</sup> <sup>36</sup>

#### Organisation and delivery of the interventions

Sixteen interventions were delivered by the community pharmacy staff; one photoageing intervention<sup>31</sup> was delivered by a research pharmacist employed by the

Table 1 Summary characteristics and outcomes of alcohol reduction interventions (further details are presented in online supplementary files 2–8)

				AUDIT tot	al scores		FAST tota	FAST total scores					
Study ID	Study characteristics	Description	Baseline behaviour	Mean change from baseline*	95% CI	N	Mean change from baseline*	SD	N	Global quality rating†	Effectiveness‡	Cost- effectiveness	Differential effects§
Dhital et al <sup>27</sup>	Design: RCT Duration: 12 weeks¶ Country: UK	Brief alcohol advice	AUDIT Scores: 11.93 (SD 3.24)	-0.11	-0.82 to 0.61	168				Strong	$\leftrightarrow$	NR	NR
	Number of pharmacies: 16 Number of participants: 407 Mean age: I:39.6; C: 40.5 % female: I: 47.8; C: 43.6	Usual care control	AUDIT Scores: 11.53 (SD 3.19)	-0.74 p=0.24	-1.47 to 0.00	158							
Watson and Stewart <sup>28</sup>	Country: UK Number of	Brief alcohol advice Usual care control	FAST score ≥3: 29.2% FAST score ≥3: 24.6%				2.25 0.50 -1.25 0.75 NS	3.20 0.71 2.87 1.67	2F 4M	Weak	$\leftrightarrow$	Cost analysis only	NR
	Pharmacies: 20 Number of participants: 69 Mean age: NR % female: I: 48.1; C: 57.1												

<sup>\*</sup>p Values were extracted directly from the study papers and relate to between group differences.

<sup>†</sup>Global rating: 'strong'=no 'weak' ratings, 'moderate'=one 'weak' rating and 'weak'=two or more 'weak' ratings.

<sup>‡</sup>Effectiveness was assessed using between group differences.

<sup>§</sup>Differential effects: age, gender, ethnicity or socioeconomic status (education, income, occupation, social class, deprivation or poverty).

<sup>¶</sup>From baseline to last follow-up.

<sup>↑,</sup> intervention effective; ↓, intervention not effective; ↔, no statistically significant between group difference; AUDIT, Alcohol Use Disorders Identification Test; C, control group; F, female; FAST, Fast Alcohol Screening Tool; I, intervention group; M, male; NR, not reported; NS, non-significant; RCT, randomised controlled trial.

Study ID	Study characteristics	Description	Baseline behaviour	Quit rate*	quality rating†	Effectiveness‡	Cost- effectiveness***	Differential effects§
Bauld <i>et al</i> <sup>29</sup>	Design: CBA Duration: 52 weeks¶ Country: UK	Individual pharmacy- based NHS smoking cessation service + NRT	21+ cigarettes/ day: 396 (40.1%)	38/1374 (2.8%)	Weak	?	Yes both services compared to	NR
	Number of pharmacies: >200 Number of participants: 1785 Mean age: I: 44.0; C: 49.8 % female: I: 56.5; C: 65.5	Group community-based NHS smoking cessation service + NRT	21+ cigarettes/ day: 169 (41.6%)	26/411 (6.3%) p=0.001			control	
Bock <i>et al<sup>90</sup></i>	Design: RCT Duration: 26 weeks Country: USA Number of pharmacies: 2 Number of participants: 299	Smoking cessation training for pharmacists + tailored counselling using computer software + NRT	Number of cigarettes smoked/day: 18.2; Fagerström score: 5.3	28/100 (28.0%)	Moderate	<b>↑</b>	NR	NR
	Mean age: I1: 45.5; I2: 46.5; C: 42.3 % female: 59.0	Smoking cessation training for pharmacists + tailored counselling using computer software	Number of cigarettes smoked/day: 17.7; Fagerström score: 5.1	15/100 (15.0%)				
		Observation only control (not randomised)	Number of cigarettes smoked/day: 13.8; Fagerström score: 4.9	8/99 (8.1%) p<0.01				
Burford <i>et al</i> <sup>β1</sup>	Design: RCT Duration:26 weeks Country:Australia Number of pharmacies:8	Smoking cessation advice + computer- generated photoageing	Fagerström score: 2.87; >21 cigarettes/ day smoked: 10%	11/80 (13.8%)	Moderate	<b>↑</b>	Yes	NR
	Number of participants:160 Mean age:l:24.2; C:25.1 % female: I:68.7; C:56.2	Smoking cessation advice	Fagerström score: 2.96; >21 cigarettes/ day smoked: 15%	p=0.003				
Costello et al <sup>32</sup>	Design: RCT Duration:5 weeks Country:Canada Number of pharmacies:98	1 week then fortnightly visit for NRT plus 3 sessions brief behavioural counselling	HSI ≥3: 91.8%	612/3503 (17.5%)	Weak	$\leftrightarrow$	NR	NR
								Continued

Table 2 Summary characteristics and outcomes of smoking cessation interventions (further details are presented in online supplementary files 2–8)

Global

Table 2 Continu	ued							
Study ID	Study characteristics	Description	Baseline behaviour	Quit rate*	Global quality rating†	Effectiveness‡	Cost- effectiveness***	Differential effects§
	Number of participants:6987 Mean age:NR % female: I:54.4; C:54.9	5 weeks NRT at initial visit plus 1 session brief behavioural counselling	HSI ≥ 3: 91.4%	604/3350 (18.0%) p=0.4				
Crealey <i>et al</i> 1990 <ce:< td=""><td>Design:nRCT Duration:26 weeks</td><td>Behavioural support, 67% (35/52) nicotine gum</td><td>NR</td><td>24/52 (46.2%)</td><td>Weak</td><td>1</td><td>Yes</td><td>NR</td></ce:<>	Design:nRCT Duration:26 weeks	Behavioural support, 67% (35/52) nicotine gum	NR	24/52 (46.2%)	Weak	1	Yes	NR
Please check year is not matching with reference list.>	Country:UK Number of pharmacies:2 Number of participants:169 Mean age:NR % female: NR	Nicotine gum only Control (expressed wish to stop smoking)	NR NR	3/48 (6.3%) 0/60 (0%) p<0.01 (I vs C)				
Hoving et al <sup>34</sup>	Design: RCT Duration:52 weeks Country:Netherlands	Computer-generated tailored advice	Number of cigarettes smoked/day: 22	2/256 (0.8%)	Strong	$\leftrightarrow$	NR	NR
	Number of pharmacies:65 Number of participants:545 Mean age:I:46; C:47 % female: I:53; C:54	'Thank you' letter control	Number of cigarettes smoked/day: 21	2/289 (0.7%) NS				
Howard-Pitney et al <sup>35</sup>	Design: RCT Duration:26 weeks Country:USA Number of pharmacies:5 Number of participants:410 Mean age:I:36.3; C:34.7 % female: I:1; C:1	Advice and support + nicotine patch Advice and support + placebo patch	Number of cans chewed/week: 3.9 Number of cans chewed/week: 4.1	78/206 (37.9%) 69/204 (33.8%) p<0.40	Moderate	$\leftrightarrow$	NR	NR
Maguire <i>et al</i> <sup>66</sup>	Design: RCT Duration:52 weeks Country:UK Number of pharmacies:51	Behavioural support, 87% (230/265) NRT	Number of participants 10–20 cigarettes/day: 197/265	38/265 (14.3%)	Weak	<b>↑</b>	NR	NR
	Number of participants:484 Mean age:I:42; C:38 % female: I:40; C:44	Ad hoc advice, 84% (183/219) NRT	Number of participants 10– 20 cigarettes/day: 121/219	6/219 (2.7%) p < 0.001				
								Continued

Study characteristics	Description	Baseline behaviour	Quit rate*	Global quality rating†	Effectiveness‡	Cost- effectiveness***	Differentia effects§
Design: RCT Duration:12 weeks Country:Japan Number of pharmacies:14 Number of participants:28 Mean age:I:44.1; C:49.1	Nicotine gum plus advice on usage, initial and follow-up cessation advice	Number of cigarettes smoked/day: 23.0; Fagerström score: 4.56	5/11 (45.5%)	Strong	$\leftrightarrow$	NR	NR
% female: I:18.2; C:18.8	Nicotine gum plus advise on usage	Number of cigarettes smoked/day: 25.7; Fagerström score: 6.31	5/16 (31.3%) OR=1.83, NS				
Design: RCT Duration:36 weeks Country:UK Number of pharmacies:62	Training pharmacists/ assistants in smoking cessation behaviour change + NRT	Fagerström score: 5.2	26/217 (12.0%)	Strong	$\leftrightarrow$	Yes	NR
Number of participants:492 Mean age:1:41.7; C:41.5 % female: I:61.2; C:62.7	Standard professional pharmacy support + NRT	Fagerström score: 5.2	19/257 (7.4%) p=0.089				
Design: RCT Duration:26 weeks Country:Denmark Number of pharmacies:42 Number of participants:522	21 mg nicotine patches Placebo 14 mg nicotine patches	7.0 Fagerström score: 8.1	(11.4%) 6/142 (4.2%) p<0.05 27/119	Strong	↑ 21 mg; ↔ 14 mg	NR	No (gender)
Mean age:I(21 mg):39.1; C(21 mg):39.9; I (14 mg):38.2; C (14 mg):38.9 % female: I(21 mg):47.5; C(21 mg):52.5; I (14 mg):51.7; C (14 mg):48.3	Placebo						
	Design: RCT Duration:12 weeks Country:Japan Number of pharmacies:14 Number of participants:28 Mean age:I:44.1; C:49.1 % female: I:18.2; C:18.8  Design: RCT Duration:36 weeks Country:UK Number of pharmacies:62 Number of participants:492 Mean age:I:41.7; C:41.5 % female: I:61.2; C:62.7 Design: RCT Duration:26 weeks Country:Denmark Number of pharmacies:42 Number of participants:522 Mean age:I(21 mg):39.1; C(21 mg):39.9; I (14 mg):38.9 % female: I(21 mg):47.5; C(21 mg):52.5; I (14 mg):51.7; C	Design: RCT Duration:12 weeks Country:Japan Number of pharmacies:14 Number of participants:28 Mean age:I:44.1; C:49.1 % female: I:18.2; C:18.8  Design: RCT Duration:36 weeks Country:UK Number of pharmacies:62 Number of participants:492 Mean age:I:41.7; C:41.5 % female: I:61.2; C:62.7 Design: RCT Duration:26 weeks Country:Denmark Number of pharmacies:42 Number of participants:522 Mean age:I(21 mg):39.9; I (14 mg):38.9 % female: I(21 mg):47.5; C(21 mg):52.5; I (14 mg):51.7; C	Design: RCT Duration:12 weeks Country:Japan Number of pharmacies:14 Number of participants:28 Mean age:l:44.1; C:49.1 % female: l:18.2; C:18.8  Design: RCT Duration:28 Mean age:l:44.7; C:49.1 % female: l:18.2; C:18.8  Design: RCT Duration:36 weeks Country:UK Number of pharmacies:62 Number of participants:492 Mean age:l:41.7; C:41.5 % female: l:61.2; C:62.7 Design: RCT Duration:26 weeks Country:Denmark Number of pharmacies:42 Number of participants:492 Mean age:l:41.7; C:41.5 % female: l:61.2; C:62.7 Design: RCT Duration:26 weeks Country:Denmark Number of pharmacies:42 Number of participants:522 Mean age:l(21 mg):39.1; C(21 mg):39.9; I (14 mg):38.2; C (14 mg):38.2; C (14 mg):51.7; C  Design: RCT Duration:26 weeks Country:Denmark Number of pharmacies:42 Number of pharmacies:44 Number of ph	Design: RCT	Design: RCT   Discription   Description   Discription   Discription	Design: RCT	Design: RCT

Table 2 Continued	nued							
Study ID	Study characteristics	Description	Baseline behaviour	Quit rate*	Global quality rating†		Cost- Different Effectiveness*** effects§	Differential effects§
Vial <i>et al</i> <sup>39</sup>	Design: RCT Duration:52 weeks Country:Australia Number of pharmacies:9 Number of participants:102 Mean age:51.0 % female: 11:41; 12:54; C:36	Pharmacy-based nicotine Fagerström score: 4/21 (19.0%) patches plus weekly 5.79 counselling Hospital outpatient clinic nicotine patches plus weekly counselling Minimal intervention (written and verbal 6.33 information at baseline)	nicotine         Fagerström score:         4/21 (19.0%)         Weak           kly         5.79         Weak           nt clinic         Fagerström score:         5/21 (23.8%)           olus         5.94         Gon           ion         Fagerström score:         1/22 (4.5%)           al         6.33         NS           seline)         Seline)	4/21 (19.0%) 5/21 (23.8%) 1/22 (4.5%) NS	Weak	<b>‡</b>	R R	E Z

local university in collaboration with the community pharmacist, who delivered standard smoking cessation advice (see online supplementary file 5). Another smoking cessation intervention was conducted by a research pharmacist as part of an MSc project; the research pharmacist delivered the hospital-based intervention programme, and the community pharmacists delivered the community-based intervention programme.<sup>39</sup> One smoking cessation intervention involved the postal delivery of a computer-generated letter.<sup>34</sup> Most studies included standardised staff training, although this was usually brief (ranging from 2 h to 2 days). Two smoking cessation studies mentioned they also included role play as part of the training, 30 35 and two weight management studies reported 'practical tasks' as part of the training. 43 45

Index, higher score indicates greater number of cigarettes smoked

no statistically significant between group difference; C, control group; CBA,

5 min of waking; I, intervention group; NHS, National Health Service; NR, not reported; nRCT, non-randomised controlled trial; NRT, nicotine, RCT, randomised controlled trial.

day and smoking

Heaviness of Smoking

intervention not effective;

gender, ethnicity or socioeconomic status (education, income, occupation, social class, deprivation or poverty)

'moderate'=one 'weak' rating and 'weak'=two or more 'weak' ratings.

In terms of quality assurance, one alcohol reduction intervention provided a 2 h evening follow-up training session during the intervention to address challenges and share learning across the pharmacists who were delivering the intervention.<sup>27</sup> In two smoking cessation studies, <sup>33</sup> <sup>36</sup> a researcher visited the pharmacists after the group training session, to provide support and to address any queries they had in implementing the training. In one smoking cessation study that was organised by a pharmaceutical company,<sup>40</sup> the company contacted pharmacies at least once a week during the intervention.

#### Behaviour change strategies used in the interventions

Seven studies reported that a behavioural theory/model informed the intervention and provided details of behaviour change strategies used; six studies only reported details of behaviour change strategies used; six studies reported no relevant information (see online supplementary file 6). The most commonly reported theoretical model was the Transtheoretical ('Stages of Change') Model, which was reported by six studies; motivational interviewing was reported by five studies. The descriptions available did not allow for the coding of specific aspects of theory and behavioural content. Using the Behaviour Change Wheel, 18 the intervention functions of the majority of interventions were 'education' and 'enablement'. In addition, interventions that included the provision of NRT or commercial weight management programmes or products free of charge, were also deemed to include 'incentivisation'. Using the policy category of the Behaviour Change Wheel, <sup>18</sup> all the interventions were categorised as 'service provision'. Six of these interventions also included 'communication/marketing'. No other policy categories were identified. Using the Nuffield intervention ladder, <sup>19</sup> most interventions were coded as 'enable choice'.

#### **EFFECTS OF INTERVENTIONS**

#### Alcohol reduction interventions (n=2)

There were two RCTs of brief alcohol reduction interventions (table 1) compared with usual care or

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OF

				BMI (kg/m²	<sup>2</sup> )	WC (cm)		WT (kg)						
Study ID	Study characteristics	characteristics	N	Description	Mean change from baseline§	SD/95% CI	Mean change from baseline§	SD	Mean change from baseline§	SD/95% CI	Global quality rating*	Effectiveness†	Cost- effectiveness	Differential effects‡
Ahrens <i>et al</i> <sup>41</sup> 2011	Design: RCT	45	Meal	NR	NR	-8.08	NR	-5.6	NR	Weak	$\leftrightarrow$	NR	NR	
2011	Duration: 22 weeks¶ Country: USA Number of pharmacies: 1 Number of participants: 95 Mean age: I: 47.6; C: 47.8 % female: 87 Baseline BMI: I:	43	replacement diet Low calorie diet	NR	NR	-7.82	NR	-5.2	NR					
Bush et al <sup>42</sup>	29.5; C: 29.0 Design: CBA Duration: 15 weeks¶ Country: UK	60	Pharmacy-based diet + physical activity	-1.3	0.4	-6.5	1.6	-3.4	1.1	Weak	?	Unclear which service was more cost	Yes, demograph of participa	
	Number of pharmacies: 12 Number of participants: 451 Mean age: I: 38.9; C: 42.6 % female: I: 87; C: 85 Baseline BMI: I: 33.0; C: 35.6	22	GP-based diet + physical activity	-0.8	0.7	-4.9	2.6	-2.3	1.9			effective	differed significantly between settings	
Jolly <i>et al<sup>43</sup>**</i>	Design: RCT Duration: 52 weeks¶ Country: UK	70	Pharmacy-based diet + physical activity	-0.31	-0.7 to 0.0	NR	NR	-0.66	-1.7 to 0.4	Moderate	$\leftrightarrow$	Cost analysis only, commercial	No (gende	
	Number of pharmacies:NR	100	Exercise only control	-0.45	-0.8 to -0.1	NR	NR	-1.08	−2.1 to −0.1		‡	organisations lower cost		
	Number of	100	Weight Watchers	-1.17	-1.7 to -0.7	NR	NR	-3.46	-4.8 to -2.1		<b>↑</b>	than GP and		
	participants: 740		Slimming World	-0.71	-1.0 to -0.4	NR	NR	-1.89	-2.9 to -0.9		↔	pharmacy-		
	Mean age: Ph: 48.9; Ex: 49.7; WW: 50.7;		Rosemary Conley	-0.75	-1.1 to -0.3	NR	NR	-2.12	−3.4 to −0.9		$\leftrightarrow$	based services		
	SW: 48.8;RC: 48.8;	100	NHS Size Down	-0.67	-1.0 to -0.3	NR	NR	-2.45	-3.6 to -1.3		$\leftrightarrow$			
	NHS SD: 48.8; GP:		GP	-0.32	-0.7 to 0.1	NR	NR	-0.83	-2.0 to 0.4		$\leftrightarrow$			
	50.5; POC: 47.5 % female: Ph: 73; Ex: 75; WW: 72;	100	Participants own choice	-0.90	−1.3 to −0.5	NR	NR	-2.15	-3.4 to -0.9		$\leftrightarrow$			

 $\rightrightarrows$ 

Table 3 Continued

				BMI (kg/m <sup>2</sup> Mean	2)	WC (cm) Mean		WT (kg) Mean					
Study ID	Study characteristics	N	Description	change from baseline§	SD/95% CI	change from baseline§	SD	change from baseline§	SD/95% CI	Global quality rating*	Effectiveness†	Cost- effectiveness	Differential effects‡
	SW: 65; RC: 69; NHS SD: 64; GP: 67; POC: 70 Baseline BMI: P: 33.4; Ex: 33.9; WW: 34.0; SW: 33.8; RC: 33.4; NHS SD: 33.8; GP: 33.1; POC: 33.4												
Malone and Alger-Mayer <sup>44</sup>	Design: nRCT Duration: 26 weeks¶ Country: USA Number of	15	Pharmacist support + orlistat + usual outpatient care	NR	NR	NR	NR	-3.5	2.9	Weak	<b>↔</b>	NR	NR
	pharmacies: NR Number of participants: 30 Mean age: I: 44.9; C: 42.8 % female: I: 93; C: 80 Baseline BMI: I: 48.3; C: 42.8	15	orlistat + usual outpatient care	NR	NR	NR	NR	-3.0	5.2				
Phimarn et af <sup>45</sup>	Design: RCT Duration: 16 weeks¶	33	Pharmacist individual support	-0.8	0.07	0.1	0.03	-0.82	0.29	Strong	$\leftrightarrow$	NR	NR
	Country: Thailand Number of pharmac ies: 1 Number of participants: 66 Mean age: I: 60.1; C: 59.1 % female: I: 75.8; C: 84.8 Baseline BMI: I: 27.5; C: 27.7	33	Primary care unit group support	0.19	0.04	-0.28	0.08	0.92	0.19				

<sup>†</sup>Effectiveness was assessed using between group differences.

<sup>‡</sup>Differential effects: age, gender, ethnicity or socioeconomic status (education, income, occupation, social class, deprivation or poverty).

\*\*All intervention groups in the Jolly trial were compared to the exercise only control group (intervention groups were not directly compared).

 $<sup>\</sup>$  Values were extracted directly from the study papers and relate to between group differences.  $\$  From baseline to last follow-up.

<sup>↓,</sup> intervention not effective; ↑, intervention effective; →, no statistically significant between group difference; ?, unable to assess effectiveness; cost-effectiveness; BMI, body mass index; C, control group; CBA, controlled before-after study; Ex, exercise only control; GP, general practitioner; NHS SD, NHS Size Down; NHS, National Health Service; NR, not reported; nRCT, non-randomised controlled trial; NS, non-significant; Ph, Pharmacy-based diet + physical activity; POC, participants own choice; RC, Rosemary Conley; RCT, randomised controlled trial; SW, Slimming World; WC, waist circumference; WT, weight; WW, Weight Watchers.

leaflet-only control (see online supplementary files 7 and 8). One RCT<sup>27</sup> used the Alcohol Use Disorders Identification Test total scores (AUDIT), and reported a baseline AUDIT score of 11.93. The other RCT<sup>28</sup> used the Fast Alcohol Screening Tool (FAST), and reported 29.2% of participants scoring  $\geq$  3 at baseline. Possible 'harmful or hazardous' alcohol consumption, but not alcohol dependence is indicated with an AUDIT score 8–19 or a FAST score of 3–16. Global quality ratings were 'strong' for one study<sup>27</sup> and 'weak' for the other, <sup>28</sup> which was a small pilot study. Both studies involved one-to-one contact with the pharmacist. Dhital *et al*<sup>27</sup> encouraged self-directed behaviour change; the intervention included reflection and feedback of the AUDIT score.

#### Behavioural outcomes

Neither intervention significantly reduced alcohol scores compared with control. At 12 weeks, the AUDIT total change score did not differ significantly between the two groups and did not change significantly between baseline and follow-up in either group. Twelve-week AUDIT between group difference, adjusted for pharmacist gender, age, ethnicity and education, was -0.57 (95% CI -1.59 to 0.45). There was no significant difference between FAST score for the intervention group compared with control at 3 or 6 months, adjusted for baseline FAST: the difference between groups was -1.84 (95% CI -4.49 to 0.82). At 6 months, there was substantially lower follow-up of intervention participants (22.2%) compared with control participants (33.3%).

#### Costs

Cost-effectiveness of community pharmacy-based brief alcohol reduction interventions cannot be ascertained; only one pilot study<sup>28</sup> reported direct intervention costs.

#### Differential effects by demographic or socioeconomic factors

One pilot study<sup>28</sup> reported change in FAST scores by gender within the intervention and control groups. However, the study was not powered to detect differences between the two groups.

#### Smoking cessation interventions (n=12)

There were 10 RCTs, <sup>30–32</sup> <sup>34–40</sup> 1 nRCT<sup>33</sup> and 1 CBA<sup>29</sup> of smoking cessation interventions (table 2). Global quality ratings were 'strong' for four studies, 'moderate' for three studies, and 'weak' for five studies. Eleven studies carried out analyses with the assumption that those lost to follow-up had not stopped smoking. Half (6/12) the smoking cessation interventions relied on self-reported change in smoking behaviours, <sup>32</sup> <sup>34</sup> <sup>37</sup> <sup>38–40</sup> and half used biochemical measures (carbon monoxide (CO) or cotinine levels). <sup>29–31</sup> <sup>33</sup> <sup>35</sup> <sup>36</sup>

Ten studies included NRT (in either the intervention or control group or both). <sup>29</sup> <sup>30</sup> <sup>32</sup> <sup>33</sup> <sup>35</sup> <sup>36</sup> Seven studies evaluated some form of behavioural support. <sup>30</sup> <sup>32</sup> <sup>32</sup> <sup>36</sup> <sup>38</sup> Two studies evaluated the effect of intervention setting;

one study assessed behavioural support plus NRT provided in a hospital outpatient setting compared with pharmacy setting. Another compared individual pharmacy-based behavioural support plus NRT with group-support provided in a community setting. One study evaluated the effect of a photoageing intervention.

Despite a variety of different components being evaluated within the individual interventions, the studies were grouped together to assess the effectiveness of any type of community pharmacy-delivered intervention for smoking cessation compared with either an active control or a non-active/usual care comparator. 'Usual care' varied between studies but was, in general, a minimal intervention, such as observation only, ad hoc smoking cessation advice or a thank you letter. However, in one study, the control group received placebo nicotine patches<sup>40</sup> and in two studies the control group received standard cessation advice plus NRT.<sup>36 38</sup>

#### Behavioural outcomes

Five of the 12 studies demonstrated effectiveness compared with control. In addition, Bauld *et al*.  $^{29}$  evaluated one-to-one pharmacist support with group-based smoking cessation clinics based in the community; the group-based service attracted fewer clients but was more effective.

The five effective studies included:

- ▶ An American RCT<sup>30</sup> of additional training to pharmacists to enable them to provide a tailored counselling service with and without NRT, compared with a nonrandomised control group that received observation only, showed a significant increase in validated 7-day point prevalence at 6 months (28% for counselling and NRT, 15% for counselling, 8% for control).
- An Australian RCT<sup>31</sup> of a computer-generated photoageing service (demonstrating the detrimental effects on facial physical appearance of smoking) in addition to standard smoking cessation advice from a pharmacist, was effective in stopping young people (mean age 24 years) smoking compared to control using CO-validated measures (13.8% n=22/80 vs 1.3% n=11/80) at 6 months.
- ▶ A cost-effectiveness study<sup>33</sup> in two UK pharmacies compared a behavioural intervention group based on the Pharmacist Action on Smoking (PAS) model with a control group that received nicotine gum, and another control group who expressed a wish to stop smoking. At 6 months, there was a statistically significant difference in cessation rates between intervention and control groups. Six-month CO-verified abstinence was 46% in the intervention group, 6% in the nicotine gum control group, and 0% in the control group that expressed a wish to stop smoking.
- ▶ A UK RCT<sup>36</sup> compared an intervention based on the PAS model to ad hoc smoking cessation advice; over 80% in each group also had NRT. The PAS intervention significantly increased validated smoking

cessation compared with control at 12 months (14.3% vs 2.7%).

▶ A Danish study<sup>40</sup> evaluated the effect of two different strengths of nicotine patches compared to placebo. Those smoking ≥20/day at baseline were randomised to 21 mg patches or placebo, those smoking <20/day at baseline were randomised to 14 mg patches or placebo. Self-reported point prevalence included participants who had one episode of smoking (<6 days). At 26 weeks, the intervention was effective for those smoking ≥20/day at baseline (11% vs 4.2%) but not effective for lighter smokers (22.7% vs 18.4%) compared with the respective placebo groups.

#### Meta-regression and meta-analysis

Meta-regression of ORs of smoking cessation between the intervention and the control groups was undertaken; in model 1, a random effects model was fitted including all the RCTs. The pooled OR for the intervention effects was 1.85 (95% CI 1.25 to 2.75), an indication of the positive effect of the interventions on smoking cessation. However, there was 72% unexplained differences between the studies. In model 2, a meta-regression model was fitted accounting for whether a study had an active comparator or non-active/usual care comparator. The pooled ORs were 1.21 (95% CI 0.86 to 1.71) and 2.56 (95% CI 1.45 to 4.53) for the active comparator or non-active/usual care comparator, respectively (figure 2).

As expected, there was a larger effect when compared with non-active/usual care comparator than with active comparator. The proportion of unexplained heterogeneity reduced to 52%. In model 3, a meta-regression model was fitted accounting for whether a study had an

active comparator or a non-active/usual care comparator, and also the intervention duration; the unexplained heterogeneity reduced to 27.2% with a non-significant Q-statistic test (10.99, p <0.2026). In model 4, quality rating was accounted for; quality rating did not appear to contribute much to the model after accounting for intervention duration, and whether a study had an active comparator or a non-active/usual care comparator. Figure 3 shows a meta-analysis of smoking cessation accounting for global quality rating, and shows that most variations between studies are from studies rated as 'moderate' or 'weak' quality. A funnel plot demonstrated asymmetry, with larger studies showing effects closer to the null than smaller studies. Such a pattern is compatible with publication bias, on the assumption that smaller studies with uninteresting effects are withheld from publication. However, the funnel plot must be interpreted with caution, taking into account that it contains only 10 studies, which is the recommended study size threshold for creating such plots.<sup>11</sup>

#### Costs

Four studies reported cost-effectiveness analyses; the costs and benefits differed between the studies, and costs years ranged from 1995 to 2011, making comparisons across the analyses difficult. All four studies used quit rates observed within the trials, these ranged from 2.8% to 12% for UK pharmacist-based behavioural support with NRT.

By comparison with a self-quit attempt, the incremental cost per Quality Adjusted Life Year was £2600 for pharmacy one-to-one counselling, and £4800 for group community-based NHS smoking cessation service. Incremental Cost Effectiveness Ratios (ICER) per

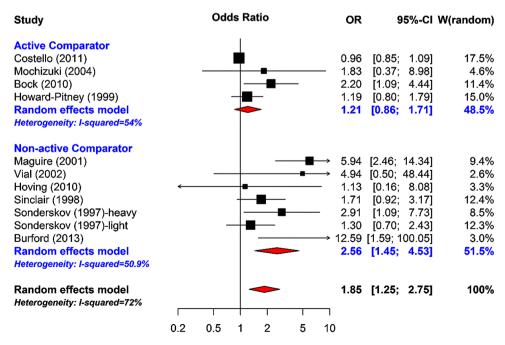


Figure 2 Meta-analysis of smoking cessation accounting for whether active comparator or non-active comparator.

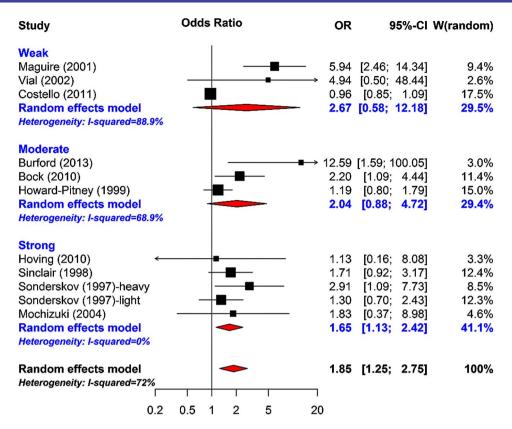


Figure 3 Meta-analysis of smoking cessation accounting for global quality rating.

additional quitter ranged from £79 to £509 for pharmacist-based behavioural support with NRT. The ICER per additional quitter using photoageing was \$A46 (Australian dollars 2011). In summary, three UK pharmacy-delivered interventions appeared cost effective across a range of quit rates, and an Australian photoageing intervention was cost effective compared to standard advice among young adults.

#### Differential effects by demographic or socioeconomic factors

A Danish study<sup>40</sup> evaluated the effect of two different strengths of nicotine patches compared with placebo. There were no differences in smoking cessation rates between men and women according to starting dose and treatment.

#### Weight management interventions (n=5)

There were three RCTs, <sup>41</sup> <sup>43</sup> <sup>45</sup> one nRCT<sup>44</sup> and one CBA<sup>42</sup> of weight management interventions (table 3). Global ratings were 'strong' for one study, 'moderate' for one study, and 'weak' for three studies. Three studies <sup>42</sup> <sup>43</sup> <sup>45</sup> compared a pharmacy-based intervention with similar interventions in other primary care settings, and commercial programmes in community settings. One study <sup>41</sup> compared a meal replacement diet with a conventional low-energy diet (identical recommended total daily energy intake); both interventions were set in a pharmacy. One small study <sup>44</sup> assessed the added value of community pharmacy support for an obesity

management intervention that included orlistat and an outpatient nutrition programme.

#### Anthropometric outcomes

Three studies reported body mass index (BMI), three studies reported waist circumference (WC) and all five studies reported weight (WT). None of the studies found a significant difference in favour of a pharmacy-delivered intervention compared with the comparator, for any anthropometric outcome. However, all comparators are 'active' interventions (smoking cessation studies demonstrated larger effect when compared with non-active controls compared to active controls). One UK RCT<sup>43</sup> compared seven groups (Weight Watchers, Slimming World, Rosemary Conley, Size Down an NHS communitybased group, GP, Pharmacy, participants' own choice to an exercise-only control group). This study compared each intervention group with a control group, and was not designed to directly compare the active interventions which were delivered across different settings. All, except the GP and pharmacy groups, resulted in significant weight loss at 1 year compared with baseline. Mean weight loss at 1 year, with baseline value used for imputation, was 0.8 kg (SD 4.7 kg) for primary care (GP and pharmacy) and 2.5 kg (SD 6.2 kg) for commercial programmes. Only the Weight Watchers group demonstrated significant weight loss at 1 year compared to control.

One CBA<sup>42</sup> study compared diet and physical activity in a pharmacy to a GP-based intervention: both groups

appeared to reduce BMI, WC and WT at follow-up (statistical significance not reported). Despite participants choosing the service, there was very high attrition (93%). One study<sup>41</sup> demonstrated significant and similar amounts of weight loss from baseline to follow-up for participants in a meal replacement group, or a low-calorie diet group (both pharmacy-delivered). In another study, pharmacy-based support in addition to orlistat did not improve weight loss.<sup>44</sup> Another study demonstrated no significant improvement in weight from baseline to follow-up for participants receiving group-based support in a primary care unit compared with individual support from a pharmacist.<sup>45</sup>

#### Costs

Two trials reported intervention costs, one of which also reported costs per kg weight lost. <sup>42</sup> The Jolly *et al* <sup>43</sup> trial reported similar costs (£112) for both the pharmacy group and the GP group; both settings had higher costs compared with commercial weight management programmes (£71–£77), the NHS community-based group costs fell in-between at £92.

A study<sup>42</sup> of weight management programmes based in pharmacy or GP settings reported costs ((£126.90 per participant (n=183) in the pharmacy intervention and £100.60 per participant (n=268) in the GP intervention)), that were broadly similar to that of the pharmacy-based group in the Jolly trial. It is unclear which provider type delivered the intervention more cost-effectively; at session 12, the ICER (£ per kg per participant) cost –£8.29 through pharmacy providers (favours GP). Conversely, at the final session 15, the ICER was £2.91 through GP providers (favours Pharmacy).

#### Differential effects by demographic or socioeconomic factors

In a study of weight management programmes in various commercial, primary care and NHS settings, there was no statistically significant interaction between gender and the type of weight management programme. He also compared a weight management programme set in pharmacies with the same programme set in GP surgeries. Female participants in GP surgeries lost a significantly larger proportion of their initial weight than female participants in pharmacies; participants aged 40–49 years lost a greater proportion of their initial weight at GP providers than at pharmacy providers.

#### **DISCUSSION**

Community pharmacy-delivered smoking cessation interventions including behavioural support and/or NRT, are effective and cost effective, particularly when compared with usual care. The pooled ORs for smoking cessation were 1.21 (95% CI 0.86 to 1.71) and 2.56 (95% CI 1.45 to 4.53) for active control and usual care, respectively. The heterogeneity of types of interventions precluded the ability to evaluate effectiveness by specific types of

interventions. There was little evidence comparing pharmacy-delivered smoking cessation with smoking cessation delivered in other settings. This was in contrast with the majority of the weight management evidence which compared active interventions in various settings. Although there was no significant difference in weight loss between active interventions in different settings; pharmacy-based interventions produced similar amounts of weight loss (3–5 kg) from baseline to short-term follow-up (6 months or less), compared with active interventions in other primary care settings. There was insufficient evidence to evaluate community pharmacy-delivered interventions for alcohol reduction.

Community pharmacy-delivered smoking cessation interventions are cost-effective (compared to self-quit or standard care) across a range of quit rates. Cost-effectiveness of pharmacy-delivered weight management interventions is unclear; they have similar provider costs to those delivered in other primary care settings, which are greater than those delivered by commercial organisations. This review aimed to extract information on intervention costs and potential cost savings; however, it is not a review of economic evaluations and, as such, the methods of the economic evaluations are not critically appraised; we simply report the results of the economic evaluations that were conducted alongside included interventions.

Evidence suggests that duration of intervention is a predictor of effectiveness, for both the smoking cessation and weight loss studies; in the case of weight management, longer term weight loss may differ by setting. Regression analysis showed that duration of intervention accounted for some heterogeneity across the smoking cessation studies. One longer term weight management study compared interventions in a range of primary care and commercial settings; all except the pharmacy and GP groups resulted in significant weight loss at 1 year compared with baseline. The data reported in the studies identified for this review highlight the potential importance of predictors of success.

In terms of the effects of the interventions on health inequalities, some studies examined demographic and/ or socioeconomic factors at recruitment stage, as potential predictors of outcomes within group, and/or to explain differences in retention. However, none of the studies reported subgroup analysis of treatment effect by SES. Three studies adopted a targeted approach to addressing inequality, by recruiting participants from deprived areas, and compared a pharmacy setting with other settings. In two of these 'targeted' studies (one smoking, one weight) the participants self-selected the service; there were demographic and socioeconomic differences between participants who self-selected treatment by setting. The evidence shows that the community pharmacy is an appropriate and feasible setting to deliver a range of public health interventions, and this setting has the potential to reach those most in need.

The original analysis plan included an examination of any potential relationships between intervention effectiveness and behaviour change strategies and/or models used, also whether any patterns existed between effective interventions and implementation factors (eg, pharmacist training or resource intensity) or the organisation and delivery of service (eg, stakeholder involvement). Unfortunately, the lack of relevant data reported meant that this analysis could not be undertaken. It is worth noting that the majority of interventions were implemented within the political context of extending the public health role of pharmacists.

These findings build on previous work; looking to the future, there is a Cochrane review(<sup>46</sup>) in progress with a broader remit than this review; it evaluates the effectiveness of a wider variety of health promotion, or health behaviour interventions, set in community pharmacy. This work will further develop the evidence base; in particular, evidence regarding implementation, organisation and delivery of other types of public health interventions which may be transferable to alcohol reduction, smoking cessation and weight management interventions.

Implications for policy and practice. The evidence shows a range of types of smoking cessation interventions that are feasible and effective within community pharmacies, and supports the commissioning of smoking cessation services in a community pharmacy setting. Smoking cessation services, contracted as a core part of the national contract, or part of a national 'advanced' service, may well be a reasonable option. In addition, the evidence shows that weight management services are no less effective compared with those delivered in other primary care settings. Therefore, given the potential reach, effectiveness and associated costs of these interventions, commissioners may consider using community pharmacies to help deliver some of their smoking cessation and weight management services.

Implications for future research: Further research is required to assess the effectiveness of community pharmacy-delivered alcohol reduction interventions, and more research is needed on the cost-effectiveness of community pharmacy-delivered alcohol, smoking and weight management interventions compared with other providers. It appears that the duration of intervention impacts on effectiveness, and this is likely to impact on cost-effectiveness. There is a lack of evidence regarding the effect of community pharmacy-based interventions for alcohol reduction, smoking cessation and weight loss on health inequalities. Targeted intervention studies provided some evidence that adults accessing pharmacies are a distinct group that may not access other primary care or commercial organisations. This evidence is derived from participants who self-selected the intervention and setting. However, more research is required on the reach of public health interventions delivered from a community pharmacy setting. Future studies should be sufficiently powered to detect small changes in behavioural and health outcomes and measure the equity

effects of these small changes at a population level. Future studies should assess and report sociodemographic and socioeconomic variables, behaviour change strategies and models, implementation factors, the organisation and delivery of interventions, and costs.

#### **CONCLUSIONS**

The evidence demonstrates that the community pharmacy is an appropriate and feasible setting to deliver a range of public health interventions. Community pharmacy-delivered smoking cessation interventions are effective and cost effective, particularly when compared with usual care. Evidence from a heterogeneous group of weight management interventions suggest that community pharmacy-delivered weight management interventions are as effective as similar interventions in other primary care settings, at least in the short term, and have similar provider costs. There is insufficient evidence to assess the effectiveness of community pharmacy-based interventions for alcohol reduction. The impact of community pharmacy-delivered interventions on inequalities in priority public health conditions is unclear.

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and synthesis input, and contributed to data collection and synthesis. AH, CB, FFS and LS provided methodological, analysis and synthesis input. AK contributed to analysis. HJM designed and conducted the searches with support from LS, and contributed to data collection. CO contributed to data collection and synthesis. SS and LN contributed to data collection. All authors contributed to revised successive drafts of this article and approved the final version submitted for publication.

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# 2.3 Paper 3: An antenatal wish list: A qualitative systematic review and thematic synthesis of UK dietary advice for weight management and food borne illness.

This qualitative systematic review and thematic synthesis explored women's experiences of antenatal dietary advice for weight management and food borne illness in the UK. Many women start pregnancy with excess weight or gain excess weight during pregnancy which leads to additional complications during pregnancy and childbirth (Langley-Evans, Pearce, & Ellis, 2022). Despite this, many dietary advice sheets supplied in maternity care do not focus on healthy eating and lifestyle for weight management. Maternal weight management guidelines have been described as "vague and inadequate" (Johnson et al., 2013).

Women described barriers to desired behaviour change including the pressure and dehumanisation experienced which stifled their feelings of self-control in some cases. The findings outline a wish list of requests to change current antenatal care to support appropriate behaviour change. The wish list highlights a desire for tailored information, education and support on preventing weight gain, dietary requirements, safe physical activity and food consumption and a deprioritisation of food safety guidelines. This provision should be delivered by health care professionals (HCPs) e.g., midwives, in a tailored, sensitive and supportive way and providing 'realistic' goals to bridge the gap between women's needs and the current antenatal provision. It was concluded that, "Provision of practical, high-quality information with a focus on emphasising and recommending diet and physical activity, as opposed to avoidance, may support women's autonomy and lead to improved pregnancy experiences".

The findings from this work and the wish list developed demonstrate the misalignment between current healthcare practices and the needs of the women in this underserved group which renders services ineffective. By embracing the knowledge and lived experience of pregnant women, more effective, patient-centred, and holistic services could be designed and developed which overcome some of the barriers and provide tailored, appropriate support for this marginalised population.



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#### An antenatal wish list: A qualitative systematic review and thematic synthesis of UK dietary advice for weight management and food borne illness



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#### ABSTRACT

Objectives: To understand UK women's experiences of antenatal dietary advice for risk of food borne illness and weight gain.

Design: A systematic review and thematic synthesis of peer-reviewed qualitative studies. PubMed, MED-LINE, CINAHL and PMC databases were searched for articles published from January 2008 to June 2018. The search strategy combined terms for pregnancy with terms for body composition, weight change, food safety, nutrition, diet and qualitative terminology. Studies were eligible for inclusion if (1) they explored experiences of implementing advice received during pregnancy for nutrition, physical activity and/or weight gain, and (2) participants were women who had experienced maternity care in the UK. Study quality was appraised using the Critical Appraisal Skills Programme (CASP) qualitative research appraisal tool.

Findings: Of 25,688 articles identified by the search strategy, 20 studies were identified that met the inclusion criteria. Five major themes were recognised: control, barriers to diet and exercise, motivators, relationship with weight, and information, with a further 12 subthemes. The majority of studies reported on weight gain (n = 10).

Key conclusions: Evidence shows that UK antenatal dietary advice is currently inconsistent, vague and overwhelming despite pregnancy being an excellent time for lifestyle change. Women are primarily driven by the health of their baby and desire support to facilitate positive changes.

*Implications for practice:* Findings outline a wishlist which highlights a desire for tailored information on preventing weight gain, dietary requirements, safe physical activity and a deprioritisation of food safety guidelines. This provision should be delivered by HCP. e.g. midwives, in a sensitive and supportive way to bridge the gap between women's needs and the current antenatal provision.

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associated with an increased intake of micronutrients essential for

foetal development during pregnancy (Tanha et al., 2013). Effective

antenatal nutrition reduces the likelihood of developing chronic

illnesses and contributes to the baby's well-being (Fowles and

Fowles, 2008), though many women do not maintain an adequate diet during pregnancy (Langley-Evans, 2015). Current UK guidance promotes use of the Eatwell Guide (NHS, 2016) but factors affect-

ing dietary behaviour are not yet fully comprehended and there is limited research on UK women's experience of gathering antena-

BMI Body Mass Index
GWG Gestational Weight Gain
GDM Gestational Diabetes Mellitus
HCP Health Care Providers
T2DM Type 2 Diabetes Mellitus

#### Introduction

Nutrition received during a baby's first 1000 days of life, beginning upon conception, is crucial to their development and disease risks in later life (Baidal et al., 2016). Adherence to a healthy diet is

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tal nutritional information and their subsequent behaviour change (Bookari et al., 2017).

Maternal obesity is a growing concern in the UK, with 1 in 20 pregnant women living with obesity (Morgan et al., 2014) and first trimester obesity significantly increasing (Heslehurst et al., 2009). Despite this, antenatal dietary advice is often only provided

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**Table 1** Search strategy.

TITLE	Pregnan* OR matern* OR antenatal OR perinatal OR gestation*
AND	qualitative OR focus group OR interview OR experience
AND	foodborne illness OR food-borne OR food poisoning OR food safety OR pathogens OR infection OR parasite OR Listeria OR Listeriosis OR Salmonella OR
	Toxoplasma gondii OR Toxoplasmosis OR mercury OR dioxins OR campylobacter OR weight gain OR weight OR obesity OR obese OR overweight OR BMI
	OR exercise OR physical activity OR body composition OR nutrition* OR diet* OR guidelines OR guidance OR behaviour change
DATE	after January 2008

in physical handouts, which have been found to provide no guidance on weight management (Heslehurst et al., 2007). Macronutrient consumption during pregnancy is directly associated with birth weight outcomes (Sharma et al., 2018) and an elevated Body Mass Index (BMI) increases the risks of miscarriage, caesarean section, preeclampsia, gestational (GDM) or subsequent type 2 diabetes mellitus (T2DM) (Baeten et al., 2001; Fitzsimons et al., 2009). The cost of providing healthcare to pregnant women also increases with maternal BMI (Morgan et al., 2014). NICE (2010) guidance states that health care providers (HCP) should not routinely weigh women during pregnancy, however, there is insufficient clarity on how to achieve and maintain a healthy weight. In-depth conversations regarding gestational weight gain (GWG) are infrequent (Nikolopoulos et al., 2017), with weight management guidance described as "vague and inadequate" (Johnson et al., 2013), RCOG green top guidelines (2018) agree there is lack of consensus regarding optimal GWG (Denison et al., 2018). Physical activity during pregnancy is a safe and effective way to reduce adverse pregnancy outcomes (e.g. GDM), and prevent further GWG (Mijatovic-Vukas et al., 2018). Pregnant women should strive to achieve 30 min of moderate physical activity per day (NICE, 2010) which is in line with the majority of international guidance (Coll et al., 2017), yet compliance with recommendations is low (Lindsay et al., 2015).

Antenatal dietary guidelines highlight the importance of excluding certain foods from the diet which may cause foodborne illnesses such as Listeriosis and Salmonella (NHS, 2017). Foetal Listeriosis can lead to pregnancy loss, stillbirth or preterm birth (Kourtis et al., 2014) but severe infection is rare during pregnancy with 3 cases per 100,000 births worldwide (Madjunkov et al., 2017) and 462 cases in England and Wales between 1990 and 2010 (Awofisayo et al., 2015). In 2018, 'lion mark' eggs were declared safe for consumption during pregnancy almost 30 years after a salmonella scare (BNF, 2017). In comparison, risks of early miscarriage, stillbirth and preterm births were found to be significantly higher in women living with overweight and obesity when compared to healthy weight controls (Lashen et al., 2004; Denison et al., 2008; Callaway et al., 2006). Low rates of foodborne infections compared to the significant risk of excess weight prompts questions about how relevant current antenatal advice is and whether midwives may be able to use their clinical times more effectively in maternal overweight and obesity.

A UK based literature review of antenatal healthcare conducted by Downe et al. (2016) found overwhelmingly that 'women want and need a more positive pregnancy experience'. As yet, it is not clear what this support and advice should consist of in order to incite the necessary behaviour change. The aim of the current research is to examine women's experiences of nutritional information during pregnancy within UK antenatal care.

#### Methods

This thematic synthesis was based on principles previously published by Thomas and Harden (2008). The search strategy combined terms for pregnancy with terms for body composition, weight change, food safety, nutrition, diet and qualitative termi-

nology. The full strategy was kept consistent across databases (see Table 1). Comprehensive searches were conducted on the following online databases and undertaken on 21st June 2018: PubMed, MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Pub Med Central (PMC). Reference lists were screened for additional articles. Duplicates were removed before screening was undertaken in a three stage process: (1) Titles were screened for eligibility; (2) Abstracts screened against inclusion criteria (see Table 2); (3) Full texts were obtained and final selection made first independently by two reviewers and then by discussion.

Quality of the search strategy was assessed by checking for inclusion of five pre-defined relevant papers from: Padmanabhan et al. (2015), Heslehurst et al. (2017), Ferrari et al. (2013), Bloomingdale et al. (2010) and Dinsdale et al. (2016). As all five studies were found to be present in the search strategy, it was determined to be of high quality and no further adjustments were made. Quality of the individual studies was assessed and classified using the Critical Appraisal Skills Programme Qualitative Study Appraisal Tool (CASP, 2018) to rate each study as low, medium or high quality (see Appendix 1). This was undertaken by two researchers who found none of the 20 studies to be of a low quality. Research was not excluded from the synthesis on the basis of quality alone but instead considered within the findings.

The process of thematic synthesis followed as such: (1) Codes were assigned on a line-by-line basis to every applicable finding, resulting in a preliminary 38 codes; (2) Descriptive themes were generated from the free codes, which began to take on a hierarchical order to group the data; (3) Analytical themes were developed by generating new concepts and attempting to analyse the themes independently from their original publication. NVivo (2015) (NVivo qualitative data analysis software, QSR International Pty Ltd. Version 11, 2015) was used for coding and data analysis. Findings were considered to be all quotations reported in the 'results' section of studies that were recorded from pregnant women. An inductive verbatim approach was taken, with the objective of generating new theory via a data search to identify relationships that could relate to the research aim. Final themes were deemed complete when they were distinct and internally consistent.

#### Findings

Stages of the literature search can be seen in Fig. 1. Included papers providing wide geographical coverage of the UK, were published between 2010 and 2018 and included 825 women (see Table 4 for study characteristics). The majority of studies focussed on weight gain (n=10), with the remainder exploring GDM (n=4), behaviour change (n=4) and nutritional advice (n=2). Focus groups and interviews were the most commonly applied methods for data collection (n=19), with one study using secondary data collection. Thematic synthesis identified five overarching themes: (1) Control; (2) Barriers to Diet and Exercise; (3) Motivators; (4) Relationship with Weight; (5) Information. There were a further 12 sub-themes, which can be seen in Table 3 and relationships between the subthemes are presented in Fig. 2.

**Table 2** Inclusion and exclusion criteria.

	Include	Exclude	
Participants	Women who had experienced pregnancy and received maternity care in the UK	Women < 16 years old Women with pre-existing medica conditions (excluding GDM and T2DM) Women with a BMI <18.5 kg/m2 or malnourishment	
Study focus	Quality of advice provision with regards to nutrition, physical activity and/or weight gain Attitudes towards implementing nutritional and physical activity changes Women's perceptions of additional information required during pregnancy	Smoking, alcohol and substance abuse, breast feeding, clinical outcomes, birth defects and other 'irrelevant' areas Not focusing on the experiences of a pregnant individual	
Study design	All primary qualitative studies, including research from mixed-methods papers	Quantitative studies or findings	
Time period	Published from January 2008 onwards	Published before January 2008	
Publication type	Peer-reviewed primary studies	Systematic reviews	
ocation Studies conducted in the UK		Studies conducted outside of the UK	

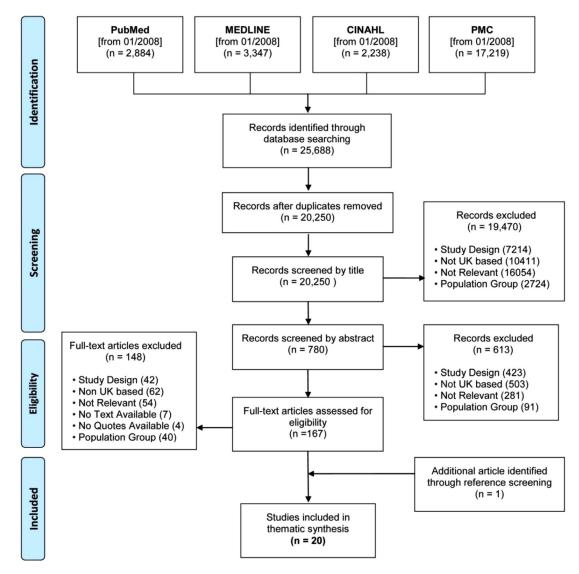


Fig. 1. PRISMA flow chart.

#### Theme 1. Control

Letting pregnancy run its course (11/20 studies)

Women referenced pregnancy as a 'free pass' to undertake indulgent behaviour and consume unhealthy foods (Dinsdale et al., 2016; Keely et al., 2017; McMillan et al., 2018; Padmanabhan et al.,

2015; Swift et al., 2017). Some women reported 'embracing' this temporary pause in healthy behaviour and feeling liberated with their attitude to weight.

"I just embraced being pregnant...I just loved it and I thought what goes on can come off again... if you want two pieces of cake, then you will have it." (Dinsdale et al., 2016)

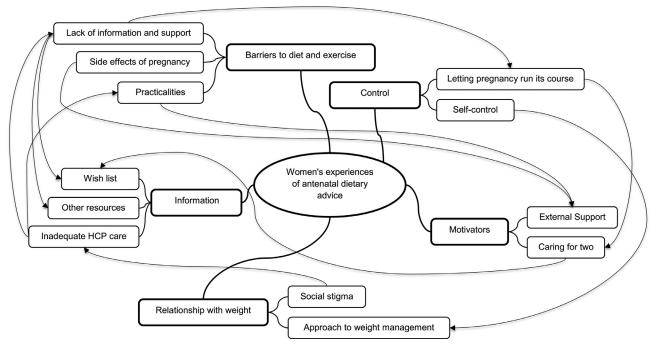


Fig. 2. Thematic inter-relationships.

**Table 3**Themes and sub-themes.

Overarching themes	Sub-themes		
1. <b>Control</b> The extent to which women feel in control of their pregnancy and the conditioning that influences this relationship	1.1 Letting pregnancy run its course 1.2 Self-control		
2. Barriers to Diet and Exercise Obstacles affecting women's ability to put healthy lifestyle advice into practice	2.1 Side effects of pregnancy 2.2 Practicalities 2.3 Lack of information and support		
3. <b>Motivators</b> Internal and external factors which encourage women to negotiate barriers and make a desired change	3.1 Caring for two 3.2 External support		
4. Relationship with Weight Women's perception and resulting impact of professional and unsolicited commentary on their weight.	4.1 Social Stigma 4.2 Approach to weight management		
5. <b>Information</b> The experience women undergo in order to educate themselves during pregnancy	5.1 Other resources 5.2 Inadequate HCP care 5.3 Wish list		

Weight gain was seen by some as synonymous with pregnancy and necessary for the health of the baby. Therefore, less concern was shown to the implications of GWG and the consumption of less healthy foods (McMillan et al., 2018; Padmanabhan et al., 2015; Swift et al., 2017; Weir et al., 2010). Whilst some women were untroubled by 'inevitable' weight gain and believed that GWG would disappear postnatally (Heslehurst et al., 2013; Weir et al., 2010), others were anxious about this prospect and less able to relinquish control of their body (Arden et al., 2014; Padmanabhan et al., 2015). One participant spoke about an overwhelming sense of doom and loss of self.

"In the end you just feel like you're a dead person walking with a baby inside you, do you know what I mean? Like all these terrible things are going to happen to you" (Parsons et al., 2018).

Self-control (14/20 studies)

Women felt pressure from HCP to make informed and guided choices during pregnancy (Parsons et al., 2018). Participants believed that their control over making decisions on potential food risks and healthy behaviour was taken away from them. As a result they felt policed and believed that their autonomy was suppressed.

We are no longer credited with having the brains or common sense to assess for ourselves the risks we are taking, and so they err on the side of not so much caution but absolute suppression...... If it has happened with booze, nuts, cheese, pate, liver and mayonnaise, why shouldn"t it happen with BMI? (Arden et al., 2014)

Some participants were open about disregarding HCP advice, feeling that they were intelligent enough to make their own choices and preferring to listen to their bodies (Atkinson et al., 2016; Parsons et al., 2018).

"That put a lot of pressure and a lot of guilt on me, but the second time round I decided to be a bit more relaxed and trust my body a bit more." (Bouga et al., 2018)

Several participants felt able to exercise self-control throughout their pregnancy, through physical activity and dietary choices. These women believed that it was possible to maintain their weight and relished the resulting empowerment (Arden et al., 2014; Denison et al., 2015; Heslehurst et al., 2013). Others recognised that despite sufficient knowledge of antenatal advice, selfdiscipline and ignorance sometimes acted as barriers to desired behaviour change (Weir et al., 2010).

#### Theme 2. Barriers to diet and exercise

Side effects of pregnancy (5/20 studies)

Women started pregnancy with positive lifestyle intentions but became waylaid after encountering pregnancy specific symptoms (Arden et al., 2014). Back pain and fatigue prevented women from

**Table 4** Characteristics of included studies.

Study	Research aim	Region	Data Collection Method	Participants	Themes identified
Arden et al. (2014)	Examine reception of gestational weight management guidance	UK	Secondary collection of online parenting forum posts	n = 202 pregnant women	Perceived control / responsibility, Risk perception, Confused messages
Atkinson et al. (2016)	Investigate whether pregnant women are receptive to behaviour change	Midlands UK	Face-to-face open interviews and video open interviews	n=7 pregnant women between 24–33 weeks gestation and experiencing their first pregnancy (aged 28–42)	Acceptance of the pregnancy, Influence of pre-conception experiences, Listening to your body versus following advice, Retaining self versus selflessness
Bouga et al. (2018)	Experiences of pregnancy nutrition, with a focus on iodine	UK	Face-to-face and phone interviews	n = 48 women with a child over 2 years, at pre-conception stage or pregnant	Dietary information received, Iodine knowledge Iodine sources, Receiving information
Brown and Avery (2012)	Exploration of information and advice provided during pregnancy with a focus on BMI	Nottinghamshire UK			Weight gain advice wanted, Diet and exercise advice wanted, Lack of advice and support, Anxiety
Denison et al. (2015)	Exploration of the barriers and facilitators to lifestyle interventions during pregnancy	Edinburgh UK	Semi-structured interviews	$n=13$ pregnant women over 16 weeks gestation and a BMI $\geq 40~{\rm kg/m^2}$ (aged $\geq 18$ )	Healthy lifestyle awareness, Complex barriers to change, Personalised solutions
Dinsdale et al. (2016)	Exploration of experiences of maternal obesity care pathways	North East England	Semi-structured interviews face-to-face and via telephone	$n = 24$ women who had given birth 3–9 months prior to recruitment and a BMI $\geq 30/35 \text{ kg/m}^2$	Communication, Treating obesity with sensitivity and respect, Appropriate and accessible lifestyle services
Draffin et al. (2016)	Exploration of the concerns, needs and knowledge of women with GDM	UK	Focus groups	n = 19 pregnant women with a history of or current GDM (aged 18–45)	Dealing with a GDM diagnosis, Having adequate support Challenges of lifestyle change, Consequences of GDM
Eades et al. (2018)	Exploration of experiences, knowledge and perceptions of women with GDM	Scotland UK	Semi-structured interviews	$n = 16$ pregnant women with GDM (aged $\geq$ 18)	Understanding of GDM, Impact of GDM, Understanding of T2DM, Lifestyle change, Prevention of T2DM
Furness et al. (2011)	Exploration of experiences managing weight in pregnancy	Doncaster UK	Focus groups	$n = 6$ pregnant women with a BMI $\geq$ 30 kg/m <sup>2</sup> $n = 7$ midwives	Explanations for obesity and weight management, Best care for pregnancy
Heslehurst et al. (2013)	Experiences of pregnant women with obesity	North East England	In-depth interviews	$n = 15$ pregnant women and BMI $\geq 30 \text{ kg/m}^2$	
Heslehurst et al. (2017)	Experiences of women with obesity's referral to an antenatal dietetic service	North East England	In-depth interviews	$n=15$ (same sample as above) pregnant women and BMI $\geq$ 30 kg/m <sup>2</sup>	Service experience, Process of referral, Delivery of the service, Content of the service
Jarvie (2017)	Exploration of experiences of women with maternal obesity and GDM	South West England	In-depth narrative interviews	n = 27 pregnant women with coexisting obesity and GDM	Social and economic stressors, Stigma
Keely et al. (2017)	Experiences and perceptions of pregnancy by women with obesity	Scotland	Semi-structured interviews	$n=11$ pregnant women and a BMI $\geq$ 40 kg/m <sup>2</sup> $n=7$ male partners	Weight histories, Relationship with food, Resisting risk together, Resisting stigma together, Pregnancy as a 'pause', Dietary advice, Postnatal intentions
Lavender and Smith (2016)	Gain insight into experiences of pregnant women with an elevated BMI accessing maternity services	North West England	Semi-structured interviews and focus groups	$n=34$ post-natal women with an antenatal BMI $\geq 30 \text{ kg/m2}$	Disappointment with pregnancy, Readiness to make a lifestyle change, Spurred on by success
McMillan et al. (2018)		Yorkshire UK	Semi-structured interviews	n = 27 6-12 weeks postnatal women with previous GDM	Barriers and facilitators to a healthy lifestyle, Support from HCP, Suggestions for postnatal support, Technology to assist with a healthy lifestyle
Olander et al. (2012)	Identify characteristics of services and support wanted by pregnant women	Midlands UK	Focus groups	n = 9 prenatal women $n = 14$ postnatal women	Early information leading to routine formation of eating habits, Delivery of practical sessions, HCP providing support and signposting
Padmanabhan et al. (2015)	Exploration of factors influencing lifestyle behaviours during pregnancy	North East England	Face-to-face interviews	n = 19 pregnant women in their 3rd trimester (aged $> 16$ )	Fragmentation of self, Legitimising behaviours, Body and behaviour surveillance
Parsons et al. (2018)	Exploration of women's experiences of GDM and GDM care	London UK			Disrupted Pregnancy, Projected anxiety,
Swift et al. (2017)	Investigate experiences and motivators of behaviour change during pregnancy	Nottingham UK	Mixed methods questionnaires	$n = 193$ pregnant women over 27 weeks gestation (aged $\geq 18$ )	Risk management, Coping with symptoms, Self-control Deviation from norm, Nature knows best
Weir et al. (2010)	Exploration of the views of pregnant women living with overweight and obesity to inform interventions	North East England	Semi-structured interviews	$n=14$ women with a singleton pregnancy and a BMI of $\geq 25~\text{mg/m}^2$ (aged $> 16$ )	Behavioural beliefs and attitudes, Control beliefs, Normative beliefs

maintaining their regular activity levels and had a subsequent effect on weight management (Draffin et al., 2016; Swift et al., 2017). Furthermore, consuming a healthy diet was compromised by nausea, heartburn and food cravings (Arden et al., 2014; Bouga et al., 2018; Denison et al., 2015; Swift et al., 2017). Healthy foods were described as 'bland' or 'undesirable' with women prioritising comfort foods high in fat and sugar (Swift et al., 2017).

"I was going to have such a healthy pregnancy, eat only good food and be worthy, but then the sickness started, so I eat what I can keep down." (Arden et al., 2014)

#### Practicalities (10/20 studies)

Practical barriers to change were classified as financial, time dependant or social. Despite intent to exercise and maintain weight, women found gym classes and weight loss services unaffordable and healthy food financially unobtainable and impractical (Denison et al., 2015; Jarvie, 2017). Frustration was expressed at class difference, with women believing that eating healthily would be an easier task for those better off.

"It's all very well saying you are not supposed to be having all this stuff that you are eating, but don't make everything that is healthy expensive. Because ...if you go and buy a week's worth of fruit and veg and it's expensive. I mean it's madness." (Jarvie, 2017)

Women lacked time to cook the food they knew they should be eating and resorted to convenient options such as frozen food (McMillan et al., 2018; Padmanabhan et al., 2015). Some women struggled to cook a healthy meal to please the whole family and one participant lacked the knowledge on how to cook fish (Bouga et al., 2018; Jarvie, 2017). Time pressures further affected physical activity, with women feeling too exhausted after a long working day (Denison et al., 2015; Weir et al., 2010).

I know that breakfast is the most important meal of the day ... but that's the time of the day that it's chaotic. So, you've got to feed a baby, your husband's walking out the door, you've got a tod-dler to get to nursery and then you need to try and cook scrambled eggs because you can't have cereal. It's like, "What am I supposed to do?' (McMillan et al., 2018)

#### Lack of information and support (14/20 studies)

It would appear that women are not currently receiving sufficient antenatal guidance. Gaps in support and advice provision translated into barriers to leading a healthy lifestyle. Johnson et al. (2013) confirmed that women frequently felt anxious about engaging in behaviour that would cause harm to their baby. Negative symptoms encountered during pregnancy were linked back to exercise, which held women back from partaking even in gentle activities and indicated a lack of knowledge about appropriate and safe types of physical activity (Denison et al., 2015; Dinsdale et al., 2016; Heslehurst et al., 2017; Padmanabhan et al., 2015; Swift et al., 2017; Weir et al., 2010).

I think we were paranoid about doing anything that might harm the baby' (Denison et al., 2015)

Cravings for certain foodstuffs, mostly carbohydrates or high fat snacks, were perceived as beneficial for the baby as they provided nutrients that were previously lacking (Bouga et al., 2018; Keely et al., 2017; Padmanabhan et al., 2015; Swift et al., 2017). Women were therefore likely to entertain these cravings, seemingly unaware that this behaviour is not always nutritionally beneficial and strongly predicts GWG (Renault et al., 2015). Cultural ignorance from HCP was an additional barrier to implementing

change; with many women feeling that dietary advice was exclusive of their heritage and cultural preferences and reducing desire to attend subsequent appointments (Draffin et al., 2016; Parsons et al., 2018).

I remember when I first met the nutritionist. I was trying to describe a yam to her – she didn't know what it was. So, I said, when I come in for my next appointment, I'll bring a yam to show you what it is, because, you know, I was trying to describe, this is what we eat,' (Draffin et al., 2016)

In some cases, despite adequate knowledge, some women struggled to implement the change they desired, leading to frustration (Denison et al., 2015; Keely et al., 2017). It was recognised that HCP were not currently afforded enough time to assist women with breaking a lifetime of habits (Arden et al., 2014)

#### Theme 3. Motivators

Caring for two (10/20 studies)

Women desired to have the healthiest possible pregnancy and were therefore very aware of their behaviour during this time frame (Eades et al., 2018; Heslehurst et al., 2013; Lavender and Smith, 2016; Padmanabhan et al., 2015; Weir et al., 2010). One participant discussed pregnancy as a motivator to make changes that would last a 'lifetime' (Lavender and Smith, 2016). Women place particularly high value on nutritional knowledge, as found by Bookari et al. (2017), and wanted to feel that they had done their utmost to support the health of their child.

"I'd just explain and try and promote the benefits to the baby more than to themselves, because as soon as you mention the baby that'll be it. I know my head now is about 'what do I need to eat that's best for the baby', rather than what's best for me, you know so...that might trigger a positive response rather than a negative response." (Heslehurst et al., 2013)

It was also recognised that engaging in healthy behaviour benefitted both mental health and the birth experience. Women who undertook regular physical activity felt happier and believed they were more likely to undergo an easy birth and pregnancy (Denison et al., 2015; Weir et al., 2010).

#### External support (13/20 studies)

Women desired encouragement and assistance during pregnancy and welcomed the idea of someone taking control of their health to alleviate pressure on them. One participant described supportive figures as 'miracle workers' and was grateful to receive help, despite it being unsolicited (Draffin et al., 2016). Women generally trusted HCP and some were pleased that their weight or ill health had been brought to their attention as it led to increased motivation to change (Bouga et al., 2018; Dinsdale et al., 2016; Eades et al., 2018; Heslehurst et al., 2017; Lavender and Smith, 2016; Olander et al., 2012).

"Uhm, I was quite pleased really.... they"ve pointed something out that I have a problem, but I can act on it and do something about it and personally felt like yes, really eager to participate" (Lavender and Smith, 2016)

"I trust very much what the midwife has to say in terms of my nutrition regarding my pregnancy, because they are quite experienced in that field." (Bouga et al., 2018)

Partners provided support with engaging in physical activity and making dietary changes (Denison et al., 2015; Draffin et al.,

2016; Heslehurst et al., 2013), but were occasionally a barrier when they were not on board with the desired change (Bouga et al., 2018; Heslehurst et al., 2013). Furthermore, support groups were overwhelmingly viewed as positive experiences as women relished being 'in the same boat' as other participants (Furness et al., 2011). O'Brien et al. (2017) agreed that intimate social relationships encourage healthier behaviours during pregnancy.

#### Theme 4. Relationship with weight

Social stigma (11/20 studies)

Women encountered disparaging comments about their weight, unwanted dietary advice and general undesirable attention during their pregnancies (Arden et al., 2014; Denison et al., 2015; Furness et al., 2011; Jarvie, 2017). This weight stigma was not unique to pregnancy but escalated during this period due to the perception of public ownership over the baby. This critique manifested in strong emotional responses; some women felt able to dismiss it (Denison et al., 2015) whilst others were made to feel very anxious and uncomfortable (Arden et al., 2014; Heslehurst et al., 2013).

"Women's bodies are considered public property; something to be legislated about or publically shamed into different shapes." (Arden et al., 2014)

This stigma and resulting self-consciousness held women back from engaging in physical activity and feeling able to leave their houses (Heslehurst et al., 2013; Furness et al., 2011; Weir et al., 2010), hence the need for exercise recommendations that can be undertaken in comfortable and accessible environments. Women living with overweight and obesity felt selfish for choosing to start a family and believed that people perceived them as a bad mother due to their likelihood of delivering a 'big baby' (Arden et al., 2014; Jarvie., 2017). This fear of shame existed beyond pregnancy into their parental future (Keely et al., 2017).

"I think there's just something wrong with the way that people who are overweight are viewed in this country by everybody, whether you are pregnant or not...there's just an assumption that you're a bit thick, and that's why you are overweight, and it's not necessarily true." (Heslehurst et al., 2013)

Weight stigma extended to a healthcare setting, HCP were seen as biased against women living with overweight and obesity. Participants believed that HCP projected judgement onto them and made unfair assumptions about their lifestyle choices (Arden et al., 2014; Denison et al., 2015; Jarvie, 2017; Keely et al., 2017; Parsons et al., 2018). This perception added unnecessary stress to the women and inflicted a feeling of guilt, particularly when a diagnosis of GDM was received (Arden et al., 2014; Jarvie, 2017). Some women felt they had let HCP down and were embarrassed to discuss weight issues; leaving appointments feeling overwhelmed and misunderstood (Heslehurst et al., 2017). O'Brien et al. (2017) confirm that weight bias and victimisation will only result in poor self-efficacy.

Approach to weight management (10/20 studies)

Approaches by HCP to antenatal weight management were found to be inconsistent; leaving women to feel dissatisfied and confused about the importance of their weight. Whilst some staff avoided the topic, others handled it insensitively or appeared uncomfortable (Lavender and Smith, 2016); a finding confirmed

by Johnson et al. (2013) and Jones and Jomeen (2017). Some women were told not to be concerned by GWG (Furness et al., 2011; Lavender and Smith, 2016), others had no weight discussion or monitoring during their entire pregnancy (Arden et al., 2014; Brown and Avery, 2012). Findings that HCP were often unconcerned about GWG, agrees with Stengel et al. (2012) and Whitaker et al. (2016). As a result, women were not provided with an incentive to maintain their weight or offered substantial practical advice on managing further GWG. Smith and Lavender (2011) believe that pregnancy is an ideal period for HCP to intervene with weight and blame depersonalisation of care for this GWG acceptance.

"I've never been told before either by my doctor, or anything, that I needed to lose weight either which has surprised me because I'm like really overweight,...so they must have thought, right, well, you're fairly healthy, you're just overweight." (Lavender and Smith, 2016)

Some participants were unhappy with the frequency and deliverance of weight discussions (Dinsdale et al., 2016; Jarvie, 2017). Present findings reported animosity around BMI terminology as women felt that the classification of 'obesity' was insensitive and was used to place shame. Weight labels should be accompanied by reassurance and support with preventing further GWG. However, one participant expressed preference for direct treatment and preferred HCP not to skirt around the issue of weight management due to politeness (Dinsdale et al., 2016). HCP may be lacking confidence in their approach as a result of the imprecise weight management guidelines (NICE, 2010; RCOG, 2018).

"Just stop going on about it quite as much as they do. Say it once or twice, but constantly being severely obese and BMI, BMI, BMI it's kind of drummed into your head all the time." (Dinsdale et al., 2016)

The bedside manner of HCP was critiqued; women felt lectured and picked on due to their size (Arden et al., 2014; Heslehurst et al., 2013; Parsons et al., 2018). This dynamic affected the relationships between women and their healthcare staff and caused a reluctance to attend appointments (Heslehurst et al., 2013). As Hodgkinson et al. (2017) proposed, midwives may benefit from communication skills training to reduce perception of stigma. Women believed HCP found it easier to blame them rather than recognise the impact of an obesogenic and unjust societal environment (Arden et al., 2014). Weight management is a complex issue and participants felt that HCP should strive to understand the underlying personal cause by asking the women what support they would benefit from (Dinsdale et al., 2016).

#### Theme 5. Information

Other resources (12/20 studies)

Women appeared to prefer receiving information from trusted HCP above other sources, as confirmed by Whitaker et al. (2016), but find this advice to be infrequent and limited. HCP are currently time poor and unable to provide the quality and quantity of information and support required to elicit change during pregnancy, leading to reliance on external resources. This knowledge gap was particularly apparent with nutritional information; which women wanted and actively sought out but did not receive in adequate quantities.

'I would welcome information regarding my diet and have been searching the Internet for some.' (Brown and Avery, 2012).

Leaflets can provide a useful care alternative when HCP are overstretched and short on time, but the number of physical hand-

outs received was seen as excessive and the information often ignored (Bouga et al., 2018; Brown and Avery, 2012; Olander et al., 2012). Despite reliance on digital advice, women were aware of the pitfalls of the internet and questioned its reliability (Bouga et al., 2018; McMillan et al., 2018). Information online was found to conflict with guidance provided by HCP (Atkinson et al., 2016) which may explain why some women were left feeling overwhelmed when conducting research (Atkinson et al., 2016; Bouga et al., 2018; Weir et al., 2010).

"You read so much or you get so much off the internet or whatever that it can be quite overwhelming. And the information is conflicting..." (Weir et al., 2010)

#### Inadequate HCP advice or care (15/20 studies)

Women found HCP support to be inconsistent and reported that being switched between midwives resulted in a loss of rapport, decrease in reliable care and provision of conflicting advice (Bouga et al., 2018; Brown and Avery, 2012; Draffin et al., 2016; Furness et al., 2011; McMillan et al., 2018). One participant felt that their GWG was a result of seeing a different HCP at each appointment (Furness et al., 2011). These inconsistencies resulted in women feeling at a loss for who to trust (Brown and Avery, 2012; Weir et al., 2010).

"I was forever asking the midwives [about exercise activities] but I got swapped between a few midwives ... so I kind of found out there wasn't much information out there." (Furness et al., 2011)

Guidance was described as generalised and inadequate with little explanation behind it. This particularly applied to GWG advice, with some staff stressing weight maintenance and others suggesting weight loss (Heslehurst et al., 2017), despite guidelines clearly advocating against the latter (NICE, 2010). Women felt that emphasis on food and physical activity avoidance was notably disorientating, overly restrictive and caused unnecessary anxiety (Weir et al., 2010). Participants were aware of foods to avoid but lacked knowledge on foods to increase as confirmed by Crozier et al. (2009), Downs et al. (2014) and Poston (2017). As a result, women are overly cautious with food for fear of causing harm to the baby, reported also by Lucas et al. (2016).

"...it's always you shouldn't do this, this and this.... if you listened and took notice of everything that you heard, you wouldn't know where you were..." (Weir et al., 2010)

Whilst women were critical of the advice that they had received from HCP, they reported feeling abandoned when pre-natal healthcare appointments were terminated, potentially demonstrating the value of HCP contact (Eades et al., 2018; Heslehurst et al., 2017; McMillan et al., 2018). Feelings of abandonment also occurred postnatally, leading women to believe that the lifestyle advice they had received was no longer relevant (Dinsdale et al., 2016; Parsons et al., 2018).

#### Wishlist (12/20 studies)

A 'wishlist' of requests for changes to existing antenatal care has been compiled using findings of the present research and can be seen in Fig. 3. Many participants desired more information on ideal and average GWG and women were anxious to know if their GWG was adequate (Brown and Avery, 2012; Heslehurst et al., 2017). One participant believed that education about the risks of weight gain did not address the issue unless accompanied by support on managing weight (Arden et al., 2014). Women were keen to increase physical activity but aside from walking, were

Information on risks of dieting during pregnancy
Information on risks of an elevated BMI during pregnancy
Guidance on expected and appropriate GWG
Information on safe exercise and where to access it
Advice on which foods to eat and what 'healthy eating' is
Practical meal ideas and recipes
Guidance on portion control
Information on importance of micronutrients and recommended intake
Information about the consequences of GDM
Realistic and personalised advice that accounts for day to day pressures

Tailored advice which is individually or culturally sensitive

uncertain about 'safe' recommendations, which resulted in ex-

Asking the individual what they would like to get out of their care experience

Fig. 3. Wishlist information.

ercise avoidance (Bouga et al., 2018; Brown and Avery, 2012; Padmanabhan et al., 2015; Weir et al., 2010).

Existing nutritional advice was described as too simplistic and vague and there was confusion over what a healthy diet constitutes of, as found by Fowles and Fowles (2008) (Arden et al., 2014; Denison et al., 2015; Furness et al., 2011; Heslehurst et al., 2017). Despite a demand for knowledge, findings confirm that women are not receiving adequate nutrition education during pregnancy (Lucas et al., 2014). Information on foods to avoid was often not accompanied by practical knowledge about risks of consumption or with sources of the food such as vitamin A (Bouga et al., 2018). There was a clear desire for less information on foods to avoid and more guidance on foods to include (Padmanabhan et al., 2015).

"It was more about what you couldn't eat though than what you should eat. It was more about avoiding things like caffeine and certain types of food rather than what was the best to eat." (Bouga et al., 2018)

Women requested personalised guidance which could not be found online and did not relish being seen as just another patient (Arden et al., 2014; Denison et al., 2015; Heslehurst et al., 2017). Women felt that this could be achieved by HCP asking what type of advice they would like to receive (Heslehurst et al., 2017).

"...helping people set realistic goals, you know. And I mean realistic goals 'cause I've been to the um nutritionists in the NHS and they're not realistic" (Denison et al., 2015)

#### Strengths and limitations

The study benefitted from use of thematic analysis to develop insight beyond the initial findings of the individual studies and contextualise the research. It should be acknowledged that the significance of this research is dependant upon the twenty studies that it draws upon. However, quality assessment identified that all studies fell into either the medium or high category; therefore the initial data can be considered reliable. Whilst the results appear to conform to international research, care should be taken when generalising the findings for population groups outside of the UK or for women with a BMI classification  $\leq 18.5 \text{ kg/m}^2$ . Furthermore, it should be recognised that there were a distinct lack of studies reporting qualitative data on foodborne illness prevalence and development (n=2) so the research unintentionally favours weight management.

To the author's knowledge, this is the first time that a 'wishlist' of requirements derived from pregnant women has been published to enable person centred antenatal care. It is important that future research investigates HCP views and experiences with the provision of this wishlist information so as to explore potentially unaccounted for challenges with antenatal care. Further research should seek to highlight reasons for inconsistencies with dietary and weight management advice in order to improve evidence-based guidelines and better support HCP.

#### Conclusion

It is recognised that time with midwives is valued by women, but that if inconsistent or seemingly irrelevant advice is provided, women feel demotivated and disengaged. Findings of this review were consistent with the wider field of research (Bookari et al., 2017; Downe et al., 2016; Jones and Jomeen, 2017; Lucas et al., 2014) and confirm that women in the UK are having contrasting care experiences which are not providing them with adequate knowledge and support, or care in keeping with NICE guidelines. The 'wishlist' provided by this review may go some way to bridging the gap between women's needs and the current antenatal provision in order to reduce the burden of anxiety during this period.

The lack of existing research on food safety risks and advice during pregnancy meant it was difficult to reach a reliable conclusion. It appears that, despite the low risk of foodborne illnesses, such as Listeriosis, existing food safety evidence is overly restrictive. Whilst women seek to engage in healthy behaviours that nourish their baby, they are also anxious about inflicting harm; leading to excessively cautious behaviour which is compromising nutritional adequacy. Food borne illnesses are not always the highest risk to pregnancy for many women, such as those living with overweight or obesity.

Provision of practical, high quality information with a focus on emphasising and recommending diet and physical activity, as opposed to avoidance, may support women's autonomy and lead to improved pregnancy experiences. Although HCP recognise the importance of nutrition education, a lack of time and training are key barriers currently affecting their ability to provide this support (Lucas et al., 2014). As the caseload for midwives expands and becomes more complex, multidisciplinary support from other relevant HCP e.g. dietitians, physiotherapists, may be a more appropriate and effective use of clinical time and input. This may involve maximising the effectiveness of clinical referral pathways for women living with overweight and obesity to seek time-critical, tailored dietary and weight management advice. Midwives may also benefit from dietary and weight management training provided by appropriately qualified dietitians and nutritionists. This training should address issues raised on the 'wishlist' and allow the nutrition-based conversations to be patient-centric.

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None.

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#### **CRediT authorship contribution statement**

**Jessica Stockton:** Conceptualization, Methodology, Validation, Investigation, Data curation, Writing - original draft, Writing - review & editing. **Lucie Nield:** Conceptualization, Methodology, Validation, Data curation, Writing - review & editing.

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None.

Appendix 1. CASP quality assessment criteria

Study	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	Overall studyquality
Arden et al.	-	-	+	+	++	-	++	++	+	++	Medium
(2014) Atkinson et al.	++	++	+	++	+	_	_	++	++	++	Medium
(2016)											
Bouga et al. (2018)	++	++	++	+	++	-	+	+	++	++	High
Brown and Avery (2012)	++	++	+	+	+	+	-	-	+	+	Medium
Denison et al. (2015)	+	++	+	++	++	++	+	++	++	++	High
Dinsdale et al.	++	++	++	++	++	++	++	++	++	++	High
(2016) Draffin et al.	+	++	++	++	++	-	-	++	++	++	High
(2016) Eades et al.	++	++	++	++	++	+	+	++	++	++	High
(2018) Furness et al.	++	++	++	++	++	+	_	++	++	++	High
(2011) Heslehurst	++	++	++	+	++	+	_	+	++	+	Medium
et al. (2015) Heslehurst	++	++	+	+	++	++	++	++	++	++	High
et al. (2017)											
Jarvie (2017)	+	++	+		++		++				High
Keely et al. (2017)	++	++	++	++	++	-	+	++	++	++	High
Lavender and Smith (2015)	++	+	+	+	++	++	-	+	++	++	Medium
McMillan et al. (2018)	++	++	+	+	+	++	+	+	++	++	Medium
Olander et al.	+	+	++	++	++	-	+	+	++	++	Medium
(2012) Padmanabhan	-	++	++	++	++	+	-	++	++	++	Medium
et al. (2015) Parsons et al.	+	+	++	++	++	++	_	++	++	++	High
(2018)											Madhan
Swift et al. (2017)	++	+	+	+	+	-	+	+	++	+	Medium
Weir et al. (2010)	-	++	++	++	++	+	-	++	+	+	Medium

\* - = LOW; + = MEDIUM; ++ = HIGH.

Was there a clear statement of the aims of the research?

Is a qualitative methodology appropriate?

Was the research design appropriate to address the aims of the research?

Was the recruitment strategy appropriate to the aims of the research?

Was the data collected in a way that addressed the research issue?

Has the relationship between researcher and participants been adequately considered?

Have ethical issues been taken into consideration? Was the data analysis sufficiently rigorous? Is there a clear statement of findings?

How valuable is the research?

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# 2.4 Paper 4: Impact of Voluntary, Community and Social Enterprise organisations (VCSE) working with people living with type 2 diabetes mellitus in underserved communities: a complex evaluation.

This coproduced piece of work adopted a qualitative approach to exploring the lived experience of underserved communities using AI methodologies. The interviewees described how diabetes services are not consistently providing the support required by underserved communities leading to poorer health outcomes and care.

This study described the multiple barriers to healthcare engagement experienced by these communities and the different approaches to support which were offered by the VCSE sector to facilitate better wellbeing. The work demonstrated the challenges associated with offering sustained long term tailored support that meets the needs of culturally diverse populations and resulted in the development of an initial theory of change.

This work demonstrates the importance and benefits of engaging with communities to understand barriers to impactful change. It suggests suitable alternate approaches to service delivery.





## Impact of Voluntary, Community and Social Enterprise (VCSE) Organisations Working with Underserved Communities with Type 2 Diabetes Mellitus in England

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Abstract: The Voluntary, Community and Social Enterprise (VCSE) sector offers services and leadership within the health and care system in England and has a specialist role in working with underserved, deprived communities. This evaluation aims to identify best practices in self-management support for those living with type 2 diabetes mellitus (T2DM) and to develop a theory of change (TofC) through understanding the impact of VCSE organisations on diabetes management. An appreciative inquiry (AI) was carried out and co-delivered using qualitative interviews and an embedded analysis with VCSE partners. A voluntary service coordinated seven VCSE organisations who assisted with recruiting their service users and undertook interviews to identify the impact of existing activities and programmes. People living with T2DM were interviewed about services. Themes were as follows: (a) individual and group activities; (b) trusted services and relationships across the community; (c) long-term engagement; (d) sociocultural context of diet and nutritional choices; (e) experience of adaptation; and (f) culturally appropriate advice and independent VCSE organisations. The structured educational approach (DESMOND) for T2DM was accessed variably, despite these services being recommended by NICE guidelines as a standard intervention. The VCSE offered continuity and culturally appropriate services to more marginalised groups. This evaluation highlights the importance of targeted engagement with underserved communities, particularly where primary care services are more limited. The TofC is a unique insight into the impact of VCSE services, offering bespoke support to manage T2DM, suggesting areas for improvements in capacity and offering the capability to sustain the VCSE sector as an essential element of the T2DM care pathway in England.

Keywords: voluntary sector; diabetes; VCSE; complex evaluation; self-management; England



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#### 1. Introduction

In England, the Voluntary, Community and Social Enterprise (VCSE) sector comprises organisations that are independent of the government and are constitutionally self-governing. They exist to represent and advocate for the local community or groups with specific needs and aim to promote social, economic, environmental or cultural benefits [1]. The diversity of these organisations and the delivery of their activities are being recognised for their contribution to the wellbeing of populations within communities [2], and the recent formation of Integrated Care Systems (ICSs) across England aims to address further transdisciplinary working and joined up, coordinated care pathways for individuals [3] This is different from the international non-government organisation (NGO) context due to their continuous, bespoke support of VCSEs of marginalised groups in their local

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communities. The National Institute for Clinical Excellence (NICE) recommend that a variety of self-management support is needed for people with type two diabetes mellitus (T2DM), particularly for those who do not access the typical pathways of care following diagnosis [4]. The academic literature on the VCSE's role and its impact on health and social care is still being explored but emerging. A joint review (2016) on the partnerships of the VCSE sector in health and social care highlighted that community-based small, local charities; social enterprises; faith-based organisations; and health and social care professional networks often deliver important services, including social groups, community exercise groups and T2DM management services [5]. People living in marginal and underserved communities are sometimes deemed 'seldom heard' by statutory services and require the support of VCSE service providers to engage with and meet those communities' needs [6]. Most recently, COVID-19 has shown how health and care systems and the VCSE sector can be partnered effectively in identifying and developing co-production interventions for specific populations [7].

VCSE organisations play a key role in facilitating dialogue between a system and its residents, ensuring that services are co-produced with residents at the heart of service provision [5]. However, there is a diversity of provision and in many cases best practices are not shared across the many different groups that participate in the planning and provision of community services, particularly where they are contracted to support self-management of specific medical conditions. The wider perceived benefits to VCSE users have been well documented, but further clarity is needed to demonstrate the impact of services [8]. VCSE organisations can play a hugely important coordinating role, brokering between beneficiaries and other stakeholders in the system (e.g., clinical professionals and local authorities). A partnership approach for conditions like T2DM is advantageous for planning sustainable, long-term management [4].

Management of T2DM can be complex and requires, among other components, continuous self-management, multidisciplinary team input and community support [9]. The prevalence of T2DM is rising rapidly, putting increased pressure on the statutory healthcare system and challenging the provision of optimal, tailored diabetes care. In England, healthcare is typically accessed via free-of-charge primary care services for individuals experiencing symptoms or concerns regarding their health. Following assessment, people with T2DM receive a medical diagnosis triggering a referral and ongoing monitoring depending on the severity of symptoms and co-morbidities. Person-centred self-management of T2DM is widely recognised as key to achieving better health outcomes [10]. There is a complex range of interacting factors that follow the diagnosis and lead to variation in the quality of long-term management, including emotional and physical challenges [11], relationships with healthcare professionals [12], glycaemic control [12] and psychometric assessments [13]. People with T2DM require tailored, consistent and ongoing information, which the healthcare professional delivers briefly [14], with ongoing referral to the UK's current structured education programme for T2DM: Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND). DESMOND is one of several structured education programmes available in the UK [15] which has been found to improve some clinical outcomes and reduce costs [16]. Its purpose is to increase activation for necessary behaviour change, but this tends to affect only those who are already highly active [17]. It is also more effective in white Europeans [18], despite ethnically diverse individuals being disproportionately represented in UK-based T2DM populations.

Psychologically, a diagnosis of T2DM can also lead to a 'biographical disruption' [19], a term used to identify the reaction to managing a long-term condition. People react variously to the advice offered for weight loss or smoking cessation associated with improving health and can also recognise a stigma with T2DM, often associated with unhealthy lifestyle factors enshrined in household norms and behaviours. The diagnosis can also sit uncomfortably with individuals who viewed themselves as previously healthy. When healthcare professionals focus on the aetiology, diagnosis and treatment of T2DM, the patient may be more concerned with the consequences of diagnosis and the influence on

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their daily life [14,20]. The perception of the disease process is contextual to social and cultural experience and whilst emotional support may be helpful [21], any intervention must be adapted and endorsed by the patient and 'fit' their lived situation [22].

Previous studies in the UK identified a greater risk of diabetes in ethnic minority groups, particularly South Asians [23–25]. Several studies have also identified inequalities in access to [26] or compliance and uptake of diabetes services [27–29], although not exclusively in ethnically diverse groups. Inequalities exist in primary diagnosis, access to primary healthcare and initial assessment and treatment [30]. T2DM is characterised by an emphasis on individuals making decisions to change their lifestyle, eating habits and exercise regimes; however, some people from poorer communities have difficulty managing personal changes about health based on limited access to support and community assets that enable healthier patterns [31].

This research aimed to critically engage with and understand the role of VCSE organisations and their impact on the self-management of people with T2DM from underserved communities and to produce a theory of change (TofC) [32]. A TofC is defined as a theory of how and why an initiative works [33] and is increasingly used in evaluations to capture, as an outcome of qualitative and mixed methods analyses, the initial programme and how it aims to improve the outcomes for a specific population. A TofC describes an impact pathway, seeking to demonstrate the causal assumptions behind the links in the pathway. The aim of a TofC is to demonstrate how processes lead to common desirable outcomes. TofCs are useful for predicting how change is expected or conceptual tools for how the impact on care was achieved [34].

#### Evaluation Design

Local VCSE partners were invited to take part in the study via the sponsor. Seven VCSE partners participated in the project, representing organisations from across the city. The VCSE partners provided a variety of services, including a drop-in cafe for people of African— Caribbean heritage, weight management programmes in groups and/or online, exercise referral programmes, diabetes education in the Urdu language, outreach activities for the Roma-Slovak community, men's health groups and wellbeing clinics at local community centres. A co-ordinating voluntary services organisation commissioned the evaluation from an academic team. Their complex programme of work was ongoing and sought to identify the impact of VCSEs offering a health-oriented service to people with T2DM. The sponsor sought to co-produce a TofC from the existing work of VCSE organisations that participate in the delivery of T2DM services as part of the statutory care pathway. To be included, the VCSE had to offer a service in a specific underserved community and have pre-existing embedded connections and relationships with ethnic groups or socially or financially deprived areas. The evaluation team used the appreciative inquiry (AI) model as an evaluation framework because the process examines, identifies and further develops the best of what is happening [35]. This enables actors to co-create a shared understanding of, in this case, how VCSE organisations could work together productively on behalf of those with T2DM in a northern city in England. The evaluation design was co-produced [36] with the participating VCSE organisations familiar with the communities of interest but less experienced in research processes. Therefore, the interview methods and data collection were fully discussed and 'rehearsed' with the participant organisations.

#### 2. Materials and Methods

The theoretical approach to the study was based on organisational development and systems thinking used in health and care services in the UK [37]. This recognises that the individual is the central focus, but that healthcare is made up of multiple organisations and this broad context was important for this study.

The AI approach provides a framework for data collection based on the 4D cycle, i.e., discovery (what is the best of what it is), dream (envision the impact), design (coproduction) and destiny (how to empower, learn and improvise). The participation of the

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seven VCSE services was particularly welcomed, in part to engage and build capacity for evaluation practices; in AI terms building "images of possibility into reality and belief into practice" [38]. In a community context, the method is aligned with an asset-based approach [39] where atypical populations are engaged and more marginal views are sought [40]. The evaluation had a pragmatic outcome of preparing the VCSE organisations for a joint application for further funding. In order to position organisations to apply for more strategic funding, the evaluation of practices also sought to generate a shared understanding of how VCSE outcomes could be defined and what benefits might be measured in relation to their practices [34]. The approach enabled organisations to share feedback from their constituent membership, and this data were analysed for themes and subsequently re-reviewed for the purpose of collaborating on the TofC development.

The research team comprised a dietitian (LN), an occupational therapist and systems researcher (SFD), a community and practice nurse (AY), a director of voluntary services organisation (HS) and a senior research fellow in global public health (SB).

#### 2.1. Data Collection

A semi-structured interview guide was co-produced and designed in collaboration with the VCSE partners to ensure appropriate questions and prompts were used to gather the required information. It was developed to lead participants from their initial diagnosis to the present day, with specific questions regarding what having diabetes meant to them, how they manage their diabetes, where they access support and appropriate advice, what they liked and what could be improved regarding their experiences with primary care, secondary care and the VCSE sector regarding their diabetes. They also were asked what they felt would be important when designing a diabetes service for their community. The full interview guide is provided in the Supplementary Materials.

VCSE organisations recruited participants (either face-to-face or via telephone or e-mail) if they had received support and advice from the VCSE and had a diagnosis of T2DM. Participants were recruited and interviewed between December 2021 and February 2022 when COVID-19 rules were variable in the UK. Participants were given a detailed participant information sheet before the study commencement, with information about the voluntary nature of the input, assurance of data anonymisation and maintenance of confidentiality. Consent was confirmed before participation in the evaluation. Participants were free to withdraw from the study at any point during the process without impacting their routine care.

Demographic questionnaires and qualitative semi-structured individual interviews were used to collect data for this study. VCSE partners and staff members conducted the interviews. The project team members (LN and SB) provided training to the interviewers before they interviewed the participants. All interviewers completed a pilot questionnaire, and the project team provided feedback on their interviewing process and skills. The interviewers then completed their questionnaires and qualitative interviews with two to seven participants recruited by the VCSE organisations. The influence of the interviewers on the research processes and data could not be assessed as they needed to maintain field diaries or document their observations to achieve this.

The questionnaires were designed to collate basic demographic information such as age, gender, postcode, time since diagnosis and education status.

The interviews were conducted online, face-to-face or via telephone using a predetermined co-developed topic guide; each lasted between 20 and 40 min. After obtaining informed consent, the interviews were audio-recorded or hand-written verbatim, with some interviews translated from Urdu to English. The research team (SFD, LN and SB) received anonymised voice files which were transcribed by Otter.ai transcription software [41]. The research team immersed themselves in the data by listening to the audio interviews and reading and editing the transcripts produced by Otter.ai.

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#### 2.2. Data Analysis

The data were analysed by the research team using the qualitative framework analysis approach [42–44]. This approach was developed in an applied research context to systematically manage qualitative data to identify the potential for actionable outcomes by providing transparent results and conclusions that can be related to the original data.

Three researchers (SFD, LN and SB) analysed the data manually by following the five steps in framework analysis: (a) data familiarisation: the researchers read the transcripts several times to develop an understanding and interpretation of the participant's perceptions of their diabetes journey; (b) framework identification: each researcher suggested a theme heading for the framework analysis and these were discussed and amended until a consensus was reached; (c) indexing: condensed data from the transcripts; (d) 'charting'; and (e) mapping and interpretation [43,44]. Following Gale et al. (2013), quotes were extracted from the transcripts to populate the framework. The framework interpretation involved reviewing and discussing the data and developing a TofC [43]. The data are reported using Standards for Reporting Qualitative Research (SRQR) using the Consolidated Criteria for Reporting Qualitative studies (COREQ) based on a 32-item checklist [45].

#### 2.3. The Theory of Change

The initial TofC was developed from the framework analysis, with the themes forming the basis of further discussion between the research team, the participating VCSE organisations and the coordinating VCSE agency. The charted data and thematic descriptors were shared and used to highlight the collated impact of VCSE interventions [46]; the discussion described the process and the change sequence to consolidate the outcomes and impact on the T2DM population. Using 'sense-checking' through participant validation [47] of the framework analysis enabled a deeper understanding of the context of the intervention, particularly the cultural diversity of both the population and VCSE focus. The results were also presented to the wider VCSE community and National Health Service (NHS) organisations working to improve the management of T2DM in the area. A robust TofC model can be evaluated in subsequent studies. Still, the TofC provided a preliminary illustration by clearly mapping out the process between the intervention and desired outcomes [48].

#### 2.4. Patient and Public Involvement

Participant organisations working within local communities were invited to sessions to scope the research area, agree on the key research topics and devise, pilot and agree on the interview topic guide. The local VCSE organisations' interviewers recruited community members to understand their lived experience of T2DM in the local setting.

#### 3. Results

#### 3.1. The Study Participants

In total, 33 interviews were collated from seven organisations and 30 were included in the analysis (2 interviews were excluded as the interviewees had type 1 diabetes and 1 interview was a duplicate). The sociodemographic characteristics of the participants are described in Table 1. ]

Participants were diagnosed between 12 months and over 30 years ago, with most participants being diagnosed within the last 5 years. Nearly half of the participants lived in the top 20% most deprived centiles, according to the English Indices of Multiple Deprivation (2019) from postcode data.

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**Table 1.** Participant characteristics and demographic data (n = 30).

Sex (Male/Female) (%)	14/16 (47%/53%)				
	26–45	4 (13%)			
	46–55	8 (27%)			
Age (years) (%)	56–65	5 (17%)			
	65+	9 (30%)			
	Unknown	4 (13%)			
	Asian or Asian British	4 (13%)			
	Black or Black British	7 (23%)			
	Mixed—Other	3 (10%)			
Ethnicity (%)	White—British	11 (37%)			
	White—Other	1 (3%)			
	Unknown	4 (13%)			
	No formal qualifications	2 (7%)			
	Up to GCSE or equivalent	5 (17%)			
	AS/A level or equivalent	2 (7%)			
	Apprenticeship	1 (3%)			
Education status (%)	Further Education	6 (20%)			
	Undergraduate degree	4 (13%)			
	Postgraduate degree	1 (3%)			
	Prefer not to say/unanswered	9 (30%)			
	0–4.9	13 (43%)			
	5–9.9	2 (7%)			
	10–14.9	5 (17%)			
Time since diagnosis (years) (%)	15–19.9	1 (3%)			
	20+	2 (7%)			
	Prefer not to say/unanswered	7 (23%)			
	0–20% most deprived	14 (47%)			
	21–50%	7 (23%)			
English Indices of Multiple Deprivation	51-80%	1 (3%)			
(2019) [by postcode data] (%)	20% least deprived	2 (7%)			
	Prefer not to say/unanswered	6 (20%)			

#### 3.2. Identified Themes

Six themes were identified overall: individual and group support for self-management; trusted services and relationships across the community; long-term engagement with services; sociocultural context of diet and nutritional choices; multifaceted adaptation to the long-term condition; and shared community support network.

#### 3.2.1. Individual and Group Support for Self-Management

The study participants reported several ways they were given initial information, which they thought was generic but a good start. Most said that they commonly received

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early advice and guidance, but the overall messaging was associated with nutrition and lifestyle. For example, a White British male participant (65+ years old) said,

"they told me to watch my diet, watch what I eat-plenty greens, fewer carbs, and to exercise, and that will keep my blood sugars down".

However, many of the interviewees mentioned that they preferred tailored or specific information that could meet their individual needs.

In the initial information, the participants were offered medication such as Metformin and referred to DESMOND. DESMOND was attended and received variably by the participants. Due to ongoing comorbidities, there were many barriers to attending DESMOND, such as timings, location and inaccessibility. As a participant expressed his concern that:

"I was invited to some talks, but I didn't go. I was overweight and struggled to walk, and nobody could take me in their car" (Asian British Male, 65+ years).

However, some that did attend found it useful and reiterated their existing knowledge. For example, a Black Caribbean female (age 65+ years) mentioned that:

"I was signposted to DESMOND. The programme affirmed things I know. It was useful"

Therefore, when attending the programme, she found it to be a good source of information for diabetes self-management.

Nevertheless, some participants felt the information was ad hoc and only sometimes available when needed. Similarly, many respondents felt overwhelmed by the information they were provided with at diagnosis and could not initiate any positive behaviour change. When the shock of the diagnosis had settled, and they could act on the information, they felt that additional support was lacking. A participant expressed his concern as:

"...very disjointed, and it's difficult to find out about that. I tended only to find out about things by chance, in some instances through desperation" (White British Male, 65+ years).

It was evident from the interview data that there was shared knowledge in families and across communities. In the absence of other information, this was also used to supplement understanding from health professionals. A Pakistani female (65+ years) said:

"My GP told me to lose weight and stop eating rice and chapati and other things. My sister also had diabetes a few years before, and she also told me some tips".

However, following initial advice from the GP or the DESMOND programme, many participants stated that there was confusion and uncertainty associated with the long-term effects of living with diabetes and what strategies to take forward in daily living. The advice was limited and from mixed quality sources. As a participant shared:

"At present, I don't get any [information]. I am just living with the original information I was given about diet and taking one tablet until today. It concerns me because I don't know whether my blood sugar is gone" (White British Male, 65+ years).

For those who could use the internet for information about the management of their diabetes, the quality of the information was varied, and some of the behaviour changes they took from it were inconsistent with usual dietary advice. A White British male (aged 65+ years) found it useful and emphasised that,

"I think it has to be the internet, to be honest. Yeah. I found a lot on the internet about various foods and how they affect your blood sugars".

Many participants reported finding answers and support from neighbours, friends, the local community, and voluntary organisations. This support was tailored to the community and individuals' needs and delivered when the participants were ready to accept the information to improve their diabetes knowledge or control. A Black Caribbean female (age 65+ years) participant said that:

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"And it also happened that she [neighbour] had diabetes. And she says to me, "oh, there's a group going on at [name of VCSE]"... And I felt renewed, elated because it was a group that, that there were other people with the same diagnosis, the same struggle".

Most participants stated that they received formal and informal information from various sources such as healthcare professionals, DESMOND, peers, relatives, family members and the internet. Most of the participants valued the information they received from their family, community or peers as they believed it was based on the lived experience of people, and they found it relevant to their lived experience.

#### 3.2.2. Trusted Services and Relationships across the Community

There was a strong recognition by the participants of "good" services that they trusted and those they felt had let them down. Many of the services also seemed to have been impacted by the COVID pandemic, so the patients felt they were receiving a substandard service. A participant said:

"Diabetic nurse.... Well, it's just generally sent me for bloods, look at my feet. Quick chat. Jobs a good 'un!" (Unknown).

In contrast, a White British male (age 65+ years) felt that:

"at the moment, due to the pandemic, no one [is supporting with diabetes management]; that's what I feel let down by because I think if you've got something like diabetes, I should be getting support".

Characteristics of the health professionals and services which participants appreciated were regular contact, building a good rapport, being personalised/culturally appropriate and referring or signposting them to services in the local community which were delivered primarily by the VCSE organisations. For example, an Asian British female (56–65 years) stated that:

"the information I was given was appropriate for me. I visited the nurse at the doctor's surgery every 3 months for my bloods, she was very good, and I developed a good relationship with her. She told me about exercise classes in the area and also told me about health walks".

Some participants also discussed how their personal circumstances prevented them from attending some of the services or how they avoided appointments because they knew that they had poorly controlled diabetes. As a mixed heritage male (26–35 years) said:

"my mental health is really bad due to not managing diabetes. It has affected my life. I try to avoid my GP appointments because I know I struggle to manage my diabetes".

Many respondents also spoke about the VCSE organisations they had received support from and how it improved their knowledge of diabetes control. As a participant said,

"I get most of my information now from community hub, I go for the keep fit sessions, and they do some health information cafes where they talk about healthy things to eat and portion sizes. They also tell you what food to avoid if you have diabetes. It has been a good refresher for me". (Pakistani Female, 65+ years).

The level of participants' trust in service providers and healthcare professionals varied. Still, most patients trusted those services and healthcare professionals who listened to them and addressed their individual needs.

#### 3.2.3. Long-Term Engagement with Services

The diabetes journey reported by many of the participants was similar. They had gone to the GP with symptoms of thirst, tiredness, poor wound healing, etc., and were diagnosed with diabetes. For many, this was expected, and participants reported having parents and

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siblings with diabetes. Participants linked their diabetes journey to their family history and said,

"I had a couple of things that I spoke to a doctor about: dehydration, night sweat, that kind of thing. And they did a blood test. So, it was a blood test that revealed. Like yeah, because yeah, my mom's diabetic. And then I've always known it was coming. Yeah, it was just a case of, obviously, two brothers. And I was never sure if it was going to be me or them too. But it seems to have come down the female line" (White British Female, 56–64 years).

However, for some participants, this was a complete shock due to their perceived idea of who gets diabetes, and this caused a large biographical disruption. For instance, for an Asian British female (56–65 years), it was a shock when she learnt that she had diabetes. She shared that:

"the doctor sent me for blood tests, and they came back showing I had diabetes. I was so shocked and upset. I didn't even know young people got diabetes".

Most participants expressed that the diabetes diagnoses often led to strong emotional responses where people were stressed and upset. It took a long time for them to process their new diagnosis and accept what this might mean to them. As it was for a Pakistan female (65+),

"I was very, very upset when I found out I had diabetes. I was scared that I would not be able to eat all the food that I loved and worried about what I would eat".

After the initial support and advice that was offered, participants reported a period of struggling, anxiety and uncertainty. The reported impact of the diagnosis on their mental health was incredibly significant. It often prevented them from processing or using the diabetes management information they were provided with at this time to make any meaningful lifestyle change. An Asian British female (56–65 years) shared her experience,

"The first few years were very tough. I stopped eating out and I stopped visiting parties and friends because I was worried that they would offer me food and I wouldn't be able to eat anything. I was also scared that people would be watching me and watching what I eat. This made me isolated and depressed, and I developed social anxiety. It has taken me years to get over this, and now I feel I am confident and in control".

The participants also reported ongoing concerns about the long-term implications and co-morbidities associated with their diabetes diagnosis. For example,

"I didn't really take on board or understand how serious diabetes is. I thought if I take my tablets, watch my diet, and look after my feet, I'd be ok. . . . but talking to people, they tell me about problems with their kidneys and blood flow to their legs, lots of problems. I hope I don't get any of this" (Black Caribbean British Female, 65+ years).

The participants had mixed feelings and responses when they were diagnosed with diabetes. Where participants had a family history of diabetes, they knew that they would have diabetes too; however, some of them were shocked when they were diagnosed with it and had a need for long-term support.

#### 3.2.4. Sociocultural Context of Diet and Nutritional Choices

The interview data revealed that some participants were self-motivated or had household support that seemed to be a significant beneficial factor in their response to the diagnosis by driving more appropriate food choices and aiding weight loss, whilst others relied on food banks and struggled to make appropriate food choices due to the limited availability of foods. As an Asian British Female (56–64) said,

"My husband was very helpful and supportive...he helped me reduce some weight. . . I realised that when I cut down on sugary stuff and started eating less

rice and chapati, my weight dropped by itself. I also started walking a lot, and me and my husband would go for walks after the evening meal."

Moreover, the participants spoke about dietary changes they had been advised about or initiated. It was apparent that carbohydrate-rich foods are ones that people regard as bad for them, and the participants have engaged with the idea of eating more fruit and vegetables. However, the messaging they had retained from the advice appeared generic and only sometimes helped the individuals make a specific dietary change suitable for them. As a White British male (56–64 years) said,

"Anyway, apparently, you're not supposed to have carbohydrates and sugars, which is, like, most of what I eat, potatoes, bread".

In addition, advice from healthcare professionals was combined with advice from other sources such as the internet, family and friends. For instance, a White British male (65+ years) stated that:

"I eat a lot of onions and green onions and leeks and that kind of thing...very particular triggers and learning how to regulate how much fruit I eat, shouldn't eat too much fruit, certain fruits you should avoid, and so on. Yeah, I learned a lot from the internet".

It was evident from the interviews that most participants were conscious of their diet and followed the nutritional advice they received. Moreover, they mentioned a variety of sources of information concerning diet, including healthcare professionals, family, friends and neighbours, but were only able to enact behaviour change within their social, economic and cultural resource constraints.

#### 3.2.5. Multifaceted Adaptation to the Long-Term Condition

Most participants were users of VCSE services and appreciated the focus on local knowledge and shared information in a familiar setting. The support was focused on practical daily activities and was derived from discussing and planning with others with similar concerns. For example, a Black British Caribbean female (65+ years) said:

"The information I got was from .... a really good group. You know, it's, it helps me really, to manage.. day -to-day menu, day-to--to-day exercising, everything. I mean, every...everyone that was there was going through the same thing. I mean, the shared experience, we all shared our experience, you know, because everybody was different there. And they understood what everybody else had going on. So, it helped".

A common consideration was that participants had multiple morbidities and often multiple stresses arising from household challenges, including social stress and deprivation. These competing priorities made lifestyle behaviour change difficult for participants, resulting in a deprioritisation of diabetes self-management. For some, the initial stages following diagnosis were easier to manage, involving weight loss and a degree of support via the DESMOND programme. Still, the progress of the disease was difficult to manage, and there were varying responses—some more positive than others—but predominantly associated with medication changes or blood checks. A participant said:

"I immediately started walking and eating more fruits and vegetables and lost a lot of weight. I controlled it via diet for at least 2 years. After 2 years, I was put on medication. I am still learning about things even at this stage. I have stopped eating all sugary stuff; I have a lot of self-control" (Pakistani Female, 65+ years).

Home remedies were recognised as alternatives to allopathic medicine and a part of active self-management, and some participants favoured mixing these with their medications and lifestyle choices. For example, a Pakistani female (65+ years) shared examples of using home remedies:

"I also tried some bitter drinks that people in Pakistan drink when they have diabetes, that helps me keep my sugar level under control, and I also eat bitter gourds, that is a very bitter vegetable. I also put cinnamon in my tea as I have heard that it helps lower when levels are high. I am very careful I don't let my levels go high".

In an extreme case, the self-management of diabetes was complicated by other habits and problems or a sense that there were limited options concerning being well and managing their lifestyle. One man reported having a perforated eardrum.

"So, there's nowt [nothing] he's going to do for me, says you...you've got diabetes, and you smoke. So anyway, so basically, I'm just left here with a perforated eardrum," said a White British Male (56–64 years).

As a part of active self-management, there was a range of comments about the continuity of activities, what participants liked to do, and what they stopped doing—particularly associated with exercise. In many cases, people wanted to move but were out of practice, had their routine altered due to COVID, found it difficult to find time or were too embarrassed to use municipal facilities.

#### 3.2.6. Shared Community Support Network

Following the appreciative inquiry model, the participants were asked how they envision existing services' improvements and impacts. The participants from black and ethnic minority backgrounds dreamt of being recognised as having a cultural heritage and a health support need. For example, older adults from Pakistan wanted information in Urdu, which they saw as the only culturally appropriate way to overcome language barriers. On the other hand, there was recognition that some groups needed to include collective knowledge about health. As an Asian British male (46–55 years) put it,

"There is a need for a lot of improvement culturally because then if we introduce ... traditionally if there is one person gets the information, he spread it out to the [the rest of the community]... a big job to for the people's awareness in mainly an Asian community".

Both participants from ethnic minority and white backgrounds suggested they would like simple but meaningful practical formats for health advice, including regular exercise and cooking support, that were associated with a healthy lifestyle but delivered in ways specific to the community. For instance, a Black British Caribbean woman (65+ years) wanted to incorporate exercise, with different topics and ideas about how she would take the group outside to get fresh air.

The social and collective stimulus was repeated with the suggestion that groups learn, support and share informal information in a way that promotes long-term communication associated with changing personal behaviours. A participant emphasised that

"we need to meet up regularly and consistently. Peer support and good communication" (Black British Caribbean Male, 56–64 years).

The social nature of these interventions was associated with inclusion and, for some, was not exclusively about their diabetes but was a 'place-to-be', where a sense of belonging was experienced. For example, a White British man (46–55 years) reflected that:

"A safe place, a comfortable place.... I'd like to make a place where anybody can come. You don't have to talk about it if you just want to come to sit. Have a cup of coffee—a bit like the men's group".

Many wanted to see more proactive services associated with primary care. These were associated with the need for physical checks and professional advice from a service based on technical knowledge. There was a suggestion that the technical knowledge must be complemented with a different communication style and a more nuanced, local and community understanding. Overall, there was consensus among the participants concerning using and

sharing collective wisdom and experiences to have culturally appropriate and accessible spaces that can stimulate participants to embark on active management of T2DM.

#### 4. Discussion

This evaluation used AI and qualitative framework analysis synthesised into a TofC ([33,48]) to provide an explanatory process for the impact of VCSE services that support people with T2DM in underserved communities. A TofC diagram was produced with the participants and the sponsor to evidence the impact of the combined VCSE services. The TofC was based on themes and theme content that reflected the current status of the service offer, the short- and long-term outcomes which were elicited from the conversations and interviews and the impact which was derived from the interview participants' data. The TofC restates the strategic aim that VCSE organisations aim to operate in collaboration across the health and care sector and economy, offering supportive guidance to diverse communities to support and improve self-management of T2DM (see Figure 1).

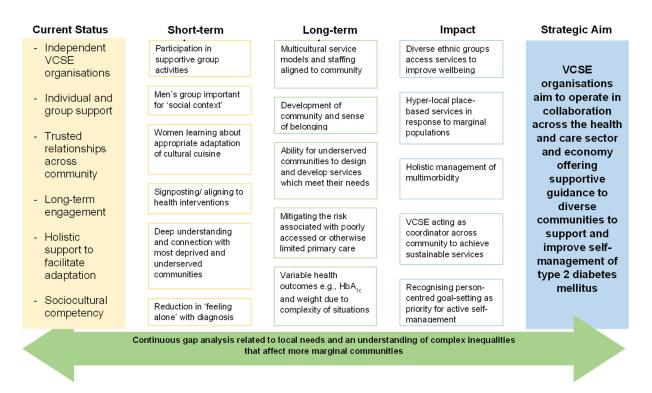


Figure 1. Initial theory of change for VCSE organisations in diabetes management.

The TofC proposes that trusted local VCSE services are embedded into the diabetes care pathway alongside their primary and secondary care partners. The VCSE's appear to offer nuanced information that can be delivered at a time and in a way that meets the needs of underserved communities and thus may be a more effective model of working. Short-term outcomes involve the use of current services by marginal communities, whilst longer-term service development and delivery may be undertaken by individuals from such communities, representing a deeper understanding of the needs of the population. It is noted that the multicultural service models and staffing are aligned to the community, and the sense of belonging afforded to communities by VCSE organisations is significant to the perceived impact, with VCSEs acting as coordinators across the community to achieve sustainable services which work for underserved communities within a complex health system.

The themes contributing to the TofC suggest that a combination of statutory and VCSE services is available, but that many participants in this evaluation preferred to use 'local' advice and more community 'embedded' knowledge. An important finding was that the

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needs of individuals changed whilst living with diabetes. Initially, people with T2DM seek reassurance at an early stage post-diagnosis; however, latterly, they need to 'check in' and appreciate 'technical' support to monitor and manage the disease process. Primary care is recognised as the professional service and emphasises patient-centred, comprehensive care where communities are underserved, as is often the case with marginal and diverse ethnic groups [21]. However, the assets within the local communities make up for some of the perceived lack of personalisation and support from statutory services.

The findings of the study are reflective of previous research; the Care Quality Commission (CQC) report 'My diabetes, my care' (2016) recommended the development of local plans to put people at the centre of their own care, with appropriate levels of support for self-management and ensuring emotional and cultural considerations are met [49]. Similarly, the NHS Confederation (2021) recommends that "Local VCSE organisations need to be included in health and care pathways and service redesign planning across systems, including population health management and social prescribing in primary care networks" [2]. Debussche et al. (2022) also recommended that interventions and services designed for people living with T2DM need to consider the multidimensional nature of diabetes self-management and health literacy as well as the social context of the individuals for it to deliver effective outcomes [50]. By giving a voice to underserved communities with lived experience in service design and delivery, systems can be more effective, reduce health inequalities and deliver meaningful outcomes [51].

VCSE services receive marginal and short-term funding to deliver pockets of activity [7]. Their role is often one of an advocate, enabling communities to meet, share experiences and voice their concerns in a socially constructed space [1]. The assets are created, sometimes in the short term, co-produced with the community and so often meet a need that a healthcare provider cannot. However, the provision is weak by virtue of its organisational form: small, responsive and contractually regulated. This project usefully highlights the value of the core purpose: engagement and association with marginalised communities and management of the associated risk. It also highlights that the VCSE services are bridging the gap between primary care and population needs. However, the input from the VCSE needs to be more cohesive and consistently meet the needs of its community, which is challenging due to limited resources, infrastructure and expertise. As the ICSs integrate traditional health and care systems with the VCSE sector, clinicians may be more closely aligned with community assets and be able to signpost patients to additional support for diabetes self-management which may ensure more tailored, targeted and culturally competent practice and improved health outcomes for those most marginalized communities.

The strengths of this study lie in the collaborative working and co-design of the research tool and protocol between different organisations, which has built on existing relationships with VCSE providers and enabled access to seldom heard and more marginalised patient groups. The findings and the TofC were also shared with all VCSE groups and stakeholders within the region to obtain feedback and ensure that the process was transparent and representative of the data collection. If a strong collaborative process is established in the initial stages of a TofC evaluation, it can help assure that stakeholders will work with the evaluator to explore creative measurement strategies [52]. However, additional tools are required which will help to scale up successful coproduction interventions for new people within new contexts or place. There is also a challenge to provide appropriate development and professional practice skills and knowledge to current and future professionals in order for them to engage and confidently work with coproduction approaches [53].

The study methodology had some limitations, as the participants were interviewed by staff members from a VCSE service that they had accessed, which may have constrained what they said about the organisation. There may have been selection bias towards those individuals who experienced a VCSE service more positively, and these individuals were likely to be more engaged with their own self-management of diabetes as they were accessing healthcare and VCSE organisations. However, the researchers believe this elicited

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high-quality data due to the prior relationship with the 'trusted' organisation and the interviews were not generally carried out by the participants' usual contact at the VCSE organisation. Using non-academic researchers for data collection led to some inconsistencies in data collection. Still, the benefits outweigh the limitations, and the interview data collected are equally critical for all diabetes care providers. Other limitations may relate to the specific context and configuration of VCSE services that may not be replicated in other countries. Whilst the findings are recognised to be context specific, and have no clinical implications, they do have implications for changes in health and care utilization. Additional research to understand the perceptions of those who have not engaged with VCSE services would also be beneficial to determine factors which lead to engagement with such services. The initial TofC seeks to map the impact of services, and the study demonstrates again the preferences for tailored person-centred interventions delivered in a local context. There is value in assessing whether this TofC is replicable in other contexts, including different cultures and other long-term health conditions, and in assessing the impact of the VCSE sector on reducing the NHS burden.

#### 5. Conclusions

Participants with T2DM presented challenges associated with their diagnosis and early management and appreciated the consistent and embedded community support of the VCSE providers. Participants reported an inconsistent range of support post-T2DM diagnosis and very limited engagement with the main educational programme offered as a standard (e.g., DESMOND). The evaluation identified the benefits of hyper-local group activities, often employing peer-to-peer processes to share information about living with T2DM and providing support at a time which suited them. Advice, guidance and long-term support were only sometimes available but deemed important. The strength of the impact of VCSE organisations was associated with the engagement and continuous relationships with individuals, knowledge of the community and culturally appropriate provision (concerning language and cultural diets); there was still a demand for more responsive and cohesive support for lifestyle and behaviour changes. The services appear to strengthen the specific lifestyle behaviour change based on 'what mattered' to individuals—recognising and overcoming some barriers to accessing statutory care.

The findings highlight a systemic and organisational issue which can be resolved by a cross-sector integrated health and care system which embeds the VCSE organisations into the diabetes care pathway. The TofC indicates that with consistent, sustainable funding and recognition, VCSE organisations can contribute valuable services targeted to more marginal and underserved communities. Other competencies through health coaching training or similar may be helpful and require collaboration across the sector to enable a specific response to diabetes management.

**Supplementary Materials:** The following supporting information can be downloaded at: https://www.mdpi.com/article/10.3390/healthcare11182499/s1, S1: VAS Diabetes topic guide for interviews; S2: COREQ checklist.

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# 2.5 Paper 5: "I prefer eating less than eating healthy": Drivers of food choice in a sample of Muslim adolescents

This qualitative study worked with adolescents from a deprived area to understand their food choices, how they are evolving during adolescence (at a time when autonomy is developing) and the drivers of food choice behaviour. The study used PhotoVoice to provide an insight into the lived experience of these adolescents and to explore how their food choices related to health and wellbeing. For most, health was not a key priority, despite knowledge of healthy eating. This was overridden by the desire to eat fast food and convenience food which was perceived to be tasty and more appealing than traditional or home cooked foods. Adolescents demonstrated that their basic concept of healthy eating was synonymous with weight management and that they would rather eat smaller quantities of "unhealthy" food than eat healthily. They also described how eating healthily was, to their mind, more time consuming and required greater effort than their current food practices.

This work reflects the impact of the food environment on food decision making, healthy practices and the association with higher obesity levels (Swinburn et al., 2011). Large bodies of work have evaluated trends in obesity levels and the food choice environment, and this study contributes a nuanced understanding of the challenges and barriers faced by a particular segmented population and their suggestions for facilitating healthier food choices. Adolescence is a developmental period of particular importance where individuals are becoming more autonomous and establishing practices to take into adulthood. By increasing the availability and sustainability of healthier food choice practices in adolescent populations, including within their food environment, successful weight management may be possible. However, for these systems-change benefits to be realised, this study demonstrates the importance of understanding the lived realities of these underserved and seldom heard populations to tailor appropriate and acceptable interventions.





## "I Prefer Eating Less Than Eating Healthy": Drivers of Food Choice in a Sample of Muslim Adolescents

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Abstract: Adolescence is a time of significant change which is experienced differently across sociocultural contexts. Understanding drivers of food practice in adolescence is vital as these impact future health outcomes and can drive health inequality. This study investigates drivers of food choice in predominantly British-Asian, Muslim adolescents living in a deprived urban area of England. It identifies dominant drivers of food choice and their impact on health and wellbeing, and explores how Muslim adolescents from a low socioeconomic, British-Asian group understand and action autonomy in their food practices. PhotoVoice, a focussed ethnographical methodology where participants reflect on lived experience, was used to address the study aim. Participants (n = 21) were secondary school pupils aged 14-15 years, recruited from a school situated in an area of deprivation. Four overarching themes were developed from the qualitative data framework analysis: (1) food preference and other determinants of food choice; (2) concept, understanding and importance of health; (3) developing autonomy, skills, and independence; and (4) role of community, friends, and family in food practices. The adolescents were developing autonomy in relation to their food practices, whilst navigating a complex web of factors which were, in part, determined by their social class location and demographics. Participants understood the constituents of healthy eating. However, there was a perceived "effort" of being healthy, including additional time for preparing healthier food and sacrificing taste preferences. Parents, friends, and schools highly influence food choices, with adolescents preferring a broad palate of takeaway and convenience foods and would prefer to eat less of these "unhealthy" options than eat healthily.

Keywords: Adolescence; food practices; autonomy; sociocultural context; Muslim; British Asian; food choice



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#### 1. Introduction

Adolescence is the phase between childhood and adulthood, from 10 to 19 years of age [1], which is marked by rapid physical, sexual, mental, and social development [2,3]. The nutritional needs of adolescents are significant due to the growth of all physiological systems, with adolescents typically gaining 20% of their final adult height and 50% of adult weight from ages 10 to 19, and an increase in bone mass of up to 40% [4]. Therefore, it has been recognised that adolescents have specific requirements, risks, and opportunities related to their dietary intake and food choice and that they are a unique population group who cannot be defined as older children or younger adults [2]. However, there is a lack of research and policy development which addresses nutrition during adolescence specifically. The Lancet Series on adolescent nutrition highlighted a paucity of intervention and policy research focussed on adolescent growth and nutrition [2,5,6]. The series recommended that future research should consider the relationship between adolescence and nutrition for the prevention of disease into adulthood [6,7], which also addresses the multiple drivers of adolescent diets. Some research has started to address this knowledge gap by studying the food environment and ecological context in adolescents [8,9]. Despite the knowledge that today's generation of adolescents is exposed to dramatic change in food environments,

whereby diseases of nutritional inequality (e.g., obesity, malnutrition) persist, adolescent-responsive nutritional policies and practices remain underdeveloped [6].

#### 1.1. Health and Weight Management

Adolescence is critical for the development of healthy eating behaviours, yet previous research has reported that adolescents are not meeting dietary guidelines, consuming higher intakes of high-fat, salt, and sugar (HFSS) foods such as fast foods and confectionary and lower intakes of fruits, vegetables, and wholegrains [10,11]. Adolescents report diverse barriers to, and enablers of, healthy nutrition, physical and sedentary activities, and sleep habits which have been summarised into three themes including degree of controllability, the impact of mental health, and social pressures related to weight management [12].

The worldwide epidemic of overweight and obesity represents a major challenge to government and public health policy makers [13]. The risk of obesity disproportionately affects the poorest people of Britain and despite a rise in childhood overweight and obesity, current paediatric weight management programmes are recognised to be largely ineffective [14]. In addition, adolescents often fall into a poorly managed "care gap" when they transfer from child to adult health care services as it fails to meet the needs of young people and their families. This suggests that their voices are not being heard and appropriate action is not being taken [15].

Overweight and obesity are outcomes of complex, lived realities that reflect a range of sociocultural dimensions shaping people's capacities to make healthy food practice choices. It has been acknowledged that nutrition and the adolescent transition are closely interrelated due to the multifactorial influence on eating patterns and behaviours [16].

#### 1.2. Food Practices

Food practices defined as "any activity in which food is involved, ranging from food preparation, gifting food, sharing meals, or cleaning up" [17] can be seen as the outcome of the food environment. The food environment is defined as "the collective physical, economic, policy and sociocultural surroundings, opportunities and conditions that influence people's food and beverage choices and nutritional status" [18]. Story et al.'s (2008) ecological framework of food choice extends the concept of food environment to reflect the complexity of interactions between the food environment and individual factors [19]. The drivers of food practices may go beyond material and environmental constraints (lack of money and access to supermarkets for example); other explanations drawn from adaptive behavioural ecology have been proposed [20]. These sociological principles are reflected in the work of Bourdieu who recognises that food practices occur at the intersection of skills, knowledge, identities, values, and competing priorities and are therefore not simply an exercise in willpower [21]. Food decision making, and food processes are complex and are driven by numerous interrelationships such as social class, budget, experience, access to food, preferences, rituals, and routines [22]. Food habits are therefore seen as a symbol and medium for the reproduction of class/socioeconomic status (SES) [21]. Unhealthy eating habits are noticed to run in families, for example, a young child may develop poor eating habits from their parents and then carry them into adulthood [23] whilst cooking and food preparation skills have a positive association with healthier eating habits and attitudes [24].

Food choice is the process through which we decide what food to buy and eat. Factors which influence food choice include availability in the home, parental control, peer behaviour, taste, food preference, self-efficacy, preparation, and cost [2]. An additional layer of complexity is curated by the exposure to social media platforms such as Instagram and TikTok and "influencers" who market HFSS foods. Evidence suggests that this exposure can lead to immediate consumption of such products [25,26]. Understanding the current drivers of food practice in adolescence is crucial as these decisions are pivotal to the long-term health and weight outcomes in adulthood and can be a key driver of health inequality [27].

#### 1.3. Adolescence and Autonomy

Adolescents develop autonomy, social and economic independence, discover their self-identity, acquire the skills needed for adult life [16] and develop responsibility for their decision making, behaviours and actions [28] including that of food and health choices [29]. Health choices are related to autonomy, yet influenced by family, peers, the wider social environment, and society [30,31]. However, the way in which adolescents experience that autonomy is not universal as adolescence is not homogeneous, and will reflect sociocultural context amongst other factors [7,21]. Additionally, people from ethnic minority groups develop their dual identities (i.e., their ethnic and national identities) during adolescence [32]. Adolescents' experiences of acculturation and development of dual identity is associated with adjustment and wellbeing outcomes [33].

It is therefore of interest to understand how adolescents' lived experiences of autonomy varies due to individual and contextual factors, and their perceived sense of control and power over their own food and health choices [34]. This has not yet been explored in UK Muslim adolescents.

This focussed ethnographic research will help to understand how UK Muslim adolescents, at a life stage at which autonomy is emergent, negotiate and accomplish food practice choices, and how this is inflected by sociocultural factors. This research is important as it will help practitioners and policy makers to understand the key drivers of food practice choices in this specific adolescent group which may enable the development of more innovative, inclusive, engaging, and tailored public health messaging, and food system design.

#### 1.4. Research Aims

The aim of this study was to investigate the drivers of food choice in predominantly British–Asian, Muslim adolescents living in deprived areas of an English city. The secondary aims were to identify dominant drivers in food practice choices that enhance or mitigate risks to health and wellbeing for this particular group and to explore how these adolescents understand and action autonomy within their food practices.

#### 2. Methods

The study was developed reflecting the growing consensus that children and adolescents are active social agents and experts in and of their own lives [35] and have a right to participate in research which may affect them [36,37]. The topic of food choice was used to understand how adolescents navigate food practices, develop autonomy and how this may impact on longer term food decision making and health.

#### 2.1. Study Design

A cross-sectional study which employed PhotoVoice was used to address the study aim. The inclusion criteria were participants aged 13-17 who were recruited from a local secondary school which was situated in an area of deprivation in a large city in North-East England. The secondary school is a large mixed-sex, ethnically diverse school with over 46% of students eligible for the income-assessed free school meals programme [38]. Most pupils come from Asian backgrounds, with the remainder coming from a wide range of minority ethnic backgrounds and a few pupils are White British. A much higher-thanaverage proportion of pupils speak English as an additional language and are eligible for the pupil premium. Participant information sheets were distributed to students and their families via the school and both parental consent and participant assent to the study was sought. Participants were free to withdraw at any stage during the research process. The research project was approved by the Sheffield Hallam University ethics committee (ethics number ER37936285) on 7 February 2022. Following consent, participants were asked to complete a short online demographic questionnaire which captured their gender, age, ethnicity, religion, highest educational attainment of parents, and full postcode which allowed the researchers to identify the Multiple Index of Deprivation centiles for the

research participants. The data capture period for half of the participants coincided with Ramadan (a period of fasting between sunrise and sunset observed in the Muslim faith) and Eid (a large celebration at the end of Ramadan) which provided additional cultural context to the data.

PhotoVoice is a participatory research methodology which uses focussed ethnography to allow people living within their community to record, share, and disseminate information and to become a catalyst for change [39]. Individuals use a camera to take photographs of issues that are important to them based on a specific research topic or idea. It can therefore be a tool which can reach, inform, and organise community members to discuss their concerns and issues and find group solutions. PhotoVoice is an appropriate methodology to address the study aim as images can trigger a deeper reflection on lived experiences and prompt emotional responses which narrative alone cannot [40]. Previous research has suggested that PhotoVoice is a powerful tool to use with adolescents. Adolescents reported feeling empowered and were able to demonstrate critical thinking and self-reflection amongst other skills [41]. In addition, there is a well-established argument that images can act as signifiers of culture which highlight values and expectations of individuals, communities, and society [42]. What individuals choose to photograph, when and how, is shaped by community values as well as how they would like to reflect their lives to others. PhotoVoice can therefore be used as an advocacy tool and to "give voice" to underserved communities aligning well with the process of co-production, where atypical populations are engaged, and more marginal views are sought [43].

The research team was comprised of the lead researcher (LN) and research assistants (PA, AC, HW, DZ, RH, YH) who were involved in the data collection and collation. Participants were invited to a 1-hour briefing session at their school, within which they were trained and guided on the aims of the research and the PhotoVoice methodology (its aims in the project, ethics of photography, and photography skills) by the lead researcher (LN). Participants used their own mobile device or tablet or had the option of being provided with a basic camera if required. They were asked to take photographs of images that represent "anything related to your food practices in your neighbourhood" for a 2-week period. Food practices were broadly defined as "any activity in which food is involved, ranging from food preparation, gifting food, sharing meals, or cleaning up" [17]. Participants were split into two groups and with half the participants taking photographs in May and half in June 2022. The data collection period of the May participants coincided with the end of Ramadan and Eid. The participants were asked to submit 5-10 photographs with a brief description to an online portal by the end of the data collection period. Participants were reminded to take and submit photographs after a 1-week period. The photographs were printed out and labelled by the research team with the participant number and brief description provided by the participant.

Participants were then invited to attend a focus group to share their experiences of food practices and discuss the significance of the photographs they chose to take. The participants were given printed copies of their own photographs and were split into six groups over two sessions (Session 1 consisting of 10 participants, groups A–C (May) and Session 2 consisting of 11 participants, groups D–F (June)) to allow adequate time for discussions and for each participant to have space to tell their story. These focus groups were held in the research centre close to the school.

In the first part of the session, participants were asked to look at their photos in small groups of 2–3 and share their thoughts using the first 4 questions of the SHOWed method to guide the conversation. In the second part of the session, findings were shared with the larger group, and participants were encouraged to look for any common themes amongst their photographs as well as any differences. The research team guided the discussions within the focus groups using the SHOWed method—a set of six semi-structured questions which facilitated an open-ended interpretive approach to the research questioning [44]. The questions were the following:

(1) What do you See happening here?

- (2) What is really Happening here?
- (3) How does this relate to Our lives/health?
- (4) Why does this situation, concern, problem, or strength exist?
- (5) How could this image Educate the community or policy makers etc....
- (6) What can we **D**o about it?

The purpose of the SHOWed questions is to identify the problem or asset being examined through PhotoVoice, critically discuss the roots of the situation, and develop strategies for change [45].

All discussions were voice recorded using Zoom or voice note software on multiple laptops and iPads (1 per group) to capture small group and larger group discussions. The voice recorded files were downloaded and saved securely on a university research drive.

After session 1, the researchers collated the learning, synthesised the data and prepared a presentation to outline the main findings. This was presented back to the participants as a way of "sense-checking" the researchers' interpretation of the data to determine whether the information had been understood appropriately from the series of focus groups and whether the participants agreed with the interpretation and findings and felt they were representative of their views and the discussions they had been involved in. This session took place at their school. During the session, questions 5–6 of the SHOWed criteria were addressed. Participants were encouraged to give feedback on the learning to date and suggest action which can be taken to policy makers and advocates for the adolescent participants. Participants were provided with a GBP 20 gift voucher as an acknowledgement of their time.

#### 2.2. Data Synthesis and Analysis

The researcher and research assistants (consisting of master's students who were trained and closely supervised by the lead author) uploaded the voice files which were transcribed by Otter.ai software [46]. The researchers immersed themselves in the data by listening to the audio interviews and reading and editing the transcripts produced by Otter.ai. The qualitative framework analysis approach was used for data analysis [47]. This approach aims to systematically manage qualitative data in an applied research context, provide transparent results and conclusions, and identify appropriate outcomes related to the original data.

The data are reported using a Standards for Reporting Qualitative Research (SRQR) using the consolidated criteria for reporting qualitative studies (COREQ), based on a 32-item checklist [48].

Qualitative analysis was undertaken using framework analysis [49] which created and applied an analytical framework. The five steps in framework analysis were followed: (a) data familiarisation: the researchers read transcripts several times to develop an understanding and interpretation of the participants perceptions; (b) framework identification: each researcher suggested a theme heading for the framework analysis and these were discussed and amended until a consensus was reached; (c) indexing: condensed data from the transcripts; (d) charting: rearranging the data and framework to create order and (e) mapping and interpreting: visually representing all the themes and investigating their interconnectedness [47]. Following Gale et al. (2013), quotes were extracted from the transcripts to populate the framework [47].

Further synthesis of the data led to an adaptation of the ecological model of food choice proposed by Story et al. (2008) [19].

#### Transparency Declaration

The lead author affirms that this manuscript is an honest, accurate, and transparent account of the study being reported. The reporting of this work is compliant with STROBE [50]. The lead author affirms that no important aspects of the study have been omitted.

#### 2.3. Patient and Public Involvement

Public involvement was crucial to this project and underpinned the study design. Prior to the recruitment of participants, a group of four 14–15-year-old participants from the same school met with the researchers. The research study aims and methodology were discussed, and all paperwork and questions were shared. The researchers asked questions to ensure that the research felt appropriate and asked for feedback and input from the participants for sense checking of information through to alternative study design ideas. At the briefing session and the two data collection and feedback sessions, participants took an active role in the design, development, and delivery of the study and how and where the results would be disseminated.

#### 3. Results

#### 3.1. Study Population

In total, 28 participants consented to take part in the study. A total of 22 participants provided demographic data and 21 participants participated in the PhotoVoice interviews, with some participants absent on the day of the focus group. The sociodemographic characteristics of the participants who took part are described in Table 1.

**Table 1.** Participant characteristics and demographic data (n = 21, aged 14–15 years old).

Variable	N (%)
Gender	
Male	3(14%)
Female	18 (86%)
Ethnicity	
Asian or Asian British–Pakistani	6 (28%)
Asian or Asian British–Bangladeshi	3 (14%)
Black or Black British-African	2 (10%)
Arab	2 (10%)
Other Asian/Asian British	1 (5%)
Any other ethnic group (incl. Caucasian)/prefer not to say/unknown	7 (33%)
Religion	
Islam	17 (81%)
Unknown	4 (19%)
Self-reported health status	
Poor	1 (4%)
Average	5 (24%)
Good	5 (24%)
Very good	5 (24%)
Prefer not to say/unknown	5 (24%)
Highest level of parental education	
They did not go to school	1 (4%)
Secondary school/college	3 (12%)
University	1 (4%)
Prefer not to say/unknown/unanswered	16 (80%)
English Indices of Multiple Deprivation (2019) (by postcode data)	
0–10% most deprived	10 (48%)
11–20%	2 (10%)
Prefer not to say/unanswered	9 (42%)

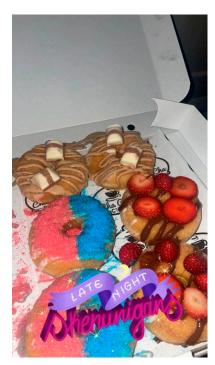
All participants attended the same school and were in Year 10 (aged 14–15 years old). All the participants who reported their full postcode lived in the top 20% most deprived centiles, according to the English Indices of Multiple Deprivation (2019). The majority of participants were Muslim, female, and reported that they were British Asians. Their self-reported health status was very variable ranging from poor to very good. Parental education level was largely unreported by participants.

#### 3.2. Summary of Photographs

In total, 143 photographs were submitted, 105 photographs were uploaded to the online portal by the participants with some participants e-mailing an additional 38 photos. Each participant submitted between 2 and 10 photographs with a brief description such as "Cheat day!", "Margarita Pizza", and "A healthy smoothie".

Most photographs that were discussed by the participants were of HFSS food items which the participants justified as appearing more exciting, "Healthy foods are boring, we don't want to take pictures of them". Therefore, regular food practices were elicited throughout the focus groups to understand the "boring" foods which were being consumed frequently.

Some example photographs are shown below in Figure 1.







**Figure 1.** Selection of photographs (from **left** to **right**: "Late Night Shenanigans"; "My healthy choice meal (5-a-day)"; "McDonalds in the park").

#### 3.3. Focus Group Themes

Four overarching themes were developed from the qualitative data, each with several sub-themes as described in Table 2.

#### 3.4. THEME 1: Food Preference and Other Determinants of Food Choice

Participants reported that food choices were often determined by a number of factors including influencers (i.e., friends, social media), convenience, cost, and personal preferences.

#### 3.4.1. Availability, Convenience, and Cost

Participants reported a desire for takeaways or purchasing HFSS products but had to reduce the frequency of their consumption due to cost.

Geographical location and opening times also dictated availability of food, and convenience was of primary importance to the participants sometimes resulting in the consumption of food that they would not necessarily have chosen (i.e., out-of-date/end of shelf-life items) or repetition of food practices resulting in frequent consumption of foods from the same restaurant.

**Table 2.** Themes and sub-themes with example quotes.

Theme	Sub-Theme	Example Quotes		
	Availability, convenience, and cost	"when I order food and it's just for me, it does get expensive because on Uber you get the service fee and the delivery feefor me that is expensive. Then sometimes I do like clear my basket and find something in the kitchen to eat". (Session 2, group D, female) "I do [eat out of date chocolate] cuz it's the only shop near me" (Session 1, group B, female) "I go to McDonald's actually more than I realise because it's literally a five-minute walk from my house." (Session 1, group B, female)		
THEME 1: Food preference and other determinants of food choice	School food	"The food in Year 7 was sick fam [sic]. Used to make lasagnes and everything, and now it's like" (Session 1, large group, male). "Because they say it's Halal, but it's not, because basically, in order for it to be Halal, they need to justso they say like a little prayer, which they do there But when you stun it, it still feels pain, even if it's for a slight moment, and that'sthat's not Halal" (Session 1, large group, male) "Yeah, so I feel like they should cater to us as well. Actually, we don't have much option." (Session 1, large group, female). "Most people have school [meals], but no one really likes it, we'd only really get the paninis" (Session 2, group D, female). "The line's fun. We just like standing in the line. That's why we end up getting the food. We pay for the food, but then we don't end up actually eating it." (Session 2, group F, female) "We're used to not eating in school" (Session 1, large group, female) "for school meals that I make, I have a lot of choice. I make them myself." (Session 1, group A, female) "I feel like they have to ask us, like if we actually like the food because most people, I'd say, they don't like the food, but then, they don't really care because they keep making the exact same thing like every single day. So, if they asked like, oh um, give us a choice" (Session 1, large group, male)		
	Taste and desire (e.g., takeaways, treats, and eating out)	"I feel like it's my favourite food. I literally live off noodles." (Session 2, group F, female) population "We have to restrict on a lot of things When we go out, we have to find a Halal place. That's why we don't have a big option. (Yeah). We just have the same few places that we go." (Session 2, group F, female). "My mum will pick what I eat. I just feel like it's easier because you don't actually have to think about it. Like you can eat whatever's there." (Session 1, large group, female). "Usually the food that's more tastier, sometimes that's the more unhealthy choice" (Session 1, group C, female) "if like a takeaway said oh, they are giving free delivery today then I'll just take that chance" (Session 2, group D, female)		
	Influencers (e.g., social media, friends, and parents)	"I personallyI like trying new thingsbut my familythey like to stick to the same thing" (Session 1, group C, female). "I feel liketo me, when I cook something say I've seen a video on TikTok and like, I feel like I'm craving it" (Session 2, group F, female)		
THEME 2: Concept, understanding, and importance of health	Strong polarisation of healthy vs. non-healthy options	"This is a fruit saladit's healthyI don't recommend having this all the timeit will make you more skinny", (Session 1, group A, female) "So like you haven't ate all day. So then if you've balanced your diet out then it'll help you for the next day" (Session 1, group A, female)		
	Parents and school as knowledge providers	"The Eatwell Plate that you do like in primary school I feel like it's gotten into our head. We know what healthy is, but we still don't eat it." (Session 2, group F, female) "Like my mum, she always says to me, 'Eat the chicken, not the like, too much of the rice. Eat more of the chicken. Cos, like, you want more protein than carbs.' Like just stuff like that." (Session 2, group F, female). "Yeah, you know, like when you look at something, you can just tell that's really unhealthy but I'm still gonna eat it" (Session 2, group F, female).		
	Health decision making	"I'm probably just the most unhealthiest person on the planet. Yeah, I'm just like ordering McDonald's or I just can't survive another day." (Session 2, group F, female) "I want to actually try eating healthy, but it's just so much effort cooking all the like" (Session 2, group F, female) "I prefer like I prefer eating less than eating healthy" (Session 2, group F, female) "When I eat at home it's more healthy, but when I eat out, it's just takeaways. [I] Prefer takeaways." (Session 2, group F, female)		

 Table 2. Cont.

Theme	Sub-Theme	Example Quotes
THEME 3: Developing autonomy, skills, and independence	Cooking and preparing independently (e.g., breakfast and snacks)	"After school that's when I have what my mum gives meand then in between that I just kind of choose what I'm gonna have" (Session 2, group D, female).  "I just have breakfast on the weekends." (Session 1, group C, female) "I can make anything in the world, I just, I just experiment. I just did it myself, I'm a self-learner" (Session 2, group E, male) "I just don't know how to cook, I mean, I could learn but I choose not to" (Session 2, group E, female).  "I can't cook, wish I could. My mum doesn't want me to. She just says, "Focus on your studies and go upstairs." So I can neverthe most I can do is just like cut like vegetables and that's it. Most I can do it right now is just washing the dishesshe says it's faster by herself. I'm just holding her back." (Session 1, group C, female)
	Helping in food practices (e.g., meal planning, shopping, and vegetable preparation)	"Yeah, I don't cook, I don't cook that much. But I do help my sister out Like she gives me like little instructions. Like I don't know how to actually do it 'you chop up this and then I'll do this'" (Session 2, group F, female)  "we have to wait [and all eat together in the evenings]" (Session 1, group B, female)  "if I don't like the food that my parents make, I would cook my own food" (Session 2, group E, female)  "I get my own meals, I don't order for anyone else I don't like what my mum cooks all the time" (Session 2, group D, female)
	Personal experiences of developing food autonomy	"I tried making wedges like, you know, the takeaway ones and it didn't work. Iused gasoline instead of normal oillike the oil you put in the carThey didn't die, they didn't die. They just got food poisoning. They didn't die though." (Session 2, group F, female). "I wake up. I won't have breakfast. If it's a school day, I'll just have a cup of tea. Then I'll survive all of school without food, maybe a chocolate bar or something. And then, three, four o'clock, I'll eat and then I'll go sleep for a bit and then wake up around eight and eat again. And I'll probably eat again around like half 12 and then go to sleep." (Session 2, group F, female) "after school yeah we go [to] shops and takeaways" (Session 2, group D, female)
THEME 4: Role of community, friends, and family in food practices	Celebrations and special occasions	"I tend to go out with family for meals Sometimes I do go with my friends. But when you're with family, you can travel to more places But when you're with just with your friends it's preferred to go eat locally or somewhere that's within walking distance" (Session 2, group E, female).  "Everyone comes to my house, my mum's the oldest" (Session 2, group D, female).
	Cultural and traditional foods	"we have different foods that we eat. Like IndianSouth Asian food. Yeah, we eat like, yeah, food that has a lot of like spices in it. That's why we're not used to that" (Session 2, group F, male) "she [mum] made rice and curry, she made roast chicken, kebabs, samosas" (Session 2, group D, female).  "in like Asian like households normally we have more oily food like everyday. I personally don't think is healthy" (Session 1, group A, female)  "I feel in our culturein my culture, we eat a lot of carbs [carbohydrates]. We literally like we have rice or like chappatis, yeah, with like every almost every meal. I don't have it, but like my parents, they can literally eat rice and curry every meal every single day." (Session 2, group F, female)  If i could cook, [] I wouldn't be making curry all the time. I like pasta" (Session 2, group E, female)
	Gifting and sharing of food	"This is Ramadan Mubarak, ok. It tells us more about my culture and religionso it is mostly about religion, and how we normally share food, give food, and also receive food from other people" (Session 1, group C, female).  "And there's like charity work as well. So you can help people Or they could give like donations, you could buy food baskets and give it to the people." (Session 1, group C, female).  "It doesn't matter because it's more about giving than receiving. So, like my mum, she makes food for everyone. She never expects anything back. She gives it to the neighbours, my family"  (Session 1, group C, female).  "I'll be unhealthy [driving to a takeaway] but it means I can spend time with my sister" (Session 2, group F, female).  "Once every two weeks, like my whole like uncles, aunties will all go to a restaurant. Full family meal. And then it's like fun because all the families together when there's food, they're all happy." (Session 2, group F, female).  "And you'll never see an angry person when you go out to eat food, unless they're paying. I've never paid, so I don't really".

#### 3.4.2. School Food

School food was a hotly debated topic. There was a sense that school food had gone "downhill" since they started school and that the variety and availability of food had reduced. Participants reported that 95% of the students were Muslim and therefore ate Halal foods, but that the meat provided in school was not Halal which significantly reduced their lunch time options, often resulting in an enforced vegetarianism. Participants reported that 50% of the school population are eligible for free school meals but that the food provided was "repetitive", "bland", and "boring" with limited Halal options. This led to participants having cheese and tomato paninis or a jacket potato four days per week, with pizza and chips, or fish and chips being served on a Friday. This lack of choice often led participants to skip meals and waste food, sometimes queuing for school lunches purely for a social activity, only to then discard their meals when staff were not watching. As a result, students developed erratic meal patterns, eating primarily outside of the school day. Alternatively, participants took their own packed lunch to school which allowed them to have more control over the food they consumed and determine their food options. Participants felt that if the school and catering teams wanted to improve their provision then the school pupils needed to be involved and asked for their opinion. The participants were able to identify the flaws in the current school meal provision and identified solutions to issues such as lack of choice and long queuing times. Participants suggested that the school caterers should provide cold food items such as sandwiches to improve choice and reduce queue times, improve Halal provision, season food more appropriately to their tastes, provide a diversity of authentic international cuisine, provide nutritional labelling, and involve them in decisions around the foods that were being prepared for them.

#### 3.4.3. Taste and Desire (e.g., Takeaways, Treats, and Eating Out)

Taste was recognised to be the primary driver of food choice and better taste was associated with unhealthier food options. However, taste was only one factor in a complex interplay that determined decision making. Participants mostly described a preference for takeaway and HFSS convenience foods such as pot noodles, pizzas, and desserts. There was a sense that takeaway options were limited by the provision of Halal foods and that even local fast-food restaurants were not catering for the local population. Therefore, restaurant and takeaway choices were restricted based on the provision of Halal food, accessibility (for restaurants), delivery fees (for takeaways), and access to public transport, with participants demonstrating a sense of value-for-money and autonomy in their decision making. However, some participants were content with the food provided at home and enjoyed home-cooked curries and meals.

#### 3.4.4. Influencers (e.g., Social Media, Friends, and Parents)

Participants described a difference between their parents' food preferences and their own. Generally, parents preferred traditional foods such as curries, whilst participants had a more varied palate and enjoyed trying new foods and cuisines (e.g., Japanese foods), and other less traditional home-cooked options such as salmon and pasta.

Participants also discussed the ways in which they are influenced by family, friends, and social media, which drove a desire to try new or different foods and ultimately determined their food choices.

#### 3.5. THEME 2: Concept, Understanding and Importance of Health

Health was strongly related to the concept of weight, with most discussions pertaining to health being correlated with weight loss, preventing weight gain, and being a healthy weight. Participants demonstrated a basic understanding of key healthy eating principles, such as the recognition of food groups, 5-a-day messaging and negative perceptions of HFSS foods. However, food items were polarised into "good" and "bad" choices and despite their interest and knowledge of healthy eating, participants preferred to eat less nutritious, takeaway, and convenience foods.

#### 3.5.1. Strong Polarisation of Healthy vs. Non-Healthy Options

Many food items were categorised as healthy or unhealthy in a polarised manner, whilst some participants referred to the importance of balance. There was a sense that poor dietary choices and unhealthy food consumption could be counteracted by skipping meals or eating "healthy" meals of fruit and vegetables.

#### 3.5.2. Parents and School as Knowledge Providers

Concepts and knowledge of health and healthfulness were primarily driven by parents and educators but were not generally an overt consideration for adolescents when they were making their own food decisions. As a result, participants described themselves as "unhealthy". Whilst many participants reported skipping meals and erratic meal patterns, this was not highlighted as being a concern. When questioned, participants did not feel that the 'healthiness' of a food determined their decision to eat it. Indeed, participants described how their desire to eat unhealthy food overrode their knowledge around healthy eating, better food choices, and any future health concerns. They felt that they had a good understanding from school, referring to tools such as the Eatwell Guide and the 5-a-day campaign and saw parents (particularly mothers) as advocates for eating a more balanced diet. Participants often referred to their parents as the gatekeepers for healthy eating who would encourage their children to eat less sugary or carbohydrate-heavy foods and ensure that they ate fruit and a range of food groups.

#### 3.5.3. Health Decision Making

Participants identified themselves as "unhealthy". Nevertheless, participants described an understanding of healthy eating and articulated that they would like to be healthier, but they felt that there were a number of barriers that prevented them from doing so, including time, food preferences, and a perceived requirement for "so much effort" to be required for healthy eating. Health was predominantly driven and measured by weight management goals with many participants discussing that they prefer to eat less of the "unhealthy" foods than to try and eat a more balanced "healthy" diet. There was a big divide that participants perceived between "healthy" home-cooked food and "unhealthy" takeaways. Participants described how eating smaller quantities of unhealthy food was their health and weight loss strategy rather than eating more balanced meals.

#### 3.6. THEME 3: Developing Autonomy, Skills and Independence

The participants were starting to develop some autonomy with their food and meal choices, and this was described in a number of settings.

#### 3.6.1. Cooking and Preparing Independently (e.g., Breakfast and Snacks)

Participants often selected, prepared, and served their own breakfast and snack items, but had their evening meal provided and cooked by parents at home. Participants were usually responsible for preparing and organising their own breakfast. This resulted in participants sometimes skipping breakfast where there was a perceived lack of time or need on a school day, but more regularly consuming breakfast at weekends. Less commonly, participants described themselves as avid cooks and felt confident that they could cook anything they wanted, whilst others chose not to cook. In some cases, participants reported that their families prioritised their education and discouraged them from carrying out tasks in the kitchen so that they could focus on their studies. For those who had the opportunity to cook and be involved in food preparation tasks, there was a feeling of responsibility and maturity which gave confidence to the participants.

#### 3.6.2. Helping in Food Practices (e.g., Meal Planning, Shopping, and Vegetable Preparation)

Adolescents helped with meal planning, shopping, and preparation within the family unit with variable levels of input and success. Parents or family members usually cooked the evening meal which tended to be eaten together with the family. However,

some participants ate alone or ordered takeaway food individually, depending on their preferences and home circumstances. Participants also reported an autonomy over their finances, with money available to purchase food out of the home and to buy takeaway food when they chose to. The organisation of the household determined the food practices of the adolescents to a large extent. Where families were home together in the evenings, meals were prepared and eaten together with adolescents contributing to food preparation tasks. However, autonomy in food choice was demonstrated, resulting from differences in food preference, leading to the cooking or ordering of alternative foods.

#### 3.6.3. Personal Experiences of Developing Food Autonomy

Participants shared stories which reported several attempts to cook for families and friends which had ended disastrously with bouts of food poisoning, use of non-consumable ingredients, and burning of food items. As a result, these attempts knocked the participants' confidence and made them more reluctant to practice cooking skills again in an unsupervised manner.

As participants developed their food autonomy, breakfasts and snacks were the first eating occasions that they had control over, with some contribution to family meal selection, preparation, and planning.

However, skipping breakfast and disposing of uneaten lunchtime items of food that were purchased often resulted in erratic and irregular food patterns. After limiting food during the school day, participants reported eating larger meals or snacks after the school day had finished, which resulted in higher consumption of HFSS foods, especially if they were bought out of the home.

#### 3.7. THEME 4: Role of Community, Friends, and Family in Food Practices

The idea of a community and eating occasions being a very social time was a clear overarching theme amongst the participants with one participant expressing their views on eating alone as "depressing". Food was used as a way of celebrating and acknowledging special occasions, representing and expressing cultural beliefs and identifying with traditional and religious food practices.

#### 3.7.1. Celebrations and Special Occasions

Many participants shared photographs of meals that they had eaten outside the home. Eating out was popular with groups of friends and family and particularly when celebrating a special occasion such as birthdays and Eid. During Ramadan, meals were cooked and provided for the extended family but usually eaten in the home. Participants described how many of them lived close to each other and so would sometimes share food (usually desserts and sweet foods) with each other when there was an excess.

#### 3.7.2. Cultural and Traditional Foods

Adolescents described how they enjoyed and preferred spicy foods due to the types of food that were traditionally served at home. They described school food as "bland", explaining their preference for aromatic food containing spices. However, participants believed that the health profile of traditional foods that were served at home was not always ideal, and also described how foods tended to be high in carbohydrates. Participants felt that things would be different if they had more skills and autonomy. They described a preference for a range of foods that combined traditional foods with Western foods (e.g., pasta) and how they would experiment with a range of cooking methods.

#### 3.7.3. Gifting and Sharing of Food

A strong sense of community was discussed by all the participants, with food being gifted and shared regularly, which was particularly heightened around the time of Ramadan and Eid. They also described the importance of charitable aspects of Ramadan, and their religion, including giving and distributing donations and food baskets. There was a belief

that this work was important and that it aided other less fortunate families and ensured that food was provided to those who most needed help.

Participants and their immediate and extended family units would share food regularly with friends, family, and neighbours that had been cooked in the home.

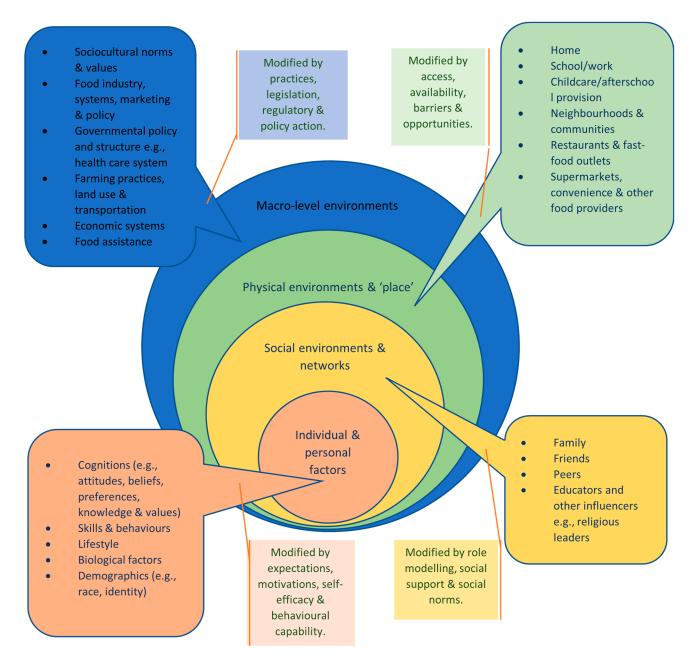
Participants disclosed other motives for eating out such as the ability to spend time with friends and family which would otherwise not happen, and they related eating out to feelings of happiness and enjoyment. The emphasis on sharing food and it being synonymous with a sense of enjoyment and spending time with friends or family was very clear; however, the discussion around payment when eating out demonstrated that adolescents still have limited autonomy with payment of group meals which remains the responsibility of other family members.

#### 4. Discussion

The aim of this study was to investigate the drivers of food choice in predominantly British–Asian, Muslim adolescents living in deprived areas of an English city [51].

The taste and appeal of food was identified as a dominant driver of food choice within the adolescent population, with many participants reporting that if they had a free choice, they would choose "unhealthy" takeaway foods every day, with one participant summarising this as "I prefer eating less, than eating healthy". Whilst taste appeared to be the dominant motivator of food choice [51], this was mitigated within a complex web of structures which limited food choice based on availability of these foods, and sometimes the prohibitive costs [52]. Therefore, food practices were driven by several factors such as availability, cost, friends, social media, parents and family, culture, external influencers, food preferences, and the autonomy they experienced in their own food decision making. This is well documented in previous work that demonstrates how health choices are related to autonomy, yet influenced by family, peers, the wider social environment, and society [30,31].

Participants in this study highlighted multifactorial influences on their food practices as described in the ecological framework proposed by Story et al. (2008) [19]. This model categorises the influences into the individual characteristics (personal), social environment (networks), physical environment (settings), and macro-level environment (see Figure 2) which are all interrelated [19]. This model has been adapted to include the additional impact of other influencers on the adolescent participants such as social media and educators and the importance of free school meal provision which can be an important influence in deprived communities [53]. The social environment such as eating occasions shared with friends and family dictated the food consumed, with home-cooked meals frequently being perceived as healthier, more traditional or "boring". Physical environments (food access, food availability, eating outlet provision in the area, and financial affordability) dictated the availability of food and was seen to be a dominant driver of food practices. The influence of physical environments was seen in school or restaurants when Halal food was unavailable and therefore selection was limited. Examples of this include at home where families' food purchases, lifestyle and home cooking practices influenced the availability of food [54]; and, unique to this study, place-based influences within the city itself due to the provision of Halal food only at select takeaways and restaurants. The macro-level influences (e.g., sociocultural norms) were apparent throughout the whole discourse, with Halal food being a primary driver and barrier of food choice for the participants. Some participants also described the influence of social media on food decision making which is more unique to this population group [55] and adds a more nuanced context to the ecological model of food choice (Figure 2).



**Figure 2.** Ecological framework for food decision making in Muslim adolescents (adapted with permission from Story et al., 2008 [19]).

Preference for particular types of food was dictated by individual characteristics, including taste and appeal of foods, and usually drove a trend towards less healthy foods. Contrary to previous work, good health did not appear to be a key priority for these adolescents, although they did understand the connection between diet and good health [56]. Some participants felt more interested than others in pursuing a healthy diet. However, as previous work has summarised, there were numerous barriers to the consumption of health-promoting foods and whilst adolescents have a good understanding of healthy eating, they struggle to implement a health-promoting diet [3].

Erratic meal patterns and skipped meals were frequently reported, often because of a lack of time or enjoyment from the food provided, or irregular sleeping habits. Skipping meals was also seen as a way of managing weight and "eating less" which allowed HFSS foods to still be consumed but without impacting on the individuals' weight [57] and was therefore perceived as a healthier food practice.

Adolescence is defined as a period where autonomy is increased; however, in relation to cookery skills and producing their own meals, the current population appeared to have variable experience and motivation, which is also evidenced in the literature [58,59]. The data collated regarding autonomy of the individuals supported the view that adolescence is a transitional phase of acquiring and developing new food skills, knowledge, and practices [16]. Whilst some adolescents were reportedly very advanced in these areas, others are setting out in their acquisition of this skillset and were happy to rely on the safety net of family practices and provision. These influences on the family food environment are evident in previous research in a mixed population in Western New York [8]. A lack of autonomy in meal preparation has been noted within previous findings, with children stating that they will eat any food which is made for them, highlighting that parents have a strong direct influence on their child's food choices whilst they are still living at home [60]. Within this particular population group, parents and adult family members were primarily responsible for the evening meal and therefore the adolescents had less autonomy at this meal occasion.

In general, participants reported that they were free to choose and prepare all meals and snacks other than the evening meal, which was often provided at home, usually after consultation with the whole family. However, the level of autonomy was variable with most participants being allowed to prepare their own breakfast, make their own snacks, and take part in meal planning, shopping, and preparation such as chopping vegetables or setting the table. Some participants were discouraged from cooking by parents or were "not trusted" to cook the family meals but carried out other food-based activities such as baking. Attempts to be more autonomous in the kitchen sometimes led to poorly prepared food and food safety issues which reinforced the rhetoric that they were not to be trusted. Women have found that allowing their children to cook occasionally can lead to potential conflict as they may not be so familiar on the whole family's food preferences, and they tend to argue over getting the kitchen back into its clean, original state [61,62]. Within low-SES households, there may also be unspoken nuances about the cost of food which could be wasted if the meal cooked by the adolescent is unsuccessful. Where this is the case, there is likely to be a lack of resources to prepare an alternative meal, especially as a greater proportion of household expenditure is spent on food compared to high-income households [63].

Other participants demonstrated a large amount of autonomy and skill, cooking frequently at home, and felt confident in their abilities to provide a meal of their choice. The types of food prepared were often representative of both traditional, cultural foods and Western food items, perhaps expressing their dual identity through food with many adolescents only cooking for themselves rather than large family meals [32].

Despite this research being carried out with adolescents from the most deprived postcodes in the UK, financial pressures did not appear to be overtly significant in the focus groups and food insecurity and poverty were not disclosed to be factors in the adolescents' food decision-making processes. However, with financial constraints being ever-present in the background for low-SES groups, their food practices were likely to be determined within an already constrained financial environment, which perhaps participants felt did not need highlighting. Participants perceived that the majority of students attending their school were entitled to free school meals but that there was no stigma or shame associated with that and that "no-one cares". Therefore, the omission of food poverty from these discussions could indicate that it was a permanent feature within households and was therefore normalised by participants, or that there was a sense of stigma around food poverty and therefore participants did not disclose this information. Alternatively, there may have been a genuine lack of food insecurity within this population, perhaps biased by the self-selection of participants and families who consented to the study. Previous research has shown that in the UK, despite Pakistanis experiencing greater deprivation and poorer health outcomes compared to the white ethnic majority [64], Pakistani groups are at lower risk of food insecurity [65]. There are a number of proposed factors including the role

and importance of an 'informal security network' within South Asian communities [66,67]. These social networks and the associated systems of reciprocity—in particular the sharing of food which was demonstrated in the current study—amongst families in poverty within ethnic minority communities may mitigate the likelihood and impact of food insecurity [66].

Beyond social networks, established systems of welfare provision within Muslim communities may manage the severity of food insecurity. Participants discussed the gifting of food baskets and money during Ramadan to those less fortunate as a charitable activity. Zakat (compulsory almsgiving for Muslims) is an altruistic act, and it also has a fundamental economic function: to seek a fair distribution and circulation of wealth [68] and provides a practical and moral basis for welfare provision within Muslim societies [69]. In practice, Zakat tends to provide a supplementary channel of revenue raising and distribution alongside the welfare state. Money donated is used to support international charitable programmes and to fund independent Islamic educational initiatives and provide individual welfare grants to British Muslim families [69].

Despite this, more than 50% of the study population was living in the top 20% most deprived areas of the UK. It was apparent that adolescents had a concept and judgement of value-for-money when making food decisions, which particularly limited takeaway meals.

During the feedback session, participants advocated for changes to their school food provision, including more variety and flavoursome meals, cold food options (to reduce queuing time), better seasoned international foods, and meat-containing Halal meals. Although contentious, as many adolescents felt that they would not look at the information, some participants would like to see readily available nutritional information which indicated the calories and protein content of school food options. This is reflective of findings from previous research in the external school environment which found that while some adolescents were satisfied with their current food options, others wanted more variety and more healthy options at affordable prices [70]. A number of interventions have examined changes in food-purchasing behaviours [71] or health-related outcomes [72], in studies that manipulate price and/or item availability or suggest alternatives in shops/grocery stores. However, these studies have predominantly been among adults or families [73] but the impact of such interventions of adolescent food-purchasing behaviour is still under-researched.

The findings of this study are consistent with prior research using socioeconomically diverse adolescents which also found that this population group has a grasp of basic nutrition knowledge, thus suggesting that healthy eating dietary guidelines are taught and learnt about consistently regardless of SES [74,75]. International adolescent food surveys of those aged 11–15 years reported that only 48% eat fruit and vegetables daily with consumption declining as age increases [11]. Importantly, intake was lower in adolescents from more deprived backgrounds in most developed countries, highlighting the presence of food-related social inequalities [11]. However, the application and understanding of this basic knowledge is shown to vary across social class. Research carried out by Fielding-Singh (2019) discovered that high-SES adolescents believed that they have a greater opportunity to be healthy compared to those of lower-SES as they felt healthier food was too expensive for others to afford [75]. This could explain why participants in the current study had a perceived acceptance that they were comfortable with being unhealthy.

By addressing the identified barriers to healthy eating within this low SES, Muslim adolescent population, a whole systems approach to addressing nutritional inequalities can be realised which has the potential to prevent malnutrition, obesity and associated non-communicable diseases. Participants were able to identify and clearly articulate issues which were most pertinent to them and had a good understanding of their barriers to healthy eating, and suggestions for overcoming these barriers, particularly within the school food environment. What was evident is that poor food provision in school influences food practices over the rest of the day with HFSS snacks used to compensate for skipping school meals, leading to poorer quality nutritional intake, and erratic meal patterns. Policies, school food programmes, and interventions therefore need to be tailored to address all levels of the socioecological model including the socioeconomic and cultural context, and

place of residence of their target population. By including the voices of these underserved populations in the development of policy, practice, and interventions, there is a better chance of addressing these challenges in an effective and sustainable manner.

#### 4.1. Strengths

To the author's knowledge, this is the first study to address experiences of low-SES, predominantly British–Asian, Muslim adolescents in England and their experiences of food practices and autonomy. It presents evidence on the barriers to and facilitators of healthy food practices in this group, and highlights the issues associated with healthy choices experienced by these individuals, raising concerns for their longer-term health.

A strength of this study is that PhotoVoice was used which allowed adolescents the opportunity to discuss their photographs and provide rich data which may not have been elicited from focus groups alone. It is an inclusive and collaborative methodology which allowed all participants to respond to the set task with a sense of empowerment. However, one of the critiques of PhotoVoice is that if the context of the photograph is not fully explored and understood by researchers, there is a risk that marginalised communities have stereotypes reinforced, thus undermining the research process [76]. It was therefore important that researchers were able to "sense check" the data collated and ensure that the views of the participants were accurately represented prior to publication. The study is reported in line with the Standards for Reporting Qualitative Research guidance [77].

#### 4.2. Limitations

A main limitation of this study is the small sample size of participants from a very segmented population of 14–15-year-old predominantly female, Muslim, British–Asians from deprived urban areas who all attended the same school. Therefore, the findings are limited to this population group. Despite this, the findings are largely consistent with previous research in other ethnic groups and add additional context and nuance to the current body of literature from this under-researched population.

Due to the timing of the study, many participants discussed important cultural events such as Ramadan and Eid which were significant influences on their food choice and may bias the data collected. However, research is currently inconclusive as to whether Ramadan has a significant impact on adolescent food choice behaviour and nutritional intake [78–81], although further consideration is warranted.

In addition, whilst basic quantitative demographic data were collected, further data such as work status of parents, household composition, annual income, and free school meal eligibility may also have added additional context. However, it would be important to collect these data in a sensitive manner which adolescents could answer accurately, and without feeling stigmatised.

As with all qualitative data, there is the potential for respondent bias with those participants who take part in the research being more interested in the subject matter and presenting data which they feel the researcher is wanting, rather than describing their lived realities.

#### 4.3. Future Research

Further research is required within this population group in older ages groups (i.e., 15–18-year-olds) to monitor and understand the evolution of autonomy throughout the period of adolescence and the impact on their food practices as they transition into adulthood.

Further one-to-one interviews with the adolescents to discuss food budgeting and insecurity would be valuable to establish the role of the social networks in mitigating food poverty in British Asian communities, and to gain insights from Muslim adolescents in non-deprived areas to see whether food practices are consistent across the socioeconomic spectrum.

It may also be useful to collect additional field data such as food diaries alongside the PhotoVoice methodology to understand the nutritional quality and energy intake of these individuals for predicting appropriate, tailored health messaging.

#### 5. Conclusions

The adolescents in this study were developing autonomy in relation to their food practices, whilst navigating a complex web of factors which were in part determined by their social class location. The study demonstrates that low-SES, Muslim adolescents understood the constituents of healthy eating, but found it difficult in practice due to the perceived effort of being healthy and length of time spent preparing and cooking healthier food, rather than presenting an overt conversation regarding it being a monetary challenge. Parents and schools still highly influence food choices with adolescents preferring a broad palate of takeaway, HFSS, and convenience foods. When considering how to be healthier, adolescents reported that they would choose to eat less rather than focussing on the quality of their diet in response to their overriding desire for taste. Using a focussed ethnographical approach to data collection was highly effective in this population group and further studies to develop policy and practice are required.

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**Informed Consent Statement:** Informed consent was obtained from all subjects involved in the study. Written informed consent has been obtained from the participants to publish this paper.

**Data Availability Statement:** Data is available by request at the Sheffield Hallam University Research Data Archives at the following link: http://doi.org/10.17032/shu-0000000177 (accessed on 19 October 2023).

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## 2.6 Paper 6: Empowering and including 'seldom heard' communities in systems thinking for weight management.

This opinion piece draws on the recent acceptance of systems thinking for weight management and strongly advocates for the voices of those with lived experience to contribute to the development and design of weight management services and systems to prevent diseases associated with nutritional inequality. It summarises the core argument of this thesis – that current management of diseases of nutritional inequality, including obesity, is inadequate in its transactional, individual-blaming approach and lack of systems thinking. Coproduction and community participation, particularly from groups who are underserved, is the key to unlocking the vast, rich knowledge held within communities which can help to identify problems which perpetuate health inequalities and contribute to the design and delivery of effective solutions. It contributes to the expert body of knowledge, which is being created, to challenge current practice, disrupt the ineffective system and ultimately change policy within the weight management and broader nutritional inequalities fields.

# Empowering and including 'seldom heard' communities in systems thinking for weight management

This article initiates an important conversation about how underrepresentation of stakeholders risks perpetuating health inequalities by designing seldom-heard communities out of the system.

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Obesity research, service provision and policy have attempted to stem the tide of obesity to alleviate financial, social and healthcare pressures. While much of this work has been well-intentioned, well-designed and well-managed, outcomes for weight loss are poor, and weight regain is common.<sup>1</sup> The prevalence of obesity is associated with deprivation, gender, ethnicity, household income and geographic location,<sup>2</sup> confirming that obesity is a disease of inequality.

Weight management is recognised to be complex as highlighted by the Foresight obesity systems map which challenged the simple 'energy in vs. energy out' rhetoric.3 In recognition of the complexity of factors at play, attention has turned to a whole systems approach (WSA) to address such complex issues.4

A system is defined as 'a set of interconnected parts that have to function together to be effective'.5 There is no single agreed definition of a health system, and as such, healthcare and public health are often described in academic literature as separate systems.<sup>6</sup> The health system is therefore separate from, but influenced by, larger

systems including political and social systems.6 Within a traditional biomedical-focused health system, 'health' may be attributed to individual factors including access to and participation in public health and healthcare services. However, the wider determinants of health recognise the significant influence of sociocultural, economic, environmental and political factors on health.7

The Institute of Health Equity report (2018) proposed a broad health system approach to improve and tackle health inequalities and advocated for a placebased health system which focuses on prevention and treatment of ill-health, understands local population health risks, collaborates across sectors, acts on social determinants of health and develops 'proportionate universalist' approaches.8 Despite this, weight management policy and provision has not adequately addressed the multifaceted causes of obesity and continues to focus on individual behaviour change approaches putting the onus for weight loss on individuals, with success or failure dependent on their personal agency.9

Population health approaches drive public health outcomes and are key to systems thinking. Population health extends beyond the health system and is based on an ecological model of health, considering how individual, social and environmental determinants influence health and recognising 10 that people are active participants in their own health



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outcomes. It is, therefore, important to recognise that individual health and health outcomes are underpinned by both public health and healthcare activities and also by how individuals are enabled to interact with these systems and their broader social environments.6

The 2010 Marmot review highlighted the structural inequalities driven by the social determinants of health and argued for change to prevent ill-health and social injustice caused by inequality and to protect the health and wellbeing of future generations. It described how inequalities across communities are driven by inequalities in health and clearly articulated the need for community empowerment to reduce health inequalities.11

Many of the factors which prevent engagement with and adherence to current weight management services demonstrate that such interventions<sup>12</sup> are inappropriate for individuals from underserved and more deprived groups, and as a result, lack of engagement with these populations continues to drive health inequality. It highlights the need for a significant overhaul of current weight management provision, embracing a more systemsled approach and for the voices of

Empowering and including 'seldom heard' communities in systems thinking for weight management

where participants

identified the needs

solutions at a local

level.<sup>17</sup> The review

also highlighted that

and actively

participated in

whole systems

thinking is in its

consistently

evaluation of

infancy and is not

embedded into the

interventions. This is

exemplified with few

published studies

implementation or

underserved and seldom heard communities to be involved in the design and development of weight management provision. Participatory methodologies such as co-design and co-production are crucial to systems approaches and understanding the needs and demands of these underserved

groups in a considerate rather than tokenistic way. 13

The inclusion of stakeholder networks is vital. <sup>14</sup> In the case of obesity, stakeholders should be representative of healthcare, actors within the wider system, and should also include users or potential users and beneficiaries of the system such as those living with or at risk of obesity. <sup>15</sup> Each stakeholder may have

a different viewpoint which allows a broader perspective and new insights into how the system works, what the problems are and why, what can be improved or changed, and the impact of changes on other components in the system. <sup>16</sup> It is important that stakeholders are representative of the

community and populations targeted by weight management systems. A recent systematic review concluded that the most successful WSA weight management and public health projects included effective community involvement

the need for a significant overhaul of current weight management provision, embracing a more systems-led approach and for the voices of underserved and seldom heard communities to be involved in the design and development of weight management provision

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successfully targeting 'at risk' population groups, such as low socioeconomic status, those with low educational attainment levels, and Black and minority ethnic groups. <sup>17</sup> Not only does this restrict the usefulness of the findings but it also demonstrates how systems thinking in weight management has not always been inclusive and has engaged minimally with some communities,

rendering them 'seldom heard'. 15,17

The term 'seldom heard' refers to under-represented communities, groups, populations or people who use or will potentially use services but who are less likely to be heard by professionals and decision-makers.<sup>15</sup> However, the

importance of including seldom heard groups in health and social care research is crucial on scientific, policy and ethical grounds. <sup>18</sup> The under-representation of these groups in health research impacts the validity and generalisability of data, <sup>19</sup>

the development of services and interventions that meet their needs,<sup>20</sup> allocation and access to resources<sup>21</sup> and can perpetuate health inequalities, especially as some of these groups have more health needs.<sup>22</sup>

WSA success metrics have been proposed by the Public Health England (PHE) logic model which describes outcomes including a reduction in obesity levels and health inequalities, effective use of community and other assets and an overall improvement in population health and wellbeing. While the move towards, and expansion of systems thinking is encouraged, this model lacks patient-led outcomes and an understanding of 'what matters most' to populations involved in, and targeted by, weight management systems.

It is, therefore, of paramount importance that future obesity approaches adopt a strong WSA that is inclusive of the voices of underserved communities and that actively recruits and engages people from seldom heard groups in the identification of systemic issues, challenges and barriers, service design, delivery and development, and the implementation of actions for systems change and evaluation. Co-production and co-development methodologies need to be embedded within WSA from the start, and effort needs to be made to ensure that the participants are truly representative of the target populations. Without capturing the voices of these communities, WSA to weight management (including weight management provision) may inadvertently ignore the needs of those at high risk of obesity and perpetuate further health inequalities.

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#### **CURRENT TOPICS & OPINIONS**

### Empowering and including 'seldom heard' communities in systems thinking for weight management

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### 3. Discussion, Key Findings and Recommendations

Each of the studies presented in this thesis provided a unique and original contribution of evidence to the field of nutritional inequalities and weight management at the time of publication. Each paper contains its own discussion and sets the project within the context of the literature available at the time. The body of work presented identifies the challenges associated with the complexity of weight management at a population level and the failures of the current approaches to address nutritional inequalities. This thesis contributes to 3 key areas which are discussed in detail below, highlighting the key findings from the thesis and providing a synthesis of the studies within the wider place-based and health and wellbeing systems context. It has been clearly identified that current public health practice contributes to health inequality thereby perpetuating weight gain and diseases of nutritional inequality. Place-based coproduction approaches provide an understanding of what matters most to people which can help to determine systems change. System improvements are then driven by accountability to the people being 'served' by the system, providing fairer and more 'just' outcomes (Lankelly Chase, 2024).

The six publications presented here collectively provide an account of aspects of the weight management services which are experienced by different seldom heard and sometimes underserved populations. This research makes three unique contributions to knowledge, advancing existing understanding in the following areas.

1. Nutritional inequalities, including obesity, can be managed more effectively by recognising the lived experience of, and empowering, seldom heard communities and individuals to contribute to solutions that reflect their sociocultural norms (Papers 3, 4 & 5).

Seldom heard populations host a wide-ranging knowledge pertaining to their lived experiences which, when empowered to share this knowledge through appropriate Patient and Public Involvement (PPI) activity, enables researchers and professionals to identify 'what matters most' to them, understand what is or is not effective about the current processes and practice and how to overcome barriers and improve service provision which better reflects service user opinions. However, PPI practice in healthcare has been heavily critiqued due to being 'tokenistic', with poor representation and failure to address barriers to engagement for underserved populations (Denegri et al., 2015). In turn, this allows the 'usual suspects' (white, retired professionals) to contribute the most (Reynolds, Ogden, & Beresford, 2021; Denegri et al., 2015) and omits the views of those most underserved (Dawson, Campbell, Giles, Morris, & Cheraghi-Sohi, 2018; Shimmin, Wittmeier, Lavoie, Wicklund, & Sibley, 2017). Lankelly Chase summarise the key systems behaviours which drive system improvements as power, perspectives and participation. By embedding these core behaviours, systems can function

better for people facing severe and multiple disadvantage (Lankelly Chase, 2018). This research is based upon these principles and is important as it enables practice and policy makers to conceptualise the issues associated with poorer health outcomes and can inform judgement of how system improvement can lead to better health outcomes for seldom heard groups. Papers 3 and 4 explore the knowledge held within two underserved population groupspregnant women with high BMIs and those living with diabetes from an ethnically diverse, deprived community. These papers describe the capacity of underserved populations to identify their wants and needs within interventions design but highlights the pitfalls of services designed without the inclusion of service user voices (Stockton & Nield, 2020; Nield, Bhanbhro, Steers, Young, & Fowler Davis, 2023). Paper 5 demonstrates the potential impact of empowering Muslim adolescents by identifying systems which perpetuate sociocultural inequalities and advocating for changes to school food (Nield, 2023). It is therefore important to recognise the value of this work and to embed true coproduction into the system and service design, development and evaluation processes to ensure that solutions are effective, address the needs of the target groups and provide meaningful, sustainable changes which can be embedded into the health and wellbeing system. Ultimately, this work needs to take a proportionate universalist approach as advocated by Marmot (Marmot, 2010) to ensure greater understanding of seldom heard populations leads to better health outcomes and reduced inequality.

#### Key Findings:

- Less affluent households, populations and communities eat less expensive foods and poorer quality HFSS foods which can lead to diseases of inequality. The current system provides an unintended barrier for underserved populations to weight management provision which further exacerbates existing inequality.
- Current hyperlocal food systems at place e.g., a school or local community can
  exacerbate nutritional inequalities through the provision of poor quality, nutritionally
  and culturally inadequate food.
- Embedding the voices of underserved and seldom heard communities in weight management research can help to drive systems change with the individuals at the heart of the solutions.
- Populations know what they need and can identify failings of the current system.
   Commissioners and systems stakeholders should work with local communities and population groups to design, develop, implement, and evaluate approaches to weight management/obesity systems.

# 2. Methodological contributions for working with and coproducing research in novel ways which benefit seldom heard populations and reduce health inequalities (Papers 4, 5 & 6)

Identification and empowerment of underserved populations who can contribute to the public health agenda is crucial to the success of health and wellbeing interventions. Policymakers and key stakeholders need to invest time and resource to build trust in local communities and underserved population groups to establish effective working relationships which drive change and reduce health inequalities. The participatory methods described in this thesis highlight the importance of selecting and operationalising ways that facilitate and include the views of underserved populations. Coproduction research amplifies the voices of those with lived experience for improved community empowerment and more just outcomes. Coproduction of services using principles of inclusion, equity, and empowerment of underserved populations is an effective, transformative way of advancing academic enquiry into issues at place. Paper 5 presents research in the adolescent food environment which highlights the need for placebased, system-wide interventions in schools, communities and other localities to provide better nutrition and prevent excess weight gain from an earlier age (Nield, 2024) whilst Paper 6 (Nield, 2023) consolidates the learning from systems-based approaches and the value of coproduction in identifying and addressing health inequalities for seldom heard populations. It solidifies my expertise in this area and highlights the valued contribution of this work in consolidating novel perspectives by advancing understanding of how coproduction methodologies can improve public health outcomes.

Methods used in this type of research need to consider the inclusivity agenda and ensure that barriers to participation in research have been identified and removed. PhotoVoice (used in Paper 5) is a great example of how the appropriate choice of methodology makes a real difference to the quality and quantity of data collection. Adolescents from deprived communities have typically been considered 'hard-to-reach'. However, using a photo elicitation methodology which empowered the adolescents and embraced their use of technology, and coproduction methods which advocated for them as valuable knowledge holders enabled the adolescents to build a rapport with the researchers and provide in-depth information which allowed a detailed understanding of their food choice environment and the socioecological context of their health decision making.

Truly inclusive community participation requires innovative and novel research method development to overcome the known barriers to engagement with traditional research recruitment and engagement strategies. The role of the VCSE sector within systems work for health, wellbeing and inequality is of paramount importance as VCSE organisations hold a huge amount of nuanced, valuable community knowledge, and as such are trusted

stakeholders for the communities they support (Paper 4). Working with local VCSE service providers is a particularly useful way of working at place to build on the trusted relationships and rapports that are established within seldom heard, deprived communities.

#### Key Findings:

- Each population, community or segmented group requires a tailored provision to overcome existing systemic barriers and to increase their chances of improved wellbeing and reduction of health inequalities, which aligns to the proportionate universalist approaches suggested by the Marmot report.
- Multimethod research expertise is required to engage with seldom heard communities and elicit novel approaches to inclusive participatory research.
- Qualitative research methodologies including coproduction, offer an appropriate, robust methodology for working with underserved populations to understand their lived experiences, recognise barriers to engagement or lifestyle change and identify systems changes which help to address and overcome some barriers which drive inequalities.

# 3. To further evidence the importance of systems-thinking in addressing policy and practice challenges for obesity management to reduce health and nutritional inequalities (Papers 1, 2 & 6)

The thesis challenges the individualised current behaviour change approaches to management of such conditions and suggests a more systemic approach that addresses the social determinants of health as opposed to the current focus on individual agency. Current approaches rely on individual agency of people who often carry the most health burden and have the least agency and resource to self-manage their weight or health outcomes (Holt-White, 2019; Adams, Mytton, White, & Monsivais, 2016). Paper 1 evaluates a transactional tier 3 weight management service and is one of the first service evaluations which showcases the successes and failures of a holistic multidisciplinary approach to weight management (Nield & Kelly, 2016). The paper highlighted the usefulness of a tailored weight management provision in the most deprived areas where levels of obesity were highest, in-keeping with the proportional universalist approach and demonstrated also by Paper 2 which showed that community pharmacies may be a way of growing capacity for weight management and other public health interventions (Brown et al., 2016). They support the idea of 'place' as being meaningful to health and affirm that the quality of environments in which people live and work are important for determining health inequalities. Paper 6 advocates for the importance of systems-thinking in underpinning policy and practice for more just health outcomes (Nield, 2023).

#### Key Findings:

- Weight management approaches which rely heavily on the agency of individuals are unsuccessful and drive inequalities. Obesity and weight management policy should be driven by WSAs which help to change the environment for populations and individuals and help to reduce inequalities.
- Current individual behaviour change-based weight management provision is unsuccessful as it fails to address the complexity of the weight management system and the multiple factors which drive nutritional inequalities, including obesity.
- Obesity and weight management interventions should be set within a broader scope
  of nutritional inequalities. Addressing diseases of nutrition related ill-health through a
  wider system focus could be effective in reducing inequalities and providing a healthier
  food environment for all.

Together, these publications provide an original contribution for the management of nutritional inequalities, including obesity. Paper 6 synthesises the 3 key points discussing the importance of identifying and working with underserved populations, choosing appropriate, coproduction methodologies to engage seldom heard voices and facilitate stakeholder involvement and input, and focussing on place-based challenges from a systems perspective to ensure inclusive, sustainable and effective solution design to challenges of nutritional inequality.

The publications provide unique insights into a diverse array of underserved groups, highlighting the complexity of nutritional inequality and weight management, but providing hope that working in a coproductive way with communities and populations, and augmenting the voices of those with a lived experience, can effectively turn the tide on the obesity epidemic, and reduce the wider nutrition-associated health inequalities.

### 3.1 Recommendations for policy and practice

The PHE WSA to obesity guide (2019) provided an initial consensus statement and described the benefits of systems thinking. It aimed to support local authorities and commissioners of weight management services to improve the health and wellbeing of individuals using a 'Health in All Policies' approach (Public Health England, 2019b). This guide presented a new way of thinking about weight management which embraced systems science and recognised that knowledge and practice will continue to develop and evolve over time. However, the explicit recognition of the value of participation from underserved communities is omitted from this document and the resulting logic model underrepresents the value of these seldom heard voices in coproduction activities to achieve proportionate universalism from the solutions. A subsequent briefing from PHE (2020) does describe the need for community-centred approaches to be at the heart of the WSA and recognises that actively involving citizens within

this work will help to improve the health outcomes of the poorest, fastest (Public Health England, 2020).

Therefore, future policy needs to emphasise the importance of public involvement and engagement and community participation, particularly ensuring representation of the target population and augmenting the value of the lived experience voice in service and system design and development. This will require significant changes to practice and comes with its own challenges such as recruitment and engagement of appropriately diverse community members and stakeholders which may slow down the process and present inclusivity hurdles to overcome. It may increase the costs of the initial planning and development of projects and initiatives in an environment which is already cash-poor, and it will require other systems actors such as the VCSE sector organisations to be recognised, valued and supported to provide sustainable, meaningful changes within the communities and local authorities. However, some of this joined up, transdisciplinary working may come to fruition through the newly established Integrated Care System (ICS) model (Department of Health and Social Care, 2022). It is envisaged that by employing whole systems thinking, community participation and coproduction that resultant outcomes will be much more powerful, inventive, engaging and effective at reducing health inequalities and driving better outcomes for all.

Additionally, obesity and weight management interventions should be set within a broader policy context of nutritional inequality. Obesity, its associated comorbidities (e.g., type two diabetes mellitus, some cancers and cardiovascular disease), and other malnutrition-related disease such as stunting are all the end product of, and perpetuated by, nutritional and lifestyle inequalities which are persistent within the broader food and health system. Whilst the system remains broken, disease of inequality will persist and worsen leading to greater health, financial and social burdens for society and the individuals involved.

#### 3.2 Future research

As I develop and consider post-doctoral research, I am committed to highlighting the structural inequalities which are persistent in the current healthcare and public health systems. I recognise that obesity (and its associated comorbidities) is just one example of a plethora of nutritional inequalities that we face in the UK today. A recent report highlighted the impact of austerity measures in the UK on stunting of growth in children, compared to European and international peers (NCD RiSC, 2023; The Guardian, 2023). Height of children is a key metric used to understand nutritional status, with stunting indicative of poor-quality nutrition and/or inadequate energy intakes (Perumal, Bassani, & Roth, 2018). The association of poor growth and stunting in children as a consequence of austerity measures is yet more evidence of policy failure driving health inequality. There is much more work to be done to recognise, manage

and prevent inequality-related ill health. The learning from this thesis will help to develop a body of work with a systems-focus on health inequalities and the impact of nutritional inequalities on health and wellbeing of underserved communities and segmented populations.

Key areas which need addressing in future research are:

- The development of effective novel recruitment, engagement and research methodologies to ensure true community participation and complete representation of diversity in coproduction activities.
- Further population segmentation to understand the differences between and within communities to identify what matters most to people and identify the nuanced distinctions and how this learning can be embedded in research, policy and practice.
- The development of effective tools and resources to evaluate and measure the success of coproduction activities and provide evidence of efficacy which is recognised and valued by actors within the system.
- A deeper insight into structural inequalities which drive health inequalities to identify
  and remove the barriers to health and wellbeing provision for individuals and groups
  and provides focus to a wider nutritional inequalities arena.

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