



Type 2 diabetes prevention policy and practice:
A multimethod qualitative study exploring the perspectives of
patients, clinicians, and policy makers.

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Statement of contributions

The doctoral thesis is independent and original work of which I am the sole author. My supervisors Professor Greenhalgh, Professor Shaw and Associate Professor Papoutsis contributed by providing intellectual guidance on the research strategy, analysis and presentation of results.

Other individuals have made contributions in the following ways.

1. Dr Samantha Roberts acted as the second reviewer of the papers extracted for the quantitative systematic review discussed in chapter 2.
2. Dr Rebecca Normansell undertook an independent GRADE assessment of the papers used in the quantitative review systematic review discussed in chapter 2.
3. Dr Jason Oke completed the bi-variate meta-analysis of the data extracted from the 'test' papers to complete the diagnostic accuracy meta-analysis for the systematic review discussed in paper 2.
4. Dr Nicholas Fahy was the second reviewer of the psychological studies included in systematic review 2, as requested by the journal as part of the publication peer review process.
5. Dr Jonathan Bowley helped to facilitate two of the focus groups whilst working as a summer intern with the IRIHS team in 2018.
6. Ms Helen Elwell is a BMA librarian who assisted with the search literature strategies for the quantitative and qualitative systematic reviews.

Some parts of this thesis have been published in peer reviewed journals. Details of these publications are outlined below.

1. Barry E, Roberts S, Oke J, Vijayaraghavan S, Normansell R, Greenhalgh T et al. Efficacy and effectiveness of screen and treat policies in prevention of type 2 diabetes:

systematic review and meta-analysis of screening tests and interventions.
BMJ. 2017; 356 :i6538 doi:10.1136/bmj.i6538

2. Barry E, Greenhalgh T. How do UK general practice staff understand and manage prediabetes? A focus group study. *BJGP Open*. 2022 doi: 10.3399/BJGPO.2021.0166c
3. Barry E, Greenhalgh T, Shaw S, Papoutsi C. Explaining the UK's 'high-risk' approach to type 2 diabetes prevention: findings from a qualitative interview study with policy-makers in England. *BMJ Open*. 2023 Feb 7;13(2):e066301. doi: 10.1136/bmjopen-2022-066301. ¹

Abstract

Introduction

There are broadly two approaches to type 2 diabetes prevention. 'Population' approaches which target *structural influences*, and 'high-risk' approaches which focus on identifying *individuals* at risk of type 2 diabetes and encouraging lifestyle change. There is a paucity of evidence on how people respond to pre-diabetes and evaluations of high-risk approaches have shown limited effects in women, deprived and diverse groups. Despite this, there is relatively little focus on the structural drivers of ill health.

Aims

To understand the impact of pre-diabetes policies from different stakeholder perspectives.

Objectives

1. Explore the perspective of primary care teams; how they deliver the pre-diabetes diagnosis and manage the condition.
2. Explore what pre-diabetes means to people and how this influences their lifestyle choices.
3. Explore policymakers' perspectives and understand why individualist health promotion policies dominate the policy agenda.

Methods

1. Three focus groups with primary care practice teams.
2. In depth case studies with people diagnosed with pre-diabetes.
3. Semi-structured interviews with commissioners and policymakers.

A thematic analysis was undertaken applying critical social science perspectives; Bourdieu's Theory of Practice and Shiffman and Smith's framework for determining political priorities to the data.

Findings

Pre-diabetes was largely framed as a biomedical diagnosis by all participant groups. GP practices and policymakers were tasked with individual-level monitoring with little power to address population-level influences due to the distribution of funding and power.

Participants with pre-diabetes whose social-cultural backgrounds did not align with health promotion messages reported difficulties changing lifestyles. Disrupting social norms posed risks to social positioning, cultural belonging and relationship building. This risk was greater than a future type 2 diabetes risk. Structural influences determined whether participants could eat well and exercise.

Conclusion

Type 2 diabetes prevention strategies reflect our strongly neoliberal political context, placing the responsibility on individuals to reduce their type 2 diabetes risk with limited emphasis on addressing structural influences on health. Individuals who sustain lifestyle change, are those whose 'habitus' aligns with these interventions, have the capital to enact change, and live in communities which facilitate health promoting practices.

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List of Abbreviations

ADA	American Diabetes Association
AUC	Area Under the Operating Curve
BMJ	British Medical Journal
CCG	Clinical Commissioning Group
CMO	Chief Medical Officer
CVD	Cardiovascular Disease
DM	Diabetes Mellitus
DPH	Director of Public Health
FG1	Focus Group 1, 2, 3 etc
FPG	Fasting Plasma Glucose
GDM	Gestational Diabetes Mellitus
GP	General Practice
GPRD	General Practice Research Database
HRA	Health Research Authority
HTN	Hypertension
ICB	Integrated Care Board
IEC	International Executive Committee
IFG	Impaired Fasting Glucose
IHD	Ischaemic Heart Disease
IRIHS	Interdisciplinary Research in Health Sciences
MOU	Memorandum of Understanding
NHS DPP	NHS Diabetes Prevention Programme
NICE	National Institute of Health and Care Excellence
NIHR	National Institute of Health and Care Research
OGTT	Oral Glucose Tolerance Test
PHE	Public Health England
QOF	Quality Outcome Framework
RCGP	Royal College of General Practitioners
REC	Research Ethics Committee
SH4	Stakeholder 4, 5, 6, etc.
ST4	Specialist Trainee, Year 4
UCL	University College London
WHO	World Health Organisation

Chapter 1 – Background

1.1 Motivations for undertaking this DPhil.

I first developed an interest in academic public health and primary care while undertaking a public health placement during my GP vocational training. During my six-month placement I split my time between a local public health team working on health improvement projects commissioned by the CCG and the Primary Care and Public Health Department at Imperial College, working on a data analysis project. As part of the health improvement projects, we used primary care-based research to inform policies in identifying undiagnosed people with pre-diabetes.^{2,3} I was particularly interested in type 2 diabetes prevention because of the large health inequalities related to type 2 diabetes development. And so, when looking for an academic project for my ST4 year I contacted Professor Greenhalgh. By chance Professor Greenhalgh was looking for a trainee to join an academic-policy partnership funded by UCL Partners, to undertake several systematic reviews aimed at informing type 2 diabetes prevention strategies in Newham. The team met regularly to discuss the progress of the research and policy development. At these meetings I would present our advancements with the systematic reviews and gauge the groups perspectives on our findings. The group included clinicians, commissioners, public health leads, academics and patients. Feedback from these stakeholders alongside my findings from the systematic reviews led to the writing of a BMJ editorial entitled ‘Time to question the NHS diabetes prevention programme’ (see Appendix 1).⁴ The editorial ignited an active debate via rapid responses, with some academics describing our interpretation of the evidence as “unbalanced and poorly informed” or that we had “misinterpreted the evidence”. These systematic reviews, which have now been published, are summarised in chapter 2 of the thesis.^{5,6}

I struggled for some time with the rapid responses from the editorial, firstly from a confidence perspective: as an academic GP trainee, receiving such comments made me question my academic ability. Secondly, I found it baffling that some academics were so vehemently opposed to how we had interpreted the evidence. As a frontline clinician working in an inner-city general practice, I saw first-hand the limitations of blood glucose testing and the difficulties patients reported in changing their lifestyles. The systematic review on which the editorial was based won one of the most acclaimed prizes in academic primary care (RCGP paper of the year), further adding to the confusion as to why some academics understood our interpretation, yet others very much did not. The critical appraisal of the policy outlined in the editorial is in some ways more relevant today than it was 10 years ago, particularly against a backdrop of a cost-of-living crisis and rising type 2 diabetes prevalence, especially amongst younger adults.

Following on from my academic GP training, I undertook an NIHR In-Practice Fellowship, within which I completed an MSc in Public Health at the London School of Hygiene and Tropical Medicine. In preparation for this DPhil, I completed modules related to social research, qualitative research methods as well as theoretical modules in sociology, anthropology and public health ethics.

I have sustained the relationships I developed during the UCL Partners project as a member of the Newham Diabetes Partnership Group, which meets monthly to update on local type 2 diabetes priorities. Attending these meetings has allowed me to present the findings of my DPhil whilst collecting and analysing my data; I have found the feedback of residents, clinicians and policymakers incredibly helpful in grounding my thinking in everyday policy

and practice. A year ago, I joined the Diabetes UK research steering group for the prevention and management of type 2 diabetes which has helped me keep up to date with developments and national priorities in this area.

I started my DPhil in January 2018 – it has taken longer than first anticipated to complete the DPhil because of two periods of parental leave in 2018 and 2020. Further to this I was diagnosed with an auto-immune condition and had poorly controlled symptoms for two years of the DPhil. The experience of receiving a significant diagnosis and having to make major lifestyle changes, whilst also assuming a new identity as a working mum, has given me unique insight and empathy for the participants when analysing my qualitative data. My personal circumstances combined with my role as a clinician and public health training, influenced my thinking as the DPhil developed.

This thesis is a multimethod qualitative study exploring how type 2 diabetes prevention policies are enacted in real world settings from a variety of different perspectives including clinicians, patients, and policymakers.⁷ I explore how and why individual-based disease prevention policies dominate the type 2 diabetes policy agenda and why population-based strategies to create healthy communities are politically unfavourable. In this chapter I give the contextual basis for my thesis describing why preventing type 2 diabetes is an important health priority and an overview of current individual-level diabetes prevention and population-level disease prevention policies. I explore the overarching theoretical approaches to disease prevention, competing research paradigms, and how my own personal context has influenced the construction of this DPhil.

1.2 Type 2 diabetes: the scale of the problem

Type 2 diabetes is a health priority both nationally and globally. Currently in the UK five million people are living with diabetes, 90% of whom have type 2 diabetes. A further 2.4 million people are estimated to be at risk of type 2 diabetes due to elevated blood glucose levels.⁸ 10% of the NHS budget is spent on diabetes and related conditions, and the cost is anticipated to rise from £23.7 billion currently to £39.8 billion by 2035/2036.^{8,9} Type 2 diabetes is a complex condition with several risk factors for its development including ethnicity, age, weight, socio-economic status, genetics, health literacy and deprivation. For people with type 2 diabetes life expectancy reduces by 6 years with 52% of deaths attributable to cardiovascular disease. In addition, patients are at high risk of chronic kidney disease, eye disease, amputations, neuropathy, sexual dysfunction, dementia and depression.¹⁰ For people with type 2 diabetes, their risk of dying from COVID-19 was doubled compared to those without the condition.¹⁰

Due to the significant individual and national burden of type 2 diabetes and its sequelae, type 2 diabetes prevention has been prioritised by NHS policies and NICE guidelines. NICE Public Health guideline 38 (PH38) outlines that those patients identified as being at high risk of type 2 diabetes (using a risk score calculation) should have a blood test (either a fasting plasma glucose or the HbA1c) to screen for type 2 diabetes. Other at-risk patients are either identified through NHS Health Checks or opportunistically through consultations with a member of the GP practice team. If the patient's blood test results show elevated blood glucose (either an impaired fasting plasma glucose or an elevated HbA1c) but not at the diabetic threshold then the patient should be given a diagnosis of 'non-diabetic hyperglycaemia', commonly known as 'pre-diabetes'. Once diagnosed it is recommended that patients have an annual review with a member of the GP practice team, which should consist

of a blood test, blood pressure, weight measurement and be given advice on how to minimise their risk.¹¹ From April 2021, this guideline was formalised in England as part of the NHS GP contract with practices incentivised to identify and maintain a register of those with 'non-diabetic hyperglycaemia' ('pre-diabetes') and offer referrals to lifestyle interventions. In the UK, type 2 diabetes prevention policy is constructed by the NHS with local public health teams commissioned to support policy implementation of the programme (in some areas). Some local areas incentivise an annual type 2 diabetes prevention review as recommended by the NICE guidelines. However, this is not universal, and as a result some patients will receive the diagnosis and limited support thereafter. To try and bridge this gap NHS England introduced a Diabetes Prevention Programme (DPP), to provide an opportunity for all patients with pre-diabetes to understand how they can best minimise their risk of future type 2 diabetes development.

1.3 Individual-level approaches to prevention

Evidence from randomised controlled trials has shown that those who have 'pre-diabetes' could delay or prevent the onset of type 2 diabetes by enrolling in lifestyle improvement programmes and undertaking sustained behaviour change.¹² The NHS Diabetes Prevention Programme (NHS DPP) has been developed based on systematic review evidence and was piloted in selected sites in June 2016 with further roll out in April 2017. NHS DPP is widely available across the country. The intervention consists of 13 classroom based lifestyle intervention sessions delivered over nine months.^{12 13} Real-world evaluations of the programme have shown that the intervention has helped individuals improve their weight and HbA1c, if they are able to attend the intervention, engage in the full programme and sustain behaviour change.¹⁴ However, evaluations of the programme have also highlighted several concerns:¹⁵

- There are low referral rates to the programme from primary care (particularly minority ethnic groups) and of those that are referred there are high attrition rates from initial referral to programme completion.¹⁴⁻¹⁶ This is likely due to how individuals are informed, internalise and contextualise the pre-diabetes diagnosis.¹⁷
- There are reported concerns over variations in the intervention's accessibility, quality, and fidelity.¹⁸⁻²⁴ Evaluations have also identified limited improvements in weight and glycaemic markers in women, Black and Asian ethnic groups and people from lower socio-economic backgrounds.^{15 25}

To be sure, the NHS DPP does help some individuals reduce their risk of progression to type 2 diabetes. However, lifestyle change is difficult, especially for those who face overwhelming structural barriers.^{26 27} For example, the most deprived 10% of the country would need to spend 75% of their income to meet the NHS's Eatwell guidelines.²⁶ As a result, there is a concurrent risk of widening health inequalities if current engagement patterns and outcomes continue.

1.4 Current community and population approach to type 2 diabetes prevention

The UK government's population-based approach to tackling rising obesity levels (and subsequently non-communicable diseases such as type 2 diabetes and cardiovascular disease) was updated during the COVID-19 pandemic.²⁸ The strategy currently consists of a soft drinks levy, a schools-based approach to sugar reduction, increasing physical activity, and food calorie labelling initiatives. These population-level initiatives have been criticised by diabetes organisations and public health leaders as not doing enough to reduce health inequalities and disease because they do not address the underlying drivers of ill health.^{26 27}

²⁹⁻³³ Plans to restrict supermarket promotion for foods high in fat, salt and sugar, as well TV

advertising restrictions on unhealthy foods before 9pm have been delayed. A decision described by some academics as an 'act of supreme self-harm'.^{28 32 34}

Health behaviours contribute to the development of non-communicable disease such as type 2 diabetes. However, it is the social determinants of health which lead to these behaviours and subsequent health inequalities.^{12 26 29} Population health strategies to reduce diseases such as type 2 diabetes are limited and poorly financed despite the success shown from the implementation of the sugar tax in changing purchasing behaviours and estimated effects on obesity levels.^{35 36} Calls to address commercial determinants of health gained momentum during the COVID-19 pandemic, because the infection disproportionately affected those with type 2 diabetes and obesity; however, population-based disease prevention strategies have been delayed.^{37 38}

In England public health teams within local governments are tasked with tackling the community level determinants of health. Public health teams transitioned to the local authority setting from the NHS 10 years ago. In this transition they have had to build new relationships, work to re-establish their identity within a different context and consider how to influence the policy agenda. Sustained public health budget reductions (up to 25%) have undermined public health disease prevention strategies addressing the community-level influences on health.²⁹ Local governments vary hugely on their commitment to improve population health.^{29 39 40} Public health teams need to engage politically with democratically elected councillors to maximise their influence, so in addition to making a case for disease prevention based on local and national evidence, they must make a political case for change.⁴¹ With the dissolution of Public Health England, there is an absence of national

leadership for public health teams in the areas of health improvement with limited guidance on how to address the social determinants on a community level.⁴²

1.5 Research paradigms and the prevention paradox

The overarching theme and thread running throughout my DPhil is the tension between taking a 'high risk' individual approach to disease prevention versus taking a population approach as described by Geoffrey Rose.⁴³ The 'high risk' prevention strategy consists of a medical professional identifying individuals with risk factors for the condition, to whom they then give lifestyle advice or treatment to reduce the risk of disease. This approach is said to allow for the tailoring of health promotion messages to the individual to assist lifestyle change.⁴⁴ This approach has been criticised by social scientists and public health academics as it largely excludes the wider influences on health, which have been shown to restrict an individual's choices and ability to undertake sustained behaviour change.^{26 29} In contrast, Rose's prevention paradox suggests that if you take a population approach, reducing everyone's risk of disease by a small amount (through societal level interventions such as the soft drinks levy or limiting salt content in food), this may lead to larger changes in the incidence of disease at a population level.^{36 45-47} It is widely thought by public health leaders that without addressing societal influences, it is unlikely that behaviour change will be possible for those with overwhelming structural barriers.^{26 29} How academics, policymakers and clinicians approach the problem of disease prevention depends on their ontology (how they view the world) and their epistemology (how they construct knowledge).⁴⁸

'Paradigms' are the ontological, epistemological and methodological assumptions made by those exploring a particular topic.⁴⁹ Researchers from different paradigms will research type 2 diabetes prevention very differently. A positivist researcher assumes a firm reality and a

single, potentially knowable truth which the researcher can ascertain using appropriate tools and techniques (this largely aligns with the biomedical model of research). In contrast a constructivist researcher begins from the standpoint that the social world (and the world of human behaviour) is open to multiple interpretations and that there is, therefore, more than one 'truth'.⁴⁹ Different interpretive lenses and different theorisations, produce different 'findings' even when they have addressed what appears to be the same topic or question.⁵⁰ In many disciplines (such as sociology and anthropology), qualitative research tends to be undertaken within a constructivist or interpretivist paradigm whereas quantitative research undertaken in biomedical fields may assume an objectivist or positivist paradigm.⁴⁸ The tensions between the different paradigms are seen throughout the DPhil and explored in chapter 2 which provides an overview of the literature.

Throughout this DPhil I take an interpretivist epistemological perspective, seeking to explore how behaviours and policies are socially and culturally shaped. I recognise that my findings are influenced by the context in which data is gathered and the background and assumptions of researchers and participants.^{48 51}

1.6 Structure of the thesis

Chapter 2 provides an overview of the literature, where I summarise two large systematic reviews undertaken to inform the UCL Partners type 2 diabetes prevention strategies for Newham in East London (discussed previously). At the end of this chapter, I detail my aims, objectives, and research questions for the DPhil.

Chapter 3 details my methods, methodological approaches and the theoretical principles used in the DPhil. For clarity my findings chapters have been presented by each sub-study.

Chapter 4 presents the findings of a focus group study undertaken with primary care teams exploring their understanding and perspectives on pre-diabetes. Critical social science approaches were used in the analysis of this data.

Chapter 5 presents the first part of my findings from my in-depth case study of people with pre-diabetes. This chapter focuses on how participants internalise the diagnosis and their views on the management of pre-diabetes.

Chapter 6 presents the second part of my findings of my qualitative study with people with pre-diabetes. This chapter undertakes a detailed analysis on how people make everyday lifestyle decisions and how lifestyles are socially constructed over time using Bourdieu's theory of practice.

Chapter 7 presents my findings from my interviews with policymakers exploring how they implement national directives into local initiatives and why individual-level policies dominate the disease prevention agenda. I present my findings using Shiffman and Smith's framework for understanding the determinants of political priorities for health. Further depth is added to the analysis by using Luke's three-dimensions of power as well as Weiss's models of the utilisation of research into policy.

Chapter 8 forms my discussion and conclusion chapter within which I draw together findings from the sub-studies in my DPhil. In this chapter I also identify areas for further research and policy priorities.

Chapter 2 – Review of the literature

This chapter summarises reviews of the literature I have undertaken relating to type 2 diabetes prevention. In preparation for implementing the diabetes prevention programme, Public Health England (PHE) undertook a systematic review and meta-analysis of intervention trials assessing the effectiveness of lifestyle interventions in reducing an individual's risk of type 2 diabetes. At the same time, as an academic GP trainee and in preparation for this DPhil, I was undertaking an independent systematic review and meta-analysis assessing the diagnostic accuracy of the tests used to identify those with 'pre-diabetes' and the effectiveness of interventions tested by randomised controlled trials. This review was undertaken as the academic input to a UCL Partners project in East London (as discussed in the background section) exploring the best strategies to prevent type 2 diabetes in a deprived ethnically diverse part of London. Each part of the data extraction and analysis undertaken as part of the review was presented to the group's stakeholders whose reflections guided further interrogation of the data. The summary of this review discussed in this chapter is based on the BMJ publication below and was awarded RCGP paper of the year (see Appendix 2) .

Barry E, Roberts S, Oke J, Vijayaraghavan S, Normansell R, Greenhalgh T et al. Efficacy and effectiveness of screen and treat policies in prevention of type 2 diabetes: systematic review and meta-analysis of screening tests and interventions.

BMJ 2017; 356 :i6538 doi:10.1136/bmj.i6538

I was first author on the publication and undertook the searches, data extraction, review of the data, completed the RevMan analysis of the intervention trials, the prevalence analysis

and applied the Cochrane risk of bias tool to the literature. Dr Samantha Roberts (undertaking her own DPhil on the cost-effectiveness of type 2 diabetes prevention policies) was the second reviewer of the literature, Dr Jason Oke undertook the bivariate meta-analysis on the test diagnostic accuracy data. Dr Rebecca Normansell, a Cochrane editor, did an independent analysis of the strength of the evidence using the GRADE tool and Dr Vijayaraghanan and Professor Greenhalgh were the clinical and academic leads on the project.

Following this systematic review, I completed a meta-narrative review of the qualitative literature to appraise qualitative studies relating to how people understood a diagnosis of pre-diabetes and how people with pre-diabetes navigated lifestyle change. This review was published in BMC Medicine (see citation below).

Barry, E., Greenhalgh, T. & Fahy, N. How are health-related behaviours influenced by a diagnosis of pre-diabetes? A meta-narrative review. *BMC Med* **16**, 121 (2018).

<https://doi.org/10.1186/s12916-018-1107-6>

This review formed part of my dissertation for my MSc in Public Health. As such I will not go through this review in detail but will give a summary of my findings to explain how the findings led to my DPhil research. Professor Greenhalgh supervised the MSc dissertation project and Dr Nicholas Fahy was the second reviewer on the psychological studies, requested as part of the publication peer review process.

2.1 Systematic review 1: efficacy and effectiveness of screen and treat policies in type 2 diabetes prevention.

This was a large quantitative systematic review including 99 studies and was an independent assessment of the evidence relating to each part of the patient pathway from diagnostic testing to interventions. The first half of the review consisted of a bivariate meta-analysis of international epidemiological studies. These compared the results of the oral glucose tolerance test, fasting plasma glucose and HbA1c in people who had been tested for type 2 diabetes. The Oral Glucose Tolerance Test (OGTT) has traditionally been the gold standard test for diagnosing those at high risk of type 2 diabetes, but it is very inconvenient to undertake in a real-world primary care setting. The benefits of this test are that it checks for two of the processes which lead to type 2 diabetes development, gluconeogenesis (reflected in the Fasting Plasma Glucose (FPG) result) and peripheral insulin resistance (reflected in the second blood test checking for impaired tolerance to glucose). However, this test is subject to the patient fasting appropriately and has been criticised for individual daily variation, so if abnormal, the test needs to be repeated. Despite these limitations the OGTT is still used as the gold standard to recruit individuals to type 2 diabetes prevention trials. The HbA1c blood test checks the glycation of the haemoglobin chains in the circulating red blood cells over a 6 to 8-week period. Its benefits are that no fasting is required prior to the test and it is more reflective of glucose regulation over a longer period. Because of this the HbA1c is now widely used as the test of choice by GPs. However, it was unclear to what extent the HbA1c was able to accurately identify impaired fasting glucose and impaired glucose tolerance and whether the HbA1c identified the same population of individuals as the OGTT (which identifies impaired fasting glucose and impaired glucose tolerance). This has implications in determining who is diagnosed with pre-diabetes, the personal impact this has on the

individual and subsequent eligibility for type 2 diabetes prevention programmes. In addition, this has commissioning implications in the form of service capacity and cost. If the tests identify different disease populations with varying prevalence this impacts the ability of an area to offer type 2 diabetes prevention initiatives and annual reviews within general practice.

I extracted the raw data from 49 primary international studies, and with the assistance of a senior statistician a bivariate meta-analysis was undertaken assessing how accurate the HbA1c was in identifying the abnormalities identified from the OGTT and FPG. The analysis showed that the HbA1c has a sensitivity of 0.49 (CI 0.40-0.58) when compared to the OGTT, meaning that it correctly identified half the abnormalities as per the OGTT. The area under the receiver operating curve (AUC) is a further measure of accuracy with a score of 1 indicating perfect accuracy and a score of 0 indicating complete inaccuracy. When compared to the OGTT the HbA1c had a partial AUC of 0.59. A further analysis was undertaken assessing the performance of the HbA1c compared to the fasting plasma glucose. The HbA1c had a sensitivity of 0.25 in identifying Impaired Fasting Glucose (IFG) and a partial AUC of 0.42. This translates to the HbA1c correctly identifying IFG a quarter of the time and had a low accuracy in identifying impaired fasting glucose. These results do not mean that the HbA1c is a 'bad test', the results reflect that each test identifies a different underlying disease process which leads to pre-diabetes. However, with the increasing use of the HbA1c to identify those at risk, these results suggest that it will miss people with impaired glucose tolerance or impaired fasting glucose and therefore these people will not be highlighted as 'pre-diabetic' and offered lifestyle interventions.

To try and estimate the real-world commissioning implications of these findings I extracted data from epidemiological studies which estimated the prevalence of each pre-diabetic subset within their population and assessed the differing degrees of population overlap depending on which diagnostic criteria are used. There was limited overlap in the populations identified as 'pre-diabetic' by each diagnostic test. In addition, each test identifies a different prevalence of abnormality. Using the WHO and IEC criteria, currently used in the UK, the overall prevalence of pre-diabetes was 27%. Half of those with pre-diabetes had an abnormal HbA1c alone with the other tests having very limited overlap with this group. The American Diabetes Association (ADA) has a substantially lower cut offs for HbA1c and FPG defined 'pre-diabetes' than the WHO and IEC. This led to a significant improvement in the degree of overlap between the tests. However, the overall prevalence of pre-diabetes was 54%. This has significant implications for commissioners as the choice of test and diagnostic cut offs used identify different at-risk populations as well as the size of the population who need to be offered interventions.

The second part of the systematic review assessed the effectiveness of preventing type 2 diabetes through lifestyle and metformin interventions. Lifestyle interventions varied in length, intensity, and composition. Interventions ranged from 6 months to 6 years. The most intense interventions engaged participants weekly initially and monthly thereafter, giving people exercise, diet and weight targets with regular monitoring. The lifestyle interventions composed of a mixture of 1:1 and group lifestyle sessions, dietician reviews, exercise classes, personal trainers and pedometer interventions. The metformin intervention involved giving a dose of metformin to the treatment group and placebo to control. The dose and frequency of metformin given differed between each trial. Data on type 2 diabetes incidence in control groups and intervention groups were collated and analysed using the RevMan tool. Lifestyle

interventions were associated with a 36% relative risk reduction in type 2 diabetes development. This attenuated to 20% in trials which followed participants up after a time period. Trials testing metformin as a type 2 diabetes prevention intervention showed this intervention gave a 26% relative risk reduction whilst taking this medication. However, none of the trials followed patients up after ceasing the medication to see if this risk reduction was maintained. The systematic review showed that the more intensive and longer the trial was, the greater the type 2 diabetes risk reduction. For example, the US Diabetes Prevention Programme, one of the seminal studies, lasted for approximately three years, and participants in the lifestyle intervention arm of the study had a weekly 1:1 session in the first 24 weeks, followed by monthly 1:1 and group sessions. This study had a 50% relative risk reduction for the lifestyle intervention arm from our calculations. In contrast, a UK based trial called 'Let's Prevent' consisted of a six-hour structured education session over one or two days, with a refresher session at 12 and 24 months. Of the trials reviewed this was the most like the NHS Diabetes Prevention Programme, but only showed a relative risk reduction of type 2 diabetes development of 5%.

In addition, the attrition rate seen in these intervention trials was dramatic with only 27% of participants completing the trial interventions. Also populations who engage in trials are not reflective of the wider population: they are more affluent, have higher health literacy, fewer co-morbidities and tend to be more engaged with their healthcare.⁵²

As an update to this systematic review and meta-analysis I reviewed 360 citations in Google Scholar to ascertain whether there had been any new evidence which would have changed the findings of this review (which took two years to undertake). A number of studies have continued to show the discordance between the different blood tests with limited over-laps

between the two groups.⁵³⁻⁵⁶ To better understand the different at risk groups there have also been new studies exploring new biomedical markers and genetic sub-types of type 2 diabetes with the aims of better identifying those at most risk; however, it is unclear whether these will lead to changes in clinical practice.⁵⁷⁻⁶⁰ There were a number of new interventions trials which were similar to the trials included in this systematic review and showed small improvements on glycaemic and cardio-vascular risk factors for participants who were able to partake and engage in the interventions.⁶¹⁻⁶⁴ These more recent trials are fully in line with the findings of the original meta-analysis and confirm that the recommendations are still valid.

This quantitative research fails to acknowledge that the lifestyles targeted in interventions are constructed by political, economic, and social-cultural influences throughout an individual's life. This review also identified an absence of research exploring the complexity of type 2 diabetes and the social influences in disease development. This quantitative research also did not give any insight into how people respond to the diagnosis of pre-diabetes, how it influences their risk perception and how social, cultural, and economic influences affect health related behaviours.

2.2 Systematic review 2: meta-narrative review of the qualitative literature

The second systematic review undertaken on the topic of type 2 diabetes prevention was a meta-narrative review of the qualitative literature exploring how risk perception and social-cultural influences influenced the health-related behaviours of those identified as having pre-diabetes. This review was undertaken to try and better understand the complexity behind type 2 diabetes development and whether diagnosing people with pre-diabetes acts as a

catalyst to behaviour change. Lifestyles targeted by policy interventions are more than just 'behaviours'; they are social practices that are socially and culturally shaped. This line of thinking is not considered by randomised controlled trials. From the initial searches of literature, the evidence on behaviour change was conflicting and diverse. Researchers investigating the same topic approached the research very differently based on their epistemological perspective. There was variation in the framing of the research questions, which methodologies were used, and how the data was interpreted and analysed using disciplinary theories. A meta-narrative approach to synthesising the literature was chosen because it allowed me to identify contrasting ways different research traditions study the same topic.⁶⁵ Using these principles with Boells hermeneutic principles I took an iterative approach to the literature using an interpretivist perspective to analyse the data. The data was applied to William Cockerham's Health Lifestyle Theory which uses Bourdieu's theory of habitus and Amartya Sen's health capabilities framework to understand and explain the dynamic nature of behaviour change.⁶⁶ The studies were mapped onto the Healthy Lifestyle theory to visualise the emphasis and the focus of the literature and to what extent they portray the dynamic complexity of lifestyle change described by the theory.

Two overriding meta-narratives emerged from the literature. The first was a bio-psychological metanarrative which included studies taking a biomedical and psychological approach to type 2 diabetes prevention. These were placed together because of the epistemological position and view that type 2 diabetes is an individual problem with individual level solutions to prevent the condition. The biomedical studies placed all the emphasis on the individual to act, even when structural barriers were acknowledged to be influencing people's ability to make choices. The resulting conclusions focused on simple individual behaviour change solutions. This positivist perspective perpetuates individual level

interventions as the solution to the problem of disease prevention. Despite the acknowledgement of the presence of economic, environmental, social, and cultural influences, these were not identified as policy considerations. The studies taking a psychological perspective to the problem used psychological theories to explore their findings, identifying structural influences on behaviour change such as peer, family, and community support. Social cognitive psychological theories analysed how contextual influences determined health-related behaviours and an individual's ability to achieve intervention targets. However, like the biomedical studies, the psychology studies focussed on individual agency as the object of further intervention, research, and policy action.

The second metanarrative was a social realist metanarrative whose authors took an interpretivist perspective. Only two studies fulfilled this criterion: these challenged the risk categorisation and diagnostic labelling of people with pre-diabetes. These studies used sociological theories to depict the dynamic interplay between agency and structural influences and the complexity behind changing health related behaviours. The themes described as barriers to lifestyle change included cultural obligations, identity, self-control, self-surveillance, social capital, economic, and material circumstances. For people from deprived areas with lower health literacy, lower educational attainment, and whose second language is English, these barriers may be insurmountable. Lifestyle change is more likely to be successful in those people with the social, material, and personal resources available to support this change e.g., having a supportive spouse, able to afford gym membership, or live in a low crime area with green spaces.

To update this review as part of the DPhil thesis I reviewed 38 citations of this meta-narrative review. A new systematic review came to similar conclusions to my own review. Skoglund et al found that there was a paucity of understanding in how the pre-diabetes diagnosis was

internalised, that the diagnosis did not necessarily lead to lifestyle changes, which were the result of a complex interplay between in the individual, their environments and structural determinants of health.⁶⁷ In addition, three new qualitative studies have been published which similarly followed a biomedical paradigm,^{22 68 69} one interpretivist qualitative study exploring resistance to the pre-diabetes diagnosis¹⁷ and one constructivist study critically questioning the construction of the 'pre-diabetes' diagnosis.⁷⁰ Despite these new publications most of the studies published (both qualitative and quantitative research) support the biomedical disease prevention paradigm and focus on life choices to change lifestyles. Consequently, most of the evidence available for policy use depicts rational, simplistic solutions to type 2 diabetes prevention strategies, whilst social science research has been criticised for being difficult to utilise in policy making.⁷¹ Additionally, none of the studies explored policymakers perspectives in how they make everyday decisions, enact national directives, or construct care pathways for patients, which will hugely influence the experience of patients with a pre-diabetes diagnosis.

The two systematic reviews discussed in this chapter have shown that type 2 diabetes prevention research is dominated by the biomedical research paradigm. This takes a positivist approach to the construction and framing of the risk condition pre-diabetes, 'treating' the risk condition with lifestyle interventions. Type 2 diabetes prevention policies focus on randomised controlled trial-based research which lacks an appreciation of the complexity and social influences within type 2 diabetes development. Despite wider recognition of the social determinants of health as a cause of health inequalities and long term conditions, public health research is focused on statistical, epidemiological and economic models which drive individual-level solutions to type 2 diabetes prevention.^{72 73} The existing evidence base used in the construction of public health prevention policy

currently contains little insight into how people navigate their social influences. Undertaking these systematic reviews led to the formation of the following aims and research questions for this DPhil study.

2.3 Aims

The aim of this DPhil study is to inform type 2 diabetes prevention strategies with a richer understanding of how the diagnosis of pre-diabetes affects people's feelings, attitudes, and health behaviours in different socio-cultural contexts. In addition, I seek to understand why individualist approaches dominate in both type 2 diabetes prevention policy and research (despite the documented limitations of such approaches).

2.4 Objectives

1. Explore how primary care teams communicate a diagnosis of 'pre-diabetes' and deliver health promotion messages to their patients.
2. Understand the patient perspective of a pre-diabetes diagnosis, how it influences their lifestyle choices and what they perceive to be the barriers to behaviour change.
3. Explore how local policymakers translate national directives and research into deliverable programmes in real world settings.

2.5 Research questions

1. How (and in what context) is the diagnosis of pre-diabetes and health promotion messages communicated to patients in general practice settings? How is this diagnosis constructed and framed for patients?

2. How do patients from different backgrounds react to (feelings, attitudes) and respond to the pre-diabetes diagnosis? How does this diagnosis influence health related behaviours and how are these behaviours socially constructed?

3. What do policymakers describe as the key influences in implementing type 2 diabetes prevention policies? Why is there a dominance of individualist health prevention strategies in type 2 diabetes prevention?

Chapter 3 – Methodology, Methods, Theoretical Approaches

In this chapter I outline the methodological approach used throughout the study, the methods used to collect data, and the theoretical approaches used in data analysis. I begin the chapter by outlining my epistemological approach. The second part of the chapter details the methods used as part of the study. I finish the chapter by detailing the theoretical principles used as part of my data analysis.

3.1 Methodology

Epistemological perspective

I have taken an interpretivist approach throughout this study. I believe that different realities of the world exist and I sought to understand how people interpreted pre-diabetes as a diagnosis and their interpretation of type 2 diabetes prevention strategies, whilst exploring the complexities which underpin health-related behaviours.⁷⁴ I acknowledge that my research findings are influenced by the context in which data was gathered, as well as my background and my underlying thoughts and assumptions.⁷⁵ A researcher's identity and how they present themselves have an impact on the information participants give.⁷⁶ Researchers are active participants in the construction of knowledge within the account, which is the result of a dynamic interplay between the researcher and the participants.⁷⁷ I am a practising GP but also have an MSc in Public Health which may have influenced how different participants volunteered and shaped their answers depending on their world viewpoint. For example, being a GP influenced how clinicians interacted with me during the focus groups, whilst having a public health background influenced how public health and policymakers responded to me. As discussed in the background section, during the time of the DPhil I was

diagnosed with an auto-immune condition and become a parent (twice) which meant I was more able to understand and empathise with participants about the difficulties of changing lifestyles in the context of complex lives (particularly for those who are carers).

As a practising GP I understand the system pressure currently experienced in general practice and the impact this has on providing continuity of care. My MSc in Public Health influenced how I view primary and secondary disease prevention and the importance of upstream influences on health. These experiences influence how I analyse and interpret the data collected during the DPhil, and I have reflected on these. Throughout the DPhil I have been part of the Newham Diabetes Partnership Group; being part of the group has allowed me to keep up to date with changing patient pathways, policy decisions and patient perspectives. At the monthly meeting I have presented findings from parts of my DPhil to the group who have in turn shared their thoughts on the research. I also discussed my data analysis and theoretical perspectives regularly during supervisions with my DPhil supervisors.

For this DPhil study I wanted to understand the perspectives of the different groups that are part of the type 2 diabetes prevention policy pathway (clinicians, patients, and diabetes prevention policymakers) and what influences their decision making.

Clinicians: how they inform patients of a pre-diabetes diagnosis and deliver initial lifestyle advice.

People with pre-diabetes: how they feel about the diagnosis and internalise this in the context of their everyday lives and how it influences their approach to lifestyle change.

Policymakers: how their views, experiences, and organisations they work in influence their approach to type 2 diabetes prevention policy making and decisions.

To achieve this, I selected qualitative methods to ensure I obtained both the breadth and depth of data required in the timeframe of the DPhil.

Data analysis

As part of my interpretivist approach I used an abductive approach to analyse my data and applied multiple theoretical perspectives to the different datasets in an iterative process.⁷⁸

This approach allowed me to be data led, whilst also testing different ideas and theories with the data during the analysis (as outlined in the section below, on [Analysis of Qualitative Data](#)). Multiple theoretical perspectives were used to inform the analysis of the different datasets (see [Theoretical Approaches](#)) to help make sense of the different perspectives and world views of those involved in type 2 diabetes prevention and understand why prevention policies exist in their current form. In the following section I discuss the methods used as part of the DPhil.

3.2 Methods

This section explains the methods used within the DPhil study in more detail.

Focus groups

Focus groups are a form of group interview where 'people are brought together to discuss a particular issue under the direction of a facilitator who has a list of topics to discuss'.⁷⁴ I selected focus groups as the data collection method for primary care teams because I wanted to capture the views and opinions of a variety of clinical and non-clinical practice team members. Doctors give the diagnosis of pre-diabetes and initial lifestyle advice while practice nurses, health care assistants and community pharmacists (depending on the practice) undertake annual prevention reviews. The administrative team, often live in the

local area, and interact with patients before and after their appointments which can provide a wealth of information outside the formal consultation. Therefore, I used focus groups to observe how consensus was (or perhaps wasn't) made within the group building on each other's knowledge through their interactions as well gathering insights from multiple perspectives simultaneously.^{74 79 80} I developed hypothetical case examples and presented these in the form of personas, this allowed me to see how the team members interacted with each other when approaching a real life situation to produce knowledge. From a practical perspective these focus groups generated a large volume of information in a short timeframe.⁸¹

I undertook three focus groups in 2018 with clinical and non-clinical staff including doctors, nurses, clinical pharmacists, health care assistants, administrators, and practice managers from three different practices across the borough of Newham with 24 participants in total. Two of the practices were purposively selected for their differing population demographics (one in East Ham with a predominantly south Asian population, the other in the Docklands with a larger proportion of Afro-Caribbean patients, as well as a younger student cohort) reflecting the diverse population that general practice cares for in the area. The third practice responded to an NIHR Clinical Research Network email expressing interest in joining the group and was in the most deprived area in Newham with a predominantly south Asian and increasingly eastern European population. These three practices allowed me to obtain a range of opinions from different localities in a deprived multicultural area. The focus groups took place at each of the GP practices, during the practice team weekly clinical meeting.

This was the first time I had facilitated focus groups. In preparation for this I completed a module in qualitative methods as part of my MSc in Public Health. In addition, I took part in

the Health Experiences Research Group qualitative methods course and data analysis course as well as drawing on advice and guidance from my supervisors. During the first two interviews I was accompanied by a medical student (now doctor), Dr Jonathan Bowley who was undertaking a summer internship with the IRIHS group. Dr Bowley assisted with the focus groups by documenting which participant spoke at each time point and made notes on non-verbal cues and communication. We met an hour before each focus group to prepare and an hour after each session to debrief on our thoughts and findings from the groups.

The sessions explored each group's understanding of pre-diabetes; how they communicate the diagnosis to their patients, whether they feel giving people this diagnosis enables behaviour change and how they support their patients in lifestyle change. I asked open ended questions to allow participants to formulate their opinions and generate discussions within the groups, whilst using a broad topic guide to ensure a flexible approach (see Appendix 3).⁷⁹ I used three different personas to act as hypothetical case studies for the focus groups. These were developed following attendance to the University of Oxford Knowledge into Action MSc module, the pdf template for the personas was provided by Stefania Marcoli (frog design; a qualitative market research company) and used with permission (see Appendix 4). The information I included in the personas was based on common clinical scenarios with east-London characters who had differing risk factors for developing type 2 diabetes and HbA1c blood tests in the 'pre-diabetes' range. Each persona had a different age and socio-economic background. I used them to see how the team members approached a clinical scenario, the similarities, and differences in approaches, language, and judgements used by group members. The personas acted as an important tool in the focus groups, animating the clinical teams, provoking discussions and illustrated how the team worked together to approach the clinical scenario.

GP Partners are the employers of the practice, and in Newham are incentivised to undertake type 2 diabetes prevention reviews. This may have impacted how the rest of the team responded to questions on the diagnosis and management of pre-diabetes. It may have meant that some staff were not as willing to voice outlier opinions; I tried to mitigate this by gently encouraging all members of the focus groups to participate in discussions. Written consent was obtained from all participants, the group discussions were audiotaped and then transcribed verbatim (anonymised to place and person).

Qualitative Case Studies of People with Pre-diabetes

There were three components to the qualitative study of people with a diagnosis of ‘pre-diabetes’:

3. An initial narrative interview,
4. A cultural probe exercise
5. A follow-up reflective interview

Initial Narrative. The narrative component provided a rich understanding of how people respond and internalise a diagnosis of ‘pre-diabetes’, to what extent it enables or inhibits lifestyle change and explore how type 2 diabetes prevention policies (and wider public health policies) influence individual lifestyle change. This interview was undertaken as an unstructured narrative interview.^{51 79 82} Participants told the story of how they came to be diagnosed, what they thought about this experience and whether they had made any changes to their daily lives as a result. Participants were allowed to talk with minimal interruption and led the direction of this interview. This interview was used to gain an understanding of people’s experiences of the health service in the context of type 2 diabetes

prevention, how they received the pre-diabetes diagnosis, health promotion messages received in primary care and their experience of type 2 diabetes prevention programmes (if they attended).

Cultural Probe exercise. The next part of the qualitative study was the cultural probe exercise.^{74 83 84} This methodology allows participants to be their own researchers, collecting materials which they feel are important to them and reflects their lifestyles. Participants could choose what observational data they wanted to collect (this included food diaries, pictures of food, pictures of leisure or cultural activities, shopping receipts, take away/restaurant/café menus). This exercise gave me an insight into the competing priorities the patients experienced with regards to their lifestyles. The data submitted by the participants allowed me to really ascertain what was of most importance to them in the context of their lives and to what extent being given a pre-diabetes diagnosis sat alongside this.

Reflective Interview. This interview was an exploration of the observational data submitted by participants who led the discussion on the items they had submitted. The data was reviewed with the participants in an unstructured way. They explained why they had submitted each item and what each item meant in the context of their lives (such as the importance of watching their grandchildren play football and participating in the following meal). This interview differed from the first because it focused on the participants lifestyles, how they made everyday choices. In this interview the participant and I co-constructed a narrative of their social lives and how this influenced their thoughts and behaviours towards their lifestyles.⁷⁹ I explored with the participants how they interacted with their communities and local environments, for example why they chose to walk to certain places, why they shopped at particular outlets or how they choose where to get lunch with their colleagues.

Exploring their own interpretations of their community context gave a unique insight into how the external environment and wider social context influenced their health-related behaviours. This data provided me with a rich understanding of how behaviour change is sustained and influenced on a longer-term basis and what might influence this over time.

A maximum variety sample of 25 people with a diagnosis of pre-diabetes completed the participant interviews. Initially, participants were recruited via one of the participating GP practices from the focus groups. A study infographic was circulated via email to the Newham Diabetes Partnership Group (with over 50 stakeholders listed) to share with their networks. The Newham Outreach team (a service commissioned by the local authority where patients are referred to for lifestyle advice and support) agreed to hand out study adverts at their five sites across the borough (100 print outs were sent to their location). A specially designed text message was sent to 400 people registered with pre-diabetes at a participating GP practice in Newham (see Appendix 5). The study was also advertised by nurses and health care assistants when undertaking annual reviews of patients with pre-diabetes in this participating practice. Recruitment for these interviews began in September 2022; however primary care in Newham was under great pressure to roll out a COVID-19 booster vaccine, the flu vaccine, and a polio booster for children at the time. Combined with staff shortages due to sickness (from COVID-19 and long COVID), it was difficult for type 2 diabetes prevention to be a clinical priority. Annual prevention reviews had ceased during COVID and hadn't restarted by the time of the recruitment. Due to low recruitment rates at the initial site (only two participants recruited) the study advert was also shared via social media by one of my DPhil supervisors. A practice nurse with an interest in diabetes and type 2 diabetes prevention responded to the social media advert and a second practice was recruited as a

study site. The study text message was sent to 654 patients registered as having a diagnosis of pre-diabetes on the practice IT system EMIS.

A simple non-technical information sheet was sent via email to participants prior to taking part in the study, outlining: the purpose of the study, why the person had been invited and study requirements (see Appendix 5). It was made clear that all information gathered would remain confidential and only be reproduced with their permission. Consent forms were completed prior to the narrative interview, I received ethics approval for verbal consent forms to be completed for online interviews. All study materials, consent forms and study amendments were reviewed and approved by the London-Surrey NHS Ethics Committee (see Appendix 6).

All the interviews were undertaken online using either MS Teams or Zoom, participants were given the option of face-to-face interviews, but all preferred online interviews due to their convenience. Each interview lasted 30-90 minutes.

In between the two interviews participants undertook a cultural probe exercise, collecting their own observational data. At the end of the first interview, I asked the participants to record information on what they liked to eat, who with, leisure activities they enjoyed as well as information on what was important to them. Participants mostly took food pictures, pictures of their local area, events they had been to as well as some family members and friends. People who used lifestyle apps (mostly used for monitoring weight, diet, and exercise) gave screen shots of their self-surveillance tools and progress, whilst others submitted shopping receipts. Some participants also submitted written food diaries.

Using these different qualitative techniques allowed time to gather in-depth narratives but also ensured that there was sufficient variety in the sample. This sample is not statistically representative of a UK population and could not produce findings directly generalisable in a quantitative sense. But the themes and concepts developed from the analysis will be transferrable and relevant to many populations at high risk of developing type 2 diabetes as well as more broadly to populations trying to undertake lifestyle change. The drawback to doing a three-part study was the additional time it took to complete this part of the study (eight months in total) and the volume of observational and transcribed data to analyse. However, the reflective interview with the observational data greatly enhanced the contextual basis of the research, gave additional cultural meaning to data, and helped me understand the complexity within which people make their lifestyle decisions, as well as providing a way to gather data on the social determinants of health in an unobtrusive manner.

Semi-structured policymaker interviews

I undertook semi-structured interviews with a sample of nine policy policymakers involved in developing and implementing type 2 diabetes prevention policy. For these interviews I wanted the policymakers to be able to express their opinions freely, while adhering to a carefully tailored topic guide (to each stakeholder) with the topics I wanted to explore.⁷⁷ With these interviews I set out to try to understand why individualist disease prevention strategies dominate in UK type 2 diabetes prevention policies despite their published limitations.^{15 20} This is the first time type 2 diabetes prevention has been examined from a policymaker's perspective, examining the main influences on policy making process and the role of academia in this. In keeping with an interpretivist approach, I sought to understand

how prevention policies are socially and culturally shaped whilst exploring the complexities which underpin the decision-making process.

I sought perspectives from a range of local and national policymakers, using a combination of purposive and snowball sampling. I first selected four policymakers with experience of local or national policy making, ensuring representation of public health and NHS settings with experiences in commissioning, health consultancy, clinical practice, and public health. I then recruited further policymakers via participant recommendations. Nine semi-structured interviews with ten policymakers took place between 2018-2020 (one interview was done jointly with two policymakers). Three policymakers were then re-interviewed in 2021 to ascertain how the COVID-19 pandemic influenced decision making. Interviews lasted from 30 to 90 minutes and were audio-recorded (with consent), anonymised and transcribed verbatim. The interviews were semi-structured with each policymaker describing their roles and experiences in developing and implementing type 2 diabetes prevention policy. The interviewees were encouraged to express their views on type 2 diabetes prevention strategies and how the policy process is influenced. I used prompt questions to explore how research evidence was used practically to guide decisions (see Appendix 7 for example topic guide).

Interviewees at local authority level included six policymakers with a public health background including two commissioners, one strategist, a public health consultant and a director of public health. A national public health policymaker was also interviewed. NHS participants included a GP clinical lead, a GP primary care network clinical director, a primary care commissioner and former national healthcare policymaker. I re-interviewed the GP leads and the national public health policymaker in 2021 to ascertain if the policy process had changed over the course of the COVID-19 pandemic and to gather feedback on initial

findings. The final interview acted as a fact checking interview to test the emergent themes and theories from the data. I approached all interviewees by email, and all agreed to take part. The interviews took place in places of work or online via Microsoft Teams.

All the interviews were recorded using a digital recorder, anonymised, and transcribed verbatim. I made notes on non-verbal information gathered during the interviews, participant interactions, as well as reflections in the form of field notes (written in notebooks) to complement the narrative gathered in the accounts.⁸⁵ A transcriber assisted with the transcription of the audio files (all transcripts were password protected and transferred using online secure platforms OXfile and OneDrive in accordance with departmental guidelines).

3.3 Analysis of qualitative data

I began my analysis by printing the transcript, familiarising myself with the data, re-listening to the tape recordings and writing initial thoughts and reflections in the margin. I used the data management programme NVivo to further manage the data. I found that the software allowed large amounts of data to be organised and rearranged whilst still maintaining its original source. I undertook a thematic analysis of the data, consisting of line by line coding of the first few manuscripts, developing an initial coding scheme.⁷⁴ Following this, sections of each subsequent transcription were analysed with codes assigned to sections of the text. The codes were developed using an iterative process of constant comparison between different interview accounts creating a consensus meaning to a section of text.⁸¹ These were refined as the research progressed and developed. Some of the initial codes used were a mixture of in vivo codes (words used by the participants to describe a phenomenon), others were codes

describing actions and processes.⁷⁴ I comprehensively analysed all the transcripts from every interview.

The second stage of analysis moved from a descriptive analysis to a more interpretative analysis. Themes were constructed by looking at how the codes related to each other and summarised beliefs, views, or topics. Codes were arranged into themes through cut and paste methods across the cases (performed in NVivo). Code books were reviewed as part of my regular DPhil supervisions. I made notes under each theme to document what was included in each theme and how themes relate to potential theoretical approaches.⁷⁷ For the focus groups the themes described the groups' thoughts on the pre-diabetes diagnosis, the management of pre-diabetes patients, the barriers to lifestyle change and the doctor-patient relationship. In the analysis I sought to gather consensus opinion as well as identifying outlier perspectives (although these were an exception). For the interviews with policymakers, I grouped codes under preliminary themes describing the most significant influences on the policy process, i.e., decision-making about policy taking place in a complex system influenced by different structural factors and socio-economic contexts,⁸⁶ prior to applying the theoretical framework to the data. For the interviews with patient participants, I focused on how the diagnosis was internalised by individuals, how this influenced their daily lives, how they interacted with the wider determinants and to what extent this influenced lifestyle change.

Prior to starting my DPhil, I had an idea as to which theories might be applicable to the data (informed by my qualitative systematic review and my MSc). The themes from the data were then compared in an iterative way with different theoretical principles in a process of going back and forth from the data to the theories to see to what extent the data corresponded or

refuted the theoretical principles and frameworks.⁸⁷ For example, the themes I identified from the interviews of people with pre-diabetes were initially tested against William Cockerham's 'Healthy Lifestyle Theory'; however I did not think this model reflected socio-political influences on lifestyles or the 'messiness' of everyday health-related decisions and so I tested different elements of Bourdieu's Theory of Practice. I found this better reflected my findings, and constructed my own model based on this theory. In this thesis I present my descriptive analysis and then my analytical findings in the findings chapters for the focus groups study (chapter 4) and case study of people with pre-diabetes (chapter 5). The findings from the interviews with policymakers were done slightly differently. The relationships and associations between the codes generated from the descriptive analysis were explored and common concepts were grouped beneath the relevant section of Shiffman and Smith's framework (as discussed below) to be examined in more detail.⁷⁴ Hence the findings in this chapter are presented in the form of this theoretical framework.

3.4 Theoretical approaches

Critical social science approach to type 2 diabetes prevention

Social scientists such as Lupton, Baum, Nettleton (informed by the work of Foucault)

consider pre-diabetes, at least to some extent, as a social construction—that is, not so much a biomedical condition that the person *has* but a condition which they are *constructed by society* as having. Constructing people as 'having' pre-diabetes perpetuates an individualist disease prevention discourse with several negative consequences. These theorists believe these conditions ascribe the cause of disease as a failing of an individual's biology and that discussing disease risk in terms of numerical results (see background section) removes the individual's social context from disease development.^{88 89} They set out how such policies work to blame individual social actions for creating disease, with individuals told by medical

professionals to take responsibility for their actions and change their lifestyles according to the prescribed medical advice. Delivering the diagnosis in a medical setting reaffirms the risk diagnosis as a medical entity, giving an appearance that the individual can 'control' the perceived linear progression to type 2 diabetes.^{90 91} The use of shock tactics in consultations to encourage behaviour change are thought by these theorists to lead to perpetuating unnecessary fear and stigmatising individuals.⁹¹ Deviations from reference ranges and norms lead to victim blaming which may influence how health messages are internalised by the individual and whether they undergo behaviour change.^{79 92} This individualist discourse minimises the social, economic, political influences and complexity of type 2 diabetes development, as well as diminishing alternative disease prevention models.^{43 79 93} These perspectives were used in the analysis of the focus group data (chapter 4) and data from narrative interviews of people with pre-diabetes relating to the diagnosis (chapter 5).

Further to this, critical social scientists such as Armstrong have described policies such as type 2 diabetes prevention as examples of overreaching medical surveillance medicalising lifestyles.^{88 89} Surveillance tools used within the consultation (numerical and colour graphs, charts and ranges) and outside the consultation (weight and physical activity self-monitoring) are promoted to help people regulate themselves and their bodies to prevent type 2 diabetes.⁸⁹ Some social scientists such as Deborah Lupton see the formation of the 'quantified self', as a tool of biopower promoting citizens to self-regulate.⁹⁴ This fits into the wider neoliberal model of governing populations placing the emphasis on individuals to take responsibility for their own behaviour regardless of structural influences.^{91 94}

Bourdieu's theory of practice

I used Bourdieu's theory of practice to inform the analysis of my interviews with people with pre-diabetes, particularly in data related to how health behaviours are constructed and why changing lifestyles was challenging for many people with pre-diabetes.⁹⁵ I explored how Bourdieu's principles of habitus, life worlds (fields), doxa and capital interact to explain food and leisure choices.

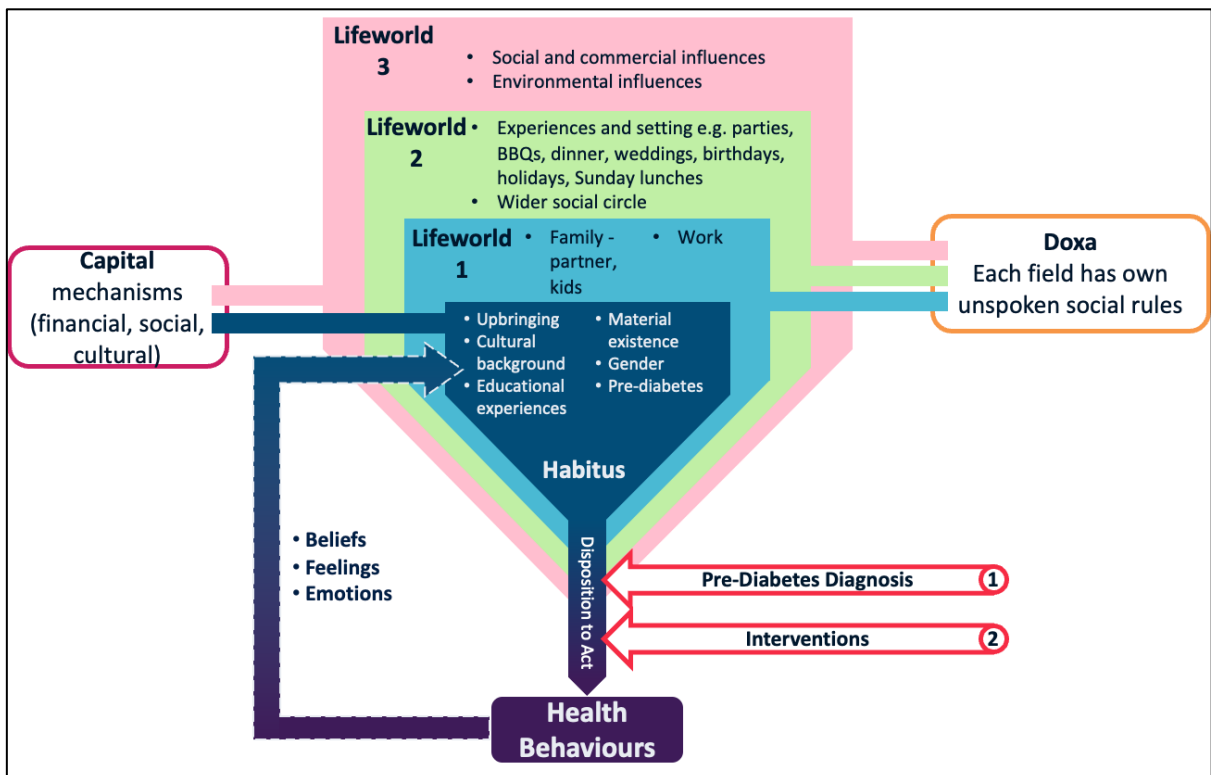
'Habitus' is a set of dispositions which are developed over a life course from our social context (including upbringing experiences, gender roles, cultural background).⁹⁶ Every time an individual (and their habitus) approaches a social context, their choices are influenced by those around them and their position within their life worlds. From my data I have explored three different life worlds: 1) home and work settings, 2) social influences (social circles and events), 3) wider community setting. These life worlds were identified from what people talked about as important to them in both the interview data and observational data. Each lifeworld has its own set of unwritten rules for players to follow (doxa), these rules underly the practices within each context.⁹⁷ These rules are part of an individual's intuitive knowledge developed over time, shaped by experiences, and often taken for granted as inherent knowledge within the social setting. They maintain the social order and lead to the development of unquestioned social norms.⁹⁷ From Bourdieu's theory of practice these rules can lead to social inequalities and are determined by experience, language, gender, economic conditions, and educational background.⁹⁵ This gives people the appearance that they can change their lifestyles, whilst at the same time working to constrain people.

'Capital' is the resource with which people can enact decisions within a particular context.⁹⁸

From the data, I examined two forms of capital acting on an individual level - financial and

cultural. Cultural capital influences an individual's tastes, values, and within a group setting determines the lifestyle of that social group. By abiding by the rules of the social setting, people gain capital in the form of relationships within the social sphere. Financial capital relates to the use of monetary means to enact health behaviours. Capital also operates at a community and structural level, by influencing things such as the commercial food environment, accessibility to safe green spaces, leisure facilities etc which enable or hinder lifestyle choices.⁹⁸

Below is a visual representation I constructed showing the relational interaction between each component of the theory which explains health behaviours. This is a dynamic system which changes over time, as the individual makes a decision and when circumstances change. The decisions people make in turn influence the social contexts they are part of.



1. Figure 3.1 - Bourdieu's Theory of Practice

Shiffman and Smith's political priorities framework

I selected Shiffman and Smith's framework to interpret the data from policymaker interviews.⁹⁹ This framework was developed to investigate the determinants of global priorities for health, and assess why some health agendas receive political support whilst others do not. I used the framework to explore how national directives on type 2 diabetes prevention were interpreted and implemented at a local level and understand why disease prevention policies focus on targeting high-risk individuals rather than upstream population level interventions. The framework consists of four domains, actor power, political context, power of ideas and lastly issue characteristics. I combined the first domain of 'actor power', with Lukes' three dimensions of power, to undertake an in-depth analysis of how power operates in policy implementation. Lukes understood power to be a multi-dimensional social influence,^{100 101} which allowed me to explore how individuals and organisations use their power in the policy process and how this influences decision making. For the second domain, 'political context', I unpacked the influence of our neoliberal political system on health policy. For the third domain I explored the 'power of ideas' behind the policy approach, particularly the emphasis on individual responsibility in prevention policy. Finally, for the fourth domain of 'issue characteristics' I explored what aspects of pre-diabetes as a condition make it amenable to a high-risk disease prevention policy. Throughout the analysis I also explored the role of research in the decision-making process. Weiss identified that research could be used in the policy process in several different ways alongside other sources such as the policymaker's own experiences. Weiss constructed dialogical model to reflect on the differing roles of evidence in the policy making process.^{102 103} I tested each model against the data to see which was most applicable.

3.5 Ethics and governance

There were several ethical considerations as part of the study, particularly for participants with pre-diabetes. The interviews were asking questions of individuals and about their lifestyles which were potentially intrusive not just to them but to their wider family. These interviews placed demands on people's valuable time. Throughout the interviews I ensured that I asked questions sensitively, drawing on my experience as a clinician and only probing when participants appeared confident talking about the subject. Participants chose what observational data they wanted to collect for the study; there was no 'required list' of information I sought. If a participant wanted to withdraw from the study or did not want to partake in the follow up study, they were removed immediately and thanked for the time they had already given. It was made clear that their participation will not impact on their current or future NHS treatment in any way.

Health professionals and policymakers are busy people; it would be unethical to waste their time on unnecessary or poorly prepared interviews and so I ensured that all study materials were circulated prior to interview and that topic guides and interview topics had been thought out in advance.

A study protocol and all study materials (consent forms, information sheets, interview topic summaries) were reviewed by the NHS Research Ethics Committee (REC) through the IRAS system and HRA application. Formal approval of the study was received in May 2018 from both the NHS REC and HRA. Further substantial amendments were made to adjust the recruitment of participants, as well as how the interviews were conducted due to COVID-19 restrictions. A minor amendment was made to change the end date of the study to account

for my two periods of parental leave (see Appendix 6 for NHS Ethics approvals). Data were managed strictly in accordance with the data protection policies of the University of Oxford. I undertook annual departmental information governance training throughout the DPhil.

All participating GP practices were registered on the NIHR clinical research network and participants were registered anonymously via Sitaline and on the NIHR Central Portfolio Management System. This had to be done in two parts, the North Thames Clinical Research Network input the recruitment for the professionals and people with pre-diabetes recruited from Newham Practices. I input the policy participants (who participated nationally) as well as individuals who self-referred themselves to the study (via recommendations or responding to the study advert online).

In the following four chapters I will discuss the findings of the focus group study, interviews with participants with pre-diabetes and stakeholder interviews.

Chapter 4 – Pre-diabetes: a primary care team’s perspective

4.1 Introduction

Primary care teams play a central role in the type 2 diabetes prevention pathway. As discussed in the introductory chapter, clinicians make decisions on who to test, how to deliver the diagnosis, communicate test results to patients and give lifestyle advice. GP practices in England are incentivised to invite everyone with pre-diabetes for a blood test to ensure they have not progressed to type 2 diabetes. Depending on the area, GP surgeries may be further incentivised to undertake an annual review of people with pre-diabetes.

All the focus groups took place in the London borough of Newham, one of the most deprived boroughs in England with an estimated 23% of families living in low-income households.¹⁰⁴ It is an ethnically diverse area, 42% of the population identifying as Asian/Asian British, 17.5% as Black/Black British, and 30.8% identifying as white ethnic groups.¹⁰⁵ Newham’s type 2 diabetes prevalence is currently 8.6%, the 5th highest prevalence in London, (England average 7.1%).¹⁰⁶ Its population is especially vulnerable to developing type 2 diabetes due to the interaction of social, environmental, economic, and individual (genetic) risk factors. Consequently, the CCG and now integrated care board (ICB) have prioritised type 2 diabetes prevention and care locally. GP practices are incentivised to undertake additional reviews of people with pre-diabetes and remunerates the practice for completing type 2 diabetes prevention reviews and offering onward referrals to intervention programmes.

How primary care teams communicate a pre-diabetes diagnosis and deliver subsequent health promotion messages has been shown to affect how people respond and influences whether they engage in lifestyle change.^{69 107} Pre-diabetes may have different meanings, interpretations and implications for clinicians and patients, with people entering a new risk state once they have been given this diagnosis.¹⁰⁸ Despite the central role primary care plays in type 2 diabetes prevention, the literature has a limited focus on the practice team's perspectives of the condition.⁶

The aim of this part of the DPhil was to understand the views and perspectives of primary care teams with regards to the pre-diabetes diagnosis, supporting behaviour change and delivering health promotion messages. As an overview, the primary care teams accepted the pre-diabetes diagnosis without question and understood the condition in terms of a biomedical diagnosis which is likely to lead to type 2 diabetes. The primary care teams situated the responsibility of preventing type 2 diabetes with the patients, whilst also acknowledging the difficulties and structural barriers many people encounter in undertaking lifestyle change. Many GPs recognised the importance of relationship-based medicine as an important tool in encouraging small lifestyle changes over longer periods of time, an approach not supported due to the system pressures experienced within primary care.

The findings of this part of my DPhil study have been published in *BJGP Open* as outlined below (see Appendix 8).⁴ Professor Greenhalgh was second author on the paper as the DPhil supervisor and reviewed revisions of the paper in preparation for manuscript submission.

Barry E, Greenhalgh T. How do UK general practice staff understand and manage prediabetes? A focus group study. *BJGP Open* 2022 doi: 10.3399/BJGPO.2021.0166

4.2 Overview of the dataset

The focus group sample included GPs, practice nurses, practice managers, reception staff, health care assistants and community pharmacists (see table 4.1), for a total of 25 participants from three different practices in east London. The focus groups gave an insight into the dynamics of the practice teams by how people interacted to answer questions, contradicted each other, built on ideas, debated and responded to each other.^{74 81} This was seen particularly when the groups approached the mock personas (as discussed in chapter 3), each professional building and adding into the others' previous comment and approaches. The use of these personas prompted discussions amongst the group and facilitated discussions on the (mock) individual's social context and how they may hypothetically navigate this. Of note, participating reception staff provided particularly key insights as they lived in the local area and felt that they knew the patients in a different way from the clinical staff.

Focus Group	Practice Roles						Ethnic group	Gender
	GP	Practice Nurse	HCA	Community Pharmacist	Practice Manager	GP Trainee		
1	5	1	0	0	0	1	White (3), Asian (2), Afro-Carib (2)	M – 3 F – 4
2	5	1	1	2	1	1	Afro-Carib (6), White (2), Asian (3)	M – 3 F – 8
3	3	1	1	0	2	0	Asian (6), White (1)	M – 4 F – 3
Total	13	3	2	2	3	2	White (6), Afro-Carib (8), Asian (11)	M – 10 F – 15

1. Table 4.1- Focus Group Participants

4.3 Pre-diabetes in practice

The following section is a descriptive analysis of the focus group data. As discussed in Chapter 3, the methods chapter, an iterative thematic analysis was undertaken, and four descriptive themes were identified from the data. The following section gives an overview of each theme with supporting extracts from the focus groups data. The four themes identified were diagnosis and managing pre-diabetes, motivating patients to change their lifestyles, relationship-based care, and the social determinants of health recognised but not addressed.

Theme 1: Diagnosing and managing pre-diabetes.

Diagnosis

GPs understood the diagnosis of pre-diabetes as either a pathophysiological process or as an epidemiological condition defined by a particular diagnostic threshold in a biomarker (an HbA1c level of “42-47” for example). The clinicians returned to their biomedical training to explain the condition, as seen in the quote below by a GP who understood the condition in terms of insulin sensitivity causing a rising HbA1c level.

“It's defined by decreased insulin sensitivity. And it's a stage that happens gradually... towards the person then becoming diabetic, puts them at a much higher risk of them becoming diabetic. And essentially happens when the body loses sensitivity to insulin, so the pancreas ends up making more and more and more and more. And then you see a gradual rise in HbA1c. And it's linked into a lot of things.”

FG1 GP

Participants found numerical diagnostic cut-offs useful in explaining to the patient that they were at risk of type 2 diabetes. They said that they conveyed the diagnosis in relation to type 2 diabetes, emphasising that ‘pre-diabetes’ means ‘before diabetes’, suggesting a linear

progression to the condition. As seen in the quotes below the GPs situated the diagnosis in relation to diabetes and stressed the importance of measures needed to stop the progression to the condition.

“People [with pre-diabetes] who don't have diabetes are at risk of developing diabetes in the future if they do not take certain measures to prevent it.”

FG2 GP

“So, you can go through, you know, the different ranges and what they, what they mean. So, if they're like forty-something, they're like high, like in the pre-diabetes range, then you can tell them that if it keeps going this way, then they're at risk of full-blown diabetes, and this is what you need to do to stop that from happening.”

FG1 GP

The pre-diabetes diagnosis was mostly welcomed by practice teams. It was seen by most participants in positive terms as a window of opportunity for action. They thought it allowed the patient to act in a 'treatable stage' with lifestyle measures that could prevent disease progression and improve outcomes. Focus group participants placed the responsibility of reducing type 2 diabetes risk with the individual patient. This was done from the outset as soon as the diagnosis was delivered by the clinicians to their patients (as seen above). People were being asked to review their lifestyle choices, explore their ability to act, whilst having 'discipline' and 'self-control' to reduce their risk of type 2 diabetes. These messages were reported to be repeated at annual reviews and opportunistically by clinicians.

Monitoring and surveillance

The focus group participants discussed the management of pre-diabetes in face-to-face annual reviews conducted by nurses and healthcare assistants which act as surveillance and monitoring reviews. At the annual review the patient's weight, HbA1c and blood pressure

are monitored, and their lifestyle is discussed. The consultation is recorded through a computerised template which links the numerical results to the diagnosis. As seen in the quote from the practice nurse below, graphs of results and colour scales are used to reflect to the patients their progress, how far they have deviated from normal ranges (in relation to their HbA1c, weight) and what the implications of this might be.

“Sometimes I used the colourful chart where the green is the safe numbers. Then the yellow, you know, the amber one is from [um] 42 to 47. Then the red start from 48. So, when they come in, I just pull out the (measuring) tape. And I say, ‘this is where you belonged before – now you’ve decided to jump into the yellow zone, and if you don’t take care and you don’t change your lifestyle by eating the right food, exercising and that, you jump into the red as well’.”

FG1 Nurse

The clinicians all found the numerical scales – in particular correlating these to colour scales and graphs – very helpful in explaining progress or deteriorations to the patient and played a key role in delivering health promotion messages within the consultation. Using a traffic light system helped visualise to patients how their risk factors (such as waist circumference in the example below) were contributing to their overall risk of developing type 2 diabetes. There was also an assumption that if patients were able to change their behaviour, keeping their parameters in the ‘safe zone’ then progression to type 2 diabetes would be stemmed.

Theme 2: Motivating patients to change their lifestyles.

Fear of consequences

Clinicians said that they used the patients’ fear of type 2 diabetes and its consequences as tools to try and motivate patients into changing their lifestyles. The quotes below from a GP and health care assistant discuss how health care professionals use the fear of life-long

medication or the macro-vascular consequences of type 2 diabetes to try and motivate people.

“And a lot of patients do not want to go on medication. I've encountered a lot that don't, 'oh, I don't want blood pressure medication - don't give me that', 'then do something about your lifestyle, if you don't want medication'. Because that's what we say for people with diabetes - they don't want it, but they need to do something to make a change, we can't just make the changes for you, you need to take control of your own life.”

FG3 Health Care Assistant

“If they're scared about it, they're worried about it, then fine - I'll go with them, and we'll go with it. If they seem nonplussed, then my response is a lot more kind of aggressive, in the sense that, 'do you not know what it means - you could lose your foot, you could lose your vision, you could have a heart attack'. Then you start putting the kind of complications in their mind, to get them worried about it.”

FG1 GP

In these quotations we can see the clinicians are conveying the message that people needed to control themselves to stop the development of type 2 diabetes. Both clinicians felt that their language was both shocking and aggressive, but felt it was justified if it meant the patient took their risk of type 2 diabetes seriously. Many clinicians considered that scare tactics were justifiable if they raised the awareness of risk and triggered the individual to act accordingly to change their lifestyles.

A few participants recognized that these tactics had negative consequences such as stigmatizing people who were unable to change their lifestyles or scaring patients from returning for review. This approach had to be tailored and timed correctly for each patient. However, many clinicians despite accepting this risk, dismissed it, because they often held onto an anecdotal case where this approach had worked. This is illustrated in the quote

below; the GP is referring to a patient with multiple risk factors for type 2 diabetes as a 'ticking timebomb' but felt that this approach was justified if it meant that a patient could dramatically change their lifestyle and as such continued to use this approach.

"It was the first time I think anyone had addressed the fact that everything you're doing was adding up to him being a ticking time bomb, it was a wake-up call. For some people, they run away because they are scared. But other people, it will shock them into 'okay, I've got to listen now'."

FG2 GP

Diabetes Prevention Programme

Overall, clinicians felt that the introduction of the diabetes prevention programme and similar initiatives were largely positive and a further opportunity for individuals to seek lifestyle advice. From the quote below from a GP we can see there was little resistance to the introduction of these type 2 diabetes prevention policies (from the risk diagnosis all the way to interventions) locally within primary care.

"Because I think it is a risk stratification, because you're identifying an intervention group, which changing something will have a positive outcome. Otherwise, you wouldn't really have that range as pre-diabetic range, if it didn't have any clinical significance. So, I think at risk and intervention is kind of what pre-diabetes is kind of aimed at."

FG2 GP

From this quote we can see the existence of this new diagnosis and the presence of a prevention programme was interpreted by some members of the practice team to mean that the policy and intervention must be a positive thing for patients, otherwise why would GP practices be commissioned to deliver these initiatives. However, a minority of clinicians felt that the numerical cut-off threshold caused some issues around overdiagnosis and uncertainty. From their experiences using blood tests alone did not identify those at most risk, with a high proportion of patients having a normal

or borderline HbA1c, who therefore wouldn't be selected for interventions. They also commented that people who had normal test results yet multiple risk factors for developing type 2 diabetes could be falsely reassured based on a single annual blood test.

Theme 3: Relationship-based care

Clinical team members discussed the need for a long-term approach to supporting behaviour change based on patient centred relationship orientated care. The teams discussed that this was best done with mutual trust between the clinician and patient with knowledge of their social circumstances and cultural context. These relationships required time to develop with repeated consultations both with themselves and family members. The focus group participants reported that this approach had a different emphasis which aimed to make small behaviour changes over longer periods of time. There was very little intervention from the clinician described apart from active listening and the patient identifying their own goals. This approach requires time and space for the patient to communicate their narrative, free from judgement, and feel that they have been heard; this is illustrated in quote below (from discussion about one of the personas), by a male GP.

"I think concordance is another thing. To get the patient on board and feeling involved in the decision-making about what changes they make. So, where he's got practically everything wrong with him [laugh], you know? It might be useful to sort of put the ball in his court... I know from experience in prescribing, that concordance is very important. And when they're made to feel like they're involved, and not just being told what to do, there's a bigger chance of success with, with even small changes".

FG1 GP

When discussing one of the mock personas (a case of a gentleman who lived alone whose attended the pub on Fridays for fish and chips) the clinicians reported encouraging patients

to decide what was possible within their lives, alongside showing an interest, offering kindness, and understanding that lifestyle change was difficult. This approach was done opportunistically and seen as slower and more incremental, often taking years. With this approach the patient and clinicians were seen by participants as equal partners in the process with the patients using their agency to decide which of their 'life choices' they can work on. As discussed in the quote above, it was important for patients to feel that they weren't being told what to do and rather focusing on what the patient thought was possible. However, the primary care teams reported that workload pressures often meant that it was difficult to take the above approach with little capacity for follow up care.

Theme 4: Social determinants are recognised but not addressed

The practice teams had a breadth of knowledge of the everyday lives of their patients. In particular, the administrative staff had huge insight into the social situation of the patients at their practice. Every practice team recognised that people's lifestyle choices were constrained by poverty, cultural expectations, and the built environment. When discussing the mock personas, they all discussed the importance of understanding a patient's social context when delivering health promotion messaging. Table 2 gives examples of how the social determinants were discussed by the groups. The key barriers to behaviour change raised were financial insecurity, cultural norms on food and exercise, the obesogenic environment, the food environment, gender roles and expectations, and health literacy. There was limited time to address such upstream influences during consultations.

Some of the participants from the administrative teams were south Asian women, living in Newham, they particularly discussed the barriers south Asian women faced in trying to reduce their risk of type 2 diabetes. As seen in Table 4.2, quote 3, women were reluctant to

exercise because of two important cultural barriers. Firstly, the cultural requirement for wearing traditional dress such as the hijab and saris making it difficult to exercise, and secondly there remained a cultural expectation that these women would stay at home and must ask their husband's permission to leave the house. The focus group participants felt that demands of family life and work for south Asian women meant that this was prioritised over their own self-care.

On discussing barriers to lifestyle change practice teams had a good understanding of the community level influences on health. Exploring this in more detail the participants understood both the impacts on a biological level on the individual as well as the wider political influences on health. In the quote below the GP is discussing the widely available cheap fast food in the area.

“Just a walk round. You can see, you see all the chicken & chip shops. Fast food: Cheap and cheerful. So, keep you happy for that moment, but after that, it depletes you, really. Drains you all the time...There's not enough (health options) And probably because it's too expensive”

FG1 GP

The GP is suggesting that ingesting this food leads to further cheap, fatty, sugary food consumption. At an individual level this will lead to weight gain, influence hormone production, increase cholesterol levels, increase insulin resistance, increasing the risk of cardiovascular disease, type 2 diabetes, and hepatic disease. On a community level, the large number of fast-food outlets in the area reflects the demand for quick cheap food (and the paucity of affordable healthy food) and its cultural acceptance. It also reflects how local governments prioritise the local economy, maximising jobs, and revenue these outlets provide. Further to the availability of food options, housing and financial stresses were mentioned recurrently as a large structural barrier to behaviour change. The GP in the quote

below had recently performed a home visit and reflected on the living conditions of the family he saw.

“Housing, a healthy house. In a three-bedroom flat, if there are three families, or three individual - with a child, or something. Very difficult for them.”

FG3 GP

Overcrowded, poor quality housing has a large impact on an individual’s ability to cook healthy meals (lack of facilities) and undertake exercise at home (lack of space).

Overcrowding may lead to stress within the family units and mental health problems. All these lead to increasing weight, sedentary lifestyles with very few opportunities to change lifestyles. Despite individual level interventions being present, many felt that the barriers to engagement would be too overwhelming for most of their patients. In addition, the practice teams did not feel they had the power to advocate for wider social and political change for their patients.

Social Determinant	Description
1. Financial Insecurity	<i>If like finances, worried about their finances, and things like that. The last thing they're going to be thinking about is their health. Going to be like 'I need to get these bills paid'. You know? So, I think their personal situations matter a lot, as well. And how they, you know they deal with their lifestyle.</i>
2. Cultural norms about food and eating	<i>You know, will you - like changing the food, and things like that – they (the family) probably wouldn't like that. Like, 'why are you making it healthier, why are you changing our cooking method, we don't want it like it that'. (FG3 Manager)</i>
3. Gender roles and expectations	<i>The expectations of sometimes what men and women do. So, sometimes we think that you wouldn't make a with men, but they're the ones who have the permission within society to go to the gym, to be out, and not to have to do the housework and the childcare. And for women, especially sort of women in their forties and fifties, that there's an expectation that you know, there is no social life, there's no going out, you know, to go to an exercise class, and they're more at home. And, and/or you need to ask permission to go out. And it's still - It surprises me that there's still quite a lot of that around. (FG 2 GP)</i>
4. Obesogenic environment	<i>Just a walk round. You can see, you see all the chicken & chip shops. Fast food. Cheap and cheerful. Keep you happy for that moment, but after that, it depletes you, really. Drains you all the time. (Interviewer: So, do you think it's that there's not enough healthy options?) There's not enough. Not enough. And probably because it's too expensive. (FG1 GP)</i>
5. Health Literacy	<i>I guess sometimes the actual underlying knowledge about healthy eating isn't always there, as well. Especially when you're dealing with someone who comes from a relatively isolated, who hasn't necessarily had the best schooling, is relatively new to the country. Changing everything round like eating, your entire life – you need to change everything, you need to eat what's on the NHS website - it's sometimes difficult to make that leap. (FG1 GP)</i>

2. Table 4.2 - Social determinants of health identified by the focus groups

4.4 Critical social science perspectives

The following section is a further analysis of the data applying critical social science principles to better understand the meaning of the descriptive findings. In this section I draw on the work of critical social scientists such as Deborah Lupton, Sarah Nettleton, and David Armstrong.

Competing paradigms in preventing diabetes.

Analysis of the focus group data reveals that UK general practice is currently navigating two competing paradigms. On the one hand, GPs are incentivised and told to subscribe to the biomedical model of disease prevention, which perpetuates an individualist approach to type 2 diabetes prevention focused on encouraging people to take responsibility and control their behaviour to halt progress of the condition. On the other hand, through their therapeutic relationships, clinicians are very aware of how the social and economic causes of type 2 diabetes play out within their patients' narratives and the complexity of the lives they live. These therapeutic relationships were seen as a longer-term intervention in themselves to try and help people reduce their risk of type 2 diabetes.

The biomedical model of disease views disease development arising from individual biology. 'Pre-diabetes' is portrayed as a medical certainty and people are given prescribed medical advice on how to prevent the perceived linear development to type 2 diabetes. The use of "scare tactics" (presenting the individual with a dire health outcome that could happen if they do not change their behaviour), may seem ethically justified if it leads to behaviour change but could cause harm by perpetuating unnecessary fear and stigmatising

individuals.⁹¹ This form of health promotion messaging is in keeping with wider health promotion messages seen in national disease prevention campaigns.⁹¹

Despite being commissioned to take a biomedical approach to disease prevention the practice teams spoke extensively on the local social and political context in Newham. The descriptive analysis of the social determinants of health illustrates the structural barriers which act to hinder lifestyle changes. The quote below from a south Asian GP discusses how he has never seen type 2 diabetes prevented or hypertension treated through lifestyle changes alone.

“However, it's easier said than done. I do know that I have not been able to control blood pressure just through lifestyle in any of my patients. You know? I've tried my best, because I think that if they reduce blood pressure, if they cut down on their smoking, and then the smoking has stopped, cut down on - they're helping... Unfortunately, I am still waiting for my first success. This has not happened”

FG3 GP

Primary care teams are also experts in their patients' social contexts and the circumstances they must mediate. They see first-hand how the social determinants play out in the lives of their patients and the overwhelming structural barriers they face when trying to undertake behaviour change. The primary care teams do not blame people for their social circumstances, but my findings suggest that they feel they have little choice but to give individualist health promotion messages with limited power or avenues to advocate for community level influences on health.

Critical social scientists and public health scholars such as Lupton, Armstrong, Baum and Nettleton, view the diagnoses of states such as pre-diabetes as a social construction.^{79 88-90 109} Whilst objective (numerical) criteria are used to make the diagnosis, this categorisation effectively situates the cause of disease and pre-disease as a failing of the individual's biology. Delivering the diagnosis in a medical setting, as discussed in the descriptive analysis above, implies that the condition can be treated and that the individual will be able to control the progression to disease through behaviour change. This individualist discourse of personal risk diminishes the condition's complexity and the role of the wider determinants of health in disease development.^{79 93} Focusing on the individual downplays the role of social, economic, and political influences in disease development.¹¹⁰

These authors also point out that primary care-based disease prevention such as annual blood tests and reviews of patients with conditions like pre-diabetes are an example of mass medical surveillance. These initiatives medicalise lifestyles which are socially constructed entities developed from birth.^{88 89 109} Deviations outside normal ranges for HbA1c, weight and waist circumference, may lead to victim blaming which can influence how health messages are internalised by the individual.^{79 92} Patients are encouraged outside the consultation to continue to undertake self-surveillance of their diet, weight and exercise in order to prevent the progression of pre-diabetes. The risk of victim blaming and the potential of perpetuating the stigma associated with type 2 diabetes was acknowledged by the primary care teams as an unintended consequence of current disease prevention strategies.

4.5 Chapter summary

In summary, I have presented my findings from focus groups with primary care teams on their understanding of pre-diabetes and how the condition is managed in primary care. The diagnosis was understood in terms of biology and epidemiology, with shock tactics used to try and motivate participants to change their behaviour. Diagnosing pre-diabetes and focusing on the individual to take responsibility for the condition and to change their behaviour minimises the social, political, and economic influences on type 2 diabetes development. Although the social determinants of health were widely acknowledged by practice teams with detailed local examples given, they felt that they did not have the power to address these and were not discussed with patients. Primary care teams provide continuity of care and, over time, can build trust and therapeutic relationships with their patients. However, the importance of relationship-based care is not acknowledged as part of type 2 diabetes prevention strategy and the primary health care system currently doesn't support this due to the demand on appointments. Critical social science perspectives illustrate the consequences of taking a predominantly individualist biomedical approach to type 2 diabetes prevention, in that it minimises the socio-political complexity of the condition, may perpetuate victim blaming and in some cases stigmatise individuals who face overwhelming structural barriers to lifestyle change.

In the next chapter I will present my findings from the narrative interviews with participants with pre-diabetes focusing on how they interpret the diagnosis and manage the at-risk condition.

Chapter 5 – Pre-diabetes from a patient’s perspective

5.1 Introduction

In the previous findings chapter, I presented my findings from focus groups with primary care teams exploring how clinicians interpret a pre-diabetes diagnosis and managed the pre-condition in a primary care setting. Primary care teams saw the diagnosis as a positive opportunity for people to access surveillance for type 2 diabetes development and gather the knowledge to change their lifestyles either from the primary care team and/or from lifestyle interventions. However, there is a paucity of evidence exploring how people interpret and internalise this risk diagnosis and to what extent the diagnosis leads to lifestyle changes.⁶

In addition, how people interpret the pre-diabetes diagnosis influences whether people engage with interventions or undertake lifestyle changes.^{17 107}

A pre-diabetes diagnosis has several consequences for the patient. Once diagnosed ‘pre-diabetes’ is coded within the participant’s GP record and remains there indefinitely (unless the patient progresses to type 2 diabetes), with consequences for health insurance and their further health care management. The NHS GP contract now incentivises GPs to invite people with pre-diabetes for annual blood tests with alerts within the patient’s record prompting clinicians to offer referrals to the NHS DPP or weight management programmes (if appropriate). Only two of the patient participants lived in an area where the primary care teams were incentivised to provide an appointment for a type 2 diabetes prevention review. The remaining 23 participants lived in areas where GPs were incentivised as part of the Quality Outcome Framework (QOF) to undertake annual blood tests for people identified as

having pre-diabetes, without financial support to provide further care. This impacts diagnosis delivery and management.

In this chapter I discuss the findings from qualitative interviews with people with pre-diabetes, exploring how participants understood the pre-diabetes diagnosis and managed the condition. I begin with an overview of the dataset and my descriptive analysis which illustrates that participants widely accepted and interpreted the diagnosis as a medical entity with little resistance. I explore how people were informed of the pre-diabetes diagnosis, how their relationship with health care professionals influenced how they felt about reducing their risk of type 2 diabetes and their confidence in undertaking lifestyle changes. I complete the chapter by applying critical social science perspectives to the descriptive analysis to gain further understand as to what the data represents.

5.2 Overview of the Dataset

The full list of participants is outlined in Table 3 - pre-diabetes study participants. Fourteen female participants and 11 male participants took part in the study, ranging in age from 41-89 and spanning a wide variety of ethnicities, cultural backgrounds, and professions. Most of the participants fell in the 50-75yr old category, which is when most people develop pre-diabetes. 25 participants took part in the initial interview, 21 participants completed the follow up interview and 17 participants collected contextual observational data. I received pictures of food, environments, shopping, meals, app screen shots and food diaries. The interviews resulted in a large amount of both text (each interview produced approximately 30 pages of transcript) and pictorial data.

The seventeen participants who collected and provided observational data dedicated a large amount of time collecting the materials and, in some instances, participants discussed in the second interview how the process of collecting data had triggered several thoughts and feelings about their lifestyles (a few participants felt upset that although they wanted to change their lifestyles, they did not feel that they could). Several participants used the interviews to explore difficulties in reducing their risk of type 2 diabetes amongst the complexity of their social situations and the dilemmas they face in health-related decision making (this is discussed in full in chapter 6). Some participants reported that taking part in the study helped them unpick why it was so difficult to change their lifestyles.

Study Number	Age	Sex	Cultural background	Country of Birth	DM Family History	Living Arrangement	Accommodation	Occupation
PDM 1	42	F	Afro-Caribbean	Kenya	Father, Grandmother, complications	Partner	One bed maisonette- no outdoor space	Physio
PDM 2	40	F	Asian-Chinese	Indonesia	Father, Mother, both grandparents. No insulin. Siblings have pre-DM	Daughter	Two bed flat- balcony	Doctor
PDM 3	57	M	Indian	India	nil	Wife, two children and daughter in law	Four bed house	Post Office
PDM 4	60	M	Pakistani	Pakistan	Mother, GDM	Alone	Two-bed house – no garden	Businessman
PDM 5	83	M	White British	England	nil	Wife	two bed flat, ground floor, garden	Retired dentist
PDM 6	53	F	Chinese	UK	Mother, GDM	Partner, teenage stepdaughter	two bed flat	Civil servant
PDM 7	69	M	White British	UK	Father	Alone	flat	Engineer
PDM 8	80	F	White British	England	nil	Alone	flat	Retired-finance
PDM 9	72	M	Declined to Identify	London	nil	Wife	house	Textile industry
PDM 10	52	F	Bangladeshi-American	New York	Mother, Father, Grandparents	Husband and two children	House	FT Mum
PDM 11	72	F	White British	London	nil	Alone	Small flat	Ex-publican
PDM 12	78	F	White British	England	nil (mother IHD)	Husband	House, small garden	Retired teacher
PDM 13	80	M	White British	England	nil	Wife	House	Carer (retired engineer)

PDM 14	63	F	Iranian	Iran	Father DM, mother IHD	Husband and daughter	house	Carer and volunteer
PDM 15	76	M	White British	England	nil	Alone	Flat with communal gardens	Retired architect
PDM 16	74	F	White British	England	nil	Partner	house	Media/ retired
PDM 17	68	M	White British	England	Father- HTN CVD<60	Wife and son	house	Finance
PDM 18	83	F	Jewish	south Africa	nil	Alone (widow)	2 bed flat, no garden	Retired accountant
PDM 19	64	M	White British	England	Mother and father	Alone	top floor flat- communal garden	Retired accountant
PDM 20	78	F	White British	Scotland	nil	Alone	flat	Retired publisher
PDM 21	89	F	Jewish	Germany		Alone	flat	Retired insurance
PDM 22	52	F	American (2 nd generation Iraqi British)	Florida- USA	nil	Alone (partner in France, son lives in London)	Flat with communal gardens	Musician
PDM 23	77	F	White	Scotland	nil	Husband	House	Retired
PDM 24	63	M	white	England	nil	Sister	house	Engineer
PDM 25	69	M	Jewish	London	nil	Wife	flat	Doctor

3. Table 5.1 - Pre-diabetes study participants

5.3 Pre-diabetes diagnosis and management

The following section is a descriptive analysis of the data from the participant interviews as well as the observational data. As discussed in chapter 3, the methods chapter, an iterative thematic analysis was undertaken, and four descriptive themes were identified from the data. The following section gives an overview of each theme with supporting extracts from the interviews as either transcript quotations or pictorial data. The four themes identified were the pre-diabetes diagnosis, pre-diabetes management in primary care, lifestyle interventions and self-management.

Theme 1: Pre-diabetes diagnosis

Understanding the diagnosis

Participants felt that diagnosis of pre-diabetes was significant because it was seen as a precursor to type 2 diabetes. The quotes are from participants discussing their understanding of pre-diabetes. Neither was medically trained, but both had good levels of health literacy.

“I understand that my blood sugar levels were very high, and if we didn’t do something about them pretty quick, we were going to move into type two diabetes, which was... although it can be reversible, a much more serious stage of things, the GP said, ‘not to frighten you that much but you’re on the verge’.”

Pre-diabetes Participant 20

“I have a HbA1c reading which is in that sort of zone where it’s not quite diabetes, I think it’s about 40 or something like that. I’m not sure what the units are, you must know that, and it’s been hovering at around 41 or 42. I did have a blood test about two weeks ago and it had gone up a bit probably to about 45 I think so [um] I got to perhaps be a bit more careful

particularly about my weight because I know there's a strong link between weight and diabetes."

Pre-diabetes Participant 17

The first quote above reflects what many participants believed that the diagnosis meant that they were imminently about to develop type 2 diabetes unless action was taken in the form of lifestyle change. Secondly, as described by participant 17, the diagnosis was understood as a numerical diagnosis defined by diagnostic thresholds. Most participants discussed their results as being on the borderline or on the "verge" of type 2 diabetes. When discussing the diagnosis, the participants, without being asked or prompted, linked their lifestyles to the diagnosis. They ascribed blame to their eating habits, weight, lack of exercise, or alcohol intake. As discussed by the participants above, if something wasn't done to improve their lifestyles, they felt that developing type 2 diabetes was an inevitability. The only exception to this were participants who had a strong family history of type 2 diabetes who felt that type 2 diabetes development was an inevitability. The language the participants reported being used by health professionals to explain the diagnosis aligned with the findings of chapter 4, where scare tactics were employed to try and motivate individuals to reduce their risk of type 2 diabetes. None of the participants resisted the pre-diabetes diagnosis owing to the relational nature of pre-diabetes to type 2 diabetes and the quantifiable nature of the investigation results which define the condition.

Theme 2: Pre-diabetes management in primary care

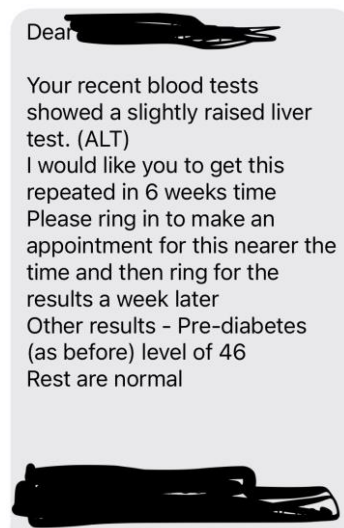
Communicating the diagnosis

The diagnosis of pre-diabetes was communicated to participants in a variety of ways including telephone consultation, text message or written letter from their GP. Below are two examples of communication from GP practices, the first explaining a new diagnosis of pre-diabetes via letter, and the second are annual blood test results communicated via text message. Both participants had professional backgrounds and a good level of health literacy.

I received the results of your blood test which demonstrated 2 things:

1. Your blood sugars are in a range that we would classify as pre-diabetic. This means that you should take precautions with your diet and exercise to try and lower your risk of progressing to diabetes. I have included a little information which I'm sure you already know about with regards to dietary advice. There is also a diabetes prevention programme that you can enrol in if you would like support with this.
2. Your cholesterol is high, although it is improved from when last checked in 2017. We could offer you cholesterol lowering medication if you would like to try to help bring down further, otherwise again managing this with diet is important.

1. Figure 5.1 - Letter extract from participant 23



Dear [REDACTED]

Your recent blood tests showed a slightly raised liver test. (ALT)
I would like you to get this repeated in 6 weeks time
Please ring in to make an appointment for this nearer the time and then ring for the results a week later
Other results - Pre-diabetes (as before) level of 46
Rest are normal

[REDACTED]

2. Figure 5.2 - Text message from participant 2

Neither of the two correspondences give an explanation as to what pre-diabetes is or sign post the participant to information should they have queries. Participant 2 reported that she had never had a consultation discussing pre-diabetes and participant 23 reported that the

patient information leaflets she received gave general information on the importance of staying active and eating healthily (although these weren't available for review at the time of interview). The participants hadn't discussed with a health-care professional how they felt about being told they had pre-diabetes, and therefore did not have an opportunity to explore their fears or concerns with the primary care team.

Lifestyle advice from primary care teams

The lifestyle advice participants received from their GP varied in detail and nature. Many reported that they received some lifestyle advice when they were informed of the diagnosis, others reported that this was done opportunistically at consultations related to other matters. Examples of these discussions are outlined in the quotes below. The first from participant 1, an Afro-Caribbean patient, discussing weight management conversations she had with a GP. The second quote, from a south Asian participant 3, discussing the exercise and eating advice he received from his GP.

"I think when they do my BMI it never, has never been in a normal range. Oh, I think once I'd had the fibroids out, I went in for my check, a six week check with a GP, and they told me "Well done." I remember that very well because he said, "Well done, your weights down." I don't remember it's probably like, I was probably like 60 kilos at the time, and I was like, that's fine but I've not been eating anything but soup for six weeks... no-one's ever asked me what do you eat?"

Pre-diabetes Participant 1

"The doctor said if I do exercise regularly then this will be controlled, and this can be prevented. The doctor said last time not to eat any fruit. I think fruit is sweet, that's why maybe she said not to eat it. I used to eat apple sometimes, but I stopped it now."

Pre-diabetes participant 3

The quotes suggest that very little exploration was undertaken into the everyday lives of patients. Any information or discussions undertaken were reported as largely didactic with information flowing from clinician to patient. Due to the brevity of GPs time, participants were often told to eat healthier or do more exercise without further details of the patient's context. In the quote from participant 1, the clinician is inappropriately congratulating the participant on her weight loss, which was due to being in so much pain post-operatively that she was unable to eat anything but soup. Further on in the interview the participant reported that clinicians often made assumptions on her diet based on her ethnicity. Equally, participant 3 had been told to avoid apples, which was the only fruit he ate, leaving him confused as to what he could eat as a healthy snack. In addition, this participant reported that he had also been told to avoid lentils and rice, given his south Asian cultural background this was impossible for him to follow. Several participants reported that they were confused as to what advice to follow regarding their diets. Some participants had been signposted to leaflets and websites but none of this information was applicable to them. Participants reported that they obtained their own information from the internet, friends, family, gym instructors and colleagues.

Consultations and management by primary care team

The management of pre-diabetes was discussed by participants in terms of annual blood tests to ensure they hadn't progressed to type 2 diabetes with lifestyle advice given at the time of diagnosis, at annual reviews (if commissioned) or opportunistically in consultations for other matters. During the interviews some participants reflected on their experiences of the primary care health system and how this impacted their ability to reduce their risk of type 2 diabetes. Below are two contrasting experiences of the primary care teams, firstly from participant 10 a south Asian female participant and participant 24 a white British male.

"I did adjust my diet, but I thought that because everything was done over the phone I felt like slightly abandoned by the system because the follow up was so far away, you know, it was months and months between check-ups and it just seems very anonymous. I never really knew my GPs because the system is like you deal with different GPs so because you don't really, even though they say you have a family doctor, you never really see that person, you know."

Pre-diabetes participant 10

"we get a really good diabetic care, because she's (the nurse) has got so much background information. Cause that's what her master's was on. So, she is probably more aware of a lot of the issues."

Pre-diabetes participant 24

The participants are discussing the importance of tailored information and continuity of care within primary care teams. This affects their patient experience and how supported they felt in reducing their risk of type 2 diabetes. Participant 10, a busy mum of two children, did not feel supported by the primary care system in her efforts to reduce her risk of type 2 diabetes, she saw a different clinician each time she attended the practice and hadn't formed a therapeutic relationship with any members of the clinical team. The participant had, what is now seen to be as an outdated perspective of what a GP should be as a 'family doctor', implying that she wanted to see the same person at each consultation, who knew her background and that of her family and was there to care for the participant and her family when needed. This participant had a very strong family history of type 2 diabetes and was keen to try and minimise her risk. However, most of the information she had received centred around weight loss, which as someone with a low BMI left her confused as to how to minimise her risk of type 2 diabetes. In contrast, participant 24 offered a very different narrative of the support provided by his practice. This participant's practice nurse had advanced training in diabetes whilst also being a personable and approachable clinician. This patient was reviewed by the nurse annually and had developed a therapeutic relationship

with her. He trusted her knowledge and judgement and felt comfortable discussing his social context and lifestyle with her. The practice nurse offered tailored lifestyle advice and the participant felt supported and encouraged to make changes to his lifestyle which resulted in a large amount of weight loss.

Theme 3: Lifestyle interventions

Seven of the participants had attended a lifestyle intervention. Other participants had either not been offered a referral or declined to attend. Work schedules or caring responsibilities were the most common reasons for not attending these. A few participants felt they had sufficient knowledge on how to prevent type 2 diabetes, but it was enacting this knowledge that they found difficult.

For those who did engage in the interventions there were mixed experiences of the these which impacted the quality of the information they received and how they felt about lifestyle change. The first quote is from a participant who partook in an online type 2 diabetes prevention course during a COVID-19 lockdown, the second from a participant who partook in a face-to-face group course before COVID-19 and the third quote is from a female participant who partook in a recent online NHS digital weight management intervention.

“It was a, it was a mixture of, you know, some, some people came every time, other people didn't. Some people didn't understand what the program was. So, a lot of time was repetition. Uh, people were dropping out of the calls, and as we were going along, um, a lot of people didn't really want to participate, actively. You know, they'd just sort of sit on the phone and then at the end. So, I didn't really understand much of that. So, it was all, really, quite hard to, benefit and to motivate through those calls.”

Pre-diabetes participant 19

“Very interesting, very wide-ranging but of course it depends on the main lecturer, and she was quite young and personable and brought a very disparate group of people together. All of different weights [laughs] and sizes and backgrounds and managed to co-, inspired all of us.”

Pre-diabetes participant 16

“I have some frozen Dim Sum usually in my freezer so on the days where I’m like, ‘Oh, you know, I wish I’m going out for Dim Sum but actually I’m just going to save this for my breakfast and then I said to her and she’s like, ‘Oh that’s interesting, what are all of those?’ you know, like she’s never seen it before. And I said, ‘Oh that’s a Dim Sum, that’s like a bit of prawn thing there, prawns in those dumplings.’ I think she thinks it’s probably not as high in carbohydrates as it is because she doesn’t know what they are.”

Pre-diabetes participant 2

As we can see from the feedback of these participants their experiences varied hugely. The participants discussed three different ways of engaging with an intervention, face to face, an online group, and an app-based course with feedback from a lifestyle coach. Those who took virtual courses reported that it was much harder to engage with the learning. As illustrated from the second quote above the participant who attended a face-to-face course with an enthusiastic facilitator reported the most positive experiences. The interactions with the other participants were just as important as the facilitator in assisting learning and development throughout the course. Participants from Asian backgrounds, such as participant 2 above who had an Indochinese cultural background, found that the interventions were not culturally competent. As seen in the quote, the coach from the app did not recognise a picture of the dim sum the participant had for breakfast. The coach then could not give advice on culturally competent alternatives for the participant to eat. The participant disengaged soon after this encounter, she felt that the intervention was not applicable to her and her social-cultural context.

Most of the participants who had taken part in interventions reported that there were one or two learning points which they learnt from the courses and tried to implement these into everyday life, whether it was to increase their self-monitoring, avoid certain foods or limit their food portion sizes. Participants reported that interventions were not purely focused on diet and exercise information but encouraging participants to increase their self-surveillance to facilitate these lifestyle changes. After the intervention people found it difficult maintaining behaviour changes without the ongoing support and accountability, which was part of the programme (such as weight monitoring). Some participants lived in areas which supported lifestyle change beyond the interventions with gym memberships and food vouchers; however, this support has now been stopped.

Theme 4: Self-monitoring

Away from the consultations and interventions, individuals reported trying to manage their risk of type 2 diabetes in the form of self-monitoring. The example below from participant 22, a 52yr old woman with an Iraqi cultural background describes calorie monitoring whilst eating out, whilst participant 23, a 77-year-old Scottish woman describes how weight monitoring influenced her portion sizes and alcohol intake.

“Well, I used to go to Pizza Express, the pizza that I really like is nearly 1000 calories. I do not get those anymore. So, I go for the one which has the hole cut-out and salad in the inside. I'm not gonna eat something which is my total day's calorie in one meal,”

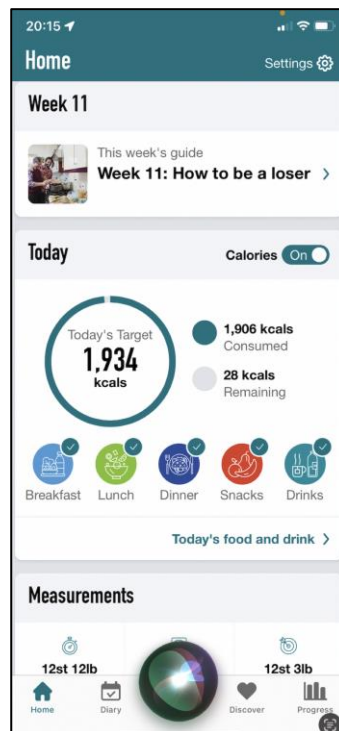
Participant 22

“I do weigh myself every day. It keeps you on that straight and narrow. You know where you've erm, had an excessive meal or the odd glass of wine. You know to not have another glass of wine, in the next week or so. And it will [the weight] balance down again.”

Participant 23

All participants reported engaging in some form of self-surveillance including monitoring weight, calorie intake, food nutritional content, clothing sizes, portion sizes, step counts to some degree. The frequency varied greatly between participants with some undertaking self-monitoring in multiple forms daily, whilst others did this infrequently. Some participants wrote down their monitoring in diaries, whilst others used apps to monitor their physical activity or dietary intake. Participants partaking in self-monitoring most intensively, as seen in the quotes above from participant 22 and 23, reported that this helped control their health-related behaviours.

Below is a screenshot from participant 22's NHS weight management app, a 69-year-old male participant.



3. Figure 5.3 - Screenshot from the NHS weight management app sent by participant 22

Participants such as participants 22 and 23 felt reassured by monitoring their numbers whether that was by using apps or a paper diary to do so. They felt that it was a way of exerting some control over developing type 2 diabetes, which they felt was largely unpredictable. Sometimes participants reported that if they did exercise, they had earned their 'treat' or if they reduced their calorie content for one part of their day, they would add in a pudding later on. Participant 22, whose app screen shot is above, reported 'allowing himself' a kit-kat if he was within his daily 2000 calorie limit by the end of the day.

However, self-surveillance also had some negative effects for some participants as discussed in the quotes below from participant 1.

"It just it draws your attention to it in a, I don't think in a healthy way because then I'd say I'm eating well, I'm exercising, I'm fine but if I stepped on the scale in the morning and it was different from yesterday, I'd be like why, '

Pre-diabetes participant 1

"it seems to be very much the consensus of you can't be on a low calorie diet forever, I was noticing things like headaches, I pretty much had a constant headache"

Pre-diabetes participant 1

This participant had a very strong family history of type 2 diabetes and cardiovascular disease and so therefore had tried many different approaches to try and minimise her risk, including strict self-monitoring and very low-calorie diets. This participant illustrates how self-monitoring can lead to some quite harmful and unsustainable behaviours such as severe calorie limitations. Although the quotes from participants 22 and 23 could be interpreted as successes in type 2 diabetes prevention and examples of exemplary self-control, they could

also be interpreted through a different lens. Firstly participant 22 thought that she should only have had 1000 calories a day and was often disheartened if when she deviated from this. Whilst participant 23 controlled her lifestyle so closely with regards to weight gain, keeping oneself on the 'straight and narrow' could be seen as a state of over stringent self-governing and self-control. Several participants found self-monitoring disheartening and making them self-conscious, particularly if they had fluctuations in their weight or deteriorations in their blood test results which they couldn't account for.

5.4 Pre-diabetes: navigating a new risk state.

In the following section I apply critical social science theoretical perspectives to my descriptive analysis exploring how individuals navigated the liminality of a 'pre-diagnosis' and the individualist diabetes prevention pathway. I complete this section by reflecting on the role of relationship-based care and the primary care health system.

Navigating liminality

A pre-diabetes diagnosis was widely accepted by participants as a defined medical entity. What was less certain from the participants was how to respond to the future risk of type 2 diabetes and to what extent they should change their lifestyles. Participants were navigating a liminality of not yet having the disease (type 2 diabetes) but also no longer considered well, whilst having varying degrees of fear about developing the condition. In the first quote below participant 17, a white British male, is talking about his response to the pre-diabetes diagnosis, and in the second quote the same participant is discussing how they would respond differently if they developed type 2 diabetes.

“Yes, I mean they tell you it’s above the completely normal range but it’s not in a range that requires you know, it’s not at a level that requires any intervention but it’s sort of an amber light where you’ve got to be a bit more careful about things. With regard to diet, exercise and weight and that’s pretty much it.”

Participant 17

“Both of those things, I don’t want to get to that stage so I would immediately lose weight, I would immediately cut out, you know, sugar and cut back on carbohydrates. I’d immediately start taking more exercise. I mean those are the only three lifestyle things you can do.”

Participant 17

This difference in the response between the pre-diabetes state and the type 2 diabetes state was consistent throughout many of the interviews. People seemed to be unsure to what extent they should change their lifestyles in the ‘at risk’ state, whilst reporting that if they became diabetic, they would undergo big lifestyle changes. How people navigated this ambiguous risk state was closely linked to their habitus. As discussed in chapter 3, an individual’s ‘habitus’ is a set of dispositions which are developed over a life course from our social context (including upbringing experiences, gender roles, cultural background).⁹⁶ An individual’s habitus normally assists them to navigate different social contexts. In terms of the pre-diabetes diagnosis, all the participants accepted the diagnosis because it was usual practice within their habitus to accept quantified medical information within the social context of a GP consultation. Additionally, an individual’s experience of type 2 diabetes amongst friends and family (also part of their habitus) influenced how they internalise and respond to the diagnosis. The quotes below are from two participants whose immediate family members had type 2 diabetes.

“Obviously knowing that my family, like my grandmother lost both her legs. She had double amputation, so I think I just thought about that and thought, ‘I’d rather not.’

"I think that'll be motivation for me to do something, you know, and I think the fact that I have seen a lot of my family members with diabetes who all led I would say fairly normal life because nobody really had very bad diabetes and because of the family history and this inevitability it I think I just feel like yes I'm continue to try to be healthy, I could probably do a little bit more."

If participants were exposed to people with type 2 diabetes and its complications throughout their childhood and into their adult lives, they were more likely to be fearful of developing type 2 diabetes as adults. This experience had become part of their habitus as illustrated by participant 1. The second participant differed to the first in her responses, although she felt that type 2 diabetes development was inevitable, she hadn't drastically altered her diet in response to a pre-diabetes diagnosis because her own experiences were of family members living well with type 2 diabetes.

As seen in the descriptive analysis, some people navigated their liminality by undertaking self-surveillance, which I have interpreted as a process of trying to create some certainty and control over the development of an unpredictable and complex condition. Self-surveillance helped some people make changes to their lifestyles, but these changes had to be congruent with their habitus and social context (discussed further in chapter 6). The process of undertaking self-surveillance is also a social practice, undertaken by participants if it was within their habitus to engage in such behaviours, for example having the necessary health literacy to engage in the NHS weight management app, as shown by participant 22. However, self-surveillance did not necessarily equate to lifestyle changes with participants aligning

with the lifestyles of the people around them and their social contexts. This will be explored in detail in chapter 6.

At-risk individuals

From my analysis, I've shown that all the participants accepted the pre-diabetes diagnosis. For all participants the diagnosis was delivered by a medical professional, supported by numbers, graphs, diagnostic cut offs, and coded in the patient's medical records. Many participants understood pre-diabetes as 'before diabetes' adding an inevitability to this diagnosis unless something was done by the participant to change their trajectory. The annual surveillance undertaken by primary care teams and self-surveillance individuals carried out themselves acted to further reaffirm the diagnosis as a failing of an individual's biology and lifestyle. When discussing the diagnosis participants inherently tied the diagnosis to their own lifestyles, creating a lifestyle condition. This individualist discourse of type 2 diabetes development diminishes the condition's social complexity and the structural determinants of health, key in type 2 diabetes development,^{79 93} and will be explored further in chapter 6. This interpretation mirrors my findings from the focus groups of primary care teams, discussed in chapter 4.^{79 88-90 109}

From the descriptive analysis I've shown that the surveillance and medicalising of lifestyles continues beyond the consultation into the everyday lives of the individual. Critical social scientists such as Armstrong argue that health promotion strategies, such as those undertaken in type 2 diabetes prevention, over medicalises lifestyles through surveillance medicine.^{88 89 109} From the interviews there were a number of negative consequences of health promotion messages (such as self-blame, over stringent self-surveillance, severe calorie restriction) delivered through primary care and lifestyle interventions. From the

examples above I have identified stigmatising consequences of weight loss discussions undertaken by primary care. Deviations outside normal ranges for HbA1c, weight and waist circumference, left participants disheartened if their prevention efforts were not reflected by improvements in the bio-medical markers.^{79 92} This further places the responsibility on the individual to reduce their risk of type 2 diabetes. In the descriptive analysis I also identified examples of lifestyle interventions giving culturally incongruent feedback to participants, leading to disengagement in the interventions and perhaps further stigmatization of these individuals.

Relationship based care

From a health systems perspective, this prevention policy was introduced into primary care with case finding, testing, recall and communication of results being undertaken differently by different GP practices. In the interviews there were isolated examples of relationship-based care with health professionals given dedicated consultations to explore lifestyle change with participants. In most cases, it was left to the GP to communicate results without an appointment (so in the form of text messages and letters), leaving the patients feeling confused and unsupported. Relationship-based care was also discussed by the clinicians in the focus groups as an important prevention strategy (see chapter 4). Gently encouraging behaviour change over time through multiple consultations, gaining trust with patients and discussing their lifestyles was discussed as a slow yet effective strategy. The analysis from this study suggest that the health system doesn't currently have capacity for relationship-based care to be part of a type 2 diabetes prevention strategy.

5.5 Chapter summary

In this chapter I have explored how participants internalise a diagnosis of pre-diabetes.

Mirroring the findings from the focus groups with clinicians, the diagnosis was understood as a biomedical and numerical entity. Most participants related the diagnosis inherently to their lifestyles, placing the responsibility of type 2 diabetes prevention on the individual. Health promotion messages in primary care settings were effective if it was supported by the health system, with time and space for exploration of an individual's social context, within a therapeutic relationship. Participants managed their risk by partaking in self surveillance of their weight or food intake. For some people this gave them a feeling of being in control of their progression to type 2 diabetes. For others this had negative consequences, particularly if they gained weight without an obvious reason. Many participants found it very difficult to change their lifestyles despite self-surveillance methods.

Critical social science perspectives illustrate that participants were navigating a liminality of not being 'well', whilst also not having a disease state. This led to confusion on the strength of their response to the 'pre-diabetes' diagnosis. People with pre-diabetes were navigating the two competing paradigms of disease prevention, on the one hand they were trying to abide by the prescribed individualist biomedical approach to type 2 diabetes prevention but found that this did not align with the socio-cultural complexity of their everyday lives.

In the next chapter of my thesis, I will explore how people with pre-diabetes incorporate this diagnosis in making everyday health related decisions away from the medical consultation and lifestyle interventions.

Chapter 6 – Navigating lifestyle change with pre-diabetes

6.1 Introduction

In the previous two findings chapters I presented my focus group findings with primary care teams and findings from the first part of the narrative interviews of people with pre-diabetes. There, I explored how clinicians and patients interpret a pre-diabetes diagnosis and manage the condition. In this chapter I discuss my findings from qualitative interviews and observational data on how participants navigate lifestyle change and make every-day decisions on food and exercise. The purpose of informing people that they are at risk of having type 2 diabetes is to provide the person with an opportunity to reduce their risk of progressing to type 2 diabetes by attending lifestyle interventions and then enacting lifestyle change. However, these interventions have high attrition rates and there is little evidence for long-term sustainability of any lifestyle changes.^{15 16} In addition, these interventions have been found to be less effective in women and those from deprived minority ethnic groups.²⁵ Despite the NHS Diabetes Prevention Programme having been in place for six years, the incidence of type 2 diabetes continues to rise.

The aim for this part of the study is to understand how people navigate their lives with the knowledge that they are at risk of type 2 diabetes and how this influences their lifestyle choices. This led me to explore the enablers and inhibitors to lifestyle change and how participants navigated different social contexts. As discussed in the methods chapter, I performed narrative and follow up reflective interviews with participants who have been diagnosed with pre-diabetes. Between the interviews participants collected observational

materials (such as food diaries, pictures of food or restaurant menus) which gave invaluable contextual data and led the discussions in the follow up interview. Throughout the interviews I found that food related activities (eating, purchasing, preparing) were key social practices, and important to the development of an individual's identity whilst also being an essential tool in relationship building amongst friends, family, and work colleagues. From the data analysis I found that lifestyle decisions are the result of a complex interaction with an individual's habitus, their social context, their ability to navigate social rules and to what extent their capital (social and financial) facilitates lifestyle changes.

A full description of this data set was given in chapter 5 with Table 5.1 giving a demographic description of the participants.

6.2 Food and the practice of eating for those with a pre-diabetes diagnosis.

The following section outlines the descriptive themes identified from the data analysis, based on what participants described as the main influences on their lifestyles. What links all these descriptive themes is that food and the practice of eating is not something that people undertake in an isolated social vacuum, it is something people do with others in a variety of different environments.

"Food is not something you do in isolation, it's something you do with other people."

Pre-diabetes participant 22

Eating at home

All participants discussed the practice of eating food as something that forms a key social practice. People who live alone discussed making plans to invite friends over for dinner or ate outside the home. In the interviews all participants recognised its importance in relationship building. For those living with a partner or children, the practice of eating together as a unit (in whatever form that was), was very important to participants with many waiting for grown children or partners to get home from work to eat, even if it meant eating late at night.

Many participants reported that the strongest influence on what they ate was their partner. If a partner's habitus was in-keeping with prescribed lifestyle advice, it was easier for the participant to adjust their lifestyles. This is illustrated by this response from participant 1, who lives with her partner.

"Oh, it was quite easy, I think I was like, 'I think I've got diabetes and he was like, "Oh my God, we must make sure you have all the vegetables. I think it would be harder if he wasn't supportive because he sits in my house all day."

Pre-Diabetes Participant 1

In this example, the spouse was training for a half marathon and so already ascribing to the lifestyle changes the participant herself was making. This spouse exercised regularly, ate well, and ensured the home environment supported the participant's lifestyle changes as well as going out for walks together and encouraging each other to exercise.

In contrast, if a partner had different health beliefs, then it was harder for the individual to change their food choices. In the example below the participant lives with her husband who had a different socio-cultural upbringing, and liked a diet based on meat, carbohydrates and drank alcohol to excess.

“He’s doing pork medallions in some vegetable casserole. It will involve potatoes knowing him. He doesn’t feel a meal is complete without them. Sometimes I can avoid them, you can’t if they’re in a pot. The evening, I mean I have to say he’s an alcoholic so that’s another problem for me to cope with.”

Pre-Diabetes Participant 16

This made it particularly difficult for this participant to change her lifestyle. Living with someone with addiction is incredibly stressful and isolating as suggested by the participant at the end of the quote. The participant did not feel able to put her own needs before that of her partner.

In the next example, participant 6 who lives with her partner (unmarried) and his daughter, discussed a particular issue of having chocolate in the house, which in this example was kept in a drawer below the TV.

“ ‘yeah and I was telling her about the chocolate drawer and it’s, you know, it is quite difficult for me,” and he was like, “Oh don’t be ridiculous, chocolate is good for you, even milk chocolate.”

Pre-Diabetes Participant 6



4. Figure 6.1 - Picture of the household chocolate drawer

At the end of the day, the participant and her partner shared a daily practice of watching TV and eating chocolate. As seen in this example, the participant resorted to using the interview as a tool to be taken more seriously with how she needed the home environment to adapt to support her lifestyle change. In response her spouse dismissed her concerns calling her ridiculous and emphasising his own health beliefs.

Several participants explained that if they tried to change the food options at home, they were met with resistance, and at times this led to conflict with their spouse and children. The quote below is from participant 14, an Iranian lady who lives with her husband and adult daughter. She found it particularly difficult to change the meal options at home due to repeated conflicts with both her husband and daughter.

"My husband and I and our third daughter is here at the moment living with us and she loves a lot of food with sauces and things which I cannot eat and there's a lot of problem if I say I'm not going to eat this because it's got sauces in it or it's got this in it, it becomes quite an issue, that I'm making a lot of trouble at home so I just, I just go with the flow. Yeah, it becomes too stressful, you know, otherwise we have to cook for three people because [daughter] is very fussy, and the food that she eats is calorific."

She reported that they did not understand why changes to eating practices needed to happen as she did not have type 2 diabetes yet. To avoid these conflicts this participant reported conceding and going along with what others wanted to eat to maintain their relationships. Others reported that family members had different ready-made meals or different take-aways to prevent disagreements. This and the proceeding two quotes show how incredibly difficult it is to change your lifestyle without the support of people immediately around you.

Caring responsibilities

Participants with young children or relatives with significant health conditions found it particularly difficult to adapt their lifestyles to minimise their risk of type 2 diabetes. For participant 2, a single mum,

“You have to take into account what she wants to eat, so things that may be healthier and may be better for me, if I take half an hour to cook it and she doesn’t want to eat it, I’ll have to spend another twenty minutes to make something else for her [daughter].”

Pre-Diabetes Participant 2

In the next example, the participant is a carer for his wife who has dementia. Similarly, to the previous quote the participant adjusted his meal options to meet his wife’s high calorie dietary requirements as well as requiring a soft diet due to difficulty swallowing as discussed below.

“She eats different things now. Her problem really, she’s not eating enough so it’s quite the opposite problem, so I try to encourage her to eat chocolate cake, eat lots of ice cream. That we did have a consultation with the doctor, and she said, “Yeah, eat as many sweet things as

you possibly can,” and I try to get her to eat mashed potatoes, she seems to like those. Anything which is not very hard I think she quite likes the mashed potatoes, things that are easy to swallow.”

Pre-Diabetes Participant 13

As seen in these quotes the participants prioritised cooking quick and easy meals that met the needs of the people they were caring for even if they weren't the right meal choices for them. It may appear that cooking two meals might be the solution and that this was a straightforward adjustment. But practically, thinking of three meals a day for each family member is a huge undertaking especially as this is only one task required in running a household. The six participants who had caring responsibilities also found it very difficult to exercise or have time alone, even when their children were older. For participant 13, he found it impossible to leave his wife at home due to the anxiety she experiences when alone. Neither participant had the support of family or friends who could assist and provide respite care. These accounts give an insight into the exhausting nature of care giving, not leaving the participants with pre-diabetes much time or energy to look after themselves. This made it incredibly difficult for these participants to attend lifestyle interventions or undertake activities (such as going swimming or to exercise classes) which could help with reducing their risk of progressing to type 2 diabetes.

Cultural influences on food

Many participants discussed the influence of their cultural background in their everyday food choices. Participants talked about eating practices learned in childhood continuing throughout adulthood and influenced current day purchasing, cooking, and gardening practices. This was discussed in detail by participant 6 who had a Chinese cultural

background (see quote below) and participant two who had a Bangladeshi cultural background.

“My grandmother was very loving and was a great cook of especially of, really quite gorgeous Chinese food, so I kind of picked that up and associated that with her. And my father was a kind of, you know, something like, like something out of the Good Life, he was desperately trying to grow his own veg because he loved feeding his own family with fresh vegetables and telling you this now, I realise to the extent to which my own kind of attitudes to food still reflect that.”

Pre-Diabetes Participant 6



5. Figure 6.2 - Picture of a Bangladeshi curry

It is important not to underestimate the importance of these experiences. Cooking with other family members was an important source of enjoyment and provided a bonding experience. Participants tried to reproduce these experiences with their own family and symbolised a passing on of love and comfort, rather than preparing food purely for fuel. For participants these cultural practices gave them a sense of understanding of who they were

and a sense of belonging to their families. Cooking these foods regularly for their own families symbolised passing on this love to future generations.

Some meals held significant value for several participants. This was illustrated by the discussion of Jewish chicken soup with both participant 22, who lives with his wife and regularly sees his grown-up children (who he is discussing in the quote), and participant 21, a grandmother with a large extended family.

“Not always but my wife she will often cook it [chicken soup] because the kids like it, so we make a huge, big pot of it and my younger son, so we see quite a lot of the kids who have got the grandchildren. My youngest son he’s got a girlfriend, he’s the one who got engaged. We see him less often. When he comes round on a Friday and likes to have, he says, “Can I have some chicken soup please?””

Pre-Diabetes Participant 22

“if you eat chicken it’s chicken soup, which we always say is Jewish penicillin. We’ve always had that. ‘Cause it’s meant to cure you of everything that’s wrong with you.”

Pre-Diabetes Participant 21

In these examples chicken soup is not prepared for its nutritional value but rather because it is a traditional food shared with family members for the Sabbath meal. The first quote shows how the meal is used to maintain intergenerational closeness, an exchange of warmth and love within the family unit, whilst maintaining family traditions.

The second quote illustrates that this traditional soup was thought to have medicinal properties, with the participant believing that this comforting food could heal multiple

ailments from stress to colds. Healing properties of foods was a belief shared by many people from a variety of different cultures.

Celebrations

Participants discussed the importance of celebrations and being able to fully partake in these which meant eating the food associated with the event. The celebrations discussed included, birthday parties, religious festivals, Thanksgiving, and Christmas (including related activities such as carol concerts). Participant 11, a Pakistani national, was particularly daunted by the prospect of attending a week-long wedding ceremony in Pakistan as seen in the quote below. Similarly, but perhaps a more everyday social gathering, participant 1 discussed attending a BBQ for her neighbour's birthday see pictures of the food prepared below. The party happened in the communal gardens where the participant lived.

“But then when I go home back to Pakistan for example then that one week will be disaster for my food, you know, because I’m going, attend some wedding ceremonies so you imagine this, you know, what kind of food they serve there.... Biryanis, rice probably, naans, parathas, kebabs, fried samosas, everything, and a lot of desserts every day.”

Pre-Diabetes Participant 4



6. Figure 6.3 - Picture of BBQ food with neighbours from participant 1

The food options available during both celebrations were high in sugar, fat, and carbohydrate. These participants (and others in similar situations) did not feel they had much choice but to partake in the celebrations which meant eating the food. These foods have shared cultural meaning with their social group and family. The examples above show how difficult it is to break from social food norms and change lifestyles in these circumstances. Belonging to their social cultural group was of vital importance to many participants. I explored this further with participant 19, asking why it was so difficult to break the rules at celebrations, the participant himself had recently attended a carol concert and had eaten several mince pies and a large amount of alcohol.

“Whereas with external parties or [people] who you might not meet that often or if you’re meeting someone for the first time and they offer you something... I suppose...you feel especially obligated to take it. As if part of forming that relationship”.

Pre-Diabetes Participant 19

The key point here for participants is that if they were not seen to be eating the food, part of the event, it would appear (both to the participant and others) that they were not fully engaging in the event. Participants felt this would threaten the formation and maintenance of new and existing relationships leaving the participant socially isolated, a feeling that not many people could tolerate.

Eating out with others

Most participants reported that they partook and enjoyed social eating outside the house, this included going out for dinner, pub lunches, summer BBQs and picnics, coffee and cake, attending art galleries, food markets. These activities ranged from weekly to monthly and partaking in these gave participants great enjoyment. Participants who lived alone discussed going out with friends as particularly important as these events provided protection against social isolation and helped improve mental wellbeing (even if this meant consuming large amounts of cake). Participants reported following the social norms and eating the food that was part of the environment (e.g., burgers at a BBQ). Different environments and settings were associated with different social rules. The pub came up several times in the interviews. In the following quotes and illustrations participants were attending the pub with friends and family members and discussing their food choices.

“Yesterday when we went to the pub for lunch, it’s Sunday, I want a Sunday roast, usually I have the pork belly, that’s my favourite roast, 2600kcal was on the menu. It just turns you off right away, I ended up having the burger and chips which was like 1600kcal or something. But I think the fact it’s there in your face, makes you rethink your options. Even pudding, sticky toffee pudding was 900kcal, I know! 900kcal for a sticky toffee pudding with ice cream. It’s like a day and a half’s calories if you had chosen that. So I had the brownie instead which was like 650kcal.”

Pre-Diabetes Participant 2



7. Figure 6.4 - Pub lunch pictures from participant 25

When people went to the pub, they would make a point of choosing things that they would not normally eat at home. In the first quote the participant discussed how she changed her food choices to be lower calorie options when she went out for lunch at the pub (in response to the public health intervention labelling foods with calories), but she still made choices in keeping within the context of the pub. Eating a burger and chips instead of roast pork belly is better from a calorie perspective, but still a choice high in saturated fat, salt and ultra-processed food. Similarly, the pictures from participant 25, show an almost identical meal of steak sandwich, chips, and pudding. Sitting in the pub environment, participants innately knew the rules as to what was socially acceptable to eat in that setting. For participant 2, a single-mum, meeting friends was particularly important to prevent social isolation. Participant 25 was meeting his son and grandsons who he doesn't see very often. Consequently, deviating from the pub norms and eating something like a salad was not seen as an option for participants because they wanted to fit in with the social group around them.

This behaviour pattern was seen in restaurants as well as pubs. In the next example participant 10 is discussing eating out with extended family members who were staying with the participant for the Christmas holidays. She had to cater for the interests of family members who wanted to go out and eat unhealthy items most days.

“the holidays, my brothers were over, so we went out all the time and they love eating bad food, a lot of Korean fried chicken burgers and they were like on this kick, so they eat a lot of that, too much. Of course, they’re on holiday as well but they really, you know, I, we cook a lot at home, it makes you quite-, everything’s quite fatty and very salty and sweet and urgh, so anyway. I love it but then after I, I have it, like I love it the first time. The second time I get it and then it’s like horrible, so I never eat it again. But when I was with my brothers, no there’s no options there, it’s just all bad.”

Pre-Diabetes Participant 10

As seen in this example the participant still felt obliged to continue eating unhealthy foods even though after the first episode, she no longer enjoyed these meals. This example illustrates how difficult it is to vocalise objections to family members and suggest alternative eating venues which might better suit the participants needs. Then once in the environment it does not seem that the participant had much choice but to order what was available. Going to a restaurant and not eating because of menu limitations, whilst others eat around you would break several social rules and, participants felt, would likely result in comments from the members of the social group. Here the participant is both constrained by her environment whilst also choosing not to create any conflict and abide by social norms.

Eating at work

Many participants discussed that work food environments did not support healthy food choices. Participant 2, an NHS worker, below is discussing food options available at the hospital canteen where she works.

"I usually do pack my lunch to work so, you know, and that because I know the days that I don't pack my lunch and I end up eating from, getting something from the work canteen is always, you know, I always regret it after that because basically they're not that healthy and they're always bigger portion. I hate wasting food and you end up finishing everything and then feeling quite sick after that because you've eaten something that's a lot more than you want, than you should be eating."

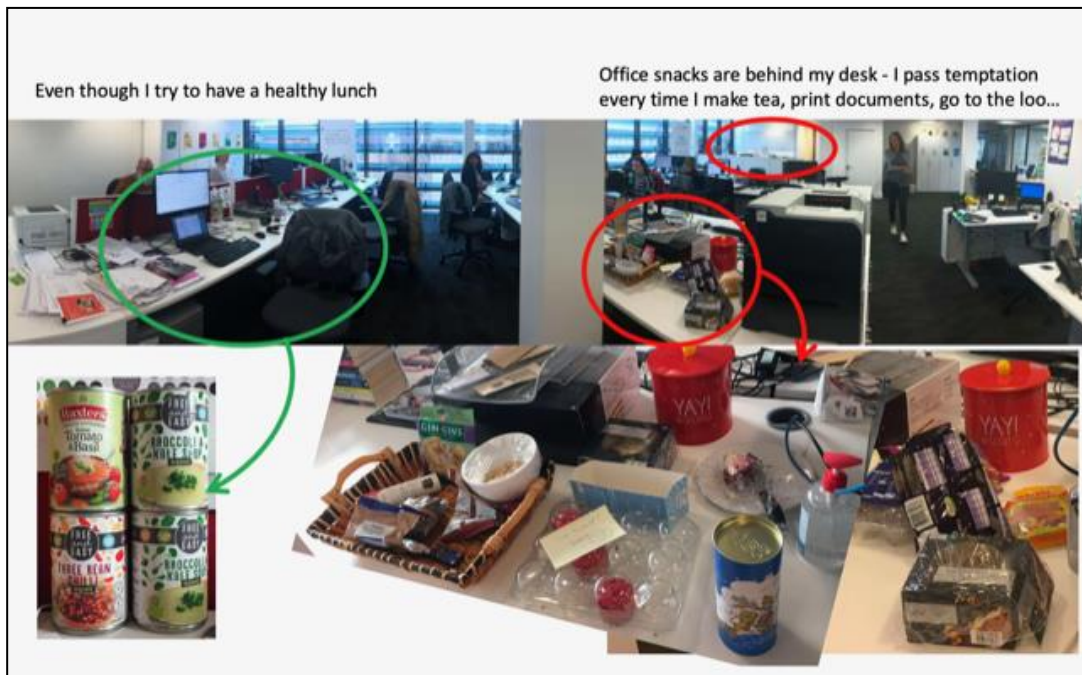
Pre-Diabetes Participant 2

The participant describes eating large portion sizes of high fat and salt foods which led to the participant overeating and a feeling of being unwell because of it. Unless the participant brought a packed lunch, they did not feel that they had much choice but to eat what was available. This may seem like a simple solution to the problem; however, having the time and energy to prepare a packed lunch at the end of the day or get up early to make something (whilst having to get her child ready for nursery) was an insurmountable task for most days for this participant.

Further to this participant 6 who works in a traditional office environment describes a 'sugar gauntlet' which she must pass to use the kettle or go to the toilet, as discussed in the quote and pictures below.

"I'd probably have picked up some biscuits to go with my tea because if I'm making myself tea I'd sort of be walking past the biscuit table [um] and every now and then I'd try and buy some fruit and I'd eat that instead but there'd still be biscuits and cake there... yeah that is interesting about the environment because then the cakes are always there and if you're introverted one way to sort of maybe break barriers is to have a conversation over a biscuit."

Pre-Diabetes Participant 6



8. Figure 6.5 - An example of an office environment

As seen from the quote and pictures, the participant had to pass several different biscuits, cakes, and sweets. The patient tried to navigate these obstacles by bringing in tins of soup, avoiding the biscuit area or buying fruit snacks. However, these food treats played an important role in breaking down barriers to build working relationships. The tea area was discussed as a place where colleagues came together and shared discussions. Participants discussed cake as playing important role in workspaces. People brought in cakes for birthdays, important announcements, and when they came back from holiday as an act of sharing their experiences.

Participant 19, who was a retired accountant, reflected on why it was so hard to break from the social norms at work in the extract below.

“When it comes down to who we are gonna choose to promote, are we gonna choose the person who is...er if...if they’re equal candidates, are we gonna choose the person who’s ill? Who’s got a condition or we gonna choose...the other person. You know, it’s quite a tough call for an employer... and therefore, you know, you can understand why... staff don’t talk about their conditions a lot.”

The participant thought that people felt anxious to allude to any health concerns at work. He felt that if someone disclosed a health condition then it would negatively impact on their work opportunities such as promotions and income. This suggests that there is significant stigma attached to being at risk of type 2 diabetes.

Community influences

Participants discussed several community and societal level influences which helped or hindered their ability to live well. These included the commercial environment, community relationships, the cost of living and access to green spaces, each of these will be discussed in turn.

Commercial environment

Participant 1, who often worked from home, is discussing lunch food options locally to where she lives in London.

“I could go to Pret if I wanted to...I’d more likely eat at home or make something or go to Tesco’s and get supplies that kind of thing. I think it’s that kind of balance because if I wanted to there’s like four fried chicken places, I could go to... like the other day when I popped to Pret and got a salad, I couldn’t do it if it wasn’t there could I? I would probably eat something else entirely.”

Pre-Diabetes Participant 1

This quote illustrates the importance of having supermarkets and food outlets which stock healthy food items within walking distance of an individual’s home. Healthy food options needed to have the same convenience and accessibility as fast-food options.

This was particularly important for working people who needed quick and easily accessible food. However, we can see from this quote, even though there is a healthy food option close to the participant, there are four fried chicken shops in close proximity, illustrating how easy it would be to make unhealthy food choices.

Further to the convenience discussed above, participants discussed a shift in the accessibility of fast food into the home through delivery services (such as Deliveroo and Uber Eats) as shown by the quote below from participant 17 who lives with his son who is a young adult.

“Our son comes home quite tired and, you know, over worked and he’ll just sort of sit down. He just doesn’t get why people don’t just spend their lives ordering Deliveroo. He lives in that world of everything being on the end of the phone.”

Pre-Diabetes Participant 17

Several participants said that their children were using app-based delivery services to access food instead of cooking or eating meals prepared at home, which led to the participants also using the service (although they reported not as frequently). This appeared to represent a generational shift in how people access food. This service provides an important convenient option for people who are time poor.

Community relationships

Participants also discussed the social capital gain from forming relationships with independent shop owners, cafes, small culturally congruent supermarkets, farmers markets, greengrocers etc as discussed in the quote below from participant 6.

“Because we, we wanted them still to be there and very much, you know, the owner works in there, they’re super friendly, they remember who you are so I don’t know if I kind of captured those in those photographs but they will remember who you are and what your order is and if they’re not completely run off their feet, you’ll have a chat while they’re making it and it’s a

proper kind of local business so I actually felt my enormous breakfast of spaghetti bolognese were contributing to the community because they were supporting a small business.”

Pre-Diabetes Participant 6

In the quote above the participant is visiting the independent café and ordering food items to keep supporting the local independent business even though they did not provide the healthiest options available. The above was discussed in relation to wanting the business to survive after COVID lock down. Here the participant is gaining social capital through the relationships she forms with the café and their owners. This gave the participant a sense of satisfaction that she was being a ‘good citizen’ and giving back to the community by supporting an independent, local business. This was reflected by several participants who shopped at local green grocers, farmers markets and south Asian supermarkets. This helped participants maintain their cultural identity associated with food, by supporting small businesses and buying food ingredients required to build culturally competent meals whether that was a south Asian curry or Sabbath meal.

Cost of living

Several participants discussed the current cost of living and the cost of eating well as illustrated in the quote below. Participant 1 is a medical professional and from dual income household without dependants but reflected on how difficult it is to eat healthily due to the cost of food.

“We have a fishmonger we’ll get fish from there or from the farmer’s market which might be tuna steaks or cod and then we’ll have that and we usually get me some smoked salmon for some of my lunch if I’m if I’m feeling it that week. Yeah, and so farmer’s market, lots and lots and lots of veg and fruit and stuff but the main shop is the big Sainsburys and stuff that yeah, I would say it’s pretty expensive to live the life I live.”

Pre-Diabetes Participant 1

As we can see from this extract this participant is reflecting on how expensive it is to buy fresh produce from local independent shops. Eating foods such as fresh fish has become prohibitively expensive for some people. Participant 8 lives alone and is a pensioner; as a result she has had to make difficult decisions on food choices and did not want to 'waste' electricity cooking a meal for one.

"I have been known to buy because I worked it out the other day there was something in Tesco, what was it? Oh, it was [um], not macaroni cheese, oh it was cauliflower cheese and it was something like £1.65 and I thought, I couldn't make it for that."

Pre-Diabetes Participant 8

"Now my healthy meal is on Thursdays. Should probably note I do have a proper meal because I help with the homeless people at that church...so you come and cook, you know, from scratch, I mean, fabulous, you know, ah! I have this wonderful meal every week. So that's my proper meal of the week."

Pre-Diabetes Participant 8

Participant 8 discussed the realities for many people in that they are not able to access fresh food options due to their cost. The only freshly cooked meal that participant 8 was a free meal because of volunteering at a homeless soup kitchen; at other times she bought cheap ultra-processed ready-made foods because economically it did not make sense to cook foods from scratch. The participant would attend Boots at 4pm every day to buy what they had on offer with a 'yellow sticker' for dinner.

Green spaces

Green spaces featured heavily in the follow up interviews and pictures participants sent of their local area; this is illustrated below by a picture taken by participant 2 of the local park

and green space near where she lives and often takes her daughter. As well as the open fields there is an extensive adventure playground.



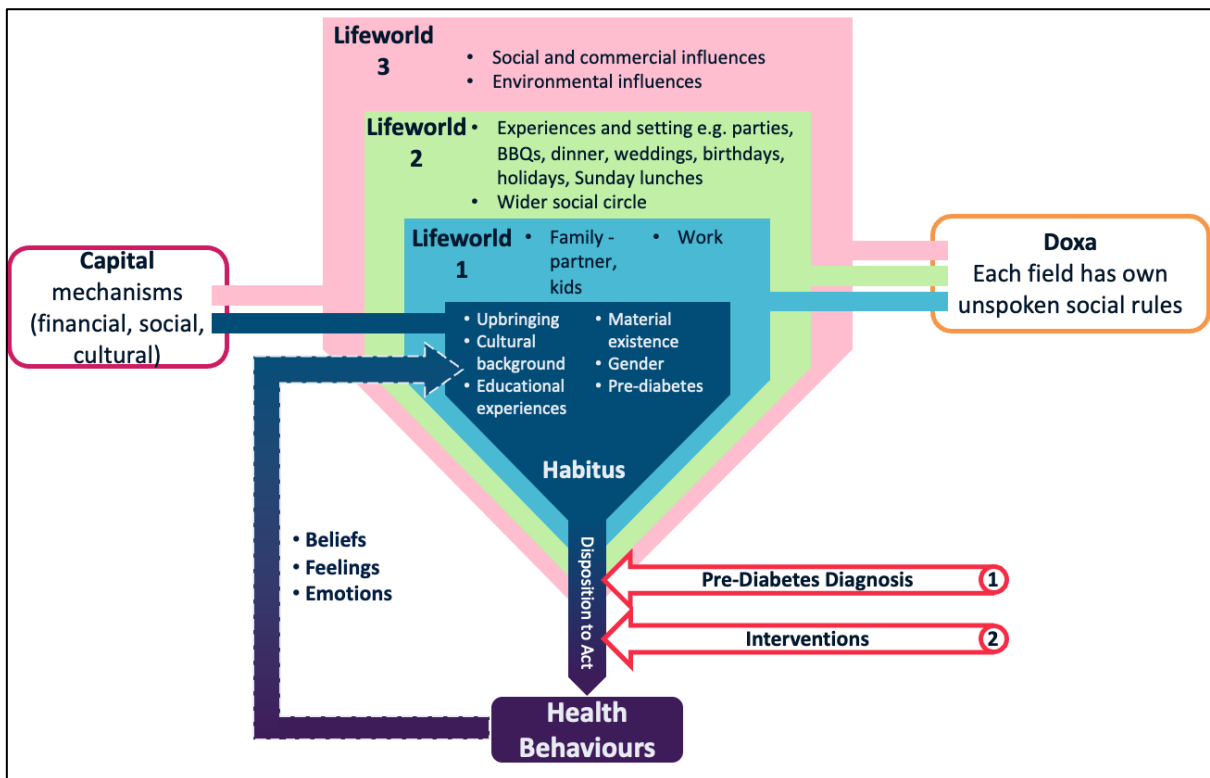
9. Figure 6.6 - A local park and playground from participant 2

Green spaces were particularly important for people with caring responsibilities. Taking loved ones on walks and children to playgrounds were key parts of the day and helped the carers get out of the house was important for both their physical and mental wellbeing.

Playgrounds and outdoor spaces provide key opportunities for social, gross, and fine motor development for children, the above photo was taken whilst participant 2 took her daughter to the park. Most participants talked about the importance of green spaces and going outside to maintain their mental health and well-being. Participants engaged more frequently in walking practices if the green spaces themselves were within walking distance of home.

6.3 Understanding health related behaviours using Bourdieu's theory of practice

In the following section I will explain my analytical findings by applying Bourdieu's theory of practice to the descriptive data. Central to this theory is an individual's habitus, which is our disposition to act, shaped from the combination of cultural backgrounds, social contexts, gender roles, upbringing, and educational influences.⁹⁶ My findings show that health behaviours arise from the interaction of the habitus with the intersecting lifeworlds⁹⁵ The metaphor of 'lifeworld' most applicable to my analysis was a football field, with each player having a set of pre-determined positions and roles (Bourdieu's Doxa) to abide by.^{97 111} Grounded in my data and analysis I separated these into three nested contexts: home and work, social influences and community influence. As summarised in Figure 1, each social context determines the possible lifestyle choices for the individual at that time, with choices the individual makes, feeding back into the dynamic system which further shapes their understanding of the world around them. It is the interaction between the habitus (individual) and these contexts which gives rise to health-related behaviours. In addition, capital was identified within the interviews at both an individual and community level to act as an important mechanism to enact health-behaviours.



10. Figure 6.7 - Bourdieu's theory of practice

In the following sections, I will examine in more detail how Bourdieu's theory of practice relates to my data analysis.

Habitus

The themes identified from the interview data relating to an individual's habitus were cultural influences, upbringing experiences, gender roles and material circumstances. As discussed in chapter 5, an individual's habitus determined how people responded to a diagnosis of pre-diabetes. Those who had a family history of type 2 diabetes, and particularly those who had experienced a close friend or relative with complications related to type 2 diabetes (such as limb amputations or sight loss) reported a more fearful response to being informed that they had pre-diabetes and a greater willingness to change their lifestyles. However, despite this, participants found it incredibly difficult to adapt their lifestyles. Even though the diagnosis became part of the individual's habitus, going against cultural practices

and social rules learnt throughout their lives posed a greater risk to participants than a potential risk of developing type 2 diabetes in the future.

Cultural food practices were not just a representation of what people liked to eat, but also formed an important part of their identity. As illustrated in my descriptive analysis participants with Bangladeshi, Indian, Pakistani, Chinese, Jewish, and Indonesian cultural backgrounds discussed food as being an important part of their cultural identity. Cultural backgrounds not only influenced food choices but also where people bought their food, opting for culturally congruent independent shops over large chain supermarkets.

In the interviews, I identified a persistence of traditional gender roles within households and workplaces as discussed below in the following three quotes.

“I constantly I’m, I mean every day for lunch I give him bowls of soup so that he’s got a load of vegetables going down him and he usually gets a sandwich, but he has to have soft bread. Apart from breakfast which my husband makes, I make, I do all of the cooking.”

Pre-Diabetes Participant 12

“I think between COVID, having the kids home for two years practically non-stop and then, I was literally bringing, like a waiter, bringing them breakfast in the morning to their computer in their room, you know, I was just doing everything. I think I’m totally out of sync now and I, it’s kind of torture to break out of it mentally. I think it’s really hard. And I’m trying to, now is the time but I’m still, I feel like I’m crashing a bit right now. I’m a little bit, I am active, I’m still doing stuff, but I find it I have to kind of force myself sometimes to, yeah, shifting gears after doing this kid thing for so long.”

Pre-Diabetes Participant 10

“So, I’ve noticed successful women who’ve been promoted will often arrive with treats in their new environment. So, you come in to take over, you are going to be bossing everyone

because that's your job but you're going to take the edge off by well in one case it was prosecco Fridays but more usually it's cake or other sweet treats. Because as a woman you must be caring."

Pre-Diabetes Participant 6

From these quotes we can see that women were largely responsible for shopping, meal planning, cooking as well as care giving. Although there were two examples of men doing these tasks (as identified in the data), they overwhelmingly fell to female participants to undertake. This was discussed by most female participants who talked about preparing food that others wanted or needed to eat, rather than what their own tastes were, persistently putting their needs last. For example, the participant in the first quote above was cooking soup for her partner who for medical reasons must have a soft diet. In the second quote, the participant had a Bangladeshi cultural background and found it incredibly difficult to prioritise exercising and eating well above caring responsibilities of her teenagers. Women appeared to be under pressure to maintain their caring roles and responsibilities, whether this was at home or in the workplace.

Capital and Doxa

Capital operates at multiple levels of Bourdieu's theory of practice. In the interviews this was seen as an expression of an individual habitus by making culturally appropriate decisions. When people made decisions in keeping with cultural norms, people would receive praise and positive reinforcement, further encouraging the behaviour. This was seen when people were making food for others, people would cook things they knew they would get praise for and that other people enjoyed, maintaining their status a 'good' citizen belonging to that community or culture. Additionally, I also identified capital as an important financial mechanism allowing the individual to exercise greater autonomy over lifestyle decisions.

Material circumstances played an important role for participants in being able to afford and enact healthy living and an important element in an individual's habitus. The cost of living meant that healthy food options were only available to those who could afford it, as was illustrated by shopping receipts, gym memberships as well as verbal accounts.

Capital also acted at a community and societal level influencing what choices were available to people. I identified this in both the verbal accounts and observational data of safe green spaces, well maintained playgrounds, commercial food outlets which provide affordable healthy food options. Heating costs, safe housing, and affordable childcare were also identified as important community-level influences. Participants living in more affluent areas had safer environments, better maintained outdoor spaces and greater access to healthy food options. This increases the 'choices' available to the participant when making health related behaviour decisions.

Doxa refers to a set of beliefs and opinions inherent in a particular lifeworld or habitus. This is developed over a life course, shaped by experience, and reflects an individual or groups tacit knowledge regarding a situation (for example, this could represent eating birthday cake at a party) which develop into social norms. From the interview data I identified social norms and rules operating within every social context. Most of the time these acted to constrain health related behaviours. This is discussed in more detail within each social context (lifeworld) in the following section.

Life worlds

Lifeworld 1: Home and Work. The lifeworld of home and work were separated out from other contexts because these had the greatest effect on a participant's daily behaviours.

Navigating this world was particularly important for participants because of the key relationships they contained. It is also the context where they interact with other people's habitus most closely and are heavily influenced by other people's health beliefs (from their partner to their boss). The habitus of the people within the home and work lifeworlds determine the environmental context and therefore food context. In the contexts of home and work people had assigned roles and social rules that they had to follow and navigate. If a participant tried to deviate from social norms or their prescribed role (doxa) in this lifeworld, this threatened their positions, roles, and relationships within these contexts. In the descriptive analysis in section 3, I identified an example of a mother trying to change meal options to be more in keeping with her health-related goals. This created conflicts with both her partner and daughter, threatening her prescribed social role as a wife and mother of putting others' needs and wishes before her own.

Lifeworld 2: Social influences. Identities develop over time from our cultural social upbringings; identities discussed in the interviews included cultural, musical, health/foodie and art. Each identity was associated with an activity and food played a role in the identity when shared with others. Part of the maintenance of these identities is the cultural capital gained from following the rules associated with the identity (such as going to the pub after playing sport, coffee and cake at an art show, going to a carol concert), which gave the participants a sense of belonging. Playing sport with others or attending art galleries with other people meant people partook in experience with someone who also has the same identity.

From the data I identified that shared cultural identities were very important for people.

Eating the same food as other people from the same cultural background, as well as cooking

culturally congruent foods for the participant's own children, was seen as a positive act in maintaining cultural traditions. People were praised by those around them for maintaining their cooking practices to obtain cultural capital as a good wife/mother/friend.

If participants did try and change the content of their food, it had to be in keeping with the group's cultural context. For example, this Iranian participant found it difficult to adjust her carbohydrate cooking when she was cooking for others who shared the same cultural background. If others did not like her cooking as much it was seen as a threat to her role in her friendship group as a good cook and so it was important for her to maintain this identity, abiding by cultural rules, as seen in the extract below.

"Generally, all my friends want Iranian rice, so I cook the rice myself and I always make basmati rice. I don't use any other rice which has got lower glycaemic index than other rices apart from brown, but most people don't like brown."

Pre-Diabetes Participant 14

Lifeworld 3- Structural Influences. As illustrated by the descriptive analysis the wider community plays an incredibly important role in influencing health related behaviours. Despite the participants being able to discuss at length the complexities of their own lives and environments, they still took on the responsibility of reducing their own risk of type 2 diabetes as seen in the quotes below.

"Well, I can't see how one can avoid that conclusion. I mean who else, who else is responsible... I think it's just the discipline, I lack discipline."

Pre-Diabetes Participant 15

“You know, I can wake up with the best intentions in the world and then find all sorts of reasons why I’m not gonna do it [exercise]. So, I’m afraid it’s just weakness of character and self-discipline. I’m not going to cure that anytime soon.”

Pre-Diabetes Participant 7

Participants felt it was their responsibility to reduce the risk of type 2 diabetes, even if they felt limited in their ability to do so. Participants saw their inability to reduce their risk of reducing type 2 diabetes as a personal failure, referring to a lack of will power or not having discipline. This was despite discussing at length with participants the role of cultural norms, environmental influences, gender roles, commercial influences, social contexts, material circumstance, and the people around them. These quotes align with an individualist discourse of disease prevention and reflective of our wider neo-liberal socio-political context which situates the responsibility of reducing type 2 diabetes on individuals.

Intersectionality

Bourdieu’s theory of practice was originally used to describe the construction of the social class system and how structural influences are used to maintain these social class structures. From the analysis I can see to some extent this is true, for example, those with greater financial capital (and higher social classes) are better able to afford healthy food, gym memberships and live in areas with green spaces with low crime rates and have lower morbidity and premature mortality rates. However, I found that participants of all cultural backgrounds, religions and professional backgrounds found being told that they had pre-diabetes stigmatising. This made subsequent behaviour change challenging, particularly if the responses of the people immediately around these participants (family, friends, spouse) reinforced this stigma. It was of upmost importance to all participants regardless of socio-economic status that they belonged to their social and cultural groups. My analysis also

suggests that the structural influences described in the life worlds above may be intersectional in nature. Intersectionality is a framework which explores how cumulative individual repetitive experiences (of structural influences) become ‘interlocking’ tools of oppression, which in this analysis may explain why behaviour change is insurmountable for some groups.^{112 113} For example, in my sample women from diverse ethnic groups described societal sexism (for example, being structurally conditioned to place their needs last as care givers) and structural racism (exhibited by the incorrect assumptions health professionals made of participants’ lifestyles and limited knowledge of culturally diverse foods). The conceptual tools of habitus, fields, doxa and capital could help explore how intersectional structural forces limit health-related behaviours. This is a preliminary reflection to my analysis and an area for further research after the DPhil.

6.4 Chapter summary

In this results chapter I have explored how participants with a pre-diabetes diagnosis make health related lifestyle decisions in the context of their daily lives. Although people are reflexive individuals who can make their own lifestyle choices, these choices are constrained by an individual’s habitus, life worlds, capital (individual and community) and ability to navigate social rules. I have found that those most able to change their lifestyles according to prescribed behaviour change interventions (mainly western dietary advice and exercise practices), are those whose habitus and social context already aligns with these interventions. In addition, participants are better able to navigate a context if they have the necessary social and cultural capital (such as a supportive spouse and family) to maintain these changes and sustain them in different settings. They must also have the financial capital to afford a healthy diet whilst living in an area which makes healthy eating convenient

and accessible. In most cases participants found it very difficult to navigate each lifeworld's doxa; if they tried to go against the social norms of a social context, they reported examples of conflict threatening the formation and maintenance of social relationships. For many participants, the risk of disrupting social relationships was far greater than a hypothetical risk of developing type 2 diabetes. This is particularly evident if there is stigma in admitting in a social setting that one is at risk of developing type 2 diabetes, as it is seen by many as a personal failing; these considerations are largely ignored by the delivery of a pre-diabetes diagnosis and 'individualist' health promotion messages. Participants with pre-diabetes felt it was their own responsibility to reduce their risk of developing the condition, even when they felt limited in their ability to do so.

In the next chapter I will present the findings of my interviews with UK policymakers, delivering type 2 diabetes prevention policies in real world settings and analyse further why individualist health promotion policies (which filter down to the general public's own views and perceptions) predominate in type 2 diabetes prevention policies.

Chapter 7 – Policymakers’ perspectives on diabetes prevention

7.1 Introduction

In chapters 4 and 5, I explored the perspectives of practice teams and people with a diagnosis of pre-diabetes. I showed that in my sample, there was largely an individualist focus to type 2 diabetes prevention, encouraging individuals with pre-diabetes to reduce their risk of developing type 2 diabetes through behavioural means. Both the focus group and interviews of people with pre-diabetes showed that community level influences, such as the commercial food environment, access to green spaces and rising cost of living, play very important roles for individuals trying to reduce their risk of type 2 diabetes; yet these do not appear to play a major role in type 2 diabetes prevention policies or in health promotion advice from clinicians.

As discussed in the background section (chapter 1), in England public health teams within local governments are tasked with tackling the community level determinants of health. NHS-based public health teams transitioned to the local authority setting in 2014 and have had to build new relationships and ways of working to establish themselves within a different context. Public health budgets have been significantly reduced, with huge variations between local authorities'.^{29 39 40 114} Despite evidence that health behaviours can improve with population level interventions, measures that were due to be put in place after the COVID-19 pandemic (such as advertising restrictions on unhealthy foods before 9pm) have been delayed.^{28 32 34}

Policy making has been defined as 'an authoritative exposition of values... defining and pursuing the right course of action in a particular context, at a particular time, for a particular group of people and with a particular allocation of resources.'¹¹⁵ In this chapter, I explore why England is pursuing a largely individualist type 2 diabetes prevention policy strategy and the complexity behind this. Through the analysis of my interviews with policymakers I explore how policy decisions were made in implementing national diabetes prevention directives and identify key influences that shape, enable, and constrain these decisions. Overall, I found that policymakers discussed type 2 diabetes prevention on an individual level, focusing on preventing type 2 diabetes in those labelled with 'pre-diabetes' with little attention to addressing the community determinants of health. Academic research evidence was reported to be used in a limited way to support local initiatives, funding applications and business cases for services. My findings are structured according to the four domains of Shiffman and Smith's framework (which I introduced in chapter 3, the methods chapter), exploring why an individualist diabetes prevention policy approach currently exists. I use Lukes' three faces of power to increase the depth of my analysis, exploring how power is used to implement policy directives and Weiss's models of research utilisation to understand how policymakers viewed and used academic research.¹¹⁶ Findings from this chapter have been published (see Appendix 9 for full paper):

Barry E, Greenhalgh T, Shaw S, Papoutsi C. Explaining the UK's 'high-risk' approach to type 2 diabetes prevention: findings from a qualitative interview study with policy-makers in England. *BMJ Open*. 2023 Feb 7;13(2):e066301. doi: 10.1136/bmjopen-2022-066301. ¹

I was lead author on the paper, having undertaken the interviews, carried out the data analysis and wrote and revised the drafts of the paper. Professor Greenhalgh, Professor Shaw

and Associate Professor Papoutsis supervised the DPhil, discussed the analysis as part of regular supervisions and made comments on drafts of the paper.

7.2 Description of the dataset

Nine semi-structured interviews with ten policymakers took place between 2018 and 2020 (one interview was done jointly with two policymakers). Three policymakers were then re-interviewed in 2021 to discuss how the COVID-19 pandemic had influenced decision making (see Table 7.1). Interviewees at local authority level included six policymakers with a public health background, two commissioners, one strategist, a public health consultant and a director of public health. A public health policymaker working at a national level was also interviewed. NHS participants included a GP clinical lead, a GP primary care network clinical director, a primary care commissioner and former national healthcare policymaker. The GP leads and the national public health policymaker were re-interviewed in 2021 to ascertain if the policy process had changed over the course of the COVID-19 pandemic and to gather feedback on initial findings.

Stakeholder interview	Role	Interview date	Follow up	Sex
1	PH strategist	08/08/2018		F
2	PH Commissioners 1 and 2	06/09/2018		2 M
3	GP Diabetes Lead and LMC Chair	26/09/2018	04/06/2021	F
4	Primary Care Commissioner	03/10/2018		F
5	GP and PCN Clinical director	07/10/2019	27/04/2021	M
6	PH National policymaker	21/10/2019	16/06/2021	M
7	PH Consultant	10/12/2019		F
8	DPH	17/01/2020		F
9	NHSE policymaker	18/05/2021		F

4. Table 7.1 - Study participants

7.3 Findings

Power and funding shaping individualist policy

Direct power

In this section I will explore the role of power in the translation of policy into community settings and how power was used by different actors. In Shiffman and Smith's framework, direct power is that where those with authority give direct instructions to others to undertake actions, or in this case policy directives. Policymakers consistently reported that money and power sat within the NHS. Type 2 diabetes prevention policy is enacted through the NHS GP contract and the roll out of the NHS Diabetes Prevention Programme. My interviewees gave examples of how NHS England exercised direct power on the policy process, as seen from the quote from a public health strategist below, who is referring to how project extensions and amendments were communicated to local public health teams.

"We hadn't been informed that the (NHS Diabetes Prevention pilot) extension had been further extended by additional four months, until the MOU [memorandum of understanding] was sent through to us. And that additional four months didn't reflect the amount of mobilisation fund that we received from NHS England. And our targets for initial assessments had been increased. There was very little leeway in terms of conditions. Which we then tried to (address) but didn't get far with that."

SH1 Public Health Strategist

The use of direct power by NHS England was identified by all policymakers as a key influence on how type 2 diabetes prevention policies were designed and implemented. As seen in the quote above, information and funding from NHS England was seen to flow in a top-down fashion, with limited scope for local policymakers to feed into the decision-making processes and with little time for them to act upon new directives. Resistance or feedback from local

policymakers seemed to have limited influence on the policy. Further to this, industry providers commissioned by NHS England were contracted to deliver the NHS Diabetes Prevention Programme without input from local NHS or public health teams on the selection of these providers. Consequently, local policymakers, with knowledge of the local area, community, and residents, had no influence on who the intervention provider was or any ability to ensure the interventions were culturally competent, going against their duty to meet the needs of their residents (as discussed in chapter 6, these interventions were not always culturally competent).¹¹⁷ Due to this, in some areas local NHS policymakers continued their own type 2 diabetes prevention initiatives, tailored to the needs of their residents.

Many policymakers saw funding and power as being inherently linked which had implications for the models of disease prevention employed, as discussed below by a national public health policymaker.

“So, using diabetes as an example, because it seems to be very stuck in the biomedical model which means that the way it’s going, we’re only really going to get DPP as the solution to preventing diabetes. Because all the money’s gone to NHS England, so you can talk to any of the other government departments, they say NHS, the NHS has taken all our money.”

SH6 National Public Health Policy Official

Disease prevention funding is currently being disproportionately allocated to the NHS and not to other government departments, local authorities, or public health teams. The organisational scope of the NHS is to focus on the prevention and treatment of individual diseases. Thus, for all practical purposes, the only permitted model of disease prevention is the biomedical model focusing on individual behaviour change.

Local influence, but without authority

Funding to public health and other government departments has significantly reduced. As a result, public health policymakers talked about their role as having “*influence without authority*” and “*getting stuff done with other people’s money*” (SH7 Public Health Consultant). Consequently, two strategies were used by public health professionals to exert their influence. Firstly, they operationalised power from their knowledge and expertise. Moving into the local authority, as well as using epidemiological data, public health policymakers increasingly used resident narratives to give the data additional meaning. Presenting these lived experiences and story imagery to local politicians was seen as an incredibly effective strategy in engaging politicians who understood individual narratives from working in their constituent surgeries. This illustrates public health teams aligning with local authority policymakers as ‘street-level bureaucrats’, whose work is characterised by reaching out and engaging with the community to make actionable policy to improve the lives of constituents.¹¹⁷ Secondly, public health policymakers discussed the importance of building trust with other policymakers to exert their influence as illustrated in the quote below from a director of public health.

“We’ve got to kind of build those relationships. We’ve got to understand, get out and about understanding Local Government to start with because I think, you know, clearly when we joined, we had very little understanding generally probably of what Local Government is and does and how it works so it has been that kind of journey of understanding and building relationships, building trust and only through that are you going to ever achieve anything really I think.”

SH8 Director of Public Health

As discussed in the quote above in transitioning from the NHS to a local authority setting, public health teams had to create new identities and build new working relationships within

local government. Key to this relationship building was understanding each stakeholder's perspectives, priorities, ways of working as well as recognising power and funding imbalances. At the same time public health teams were expected to maintain NHS relationships as discussed below by the same director of public health.

"A conversation last week about PCNs, it's all very well us coming in with ambitious big population health stuff and they're so underfunded and new and developing what they're going to be primarily occupied with 'We've just received this national DES [directly enhanced service – i.e., funding for a specific initiative] specification and we've got to work out how we've got to go and deliver it, how can you help us do that?' That's the kind of normal conversation."

SH8 Director of Public Health

The quote above illustrates how restricted public health partners felt in some of their working relationships due to their lack of power. To maintain existing relationships with NHS partners, public health policymakers discussed needing to set aside ambitious agendas to help these partners reach their own goals and objectives as discussed above. This restricted their parameters to achieve the operational goals of other stakeholders rather than furthering the public health agenda, addressing the wider determinants of health. This limited the team's ability to discuss what they saw as priorities for reducing the population's risk of developing type 2 diabetes.

Limited influence of research evidence

Research evidence was reported as having the least influence in the policy process with regards to both implementation and translation. At times, policymakers reported using research selectively and instrumentally to fit with the policymaker's particular need as discussed in the quote below from an NHS commissioner.

"I sat in a room with a finance man when I was trying to come up with my business case. I had four business cases at one point, on diabetes. And I said to him, 'if you're diabetic and you're type one, you live twenty years less than somebody - if you're type two, you live ten years less, if you have -', you know?"

SH4 NHS commissioner

Academic research was reported as being used to support funding applications and business cases, making them more impactful. Here research headlines, hard-hitting phrases and statements were needed to add prestige and importance to the funding application.

'Evidence' such as the quote above, is not the most up to date statistic but might be the best available if the use of these statistics has the desired effect of securing funding for the initiative.^{118 119} This reflects what Weiss described as the tactical model of research utilisation, where research is strategically used to increase the urgency and standing of a business case, particularly when in competition with other applications (trying to increase funding for other conditions).^{116 120}

Policymakers pointed out several perceived limitations to academic research. They thought that results seen in clinical trials of behaviour change interventions did not reflect results seen when interventions were introduced in the community setting. Further to this, local policymakers expressed frustration that clinical trials had shown that behaviour change interventions were not as effective for people living in deprived areas and for minority ethnic groups. This is supported by independent evaluations of type 2 diabetes prevention interventions. This left local policymakers at a loss as to what to do for these groups, with some working in areas of high deprivation and ethnic diversity. Policymakers reported that quantitative measures such as BMI and HbA1c were only one aspect of the translation of the research to a real-world setting. Additional outcomes such as wellbeing and social cohesion,

which are typically unmeasured or downplayed in clinical trials, were seen as just as important to policymakers in assessing the social impacts of an intervention.

Three additional challenges were mentioned. The research cycle was considered too slow to meet the needs of policymakers, who needed quick answers. Academic papers were long and difficult to follow, yet it was essential for research findings to be communicated in a way that was easier for policymakers to process and digest. Research findings from trials were considered of dubious relevance to the actual populations they were serving. To try and bridge the gap between timeliness and rigour, whilst also needing information specific to their populations, policymakers reported using external market research companies to run focus groups, narrative interviews, and co-design projects to quickly gather information they could act upon.

To overcome the research-policy gap, and to try to increase academic influence, the policymakers discussed a need for stronger partnerships between academics and policymakers to understand each other's knowledge needs, world views and operational constraints as discussed in the quote below from a director of public health.

"I know that's really hard in the context when it's all about kind of peer review publications and funding grants and all that kind of stuff but unless you can kind of genuinely sort of think through, you know, an issue together and work out what each partner kind of needs and wants from a collaboration"

Director of Public Health SH8

This policymaker is describing a process of academics and policymakers working together to co-produce the research questions, data collection methods, seeking feedback from the data analysis in its interpretation. Weiss refers to this as the interactive model of research

utilisation, where researchers work alongside policymakers and other stakeholders and together for 'knowledge partnerships'.^{116 120 121} Currently the academic environment emphasises the need for high numbers of peer-review publications in high impact journals, obtaining large grant applications, whilst also taking on substantial teaching roles to maintain university positions. This does not support what is required to be part of an interactive model of research, which is for academics to be present, attend meetings and be part of the policy process contributing to the overall body of research available for policy making (an iterative process which may not appear to help academics reach their own academic objectives). Some academics have called for reform of the system in which evidence is generated, moving away from an academic system which rewards the publication of high impact individual studies, to a system which supports evidence informed policy and interdisciplinary research synthesis. This requires synthesising bodies of literature from different epistemological perspectives and assessing the wider societal impact of decision making.¹²¹

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How political context shapes type 2 diabetes prevention

Policy making occurs within a political environment which influences (and is influenced) by how the wider public perceive health and illness and what policies are politically acceptable. At the time of writing, England has a neoliberal political system based on ideals of competition, free markets with minimal state intervention and corporate regulation to promote economic prosperity.^{91 123-125} Neoliberal systems downplay the idea that health is the product of structural forces placed on individuals, diminishing the role of social, economic, and commercial influences on health.⁹³ In this system, governments might be reluctant to use population-level structural interventions to address upstream drivers of ill health.^{91 123 126 127} Instead, downstream individual level lifestyle interventions, focused on a

narrative of individual responsibility are used as disease prevention strategies.^{124 126 128} |

found examples of neoliberal influences on policy making within the interviews. The first example is given by a director of public health below.

“Yeah, so we tried to have that probably a bit ahead of our time a few years ago and absolutely given the kind of financial circumstances and any concern about doing anything about that would lessen local government revenue we didn’t win out...”

Director of Public Health SH8

In the example above the director of public health was discussing a public health initiative reducing fast food advertising in the local area during times of austerity. Initiatives such as these which would risk lessening the local government revenue, were promptly rejected by local politicians. This is a direct example of industry and economic interests being protected over population health improvements. Further to this, public health initiatives were discussed as needing to align with local authority political viewpoints and ideals to ensure continued funding for community level interventions, as illustrated by the quote below from a public health consultant.

“Yeah, so you get stories where it is politically, one has to phrase things in Tory areas differently. So, there’s a really nice session I went to as part of training in my last job where democratic services shared how they’d gone from a Labour administration to a Tory administration and they kept on the same, they went through the manifestos with a fine-tooth comb. They made lots of notes and then they renamed all their programmes. They kept all their programmes; they kept all their funding, but they renamed them to fit with the ethos of the incoming administration so the holiday hunger programme which makes perfect sense to me, holiday hunger became social eating because it’s just nicer and so there’s certain things that, that conservative authorities will make all the right decisions and all the right thoughts and feelings. It just needs to be dressed up slightly differently so it’s not, it’s never a class war thing. It’s a sort of nice to do or better if thing.”

Public Health Consultant SH7

Public health teams needed to tailor the language and messaging of the same initiatives, to fit the new local administrations political ethos. Being part of a local authority setting, and out of the NHS, meant that public health teams were strongly influenced by their new political context adding a layer of complexity to policy implementation. Policymakers commented that academic research had not caught up with this change in context, hence did not reflect the operational constraints of working in a political environment, as discussed by the director of public health below.

“Academic research doesn’t recognise the context in which that then has to get operationalised. I suppose the gap in translational public health... I do think maybe there is something about face time in local government I think for academics. I think they just don’t understand local government what it is and does and how it works genuinely, and I think there’s, a lack of social evidence”.

Director of Public Health SH8

Interviewees discussed what they saw as researchers’ lack of understanding of political influences. Public health policymakers thought that research and guidelines did not reflect the socio-political complexities they were now operating in, and that research regarding type 2 diabetes prevention was still orientated to an NHS biomedical perspective. Policymakers criticised academics for believing that policy making, and implementation was a linear process with knowledge being directly translated into policy (what Weiss describes as the ‘knowledge driven’ model) when in fact the policy process was a messy, non-linear development, strongly influenced by a socio-political and economic context.

Framing ideas about diabetes prevention as individual responsibility

In this section I explore how policymakers framed ideas around disease prevention, particularly in terms of individual responsibility. An example of how type 2 diabetes prevention was framed by policymakers is given in the quote below by a policymaker.

“How can we help that person? How can they be empowered? And so that they are self-caring, and it’s their – it’s their lives, rather than this you know, this deferring all the time to the doctor... it’s about trying to get people to, to have that ownership of their own health, and the fact that they can make a change... whose intervention, is it? So, responsibility is not on us to provide, provide you with a tablet. Our responsibility is to provide you with education and support.”

SH3 NHS Commissioner

Policymakers working within the NHS believed type 2 diabetes could be prevented by empowering individuals through increasing their knowledge via interventions. For NHS commissioners and clinical leads, it was the responsibility of the individual to reduce their risk of type 2 diabetes, despite their social context. This emphasis on empowerment and education was assumed to linearly lead to less reliance on the medical system and state intervention (a key principle of our neo-liberal social context). Similarly, most research in type 2 diabetes prevention was discussed as being undertaken on an individual level through intervention trials. This was in part due to type 2 diabetes being framed as a failing of individual biology and measured via outcomes such as weight and HbA1c in trials and in diabetes prevention reviews. This aligns with the views of some policymakers that type 2 diabetes can be prevented by increasing an individual’s knowledge and monitoring them through the process leading to lifelong behaviour change. The dominance of this type of research indirectly feeds back into the policy process to maintain the status quo of how both policymakers and academics think about type 2 diabetes prevention. Weiss calls this the enlightenment model where ideas and concepts shape and develop the policy process over time influencing the way problems are framed and responses are shaped. Here research has an indirect effect of maintaining the policy agenda to focus on individual level behaviour change.

Policymakers working in public health settings framed disease prevention in a different way, talking more about upstream community level influences on health as illustrated by a public health consultant below.

“The things I found frustrating; 1) everything’s individual, 2) the level at which we put in interventions, I think it’s homeopathic. You’ve got whole population, you need something at scale and then we have like, ‘Well we’ve got a cooking project here and we’ve got our sort of reading after school project here,’ and the NHS commissioning our local diabetes prevention project... we’ve got 8,000 pre-diabetics but provide a service for a quarter of them... (GPs) drive up their (commissioned) activity and then box checked and result, but that doesn’t actually work for diabetes prevention.”

SH7 Public Health Consultant

As seen from this extract, public health policymakers felt that type 2 diabetes prevention strategies were confined to short-term interventions with limited population-level impact. NHS structures such as the GP contract and primary care commissioning cycles perpetuated an individualist discourse of disease prevention. This has led to individual-level, small scale commissioned interventions, evaluated by down-stream surrogate markers, which had little evidence of sustained improvements or type 2 diabetes incidence reduction. The extract above also highlights a capacity issue within the NHS, with rising levels of obesity and pre-diabetes it is not possible to provide the commissioned interventions for everyone in this population.

The practicalities of diagnosing, managing, and monitoring pre-diabetes.

In this section I explore the features of pre-diabetes diagnosis and management which construct the individual-level disease prevention strategy (as discussed by policymakers). Firstly, risk factors for developing type 2 diabetes can be identified and quantified in a primary care setting, making it possible for GPs to monitor individuals and detect type 2

diabetes development. Because the diagnosis is made via a blood test and in turn interpreted and communicated via a GP, it categorises the 'at-risk' state as a biomedical condition. From a commissioning and contracting perspective, it is possible to use patient-level surrogate markers (from GP electronic records or commissioned interventions) to monitor targets and use these as terms for payment as discussed by a public health commissioner below.

“Things like grip tests, and step tests, and stuff like that - if we're getting improvements after six weeks, then they are indicative of improvements over a longer period of time. So, it's - We're not going to see a reduction in diabetes, but if a hundred and fifty people finish a course, and after six months they've maintained their behaviour, and we've seen a ten to twenty percent improvement in grip strength, or their ability for their heart to come back to a normal rate after a step test, that's indicative of a health improvement.”

Public Health Commissioner SH2

This quote illustrates how small improvements in downstream markers were used as evidence for intervention adherence and success. Our interviewees emphasised and valued the collection of quantitative data to monitor GP activity and patient progress during interventions as discussed above. This data collection process allowed the treatment and management of pre-diabetes to fit into short-term funding and commissioning cycles. Similarly, how pre-diabetes is defined and measured clinically lends itself to being researched with quantitative methods such as the analysis of GP data sets, or lifestyle intervention trials. These largely support an individualist approach to reducing type 2 diabetes by targeting individuals at high risk.^{5 6 12} This type of research was helpful when making the case for funding initiatives, as discussed by a commissioner in section 1. However, other policymakers identified limitations of this research, as seen from the two quotes below from a diabetes clinical lead.

“Whether they sustain the physical activity is quite, you know, helpful to know. So even though it's - We're not, we're not measuring you know, a diabetes measure, but if they could still say to you 'yes, I went to this and I'm still exercising twice a week' in ten years' time, then that intervention was worthwhile, regardless. Because it's made them behave - you know, they weren't doing it before, they've been done an intervention and they've sustained that for ten years. Surely that's a positive outcome?”

GP SH3

“Because I think it's important to sort of work out why people choose, make the choices that that they make in a shop, at that time. You're here, what are you having? How did you, how did you make that? What made you come into the shop in the first place? You know? Are you aware of your, of your risk? Are you aware of how they cook this?”

GP SH3

As illustrated by the quotes, quantitative research using the biomedical model of disease prevention, was not seen as reflective of the real lives of the people living in their communities nor did it explain how people make their health-related lifestyle choices on a longer-term basis. The policymakers identified a need for more applied social science research to understand the lived experience of being diagnosed with pre-diabetes and how that influenced everyday health related behaviours.

7.4 Chapter summary

In this chapter I have presented data to support the argument that an individualist approach to disease prevention is perpetuated in the current English context on multiple levels. This was seen from how the prevention policies are constructed and translated to local contexts, what research was selected to support policy making, as well as the overriding individualist discourse of how type 2 diabetes prevention was framed by policymakers. Informed by the work of Shiffman and Smith, and Lukes, I identified three dimensions of power and how this is operationalised to shape such policy.^{129 130} Power is exerted: a) directly via top-down NHS England policy directives such as the NHS Diabetes Prevention Programme, b) indirectly with public health professionals using their expertise to subtly influence the policy agenda, and c) through the prevailing neoliberal political context shaping how people think about disease prevention. The onus is on the individual to reduce their risk of disease which is amplified by measurable downstream characteristics used in policies and interventions, such as weight and HbA1c. In addition, lifestyle advice given in primary care medicalises socially constructed lifestyles and neglects the complexity of how people make health related behaviour choices (as explored in chapter 6 using Bourdieu's Theory of Practice).^{4 6}

My analysis of how our political context shapes disease prevention policies, suggests that a whole-population approach to type 2 diabetes prevention may be politically problematic. National infrastructure changes (such as limiting fast food outlets or restricted advertising) goes against the neoliberal ideals of a 'free market' economy and involves regulating profit making corporations.¹³¹ As illustrated by my interviews, reducing local or national economic revenues was deemed to be politically unfavourable.

Throughout this chapter I have examined the role of academic research in implementing national directives or in the construction of new local policies. Although research was reported as having a small influence in the policy making process (with many documented limitations throughout the interviews), research was used tactically to support current type 2 diabetes prevention health policies. Policymakers use quantitative epidemiological and biomedical research (from a positivist epistemological paradigm) such as the analysis of data sets or behaviour change trials. This research perpetuates the traditional hierarchy of evidence-based medicine. Despite the presence of social science research exploring the complexity of lifestyle change, this was not research that the policymakers drew upon when undertaking their decision making.^{6 17 69 132} This could be in part due to the fact that complexity is hard to tackle and some policymakers have reported that the social science literature is hard to engage with, whereas the biomedical model of behaviour change seems more simple and clear (even if it leads to limited results).⁷¹ However, biomedical research is also influenced by our prevailing neoliberal context. As illustrated in chapter 2 of this thesis, most of the funded and published research relating to type 2 diabetes prevention comes from individual-level interventions using a biomedical (and largely positivist) epistemological perspective. This type of research perpetuates the idea that the responsibility of preventing type 2 diabetes aligns with the individual by focusing on individual-level and so supports our neo-liberal socio-political context, making it easier to use as part of the policy process.

Chapter 8 – Discussion and Conclusion

8.1 Thesis summary

In this thesis I have explored pre-diabetes through a variety of perspectives and theoretical lenses to understand how it is interpreted by the groups which design, implement, and partake in the type 2 diabetes prevention pathway. I began this thesis by describing the rationale for studying the topic based on my experiences of an academic-policy partnership developing type 2 diabetes prevention strategies in a deprived and diverse population. In chapter 2, I summarised the findings from systematic reviews I completed in preparation for the empirical work of this DPhil. In chapter 3, I described the methods, methodologies and theoretical principles used in different sections of the DPhil. In chapter 4, I used critical social sciences perspectives to explore how primary care teams diagnose and manage people with pre-diabetes. In chapter 5, I explored the diagnosis and management of pre-diabetes from the perspectives of those who have been given the diagnosis. In chapter 6, I used Bourdieu's theory of practice to explore how health related behaviours are constructed and how people make everyday lifestyle decisions. In chapter 7, I used Shiffman and Smith's framework to explore how policymakers make decisions and implement national directives into local initiatives, exploring why a high-risk individual focused strategy dominates type 2 diabetes prevention discourse and policies.

8.2 Overarching themes and paradigms

As discussed in the introductory chapter the overarching theme explored in this qualitative study is Geoffrey Rose's prevention paradox; the tensions between an individualist 'high-risk' approach to reducing an individual's risk of type 2 diabetes, versus a population approach of reducing everyone's risk by a small amount, thereby reducing the prevalence of disease at a population-level. The individualist disease prevention approach aligns with the largely positivist bio-medical model which considers type 2 diabetes as a medical disease with specific risk factors and antecedent causes. As we saw in the interviews this was the dominant disease model used by primary care teams, people with pre-diabetes and policymakers. The pre-diabetes diagnosis was widely accepted by clinicians, policymakers and by those given the pre-diabetes diagnosis because of the acceptance of the biomedical model of disease which sees type 2 diabetes development as a failing of individual biology and lifestyle choices. Consequently, the responsibility for behaviour change was situated with the individual who was expected to halt their own type 2 diabetes development through self-surveillance and self-control. However, there was also recognition from these groups that this approach was limited, recognising (if not explicitly stated) that it is also necessary to employ an interpretive social realist approach to prevention which recognises that type 2 diabetes is the result of a dynamic interplay of individual predispositions and behaviour with social, cultural, political, and economic influences. The primary care teams in the focus groups saw the social determinants of health played out in their patients' narratives but were powerless to do anything about these. The participants diagnosed with pre-diabetes recognised the huge influence of social contexts and how, in many cases, these prohibit lifestyle change (as discussed in chapter 5). Similarly, public health policymakers

expressed frustration that the only accepted way to prevent type 2 diabetes was by aligning with neoliberal political perspectives which largely focus on individual behaviour change delivered by the NHS, rather than addressing the structural and commercial influences on health. All participants navigating this tension were having to abide by the positivist biomedical construct whilst dealing with the social-cultural complexity of everyday life, whether it was through discussing the diagnosis as a clinician, enacting behaviour change as a participant or making policy decisions as a policymaker.

8.3 Key findings

1. Individualist diabetes prevention strategy

Pre-diabetes is an arbitrary category, it is not fixed or absolute; different diagnostic criteria in different countries will give the same individual a different diagnosis.¹³³ Despite this, pre-diabetes is portrayed as a medical certainty because of the quantified way the diagnosis is delivered and explained to people using numerical cut offs, graphs, and biomedical terminology. People with pre-diabetes are then given prescribed medical advice on how to prevent the perceived linear development to type 2 diabetes. This categorisation provides an unproblematic, simple approach to type 2 diabetes prevention. Focusing on the individual to address their 'risky' behaviours minimises the social, economic, political, and ideological influences driving ill-health.^{89 133}

Primary care teams discussed how social and economic determinants play out in the lives of their patients and the overwhelming structural barriers they face when trying to undertake behaviour change. Despite this they felt they had little choice but to give individualist health promotion messages even when they know that this approach is likely to have limited effect

without addressing the social and economic determinants of health. Primary care teams did not feel they had the power to advocate on addressing these factors.¹³⁴ The use of scare tactics and 'surveillance medicine' described in chapter 3 (presenting the individual with dire health outcomes if they did not change their behaviour), was justified if it led to behaviour change even if only witnessed in isolated cases. However, some participants illustrated how this approach can cause harm by perpetuating unnecessary fear, promoting harmful restrictive diets whilst also stigmatising individuals. This form of health promotion messaging aligns with national diabetes prevention campaign using scare tactics to promote behaviour change.⁹¹ This further contributes to the acceptance of this individualist approach of pre-diabetes categorisation and health promotion messages.

COVID-19 disproportionately affected those with type 2 diabetes and obesity. This led to calls to address the social determinants of health and tighter regulations on the food industry.^{33 37}
¹³⁵⁻¹³⁸ However, findings from chapter 7 of how our political context shapes disease prevention policies, suggest that a whole-population approach to type 2 diabetes prevention may be politically problematic. National infrastructure changes (such as limiting fast food outlets or restricted advertising) go against the neoliberal ideals of limited state intervention in the pursuit of a free market economy and with minimal regulation of profit making corporations.^{131 139} As illustrated by my policymaker interviews reducing local or national economic revenues was deemed to be politically unfavourable and public health initiatives rejected as a consequence. As such, now several years after the COVID-19 pandemic, all the national population level-interventions aimed at reducing obesity levels have all been delayed with little information as to when they might be reconsidered.

2. Primary care health system in prevention

At present, General Practice is navigating two competing paradigms. On the one hand GPs are incentivised and told to subscribe to the biomedical model of disease prevention, which perpetuates an individualist focus encouraging people to take responsibility and control their behaviour to prevent type 2 diabetes. On the other hand, practice teams are very aware of how the social and commercial causes of disease play out within their patients' narratives.

Even with the dominance of an individual-level approach, from the participant interviews it was clear that type 2 diabetes prevention is not always given the attention it requires from primary care teams. The pre-diabetes diagnosis was of great significance to participants, being informed that they were at risk of a life limiting condition was met with fear and uncertainty.⁹² Pre-diabetes is different to other liminal diagnoses (such as high cholesterol) because of its direct link to a life limiting condition.^{133 140} Everyone responded according to their habitus and the life-worlds they occupy. However, most participants did not feel the risk diagnosis was being given due attention from the primary care team. Most participants hadn't had a face-to-face consultation to discuss the diagnosis and its implications.

Subsequent yearly monitoring was done remotely with results often communicated via text messaging. Some participants felt that they had been abandoned by the system, without a clinician who knows them and their social context to discuss lifestyle change with. Currently primary care systems are under-resourced, faced with rising workloads, with a high turnover of patients and staff. Health policies and societal pressures demand rapid access to health services, resulting in prioritisation of patient access over continuity of care, even though it is well known that continuity of care is both cost effective and increases patient satisfaction.¹⁴¹⁻

¹⁴³ Unless an area commissions type 2 diabetes prevention reviews in a primary care setting,

GPs may find it difficult to give patients dedicated times to discuss the diagnosis and lifestyle change. The GP-patient therapeutic relationship was neither referred to nor valued by the policymakers in their interviews and is largely overlooked by type 2 diabetes prevention policy. Primary care teams provide a unique opportunity to support people with lifestyle change on a longer-term basis. There is little guidance for primary care teams with how 'pre-diabetes' and lifestyle changes should be discussed in primary care. The interviews highlighted examples of where health promotion messages delivered to people can be stigmatising and cause offence. Modern day General Practice is a highly complex system, due to the increasingly diverse range of health care professionals in primary care, delivering both in person and remote services. With new roles being developed in primary care teams, it is unclear who is best placed to discuss individual lifestyles with patients, what training they need to deliver non-stigmatising health messages and support people with lifestyle change. The traditional concept of continuity of care is not currently possible due to system pressures so some have suggested a modernised concept of continuity of care provided by a team rather than by individual clinicians.¹⁴² Given the rising numbers of people with pre-diabetes and type 2 diabetes it is unclear what the best model of care is for these groups. Even though evaluations continue to show the success of the type 2 diabetes prevention programmes for those who can engage, complete interventions, and change their lifestyles on a longer-term basis, this is likely to be a minority of patients. Further to this there are reported concerns over the intervention's fidelity, accessibility, and cultural competence.^{14 18 19 23 24} If this policy of identifying people at risk of type 2 diabetes remains, then as a medical profession we have an ethical duty to ensure non-stigmatising culturally competent health promotion messages and interventions are delivered to people and that long-term support is offered outside intervention settings. Otherwise, there is a risk that those who are able to engage in

interventions and maintain behaviour change (which evaluations suggest to be men from white ethnic backgrounds with good health literacy and from higher socio-economic groups) improve their behaviours and reduce their risk of type 2 diabetes whilst others who are unable to engage in interventions (women and those from minority ethnic groups) are left with the health promotion messages (or no messages) delivered via primary care discussed in chapters 3 and 4.

3. Complexity of lifestyles

Chapter 6 was dedicated to exploring the how people undertake everyday decisions regarding their health-related behaviours. Using tools from Bourdieu's theory of practice I explore the complexity behind how behaviours develop over a life course through an individual's habitus. When making lifestyle decisions this habitus interacts with the life world context producing decisions heavily influenced by the social rules of the setting (doxa) and the associated capital (whether that was social or financial). Health-related behaviours are the result of a dynamic interplay between all the different components, explaining why at different times, in different contexts people make different decisions. Similarly to Hindhede's ethnography of people with pre-diabetes, my in-depth study suggests that people navigate their risk of type 2 diabetes whilst also considering the impact on their social lives. As a result, it is very difficult for people to completely change their lifestyles and there were no examples of this in my dataset. This is supported by Howells et al, who similarly showed that people resisted making any lifestyle changes because of their social context.¹⁷ The contexts reported as having the biggest influence on people's health related behaviours in my study were the home and work contexts. Women from diverse cultural backgrounds with work and caring responsibilities found behaviour change particularly challenging. Eating is a social

practice, done with others in a social context, not a social vacuum.¹⁴⁴ This practice includes what is eaten, how it's cooked, where the food is bought, as well as who does the cooking. If the participant wasn't surrounded by people (such as their family) who supported their lifestyle change, then it was very difficult to make changes which disrupt social norms. People did not want to admit that they were at risk of type 2 diabetes with wider friends and work colleagues because of the stigma associated with the condition. Therefore, it was very hard not to comply with the 'cake and cuppa' or canteen cultures within the workplace as described within the chapter. People were worried that if they admitted they were at risk of type 2 diabetes it may influence how others perceived them or hinder their promotion opportunities. The groups that found it particularly difficult to change their lifestyles were those with caring responsibilities and those from diverse ethnic groups. This complexity wasn't fully appreciated by either health care professionals or policymakers. Although they could appreciate and list the commercial and social determinants of health, the solutions offered were based on simple individual-level behaviour change.

8.4 Neoliberal policy mechanisms

England is thought to have a neoliberal political system based on ideals of competition, free markets with minimal state intervention and corporate regulation to promote economic prosperity.^{91 123-125} Neoliberal systems downplay the idea that health is the product of structural forces placed on individuals, diminishing the role of social, economic, and commercial influences on health.⁹³ Both the primary care teams and the policymakers acknowledged the central role of the social determinants of health in non-communicable disease development. However, as seen throughout this DPhil, the solutions presented to

these problems are rarely to target the upstream causes, but to focus on individuals to minimise their health risks by becoming responsible, self-governing citizens, changing their behaviours.^{34 91 123 124 126 128} This phenomenon is called “lifestyle drift”, and three mechanisms were seen as part of this qualitative study.

The first mechanism was illustrated from the accounts from public health policymakers. Moving public health teams into a political system with local authorities and their associated structures has left these teams with reduced funding, power, and influence. This has been reinforced by the removal of Public Health England which has raised several concerns from public health leaders.⁴² There is now no national public health voice for ‘health-care public health’, which requires a dedicated public health work force focused on preventing long term conditions, reducing inequalities related to these, whilst also linking these to the wider determinants of health.¹⁴⁵ This shifts the responsibility of type 2 diabetes prevention away from national and community-level interventions to individuals.¹²⁴

A second (and complementary) mechanism of lifestyle drift demonstrated in this study is the situating of disease prevention in primary care. This medicalises lifestyles, further emphasising the need for individuals to use their agency to prevent type 2 diabetes. This diverts attention away from the socio-economic causes of disease (such as the obesogenic environment) and in doing so oversimplifies the complexity of type 2 diabetes development.^{27 128 131 146} Inherent in this strategy is the assumption that health inequalities are due to individual life choices, not the underlying social causes of disease.^{128 131}

Subsequent individual health promotion messaging in lifestyle interventions promotes the belief that people should be able to overcome their structural barriers, becoming self-

governing individuals, making rational choices despite difficult living circumstances.^{88 128 131}

As a result, individuals are 'blamed' and left with the responsibility of developing type 2 diabetes, when in fact given the deprivation, complexity of lifestyle construction and obesogenic environments described in chapters 5 and 6, it is in fact not their 'fault'. Some academics believe that the framing of individual responsibility for disease prevention is a powerful industry tactic to deflect their responsibility for disease development, with the targeting of upstream influences such as removing sugar subsidies framed by them and their lobbying groups as excessive government involvement in people's everyday lives (the nanny state).^{122 147}

The third mechanism of lifestyle drift seen in this DPhil is how and what research is funded and how this has been used to justify type 2 diabetes prevention policies. The emergence of evidence-based medicine in the 1990s was followed by the development of evidence-based healthcare policy. Its supporters argued for an increased role of research in clinical decision making and policy construction, moving away from uninformed, opinion-based policy. There have been many positive outcomes from the role of evidence in policy making with increased rigor and justification of policies. However, "evidence based policy" implies that complex political and social problems can be solved with simple technical solutions.¹¹⁵ As seen in the type 2 diabetes prevention research described in chapter 2, trial based evidence (based on largely positivist epistemological perspectives) offers a simple solution to an inherently incredibly complex problem of type 2 diabetes development. This supports the theory that type 2 diabetes can be prevented through the unpolitical, rational translation of evidence into policy implementation. Chapter 7 has shown that the policy implementation process is a

dynamic interplay of ideas, power, political contexts and social processes which change over time.¹⁴⁸

8.5 Ethical reflections

Public health ethics is defined as ‘a societal responsibility to protect and promote the health of the population *as a whole*’.¹⁴⁹ A key tenet of this is the goal of reducing health inequalities between and within societies in the pursuit of social justice.¹⁵⁰ As medical and public health academics and policymakers, we have a duty to reflect on commissioned public health initiatives, to ask if they will benefit the populations we serve, to explore the power forces behind them and question whether they are truly just. In this thesis I have explored from multiple perspectives the framing of type 2 diabetes prevention, how individualist solutions are presented as the solution to complex problems and how research is used by policymakers. Current health policies propose ‘simple’ solutions to address inherently complex problems; using evidence-based medicine to justify these distracts the exploration of the underlying societal values and market forces driving health inequalities. This is an example of governmentality placing the emphasis of health on its citizens rather than placing an emphasis on the wider structural causes of health inequalities, which is particularly unjust and exacerbated by the current cost of living crisis and unaffordability of healthy food options.¹⁵¹ My qualitative interviews of people with pre-diabetes have shown that these policies may be stigmatising and harmful on an individual level, telling people they are at risk of a life limiting condition without the associated tailored support in primary care settings. Further to this, trial-based research and programme evaluations have shown limited effectiveness of these in minority ethnic groups and those who are most deprived. I do not believe that individual-level strategies, which do help some people reduce their risk of type 2 diabetes, need to be sacrificed to strive for a greater emphasis on social justice.¹⁵² There will

always be a need for individual-level interventions based in the NHS, however these must be performed in parallel with upstream population level initiatives to reduce health inequalities.^{27 32 33 37 44}

Exploring the benefactors of policies such as type 2 diabetes prevention is of vital importance for public health, particularly vested interests from food industry, pharmaceutical companies and disease advocates.¹⁵³ Here public health has an important advocacy role to strive for social justice and the dissolution of Public Health England has affected the ability to do this on a national level. It is not just to place the blame on people's lifestyles for causing disease when structural influences such as housing, jobs, the obesogenic environment, affordability of healthy foods and regulation of marketing and advertising strategies have a greater long-term impact on the population's health. By allowing an individualist agenda to be perpetuated, current policies such as the type 2 diabetes prevention policy will continue to be unchallenged based on arguments of free choice. I believe those who are the most vulnerable in society are constrained by social norms and structural forces and while they are believed to have free choice, this is not the case. As a public health community we need to consider ethical principles on a population level and explore how we can create a health producing society.¹⁵⁴ This will involve challenging political and industry interests (food, health and pharmaceutical) who are driving the medicalisation of non-communicable diseases for their own benefit and advocate for wider structural and environmental improvements.¹⁵³

8.6 Strengths and limitations

In my DPhil I have undertaken an in-depth multimethod qualitative study exploring the experiences of people with pre-diabetes, general practice teams and policymakers. To my knowledge this is the first study which has explored the perspective of all three of these groups. Several changes had to be made to how the study was conducted due to the COVID-19 pandemic, but I think the changes have meant that the study recruited a more diverse population and was more convenient for participants to take part in due to being online rather than in-person (which has become much more normal since lockdown). Doing a three-stage qualitative study did mean that it took longer to collect the qualitative data and was more demanding on participant time, but the follow up interviews and observational materials provided a far greater depth to the study, allowing people time for reflection on the social construction of their lifestyles. This meant participants were actively involved in the research process, becoming their own researchers, giving them space to reflect on what mattered most to them and constructing knowledge with the observational materials at the follow up reflective interview. The study explored the perspectives of people outside of a trial or lifestyle intervention, which means the interview accounts are more reflective of everyday life.

The primary care team focus groups worked very well to gather large amounts of information from multiple perspectives in a short space of time, allowed for consensus building and gathering a range of opinions.⁸¹ All members of the practice team, from the administrative staff, GPs (who discuss blood test results and give the initial diagnosis of 'pre-diabetes'), practice nurses, health care assistants, community pharmacists (who undertake annual reviews of patients and give health promotion advice) play a crucial role at different stages of the patient pathway. The focus groups allowed me to explore how the practice teams

interacted with each other producing knowledge together.^{74 80} The groups collectively generated insights and solutions to the mock scenarios, presented by the personas which would not have occurred without the other participants.⁷⁹ However, all the practices taking part in this focus group had signed up to the enhanced service incentivised by the CCG, and all saw type 2 diabetes prevention as a clinical priority for their practice population. Not all areas in the country are offering this incentivised scheme or something similar, therefore the views in these focus groups are not representative of all GPs.

To my knowledge this is the first analysis of type 2 diabetes prevention policies in the UK using a political science perspective. Other studies have focused on either the policy process, or the research-policy gap, but this is the first to examine both as part of the same social-political context.^{103 120 155 156} One limitation of this approach was that policymakers' views tended to align with the organisation that they were working for (rather than their own opinions) and may have influenced how they responded to questioning. A further limitation to this part of the study was the small sample size and as such the results are preliminary.

8.7 Implications for policy and practice

Population Health Reforms

Following the COVID-19 pandemic the national health improvement functions of PHE were moved to the Department of Health and Social Care with a new Office of Health Promotion and Disparities constructed under the leadership of the CMO.¹⁵⁷ Secondly, integrated care systems have formed which include integrated care partnerships, integrated care boards (previously known as CCGs, responsible for commissioning services and managing budgets)

and local authorities (where local public health bodies remain), with the aim of developing place-based partnerships. GP practices have been organised into Primary Care Networks tasked with improving community health, prioritising disease prevention and reducing health inequalities.¹⁵⁸ This study has shown that the scope of the NHS is largely to focus on the individual, but with these integrated care systems they now have a new portfolio to tackle 'population health'. For these organisations to meet their new responsibilities it is vital for them to form partnerships and working relationships with local authorities and public health teams with funding to support this.¹⁵⁹⁻¹⁶³

Primary Care Practice

Even though the emphasis of the type 2 diabetes prevention pathway is largely based on giving individuals a pre-diabetes diagnosis and encouraging behaviour change, and it may appear to be a natural task for primary care teams, that does not mean the policy is currently being well executed. There currently are no guidelines on how to deliver this risk diagnosis and health promotion messages in a non-stigmatising way. Due to the pressures on primary care health systems, clinicians do not seem to have the capacity to deliver the diagnosis and management of the condition in ring fenced consultations. As seen in chapters 3-5, to manage the volume of work in primary care clinicians are increasingly using text messages to deliver information to patients often before or after clinics. Incentivising GP practices to do annual blood tests on people with pre-diabetes through the GP contract does not seem to be enough to prioritise this group of people. Currently, relationship-based care does not seem to be part of type 2 diabetes prevention policies, yet it is recognised as an incredibly important disease prevention strategy by patients and clinicians. Prioritising continuity of

care for people with pre-diabetes could help facilitate sustained behaviour change on a longer-term basis through therapeutic relationship-based care.

8.8 Areas for further research

Regardless of the political party, it is unlikely that the neoliberal socio-political system we occupy will change soon. Therefore, future research directions need to consider what can be done within the system to help reduce everyone's risk of type 2 diabetes.

Health system research

The primary health care system has undergone major changes in the last five years. There are several new roles within primary care teams such as physician's associates, community pharmacists, social prescribers, nursing associates and paramedics. These new roles are adding to an increasingly complex and fragmented health system with consultations now being undertaken remotely as well as face to face. It is unclear whether the skill sets of these new professionals are being appropriately used and how their introduction is impacting the care of people with type 2 diabetes and pre-diabetes. As part of a post-doctoral programme of research I propose to take a health systems approach in examining how these new actors influence health outcomes for those at risk of type 2 diabetes. It is unclear across the country how a diagnosis of pre-diabetes is being delivered to people and what health messages are being given in primary care. I hope to undertake a mixed methods study which will aim to:

1. Analyse the current pre-diabetes diagnosis practice, understanding who is being diagnosed, how are they being diagnosed, by whom, and what follow up are they

having. I hope to do this in collaboration with a statistician by undertaking an analysis of a large data set (such as the GPRD).

2. Qualitative interviews with GPs and allied health professionals working in primary care seeking to understand their areas of expertise and skill sets and understanding who would be best placed to deliver the diagnosis of pre-diabetes, how the diagnosis is being given and what is required from the health system to ensure the delivery of tailored health promotion messages in primary care settings.
3. A co-design programme of work to understand how we improve the delivery of the pre-diabetes diagnosis and associated health promotion messages within consultations. Several co-design workshops with patients and primary care teams (from part 2) to explore how the delivery of the diagnosis, health promotion messaging can be delivered in a culturally competent, non-harmful and non-stigmatising way. Additionally, from this co-design exercise I will seek to explore what it is patients need from the health system and what continuity of care is required for patients with a pre-diabetes diagnosis.

Social science research

Accounts from the patients who took part in the in-depth case study suggested there may be several intersectional influences, acting as forces of oppression, precluding lifestyle change in some people. This was seen particularly in the accounts from women from diverse ethnic backgrounds. Women's health research strategy for England was published in 2022 calling for increased research and policy making to include women's voices and perspectives addressing women's health across the life course.¹⁶⁴ I plan to undertake a secondary analysis of the existing DPhil data, using an intersectional lens to see how societal influences impact women's health. I hope that this will inform further ethnographic work of women from

diverse ethnic groups with pre-diabetes (as there were only four women who fulfilled this criterion as part of the DPhil sample), exploring in more detail how the health system and societal influences impact their ability to reduce their risk of type 2 diabetes.

Academic – policy – practice gap

This study has illustrated several research-policy gaps in disease prevention. Policymakers did not feel that research considered their own socio-political contexts, emphasising that policy development was a messy, non-linear process taking place within a socio-political economic context.⁷¹ The policymakers discussed a need for increased partnerships between policy and academia to understand each other's needs, world views and operational constraints.

Working together to co-produce from the start may help bridge translational research gaps.

This approach aligns with Weiss's interactive model of research utilisation but requires a shift away from the traditional hierarchy of biomedical research.^{15 103} As part of a post-doctoral study of work I hope to extend and update the DPhil by undertaking a qualitative study of policy working within integrated health boards, integrated health systems and public health teams to see how the NHS and local authorities are using research and working to reduce long-term conditions such as type 2 diabetes at a community level.^{165 166}

Incorporating the findings of my DPhil and in collaboration with policymakers, I hope to map out an evidence informed 'prevention triangle', identifying where the further research and policy needs are. At the top of the triangle are those at greatest risk of type 2 diabetes, whilst the bottom is the general population. Each point of the triangle would outline a research-policy strategy. For example, the systematic review summarised in chapter 2 highlighted flaws in how we identify those at most risk of type 2 diabetes, yet the strategy to

identify those at most risk has not changed since the publication of this systematic review (in 2017). Further to this, greater policy emphasis lower down in the triangle on population level initiatives may help shift the responsibility of type 2 diabetes prevention away from the individual to a more collective community or population level responsibility to reduce the burden of disease. This may help to reduce the stigma of those with 'pre-diabetes'. As outlined by a recent All Party Parliamentary Group on medical research, there is a greater need for academic research to be used as an advocacy tool for reducing health inequalities and targeting the structural influences on health, I hope that this collaborative academic-policy partnership will contribute to this.^{167 168}

8.9 Conclusion

My thesis study is the first to use a critical social science lens to explore pre-diabetes from the perspectives of primary care teams, people with pre-diabetes and policymakers. In this thesis I explore the framing of the pre-diabetes diagnosis, the delivery of health promotion messages, the barriers to lifestyle change and why type 2 diabetes prevention is constructed in its current form. The key finding of my DPhil is the focus on, and acceptance by participants, of the individualist discourse in type 2 diabetes prevention, largely attributable to our neo-liberal socio-political context. Without a shift away from focusing on individual responsibility, and greater focus on the structural determinants of health, it is unlikely we will see a significant reduction in type 2 diabetes incidence and prevalence. There is a risk that current type 2 diabetes prevention policies will widen health inequalities. Those who are affluent, have a supportive social context, with good health literacy will be better able to

reduce their risk of type 2 diabetes than those from more deprived ethnically diverse populations.

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Appendices

Appendix 1: BMJ editorial

EDITORIALS



Time to question the NHS diabetes prevention programme

Public Health England's focus on individual behaviour change is unlikely to stem the epidemic of type 2 diabetes

Eleanor Barry *NIHR in-practice fellow*¹, Samantha Roberts *DPhil student*¹, Sarah Finer *honorary clinical senior lecturer*², Shanti Vijayaraghavan *consultant diabetologist*³, Trisha Greenhalgh *professor*¹

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A new Public Health England report on the rising prevalence of type 2 diabetes proposes targeting people with non-diabetic hyperglycaemia (defined as an HbA_{1c} concentration of 42–47 mmol/mol) with behavioural interventions (diet and exercise).¹ Action for this group (10.7% of the adult population) is to be the cornerstone of the NHS Diabetes Prevention Programme, which will be rolled out nationally from 2016.²

Such individualised policy is divorced from the multilevel, community-wide, and politically engaged prevention plans recommended by the World Health Organization³ and Robert Wood Johnson Foundation.⁴ In its report on non-communicable disease WHO calls for “multisectoral action that simultaneously addresses different sectors that contribute to the production, distribution and marketing of food, while concurrently shaping an environment that facilitates and promotes adequate levels of physical activity.”³

Targeting individual behaviour as a preventive strategy rests on five doubtful assumptions: that it is possible, on the basis of a risk score and blood test, accurately to identify a population subgroup with the highest risk of developing diabetes; that individuals thus targeted will behave like participants in research studies; that behaviour changes will be sustained indefinitely; that clinically important improvements in patient relevant outcomes will follow; and that the programme will be affordable and cost effective.

Risk scores and confirmatory tests of hyperglycaemia are imperfect. People excluded on the basis of a risk score (hence, not offered testing) may be falsely reassured.^{5–8} For example, few risk scores ask about a history of gestational diabetes, which disproportionately affects Asian women and increases the risk of type 2 diabetes sevenfold.⁹ Three systematic reviews (not cited in the Public Health England report) were circumspect about the usefulness of diabetes risk scores and warned that a

score's external validity may be weak if the population on which it is used differs from the one on which it was developed.^{5–8}

The risk scores were designed to predict type 2 diabetes, but the Public Health England report seems to conflate this with their ability to detect non-diabetic hyperglycaemia. Using HbA_{1c} to identify non-diabetic hyperglycaemia defines twice as many people as “prediabetic” than does the gold standard but impractical oral glucose tolerance test¹⁰; it may be inaccurate in some groups.^{11–14} Substantial underdiagnosis and overdiagnosis is thus likely, with huge workload implications for both primary care and community services.

Public Health England justifies its proposed policy using a new (non-peer reviewed) meta-analysis of behavioural interventions in diabetes prevention,¹⁵ which extends a previous meta-analysis.¹⁶ The 36 primary studies are described—somewhat curiously—as “pragmatic” and “real world.” Yet each was limited to a tightly specified individual intervention delivered as part of a research study; half were randomised trials.¹⁵ Average follow-up was one year. All participants met specific inclusion criteria, including willingness to engage and, in most if not all cases, speaking the same language as the researchers. Individuals drawn from an unselected, free living population are unlikely to respond similarly, given their lower health literacy, higher comorbidities, and greater ethnic diversity,^{17–19} and changes achieved by short term interventions may not be maintained in the longer term.^{20–22}

The pathogenesis of diabetes incorporates genetic, physiological, psychological, sociological, and wider environmental influences that play out differently for different individuals in different settings.²³ Overlooking this complex reality, Public Health England's meta-analysis sought to identify components of behavioural interventions associated with “success,” usually measured by surrogate endpoints. For example, it says: “Offering

13 or more contacts over the first 18 months was associated with a 3.15 kg greater weight loss in intervention arms compared to control arms, than offering less than eight contacts.”¹⁵

Statements of this kind were used to build a specification for a complex intervention that would, its architects assumed, be maximally effective across a diverse population. Implicit in this approach is the flawed assumption that particular components of a complex intervention have a transferable effect size whatever else they are combined with, whoever receives the intervention, and in whatever context.²³⁻²⁶

The NHS Diabetes Prevention Programme expects a 26% reduction in incidence of diabetes and implies that associated morbidity and mortality will fall. Yet the meta-analysis contains no evidence of any sustained reduction in morbidity or mortality relating to diabetes or cardiovascular disease after lifestyle intervention in prediabetes.¹⁵ Rather, it focuses on changes in surrogate endpoints that were statistically but not clinically significant, such as HbA_{1c} reduction of 0.07%, two hour glucose reduction of 0.28 mmol/l, and weight reduction of 1.57 kg.¹⁵ A newly published evidence synthesis of the effect of lifestyle interventions on overall mortality in prediabetes cites 17 trials that failed to show a significant effect and one that just reached statistical significance.²⁷ Effects tend to be far smaller in unselected free living populations than in trial participants.²⁸

Astonishingly, given that this lifestyle intervention will become national policy, the Public Health England reports offer no formal estimate of the programme's cost or cost effectiveness. The assumption that it will save money is based on speculation that the intervention will produce “optimal effects whilst keeping costs to a minimum.”¹⁵ The proposed payment by results model may create perverse incentives to focus on “compliant” populations rather than those at greatest risk of diabetes, which often experience multiple barriers to achieving the desired outcomes.²⁹⁻³⁰

The public consultation on England's proposed NHS Diabetes Prevention Programme runs until 18 September 2015 (www.england.nhs.uk/ourwork/qual-clin-lead/action-for-diabetes/diabetes-prevention). We have serious concerns that the programme consists entirely of a top down, highly standardised behavioural intervention offered to a fraction of the population. Public Health England's estimates suggest that 18.2% of adults in England now have abnormal glucose metabolism (10.7% prediabetic, 7.5% diabetic) and that this figure is rising. This surely necessitates investment in population based strategies such as improving the neighbourhood environments for healthy food choices and physical activity opportunities as well as support for individuals.^{10 29 30 31} Readers who share our concerns may wish to contribute their views to the consultation.

Competing interests: We have read and understood BMJ policy on declaration of interests and declare we are all clinical academics who are working with Newham Clinical Commissioning Group and other local partners to design a multifaceted community based diabetes prevention programme for an ethnically diverse and deprived local population.

Provenance and peer review: Not commissioned; externally peer reviewed.

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Appendix 2: Systematic review 1



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Efficacy and effectiveness of screen and treat policies in prevention of type 2 diabetes: systematic review and meta-analysis of screening tests and interventions

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ABSTRACT

OBJECTIVES

To assess diagnostic accuracy of screening tests for pre-diabetes and efficacy of interventions (lifestyle or metformin) in preventing onset of type 2 diabetes in people with pre-diabetes.

DESIGN

Systematic review and meta-analysis.

DATA SOURCES AND METHOD

Medline, PreMedline, and Embase. Study protocols and seminal papers were citation-tracked in Google Scholar to identify definitive trials and additional publications. Data on study design, methods, and findings were extracted onto Excel spreadsheets; a 20% sample was checked by a second researcher. Data extracted for screening tests included diagnostic accuracy and population prevalence. Two meta-analyses were performed, one summarising accuracy of screening tests (with the oral glucose tolerance test as the standard) for identification of pre-diabetes, and the other assessing relative risk of progression to type 2 diabetes after either lifestyle intervention or treatment with metformin.

ELIGIBILITY CRITERIA

Empirical studies evaluating accuracy of tests for identification of pre-diabetes. Interventions (randomised trials and interventional studies) with a control group in people identified through screening. No language restrictions.

RESULTS

2874 titles were scanned and 148 papers (covering 138 studies) reviewed in full. The final analysis included 49

studies of screening tests (five of which were prevalence studies) and 50 intervention trials. HbA_{1c} had a mean sensitivity of 0.49 (95% confidence interval 0.40 to 0.58) and specificity of 0.79 (0.73 to 0.84), for identification of pre-diabetes, though different studies used different cut-off values. Fasting plasma glucose had a mean sensitivity of 0.25 (0.19 to 0.32) and specificity of 0.94 (0.92 to 0.96). Different measures of glycaemic abnormality identified different subpopulations (for example, 47% of people with abnormal HbA_{1c} had no other glycaemic abnormality). Lifestyle interventions were associated with a 36% (28% to 43%) reduction in relative risk of type 2 diabetes over six months to six years, attenuating to 20% (8% to 31%) at follow-up in the period after the trials.

CONCLUSIONS

HbA_{1c} is neither sensitive nor specific for detecting pre-diabetes; fasting glucose is specific but not sensitive. Interventions in people classified through screening as having pre-diabetes have some efficacy in preventing or delaying onset of type 2 diabetes in trial populations. As screening is inaccurate, many people will receive an incorrect diagnosis and be referred on for interventions while others will be falsely reassured and not offered the intervention. These findings suggest that “screen and treat” policies alone are unlikely to have substantial impact on the worsening epidemic of type 2 diabetes.

REGISTRATION

PROSPERO (No CRD42016042920).

Introduction

The prevalence of type 2 diabetes is rising globally; 422 million adults are living with diabetes,¹ and the number expected to die from its complications is predicted to double between 2005 and 2030.¹ In the United Kingdom about 3.2 million people have type 2 diabetes, and by 2025 it is predicted that this will increase to five million.² This places considerable financial burden on the National Health Service (NHS). The healthcare cost of diabetes is estimated to be £23.7bn (\$30.2bn, €28.2bn), a figure expected to rise to £39.8bn by 2035-36.² Preventing or delaying type 2 diabetes has become an international priority.

There are two approaches to prevention: screen and treat, in which a subpopulation is identified as “high risk” and offered individual intervention, and a population-wide approach, in which everyone is targeted via public health policies on environmental moderators³ (sociocultural influences, socioeconomic influences, transport, green spaces). Finland is taking a multi-level

WHAT IS ALREADY KNOWN ON THIS TOPIC

Type 2 diabetes is increasingly common; its prevention is an international health priority

There is no agreement on how best to define or detect “pre-diabetes” (that is, high risk of developing type 2 diabetes in the future)

Trials in people with pre-diabetes have shown that the onset of type 2 diabetes can be delayed or prevented with lifestyle measures or metformin

WHAT THIS STUDY ADDS

This is the first systematic review to assess both the diagnostic accuracy of screening tests for pre-diabetes and the efficacy of interventions in those detected by screening. As different tests for pre-diabetes define vastly different populations, large numbers of people will be unnecessarily treated or falsely reassured depending on the test used. “Screen and treat” policies will benefit some but not all people at high risk of developing diabetes; they might need to be complemented by population-wide approaches for effective diabetes prevention.

Definition of terms

Oral glucose tolerance test

- Two part blood test
- Part one: fasting plasma glucose (FPG). Blood test after overnight fast. If result is abnormal, diagnosis is impaired fasting glucose (IFG)
- Part two: 2 hour glucose tolerance test (2hrGTT). Blood test two hours after ingestion of sugary drink. If result is abnormal, diagnosis is impaired glucose tolerance (IGT)
- Both tests can be performed independently of each other

HbA_{1c}

- Measurement of glycated haemoglobin, which reflects glucose concentration over two to three months. Accuracy impaired by haemoglobinopathies

Pre-diabetes

- Arbitrary category to encompass either IFG or IGT or abnormal HbA_{1c}

American Diabetes Association (ADA) diagnostic criteria

- Impaired fasting glucose 5.6-6.9 mmol/L
- Impaired glucose tolerance 7-11.1 mmol/L
- HbA_{1c} “at risk” range 39-47 mmol/mol (5.7-6.4%)

WHO diagnostic criteria

- Impaired fasting glucose 6.0-6.9 mmol/L
- Impaired glucose tolerance 7-11.1 mmol/L
- HbA_{1c} “at risk” range 42-47 mmol/mol (6.0-6.4%)

International Expert Committee (IEC) diagnostic criteria

- HbA_{1c} “at risk” range 42-47 mmol/mol (6.0-6.4%)

approach to prevention by using both strategies.⁴ In contrast, the UK's National Diabetes Prevention Programme^{5,6} follows Australia⁷ and the United States⁸ in placing the emphasis on a screen and treat approach.

There is international inconsistency on how to identify individuals at high risk of diabetes, to the extent that “a transatlantic trip may cure or cause diabetes simply as a result of small but important differences in diagnostic criteria.”⁹ In the US, the American Diabetes Association criteria recommend a diagnosis of pre-diabetes in people with a fasting plasma glucose concentration of 5.6-6.9 mmol/L or HbA_{1c} of 39-47 mmol/mol (5.7-6.4%). WHO (World Health Organization) and the International Expert Committee recommend a fasting plasma glucose cut off of 6.0-6.9 mmol/L and HbA_{1c} of 42-47 mmol/mol (6.0-6.4%). The term pre-diabetes is used to encapsulate these ranges and implies that if individuals do not take action they will develop diabetes (though in reality this is not always the case). Since the recognition of pre-disease states (impaired glucose tolerance, impaired fasting glucose, and raised HbA_{1c}), trials of lifestyle interventions have been associated with reduced or delayed onset of type 2 diabetes.¹⁰ Studies of screening and intervention programmes in real world settings, however, are sparse.¹¹ Women with a history of gestational diabetes have a sevenfold risk of developing diabetes postpartum.¹² These women might not be captured by the pre-diabetes umbrella term because many have normal glycaemic markers at the six week postpartum review and then fail to attend for annual review thereafter.¹³⁻¹⁷ Gestational diabetes is common in certain minority ethnic groups,¹⁸ and in

deprived multi-ethnic areas a history of this condition could identify a considerable proportion of individuals who could benefit from preventive interventions.

We sought to inform national and local policymaking on prevention of type 2 diabetes by asking two questions. Which (if any) screening test should be used to identify people at risk of developing type 2 diabetes? What is the efficacy of preventive interventions (lifestyle and/or metformin) in those identified as high risk by screening?

Methods

Search strategy

We sought to identify all diagnostic accuracy and prevalence studies focusing on laboratory assessed HbA_{1c} and fasting plasma glucose (as recommended by the UK NICE (National Institute for Health and Care Excellence)¹⁹) as screening tools. Capillary glucose and HbA_{1c} point of care testing were excluded because of the lower reliability of these tests. For intervention studies we included trials whose participants were aged ≥ 18 and had been identified as being in one of the “at risk” groups (impaired glucose tolerance, impaired fasting glucose, raised HbA_{1c}, or a history of gestational diabetes). We studied two kinds of intervention: lifestyle programmes and metformin, compared with a control, in any setting, and that included weight change, change in glycaemic index, or incidence of diabetes as an outcome measure. Animal studies, molecular biology studies, studies related to children, surgical interventions, and interventions related to drugs other than metformin were excluded.

The study was undertaken from December 2014 to June 2016. It was commissioned by policymakers in a London borough with high prevalence of type 2 diabetes, and concerns about applicability to a real world setting helped shape the review questions. With assistance from a specialist librarian, three searches were undertaken: one for screening tests for pre-diabetes, another for intervention trials, and a third to identify studies relating to the prevention of type 2 diabetes in women with a history of gestational diabetes. Appendix 1 shows the full search strategy. Search terms (MESH and free text) included test, screening, pre-diabetes, impaired glucose tolerance, impaired fasting glucose, gestational diabetes, post-partum, ethnic groups, metformin, and lifestyle. EB manually extracted relevant titles from this dataset and reviewed abstracts to identify papers for full review. SR checked a random sample of 750 abstracts (20%). Disagreements were resolved by discussion. Bilingual colleagues translated non-English papers and extracted data with guidance from the research team.

Diagnostic accuracy meta-analysis

Diagnostic accuracy studies were tabulated by index and reference test. Raw data for the meta-analysis on true positives, false positives, true negatives, and false negatives were extracted directly or calculated with the sensitivity and specificity information given in the paper. Additional data were extracted on population demographics, ethnicity, and diagnostic criteria used. We pooled studies in which HbA_{1c} was the index test and

an oral glucose tolerance test was the reference standard. We presented these data separately for studies using the WHO criteria and studies not using these criteria (notably, some studies used the more stringent American Diabetes Association criteria to define pre-diabetes). We also pooled studies with the fasting plasma glucose as the index test and 2 hour glucose tolerance test as the reference test. Again we examined the data as a whole as well as separately by diagnostic criteria.

We undertook a bivariate diagnostic random effects meta-analysis²⁰ to pool study level estimates of diagnostic accuracy using the reitsma function from the R²¹ package *mada*.²² In each case, we reported the pooled sensitivity, false positive rate, false negative rate, and 95% confidence intervals. We plotted the bivariate summary receiver operating curve (sROC) over points representing study estimates of sensitivity and false positive rate, weighted by study size, and summarised the discriminative ability of each test using the area under the ROC (receiver operating characteristics) curve (AUROC) and the partial AUROC (which restricts the area to the observed false positive rates). Statistical heterogeneity was described with I^2 statistic for bivariate meta-analysis.²³

Defining at risk population

To compare differences in the at risk population identified by each test, we undertook a prevalence analysis. Using *eulerAPE v3*²⁴ we analysed raw data from prevalence studies to assess the degree of overlap in the population identified as abnormal by each test. This analysis highlights the differing number of people eligi-

ble for interventions, depending on which test and criteria are used. We created Venn diagrams with the area of each ellipse proportional to the prevalence.

Intervention trial review and meta-analysis

Data extracted into Excel files from intervention trials included participants' demographics, type of intervention, intervention length, and primary and secondary outcomes. A second Excel sheet was used to tabulate results, including a clinically significant reduction in BMI (1 kg/m²) or weight (2 kg), clinically significant improvement in glycaemic markers (normoglycaemia, or reduction in fasting plasma glucose by 0.5 mmol/l, 2 hour glucose tolerance by >1 mmol/L, HbA_{1c} to <42 mmol/mol), differences in incidence of diabetes between groups and whether this was significant.²⁵ We included in the meta-analysis any trial that collected data on incidence of diabetes. Data were extracted directly from the publications and processed with RevMan software. Because of the heterogeneity of the data we used a random effects model to create forest plots showing relative risk of developing type 2 diabetes after lifestyle interventions and metformin compared with usual care or no additional intervention.

Assessment of study quality, applicability, and bias

To assess the quality and applicability of the test papers we used the validated QUADAS-2 tool, designed for the evaluation of diagnostic accuracy papers.²⁶ After the refinement steps as recommended by the creators, two authors (EB and SR) piloted, adapted, and refined the tool before it was applied to all the papers used in the meta-analysis (see appendix 2). The limitations of the intervention trials were assessed with the Cochrane risk of bias tool²⁷ and the CONSORT checklist. One author (RN) used the GRADE principles to assess the overall quality of the evidence at outcome level.²⁷ An additional assessment was conducted to examine the extent to which participants were involved in the design of the intervention, if feedback was sought, if non-enrolment reasons were given, and if interventions could be adapted to meet the individual's needs.

Patient involvement

The review was conceptualised by a patient participation group led by the project lead (SV). Patients and clinicians raised questions on how best to identify those at risk of diabetes and explore how the Clinical Commissioning Group can support people in Newham to minimise their risk. In this way, patient and citizen involvement shaped the research question and methods of this review. The authors attended regular project meetings, reporting back the results of the review to the rest of the team, which included GP leads from the practices piloting interventions as well as the area lead for diabetes.

Results

Search results

Figure 1 shows the review flowchart. We fully reviewed 148 publications (83 relating to diagnostic accuracy testing and 65 relating to intervention trials). Data from

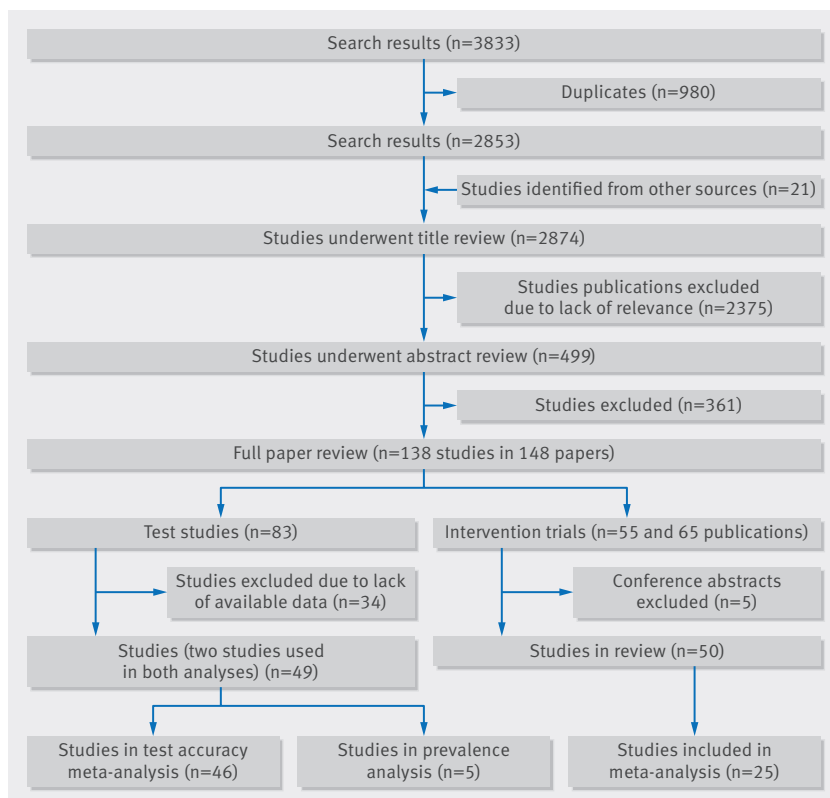


Fig 1 | Flow diagram of studies identified and included in review of efficacy and effectiveness of screen and treat policies in prevention of type 2 diabetes

46 papers were extracted and used to construct the diagnostic accuracy meta-analysis. We reviewed 50 unique intervention trials in full as well as publications related to these (protocol designs, subanalyses).

Diagnostic accuracy of tests for pre-diabetes

Table 1 lists the studies included in the diagnostic accuracy meta-analysis, with country of origin, population demographics, and QUADAS-2 assessment for bias and applicability. Figures 2 and 3 show the ROC curves constructed from data extracted from these trials. The pooled sensitivity of HbA_{1c} at identifying abnormalities as defined by the oral glucose tolerance test was 0.49 (95% confidence interval 0.40 to 0.58); its specificity was 0.79 (0.73 to 0.84). Data were extracted from studies with both WHO and American Diabetes Association criteria, as well as studies that determined the optimal diagnostic cut offs using the optimal sensitivity and specificity assessed from their own populations. AUROC are used to estimate the overall diagnostic accuracy of a test with a value of 1 equating to the perfect test. The calculated AUROC of the HbA_{1c} was 0.71. A low sensitivity, however, leads to a high number of false negative results (that is, people incorrectly identified as not having diabetes). When this is taken into account (with the partial AUROC calculation) the accuracy reduces to 0.59. A subanalysis with the International Expert Committee/WHO criteria for HbA_{1c} did not alter the sensitivity of this test.

Analysis of studies that used the fasting plasma glucose as the index test found that this test had a sensitivity of 0.25 (95% confidence interval 0.19 to 0.32) and specificity of 0.94 (0.92 to 0.96) at identifying impaired glucose tolerance. The analysis calculated an AUROC of 0.72, with a partial AUROC of 0.42. A subanalysis of studies using the criteria implemented in the UK did not change the results.

The main source of potential bias from these studies was selection bias. In many studies, the sampling strategy was unclear or participants self selected to attend for screening (for example, by answering an invitation or advertisement) rather than using a true population sample (random or consecutive). This was a particular concern in studies of follow-up after gestational diabetes, which usually defined their populations as women who had attended for the oral glucose tolerance tests, with no information on those who did not attend. Most diagnostic accuracy studies scored well on the QUADAS scale for applicability, indicating that the populations of patients were similar to those tested in primary care settings and the use of diagnostic tests and their interpretation was in keeping with our review question. These analyses showed a high level of heterogeneity, indicating that the test performs differently depending on population and setting. These are important considerations in the assessment of the diagnostic accuracy of the tests with specified populations. The results of the QUADAS tool were used to undertake a sensitivity analyses. Exclusion of studies at high risk of bias and outlying studies did not significantly alter the results (tables A and B in appendix 4).

Agreement between different diagnostic tests for pre-diabetes

Only five studies (table 2) gave a comparison of prevalence of pre-diabetes for all three tests (HbA_{1c}, fasting plasma glucose, 2 hour glucose tolerance test). With current International Expert Committee and WHO guidelines, 27% of the populations studied were identified as having “pre-diabetes” by one of the tests (of whom 48% had a raised HbA_{1c} alone, fig 4); if American Diabetes Association criteria for the HbA_{1c} is applied to the same cohort, this figure was 49% (of whom 71% had a raised HbA_{1c} alone, see fig F in appendix 4). There was low agreement between the three tests on which individuals were classified as having pre-diabetes. Figure 4 illustrates this limited overlap. Substitution of the American Diabetes Association criteria for both the oral glucose tolerance test and HbA_{1c} increased the degree of overlap between the test results, but this doubled the estimated prevalence of pre-diabetes (fig 5).

Interventions to prevent diabetes in screen detected pre-diabetes

Fifty trials met our eligibility criteria¹⁰⁷⁸⁻¹²⁶ (tables A-D in appendix 3 summarise the methods and results of these studies). Only 25 of the trials (21 of lifestyle interventions alone, two of metformin alone, and two assessed both) had the necessary information available to be included in the meta-analysis. All trials were performed in adults identified as at risk of developing diabetes defined by the oral glucose tolerance test or had a history of gestational diabetes. There was heterogeneity in the number of participants in each trial (ranging from hundreds to thousands), length of interventions (four weeks to six years), intensity of intervention (frequency of contacts), and delivery method. Agreement between raters on data extraction was 100%, with the exception of a single paper in which the authors did not distinguish between primary and secondary outcomes. Of 49 trials, 19 used the development of diabetes as a primary outcome measure. Some trials had begun with this outcome but during the trial substituted it for weight reduction and/or change in glycaemic markers because of low recruitment.⁷⁸ Many studies showed differences in weight and change in glycaemic markers between groups that were statistically but not clinically significant. At the end of the intervention, 20 of the 49 trials showed a clinically significant reduction in weight between the groups, 15 showed a clinically significant improvement in glycaemic markers, and 23 showed some difference in favour of the intervention arm in the number of people developing diabetes, but this difference was significant only in seven of those trials (tables C and D in appendix 3).

Meta-analysis (fig 6) showed that lifestyle interventions reduced the relative risk of developing diabetes by 31% (95% confidence interval 15% to 44%) if the intervention lasted six months to two years. This translates to 69 (95% confidence interval 56 to 85) out of 1000 people in the lifestyle intervention group developing diabetes compared with 100 out of 1000 without the intervention, or a number needed to treat (NNT) of 33

Table 1 | Details of diagnostic accuracy data of for detection of pre-diabetes and QUADAS analysis in studies included in review

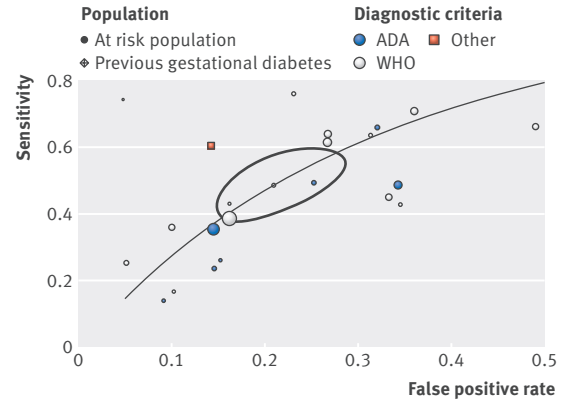
Country	Reference test criteria	Population information	Positive predictive value	Negative predictive value	Index sensitivity	Index specificity	QUADAS bias*			QUADAS applicability*		
							Bias	Index test	Reference test	Test timing	Patient selection	Index test
OGTT reference test (FPG+/-IGT), HbA_{1c} index test												
Italy	ADA	One risk factor	0.81	0.37	0.53	0.7	U	L	L	L	L	L
US	ADA	National survey	0.71	0.57	0.35	0.86	L	U	U	U	L	L
China	WHO	Rural Chinese	0.75	0.57	0.72	0.61	H	H	L	L	U	L
Korean	ADA	Korean	0.73	0.39	0.49	0.66	H	H	L	L	H	L
India (Bangladesh)	WHO	Rural	0.18	0.96	0.64	0.73	L	H	L	L	U	L
China	WHO&ADA	Urban	0.34	0.76	0.45	0.67	U	H	L	L	U	L
Netherlands	ADA	South Asian	0.35	0.88	0.66	0.68	L	L	L	L	U	L
North India	WHO/IEC	South Asian	0.43	0.85	0.36	0.9	L	L	L	L	U	L
Bulgaria	WHO	One risk factor	0.47	0.43	0.71	0.64	H	H	L	L	L	H
US	ADA	Arabic ethnicity	0.57	0.55	0.14	0.91	L	L	L	L	U	L
UK	WHO	23% South Asian	0.30	0.89	0.40	0.84	L	L	L	L	L	L
China	WHO	Chinese	0.52	0.65	0.66	0.51	L	H	L	L	U	L
US	ADA	Mixed	0.63	0.51	0.24	0.85	U	U	L	H	L	L
South India	ADA&WHO	Indian	0.20	0.93	0.66	0.62	L	H	L	L	L	L
China	WHO	Chinese	0.62	0.79	0.25	0.95	L	H	L	L	U	L
Japan	WHO	Japanese	0.80	0.73	0.76	0.77	U	H	L	L	U	L
Japan	WHO	Japanese	0.43	0.65	0.43	0.65	L	H	H	L	U	L
China	WHO	Chinese	0.39	0.86	0.647	0.828	H	H	L	L	U	L
China	WHO	One risk factor	0.63	0.94	0.70	0.87	U	H	L	L	L	L
China	WHO	Raised BMI	0.72	0.50	0.81	0.39	U	L	L	L	L	L
Canada	ADA	GDM, raised WC	0.89	0.33	0.76	0.62	L	L	L	L	L	L
Ireland	WHO	GDM	0.19	0.88	0.28	0.80	L	L	L	L	L	L
Spain	ADA	GDM	0.55	0.56	0.23	0.84	H	L	L	L	U	L
FPG reference, HbA_{1c} index test												
China	ADA	One risk factor	0.55	0.78	0.47	0.83	L	L	L	L	U	L
UK	ADA	One risk factor	0.63	0.88	0.21	0.98	L	L	L	L	U	L
US	ADA	GDM	0.75	0.62	0.39	0.81	H	L	L	L	L	L
China	ADA	Metabolic syndrome	0.31	0.92	0.6	0.76	L	L	L	L	U	L
HbA_{1c}+FPG combined index, IGT reference test												
Hu (repeat) ³⁹	—	—	0.59	0.70	0.42	0.82	—	—	—	—	—	—
Tanaka (repeat) ⁴³	—	—	0.97	0.68	0.62	0.98	—	—	—	—	—	—
Modan 1984 ⁵⁵	ADA	National data set	0.16	0.99	0.92	0.45	L	H	L	L	U	L
Noctor 2012 ⁶⁵⁷	ADA	GDM	0.56	0.97	0.9	0.84	U	U	L	L	U	L
FPG index, IGT reference												
Hu (repeat) ³⁹	—	—	0.62	0.69	0.82	0.81	—	—	—	—	—	—
Picon (repeat) ⁵⁰	—	—	1	0.87	0.83	1	—	—	—	—	—	—
Ihsan 2004 ⁵⁸	WHO	Unclear	0.27	0.75	0.3	0.9	U	L	L	L	U	L
Myers 2014 ⁵⁹	WHO	GDM	0.32	0.96	0.61	0.93	H	L	L	L	L	L

(Continued)

Table 1 | Details of diagnostic accuracy data for detection of pre-diabetes and QUADAS analysis in studies included in review

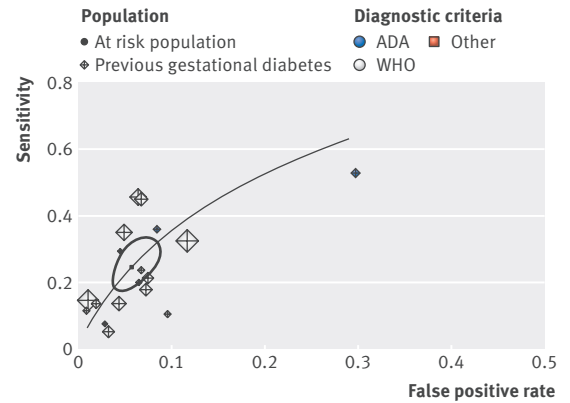
Country	Reference test criteria	Population information	Positive predictive value	Negative predictive value	QUADAS bias*			QUADAS applicability*			
					Index sensitivity	Index specificity	Bias	Index test	Reference test	Test timing	Patient selection
UK	WHO	GDM	0.63	0.84	0.86	0.88	U	L	L	L	L
Mehmet 2010 ⁶⁰											
UK	WHO	GDM	0.43	1	1	0.94	U	L	L	L	L
Holt 2003 ⁶¹											
UK	WHO	GDM	0.51	0.92	0.73	0.94	U	L	L	L	L
McClean 2010 ⁶²											
Canada	WHO	GDM	0.2	0.87	0.05	97	H	L	L	U	L
Kwong 2009 ⁶³											
Canada	WHO	GDM	0.84	0.61	0.14	0.98	H	L	L	U	L
Reinblatt 2006 ⁶⁴											
UAE	WHO	GDM	0.33	0.85	0.18	0.92	U	L	L	U	L
Agarwal 2003 ⁶⁵											
Spain	WHO	GDM white	0.25	0.89	0.08	0.97	U	L	L	U	L
Costa 2000 ⁶⁶											
Conway 1999 ⁶⁷	ADA	GDM	0.45	0.88	0.36	0.92	H	L	L	L	L
US	WHO	GDM	0.48	0.92	0.35	0.95	U	L	L	L	L
Mudalige 2014 ⁶⁸											
UK	WHO	GDM	0.22	0.93	0.14	0.96	U	L	L	L	L
Venkataraman 2014 ⁶⁹											
UK	WHO	GDM	0.13	0.96	0.2	0.93	H	L	L	L	L
Russell 2013 ⁷⁰											
UK	WHO	GDM	0.38	0.87	0.45	0.93	H	L	L	L	L
Joseph 2013 ⁷¹											
China	WHO	Unclear	0.63	0.92	0.17	0.99	L	U	U	U	L
Ko 2001 ⁷²											
UK	WHO	GDM	0.36	0.86	0.21	0.93	H	L	L	L	L
Kakad 2010 ⁷³											
Poland	WHO	GDM	0.75	0.83	0.12	0.99	U	L	L	U	L
Cypryk 2004 ⁷⁴											

ADA=American Diabetes Association; OGTT=oral glucose tolerance test; FPG=fasting plasma glucose; IGT=impaired glucose tolerance; GDM=gestational diabetes mellitus.
 *U=unclear risk of bias; L=low risk of bias; H=high risk of bias.
 †In table already, data values for that test combination specified.



	All studies (n=23)	Excluding high risk of bias studies (n=18)
Pooled sensitivity	0.49 (0.40 to 0.58)	0.47 (0.37 to 0.58)
Pooled false positive rate	0.21 (0.16 to 0.27)	0.19 (0.14 to 0.26)
AUC	0.71	0.71
Partial AUC (restricted to observed positive rates)	0.59	0.60
Specificity	0.79 (0.73 to 0.84)	0.81 (0.74 to 0.86)
False negative rate	0.51 (0.42 to 0.60)	0.53 (0.42 to 0.63)
I ²	80%	76%

Fig 2 | ROC curve for studies using HbA_{1c} as index test and OGTT as reference standard. Area of ellipse is proportional to prevalence



	All studies (n=19)	Excluding high risk of bias studies (n=11)
Pooled sensitivity	0.25 (0.19 to 0.32)	0.24 (0.17 to 0.32)
Pooled false positive rate	0.06 (0.04 to 0.08)	0.05 (0.03 to 0.07)
AUC	0.72	0.73
Partial AUC (restricted to observed positive rates)	0.42	0.27
Specificity	0.94 (0.92 to 0.96)	0.95 (0.93 to 0.97)
False negative rate	0.75 (0.68 to 0.81)	0.76 (0.86 to 0.83)
I ²	99%	99%

Fig 3 | ROC curve studies using FPG as index test and IGT as reference standard. Area of ellipse is proportional to prevalence

Table 2 | Prevalence analysis of three tests used to identify people with pre-diabetes

Author	Country	Population demographics	Diagnostic criteria for HbA _{1c}	Diagnostic criteria for OGTT	Total population tested	% Tested population "pre-diabetic"	% pre-diabetic population with abnormal HbA _{1c} alone
Incani ²⁸	Italy	BMI >35 or DM risk factors	ADA	ADA	1054	49	17
James ⁷⁵	USA	Mixed ethnicity. NHANES survey	ADA	ADA	3627	37	8
Zhang ⁷⁶	China	Chinese. GHS population survey	ADA	ADA	3590	66	29
Benaiges ⁷⁷	Spain	Mixed ethnicity. GDM	ADA	ADA	141	42	25
Mostafa ³⁸	UK	WE and SA ethnicity	IEC	WHO	8696	27	48

ADA=American Diabetes Association; OGTT=oral glucose tolerance test; WE=west European; SA=South Asian.

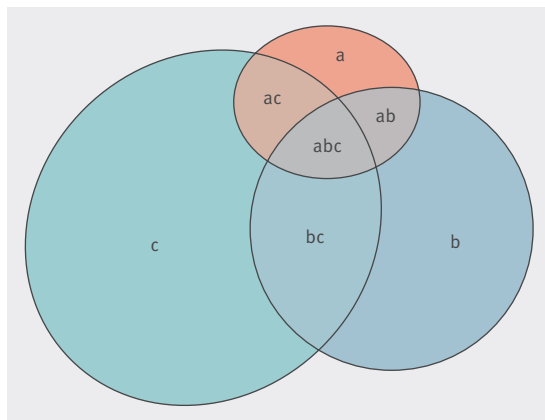


Fig 4 | Prevalence of pre-diabetes by diagnostic test with IEC and WHO criteria, showing overlap with all three tests. Prevalence of pre-diabetes was 27%. Of those with abnormal results, a=4.7% isolated IFG; b=24.4% isolated IGT; c=47.8% isolated HbA_{1c}; ab=2.9% IFG+IGT; ac=4.1% IFG+HbA_{1c}; bc=12.2% IGT+HbA_{1c}; abc=3.9% IGT+IFG+HbA_{1c}; d (area outside ellipses)=72% (normal result)

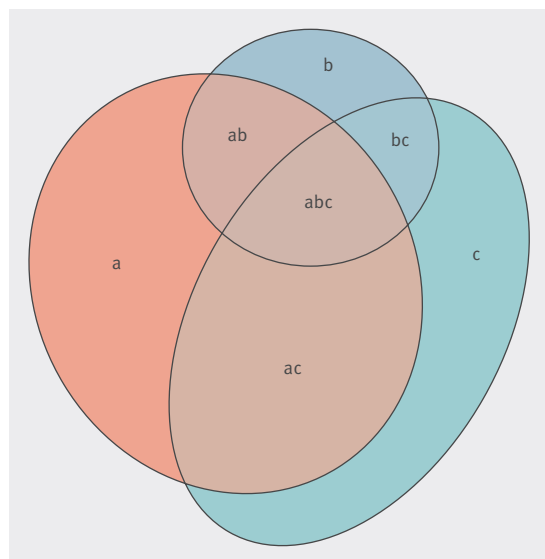


Fig 5 | Prevalence of pre-diabetes by diagnostic test with ADA criteria for all tests. Prevalence of pre-diabetes was 54%. Of those with abnormal results, a=25.4% isolated IFG; b=6% isolated IGT; c=22.4% isolated HbA_{1c}; ab=7.2% IFG+IGT; ac=26.7% IFG+HbA_{1c}; bc=3.6% IGT+HbA_{1c}; abc=8.7% IGT+IFG+HbA_{1c}; d (area outside ellipses)=46% (normal result)

(95% confidence interval 23 to 67). Lifestyle interventions lasting three to six years showed a 37% (28% to 46%) reduction in relative risk, equating to 151 (129 to 172) out of 1000 people in the lifestyle intervention group developing diabetes compared with 239 of 1000 in the control group (NNT 12, 10 to 15). The overall relative risk reduction of developing diabetes after lifestyle interventions was 36%. Because of the small number of follow-up studies it is difficult to assess the reduction in risk of diabetes after the completion of lifestyle interventions. Our estimates show that relative risk reduction of developing diabetes fell to 20% (8% to 31%)^{84 96 110 127-129} in the period after the trial (fig 7).

Meta-analysis evaluating the impact of metformin (fig 8) showed a relative risk reduction of 26% (95% confidence interval 16% to 35%) while participants were taking this drug, translating to 218 (95% confidence interval 192 to 248) out of 1000 developing diabetes while taking metformin compared with 295 of 1000 not receiving this drug (NNT 14 (95% confidence interval 10 to 22)). The benefits of metformin were assessed at the end of the trial periods once the participants had been taking the drug for a prespecified length of time. There were no follow-up studies examining for persistence of benefit once metformin had been discontinued, but the US DPP study did show some improvements in reduction in incidence of diabetes with long term metformin use.¹³⁰

The main sources of potential bias (as estimated by Cochrane risk of bias tool) were selection bias (lack of allocation concealment) and attrition bias (where authors used per protocol analysis instead of an intention to treat analysis to assess changes in outcome measures), potentially leading to overestimation of the benefits of the intervention. To provide the most comprehensive synthesis of relevant studies we did not pre-specify a minimum threshold of methodological quality for included studies. However, we performed a sensitivity analysis removing the studies at high risk of bias to test whether the exclusions of some trials changed the overall findings. Omission of these did not significantly change the overall results (for example, removal of the 2006 study by Ramachandran and colleagues¹⁰⁶ did not significantly alter the relative risk reduction).

Using the GRADE approach, we assessed the evidence to be of moderate quality for progression to type 2 diabetes with metformin versus control, low quality for lifestyle interventions of one to two years and three to six years' duration versus control, and very low qual-

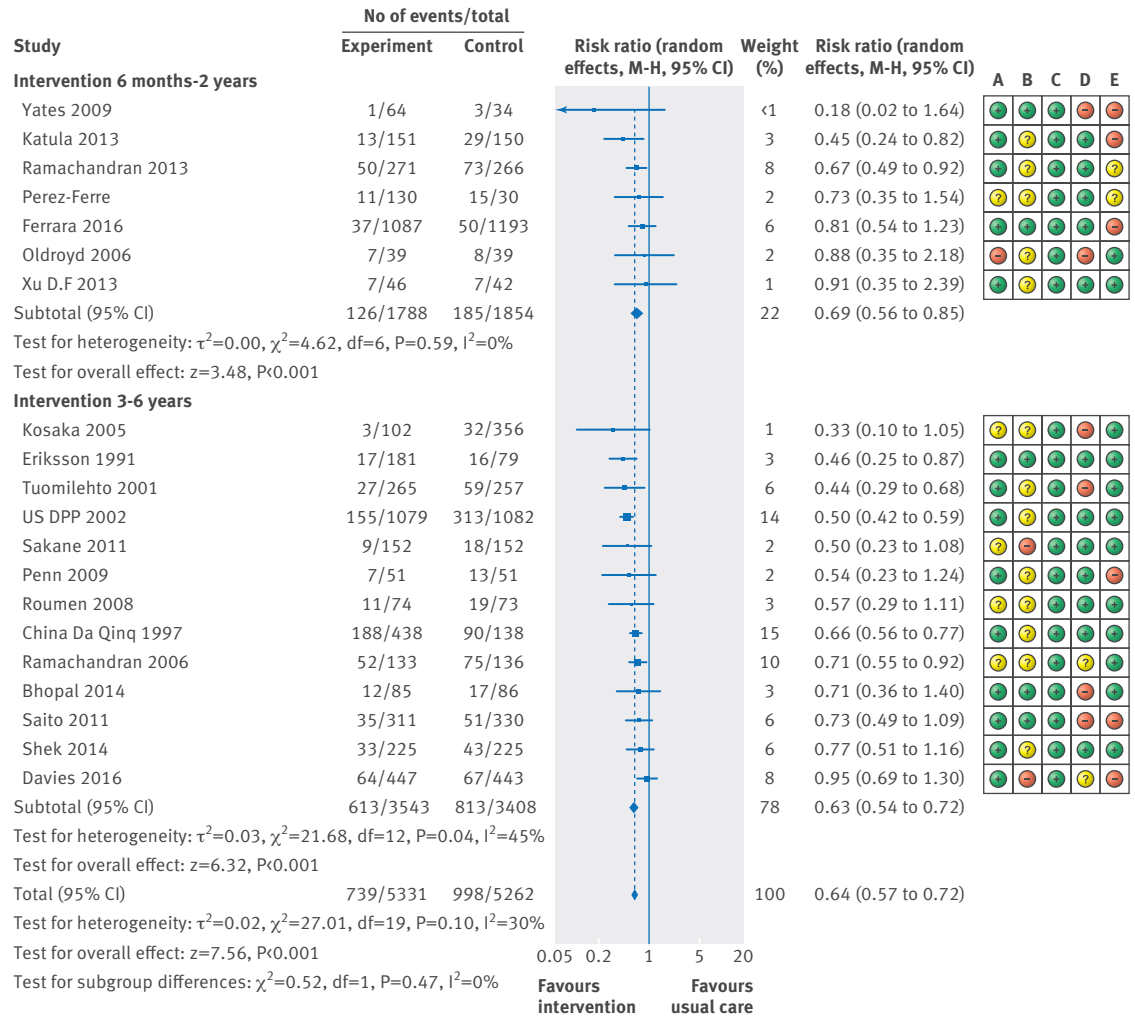


Fig 6 | Relative reduction in risk of diabetes at end of lifestyle trials. A= random sequence generation (selection bias); B= allocation concealment (selection bias); C= blinding of outcome assessment (detection bias); D= incomplete outcome data (attrition bias); E= selective reporting (reporting bias)

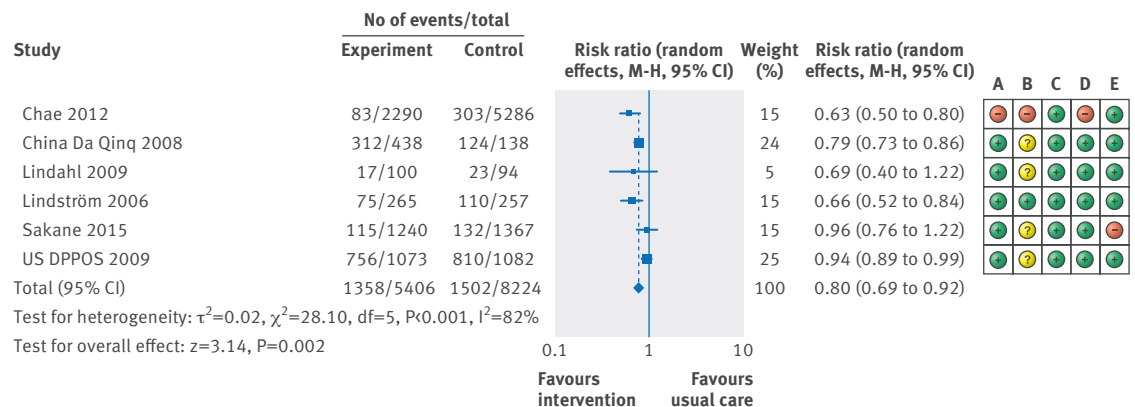


Fig 7 | Relative reduction in risk of diabetes at follow-up after intervention. A= random sequence generation (selection bias); B= allocation concealment (selection bias); C= blinding of outcome assessment (detection bias); D= incomplete outcome data (attrition bias); E= selective reporting (reporting bias)

ity for progression to diabetes at follow-up after the trial for lifestyle interventions versus control. This means that the true risk reductions from interventions could be substantially different from the meta-analysis esti-

mates. All outcomes were downgraded for indirectness as the study populations might not be representative of those who would receive the intervention in a real life setting and the measure used to identify those at most

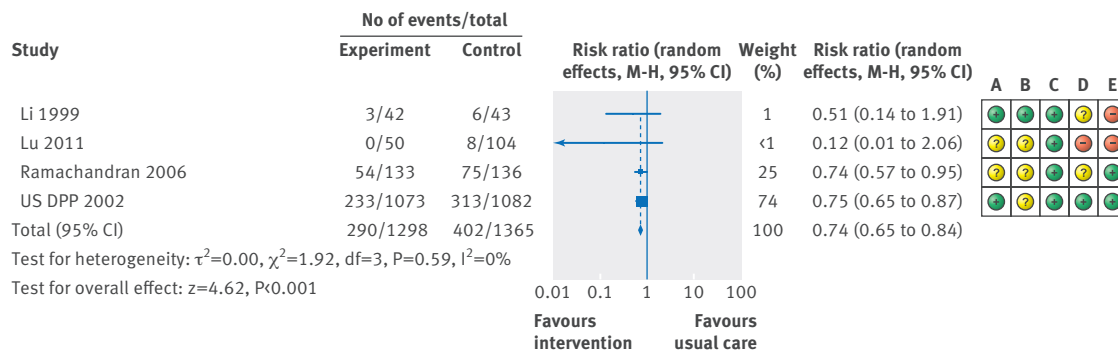


Fig 8 | Relative reduction in risk of diabetes at end of metformin trial. A=random sequence generation (selection bias); **B=**allocation concealment (selection bias); **C=**blinding of outcome assessment (detection bias); **D=**incomplete outcome data (attrition bias); **E=**selective reporting (reporting bias)

risk (oral glucose tolerance test) is not widely used in practice. A further downgrade was because of the statistical heterogeneity in two out of the four outcomes (lifestyle interventions with a three to six year follow-up ($I^2=45\%$; downgraded once) and follow-up after intervention ($I^2=82\%$; downgraded twice)). This high degree of heterogeneity is probably because of differences in sample size and length and intensity of interventions included in this analysis, but the small number of trials contributing to the follow-up analysis after intervention limited our ability to explore this using subgroup analysis. Seven papers^{10 95 101 105 106 116 126} described at least one element of patient and participant involvement. Most interventions were inflexible, with a one-size-fits-all approach.

Gestational diabetes

Nine trials assessed lifestyle interventions in women with a history of gestational diabetes (see tables B and D, appendix 3). These focused on diet, exercise, and increased uptake of breast feeding. None showed a significant reduction in incidence of diabetes between the intervention and control groups. Attrition rates were high in these trials. Only three trials had sufficient data to be included in the meta-analysis.

Withdrawal and attrition rates

Sixteen studies had the necessary data available to assess withdrawal and attrition rates.^{10 78 81 92 96 97 101 103 105-107 109 110 116 118 126} Of the pre-diabetic population identified, only 27% went on to complete the trial (the rest were either not eligible, declined to participate, or withdrew from the intervention (fig 9)). Therefore, relative risk reductions calculated from intervention trials reflect risk improvements seen in a limited proportion of the total pre-diabetic population.

Discussion

Principal findings

This systematic review, commissioned by local policy-makers who wanted to identify an effective “screen and treat” strategy for prevention of type 2 diabetes in an area of high prevalence, included 99 studies and produced four main findings. Firstly, the diagnostic accuracy of tests used to detect pre-diabetes in screening

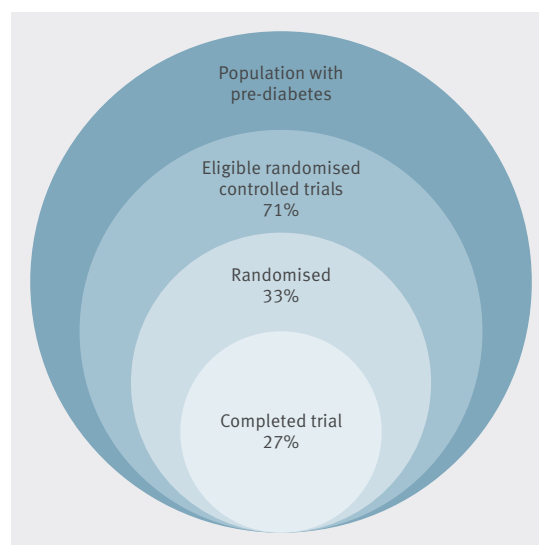


Fig 9 | Attrition rate from at risk population to trial completion. Data from research studies suggest high attrition and withdrawal rates in screen and treat programmes. Overall, only 27% of people in eligible pre-diabetic population completed trial of preventive intervention

programmes is low. The most commonly used test (HbA_{1c}) is neither sensitive nor specific; the fasting glucose test is specific but not sensitive. Low sensitivity results in a high number of people with false negative results, resulting in a large number being falsely reassured. Secondly, the diagnostic tests identify different pre-diabetic population groups with limited overlap. If the American Diabetes Association criteria are used instead of WHO ones, the prevalence of those with a diagnosis of pre-diabetes doubles. Thirdly, both individually targeted lifestyle interventions and metformin have some efficacy in preventing or delaying the onset of type 2 diabetes, though the protective effect of the former is greatest in longer interventions (three to six years) and attenuates with time from intervention. We have only moderate to very low confidence in these estimates, however, because study quality was often low. Finally, in women with a history of gestational diabetes, the evidence base for lifestyle interventions in preventing progression to type 2 diabetes is currently weak.

Most intervention trials included in this study used the oral glucose tolerance test to identify their study population. In practice, however, this test is not widely used. It is time consuming, requires fasting and ingestion of a sugary drink (which many people find unpleasant), and, because of variability within an individual, needs to be done twice. HbA_{1c} is estimated on a single non-fasting blood test but varies by ethnicity, leading to overestimation and underestimation of the result,¹³¹⁻¹³³ and could be inaccurate in the presence of haemoglobinopathy. The fasting plasma glucose test is a single blood test but requires the person to have fasted for several hours so is impractical for mass screening.

Accuracy of tests depends on cut-off points. By using the International Expert Committee and WHO criteria for defining pre-diabetes, HbA_{1c} correctly identifies only half the individuals with an abnormal result on an oral glucose tolerance test but also assigns the label of pre-diabetes to large numbers of individuals with a normal test result. Different diagnostic criteria result in a different estimate of the prevalence of pre-diabetes; this will have implications for which (and how many) individuals are eligible for lifestyle interventions. Furthermore, people identified with HbA_{1c} might not have the same glycaemic abnormality as those entered into trials on the basis of an oral glucose tolerance test and might respond differently to interventions.

Systematic reviews assessing progression from at risk states to diabetes have shown that those at most risk of developing diabetes had both impaired fasting glucose and impaired glucose tolerance; HbA_{1c} showed a lower progression rate, similar to impaired fasting glucose alone.¹³⁴⁻¹³⁶ Those with a history of gestational diabetes have the highest rates of progression to diabetes, with a sevenfold increased risk after the first diagnosis¹² and a 70% cumulative incidence at 10 years.¹³⁷

Of the 50 intervention trials included in this review, 34 used surrogate endpoints (most commonly, weight loss) as their primary outcome. While most found significant changes in these endpoints, authors rarely commented critically on the sustainability or clinical importance of these. Weight reduction has been shown to correlate poorly with the reduction in incidence of diabetes in some populations.¹⁰⁶ The trials in our sample that did show a significant reduction in the definitive endpoint of incidence of diabetes lasted between three and six years and were intensive in nature with individuals closely monitored.

While reduced incidence of diabetes seems to be possible if the interventions are intensive, the relative risk reductions seen in trials apply only to those who enrol and adhere to the intervention. Given the number of people who will not meet eligibility criteria or who decline or do not complete the intervention (fig 9), there is no scientific basis for extrapolating percentage risk reductions seen in trials to an equivalent reduction in incidence of diabetes across an entire community. Poor enrolment and completion of lifestyle interventions will limit the impact national prevention programmes will have on the overall burden of disease.

Comparison with other systematic reviews

This systematic review is the first to combine the analysis of diagnostic accuracy with efficacy of interventions to give an overall estimate of how screen and treat policies could play out in populations, focusing on the endpoint of progression to type 2 diabetes. Edwardson and colleagues reviewed the effectiveness of risk scores and lifestyle interventions but did not assess their accuracy and the implications of their use.¹³⁸ Other systematic reviewers performed a more in-depth analysis of improvement in surrogate endpoints such as weight loss and improvements in glycaemic markers.^{11 139-142} A review carried out by the Institute for Clinical and Economic Review, however, raised concerns regarding the clinical importance and sustainability of improvements of these surrogate markers.¹⁴³

Other systematic reviews have found similar relative risk reductions in incidence of diabetes with lifestyle interventions and metformin in study populations.¹⁴² Previous meta-analyses showed a higher relative risk reduction when they included only the most tightly controlled trials with stringent population enrolment criteria.^{144 145} In contrast, Public Health England's meta-analysis of translational studies identified a lower relative risk reduction because of the inclusion of pragmatic trials and observational studies¹⁴⁶ and showed high levels of statistical heterogeneity between primary studies. One systematic review assessed UK based community and national interventions whose participants were the most deprived, vulnerable, and socially excluded (groups often omitted from clinical trials).¹⁴⁷ They found that the effects of the interventions were small in these groups, with no evidence of long term reduction in incidence of diabetes.

Labelling people as having "pre-diabetes" has important personal implications (medicalisation, intrusive testing, and stigma) for people who might never go on to develop diabetes. Other scholars have voiced similar concerns to those raised in this systematic review with regards to the danger of inaccurate classification and/or overdiagnosis with tests for pre-diabetes,¹⁴⁸ effectiveness of lifestyle interventions in the real world,¹⁴⁹ and the limited impact of screen and treat policies in the absence of a complementary population based approach.¹⁵⁰

Whether these interventions reduce longer term cardiovascular morbidity and mortality remains unclear. A meta-analysis and systematic review undertaken by Hopper and colleagues¹⁵¹ agreed with our findings that lifestyle interventions can reduce the relative risk of developing diabetes. While these interventions did result in a reduction in incidence of cardiovascular events, this did not translate into a significant reduction in all cause or cardiovascular mortality. Long term follow-up studies undertaken by the Chinese Da Qing study and the Finnish Diabetes Prevention Study found that there was no significant difference between intervention and control groups in first cardiovascular events¹²⁷ or cardiovascular morbidity,¹⁵² though the study was not powered to detect such a difference.

Meaning and implications for policy makers, clinicians, and academics

This review was requested by a local clinical commissioning group in an inner London borough where the local diabetes prevention programme has largely consisted of a community prescription initiative offered to people classified as having pre-diabetes with a BMI of 27 or above, a history of gestational diabetes, or a QRISK >20%. Intensive interventions lasting years, such as those included in this systematic review, are not an option given its limited budget.

Our findings indicate that in settings such as this, screen and treat policies for pre-diabetes will benefit individuals who are “true positives” and have sufficient personal, family, and community resources to enable them to attend and comply with preventive interventions. Incentivised diabetes prevention programmes will also pick up people with undiagnosed diabetes (an estimated 2-10% of those screened^{38 78 81 116 126}), who can be offered timely management. A considerable proportion of people at high risk of developing type 2 diabetes, however, will go on to develop the condition despite such programmes. These include people who test “false negative” and those who, despite testing positive and being offered a lifestyle intervention, lack the personal resources and social connections to support and sustain lifestyle change.

Because of the low accuracy of screening tests and the limited reach of intervention programmes, policy-makers might want to consider supplementing screen and treat policies with population based approaches aimed at entire communities. WHO, for example, proposes “multisectoral action that simultaneously addresses different sectors that contribute to the production, distribution and marketing of food, while concurrently shaping an environment that facilitates and promotes adequate levels of physical activity.”¹⁵³

Strengths and limitations

This is the first systematic review to assess both the diagnostic accuracy of screening tests for pre-diabetes and the efficacy of interventions in those classified through screening as having pre-diabetes. Furthermore, it is a comprehensive review synthesising a large volume of international literature, including translations from languages other than English. It was inspired by a question by front line policymakers and focused on producing a practical answer to that question. As such, and unlike much secondary and primary research, it fulfils the important criterion of “usefulness.”¹⁵⁴

The main limitation of the review was the number of exclusions because of incomplete data available in published studies. Despite efforts to contact authors, we were unable to obtain the data needed to contribute to the meta-analysis in 18 potentially eligible papers. In the prevalence analysis, only five out of 28 papers compared all three diagnostic tests, so these findings should be interpreted with caution. A high proportion of studies that assessed the diagnostic accuracy of fasting plasma glucose did so in participants with a history of

gestational diabetes—a bias that could influence the generalisability of this analysis.

Only half of the intervention studies were included in the meta-analysis because the lengths of the trial or intervention were too short to be able to capture incidence of diabetes. Additionally, the analysis of the reduction in the risk of diabetes at various follow-up periods was limited because of the small number of primary studies that performed follow-up analyses. We recommend that primary studies of diabetes prevention programmes should be resourced to undertake long term follow-up to assess for sustained benefits including incidence of diabetes, cardiovascular morbidity, and mortality.

Intervention studies that used risk scores to identify their population instead of blood tests do exist¹⁵⁵ but were outside the scope of this systematic review. Further synthesis of interventions using wider population eligibility criteria could provide additional insights into the benefits of these.

Future work

On the basis of the findings of this review, we suggest three avenues for further research. The first is pragmatic real world effectiveness and cost effectiveness studies of interventions for pre-diabetes that have already been shown to be efficacious in trials.^{149 156} Studies of the translational gap between evidence from randomised trials and real world uptake and impact is always important¹⁵⁷ but particularly so when the “real world” seems unlikely to be able to replicate the conditions (for example, health literacy, language fluency, and comorbidities of target population; intensity and duration of intervention; completeness of follow-up) that characterised the trials with the most positive results.^{149 158} These real world studies should deal with the impact on behaviour of individuals who test positive for pre-diabetes (only a third of whom would be predicted to engage with interventions; fig 9) and the costs (to both participants and the health service). More specifically, effectiveness and cost effectiveness studies should explore the implications of screen and treat programmes for both commissioners and providers—including the opportunity costs of spending a limited budget on a programme for which a variable proportion of the pre-diabetic population would be eligible for and engage with depending on locality.

The second avenue for further research is the evaluation of population level and/or health system interventions. Individual lifestyle choices are constructed by sociocultural, political, and economic influences, which might be more effectively deal with by using population-wide strategies such as protection of green spaces, increased walkability of the environment, affordable leisure activities, improved food labelling, independent regulation of food nutritional standards, regulation on food advertising, affordable fruit and vegetables, and school based programmes. Such systematic structural approaches dealing with “upstream” influences on the pathogenesis of diabetes require well supported public health teams working alongside local

governments to improve the health of communities and could be vital components of a multifaceted long term primary prevention strategy.¹⁵⁹

Currently, only a tiny fraction of the literature on diabetes prevention is informed by an appreciation of the social complexity underlying pathogenesis of diabetes.¹⁶⁰⁻¹⁶² The 2014 Foresight Report on Obesity was a model of good practice in teasing out the complex interactions between genetic, physiological, psychological, sociocultural, economic, and political determinants of obesity; it provided a strong and consistent message that short term “behaviour change” interventions were unlikely to succeed in isolation.¹⁶³ A comparable initiative for type 2 diabetes could add richness to our current understanding of the condition and help to inform the design of evidence based strategies aimed at influencing its “upstream” determinants.

Conclusion

As the prevalence of type 2 diabetes rises inexorably in high, middle, and low income countries alike, controversy continues to surround the questions of who is “at risk” and what preventive interventions to offer them. A screen and treat policy will be effective only if a test exists that correctly identifies those at high risk (sensitivity) while also excluding those at low risk (specificity); and an intervention exists that is acceptable to, and also efficacious in, those at high risk. This review has shown that of the two screening tests for pre-diabetes that are available and acceptable to patients and clinicians, fasting glucose is specific but not sensitive and HbA_{1c} is neither sensitive nor specific. Trial evidence suggests that lifestyle interventions have a potential role in reducing individual progression to diabetes and could benefit those high risk individuals who have the motivation and social support to achieve sustained lifestyle change. Given that this is likely to be a limited proportion of the population identified with pre-diabetes, however, substantial research resources should be directed at the evaluation of upstream interventions aimed at the entire population.

Contributors: EB conceptualised the review, assisted with developing the search strategy and ran the search, scanned all titles and abstracts, extracted quantitative data on all the papers, checked citations, performed the prevalence analysis, performed the meta-analysis of the intervention studies, undertook the QUADAS, risk of bias, and CONSORT assessment, and co-wrote and revised drafts of the paper. SR conceptualised the review, independently reviewed the data extraction process from the search results and methods from the intervention papers, adapted the QUADAS and risk of bias tool verifying the methods, and checked a sample of this assessment. JO advised on the analysis of the quantitative data and carried out the diagnostic accuracy bivariate meta-analysis. RN advised on the quality assessment of the literature and undertook the GRADE assessment. RN also reviewed drafts of the paper and assisted with graphically representing the risk of bias tool using RevMan. SV conceptualised the study, framed the question, and manages the project steering group. TG is the academic supervisor for the project, conceptualised the study, advised on systematic review methods, and co-wrote and revised drafts of the paper. TG is guarantor. All authors, external and internal, had full access to all of the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

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Transparency: The lead author (the manuscript's guarantor) affirms that the 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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Appendix 1: Search strategies

Appendix 2: Adapted QUADAS2 Tool to assess quality of diagnostic accuracy studies

Appendix 3: Interventions to reduce the risk of developing diabetes methods and results tables

Appendix 4: Diagnostic accuracy meta-analysis and prevalence analysis supplementary results

Appendix 3: Example focus group guide

- Introductions
- Answer questions from information sheet sent a week ago
- Sign consent forms

Questions on diagnosis

- What do you understand by the phrase 'pre-diabetes'?
- Discuss how do you inform people of this diagnosis?
- Can you give examples
- Personas- give a few minutes to look at the details
 - How would you inform persona A of the diagnosis
 - How would you inform persona B
- How do people respond when you tell them of the diagnosis?
 - Examples of positive and negative responses
- In your experience does identifying people with pre-diabetes help people change their lifestyles or lower their risk of developing diabetes?
- Have you had feedback from people who have engaged in interventions? What sort of feedback have you had on these?
- What reasons do people give for not engaging in interventions or seeing the lifestyle advisors?
- Influences have you recognised as the barriers to preventing diabetes
 - Individual level
 - Community level

Appendix 4: Example focus group persona

Mrs Shamim Begum



42 years old
Housewife

“ I feel very tired and achey looking after my family and helping the family newsagent business”

I'd like to have more energy and be able to look after myself better



Income



Education



Health information

- GDM
- BMI 31
- HbA1c 6.4%
- Sedentary Lifestyle

Something About Me...

- I moved to London aged 19 and married my husband.
- Finished school and college
- Misses family in Bangladeshi

My Community

- Extended family
- 1-2 friends



My Personal Life

- My husband works long hours
- I have two daughters
- I do all the cooking, cleaning and household chores.
- I look after my mother in-law who lives close by



Tech



Smartphone

Mr P. Mitchell



54 years old

Publican

“ I feel fine but my girlfriend complains that I drink too much”

I don't think there's anything wrong with me



Income



Education



Health information

- BP 160/100
- BMI 31
- HbA1c 6.2%
- Heavy smoker
- Alcohol 60u/wk

Something About Me...

- I run a pub, car garage
- I dropped out of school aged 13
- No qualifications

My Community

- Pub mates
- No family locally



My Personal Life

- Works long hours
- Lives above the pub
- Eats unhealthily
- Disconnected from family
- Partner only source of support



Tech



Smartphone



Laptop

Mr Terence Wilson



82 years old
Retired School Keeper

“ I’m very worried about my health. I want to live long enough to see my grandchildren grow up”

I’ve been quite lonely since my wife died of cancer.



Income



Education



Health information

- Hypertension
- Previous MI
- High cholesterol
- HbA1c 6.1%
- Alcohol 24u/wk

Something About Me...

- Widowed
- Moved to the UK 50 years ago
- Lives alone

My Community

- My family live in south London and visit weekly
- Friends at the local pub



My Personal Life

- Daughter bring Caribbean food once a week.
- Lives in a one bed flat
- Sees friends at local pub once a week for fish and chips.



Tech

Appendix 5: Patient information leaflet for people with pre-diabetes and study adverts

GP Text Message

The practice is taking part in a diabetes prevention research project led by Eleanor Barry at the University of Oxford. She is looking for people with 'pre-diabetes' to take part in online interviews. Please see the advert attached. If you're interested in taking part email eleanor.barry@phc.ox.ac.uk

Social Media Message

We are conducting a study interviewing people who are at high risk of developing diabetes to understand their experiences in trying to prevent developing the condition. If you have been diagnosed with 'pre-diabetes' or 'non-diabetic hyperglycaemia', over 18, registered with a UK GP, and would like to find out more email eleanor.barry@phc.ox.ac.uk

Patient information leaflet



NUFFIELD DEPARTMENT OF
PRIMARY CARE
HEALTH SCIENCES

PARTICIPANT INFORMATION SHEET (PATIENTS)

Understanding pre-diabetes from the patient's perspective

We'd like to invite you to take part in our research study. Before you decide, it is important that you understand why the research is being done and what it would involve for you. Please take time to read this information, and discuss it with others if you wish. If there is anything that is not clear, or if you would like more information, please ask us.

What is the purpose of the study?

We are studying how people respond to being told they are at risk of developing diabetes and how this influences health related behaviours. We will be doing group interviews with health care professionals as well as interviews with patients to understand how the diagnosis

of pre-diabetes is discussed and what advice is given. We want to use this information to try and improve efforts to prevent diabetes in the community.

We are also interested in how the community, environment and social influences (such as friends and family) affect people's lifestyles and decisions they make about their health. In order to understand how we can best help people reduce their diabetes risk we are conducting a detailed study of their experiences of being told they are at risk and how they decide what to do about this (if anything).

Why have I been invited?

You have been chosen either because you have expressed an interest in taking part in the study or because your doctor, nurse or carer has identified you as someone who might wish to do so. We will be asking 30-40 people to take part in individual interviews.

Do I have to take part?

No, taking part is entirely voluntary and you can withdraw at any time if you later change your mind, without giving a reason. Withdrawal will not affect your clinical care.

What will happen to me if I decide to take part?

You will be given one week to think about whether you wish to participate (and longer if you would like more time). If you consider taking part you will be asked to sign a consent form. I would like to contact you on up to three occasions (but probably two). I will interview you (via video or telephone) about your experiences of the being told you are at risk of diabetes, as well as contacting you whilst you walk around your local area talking about the places that are important to you. With your permission, we would like to audio record the interview.

In addition, and if you are happy with this, the researcher will ask you to collect some pictures of things and people that are important to you as well as noting down some meals and foods you particularly enjoy. Your details from these materials will be anonymised (such as blurring any faces in pictures). This will give us a different perspective of what you feel is important to you and what is important within your daily life. The interviews will be done online using a video call or on the phone. Each interview will take approximately 60-90 minutes to complete.

What should I consider?

The main thing to consider is whether you are comfortable with researchers asking you questions about diabetes prevention and different aspects of your life.

Are there any possible disadvantages or risks from taking part?

The main disadvantage of the interview is we are asking you to commit some time and we will ask questions about your personal medical details and other elements of your life.

What are the possible benefits of taking part?

The main benefit of taking part is this is an opportunity for you to contribute to improving how people are told they are at risk of diabetes and also improving the local diabetes prevention strategies. If you raise issues about your personal experience of the service we

will feed these back to the service team and however it may not be possible to improve your own experience.

Will my taking part in the study be kept confidential?

Yes. All data from the study (audio recordings of the interviews, photos from the diary exercise) will be made anonymous (unless you would prefer us not to blur your face). They will be kept on a secure, non-networked computer at the University of Oxford. In those stored data, you will be referred to only by a code name ('pseudonym'). We will keep a separate paper record in a locked cabinet of participants' real names and corresponding code names. Audio recordings will be destroyed at the end of the study.

Responsible members of the University of Oxford and the relevant NHS Trust(s) may be given access to data for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations.

Will I be reimbursed for taking part?

No, and since the interview will take place remotely we do not anticipate you incurring any travel or expenses. However, if you do need to travel to conduct the interview your travel expenses will be reimbursed.

What will happen to my data?

Data protection regulation requires that we state the legal basis for processing information about you. In the case of research, this is 'a task in the public interest.' The University of Oxford is the sponsor for this study, based in the United Kingdom, is the data controller and is responsible for looking after your information and using it properly.

We will be using information from you and your medical records, in order to undertake this study and will use the minimum personally-identifiable information possible. We will keep identifiable information about you for 12 months after the study has finished. This excludes any research documents with personal information, such as consent forms, which will be held securely at the University of Oxford for 15 years after the end of the study.

Data protection regulation provides you with control over your personal data and how it is used. When you agree to your information being used in research, however, some of those rights may be limited in order for the research to be reliable and accurate. Further information about your rights with respect to your personal data is available at

<https://compliance.web.ox.ac.uk/individual-rights>

You can find out more about how we use your information by contacting

Eleanor.barry@phc.ox.ac.uk

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

You can stop at any time. Participation is voluntary and even if you originally said yes, you may change your mind at a later stage. If you withdraw from the study, unless you state otherwise, any interview or material that has been collected whilst you have been in the study will be used for research as detailed in this participant information sheet. You are free to request that your data are destroyed at any time during or after the study. Withdrawal will not affect the care you receive from the NHS now or in the future.

What will happen at the end of the study?

We will analyse the data and write some papers and reports, including a 'lay summary'. We will provide you with a summary of the findings if you would like us to.

You will not be identified from any report or publication placed in the public domain. We may wish to use some of the materials we ask you to use to document different elements of your life in a conference presentation or workshops when discussing diabetes prevention. If you are happy for this to happen, tick the relevant box on the consent form.

What if you find something unexpected?

If anything you tell us in an interview has a bearing on your clinical care (for example if you disclose to us that you have a new symptom), we will inform the GP.

What if there is a problem?

The University of Oxford, as Sponsor, has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this study. NHS indemnity operates in respect of the clinical treatment which is provided.

If you wish to complain about any aspect of the way in which you have been approached or treated during the course of this study, you should contact Dr Eleanor Barry whose details are given below, or Professor Trish Greenhalgh (Dr Barry's supervisor, same address). Alternatively, you may contact the University of Oxford Clinical Trials and Research Governance (CTRG) office on 01865 (6)16480, or the head of CTRG, email ctrig@admin.ox.ac.uk.

Who is organising and funding the study?

The study is funded by the NIHR. It is part of a doctoral course of study for Dr Barry who is a GP carrying out this research. The study is supervised by Professor Trisha Greenhalgh, a GP who works at the University of Oxford; she is also custodian of the study information.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given favourable opinion by London- Surrey NHS Research Ethics Committee.

Further information and contact details:

Please contact the following individual if you would like further information.

Dr Eleanor Barry (Chief Investigator)

Nuffield Department of Primary Care Health Sciences

University of Oxford

New Radcliffe House

Walton St

Oxford OX2 6GG

01865 289363

eleanor.barry@phc.ox.ac.uk

Thank you for considering taking part.

Appendix 6: NHS Research Ethics Committee approval letters

Dr Eleanor Barry
DPhil Student
University of Oxford
Nuffield Department of Primary Care Health Sciences
University of Oxford, Radcliffe Primary Care Building,
Woodstock Road
Oxford
OX2 6GG

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

14 May 2018

Dear Dr Barry

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title: Understanding pre-diabetes from the patient's perspective: A mixed-methods study aimed at improving the success of diabetes prevention programmes.

IRAS project ID: 242219

REC reference: 18/LO/0479

Sponsor University of Oxford

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?

You should now provide a copy of this letter to all participating NHS organisations in England and Wales*, as well as any documentation that has been updated as a result of the assessment.

*In flight studies' which have already started an SSI (Site Specific Information) application for NHS organisations in Wales will continue to use this route. Until 10 June 2018, applications on either documentation will be accepted in Wales, but after this date all local information packs should be shared with NHS organisations in Wales using the Statement of Activities/Schedule of Events for non-commercial studies and template agreement/ Industry costing template for commercial studies.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "summary of assessment" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed [here](#).

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?

You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Clinical Trials & Research Governance

Email: ctrq@admin.ox.ac.uk

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **242219**. Please quote this on all correspondence.

Yours sincerely

Kelly Rowe
Assessor

Email: hra.approval@nhs.net

*Copy to: Clinical Trials and Research Governance, University of Oxford, Sponsor representative
Noclor Research Support Service, Lead NHS R&D contact*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Insurance]	V1	21 February 2018
GP/consultant information sheets or letters [Plain English Summary for GPs]	V7	21 February 2018
HRA Schedule of Events [Validated SOE]	1.0	21 March 2018
HRA Statement of Activities [Validated SOA]	1.0	21 March 2018
IRAS Application Form [IRAS_Form_28022018]		28 February 2018
Letter from funder [Funding Letter NIHR]	V1	21 February 2018
Letter from sponsor [Letter from Sponsor]	V1	21 February 2018
Other [PIS Clinical Staff]	V3	21 February 2018
Other [Clinical Staff Consent form]	V3	21 February 2018
Other [Responses to NHS Ethics review]	V1	12 April 2018
Other [Interview Scripts Revised]	V2	21 March 2018
Other [PIS Patient Revised]	V4	21 March 2018
Participant consent form [Patient Consent Form]	V3	21 February 2018
Referee's report or other scientific critique report [NIHR Peer review]	V1	21 February 2018
Research protocol or project proposal [Research Protocol]	3	21 February 2018
Summary CV for Chief Investigator (CI) [CV]	V1	17 January 2018
Summary CV for student [Eleanor Barry CV]	V1	01 September 2017
Summary CV for supervisor (student research) [Greenhalgh CV]	V1	21 February 2018

Summary of assessment

The following information provides assurance to you, the sponsor and the NHS in England and Wales that the study, as assessed for HRA and HCRW Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England and Wales to assist in assessing, arranging and confirming capacity and capability.

Assessment criteria

Section	Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	Applicant has confirmed that consent to contact will be documented in the patient EMIS notes.
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The statement of activities will act as agreement of an NHS organisation to participate. No further agreements expected.
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	Funding secured as part of an NIHR Doctoral Research Fellowship. The statement of activities confirms that there is no funding available to sites from the sponsor.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments

Section	Assessment Criteria	Compliant with Standards	Comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England and Wales

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

Participating NHS organisations will conduct all activities as per protocol.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England and Wales in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. Where applicable, the local LCRN contact should also be copied into this correspondence.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England and Wales which are not provided in IRAS, the HRA or HCRW websites, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net or HCRW at Research-permissions@wales.nhs.uk. We will work with these organisations to achieve a consistent approach to information provision.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and Wales, and the minimum expectations for education, training and experience that PIs should meet (where applicable).

A local collaborator is expected at participating sites.

GCP training is not a generic training expectation, in line with the [HRA/HCRW/MHRA statement on training expectations](#).

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance.

As this study is taking place in GP practices you are advised to contact the primary care management function to follow local processes.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales to aid study set-up.

The applicant has indicated that they intend to apply for inclusion on the NIHR CRN Portfolio.



Health Research Authority

London - Surrey Research Ethics Committee

Whitefriars
Level 3, Block B
Lewins Mead
Bristol
BS1 2NT

Telephone: 02071048033/53

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

12 April 2018

Dr Eleanor Barry
Nuffield Department of Primary Care Health Sciences
University of Oxford, Radcliffe Primary Care Building, Woodstock Road
Oxford OX2 6GG

Dear Dr Barry

Study title: Understanding pre-diabetes from the patient's perspective: A mixed-methods study aimed at improving the success of diabetes prevention programmes.
REC reference: 18/LO/0479
IRAS project ID: 242219

Thank you for your letter of 12 April 2018, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion” above).

Approved documents

The documents reviewed and approved by the Committee are:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Insurance]	V1	21 February 2018
GP/consultant information sheets or letters [Plain English Summary for GPs]	V7	21 February 2018
Interview schedules or topic guides for participants [Interview Scripts]	V1	21 February 2018
IRAS Application Form [IRAS_Form_28022018]		28 February 2018
Letter from funder [Funding Letter NIHR]	V1	21 February 2018
Letter from sponsor [Letter from Sponsor]	V1	21 February 2018
Other [PIS Clinical Staff]	V3	21 February 2018
Other [Clinical Staff Consent form]	V3	21 February 2018
Other [Responses to NHS Ethics review]	V1	12 April 2018
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Participant consent form [Patient Consent Form]	V3	21 February 2018
Referee's report or other scientific critique report [NIHR Peer review]	V1	21 February 2018
Research protocol or project proposal [Research Protocol]	3	21 February 2018
Summary CV for Chief Investigator (CI) [CV]	V1	17 January 2018
Summary CV for student [Eleanor Barry CV]	V1	01 September 2017
Summary CV for supervisor (student research) [Greenhalgh CV]	V1	21 February 2018

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

We are pleased to welcome researchers and R & D staff at our RES Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

18/LO/0479

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



**pp Mrs Chrissie Lawson
Chair**

Email: nrescommittee.secoast-surrey@nhs.net

Enclosures: *"After ethical review – guidance for researchers"*

Copy to: *Clinical Trials and Research Govern*

Newham CCG- Noclor Research Support Service



Health Research Authority

London - Surrey Research Ethics Committee

Nottingham Centre
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Tel: 0207 104 8372

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

06 May 2021

Dr Eleanor Barry
Nuffield Department of Primary Care Health Sciences
University of Oxford, Radcliffe Primary Care Building, Woodstock Road
Oxford
OX2 6GG

Dear Dr Barry

Study title: Understanding pre-diabetes from the patient's perspective: A mixed-methods study aimed at improving the success of diabetes prevention programmes.

REC reference: 18/LO/0479

Amendment number: Substantial Amendment 1

Amendment date: 22 March 2021

IRAS project ID: 242219

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Completed Amendment Tool [Amendment Tool]		
Other [Social Media Text]	1	21 March 2021
Other [Responses to queries]		
Participant consent form [Patient Verbal Consent form]	1	21 March 2021
Participant information sheet (PIS) [PIS Patients V6]	6	04 May 2021
Research protocol or project proposal [Pre-DM DPhil Protocol V5]	5	04 May 2021

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities— see details at: <https://www.hra.nhs.uk/planning-and-improving-research/learning/>

IRAS Project ID - 242219:

Please quote this number on all correspondence

Yours sincerely

pp. Philip Evans

Mrs Chrissie Lawson
Chair

E-mail: surrey.rec@hra.nhs.uk

Enclosures: List of names and professions of members who took part in the review

Copy to: Dr Eleanor Barry



Health Research Authority

London - Surrey Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 30 April 2021

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Ms Marian Hodges	Retired - Associate Director in Publishing	Yes	
Mrs Chrissie Lawson	Nurse Specialist	Yes	Chair

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Mr Philip Evans	Approvals Administrator

Appendix 7: Example topic guide for policymaker interviews

- Stakeholder description of policy background and current role
- Description of current work portfolio
- Discussion of the role of public health in diabetes prevention (locally/nationally)
- Discussion of the public health transitioning to local authorities and challenges and opportunities associated with this.
- What funding challenges have public health faced.
- Discussion on the strategies used to engage with political leaders (locally/nationally)
- Skill sets used by public health to exert their influence on decision making and policy development.
- Discussion on the relationship between Public Health and the NHS, particularly since the 2012 transition.
- What population-level strategies/policies are public health currently targeting. What are the challenges with taking this approach.
- How does the local/national political climate influence what is possible with regards to diabetes prevention policy.
- What kind of research evidence is used by policy makers and how is this used? Give examples.
- What are the main research-policy gaps from the policy maker's perspective.

Appendix 8: Focus group paper

How do UK general practice staff understand and manage prediabetes? A focus group study

Eleanor Barry^{1*}, Trisha Greenhalgh¹

¹Department of Primary Care Health Sciences, University Department in Oxford, Oxford, UK

Abstract

Background: Preventing type 2 diabetes is a national priority; one aspect is the identification and active management of 'prediabetes' through lifestyle change.

Aim: To explore what primary care clinicians understood by 'prediabetes', how they communicated this diagnosis to people, how they delivered lifestyle advice, and their views on barriers to lifestyle change.

Design & setting: Three focus groups were undertaken with 25 individuals from primary care teams (GPs, nurses, and healthcare assistants) in Newham, a deprived and ethnically diverse part of London, UK.

Method: Recordings were transcribed verbatim and analysed thematically before integrating social and behavioural science theories.

Results: Focus groups participants described four main influences on their management of prediabetes in the consultation: social determinants, clinical aspects of diagnosis and management, patient motivation and behaviour change, and long-term care. Since most felt unable to address social determinants such as poverty, discussions with patients tended to focus on attempts to change individual behaviours and achieve particular numerical targets, with limited attention to the social context in which behaviours would play out.

Conclusion: Type two diabetes prevention efforts in general practice may fail to address the upstream causes of this disease. A narrow focus on numerical targets and decontextualised behaviours overlooks the social complexity of human behaviour and lifestyle choices. Within the consultation, the authors recommend that greater attention is paid to discussing the social context and meaning of particular behaviours. Beyond the consultation, collaboration between primary care clinicians, public health bodies, and local governments is required to address community-level constraints to behaviour change.

*For correspondence: eleanor.barry@phc.ox.ac.uk

Received: 06 September 2021

Accepted: 28 September 2021

Published: 18 May 2022

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Author Keywords: Prevention, Qualitative research, Diabetes

Copyright © 2022, The Authors; DOI:10.3399/BJGPO.2021.0166

How this fits in

People with prediabetes are typically managed with lifestyle advice in general practice. There is limited research on how clinicians inform people of the diagnosis of prediabetes and deliver lifestyle advice. This focus group study found that advice was often narrowly focused on individual behaviour change and numerical targets for glycaemic biomarkers. Clinicians recognised the social determinants that influenced a patient's risk of developing diabetes, but felt powerless to address these. Individual consultations for prediabetes should be supplemented by community-level action on social determinants

Introduction

One-third of people who died in the first wave of the COVID-19 pandemic had diabetes.¹ Risk factors for type two diabetes (ethnicity, deprivation, and obesity) were also associated with poorer outcomes from COVID-19.²⁻⁴ Preventing type two diabetes was a national priority before the pandemic,⁵⁻⁷ and as general practice resumes chronic disease management clinics, it has become one again.⁸

National Institute for Health and Care Excellence (NICE) Guideline PH38⁷ states that those with an elevated HbA1c (42–47 mmol/mol) or impaired fasting glucose (5.7–6.9 mmol/L or WHO cut offs 6.1–6.9 mmol/L) are diagnosed with 'non-diabetic hyperglycaemia', also known as 'prediabetes'. People with non-diabetic hyperglycaemia should be reviewed annually for disease progression and considered for prevention programmes. The NHS Diabetes Prevention Programme (NHS DPP) is now available nationwide, but completion is limited (19% of participants completing six out of 13 sessions) with high attrition rates in deprived areas and participants of Black or Asian ethnicity.^{9,10} General practice plays a central role in the diabetes prevention pathway. Clinicians make decisions on testing and diagnosis, communicate results, and give lifestyle advice before offering referrals to prevention programmes. General practice provides continuity of care, annual reviews of people at risk, and opportunistic delivery of health promotion messages.

How practice teams communicate a prediabetes diagnosis and deliver subsequent health promotion message affects how people respond and influences lifestyle change.^{11,12} Prediabetes may have different meanings, interpretations and implications for clinicians and patients, with a new risk identity for those given this diagnosis.¹³ The literature has a limited focus the practice team's perspectives on this condition.¹⁴

Given the central role of general practice in diabetes prevention, the authors undertook focus groups with practice staff (pre-COVID-19) to understand their views and perspectives on the prediabetes diagnosis, supporting behaviour change, and delivering lifestyle messages.

Objectives

The objective was to explore, from the accounts of practice staff:

1. How they convey a diagnosis of prediabetes (or NDHG) to patients.
2. How they encourage and support behaviour change in such patients with a view to preventing progression to type two diabetes.
3. How they view the barriers and enablers to lifestyle change.

Method

Study context and governance

An interpretivist approach was taken, seeking to explore how prevention strategies are socially and culturally shaped while investigating the complexities that underpin health-related behaviours. The authors acknowledge that the study's findings will have been influenced by their professional roles (as GPs), prior assumptions, and the context in which data is gathered and analysed.^{15,16}

The study was a component of a doctoral research study funded by an NIHR Doctoral Research Fellowship. A study protocol and all study materials (consent forms, information sheets, interview topic summaries) were approved by the University of Oxford who sponsored the study and by an NHS REC (London-Surrey REC 12th April 2018) and HRA. Data were managed in accordance with the data protection policies of the University of Oxford. EQUATOR reporting guidelines were followed in the reporting of this study.¹⁶

Study setting

Newham, an east London borough, is a deprived area with 37% of residents living in poverty.¹⁷ It is an ethnically diverse community, with 45% of the population identifying as Asian ethnicity, 26.5% as White, and 17.8% as Black.¹⁸ Newham has a high diabetes prevalence due to the interplay of social, environmental, and economic influences.⁶ The Clinical Commissioning Group (CCG) commissions practices to maintain a register of people with prediabetes and incentivises them to undertake patient annual reviews, checking for diabetes, reviewing cardiovascular risk factors, and delivering health promotion messages.

Sampling

Practices were recruited from three sites in Newham. Two practices were purposively selected because of their differing population demographics. The third practice responded to an NIHR Clinical Research Network email invitation to join the study. The practices serve populations with different ethnic makeups, giving a variety of perspectives. Newham is not statistically representative of a UK population, but themes and concepts developed from the analysis may resonate with teams in deprived areas with a high diabetes prevalence.

Focus groups

Three focus groups were undertaken with doctors, nurses, health care assistants, clinical pharmacists, and managers in 2018. Open questions allowed participants to express opinions and generate discussions within the groups. A topic guide (reproduced in Box 1), guided exploration of their interpretation of prediabetes; how they said they communicated the diagnosis to patients; whether the diagnosis prompted behaviour change; how they supported patients in lifestyle change; and what the barriers to change were. Three fictional personas (case vignettes) were shared in each focus group to generate discussion on how clinicians might approach a specific case. Field notes describing the environment, non-verbal communication, and group interactions added contextual information to the analysis.

Data analysis

Audio recordings were anonymised and transcribed verbatim. Each focus group transcript was read several times, with notes, thoughts, and initial codes handwritten in the margin. The data was further organised and managed using NVIVO (version 12) software. This allowed data to be organised and rearranged while maintaining its original source. NVIVO sub-codes were assigned beneath the initial indexing. The authors undertook a preliminary thematic analysis of the data,¹⁹ assigning broad codes to the data starting with the first focus group. Data from the other two focus groups was tested against the coding frame working in an iterative process, allowing for progressive refinement. Following this, the authors tested behavioural and social science theories against their analysis. A spreadsheet documented how coding decisions were made and how each theme was constructed.

Theoretical approach

The authors align with critical social scientists and public health scholars such as Lupton, Baum, and Nettleton, who view the diagnoses of states such as prediabetes as a social construction.^{20–23} While numerical criteria are used to make the diagnosis, this categorisation tends to depict the cause of a disease as a failing of the individual's biology. Delivering the diagnosis in a medical setting implies that the individual is now on a trajectory to disease development, but will be able to control that progression through behaviour change. This individualist discourse of risk diminishes the condition's complexity and the role of the wider determinants of health in diabetes development.^{23,24} These

Table 1 Demographic and professional characteristics of study participants

Focus group number, participants (n)	Practice roles, n						Ethnic group, n	Sex, n
	GP	Practice nurse	HCA	Community pharmacist	Practice manager	GP trainee		
1 (7)	5	1	0	0	0	1	White = 3 Asian = 2 Afro-Carib = 2	M = 3 F = 4
2 (11)	5	1	1	2	1	1	Afro-Carib = 6 White = 2 Asian = 3	M = 3 F = 8
3 (7)	3	1	1	0	2	0	Asian = 6 White = 1	M = 4 F = 3
Total (25)	13	3	2	2	3	2	White = 6 Afro-Carib = 8 Asian = 11	M = 10 F = 15

Afro-Carib = Afro-Caribbean. F = female. HCA = healthcare assistant. M = male.

authors depict this type of health promotion as a form of medical surveillance.^{20,21} Non-adherence to behaviour change with deviations outside defined 'normal ranges' may lead to victim-blaming, influencing how health messages are internalised by the individual.^{23,25} Focusing on the individual downplays, intentionally or not, the role of social, economic, and political influences in disease development, and draws attention away from upstream disease prevention models.^{23,26}

Results

Description of sample and dataset

The focus groups included a wide range of practice staff, although GPs were predominant. **Table 1** shows the demographic and professional characteristics of participants. The participants in each focus group had existing working relationships with one another, allowing the researcher to witness collaboration on a clinical scenario. These groups provided insight into the dynamics of the practice teams by how people interacted to answer questions, contradicted each other, built on ideas, and debated and responded to each other.^{19,27} The facilitator encouraged all members of the group to voice their opinions and respond to questions. While the group was allowed to explore ideas, a topic guide was used to keep the discussions relevant to prediabetes. Fictitious personas were used to see how the group approached clinical scenarios (see Supplementary Box S2 and Supplementary Figures S1-S3 online).

Theme 1: Diagnosing and managing prediabetes

Diagnosis

GPs understood the diagnosis of prediabetes as either a pathophysiological process or as an epidemiological condition defined by biomarker diagnostic thresholds.

'Chemically, it's defined by decreased insulin sensitivity. And it's a stage that happens gradually ... towards the person then becoming diabetic.' (FG1 GP)

Participants found numerical cut-offs useful in explaining to the patient that they were at risk. They conveyed the diagnosis in relation to a progressive linear trajectory to type two diabetes, emphasising that 'prediabetes' means 'before diabetes'. Many depicted prediabetes as a definitive medical category that needed to be acted upon to prevent progression. The diagnosis was seen positively by most participants as a window of opportunity for action. It meant the patient could be 'treated' with lifestyle measures preventing disease progression:

'you're identifying an intervention group, which changing something will have a positive outcome. Otherwise you wouldn't really have that range as prediabetic range, if it didn't have any clinical significance.' (FG2 GP)

A minority of clinicians felt that the numerical thresholds caused some issues around overdiagnosis and uncertainty. Cut-offs alone did not identify those at most risk, with a high proportion of patients having an abnormal HbA1c. Additionally, people who had normal test results yet multiple risk factors for developing type two diabetes could be falsely reassured.

Monitoring and surveillance

The focus groups discussed the management of prediabetes as communicating the diagnosis, annual reviews, and surveillance and monitoring of the individual. In the annual reviews, the nurse or healthcare assistant monitors the patient's weight, HbA1c, and blood pressure. Graphs of numerical results and colour scales were used to reflect back to the individual their progress and the implications of this. The clinicians found these tools helpful in delivering health promotion messages. Many participants appeared to assume that if the patient changes their behaviour then deterioration into diabetes will be stemmed:

'Sometimes I used the colourful chart where the green is the safe numbers. Then the yellow, you know, the amber one is from 42 to 47. Then the red start from 48. So, when they come in, I just pull out the tape. And I say 'this is where you belonged before — now you've decided to jump

into the yellow zone, and if you don't take care and you don't change your lifestyle by eating the right food, exercising and that, you jump into the red.' (FG1 Nurse)

Theme 2: Motivating patients to change their lifestyles

Participants placed the responsibility of reducing diabetes risk with the individual patient. People were asked to review their lifestyle choices and explore their ability to act, while having 'discipline' and 'self-control' to reduce their diabetes risk. This was done at diagnosis and at their annual reviews.

Fear of consequences

Fear of diabetes, medication, and diabetes complications were mentioned as a means to spur people into action. In some cases, participants indicated that they used scare tactics (depicting dire outcomes if no action was taken) to help motivate patients:

'And a lot of patients do not want to go on medication. I've encountered a lot that don't, "Oh, I don't want blood pressure medication — don't give me that", "Then do something about your lifestyle, if you don't want medication". Because that's what we say for people with diabetes — they don't want it, but they need to do something to make a change, we can't just make the changes for you, you need to take control of your own life.' (FG3 Healthcare Assistant)

'If they're scared about it, they're worried about it, then fine — I'll go with them, and we'll go with it. If they seem nonplussed, then my response is a lot more kind of aggressive, in the sense that, 'Do you not know what it means — you could lose your foot, you could lose your vision, you could have a heart attack'. Then you start putting the kind of complications in their mind, to get them worried about it.' (FG1 GP)

Some clinicians considered that scare tactics were justifiable if they raised the awareness of risk and triggered the individual to act accordingly to change their lifestyles. Others recognised that these tactics had negative consequences, such as stigmatising people, which may prevent them from returning for review, or engaging in behaviour change or lifestyle interventions. This approach had to be tailored and timed correctly for each patient:

'I think she got the fear of God in her, as soon we said, "You're diabetic". [um] Managed to change everything' (FG1 GP)

'It was the first time I think anyone had actually addressed the fact that everything you're doing was adding up to him being a ticking time bomb, it was a wake-up call. For some people, they run away because they are scared. But other people, it will shock them into "Okay, I've got to listen now".' (FG2 GP)

Theme 3: Long-term support

Clinical team members discussed the need for a long-term approach to supporting behaviour change based on patient-centred, relationship-orientated care. This approach is based on mutual trust between the clinician and patient, with knowledge of their social circumstances and cultural context. The focus group participants reported that this approach had a focus on small behaviour changes occurring incrementally over time. It required time for the patient to communicate their narrative, free from judgement, and feel that they have been heard. Encouraging the patient to decide what was possible, alongside showing an interest and offering kindness, was reported as key in this approach. Here the patients use their agency to decide what they can do, rather than being told what to do:

'This is where it's kind of important if the doctor gets it right and pitches it at the right level for the patient, and tries to understand the circumstances, rather than using circumstances against the patient.' (FG1 GP)

'I think concordance is another thing. To get the patient on board and feeling involved in the decision making about what changes they make. So, where he's got practically everything wrong with him, you know? It might be useful to sort of put the ball in his court ... And when

they're made to feel like they're involved, and not just being told what to do, there's a bigger chance of success with, with even small changes.' (FG1 GP)

Theme 4: Social determinants of health

Practice teams showed considerable depth and breadth of knowledge of the everyday lives of their patients. Every team recognised that people's choices were constrained by poverty, cultural expectations, and the built environment. Understanding this context was vitally important, they felt, in tailoring health promotion messages. **Table 2** gives examples of how these influences were discussed by the groups. Key barriers to behaviour change included financial insecurity, cultural norms, the obesogenic environment, gender roles, and health literacy. Housing and financial stresses were mentioned recurrently as structural barriers to behaviour change (**Table 2**, quote 1). Lifestyle change was seen as particularly difficult for women, (**Table 2**, quote 3): the demands of family life and work were prioritised above self-care. Overcrowded, poor quality housing has a large impact on preparing meals and exercising at home. The focus groups reported that people were constrained to eat what they can afford (quote 4, **Table 2**), which was often poor quality food that was high in sugar and salt. The high number of fast food outlets in the area reflects the demand for quick, cheap food and its cultural acceptance. Despite the availability of lifestyle interventions, like the NHS DPP, and the presence of green spaces, many participants felt that barriers to engagement in lifestyle were too overwhelming for patients:

'However, it's easier said than done. I do know that I have not been able to control totally blood pressure just through lifestyle in any of my patients. You know? I've tried my best, because I think that if they reduce blood pressure, if they cut down on their smoking, and then the smoking has stopped, cut down on — they're helping ... Unfortunately, I am still waiting for my first success. This has not happened.' (FG3 GP)

Table 2 Quotes discussing the social determinants of health

Social determinant	Description
1. Financial insecurity	<i>Finance: 'Yes. I mean, well what you are saying is if the person has a healthy mind. Now, he's unhealthy not because only of his not walking or walking. He's unhealthy also because he's occupied with something else, all the time. If like finances, worried about their finances, and things like that. The last thing they're going to be thinking about is their health. Going to be like "I need to get these bills paid". You know? So, I think their personal situations matter a lot, as well. And how they, you know, they deal with their lifestyle.'</i> (FG3 GP)
2. Cultural norms about food and eating	<i>'You know, will you — like changing the food, and things like that — they [the family] probably wouldn't like that. Like, "Why are you making it healthier, why are you changing our cooking method, we don't want it like it that".'</i> (FG3 Manager) <i>"The other thing for me is oil in curries — I remember a patient who I was always telling to eat fish, and they brought me a little bowl full of oil, but a little piece of fish sitting in the oil. And so I try and say "How much oil do you buy in a month?" And it's like five litres or something.'</i> (FG1 GP)
3. Gender roles and expectations	<i>'The expectations of sometimes what men and women do. So, sometimes we think that you wouldn't get anywhere with men, but actually they're the ones who have the [um] permission within society to go to the gym, to be out, and not to have to do the housework and the childcare. [um] And for women, especially sort of women in their forties and fifties, that there's an expectation that you know, there is no social life, there's no [um] going out, you know, to go to an exercise class, and they're more at home. [um] And, and/or you need to ask permission to go out. And it's still — it surprises me that there's still quite a lot of that around.'</i> (FG 2 GP)
4. Obesogenic environment	<i>'FG1 GP: Just a walk round. You can see, you see all the chicken and chip shops. Fast food. Cheap and cheerful. So. Keep you happy for that moment, but after that, it depletes you, really. Drains you all the time.'</i> <i>Interviewer: So do you think it's that there's not enough healthy options, or they're too expensive?</i> <i>FG1 GP: Yeah.</i> <i>Interviewer: Not enough?</i> <i>FG1 GP: There's not enough. Not enough [healthy food options]. And probably because it's too expensive.'</i>
5. Health literacy	<i>'I guess sometimes the actual underlying knowledge about healthy eating isn't always there, as well. [um] Especially when you're dealing with someone who comes from a — is relatively isolated, who hasn't necessarily had the best schooling, is relatively new to the country. Changing everything round like eating, your entire life — you need to change everything, you need to eat what's on the NHS website — it's sometimes difficult to make that leap.'</i> (FG1 GP)

Discussion

Summary

In this small focus group study undertaken in a deprived part of London, clinicians described four main influences on prediabetes and its management in the consultation: social determinants of health, clinical aspects of diagnosis and management, patient motivation and behaviour change, and long-term support. Since most felt unable to address social determinants such as poverty, discussions with patients tended to focus on attempts to change individual behaviours with limited attention to the social context in which behaviours would play out.

These findings suggest that clinicians in general practice are navigating two competing paradigms: individual and social. At the individual level, they are incentivised to subscribe to the biomedical model of disease prevention, which perpetuates an individualist focus encouraging people to take responsibility and control their behaviour to prevent diabetes. Prediabetes is portrayed as a medical certainty and people are given prescribed lifestyle advice (sometimes using controversial 'scare tactics')²⁸ on how to prevent the perceived linear development to diabetes, and monitored using glycaemic biomarkers. Focusing on the individual foregrounds individual behaviours, and backgrounds the social causes of disease and underlying complexity of disease development.

At the societal level — as is often revealed through the ongoing therapeutic relationships possible in primary care — clinicians see first-hand how social determinants of health provide overwhelming structural barriers inhibiting patients' behaviour change. This study's findings suggest that they feel they have little choice but to give individualist health promotion messages, despite knowing that this is likely to have limited effect.

Strengths and limitations

The focus groups worked well to gather large amounts of information from multiple perspectives, and to facilitate consensus-building in a short space of time.²⁷ The focus groups allowed the authors to gather individual opinions and document group knowledge production.^{19,29} The groups generated insights and solutions to the mock scenarios that would not have occurred without the other participants.²³

The study has limitations: all the practices took part in the local enhanced service and saw diabetes prevention as a priority. This may not be true for other areas, thus the views in these focus groups are not representative of all GPs. Furthermore, the small size of the study means the findings are preliminary. General practice has a hierarchical structure with GP partners the main employers, and this may have shaped how people answered questions and gave their opinions in the group discussions. GPs predominated in the focus groups: they communicated the diagnosis, discussed the risk of diabetes, and gave initial health promotion messages, while other staff (less well represented in the focus groups) undertook the annual reviews. The authors did not observe consultations as part of this study, but are conducting an ethnographic study of people with prediabetes, exploring their experience of being diagnosed with the pre-condition; how they internalise this diagnosis; how the diagnosis influences health related behaviours; and the role of risk regulators in behaviour change.

Comparison with existing literature

The authors used a critical social science lens to explore prediabetes from the perspectives of primary care teams, which included the framing of the diagnosis, the delivery of health promotion messages, and the barriers to lifestyle change.

It is worth considering these findings in relation to Rose's prevention paradox, which states that if you make societal level changes to reduce everyone's risk of disease by a small amount, this is likely to lead to larger reductions in the incidence of disease than if prevention is targeted to 'high-risk' individuals.²⁶ Currently, high-risk disease prevention strategies predominate in health policy. This reflects a 'neoliberal' approach to policy in general, emphasising individual responsibility and self-maintenance with less reliance on the state.²⁸ This stance does not align with the view that individual health is largely the product of structural forces in society.²⁴ Rose,²⁶ and more recently Marmot,³⁰ have argued that without addressing societal influences, it is unlikely that behaviour change will be possible for those with overwhelming structural barriers. For example, the poorest 10% of the country would need to spend 75% of their disposable income to meet the NHS's Eatwell guidelines.³⁰ A

whole-population approach to diabetes prevention is politically problematic as it involves regulating corporations that make profits from selling high fat and high sugar content food, and that are also adept at political lobbying to support their positions. Affordability of healthy food and the commercial environment were discussed in all of the focus groups as some of the biggest barriers to lifestyle change. Given the devastating effects of COVID-19 in those with obesity, with diabetes, and from deprived areas, there have been calls for greater regulation on the food industry with improved affordability of healthy food options.^{31,32}

Twenty years ago, Wylie *et al*³³ published a study of 34 clinicians' views on the identification, treatment and management of impaired glucose tolerance. They found that GPs were reluctant to engage with health promotion, which they viewed as 'paternalistic' and medicalising the social causes of disease. The present study showed a greater commitment of clinicians to engage in disease prevention, perhaps due to specific financial incentives and the growth of functionally differentiated practice teams. Burch *et al* undertook qualitative interviews with primary care staff exploring the diagnosis and management of prediabetes in older populations.³⁴ Similarly to the present study, they found that a person-centred approach was key in diagnosing and managing patients with an elevated HbA1c.

Others have undertaken qualitative work with clinicians as an adjunct to interviews with people labelled with prediabetes. Three studies aligned with the present study's findings that health promotion strategies deliver individualist messages, asking individuals to control their disease prevention and using the diagnosis as a motivational tool.^{12,13,35} Twohig *et al* identified a number of key community constraints individuals faced when trying to engage with behaviour change programmes, but didn't consider these as intervention opportunities.¹¹

The empirical literature from critical public health is also relevant. Baum *et al* undertook qualitative interviews with health workers who, like the clinicians in the present study's sample, described how the social determinants influenced their patients' ability to partake in behaviour change.³⁶ Acting as advocates for addressing these determinants was considered at odds with being a public servant, with structural barriers and workload pressures preventing clinicians engaging in the policy process.

Implications for practice and policy

From April 2021, GP practices in England have been incentivised through the NHSE GP Contract to maintain a register of people with non-diabetic hyperglycaemia and invite them for annual blood tests to check for progression to diabetes. The present study's findings suggest that it may be beneficial to shift health messages away from quantitative markers to exploring the patient's lived experience and what is possible within their social context. The findings also suggest that a longer-term approach was a key prevention strategy in assisting people with behaviour change. Disease prevention policies do not currently reflect the importance of patient-centred care, with the current model of annual reviews placing a greater emphasis on numerical targets than on therapeutic relationships.³⁷

GP practices in England are now organised into primary care networks tasked with addressing population health priorities. The focus groups suggested that primary care workers have unique insights into their patients' social contexts and the barriers they face in trying to undertake lifestyle change. These patient narratives may be useful in identifying community-level opportunities and constraints on health.^{38,39} Additionally, Clinical Commissioning Groups are transitioning to Integrated Care Systems (ICS). These ICSs are tasked with addressing the upstream influences on health and reducing health inequalities. Primary care teams working alongside public health bodies and local government, may be key in tackling the upstream influences on health as part of a multi-faceted, place-based disease prevention strategy.⁴⁰⁻⁴²

This small study of primary care teams has highlighted the efforts made by staff to support people diagnosed with prediabetes and the powerlessness of such staff to address structural barriers to diabetes prevention. The system of structured care oriented around numerical targets and a linear model of progression from prediabetes to type two diabetes lend themselves to the use of individual health promotion messages and a narrative of inevitable progression unless behaviour changes — an approach that overlooks the complexity of diabetes development. These findings also highlighted the potential for relationship-based care to explore barriers to lifestyle change within the context of the individual's social sphere. Primary care teams have key insights, through their patients' narratives, into how the social determinants directly lead to disease development. New ICSs and Primary Care

Networks are tasked with taking a population health approach to address the social determinants of health, reduce health inequalities, and reduce the burden of disease.⁴² Individual narratives play an important role — along with the co-ordinated working of primary care teams, public health teams, and local government — in maximising the benefit of new opportunities to address the community constraints to behaviour change.

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Ethical approval

This study was approved by the NHS HRA London-Surrey Research Ethics Committee [REC reference: 18/LO/0479].

Provenance

Freely submitted; externally peer reviewed.

Data

This is a qualitative study and so does not rely or relate to any datasets.

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Appendix 9: Policymaker paper

BMJ Open Explaining the UK's 'high-risk' approach to type 2 diabetes prevention: findings from a qualitative interview study with policy-makers in England

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ABSTRACT

Objectives When seeking to prevent type 2 diabetes, a balance must be struck between individual approaches (focusing on people's behaviour 'choices') and population approaches (focusing on the environment in which those choices are made) to address the socioeconomic complexity of diabetes development. We sought to explore how this balance is negotiated in the accounts of policy-makers developing and enacting diabetes prevention policy.

Methods Twelve semistructured interviews were undertaken with nine UK policy-makers between 2018–2021. We explored their perspectives on disease prevention strategies and what influenced policy decision-making. Interviews were transcribed and analysed thematically using NVIVO. We used Shiffman's political priority framework to theorise why some diabetes prevention policy approaches gather political support while others do not.

Results The distribution of power and funding among relevant actors, and the way they exerted their power determined the dominant approach in diabetes prevention policy. As a result of this distribution, policy-makers framed their accounts of diabetes prevention policies in terms of individual behaviour change, monitoring personal quantitative markers but with limited ability to effect population-level approaches. Such an approach aligns with the current prevailing neoliberal political context, which focuses on individual lifestyle choices to prevent disease rather than on infrastructure measures to improve the environments and contexts within which those choices are made.

Conclusion Within new local and national policy structures, there is an opportunity for collaborative working among the National Health Service, local governments and public health teams to balance the focus on disease prevention, addressing upstream drivers of ill health as well as targeting individuals with the highest risk of diabetes.

INTRODUCTION

Type 2 diabetes is an enduring cause of morbidity and mortality. As its prevalence continues to increase, prevention has become a global health priority.¹ Geoffrey Rose outlined two approaches to disease

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This is the first analysis of diabetes prevention policies in the UK, using a political science perspective.
- ⇒ We have explored the policy process as well as the research–policy gap using Shiffman's political priorities framework.
- ⇒ However, our focus on a small number of elite interviews means that our findings are preliminary.

prevention. The first, 'whole-population' approach, introduces societal level changes to reduce everyone's risk of disease by a small amount. The second, 'high-risk' approach, identifies individuals with disease risk factors and focuses on individual interventions (medication or lifestyle programmes) to reduce disease incidence. There is a continuum of disease risk and reducing the population's risk by a small amount is thought to be more effective than focusing on high-risk individuals. Despite this, a number of western countries (eg, USA,² Australia³ and New Zealand⁴) have chosen to adopt mainly or exclusively a high-risk approach, identifying those considered at increased risk and offering them lifestyle education programmes. In England, the National Health Service (NHS) National Diabetes Prevention Programme was introduced in 2016⁵ and from April 2021, General Practitioners (GPs) were incentivised to follow NICE (National Institute for Health and Care Excellence) guideline PH (public health) 38,⁶ to identify and maintain a register of those with 'non-diabetic hyperglycaemia' ('pre-diabetes'), and in some areas offer annual reviews and referrals to lifestyle interventions. In the UK, diabetes prevention sits within the NHS with local public health teams commissioned to support policy implementation or evaluations.

The NHS National Diabetes Prevention Programme consists of 13 classroom-based



lifestyle intervention sessions delivered over 9 months,⁵ supported by trial evidence showing reductions in the risk of disease if individuals engage and complete the interventions.^{7 8} The programme has helped individuals to improve their weight and glycated haemoglobin (HbA1c). However, evaluations have highlighted several concerns.⁹ First, there were high attrition rates from initial referrals to programme completion, with only 19%–22% of those referred completing the programme.^{9 10} This is likely due to how individuals are informed, internalise and contextualise the pre-diabetes diagnosis.¹¹ Second, there are reported concerns over variations in the intervention's accessibility, quality and fidelity.^{12–18} Evaluations have also identified limited improvements in weight and glycaemic markers in women, black and Asian ethnic groups and people from lower socioeconomic backgrounds.^{9 19} Weight loss is difficult, especially for those who face structural barriers.^{20 21} For instance, the poorest 10% of the country would need to spend 75% of their disposable income to meet the NHS's Eatwell guidelines.²⁰ Hence, while current policies help some individuals reduce their risk, there is a concurrent risk of widening health inequalities if these engagement patterns and outcomes continue.

The UK government's population-based approach to tackling rising obesity levels (and subsequently non-communicable diseases such as diabetes and cardiovascular disease) was updated during the COVID-19 pandemic.²² The strategy currently consists of a soft drinks levy, a school-based approach to sugar reduction, increasing physical activity and food calorie labelling initiatives. These population-level initiatives have been criticised by diabetes organisations and public health leaders as inadequate to reduce the burden of long-term conditions and address health inequalities because they do not tackle the underlying drivers of ill health.^{20 21 23–27} Plans to restrict supermarket two for one promotions on foods high in fat, salt and sugar, as well TV advertising restrictions on unhealthy foods before 21:00 have been delayed, a decision described by some as an 'act of supreme self-harm'.^{22 26 28}

In England, public health teams within local governments are tasked with tackling the community-level determinants of health. Public health teams transitioned to the local authority setting 10 years ago and have had to build new relationships, logics and ways of working to establish themselves within a different context. Sustained public health budget reductions (up to 25%) have undermined action on a place-based approach to disease prevention.²³ The result is huge variations in local authorities' commitments to improving population health^{23 29} and impacts on the working relationships across local authorities and the NHS.³⁰

Health behaviours contribute to the development of non-communicable disease such as diabetes. However, it is the social determinants of health, which lead to these behaviours and subsequent health inequalities.^{7 20 23} Population health strategies to reduce diseases such as diabetes are limited and poorly financed.

Aims

We explore how policy decisions are made in implementing national diabetes prevention directives in local settings and identify key influences that shape, enable and constrain these decisions.

Research questions

In relation to England's policy on type 2 diabetes prevention:

1. What do policy-makers describe as key influences on decision-making for diabetes prevention?
2. Why is England pursuing a largely 'high-risk' strategy to diabetes prevention strategy?

METHODS

Study design

We undertook a qualitative semistructured interview study with a maximum variation sample of policy stakeholders involved in developing and implementing diabetes prevention policy.

Sample and setting

We sought perspectives from a range of local and national policy-makers, using a combination of purposive and snowball sampling. We first selected four policy-makers with experience of local or national policy-making, ensuring representation of public health and NHS settings plus experience in commissioning, health consultancy, clinical practice and public health. We then recruited a further nine stakeholders via participant recommendations.

Data collection

Nine semistructured interviews with ten stakeholders took place in-person between 2018 and 2020 (one interview was done jointly with two stakeholders). Three stakeholders were then reinterviewed (online via Microsoft Teams due to COVID-19 restrictions) in 2021 to ascertain how the COVID-19 pandemic influenced decision-making (see [table 1](#)). Each interview lasted 30–90 min, using preprepared topic guides (see online supplemental file 1 for an example). Topic guides were customised iteratively for each interview, based on the information gathered from previous interviews. We adopted a semistructured approach, enabling the interviewees to express and discuss influences on the policy process from their perspectives. Prompt questions served to elicit how research evidence was used practically to guide decisions. Interviews were audio-recorded (with written consent), anonymised and then transcribed verbatim by a professional transcriber. Each audio recording was checked against each transcription to ensure accuracy by EB.

Interviewees at local authority level included six policy-makers with a public health background, two commissioners, one strategist, a public health consultant and a director of public health. A public health policy-maker working at a national level was also interviewed. NHS participants included a GP clinical lead, a GP primary care network clinical director, a primary care commissioner

Table 1 Study participants

Stakeholder interview	Role	Interview date	Follow-up	Sex
1	PH strategist	08 August 2018		F
2	PH commissioners 1 and 2	06 September 2018		2 M
3	GP diabetes led	26 September 2018	04 June 2021	F
4	Primary care commissioner	03 October 2018		F
5	GP and PCN clinical director	07 October 2019	27 April 2021	M
6	PH national policy-maker	21 October 2019	16 June 2021	M
7	PH consultant	10 December 2019		F
8	DPH	17 January 2020		F
9	NHSE policy-maker	18 May 2021		F

In order to maintain participant anonymity, it is not possible to give further details on their roles

PH (Public Health), GP (General Practitioner), PCN (Primary Care Network), DPH (Director of Public Health), NHSE (NHS England)

and former national healthcare policy-maker. The two GP leads and the national public health policy-maker were reinterviewed in 2021 to ascertain if the policy process had changed over the course of the COVID-19 pandemic and to gather feedback on initial findings. Their feedback was that COVID-19 had amplified existing issues, rather than highlighting anything new. All interviewees were approached by email and none of the participants refused to take part. EB conducted the interviews, took field notes and maintained a reflective journal which assisted in the data analysis. This study formed part of a doctoral research study undertaken by EB. TG, SS and CP assisted in the interpretation of the data as well as paper revisions.

Data analysis

The corresponding author (EB) first used line to line coding with an initial set of three interviews, allowing us to develop a coding framework. This was refined as we coded the remaining interviews, informed by reflections and memos made during the interviews and analysis. We then grouped codes under preliminary themes describing the most significant influences on the policy process, that is, decision-making about policy taking place in a complex system influenced by different structural factors and socioeconomic contexts.³¹ Finally, we used Shiffman's framework to extend analysis of how national diabetes prevention policies are interpreted and put into practice locally. NVivo V.12 was used to manage the data.

Theoretical framework

Originally developed to investigate the determinants of global priorities for health, we used Shiffman's framework³² to explore how national directives on diabetes prevention are interpreted and implemented at a local level and understand why disease prevention policies focus on targeting high-risk individuals rather than upstream population-level interventions. The framework consists of four domains. For the first domain of 'actor power',

we combined this domain with Lukes three dimensions of power, to give us an additional understanding of how power operates. Lukes understood power to be a multi-dimensional social influence,^{33 34} which allowed us to explore how individuals and organisations use their power in the policy process and how this influences decision-making. For the second domain, 'political context', we unpacked the influence of a neoliberal political system on health policy. For the third domain, we explored the power of ideas behind the policy approach, in particular the emphasis on individual responsibility. Finally, for the fourth domain of 'issue characteristics', we explored what aspects of pre-diabetes make it amenable to a high-risk disease prevention policy.

Researcher perspective

Adopting an interpretivist approach, we sought to understand how prevention policies are socially and culturally shaped while exploring the complexities underpinning the policy process. As is usual in qualitative research, the study findings were influenced by the context in which data was gathered and assumptions of the researchers.³⁵ We acknowledge that our identities and professional roles (as clinicians and academics in social sciences, policy and public health) are likely to have influenced data collection and analysis.³⁶ A GP carried out the interviews, which may have influenced how people within the interviews volunteered and shaped their answers.

The Consolidated criteria for Reporting Qualitative research checklist was used in reporting this qualitative study.³⁷

Patient and public involvement

No patients were involved in this study.

RESULTS

Below, we set out our findings on what influences decision-making in the translation of national diabetes prevention



directives to local settings. Within the interviews, we explored with policy-makers the policy process and the role of research evidence in the decision-making process. Overall, we found that disease prevention was discussed on an individual basis, focusing on preventing diabetes in those labelled with ‘pre-diabetes’ with research evidence used in a limited way to support predetermined perspectives. We have structured our findings according to the four domains of Shiffman’s framework exploring why this dominant policy approach currently exists.

Power and funding shaping individualist policy

Direct power

In this section, we will explore the use of different forms of power in the policy process and how it is used by actors. The use of direct power by NHS England was identified by all stakeholders as a key influence in diabetes prevention policies. The NHS is currently taking a ‘high-risk’ approach to diabetes prevention, targeting people labelled as being at high risk of developing disease to change their lifestyles. This is being commissioned via the NHS GP contract and the NHS Diabetes Prevention Programme. Stakeholders reported that money and power sit within the NHS, whose scope is to focus on individual disease development, therefore an individualist discourse will likely be the overarching policy approach (quote 1 in [box 1](#)).

Our interviewees gave examples of how NHS England exercised direct influence on the policy process. Providers contracted to deliver the NHS Diabetes Prevention Programme were commissioned directly by NHS England, with reports of limited input from local NHS commissioners. Information and funding were reported to flow in a top-down fashion, with very little scope for local policy-makers to feed into the decision-making processes. Resistance or feedback from local policy-makers seemed to have limited influence on outcomes (quote 2 in [box 1](#)).

Local influence, but without authority

Comparatively, funding to public health and other government departments has significantly reduced. As a result, public health stakeholders talked about their role as having ‘influence without authority’ and ‘getting stuff done with other people’s money’ (SH7 Public Health Consultant). Two strategies were used to exert their influence. First, they operationalised power from their knowledge and expertise. Tools used included collecting resident narratives to influence political decision-making. The ‘lived experience’ and story imagery engaged politicians who understood individual narratives from working in their constituent surgeries, illustrated by quote 3 in [box 1](#).

Second, public health stakeholders used working relationships and trust building to exert their influence, see quote 4, [box 1](#). In the transition from the NHS to a local authority setting, public health teams discussed working to create new identities and working relationships within

Box 1 Money and power shaping individualist policy

1. ‘So, using diabetes as an example, because it seems to be very stuck in the biomedical model which means that the way it’s going, we’re only really going to get DPP as the solution to preventing diabetes. Because all the money’s gone to NHS England, so you can talk to any of the other government departments, they say NHS, the NHS has taken all our money.’ (SH6 National Public Health Policy Official)
2. ‘We hadn’t been informed that the (project) extension had been further extended by additional four months, until the MOU [memorandum of understanding] was sent through to us. And that additional four months didn’t reflect the amount of mobilisation fund that we received from NHS England. And our targets for initial assessments had been increased. There was very little leeway in terms of conditions. Which we then tried to (address) but didn’t get far with that.’ (SH1 Public Health Strategist)
3. ‘But they [politicians] are also very much driven by, you know, being part of the communities that they represent, the stuff that walks through their, you know, their weekly surgeries about the challenges that residents are facing and so they will be informed by that kind of sense of anecdote and story.’ (SH8 Director of Public Health)
4. ‘We’ve got to kind of build those relationships. We’ve got to understand, get out and about understanding Local Government to start with because I think, you know, clearly when we joined, we had very little understanding generally probably of what Local Government is and does and how it works so it has been that kind of journey of understanding and building relationships, building trust and only through that are you going to, ever achieve anything really I think.’ (SH8 Director of Public Health)
5. ‘A conversation last week about PCNs, it’s all very well us coming in with ambitious big population health stuff and they’re, they’re so underfunded and new and developing what they’re going to be primarily occupied with is, ‘We’ve just received this national DES (directly enhanced service – that is, funding for a specific initiative) specification and we’ve got to work out how we’ve got to go and deliver it, how can you help us do that?’ That’s the kind of normal conversation.’ (SH8 Director of Public Health)
6. ‘I sat in a room with a finance man when I was trying to come up with my business case. I had four business cases at one point, on diabetes. And I said to him, ‘if you’re diabetic and you’re type one, you live twenty years less than somebody - if you’re type two, you live ten years less, if you have -’, you know?’ (SH4 NHS Commissioner)

local government. Key to this relationship building was understanding each stakeholder’s perspectives, priorities and recognising funding imbalances. Public health policy-makers discussed needing to set aside ambitious agendas in to maintain working relationships. For example, quote 5 in [box 1](#) illustrates how engagement with NHS partners was confined to restricted parameters to achieve operational goals.

Limited power of research evidence

Academic research was discussed as having limited influence on decision-making in the policy process. Interviewees discussed (what they saw as) researchers’ lack of understanding of the policy-making context and the complexity of the policy process. Public health

Box 2 How political context shapes diabetes prevention

1. 'Yeah, so we tried to have that probably a bit ahead of our time a few years ago and absolutely given the kind of financial circumstances and any concern about doing anything about that would lessen local government revenue we didn't win out...' (SH8 Director of Public Health)
2. 'Yeah, so you get stories where it is politically, one has to phrase things in Tory areas differently. So, there's a really nice session I went to as part of training in my last job where democratic services shared how they'd gone from a Labour administration to a Tory administration and they kept on the same, they went through the manifestos with a fine-tooth comb. They made lots of notes and then they renamed all their programmes. They kept all their programmes; they kept all their funding, but they renamed them to fit with the ethos of the incoming administration so the holiday hunger programme which makes perfect sense to me, holiday hunger became social eating because it's just nicer and so there's certain things that, that conservative authorities will make all the right decisions and all the right thoughts and feelings. It just needs to be dressed up slightly differently so it's not, it's never a class war thing. It's a sort of nice to do or better if thing.' (Public Health Consultant SH7)
3. 'Academic research doesn't recognise the context in which that then has to get operationalised. I suppose the gap in translational public health... I do think maybe there is something about face time in local government I think for academics. I think they just don't understand local government what it is and does and how it works genuinely, and I think there's, a lack of social evidence'. (Director of Public Health SH8)

stakeholders thought that research and guidelines did not reflect the sociopolitical complexities they were operating in, and that research was still orientated to an NHS biomedical perspective (see quote 3 in [box 2](#)).

Research evidence was at times used selectively to fit with the policy-makers particular need. For example, to question current practices, argue for their revision or to support the development of pilot schemes. Examples were given where research headlines were used to strengthen the rhetoric in funding applications, as illustrated by quote 6 in [box 1](#) from an NHS commissioner.

How political context shapes diabetes prevention

Policy-making occurs within a political environment in which actors operate, influencing how we perceive health and illness and what policies are politically acceptable. England might be said to have a neoliberal political system based on ideals of competition, free markets with minimal state intervention and corporate regulation to promote economic prosperity.^{38–41} Neoliberal systems reject the idea that health is the product of structural forces placed on individuals, diminishing the role of social, economic and commercial influences on health.⁴² In this system, governments might be reluctant to use population-level structural interventions to address upstream drivers of ill health.^{38 39 43 44} Instead downstream individual level lifestyle interventions, focused on a narrative of individual responsibility are used as disease prevention strategies.^{40 43 45}

Box 3 Framing ideas about disease prevention as individual responsibility

1. 'How can we help that person? How can they be empowered? And so that they are self-caring, and it's their - it's their lives, rather than this you know, this deferring all the time to the doctor... it's about trying to get people to, to have that ownership of their own health, and the fact that they can make a change... whose intervention, is it? So, responsibility is not on us to provide, provide you with a tablet. Our responsibility is to provide you with education and support.' (SH3 NHS Commissioner)
2. 'The things I found frustrating; 1) everything's individual, 2) the level at which we put in interventions, I think it's homeopathic. You've got whole population, you need something at scale and then we have like, 'Well we've got a cooking project here and we've got our sort of reading after school project here,' and the NHS commissioning our local diabetes prevention project... we've got 8000 pre-diabetics but provide a service for a quarter of them... (GPs) drive up their (commissioned) activity and then box checked and result, but that doesn't actually work for diabetes prevention.' (SH7 Public Health Consultant)

We found examples of neoliberal influences on policy-making within the interviews. Working within the local authority setting, public health initiatives were discussed as needing to align with political viewpoints and ideas. There were examples of public health policies, targeting upstream influences on health (at a community level), not gathering political support because of their impact on local economic revenues, see quote 1 in [box 2](#).

Policy-makers discussed trying to align public health strategies with political agendas, to ensure continued funding for community-level interventions. This involved tailoring their language and messaging to fit the local administrations political ethos. Quote 2 in [box 2](#), given by a public health consultant, shows how the language around initiatives and interventions were adapted to remain politically neutral.

Framing ideas about disease prevention as individual responsibility

In this section, we explore how policy-makers framed ideas around disease prevention, particularly in terms of individual responsibility. Policy-makers working within the NHS believed diabetes could be prevented by empowering individuals through increasing their knowledge via interventions. This emphasis on empowerment and education was assumed to lead to less reliance on the medical system, see quote 1 in [box 3](#), from an NHS commissioner.

Policy-makers working in local authorities and public health framed disease prevention in a different way talking more about upstream community-level influences on health. However, they expressed frustration that the emphasis and funding for disease prevention was largely situated within the NHS. NHS structures such as the GP contract and primary care commissioning cycles were

**Box 4 Characteristics of diagnosing, managing and monitoring pre-diabetes**

1. 'Like things like grip tests, and step tests, and stuff like that - if we're getting improvements after six weeks, then they are indicative of improvements over a longer period of time. So, it's - We're not going to see a reduction in diabetes, but if a hundred and fifty people finish a course, and after six months they've maintained their behaviour, and we've seen a ten to twenty percent improvement in grip strength, or their ability for their heart to come back to a normal rate after a step test, that's indicative of a health improvement.' (SH2 Public Health Commissioner)
2. 'Whether they sustain the physical activity is quite, you know, helpful to know. So even though it's - We're not, we're not measuring you know, a diabetes measure, but if they could still say to you 'yes, I went to this and I'm still exercising twice a week' in ten years' time, then that intervention was worthwhile, regardless. Because it's made them behave - you know, they weren't doing it before, they've been done an intervention and they've sustained that for ten years. Surely that's a positive outcome?' (SH3 GP)
3. 'Because I think it's important to sort of work out why people choose, make the choices that they make in a shop, at that time. You're here, what are you having? How did you, how did you make that? What made you come into the shop in the first place? You know? Are you aware of your, of your risk? Are you aware of how they cook this?' (SH3 GP)

seen to perpetuate this individualist discourse due to the 'homeopathic' individual, small scale commissioned interventions and how they were evaluated by surrogate markers (see quote 2 in [box 3](#)).

Similarly, most research in diabetes prevention was discussed as being undertaken on an individual level through intervention trials. This is in part due to diabetes being framed as a failing of individual biology and measured via outcomes such as weight and HbA1c in trials and in diabetes prevention reviews. This aligns with the views of policy-makers that diabetes can be prevented by increasing an individual's knowledge and monitoring them through the process, as discussed previously.

The characteristics of diagnosing, managing and monitoring pre-diabetes

In this section, we explore the features of pre-diabetes diagnosis and management, which construct the individual-level disease prevention strategy (as discussed by policy-makers). First, risk factors for developing diabetes can be identified and quantified in a primary care setting, making it possible for GPs to monitor individuals and detect diabetes development. Because the diagnosis is made via a blood test and in turn interpreted and communicated via a GP, it categorises the condition as a biomedical risk. Second, initial lifestyle advice is given in primary care settings, medicalising individual lifestyles.

From a commissioning and contracting perspective, it is possible to use patient-level surrogate markers

(from GPs or commissioned interventions) to monitor targets and use these as terms for payment. Our interviewees emphasised and valued the collection of quantitative data as a way to monitor GP activity. This data was recorded and reflected back to practices in the form of dashboards to compare practices with each other. This data collection process allows the treatment and management of pre-diabetes to fit into short-term funding and commissioning cycles. Quote 1 in [box 4](#), from a public health commissioner, illustrates how small improvements in downstream markers were used as evidence for intervention adherence and success.

Similarly, how pre-diabetes is defined and measured clinically lends itself to being researched in a similar way using quantitative methods such as the analysis of GP data sets, or lifestyle intervention trials. These largely support an individualist approach to reducing diabetes by targeting individuals at high risk.^{7 46 47} Although this research did help when making the case for funding initiatives (see [box 1](#) in quote 6), policy-makers reported that this type of research did not reflect the real lives of their patients or explain why they make their life choices, identifying a need for applied social science research (see [box 4](#) in quotes 2 and 3).

DISCUSSION**Summary of findings**

Our findings show that the UK is largely employing what Geoffrey Rose described as individual-level high-risk disease prevention policies. Informed by the work of Shiffman and Lukes, we identified three dimensions of power and how this is operationalised to shape such policy.^{48 49} Power is exerted: (a) directly via top-down NHS England policy directives such as the NHS Diabetes Prevention Programme, (b) indirectly with public health professionals using their expertise to subtly influence the policy agenda and (c) through our neoliberal political context shaping how people think about disease prevention. In the interviews, diabetes prevention policy was framed in terms of individual responsibility to reduce the risk of disease. This is amplified by measurable downstream characteristics used in policies and interventions, such as weight and HbA1c. In addition, lifestyle advice given in primary care medicalises socially constructed lifestyles and neglects the complexity of how lifestyles develop over times.^{46 50}

COVID-19 disproportionately affected those with diabetes and obesity. This led to calls to address the social determinants of health^{27 51-54} and tighter regulations on the food industry.⁵⁵ However, our analysis of how our political context shapes disease prevention policies, suggests that a whole-population approach to diabetes prevention may be politically problematic. National infrastructure changes (such as limiting fast food outlets or restricted advertising) goes against the neoliberal ideals of a 'free

market' economy and involves regulating profit-making corporations.⁵⁶ As illustrated by our interviews, reducing local or national economic revenues was deemed to be politically unfavourable.

How health policies drift from the social determinants of health to individual solutions

Health policies acknowledge the central role of the social determinants of health in non-communicable disease development. However, analysis of the UK government's obesity strategy illustrates that solutions to these problems tend to be based on individuals minimising their health risks by becoming responsible, self-governing citizens, changing their behaviours rather than tackling upstream influences on health.^{28 38–40 43 45} Two mechanisms of this 'lifestyle drift' phenomenon were discussed in the interviews.⁴⁰ The first mechanism was moving public health teams into local authorities. This placed the responsibility of disease prevention into smaller communities away from national bodies. Focusing on communities to prevent disease puts a focus on individuals within communities to become responsible self-governing citizens, changing their behaviours for the wider benefit of the community.⁴⁰ This has been reinforced by the removal of Public Health England (PHE) as a national body leaving a potential national leadership void for local public health teams. A second example of lifestyle drift demonstrated in this study is the positioning of disease prevention in primary care. This medicalises disease risk and lifestyles, further emphasising the need for individuals to use their agency to prevent diabetes. This detracts attention away from the socioeconomic causes of disease (such as the obesogenic environment)^{45 56 57} and oversimplifies the complexity of diabetes development.²¹ Inherent in this strategy is the assumption that health inequalities are due to individual life choices, not the underlying social causes of disease.^{45 56} Subsequent individual health promotion messaging in lifestyle interventions promotes the belief that people should be able to overcome their structural barriers, making rational choices despite difficult living circumstances.^{45 56} Framing the responsibility of disease prevention in this way is believed by some academics to be an incredibly powerful industry tactic to deflect any responsibility for disease development, with the targeting of upstream influences (such as removing sugar subsidies) framed as excessive government involvement in people's everyday lives (the nanny state).^{58 59}

Implications for policy and practice

Our findings identified an unequal distribution of power and funding between the NHS and Public Health with regard to prevention policy. This study has shown that the scope of the NHS largely focuses on the individual. Two major health reforms are currently underway in England. CCGs (Clinical Commissioning Groups) are being transformed into integrated care systems (ICSs) with general practices organised into Primary Care Networks tasked with improving community health, prioritising disease

prevention and reducing health inequalities.⁶⁰ For the ICSs to fulfil their population health portfolios, it is vital they form partnerships and effective working relationships with local authorities and public health teams.⁶¹ There have been calls for greater partnerships and collaborations between the two communities for several years.^{62–64} The President of the Faculty of Public Health and Chair of the Royal College of General Practitioners recently published an editorial calling for meaningful collaboration and integration between the two specialities, despite examples of excellent partnerships, these are limited.⁶⁵ PHE has also been reorganised, with its health improvement functions moving to the Department of Health and Social Care with a new Office of Health Promotion and Disparities under the leadership of the CMO.⁶⁶ This may leave a void of national leadership advocating for reducing health inequalities and addressing the social determinants of health, with reduced support for local public health teams. There will always be a need for individual-level interventions based in primary care; however, to reduce the prevalence of conditions such as diabetes, these must be done in parallel with upstream population-level initiatives addressing the wider determinants of health.^{21 26 27 51 67}

Implications for research

This analysis has illustrated several research–policy gaps in disease prevention. Policy-makers did not feel that research considered their own sociopolitical contexts, emphasising that policy development was a messy, non-linear process taking place within a sociopolitical economic context. These views are supported by senior policy-makers who have written on the limitations of academic evidence.⁶⁸ The stakeholders discussed a need for increased partnerships between policy and academia to understand each other's needs, world views and operational constraints. Working together to coproduce from the outset of research to disseminating findings may help bridge translational research gaps. This approach aligns with Weiss's interactive model of research utilisation,⁹ but requires a shift away from the traditional hierarchy of biomedical research⁶⁹ with a greater focus on researching the social determinants of health instead of downstream individual-level interventions.^{70 71}

Comparison to the literature

While others have already examined the limitations of western health promotion strategies,^{42 72} the evidence–policy gap^{69 73} and the limitations of evidence-based medicine informing policy,⁷⁴ this is the first qualitative study undertaken to examine the policy process of operationalising a national directive into a local initiative from a policy-makers perspective, as well as trying to explain why individual-level policies dominate the policy agenda.

Our study resonates with the findings of other social and political scientists. Baum *et al* undertook a policy analysis examining why individual-level health promotion policies continue to be commissioned, despite a

failure to reduce disease inequalities and disease prevalence.⁴² They found that individual-level interventions are appealing to governments due to ideological and practical reasons and that political ideologies needed to be included more widely in research. Baum *et al* in a separate study undertook qualitative interviews of Australian primary care policy-makers, examining the primary care response to the social determinants of health.⁷⁵ They showed that primary care health workers saw their roles as advocates for individuals improving access to social services. Institutional scope and service demands acted as barriers to advocating for action on the wider determinants of health.

Maybin⁷⁶ undertook an ethnography of UK Department of Health and Social Care policy-makers. Powerful political actors, political priorities, relationships and trust determined what counted as knowledge in the policy process. Comparably, to our study, policy-makers used evidence symbolically to legitimise the decision-making process and funding.

Strengths and limitations

To our knowledge, this is the first analysis of diabetes prevention policies in the UK using a political science perspective. Other studies have focused on either the policy process⁶⁹ or the research–policy gap,^{73 74 77} but this is the first to examine both as part of the same social–political context to better reflect reality.

Our focus on a small number of interviewees means the findings are preliminary. There were no outlier opinions from the dataset which might have been ascertained from a larger sample size or if we had included policy-makers from different regions of the country. In addition, we may also have broadened the study to discuss the prevention of long-term conditions was more widely. A further limitation of the study is that most of the data was collected before COVID-19 and while we picked up on the way the pandemic amplified existing issues, we did not explicitly explore this in data collection/analysis.

CONCLUSION

This qualitative study of policy-maker perspectives on national diabetes prevention policies and their implementation has allowed us to better understand how policy decisions are made and why current policies are constructed in their present form. Current strategies align with a neoliberal high-risk disease prevention strategy, which focuses on individuals to take responsibility for their lifestyles and make changes to prevent disease. Although these policies work for some individuals to reduce their risk, continuing to perpetuate individual-level disease prevention strategies may widen health inequalities. Diabetes prevention policy sits at the intersection of public health and primary care. The advent of ICSs and primary care networks may offer an opportunity to focus on population-level drivers of disease as well as open up a new research agenda to bridge evidence–policy gaps.

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