Supporting healthful behaviour to manage type 2 diabetes in diverse UK Black African and Caribbean adults

Moore, Amanda

Awarding institution:
King's College London

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Supporting healthful behaviour to manage type 2 diabetes in diverse UK Black African and Caribbean adults

Amanda P Moore

A thesis submitted to King’s College London for the Degree of Doctor of Philosophy in the Faculty of Life Science and Medicine

Departments of Diabetes and Nutrition
King’s College London
June 2022
Dedication

For Patricia (1938 – 2019) and Paul (1941- 2016).
Acknowledgements

I would like to thank my supervisory team for their valued support and guidance. Thank you to my primary supervisor Dr Louise Goff for encouraging me to be the best I can be and for the chance to work on the HEAL-D study. It was an opportunity for which I will always be grateful. Thank you to Professor Carol Rivas for her mentorship and for her practical guidance in qualitative methodology. I also thank Professor Seeromanie Harding for the opportunities she has given me to share my work and for her authorship support. Thank you to the other academic members of my thesis progression committee for their constructive input and for the time they have spent ensuring the smooth running of the PhD process: Dr Paul Caton, Dr Amanda Amorim Adegboye and Professor Debra Bick.

For specific help to develop my expertise in working with these methods thank you to Dr Helen Scott for her grounded theory mentorship and to Dr Stephanie Stanton-Fay for her guidance in use of the COM-B and behaviour change wheel framework.

Thank you to the National Institute of Health Research South London CLAHRC for their funding support.

Finally, to my fellow PhD students, Olah Hakim, Toyosi Bello, Meera Ladwa and Nana Ocran, I could not have done this without you. Thank you for the friendship and encouragement.
Thesis Abstract

**Background:** Type 2 diabetes (T2D) is increasing in worldwide prevalence. In the UK there is a disproportionate burden of T2D amongst minority ethnicities; people of Black African or Caribbean heritage are up to three times more likely to develop T2D than the general population. It occurs at a younger age with poorer glycaemic control at diagnosis. The cornerstone of care is diabetes self-management. This involves making dietary changes, increasing moderate to vigorous physical activity, losing weight and taking medication as prescribed. People of Black ethnicity have been shown consistently to have poorer diabetes outcomes than White Europeans. Improving the cultural saliency of care and developing culturally tailored interventions to support diabetes self-management behaviour has been shown to improve outcomes, however, to date in the UK there have been no interventions specifically designed to support those of Black African and Caribbean ancestry. Engagement with medical care and diabetes self-management is influenced by sociocultural factors, such as health behaviour practices, health beliefs and health-related knowledge. Focusing on adults of Black African and Caribbean ancestry with T2D, this study aimed to: 1) understand the contextual sociocultural factors influencing diabetes self-management; 2) explore how these factors shape behaviour; and 3) identify potential intervention targets and associated evidence-based behaviour change techniques (BCTs) to develop theoretical understanding of how to support healthful behaviour in a culturally salient manner.

**Methods:** This study was nested within the HEAL-D mixed methods study and data were collected from 12 focus groups and 20 interviews (n=67). Each was audio-recorded and transcribed. Grounded theory methods were used to explore the interplay of influencing factors on self-management behaviour from the perspective of those living with diabetes. A behaviour change theoretical framework (COM-B and the behaviour change wheel) was then applied to the data to determine potentially helpful evidence-based BCTs.

**Results:** The novel theory *Integrating Perspectives* highlights that individuals experience misalignment between the lay and medical perspectives. Cultural identity,
biomedical knowledge and inter-relational trust with healthcare professionals influenced the extent of the misalignment and were key determinants of self-management behaviour. Individuals reconciled the two perspectives by information seeking and filtering out recommendations that conflicted with cultural identity to varying degrees. Four behaviour patterns were identified: Adaptation, Accommodation, Traditionalism and Detachment. The BCTs identified to address determinants of behaviour included demonstration, instruction, social support, and credible sources. Furthermore, involving community networks in supporting self-management showed potential for supporting the provision of culturally situated knowledge and social support.

**Conclusions:** This study adds to our theoretical understanding of how sociocultural factors shape diabetes self-management in UK Black African and Caribbean adults and how these factors may be leveraged to support self-management. Identification of evidence based BCTs to address these factors can inform the theoretical development of culturally tailored health promotion materials and interventions. These findings are likely to be of value to clinicians, health promotion designers and researchers in this field.
Publications & awards

Key publications:


Published abstracts


**Other publications:**


**Awards:**

- KCL Cultural Institute Early Career Researcher Funding for art and academic collaboration: for the project *Let’s Talk Sugar*: raising awareness of Type 2 diabetes amongst Black African and Caribbean teenagers in Hackney (2016)
- KCL Cultural Institute Early Career Researcher: First Prize for the *Let’s Talk Sugar* initiative (2016)
- Nutrition Society Best Oral Contribution: Student Prize (2017)
- NIHR South London CLAHRC: PhD Fee support
Statement of contribution

The data used in this thesis were collected by the author within the HEAL-D study (Healthy Eating and Active Lifestyles for Diabetes). The HEAL-D study was conceptualised by Dr Louise Goff and funded by an NIHR Career Development Fellowship for Dr Goff.

The qualitative data were collected by the author at two time points during the HEAL-D study. This was the intention from the commencement of the study so that the topic guides were designed to support data collection for the PhD, while also being congruent with HEAL-D objectives. The author was responsible for writing the HEAL-D study protocol and applying for ethics approval, recruiting participants, focus group and interview organisation and devising the topic guides. Eight initial focus groups were co-facilitated by the author and Dr Goff. The subsequent four focus groups and twenty interviews were conducted by the author solely. Subsequent analysis using grounded theory methods and the application of a theoretical behaviour change framework was conceptualised and carried out by the author. The COM-B analysis was later adopted to inform the HEAL-D intervention design. The analysis presented in this thesis is a wider analysis than required for HEAL-D (includes more behaviours) and the subsequent BCT evaluation has been specifically conducted for this thesis.

To support the development of this thesis, four key areas of training were obtained through the course of the PhD studentship. The Science of Behaviour change (1 week, UCL); Qualitative Methods (1 week, University of Oxford); Designing Complex Interventions (1 week, University of Cardiff); Grounded theory (2 days, Consultant Dr Helen Scott).

This thesis is the work of the author under the supervision of Dr Louise Goff and Professor Carol Rivas.
Contents

SECTION 1: INTRODUCTION......................................................... 22

1.1 Thesis overview...................................................................... 22
  1.1.1 Thesis scope.................................................................. 22
  1.1.2 Thesis organisation ..................................................... 23
  1.1.3 Definitions .................................................................. 24

1.2 Background .......................................................................... 31
  1.2.1 Type 2 diabetes.............................................................. 31
  1.2.2 Type 2 diabetes in people of Black ethnicity .................. 34
  1.2.3 Summary ................................................................... 45

1.3 Supporting diabetes-related health behaviour in Black African and Caribbean adults 46
  1.3.1 Culturally tailored interventions to support behaviour change .......... 46
  1.3.2 Framing exploration of sociocultural influences on health behaviour to improve cultural salience of care ................................................................. 50
  1.3.3 Self-management in Black African and Caribbean adults living in high income countries outside the UK ................................................................. 55
  1.3.4 A UK perspective on diabetes self-management in Black African and Caribbean adults ........................................................................................................ 62

1.4 Conclusions, rationale and aims for this study ......................... 76
  1.4.1 Conclusions from the literature ....................................... 76
  1.4.2 Study aims & objectives .................................................. 78

SECTION 2: METHODOLOGY & METHODS..................................... 80

2.1 Methodology ......................................................................... 82
  2.1.1 Statement of positionality .............................................. 82
  2.1.2 Situating the research ................................................... 83
  2.1.3 Research design ............................................................ 85
### 2.1 Theoretical framework

- Consideration of research methods
- Summary

### 2.2 Methods

- Participants and setting
- Ethical and regulatory considerations
- Data collection procedures
- Data handling and cleaning
- Quality and rigour
- Reflexivity
- Data analysis
- Reporting of data in this thesis
- Summary

### 3.1 The participants and the setting

- Demographics
- The setting

### 3.2 The social context

- Introduction
- Challenges of migration
- Barriers associated with roles and responsibilities
- Financial insecurity and other challenges
- Health and spirituality
- Connecting to others
- Discussion
- Summary

### 3.3 Perspectives on diabetes: a cultural picture

- Introduction
<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Pages</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.3.2</td>
<td>Overview of the category</td>
<td>152</td>
</tr>
<tr>
<td>3.3.3</td>
<td>Constructing knowledge</td>
<td>152</td>
</tr>
<tr>
<td>3.3.4</td>
<td>Belonging</td>
<td>161</td>
</tr>
<tr>
<td>3.3.5</td>
<td>Agency (a modifying influence)</td>
<td>168</td>
</tr>
<tr>
<td>3.3.6</td>
<td>Acculturation (a modifying influence)</td>
<td>169</td>
</tr>
<tr>
<td>3.3.7</td>
<td>Discussion</td>
<td>170</td>
</tr>
<tr>
<td>3.3.8</td>
<td>Summary</td>
<td>177</td>
</tr>
<tr>
<td>3.4</td>
<td>Integrating Perspectives: a grounded theory of self-management behaviour</td>
<td>178</td>
</tr>
<tr>
<td>3.4.1</td>
<td>Introduction</td>
<td>178</td>
</tr>
<tr>
<td>3.4.2</td>
<td>Misalignment – the challenge for individuals living with diabetes</td>
<td>179</td>
</tr>
<tr>
<td>3.4.3</td>
<td>The integration of competing perspectives for self-management</td>
<td>187</td>
</tr>
<tr>
<td>3.4.4</td>
<td>Self-manager typologies and patterns of behaviour</td>
<td>197</td>
</tr>
<tr>
<td>3.4.5</td>
<td>Discussion</td>
<td>207</td>
</tr>
<tr>
<td>3.4.6</td>
<td>Summary</td>
<td>219</td>
</tr>
<tr>
<td>3.5</td>
<td>Supporting healthful behaviour change for diabetes self-management</td>
<td>220</td>
</tr>
<tr>
<td>3.5.1</td>
<td>Introduction</td>
<td>220</td>
</tr>
<tr>
<td>3.5.2</td>
<td>The data and methods for this chapter</td>
<td>221</td>
</tr>
<tr>
<td>3.5.3</td>
<td>Understanding the behaviour</td>
<td>221</td>
</tr>
<tr>
<td>3.5.4</td>
<td>Identifying intervention functions and BCTs</td>
<td>238</td>
</tr>
<tr>
<td>3.5.5</td>
<td>Developing culturally salient interventions</td>
<td>241</td>
</tr>
<tr>
<td>3.5.6</td>
<td>Reflecting on what works in a real-world setting</td>
<td>243</td>
</tr>
<tr>
<td>3.5.7</td>
<td>Discussion</td>
<td>252</td>
</tr>
<tr>
<td>3.5.8</td>
<td>Summary</td>
<td>255</td>
</tr>
<tr>
<td>4.1</td>
<td>Principal findings</td>
<td>259</td>
</tr>
<tr>
<td>4.1.1</td>
<td>Summary of the importance of the collective findings</td>
<td>259</td>
</tr>
<tr>
<td>4.1.2</td>
<td>Understanding sociocultural factors influencing self-management behaviour</td>
<td>260</td>
</tr>
</tbody>
</table>
4.1.3 Theorising the self-management experience ........................................... 261
4.1.4 Supporting behaviour change in a theoretically informed way ............ 262
4.1.5 Scholarly contribution ............................................................................. 263

4.2 Discussion of results .................................................................................. 265
4.2.1 Understanding intersectionalities for improving intervention targeting. 265
4.2.2 Determinants of behaviour and relevance within the typologies .......... 268
4.2.3 Leveraging cultural assets and experiences to improve saliency and outcomes ........................................................................................................ 278
4.2.4 Trust and the therapeutic alliance ............................................................ 281
4.2.5 Exploring the findings in the context of current literature .................... 285
4.2.6 Summary .................................................................................................. 289

4.3 Reflecting on the methods ........................................................................ 289
4.3.1 My choice and combination of methodologies ....................................... 289
4.3.2 Engaging communities in the research process ..................................... 294
4.3.3 Quality and rigour .................................................................................... 296
4.3.4 Representativeness of the sample ............................................................. 297
4.3.5 Challenges & limitations ........................................................................ 298

4.4 Conclusions ................................................................................................. 301
4.4.1 What are the implications of the findings? ............................................. 301
4.4.2 Future research ......................................................................................... 304
4.4.3 Dissemination plans ................................................................................ 305

4.5 General conclusion ..................................................................................... 306

SECTION 5: REFERENCE LIST ......................................................................... 307

SECTION 6: APPENDICES .............................................................................. 338

6.1 Key studies ................................................................................................ 338
6.2 Theoretical models .................................................................................... 339
6.3 Study sample characteristics ................................................................. 340
6.4 Behavioural analysis ............................................................................ 347
6.5 The lens of intersectionality ................................................................. 352
Figures

Figure 1-1: Acculturation strategies. Modified from (Berry and Sam, 1997) ............... 28
Figure 1-2: Age-adjusted comparative prevalence of diabetes in adults (20-79 years), by region (International Diabetes Federation, Diabetes Atlas 9th edition 2019) ............... 31
Figure 1-3: Person-centred care – image modified from Hudon et al., 2011 .......... 33
Figure 1-4: Population of England & Wales by ethnicity, excluding White British (Office for National Statistics, 2011) ................................................................. 35
Figure 1-5: Prevalence of doctor diagnosed type 2 diabetes in Black African and Black Caribbean adults. Data from Health Survey for England 2006 (Harrison, 2014) .......... 36
Figure 1-6: Age distribution of patients with diagnosed diabetes stratified by ethnicity in UK (data from Paul et al. 2017) ................................................................. 37
Figure 1-7: Prevalence of hypertension, coronary heart disease and stroke by ethnicity (data from primary care databases in Lambeth) (Schofield et al., 2011) ............... 37
Figure 1-8: Prevalence of obesity across different ethnicities in the UK. (Data adapted from Gatineau and Mathrani, 2011) ................................................................. 38
Figure 1-9: Framework to identify culturally tailored strategies (modified from Kreuter et al., 2003) ..................................................................................................... 47
Figure 1-10: Surface and deep structures in designing culturally salient interventions. Modified from Resnicow et al. 1999. ................................................................. 53
Figure 1-11: Increasing prevalence of diabetes and obesity comparing rural and urban settings in Ghana with Europe (n=5659) (Agyemang et al., 2016) ....................... 66
Figure 2-1: HEAL-D study design. Qualitative patient data were collected in phase I (8 focus groups) and Phase II (4 focus groups and 20 interviews). ....................... 81
Figure 2-2: Research design overview ..................................................................... 86
Figure 2-3: Capability, Opportunity, Motivation, and the influence on behaviour (COM-B). Modified from Michie et al., (2014) .............................................................. 91
Figure 2-4: Recruitment to focus groups and interviews ....................................... 93
Figure 2-5: Timeline for each phase of the study .................................................. 96
Figure 2-6: Schematic to illustrate the conceptual development of the qualitative analysis. Modified from Saldana (2016). ................................................................. 107
Figure 2-7: Illustration of “struggling” as the sub-codes developed ..................... 108
Figure 2-8: Example excerpt from a memo ......................................................... 109
Figure 2-9: The concept-indicator approach ....................................................... 110
Figure 2-10: The process for understanding behaviours and choosing behaviour change techniques ................................................................. 114
Figure 2-11: The theoretical domains framework. Modified from Squires et al. (2014) ................................................................. 116
Figure 2-12: Matrix linking intervention functions to COM-B domains .................................. 117
Figure 3-1: Overview of the structure of the presentation of findings ................................. 120
Figure 3-2: Overview of the categories from the grounded theory analysis .................. 121
Figure 3-3: Diverse ethnic make-up of the Boroughs (Source: ONS) (Office for National Statistics, 2018) ........................................................................................................ 126
Figure 3-4: Wider contextual influences on health and diabetes care ............................. 129
Figure 3-5: Schematic illustration of the category **Attaching to traditions** and its dimensions **Constructing knowledge and Belonging** .................................................. 152
Figure 3-6: Perceived external causes of diabetes - participant quotes .......................... 156
Figure 3-7: There were a diversity of views linking weight to diabetes - participant quotes .................................................................................................................. 157
Figure 3-8: Dietary traditions described as central to cultural identity – participant quotes .................................................................................................................. 162
Figure 3-9: Traditional views about larger body sizes - participant quotes........................ 165
Figure 3-10: Stigma and culpability - participant quotes .................................................. 166
Figure 3-11: Perceiving social judgement - participant quotes .......................................... 168
Figure 3-12: The dimensions of cognitive illness representations. Modified from Quandt et al., 2013 .................................................................................................................................................. 172
Figure 3-13: Schematic illustration of where explanatory models of illness deviated from biomedical understanding ................................................................. 173
Figure 3-14: Diabetes advice was perceived to conflict with valued habits and beliefs creating a tug of war between supporting your health and conforming to norms .... 180
Figure 3-15: Lack of cultural sensitivity in advice reduced the opportunity to change habits .................................................................................................................................. 182
Figure 3-16: Knowledge gaps - illustrative quotes .............................................................. 183
Figure 3-17: Data illustrating expectations of care were not always met ........................ 184
Figure 3-18: Schematic illustrating the concept of misalignment ...................................... 186
Figure 3-19: Integrating perspectives: a theory to explain diabetes self-management behaviour in individuals of Black African and Caribbean heritage in the UK ........... 189
Figure 3-20: Schematic to illustrate absorbing ................................................................. 190
Figure 3-21: Schematic to illustrate facilitating knowledge ............................................. 191
Figure 3-22: Schematic to illustrate reconciling ............................................................... 192
Figure 3-23: Schematic diagram illustrating the concept of trust as evidenced from the data ................................................................................................................................. 194
Figure 3-24: "Having Faith" - illustrative quotes................................................................. 195
Figure 3-25: “Bonding” - Illustrative quotes ........................................................................ 196
Figure 3-26: Behaviour typologies - distinguished by propensity to trust and degree of
cultural affiliation. ......................................................................................................................... 197
Figure 3-27: Schematic to illustrate how self-management behaviour for type 2
diabetes varied by typology ........................................................................................................ 199
Figure 3-28: Reframing shifts – a change in risk perception or healthcare knowledge
influences cognitive trust and a reframing shift so an individual may change typology.
................................................................................................................................................... 205
Figure 3-29: Summary of how each type proceeds through the process of Integrating
Perspectives (HC – healthcare) ..................................................................................................... 206
Figure 3-30: Kleinman’s Explanatory Model. Modified from Kleinman (1978) ............ 210
Figure 3-31: COM-B framework showing domains with barriers for each behaviour 223
Figure 3-32: Linking COM-B domains to intervention functions and key associated
BCTs. Modified from Moore et al., 2019. .................................................................................. 239
Figure 3-33: Schematic to illustrate example of mapping of theoretical mechanism of
behaviour change ............................................................................................................................ 240
Figure 3-34: Density of coding by BCT (by participant; dark = heaviest coding) ....... 246
Figure 3-35: Key differentiating determinants between typologies ........................................ 251
Figure 4-1 Comparing behaviour determinant-identification across methodologies . 269
Figure 4-2: Summary of theoretical constructs influencing key determinants of
behaviour and associated behaviour change techniques identified ............................................ 272
Figure 4-3: Modified from de Graft et al., to explain cognitive polyphasia and
developments in health knowledge (de Graft et al., 2019) ......................................................... 274
Figure 6-1: Theory of Planned Behaviour. Modified from Ajzen (2011) ...................... 339
Figure 6-2: The common-sense model. Modified from Leventhal et al., (1992) .......... 339
Tables

Table 1-1: Evidence based lifestyle guidance for type 2 diabetes in the UK (Diabetes UK, 2018, National Institute for Clinical Excellence, 2020) ........................................ 32
Table 1-2: Results of meta-analysis showing sustained improvement in HbA1c in culturally adapted diabetes education (Creamer et al., 2016) ........................................ 44
Table 1-3: Frameworks to explore cultural influences on health behaviour to improve cultural salience .......................................................... 51
Table 1-4: Core cultural constructs associated with African American culture (Resnicow et al., 1999) .................................................................................. 54
Table 2-1: Key phases of Grounded Theory and associated coding terminology (Chun Tie et al., 2019) .......................................................... 88
Table 2-2: Recruitment ........................................................................................................ 94
Table 2-3: Eligibility criteria .......................................................................................... 94
Table 2-4: Summary of topic guides .......................................................................... 100
Table 2-5: Establishing trustworthiness in qualitative research ........................................ 101
Table 2-6: Definitions of ethnocentrism ........................................................................ 105
Table 2-7: Initial categories from the open-coding phase of analysis .......................... 110
Table 2-8: Spradley's semantic relationships (Spradley, 1979) .................................... 111
Table 2-9: The APEASE criteria. Adapted from Michie et al. (Michie et al., 2011b) .... 117
Table 3-1: Characteristics of participants (full data set n = 67) ...................................... 123
Table 3-2: Distribution of participants by country of birth ........................................... 124
Table 3-3: Description of the coping styles evident in the data .................................... 168
Table 3-4: Properties of the self-managers .................................................................. 198
Table 3-5: Characteristics shaping each type ......................................................... 198
Table 3-6: Vignette to illustrate how the Traditionalist integrates perspectives ......... 200
Table 3-7: Vignette to illustrate how the Accommodator integrates perspectives ....... 202
Table 3-8: Vignette to illustrate how the Adapter integrates perspectives ................. 203
Table 3-9: Managing misalignment between healthcare and patient perspectives (Kleinman, 1980) .......................................................... 210
Table 3-10: Dimensions of trust relevant to the healthcare engagement ..................... 211
Table 3-11: Different types of verbal communication in the healthcare interaction. Modified from Beck et al., 2002 and Ong et al., 1995 ....................... 214
Table 3-12: Identified target behaviours ................................................................. 222
Table 3-13: Description of the HEAL-D intervention components to support each BCT identified. Modified from (Moore et al., 2019). ................................................................. 242
Table 3-14: Quotations relevant to BCTS to increase knowledge and skills.............. 247
Table 3-15: Quotations relevant to Social BCTs to persuade and educate ............ 248
Table 3-16: Quotations relevant to improve self-efficacy and behavioural regulation 249
Table 3-17: Quotations describing behaviour and self-efficacy changes and improved outcomes based real-world evaluation of BCTs ......................................................... 250
Table 3-18: Summary of COM-B findings for each behaviour ................................. 256
Table 3-19: Summary of intervention functions and BCTs suggested to support each behaviour identified ................................................................. 258
Table 4-1: Consensus opinion on key determinants of health behaviour (modified from (Bartholomew et al., 2016)) ................................................................. 269
Table 6-1: Studies exploring diabetes self-management practices and perceptions in UK Black African and Caribbean adults ................................................................. 338
Table 6-2: Participant characteristics (Focus group 1 dataset n = 41) ..................... 340
Table 6-3: Participant characteristics (Interview dataset n = 20) ......................... 341
Table 6-4: Participant characteristics (focus groups Phase II n = 20) .................. 342
Table 6-5: Details of individual participants including the unique identifier .......... 343
Table 6-6: BCT mapping for daily medication...................................................... 347
Table 6-7: BCT mapping for MVPA x 30mins /pd ............................................. 348
Table 6-8: BCT mapping for dietary change ...................................................... 349
Table 6-9: BCT mapping for measuring waist circumference ............................ 350
Table 6-10: Detailed description of potential BCTs ............................................ 351
Table 6-11: Intersectionality framework.......................................................... 352
### Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AfC</td>
<td>Afro-Caribbean</td>
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<tr>
<td>BA</td>
<td>Black African</td>
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<td>BC</td>
<td>Black Caribbean</td>
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<td>BCTs</td>
<td>Behaviour change techniques</td>
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<td>BMI</td>
<td>Body Mass Index</td>
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<tr>
<td>CVD</td>
<td>Cardiovascular disease</td>
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<tr>
<td>DSME</td>
<td>Diabetes self-management education</td>
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<tr>
<td>GI</td>
<td>Glycaemic index</td>
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<tr>
<td>HbA1C</td>
<td>Glycosylated haemoglobin.</td>
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<tr>
<td>HDL</td>
<td>High density lipoprotein</td>
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<tr>
<td>HEAL-D</td>
<td>Healthy Eating and Active Lifestyles for Diabetes</td>
</tr>
<tr>
<td>HIC</td>
<td>High income countries</td>
</tr>
<tr>
<td>IMD</td>
<td>Index of multiple deprivation</td>
</tr>
<tr>
<td>LDL</td>
<td>Low density lipoprotein</td>
</tr>
<tr>
<td>MRC</td>
<td>Medical Research Council</td>
</tr>
<tr>
<td>MVPA</td>
<td>Moderate to vigorous physical activity</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health service</td>
</tr>
<tr>
<td>NICE</td>
<td>National Institute for Health and Care Excellence</td>
</tr>
<tr>
<td>PHE</td>
<td>Public Health England</td>
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<tr>
<td>RCT</td>
<td>Randomised controlled trial</td>
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<tr>
<td>T2D</td>
<td>Type 2 diabetes mellitus</td>
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<tr>
<td>QOF</td>
<td>Quality and Outcomes Framework</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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<tr>
<td>WHR</td>
<td>Waist to hip ratio</td>
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</tbody>
</table>
The language used in this thesis to describe people living with diabetes and the management of their condition follows, where possible, the Language Matters NHS guidance for diabetes. This guidance suggests language should be inclusive and avoid stigmatising the condition. Where possible therefore, use of words such as “compliant”, “sufferer”, “diabetic” and “patient” are minimised (NHS England, 2018).
SECTION 1: INTRODUCTION

In this section I introduce my thesis and describe the background and rationale for the study in the context of the current literature. This section concludes with a statement of my aims and objectives for this study.

1.1 Thesis overview

1.1.1 Thesis scope

Type 2 diabetes (T2D) is increasing in worldwide prevalence and in the UK there is a disproportionate burden of T2D amongst minority ethnicities (Meeks et al., 2016). In the UK, people of Black African or Caribbean heritage are up to three times more likely to develop T2D than the general population (Health Survey for England, 2006). In those of Black ethnicity compared to White, T2D occurs at a considerably younger age (Paul et al., 2017) with poorer glycaemic control at diagnosis (Winkley et al., 2013). The cornerstone of care for diabetes is self-management. This involves making dietary changes to reduce carbohydrate load, engaging in regular moderate to vigorous physical activity, losing weight for those above a normal BMI and taking medication as prescribed, with the goal of maintaining an acceptable level of blood glucose control. People of Black ethnicity have been shown consistently to have poorer diabetes outcomes than White Europeans (Alloh et al., 2019a, James et al., 2012, Whyte et al., 2019). Improving the cultural saliency of care and developing culturally tailored interventions to support diabetes self-management behaviour has been shown to improve outcomes, however, to date in the UK there have been no interventions specifically designed to support those of Black African and Caribbean ancestry (Creamer et al., 2016, Wadi et al., 2021).

It is increasingly recognised that self-management behaviour for T2D occurs in the social context, influenced by social and cultural factors (Napier et al., 2014). Understanding how these factors influence health behaviour is an important step in
understanding how best to support people of different ethnicities. Furthermore, this theoretical understanding can be used to explicitly underpin and inform intervention design (National Institute for Clinical Excellence, 2007, Abraham et al., 2009, Craig et al., 2008). There is paucity of relevant data to understand the sociocultural influences on diabetes-related health behaviour amongst UK Black African and Caribbean adults and their perspectives on care to support self-management.

My study aims to understand and describe the social and cultural factors influencing engagement in type 2 diabetes self-management behaviours in UK African and Caribbean adults and explore the theoretical basis upon which positive behaviour can be encouraged in a culturally salient manner. This is achieved by using grounded theory methods to explore the lived experience of T2D to understand the factors influencing self-management behaviour. A theoretical behaviour change framework is then used to identify potential intervention targets to inform the theoretical basis upon which positive behaviour can be supported.

1.1.2 Thesis organisation

This thesis is organised into four sections.

Section one is the introductory section which gives background to this study and comprises a review of the existing literature shaping current understanding of diabetes related health behaviour and the cultural factors which influence it within Black African and Caribbean communities. Section one concludes with the rationale and aims and objectives for this study.

Section two presents the methodology and the methods.

Section three is the findings section of the thesis. The findings are summarised in two parts. Part one (Chapters 3.2, 3.3 and 3.4) presents the results of the grounded theory analysis and introduces a novel grounded theory Integrating Perspectives. Part two (Chapter 3.5) presents the behavioural analysis to determine potential behaviour change techniques which may be helpful to support positive diabetes related health behaviour for this study population.
Section four summarises and critically discusses the findings and considers their relevance.

1.1.3 Definitions

1.1.3.1 Culture

There is a plethora of definitions of culture. The definition below reflects how I have used the term in this thesis:

“The totality of socially transmitted behaviour patterns, arts, beliefs, values, customs, lifeways and all other products of human work and thought characteristics of a population that guide their world view and decision making. These patterns may be explicit or implicit, are primarily learned and transmitted within the family, are shared by most members of the culture and are emergent phenomena that change in response to global phenomena.” (Purnell, 2002)

It is important to stress the dynamic, fluid nature of culture; as succinctly put by sociologist John Scott, “cultural meanings mutate” (Scott, 2011). Cultural influences are strong and important determinants of health behaviour, particularly in first generation immigrants (Napier et al., 2014), but this effect is likely to be reduced in successive generations (Bhopal, 2014). If culture is treated as something which is static and universal it can lead to stereotyping, so I have tried in this thesis to identify cultural influence but also explore the heterogeneity and the factors which shape it. Additionally, a more recent definition of culture by the World Health Organisation (WHO) stresses that examining our own culture and the perceptions which frame the provision of health care, is equally important in supporting the provision of equitable care:

“Culture is not limited to national, racial, ethnic or religious affiliation – it is comprised of overt beliefs and practices as well as the subtle and taken-for-granted conventions that frame our sense of reality.” WHO (Napier et al., 2017)

1.1.3.2 Ethnicity, race and intersectionality

The complexity of defining concepts such as race and ethnicity, is partly a consequence of the fact that these are socially constructed terms – sometimes these terms are used almost interchangeably, and sometimes they are strongly differentiated.

From my perspective, I define ethnicity broadly as:
“A multifaceted quality that refers to the group to which people belong and/or are perceived to belong as a result of certain shared characteristics, including geographical and ancestral origins, but with particular emphasis on cultural traditions and languages. The characteristics that underpin ethnicity are not fixed or easily measured, so ethnicity is a complex and fluid concept. While group allegiance is mainly dependent on culture it also encompasses physical features, particularly facial features as in race.” (Bhopal, 2014)

Ethnicity implies shared origins or social background and shared distinctive social identity, or “group-ness”, created by shared cultural traditions that are perpetuated between generations and sometimes a common language. Dimensions can also include, country of birth, colour, national identity, citizenship and religion (Gatineau and Mathrani, 2011). Importantly, part of ethnicity concerns self-identity, which may change over time. Stephens describes ethnicity in the modern era as, a “term for collective cultural identity […] shared values and beliefs, a self-definition of a group “us” (Spencer, 2014). Spencer goes on to distinguish ethnicity as socially defined but on the basis of cultural criteria, whereas race is socially defined but on the basis of physical criteria.

The discourse over race as a concept has evolved considerably over time but has its origins in biological classification – physical characteristics and features — and was intrinsically linked, historically, with concepts of intelligence and civilisation (Bhopal, 2014). As such the term race can carry negative connotations. It is underpinned by characteristics that are static, whilst those underpinning ethnicity are fluid and not easily measured. Overtime, as definitions of race have evolved to encompass social and cultural factors (Hall, 1992, Goldberg, 1992), the lines between the concepts of ethnicity and race have blurred. In this thesis I prefer to use the term ethnicity, though I do recognise reification\(^1\) in use of the term as a means of categorisation, is straying to a degree from the social construction of the term.

In fact, there is no simple way to group individuals in health research. In a globally migrating world ethnicities are highly dynamic; individuals from the same shared background may self-identify their ethnicity differently as allegiances change, making it virtually impossible to create well-defined mutually exclusive ethnic categories (Martin Burton et al., 2017). Many individuals emigrating from Africa to the UK, choose to use

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the term, Black British for example. UK Black African and Caribbean communities are diverse, originating from many different countries, speaking many languages, and holding different dietary traditions and religious beliefs. Further diversity is influenced by social class and generational status. In this study participants were categorised as of Black African or Black Caribbean ethnicity, according to their self-identification and/or country of birth as being on the African continent or within the West Indian islands in the Caribbean. This classification helps broadly inform the findings but is pragmatic and I recognise that it does simplify the heterogeneity within the study population. Ethnicity may intersect with other overlapping influences to influence inequalities. The term intersectionality refers to the theory that ethnicity, gender, class or any other characteristic that places an individual as a minority, may intersect to compound inequities (Carbado et al., 2013).

1.1.3.3 Cultural affiliation, social and ethnic identity

In this thesis I use cultural affiliation as a descriptor of the extent to which the social identity of the individual is bound with community cultural values and traditions. Cultural affiliation is important because of the recognition of the fundamental role culture plays in health and health behaviour (Napier et al., 2017). It is not exposure to cultural habits and traditions alone that influences health choices but the desire to identify with the normative influences of the “in group” (Guendelman et al., 2011). Social identity is a person’s knowledge or belief that he or she belongs to a social category or group (Abrams and Hogg, 1990). This concept of belonging to a community is strongly associated with the idea of cultural affiliation and social identity. Social identity theorists such as Cohen, suggest that this recognition of a “sense of us” in a community is a symbolic construction but nevertheless creates an important sense of belonging - “a mask of similarity which we can all wear, an umbrella under which we can all shelter” (Cohen, 1982). With minority ethnic communities this social or self-identity overlaps with ethnic identity when ethnicity is one of the factors associated

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2 Ethnic identity - “the extent to which individuals gravitate towards their ethnic group psychologically and socially”. The term encompasses “ethnic pride, affinity for in group culture, attitudes towards majority culture, involvement
with group identity (Resnicow et al., 1999). The social group is defined as a set of
individuals who view themselves as holding common identities (Stets and Burke,
2000). Factors framing a social group include beliefs, attitudes, values, behavioural
norms, styles of speech, associated history and traditions, together with any other
factors which members of the group believe relevant to the categorisation of their
social group. Racial, cultural and ethnic identities are all part one’s identity and identity
can shift with development at a personal level as well as with migration and
acculturation (Bhugra and Becker, 2005). It is suggested how closely you view yourself
as a part of a group, your self-identity, and your desire for ingroup membership, will
influence how strongly social norms exert influence on behaviour (Terry et al., 1999).

1.1.3.4 Acculturation and assimilation

Acculturation describes a process of change (cultural and psychological) which occurs
as a result of contact between two or more cultural groups and their individual
members (Berry, 2015). The classic definition of acculturation is that of Redfield, Linton
and Herskovitz:

“Acculturation comprehends those phenomena which result when groups of individuals
having different cultures come into continuous first-hand contact with subsequent changes in
the original culture patterns of either or both groups.” (Redfield et al., 1936)

Implicit in the common use of the word in health literature, is the assumption that the
health behaviour of the minority group is moving towards that of the majority
population, which is not always the case. For that reason, I focus on the more recent
expressions of acculturation as a bidimensional term (Ryder et al., 2000, Phinney et al.,
2001). Furthermore, acculturation strategies vary considerably within any one
community depending on personal characteristics, generational status and migration
status (Berry and Sam, 1996). Berry identifies four acculturation strategies amongst
individuals within a minority community - assimilation, integration, separation and
marginalisation. This reflects two dimensions of influence – cultural maintenance: the
degree to which cultural identity and characteristics are considered important and
their maintenance strived for and contact and participation: the extent to which individuals want to become involved in other cultural groups and to what extent they wish to remain separate (Berry and Sam, 1997) (Figure 1-1). Of the four strategies it is only assimilation in which the minority community habits shift to become more streamlined with the majority population.

![Acculturation strategies](image)

**Assimilation** – Individuals do not wish to retain cultural identity and seek daily interaction with the dominant culture.

**Separation** – Individuals want to retain cultural identity and wishes to avoid interaction with the dominant culture.

**Integration** – Interest in maintaining own cultural identity but also interacting with other cultures;

**Marginalisation** – Little cultural maintenance but also little interest in interacting with the dominant culture.

Figure 1-1: Acculturation strategies. Modified from (Berry and Sam, 1997)

I therefore use the term acculturation generally to describe the phenomenon of cultural shifts in either majority or minority community as defined by Redfield and assimilation to identify cultural shifts of minority group behaviours towards the majority as defined by Berry and Sam (1997).

Enculturation is an allied term and can be described as the process whereby an individual learns the traditional content of a culture and assimilates its practices and values (Tan, 2014).

**1.1.3.5 Medical, biopsychosocial and alternative models of healthcare**

I use the term medical model and biopsychosocial model when referring to the dominant paradigms governing approaches to healthcare in the UK. The medical model has been defined as:

“A model of health which suggests that disease is detected and identified through a systematic process of observation, description, and differentiation, in accordance with standard...”
accepted procedures, such as medical examinations, tests, or a set of symptom descriptions.” (Swaine, 2011)

In 2018 the BMJ reported on the continued dominance of the medical model within the NHS, despite acknowledged shortcomings (Iacobucci, 2018). Identified challenges with this model include a narrow focus on the biological determinants of illness – “seeing every symptom as a medical problem” – and that it ignores social and psychological influences (Iacobucci, 2018). In addition, it is criticised for failure to empower patients, treating biological and psychological influences separately and a focus on impairment rather than health (Swaine, 2011). Increasingly, there has been a recognition that a wider inclusion of psychosocial factors is warranted (Farre and Rapley, 2017):

“The biopsychosocial model views health and illness behaviours as products of biological characteristics (such as genes), behavioural factors (such as lifestyle, stress, and health beliefs), and social conditions (such as cultural influences, family relationships, and social support).” (Farre and Rapley, 2017)

The biopsychosocial model which considers these other influences is now favoured within the NHS as it moves towards a patient-centred health strategy (Royal College of General Practitioners, 2021). However, biomedicine and a focus on physiology are still central to both these approaches (Farre and Rapley, 2017).

In contrast to the biomedical approaches, other cultures do not necessarily place disordered physiology centrally in their explanatory models of illness and healing modalities. Looking beyond the western paradigm, Airhihenbuwa highlights how health beliefs of different cultures are manifestations of situated reality in these cultures. He highlights a range of culturally situated explanatory models where illnesses are, for example, considered a result of hot-cold imbalances, the dislocation of internal organs, impure blood, moral transgression and human relation to the spirit world. These are all valid constructions of illness in particular cultures (Airhihenbuwa, 1995). I refer to cultural, traditional or lay models of illness in my writing to distinguish between biomedical-focused models and these other explanatory models of health.
1.1.3.6 Immigrant

Guided by the definition from the Migration Observatory, I use the term immigrant to mean individuals defined by foreign birth (1st generation) and children who are UK born or are UK nationals but whose parents are foreign-born nationals (2nd generation) (The Migration Observatory, 2019).

1.1.3.7 High income countries

I use the World Bank definition of high-income countries as those where the gross national income per capita exceeds $12,056. This includes the US, Canada, Australia, Europe and selected Asian countries.
1.2 Background

1.2.1 Type 2 diabetes

1.2.1.1 The scale of the challenge of type 2 diabetes worldwide

Type 2 diabetes (T2D) is a major health priority worldwide. There are approximately 463 million adults living with diabetes around the world, half of whom have not been diagnosed. It is estimated that 11.3% of deaths globally are attributable to diabetes, almost 50% of which are in people under the age of 60 (Saeedi et al., 2019). Africa and the Caribbean present a specific challenge as the prevalence is rising rapidly with increased urbanisation and obesity. This is particularly the case for Africa where prevalence is predicted to rise as much as 143% by 2045 in urban areas. The prevalence of diagnosed T2D across geographic regions is shown below in Figure 1-2.

In Caribbean countries the prevalence of diagnosed diabetes is higher (up to 13.4% in Barbados) than reported in Africa (4.7%), with trends for significant increase by 2045 in both countries. There is also a high level of undiagnosed diabetes in African and Caribbean regions of up to 70% (Saeedi et al., 2019).

Figure 1-2: Age-adjusted comparative prevalence of diabetes in adults (20-79 years), by region (International Diabetes Federation, Diabetes Atlas 9th edition 2019)
1.2.1.2 Type 2 diabetes in the UK context

In the UK 1 in every 14 people have diabetes, equating to more than 4.8 million people. Every week diabetes leads to 185 amputations and more than 700 people dying prematurely. The cost to the NHS of diabetes is estimated to be £9.8 billion per annum (Diabetes UK, 2021a). UK minority ethnic communities carry a disproportionate burden of T2D, with a prevalence three to five times higher than amongst the general population (Goff, 2019).

**Diabetes self-management**

Diabetes self-management, the cornerstone of care, can be defined as the active participation of patients in their treatment (van Smoorenburg et al., 2019). Self-management involves behavioural management: adherence to dietary and physical activity advice, engagement with weight control and following an appropriate medication regimen, and emotional management to deal with the psychosocial consequences of the condition (van Smoorenburg et al., 2019). Changes to diet, physical activity and weight can improve HbA1c, as well as reducing BMI, blood pressure and cardiovascular risk all of which contribute to diabetes complications (Chen et al., 2015). The details of the evidence-based lifestyle guidance fundamental to diabetes self-management in the UK, are shown in Table 1-1.

**Table 1-1: Evidence based lifestyle guidance for type 2 diabetes in the UK (Diabetes UK, 2108, National Institute for Clinical Excellence, 2020)**

<table>
<thead>
<tr>
<th>Evidence-based lifestyle guidance</th>
</tr>
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<tbody>
<tr>
<td>• Daily moderate to vigorous physical activity or 30 min, at least 5 days a week but every day if possible.</td>
</tr>
<tr>
<td>• Sustained weight loss (5–10%) in overweight/obese or maintenance of healthy weight.</td>
</tr>
<tr>
<td>• Balanced carbohydrate intakes through portion control and consumption of low glycaemic index and wholegrain sources.</td>
</tr>
<tr>
<td>• Limited saturated and trans-fat intake, and replacement with mono-unsaturated fats, and oily fish consumption at least twice a week.</td>
</tr>
<tr>
<td>• Limit salt intake to less than 6g per day.</td>
</tr>
</tbody>
</table>

To support empowerment of self-management, individuals in the UK are routinely offered the opportunity to attend diabetes structured education; the most common programme in the UK is the Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) programme. Structured education provides knowledge
about how to manage T2D as well as offering support for behaviour change (Chatterjee et al., 2018).

In order to empower individuals to self-manage their diabetes, the care provision is now under pinned by the NHS “House of Care” framework (NHS England, 2019). The two key pillars of this approach are: 1) using enabling strategies to engage, educate and inform individuals to empower self-management and 2) providing a collaborative relationship with health professionals to build a trusted partnership. This collaborative supportive relationship with the diabetes healthcare team is based upon the philosophy of person-centred care, which has been a developing within the NHS, since the Health and Social Care Act 2012 (The Health Foundation, 2016). Person-centred care places the patient perspective centrally in care and encourages understanding and responding to individuals’ beliefs and treatment preferences, seeing their condition through their eyes, as well as being sensitive to social and psychological pressures (Hudon et al., 2012). Person-centred care by its nature is intended to be sensitive to culture of the individual (Saha et al., 2008). The process of person-centred care is further illustrated in Figure 1-3.

![Person-centred care – image modified from Hudon et al., 2011](image)
1.2.2 Type 2 diabetes in people of Black ethnicity

The UK population is becoming increasingly diverse, with 2018 Office of National Statistics projections suggesting 16% identify themselves as belonging to a minority ethnic group (Office for National Statistics, 2019). Given pervasive health inequalities, supporting minority ethnic communities to avoid and manage T2D is a key healthcare priority (Raleigh and Holmes, 2021).

1.2.2.1 UK Black African and Black Caribbean communities

Individuals of Black ethnicities make up a significant and growing proportion of the UK population. The latest published census data indicate that 3.3% (1.9 million) of the population of England and Wales identify themselves as being of Black ethnicity – of these 53% (just under 1 million) identify as Black African and 32% (0.6 million) identify as Black Caribbean. A further 1.1% of the UK population identify as mixed White and Black ethnicity (Figure 1-4). The percentage of the UK population of Black African heritage doubled between 2001 and 2011, making this the second fastest growing population group in the UK (Office for National Statistics, 2011). The migration history of minority ethnic communities living in high income countries is important when considering health profiles and health behaviours at population level, particularly because of the impact of acculturation on these factors (Stevenson and Rao, 2014). Peak migration from the West Indies to the UK began after the second world war in 1948, as a result of the UK Government sponsored free market labour recruitment which included sponsorship to British Rail, London Transport and the NHS. The Windrush generation arriving in the UK in the 1950s and 1960s represents the largest wave of Caribbean immigration and the majority came from Jamaica, Trinidad and Barbados (Office for National Statistics, 2011). Children of this generation account for 30% of this ethnic group and they were aged 40-55 at the time of the last census. Black Caribbean communities have the highest percentage of people currently aged 65+ of the non-white minority groups in the UK (13.9%) (Office for National Statistics, 2011).
Black African migration being more recent is reflected in the fact that 29% of the Black African population were aged 25-39 at the time of the census (Office for National Statistics, 2011). Immigration of Black Africans to the UK has consistently grown since the 1990s, with the largest numbers coming from West Africa, primarily Nigeria and Ghana (The Migration Observatory, 2020). There is much heterogeneity in UK Black African and Caribbean communities which comprise individuals originating from diverse countries with different dietary habits, cultural traditions, religions and languages. According to the last published census, the most commonly stated country of birth for people of Black ethnicity was Nigeria, Ghana and Somalia for Black Africans and Jamaica, Trinidad and Tobago and Barbados for Black Caribbeans (Office for National Statistics, 2011).

1.2.2.2 Health inequalities in UK Black communities

The breadth of health inequalities is significant amongst UK Black communities compared to those of White ethnicity, from increased maternal mortality through to
poorer mental health, risk of certain cancers and vulnerability to specific conditions such as hypertension and stroke (Health Survey for England, 2006, Raleigh and Holmes, 2021). Prevalence of diagnosed T2D is up to three times higher than for the general population (Harrison, 2014), as illustrated in Figure 1-5. This disproportionately high prevalence of diabetes amongst those of Black ethnicity is reflected across Europe (Meeks et al., 2016).

Figure 1-5: Prevalence of doctor diagnosed type 2 diabetes in Black African and Black Caribbean adults. Data from Health Survey for England 2006 (Harrison, 2014).

The SABRE study conducted in London predicted that by 80 years of age 40-50% of UK adults of Black ethnicities will have T2D (Tillin et al., 2013). The comparative figure for the general UK population is 14% (British Geriatric Society, 2018). Significantly, diagnosis in Black adults occurs up to ten years younger than in those of White ethnicity, with 23% of cases occurring under 40 years of age (Paul et al., 2017) (Figure 1-6). Furthermore, the data from Paul et al. suggest poorer glycaemic control is evident by the time of diagnosis, increasing the challenge of management. The high prevalence of type 2 diabetes in people of Black ethnicities in the UK has been attributed to a combination of genetic, socioeconomic, lifestyle and cultural factors (Creamer et al., 2016). People of Black ethnicity living in the UK self-report poorer general health than do the general population (Craig and Shelton, 2008).
INTRODUCTION

Figure 1-6: Age distribution of patients with diagnosed diabetes stratified by ethnicity in UK (data from Paul et al. 2017)

Associated risk factors for T2D such as obesity, hypertension and stroke are all more common in UK Black communities than for White British (Figure 1-7) (Raleigh and Holmes, 2021, Public Health England, 2018, Schofield et al., 2011).

Figure 1-7: Prevalence of hypertension, coronary heart disease and stroke by ethnicity (data from primary care databases in Lambeth) (Schofield et al., 2011)

Overweight and obesity prevalence is particularly high in women, with Black African women having the highest prevalence of obesity (defined by body mass index (BMI), waist circumference, or waist to hip ratio (WHR)) of any ethnic group in the UK (Gatineau and Mathrani, 2011) (Figure 1-8). The increased risk factors for diabetes in those of Black ethnicities can be tracked from childhood, with children as young as 9
years showing higher levels of glycated haemoglobin (HbA1c) and obesity than White European children (Donin et al., 2010).

In terms of cardiovascular health, African heritage confers some protective benefit on immigrant Black African men who have the lowest rate of cardiovascular illness of all ethnic groups (2.3%) (Public Health England, 2018). Data from Black adolescents suggests, however, that this protective effect may be lost in successive generations (Jolly et al., 2010, Owen et al., 2009), suggesting that it results from environmental contextual factors.

1.2.2.3 Poorer T2D outcomes for individuals of Black ethnicity

Disparities in the T2D care provision and clinical outcomes for minority ethnic groups have been reported over the last 20 years in the UK (Whyte et al., 2019). Several initiatives have been launched to tackle these inequities. These include the national Quality and Outcomes Framework (2004) which rewards primary care practice based on achieving specific diabetes targets amongst their patients, and the Health and Social Care Act 2012, which sets an explicit duty for the NHS to provide equitable healthcare access for all the UK population. Both of these initiatives were reinforced by the publication of the NHS 10-year plan in 2018. Data from primary care services in South London suggests that following the launch of the Quality and Outcomes framework glycaemic control did indeed improve across all ethnicities, however disparities between those of Black and White ethnicities remained and were
compounded by social deprivation (James et al., 2012). More recent national data indicates that people of Black ethnicity continue to show poorer glycaemic control, were less likely to complete annual monitoring (for HbA1C and for the presence of retinopathy) and were subject to prescribing disparities (Whyte et al., 2019). These findings are echoed in a recent systematic review of diabetes outcomes for Black African migrants across several high-income countries; poorer diabetes self-management outcomes (HbA1c, blood pressure and cholesterol) were noted for Black African migrants compared to both White and South Asians (Alloh et al., 2019b).

Attendance at diabetes structured education is associated with marked reductions in HbA1C (Nowell et al., 2017). However, attendance rates are relatively low in the UK for patients from minority ethnicities (Hadjiconstantinou et al., 2021). Qualitative investigation of reasons for non-attendance suggested that there were cultural barriers associated with stigma for those of African heritage (Winkley et al., 2015). There has been no subsequent assessment of perceptions of diabetes self-management education amongst UK African and Caribbean individuals. For those who do attend, meta-analysis concludes that for Black participants attendance is still not associated with an improvement in HbA1C (Cunningham et al., 2018).

There is systematic review evidence from the UK to suggest that individuals from minority ethnic groups have gaps in their understanding of the biomedical basis of diabetes and find it difficult to incorporate dietary change (Majeed-Ariss et al., 2015, Wilson et al., 2012, Zeh et al., 2014). These reviews include South Asian studies predominantly and very few studies with Black communities, however, they highlight that individuals often blamed external factors for their condition and had a lack of clarity in understanding the physiological causes of diabetes, which limited engagement with advice (Majeed-Ariss et al., 2015, Zeh et al., 2014). Inequities are further demonstrated by systematic review data to suggest that there may be cultural barriers to engaging in lifestyle interventions. A systematic review of behavioural lifestyle interventions for weight loss concluded that participants of Black ethnicity lost
consistently less weight than White participants. Goals in these trials included calorie restriction, changes to dietary composition, increased physical activity or a combination of both (Wingo et al., 2014). Similarly, African American women taking part in the US national Diabetes Prevention Programme lost consistently less weight than White participants in a controlled experimental setting; this differential was accentuated in a real-world setting (Samuel-Hodge et al., 2014).

1.2.2.4 Racism and white privilege: contributors to health inequalities

It is clear from the evidence that pervasive inequities persist, despite the UK policy changes detailed above. Diabetes UK recently published a report about the overwhelming urgency to address racism at the heart of the NHS in order to improve the diabetes-related health of UK minority ethnic communities (Diabetes UK, 2021b). Whilst there is longstanding evidence of inequities of access to, experience of, and outcomes of healthcare, the recent NHS Race and Health Observatory report was the first to analyse the overwhelming evidence of these health inequalities through the lens of racism and white privilege in the UK (Kapadia et al., 2022). This report summarises the historical evidence of poor quality and discriminatory treatment. This includes poor interactions with healthcare staff, lack of appropriate treatment for health problems, insensitive behaviour, stereotyping, cultural insensitivity, lack of appropriate interpreting services and lack of appropriate ethnic monitoring data, for example. This results in delays seeking help for fear of racism, lack of trust and poorer outcomes. Many of these issues are rooted in experiences of interpersonal and structural racism. Hobbs et al., in their 2018 paper identified such disparities as ‘assets of white privilege; disparity that occurs at the level of the system of healthcare as well as by discrimination that occurs at personal, institutional and societal levels’ (Hobbs, 2018). It is important to recognise how these system level cultures undermine healthcare for UK people from Black communities who are living with diabetes. In their systematic review exploring patient views of racism in healthcare across range of high income countries, including the UK, Sim et al., report that individuals highlighted both overt and subconscious racism as impacting upon their care (Sim et al., 2021). Overt racism included experiences of racial supremacism and labelling (e.g., making
assumptions about class and potential aggression), and unconscious racism, such as less readily connecting and empathising and making assumptions about likely compliance, when dealing with Black and minority ethnic individuals. Apart from the wide-reaching general structural inequalities, Diabetes UK, in their report, highlight three factors impacting people from UK Black communities who are living with T2D; these were prescribing biases—with Black patients 50% less likely to be prescribed newer medications for T2D than White patients, implicit bias\(^3\) of healthcare professionals, and digital exclusion (Diabetes UK, 2021b). The issues relating to digital exclusion go beyond digital literacy and lack of access to digital equipment. It is likely, for example, that lower rates of accessing of NHS digital diabetes health records from NHS apps, amongst Black individuals, has much to do with a justifiable, deep-seated lack of trust in the UK government use of data, given the UK Home Office hostile environment policies\(^4\) (Diabetes UK, 2021b). These factors, therefore, underpin wider sociocultural influences on diabetes self-management behaviour.

**1.2.2.5 The influence of sociocultural factors on self-management**

Frameworks to explain influences on self-management increasingly recognise the importance of social and environmental influences as well as individual factors (Grady and Gough, 2014). This socio-ecological approach identifies the role of relationships with healthcare providers, family and community, alongside environmental factors such as local facilities, and socioeconomic drivers of health (Whittemore et al., 2004). Intersecting characteristics such as gender, age and religion, further add to this complexity.

The consensus of the literature exploring self-management in minority ethnic communities recognises the culturally embedded nature of influences on diabetes self-management (Patel et al., 2015, Patel et al., 2021, Creamer et al., 2016). Management

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\(^3\) Implicit bias: where people act on the basis of prejudice or stereotyping without intending to DIABETES UK 2021b. Tackling inequalities in diabetes: our commitments. Diabetes UK.

of T2D happens largely in the culturally situated social environment rather than in the clinical setting: typically, people with diabetes in the UK spend only three hours a year with a health professional, leaving them with 8757 hours to manage their diabetes themselves (Diabetes UK, 2019). The need for diabetes support to be culturally centred and appropriate for people of different ethnicities and cultural backgrounds is acknowledged in the NICE guidelines for supporting adults with T2D (National Institute for Clinical Excellence, 2020). The crucial importance of understanding the nuances of cultural factors in influencing treatment adherence in conditions such as T2D was noted by the Lancet commission on culture (Napier et al., 2014). The Lancet commissions are partnerships between academics and Lancet editors to provide recommendation for health policy and practice improvement based on current evidence. The commission concluded that culture was fundamental in understanding patients’ explanatory models of health, perspectives on illness and wellbeing, behavioural norms and views about what constitutes an adequate provision of care. The Lancet report noted the particular importance of providing culturally salient care in conditions like diabetes, where outcomes are driven by patient engagement with a long-term regimen of prescribed medication and lifestyle change, and where evidence suggests clinical adherence to the biomedical model alone, does not necessarily translate to positive patient outcomes (Napier et al., 2014). Part of recognising the role of culture in understanding attitudes and health behaviour is acknowledging its role in the social construction of perceptions of illness. While narrow parameters of clinical care may focus on physiological malfunction or deviation from the biological norm, the patient’s lived experience of the illness depends upon socially constructed meanings and the influence of the condition upon their ability to follow the social norms of the groups with which they identify (Conrad and Barker, 2010). For example, carrying extra weight may be stigmatised in some cultures and revered in others (Naigaga et al., 2018) and success in making dietary change is strongly associated with social norms (Higgs, 2015). Views about what it means to be ill and well, understanding why an illness occurs and preferred treatment modalities may vary with cultural perspective. In traditional African cultures for example, culturally situated healing modalities, such
as spirituality and working with healers, are often prioritised over allopathic approaches; wellbeing is centred around the concept of balance between the individual and the environment, with imbalances judged evident from somatic symptoms (Airhihenbuwa, 1995). This can make it difficult to come to terms with a complex progressive condition like diabetes for example, diagnosed by biomarker deviance from the norm but where symptoms may not be initially overt (James and Hockey, 2007).

1.2.2.6 Improving cultural salience to improve outcomes

Improving the cultural saliency of care is a key strategy to improve outcomes for minority ethnic communities in high income settings. Improving cultural salience refers to the inclusion of ethnic and cultural characteristics, experiences, norms, values, behavioural patterns and beliefs as well as relevant historical, environmental and social forces in the provision of healthcare and the design and delivery of targeted health promotion materials and programmes (Resnicow et al., 1999). Central to the provision of culturally salient care is the concept of cultural competency:

“The ability of health systems to provide care to patients with diverse values, beliefs and behaviours by tailoring delivery to meet patient’s social, cultural and linguistic needs.” (Betancourt et al. cited in (Hanif et al., 2020)).

Cultural competency and person-centred care are similar concepts when considering diabetes care provision for people in minority ethnic communities because understanding and responding to experiences and illness beliefs, biopsychosocial pressures, treatment preferences and lifestyle habits as person-centred care suggests, requires consideration of how these factors are shaped by cultural influences (Saha et al., 2008).

The provision of culturally salient health promotion and the adaptation of interventions to meet cultural needs are all part of a culturally competent healthcare strategy (Fisher et al., 2007). In fact, a growing body of evidence concludes that targeted, culturally salient healthcare promotion programmes improve outcomes in minority ethnic communities, comparatively to generic ones. Systematic reviews of lifestyle interventions (Lagisetty et al., 2017), weight loss interventions (Martin Burton
et al., 2017), and diabetes education interventions (Creamer et al., 2016), all indicate improved outcomes when culturally adapted strategies are used. For example, the Cochrane review and meta-analysis by Creamer et al., compared 28 trials delivering culturally tailored interventions to support diabetes and found significantly greater reduction in HbA1c in interventions that were culturally adapted (Results shown in Table 1-2); in addition, improvements in diabetes-related knowledge and self-efficacy were also demonstrated (Creamer et al., 2016). The review by Lagisetty et al., demonstrated culturally tailored interventions prevented the onset of diabetes, improved diabetes control and led to greater weight loss (Lagisetty et al., 2017), and that by Wadi et al., concluded that HbA1c and knowledge improved as a result of culturally tailored lifestyle intervention (Wadi et al., 2021). From the participant perspective, culturally tailored diabetes-related interventions were perceived as acceptable and resulted in individuals feeling empowered and informed as a result of their participation (Joo and Liu, 2021).

Table 1-2: Results of meta-analysis showing sustained improvement in HbA1c in culturally adapted diabetes education (Creamer et al., 2016).

<table>
<thead>
<tr>
<th>Time</th>
<th>Reduction in HbA1c (mmol/mol)</th>
<th>95% CI (mmol/mol)</th>
</tr>
</thead>
<tbody>
<tr>
<td>At 3 months</td>
<td>-4.3</td>
<td>[-1.4 to -7.0]</td>
</tr>
<tr>
<td>At 6 months</td>
<td>-5.8</td>
<td>[-3.8 to -7.9]</td>
</tr>
<tr>
<td>At 12 months</td>
<td>-2.1</td>
<td>[-0.4 to -3.7]</td>
</tr>
<tr>
<td>At 24 months</td>
<td>-3.6</td>
<td>[-0.7 to -6.7]</td>
</tr>
</tbody>
</table>

This robust body of evidence suggests that culturally adapting interventions to support engagement with diabetes self-management shows promise. The reviews are however primarily drawing from evidence with African Americans. These studies are inherently difficult to translate to the UK setting; African American migrations patterns differ, dietary patterns are more assimilated to the general population (Liu et al., 2012) and sociocultural influences may differ. In the UK, the focus on improving the cultural salience of care to date has prioritised South Asian communities because there is also evidence of health inequalities in these communities. There have been no specific interventions designed to support those of African heritage either with diabetes self-management or health-related lifestyle change in general, in the UK setting.
1.2.3 Summary

In this background section I have highlighted the disproportionate burden of T2D amongst people of Black ancestry and the inequities in T2D outcomes. Improving the cultural saliency of care is a key healthcare strategy and designing culturally salient interventions to support engagement with T2D self-management, and lifestyle change, has been shown to improve outcomes. There has been little exploration of this approach in the UK setting for people of Black ethnicity.

The ultimate aim of my thesis is to understand how healthful diabetes self-management behaviours can be supported in UK African and Caribbean adults, in a culturally salient way. My study does this by exploring the sociocultural factors shaping self-management behaviour in order to develop theoretical understanding of the influences on behaviour and to inform the development of culturally tailored approaches to support engagement and behaviour change. In the next section I consider the current literature which informs my study.
1.3 Supporting diabetes-related health behaviour in Black African and Caribbean adults

In this section I move on to review the current literature which frames my thesis. This body of literature has developed over the last thirty years as health research has focused more explicitly on understanding and responding to health inequities in minority ethnic communities in general and Black African and Caribbean communities specifically. This section is organised as follows:

- I begin by considering the status of current understanding about effective cultural tailored strategies used in interventions to support healthful self-management behaviour change in people of African and Caribbean ancestry living in high income countries.
- I then consider the frameworks which have been developed to support exploration of cultural and social influences on healthcare engagement.
- In the final two sections I consider the current literature exploring the lived experience of diabetes amongst the African and Caribbean diaspora and the reported socio-cultural influences on diabetes-related health behaviour, first internationally and secondly specifically in the UK context.

1.3.1 Culturally tailored interventions to support behaviour change

Several reviews have recently considered which strategies improved outcomes in culturally tailored interventions. Reviews of culturally tailored weight loss interventions in people of African ancestry (Kong et al., 2014, Martin Burton et al., 2017) have used the framework from Kreuter et al., (2003). This framework considers five domains as shown in Figure 1-9 below. According to these studies, the most effective strategies were sociocultural strategies (which acknowledge and respond to cultural values, beliefs and behaviours and social factors); and constituent involving strategies (working closely with members of the target communities).
Supporting diabetes-related health behaviour in Black African and Caribbean adults

Blue highlighted strategies were identified in reviews as the most effective

**Figure 1-9: Framework to identify culturally tailored strategies (modified from Kreuter et al., 2003)**

The alternative FILLM framework was used in reviews exploring lifestyle intervention for T2D in people of African ancestry (Wadi et al., 2021) and amongst minority ethnicities more generally (Lagisetty et al., 2017). This conceptual framework considers Facilitating intervention through Language, Location and Messaging (Lagisetty et al., 2017). These two reviews also highlight the benefit of using facilitators from the target community, delivering the intervention in meaningful locations, and using content and messaging which responds to pertinent sociocultural factors within a particular target population. Neither of these reviews identify interventions in the UK setting.

The culturally tailored interventions for self-management of diabetes in Black participants have all been conducted almost exclusively in the US, to date. They include general self-management programmes as well as interventions focused specifically on elements of lifestyle change, such as weight-loss and physical activity (Wadi et al., 2021, Creamer et al., 2016). Key strategies employed include the involvement of ethnically concordant facilitators such as dance instructors (Murrock et al., 2009), church health advisors (Samuel-Hodge et al., 2009) and community health workers (Lutes et al., 2017, Spencer et al., 2011, Sharp et al., 2018, Gary et al., 2009).
Introduction: Supporting diabetes-related health behaviour in Black African and Caribbean adults

Systematic review data concluded that the cultural tailoring of messaging associated with significant outcome improvement were those focused on diet, faith, family values, and gender constructs (Wadi et al., 2021). The majority of interventions were held in community locations such as churches (Samuel-Hodge et al., 2009), community centres (Murrock et al., 2009, Keyserling et al., 2002, Spencer et al., 2011, Gary et al., 2009, Anderson et al., 2005, Lynch et al., 2019), or local parks (Lynch et al., 2019). Most of these interventions do not explicitly identify the theory underpinning the intervention. Amongst the few that do note a theoretical basis to the intervention design, the most common theories I identified were social-based theories (social learning, social interdependence, and social cognitive theory) (D'Eramo-Melkus et al., 2004, Murrock et al., 2009, Samuel-Hodge et al., 2017, Lynch et al., 2019). In addition, empowerment theory (Spencer et al., 2011, Mayer-Davis et al., 2004, Anderson et al., 2005, Ruggiero et al., 2014) and the transtheoretical model were also commonly used (Ruggiero et al., 2014, D'Eramo-Melkus et al., 2004). Most of these interventions do not further specify the mechanisms of change and how the components of the interventions map to the theoretical determinants of behaviour.

1.3.1.1 The importance of theory in health promotion and intervention

NICE guidance for developing diabetes self-management support, stresses the need to develop theoretical understanding and utilise theory to underpin interventions (National Institute for Clinical Excellence, 2007). Furthermore, when it comes to designing complex interventions such as those associated with lifestyle behaviour change, the Medical Research Council (MRC) recommends that interventions are theoretically underpinned with explicit behaviour change theory to improve effectiveness (Craig et al., 2008). In behaviour change, the theory has been likened to understanding what is happening in the black box that links the shift of behaviour from A to B, explaining why, when and how a behaviour occurs or does not occur and the important determinants of that behaviour which are being targeted to promote behaviour change (Riley and Rivera, 2014).
There is a plethora of theories to explain health behaviour that range from the ecological to the individual in their focus. Moreover, researchers aiming to design intervention and health promotion to support behaviour change are encouraged to move away from a single theory and to consider a variety of theories. This approach recognises that one theory is unlikely to fully explain a real-life problem and a multi-theory approach recognises this complexity (Bartholomew et al., 2016). Several frameworks that draw upon multiple theories have been developed to help inform the theoretical underpinnings of interventions. These include the COM-B behaviour change wheel (Michie et al., 2014), the theoretical domains framework (Cane et al., 2012) and intervention mapping (Bartholomew et al., 2016).

**Linking theory to behaviour change techniques**

Despite the acknowledged benefits of theoretically developed interventions and health promotions, the use of theory is poorly reported in published studies generally. For example, in a review of physical activity and healthy eating interventions, 90% of studies failed to report how theory was used and to make explicit the links between the theoretical constructs and the mechanisms of change (Prestwich et al., 2014). This explicitness is important both to clearly understand how an intervention is intended to work but also to allow systematic comparison to interventions to reliably build up an evidence base of what works in which situations (Michie et al., 2010). Behaviour change techniques (BCTs) are the active components of change (e.g., goal setting). A validated taxonomy of BCTs has been published (Michie et al., 2013). It is argued that these techniques need to be linked explicitly to mechanisms of action by which they exert their effect on a specified determinant of behaviour in order to clarify theoretical links within behaviour change interventions (Bartholomew et al., 2016)\(^5\).

It is difficult to draw conclusion as to which BCTs are most effective in lifestyle interventions, as systematic reviews and meta-analyses note much heterogeneity between studies. In interventions for those with diabetes, the BCTs goal setting, goal

\(^5\) *Mechanisms of action – the range of processes specified by theory to predict behaviour change*
review, action planning and social support were associated with the best outcomes in terms of weight loss, increased activity and healthy eating improvements (Hankonen et al., 2015).

To date, there a few studies identifying potential BCTs to support behaviour change in minority ethnic communities. In fact, the underlying discourse and evidence for the development of the taxonomy of behaviour change techniques is largely conceived through a White Eurocentric lens. Published studies which do identify BCTs in minority ethnic communities, include an intervention to reduce smoking in indigenous communities in Australia (Gould et al., 2017), to promote health screening uptake for Turkish Dutch communities (Van Der Veen et al., 2014), and to support gestational diabetes in Latina women in the USA (Handley et al., 2016). These studies suggest benefit from elements of control theory – action planning, feedback, goal setting etc – however, the transferability of this data to the UK setting is uncertain.

1.3.1.2 Summary

In this section I have discussed strategies used in existing culturally tailored interventions to support people of Black ethnicity living with diabetes to self-manage their condition. In addition, I have highlighted the value of developing theoretical understanding to improve efficacy of health promotional strategies.

1.3.2 Framing exploration of sociocultural influences on health behaviour to improve cultural salience of care

Health behaviour occurs in the social context. Beyond personal choices of the individual, it is influenced by social and community networks and other socioeconomic, environmental and cultural factors (Dahlgren and Whitehead, 2007). Three key cultural frameworks, developed to support understanding of social and cultural influences with a view to improving cultural salience of care, are described in Table 1-3. Purnell’s cultural model comprises twelve cultural domains suggested to be relevant to understanding culture in healthcare for minority ethnic communities. The model highlights the need to consider the wider influences of culture on engagement
with healthcare - issues such as communication styles, health beliefs, religion, rituals and the role of the individual within family structures. The PEN-3 framework emphasises the importance of understanding cultural influences on health behaviour within the dynamic and interacting social environment of family and community behaviour. Within this environment certain behaviours are acceptable and encouraged whilst others may be culturally unacceptable in which case there will be social pressure making the behaviour more unlikely. For example, food is highlighted particularly as culturally symbolic and shared meals a symbolic act supporting social connection. This makes understanding cultural influences on dietary habits essential if health education, promotion or intervention is designed to modify dietary practices (Airhihenbuwa et al., 2009).

### Table 1-3: Frameworks to explore cultural influences on health behaviour to improve cultural salience

<table>
<thead>
<tr>
<th>Author</th>
<th>Description</th>
<th>Objective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Airhinenbuwa et al.,</td>
<td>PEN-3 model. A three-domain framework: cultural empowerment (current health</td>
<td>Designing culturally tailored interventions</td>
</tr>
<tr>
<td>(1995)</td>
<td>behaviour); cultural identity (social influences); expectations and relationship (wider enablers and barriers).</td>
<td></td>
</tr>
<tr>
<td>Purnell et al., (2002)</td>
<td>12 domain framework to explore relevant cultural drivers in a given population, including family structures, communication styles, and views of the role of healthcare.</td>
<td>Improving cultural understanding &amp; competency</td>
</tr>
<tr>
<td>Resnicow et al., (1999)</td>
<td>Divides sociocultural factors into surface e.g., diet &amp; language and deep structures e.g., migration history, environmental drivers and “worldview”.</td>
<td>Designing culturally tailored interventions</td>
</tr>
</tbody>
</table>

The seminal model developed by Resnicow et al., (1999) separates cultural influences into overt “surface structures” and “deep structures” which incorporate wider sociocultural influences. Whilst the transferability of each of these frameworks to other contexts cannot be guaranteed, the focus of such models is as a heuristic to identify potential cultural and community specific factors influencing health care interactions, beliefs and behaviour, as well as community specific environmental factors which may be relevant in any context. For that reason, these frameworks have value in shaping understanding of cultural influences relevant to my study.
The Resnicow model may have particular utility, because it provides a comprehensive categorisation upon which to explore cultural and social factors influencing health behaviour. The model highlights, for example, the importance of migration history, and environmental stressors such as racism, for example, as well as broader cultural constructs. This makes it particularly relevant to considering how to improve the cultural relevance of health promotion. It has been used to develop a number of lifestyle interventions for African Americans (Liu et al., 2012) and furthermore, has informed the development of tools used to identify successful components in culturally tailored intervention design for Black communities (Lagisetty et al., 2017, Kreuter et al., 2003). The Resnicow framework separates cultural factors into surface structures – language, dietary norms and other obvious shared observable characteristics, and deep structures – the bonds, practices and beliefs, historical influences, and cultural and environmental factors which cannot be observed and are much harder to identify and define. Surface structure sensitivity in health promotion is considered by Resnicow et al., to be important in developing engagement with health promotion, but they suggest that it is the deep structure sensitivity which is of paramount importance in achieving salience and efficacy. I argue that for diabetes self-management, responding to dietary norms, classified by this model as surface structure, is paramount to also achieving efficacy. Nevertheless, understanding the deep structures that underpin this is more complex, so further consideration of these factors is warranted. These factors are illustrated in Figure 1-10. The core cultural constructs which are a result of socially transmitted behavioural values, beliefs and customs, largely derived from one’s family and community. The term “worldview” is sometimes used to describe these constructs and they include factors such as communication styles, beliefs about family and gender roles, and spirituality (Black and Purnell, 2002). Then, the more specific factors influencing the target health behaviour in a specific cultural group are considered. These may include explanatory models of illness (the specific beliefs about the cause, course and treatment of illness), views about the trustworthiness of healthcare, political structures, stressors such as discrimination, family structures, patterns of migration, normative lifestyle habits, local
structural barriers, education and health literacy (Williams, 2018, Abubakar et al., 2018, Bhugra and Becker, 2005).

**Figure 1-10: Surface and deep structures in designing culturally salient interventions. Modified from Resnicow et al. 1999.**

Systematic reviews in the US setting suggest key cultural constructs amongst African Americans, which may be considered as deep structures, relevant to improving cultural relevance of care. These include collectivism, religiosity, orality, present-focus temporality, racial pride and communication sensitivity to emotional cues and relationship building (Table 1-4) (Kreuter et al., 2003, Resnicow et al., 1999, Di Noia et al., 2013). In describing these constructs the researchers emphasise that there is much heterogeneity between individuals and identified core values may be more or less compelling for each person, but that the constructs are identified because the majority within a defined social group recognise these factors have a role or importance within their community (Kreuter et al., 2003, Di Noia et al., 2013). Resnicow et al., (1999) emphasise that heterogeneity in ethnic identity should be assumed when considering the development of culturally salient healthcare programmes, highlighting that
differences in ethnic identity are likely, even amongst seemingly homogenous groups.\textsuperscript{6} Ethnic identity shapes affinity towards in group culture, as such it can indicate the strength of normative cultural influences on health behaviour. Resnicow et al., (1999) acknowledge the importance of understanding of these influences in any given target population and for any given health behaviour. Concluding that assuming uniform ethnic identity “may paradoxically, be culturally insensitive”.

Table 1-4: Core cultural constructs associated with African American culture (Resnicow et al., 1999)

<table>
<thead>
<tr>
<th>Factor</th>
<th>Characteristic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Core cultural constructs</td>
<td>Communalism, spirituality, expressiveness, respect for verbal skills, connection to ancestors and history, commitment to family, valuing intuition, prioritising experience over empiricism and a unique sense of time, rhythm and communication style.</td>
</tr>
</tbody>
</table>

The model of Resnicow et al., is relatively comprehensive. Its strength, however, lies in identifying factors relevant to what cultural adaptations may improve delivery and content of healthcare support. It does not consider the process of adaptation, for example – that is how tailored adaptations should be made and how stakeholders should be involved. Furthermore, it does not support understanding of the process of individual behaviour change.

The important consideration of intersectionality, when developing recommendations for the design of culturally salient interventions, is also highlighted in a substantial study by Liu et al. They suggest intersectional factors can facilitate more a more complex and dynamic understanding of culture to shape intervention development (Liu et al., 2012). Their work highlights particularly age, gender, and socioeconomic factors, as having significant influence on how people respond to interventions. Intersectionality frameworks can therefore provide useful addition to the cultural frameworks described above. Bilge et al., recommend considering a range of intersecting factors in their intersectionality framework, including gender and age, as well as ethnicity, socioeconomic factors, religion, age, disability and immigration status (Bilge, 2009). Exploring how these factors influence lived experiences can add further depth to cultural frameworks such as that from Resnicow et al., (1999) ; for example

\textsuperscript{6} see 1.1.3.3 for my definition of ethnic identity.
Lui et al., highlight how ‘*surface structures*’ such as gender and age may intersect with ethnicity, specifically to influence how an individual responds to an intervention at a ‘*deep structure*’ sociocultural level (Liu et al., 2016).

1.3.2.1 Summary

In this section I have presented some of the frameworks developed to explore cultural influences on health and to design culturally salient care. In the next section, I consider the lived experience of diabetes self-management amongst African and Caribbean adults living in high income countries and highlight some of the social, cultural, environmental factors which may shape self-management behaviour.

1.3.3 Self-management in Black African and Caribbean adults living in high income countries outside the UK

There is a mature body of international literature exploring the lived experience of diabetes self-management in adults of Black African and Caribbean heritage, particularly in the North American setting, because of a longer history of developing culturally tailored support. While this literature is not directly transferable to the UK context, it provides useful insight into sociocultural influences affecting diabetes self-management in minority Black communities in other high income settings.

1.3.3.1 Considering the influence of migration patterns

When interpreting this literature, it is useful to highlight how migration patterns may differ across populations. Specifically, there is much heterogeneity behind the African American identity – some families, having origins from the forced migration of Black Africans several centuries ago, may have lived several generations in the US setting. As a result, certain lifestyle behaviours amongst African Americans, such as dietary behaviour, have been shown to be acculturated towards the American societal norms (Brown et al., 2019). In fact, less than 9% of the current African American population can be identified as first or second-generation immigrants, although this percentage is increasing (Brown et al., 2019). Unfortunately, generational status of participants as well as their ethnic heritage is rarely noted in the African American studies. On the
other hand, European migration from both Africa and the Caribbean is relatively more recent, being concentrated from the 1950s onwards. As ethnicity researcher Bhopal acknowledges, with successive generations cultural influences may become weaker (Bhopal, 2014). Whilst, this is not always the case, it is a useful distinction to bear in mind when considering the literature. For this reason, I differentiate between African American and other people of Black African ancestry and between first- and second-generation populations\(^7\) in the sections below, despite the fact these distinctions can be contested as homogenising categorisations.

The international literature is dominated by North American studies – primarily amongst African Americans. Four recent US studies, however, explore the experience of African immigrants from Somalia (Njeru et al., 2016, Kahn et al., 2013), and sub-Saharan Africa (Kindarara et al., 2017). These comprise two small qualitative studies (Kahn et al., 2013, Kindarara et al., 2017) and a small survey (n=39) about the experience of diagnosis. Nevertheless, despite these limitations, these studies provide an interesting contrast between factors shaping interaction with diabetes care between immigrant communities and African American communities. Three Canadian studies explore self-management amongst Black Caribbean immigrants specifically (Swaleh and Yu, 2020, Hyman et al., 2014, Brathwaite and Lemonde, 2017). Again, these studies are small and use qualitative methods, but as they focus on health beliefs and associated self-management, they offer insight into cultural influences in first- and second-generation immigrants, which is potentially pertinent to African and Caribbean first- and second-generation immigrants in the UK.

There is a paucity of literature from the European setting. The lived experience of diabetes and diabetes-related knowledge are explored amongst Somalian immigrants in two qualitative studies from Sweden (total n=49) (Gele et al., 2015, Wallin et al., 2007). In addition, the large RODAM study amongst Ghanaian participants, is the most extensive of these international studies (de-Graft Aikins et al., 2019). Whilst still using qualitative methods, this study explores knowledge about T2D amongst 180

\(^7\) My definition of immigrant for this study is people of first- and second-generation (see 1.1.3.6)
participants and usefully facilitates comparison between individuals in rural and urban settings in Ghana, and with individuals who have migrated to Europe. Three systematic reviews compare diabetes experiences amongst African immigrants (including those to the UK) (Jones and Crowe, 2017, Alloh et al., 2019a, Osokpo et al., 2021).

1.3.3.2 Cultural influences

Cultural influences on T2D knowledge and behaviour

Cultural influences shape the lived experience of diabetes across ethnicities and settings. The literature highlights the strength of cultural influences on health beliefs and normative lifestyle behaviours amongst first- and second-generation immigrants. The studies suggest that knowledge of diabetes is influenced by traditional understanding, for example beliefs that diabetes was caused by spiritual or psychological forces was described in three of the immigrant qualitative studies (Agyemang et al., 2016, Swaleh and Yu, 2020, Brathwaite and Lemonde, 2017), with the multi-site RODAM study emphasising how these traditional beliefs become diluted as individuals move to an urban African settings, with traditional beliefs having less resonance still in the European setting (Agyemang et al., 2016). Faith placed in natural remedies as opposed to biomedical approaches to support diabetes management is reported across a range of studies, but particularly amongst first- and second-generation Black African (de-Graft Aikins et al., 2019, Kindarara et al., 2017, Osokpo and Riegel, 2021) and Caribbean individuals (Brathwaite and Lemonde, 2017) living in the US, Europe and Canada. In most cases participants across studies used natural treatments and medication concurrently and interchangeably, with few taking medication alone. Associated with faith in natural remedies was some mistrust of biomedicine that was seen as toxic and unnatural (de-Graft Aikins et al., 2019). A general distrust of medication is presented in this body of literature as a normative belief. Studies amongst first- and second-generation immigrant populations also highlight the strength of influence of traditional cultural norms and ethnic identity, especially with regards to dietary traditions; this created difficulty in following dietary

Studies amongst African Americans were less likely to cite cultural factors in influencing their health beliefs and dietary behaviour for self-management. Given the African American studies often include individuals more acculturated to the US context (Brown et al., 2019), this highlights the important intersection with migration history when exploring sociocultural factors in minority ethnic communities. Even so, gaps in knowledge and understanding were also reported in qualitative studies with African American participants. Ball-Berry et al., (2015) suggested in their focus group study (n=13) amongst African American men in a barbershop setting, for example, that the metabolic perturbations leading to the development of diabetes were poorly understood. Similar findings were reported amongst African American women in qualitative interviews in South Carolina (Schoenberg et al., 1998). Interestingly, though dated, this latter study compared knowledge amongst White and Black women and found knowledge at that time was poorer amongst those of Black ethnicity. Mistrust of diabetes medication was also reported amongst African Americans to limit engagement with prescribed regimens, regardless of structural reasons associated with costs and insurance (Shenolikar et al., 2006, Trinacty et al., 2009). Adherence to diabetes medication has been reported as 25% lower for African Americans compared to non-Hispanic White individuals, even after compensating for financial barriers (Shenolikar et al., 2006). The use of traditional herbal remedies was not widely reported in studies amongst African Americans, highlighting potential differences between a more acculturated population and recent immigrants. In contrast to the studies amongst first- and second-generation immigrants, cultural barriers to dietary change were not a strong theme in African American studies.

**The influence of wider cultural constructs**

More general cultural constructs appear to shape attitudes toward diabetes and general health, amongst people of Black ethnicities across a range of settings and migration status. The influence of communalism and spirituality, key cultural
INTRODUCTION

Supporting diabetes-related health behaviour in Black African and Caribbean adults

Constructs identified generally amongst African Americans with diabetes (Resnicow et al., 1999, Kreuter et al., 2003, Di Noia et al., 2013), is reinforced in studies amongst immigrants in both North American settings (sub-Saharan African immigrants) (Kahn et al., 2013, Kindarara et al., 2017, Njeru et al., 2016) and European settings (Ghanaian immigrants) (Agyemang et al., 2016). Spirituality and prayer were perceived to be essential to control diabetes as well as to cope with the diagnosis, according to qualitative studies amongst first- and second-generation immigrants to Europe and the US (de-Graft Aikins et al., 2019, Kindarara et al., 2017) as well as amongst African Americans (Spruill et al., 2015, Choi and Hastings, 2019, Shiyanbola et al., 2018b).

Spruill et al., who explored the impact of spirituality in a relatively large qualitative interview study amongst African Americans (n=52), identified two typologies – “back seat drivers” and “front seat drivers” – the first and most common were empowered in their diabetes management by God’s support and the second took a more fatalistic approach, determining diabetes as God’s will (Spruill et al., 2015). In the majority of studies spiritual empowerment was more common; praying evoked spiritual assistance providing strength to make positive decisions and enhancing resilience (Choi and Hastings, 2019, Kindarara and Silva, 2019).

Community influences also shaped self-management behaviour, both positively and negatively. Social support from the family, local community and faith institutions played an important role in coping with diabetes, with storytelling and shared experiences of diabetes shaping knowledge and self-management choices (Swaleh and Yu, 2020, Schoenberg et al., 1998, Skrine Jeffers et al., 2019). In addition, practical help from others in the community improved resilience to cope with making self-management changes amongst immigrant communities (Wallin et al., 2007, Kindarara et al., 2017, Njeru et al., 2016). Collectivist attitudes, however, meant that lifestyle choices were shaped by consideration of family harmony. This limited the ability of the individual to make unilateral change, which may impact on dietary change in particular (Osokpo et al., 2021). Furthermore, not wanting to be stigmatised by the community resulted in people “suffering in silence” and could limit engagement with self-
management that may draw attention to the diabetes diagnosis (Kindarara et al., 2017, de-Graft Aikins et al., 2019).

1.3.3.3 Structural influences

Structural barriers to self-management engagement are much more evident in the American literature than in European and Canadian settings. Hawkins et al., (2019) in their systematic review of barriers and facilitators to self-management amongst African American men for example, emphasised limited resources to buy medication and testing strips and to pay for care, limited resources to buy food, and challenges with financial responsibility. In addition, poorer neighbourhood facilities, racism and discrimination in the US were strongly emphasised in a large modelling study (n=615) (Olukotun et al., 2021). This difference is likely to particularly reflect the socioeconomic disadvantage for Black communities in the US, where the legacy of slavery, neglected inequalities and discrimination have resulted in significant employment and educational discrimination (Solomon et al., 2019). These inequities are compounded by the financial barriers associated with lack of health insurance in a privatised healthcare system (Okonofua, 2013). Exploration of environmental and socioeconomic influences have not been a focus of published studies outside the US.

A lack of cultural sensitivity in healthcare communication was identified as a barrier to the practical utility of diabetes advice for African and Caribbean immigrants in Canada, America and Sweden (Swaleh and Yu, 2020, Njeru et al., 2016, Wallin et al., 2007). Barriers associated with communication with healthcare providers were previously identified as significant for ethnic minority individuals with T2D, a robust systematic review (Majeed-Ariss et al., 2015). There is some evidence in the literature that African Americans preferred a directive style of healthcare interaction for diabetes care; In a qualitative focus group study (n=31) with African Americans a paternalistic consultation was considered to represent “good counselling” (Miller et al., 2010). This preference may stem partly from the failure of cultural sensitivity in facilitating the possibility of more collaborative decision making. Certainly, Tang et al., (2008), in their
quantitative survey data, highlight persistent differences in understanding of diabetes between Black patients and their doctors (n=130).

A distinct mistrust of healthcare amongst African Americans, in general, is indicated in the US (Hostetter and Klein, 2021) and mistrust and discrimination are strong themes evident across the literature amongst people of Black ethnicities living with diabetes in the North American setting. Shiyanbola et al., (2018a) conducting focus groups with 40 African Americans living with diabetes, identified perceptions such as that healthcare providers were purposely making them sick, were withholding information that would help them because they were Black, and did not want them to be well because they wanted to make money out of them. Similarly, in Canada, Swaleh and Yu (2020) in a relatively large qualitative interview study (n=43) with Black Caribbean immigrants, also suggested that participants felt that doctors were making money from them and gave Black individuals poorer care. This strength of distrust was much stronger than is evident in the European literature. Authors highlight the role of past slavery, poverty and structural racism in America as being influential factors (Shiyanbola et al., 2018a). It is also likely that the privatised system in the US would accentuate some of these issues, perhaps compounded by lingering mistrust as a result of the historical legacy of unethical medical research such as the Tuskegee Study, where African American men were left to suffer with a treatable condition unnecessarily (Reverby, 2001). Certainly, in US studies, the impact of discrimination, racism and the stresses these place upon diabetes self-management, is more evident than amongst existing European studies (Seawell et al., 2016, Wagner et al., 2011, Olukotun et al., 2021).

### 1.3.3.4 Summary

The International literature highlights pertinent cultural, social, historical and environmental factors which influence self-management behaviour in communities of African heritage living in high income countries. Cultural influences shaped diabetes health beliefs, engagement with treatment, and in many cases reduced ability and/or
intention to engage with self-management behaviours, most notably in first- and second-generation immigrants. This emphasises the importance of responding to these cultural drivers in supporting engagement with diabetes self-management in communities of African heritage. Key cultural constructs of spirituality and communalism were evident across the studies and suggest potential deep structures which may be leveraged in health promotion design, to improve salience (Resnicow et al., 1999). This literature is dominated by studies amongst African Americans, and the data also indicate how migration patterns and, some structural and social factors shaping engagement in the North American setting may have less relevance in a European context. Overall, whilst this literature suggests several factors which may be useful to address when developing culturally salient support, transferability of the North American literature to the UK context cannot be assumed. West African heritage communities which are the largest of the UK African immigrant communities are also not a key focus of the international literature. Thus, further focus on the UK context is warranted.

1.3.4 A UK perspective on diabetes self-management in Black African and Caribbean adults

In this section, I move my focus to the UK context. Literature exploring the experience of diabetes self-management amongst African and Caribbean adults in the UK setting is comparatively limited. The details of pertinent UK studies amongst Black African and Caribbean adults living with diabetes are further documented in the appendices (Table 6-1, page 338). Overall, current UK literature has focused on describing health beliefs, whilst the impact these beliefs have on self-management behaviour is less well studied. To date exploring how to support healthful self-management behaviour change has not been the emphasis of research. The studies amongst individuals of Black Caribbean heritage by Brown et al., (2007) and Scott et al., (2001, 1997, 1998) pre-date the UK policy shift towards person-centred culturally competent care. The smaller qualitative study by Brown et al., (n=16) was conducted in Nottingham, which has a lower density of minority ethnic communities in general than London, so the data may not be transferable to inner city London, where my study is situated (Brown
et al., 2007). In contrast, the study by Scott et al., was conducted with participants from both London and Cambridge, included both White and Black Caribbean participants and encompassed both quantitative (n=160) and qualitative (n=37) methodologies. This latter study, therefore, has multiple opportunities for triangulation, suggesting the findings are likely to be robust (Scott, 2001, Scott, 1997, Scott, 1998). The two studies amongst sub-Saharan African adults living in the UK, have been conducted more recently (Omodara et al., 2021, Alloh et al., 2019a). Alloh et al., used grounded theory methods to explore the lived experience of T2D amongst 33 West African immigrants in London. Similarly, Omodara et al., interviewed 36 immigrants from across sub-Saharan Africa, living in London. These latter studies are likely, therefore, to be particularly relevant to the context for my study. Noakes et al., focus specifically on exploring acceptance of insulin in 2 focus groups with 13 Black AfC adults in London. This small study suggests some views about medication which are reinforced by the other larger studies (Noakes, 2010)

1.3.4.1 Lifestyle-related behaviour in UK African and Caribbean adults

Understanding normative patterns of lifestyle behaviour is important as it is within this context that self-management for diabetes occurs. Below I discuss the observational data from the UK, that explores lifestyle behaviour and the impact of migration upon these lifestyle habits both in UK African and Caribbean adults living with diabetes, as well as the wider UK African and Caribbean communities.

Dietary patterns

Dietary habits in immigrant groups are dynamic in nature as communities assimilate with host culture and as the age and sociodemographic profile of the community shifts over time (Bhopal, 2014). As such, observational data can only ever present a snapshot. Dietary patterns vary considerably within UK African and Caribbean communities depending on country of birth, although a predominance of complex starchy tuber-based foods and rice characterise traditional dietary patterns across ethnicities. This dietary pattern is high in carbohydrate but comparatively lower in
energy and fat than the Westernised diet (Leung and Stanner, 2011). Studies suggest that nutrition transition is associated with a decrease in diet quality and potentially increased risk for diabetes and implication for self-management. For example, in an observational study the diet of West Africans living in London compared to native Accra showed a marked increase in total energy and saturated fat in the UK setting, with the addition of high sugar processed foods, despite a predominance of traditional African foods (Gibson et al., 2015). Furthermore, comparison between the diets of UK African and Caribbean communities indicated that dietary assimilation increased with length of UK residency; length of time living in the UK was positively associated with increases in salt, fat and energy intake (Goff et al., 2015). In this robust study which used triple pass dietary recall as opposed to food frequency questionnaires, the diet of Caribbean participants was found to be more acculturated to the UK than that of their West African counterparts. However, cultural staple starches including traditional rice dishes, starchy tubers, traditional fruits like plantain, porridges and breads still formed a key part of energy intake in both groups (Goff et al., 2015). The national Health Survey for England indicated fruit and vegetable intake was higher amongst Black respondents than the general UK population (Leung and Stanner, 2011). There are limitations to the accuracy of these large dietary surveys, the Health Survey for England for example uses a brief retrospective 24h screening instrument which would not be sensitive to daily variations (Campbell et al., 2020). Collectively, however, the current data suggest both positive elements of the traditional diet in Black African and Caribbean communities, as well as potential challenges for diabetes self-management associated with normative dietary patterns including high carbohydrate, total energy, fat, and salt intake.

**Physical activity**

Physical activity seems to be reduced in the UK setting compared to lifestyles pre-migration (Misra and Ganda, 2007). There are little accurate data reporting physical activity.
activity trends amongst UK Black African and Caribbean communities. Studies which are available are limited in collecting self-reported data and using instruments such as the IPAQ⁹, which are not validated for cross-cultural use and depend on personal interpretation which can differ through the lens of different cultures. In the regularly published Active Lives report in the UK (n= 190,401) fewer Black participants reported they met physical activity guidance of 150 minutes or more per week than white British (57% compared to 64%). They were also more likely to report they were sedentary (30% compared to 24%) (Sport England, 2020). Analysis of the trends indicated a widening gap as overall activity levels increased amongst the general population while activity levels remained steady amongst most UK ethnic groups. Black women were also reported to be less active than Black men (Sport England, 2020). The last ethnicity boosted sample for the Health Survey for England was in 2006. Though dated, the report provides a more detailed breakdown of activity types, concluding that Black men were more likely to engage in sports and purposeful exercise than Black women. Black African women were reported to have significantly lower levels of engagement in purposeful exercise other Black women and men. Women reported being actively engaged in heavy housework, however. Approximately a quarter of Black respondents reported regular engagement in brisk walking (Becker et al., 2006). Thus, whilst the current data is quite limited, and does not explore behaviour amongst those living with diabetes, it does suggest that a focus on improving engagement in physical activity may be merited and that improving general activity, such as walking may have more salience than promoting general purposeful exercise, as long as it can be done at the appropriate levels of intensity.

**Weight management**

Migration and the habits associated with living in an urban setting are likely to contribute to the increased prevalence of obesity in UK Black communities. For example, the RODAM study, a multi-centre cross sectional study which compared prevalence of obesity in rural Ghana, urban Ghana and Europe, demonstrated an

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⁹ International Physical Activity Questionnaire
increasing prevalence of obesity as individuals moved from a rural to urban setting in Ghana, increasing further with migration to London and other European cities. Correspondingly, the prevalence of T2D increased in those living in Europe to almost double the prevalence compared to those living in rural Ghana for women and five times for men (Agyemang et al., 2016) (Figure 1-11). This pattern is supported by other studies investigating the African diaspora (Osei, 1999, Rotimi et al., 1999). The prevalence of hypertension associated with adiposity shows a similar trajectory and is both an associated risk factor for T2D and a key target for diabetes self-management (Kaufman et al., 1996). This highlights the importance of supporting weight management behaviours as part of diabetes self-management for these communities.

Figure 1-11: Increasing prevalence of diabetes and obesity comparing rural and urban settings in Ghana with Europe (n=5659) (Agyemang et al., 2016)

Observational data, therefore, amongst the wider UK African and Caribbean communities, highlights that social norms surrounding lifestyle behaviour following migration to the UK setting may create challenge for those trying to manage T2D within these communities.

1.3.4.2 Cultural influences on behaviour

In this section I summarise the literature exploring cultural influences on health behaviour relevant to T2D self-management behaviour.

Diabetes-related health beliefs

There are similarities between the findings amongst African and Caribbean immigrants in other high-income countries and those in the UK, with cultural influences on understanding of diabetes being apparent and natural approaches to treatment being
valued. The two qualitative studies in the UK exploring beliefs of Black Caribbean individuals by Brown et al. (2007) and Scott et al. (2001, 1998, 1997) reported gaps in understanding of diabetes physiology, with a tendency to associate development of the condition with external causes such as pollution, God’s will, the UK climate and associated stressful lifestyle. A focus on external rather than physiological causes was identified by Scott et al. (1998) to be a key difference between Black Caribbean and White participants in their mixed ethnicity study. Blood was seen by Black Caribbean participants as an index of health, and diabetes was associated specifically with sugar in the blood, rather than underlying physiology (Scott, 1998, Scott, 2001). Scott et al. (2001) specifically noted in their survey data, that weight gain in general was not recognised to contribute to T2D, both in individuals who did and did not have diabetes. Natural herbal remedies were well-regarded as viable treatments for diabetes, such as “bitters” to “clean” the blood, as well having “washouts” by drinking a lot of water or sweating out impurities and sugar in the heat of the sun (Scott, 2001, Scott, 1998, Brown et al., 2007). By contrast these studies noted Black Caribbean participants to be “mistrustful” of the chemical nature of tablets and insulin (Brown et al., 2007) and to have a particular fear of insulin use (Noakes, 2010). Individuals gave weight to their own symptoms, rather than objective measurements of glucose control such as HbA1c when determining measures to manage diabetes (Brown et al., 2007). These studies amongst Black Caribbean adults are, however, quite dated and it is unclear whether health beliefs have shifted as a result of the more recent NHS focus on person-centred, culturally competent care, which aims to address different explanatory models of illness (Hudon et al., 2012).

With regards to those of Black African heritage there have been two recent studies (Alloh et al., 2019a, Omodara et al., 2021), with the latter of these specifically focusing on exploring health beliefs amongst sub-Saharan African individuals (n=35). Misconceptions about the causes of diabetes were evident in the analysis by Omodara et al., (2021). This study highlighted the importance social influences on perceptions and beliefs about diabetes, and in particular noted perceived risk from heredity being
more apparent than the risk from individual behaviour choices. Both Omodara et al. (2021) and Alloh et al. (2019a) emphasised the faith placed in natural remedies amongst individuals of African heritage. Omodara et al. (2021) also identified a parallel mistrust of medication, which was not evident in the Alloh et al., study but which reinforces a theme reported the wider international literature. Omodara et al. also highlight stigma associated with T2D in UK African communities, which could limit health seeking and lead to social withdrawal. Comparatively, the study by Omodara et al., presents a cultural perspective amongst participants which contrasts to the more biomedical perspective reported in the study by Alloh et al. It is likely that this is due to differences in the recruitment strategy with Omodara et al. recruiting widely from community sources and Alloh et al. recruiting largely from diabetes support groups. This difference highlights the importance of encouraging engagement across communities and exploring recruitment from a range of sources in my study, in order to reflect a diversity of perspectives. Abubakar et al. (2013) concluded that compared to White British individuals, both African and Caribbean participants in their survey study (n=359) perceived diabetes to be a “benign”, “short-term” condition. Conclusions from survey data alone, however, should be treated with caution due to the level of literacy and health knowledge required to complete questionnaires. Conversely, qualitative studies suggest both African and Caribbean individuals were fearful of the consequences of diabetes, freely describing stories of witnessing amputation and incidences of diabetic coma (Brown et al., 2007, Scott, 1998, Omodara et al., 2021).

It is potentially a collective limitation of these studies that these beliefs are largely presented as universal and moderating influences of acculturation and ethnic identity are not explored. Additionally, how these beliefs translate to health behaviour remains largely unconsidered. The use of grounded theory methods, which I employ in my study, can help develop this understanding by creating a model to suggest how these factors interact to shape self-management behaviour.
Normative influences on lifestyle behaviours

Existing studies amongst those living with diabetes suggest that for both Black African and Caribbean individuals it is challenging to make dietary changes, especially if the guidance does not provide culturally salient dietary advice (Omodara et al., 2021, Brown et al., 2007, Scott, 2001). The role consuming traditional foods plays in maintaining ties with native countries is emphasised across UK qualitative studies amongst both African and Caribbean diabetic (Brown et al., 2007) and non-diabetic individuals (Ngongalah et al., 2018, Ochieng, 2011b, Rawlins et al., 2013). Furthermore, because of the role cultural foods played in affirming cultural values, individuals wanted to modify their existing diet rather than significantly change their dietary choices (Omodara et al., 2021).

Despite the importance of weight in diabetes self-management only one UK study has explored this issue in any depth (Scott, 2001). Scott et al. (2001) reported a perception of participants that traditional cultural views about weight were common in the Caribbean but not considered relevant in the UK context. This study, amongst Black Caribbean adults with and without diabetes appears to contradict the majority of the international studies which conclude cultural values perpetuated acceptance of larger body sizes amongst Black adults living with diabetes, especially women (see 1.3.2.2) This study did include 50% of the sample in the 25-45 age bracket and it may be that this finding is largely influenced by the views of the younger participants. Certainly, two UK qualitative studies conducted amongst African and Caribbean women who were not living with diabetes, reinforce findings from the US. Comparing attitudes of Black and White women, Shoneye et al. (2011), conclude Black women (both African and Caribbean) had a broader positive attitude towards larger body sizes than those of White ethnicity, influenced by a view that carrying more weight reduced vulnerability to illness and was a sign of wealth and fertility. Similarly, young Black African women in a recently published study reinforced the presence of a cultural perception that African women should be “thick and curvy” (Ngongalah et al., 2021). This latter study also suggested, that whilst knowledge of about the risks of weight gain improved in the UK
context, women were still uncomfortable with the notion that “being fat means you are unhealthy” (Ngongalah et al., 2021). In both studies obesity as a medical descriptor was strongly rejected by Black women. Factors shaping weight management amongst Black African and Caribbean men, remain largely unexplored in the UK context.

Wider normative influences on physical activity for those with diabetes are not well-explored in existing studies. In fact, a marked lack of studies exploring influences on engagement in physical activity, in general, amongst UK Black African and Caribbean adults is noted in systematic reviews (Ige-Elegbede et al., 2019, Patel et al., 2017, Koshoedo et al., 2015). However, some useful insights are evident in studies in non-diabetic individuals. In a qualitative study amongst Black Caribbean adults in West Yorkshire, engagement in purposeful activity was described as not part of the cultural norm, especially for women (Ochieng, 2011b). In a mixed ethnicity study amongst older adults, feeling marginalised in exercise classes perceived to be Eurocentric was also reported amongst older Black participants (Hartley and Yeowell, 2015). There were additional cultural barriers specific to women from Muslim African countries who reported the lack of female only leisure facilities. In these communities the benefit of community support and culturally concordant instructors was also noted (Persson et al., 2014).

There has, therefore, been little detailed exploration of normative influences on diabetes-related health behaviours amongst individuals living with diabetes, however wider literature, amongst the general UK African and Caribbean population, suggests normative influences can act as barriers to behaviour change. Further exploration of influences shaping engagement with physical activity and weight management self-management guidance particularly, is warranted.

**Wider cultural constructs**

Wider social constructs are important to understand because encompassing these deep structures can improve the salience of health promotion (Resnicow et al., 1999).
There are two constructs reported in the American literature that have some reinforcement amongst UK studies, these are spirituality and communalism.

- **Spirituality**: Spiritual coping is identified in UK studies in both Black African and Black Caribbean adults living with diabetes (Omodara et al., 2021, Scott, 1998, Brown et al., 2007). The importance of spirituality is also reinforced in UK studies amongst those coping with cancer and other long-term conditions (Alidu and Grunfeld, 2020, Mulugeta et al., 2017, Akinlua et al., 2017, Wagland et al., 2020, Koffman et al., 2008, Bache et al., 2012).

- **Communalism**: Reflecting the international literature, Alloh et al. (2019a) and Omodara et al. (2021) report reliance on social networks to support diabetes self-management in UK Black African adults. However, the wider cultural value of communalism is not explored in detail in any of the UK diabetes studies. Nevertheless, its importance is suggested by studies amongst African and Caribbean families generally in the UK. Ochieng et al. (2011a) explored the importance of kinship bonds in interviews with 10 Black families in West Yorkshire and highlighted the importance of kinship networks in providing practical and psychological support that enhanced individual wellbeing. The extended kinship network of family and friends from neighbourhood organisations gave individuals a sense of security, shaped group identity, defined behavioural rules, and contributed to the emotional, physical, and financial needs of the family. The church and social networks within the community provided practical and financial support for anyone who was struggling, according to a qualitative study amongst 31 Ghanaians living in Manchester (Osei-Kwasi et al., 2019). Similarly, in a qualitative study conducted in South London (n=45), the size and diversity of social networks comprising community organisations, friends and family was a noted advantage for Black Caribbean participants living with cancer compared to White counterparts (Koffman et al., 2011).

The current literature highlights the potential value of including spiritual and social support messaging in culturally tailored care, however, these factors are not explored
in detail in published studies amongst individuals living with diabetes. In addition, there are several other cultural constructs evident in African American studies (see Table 1-4) which have not been reported to date in UK populations and if of relevance, may be of potential value to incorporate into culturally tailored health promotion.

1.3.4.3 Social and environmental influences on behaviour

Again, there is a paucity of data from the UK setting exploring perceptions of structural influences specifically upon diabetes self-management in UK African and Caribbean adults. There are, however, some studies amongst the general UK African and Caribbean population that give some insights upon these influences. I draw on this literature below, where relevant, alongside the studies amongst people living with diabetes.

Socioeconomic factors

Alloh et al., (2019a) identified the cost of food to be a barrier to following diabetes dietary advice, however, socioeconomic factors are not explored in current studies amongst individuals living with diabetes. A small study amongst Ghanaians without diabetes (n=31), conducted in Manchester, emphasised how food insecurity was experienced by the community in general and it led it led to people opting for “belly food” which filled you up, despite being acknowledged as a less healthy choice (Osei-Kwasi et al., 2019). A recent systematic review acknowledged a limitation in the number of studies exploring socioeconomic influences upon lifestyle behaviours in general, amongst adults of African heritage living in the UK (Ngongalah et al., 2018).

The local food environment

Families living in large UK cities have described relatively easy access to affordable traditional cultural foods in local shops, markets, and restaurants (Ngongalah et al., 2021, Ochieng, 2011b). The proximity of fast-food outlets to homes, work, and schools, however, presented a challenge. The recent systematic review of evidence amongst Black African women suggests fast highlights the obesogenic nature of the food
environment UK, with fast-food food tastes and flavours being enticing, particularly for young people (Ngongalah et al., 2021).

**Structural barriers to care**

A lack of culturally salient self-management advice, particularly concerning diet was highlighted by individuals living with diabetes in several studies (Scott, 1997, Scott, 1998, Brown et al., 2007, Omodara et al., 2021), and this created a barrier to dietary change. The perspective of healthcare professionals supporting South London communities also highlighted a distinct tension between structural and responsive care needs (Goff et al., 2020). The stresses of meeting challenging service targets in an under-resourced and time-limited environment were described, creating challenge in meeting needs of ethnically diverse communities. Furthermore, healthcare practitioners considered that several sociocultural factors limited engagement. These included managing multiple working roles, social pressures, caregiving responsibilities, and deference to community-situated sources of advice as well as preferences for prescriptive advice and visual learning. Practitioners valued structured education as part of the care offering, however felt that it did not meet the needs of their ethnically diverse communities. It is likely that challenges in London, where GPs are dealing with large diverse minority ethnic communities, may not reflect the wider experience. Nevertheless, this study does provide useful insight for my thesis given the study population is from the same geographical location.

The strong distrust of healthcare evident amongst African Americans living with diabetes, is less apparent in the UK setting. Indeed, in general, the NHS diabetes provision was valued (Abubakari et al., 2013, Brown et al., 2007, Scott, 1998, Scott, 1997). Nevertheless, some disengagement due to lack of trust was evident in two studies. Both Brown et al. (2007) and Scott et al. (1998) report non-disclosure and appointment avoidance was suggested amongst some participants, due to lack of trust; the latter study relates this to a failure of the healthcare professionals to

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10 This study was conducted as part of HEAL-D but is reported as an independent analysis as it was not part of my PhD.
Introduction: Supporting diabetes-related health behaviour in Black African and Caribbean adults

acknowledge social, cultural, religious and economic factors which influence the individual’s ability to engage. This literature is now relatively dated, however, and may not reflect the current situation.

Beyond those living with diabetes, the literature amongst the general UK Black population does provide further insight into factors which may potentially influence those living with diabetes. This literature does suggest a stronger distrust of healthcare present in UK African and Caribbean adults. One reason for lack of trust was that healthcare was seen as part of the British establishment; for example in qualitative interviews with 23 sub-Saharan African women worries about legal status were considered before engaging with healthcare teams (Chinouya and Madziva, 2019). Studies also suggested that Black individuals did not feel represented in the healthcare system and alluded to discrimination and racism (Bailey and Tribe, 2020, Mulugeta et al., 2017). One study exploring views about prostate cancer amongst African and Caribbean men, for example, reported a sense of disenfranchisement and alienation from medical care with participants expressing fears about being victimised and that biomedicine was toxic and impure (Mulugeta et al., 2017). Other studies indicate that, rather than distrust, disengagement resulted from the perception that health promotion and support did not consider their culturally situated needs (Jones et al., 2015, Ochieng, 2011b, Ochieng, 2013, Scott, 2001). In diabetes self-management engagement with the healthcare team is an important part of empowering engagement with self-management behaviours (Hudon et al., 2012) and this literature suggests understanding factors influencing engagement with healthcare is an important consideration in supporting healthful self-management behaviour in my study population.

Qualitative interviews with 18 non-diabetic Black Caribbean adults in West Yorkshire emphasised pressing issues of racism, discrimination and education inequalities, impacted on the priority given to following healthy lifestyle advice (Ochieng, 2013). Racism against post-war migrants from the Caribbean has been well documented and discrimination is still pervasive in the UK context, as adolescents living in inner city
London who took part in the DASH study described (Harding et al., 2018). Racism has been linked to health both in terms of the stress it creates (Williams, 2018) as well as indirectly, reducing opportunities and access to services (Szczepura, 2005). Participants in this study by Ochieng, also voiced strong resistance to food-related health messaging which was seen to be enhancing White British values; a way to enforce social order and control. The perception that their ethnic identity was marginalised in dietary advice led to resistance in some – “I am rebelling against the whole system in this country and I eat what I want to eat.” (Ochieng, 2013). It is unclear from the current literature amongst those living with diabetes, how important these wider social factors are in influencing self-management behaviour.

1.3.4.4 Summary

Understanding sociocultural factors influencing diabetes self-management is an important first step in designing culturally salient health promotion to support the adoption of healthful self-management behaviour for people of Black African and Caribbean heritage. In the UK setting, studies to date have prioritised exploration of diabetes-related health beliefs, at the expense of wider structural and social issues; studies amongst the general UK African and Caribbean population, however, suggest the important influence of these factors on health behaviour. The intersection of acculturation and ethnic identity which may moderate the impact of cultural factors and understanding how health beliefs translate to self-management behaviour, are largely unconsidered to date in the current literature. While this literature suggests some potential avenues to address to support healthful self-management for UK African and Caribbean adults, studies to date have not considered how to develop culturally tailored support and behaviour change interventions to achieve this.
1.4 Conclusions, rationale and aims for this study

1.4.1 Conclusions from the literature

The global burden of T2D and the disproportionate burden upon those of Black African and Caribbean heritage highlight the importance of investigating ways of improving health inequalities. In the UK, focus on person-centred care and cultural competency are key policy strategies to support minority ethnic communities; developing culturally salient support interventions is recommended within these approaches.

Understanding sociocultural factors which influence engagement with diabetes self-management recommendations in UK Black communities is a priority to improve the cultural salience of care. In addition, there is a robust body of literature supporting the value of developing culturally tailored lifestyle, education and health promotion interventions to support diabetes self-management for minority ethnic communities.

Studies to date amongst people of Black ethnicity however have been conducted primarily in the US setting with African American communities, which have limited transferability to the UK setting. The cultural tailoring of healthcare interventions in the UK is a more recently explored strategy and to date has prioritised South Asian communities. There is therefore a need to understand how efficacious culturally tailored interventions can be designed to support UK Black African and Caribbean communities.

In the UK, studies to date explore diabetes-related health beliefs (Omodara et al., 2021, Brown et al., 2007, Scott, 1998, Scott, 2001). There has been little investigation of influences on physical activity and weight management amongst those living with diabetes and the influence of wider sociocultural factors not been well elucidated. It is largely unclear, from the studies to date, how these beliefs shape behaviour and how acculturation intersects with both health beliefs and lifestyle behaviours. Only one study to date, conducted amongst West African immigrants, has used grounded theory methods to explore self-management behaviour (Alloh et al., 2019a). There are no published theories to explain self-management behaviour in UK Black Caribbean
people living with diabetes. Whilst two qualitative studies in UK with Black African communities have been conducted recently (Omodara et al., 2021, Alloh et al., 2019a), the only studies amongst immigrants from the Caribbean (Brown et al., 2007, Scott, 2001, Scott, 1998, Scott, 1997) predate the policy changes towards more person-centred cultural competent care. A contemporary study amongst Black Caribbean individuals is therefore warranted.

1.4.1.1 Rationale for this study

To improve the cultural competence of care amongst UK African and Caribbean adults and to develop culturally salient health initiatives which are theoretically informed, it is necessary to understand: current patterns of T2D self-management behaviour, the associated sociocultural influences which influence those patterns, and the potential determinants of behaviour which may be addressed to support positive behaviour. The rationale for this study is based upon the over-arching hypothesis that understanding the sociocultural context shaping individual behaviour will help to inform our ability to improve the cultural salience of care for Black African and Caribbean adults living with type 2 diabetes, resulting in improved outcomes.

In my study, I use inductive qualitative methods to explore diabetes-related health behaviour and the social and cultural factors which shape it. A deductive behaviour change framework is then applied to the data to identify determinants of behaviour and associated evidence-based behaviour change techniques. The behaviour change techniques may be used in interventions to target these determinants to support positive health behaviour.

1.4.1.2 Expected contribution to knowledge

- This study provides a contemporary account of self-management behaviour in Black African and Caribbean communities in the UK. It explicitly explores sociocultural factors which may be helpful in informing the provision of culturally competent care to support health behaviour and improve diabetes-related outcomes.
• The inclusion of individuals from both African and Caribbean communities allows a useful comparison of differences, to ensure findings are relevant to both groups within the healthcare setting.

• Resultant theory adds to the understanding of self-management behaviour in UK Black communities and gives indication of when and how to target interventions.

• The identification of key determinants of behaviour and associated evidence-based behaviour change techniques will help theoretically inform the design of culturally salient health promotion for these communities.

• This work is likely to be of relevance for both health practitioners and researchers aiming to understand how to support Black African and Caribbean individuals living with T2D.

1.4.2 Study aims & objectives

Aims
1. To understand and describe the contextual sociocultural factors influencing T2D self-management behaviours in UK Black African and Caribbean adults.
2) To explore how these factors shape self-management behaviour.
3) To identify potential intervention targets and associated evidence-based behaviour change techniques (BCTs) to develop theoretical understanding of how to support healthful behaviour in a culturally salient manner.

Objectives
1. To understand the contextual sociocultural factors influencing diabetes-related health behaviour using grounded theory methods. To include:
   a. understanding the influences on engagement with self-management care and advice.
   b. identifying factors shaping engagement in physical activity, weight management, dietary management and medication use specifically.
   c. identifying wider cultural constructs which may be relevant to improve salience of culturally tailored interventions.
2. To theorise diabetes self-management behaviour using grounded theory methods. To include:
   a. understanding the lived experience of self-management.
   b. understanding how individuals differ and factors which influence different patterns of behaviour.

3. To use a theoretical behaviour change framework to systematically identify barriers and enablers to diabetes self-management health behaviours and the determinants of health behaviour that are potential targets for intervention. To include:
   a. exploring key determinants of behaviour using the framework.
   b. identifying potential evidence-based behaviour change techniques which may positively influence behaviour.
   c. evaluating the potential of these behaviour change techniques in a real-world setting.
SECTION 2: METHODOLOGY & METHODS

This section is organised in two parts. In the methodology chapter (2.1), I will explain the theoretical perspectives which guided my choice of research methods, as informed by frameworks for designing social research (Crotty, 1998, Blaikie, 2010). In the proceeding chapter (2.2) I will describe the methods in more detail.

The data for this study were collected as part of the mixed methods HEAL-D study, which is introduced below.

About HEAL-D and the data for this thesis
The stated aims of HEAL-D were to develop a culturally tailored, evidence-based self-management programme for managing T2D in UK Black African and Caribbean communities and to determine the feasibility of evaluating the programme in a future effectiveness trial (Goff et al., 2019). There were two phases to the study, the first a formative phase in which the intervention was co-designed and developed and the second a feasibility randomised controlled trial (RCT) (Figure 2-1, page 81). Study recruitment commenced in April 2017 and the programme of study lasted 36 months. In Phase I, participatory methods (focus groups, interviews, and workshops) were used to engage three groups of stakeholders in the co-design of the intervention: people of Black African and Caribbean heritage living with diagnosed diabetes, community leaders and healthcare professionals. In Phase II the co-designed HEAL-D intervention was evaluated in a feasibility study, compared to usual care in an RCT design.

My PhD study uses the patient qualitative data, which as the study’s lead researcher I collected in both Phase I and Phase II of the HEAL-D study (Figure 2-1). Data collection was designed a priori to accommodate my PhD objectives while also addressing the requirements of the HEAL-D study (see page ix for statement of contribution).
Figure 2-1: HEAL-D study design. Qualitative patient data were collected in phase I (8 focus groups) and Phase II (4 focus groups and 20 interviews).
2.1 Methodology

2.1.1 Statement of positionality

My background is in public health nutrition, and I have worked in clinical practice as well as in a research setting. This dual perspective has shaped my approach to this study. I am a British, White, middle-class female, in my late 50s. Much of my practice was similarly, amongst White middle-class patients. Nevertheless, many found lifestyle-related behaviour change very difficult and I became very motivated to understand the challenges of behaviour change as part of my work. I then became interested in cultural influences on health and health inequalities in UK minority ethnic groups during my MSc in Nutrition at KCL, when I was exploring weaning behaviour amongst UK mothers and identified strong sociocultural influences upon the behaviour of mothers (Moore et al., 2014). I subsequently worked as a public health nutritionist on a number of research studies which involved partnership with London minority ethnic communities, such as the ESTEEM trial at the Royal London Hospital, which focused on dietary behaviour change and the Attitude Study at the University of Westminster, an observational study of lifestyle behaviours in Black African women. These experiences highlighted how many challenges with lifestyle change are accentuated in London minority ethnic communities and the powerful role of cultural, social and environmental influences in shaping behaviour, beyond individual psychological factors. The opportunity to work as study coordinator for the HEAL-D study while pursuing my PhD research brought my two area of interest together. I felt sensitive to the literature surrounding white privilege and the obvious differences in perspective and experiences between myself and the participants and I think it inevitable that the differences may have reduced disclosure compared to an ethnically and socially concordant researcher conducting the research. I chose to spend more time building up trust with participants than I would have, I think, without these social and ethnic differences. This took a considerable time investment – interviews for example often involved considerable time building a bond before the formal interview began. I feel with the women, shared gender and being of a similar age to many,
helped break down some of these barriers. Certainly, by the end of the study, having met several participants multiple times, the relationships with the female participants seemed to me, frank and open. The fact many of the female participants invited me to conduct the final interviews in their own homes, was indicative of the trust between us. I think, however, that my identity is likely to have impacted on findings, reducing disclosure from some of the male participants. The choice of methodologies was also influenced by my experience as I began the study with pre-conceptions about the likely challenges of long-term behaviour change, thus was particularly motivated to use a defined framework underpinned by behaviour change theory as part of my analysis. Ultimately, the findings of the study will have been shaped by both my identity and my recognition, through experience, that health behaviour change is difficult and multi-faceted, particularly when individuals face strong cultural influences as well as inequalities.

2.1.2 Situating the research

This study is approached from an interpretive theoretical perspective. Interpretivism asserts that natural reality and social reality are different and therefore require different kinds of study method (Gray, 2017) and that social reality is a product of its inhabitants (Blaikie, 2010). Within this philosophical stance the choice of methodology is further guided by symbolic interactionist assumptions. The tenets of this philosophy most relevant to this research are that individuals act based on the meaning which objects and situations have for them\(^\text{11}\); that meanings emerge from interaction with others in the social context; and that meanings change over time as a result of experiences and interactions (Carter and Montes Alvarado, 2019). The role of culture is central and significant in the symbolic interactionist approach; culture is “the meaningful matrix that guides our lives.” (Crotty, 1998). Methodologies informed by symbolic interactionism emphasise the importance of understanding the perspective of the actor and include ethnography, grounded theory and phenomenology particularly (Crotty, 1998). This theoretical perspective is underpinned

\(^{11}\) Meaning here is the subjective significance, purpose or quality, actors impute to their actions. Mead, 1971
epistemologically by constructionist assumptions, namely that both meaning and knowledge are constructed by the researcher as he or she engages with the realities of the world, rather than there being an objective truth waiting to be discovered.

The HEAL-D study was conceptualised as a participatory study, with an objective of co-designing a culturally sensitive diabetes education programme. This inductive approach to data collection sits comfortably with the research objectives for this study. Amongst qualitative methodologies, grounded theory is well-suited to develop understanding of the perspective of the participant.

The perspective for this study is primarily etic – “concerned with comparison across cultures” (Whitaker, 2017) – as a key objective is to understand how sociocultural factors in UK African heritage communities shape health behaviour in the context of the culture of the UK healthcare system. The etic orientation, or outsider position, often starts with theories and concepts that are meaningful to scientific observers. Certainly, the use of a deductive framework to understand behaviour can be considered an etic perspective and as such findings are written from an external vantage point (Whitaker, 2017, Olive, 2014). However, in my exploration of the lived experience of diabetes with participants, using grounded theory methods, I adopt an emic perspective – “looking at things through the eyes of members of the culture being studied”, collating the “insider view” (Whitaker, 2017). It has been argued that phenomena studied in a cross-cultural context (etic) can always benefit from exploration of local and culture-specific realities (emic) (Aycan, 2008). The addition of the emic perspective has even been considered essential to cross-cultural research (Fetterman, 1989, Woolcot, 2008). Supporting the view that the etic and emic perspectives lie on a continuum rather than being mutually exclusive and incompatible (Aycan, 2008, Whitaker, 2017), my choice of methods reflect my acknowledgement that supporting health behaviour in the UK environment first begins by understanding the lived experience of individuals.
2.1.3 Research design

My study is designed in two parts (Figure 2-2). For the first part of the analysis an inductive grounded theory analysis approach is adopted to explore meaning from the point of view of the participants (objectives 1 and 2). The second part of the analysis employs a deductive approach, as a behaviour change framework is applied to the data (objective 3). These two methodologies facilitate triangulation with regards to answering the research questions. The inductive methods allow a free exploration of the data, minimising pre-conceptions (facilitated by bracketing see 2.2.6.1), giving the opportunity to allow patterns and influences to be emergent in the process of data analysis. This approach explores the development of themes which may be missed if use of a “top-down” framework was the only method of analysis. The subsequent application of the behaviour change framework is intended to help translate the data to practically inform health promotion by assisting in the identification of constructs which may be useful intervention targets, according to established behaviour change theory. Employing both deductive and inductive methods improves the validity of the findings. It also presents the opportunity to evaluate potential influences on health behaviour that may not be immediately apparent should deductive methods alone be applied. In this way, it will also allow me to reflect upon the novel utility of this behaviour change framework in the identification of behaviour change theoretical constructs to support UK Black African and Caribbean adults living with T2D.
2.1.4 Theoretical framework

Recognising that the psychology governing health behaviour of the individual is also influenced by the surrounding social environment, I am approaching this study from a sociopsychological perspective, drawing on theory both from sociology and psychology. In accordance with the recommendation for a grounded theory study, relevant theory is identified after the analysis, in order to frame the findings (Glaser, 1998). The sociopsychological perspective was relevant in the study design, however, as it influenced the choice of inductive qualitative methods to understand wider social influences more fully and to complement the use of a behaviour change framework which is psychologically focused. The topic guide and structure of the data collection involved a flexible approach to encourage a wide exploration of issues, both social and psychological, which were perceived as relevant by the participants. This approach was intended to satisfy the parameters for grounded theory methods, as well to focus more specifically on understanding the psychological parameters identified as relevant in the psychological-behaviour frameworks informing the design of the COM-B and behaviour change wheel methodology, which are further described in 2.1.5.2. below.
2.1.5 Consideration of research methods

2.1.5.1 Part 1 - Grounded theory analysis

Grounded theory has some advantages over other qualitative analysis methodologies, not least in that it has been one of the most well documented qualitative analysis processes. It is designed to anchor any findings firmly in the data, challenging the perspective that qualitative methods lack rigour. The emphasis of grounded theory is on understanding the factors important to a behaviour or phenomenon and theorising them into an explanatory model, as opposed to simply summarising and reporting descriptive themes. I chose a grounded theory approach because of the rigour of the method to assist conceptualisation of analytic themes, the focus on the participant voice facilitated by the inductive approach, and the opportunity to understand how the concepts interact and hence to develop theory. In the case of my study developing theory is important to understand how sociocultural factors interact to influence health behaviour.

Approaches to conducting grounded theory

There are several evolving iterations of the methodology. For that reason, I will briefly introduce the different schools of grounded theory, before explaining why I chose the method I did.

The most common grounded theory approaches are the classic Glaser and Strauss method (Glaser, 1998), the evolved Strauss and Corbin method (Strauss and Corbin, 1998), the constructionist approach of Cathy Charmaz (Charmaz, 2014) and the more recent Birks & Mills approach (Birks and Mills, 2015). The classic approach encourages epistemological objectivity, to the degree that this is reasonable, for example having no preconceptions about the main concern and discouraging engagement with the theoretical literature prior to analysis. The more recent constructivist methodologies are less rigid in approach, allowing the researcher to focus on any phenomena of interest in the data.
The terminology and analytical processes vary slightly between grounded theory approach. Each has three coding phases that move the analysis from the raw data to the development of conceptual categories and finally towards an understanding of how the categories relate to each other. This is illustrated in Table 2-1.

**Table 2-1: Key phases of Grounded Theory and associated coding terminology (Chun Tie et al., 2019).**

<table>
<thead>
<tr>
<th>Grounded theory genre</th>
<th>Initial</th>
<th>Intermediate</th>
<th>Advanced</th>
</tr>
</thead>
<tbody>
<tr>
<td>Classic (Glaser and Strauss, 1967)</td>
<td>Open coding</td>
<td>Selective coding</td>
<td>Theoretical coding</td>
</tr>
<tr>
<td>Evolved (Strauss and Corbin, 1998)</td>
<td>Open coding</td>
<td>Axial coding</td>
<td>Selective coding</td>
</tr>
<tr>
<td>Constructivist (Charmaz, 2014)</td>
<td>Initial coding</td>
<td>Focused coding</td>
<td>Theoretical coding</td>
</tr>
<tr>
<td>Birks &amp; Mills (Birks and Mills, 2015)</td>
<td>Initial coding</td>
<td>Intermediate coding</td>
<td>Advanced coding</td>
</tr>
</tbody>
</table>

Whichever approach is adopted, the focus is upon coding actions and potential influences on these actions to explain behaviour. As coding develops there is usually strong engagement around a “core category”. The core is chosen for its explanatory power over the rest of the data. Classic grounded theory encourages the researcher to inductively identify the main concern of the study population and the core category and subsequent theory are developed to explain how this population behaves to address this key concern. The Strauss and Corbin axial coding is a key stage which sets this evolved methodology apart from the others. Axial coding provides a framework for testing how the categories fit together around the core category. In this approach the (causal) conditions leading to the phenomena, the action strategies, the consequences, and contextual factors are identified; it can be used to identify which categories are the dominant ones. It has been criticised for its rigidity however, and for the way in which the mechanical process of fitting the data into these predefined categories can be distracting without assisting theoretical understanding of the patterns within the data (Kendall, 1999). The final stages of coding involve defining the relationships between the key concepts. Some studies will stop at this stage, but
continuing to the advanced stage of analysis, applying theoretical codes to the data gives shape to the interaction between concepts and results in theory\textsuperscript{12}.

**Choosing a grounded theory approach**

I have used a classic grounded theory approach in my analysis. I had initially gravitated towards the more evolved approaches detailed in published textbooks (Rivas, 2018, Birks and Mills, 2015, Charmaz, 2014, Bryant and Charmaz, 2019, Saldana, 2016). However, whilst these texts were detailed, they did not give me the guidance I needed to move from developing a set of concepts to generating a theory. I therefore attended a practical grounded theory data seminar, which focused on classical grounded theory, and I found this helpful in informing my approach. This classic method is supported by a raft of detailed support booklets by Glaser (Glaser and Strauss, 1967, 2005, 1998, 1978). In addition, I was able to take advantage of the grounded theory community mentorship provision, which is available to guide researchers through the classic grounded theory process. In my opinion the use of classic grounded theory analysis helps to create a tight parsimonious theory to explain behaviour, as any data not directly related to the actions is excluded from the theory. This was particularly helpful given my objectives. On the other hand, the evolved approaches encourage the development of a “*storyline*” narrative to explain the interaction between categories. This has the advantage of creating a looser, more inclusive, thematic view of how the all the data interact. The opportunity to describe the data more fully is therefore, to a degree, sacrificed in the classic approach but the result is a tighter theory to explain behaviour.

**2.1.5.2 Part 2 – Application of a behaviour change theoretical model**

**Choosing the framework**

I chose to use COM-B and the behaviour change wheel developed by Susan Michie and her team at UCL (Michie et al., 2011b), following my review of the advantages and disadvantages of this method compared to the invention mapping approach

\textsuperscript{12} Theoretical codes are codes to describe how the categories interrelate.
(Bartholomew et al., 2016). Intervention mapping is a very comprehensive, flexible framework and it has been used successfully in several health promotions to support diabetes (Shakibazadeh et al., 2015) and lifestyle change (Gillison et al., 2012, Friederichs et al., 2014, Fransen et al., 2008). Ideally, however, intervention mapping requires the involvement of a behavioural scientist to help develop the choice of appropriate theory (Bartholomew et al., 2016). COM-B and the behaviour change wheel is also a rigorous approach designed to be applicable to policy and intervention development. It incorporates elements of the theoretical domains framework which has been used extensively in the healthcare arena (see Figure 2-11 for table illustrating this framework) (Cowdell and Dyson, 2019). Its application is explicitly defined, however, which improves accessibility even for those without behaviour science expertise. My choice to proceed with COM-B was pragmatic but it allowed me to reliably apply a proven framework to inform my analysis without having to have a detailed knowledge of the plethora of behaviour change theories and the associated conditions for their appropriate use. My approach can be rationalised on the basis that many health researchers find themselves without a behaviour scientist within their research team. Use of this approach in my thesis affords me the opportunity to assess its utility within a UK minority ethnic population.

**COM-B and the behaviour change wheel: An overview**

The methodology begins with a behavioural analysis and then provides a framework within which these findings can be mapped to potential intervention functions and then to suitable evidence-based behaviour change techniques using the behaviour change wheel. At the core of the framework is a COM-B analysis of behaviour. Essentially, behaviour is conceptualised to be a result of an individual’s capability (for example, skills and knowledge), their opportunity to perform the behaviour (social and environmental factors) and their motivation to do so (conscious/reflective and automatic/reflexive) (Figure 2-3).
An initial COM-B analysis of qualitative data helps to identify potential determinants of behaviour on which an intervention may focus. The behaviour change wheel then helps the researcher to apply relevant behaviour change theory to map to behaviour change techniques (BCTs). The behaviour change wheel has been developed from 19 frameworks of behaviour change identified by systematic review (Michie et al., 2011b). It consists of three layers; the hub identifies key findings of the COM-B analysis and is then surrounded by nine possible intervention functions and the rim identifies types of policy that may be appropriate. Each intervention function can be mapped to a range of possible, closely specified behaviour change techniques from a rigorously developed and closely specified list of BCTs forming the behaviour change technique taxonomy (Michie et al., 2013).

2.1.6 Summary

In my analysis I used grounded theory analysis to explore the perspective of the individual and theoretically determine how different factors influence self-
management behaviour. This part of the analysis aimed to develop an understanding of which determinants of self-management behaviour in this population are potentially key and modifiable. The application of an a priori framework (COM-B) then allowed me to both test these findings with an alternative analysis and identify appropriate evidence-based behaviour change techniques to modify these determinants. Collectively the findings of the two strands of my analysis deepen both theoretical and cultural understanding of how to support engagement with self-management recommendations in interventions and within diabetes-related healthcare in general, in UK Black African and Caribbean communities.
2.2 Methods

2.2.1 Participants and setting

2.2.1.1 Recruitment procedures

Participants were recruited to qualitative focus groups or interviews at two phases in the HEAL-D study. Figure 2-4 details how the recruitment was structured across the two phases of the study.

![Figure 2-4: Recruitment to focus groups and interviews](image)

**Phase I recruitment (co-design study)**

Recruitment strategies focused on both community and medical settings to ensure maximum diversity and a snowballing approach was employed (Table 2-2). Participants were primarily from the South-East London Boroughs of Lambeth, Lewisham, and Southwark, all of which have a high density of Black African and Caribbean residents and are near King’s College London (KCL). The eligibility criteria included self-identification as Black British, or Black African or Black Caribbean ancestry and having had a medical diagnosis of T2D, as detailed in Table 2-3. Purposive sampling was guided by a sampling framework with groups intentionally stratified by gender and ethnicity. Sampling was designed to include a range of different faiths and both first and second generational status.
Table 2-2: Recruitment

<table>
<thead>
<tr>
<th>Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Patients who had participated in previous research, particularly the South London Diabetes Study and who provided consent to be contacted regarding future research were sent a letter of invitation to participate.</td>
</tr>
<tr>
<td>• Database searches were conducted to identify potentially eligible participants from GP surgeries within the targeted Boroughs. In addition, practice staff raised the study with patients meeting the eligibility criteria.</td>
</tr>
<tr>
<td>• Community Leaders, including Diabetes UK Community Champions were involved in promoting the study within their own local communities and were engaged to help researchers to reach members of faith congregations within churches and mosques.</td>
</tr>
<tr>
<td>• A snowballing approach was employed such that participants could recommend their own contacts to participate, providing they met the eligibility criteria.</td>
</tr>
<tr>
<td>• Posters were displayed in local GP surgeries, NHS diabetes clinics and faith institutions to allow participants to self-refer.</td>
</tr>
</tbody>
</table>

Table 2-3: Eligibility criteria

<table>
<thead>
<tr>
<th>Eligibility criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical diagnosis of type 2 diabetes</td>
</tr>
<tr>
<td>Adult (over 18)</td>
</tr>
<tr>
<td>Self-identified as of Black British or Black African-Caribbean ethnicity</td>
</tr>
<tr>
<td>Resident in London</td>
</tr>
<tr>
<td>Able to provide informed consent</td>
</tr>
<tr>
<td>English speaking</td>
</tr>
<tr>
<td>No other comorbidity that specifically affects diet and lifestyle needs e.g., chronic kidney disease.</td>
</tr>
</tbody>
</table>

Effort was made to engage individuals who may not usually access the research process. This was facilitated by working with community advocates and by building relationships with mosques and Black majority churches, all of which were crucial in achieving this objective. Diabetes UK community champions, and other community leaders well known in the area, invited their contacts to engage with the study and helped promote the study at community events. I spent a good deal of time developing these relationships and supported requests for reciprocal help where possible, such as by speaking at local community charities and groups about health and wellness in general. It was a challenge particularly to recruit male participants; as a female researcher I was allowed, for example, to address the male groups in the mosque from the front of the room but the male religious representatives interacted with the men thereafter to collect names of individuals interested to participate. Similarly, pastors in the Black majority churches were instrumental in encouraging male members of the congregation to participate. This was especially the case for the
Caribbean men, whilst I was more successful recruiting African men directly from presentations to the church congregation.

An information pack, including an introductory letter and participant information sheet was sent by email or post to all identified potential participants. They were then contacted a minimum of 3 days after the despatch of the materials for further discussion. Those who were interested in taking part were guided through a screening questionnaire. Verbal consent to participate was obtained from participants who met the eligibility criteria and were willing to take part. Self-referring participants made initial contact by telephone or email. They were informed about the study verbally and taken through the screening questionnaire by telephone and the full information pack was sent out to participants who met the criteria and were willing to take part. Potential participants were then contacted again three days later to discuss any questions and give verbal consent. Written consent was then obtained upon arrival for their scheduled appointment, prior to the commencement of the focus group. Once again, the purpose of the study was explained, and details of what participation entailed was reviewed. Participants were given the opportunity to ask questions and to clarify their understanding before signing two copies of the consent form, one of which was retained for the research files, and the other given to the participant.

**Phase II recruitment (feasibility study)**

The eligibility criteria and the qualitative data collection setting were the same for Phase I and Phase II of the study. All participants in Phase I were eligible to take part in the Phase II feasibility study and the same recruitment methods were utilised but with greater focus on recruitment via primary care. Referrals for diabetes structured education were screened in the Lambeth and Southwark diabetes hubs, and those eligible were invited to participate in the HEAL-D feasibility study. Potential participants were approached and provided with information. Consent was obtained for the qualitative data collection as part of the consent to the feasibility trial. Consent was obtained in writing from the participants at their base-line assessment in the Clinical Research Facility at Guy’s and St Thomas’ Hospital.
Following completion of the endpoint visit, 20 participants were invited to attend an interview. Ten interviews with control participants and ten with intervention participants were conducted and a sampling framework was adopted to ensure representation of genders and ethnicities. The participants were invited for interview in sequential order at their endpoint clinical assessment, according to the sampling framework. All intervention participants were invited to join one of four focus groups. The structure of the focus groups and interviews is illustrated in Figure 2-4. A timeline of the data collection phases is shown in Figure 2-5.

Figure 2-5: Timeline for each phase of the study

### 2.2.2 Ethical and regulatory considerations

Ethical approval was granted by the NHS Health Research Agency (HRA) under IRAS (Integrated Research Application System) reference 194991 (Phase I) and reference 233419 (Phase II).

The recruitment materials, information sheet and consent form were designed and written as simply and concisely as possible, to make the information as attainable as possible for a range of literacy levels. For the purposes of this study only English-speaking participants were invited to take part. While this may have excluded some groups, particularly individual of East African ancestry, the time frame and budget of the project meant it was not feasible to adequately address the needs of non-English speaking groups. The subject matter and participants within this study are not high-risk in nature. It was not anticipated that any discussions would be sensitive. To accommodate the possibility that participants may be uncomfortable talking about living with diabetes, they were told that they did not have to answer any questions that may make them uncomfortable and that they could leave the discussion at any time. If any participants appeared or expressed discomfort at participation it was planned that they would be signposted to their GP and/or the Diabetes UK charity.
helpline. To minimise risk of unanticipated discomfort, participants were fully briefed about what the study entailed during the screening and consent process.

Procedures were put in place to ensure compliance to The Data Protection Act 1998 and the General Data Protection Regulation 2018, with regards to the collection, storage, processing and disclosure of personal information. Personal information was collected and held on a screening questionnaire. Once written consent was obtained the participant was allocated a unique study ID to be used on all documentation to anonymise the participant and avoid the use of personal identifiable data. The screening questionnaires were kept in a locked cabinet in a locked office on university premises. The screening questionnaires will be kept for seven years following completion of the research, after which time they will be disposed of confidentially. All electronic records were anonymised, and data files were only available to the research team. Data files, such as transcripts and audio recordings were password protected to ensure data protection during transfer between transcribers and researchers and the transcribers signed confidentiality documentation. Audio recordings were stored in password protected files. Audio files and transcripts will be stored for five years, after this time they will be safely deleted.

2.2.3 Data collection procedures

2.2.3.1 Phase I focus groups

The focus groups were conducted in a variety of premises including community halls, faith institutions and on the King’s College London university campus. The proceedings were audio recorded for later transcription. Each group lasted for approximately two hours. Refreshments were provided. Participants completed a form for reimbursement of their travel expenses, and they were given £20 in gift vouchers for their time. The groups were loosely structured to include an introduction to hear people’s diabetes stories and then to address three main topics around diabetes-related lifestyle changes, specifically food, weight and physical activity. A topic guide helped to guide the sessions (Table 2-4), however, the intention was for the session to be quite
fluid, to allow the participants to discuss their diabetes challenges freely. Food samples and images were provided to stimulate discussion around lifestyle change. These included traditional cultural foods as well as Western foods. To stimulate discussion around physical activity, a video was played during which a range of patients and healthcare professionals discussed physical activity for type 2 diabetes\textsuperscript{13}. Finally, in the section on weight, a selection of ethnically and gender matched images of varying BMI were placed on the table. The images were of fully clothed individuals dressed in a range of clothing types including sports clothes, traditional African/Caribbean dress and casual clothing. They were chosen to represent a full BMI spectrum. In a series of activities, participants were asked three questions: i) which individuals are most likely to be at risk of T2D? ii) Can you collectively as a group put the photos in order of likely risk of T2D? and iii) Put a sticker on the image which reflects your ideal body shape. Visual elicitation methodology, such as this, can be employed to improve the richness of the data (Glaw et al., 2017) and has also been shown to enhance rapport building and to facilitate communication (Pain, 2012). Nevertheless, it is useful to recognise that the selection of visual stimuli is sensitive and the stimuli themselves can be imbibed with cultural meaning which may influence the nature of subsequent discussion. For example, the clothes and hairstyle of the photo images and the choice of particular food stuffs is likely to have had some influence how they were interpreted. Two community advocates assisted in identifying appropriate images (one from Nigeria and one from Grenada). Overall, this approach was very successful in generating lively discussion, which included conversation between individuals from different African countries about the differences in staple foods and cooking methods and discussion about weight perceptions pre- and post-migration. It is likely however, that choices of different images may have guided the discussion in a different manner. I was one of the two co-facilitators of the Phase I focus groups alongside the study Chief Investigator. Prior to beginning data collection, I received training in qualitative methods on an external training course and in a KCL university training provision. The

\textsuperscript{13} The video ‘Decide to move’ was developed by John Hopkins Medicine for use with African American communities; link to www.youtube.com
facilitators took it in turns to direct different parts of the session, rotating responsibilities between groups. All members of the discussion groups were encouraged and given space to participate. The focus groups (both in phase I and phase II) had the advantage of being held before the COVID-19 pandemic; they were very relaxed and there was a good detail of laughter and discussion between participants – moments where the facilitators could sit back and listen. This was especially the case for the groups held in community venues and amongst the women. In the mosque setting the atmosphere was particularly relaxed with participants joining the group as discussion developed, and with children present. The male groups were slightly more reticent to freely discuss their health and discussion was stimulated by involving male community advocates within the groups. Field notes were made individually by both researchers during the co-facilitated sessions and collectively following each session. The field notes were intended to capture initial impressions and key themes coming out of the discussion as well as to identify areas to probe further in subsequent groups.

2.2.3.2 Phase II focus groups and interviews

Interviews

The interview venues included a range of locations to maximise convenience for the participants. These included private rooms within the university setting, community or medical setting. Some participants were also interviewed in their home. The participants were given a £10 gift voucher for their time. Refreshments were provided.

The sessions were loosely structured using a topic guide which covered a range of topics from their experience of T2D and care, to their own self-management behaviour and the factors which shaped it (Table 2-4). Those taking part in the HEAL-D intervention discussed these general topics as well as additional process evaluation questions. Time was taken to put the participant at ease. General field notes were

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14 Several participants took part in more than one of these sessions.
written for the whole interview. I conducted both the Phase II focus groups and interviews as the sole researcher.

Table 2-4: Summary of topic guides

<table>
<thead>
<tr>
<th><strong>Phase I focus groups</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Experience of diabetes and diagnosis, general experience of diabetes-related healthcare</td>
<td></td>
</tr>
<tr>
<td>Diet for diabetes – knowledge, attitudes, difficulties and facilitators</td>
<td></td>
</tr>
<tr>
<td>Physical activity – knowledge, attitudes, difficulties and facilitators</td>
<td></td>
</tr>
<tr>
<td>Weight management – Attitude to weight, success in achieving weight management, experience of healthcare weight management guidance</td>
<td></td>
</tr>
<tr>
<td>General exploration of factors that would help diabetes self-management</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Phase II interviews and focus groups</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Experience of diabetes care – including with healthcare team and diabetes education; recent interaction with diabetes services</td>
<td></td>
</tr>
<tr>
<td>Personal beliefs about self-management of diabetes</td>
<td></td>
</tr>
<tr>
<td>Self-management behaviour (diet, activity, weight management, medication use)</td>
<td></td>
</tr>
<tr>
<td>Personal diabetes self-management practices</td>
<td></td>
</tr>
<tr>
<td>Reflections on diabetes care in their communities</td>
<td></td>
</tr>
<tr>
<td>For intervention participants: experience of the HEAL-D intervention</td>
<td></td>
</tr>
<tr>
<td>• General discussion about the HEAL-D intervention and probe freely for what was remembered; what was useful and less useful; one thing to be changed.</td>
<td></td>
</tr>
<tr>
<td>• Probed discussion related to above questions, based on images of elements of the intervention.</td>
<td></td>
</tr>
<tr>
<td>• Views about key behaviour change approaches – e.g., value of support, demonstration, modelling, graded tasks.</td>
<td></td>
</tr>
<tr>
<td>• Experience of the facilitator, presentation style, audio-visual aids etc.</td>
<td></td>
</tr>
</tbody>
</table>

**Focus groups**

Focus groups were held in the venues used for the HEAL-D intervention and all participants taking part in the intervention were invited to attend. Light refreshments were provided, and participants were given a £10 gift voucher. The focus groups lasted for two hours. The participants knew one another as they had been in the educational groups together over several weeks. They were therefore very relaxed with one another, and with me as a facilitator. Discussion, consequently, was very honest, open and fluid, whilst being structured by a pre-determined topic guide (further detailed in Table 2-4). Participants were given the opportunity to raise relevant discussion points and to shape the direction of the discussion.
2.2.4 Data handling and cleaning

Audio recordings were made of each session (one master and a second recording as a back-up). Each recording was reviewed prior to sending for transcription to assess quality and make further field notes on the content. Verbatim transcription was carried out to allow for analysis to be as sensitive as possible to the mood and emotion of the sessions. A variety of accents presented potential challenges for accurate transcription of some groups. When this was the case, where possible, the transcription company provided a transcriber with familiarity with the different accents to improve accuracy of transcription. Each transcript was then reviewed alongside the original audio recording. In the focus group data, speakers were identified and anonymised in each script. In a minority of instances, certain comments could not be transcribed due to the variety of accents and use of dialect. I listened to each audio to fill in any missing sections of the transcripts and on one occasion went back to a participant to clarify meaning. This was not an issue in the interviews.

NVivo software was used to facilitate analysis. Each transcript was uploaded and in the focus group transcripts the speakers were auto coded to allow analysis of the contribution of each individual, alongside the transcripts of the group collectively.

2.2.5 Quality and rigour

Rigour of the qualitative analysis is discussed in the context of the Lincoln and Guba criteria of trustworthiness: the principles of credibility, transferability, dependability and confirmability (Lincoln and Guba, 1985, Searle, 2018).

Table 2-5: Establishing trustworthiness in qualitative research

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Credibility</td>
<td>The extent to which the findings reflect the reality of the phenomenon (Mays and Pope, 2000).</td>
</tr>
<tr>
<td>Transferability</td>
<td>The extent to which researchers’ interpretations and conclusions are relevant to other similar contexts (Nassaji, 2020).</td>
</tr>
<tr>
<td>Dependability</td>
<td>The stability of findings over time to the degree that findings would be repeatable within the same cohort and research team (reliability) (Lincoln and Guba, 1985).</td>
</tr>
<tr>
<td>Confirmability</td>
<td>the extent to which others can confirm the interpretation and conclusions reported (Nassaji, 2020).</td>
</tr>
</tbody>
</table>
2.2.5.1 Credibility

Informed by the recommendations of Searle (2018) and Lincoln and Guba (1985) several methodological processes were adopted to ensure credibility.

1. **Triangulation:** Triangulation was approached in a few ways. The data was collected both at the beginning and end of the HEAL-D study, with some participants contributing data on three occasions. This gave an opportunity to build trust, a key element in establishing rapport and improving the likely reliability of the data as an honest reflection of the phenomenon being discussed (Qu and Dumay, 2011). The data was also triangulated with the perspectives of community leaders and healthcare professionals (Goff et al., 2021). Methodological triangulation was achieved using both interview and focus group methods. Focus groups were useful to explore similarities and differences in opinions within the participant group and allowed discussion to flow freely in a more natural way with the researcher as observer, increasingly the likelihood of honest expression. Interviews then provided an opportunity to consider some issues in more depth. Finally, investigator triangulation was achieved through the initial set of focus groups being facilitated by two researchers. Each of us made field notes and initial impressions were discussed after each session. Later, as the analysis developed, data sessions were held, and the perspective of the second researcher was invaluable in confirming and expanding interpretation of the data.

2. **Peer auditing:** My supervisory team provided peer auditing support. Monthly meetings were held as the analysis developed and throughout the writing process.

3. **Deviant case analysis:** The use of grounded theory analysis methods was particularly helpful for exploring deviant cases as it is this diversity amongst participants that helps the development of the theoretical hypotheses. The theory was adapted as different participant perspectives and behaviour patterns were found within the data, so that all the data was incorporated. The community leader data was also helpful here as the community leaders
described the diversity that they had observed in the community, which helped
to frame cases which were apparently deviant in the patient analysis.

4. **Member validation:** Finally, member validation was incorporated into the
HEAL-D study design with a team of participants offering advice and input
throughout the study. Part of this included presentation of the key themes in
the qualitative data used in this thesis, to check understanding and get further
input.

2.2.5.2 **Transferability**

The use of “thick description” of the setting to allow the reader to personally assess
details of the context is recommended to support an understanding of the
transferability of the findings (Searle, 2018). Quotations are supported with details
about participants’ gender, age, and country of birth to support the reader in
developing their conclusions about the relevance of data to other contexts.

2.2.5.3 **Dependability**

To support the process of auditing, recommended as necessary to ensure
dependability (Lincoln and Guba, 1985), I maintained a daily journal throughout the
analysis process. This documented my personal reflections and key analytical
decisions. The analysis process was further documented in methodological memos
throughout the process, providing an audit trail of what decisions were made and how
concepts were developed throughout the process, from initially designing the study
and throughout the analysis process. The memos also documented the development
of ideas about concepts and provided a link back to the original data. I used diagrams
within the memos to help to organise conceptual development of themes. This process
provides a further documented audit trail of the development of the analysis (Dey,
2007). An independent grounded theory mentor also reviewed the memos relevant to
the development of concepts and grounding the analysis firmly in the data.
2.2.5.4 Confirmability

Confirmability is addressed in two ways in this study. Firstly, illustrative quotes have been used throughout to support conclusions made. This demonstrates the diversity of individuals contributing to the themes as well as providing traceability back to the primary data. Secondly, the use of the grounded theory concept-indicator process for developing concepts (see 2.2.7.1 below) means that analytical concepts are firmly linked to the data from which they were developed. The concept-indicator models were examined throughout the process of coding both by individuals in the supervisory team and by peers in grounded theory workshops and the associated buddy system.

2.2.6 Reflexivity

Reflexivity is usually understood to be the development of a self-critical account of the potential influences of a range of factors on the research process. These factors include personal characteristics of the researcher (gender, age, ethnicity), professional status, and personal and intellectual biases (Nassaji, 2020). Searle, however, conceptualises reflexivity more widely, placing it firmly within the realms of ethics for the whole study and including the identification of power and power relations, making ethical judgements and accounting for the knowledge created (Holland and Ramazanoglu, 2002, Searle, 2018). Therefore, reflexivity may include reflection on decision making at all stages of the research process, even the decision to engage in the subject of choice. Furthermore, Searle argues that despite effort to document biases and other influences, knowledge will never be “fully objective, neutral, or value-free because it is produced by ‘knowers’ who are situated in the social world and whose knowledge reflects its values.” Knowledge is therefore situated (Haraway, 1991) and reflexive practice can help inform readers of the potential influences on the knowledge generated.

2.2.6.1 Reflexive practice and bracketing

This study is important because of the moral imperative to address inequities in our healthcare provision. Yet, it does suggest potential bias introduced from an ethical
standpoint; suggesting failing to comply or conform to the ideals of the UK medical model, when community-related beliefs and practices may prioritise other explanatory models of health could be seen as ethnocentric (defined in Table 2-6).

Table 2-6: Definitions of ethnocentrism

<table>
<thead>
<tr>
<th>Ethnocentrism is a fundamental concept, linked to the study of culture. It is a term used primarily by anthropologists to describe the situation when an individual assumes that the way he/she lives his life to be the natural or correct way such that cultural or ethnic bias is created.</th>
</tr>
</thead>
<tbody>
<tr>
<td>One of the earlier definitions of ethnocentrism comes from medical anthropologist Sumner (1906) “the view of things in which one’s own group is the centre of everything and all others are scaled and rated with reference to it”. (Sumner, 2019)(^\text{15})</td>
</tr>
<tr>
<td>Put more simply by Murdock, ethnocentrism is “a tendency to exalt the in-group and depreciate other groups.” (Murdock, 1949)</td>
</tr>
</tbody>
</table>

Ethnocentrism can potentially lead to bias, misinterpretation, and generalisations when norms from one culture are used to judge others. An awareness of cultural relativism – the principle that no one comes from a neutral position when trying to understand beliefs and actions of another – is important in overcoming ethnocentrism (Tilley, 2017). The researcher needs to acknowledge these assumptions and use the awareness that we are not neutral to inform interpretations.

I used the process of bracketing as proposed by Glaser, to acknowledge and reflect upon preconceptions and biases\(^\text{16}\) (Glaser, 1998). Bracketing has been described as a process of recognising but then setting aside a priori knowledge and assumptions (Starks and Trinidad, 2007). I engaged in the process of writing memos to acknowledge, document, and examine my own positionality throughout the process of gathering, interpreting, and presenting the data, as recommended by Glaser; he argues that once your own preconceptions are acknowledged it creates an openness to differing perspectives in data gathering and interpretation (Glaser, 1998). It also guards against the inclination to foreground certain voices which confirm preconceptions when presenting the data (Tufford and Newman, 2012). The process helps the researcher examine what they hear in the data and improves sensitivity. For example, issues I acknowledged during this process included the fact that some of the social and

\(^{15}\) Most recently published edition referenced.

\(^{16}\) Preconceptions – assumptions, values, interests, emotions, theories (Tufford and Newman, 2012).
structural constraints experienced by participants were outside my experience and that I held pre-conceived perceptions, because of reading the literature, that some patient groups were generally more disengaged in health care. In addition, the team data sessions also gave an opportunity for interpretations to be questioned and alternative perspectives presented to improve sensitivity to the data, which couldn’t be achieved with self-reflection alone.

2.2.7 Data analysis

2.2.7.1 Part 1: grounded theory analysis

Participants and data usage for the grounded theory

The grounded theory analysis used the full data set. The phase I focus groups were used for initial open coding and the Phase II focus groups and interviews for selective coding, theoretical sampling and testing the theory. Figure 2-4 gives an overview of the Phase I and Phase II datasets.

Analysis methods

Figure 2-6 below illustrates the process of grounded theory analysis in broad terms, as the analysis moves through the analytic stages to become more abstract and conceptual. The process begins with open coding.
Figure 2-6: Schematic to illustrate the conceptual development of the qualitative analysis. Modified from Saldana (2016).

a) Open coding

I closely coded by hand (line by line) one focus group transcript. I chose one of the Black African female groups to begin the process because I felt that the data from this group were particularly rich and covered a full range of the topics outlined for discussion. The code names were quite rough at this stage. Coding was primarily gerund based, focusing on actions where possible. I looked at the focus group in its entirety, and I also coded at the level of the individual, taking care to review their comments in the context of the group discussion.

Once I had an initial list of open codes these were compared and the coding was rationalised. Shorter codes were created where possible and codes were collapsed where there was duplication. The initial transcript was coded in NVivo. While this coding was useful to organise the data, I found it cumbersome for facilitating constant comparison, a key tenet of the grounded theory process. I therefore proceeded to keep, in addition to the NVivo file, a shorter constant comparison word document that detailed each incident to facilitate a constant comparison, as coding proceeded.

Constant comparison is the process of comparing incident to incident to ensure the
coding remains grounded in the data and to generate categories and their properties. This is a very key part of grounded theory.

As Glaser states “incidents are compared not summed” thus the aim is not just to summarise similar codes but to analyse the meaning of each incident in the data, to help develop very well-grounded concepts. This concept-indicator model is intended to provide the essential link between data and concept (Figure 2-9). This prevents the development of concepts that are “adhoc or impressionistic” (Glaser, 1998).

"Our concept indicator model is based on constant comparing of indicator to indicator and then when a conceptual code is generated also comparing indicators to the emerging concept. “From the comparisons of indicator to indicator the analyst is forced into confronting similarities, differences and degree of consistency of meaning between indicators, which generates an underlying uniformity which in turn results in a coded category and the beginnings of the properties of it.” Glaser, Theoretical Sensitivity, 1978"

The open codes were rationalised as the process developed. This was carried out with input from the senior qualitative researcher in my supervision team to improve rigour. For example, initially I had a code Struggling but it quickly became obvious that there were several different codes encapsulated within Struggling (shown in Figure 2-7). Without the constant comparison document, this degree of sensitivity to the nuances of meaning would have been more difficult.

![Figure 2-7: Illustration of “struggling” as the sub-codes developed](image)

Memoing was carried out consistently. This process has been described as the “cornerstone of quality” (Birks and Mills, 2015) in grounded theory analysis. Essentially memos capture the researcher’s thoughts and ideas about the codes and their inter-relationships as the study develops. I used memos to capture ideas as the codes and
theories developed: to capture my research trail, to develop the conceptualisation of categories, to physically sort (hard copies), and to help understand how the concepts fitted together and where gaps remained. Each memo was titled with a category or property of a category to facilitate this process (Figure 2-8 shows an example of one of my memos). Within my memos I also used diagrams. More recent schools of grounded theory recommend diagramming right from the commencement of the study, even when collecting data, as a way of "restoring calm to the chaos of the analytical process" (Chun Tie et al., 2019, Strauss and Corbin, 1990, Dey, 2007, Friese, 2014).

"[When] we are dealing with complex and voluminous data, diagrams can help us disentangle the threads of our analysis and present results in coherent and intelligible form." Dey, in The Sage Handbook of Grounded Theory Ed. Bryant & Charmaz (Dey, 2007)

This process was assisted using the mapping software within NVivo and the Miro interactive whiteboard software (www.miro.com).

Overall views and thoughts about themes - one of the strongest impacts on the engagement with healthcare is the historical medical narrative around traditional approach being one of self-care - natural remedies are strongly preferred, with medical professionals in the community being obvious exceptions. Rhetorical language used to help persuade researchers as to the merit of the natural approach. Trust and use of natural approaches, as well as distrust in biomedicines and pharmaceuticals is engendered by stories and informal networks; stories of other people's experiences are well-trusted. Going to the Dr isn't historically what would happen at home and even when attending Dr there are a number of examples where the Dr recommendations as to choice of medication and dosage will be put second guessed by medical people in the family or who are trusted. A lot of advice is coming through informal networks. Not all, but most are engaged with their doctor but seem to want more support than they are given (Desmond only for new diagnoses) and some times criticise Dr for not explaining things or giving them enough information. A good doctor is described as one who talks to you, takes time to help you, gives you relevant advice - this fits with the storytelling, oral focus of the community (see below). Our experience is that you need to spend time with:

Figure 2-8: Example excerpt from a memo

As the coding developed, clusters were grouped and labelled more conceptually.

Because of the concept-indicator approach this was a grounded process. For example,
the codes *Bonding* and *Having faith* emerged from the coding and were conceptualised as two dimensions of trust. (Illustrated in Figure 2-9). Ultimately, these conceptual groupings formed the basis of the categories. I also used code mapping when reviewing codes, to help assist with the process of category formation and identification of properties and dimensions (Saldana, 2016).

![Figure 2-9: The concept-indicator approach](image)

I proceeded to organise the coding into focused analytical substantive coding categories and continued to code the remaining focus-group transcripts. These steps were somewhat iterative, as the categories were developed. The initial categories are summarised in Table 2-7. Each was defined and operationalised as the concepts, dimensions and properties became more concrete. Some of these categories were later combined as the analysis developed.

**Table 2-7: Initial categories from the open-coding phase of analysis**

<table>
<thead>
<tr>
<th>Category</th>
<th>Examples of initial open coding for this category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attaching to traditions</td>
<td>Responding to norms; Following dietary norms; Emotional attachment to ‘home’; Holding traditional health beliefs</td>
</tr>
<tr>
<td>Adapting</td>
<td>Seeking support; Filtering; Regulating behaviour (willpower); Struggling; Distancing</td>
</tr>
<tr>
<td>Trust</td>
<td>Having faith; Bonding; Increasing trust; Decreasing trust</td>
</tr>
<tr>
<td>Misalignment</td>
<td>Resisting; Tug of war; Searching for cultural relevance</td>
</tr>
<tr>
<td>Identity</td>
<td>Identifying with Black culture; Impression management; Prioritising others; Centrality of traditional food</td>
</tr>
<tr>
<td>Facilitating knowledge</td>
<td>Searching for cultural relevance; Seeking information; Reasoning (measurement)</td>
</tr>
<tr>
<td>Engaging</td>
<td>Proactive; reactive; complying; not complying</td>
</tr>
<tr>
<td>Guidance (descriptive)</td>
<td>Healthcare advice; Structural constraints</td>
</tr>
<tr>
<td>Shaping perspective</td>
<td>Witnessing harm; Experiencing harm</td>
</tr>
<tr>
<td>Social challenge</td>
<td>Financial worry; Family worry; Health burden; Structural constraints</td>
</tr>
</tbody>
</table>
Understanding health advice (descriptive)
Connecting to others

Understanding; Misunderstanding
Giving support; Seeking support

Monthly supervision meetings provided an opportunity to discuss the development of the codes and the category development. As the coding continued and categories were further developed or collated, the next stage was to identify the core category around which other categories coalesced. The core category may be one of the earlier categories or may be created as the analysis develops. In many senses there may be more than one theory evident within the data, thus a potential choice of core categories. I found Spradley’s semantic relationships useful in beginning to identify the core category and inter-relationships (Spradley, 1979). Following the advice of Urquhart (Urquhart, 2012), Spradley’s codes were used in integrative diagrams to help understand how the substantive codes related to each other.

Table 2-8: Spradley’s semantic relationships (Spradley, 1979)

<table>
<thead>
<tr>
<th>How do the substantive codes relate to each other?</th>
</tr>
</thead>
<tbody>
<tr>
<td>...is a kind of</td>
</tr>
<tr>
<td>...is a part of/a place in</td>
</tr>
<tr>
<td>...is a way to</td>
</tr>
<tr>
<td>...is used for</td>
</tr>
<tr>
<td>...is a reason for, is a stage of</td>
</tr>
<tr>
<td>...is a result/cause of, is a place for</td>
</tr>
<tr>
<td>...is a characteristic of</td>
</tr>
</tbody>
</table>

Different grounded theory methods diverge on how this process develops. While schools of constructivist grounded theory, such as Charmaz, chose any central phenomenon of interest around which to centre the next stages of analysis (Charmaz, 2014), the classic approach focuses on identifying the main concern of the participants from the initial reviewing and coding of the data. The core category then explains how the participants resolve this main concern.

*Grounded theory tries to understand the action in a substantive area from the point of view of the actors involved. This understanding revolves around the main concern of the participants whose behaviour continually resolves their concern. Their continual resolving is the core variable.* Glaser, *Doing Grounded Theory*, 1998

This contrasts with analysing the data with a preconceived idea of what is of concern to the participants. It is a completely inductive process, within the parameters of the
substantive area of research. Glaser states that the main concern will emerge from field work with the participants if your qualitative approach creates “spill” – i.e., if you place the participants in a situation, with the nature of the questioning and the approach to creating an environment, where they can talk in a relaxed and expansive way about the issues in question, in this case diabetes self-management. I found the focus groups particularly useful in this respect because it was possible to absent myself from the discussion to a degree so participants could talk freely amongst themselves.

b) Selective coding

Theoretical sampling and selective coding around the core category and related categories are recommended to add depth to the data and fill gaps\textsuperscript{17}. The second phase interviews were used for selective coding in the first instance. This meant that pragmatically the sampling was guided by the HEAL-D sampling framework, rather than being designed to maximise theoretical diversity. The in-depth interviews proved a rich source of data which provided considerable depth to the analysis; after coding of ten additional interviews no further concepts or dimensions of concepts were becoming evident. I therefore considered I had achieved saturation of the key theoretical codes and no further fieldwork was considered necessary.

As analysis developed and the categories were reviewed and compared, substantive codes were developed, in relation to the core category. Essentially the substantive codes are codes reflecting the actions and influences around the core category. Ideally “they have imageric and analytic power” (Glaser, 1998). They can be generated by the researcher, or can be “in vivo”, taken from conceptual talk amongst the participants. In the case of this analysis some of the substantive codes were evident early in the analysis process, such as Trust, while others such as Filtering evolved through the analysis process. In all cases though, the substantive analytic codes were grounded in the data and built-up from the emerging concepts. Many grounded theory studies stop here with a summary of key concepts within the data and a broad idea of how the

\textsuperscript{17} To selectively code for a core variable means that the analyst de-limits his coding only to those variables that relate to the core variables in sufficiently significant ways to be used in a parsimonious theory GLASER, B. 1978. Theoretical sensitivity, California, USA, Sociology Press.
concepts fit together, however in my analysis I have continued to develop a grounded theory.

c) Theoretical coding

Theoretical coding is the final stage of the grounded theory process to conceptualise the relationships between the substantive codes.

“...Theoretical codes implicitly conceptualise how the substantive codes will relate to one another as inter-related, multivariate hypotheses.... they are emergent and weave the fractured story turned into concepts back into an organised whole story. [They] emerge during coding, memoing and memo-sorting.” (Glaser, Doing Grounded Theory, 1998)

While theoretical codes are not usually explicitly discussed within a theory, they will be “implicitly present” in a good theory. Without theoretical codes one is left with “flat conceptualisation” and the reader cannot understand how the concepts relate to each other (Glaser, 1998). Classic grounded theory authors recommend not examining theories in your substantive area before conducting your own analysis (to avoid pre-conceptions). As the appeal of grounded theory has developed, with many users not being familiar with grounded theory and theoretical codes at all, the difficulty of applying theoretical codes to your own analysis without an idea of the range of theoretical codes has been recognised (Timonen et al., 2018, Charmaz, 2014).

I chose to increase my theoretical sensitivity by looking at other theories outside the diabetes realm but only at this stage, so my concepts emerged as inductively as possible. In the case of this analysis, I identified my core category as a basic social process (Integrating Perspectives) which takes place within the social structural process of the healthcare interaction. I also identified typologies of behaviour amongst individuals who navigate this process differently and these were the key theoretical codes that shaped the development of the theory. The use of memoing and memo sorting supported this process of theoretical development.

After the initial development of the theory, it was tested against the remaining Phase II interviews and focus groups. This meant analysing each participant to see how they fitted into the typologies and whether they followed the processes in the theory. Adjustments were made for new or contradictory data to create a parsimonious theory that captured all the data.
2.2.7.2 Part 2: Behavioural analysis & BCT evaluation

**Participants and data usage for behavioural analysis**

The second part of my analysis involved applying the COM-B behaviour change framework to the Phase I focus group data and using this analysis to identify potential BCTs. The HEAL-D Phase II focus groups and interviews were then used to assess the acceptability and effectiveness of the chosen BCTs (See Figure 2-4 for an overview of the group and interview organisation for HEAL-D).

**Analysis methods**

The use of the framework, as described by Michie et al (Michie et al., 2011b) was conducted as described in Figure 2-10. The three-step process of selecting and specifying the BCTs began with the application of the COM-B framework to seek to understand the behaviour in the context and population of interest. Based on this analysis intervention functions were identified using the behaviour change wheel and finally BCTs were specified based on the framework provided.

![Figure 2-10: The process for understanding behaviours and choosing behaviour change techniques](image)

**Step 1: Understanding the behaviour**

Based on the UK evidence-based guidance I brainstormed a list of potential behaviours. A behaviour is described as “anything a person does in response to internal or external events. actions may be overt and directly measurable or covert and indirectly measurable; behaviours are physical events that occur in the body and that are controlled by the brain” (Michie et al., 2011b). For any one of the guidelines there
are multiple possible behaviours. For example, weight management behaviours may include weighing yourself daily, counting and recording calories, engaging in 30 minutes of vigorous exercise each day, or eating from a small plate to govern portion size and so forth. The focus group data and existing published literature were used to prioritise the behaviours that were likely to be helpful and each was scored according to their potential impact, likelihood of acceptability, ease of measurement and potential spill-over to other behaviours. The COM-B process generally focuses on one key specified behaviour. In the case of my analysis there was a pre-specified objective to support achievement of the guidelines and hence several key behaviour targets. Thus, a pragmatic approach was necessary to focus on a small selection of key behaviours, rather than just one. Once a short-list of behaviours was selected each was further investigated to understand the key influences, by applying the COM-B framework. To assist with coding of the data the associated theoretical domains framework was also used to further specify each of the COM-B categories (Figure 2-11). A framework approach was taken to coding the COM-B domains for each behaviour.
<table>
<thead>
<tr>
<th>Theoretical Domain</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical skills</td>
<td>A physical ability or proficiency acquired through practice</td>
</tr>
<tr>
<td>Knowledge</td>
<td>An awareness of the existence of something</td>
</tr>
<tr>
<td>Cognitive &amp; interpersonal skills</td>
<td>A cognitive ability or proficiency acquired through practice</td>
</tr>
<tr>
<td>Memory, attention &amp; decision processes</td>
<td>The ability to retain information, focus selectively on aspects of the environment and chose between two or more alternatives</td>
</tr>
<tr>
<td>Behaviour regulation</td>
<td>Anything aimed at managing or changing objectively observed or measured actions</td>
</tr>
<tr>
<td>Social or Professional role &amp; identity</td>
<td>A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting</td>
</tr>
<tr>
<td>Beliefs about capabilities</td>
<td>Acceptance of the truth, reality or validity about an ability, talent or facility that a person can put to constructive use</td>
</tr>
<tr>
<td>Optimism</td>
<td>The confidence that things will happen for the best or that the desired goals will be attained</td>
</tr>
<tr>
<td>Intentions</td>
<td>A conscious decision to perform a behaviour or a resolve to act in a certain way</td>
</tr>
<tr>
<td>Goals</td>
<td>Mental representations of outcomes or end states that an individuals wants to achieve</td>
</tr>
<tr>
<td>Beliefs about consequences</td>
<td>Acceptance of the truth, reality or validity of outcomes of a behaviour in a given situation</td>
</tr>
<tr>
<td>Reinforcement</td>
<td>Increasing the probability of a response by arranging a dependent relationship or contingency between the response and a given stimulus</td>
</tr>
<tr>
<td>Emotion</td>
<td>A complex reaction pattern, involving experiential, behavioural and physiological elements, by which the individual attempts to deal with a personally significant matter or event</td>
</tr>
<tr>
<td>Social influences</td>
<td>Those interpersonal processes that can cause individuals to change their thoughts, feelings or behaviours</td>
</tr>
<tr>
<td>Environmental context and resources</td>
<td>Any circumstances of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence and adaptive behaviour</td>
</tr>
</tbody>
</table>

Figure 2-11: The theoretical domains framework. Modified from Squires et al. (2014)

Step 2: Identifying intervention functions and choosing behaviour change techniques

I then mapped the findings of the COM-B analysis to possible interventions functions, according to the published matrix of potential links (Michie et al., 2014) (Figure 2-12). The behaviour change wheel guide gives a detailed list of potential BCTs for each intervention function (Michie et al., 2011b). In addition, a more extensive list is available (Michie et al., 2013). I made a short, pragmatic list of potential BCTs from these suggestions. My choice was based upon knowledge of the community (my own and that of the research team), the focus group data and published systematic review data about commonly used BCTs in successful lifestyle interventions (Michie et al., 2011a).
Figure 2-12: Matrix linking intervention functions to COM-B domains

These were scored according to the APEASE criteria (Table 2-9) and key BCTs chosen. The APEASE criteria offer a common-sense framework upon which to make a sound judgement.

Table 2-9: The APEASE criteria. Adapted from Michie et al. (Michie et al., 2011b)

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>A: Affordability</td>
<td>Assessing the economic feasibility</td>
</tr>
<tr>
<td>P: Practicability</td>
<td>Deciding if this is practical within the setting</td>
</tr>
<tr>
<td>E: Effectiveness &amp; cost effectiveness</td>
<td>Assessing if this will be effective in a real-world setting and whether the effect worth the cost</td>
</tr>
<tr>
<td>A: Acceptability</td>
<td>Assessing if this be judged acceptable by the stakeholders</td>
</tr>
<tr>
<td>S: Side-effects &amp; safety</td>
<td>Considering if there may be side-effects or unintended consequences</td>
</tr>
<tr>
<td>E: Equity</td>
<td>Considering the impact on social disparity and diversity</td>
</tr>
</tbody>
</table>

Step 3: Specifying intervention strategies and components

In the findings section of this thesis, I present the BCTs resulting from the analysis. To illustrate how these BCTs may then be operationalised as intervention components, I use the example of the HEAL-D intervention. For example, the BCT *credible sources*
was operationalised by the development of videos with community leaders about making dietary changes.

**Step 4: Evaluating the BCTs used in the HEAL-D Intervention**

To further evaluate the BCT choice, the ten Phase II intervention participant interviews and four focus groups were analysed using a framework approach (Figure 2-4). I have done this to give weight to my findings by assessing how my participants considered the effectiveness of the BCTs in a real-world example. This stage helped inform my opinion of the utility of the COM-B/behaviour change wheel approach. The data for each selected BCT were coded by participant and the key themes in the data reported, highlighting the BCTs which participants found the most helpful. The frequency of participants indicating the value of specific BCTs was also reported as a heat diagram to indicate coding frequency.

**2.2.8 Reporting of data in this thesis**

Individual quotes have been chosen carefully to be representative of the data. The quotations are reported as faithfully as possible to reflect the original speech and personalities of the participants; changes have not been made to discussion of medical terms even if they are misnamed or to speech patterns, for example. In the focus group data additional information is sometimes provided that indicates the mood of the group. These data are presented in square brackets (for example, [laughter]). Where changes have been made from the transcripts to improve the contextual sense for the reader, this is also indicated in the quotation text by square brackets. Where possible it is indicated in the text whether the quotes represent a majority or minority view. Where a range of viewpoints or ideas are expressed, a range of quotations have been selected to illustrate this. All but short comments (5 words or less) are annotated to indicate the participant number, their ethnicity (BA - black African or BC - black Caribbean) and gender, their age and their country of birth (for example, Participant 64, BA Female, Aged 52, Nigeria). In classic grounded theory studies, often limited data are reported to support the theoretical model presented; rather the focus of the presentation is on the model itself: “an integrated set of conceptual hypotheses” or
“probability statements about the relationship between concepts” (Glaser, 1998). This approach relies on the assertion that the concepts are firmly grounded in the data as the methodology stipulates. I have chosen to deviate from this approach and present some of the data to explain how the key concepts have been derived. I have approached the presentation this way both to portray a sense of the participants for the reader and to reinforce how the concepts were grounded in the original data.

2.2.9 Summary

In this section the methods employed in the study have been described. The findings from the two methodological approaches are reported in the next section. Part 1 comprises the grounded theory findings (3.2, 3.3, 3.4) and Part 2 (3.5) comprises the behaviour analysis findings.
SECTION 3: FINDINGS

In this section I present my key findings. Understanding current health behaviour and exploring how healthful behaviour may be encouraged and supported requires three areas of focus. Firstly, understanding the contextual sociocultural factors influencing health behaviour (Bartholomew et al., 2016). Secondly, understanding the behaviour patterns which occur and thirdly identifying potential intervention targets and exploring the theoretical basis upon which positive behaviour can be encouraged and detrimental behaviour discouraged (Fernandez et al., 2019, Michie et al., 2011b). The presentation of the findings follows this path (Figure 3-1).

Figure 3-1: Overview of the structure of the presentation of findings

This section begins with the details of the participants (3.1). In the next three chapters the grounded theory findings are presented (3.2-3.4) and the findings section concludes with the behavioural analysis (3.5).

Part 1: Grounded Theory Analysis (3.2-3.4)

An overview of the grounded theory categories resulting from the analysis is shown in Figure 3-2, page 121. This model is then developed throughout the proceeding three chapters (3.2-3.4), culminating in the final model, in Figure 3-19, page 189. The grounded theory findings begin in chapter 3.2 with a discussion of the wider social cultural factors shaping the lives of the participants. This data is from the two categories connecting to others and contextual influences. This data remains largely descriptive and is provided to give context to the more theoretical data to follow.
Findings: Introduction

Figure 3-2: Overview of the categories from the grounded theory analysis

Following this introduction, data from the category *Attaching to traditions* is presented in chapter 3.3 as it enables health beliefs and traditions that shape behaviour patterns, to be fully considered. Additionally, some of the intersecting factors that influence how strongly these cultural factors exert influence on different individuals and play a role in development of the personal perspective on diabetes and self-management are introduced. Chapter 3.4 is the main theoretical chapter in which the novel grounded theory *Integrating Perspectives* is described to explain the behaviour patterns which emerged from the analysis.

Part 2: Behavioural Analysis (3.5)

Finally, findings chapter 3.5 is concerned with understanding how to support positive health behaviour through the application of the COMB/behaviour change wheel theoretical framework that builds on the previous analysis. This framework is used to
identify potential points of intervention to support healthful behaviour. It provides a theoretical platform for the selection of potential behaviour change techniques as well as identifying existing positive behaviours which may be reinforced. The utility of the findings from the COM-B analysis is then further evaluated using process data from the HEAL-D study.
3.1 The participants and the setting

3.1.1 Demographics

As discussed in 2.2.1.1, data were collected at two time points during the HEAL-D study; eight focus groups were held in the Phase I co-design (n=41) and four more focus groups (n=20) and twenty interviews (n=20) were conducted as part of the Phase II feasibility study. Participants were able to take part in one or more of these activities, resulting in 67 participants in total. Table 3-1 summarises the complete cohort. Summary of the demographics for the focus groups and interviews separately is provided in the appendices (section 6.2).

Table 3-1: Characteristics of participants (full data set n = 67)

<table>
<thead>
<tr>
<th></th>
<th>Total (n=67)</th>
<th>% BA (n = 34)</th>
<th>% BC (n = 33)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (SD)</td>
<td>61.9 (10.9)</td>
<td>59.6 (10.5)</td>
<td>64.3 (11.0)</td>
<td>0.09</td>
</tr>
<tr>
<td>% Female (n)</td>
<td>64 (43)</td>
<td>68 (23)</td>
<td>61 (20)</td>
<td>0.62</td>
</tr>
<tr>
<td>Education (n)</td>
<td></td>
<td></td>
<td></td>
<td>0.129</td>
</tr>
<tr>
<td>% Basic</td>
<td>33 (21)</td>
<td>24 (8)</td>
<td>42 (13)</td>
<td></td>
</tr>
<tr>
<td>% Secondary</td>
<td>33 (21)</td>
<td>33 (10)</td>
<td>36 (11)</td>
<td></td>
</tr>
<tr>
<td>% Tertiary</td>
<td>34 (22)</td>
<td>46 (15)</td>
<td>23 (7)</td>
<td></td>
</tr>
<tr>
<td>% Born outside UK (n)</td>
<td>88 (58)</td>
<td>97 (32)</td>
<td>79 (26)</td>
<td>0.54</td>
</tr>
<tr>
<td>% Borough of residence (n)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Southwark</td>
<td>41 (26)</td>
<td>57 (17)</td>
<td>27 (9)</td>
<td>n/a</td>
</tr>
<tr>
<td>Lambeth</td>
<td>32 (20)</td>
<td>30 (9)</td>
<td>33 (11)</td>
<td></td>
</tr>
<tr>
<td>Lewisham</td>
<td>18 (11)</td>
<td>7 (2)</td>
<td>27 (9)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>10 (6)</td>
<td>7 (2)</td>
<td>12 (4)</td>
<td></td>
</tr>
<tr>
<td>% Employment status (n)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>44 (29)</td>
<td>42 (14)</td>
<td>46 (15)</td>
<td></td>
</tr>
<tr>
<td>Employed/Self-employed</td>
<td>38 (25)</td>
<td>46 (15)</td>
<td>30 (10)</td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>14 (9)</td>
<td>6 (2)</td>
<td>21 (7)</td>
<td></td>
</tr>
<tr>
<td>Student</td>
<td>2 (1)</td>
<td>3 (1)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Homemaker</td>
<td>3 (2)</td>
<td>3 (1)</td>
<td>3 (1)</td>
<td></td>
</tr>
<tr>
<td>% Living alone</td>
<td>59 (20)</td>
<td>50 (8)</td>
<td>67 (12)</td>
<td>0.574</td>
</tr>
<tr>
<td>% Receiving benefits</td>
<td>28 (9)</td>
<td>36 (5)</td>
<td>22 (4)</td>
<td>0.453</td>
</tr>
</tbody>
</table>

*Living alone and benefits calculated for a sub-sample only

An overview of each participant and which events they took part in is given in the appendices (see 6.2, page 339 for full breakdown).
Twenty-eight percent reported being in receipt of one or more benefit, the most cited being housing benefit. Thirty-eight percent of the sample were in paid work and 44% were retired. The complete cohort included a broad spread of educational attainment. There was a slight predominance of women. Data on religion were not collected, however, I recruited participants from mosques and churches to ensure representation of both Christian and Islamic faiths. A breakdown of the demographics of each set of focus groups and the interviews is provided separately in the appendices.

Most participants (88%) were born outside the UK. Nigeria (38%) and Jamaica (30%) were the most common birth countries. The full range of birth countries represented in the data is indicated in Table 3-2; the high percentage of people born in Nigeria and Jamaica reflects the national demographic. This spread highlights the problems with the reductive nature of ethnic classification in healthcare, as these regions represent a diversity of dietary patterns, cultural traditions, and access to healthcare, as well as a plethora of different faiths.

<table>
<thead>
<tr>
<th>Country of birth % (n)</th>
<th>Africa</th>
<th>Caribbean</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nigeria</td>
<td>38 (25)</td>
<td>30 (20)</td>
<td>12 (8)</td>
</tr>
<tr>
<td>Sierra Leone</td>
<td>3 (2)</td>
<td>8 (5)</td>
<td></td>
</tr>
<tr>
<td>Somalia</td>
<td>2 (1)</td>
<td>2 (1)</td>
<td></td>
</tr>
<tr>
<td>Uganda</td>
<td>2 (1)</td>
<td>2 (1)</td>
<td></td>
</tr>
<tr>
<td>Cameroon</td>
<td>2 (1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mauritius</td>
<td>2 (1)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3.1.2 The setting

3.1.2.1 Socioeconomic disparity and the indices of deprivation

The participants were recruited primarily from the London boroughs of Lambeth, Southwark, and Lewisham. This is an inner-city setting, with high population density, and which scores high on the index of multiple deprivation (IMD). Southwark and

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18 benefit data collected for 39% of the sample
Lewisham are within the top ten most deprived boroughs nationally (Southwark ranked 9th and Lewisham 8th) and Lambeth is 12th. The index of multiple deprivation considers seven criteria. These boroughs are particularly deprived for income, rate of crime, barriers to housing and quality of outdoor spaces. Of these criteria the high levels of crime and poverty are notable, compared to the rest of London and the UK as a whole (Ministry of Housing, 2019).

Across each borough there is a higher proportion of the working age population in receipt of out of work benefits (Lewisham - 9.3%, Lambeth - 8.4% and Southwark - 8.2%) compared to the London average of 7.7%. In general, across the UK unemployment is higher for people of Black ethnicity (14%) compared to those of White ethnicity (5%) and unemployment for those of Black ethnicity is particularly high in Lambeth (18%). Employment opportunities are more likely to be clustered in lower-paid sectors, although less than 20% of the Black working population are paid below the living wage, which is comparatively better than other minority ethnic groups (Joseph Rowntree Foundation, 2017). Minority ethnic groups experience higher levels of housing deprivation than White British. People of Black ethnicity in Central London are more likely to live in social housing than other minority ethnic groups (43% of Caribbean households and 51% of African) and to experience housing deprivation in the rental sector (de Noronha, 2019, Ministry of Housing, 2019).

### 3.1.2.2 Diversity and ethnic density

London is one of the most ethnically diverse cities in the world, with 44% of inhabitants from minority ethnic groups (Office for National Statistics, 2011). The Boroughs of Lambeth, Southwark and Lewisham are characterised by the diversity of their local populations with those of Black heritage forming a relatively high percentage of local communities compared to the UK as a whole (Figure 3-3). The global mix of communities is also reflected in the character of the setting with a rich array of food outlets reflecting the diversity of local communities. Local markets such as East Street, Peckham and Brixton markets sell many of the fresh foods (as well as herbal medicines) that are part of African culture. This is an example of one of the
benefits of the density of minority communities living in London as cultural culinary traditions can be maintained. Nonetheless, a proliferation of fast-food outlets selling traditional foods also presents a challenge to eating healthily, especially for young people (Rawlins et al., 2013). Boroughs such as Lewisham recognise the importance of food in cultural identity and providing access to cultural foods forms a central part of their food strategy (Health First and Lewisham Primary Care Trust, 2006).

“Food forms a significant part of the cultural identity of the diverse communities in Lewisham and we need to ensure that all sections of our community have ready access to the foods that are an ingredient of day-to-day life and central to the many different celebrations held every year.” (Lewisham Food Strategy, 2006)

3.1.2.3 Health profiles of the Boroughs

With regards to health, epidemiological data suggest that residents living in these three boroughs are more likely to die prematurely (from all causes) compared to the national average (Public Health England, 2019). The boroughs are more favourably placed for health deprivation amongst the 10% most deprived nationally however, than for most other criteria of deprivation. The rate of adult obesity is better (Southwark) or similar to the national average (Lewisham and Lambeth) and the percentage of physically active adults is higher than the national average in Lewisham and Lambeth and similar to national levels in Southwark (Public Health England, 2019).
3.1.2.4 Built environment

Access to green space is associated with better mental health and wellbeing (Public Health England, 2020). The boroughs where most participants live, score poorly on measures related to access to public green space and distance to walk to access green space. Of the boroughs across the UK Lambeth, Southwark and Lewisham are positioned 1st, 9th and 12th respectively in terms of the most restricted access to green space nationally (Friends of the Earth, 2020). Despite these limitations, central London boroughs score highly in terms of the walkability index (Stockton et al., 2016). Walkability is a feature of street connectivity (the feasibility of walking from one location to another), residential density (how many other people are likely to be walking) and well as the built structure to accommodate walking (pavements for example). Walkability is associated with increased physical activity, even after adjustment for socioeconomic status and neighbourhood deprivation (Stockton et al., 2016).
3.2 The social context

“I worry because I live in sheltered accommodation. The rent, the bills, all the bills. Today they are writing, ‘You are behind your rent. We are taking you to court’. Tomorrow, EDF will come with their own. So, all these worries”. (Study participant)

3.2.1 Introduction

In this chapter I introduce the participants in the context of the inner city setting from which they were recruited. The aim of this chapter is to present the data on wider social and environmental factors described by the participants, to offer context to the following three chapters which explore individual health behaviour more theoretically. The data are from the two analytical categories Connecting to others and Contextual influences. These categories are not core to the central theory presented in chapter 3.4 yet understanding more about these wider social determinants of health\(^\text{19}\), the conditions in which people are born, grow, life, work and age, offers important context to these data (see Figure 3-2, page 121 for an overview of categories). Some of the data presented below provide a framework within which to consider the priority likely to be given to diabetes self-management in the context of other challenges, whilst the direct impact of structural factors such as racism, marginalisation and the constraints of working patterns is also considered. Additionally, these social factors are discussed from an asset-orientated perspective, suggesting that there are potential social capital benefits associated with diversity in a global city like London and within UK Black African and Caribbean communities and that these may be leveraged to support health. The data in this section are summarised in Figure 3-4.

\(^{19}\) Whilst there are various frameworks to define social determinants of health, there is no consensus set of factors. For the purposes of this section I use the Hill-Briggs definition which includes socioeconomic status (income, education & occupation), neighbourhood (housing, pollution, built environment), food (food security and proximity/access to healthy un unhealthy foods), health access (barriers to accessing care), social (social cohesion, social support, social capital) HILL-BRIGGS, F., ADLER, N. E., BERKOWITZ, S. A., CHIN, M. H., GARY-WEBB, T. L., NAVAS-ACIEN, A., THORNTON, P. L. & HAIRE-JOSHU, D. 2021. Social Determinants of Health and Diabetes: A Scientific Review. Diabetes Care, 44, 258-279.
3.2.2 Challenges of migration

The duality of managing life across two continents created a challenge in people’s lives. For the majority, migration meant some separation from family – for example being split up from their children, siblings or parents who have remained living in their native countries. This duality had implications for the time spent away from the UK and for the emotional burden of separation. It also created an additional financial responsibility when family members living in Africa or the Caribbean expected financial support. Returning to visit relatives for extended periods stretching to several months each year was described “As for me I go to Nigeria. I do six months there and I come back.” Often visits were just for holidays and to catch up with friends and family, but it was not uncommon for individuals to retain caring responsibility for elderly relatives back home, despite residing in the UK. Extended periods of absence from the UK have the potential to create issues for continuity of diabetes care. This retired nurse explains how she looks after her mother in Uganda:

“I used to be a nurse and I retired about three years ago, and I’m very much involved in caring for my mum, who’s [in Uganda], so there’s a lot, because of, she’s elderly and she’s got, in advanced stage of her rheumatoid arthritis, so I travel quite a lot, so that takes up quite a bit of my time.” Participant 36, BA Female, Aged 63, Uganda

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20 Participant 13, BA Female, Aged 68, Nigeria
FINDINGS: PART 1 GROUNDED THEORY

Being separated from loved ones created an emotional burden. Several individuals talked of siblings passing away, without the opportunity to say goodbye. The participant below explained the tragedy of her daughter passing away while waiting for her visa to be approved to visit her parents the UK:

“Something that could have taken away my life, that's the loss of my firstborn. That was last year, February 4.... She graduated 2013, then died just last year. She even had to send, to ask for another visa in order to come and visit us here. The visa was approved after her death.”

Participant 35, BA Female, Aged 71, Nigeria

Participants also described an expectation from relatives living in Africa, that you are financially comfortable because you live in the UK, creating an expectation of financial provision for extended family:

“England is, there's always so much financial tension here... they just assume you are so rich. They calculate the money you use for flying alone is sufficient for three of us to live for one full year, so they just assume, but they don't know you are struggling. You've got mortgage, you've got bills, you've got this and that, even the air in England you pay for it. I'm thinking about tax, I'm thinking of electricity, I'm thinking of light, and I've got how many people I'm paying their school fees? Over six people I'm paying their fees in a year. When you get that the pressures of life on me......”

Participant 44, BA Male, Aged 64, Nigeria

Some participants also referred to the racism and marginalisation they have experienced because of their migration. With the primary focus of data collection being on health behaviour, I did not explore these factors in detail, thus it is possible and indeed likely that many of the participants will have experienced pervasive discrimination, racism and social marginalisation, as is reported in the literature (Ochieng, 2013). The data selected below, however, highlight some of the ways structural racism and discrimination reduced access to income and working opportunities and created stress and anxiety. The participant below described how, despite having a first-class degree from an African University, the rejection experienced from the UK establishment of his qualifications made him lose faith, before giving him impetus to gain further qualifications from the UK:

“I'm a graduate. My certificate is from Africa and every time I was looking for the opportunity that I wanted.... unfortunately ['this lady'] couldn't see that. I studied first class, I graduated 16 years ago but then it's a challenge when my result was from Africa. I just lost hope on everything but each time I kept reminding myself that I said I would go to university in this country. Now unfortunately I won't be able to see this lady again and tell her that I go to... to your own university, in my class I'm the oldest. I'm working with computer system and network engineering at [name anonymised] University.”

Participant 22, BA Male, Aged 41, Nigeria
I was also interested to note that some participants chose to state their (usually more elevated) roles and professions held before migration, when stressing a point – “I told you I used to work, I used to be a civil servant in my country before I came here, so I know what I am talking about,” which gave the impression that this status was considered important in the interaction between us and that they may feel their UK role does not give their opinion weight. Berry refers to the fact that first generation immigrants are often downwardly mobile in terms of occupation, not getting the jobs for which they have trained and are qualified and how these structural barriers can create psychological stress (Berry and Sam, 1996). In addition, as mentioned in the introduction, UK government hostile immigration policies underpinning the Windrush scandal of 2018, are indicative of the discrimination felt by many in UK Black communities. The lady below describes the treatment she received at a UK airport, despite having legal right to remain in the UK:

“I was delayed at the airport ... what was my business that I was here? I was delayed for five hours. Finally, I was told that I will have to check and face a court ... they're making 52 charges. That's the accusations they gave me to read. So, I had my lawyer. [we] told them my husband was a British citizen...then I was told that since he is a British citizen, I could get a stay permit through him.” Participant 35, BA Female, Aged 71, Nigeria

Collectively, these factors suggest increased emotional and financial stress, resulting from migration and that migration also presents practical barriers to continuity of care because individuals are often absent from the UK for several months at a time.

3.2.3 Barriers associated with roles and responsibilities

The majority of people immigrating to the UK from Africa and the Caribbean are economic migrants (Ziebland and McPherson, 2006). Working lives as described by participants included a predominance of caring and service professions from nursing and teaching through to less highly skilled roles such as being a care worker, working in security and for British rail and the NHS. In addition, there were a few individuals in managerial roles, either self-employed or working for others. There was also an aspiration amongst participants to improve one’s prospects by continuing education.
This seemed particularly the case with the African participants and was not raised by any of the Caribbean participants.

While just under half the participants were retired, women in particular described active involvement in supporting their community. – “I do a lot of charity work, I was a retired internal auditor, but I still help round”.22 Caring roles were central in the lives of many of the women. One participant described how, culturally, it is considered important to look after your extended family:

“We are primarily caregivers because of this extended family role within BMEs. Another thing English society don't understand, black people are always the caregivers because we don't normally put our elderly into nursing homes, we just care for everybody” Participant 29, BC Female, Aged 52, UK

Traditional caring ideology has been reported amongst African and Caribbean communities, particularly for your own parents, which is seen as an opportunity to reciprocate for care given to you (Lawrence et al., 2008). Most women (both African and Caribbean) had some responsibility for caring for grandchildren or their own elderly parents. In the case of retired individuals, they describe looking after their grandchildren so the children’s parents could work or continue their education. Caring responsibilities could be challenging and impacted negatively on time for yourself and diabetes management. The participant below described the impact of being the primary carer for her sister for the past 28 years and how the worry and stress associated with her sister’s care, negatively impacted her health and diabetes care:

“I've got caring problems as well, issues with my sister. All of that affected my ability to really deal with my diabetes properly. Most of the time I was tired. I forgot to take my medication, or thought I hadn't taken it, and then ended up taking the dosage twice......it just breaks my heart every time I visit. [...] I didn’t have any time off work because I work full-time, I was having to leave work and do the visits to the hospital, I wasn't eating right. I was eating late. I was eating rubbish food. Obviously, by the time I returned from the hospital I was just tired, and I was visiting hospital every day....my energy was more focussed on my sister. I just literally switched off on what I should have been doing for myself. It's just like I'm in that zone. I promised my mum before she died that I would not let her go into a care home. I would take care of her. I'm in that zone, this is what I'm supposed to do. I just get on with it, and just stayed focussed on that.” Participant 47, BC Female, Aged 58, Guyana

There were barriers associated with the length and structure of the working day that impacted on engagement in healthy eating, purposeful activity and ability to attend

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22 Participant 32, BA Female, Aged 70, Nigeria
longer medical appointments. Men particularly suggested that their work-life was stressful “this country is a very busy country, I’m working, ... I come back from work, I’m tired. ... go to bed”. Several male participants described a 12-hour working day and these long working hours were seen as a barrier to exercising “working long hours sometimes prevents me from going to the gym, so I have to work from seven in the morning until about seven in the night consistently”. The participant below described the many challenges he is balancing day to day on top of long hours:

“Like for me, the last six months has been very - I've had to leave my job because my wife was very sick. She was pregnant and I've got two kids already, I couldn't cope with the kids and I'm also going to school so I had to quit the job and I started working for myself. So, things like that, family issues then when I quit my job, it was about the time we were about to write exams.” Participant 22, BA Male, Aged 41, Nigeria

A structured working day and shift work associated with a predominance of blue-collar jobs meant that it was hard to plan your time: “the type of job I do I can't precisely say this day or this time.” Shorter medical appointments seemed to be prioritised by most, but the inflexible demands of work meant that attendance at structured education and other health provision classes more difficult to commit to:

“They sent me to Grantham but it was too far for me so I couldn't - because the timing... They want you to be there like, say, 12 o'clock, and, like I said before, I used to work in the afternoon, so I couldn't, if I got out too late, so I didn't even go to it.” Participant 28, BA Female, Aged 56, Nigeria

The participant below described how the structure of her working week negatively impacted on her free time, even limiting her ability to attend church:

“I haven't [gone to church in the UK] because of the work I used to do, to go out and look after clients in their home. I never had time to go to church because it was seven days a week work. Every day you must be out unless when we get a rest day. So, I never had time to. When I was home, back in Jamaica, then we used to go to church, but over here, I haven't got time to go to church.” Participant 30, BC Female, 67, Jamaica

In addition, participants discussed the challenges of eating well in some of their jobs, especially carers – “I'm working, I always have chocolate in my bag”, “I don’t have flexibility because I’m working.” Office workers had more flexibility, however, to

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23 Participant 18, BA Male, Aged 42, Cameroon
24 Participant 18, BA Male, Aged 42, Cameroon
25 Participant 13, BA Female, Aged 60, Nigeria
26 Participant 25, BA Female, Aged 61, Nigeria
take in healthy foods – “In the afternoon I would take soup to work or I would take efo, a big bowl of efo... or ackee and saltfish”.

It was not uncommon for women to hold multiple part-time jobs on top of their caring responsibilities. The participant below described her busy, active working life, which, in common with most participants, included a lot of walking and daily use of public transport, rather than the car:

“Yeah. I work in a school, so I have a lot of walking during the day. And I do dinner lady in a school, and I work in Lewisham hospital as well, in the evening, so I have a lot of walking. I don’t get the time to sit down. Up and down, up and down, every day. ... I take the bus in the morning, going to work. And, when I come off the bus, I walk half a mile, to the school. And then walk it back from there, get the bus back. So, every day, I do that every day. And in the hospital now, I have to go from ward to ward to serve the dinner, so I do a lot of walking.”

Participant 3, BC Female, Age 60, Jamaica

3.2.4 Financial insecurity and other challenges

Participants described an emotional burden associated with financial and housing insecurity and with safety concerns. They described stress and worry about paying bills, financial uncertainty, and the injustice of zero hours contracts – “mean that you got no contract....so if you’re sick...if you don’t come to work. You get no sick pay. It’s not right.”

Concern about money was raised in approximately half of the groups, and in several interviews. Cost was a barrier preventing access to leisure facilities - “the cost there is what is really chasing a lot of people away, someone like me because it's very, very expensive.”

Despite this hardship, participants described being prepared to pay more for food to support T2D – “it also means it's a different spend. It means it's a different type of shopping, as well. So, I would do all the expensive, and I did that.”

Additionally, participants worried about safety on the streets and knife crime, especially if they had children - “you are worried. You are thinking, what will happen? ... will they come in?”

In one of the Caribbean male groups the participants living in Southwark reminisced about how things used to feel safer but now they felt at risk on...
the streets, especially at night. This meant that they were less able to socialise with friends and activities such as meeting friends at the pub were avoided because of these fears:

“Years ago we enjoyed ourselves. It was night out and home. No problem. Never have a problem. You cannot do it now. No, Ma'am. At least you have to be careful when you walk on the street now. It's very dangerous. So, the best way to it, is go to the off-licence, buy a drink and take it home. Participant 9, BC Male, Aged 84, Jamaica

Participants explained how collectively such factors created stress and negatively impacted on everyday life, which can be summarised by the quote below:

Interviewer: What do you think makes life stressful in this country then?
“Oh, my goodness. I think it's probably not earning enough money to pay your bills. Not having... I think there's a lot of things - rights and things taken away from people. For instance, it's like we have a lot of knife crimes, discipline has been taken away a lot from parents, from parenting." Participant 55, BC Female, Aged 60, Jamaica

Expanding on this, the respondent below, directly linked her ability to manage her diabetes with the social challenges she faced such as adequate housing, safety fears and financial worries:

Interviewer: Is there anything that you think you need to help you manage your diabetes better?
“Well, I need my own house. A house, I will say this is my home, and then I will have more rest of mind. I worry a bit, and worries is not good. I worry because I live in sheltered accommodation. The rent, the bills, all the bills. Today they are writing, ‘You are behind your rent. We are taking you to court’. Tomorrow, EDF will come with their own. So, all these worries. Yes. If I have my own home, have enough money to look after myself, and not worry. Lie down and sleep without all this stabbing and all the… I mean, the whole chaos of what’s, in the whole country”. Participant 45, BA Female, Aged 64, Nigeria

Overall, despite these wider social determinants of health not being a significant part of the topic guide, it was evident from discussion that socioeconomic and structural factors negatively shaped the lives of many participants.

3.2.5 Health and spirituality

Traditionally in African cultures spirituality is seen as central to health as part of the triumvirate of physical body, spirituality and elements of nature, all of which need to be in balance to achieve optimal health (Airhihenbuwa, 1995), therefore, I consider health and spirituality together in this section. Within this part of the data there were several positive aspects such as elements of everyday life being active for many and the powerful benefits of spirituality. Nevertheless, individuals were also living with co-
morbidities which influenced their general health and their ability and desire engage in optimal lifestyle changes for diabetes.

### 3.2.5.1 Physical health

Participants described a multitude of comorbidities that they balance along with their diabetes. The most common were arthritis, asthma, and cardiovascular-related conditions such as atrial fibrillation, stroke, and high cholesterol. In particular, the increased prevalence of hypertension amongst individuals of Black ethnicity (Health Survey for England, 2006) was reflected in discussions, with multiple individuals talking about their high blood pressure - “I have high blood pressure, I've had it since I've had children, so it's always been there.”

Arthritis and other conditions associated with mobility were common and were perceived as barrier to engaging in activity – “Even walking from the train station I’d be limping”;

At the extreme, physical limitations impacted significantly on everyday life:

“Now, I have my total knee replacement. I've been home since November. It's not easy for me because I want to go out; I want to party; I want to put on a dress. I'm a bit like restricted, like a prisoner, that's the only way I can put it.” Participant 28, BA Female, Aged 56, Nigeria

Some participants, however, described a personal determination to keep active:

“They thought I wouldn't be able to walk normal because they had written me off, but I'd just try and walk. I'd go out every day. Because I'm not working, I try and just walk around the shops and things like that and I take my granddaughter to the school, backward and forward, so at the moment, I've still got that arthritis on the knee, but it's not as bad as when they were giving me the walking stick and the crutches to walk with. It seems to be okay now, but I've still got osteoarthritis in the knee.” Participant 30, BC Female, 67, Jamaica

Lives were generally quite active. For a lot of women their day-to-day jobs and caring roles meant they walked a lot as part of their normal routine. Shopping daily, using the bus network and walking for pleasure with friends was also described. Walking was an activity that was obviously enjoyed – “mostly I just love walking”. The bus network

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32 Participant 33, BA Female, Aged 50, Nigeria
33 Participant 24, BA Female, Aged 58, UK
34 Participant 1, BC Female, Aged 60, Jamaica
35 Participant 6, BC Female, Aged 73, Jamaica
was described as an opportunity to walk as individuals purposely got off a few stops early for exercise:

“I try and walk, because I get the bus to work and what I do is, I consciously decide to get off a stop earlier and I spend the rest of the time walking to my house instead of taking a short cut because I live not far from the Elephant and Castle, so instead of getting off and walking through the new development, I get off and walk all the way around. In the summer, I like to walk to East Street, walk down to Walworth Road.” Participant 41, BC Female, Aged 58, Barbados

3.2.5.2 Emotional health

Depression is commonly associated with diabetes (Anderson et al., 2001) and some participants made spontaneous reference to struggling with low mood from time to time. There was a circularity to the discussion of mood with some participants feeling their diabetes developed because of feeling depressed over other life events while others linked low mood directly to diabetes:

“I lost my business I was depressed. I went to my doctor, he said, 'You have to be very careful because you are approaching that level [for a diabetes diagnosis] .... So, the next time I visit he said no, we've gone above. I found out that when you are depressed a lot of things comes again.” Participant 19, BA Male, Aged 58, Nigeria

“My GP, when I go for my checks, usually asks about any mental health problems, how do I feel and stuff. Sometimes I get down, I've been quite down but then and when that happens, I go out for a walk. I find the change of environment helps me when I start to feel down. Sorry, so I think depression is when something happening to you. Isn't that it is the diabetic cause you to have depression?” Participant 40, BC Female, Aged 72, Jamaica

Some struggled with their emotions around the diabetes diagnosis - “I lost all hope” and coping with diabetes related lifestyle changes – “low moods kick in, when you deny yourself certain foods” as well as feelings of isolation – “Even though I'm depressed, because sometimes there's no-one with me at all and I'm on my own.” In general, low mood was something that individuals worked hard to contend with - “I find myself a lot more saying to myself when I'm feeling down, 'You've got to get out of this.” They found it easier to do this when they were with others and harder when they were isolated.

36Participant 31, BC Female, Aged 54, UK
37 Participant 30, BC Female, Aged 67, Jamaica
38 Participant 31, BC Female, Aged 54, UK
3.2.5.3 Spirituality

Despite these health challenges a deep sense of spirituality was evident amongst many of the participants, which was a guiding positive force in their everyday lives. According to UK census data 70% of Black Africans identify as Christian and 21% as Muslim, 74% of Black Caribbeans identify as Christians and 1% Muslim (Office for National Statistics, 2011), with 92% of Black Africans and 72% of Black Caribbeans rating their religions as extremely important in their lives (British Religion in numbers, 2011). In the discussions people thanked God for their health and had faith that God looked out for them both in terms of their health and general prosperity – “I believe that a supreme God, that I believe in, is helping me”39. In this data there was no evidence of fatalism around health, in terms of the idea that the individual is powerless in influencing health because everything is predestined, such as has been reported elsewhere (Brown et al., 2007). Rather there was a sense that God would give you the strength you need to cope – “I’m a Christian. The Lord knows what he has prepared me for”40, as well as providing for your material needs. The participant below as a successful businessman, thanked God for his prosperity and taking care of the stresses in his life, despite his own hard work:

“Thank God...a lot of my stresses here, God has taken care of them. I worked quite hard when I was younger and what I really needed in this society God provide it for me.”
Participant 44, BA Male, Aged 64, Nigeria

The positive strength and impact on illness coping associated with spirituality has been frequently reported in Black communities (Rivas et al., 2016). A healthy spiritual life was traditionally seen as central to one’s personal life as well as to connection to others in the community. Spirituality was described as a feature of ethnic identity:

Another thing, we’re faith driven. I’m a believer and we take our spiritual side very serious. It’s a Black thing. It’s our religion, that is. It’s a black thing. Participant 29, BC Female, Aged 52, UK

Religious involvement has been categorised to include organisational (involvement in services etc), non-organisational (praying alone, reading scriptures) and subjective

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39 Participant 49, BA Male, Aged 61, Nigeria
40 Participant 35, BA Female, Aged 71, Nigeria
reliogiosity (holding religious and spiritual beliefs) (Hope et al., 2020). Most participants
did attend a place of worship but even if they did not, they either retained a sense of
spirituality or still described themselves according to their faith, which can be
categorised as subjective religiosity:

“"I was brought up in the Christian faith. I’m a Christian, but I don’t know, because I don’t
think it’s really important for you to go to church to be a Christian. You can be a Christian
without going to church. It’s the way you deal with people...I was brought up in a Christian
home, we’ve been to church every Sunday, but it never really appealed to me, going to, I don’t
feel it was necessary really. I believe in God; I believe there is a God. I’m a Christian at
heart". Participant 51, BC Male, Aged 61, Guyana

In general, religion and faith positively influenced health behaviour. Religious scripture
and the faith community guided attitudes towards looking after your health, taking
medication, and promoting healthy choices. One participant explained how she used
Lent as a time to make significant changes as giving up things for 40 days helped break
habits – ““I did it for 40 days and that’s how I got myself off sugar.”41. The participant
below explains how he grew up reading the Bible and his beliefs growing up shaped his
attitudes towards drinking alcohol:

““Being a Christian there were lots of restrictions. You want to keep your spiritual mind clean
and all that and the thinking was... is that alcohol destroys that connection.” Participant 51,
BC Male, Aged 61, Guyana}

3.2.6 Connecting to others

There was a strong sense of connectedness evident in the data. This related
particularly to the family, extended family and faith communities, but also in some
cases a shared kinship between co-workers, especially carers. There was some report
of social cohesion being reduced in the UK setting, as lives were busy, but overall social
networks seemed strong and supportive.

3.2.6.1 Family and community connectedness

Children, partners and siblings were very much part of the conversation in the
discussion groups particularly. People seemed proud of their grown-up children and
often described them in the context of their educational or professional achievements.
It was not uncommon for elderly parents from countries of birth to come and stay for

41 Participant 31, BC Female 54, UK
extended periods and in this case, they would cook for the family. The home was described as a place where extended family could meet, with food playing a central role in connecting with others:

“You were brought up around your dinner table and on a Sunday, if the next-door neighbours don’t - if it’s the one day they eat, everyone cooks and carries everything and we’re going to be - there’s always extended families, bringing a friend and people can’t - Sundays used to be mad round ours.” Participant 29, BC Female, Aged 52, UK

The family played a part in supporting health behaviour. Children encouraged positive engagement, such as seeking out the bus timetable to encourage attendance at an exercise class, promoting weight loss, and reminding their parents to exercise, or stick to lifestyle habits when on holiday - “Mummy, you need to watch your diet. You need to do this.” For families where multiple members had diabetes, they helped each other. In the example below, the participant describes how her son’s knowledge about diabetes influenced a reduction in carbohydrate portion size:

“That’s – I still eat dumpling but he’s telling me, ‘Mummy, that is, um, 70 amount carbs, so you need to count.’ So, I say, ‘carb’, so he telling ... The tablet is not as strong as the insulin, so I tend to piece of half of the patty.” Participant 1, BC Female, Aged 60, Jamaica

Participants described getting together with others in the community for celebrations and in particular the African participants talked about attending weekly community parties. These social events were an opportunity to dance, meet friends and share traditional foods as the examples below illustrate:

“So yes, I enjoy going to African party, because it's not just the food. It just, it includes a lot of things. Meeting your friends, good African music, dancing, enjoying your party.” Participant 45, BA Female, Aged 64, Nigeria

“The main dishes when I go to a gathering, mostly Jamaican culture cooking. Jerk chicken, and rice and peas. Fried chicken, roast chicken. Yes, you've got roast chicken. Fish. You've got stewed chicken, fried chicken, fish, curried goat.” Participant 8, BC Male, Aged 49, Jamaica

Seeking out connectedness was also commonly described. This was more noticeable for women than men. Women talked particularly about how they enjoyed getting together with others to talk, exercise or both:

“Sister [Name] [from church]. We live on the same street and we used to go walking, from Forest Hill to Lewisham. And back! So, walking together. It helps to walk and talk, you know. You don’t think of the journey, you know, you just walk and, you know, talk. And you feel it nice,” Participant 5, BC Female, Aged 65, Jamaica

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42 Participant 33, BA Female, Aged 50, Nigeria

Findings – The social context
This connectedness around health was nuanced, however; amongst African participants the stigma associated with diabetes and a desire to keep health issues private meant that it was only a trusted core who became partners in their diabetes journey:

“If it’s my business and I’m taking care of it. My wife is aware because she has to be aware. Even my friends, none of them know. It’s none of their business. Explaining that, ‘I’m not drinking this beer because of this.’ That’s my culture from where I’m from.” Participant 22, BA Male, Aged 41, Nigeria

In addition, busy lives in the UK could challenge connectedness, which was a marked difference to the way things were “back home”:

“You know, in this country everybody’s busy! So, we don’t have the same time together. You go to work ...! You know, this country, some people work in the morning, some people work in the evening, so... Back home in Nigeria, you go to office, nine till five, or nine till four, you’re back home, but they schedule a different pattern of working in this country. It’s quite different from back home – a lot of people doesn’t go to work weekend, but here, some people go to work weekend. So that makes a difference.” Participant 56, BA Female, Aged 66, Nigeria

3.2.6.2 Faith communities

Participants described places of worship as providing a central role in community life. Members of the church community described how the church organises special events that bring the community together, for example Black History Month events, concerts, and prayer breakfasts. Again, the community cooked together and the events often involved sharing food – “Especially when we have a concert. A lot of people come...The church full. We have to put extra chairs round.”

Meeting together at places of worship, gave structure the weekends and provided space to connect with family – “Sunday I don’t take any form of exercise. I go to church with my family and it’s a day I spend with my children, the grownups, and my wife.”

Attendance was prioritised:

“A lot of Africans, they are very attached to their church. Very attached to their churches. Sunday or Wednesday, whenever they have their various evening service or whenever time they congregate, they create time. They create time to go to church. Even when they feel

43 Participant 5, BC Female, Aged 65, Jamaica
44 Participant 3, BC Female, Aged 60, Jamaica
45 Participant 44, BA Male, Aged 64, Nigeria
they’re busy, ‘I can’t attend my appointment in the clinic, or I cannot...’ They will attend their service.” Participant 46, Aged 58, Nigeria

Physical places of worship, both the church and mosque, played a central role in informing people about health. Both Muslims and Christians described a situation where faith leaders and visiting health professionals would teach about diverse health topics such as mental health, pregnancy and diabetes as well as offering practical testing support, such as finger-prick glucose monitoring or blood pressure checks:

Black History Month…we had people a psychiatric nurse, she came in and she spoke on psychiatry, and another lady who was part of the church, and she went on antenatal or postnatal depression. She’s a midwife.” Participant 7, BC Male, Aged 75, Jamaica

The trusted faith community was a safe place to seek clarification about health-related things which people did not understand. Both the church and the mosque were seen as secure familiar environments where discussions about health were expected and accepted:

“So, it’s very nice that this type of thing is being delivered in the mosque giving awareness to other people that feel shy.” - Mosque setting - Participant 12 BA Female (no demographic data given)

“it’s a friendly atmosphere ... Church buildings seem to be like a haven, where people are a bit more secure. If I shut that door, nobody will come in” - Church setting - Participant 7, BC Male, Aged 75, Jamaica

3.2.7 Discussion

In this section, the data presented paint a picture of the participants and their everyday lives. This is important because of the increasing recognition of the influence of the social context on the health of the individual. This section gives an insight into the wider sociocultural influences on health behaviour and provides a framework within which to consider self-management behaviour more closely in the proceeding chapters. Such factors are part of what Resnicow et al., describe as “deep structures” (see section 1.3.2). Participants report both positive and negative social factors. The majority of participants are first generation immigrants, a group that in general struggle to gain economic footing in the UK, compared to later generations (Joseph Rowntree Foundation, 2017). They give account of social challenges, such as stress, financial worries, general ill health, caring responsibilities, marginalisation and safety fears, which are part of the milieu framing people’s lives and which are likely to
influence quality of life and the priority given to diabetes management. Whilst the impact of these social determinants upon diabetes prevalence and outcomes is well-evidenced (Hill-Briggs et al., 2021), it is also important to acknowledge the complex interplay of racism and white privilege in determining the distribution of these resources, which ultimately drive health outcomes. Institutional racism, for example, has been described as “a critical basis of all social determinants of health” (Ramaswamy and Kelly, 2015). There were also reported factors within the data, which are likely to act as specific structural barriers to engagement and accessing care, such as inflexible work routines, periods of absence from the UK and lack of financial resources to buy special foods and access leisure facilities. Despite some comment on the erosion of social cohesion, the positive influence of family networks, the social capital within church networks and places of worship, aspects of neighbourhoods and the built environment were also evident in the data.

### 3.2.7.1 Socioeconomic factors and social challenges

The financial strain, job insecurity, housing challenges and demands of long working hours, sometimes seven days a week, described by participants are indicative of the socioeconomic challenges they face. At first glance these factors are likely to impact health in a few ways – firstly in terms of the preoccupying worry of providing for basic needs which is likely to distract from a focus on health, secondly creating stress which is associated with poorer health outcomes and poorer health behaviour and thirdly by creating barriers to health engagement, for example through the inflexibility of working hours, or financial insecurity limiting resources available to pay for leisure facilities. In fact, socio-economic status has been described as a fundamental root cause of health inequities because of its pervasive impact on the ability of communities and individuals to access material resources (healthcare, housing, food, power etc.) that impact on vulnerability to poor health (Phelan et al., 2010).

The literature review confirmed that qualitative exploration of the impact of these factors on diabetes-related health behaviour within UK Black communities, is limited. Earlier qualitative studies amongst those living with diabetes report little or no data concerning the social context. Of the more recent studies, only Alloh et al., refer briefly
to financial constraints with regards to limiting access to healthy food (Alloh et al., 2019a).

Beyond those living with diabetes, the ethnographic study of barriers to a healthy lifestyle for Black families living in Bradford (Ochieng, 2013, Ochieng, 2011b) echoes and expands on some of the issues suggested by my data. In this study participants placed every-day experiences of socio-economic disadvantage, racism and marginalisation centrally in their description of health. Addressing these factors acted as a barrier to engagement in healthy lifestyle behaviours. Moreover, addressing these issues was seen as central to what it means to have a healthy lifestyle, rather than a focus on purely on lifestyle behaviours, as the quotes below indicate:

“But as I say a healthy lifestyle for us is about having a decent job, having our voices heard, our children having a good education, and not being abused because I’m Caribbean.”

“When the government and ruling class people make all this advice, about healthy eating, exercise, relaxing … they think we are all the same; some of these things are not important to us, because we are and feel oppressed. Therefore, although they tell us these things are good for our health, we still cannot reach them … I mean, living a healthy lifestyle is easier for the people with money.” (Ochieng, 2013)

West Africans living in Manchester also suggested financial constraints limited access to healthy food in qualitative interviews (Osei-Kwasi et al., 2019). While this study doesn’t provide the depth of the ethnographic investigation, it has strengths in the sample size (n=31) and the deep understanding of the community brought to the study by the Ghanaian researcher (for example not questioning directly about money to avoid loss-of-face). Participants equated immigration and the associated lack of financial resources with limiting access to healthy food and dissuading them from a healthier option of grilling food, as it saved energy to fry. Food insecurity was also perpetuated by stigma preventing them from accessing food banks, for fear of being judged by other Ghanaians (Osei-Kwasi et al., 2019)

“Most of the times what Ghanaians can afford is not healthy. We think about the bills, especially bills and it makes us not to think or eat good foods. If I want to grill fish, no! I will think of the gas bill and instead fry because it’s faster to fry. There are so many ways we Ghanaians feel the pinch. We worry about those things even though we work normally; we are not healthy because we don’t eat healthily. We know what healthy foods are, but we do not have a choice, for instance, there are certain cheap meats that you will never find a white person buying, but we will buy.” (Osei-Kwasi et al., 2019)
FINDINGS: PART 1 GROUNDED THEORY

Potentially there are some differences between the challenges faced in Black communities living in Bradford and Manchester compared to London, but the data would suggest parallels with my findings.

Whilst there is little explicit exploration of the impact of these factors in the existing qualitative literature amongst those living with diabetes in the UK, a recent review suggested a strong association between poverty and lower educational attainment and increased risk of diabetes-related mortality and poorer control. Housing instability was associated with increased visits to hospital emergency outpatients as well as out-patient utilisation (Hill-Briggs et al., 2021). This data does seem to support an association between indicators of deprivation and poorer diabetes outcomes and comes from a rich body of evidence. A substantial proportion of the data included in the review analysis, however, come from US studies. Across the US, socioeconomic barriers are likely to be more pervasive in influencing long-term health outcomes, than in the UK, because of the financial barriers to accessing care in a largely private, insurance-driven healthcare system.

3.2.7.2 Stress, low mood and health

Stress in everyday life was commonly raised by participants along with low mood and “feeling depressed”. These factors are commonly related to cumulative adverse life circumstances associated with low socioeconomic status, such as financial worries, job and housing insecurity (Houle et al., 2016), migration (Bhugra, 2004), and traditional caring roles (Lawrence et al., 2008). On top of these factors, diabetes itself is associated with an increased risk of depressive symptoms (Anderson et al., 2001). Low socioeconomic status may be more strongly associated with mental health in Black communities in London, compared to other minority ethnic groups (Williams et al., 2015). This may be one of the reasons there is a high percentage of mental health issues in UK Black African and Caribbean communities particularly (Mansour et al., 2020). Poorer mental health as well as lower subjective wellbeing are associated with poorer health outcomes (Poole et al., 2020). It is reasonable to suppose that emotional stress and low mood will negatively impact on energy and focus given to engaging in
optimal health behaviours. Houle et al. (2016) modelled the mediating effects of socioeconomic status on diabetes outcomes in a small study (n= 295) and suggested that stress associated with both diabetes management and day to day worries led to the adoption of less active coping strategies, so less focus on taking active steps to manage the condition, and more avoidance and emotional coping, hence poorer control. While this is only a small cross-sectional study, and has other limitations associated with the use of questionnaires and scales to measure complex variables, it does suggest that supporting patients with active coping strategies may provide one avenue to help mitigate the impact of stress and low mood on health behaviour.

3.2.7.3 Strength in social networks

Despite the various social challenges, the data also suggested potential supportive factors such as family networks, ethnic membership and religious affiliation. These factors have been shown to improve resilience and these community assets are important contributors towards positive health and provide potential opportunities to leverage when considering supporting health in UK Black communities (Harding et al., 2015, Holttum, 2017). In fact, living in a global city like London, with its rich tapestry of diversity and multiculturalism, together with community values associated with spirituality and collectivism, present social capital opportunities for large minority ethnic communities to retain their cultural identity, connection to shared history and to support health (Harding et al., 2018). Social capital was defined by pioneering author Hanifan as “those tangible assets that count for most in the daily lives of people: namely goodwill, fellowship, sympathy and social intercourse amongst individuals and families who make up a social unit” (Hanifan, 1916). Rather than diversity reducing trust and social capital (Putnam, 1995), a number of authors have more recently suggested that connectedness and social cohesion associated with density and diversity of minority ethnic communities can positively influence health by mitigating stress associated with migration and hardship (Stolle et al., 2008). Social networks are

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46 Definitions of resilience are evolving however, it can be understood as positive adaptation or the ability to maintain or regain mental health, despite facing adversity HERRMAN, H., STEWART, D. E., DIAZ-GRANADOS, N., BERGER, E. L., JACKSON, B. & YUEN, T. 2011. What is resilience? Canadian Journal of Psychiatry, 56, 258-265.
central to the idea of social capital and three types of network have been identified: bonding ties (networks with people like you), bridging ties (networks with others unlike yourself) and linking ties (relating to people with power) (Waterston et al., 2004). Laurence convincingly argues that in cities with a density of diversity, such as London there is the potential for both stronger bonding ties associated with ethnic membership – these are the strong primary kinship networks characterised by a “set of attitudes and norms” – but also increased bridging ties improving tolerance between people of different ethnicities, improving social cohesion (Laurence, 2011). There is a large body of data looking at the interaction between social capital and health which was recently reviewed (Rodgers et al., 2019). In terms of the impact of social capital on physical health, the data showed a generally positive, though nuanced relationship, with a decreased risk of all-cause mortality and cardiovascular disease showing positive association with social capital. A four-year longitudinal study in Canada concluded that measures of social cohesion were also associated with improved psychological well-being (Kim et al., 2020). There have been limited studies looking at the link between social capital and diabetes outcomes but the systematic review of Flôr et al., (2018) do suggest that community social capital is associated with improved glycaemic control, although the limited number of studies measuring social capital in different ways limits the strength of the conclusions.

Linked to social capital and social cohesion, social support refers to formal and informal personal relationships (Hill-Briggs et al., 2021). Participants in my analysis described the positive benefit of their support networks, which reflects the findings of Ochieng et al., who present collectivism and kin networks as a key tenet of UK Black communities (Ochieng, 2011a). Ochieng’s study highlighted the how the extended family of grandparents, “aunts” and “uncles” contribute to active socialisation as well as offering practical support such as sharing childcare and meal provision (Ochieng, 2011a). This tradition of the Black kin network is described as a “buffer against social isolation, loneliness and discrimination” despite challenges of deprivation within the neighbourhood (Ochieng, 2011a). Some of my participants did suggest that life in the UK was socially isolating for them at times, but the influence of family seemed positive.
and strong and there were multiple examples of social support as Ochieng describes, for example with childcare. In particular, the positive influence of the younger generation in shaping their parent’s health, whether it be getting them to exercise, take medication and particularly balance their food intake was evident. A robust body of evidence suggests that the risk of all-cause mortality as well as general health is reduced when individuals are embedded in quality family relationships, as family can help support adherence to medical recommendations and assist engagement in positive health behaviour (Holt-Lunstad et al., 2017). A large London-based longitudinal study concluded that despite the experience of racism and discrimination, social support and religious affiliation are associated with increased resilience in adolescents and young people from minority ethnic communities (Harding et al., 2015, Harding et al., 2018). Specifically with regards to diabetes outcomes, social support was associated with better glycaemic control and improved quality of life, while a lack of social support has been associated with increased mortality and increased diabetes related complications (Hill-Briggs et al., 2021).

Spirituality had a centrality in the lives of most participants, which reflects national data. Places of worship, both mosques and churches, are clearly of importance in everyday life for many and provide a trusted network within which health can be promoted, and questions and problems discussed. Religious involvement has been associated with improved health outcomes, less engagement with health-prohibiting behaviours, and improved psychosocial outcomes, in the Black African diaspora (Ransome, 2020). The Black church historically was seen as “the social, educational, physical, ceremonial and sometimes the economic provider for the community” and the role of providing health information is entirely consistent with this role (Scandrett Jr, 1996). The Black majority churches in London are considered to contribute significantly to the social capital amongst Black communities (Harding et al., 2018). Receptivity and efficacy of health interventions within the church setting have proven promising amongst the African diaspora, for a range of conditions from weight management (Lancaster et al., 2014, Maynard, 2017) and mental-health support (Hays and Aranda, 2016, Adedoyin and Salter, 2013) to diabetes (Newlin et al., 2012) and cancer (Hou and...
Cao, 2018). Islamic religious settings also can play a vital role in health promotion but comparatively, there is limited data available (Mustafa et al., 2017).

### 3.2.7.4 Neighbourhoods and the built environment

Another notable finding was that while the lived environment was lacking in green space individuals described active lives. Participants refer frequently to the fact that their jobs, community roles, and responsibilities involved a lot of walking and the use of public transport. This does present significant opportunity and potentially underlies the fact that these London Borough fare relatively well compared to the national averages for physical activity levels (Public Health England, 2019). Residential density, walkability and access to public transport in a city like London, have been shown to be highly associated with increased levels of physical activity (Sallis et al., 2016, Clary et al., 2020).

### 3.2.8 Summary

The main conclusion I draw from the data presented in this chapter is that there were contextual factors in the lives of the participants that provided both challenge and opportunity. Qualitative exploration of these factors is largely unreported to date in the literature considering diabetes-related health behaviour in UK Black African and Caribbean communities. There is increasing recognition that factors within the social environment are influential in determining health inequalities in UK minority ethnic communities. Furthermore, understanding these sociocultural factors, which are pertinent to everyday lives of individuals, is important in improving cultural competence in diabetes care (Hudon et al., 2012). Within the data, financial hardship was a feature of the lives of participants and most worked hard to provide for their families. In addition, financial insecurity, fears about personal safety, adequate housing and marginalisation undoubtedly created stress and worry. It is against these contextual factors that individuals are evaluating the priority they give to their health, health behaviour and diabetes self-management. In addition, financial drivers and working structures, as well as time spent away from the UK created structural barriers to engagement and access to care. Balancing these factors, however, there were also
potential community assets which may help buffer against some of these stresses and which have potential to be leveraged to support health, in particular extended family and faith networks. The data presented provide a backdrop within which individual health behaviour is considered more closely in the proceeding chapters.
3.3 Perspectives on diabetes: a cultural picture

“The word Black brings up the word pride. You don't do Black without being proud. If you're ill you're vulnerable, and if you're ill you're sick, if you're sick you're not a whole person. You're not proud anymore”

(Study participant)

3.3.1 Introduction

In this chapter I present the first of the key categories from the grounded theory analysis, Attaching to traditions (Figure 3-5). This category comprises data concerning the community cultural influences shaping attitudes towards diabetes. The aim of this chapter is to explore the culturally situated beliefs and lifestyle habits that participants described, as well as to reflect upon how these factors intersect with acculturation, ethnic identity and personal agency to influence health behaviour. The study population encompasses a diversity of backgrounds, with individuals from a range of African countries as well as those whose families originate from the Caribbean. It is therefore expected that there will be diversity in cultural influences on diabetes and diabetes-related health behaviour. Interpretation of cultural influences also varies by individuals even within a defined social group (Scott, 2011). People do not copy everything they encounter. Community traditions may be championed or dismissed, the potential consequences of diagnosed illness may be ignored or may inspire adoption of radical lifestyle changes. Thus, the role of the “individual embodied self” (James and Hockey, 2007) should also be considered, as the individual determines how they choose to respond to cultural influences compared to other experiences and ideas encountered. Furthermore, the influence of traditional cultural factors on health behaviour usually declines across successive generations following migration (Bhopal, 2014).
3.3.2 Overview of the category

The main dimensions of the category Attaching to traditions, namely Constructing knowledge and Belonging are described in this section and these factors are considered in the light of acculturating factors from the UK environment and personal agency related to health motivations and faith in the medical model for diabetes care (Figure 3-5). Constructing knowledge concerns the experiences and beliefs that shaped the individual’s understanding of diabetes. Belonging relates social norms and social identity factors which influenced lifestyle behaviours. Both dimensions are key in understanding the culturally influenced attitudes which shaped both the participants’ explanatory model of health and diabetes and the potentially culturally derived influences on lifestyle behaviour choices.

Figure 3-5: Schematic illustration of the category Attaching to traditions and its dimensions Constructing knowledge and Belonging

3.3.3 Constructing knowledge

Health knowledge - the facts, information and skills that are drawn on in understanding health and healthcare – is typically acquired through experience or education (Gellert and Tille, 2015). Diabetes-related knowledge amongst participants was constructed from personal experiences of diabetes and exposure to community beliefs about the nature of diabetes and commonly used treatments (both traditional
and allopathic), as well as exposure to the UK health service. These sub-themes are described in more depth below.

3.3.3.1 Witnessing harm

African and Caribbean participants differed in their overt exposure to diabetes growing up but by adulthood most people had had significant exposure to diabetes within their communities. In the Caribbean setting diabetes – “sugar” (sugar in the blood) was something participants described being aware of from very young, although it was not labelled as diabetes and was poorly understood. Despite the lack of clarity about what diabetes was and what caused it, witnessing the harm associated with the condition characterised the community experience for Caribbean participants growing up:

“They didn’t know what it was in those days… When I was a boy, we heard people… ‘I’ve got sugar’ but they didn’t know what it was. Look my mum and dad – ‘sugar’. My dad’s dad – ‘sugar’. My brother slim, has got one foot, one of the foot gone.” Participant 7, BC Male, Aged 75, Jamaica

On the other hand, the African participants described more stigma and secrecy around diabetes – “ito suga” (sweet urine), during their youth – “Nigerian parents they won’t discuss it with you”\(^{47}\) – such that they were not so aware of diabetes growing up. The African participant below explained that taboos and supernatural beliefs around diabetes may have been at the root of the secrecy, although she distanced herself from holding these “uneducated” beliefs personally, indicating a degree of enculturation in the UK setting:

“…back home they will say, ‘It’s witchcraft’, or ‘It’s something that our ancestors have done’, so that’s what it’s… It is through ignorance. You see? Where I come from, from the Northern part of Nigeria, it is a shame thing. That shame, that, ‘Oh, how can you tell your family you have this?’ So, you keep it to yourself, and it’s like AIDS/HIV. So, you don’t want to tell no one.” Participant 64, BA Female, Aged 52, Nigeria

As adults however, exposure to diabetes amongst friends and family was high across both ethnicities, to the degree that participants felt it was almost inevitable that diabetes would eventually “creep, creep, creep up on you”\(^{48}\). One participant after another listed the number of relatives they had with the condition and clearly linked

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\(^{47}\) Participant 26, BA Female, Aged 66, Nigeria
\(^{48}\) Participant 2, BC Female, Aged 80, Jamaica
diabetes to strokes, loss of limbs and blindness witnessed in these individuals. The fear associated with the potential consequences of the “silent killer”, was evident in the discussions - “die, die, die…it’s what it says on the tin.” Participants described the shock, anxiety and withdrawal they experienced when receiving a diagnosis of diabetes – “I’m afraid because it’s a killer – I cried like a baby.” Witnessing serious complications of diabetes, was shocking and individuals described a perpetual worry:

“You always worry about your kidneys your liver. They say diabetic is almost like a killer. You're going to die. That's the only thing about you ... All the time you want to say ...you know maybe I never get sick... you know but my kidneys...maybe they'll pack up.” Participant 17, BA Male, Aged 57, Sierra Leone

The African individuals described a situation in Africa, where diabetes was left untreated because of lack of awareness, or lack of financial resources and available medical care. This made the African participants aware of the serious consequences of leaving diabetes untreated, as well grateful for the care they have access to in the UK.

“You are in Africa ... because of lack of resources and other things, I've seen people, I know people who have just lost their lives because they are diabetic patients. They don't know first to go to the hospital and diagnose the diabetes. Some of them don't even go, they die like that, then they attribute it to other things, not knowing. I know if you have something like this in Africa, if you don't deal with it in a way that - it's so hard, so hard. You go to the hospital, there are no drugs, there is no information, they are not helpful. People end up just dying like that for no reason.” Participant 18, BA Male, 42, Cameroon

3.3.3.2 Attaching to traditional health beliefs

Many of the participants were explicit about the influence of traditional culture and experiences on their beliefs about diabetes and appropriate treatments, whether it be health-related folklore, views about body image or beliefs in natural remedies: “it’s a cultural thing in Jamaica, when you’re growing up”; “I knew from an early age”; “it just seem to pass on from generation to generation”; “you have to remember we come from cultures way back”; “my mum gave it to me [natural medicine].”

A biomedical understanding of diabetes being associated with underlying metabolic dysregulation was only reported by a small number of participants across both

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49 Participant 33, BA Female, Aged 50, Nigeria
50 Participant 19, BA Male, Aged 58, Nigeria
51 Participant 9, BC Male, Aged 84, Jamaica
52 Participant 8, BC Male, Aged 49, Jamaica
53 Participant 26, BA Female, Aged 66, Nigeria
ethnicities. Instead, most described a lay interpretation of the causes of diabetes. If a more scientific biomedical understanding was apparent, this knowledge tended to coexist alongside traditional beliefs. For example, one participant talked about the role of the pancreas, then expressed a belief in the culturally situated understanding that incidence is lower in the Caribbean as you sweat out the sugar in the heat. Knowledge was drawn from informal stories and experiences of others as well as the media, healthcare and NHS provided courses, in addition to well-informed others within the community.

The lay understanding described by the majority related diabetes directly to acute rises of sugar in the blood or urine as a result of sugar intake. The action of treatments was therefore for “cleansing” and “purifying” the blood, “purging” or “washing” sugar from the system, rather than addressing physiological causes. Additionally, diabetes was described as an invader, something you “get out of your body”. Consequently, some were confused why they had diabetes when they felt their diet was not high in added sugar: “I was doing everything carefully, I thought I was doing the right thing ... where’s the sugar coming from?” 54 Others considered their diabetes an acute response directly to recent dietary sugar consumption, rather than recognising the long-term development of the condition.

“I went to Jamaica last year, August, and I maybe eat a few mangos ... so it might be back in Jamaica I eat all this fresh fruit and eat something and bring it [blood sugar] up ....so when I come back from Jamaica, went to my doctor and he said to me I have diabetes.” Participant 6, BC Female Aged 73, Jamaica

A handful of participants, mostly the older men of both ethnicities, seemed at a complete loss to understand why they developed diabetes at all – “I don’t know. I don’t know what caused it” 55 – highlighting the gap between culturally situated understanding and the biomedical model.

External causes were blamed for diabetes, reflecting other published literature in immigrant African and Caribbean individuals (Brown et al., 2007, Wallin et al., 2007, Brathwaite and Lemonde, 2017, de-Graft Aikins et al., 2019, Osokpo et al., 2021). For

54 Participant 18, BA Male, Aged 42, Cameroon
55 Participant 20, BA Male, Aged 76, Nigeria
example, medication, medical procedures, stress, the lack of sun in the UK to “burn off” sugar and chemically adulterated foods were all rationalised as reasons why diabetes may develop (Figure 3-6).

“Amloidine [blood pressure medication] gives you sugar.”
“I realise it [asthma inhaler] give you sugar, that’s why I stay away.”
“Steroids for once, um, can trigger off diabetes.”
“Family planning [contraceptives], I was told that long years ago. They say, it could give you, they call it in Jamaica, sugar, they say could give you sugar.”
(Participants 34, 8, 6, 1)

“Most people say that stress has got a lot to do with it. So that’s the most important part to some of us, .... because you haven’t got enough rest.”
(Participant 7)

“In the sun [back in the Caribbean] ...all the sugar burns out of you and all the salt you need, and it’s hot so you can carry on working. In this climate it’s a bit cold, it ain’t burning shit .......you can’t burn it off because you’re not sweating.”
(Participant 29)

“People go back to Africa, your diet is very, very good....When we’re back home, right, most of those things we eat are fresh. Most of us since we eat here... though it is like our African foods but ... they are adulterated....most of the things we eat here are adulterated so it adds up to whatever we’re suffering.”
(Participant 19)

Figure 3-6: Perceived external causes of diabetes - participant quotes

Lifestyle factors, diet, exercise, weight, and non-modifiable risk factors, like age and heredity were consistently linked to diabetes by the majority. The links were often made tentatively and not clearly articulated — “people don’t know what, well, what give you sugar is, must be traits of the family or if it’s something you eat or what, I don’t know.” — with only a minority of individuals describing a clear biomedical understanding of these factors: “Some will have it in the gene”; “Our foods, they’re high in natural sugar.”

The continuum of views between culturally situated knowledge and biomedical knowledge was evident particularly concerning the impact of weight as a cause of diabetes. Some dismissed it having any association — “No ma’am it’s just what you eat

57 Participant 9, BC Male, Aged 84, Jamaica
58 Participant 32, BA Female, Aged 70, Nigeria
and probably it’s in the blood”\textsuperscript{59} – or held a belief that it was important to gain weight to fight diabetes, while others were aware of biomedical reasoning, for example linking diabetes to abdominal fat (Figure 3-7). Most participants were somewhere in the middle along this continuum and were confused about the involvement of weight, either because they had diabetes and did not consider themselves overweight or it did not fit with what they saw in the community. Given that diabetes does occur at a lower BMI in those of Black heritage, this is perhaps not surprising. (Paul et al., 2017).

![Figure 3-7: There were a diversity of views linking weight to diabetes - participant quotes\textsuperscript{60}](image)

Folklore surrounding appropriate foods for diabetes were mentioned by Caribbean participants. The need to avoid pork was mentioned multiple times: “yes, it’s a cultural thing in Jamaica when you’re growing up, too much pork is a diabetic cause.”\textsuperscript{61} Added sugar was something that participants recognised should be avoided. There was an evident confusion, however, amongst African and Caribbean participants about natural sugar, as in Africa and the Caribbean people ate a diet high in fruits and sugar cane and it was not directly linked to diabetes: “in the Caribbean where people eat sugarcane, mangoes, everything and they don’t suffer like that.”\textsuperscript{62} Furthermore, the link with starchy carbohydrate was much less clear for participants and while intake of rice may be recognised by some as something to be limited, many people did not clearly understand the role of starchy staples such as yam, plantain and cassava. This participant for example struggled to manage blood sugar but was only considering sugar intake, not starch.

\textsuperscript{59} Participant 7, BC Male, Aged 75, Jamaica

\textsuperscript{60} Participants quoted in figure: \textbf{20}:BA-M-76-Nigeria; \textbf{26}:BA-F-66-Nigeria

\textsuperscript{61} Participant 8, BC Male, Aged 49, Jamaica

\textsuperscript{62} Participant 31, BC Female, Aged 54, UK
“Anything that has to do with sugar, I avoid it. So, then I have to ask myself, where is the sugar coming from? ... I tried. Look, to be honest, I’m not joking, I’ve tried to avoid anything with sugar, then I will ask myself, where is the sugar coming from?” Participant 18, BA Male, Aged 42, Cameroon

This led to a general confusion for some: “You know, they can tell you what to eat and what not to eat, and they are still diabetic”63; “I just don’t understand what’s going on.”64

The treatment beliefs described, support the robust evidence from other studies of African and Caribbean immigrants, that experience of a pluralistic system shape faith in treatments for diabetes (Brathwai te and Lemonde, 2017, de-Graft Aikins et al., 2019, Brown et al., 2007, Kindarara and Silva, 2019, Scott, 2011, Alloh et al., 2019a). A strong faith in natural remedies was evident in the discussions and exchanges were particularly animated. Participants even exchanged phone numbers to access distributors of natural herbs. Treatments used included bitter leaf and abeere seeds (African), and cerasee, sour sop and moringa (Caribbean). The actions were described as cleansing the blood with detailed descriptions given about how the herbs were prepared. The extract below is illustrative of this.

“If you’re a woman, you count seven. You wash it, and put it like water like this, for overnight. When I soak it, that water like that, after washing it, I leave it for two days. The following morning, it's the first thing you drink, before food, so that it can circulate all the system. After one hour you can eat, but it's bitter. So, it's cure all the disease on the body. If it is a male, you soak nine. Because they believe men have more bones than us.” Participant 48, BA Female, Aged 69, Nigeria

Herbs were taken in response to somatic symptoms which indicated to the individual that their sugar was high – such as prickling and tingling of the skin, or when they felt they had consumed excess sugar. Taking herbs this way was described as something that continued since childhood.

“The cerasee is more a medication for your blood. After the mango season finished our parents normally gave us cerasee...to purify the blood, get rid of some of the sugar in the blood.” Participant 8, BC Male, Aged 49, 1st generation

Responding to physical symptoms to indicate when treatment was needed has previously been described in African (Kindarara and Silva, 2019, Wallin et al., 2007,

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63 Participant 8, BC Male, Aged 49, Jamaica
64 Participant 23, BC Male, Aged 71, Guyana
Kahn et al., 2013) and Caribbean immigrants with diabetes (Brown et al., 2007, Scott, 1998). This presents a potential problem when medication is used this way.

Most were aware of potential benefits of diabetes medication; however, medication was less universally accepted than natural remedies. A general dislike and distrust of medication seemed to be perpetuated by stories shared between individuals within the community. This distrust of medication has previously been presented as a normative community belief (Brown et al., 2007, Scott, 1998, Noakes, 2010). It has been argued that generally most individuals with diabetes would prefer not to take long-term medication (Pound et al., 2005, Brown and Bussell, 2011). Many of the participants, however, did express their views strongly about medication and this data would seem to support the conclusions that this is a normative belief. Overall, a full range of views to taking medication were represented within the data. The majority following at least some part of their medicine regimen, even they did so reluctantly. Being able to stop medication was mentioned as a motivation for a many – ‘I really, really want to get off metformin.’ A more deep-seated active distrust was also evident in a sub-set of patients of both ethnicities. The quote below is from a discussion where the participants argued that medication for black patients was inferior – “The medication they’re giving some of us they don’t work I’m telling you” – or that effective treatments were withheld for cost reasons – “cost-cutting ... they’re not going to give you the thing that helps you.” Some people worried about the long-term effects of taking medication and additionally they expressed resistance to blood tests, taking insulin and needles.

“This medication we take every day. And there is side effect of it. Every day you keep taking medication. After 20 years do you think that medicine will not have another bad effect?”

Participant 34, BA Female, Aged 61, Nigeria

The example below is indicative of a generally described view that traditionally people would put more faith in their own natural remedies than allopathic medicine. It was described as “a truism” amongst both African and Caribbean communities, that they

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65 Participant 23, BC Male, Aged 71, Guyana
66 Participant 18, BA Male, Aged 42, Cameroon
67 Participant 38, BC Male, Aged 55, Jamaica
value the traditional knowledge over healthcare provided treatments — “It’s a truism about our community. We think we know better. We take what we think.”

“You have the tradition where people can make their own medicine, they still have belief in doctors. But some they chuck it out [Doctor’s medicine] if it’s not working and do their own”  
Participant 8, BC Male, Aged 49, Jamaica

Individuals who had experienced the valued support of the healthcare system for a condition such as cancer or hypertension for example, were more often more positive about doctors, while still attached to traditional beliefs. Those medically trained or who had worked in healthcare, allied health professions, or health-related academia held notably different views from other participants. They were accepting of taking medication, even insulin and they demonstrated a more biomedical understanding of diabetes. These participants described acting as advocates within the community to encourage medication adherence and in the discussion groups they defended doctors when they were criticised by other participants, highlighting that traditional views were moderated by exposure to the UK healthcare system.

“Sometimes you meet some there [at church] who said, ‘Oh, I don’t believe in taking the medication. And why do you take the medication, it’s not good for you.’ So, I can say to them that it’s good for me, because I can see the progress in my, in my health. And encourage them to take the medication when, as prescribed by the GP, and have a regular blood test and see the GP regular…. They don’t like the medication … and they’re frightened of needles…. the insulin needles. So, I would say to them that if you don’t want to be on the insulin, using the needles, take your medication, take your tablets.” Participant 4, BC Female, Aged 68, Jamaica

Overall, across all participants there was knowledge that diabetes was serious and some understanding biomedical causes and treatments but also evidence of misunderstandings and misperceptions perpetuated by culturally situated knowledge and beliefs. Between ethnicities there were many parallels and key differences were more associated with age, gender, and knowledge sources rather than ethnicity; older male participants, held strongly community-situated beliefs and were notably less likely to have biomedical understanding.

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68 Participant 33, BA Female, Aged 50, Nigeria
3.3.4 Belonging

A final part of understanding the factors influencing the personal perspective concerns social norms around diet, physical activity and weight which influence the intention and ease with which individuals can engage with lifestyle advice. The degree to which an individual attaches to traditional social norms and to which conforming to these social norms is balanced with other health priorities was a key parameter in understanding different patterns of behaviour in the data and is further discussed in the proceeding chapter,

3.3.4.1 Attaching to lifestyle related social norms

Food and cooking habits were closely tied with ethnic identity: “us West Indians we tend to cook with a lot of oil.”69; “We African guys we eat a lot of rice.”70; “I’m proper West Indian and we season and fry.”71 Many participants demonstrated some attachment to cultural foods. For some, their whole diet was based on traditional foods, particularly the Black African participants – “I only love African foods”; “I’m not keen on English foods”; “I eat mostly our food and I enjoy it”– while the majority ate cultural foods at least at weekly social and family gatherings, celebrations and parties. For all, food played a central and symbolic role in their lives and in social interaction, as the extract below indicates.

“Our whole ethos is food. The only time - like love and affection, we’ve grown up around food. Everything was food, so if you can’t cook, you get no man. Everything’s food, so in big gatherings and funerals and stuff, mostly my - it’s food. Everything on a West Indian person, its food, absolutely everything. If you’re not talking about it, you’re thinking about it.”

Participant 31, BC Female, aged 54, UK

Continuing dietary traditions is common with first generation immigrants as food is a way to remain connected to your roots (Hellman, 2007). Although reliance and centrality of traditional foods is considered likely to get diluted over successive generations (Berry and Sam, 1997), these participants seemed particularly attached to cultural foods, even if they were second generation:

69 Participant 41, BC Female, Aged 58, Barbados
70 Participant 19, BA Male, Aged 58, Nigeria
71 Participant 31, BC Female, Aged 54, UK
"Yes, I’m British, I’m born here in the 60s, but I’m Black, which means what to people? My eating habits are so much more different. [...] We have loads of these taught behaviours, what you become accustomed to. From generations what they cook is what they cook. It’s what you eat, what you get used to.” **Participant 29, BC Female, Aged 52, UK**

The key features of the traditional diet as described by the participants were the high reliance on starchy staple carbohydrate foods, consumption of sugar either added or in fruit, a habit of eating large portions – “til you belly full” – and cooking with reliance on oil and salt (Figure 3-8).

"...cornmeal porridge ... we load it with sugar and then what milk do we put in it? The tinned milk. Exactly, then, too sweet, yes... Way too sweet and you’re putting condensed in. We put no other because it’s what we know” (Participant 29)

"I remember when I was young, oh, you know that baste with sugar and garlic, pounded yam and palm oil. We mix it together. I’m used to sugar. My dad, he was a medical doctor... When you’ve got piles - my dad will make the cup of tea and put six spoons of sugar.” (Participant 25)

"the green bananas, because that's one of the staple food. It's lovely, but then you take it in quite big portions, because that's one of our, in Uganda it's one of the staple foods.” (Participant 36)

"I eat hard food, West Indian food. Sweet potato, yam, and banana...it's a terminology that Jamaicans use, hard food, yam and bananas.” (Participant 9)

"When mango time I don't cook, my mummy don't cook. Have a big bowl of mangoes and somebody will pass ....mango, mango... and if you don't have a mango tree you go and buy mangoes and you eat because you can full you belly with mango and you can't want the dinner. And sugarcane, you eat sugar cane, you eat, eat, eat sugarcane.” (Participant 40)

Figure 3-8: Dietary traditions described as central to cultural identity – participant quotes

The one exception amongst participants, was a 58-year-old woman identifying as Black Caribbean but who grew up in a white family and did not follow traditional dietary...
patterns: “I was brought up in the care thing. So, I was brought up with a white family, so I’m used to eating English food, and I don’t really like Caribbean food.” Other than this instance, traditional foods played an important role in the lives of the participants, even those who were second generation or who had come to the UK in their youth.

Moving on to consider norms around physical activity, being active was part of life “back home”, especially walking. The quote below was typical of descriptions of walking a few miles a day being a key, enjoyable part of growing up:

“We had to walk a lot because you have friends and you want to see them. I even walked to school. You walk over to them. Instead of going home you stay out with your friends.... You’re one place to another until maybe it is getting dark, then you realise you have to be home, maybe your parents are looking for you. A lot of this time you are walking. I loved my childhood.” Participant 25, BA Female, Aged 61, Nigeria

Overall, across genders and ethnicities, there was a strong acceptance of walking as being something that was enjoyable and that was an important part of everyday life: “Back home we do walk a lot”; “I don’t believe in not walking”. However, several individuals perceived themselves as being limited by comorbidities and purposeful activity was not described as the cultural norm by women: “Going to the gym is not in our culture ... not in our culture at all.” The majority of women, when pressed, expressed the opinion that their lives were probably active enough without engaging in purposeful exercise on top of their daily routine. Men were more likely to report going to the gym or using gym equipment at home but still expressed fears of injury associated with purposeful exercise: “You have to be careful because you may overdo things. You’re training but no one tell you to do those things because the heart is not strong enough.”

There were complexities regarding social norms around weight. Participants reported a traditional preference for a larger “voluptuous” female shape, and an association with a larger size being a sign of health, wealth and achievement in both men and women. Furthermore, the European weight ideals were not perceived to culturally relevant to

73 Participant 50, BC Female, Aged 58, UK
74 Participant 26, BA Female, Aged 66, Nigeria
75 Participant 39, BC Male, Aged 76, Jamaica
the Black body shape by many. When asked about the risks of carrying too much weight, participants responded that it was not advisable for their health in most cases. Yet when they were shown the photographs (see methods 2.2.3.1) many of the female participants aspired towards the larger curvy shape, with a prominent waist: “her waist is in proportion”; “she looks good and native”; “a good African woman”. The males on the other hand tended to aspire towards the toned masculine shape. The participants, in general, recognised the complexities and that views were changing, yet there was a deep part of them, especially women, that was also still attached to the traditional norm. Furthermore, people expressed concern about how they are perceived by others and how they would be judged negatively if they were seen as failing to meet the cultural body image ideals. This sub theme is summarised in Figure 3-9.
"As you hit an age in terms of maturity, in when you wear traditional wear. You want to look substantial. You want to look good in your clothes. You don’t want to be perceived to be almost a young girl. You’ve acquired some wealth in life, is of substance."
(Participant 26).

“You see a big man...Oh, that man looks very comfortable. Look at how big he is. He’s eating well!”. (Participant 46)

“You want to be perceived to be... You want, yes. Your age and...And at a certain age you’re supposed to be looked, that you’re well looked after. Well, you’re therefore relaxed. You are rounded.” (Participant 36)

“Weight is a sign of wealth. As an Afro-Caribbean, it’s wealth.”
(Participant 29)

“They don’t want when people are so skinny, because they believe something is wrong.”
(Participant 30)

Figure 3-9: Traditional views about larger body sizes - participant quotes76

3.3.4.2 Retaining social identity, stigma & impression management

Dignity and pride were a central feature of cultural identity in both African and Caribbean participants; illness in general and diabetes specifically were considered a sign of weakness that needed to be hidden from others to avoid stigma. There was also a consideration of personal culpability in the diagnosis, further creating stigma. Individuals were influenced by a perception created by UK media that they are to blame for their illness (Figure 3-10).

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The cultural representation of male identity was associated with values of strengths and pride. Male pride was a reason given for men engaging less with diabetes care, as well as other health conditions. This is reflective of the UK literature describing socially constructed masculine norms in Black African and Caribbean men being associated with delayed help seeking and reduced medical engagement (Alidu and Grunfeld, 2017, Mulugeta et al., 2017, Wagland et al., 2020, Anderson et al., 2013, Alidu and Grunfeld, 2020). Both men and women (African and Caribbean) articulated this perspective on men in their communities:

“It's a male egoism, isn't it, that you cannot admit that you're not well or something's wrong with you? You're not being a man... The man is the master of the house and all this and that rubbish, yes. That they can't admit that they're not well or something's wrong with them.” Participant 53, BC Female, Aged 71, Jamaica

“Men don’t like to talk about sickness, illness. It's just a manly thing! Probably, diminishes your macho image to say, 'Oh, I'm not feeling well.' Nobody I know will ever complain.” Participant 51, BC Male, Aged 71, Guyana

Participants widely described wanting to keep diabetes hidden to protect their pride, this was particularly the case for those of Black African heritage - “My dad doesn’t know that I have diabetes, my mum doesn't know, none of them know that I’m diabetic. Not even one.” Beyond this it was also described by one participant as being something to keep hidden from your employer in case it was perceived you would not be able to perform well. In Caribbean participants the stigma was less strongly articulated, and participants did talk to trusted others about their diabetes, although a

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77 Participants quoted in figure: 30:BC-F-67-Jamaica; 40:BC-F-72-Jamaica

78 Participant 22, BA Male, Aged 41, Nigeria
FINDINGS: PART 1 GROUNDED THEORY

taboo was still evident. Indeed, participant described a man whose wife left him following his diagnosis: “someone prick me and say, ‘you know why she getting off him?’ …because him have diabetes.”

The Caribbean participant below described more fully how difficult the vulnerability associated with diabetes is considered in the context of her social identity as a proud Black woman:

“We're very proud ... as Black people, we're proud to look as good as we do... to look like how we do and have diabetes is horrible.”

I became different and I didn’t like it. The word Black brings up the word pride. You don't do Black without being proud. It's just the way it is, and if you're Black, you're proud. My lot are from Barbados .... our motto is 'Pride and Industry'. It's a proud thing to think that you're ill. If you're ill you're vulnerable, and if you're ill you're sick, if you're sick you're not a whole person. You're not proud anymore because you're ill, you're vulnerable, you're at somebody's beck and, not call, but you're not well, and when you're not well you're vulnerable. That takes away that. “ Participant 29, BC Female, Aged 52, UK

Individuals felt pressure to modify their behaviour and the impression they gave when certain norms were seen as particularly closely aligned with cultural identity, in order to avoid judgment from others. This was the case for portion size, other dietary factors, and weight, as the quotes in Figure 3-11 illustrate. Moreover, a general desire to mask the fact you had diabetes meant that some Black African participants were conscious of any behaviour which would draw attention to the condition, even going up first for food in the church setting when diabetics were given that choice by the pastor. This shaping of behaviour to present a socially acceptable face has been articulated at length by Goffman, as impression-management or self-presentation (Tseëlon, 1992, Goffman, 1978). It is particularly important to note evidence of impression-management in the data as it suggests the social pressure to conform to societal expectations is particularly strong for some diabetes-related health behaviours. This is likely to influence intention to adopt any behaviour which may be contradictory to this norm.

79 Participant 42, BC Male, Aged 55, Jamaica
3.3.5 Agency (a modifying influence)

The range of evident normative beliefs and habits intersected with personal coping styles, which ranged from active to avoidant as described in Table 3-3. At the two opposite extremes were the avoidant and active strategies. Participants also described an attitude that was more passive, somewhere between the two. The coping strategy adopted is likely to ultimately influence engagement and adherence behaviour. It was a feature of those pursuing more active strategies, that they had a better knowledge of the biomedical causes of, and treatments for, diabetes.

Table 3-3: Description of the coping styles evident in the data

<table>
<thead>
<tr>
<th></th>
<th>Active</th>
<th>Passive</th>
<th>Avoidant/fatalistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Example</td>
<td>“I knew it was a silent killer. I said no. I will follow the Doctor’s instruction. I will never be defeated by diabetes, so I just have to remain focused.” 81</td>
<td>“I just don’t think about it. I just try to live my life.” 82 “You just have to pretend you don’t have it, psychologically” 83</td>
<td>“You will still die of something. At the end of the day, I’m going to die. Let me drink it. I’m over 50! At the end of the day, I’m nearly 60 so why not” 84</td>
</tr>
<tr>
<td>Attitudinal and psychological factors associated with this strategy</td>
<td>Strong willpower &amp; determination; understanding of what behaviour is needed, belief in</td>
<td>Aware of the consequences of diabetes; fearful; confused about causes; unsure of</td>
<td>Distancing self from diagnosis; not engaging with understanding or controlling diabetes;</td>
</tr>
</tbody>
</table>

80 Participants quoted in figure: 36: BA-F-63-Uganda; 24: BA-F-58-UK
81 Participant 19, BA Male, Aged 58, Nigeria
82 Participant 13, BA Female, Aged 68, Nigeria
83 Participant 39, BC Male, Aged 76, Jamaica
84 Participant 7, BC Male, Aged 75, Jamaica
### 3.3.6 Acculturation (a modifying influence)

Acculturating influences were evident upon dietary habits and attitudes towards weight management and physical activity.

While attachment to dietary norms was also strong in both African and Caribbean participants, those from the Caribbean described the inclusion of more typically English foods in their staple diet, influenced both by British colonialism and by virtue of the fact they had lived a long time in the UK. For the African participants on the other hand, the main meal intake for the majority was almost completely centred around traditional foods, with only breakfast and snacks more influenced by British foods, highlighting a particular challenge to making change for those of Black African heritage. The African participant below, explains how because of the coming to the UK when he was younger, his ability to shift the traditional diet for the sake of his health is greater than for others who came to the UK later in life.

> “Some of them will never give up that traditional food for anything. Then the quantity, they need to be able to get around quantity [portion size]. I came here when I was a younger person, so my mind is very open. I came here just about 17 years of age, so I've been here, my upbringing has made me to have an open mind to a lot of things. And…. I solidly believe this is what I've got to do. I believe in changing, especially if it's beneficial to my health. Whereas when I look at people around me, they came in the area much older and they are set in their ways ‘I'm meant to eat the normal meal’ .... they feel you are against the norms.” Participant 43, BA Male, Aged 68, Nigeria

Regarding weight, participants discussed changing views and acculturating influences upon traditional aspirations for a larger body size: “nowadays they know you don’t have to be big to have money.”\(^{85}\). As discussed above (Figure 3-7, page 157) there was complexity here demonstrated in the women’s groups, with many still valuing the traditional larger body shape, some recognising the need to change but being worried about how people may judge them if they lost weight and others being focused

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\(^{85}\) Participant 36, BA Female, Aged 63, Uganda

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**Findings – Perspectives on diabetes: a cultural picture**
primarily on health, to the degree that they intended to lose some weight if that was what was needed: “It’s about staving off anything that is a repercussion of diabetes.”

This suggests that if motivation to manage diabetes is high, individuals may challenge the traditional social norm, even though their social identity is associated with their ethnic membership. Regarding physical activity, there was evidence from the discussion that while purposeful exercise was not traditionally part of the cultural norm for women, some had adopted a habit of purposeful exercise for the sake of their health. Thus, while social norms and social identity appeared to be key influencers of lifestyle behaviour for the majority, the data suggested that some individuals had shifted their perception towards dietary change, weight management and/or physical activity. These tended to be those with biomedical knowledge of diabetes and an active coping style.

3.3.7 Discussion

In this chapter the cultural influences – the beliefs, experiences and cultural norms that shape participants’ attitudes towards T2D, and the influence of lifestyle social norms – are discussed through the category Attaching to traditions. In terms of knowledge about diabetes and associated treatments, most individuals drew from informal sources and community-situated knowledge and some also drew from healthcare experience and other biomedical sources. There was evidence that in both biomedical and cultural knowledge coexist, but biomedical understanding of diabetes was less common. The importance of maintaining cultural traditions, especially dietary patterns was evident across the data, even for second generation participants. Despite obvious differences in types of foods and cooking traditions, there was uniformity in the centrality of starchy staples and in the centrality these traditions played across the diverse sample. Furthermore, whilst there were subtle differences in the perceptions of diabetes amongst those from African and Caribbean backgrounds the patterns were similar in terms of the motivation to engage with care and the balance of weight given to traditional influences and biomedical knowledge.

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86 Participant 33, BA Female, Aged 50, Nigeria
The findings build on current literature in several respects. The importance of stigma has been previously alluded to as a reason for non-engagement with diabetes structured education in the UK, without detailed exploration (Winkley et al., 2015). My analysis confirms the finding from Omodara et al., that stigma was an important part of the lived experience of diabetes for Black African individuals particularly and is likely to impact upon self-management (Omodara et al., 2021). Furthermore, the role of self-regulation of dietary and weight management behaviour to preserve social identity and minimise diabetes-related stigma has only been reported amongst people of Black ethnicity in one small study amongst Somalian immigrants in the US to date (Kindarara et al., 2017). Amongst Black Caribbean individuals this is the first study to investigate diabetes beliefs and knowledge since the policy changes towards promoting a person-centred, culturally competent healthcare provision (see 1.2.1.2). My analysis confirms that misinterpretations and misunderstandings about causes and treatments for diabetes persist, despite these policy changes. Finally, the data also extend the existing UK literature concerning attitudes to weight and body image and to physical activity amongst those living with diabetes. Exploration of culturally influenced attitudes to weight have not been previously reported amongst Black African individuals living with diabetes in the UK. My analysis suggested that cultural drivers towards the acceptance of larger body sizes was evident in both men and women of Black African heritage, despite evidence of integration of biomedical knowledge about weight and health. In Black Caribbean individuals, similar patterns were evident. These findings contradict evidence from a small qualitative study in mixed population of Black Caribbeans (with and without diabetes) that suggested cultural drivers did not support larger body shapes (Scott, 2001), and in doing so the findings reflect the general consensus of the international literature.

There were several similarities between African and Caribbean participants, namely: faith in natural remedies, conceptualisation of diabetes as an acute issue of sugar levels in the blood, belief in non-biomedical causes of diabetes and some distrust of
medication. Participants of both African and Caribbean heritage demonstrated the importance of community-situated sources, stories, and experiences in shaping health knowledge. Key differences between ethnicities were the degree of acculturation being higher in the Caribbean participants and slightly less stigma and privacy surrounding the condition being evident.

### 3.3.7.1 Illness representations

The illness representations framework from the common sense model (see Figure 6-2, Page 339) has previously been used extensively to explain how patients respond to chronic conditions, in particular diabetes (Harvey and Lawson, 2009, Breland et al., 2013, Alyami et al., 2021, Dimova et al., 2019). According to this model, illness beliefs are constructed from, or influenced by, exposure to symptoms, external stimuli, personal experiences of the condition, religion and spirituality, personal vulnerabilities and the surrounding social and cultural norms (Albert et al., 2014). An overview of this framework is shown in Figure 3-12.

![Figure 3-12: The dimensions of cognitive illness representations. Modified from Quandt et al., 2013.](image)

My data indicated that the main differences in the participants’ explanatory model of illness compared to a biomedical perspective were in the domains of the identity of the illness, the causes, timeline, and control, as illustrated in Figure 3-13. Overall, the biomedical model of T2D as a progressive metabolic condition resulting from long-term poor glucose management, weight-gain and lifestyle-related behaviour was only
articulated by a minority of participants. The fact that the incidence of diabetes is up to three times higher in UK Black African and Caribbean communities than in the general population reinforces the idea that individuals are likely to have had higher exposure than many UK individuals by the time they are diagnosed. It is also of enormous relevance to the beliefs of the individual that they had witnessed a high degree of diabetes-related harm, as many of their relatives have not lived with well-managed diabetes through lack of awareness, intention, or availability of support. This qualitative data refutes survey data from Abubakari et al., which suggested that Black African and Caribbean individuals living in the UK viewed T2D as a benign condition (Abubakari et al., 2013).

<table>
<thead>
<tr>
<th>Domain</th>
<th>Consensus within the data</th>
<th>Aligned with biomedical explanatory model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identity</td>
<td>Diabetes was described by the majority reflected a traditional belief of sugar in the blood or urine, which needs to be removed or washed out to restore balance, or alternatively, as something that invades your body.</td>
<td>NO</td>
</tr>
<tr>
<td>Perceived seriousness</td>
<td>The majority recognised the seriousness of diabetes. This was evidenced by the very strong reactions describing the fear and anxiety aroused by the diagnosis.</td>
<td>YES</td>
</tr>
<tr>
<td>Consequences</td>
<td>Almost universally, well-understood.</td>
<td>YES</td>
</tr>
<tr>
<td>Cause</td>
<td>Inevitable sometimes. Attributed to external causes, many of which the participant had no direct control over. Links to lifestyle-related factors, such as weight were questioned. Come confusion evident.</td>
<td>NO</td>
</tr>
<tr>
<td>Timeline</td>
<td>Some treated it as an acute condition, believing that treatment was needed when blood glucose was elevated but not when it was normal. Focused on somatic symptoms to guide them as to when treatment was needed.</td>
<td>NO</td>
</tr>
<tr>
<td>Control</td>
<td>Coping strategies included avoidant and engaged intention. Faith placed in traditional remedies, with or without allopathic medication. The traditional natural remedies were conceived to act by cleansing the blood, in line with the traditional views about the identity of diabetes.</td>
<td>Mixed</td>
</tr>
</tbody>
</table>

Figure 3-13: Schematic illustration of where explanatory models of illness deviated from biomedical understanding

However, the analysis did suggest that in the Caribbean context growing up “sugar” was normalised in a way that it was not for the Black African participants, which may
be why studies of Black Caribbean immigrants in other high-income countries report a perception of diabetes being less serious (Swaleh and Yu, 2020).

What does this mean for potential adherence to self-management approaches to care? Recent assessments of illness representation constructs in patients with diabetes suggest that limitations in understanding of the condition, how to control it, coping strategies and failure to appreciate the long-term chronic nature of the condition negatively affect therapeutic adherence and diabetes control (Houle et al., 2016, Alyami et al., 2021, Fall et al., 2021). Whilst application of this model to diabetes is relatively recent, there is a developing body of data attesting to its usefulness; self-regulatory theory and the associated common-sense model have the advantage of a robust body of data testing and refining of the model (McAndrew et al., 2019) since its conception in the early 1990s (Leventhal et al., 1992). The data suggest that elements of diabetes illness representations, particularly concerning the nature of diabetes and approaches to control it, are influenced by traditional beliefs and experiences. There are some elements of the illness representations of participants where there are gaps in understanding and knowledge of diabetes, which may highlight where intervention may positively influence self-management behaviour.

3.3.7.2 Health promoting behaviour and social norms

The findings indicate that dietary behaviour and attitudes towards physical activity were strongly tied with social norms. Cultural dietary norms were valued and influenced habits across the sample, even in the case of those participants who have lived for many years in the UK and for second generation individuals engaged in culturally conditioned dietary norms to some degree, reflecting the consensus of the literature to date amongst immigrant African and Caribbean communities in the UK and other high-income settings. Lifestyle behaviours, especially dietary norms, are developed by emulating the example of those in the social group. These behaviours become habitual and so are resistant to change (Higginbottom, 2006). Moreover, individual choices are influenced by the injunctive (prompts of what should be done) and descriptive norms (what is actually done) of those around them. This notion that
our beliefs about the behaviour of those around us is influential on how we behave is integral to social cognitive models of behaviour, such as models of health belief. This understanding has implications for African and Caribbean individuals if healthcare advice for diabetes is contradictory to any of these social norms, as the individual needs to be particularly motivated to resist normative pressure (Ajzen, 2011).

Health promotion activities such as exercising, restrained eating, reducing salt and sugar have been considered “social identity infused habits”. These activities are therefore not just personal choices but are influenced by normative influences of the social group with which one’s identity is connected (Oyserman et al., 2007). Beyond commonly observed traditions, the findings also indicated that elements of social identity were associated with body image and with images of pride and strength (illness meaning weakness). The pressure to follow norms is intensified especially when the individuals’ identity is closely associated with group membership as indicated by my data, creating additional pressure to comply to avoid stigma (Goffman, 1963). The pressure of social norms and risk of stigma can result in people regulating their behaviour to present a socially accepted face (Tseëlon, 1992, Goffman, 1978). Self-presentation or impression-management strategies include behaviour matching and adjustment of behaviour to situational norms87 (Leary and Kowalski, 1990). This may present challenges when social norms are at odds with recommended health behaviour. My findings suggest that these factors may influence engagement in overt behaviour that may signify diabetes or when weight management results in a shape not consistent with cultural ideals.

Keeping cultural dietary traditions alive is commonly reported in immigrant communities as a way to remain connected to the culture of the native community and as an expression of ethnic identity (D'Sylva and Beagan, 2011). Therefore, traditional influences on diet found in these data are not surprising. The centrality of traditional

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87 Impression Management (IM) and Goffman’s Self-presentation (SP) are sometimes used synonymously. However, IM theorists differ slightly from Goffman as the term IM often assumes manipulative intention, whilst (SP) is generally considered more sincere. TSEEĽON, E. 1992. Is the Presented Self Sincere? Goffman, Impression Management and the Postmodern Self. Theory, Culture & Society, 9, 115-128.
foods does seem quite resistant to acculturating influences in this analysis. Some US literature proposes an alternative that new immigrants have a strong desire to “be American”, as such they attach value to the social identity associations of the American diet and dissociate from cultural traditions (Guendelman et al., 2011). This once again demonstrates that though US studies dominate the literature, they should not be considered automatically transferable to the UK context. Overall, there is strong evidence in the data that lifestyle-behaviour norms are strongly associated with socially constructed cultural traditions. This has obvious implications for healthcare advice which needs to be sensitive both to the normative behaviour but also to the pressure to conform to traditions, which may influence an individual’s ability to perform the behaviour, even if they have intention to do so.

3.3.7.3 Agency and the individual

Individuals differed in their coping strategies for diabetes. Other literature has suggested that the burden and emotion associated with diabetes can lead to a defeatist attitude, feelings of powerlessness and an avoidant coping pattern in Black African (Njeru et al., 2016, Wallin et al., 2007, Kahn et al., 2013, Jones and Crowe, 2017, Omodara et al., 2021) and Black Caribbean (Brown et al., 2007) individuals. Additionally, African-Americans have been shown to commonly using emotional, less active forms of coping, both for mental health issues (Knight et al., 2000) and in response to diabetes (Samuel-Hodge et al., 2008), compared to the majority American population who adopt engaged and active problem-solving coping strategies (Knight et al., 2000). Whilst a denial and avoidant pattern was evident in my analysis, it appeared to be the least common. A more engaged, proactive intention to manage diabetes appeared to be associated particularly with biomedical knowledge and a faith in healthcare advice to manage diabetes. These findings were consistent across the participants, despite the diversity. How this faith in healthcare intersects with culturally influenced health behaviour develops in my analysis and will be further discussed in the proceeding theoretical chapter in the context of self-management behaviour.
3.3.8 Summary

In this chapter, I have presented data from the category *Attaching to traditions*. The findings describe how diabetes knowledge was socially constructed through experience and community interaction. Current lifestyle habits were strongly influenced by cultural identity and social norms and despite the diverse origins of the study population, there was much commonality in the overall influence of cultural beliefs and norms. In the following chapter I present the ground theory *Integrating Perspectives* which describes how the data suggest these factors influence self-management behaviour.
3.4 Integrating Perspectives: a grounded theory of self-management behaviour

“They say that we're obese because we're heavy-boned and this and that because you're measuring a Black lady on a European chart. How are we obese? You're telling us incorrect information because you're going by British standards” (Study participant)

3.4.1 Introduction

In this chapter I move away from considering more distal influences on health behaviour to exploring the behaviour patterns of self-management more explicitly, through presentation of the novel grounded theory Integrating Perspectives. The aim of the chapter is to theorise the main concern of the participants and explain the patterns of behaviour observed in the data through this lens, identifying how sociocultural factors shape engagement. Person-centred care is at the heart of modern medicine (Royal College of General Practitioners, 2021). This philosophy encourages placing the patient perspective centrally in care, seeing illness through their eyes and understanding the whole person from a psychosocial point of view (Hudon et al., 2012). In intercultural interactions, cultural-competence is an integral part of providing person-centred care (Saha et al., 2008). It is therefore of crucial importance to understand the lived experience and how sociocultural factors intersect with the healthcare provision to influence behaviour surrounding adherence to self-management recommendations.

The chapter begins by presenting the concept of misalignment. The grounded theory analysis showed that individuals were motivated to manage their diabetes, but they experienced a misalignment between their perspective (shaped by health beliefs, cultural norms and expectations of care) and that of their healthcare team, which is shaped by the biomedical model and associated frameworks for care. This created
gaps in knowledge, perceived conflict with traditions and distrust. It was difficult for individuals to proceed with self-management without these two perspectives being reconciled. The dynamic process of Integrating Perspectives explains how individuals resolve these challenges and how that then influences diabetes self-management behaviour. Different behavioural typologies emerged from the analysis, and each approached the process of integrating perspectives differently, ultimately resulting in different patterns of self-management behaviour and presenting different challenges to care. Part of this data is published in the following paper:


3.4.2 Misalignment – the challenge for individuals living with diabetes

Misalignment explains the relationship between the community situated perspective – the social norms, beliefs and expectations of the participants (see chapter 3.3, page 151) – and the healthcare perspective – the biomedical framework, guidance and structural constraints that are comprised within the healthcare processes. The concept of misalignment is illustrated in Figure 3-18, (page 186). Participants described three areas of challenge resulting from this misalignment: 1) a “tug of war” with conflicting social norms; 2) professional alignment lacking sensitivity to both culturally situated social norms and the diabetes-related illness representations (including beliefs about manageability, treatment, and illness origins), so that knowledge provision lacked relevance; 3) expectations of care which were not always met in practice.

A tug of war with traditions

Most individuals described being in “a kind of balance”, a “tug of war” between diabetes advice and social norms, as some self-management advice was perceived to be in direct conflict with common cultural habits and beliefs. Not only did this influence the desire to make changes it also meant that individuals worried about
being judged by others and were vulnerable to social pressure to follow norms (Figure 3-14). This was the case particularly for dietary factors such as carbohydrate reduction, use of salt and oil in cooking and portion size – “having to give up that which comforts us”88 – and for weight-related advice, especially for women – “There are complexities around it, we know now that to be slim is good but traditionally you don’t want to be skinny”89; “You’re in this sort of balance.”90

“...boiling plantain? ....like woah what's that shit? Thank you but no!” (Participant 29)

“If we anticipate looking like at 50, 60, 70 is not necessarily what we should look like, we should look like we’re 14 or 20!” (Participant 36)

Figure 3-14: Diabetes advice was perceived to conflict with valued habits and beliefs creating a tug of war between supporting your health and conforming to norms91

The conflict also extended to use of medication as a first-line treatment, which was seen as premature and disempowering. Participants described the doctor as seemingly not having faith in more natural approaches, which they wanted to try before resorting
to medication: “His response to me, well you could lose 40 or 50 pounds and do a lot of exercise, but hey, I’ve only seen that once or twice in a lifetime so really our aim is to get you up to metformin twice a day.” Furthermore, healthcare professionals were seen to be discouraging use of natural remedies as they were contraindicated with prescribed medication. In the quote below the individual explains that even though he felt the natural medicine reduced his blood sugar and helped his diabetes, the doctor told him not to take it.

“Doctor will advise you, say I don't give you, don't take it. He said, 'What I advise you to take, what I don't prescribe you don't take.' [It took my] diabetes down but when I went to the doctor he said, 'Look, how come it does dropped down like that? [You need to be careful of] your organs.'”  

Participant 17, BA Male, Age 57, Sierra Leone

In general, individuals perceived that the healthcare practitioner prioritised prescribed medication. It was interesting how across several focus groups the participants justified their continued use of traditional remedies amongst themselves, re-interpreting what they thought doctor meant and rationalising that they could reduce potential problems – such as by diluting the herbal remedies.

**Lack of cultural sensitivity of the knowledge provision**

The biomedical knowledge provision did not address culturally situated knowledge and illness representations, creating misunderstandings and knowledge gaps (see 3.3.7.1 for discussion of illness representations), and presumed an understanding of diabetes which was not necessarily present. This left unaddressed significant fears about the likely outcomes and the likelihood of the condition being controlled. Instead, some continued to perceive it as “*a death sentence*” and others were left feeling shocked and disempowered. There was also uncertainty about how weight and physical activity impacted on diabetes, as well some evidence of lack of understanding about the physiological reasons for diabetes and the need for consistent adherence to a medication regimen. Furthermore, the lifestyle advice given was seen to be Eurocentric and difficult to translate to lifestyle habits which were culturally influenced (see Figure 3-15).

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92 Participant 33, BA Female, Age 50, Nigeria
“Well, I eat yam, banana. So, when I went to that course with DESMOND and I was telling them about breadfruit, they didn’t know what I was talking about, so they didn’t really give us anything on West Indian food or anything like that. It was all about English food! She showed me pictures of bread and potatoes and said that’s what I should cut down on….90% of my meals are West Indian meals... There was nothing to do with West Indian food that was there at all [...] when I went home I was thinking ‘what levels of sugar are there in yam’? DESMOND didn’t really help me to do that because it’s not the type of food we eat”. (Participant 31)

Figure 3-15: Lack of cultural sensitivity in advice reduced the opportunity to change habits

This was particularly the case for dietary factors and there was a persistent lack of certainty around how to translate advice to the traditional diet and consistent confusion over natural sugars and starches. This uncertainty also extended to physical activity. Promoting activities such as going to the gym, which were not part of the cultural norm for many, meant that an opportunity was lost; promoting increasing the intensity of more culturally salient activity, such as walking, may have been more useful. In addition, as purposeful exercise was not the norm for many, there remained a lack of prescriptive detail of how to follow the guidance, which compounded misunderstanding, leading many to feel they were active enough in everyday life. The knowledge gaps evident in the data are illustrated by participant quotes in Figure 3-16.

**Findings: Part 1 Grounded Theory**

**Expectations of care**

Participants expressed gratitude to have access to free healthcare in the UK. Expectations of care, however, were not always met (Figure 3-17). Expectations included an anticipation that their cultural beliefs and practices and Black identity should be respected. Automatic use of BMI charts considered inappropriate for the typical Black body shape and not appreciating importance of traditional cooking traditions alienated participants. Use of BMI charts as an indicator of need for weight loss was questioned even amongst individuals who generally had positive belief in the

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FINDINGS: PART 1 GROUNDED THEORY

diabetes medical model. Individuals wanted to be given time and responded to being supported.

“And there are no real tools when you've been told. You're being told, yes, you really must exercise. What does that mean? [Laughter]. You really must lose weight. What does that mean? There are no tools when you're being told that.” (Participant 33)

“He has so many patients he is going to attend, the time factor is always there. My doctor wouldn't have this time I'm having with you now, you understand? He wouldn't have this time, five minutes at most he is done with you because there are other patients to be seen.” (Participant 44)

Some lamented the lack of time for face-to-face interaction by the healthcare team. Appointment times were perceived as too short: “when I go doctor it’s 5, 10 minutes

“‘They say that we're obese ....because you're measuring a black lady on a European chart. How are we obese? You're telling us incorrect information because you're going by British standards. I'm not obese because I'm 17 stone.[Our] English counterpart, they've got batty [Creole: buttocks] ...but you're going by a European chart ....this Caucasian, matching it to normal standards, normal generics [sic], so a black woman, she's going to get an overweight person. It's incorrect.” (Participant 31)

“‘You can't just go to your employer and says 'I want these days off'. They will never allow.” (Participant 54)

“They sent me to Lewisham. They have this diabetes programme. [...] They always meet in the afternoon, so that time I was working, so I couldn't continue because my job was to start at four o'clock. I couldn't continue.” (Participant 3)

Figure 3-17: Data illustrating expectations of care were not always met

Some lamented the lack of time for face-to-face interaction by the healthcare team. Appointment times were perceived as too short:


Findings – Integrating Perspectives: a grounded theory of self-management behaviour
then you have to go, everyday it's the same thing!” Conversely, when the GP did take time over the consultation, expressed empathy and interest in the person and prioritised talking over written communication, individuals were more positive about their care. The shared decision-making framework adopted by the healthcare team did not sit comfortably with the naturally less assertive communication style of some of the participants as it meant that they didn’t ask for clarification. For example, medical language was sometimes neither understood nor questioned, as this participant explains: “With the diabetes, sometimes they say some word, like a BMI or, and you, um, ketones and so........You know, you just take the word and go.” Individuals preferred a more prescriptive, paternalistic approach and some were left confused by the lack of clarity. With regards to attendance at longer educational sessions, most wanted to attend, however inflexibility in session times meant that some missed out on the opportunity to do so, because of their work schedules. Participants showed no strong desire for the healthcare practitioner to be culturally matched with their own ethnicity, just that their healthcare professionals were able to give them practical pertinent advice: “It's all about the information [...] so the ethnicity, it wouldn't bother me. I don’t think I’d notice.”

96 Participant 9, BC Male, Age 84, Jamaica
97 Participant 6, BC Female, Age 73, Jamaica
98 Participant 29, BC Female, Age 52, UK
FINDINGS: PART 1 GROUNDED THEORY

Figure 3-18: Schematic illustrating the concept of misalignment

Community perspective

Knowledge: illness representations
"Illness" associated with symptomatic state: Belief in external causes of diabetes
Preference for natural remedies, distrust of medication
Diabetes as a disease in the blood
Stigma associated with illness and diabetes
Some uncertainty about controllability

Cultural norms
Fruit, natural sugar, starchy carbs associated with identity
Traditional norms include frying, use of salty seasoning
Traditional acceptance of preference for larger body shape
Purposeful exercise not part of the cultural norm
Preference for relationship building, prescriptive advice

Expectations of care
Respectful, empathetic engagement; accessible care; clear communication

Personal operational perspective
Shaped by degree aligned with community perspective and faith in healthcare

Healthcare perspective

Knowledge: illness representations
Diabetes metabolic conditions diagnosed by abnormality in biological parameters
Medication a first-line treatment & contraindicated with natural remedies
5-10% weight loss advised based on BMI
Dietary advice to reduce carbs, eurocentric understanding of meal planning
Promotion of 150 mins moderate to vigorous physical activity per week

Cultural norms and expectations of care
Time-limited, shared decision making biomedical language, procedural governance

Tug of war
Knowledge provision not sensitive needs
Expectations of care not met

Tension
Conflict
Distrust
Misinformation
3.4.3 The integration of competing perspectives for self-management

3.4.3.1 Overview and key concepts

*Integrating Perspectives* was the process that individuals went through to reconcile this misalignment and adapt to manage their diabetes. Ultimately it resulted in reconciling diabetes guidance with the personal perspective – social identity, cultural affiliation, lifestyle habits and illness beliefs and knowledge – in order to accommodate self-management of the condition.

*Integrating Perspectives* was a three-stage iterative process which involved: 1) **Absorbing** – “taking it in”; 2) **Facilitating knowledge** – “finding a sense of knowing”; and 3) **Reconciling** – “choosing a path”. A fourth stage, **Reframing**, occurred in some cases. The full model is shown in Figure 3-19 on page 189.

The degree of misalignment varied between individuals and depended upon biomedical knowledge and propensity to trust in healthcare as well the strength of cultural affiliation. Four different patterns of behaviour were identified in the data: adaptation, accommodation, traditionalism and detachment. Within each the degree of misalignment differed, this influenced the personal approach to self-management. The typologies are described in section 3.4.4.

Trust played a fundamental role in *Integrating Perspectives* and influenced how individuals navigated the process. The data indicated two dimensions to trust: “having faith” and “bonding”. The first of these was a generalised cognitive trust based on familiarity with and belief in healthcare and the biomedical model for diabetes. It was primarily a result of experience and knowledge. It influenced the general attitude towards engaging with healthcare. The second dimension was an inter-relational emotional trust based on the interaction between the patient and healthcare professional. When the healthcare professional met the individual’s expectations for
respect and empathy it mitigated misalignment issues, addressed some barriers to engagement and positively nudged health behaviour.

Ultimately, this process influenced patterns of behaviour and adherences to self-management recommendations.

Below I will describe the process of Integrating Perspectives. Illustrative quotes are then presented alongside the description of the different typologies in section 3.4.4.2.
Figure 3-19: Integrating perspectives: a theory to explain diabetes self-management behaviour in individuals of Black African and Caribbean heritage in the UK
3.4.3.2 The process of Integrating Perspectives

**Stage one: Absorbing** — “taking it in”

![Diagram](image)

**Figure 3-20: Schematic to illustrate absorbing**

During the first stage, the individual was *Assimilating* the diagnosis in the context of their existing understanding and beliefs about diabetes. Fear and shock were high because of past experiences of diabetes, particularly when the personal illness representations for diabetes associated it with stigma and life-limiting inevitability. This was exacerbated when inaccurate beliefs and misunderstandings were not explored and addressed by the healthcare practitioner. In many cases diagnosis had occurred in an emergency and individuals reported receiving the diagnosis quite bluntly, with little regard for the shock and fear felt by the individual. In addition to having to manage emotions, the process could seem over-medicalised to individuals who may have experienced a more natural approach to care in Africa and the Caribbean. Some moved quickly to *accepting* the diagnosis and *engaging* further with self-management. Others went through a period of *dissociation*, in which they did not engage further with diabetes advice. For some individuals this lasted a matter of months, for others it lasted years during which time they did not engage and may not have even fulfilled their prescription for diabetes medication. This could be exacerbated by the lack of obvious symptoms, reducing the perception of immediate risk. A lack of understanding about whether the condition could be controlled and of the efficacy of proposed treatments compounded this.

The interaction with the healthcare professional engendered trust if the diagnosis was handled sensitively, the advice was sensitive to personal illness representations and cultural habits, and if the individual felt supported. This helped the individual cope.
more successfully with the stressful news, reducing likelihood of dissociation and improving likelihood of proactive acceptance. Figure 3.20 illustrates this stage.

**Stage two: Facilitating knowledge** – “finding a sense of knowing”

Once individuals began to engage with self-management advice, they needed to develop their own understanding and fill gaps in their knowledge to proceed in a way that facilitated maintenance of individual cultural identity. Because of a difference in beliefs and understanding of diabetes and perceived cultural conflict in the advice, compounded by a lack of cultural relevance, all participants seemed to experience some degree of struggle with and resistance to it. Most felt they needed more information, particularly around how to change their diet while still following any cultural traditions that were important to them. Confusion about medication and lifestyle advice was also described. Further *Information seeking* was necessary to allow individuals to make sense of their condition in the context of their own beliefs about diabetes and treatments and to develop understanding of how to translate advice in a culturally relevant way. This was particularly true for dietary changes but also extended to the juxtaposition of allopathic and alternative herbal medication, for example. Crucially, information needed to come from trusted sources. Those that had less trust in healthcare sought information from trusted sources within the community including friends, family and faith leaders. Some verified the doctor’s advice with their own trusted sources within their social networks and made unilateral changes to their approach based on this guidance, for example changing their medication dosage. Those with more trust in healthcare sought information about cultural foods from
medically endorsed sources both in the UK and their native countries. If they had problems with medication or in making changes, they also sought further information from their healthcare team. Information seeking was either passive or active depending on coping style. Passive information seekers gathered further information opportunistically, for example they may attend diabetes education events at church or in a clinical setting if they were offered the opportunity but would not engage in their own proactive research. Active information seekers proactively researched to fill gaps in knowledge. In either case, information seeking was often incomplete, and some gaps in knowledge and misunderstanding persisted for many individuals.

The interaction with healthcare professionals engendered trust where the knowledge provision was culturally salient and practical and when the individual felt understood. If bonding and a trusting relationship was established it positively influenced the individual to consult healthcare sources with problems and questions, reducing misinformation and encouraging adherence. Figure 3.21 illustrates this stage.

**Stage three: Reconciling – “choosing my path”**

![Figure 3-22: Schematic to illustrate reconciling](image)

Finally, individuals reconciled the guidance in a way that was compatible with their cultural habits and health beliefs. *Filtering* was a continuum between sacrificing cultural traditions for the sake of health and shaping application of the guidance to be compatible with cultural identity. This part of the process had a significant influence on
the final patterns of behaviour. At the extremes, it meant that some individuals rejected advice that was incompatible with their personal perspective, for example being unwilling to make any changes to traditional meals seen as central to cultural identity or moderating behaviour while remaining influenced by the pressure of social norms, for example losing weight, but not to degree that others would notice and stigmatise them. At the other extreme, some sacrificed traditions for sake of their health. Individuals also rejected advice that did not fit with environmental and personal limitations, for example work schedules and mobility constraints.

The process of Adapting involved settling into a pattern of behaviour that fitted within personal identity, lifestyle and health beliefs. The individual endeavoured to change habits within this framework, through a process of experimentation. For example, they may try medication or reducing sugar but altered their habits if they had a negative response. Those relying on culturally situated knowledge were less reliant on empirical data and listened to their own body to determine the need to adhere, take medication or reduce sugar. Those with biomedical knowledge and a faith in healthcare were more reliant on scientific data. For example, to help their understanding of how cultural foods affected their blood glucose, some individuals experimented with different foods and tested their blood glucose to determine for themselves how they should make modifications. At this stage individuals sought support from others. For most their social networks were key, particularly immediate family. However, for those with trust in healthcare, support from their healthcare team was also valued. Taking control my way was not achieved by all individuals but refers the state of general resolution that personal self-management goals were achieved in a way that was compatible with cultural identity and health beliefs. This did not necessarily reflect biomedical targets for adherence. Figure 3.22 illustrates this stage.

Stage four: Reframing

Reframing was a fourth stage that occurred for some individuals when they experienced either an increase in their perception of personal risk, such that they valued biomedical knowledge more highly, or a shift in their own knowledge, improving understanding of the biomedical explanatory model. In this case the
individual went through facilitating knowledge and reconciling again with improved intention to adhere to healthcare recommendations (Figure 3-19).

3.4.3.3 The role of trust as a key moderating factor

Trust played a fundamental role in Integrating Perspectives and influenced how the individuals navigated the process. The two key dimensions of trust related to diabetes care in the participants of this study, “having faith” and “bonding”, are explained further below (Figure 3-23).

Figure 3-23: Schematic diagram illustrating the concept of trust as evidenced from the data

Cognitive trust – “having faith”

“Having faith” was cognitive, a generalised trust in healthcare and the biomedical model for diabetes. “Having faith” positively influenced initial engagement and outlook on self-management. Participants in general did not mention trust explicitly but it was evident when they had faith in healthcare. It was evident in their positive intent to follow the guidance and in their confidence that this would result in improved outcomes. They also expressed positive views about the NHS and healthcare professionals in general. “Having faith” was associated with familiarity with the biomedical model and with health literacy (Figure 3-24). Those individuals whose
illness representations were strongly influenced by traditional beliefs were less likely to have faith in healthcare. If their perception of risk increased, such as the threat of complications, or their level of knowledge improved, then this generalised trust appeared to increase.

“I read much about diabetes and I knew it was a silent killer and based on that fact that I’ve got it for myself, I said no, I will follow the doctors instructions. I said no, I will never be defeated by diabetes so I just have to remain focussed.” (Participant 19)

“I knew the NHS will not bring in somebody that’s not an expert in diabetes. That’s what I’m very sure of so I tried to digest the information”. (Participant 22)

Belief in the medical model

Belief in the NHS

"Having faith"

Health literacy

"You’ve got to study. They got books in the library. [...] I do a lot of reading. I got a lot of books there. I bought books, my own books.......” (Participant 37)

Familiarity

"It was about 12 years old. My grandma died ....We have medical people in my family and they said, ‘She died of diabetic acidosis.’ ... When I became a nurse, I used to monitor my mum and my sister, so I kept on going to the doctor regularly and monitor myself, regularly. I kept on having a follow up all the time even if they don’t ask me because I knew this would come”. (Participant 25)

Figure 3-24: "Having Faith" - illustrative quotes

Inter-relational trust - “bonding”

The second dimension of trust was an affective, inter-personal element, identified in the analysis as “bonding”. This was the interpersonal assessment of trustworthiness. As the individual interacted with healthcare professionals in a series of events, each was evaluated and there was a feedback loop. If relationship building behaviour was present (empathy, cultural sensitivity, giving time and support) and the knowledge


Findings – Integrating Perspectives: a grounded theory of self-management behaviour
provision was useful and sufficient, then trustworthiness was established, bonding with the healthcare professional increased and trust was engendered. When “bonding” was present it nudged individuals to take medication and to have a more positive outlook on their diabetes. Individuals also felt a responsibility to try harder when the doctor went out of their way to offer support: “When you don’t try it’s like you don’t respect what the doctor... They’re trying to help you”\(^{100}\) Behaviour was reinforced by praise. Conversely, without an effort from the doctor to respect culture, understand fears and beliefs about diabetes and offer empathetic salient support, individuals disengaged (Figure 3-25). In summary, while knowledge and beliefs influenced the propensity to have generalised trust in healthcare, the behaviour of the healthcare provider appeared to have a significant impact on how well the patients engaged and were motivated to follow self-management advice.

\(\text{“I think my doctor has been very helpful. I travel a lot, even when I’m outside the country I contact him, I email him, he advises me what I should not be eating. I have a good relationship with him and he has been really there for me. The day I saw Dr [name] the way we related, there was a kind of rapport, you know, some people you just meet them for the first time. [...] He’s a very nice chap. If I’m in Nigeria I relate to him and I call him, if I can’t get him he will send me a mail, what the problem is, he will tell me what to do.” (Participant 44)\)

\(\text{“Myself and my doctor we have very good rapport...he said look at your record. I’m saying that when you lost your business, that’s not the end of everything, you can bounce back but you need to have good health. He encouraged me. Said ‘follow this, listen to Desmond.’” (Participant 19)\)

\(\text{“My first dietitian that I saw she said, ‘oh don’t take this, don’t take that...’ Then I was anxious Her telling me don’t take this, don’t take that, make me not want to listen. But the second dietitian I spoke to she knew our food. She had a model of fufu so it make me more welcome... She said eat you can eat it but take your hand take like this... that makes me more compliant listening to her, so with that I was able to control it better because she knows what we eat and she gave me very good dietary information that I needed’” (Participant 15)\)

\(\text{“It was the way she said it It’s like ‘oh you can lose your feet. You’d better go to your eye thing because you can end up blind’. It was just all the negative things and I went home and I was in tears. When I had to go back the second time - ...I was confused about the medication and I said ‘Do I have one...?’ And she goes ‘Didn’t you listen?’ The nurse, she’s just really cold.” (Participant 50)\)

Figure 3-25: “Bonding” - Illustrative quotes\(^{101}\)

\(^{100}\) Participant 41, BC Female, Age 58, Barbados

\(^{101}\) Participant quotes in figure - 44: BA-M-64-Nigeria; 19: BA-M-58-Nigeria; 15: BA-F (no further data); 50: BC-F-58-UK
3.4.4 Self-manager typologies and patterns of behaviour

3.4.4.1 Defining the typologies

Because of misalignment between the cultural and biomedical perspectives, individuals differed in their behaviour depending on their cultural affiliation and faith in the biomedical model. Collectively these factors influenced how individuals engaged in the process of Integrating Perspectives, such that they privileged the healthcare perspective, community perspective or a balance of both. Four behaviour types emerged from the analysis. Based upon the data, I identified the patterns of behaviour as adaptation, accommodation, traditionalism, and detachment. The different approaches resulted in differences in intention and adherence to self-management guidance. Figure 3-26 shows the different typologies graphically.

![Behaviour typologies - distinguished by propensity to trust and degree of cultural affiliation.](image)

Table 3-4 summarises the differentiating characteristics of each type and each characteristic is further defined in Table 3-5. I use the terms Adapter, Accommodator, Traditionalist and Detacher to describe those adopting each pattern of behaviour. The
use of the typology labels is to aid communication and is not meant to denigrate the study population in any way. The patterns of behaviour are not fixed, and individuals switched typology because of significant change in perception of risk or biomedical knowledge. This shift was identified as a fourth stage in the process of integrating perspectives: (Stage four: Reframing).

Table 3-4: Properties of the self-managers

<table>
<thead>
<tr>
<th>Type</th>
<th>Operational perspective**</th>
<th>Risk perception</th>
<th>Propensity to trust in healthcare*</th>
<th>Coping style</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adapter</td>
<td>↔ ↔ ↔ ↔</td>
<td>↑ ↑</td>
<td>↑ ↑</td>
<td>Active</td>
</tr>
<tr>
<td>Accommodator</td>
<td>→ ↔ ↔ ↔</td>
<td>↑ →</td>
<td>↑</td>
<td>Active</td>
</tr>
<tr>
<td>Traditionalist</td>
<td>↑↑ ↑↓ ↑↑</td>
<td>↑ ↓</td>
<td>↓</td>
<td>Active or passive</td>
</tr>
<tr>
<td>Detacher</td>
<td>↑↑ ↑↑ ↑↑ ↑↑</td>
<td>↓ ↔ ↔ ↔ ↔</td>
<td>↓ ↔ ↔ ↔ ↔</td>
<td>Avoidant</td>
</tr>
</tbody>
</table>

*Propensity to trust was a factor of risk perception and degree of biomedical knowledge. ** Operational perspective was the primary motivation for the individual when they weighed up their health-related knowledge and community influences.

Table 3-5: Characteristics shaping each type

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health knowledge</td>
<td>The knowledge and beliefs that shape illness representations - the explanatory models of diabetes and faith in treatments. Health perspective has the dimensions of Cultural knowledge: traditional knowledge and beliefs influenced by community traditions and experience and Biomedical knowledge: knowledge and beliefs about the biomedical model of care for diabetes and is influenced by their experience of the healthcare system. The primary motivation reflects the relative weight given to each of these two dimensions.</td>
</tr>
<tr>
<td>Risk perception</td>
<td>The subjective judgement a person makes about the likelihood of personal harm resulting from diabetes and possible complications.</td>
</tr>
<tr>
<td>Cultural affiliation</td>
<td>The degree personal social identity is influenced by cultural attachment so that health-related behaviour decisions are shaped by traditional normative influences (see 3.3.4).</td>
</tr>
<tr>
<td>Coping style</td>
<td>The way the individual engages with treatment. Styles identified in the data were active, passive and avoidant (see 3.3.5).</td>
</tr>
</tbody>
</table>
3.4.4.2 Understanding self-management behaviour patterns

The theory explicates the different behaviour patterns found in the data. Each of the types addressed the challenges thrown up by misalignment differently, as they balanced the trust they had in the healthcare advice with their desire to conform to cultural norms in the process of Integrating Perspectives. Figure 3-27 shows schematically how the behaviour patterns differed by typology. This is further illustrated in more detail in Figure 3-29 on page 206).

Figure 3-27: Schematic to illustrate how self-management behaviour for type 2 diabetes varied by typology

The Traditionalist

The most common type in the data, the Traditionalist was strongly influenced by community knowledge. Their explanatory model for diabetes was grounded in traditional beliefs and their understanding of diabetes and treatment options was low. The shock of the diagnosis against uncertain understanding of why they have diabetes
and how treatments work meant that during the initial absorbing phase the tendency to dissociate was high as they denied the diagnosis. As indicated in Table 3-6, some individuals did not initially take prescribed medication, even delaying for many years. Community influences were strong for this group of individuals, so they keenly felt the misalignment between traditions and the advice and struggled to integrate the two, prioritising the cultural norms over health. This group had a lot of knowledge gaps, as the vignette below illustrates, because their understanding of diabetes did not reflect the biomedical model. To help this struggle and uncertainty, the Traditionalist turned to trusted community sources to fill gaps in knowledge; they verified medication recommendations with family medics, listened to advice about diet and natural remedies from informal sources and tried remedies they were recommended. If they had problems, they were less likely to discuss them with their medical team. They also listened to their bodies rather than relying on empirical data; they were more likely to self-determine whether they need to take medication on a day-to-day basis. Misinformation was high in this group. When it came to adapting habits to diabetes self-management, this group filtered out advice that did not fit with their cultural identity. As Table 3-6 illustrates, this meant little change to the diet and uncertain adherence to medication regimens. Overall, this group were less likely to adhere to any recommendations that conflicted with cultural identity, such as losing weight and cooking differently. They retained a faith in natural remedies, preferring this approach to taking medication. Traditionalists were happy to be active as this fitted with their cultural identity, especially favouring walking and dancing. Engagement, however, could be limited by uncertain understanding of the guidance. Overall, the level of adherence to self-management advice was low in this group (Figure 3-27 and Figure 3-29).

Table 3-6: Vignette to illustrate how the Traditionalist integrates perspectives

<table>
<thead>
<tr>
<th>Taking it in:</th>
</tr>
</thead>
<tbody>
<tr>
<td>“At first it is a bit of a death sentence... it took me a long time to accept my diagnosis. [...] [The GP] said, 'I'm going to give you one more final blood test, and I'm afraid you're going to have to go on meds'. I remember being so upset even thinking about it. I was extraordinarily upset and in so much denial. To be fairly honest, my GP doesn't know, they started me on over 2000 metformin, which it took me some time to even take because I refused it. Friend of mine's dad died from it, and she cried and begged me, and I started at 1000, never took that 2000 because I just thought, no way. I'm a reader, I do medications myself, so I wasn't having a bar of it. I started myself on 1000,</td>
</tr>
</tbody>
</table>
Findings

Integrating Perspectives: a grounded theory of self-management behaviour

**Finding a sense of knowing:**

*Struggling:* “If you eat that plantain...you eat it like that [boiled]. You will not enjoy it, but when you fry it... [Laughter] Yes. The oil will go in there. The sugar will go in there. Yes. Every combination destroy the body. But that is the only way you can enjoy plantain... you cannot enjoy it the way you enjoyed when you fry it”. Participant 34, BA Female, Age 61, Nigeria

“I’m basically really confused as to what I can have and what I shouldn’t have and the reasons why I shouldn’t have it. Somebody told me that taking sugar doesn’t make you diabetic, so I’m really confused. I’m really honestly confused.” Participant 23, BC Male, Age 71, Guyana

*Information seeking (prioritises trusted community sources):* “[The doctor] put me on the tablets, one in the morning one in the evening but I have a nephew of mine in Trinidad that’s a doctor. So, I discuss this with him, and he say what she’s given me... that for that level of sugar that’s too much. So, I started taking one a day.” Participant 34, BA Female, Age 61, Nigeria

“When we get together... our church when we test in back, she will explain tell us what does ‘ketone’ mean, ‘BMI’, then we get it more... I get it clearer.” Participant 6, BC Female, Age 73, Jamaica

“A friend of mine, she was saying to me ‘just take cinnamon tea’. I tried it and it works. I try whenever I’m told advice because I really, really want to get off the metformin.” Participant 23, BC Male, Age 71, Guyana

**Choosing a path:**

*Filtering (prioritises traditional beliefs and norms; guided by subjective norms):* “He told me what I cannot eat but if I followed the doctor’s orders I will be starving”; “I eat mostly our food and I enjoy it. I can’t leave my African food. No matter what the doctor say. [...] Yes. I don’t need medication. Sometimes I take it sometimes I don’t.” Participant 20, BA Male, Age 76, Nigeria

*Adapting:* “Chicken rice and peas, I love that! Dinner at home with the rice, and you’ve got banana, yam, dumpling, and maybe plantain, sweet plantain....yes ...that’s the ripe plantain” Participant 9, Age 84, Jamaica

**The Accommodator**

This was the second most common type found in the data. Like the Traditionalist, this group had a strong cultural affiliation, but the types differed in the faith they had in the biomedical approach to manage diabetes. The Accommodator accepted the diagnosis quickly, recognising that it would be possible to control the condition with change in lifestyle behaviour and medication (Table 3-7). Accommodators struggled to integrate the advice, however, as they were not prepared to sacrifice traditions but did want to manage their health. This group felt the tug of war with traditions strongly. Where advice was not culturally salient, they tried to fill the knowledge gaps with information from reputable medical sources and they would seek clarification from their medical teams but gaps in knowledge and some misinformation persisted. When it came to adapting to self-management, the Accommodator was motivated to make changes but only to the degree that it fitted within their attachment to community
traditions, so they would filter incompatible advice to a degree, engaging in weight management behaviour but only to the degree that weight-loss was not noticeable to others, or changing portion size to some degree but again being conscious of community pressure and still eating all the traditional starches. Some Accommodators took medication reliably but also valued traditional natural remedies. Adherence to self-management advice was moderate in this group (Figure 3-27 and Figure 3-29).

Table 3-7: Vignette to illustrate how the Accommodator integrates perspectives

<table>
<thead>
<tr>
<th>Taking it in:</th>
<th>Finding a sense of knowing:</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I wasn’t really happy there. Yes, because I know patient that have got diabetes, and I know what it entails. So, I wasn’t feeling happy at all about it. […] They start enlightening you, then you know the implication. What might come out of it if you are not careful about what you are taking, what you are eating!”</td>
<td>“What I observe, the BMI table, each time you do it, it tell you, you are overweight, which psychologically, it make you feel you are not doing anything because each time you check it, it always says you are overweight.”</td>
</tr>
<tr>
<td>Participant 56, BA Female, Age 66, Jamaica</td>
<td>Participant 22, BA Male, Age 41, Nigeria</td>
</tr>
<tr>
<td>Finding a sense of knowing:</td>
<td>“You talk about African food. This is something we all grew up with and to avoid our food is somehow difficult for us because that is something we knew right from when we were born, especially we that came from a poor background. For the rich one that came from the rich ones, maybe they were subject to other foods and [...] For people from [my own] background, it’s our Nigerian food, our African food morning, day and night, you understand? So, to avoid it, it would be difficult but what I advise anybody is [...] cut it short [...] reduce the quantity, because quantity matters a lot, no matter how you crave to eat.”</td>
</tr>
<tr>
<td>Information seeking - “I want to see more articles talking about the people that have done research on African foods [...] When you are trying to picture the African foods you want to look at in in terms of quantity and you can’t see that information for African foods”.</td>
<td>Participant 22, BA Male, Age 41, Nigeria</td>
</tr>
<tr>
<td>“Whatever I take now, I ask, I speak to my doctor or the pharmacist. Somebody who knows better. Like now I take turmeric, cinnamon, lemon juice and ginger every morning [...] before I started to read about it, and they said if you are diabetic, you should be careful with turmeric. So, I had to go to my pharmacist and spoke to him and he said that turmeric is just a herb and he doesn’t think it will have any reaction, so that is OK. So that is why I started, but if he said otherwise, I wouldn’t take it.”</td>
<td>Participant 45, BA Female, Age 64, Nigeria</td>
</tr>
<tr>
<td>Choosing a path:</td>
<td></td>
</tr>
<tr>
<td>Filtering (weight) – “Any weight loss that will be significantly noticeable, I don’t think I want to go to that extent. [...] It’s not going to work because then I will start avoiding people, because sorry to say, like the culture from where I’m from, I can’t see my friend and say ‘Oh I’m diabetic...definitely weight, you are looking to start a different – explaining to people... or you start avoiding people, avoiding places.”</td>
<td>“Rice, yam, ground rice, you know fufu we eat, I like fufu...all these things I cut down. I eat them. All these things I cut them down”</td>
</tr>
<tr>
<td>Participant 22, BA Male, Age 41, Nigeria</td>
<td>Participant 45, BA Female, Age 64, Nigeria</td>
</tr>
</tbody>
</table>

The Adapter

The Adapters, like the Accommodators, had faith in the medical model and were motivated to manage their health. The difference between the two was that the
Adapter was prepared to sacrifice cultural traditions for their health. According to the Tan, (2014) definition of enculturation highlighted in section 1.1.3.4, this pattern of behaviour may be classed as enculturated. However, understanding the nuances of motivation suggested by my data, the flaws in this definition are highlighted, as whilst knowledge of this group does reflect biomedical understanding, the decisions to follow guidance is very much a result of personal agency and the weight the individual chooses to place upon health over tradition. This emphasises potential ethnocentrism in use of words such as enculturation, which could presume an acknowledged superiority of Western culture to the degree that individuals would choose automatically to follow Western traditions once aware of them. The result of this approach however, for this group is that issues of misalignment were less keenly felt because the tug of war with traditions was less evident for them. When diagnosed, the Adapter could still feel strong emotions but they were motivated and active in addressing their self-management programme (Table 3-8). The lack of culturally salient advice created challenges in the context of the traditional diet particularly, but this group actively researched reputable sources to fill knowledge gaps. They relied on empirical data and in the absence of other knowledge provision many used their own glucose monitoring to work out which traditional foods impacted blood sugar. Adapters also involved their healthcare teams in sorting out problems. Misinformation was lowest in this group. When it came to adapting behaviour, very few of the recommendations were filtered out. Individuals were motivated to lose weight and would sacrifice traditional foods if it meant their diabetes would be better managed (Figure 3-27 and Figure 3-29).

Table 3-8: Vignette to illustrate how the Adapter integrates perspectives

<table>
<thead>
<tr>
<th>Taking it in:</th>
<th>Finding a sense of knowing:</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;I felt so sad anyway, because it's not, to be ill is not a good thing. I felt so sad, but again ... I know my daddy was diabetic [...] so you decide how to go about it, and that's the more reason why I want to see a dietitian. I will have my list and ask questions.&quot; Participant 45, BA Female, Age 64, Nigeria</td>
<td>&quot;So the food presented at DESMOND course is nothing like what I eat generally. They're talking about Lucozade bottles and things like that. Yes. It's outside my remit. But then you then start doing all the internet research and asking question and realise, well, actually a lot of my own food isn't quite working here. Yes. It goes against everything everyone says you're supposed to eat. [...] The same thing with dodo. I know that if you fry the plantain in oil the sugars concentrate,</td>
</tr>
</tbody>
</table>

Findings – Integrating Perspectives: a grounded theory of self-management behaviour
you get oil, you get... Oh, yes. So, it's worse, so I'll eat a boiled plantain. I don't like it, but... It's not really. It's not what I want to eat, but if everyone else is eating dodo then, okay, give me plantain and I'm happy”. Participant 33, BA Female, Age 50, Nigeria

Information seeking (reputable sources, healthcare, and empirical data):
“Going on to the DUK website and reading things for myself. The DUK website is really helpful I get quite a bit from that. I also pay a certain amount each year and I get the magazine and stuff, so I always read it and see what’s going on. I find it really useful, really helpful, but I still think the GP or the diabetes clinic could do more.” Participant 41, BC Female, Age 58, Barbados

“I would begin to feel a bit like blurred vision. I went to complain to my doctor. That was when he increased my metformin” Participant 44, BA Male, Age 64, Nigeria

“To be fair with eba and gari I actually go a tester and so when I eat eba my blood sugar goes ‘whoosh’, so I realise and I don’t touch it.” Participant 33, BA Female, Age 50, Nigeria

Choosing a path:
Filtering (sacrifices traditions) - “I said ‘Gari, now you are culprit number one’ I want to say forever, I have it in my mind, banished it for eternity [...] I was tempted all throughout in Nigeria but I avoided it.” Participant 44, BA Male, Age 64, Nigeria

“[People say] ‘Oh you're a mother. Oh with your age... you are like a stick.’ This that [...] or 'men, they like a plumper person’. I don’t listen to them, because getting fat is a sickness on its own. You know the slimmer you are, the better for you health wise.” Participant 45, BA Female, Age 64, Nigeria

Adapting - “So, between November and now I've lost 35lbs. I also know that that's not enough, but again for me it's about, for me and my mind it is about staving off anything that is a repercussion of diabetes, so for me it's about every time I, in my mind, every time I lose a pound or two it means I'm less likely to get a foot ulcer”. Participant 33, BA Female, Age 50, Nigeria

The Detacher

Detachers were present but uncommon in the study sample. Detachers differed from the other three types in that cognitive trust was low and risk perception was low. Detachers remained in the initial Taking it in phase and did not move through the process of Integrating Perspectives. Their engagement with healthcare remained reactive. They may (or may not) have taken medication, however, they were unlikely to have made significant lifestyle changes because of their diabetes. They attended medical appointments if reminded. Detachers had an avoidant coping style and low motivation to engage further in self-management unless Reframing occurred.

Adherence to self-management recommendations was particularly low for this group (Figure 3-27 and Figure 3-29).

“I don’t really worry about it. I don’t really think about it. I just get on. I’ve got a sweet tooth and I like to eat cakes and stuff like that [...] I think I had a couple of letter, but I think, but I’ve put them down and then forgotten about it. I think they’ve had sessions where you had people talking about diabetes but I’ve missed those. I just forgot. I just put the letter down.” Participant 57, BC Male, Age 73, Jamaica
**Shifts in typology - Reframing**

Individuals may shift typology if the degree of trust in the healthcare shifts. This occurred if the perception of risk increased or if healthcare knowledge shifted such that the individual had more faith in the medical model of care for diabetes (Figure 3-28). For example, the participant below matched to traditionalist type, and she made little change to her traditional diet for 10 years. She then had a shock when undergoing pre-op test for another condition. This experience is what changed her perception of risk and made her follow the dietary advice, nudging her towards the Accommodator pattern of behaviour:

“[He said] ‘I think you need to go to accident and emergency’. I went ‘what for?’ He said your sugar level is 39 […] you’ve got to go now’. So, they put me on a drip, and that’s when I realise. I’ve been trying… for a couple of months now I’ve been doing it and I’m getting very serious… I’ve been walking a lot. I’ve joined the gym.”  
*Participant 45, BA Female, Age 64, Nigeria*

![Figure 3-28: Reframing shifts – a change in risk perception or healthcare knowledge influences cognitive trust and a reframing shift so an individual may change typology.](image)

The behaviour of the Detacher is indicated by a dotted line as there were too few of this typology in the data to examine how reframing applied to this group.
Figure 3-29: Summary of how each type proceeds through the process of **Integrating Perspectives** (HC – healthcare)
3.4.5 Discussion

This part of the analysis aimed to explore diabetes self-management from the perspective of the participants and to theorise patterns of behaviour. This is an important step in my study as it helps identify how health beliefs, knowledge and cultural affiliation intersect to determine self-management behaviour. The novel emergent theory Integrating Perspectives suggested that misalignment between the perspective of individual living with diabetes and that of their healthcare team, limits both the ability and intention to adhere to self-management recommendations. Key determinants of behaviour suggested by the analysis were knowledge, cultural affiliation and trust. Because of the lack of cultural saliency in the knowledge provision, there were practical barriers to following the guidance, and individuals with a strong cultural affiliation felt that much of the guidance was incompatible with their desire to follow cultural norms. Ultimately individuals endeavoured to adapt in a way that was compatible both with their cultural identity and health beliefs, following recommendations from trusted sources. From the wider perspective of my study this theoretical understanding highlights the sectors of the population that could most benefit from intervention and support and that within personal diabetes journeys, the point of diagnosis may be a key intervention point to offer tailored support, particularly for those groups currently less likely to engage with self-management.

3.4.5.1 Situating the theory within the literature

The core theoretical category Integrating Perspectives builds upon several well-established concepts within self-management theory. It is increasingly recognised that adapting to chronic illness means significant long-term change to existing lifestyle and adherence to a complicated regimen, in this the patient is not a passive recipient of care (Whittemore and Roy, 2002). Adaption theory suggests that successful adaptation requires the individual make changes to accommodate the new reality of chronic illness. The theory of adapting to diabetes from Whittemore and Roy, fits the data relatively well; it was modified from two key models of adaption (The Roy adaption model (Roy, 2011) and the adaptation to chronic illness theory (Pollock et al., 1989))
and highlights a key phase of adaptation involving absorbing self-management activities into one’s life and identity (Whittemore and Roy, 2002). However, this is a dynamic and systematic process of changing identity to accommodate living with T2D, while my theory suggests that for many, cultural identity was a key immutable driver of self-management behaviour, and that behaviour therefore was adapted to fit this identity, rather than identity shifting to incorporate T2D. Several mid-range grounded theories reinforce this finding. For example, Hernandez et al. have explored T2D in indigenous communities in Canada and White Canadians, testing their theory of self-management to explain how in both conditions the individual gradually incorporates self-management in a way that is compatible with their everyday life and social framework (Hernandez et al., 1999). The driving influence of personal identity was also highlighted by Page-Carruth et al. in their grounded theory of normalisation in rural-dwelling Australians, where self-management strategies were developed to be consistent with existing valued identity of stoic independence (Page-Carruth et al., 2014). My theory Integrating Perspectives builds on this theoretical literature by highlighting the importance of cultural identity in shaping behaviour in the intercultural healthcare context. In addition, the phases in the process of Integrating Perspectives have some parallels with other published theories. Elements of the phase taking it in are noted in several studies, with theories identifying denial and disengagement as being a normal part of the process of diagnosis (Hernandez, 1995, Mousavizadeh et al., 2018, Nantha et al., 2021a, Areshtanab et al., 2018). Alloh et al. in their theory Normality in UK West Africans noted an emotional burden associated with diagnosis however a disengagement was not a part of their theory (Alloh et al., 2021). This study is discussed and compared with my results more extensively in the final discussion chapter of the thesis. In summary, however, key differences in findings may result from the recruitment in the Alloh et al. study being from diabetes support groups and the majority having tertiary education, suggesting they may be more knowledgeable and empowered to support diabetes than many individuals in general UK African and Caribbean communities. Facilitating knowledge from trustworthy sources was suggested to be a key part of several self-management theories. In most
cases, as in my data, this included experiential learning through social networks (Low et al., 2016, Mousavizadeh et al., 2018, Smith-Miller et al., 2020). The role of trust was paramount, however, such that if trust in healthcare was present, information seeking from medical sources was also important (Ligita et al., 2019). A lack of trust conversely meant information and advice was ignored from both healthcare and informal sources (Peeters et al., 2015). Choosing my path as a final phase of reconciliation and adaption was also similar to the final phase of two other theories, one in indigenous Canadian communities (Hernandez et al., 1999) and the other in Mexican Americans (Hunt et al., 1998). The integral role of social support was also identified as part of successfully engaging in self-management in several studies (Nanha et al., 2021a, Ligita et al., 2021) including amongst West Africans in the UK (Alloh et al., 2019a).

In summary, the theory Integrating Perspectives resonates with several other theories exploring diabetes self-management. It is similar, particularly to that of Hernandez et al., and Page-Carruth et al., both of which suggest that self-management is shaped to fit in with self-identity and it adds to this theoretical understanding by highlighting the importance of cultural identity as part of self-identity in this population. Additionally, the different phases of the process of integrating Perspectives are supported by other theories. My theory adds insight as to the role of the healthcare interaction and particularly trust in this relationship. In addition, the typologies identified illustrate how cultural affiliation and knowledge intersects with these factors to influence self-management behaviour.

### 3.4.5.2 Misalignment

Medical anthropologist Kleinman was one of the first to consider cross-cultural healthcare interactions and his explanatory model resonates with the misalignment elements of my grounded theory analysis. In Kleinman’s model of the healthcare interaction the perspectives of the healthcare system and that of the individual, shaped by the popular system, can be discordant and when this happens Kleinman’s data suggest there will be misunderstanding and disengagement. There are limited published theories to explain diabetes self-management in individuals of African
heritage. The one study focused on UK West African individuals does not identify misalignment issues, which may be as a result of the sample differences as discussed in the section above (Alloh et al., 2019a). The conflict between self-management advice and specific cultural traditions was, however, a key finding in a review of 19 studies situated within UK South Asian communities. This review identified conflict between self-management advice and cultural identity, cultural foods, normative physical activity behaviour, attitudes to medication and natural alternatives, health beliefs and diabetes-related knowledge (Patel et al., 2021).

Outside the arena of diabetes, this misalignment in the intercultural health interaction has been theorised as “circling the undefined” (Rothlind et al., 2018) and a “lack of shared meaning” (Degrie et al., 2017), echoing the work of Kleinman (Kleinman et al., 1978). What Kleinman stressed and what the person-centred approach highlights, is that within the healthcare interaction differences in explanatory models of understanding and expectations of care need to be addressed to avoid patient disengagement (Michie et al., 2003, Hudon et al., 2012).

**Table 3-9: Managing misalignment between healthcare and patient perspectives (Kleinman, 1980)**

<table>
<thead>
<tr>
<th>Managing differences in understanding and expectations in the healthcare consultation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Elicit the patient’s understanding, beliefs and priorities.</td>
</tr>
<tr>
<td>2. Present recommendations by translating the complex concepts of medical science to match the patient’s practical knowledge and framework of understanding, including addressing different explanatory models of illness – not merely simplifying knowledge.</td>
</tr>
<tr>
<td>3. Negotiate a consensus and shared understanding</td>
</tr>
</tbody>
</table>

**Figure 3-30: Kleinman’s Explanatory Model. Modified from Kleinman (1978)**

Managing misalignment in the intercultural health interaction
Kleinman calls this a “negotiation of shared models”, an active process resulting in consensus (Table 3-9). Kleinman’s model, like the other similar mid-range theories (Rothlind et al., 2018, Degrie et al., 2017), is, however, heuristic and does not consider how the misalignment in perspective is resolved by the individual in the absence of the healthcare professional negotiating shared understanding. The theory Integrating Perspectives is useful in extending our understanding of how the individual navigates this problem and how this translates to self-management behaviour.

3.4.5.3 Trust as modifier of self-management behaviour

Self-management behaviour was influenced by advice from trusted sources, which for some included the healthcare team but for others meant turning to trusted sources within the community.

Trust in healthcare and healthcare providers proved to mitigate problems of misalignment to a degree, increasing engagement and encouraging the seeking of medically endorsed knowledge. The two dimensions of trust associated with healthcare identified in the analysis align with definitions of different types of trust reported in academic analyses (Pilgrim and Vassilev, 2011, McKnight and Chervany, 1996) (Table 3-10).

Table 3-10: Dimensions of trust relevant to the healthcare engagement

<table>
<thead>
<tr>
<th>Dimension of trust</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Institutional trust&lt;sup&gt;102&lt;/sup&gt;</td>
<td>The belief, even in the absence of scrutiny on the part of citizens, that the system of societal institutions produces preferred results (Miller and Listhaug, 1990).</td>
</tr>
<tr>
<td>Interpersonal trust</td>
<td>A belief about another person’s trustworthiness with respect to a particular matter (Robbins, 2016).</td>
</tr>
</tbody>
</table>

**Trust in the system**

“Having faith” fits comfortably with the concept of systems of institutional trust: a generalised trust in the system of healthcare, both placing trust in the institution and the framework of care offered (the cultural context, knowledge and beliefs of the

<sup>102</sup> Also referred to as systems trust
medical professionals within it) (Schwei et al., 2014). Arguably, this generalised system of trust is the most important element of trust with regards to this analysis as it influences the general willingness of the individuals to engage, seek help and have confidence in healthcare, which then allows the opportunity for interpersonal trust to develop (Schwei et al., 2014, Pilgrim and Vassilev, 2011). A rich body of literature from the US suggests that there are lower levels of generalised trust in healthcare institutions in the US amongst African Americans (Schwei et al., 2014, Musa et al., 2009). In the context of the COVID-19 pandemic in the UK, trust in healthcare as an institution amongst minority ethnic groups is very much part of the urgent narrative to ensure equitable care (Dodds and Fakoya, 2020). In a 2020 UK survey, vaccine hesitancy was 12 times higher amongst Black British citizens compared to White British (Robertson et al., 2021). An erosion of trust amongst Black communities has previously been attributed to racism and discrimination (Razai et al., 2021), historic unethical health research (UK Government Scientific Advisory Group for Emergencies, 2020) and experience of culturally insensitive healthcare (Razai et al., 2021). With regards to diabetes and UK African and Caribbean communities however, the picture is not completely clear. For example, a number of studies in Black Caribbean communities highlighted a degree of distrust of doctors and in medication (Scott, 1998, Brown et al., 2007, Noakes, 2010, Higginbottom, 2006) but service utilisation has indicated relatively high engagement with clinical services (Sedgwick et al., 2003). In my analysis, most individuals were grateful for the NHS, particularly in comparison to the healthcare that was available in their country of birth. So, lack of institutional trust in the NHS in general was not particularly evident, although this may be due to the self-selecting nature of the sample. Certainly, as discussed in the introduction, there is contemporary evidence of systemic racism within the NHS, which includes cultural insensitivity, stereotyping, discriminatory practices, lack of active listening, and failure to bridge cultural differences (Kapadia et al., 2022), all of which are likely to contribute to a lack of institutional trust in healthcare across minority ethnic communities. Discriminatory government policies, such as the treatment of Black communities in the 2018 Windrush scandal, also erodes trust and influences wider trust in UK institutions.
This is likely to further develop inequities as this lack of trust breeds a general lack of confidence that institutions will act in your best interests; it directly influences factors such as willingness to share health data via government sponsored apps, which is increasingly recommended for diabetes monitoring (Diabetes UK, 2021b). Where individuals across the study population did differ, was in generalised trust in medical practices, the medical model and treatments proposed to manage diabetes. This generalised trust was lower for a sub-group of participants (the Traditionists and Detachers). Pilgrim, like a number of sociologists such as Luhmann (Luhmann, 1979), argues that there is a transition from specific familiarity to general confidence, so that an individual is more likely to have faith or general confidence in what they know (Pilgrim and Vassilev, 2011). This would suggest that the misaligned explanatory models for diabetes, and associated lack of health literacy and knowledge, would, at least in part, explain some of this distrust. Given the complexity of these issues and the relatively broad nature of the research questions for this study, further focussed data collection would be necessary to fully understand trust-related attitudes within these communities.

**Trust in the healthcare practitioner**

In my analysis the concept “bonding” refers to the interpersonal trust that is built up between healthcare practitioner and patient (Table 3-10) and it appeared to nudge behaviour positively. The idea that intercultural misalignment can be mitigated to a degree by meaningful trusting care relationships is also supported in systematic reviews; affective communication at a personal level, which respects the patient’s sociocultural context and connects in an empathetic manner (sharing personal experiences, spending time with the patient and responding to cultural difference and providing personal support beyond the medical) helped individuals engage (Degrie et al., 2017, Rothlind et al., 2018). The traditional African culture is reported to be a relationship-driven, collectivist culture (Di Noia et al., 2013, Airhihenbuwa, 1995) and therefore it is unsurprising that when individuals felt they were given time and the healthcare practitioner used affective communication (Table 3-11) to support
development of personal relationship with their doctor, it appeared to improve both engagement and trust.

Table 3-11: Different types of verbal communication in the healthcare interaction. Modified from Beck et al., 2002 and Ong et al., 1995.

<table>
<thead>
<tr>
<th>Affective communication – relationship-building</th>
<th>Instrumental communication – information related</th>
</tr>
</thead>
<tbody>
<tr>
<td>Encouraging, being relaxed, friendly, open, showing concerns, giving reassurance and support, showing approval, showing empathy, providing verbal support, addressing the patient by name, engaging the patient in ‘small talk’, using humour, psychosocial talk (considering emotions), receptivity to patient’s questions.</td>
<td>Giving information, asking questions, counselling, discussing tests, explaining details of health conditions, sharing information.</td>
</tr>
</tbody>
</table>

The powerful positive effects of trust between doctor and patient are well-reported for all patients, regardless of ethnicity (Brown et al., 2017, Zeh et al., 2014, Birkhauer et al., 2017, Bensing et al., 2011, Mazzi et al., 2016). While my data suggest that lack of culturally relevant advice, lack of respect for culture and insensitivities to physiological ethnicity differences erode trust, causing disengagement and tension, older UK studies report a stronger distrust of healthcare professionals than my data suggest (Scott, 1998, Brown et al., 2007). Scott (1998) describe an acute ignorance of important social, religious and economic factors on the part of the healthcare professional. Brown et al. (2007) echoed the view amongst Black Caribbean individuals that they did not receive the same quality of care as White individuals. This disparity suggests that since these older studies, the considerable policy shift towards inclusivity and person-centred care within the UK health service has improved cultural competence to a degree. Nevertheless, given recent evidence, there is still much room for improvement (Kapadia et al., 2022)

**Trust in informal sources**

The strength of faith in trusted community sources and the reliance on informal sources of advice was also evident in my analysis, particularly for the Traditionalist typology. A preferential reliance on informal community sources on health-related matters is well-documented amongst African Americans (Copeland et al., 2003, Musa
et al., 2009); family, friends, neighbours and church members, especially religious leaders are consulted to provide health-related advice (Caldwell, 1996). Scott et al. report the reliance on familial and social networks for advice on diabetes amongst those of Black Caribbean ethnicity to be in contrast to White participants in their study (Scott, 1998). My analysis suggests this may be the case for some individuals but not all. Empowering trusted members of the community to support self-management in partnership with healthcare has potential to reduce the misalignment patients experience and has potential to provide a trusting environment for improving knowledge. It is necessary for community advocates to be equipped with culturally relevant tools to address the specific gaps in knowledge identified, as well as to be empowered with robust evidence-based diabetes-related knowledge.

3.4.5.4 Knowledge and self-management behaviour

The search for culturally salient knowledge, which responded to health beliefs and accommodated cultural preferences was a central to self-management across participants. When a shared understanding is not evident and advice is not culturally salient, gaps in knowledge are inevitable and reduce the likelihood of adherence and engagement (Van Wieringen et al., 2002). The provision of knowledge alone is not typically associated with health behaviour change (Eibich and Goldzahl, 2020), however the absence of relevant knowledge is considered a key limiting factor on behaviour change (Scrimshaw et al., 2002). Health belief models such as the theory of planned behaviour (Figure 6-1, Page 339) suggest that knowledge influences behaviour in two respects, firstly through beliefs about the perceived benefits of the action regarding its likely effectiveness in reducing disease threat and secondly, through provision of skills to perform the behaviour (Ajzen, 2011). In the COM-B model these factors are part of the motivation and capability domains (Michie et al., 2014).

The theory of Integrating Perspectives provides new insight as to how the individual uses information seeking to support their self-management and improve their knowledge despite the deficits in care, with behaviour varying by typology. My analysis suggested that the Traditionalists needed to increase understanding both about the
perceived benefits of action and to develop skills and knowledge to help them follow advice in a way that was compatible with their cultural identity – including cultural foods, for example. For the Accommodators and Adapters, the main gaps were associated most specifically focused on the skills and knowledge to adapt the traditional diet.

Overall, individuals were not successful in this information seeking to improve their own knowledge, partly because information was not readily available, but also because trusted informal sources sometimes gave incomplete or contradictory guidance. The data suggest that despite the more recent recognition of the importance of offering culturally salient care (World Health Organisation, 2015, Royal College of General Practitioners, 2021) and changes in diabetes care guidance to reflect this (National Institute for Clinical Excellence, 2020), these individuals are still not receiving equitable care. Furthermore, failure to address individual’s experiences and belief systems around the condition, as advocated in a person-centred care approach (Hudon et al., 2012) meant that misunderstandings about the condition and the relevance of the self-management behaviours were not addressed. For the Traditionalist group particularly, this appeared to reduce adherence and their perceptions and beliefs largely remained unaltered during the process of Integrating Perspectives.

3.4.5.5 Cultural affiliation

After trust and knowledge, the degree of cultural affiliation appeared to be a third key moderating factor in self-management behaviour. This was primarily because advice was perceived to conflict with social norms so those more strongly attached to these norms had greater difficulty. As discussed in 3.3.7.2 pressure to follow social norms, especially those closely associated with ethnic cultural identity can be strong (Oyserman et al., 2007). The grounded theory analysis highlighted the interplay between the desire to follow norms and to support one’s health. As individuals filtered out and rejected advice that did not fit within their personal perspective, the data suggested that when culturally situated normative influences were strong, they were given weight over healthcare advice. Limited data suggest that in the US setting
adherence to diabetes self-management is lower amongst minority ethnic individuals with high affiliation to their cultural identity (Xu et al., 2011). Likewise, in the US those wishing to identify with their traditional ethnic membership were resistant to lifestyle-related health promotion messages which they didn’t feel appropriate to their “in group” norms (Oyserman et al., 2007). Recent evidence synthesis suggests that South Asian individuals experiencing this similar conflict were more likely to prioritise cultural identity, aligning their behaviour with cultural preferences rather than professional guidance, thus reducing self-management adherence (Patel et al., 2021).

What is not clear from the analysis is the degree to which the powerful influences associated with cultural identity can be mitigated by adequate knowledge provision, sensitive to the personal explanatory model; both Accommodators and Traditionalists had a high degree of cultural affiliation but the data suggested it was the familiarity and understanding of the medical model for diabetes that supported higher engagement in Accommodators (Figure 3-26, page 197). This highlights the importance of developing biomedical knowledge to increase engagement with self-management advice. Secondly, the perception that advice conflicted with social norms reflects reality to the degree that weight loss, reduction in starchy carbohydrate, fat and oil and portion size all clash with normative influences for those with strong cultural affiliation. In reality, provision of culturally salient advice such as how to modify portion sizes of traditional starches may reduce disengagement to a degree, allowing the individual to modify behaviour whilst still following traditions.

3.4.5.6 Implications of the findings for culturally salient intervention

Overall, the findings presented in this chapter further develop the analysis presented in the preceding chapters by conceptualising how beliefs and sociocultural factors intersect to shape self-management behaviour.

There are several implications for cultural salient intervention evident in this analysis. This inductive approach identified trust, cultural affiliation, and knowledge as key influencers of behaviour, which are potential factors to address through intervention.
While some individuals can adapt to the current healthcare provision successfully (Adapters), those strongly influenced by normative influences from within their community (Accommodators and Traditionalists) need further specific culturally focused advice to provide appropriate knowledge, sensitive to their tradition beliefs and cultural norms surrounding diet, weight and physical activity. Dietary resources (such as GI values for traditional foods) has more recently been made publicly available, facilitating the provision of culturally salient dietary advice (Mehar et al., 2019). Providing support for the Traditionist type seems particularly important. This group were less likely to adhere to guidance. Whilst this was partly due to the knowledge provision discussed above, the generalised lack of faith in health care and lack of health literacy and understanding of diabetes increased misalignment and further accentuated the issues. Given the relationship between familiarity and generalised trust (Luhmann, 1979, Pilgrim and Vassilev, 2011), it is likely that effort made to increase familiarity with the healthcare model for diabetes care and to increase health-related and diabetes-related knowledge may assist to build this generalised trust in this group of individuals. This may well be more effective in a trusted community setting. In addition, given the value placed on trusted informal sources, partnerships with trusted community figures to build relationships with healthcare teams are likely to help build generalised trust, provided they are equipped with accurate culturally relevant advice. Support within the community setting may also help the Detacher type, for whom the key objective would be to develop their knowledge about diabetes to increase intention to engage with self-management.

Finally, the value of investing in building interpersonal trust on the part of the healthcare professional is clearly highlighted and resulted in improved engagement. Taking time to build trust, both through affective communication and simply being respectful of culture, may assist in building adherence for all individuals, but most particularly those who may struggle with a misalignment between their own cultural perspective and that of their healthcare team.
3.4.6 Summary

In this chapter I have presented the novel grounded theory *Integrating Perspectives* and have identified four key typologies to describe patterns of self-management behaviour. Using this inductive approach data suggested behaviour patterns were particularly influenced by the degree of cultural affiliation, knowledge and trust. In the next chapter I will build on this analysis by applying a behaviour change framework to understand which evidence-based behaviour change techniques may support engagement with diabetes-related health behaviour.
3.5 Supporting healthful behaviour change for diabetes self-management

“You’ve got all the tools there and it’s up to you to use it. If you’re going to not do it, you can’t blame anyone but yourself. It’s my responsibility now. I can’t blame anyone for this, so I feel that I’ve taken it onboard and it’s not that difficult.” (Study participant, post HEAL-D intervention)

3.5.1 Introduction

The data in the previous chapters elucidate some of the factors influencing self-management related health behaviour and in the last of the findings chapters I shift focus towards achieving conceptual clarity on how interventions and health promotions can be developed and under pinned by behaviour change theory to support healthful self-management behaviours for UK Black African and Caribbean adults living with diabetes.

The data presented in previous chapters (3.2-3.4) suggest that in these primarily first-generation individuals there are some social challenges which may influence the priority given to health and that cultural influences remain very powerful. The misalignment associated with differing explanatory models of illness, diabetes advice which conflicts with cultural habits and beliefs, and a Eurocentric knowledge provision, can make it difficult for individuals to move forward with self-management of their condition. These issues are exacerbated by differing expectations of care, a lack of trust in the healthcare process for some individuals and normative social influences. Four behavioural patterns were identified. This resulting theoretical understanding provides an insight from the patient perspective of the challenges they face. However, in order to inform the design of theoretically-based healthcare promotion and intervention as best practice recommends it is helpful both to methodically identify key determinants for specific self-management behaviours of interest and to link them
theoretically to potential mechanisms of change (Bartholomew et al., 2016) (Van Achterberg et al., 2011). Behaviour change techniques (BCTs) are the evidence-based, active components of change embedded in health promotion and interventions.

The specific aims of this chapter are: 1) to identify potential determinants of behaviour which may be leveraged in interventions, 2) to identify potential BCTs which may be effective to support healthy behaviour for diabetes self-management and 2) to reflect on the BCT effectiveness in a real world setting, using the HEAL-D intervention as an example.

3.5.2 The data and methods for this chapter

In this part of the analysis, I move away from the grounded theory methodology to apply the COM-B framework. The detailed methods for this part of my study are outlined in the methodology and methods section (section 2.1.5.2 and section 2.2.7.2, beginning on page 89). Unlike the previous three chapters which utilised the full dataset, in this part of the analysis the phase I focus groups were used for the COM-B analysis and to identify BCTs. The Phase II process interviews, from the HEAL-D feasibility trial, were then used to consider the acceptability and effectiveness of these operationalised BCTs in a real-world setting. This chapter presents an extended version of the data in the following published paper:


3.5.3 Understanding the behaviour

3.5.3.1 Defining the problem and selecting target behaviours

The focus of this analysis is to identify how to support an improvement in everyday adherence to lifestyle related recommendations and to any prescribed medication regimen (See Table 1-1 for the evidence-based lifestyle recommendations for type 2
diabetes). The phase I focus group data were used to help identify which of the guidelines were likely to be challenging in this community and the barriers and facilitators to change. Each of the recommendations were considered in turn and a pragmatic list of specific positive behaviours were generated and evaluated according to the APEASE criteria (impact, likelihood, spill-over benefit) (see Table 2-9). The key behaviours selected are identified in Table 3-12.

Table 3-12: Identified target behaviours

<table>
<thead>
<tr>
<th>Guideline</th>
<th>Key behaviour identified</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily moderate to vigorous physical activity or 30 min, at least 5 days a week but every day if possible.</td>
<td>Engage in moderate to vigorous exercise of choice for 30 mins/day.</td>
</tr>
<tr>
<td>Modest weight loss (5–10%) in overweight/obese and maintenance in those of healthy weight.</td>
<td>Monitor waist circumference (and engage in the portion size and activity behaviour specified).</td>
</tr>
<tr>
<td>Balanced carbohydrate intakes through portion control and consumption of low glycaemic index and wholegrain sources.</td>
<td>Reduce starchy carbohydrates to a fist or palm-size maximum each meal.</td>
</tr>
<tr>
<td>Limited saturated and trans-fat intake, and replacement with mono-unsaturated fats, and oily fish consumption at least twice a week.</td>
<td>Switch saturated fat for unsaturated fat sources (including oily fish).</td>
</tr>
<tr>
<td>Limit salt intake to less than 6 g per day</td>
<td>Reduce salt intake to a maximum of 1 teaspoon/day.</td>
</tr>
<tr>
<td>Take medication as prescribed</td>
<td>Take medication according to doctor’s instructions.</td>
</tr>
</tbody>
</table>

This is not an exhaustive list of potential behaviours but includes those considered likely to have the greatest impact based on the qualitative data and the existing literature. Cultural preferences evident from the data shaped these choices considerably. For example, it was very clear from the discussions that cooking was casually approached, without ingredients being weighed and measured, and as such individuals were resistant to the idea of portions being weighed and calculated: “we measure with our eyes”. Similarly, regarding weight, as described in section 3.4.2, BMI charts were universally seen as inappropriate for Black body shapes, access to weighing scales was limited and weight management was not a common focus: “It’s
not weight. It’s how we look because we’re about appearance.” On the other hand, having a defined waist was desirable for both women and men and risks associated with “middle fat” were understood by many in the groups, hence a decision to focus specifically on abdominal obesity, rather than weight per se.

### 3.5.3.2 Using COM-B to understand barriers and facilitators to change

![COM-B framework showing domains with barriers for each behaviour](image)

The COM-B framework was used to identify what needed to change for the behaviour to occur, for all six behaviours. In addition, facilitators were noted for each domain when present. The analysis was based on the majority viewpoint but differences across the typologies identified in the previous chapter (Adapter, Accommodator, Traditionalist and Detacher) were noted where apparent (see 3.4.4 for the breakdown of typologies). The COM-B domains where significant barriers to change were noted are summarised in Figure 3-31. I now consider the capability, opportunity, and motivational factors for each behaviour and further summarise this information in Table 3-18.

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103 Participant 30, BC Female, Age 67, Jamaica

Findings – Supporting healthful behaviour change for diabetes self-management
**Behaviour 1: Engage in moderate to vigorous activity for 30 mins per day**

a) Capability:

**Psychological capability** – Knowledge about the importance of exercise for health in general was common across all participants and all typologies. This was typified by the participant below.

“I do quite a lot of exercise. Eight years ago, I retired. I know friends – three of them retired around the same time. They got sick because they don’t do activities [...] My mother was 96, used to take about three spoons of sugar and never had diabetes because most of the time she was in a big piece of land. She was very fit. No heart problems, nothing.”

*(Participant 21, BA Male, Age 73, Mauritius)*

However, individuals described a lack of specificity in physical activity advice which left them with a lack of knowledge about the specific details of the recommendations for diabetes, particularly because purposeful activity was not part of the cultural norm for most. They expressed uncertainty about whether they were doing the right thing and wanted more prescriptive advice: “We need to know how to go about it properly.”

104; “I do exercise, but whether I do it enough, I don’t know.”

105 Those who had more detailed knowledge tended to be the Adapter and Accommodator types who had done their own research. Comorbidities which limited movement were common amongst participants and when injuries limited movement individuals did not have the knowledge or skills to adapt activity strategies and they therefore would disengage. Capability was facilitated when sufficient detailed advice was given and when social prescribing took place, for example the GP facilitating attendance at a gym. The participant below describes how, despite her lack of familiarity with the gym setting, having been referred by her GP, meeting someone face to face to develop her skills was valued.

“I’ve never been to things like that before, so when I went there it was quite interesting. You’ve got people showing you around, what to do, and it was okay [...] You’ve got someone there with you all the time to make sure you do it because they’ve got different things that you go on. [...] Here, somebody's there with you and will make sure you do it. So, I do like that there.”

*(Participant 30, BC Female, Age 67, Jamaica)*

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104 Participant 12, BA Female, Age 60, Nigeria
105 Participant 57, BC Male, Age 57, Jamaica
Physical capability – Physical capability was limited by stamina to engage in higher intensity activities because individuals generally weren’t used to higher intensity activity and by comorbidities: “I get too tired when I'm walking”\(^{106}\); “My mobility, I’ve got arthritis, I’ve got the sciatica in my back now, yeah, so my walking is limited.”\(^{107}\)

b) Opportunity:

Social opportunity – Social opportunity was limited by a lack of cultural salience to engage in purposeful exercise, particularly for the Traditionalist group, which led to a reticence to engage in activities that may be suggested by the healthcare team such as going to the gym or swimming. This was particularly apparent for women: “People back home, they don’t go to the gym \textit{[but]} we do walk a lot back home.”\(^{108}\)

Walking, however, was well accepted. The social interaction of walking with friends encouraged exercise participation, particularly amongst women:

“I think it’s the camaraderie of a group. You get to know people. Support... When you walk in a group you can hear more from people what they are saying and how they treat themselves” (Participant 40, BC Female, Age 72, Jamaica)

Social support provided by family was not described by many participants but when it was present it appeared to facilitate engagement:

“But [my mother] pushes and she’ll ask you, ‘What do you do?’ That kind of... and my husband, obviously, is happy that I'm doing it, and the boys ... one of them keeps on going, ‘Are you going today? ... oh, Mum, it's been four weeks... ’” (Participant 33, BA Female, Age 50, Nigeria)

Physical opportunity – As participants often held multiple jobs as well as juggling caring roles it could be difficult to find time to exercise (see 3.2). This participant was typical in his description of the long hours he worked limiting the time he had available to exercise:

“... working long hours sometimes prevents me from going to the gym, so I have to work from seven in the morning until about seven in the night consistently. So, it affects me going to the gym.” (Participant 23, BC Male, Age 71, Guyana)

\(^{106}\) Participant 7, BC Male, Age 75, Jamaica
\(^{107}\) Participant 6, BC Female, Age 73, Jamaica
\(^{108}\) Participant 25, BA Female, Age 61, Nigeria
In addition, the cost of leisure facilities was felt to be prohibitive for many:

“The cost there is what is really chasing a lot of people away, someone like me because it’s very, very expensive [...] because the cost was really eating at me. Presently I’m not working like I used to work because I’m going on studies to just change career, since my business went down.” (Participant 19, BA Male, Age 58, Nigeria)

In terms of the built environment, safety was described as an issue in one focus group of older men, who suggested that they didn’t feel safe going out to exercise on the street, walking for example: “you have to be careful when you walk on the street now. It’s very dangerous. I don’t really go that far.”

Facilitators were also associated with the built environment (see 3.2.5.1), however, such as regularly climbing steps at home because of a lack of lift facilities. Use of public transport, like the bus network was habitual for most participants and was mentioned in every focus group. It was commonly described that people would get off a few stops early than was necessary just so they could walk. The quote below typifies the level of daily activity described:

“I take the bus in the morning, going to work. And, when I come off the bus, I walk about, erm, it’s about half a mile, to the school. And then walk it back from there, get the bus back. So, every day, I do that every day. And in the hospital now, I have to go from ward to ward to serve the dinner, so I do a lot of walking.” (Participant 3, BC Female, Age not given, Jamaica)

Social prescribing was acceptable and meant that barriers associated with costs for the use of leisure facilities could be alleviated:

“He [the doctor] referred me to the gym [...] she said being as my blood pressure was up they had to check to see if I was okay to go to the gym and then after they did all the tests on the blood and that, then the doctor said it was okay for me to go. You get a medical referral within Lewisham, it’s on your library card, so then you get free use if it’s for a medical reason.” (Participant 20, BC Female, Age 52, UK)

c) Motivation:

Reflective motivation – Intention to engage in activity at the recommended intensity and frequency was generally low across participants. This appeared to be mainly because links between engaging and the associated benefits in

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109 Participant 9, BC Male, Aged 84, Jamaica
diabetes control were not clear to people. People felt they were active enough to be healthy:

“I do a lot of exercise in my domestic time... I don’t sit one minute. So that’s my exercise really and I don’t think I will take up fully exercise. I think I do enough domestic one.” (Participant 2, BC Female, Age 80, Jamaica)

The men were more comfortable with the idea of purposefully exercising, such as attending a gym, however still had low intention to engage with daily activity as they believed it was enough to be generally fit:

“I used to go three times, or twice a week but now I don’t need to. I don’t need... have to go to [the gym], because there’s other things to do, and I’m fit, so I’m all right. I spend a good time when I go in there. I spend a good time, like once a week, good, so I’m all right. It’s different for the person who just is big... I’m all right.” (Participant 37, BC Male, Age 66, Jamaica)

The Accommodator and Adapter types were more likely to believe that engagement in daily physical activity would have beneficial consequences for their diabetes. When this clear association between purposeful activity and diabetes was present, motivation was increased. For example, the participant below battled with barriers to activity such as lack of time and competing priorities, but he found ways to exercise at home as he believed it would help his diabetes and intention to engage was high:

“I bought an exercise bike and I do a lot of walking [...] When I wake up in the morning, I use the bike, go on it for 10, 15 minutes then sometimes when I come back in the evenings. When I'm tired, I just take my shower and go to bed. I try as much as possible to do at least 20 to 30 minutes or a long walk every day.” (Participant 22, BA Male, Age 41, Nigeria)

A fear of injury and the constraints associated with comorbidities also limited self-efficacy beliefs and instances were widespread in the data. For example, this participant felt you had to be careful as you get older: “I'm now getting older. I'm 61. So, if I keep doing that... It's when you make it higher [intensity], one has to be very careful.”¹¹⁰ Those who had mobility issues believed it was not possible for them to meet the guidelines: “I can't do all these things because I can't stand for a long time.”¹¹¹

¹¹⁰ Participant 25, BA Female, Age 61, Nigeria
¹¹¹ Participant 7, BC Female, Age 75, Jamaica
Facilitators to exercise on the other hand included the wide participation in walking and dancing which resonated well with cultural identity. Walking was familiar from childhood, so motivation to engage in walking was high:

“I was born in Accra, Ghana, but going to school, you walk. I walk going and coming and then then later, there's this plantain thing that - they slice it in small pieces, then they sell it at the roadside. We just loved to go there and buy it, and it's a hobby .... every day in Accra. I started working, and the job, too, I walk. It was normal, like a normal childhood.”

(Participant 27, BA Female, Age 56, Ghana)

Walking provided positive emotional benefits: “It's the open space ... the clearing of the mind ... that’s what I get out of it. It’s awesome and being in the fresh air”\textsuperscript{112}; “walking’s the big one. I love walking.”\textsuperscript{113} In addition, motivation to engage in dancing was also positive, both at church and community parties, both of which were a part of the normal week for lots of the participants:

“What I do is walk. I do walk around every day. The only time I don’t is Saturday and Sunday. I go to church and party, but in party I do dance as well, so it's enough exercise.”

(Participant 26, BA Female, Age not given, Nigeria)

“So, the people sing and dance and clap, even the old people they dance a lot.”

(Participant 8, BC Male, Age 49, Jamaica)

This 71-year-old explained how dancing was something she did regularly at home to help her alleviate pain: “At times I may feel the pains ... so I try to exercise whenever I'm feeling pain [...] I may even be sleeping ... I put a cassette on and then I dance.”\textsuperscript{114}

**Automatic motivation** – no data for this domain

**Behaviour 2: Reduce carbohydrate portion size at each meal to a fist or palm size.**

a) **Capability:**

**Psychological capability** – General knowledge of the key dietary recommendations was good across participants, yet there was confusion about the foods that contributed to blood glucose (see also 3.4.2). Individuals were uncertain about the need to reduce natural sugars in fruit and traditional starchy staples were not universally recognised as carbohydrate, so were often

\textsuperscript{112} Participant 31, BC Female, Age 54, UK
\textsuperscript{113} Participant 5, BC Female, Age 65, Jamaica
\textsuperscript{114} Participant 35, BA Female, Age 71, Nigeria
ignored in dietary change. This was largely because of the dietary knowledge provision being primarily Eurocentric and participants not being able to translate advice to their traditional dietary habits. In addition, many staple foods, for example gari or maize meal, are made to different consistencies, which made it hard to judge portions with the advice given on portion size.

“With DESMOND, they need to put more of the Caribbean things into whatever they’re saying because, as I said, with me, I went to go to learn to see what I can eat from what I couldn’t eat and I didn’t really come out with anything different from when I went in, the food I ate and I would explain it to them; they never knew what I was talking about. They don’t know about breadfruit, bananas, and that, they had no idea about that. It was all about Irish potato and noodles and all of those things they were talking about. They can’t even say plantain!” (Participant 30, BC Female, Age 67, Jamaica)

“Some want it strong … some soft […] so when you try to discourage eating a [large] portion, sometimes it doesn’t work.” (Participant 22, BA Male, Age 41, Nigeria)

In addition, the challenge and willpower required to maintain dietary change was described:

“It’s a lot of hard work being diabetic because you have to consciously think about what you’re putting in your body… it’s every day you have to think consciously about what you are eating.” (Participant 11, BA Female, Age 71, Nigeria)

Physical capability – no data for this domain

b) Opportunity:

Social opportunity – Social opportunity to reduce carbohydrate portion was limited by normative social influences promoting large portions of traditional starchy carbohydrates as well as fruits commonly eaten in abundance from childhood, such as mango and papaya.

“We tend to have solid portions, and them the portions that we are used to, you have to eat and have your belly full… to feel satisfied” (Participant 34, BA Female, Age 61, Nigeria)

Individuals worried about others noticing they were eating lightly at social functions: “they will say why you eating that small amala?”

Support from family members was useful in encouraging adherence to dietary recommendations. Younger generations were also able to improve their parents’ knowledge by facilitating access to information online:

115 Participant 13, BA Female, Age 68, Nigeria
“My son has got it. The last one now. So, he goes on the internet and will tell me, ‘Mummy, this is not what you are supposed to eat’… So, because he got it, so we have to be managing and helping each other.” (Participant 26, BA Female, Age 66)

“My sisters and I … we do a lot of talking about what are you eating, what are you doing, taking pictures of food, sometimes good, sometimes bad […] so we do it a lot. So, the support helps you when you are ready to do it.” (Participant 33, BA Female, Age 50, Nigeria)

Men who lived with a partner were largely reliant on the food provided by their wife and some of the men explained how this meant they ate a larger portion if that was what was served: “Just my wife and she already decides the things that I eat, decides things that I drink.”

Physical opportunity – no data for this domain.

c) Motivation:

Reflective motivation – Cultural identity was closely aligned with some aspects of the diet as described in the previous section (see 3.4.2.1). This created motivational barriers to engagement, particularly for the Traditionalist and Accommodator types who felt the conflict with their cultural identity.

“But this, don’t eat this… this carbohydrate is our food. How can we manage that? Because we cannot do without eating all those things… How can we manage that? We cannot go without. It’s our food! We enjoy it.” (Participant 32, BA Female, Age 70, Nigeria)

Individuals had to balance this challenge with the desire to reduce complications. This was easier for those who accepted that changing their carbohydrate portion would directly improve diabetes control and prioritised this over following normative influences.

“You want to live longer and if you don’t control yourself… at the end of the you have to help yourself.” (Participant 7, BC Male, Age 75, Jamaica).

Automatic motivation – the portion sizes recommended were considered too small to assuage hunger by some of the men particularly: “If I followed the doctor’s orders I’d be starving.”

It was not clear from the focus group data how much this was to do with the absolute carbohydrate portion recommended and how much was due to low awareness of the possible

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116 Participant 22, BA Male, Age 41, Nigeria
117 Participant 20, BA Male, Age 76, Nigeria
alternatives to reduce hunger without increasing blood sugar, for example by increasing the intake of vegetables.

**Behaviour 3: reduce saturated fat and increase unsaturated fat**

a) Capability:

**Psychological capability** – The role of fat in general health was quite well understood across the participants, although not necessarily linked to diabetes. Nevertheless, there were gaps in understanding of the differences between saturated and unsaturated fat, even for those who were well-informed; coconut oil was widely seen as a healthy alternative despite it still being high in saturated fat. Media information in the public domain added to the confusion, as a participant with a nursing background explained: “You have this conflicting advice about low fat foods, which is in the paper [...] So, all that research, you just become very confused, where do I go?” Individuals also tended to think of cutting down all fat, rather than ensuring an adequate intake of beneficial fats such as from oily fish: “They were saying that mackerel fish ... they don’t normally eat it anymore [...] They said it’s too oily.”

**Physical capability** – no data for this domain.

b) Opportunity:

**Social opportunity** – While individuals may try to cook with less oil at home, at social functions traditional foods were cooked with oil: “The main dishes when I go to a gathering? Mostly Jamaican culture cooking. Jerk chicken, and rice and peas, fried chicken.” Given the regularity of these events and the centrality of food within them, this presented a significant challenge for some participants, especially the Traditionalist and Accommodator types, with strong cultural affiliation.

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218 Coconut oil though high in saturated fat has been shown to increase beneficial LDL cholesterol, therefore may have cardiovascular benefit, however is unlikely to be as helpful overall as increasing unsaturated fat.

219 Participant 36, BA Female, Age 63, Uganda

220 Participant 13, BA Female, Age 68, Nigeria

221 Participant 8, BC Male, Age 49, Jamaica
Physical opportunity – no data for this domain.

c) Motivation

Reflective motivation – As for traditional starches, oil was seen as central to
the traditional diet for both Caribbean and African participants, with Caribbean
participants traditionally frying meat and fish and the African participants using
saturated fat palm oil liberally in traditional cooking: “Even when you’re eating
your soup you want that [palm oil] on top.”122; “Us West Indians, we tend to
cook with a lot of oil.”123 There were numerous examples of individuals,
nevertheless, even the more traditional, who would grill meat and switch to
unsaturated oils, like olive oil, suggesting this behaviour was amenable to
change.

“I use olive oil. I cut, and even the butter, I cut down butter, all this fat or something. When
I go shopping, I check the content of the fat.” (Participant 35, BA Female, Age 71,
Nigeria)

The positive intention to cook with less saturated fat was particularly the case
for those who had pre-existing cardiovascular related comorbidities,
demonstrating the importance of understanding the link between behaviour
and disease outcomes. For example, for Participant 38 below, who had
previously had a stroke, the direct link between saturated fat reduction and
health improvement was clear and he was comfortable making changes.

“I’m still eating chicken, but it’s the way I cook it. I’m still eating fish, but it’s the way I
cook it. You don’t have to fry it... You don’t have to fry it. The same thing, but I’m doing it a
different way, a healthier way.” (Participant 38, BC Male, Age 55, UK)

Fish was commonly consumed by all. One African participant reported that
historically oily fish was seen as a poor person’s food – “those people eating
mackerel, we looked down on them […] low, low class, for the poor”124— but in
general the recommendation to eat more oily fish was acted upon even by the
most traditional and proved an easy adjustment to make, even if the
technicalities of the types of oil were not fully understood:

122 Participant 34, BA Female, Age 61, Nigeria
123 Participant 8, BC Male, Age 49, Jamaica
124 Participant 10, BA Female, Age 76, Nigeria

Findings – Supporting healthful behaviour change for diabetes self-management
“... Also, the doctor recommended fish. I think they said my...my medical records say I am lacking a certain oil...a certain amount of ...I can't remember what it had in it. I need to higher the fish, to build that up. So, I get some sardines, and so on.” (Participant 9, BC Male, Age 84, Jamaica)

“... Moi moi, mackerel and seabass is very good. Sardines. Sardines, that's the fish I eat now. I don't eat any other fish. Mackerel, sea bass and sardines, that is what I eat. [...] The oil in there, that is the best one, the best oil that we should have in the body. We were having it every other day. Mackerel with okra. If you see the way we - maybe you've heard about it, the way we used to make it, it's quite nice. The tiny bit of oil and tiny bit of pepper... Mm, lovely.” (Participant 11, BA Female, Age 71, Nigeria)

Automatic motivation – no data for this domain.

**Behaviour 4: Reduce salt to a maximum of 1 teaspoon (6g)/day**

a) Capability:

**Psychological capability** – Knowledge around the need to reduce salt for health was acknowledged across all typologies: “Everything that are white are very dangerous. Sugar, you've got the rice, you've got the salt as well, everything.”

It was not clear that individuals knew how much salt was in regularly consumed traditional dishes. Given that a portion of commonly consumed food described by both African and Caribbean participants is very high in salt, it is likely that knowledge needs to be improved. For example, a single portion of jollof rice, which most of the African participants reported eating regularly, may contain almost 9g of salt, equivalent to 20 bags of ready salted crisps (Balogun and Adeboga, 2006). Additionally, some individuals did not realise that the seasonings which they liberally enjoyed contained a high level of salt:

“In Africa, people when we are cooking, we use so many seasoning and salt, and so many thing that we put into the food. You might not use the salt, but you use the seasoning, and people don't realise that there's a lot of salt in the season.” (Participant 65, BA Female, Age 68, Nigeria)

**Physical capability** – no data for this domain.

b) Opportunity:

**Social opportunity** – As for the other dietary behaviours, cultural gatherings were an occasion where dietary restrictions were usually forgotten. In addition, for those who weren’t cooking for themselves they were reliant on the cook

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125 Participant 21, BA Male, Age 73, Mauritius
reducing salt. Participant 8 below, was well-informed about the need to reduce salt, but his wife didn’t always follow the recommendations when cooking for him:

“… also salt, at this stage, as well. Too many salt have to bring diabetes on, so I stay away from it - well... sometimes my wife... Then the salt goes over.” (Participant 8, BC Male, Age 49, Jamaica)

Physical opportunity – no data for this domain.

c) Motivation:

Reflective motivation – Intention to reduce salt was limited by salty seasoning being seen as a key element of cultural cooking:

“I’ve been here over 30 years in this country, but I still stick to my native African diet. Most of our food, in most cases they are very oily, spicy, and sometimes loaded with spices and plenty of salt.” (Participant 44, BA Male, Age 64, Nigeria)

Because a lot of participants also had hypertension, they had some knowledge already about the risks of salt and these individuals were generally accepting of the need to reduce salt; this outweighed the cultural constraints.

Automatic motivation – no data for this domain.

Behaviour 5: Monitor waist-circumference

a) Capability:

Psychological capability – Participants overall had good knowledge of the health risks of “middle fat”. Although few knew the actual targets, they could judge visually who was at risk when looking at photographs: “I think she’s higher risk... because they measure by the waist”126; “Although she's big, she, her waist proportion, is actually quite narrow.”127 While being aware of the risks, no one reported measuring their waist themselves thus these skills would be required for the behaviour to be performed.

Physical capability – Tape measures would be needed by most to engage in this behaviour.

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126 Participant 24, BA Female, Age 58, UK
127 Participant 32, BA Female, Age 70, Nigeria
b) Opportunity:

**Social opportunity** – As I have shown in previous sections there were considerable complexities around losing weight as a fuller body shape was perceived culturally desirable, especially for women (179 section 3.4.2). Social norms supporting the aspiration for a smaller waist, however, were evident for both men and women. For example, social norms promoted acceptance of a natural curvaceous shape to look good in traditional dress: “she doesn’t look big because she fits what she’s got on”\(^{128}\); “She looks good and native.”\(^{129}\) 

**Physical opportunity** – no data for this domain.

c) Motivation:

**Reflective motivation** – Motivation for having a smaller waist whilst retaining a curvaceous shape resonated with cultural values more positively than desire for weight loss. Feeling fat around the abdomen was seen as a trigger that weight-loss was needed, rather than weight on the scales.

“I don’t want to lose weight and change but I’m trying to alter my shape, like my trousers. I used to wear 42 but now I wear 38.” *(Participant 22, BA Male, Age 41, Nigeria)*

“If your belly looks pot when you’re sitting there, you think, mm-mm, I look pregnant. It’s not weight. It’s how we look because we’re about appearance.” *(Participant 29, BC Female, Age 52, UK)*

“I never try to lose weight but yeah, if my tummy higher... I stop eat grease.” *(Participant 13, BA Female, Age 68, Nigeria)*

In addition, self-efficacy around weight loss was generally not high. Individuals talked about struggling to lose weight and to keep it off and finding the challenge of weight loss demoralising, particularly in the context of BMI targets:

“I try to lose the weight... it’s just that I don’t seem to be losing it at all.”\(^{130}\); “What I observe the BMI table, every time you do it they tell you, you are overweight. It makes you feel psychologically that you’re not doing anything.”\(^{131}\)

**Automatic motivation** – no data for this domain.

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128 Participant 29, BC Female, Age 52, UK
129 Participant 26, BA Female, Age 66, Nigeria
130 Participant 1, BC Female, Age 60, Jamaica
131 Participant 22, BA Male, Age 41, Nigeria
**FINDINGS: PART 2 BEHAVIOURAL ANALYSIS**

*Behaviour 6: Take prescribed medication daily*

**a) Capability:**

**Psychological capability** – Not all participants understood the need to take diabetes medication daily. This was particularly the case for the Traditionalist type, who were more distrustful of medication:

“I am on metformin one in the morning, one in the afternoon but I don’t take it all the time [...] When I check it and it’s seven point something or eight point something I take it to make it better, but when it’s around five or six I don’t take it.” *(Participant 11, BA Female, Age 71, Nigeria)*

In terms of remembering to take medication and the associated attention and decision-making activities, once individuals had committed mentally to taking medication, almost none reported issues remembering to do so.

**Physical capability** – no data for this domain.

**b) Opportunity:**

**Social opportunity** – Social influences positively reinforced motivation to take medication regularly, amongst those who struggled or resisted. Positive reinforcement came from a range of trusted sources, from faith leaders to friends, or even the doctor, depending on the degree of trust in healthcare.

This participant had a trusted relationship with her doctor (Adapter typology) and resolved problems directly:

“They increased my metformin to 2,000 which was working really well in terms of it was controlling my blood sugar, but it has nasty side effects [Laughs]. My doctor, we just had a laugh because I went to her and I said, you know what I don’t think this is for me anymore. I went and spent some time with her and then she decided, OK, we’ll reduce your metformin... So, she started me on sitagliptin 25mg, that’s it daily.” *(Participant 41, BC Female, Age 58, Barbados)*

Another individual also representative of the Adapter typology explained how she promoted the benefit of medication informally within her community.

“They don’t like the medication [...] and they’re frightened of needles. So, I would say to them that if you don’t want to be on the insulin, using the needles, take your medication, take your tablets.” *(Participant 4, BC Female, Age 68, Jamaica)*

**Physical opportunity** – no data for this domain.

**c) Motivation:**
Reflective motivation – Distrust of medication was found particularly amongst the Traditionalist type, reducing intention amongst this group to take it regularly: “This medication we take every day [...] Every day you keep taking medication. After 20 years do you think that medicine will not have another bad effect?”

Belief that insulin was associated with end of life has been reported in other literature as in Africa and the Caribbean it is often the first line treatment but only given to individuals who have well-developed diabetes (Noakes, 2010). Participants were resistant to the idea having insulin injections: “they was suggesting insulin. I said no way.” The Adapter type, however, was more comfortable with taking insulin. The participant below explains how she valued how it helped her manage her weight particularly:

“The Victoza [insulin brand] tends to keep my weight steady. Because I was wearing a size 14, size 16, now I’m wearing a 12, 14. It’s only a once a day. Once a day injection.” (Participant 4, BC Female, Age 68, Jamaica)

Participants frequently asked if they could come off medication if their diabetes improved or hoped they could reverse the condition: “if I can get off the two tablets, I’ll take no medication.” With good adherence to lifestyle recommendations this is a realistic possibility (Lanhers et al., 2017), therefore motivation may be a useful facilitator to promote engagement. Losing weight to avoid progressing to insulin was described: “I’m trying to take my weight down, and um, you know, eat sensible. Because, you know, I don’t want to go on needle, having a needle.”

Automatic motivation – As discussed in the previous chapter, the fear and emotional shock associated with diabetes sometimes resulted in a delay of several years before individuals began taking their medication (See section 3.4.4.2). In addition, a fear of needles and injections was common, influencing both a fear of taking insulin – “I wouldn’t take the injection, I’m afraid of

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132 Participant 34, BA Female, Age 61, Nigeria
133 Participant 39, BC Male, Age 76, Jamaica
134 Participant 23, BC Male, Age 71, Guyana
135 Participant 5, BC Female, Age 65, Jamaica
needles" — and of having blood tests to monitor blood glucose. Numerous participants explained how much they disliked having blood tests, while for others testing the blood regularly was helpful as a habit to monitor blood glucose and the response to certain foods.

“I just don’t like doing the blood tests. I hate needles. Then they take five ... four. Four little bottles. Yes, sometimes it’s four little bottles. That’s terrible.” (Participant 7, BC Male, Age 84, Jamaica)

Others struggled with the side-effects of taking medication – “I’m struggling with taking the medication, really struggling” – particularly if they were managing other comorbidities or had to cope with unpleasant side effects of medication, such as wind, dizziness and weight gain. This participant described how she struggled with the taste of it:

“I told him in the chemist where I got my medicine, they say it is the reaction of the tablets for me. I feel as if I have salt in my mouth. Even if I’m sitting, I’m still feeling it. They say it’s the reaction of the tablet because I’ve been taking it for so long.” (Participant 15, BA Female, Age unknown, Nigeria)

3.5.4 Identifying intervention functions and BCTs

3.5.4.1 Potential intervention functions

For each of the behaviours identified, the behaviour change wheel was used to identify the type of interventions that may be helpful, based on the published guidance (Methods section 2.2.7.2) (Michie et al., 2014, Abraham et al., 2009). The outcomes are presented in Figure 3-32. One of the challenges with applying the behaviour change wheel framework in this instance is that lifestyle-related behaviours are complex in nature and thus have diverse influences on behaviour – influences across most domains of the COM-B framework. It is therefore necessary to apply judgement as to the relative importance of the determinants of behaviour to maximise likely effectiveness of the potential different intervention functions. I made my decision based on the COM-B analysis, the grounded theory work and consensus opinion about key causal determinants of behaviour (Scrimshaw et al., 2002). I considered that for
this group of individuals the barriers in Capability related to the gaps in knowledge were significant and needed to be addressed across all the behaviours.

Figure 3-32: Linking COM-B domains to intervention functions and key associated BCTs. Modified from Moore et al., 2019.

Furthermore, these gaps in knowledge appeared to influence Motivation (Domain: belief in consequences) as clear links between performing the behaviour and diabetes control were not clearly established for the majority. Motivation was also weakened for the behaviours which were perceived for some to conflict with culturally influenced
social norms (Domain: Identity). Opportunity barriers were present in the environment but in the main would not prevent engagement. Social Opportunity barriers were evident for dietary and weight related behaviours especially but were most relevant for those for whom cultural affiliation had a strong influence (Traditionalist and Accommodator types). In common with all individuals engaging in self-management of a chronic condition, regardless of ethnicity, the data also suggested the need for willpower, determination, prioritisation and planning as part of developing Capability to manage behaviour more long-term (Domain: Behavioural regulation). The intervention types recommended to support these domains include Education, Training, Enablement, Modelling and Persuasion. Other potential functions such as Coercion, Incentivisation and Restriction were not considered appropriate in this instance. In addition, the data suggested social support could be an important facilitator across most of these behaviours.

3.5.4.2 Identifying mechanisms of change

Behavioural change techniques are theory and evidence-based change methods for influencing determinants of behaviour (Bartholomew and Mullen, 2011) (Figure 3-33).

Figure 3-33: Schematic to illustrate example of mapping of theoretical mechanism of behaviour change

A pragmatic short-list of BCTs was made for each behaviour. The list was based on four sources of information: the behaviour change wheel recommendation for the BCTs that mapped to each intervention function, findings of my COM-B analysis, knowledge of the community, and evidence from systematic reviews about effective BCTS in
lifestyle behaviour change interventions (Olander et al., 2013, Hankonen et al., 2015). This shortlist was then rationalised according to the APEASE criteria, and the results are summarised in Figure 3-32 and Table 3-19. Further detailed information for each behaviour is presented in Table 6-7, Table 6-8, Table 6-9 and Table 6-6 in the appendices. Details of the specification of the different BCTs selected is detailed in Table 6-10 in the appendices. There was overlap in the choice of BCTs between behaviours as the barriers for each were similar. To improve Capability the key BCTs here were associated with training such as Demonstration, Instruction how to perform behaviour, Graded tasks\textsuperscript{138} and educating such as, providing information about health consequences and to reinforce this learning self-monitoring and feedback on outcomes. This target of improving capability is likely to also influence motivation positively by shifting belief about consequences and self-efficacy. To support general Capability to sustain engagement with self-management and help prioritise self-management over competing priorities, goal setting, problem solving, and action planning were also identified. To help individuals resist social pressure to follow traditional norms such as dietary norms and weight expectations (Domain: Social influences) as well as shift beliefs about what feels culturally appropriate (Domain: Identity) socially focused BCTs designed to persuade and educate were selected. These include social comparison, social support and Credible sources. Information on health consequences and Feedback on outcomes are suggested to reinforce these socially situated BCTs, to further educate and persuade.

3.5.5 Developing culturally salient interventions

These BCTs, adapted within the cultural framework outlined may be translated into different applications to support self-management behaviour change to suit specific objectives of setting and whether some or all the behaviours are a target of a specific intervention. The HEAL-D Intervention is used in illustration of how the BCTs can be operationalised. The key intervention components were designed to meet the BCTs identified in this analysis and are described in Table 3-13.

\textsuperscript{138} Graded tasks specific to improving capability for physical activity
Table 3-13: Description of the HEAL-D intervention components to support each BCT identified. Modified from (Moore et al., 2019).

<table>
<thead>
<tr>
<th>BCT</th>
<th>Intervention component</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social support (unspecified)</td>
<td>Social connectedness is fostered within the group by the discursive nature of the sessions and through shared engagement in activities and structured exercise sessions</td>
</tr>
<tr>
<td>Social comparison</td>
<td>The ‘task card’ homework activities give participants opportunity to try the lifestyle targets and come back to discuss with the group and with educators. Participants are encouraged to share their successes to encourage comparison within the group. In addition, role models are be featured in the case study video</td>
</tr>
<tr>
<td>Credible sources</td>
<td>Videos are used as part of the intervention including advice and tips from community leaders, healthcare practitioners and patients from the community that have successfully changed their habits</td>
</tr>
<tr>
<td>Information about health consequences</td>
<td>The educational curriculum covers health consequences and benefits of various key lifestyle behaviours. A detailed file contains written information and activities to support each educational session. An animation video “Diabetes explained” explains the mechanisms of type 2 diabetes.</td>
</tr>
<tr>
<td>Feedback on outcomes, self-monitoring of behaviour</td>
<td>The programme starts with personal measurements and blood results, and updated outcome measures will be given at the end of the programme. Participants are encouraged to monitor weight loss progress by taking waist measurements through the course and completing their programme booklets.</td>
</tr>
<tr>
<td>Self-monitoring of behaviour, action planning</td>
<td>Participants are given pedometers to measure their steps and are taught to develop action plans and measure their progress against them.</td>
</tr>
<tr>
<td>Instruction on how to perform the behaviour</td>
<td>The curriculum communicates health guidance clearly using culturally relevant examples.</td>
</tr>
<tr>
<td>Demonstration</td>
<td>Practical games, the weekly discussion tasks, a cooking session (with cooks in the family invited) and structured exercise sessions (including African dance music and dancing) provide guided demonstration. An exercise DVD using credible sources is provided for participants to follow at home.</td>
</tr>
<tr>
<td>Graded tasks</td>
<td>Physical activity sessions and targets are graded for ability to boost chances of success hence confidence and self-efficacy.</td>
</tr>
<tr>
<td>Goal setting (behaviour)</td>
<td>Participants are guided through setting their own goals for the lifestyle targets that are important for them</td>
</tr>
<tr>
<td>Problem solving</td>
<td>The ‘task card’ homework activities will be discussed at the beginning of each session, challenges are identified, and the group problem solve collectively. Problem solving also forms part of the education sessions about lifestyle habits.</td>
</tr>
<tr>
<td>Action planning</td>
<td>Participants are guided through how to develop and adjust action plans for each of the target behaviours and for their personal objectives, to help keep them motivated.</td>
</tr>
</tbody>
</table>
3.5.6 Reflecting on what works in a real-world setting

To add further insight into the potential value of the BCTs selected for this population, the process evaluation interviews and focus groups from the HEAL-D study were analysed to determine which BCTs and associated components were acceptable and influenced positive behaviour change in each of the target COM-B domains. In order to indicate which factors were most commonly considered useful, the BCTs that individuals considered most helpful for them personally were tabulated for each respondent and the results summarised in a coding density chart (Figure 3-34) (See methods 2.2.7.2)

3.5.6.1 BCTs focused on increasing knowledge and skills to Educate

Components based on the BCTs to improve knowledge and skills were seen to be pivotal for the majority. Participants valued the balance between the theoretical and practical components designed to Demonstrate the behaviour. In HEAL-D components based on these BCTs included food related games, participatory physical activity sessions, participatory cook and taste session along-side verbal and visual information. Moreover, with regards to reducing carbohydrate intake, changing cooking habits and engaging in MVPA, the practical demonstration appeared vital. Components designed based on the other key BCTs to increase knowledge worked synergistically with the practical participatory demonstration (for example, Information on health consequences - The Animation video “Diabetes Explained”, written, visual and verbal information provision about the links between behaviour and diabetes outcomes and Instruction on how to perform behaviour - Photographic representations of portion sizes, written details about understanding exercise intensity, verbal instructions about which foods contain healthy fats). The written resources providing Instruction and Information on health consequences were valued as a reference guide which could be reviewed outside the sessions: “That file, it can be under your pillow... a solution it reminds you back.”\textsuperscript{139} It was the cultural salience of the information and demonstration that made the difference, compared to the information they had

\textsuperscript{139} Participant 17, BA Male, Age 57, Sierra Leone

Findings – Supporting healthful behaviour change for diabetes self-management
received previously. The provision of written and visual materials was supported with the physical presence of the educator who successfully helped reinforce the information. Having an educator there in person was particularly important for older individuals with more culturally situated rather than biomedical knowledge. A selection of quotations from participants reflecting on components using these BCTs is provided in Table 3-14 to support this summary.

### 3.5.6.2 Socially focused BCTs to Persuade and Enable

Components based on **social support** (group sessions facilitated for interaction and support) and **social comparison** (for example sharing experiences and learning within the group) provided individuals with much needed social support to manage their diabetes. The group interaction was key as individuals learnt a lot from each other and motivated each other. Because individuals were learning from each other it gave the information credibility and salience that they may not have previously experienced. These components supported the learning by raising self-efficacy, making it acceptable to challenge traditions, and normalised diabetes. This gave individuals confidence to be open about their condition where they would traditionally have been more hesitant about disclosure, and created confidence to resist social pressures. Furthermore, the use of **credible sources**, such as ethnically concordant lay educators and videos with tips from faith leaders and other trusted members of local Black communities, reinforced the social acceptability of the new behaviours. A selection of quotations from participants reflecting on components using these BCTs is provided in Table 3-15.

### 3.5.6.3 BCTs to improve self-efficacy and behavioural regulation

Components associated with BCTs to improve self-efficacy and behaviour regulation include the following: **self-monitoring** (measuring waist, weekly weighing, using the pedometer), **goal setting** and **action planning**\(^{140}\) (SMART goal session and exercises, weekly group goal) and **Feedback on outcomes** (Anthropometry and biochemical markers at the end of the intervention) and **Problem solving**. In general, these BCTs

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\(^{140}\) It was difficult to distinguish between Action planning and Goal setting in the data so the two BCTs are treated collectively.
were less frequently mentioned in the data than the components associated with improving knowledge and developing social support. Yet they still seemed powerful for several individuals. Many of the participants had set themselves goals for the programme – from fitting in to a dress that had become too tight to achieving 10,000 steps every day. Those participants who set themselves a personal goal found it motivating and were assisted by the Self-monitoring element facilitated by the pedometer and tape measure. When individuals saw their Hba1C, weight and other parameters had reduced it had the effect of cementing and reinforcing the changes they had made. A selection of quotations from participants reflecting on components using these BCTs is provided in Table 3-16.

3.5.6.4 Behavioural change and outcomes

Participants overall reported significant change in behaviour as a result of the collective BCTs used in the HEAL-D intervention, suggesting the BCTs selected in this section of my analysis have practical utility in a real-world setting. What was particularly noticeable in the data was the general increased self-efficacy and confidence because of the intervention. The most frequently reported changes were an increase in moderate to vigorous physical activity, reduced carbohydrate portions and engagement in weight-monitoring behaviour. With regards to the traditional starches knowing how portion guidance related to traditional foods was empowering, so traditional foods could be enjoyed with confidence: “You’re armed, you’re tooled with the information now.”141 Equally some made their own decision to avoid some traditional starches, changing eating patterns developed over many years. The majority reported improvements in measurable outcomes from including improved metabolic parameters, weight-loss, improved stamina, or medication reduction. This section is supported by participant quotations in Table 3-17.

141 Participant 60, BA Female, Age, 37, Sierra Leone
Figure 3-34: Density of coding by BCT (by participant; dark = heaviest coding)
## Findings

### Supporting Healthful Behaviour Change for Diabetes Self-Management

Table 3-14: Quotations relevant to BCTS to increase knowledge and skills

<table>
<thead>
<tr>
<th>BCT: demonstration; instruction</th>
<th>Component: Food knowledge game</th>
<th>“That was the day I realised probably I had been a big fool. [...] It was all fun and I took home a lot. It looks like a little game, but it brought the reality, the essence of the food we eat. It brought it into real-life play, and it was quite a very useful method of passing the message, other than just saying it with your mouth. ... the shock is not the same thing.” (Participant 44, BA Male, Age 64, Nigeria)</th>
</tr>
</thead>
<tbody>
<tr>
<td>BCT: demonstration; instruction</td>
<td>Component: Participatory exercise classes</td>
<td>“There are lots of people, you tell them to exercise, and they say, 'Oh yes, I'll do it', yes, but to actually participate - because I'm sure there were lots of people in that group who never did what we did during that course. They say, 'Oh yes, I did, I do walking', but it opened your awareness to certain forms of exercise that you need to do.” (Participant 51, BC Male, Age 77, Guyana)</td>
</tr>
<tr>
<td>BCT: demonstration; instruction</td>
<td>Component: Cook and taste session</td>
<td>“The food they prepared for us has given me a lot of ideas. I know I have to eat veg, but there are different ways you cook veg which they showed us the other day, which is very, very educative. They teach you how to put little bit of oil, not like the way we put. You think about eating veg, you put plenty of oil, you've spoilt it. They taught us a lot, that cooking.” (Participant 34, BA Female, Age 61, Nigeria)</td>
</tr>
<tr>
<td>BCT: information about health consequences</td>
<td>Component: Video</td>
<td>“The videos are very good. When you are first diagnosed there are a lot of conspiracy theories about what diabetes is, or what it's not. That video tried to explain, when you say somebody's diabetic, what is really happening in the inside. It talks about the key, which is insulin, that will boost the vein, and it talks about what happen when the veins is clogged [...] So that video is very concise, and it explained in the plain language that I think everybody was able to understand.” (Participant 54, BC Female, Age 55, UK)</td>
</tr>
<tr>
<td>BCT: information about health consequences; Instruction</td>
<td>Component: Written information</td>
<td>“The book is good because basically, what I've been doing is going back to my book all the time, and that's another thing its inspiring – you look back at what you've learnt. I actually find what works for me is sitting down, reading my book – I wrote little things in like if I'd done exercise – you can sit down and write your own experience.” (Participant 54, BC Female, Age 55, UK)</td>
</tr>
<tr>
<td>BCT: information about health consequences; Instruction</td>
<td>Component: Written information</td>
<td>“Where we come from, your husband can go for another woman, just because of food. Like, my husband, when he's cooking, it's salt, salt, salt. He likes salt. So, I said to him, 'If you want to cook salt and kill yourself, I'll come to your burial, but please don't add it too much on my one. For me if I had not seen the information I wouldn't know. I would keep continue doing what we are doing.” (Participant 64, BA Female, Age 52, Nigeria)</td>
</tr>
</tbody>
</table>
FINDINGS: PART 2 BEHAVIOURAL ANALYSIS

Table 3-15: Quotations relevant to Social BCTs to persuade and educate

<table>
<thead>
<tr>
<th>BCT: social comparison</th>
<th>Component: Group sessions</th>
</tr>
</thead>
<tbody>
<tr>
<td>“That was very good because people don’t really realise that there are people, other people in the same boat as you are, suffering the same thing. Exchanging ideas and views, in some small way, although it might look insignificant, could be helpful to you. By listening to this person or seeing what this person does or hear what this person does, you can benefit from it” (Participant 51, BC Male, Age 77, Guyana)</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>BCT: social support</th>
<th>Component: Group sessions</th>
</tr>
</thead>
<tbody>
<tr>
<td>“If we can share, perhaps, they were going through a bad time and they’ve relapsed and they’re not sticking to the programme, and their diabetes is going out of control. Be able to talk about it and properly try and get them back on track and that kind of thing…” (Participant 47, BC Female, Age 58, Guyana)</td>
<td></td>
</tr>
<tr>
<td>“I find myself… that I was the least-informed in the group. So, I was learning from these elderly ladies and gentlemen. Seriously, I was listening to their experience, their practical experience and what they thought […] he, my fellow countryman… he taught me a lot of things that could really increase diabetes, if I was to eat or drink certain things. What I’m saying is that I wasn’t aware before… and it’s like… it was really verifiable information. So, it comes back right into say, well, awareness and discussing and sharing.” (Participant 22, BA Male, Age 41, Nigeria)</td>
<td></td>
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<table>
<thead>
<tr>
<th>BCT: social support</th>
<th>Component: Exercise classes</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Last week I was, two weeks ago I was ill. Pains all over my body. So, this young lady, I told her that, ‘I can’t do any exercise today because I’m…’ She came to me, face to face and said, ‘You can do it’. Said, ‘But if you can’t, sit down’. So, I sat down there. I felt guilty. People are doing, I’m not doing. So, I start on the chair. When she says, ‘Do this’, she said, ‘Yes. That’s what you should do. You don’t have to stand up, you know’. I was feeling the pain but I enjoyed doing the thing. By the time we were finished, I stood up. [Laughs] the group …they encourage [me]” (Participant 65, BA Female, Age 58, Nigeria)</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>BCT: credible sources</th>
<th>Component: case study videos</th>
</tr>
</thead>
<tbody>
<tr>
<td>“The videos about the people that are living with diabetes, you see stories about people that encourage you. That some people have been doing this, have been diagnosed for years, and they are still living happily. That you can still live a happy life, even if you are diabetic […] Talking about the food and what we can eat, and our food, the type of food we have and how much carb there… It was amazing that we didn’t… I still think up to this day a lot of Caribbean, African backgrounds, we’re still not aware of that, and we still eat so much of it. So again, it was awareness and I find it was really good.” (Participant 22, BA Male, Age 41, Nigeria)</td>
<td></td>
</tr>
</tbody>
</table>
## FINDINGS: PART 2 BEHAVIOURAL ANALYSIS

### Table 3-16: Quotations relevant to improve self-efficacy and behavioural regulation

| BCT: Goal setting | “I was shopping yesterday and I was walking around Sainsbury’s, and because you know we’ve got that goal target, of getting your waistline down? So, I’m about one inch away from my goal target... All I kept hearing, every time I walked past something naughty was, “one inch away from 33, don’t do it”! We were actively encouraged. Like... ‘This is a challenge, set yourself a goal every week. Set yourself a new different goal,’ which is good because even now, like I said, I’m one step away from my waist goal, and I’m already thinking, all right, when I hit that, I’ve got to do the next goal. So, I’m always planning that in my head already.” (Participant 61, BC Female, Age 37, UK) |
| BCT: Feedback on outcomes | “My blood HbAc [sic] when I went to my GP a few weeks ago, it was 53. I feel really good. I feel, ‘Wow, all this hard work is working,’ but it's not just something you do for three months and then think, oh, I'll go back to it. It's an ongoing thing. This is what people have to understand, it's not something you can just switch off for a few months and then think, oh, I'll come back to that. It's literally ongoing all the time.” (Participant 41, BC Female, Age 58, Barbados) |
| BCT: Self-monitoring | “Yes, I've been weighing, and I've been taking my measurement round, you know, bust, stomach, or especially my long waist, and I'm wearing dresses that I wasn't going into. I hate to give away my dresses because they are expensive. Yes. So, I appreciate coming to this course, and I can see. I used to have segmented neck here, but now when I look on the mirror, I see that's reduced. I am feeling better... I can even fight my husband now!” (Participant 63, BC Female, Age 67, Guyana) |
### Table 3-17: Quotations describing behaviour and self-efficacy changes and improved outcomes based real-world evaluation of BCTs

<table>
<thead>
<tr>
<th>Improvement in glycaemic control and confidence</th>
<th>“The blood sugar has really gone down [...] This thing dropped from seven and it's six. [...] I think if you really look at my progress now, I think, I don't know how, I'm so confident. At the moment, I just feel that there's nothing wrong with me ... even though there's still much to do, but I think I've really improved a lot in so many ways, and so... Just them telling me... I'm just happy... Just I have a good feeling for myself, you know, very confident, very confident. It's just like there's nothing disturbing me. It's just like part and parcel of me now. [...] Before all the food, my living, the way I live now is, I don't know how I can describe it to you, the gap is so big.” (Participant 18, BA Male, Age 42, Cameroon)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduction in starchy carbohydrate intake</td>
<td>“Do you know, since the programme, as of the middle of the programme and since the programme ended I have not taken the garri, the cassava one, I've not taken it. Interviewer: Why is that? Because I've come to realise after eating that garri, that cassava one, swallow, especially in the evening, I get so heavy in me. I can't do anything. I was tempted all throughout in Nigeria, but I avoided it. I realised one of the things I avoided was the garri, and I could eat a big bowl of rice... I cut my rice into half now.” (Participant 44, BA Male, Age 64, Nigeria)</td>
</tr>
<tr>
<td>Reduction in necessary medication</td>
<td>“They have taken me off glazi, what do you call it? [Gliclazide], they've taken me off that they said because my blood sugar has gone down, I'm okay. I really love it. I'm just left with metformin now.” (Participant 24, BA Female, Age 58, UK)</td>
</tr>
<tr>
<td>Reduction in waist size</td>
<td>“I've lost weight, I think I have. Well, it's funny, I still weigh the same, but my trouser size is - I was taking size 36 trousers, yes? Now, all of a sudden, they're too big for me and I've started taking size 34 now... Yes, it's inches, isn't it.” (Participant 58, BC Male, Age 60, Dominica)</td>
</tr>
<tr>
<td>Increased exercise and improved stamina</td>
<td>“... because of the exercise, I mean I'm normally doing bits, but I can say that my stamina has increased. For instance, I went to Brixton today, and months back - I have a bad knee and a hernia - and I found myself walking around Brixton, so I maybe did about 45 minutes walk, so my stamina is definitely [improved]. I'm thinking it is nothing to climb up a hill and whatever, without puffing and things [...] I can feel definitely that my stamina has increased.” (Participant 66, BC Female, Age 68, Jamaica)</td>
</tr>
</tbody>
</table>
3.5.6.5 Reflecting on the typologies

Across the behaviours there was much similarity between the typologies in terms of the behaviour determinants. The key differences were in the type of knowledge required and in the need to reinforce the behaviour as acceptable within perceived norms of ethnic and social identity (Figure 3-35).

Health knowledge includes factual knowledge (declarative health knowledge) and practical skills (procedural health knowledge) (Gellert and Tille, 2015) both of which are considered integral to health literacy (Chin et al., 2011). Also important is knowledge informing outcome expectations that impact on attitudes and intention towards performing the behaviour – is performing the behaviour worth it to help my diabetes? (Scrimshaw et al., 2002, Bartholomew et al., 2016). All types needed the factual knowledge and the specific knowledge related to cultural practices, especially. Both the Adapters and Accommodators had positive outcome expectations due to the faith they had in biomedical care, engaging in performing the behaviours was worth the effort because they believed it would improve their health. For the Traditionalist type an additional key determinant was belief in consequences – the outcome expectations – as they didn’t necessarily share explanatory models of understanding of...
diabetes that reflected the biomedical understanding. Therefore, the BCT *information about health consequences* was especially important for this group. Furthermore, for the Traditionalist and Accommodator, for whom cultural affiliation more strongly shaped behaviour, the BCTs to persuade and promote social acceptability such as social support, credible sources and role modelling were key. The evaluation suggested that having knowledge about cultural foods armed these latter groups with a knowledge that was empowering, allowing them to eat foods which were culturally important, while also achieving health goals, reducing the tug of war issues (see 3.4.2 for description of these issues). Moreover, perceptions shifted with social support and credible sources, together with a better understanding of the likely beneficial outcomes of performing the behaviour such that it improved intention to engage. Armed with culturally salient knowledge and improved understanding, many reported making personal decisions to adapt their cultural diet of their own volition and to challenge social norms if necessary. Outside these key issues the determinants between typologies did not differ significantly.

### 3.5.7 Discussion

This part of my analysis aimed to identify potential BCTs to inform intervention design to motivate adherence to recommended self-management guidance and evaluated their operationalisation. The use of a theoretical framework helped identify cultural adaptations to target behaviours which have potential to significantly improve the cultural salience of advice – such as a focus on abdominal obesity rather than BMI. Significantly, intention to follow key lifestyle recommendations was limited by specific cultural beliefs and social norms, particularly in those individuals retaining strong cultural affiliation. Secondly there were knowledge deficits in two key areas: the link between health behaviour and disease progression and how to adapt the advice to culturally influenced behaviours. BCTs suggested by the mapping analysis to address these key factors supported the use of BCTs associated with Persuasion, Training and Education in particular. This combination of BCTs appeared to support positive behaviour change in the real-world setting as demonstrated by the HEAL-D group education intervention. Importantly, the significant barriers associated with advice
conflicting with social norms appeared to shift with improved knowledge about the benefits of following recommendations coupled with reinforcement from trusted credible sources from the community.

The value of harnessing social support with a focus on BCTs such as social support, social comparison and credible sources was strongly suggested by this analysis. The importance of kinship, social interaction and collectivism is well-reported for those of Black African ancestry (Di Noia et al., 2013, Nishikawa et al., 2017, Resnicow et al., 1999). In communities of African ancestry living in high income countries, lack of social support has been identified as a particular barrier to lifestyle-related health behaviour change (Tyler et al., 1997, Wilbur et al., 2002, Wolfe, 2004) particularly when healthcare advice may conflict with culturally influenced social norms (Moore et al., 2021). Lifestyle interventions in African American individuals that focus on engaging an social networks have been shown to be particularly effective (Wolfe, 2004, Kumanyika et al., 2009) and a review of weight management interventions to support African American women suggests that mobilising social support may be both “therapeutic and cost-effective” acting to improve self-efficacy and individual perception of control (Wolfe, 2004). Moreover, the presence of social support has been shown to be associated with positive diabetes self-management behaviour in African American communities, for example African Americans were more likely to successfully manage their diabetes when they could learn from family members with diabetes (Madden et al., 2011).

Appropriate knowledge provision was also suggested to be of key importance in supporting behaviour change and the BCTs chosen. The associated intervention components developed in the HEAL-D intervention highlight the value of practical demonstration and instruction, particularly from credible role models from local Black communities. Within the African American community, health education research suggests that verbal and visual provision of information is preferred to written information (Spink and Cole, 2001, Anderson-Loftin et al., 2002, Marshall, 1995).
Certainly, increasing physical activity has been shown to be more effectively achieved in African American individuals when demonstration is used compared to the provision of information alone (Whitt-Glover and Kumanyika, 2009). The relative importance given to knowledge gained and transmitted by word of mouth and in person (“Orality”) has been highlighted for African cultures (Di Noia et al., 2013, Airhihenbuwa, 1995) and is supported by this analysis. In the context of the HEAL-D study, individuals did particularly value the provision of detailed written information, to which they could later refer. It is unlikely though, that the written information provision alone would have been effective. Instead, the written information acted to reinforce and remind and would have been insufficient without the social interactive BCTs chosen. The particular gaps in knowledge around the translation of advice to cultural foods in Caribbean participants specifically have been reflected in other studies (Scott, 1997, Brown et al., 2007, Scott, 1998) and presented significant barrier to the cultural accessibility of self-management guidance, despite clinical guidance suggesting culturally relevant dietary information needs to be central to the provision of lifestyle advice (National Institute for Clinical Excellence, 2020). Skill and self-regulation are also central to diabetes management for all individuals (Snoek, 2002, Abubakari et al., 2013) and the challenge of day-to-day management was also reflected in this analysis. BCTs that have their origins in control theory such as goal setting, self-monitoring, feedback on outcomes and action-planning have been shown to be important in self-regulation for individuals living with diabetes (Hankonen et al., 2015). In addition, several reviews highlight the value of these techniques in supporting change in physical activity and dietary behaviours (Olander et al., 2013, Hankonen et al., 2015, Michie et al., 2009).

The importance of leveraging existing positive cultural values, beliefs and habits has been highlighted as particularly important in designing effective culturally salient interventions (Airhihenbuwa, 1995). In this case opportunities included a strong motivation to avoid the complications associated with diabetes. Lifestyles were also generally active and considered important; culturally salient dancing and walking were
used in the HEAL-D intervention to improve engagement. Individuals were also motivated to avoid medication, especially insulin and the associations between lifestyle change, good control and potential reduction in medication use and progression is an important message to convey.

3.5.8 Summary

In this chapter I have used COM-B and the behaviour change wheel to identify BCTs which may be useful to support healthful behaviour change in Black African and Caribbean adults living with diabetes. The framework successful identified culturally situated challenges which need to be addressed to support healthful behaviour change for self-management. The range of BCTs identified were demonstrated to be effective and acceptable.
Table 3-18: Summary of COM-B findings for each behaviour

<table>
<thead>
<tr>
<th>COM-B Domain</th>
<th>30 mins MVPA/day</th>
<th>Dietary behaviours</th>
<th>Monitor waist size</th>
<th>Take medication daily</th>
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<tr>
<td></td>
<td>30 mins MVPA/day</td>
<td>Reduce Carb. portion to fist/palm-size</td>
<td>Switch saturated fat to unsaturated</td>
<td>Reduce salt to &lt;= to 6g/day</td>
</tr>
<tr>
<td></td>
<td>Knowledge: What guidelines are; what activities meet them; how to adapt to physical limitations</td>
<td>Behavioural regulation: improve planning skills</td>
<td>Knowledge: understand which foods are carbs; understand portion size targets and what foods can replace carbs to reduce hunger (including main cook at home). Behavioural regulation: Learn to set goals and maintain motivation, including strategies for eating socially.</td>
<td>Knowledge: learn what foods contain good fats &amp; to cook differently (including main cook at home) Behavioural regulation/cognitive skills: have strategies for eating socially</td>
</tr>
<tr>
<td></td>
<td>Physical Skills: Increase stamina &amp; develop fitness</td>
<td>Skills: How to measure waist.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Opportunity Social: Have social support to encourage behaviour</td>
<td>Have social support to encourage behaviour</td>
<td>Have social support to change behaviour</td>
<td>Have social support to change behaviour</td>
</tr>
</tbody>
</table>
## Findings - Supporting healthful behaviour change for diabetes self-management

### What needs to happen for the behaviour to occur?

<table>
<thead>
<tr>
<th>COM-B Domain</th>
<th>Dietary behaviours</th>
<th>Resources</th>
<th>Identity</th>
<th>Motivation</th>
<th>Automatic</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical</strong></td>
<td>Reduce Carb. portion to fist/palm-size</td>
<td>Have suitable activities accessible &amp; affordable;</td>
<td>Address issues of cultural identity associated with portion size. <strong>Belief about consequences:</strong> Change belief about consequences/benefits of limiting carb. Portion size.</td>
<td>Increase priority to exercise</td>
<td>Cope with physiological consequences of reduced portion e.g., hunger.</td>
</tr>
<tr>
<td><strong>Reflective</strong></td>
<td>Switch saturated fat to unsaturated</td>
<td></td>
<td>Address issues of cultural identity associated with cooking traditions. <strong>Belief about consequences:</strong> Change belief about consequences/benefits of switching oils</td>
<td>Understanding how daily activity impacts blood glucose</td>
<td>Get used to new tastes and flavours.</td>
</tr>
<tr>
<td><strong>Identity</strong></td>
<td>Reduce salt to ≤ 6g/day</td>
<td></td>
<td>Address issues of cultural identity associated with cooking traditions. <strong>Belief about consequences:</strong> Change belief about consequences/benefits of reducing salt</td>
<td>Overcome lack of belief in ability; Address cultural identity issues related to exercise. <strong>Belief about consequences:</strong> Change belief about consequences/benefits of reducing salt</td>
<td>Get used to new tastes and flavours.</td>
</tr>
<tr>
<td><strong>Belief about consequences:</strong></td>
<td>Monitor waist size</td>
<td>Address distrust of medication.</td>
<td>Change belief on benefits of reducing salt</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Belief about consequences:</strong></td>
<td>Take medication daily</td>
<td></td>
<td></td>
<td></td>
<td>Address distrust of medication.</td>
</tr>
</tbody>
</table>

FINDINGS: PART 2 BEHAVIOURAL ANALYSIS
**Table 3-19: Summary of intervention functions and BCTs suggested to support each behaviour identified**

<table>
<thead>
<tr>
<th>Target behaviour</th>
<th>Social support</th>
<th>Social comparison</th>
<th>Credible sources</th>
<th>Information on health consequences</th>
<th>Feedback on outcomes</th>
<th>Self-monitoring behaviour</th>
<th>Instruction on how to perform the behaviour</th>
<th>Demonstration</th>
<th>Graded tasks</th>
<th>Goal setting</th>
<th>Problem solving</th>
<th>Action planning</th>
</tr>
</thead>
<tbody>
<tr>
<td>30 mins MVPA/day</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td>Reduce carb portion to fist/hand</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td>Switch saturated to unsaturated fat</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td>Reduce salt to 1 tsp/6g/pd</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td>Monitor waist circumference</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td>Take medication daily</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
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<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mapped to which function?</th>
<th>Persuasion</th>
<th>Enablement</th>
<th>Persuasion</th>
<th>Education</th>
<th>Persuasion</th>
<th>Education</th>
<th>Persuasion</th>
<th>Training</th>
<th>Training</th>
<th>Training</th>
<th>Enablement</th>
<th>Enablement</th>
<th>Enablement</th>
</tr>
</thead>
</table>

1 Social support – unspecified; 2 Goal setting – behaviour, *Modified from Moore et al. 2019*
In this final section, I end the thesis by discussing the findings collectively. I critically appraise the findings and methods and outline the implications for supporting diabetes self-management for UK Black African and Caribbean adults.

To develop our understanding about how to support healthful behaviour for diabetes amongst people of Black African and Caribbean heritage my study had three key aims:

- To understand and describe the contextual sociocultural factors influencing T2D self-management behaviours in UK Black African and Caribbean adults.
- To explore how these factors shape self-management behaviour.
- To identify potential intervention targets and associated evidence-based behaviour change techniques (BCTs) to develop theoretical understanding of how to support healthful behaviour in a culturally salient manner.

I addressed my objectives by conducting a grounded theory study to develop understanding of the lived experience of self-management and by subsequently applying the COM-B and behaviour change wheel framework to identify culturally salient behaviour change techniques (BCTs) to address key determinants of behaviour.

4.1 Principal findings

4.1.1 Summary of the importance of the collective findings

Collectively, the findings give insight into how we may intervene and support equitable access to healthcare, to help Black African and Caribbean individuals engage with self-management recommendations and to live well with diabetes. The grounded theory analysis facilitates consideration of four key factors: Where in the patient journey (from diagnosis through to adapting to diabetes) are key intervention points? which sub-groups are a priority for support? What the key determinants of behaviour should be targeted? And, how interventions may be shaped and situated to resonate with cultural assets and values, for these target groups, in a South London inner city.
context. This analysis is supported by the data presented from the behavioural analysis, which provide further corroborating evidence of which behaviour determinants may be successfully targeted to support behaviour change, in a culturally salient way. The identification of potential BCTs, supported by evidence of effectiveness, has potential to theoretically guide the design of future lifestyle-related behaviour change interventions for this target population.

In addition, by theorising the lived diabetes experience, the findings develop our understanding of factors that may help improve the therapeutic alliance with the healthcare team; given the current evidence of persistent racism within the healthcare setting (Kapadia et al., 2022), the data around trust and how trust may be improved, are important to consider. Certainly, developing targeted interventions is less likely to be an effective strategy if there is a disengagement and lack of trust in healthcare teams that shape the general care provision. I will discuss each of these findings further in 4.2.

Below I begin by summarising the principal findings against each key research objective.

**4.1.2 Understanding sociocultural factors influencing self-management behaviour**

- Though exploration of wider social determinants of health was not the key focus of this analysis, there were several specific structural and psychosocial which emerged from the analysis, that reduced access to care and the priority given to self-management. These included financial worries, fears about safety, duality of managing relationships across two continents, caring roles, and lack of flexibility in work schedules. Additionally, there was evidence of marginalisation and discrimination, which will influence overall life chances, socioeconomic position, living conditions, food security, healthcare access and social capital.
The majority recognised the seriousness of T2D and were motivated to mitigate risk of complications. Socially constructed knowledge and beliefs about diabetes were perpetuated in social networks. Individuals had varying levels of biomedical understanding such that misrepresentations and misunderstandings about the physiological basis and biomedical treatments for diabetes were common.

Lifestyle behaviours, especially dietary choices and attitudes to weight management, were given a centrality in perceptions of cultural identity. Recommendations to reduce carbohydrate and lose weight were therefore perceived to conflict with identity for those with strong cultural affiliation.

Core cultural constructs of spirituality and connectedness were evident in the analysis, for both Black African and Caribbean individuals, and significant community assets were identified.

4.1.3 Theorising the self-management experience

- The novel theory Integrating Perspectives conceptualised the interactions between influencing factors and self-management behaviour. The theory suggested a misalignment between lay and medical perspectives. This created misunderstandings about diabetes and self-management and a perception of conflict with normative beliefs and habits. These perspectives were reconciled by facilitating knowledge and filtering so that ultimately self-management behaviour was compatible with identity and beliefs.

- Key determinants of behaviour patterns within the theory were trust, knowledge and cultural affiliation. Four behaviour pattern typologies were identified: adaptation, accommodation, traditionalism and detachment. Those with stronger cultural affiliation and lower biomedical health knowledge had the most difficulty and were less likely to adhere to self-management guidance - these were the Traditionists and Detachers and these groups would particularly benefit from targeted support.
• Diagnosis was a key stage in the patient journey where misalignment and poor cultural understanding could lead to disengagement, particularly in the groups with lower biomedical knowledge. This presents a key opportunity for targeted culturally salient support to present the diagnosis in a person-centred way, acknowledging personal illness representations which may be misaligned with biomedical perspectives. Intervention here to raise optimism and self-efficacy, may avoid detachment from advice which the data suggest could lead to a number of years without self-management for some individuals.

• The healthcare interaction was perceived differently across participants depending upon whether healthcare in general and the healthcare practitioner specifically, was considered trustworthy. General trust ("having faith") was influenced by biomedical understanding and evaluation of previous experiences, whilst specific inter-relational trust ("bonding") was influenced by the communication style of the healthcare practitioner. The presence of trust in the healthcare team reduced misalignment and encouraged facilitating knowledge through biomedical channels.

• Inequalities in the care provision were evident and the objectives of achieving person-centred care did not appear to be met.

4.1.4 Supporting behaviour change in a theoretically informed way.

• Key determinants affecting the adoption of NICE guideline recommendations for self-management health behaviour were identified in the COM-B behavioural analysis. The key determinants were identity beliefs, outcome beliefs, and knowledge (and skills). These mapped broadly to the theory of Integrating Perspectives, however the theory also highlights the importance of trust in the healthcare interaction and this factor was not elucidated in the COM-B analysis.

• Behaviour change techniques identified fell broadly into categories of social support (credible sources, social support, social comparison); practical participatory learning (demonstration, graded tasks, information on health


**DISCUSSION**


consequences, instruction) and behavioural control and self-efficacy (action planning, feedback, goal setting, problem solving, self-monitoring).

- The behavioural analysis framework identified the potential value of harnessing social support and social learning techniques to support positive health behaviour together with participatory, practical approaches to developing skills capability and motivation.

- Participation of community leaders and community role models was identified as of potential value, especially for those struggling with the apparent incompatibility between cultural identity and diabetes guidance. Furthermore, faith-based settings may be useful for delivery of interventions.

### 4.1.5 Scholarly contribution

Current research focus to date, has been primarily on exploring diabetes-related health beliefs for this target population, with the lived experience of diabetes amongst West African being explored in one study more recently (Alloh et al., 2019a). The main novel contributions of my thesis are firstly, to theorise how these factors fit together to shape diabetes behaviour, recognising that this results in different patterns of behaviour with four key sub-groups identified and each with slightly different priorities. Secondly, by theorising potential approaches to support behaviour change, my study advances our theoretical understanding of how to intervene to provide support.

The novel theory *Integrating Perspectives* highlights the challenges and influences on diabetes-related health behaviours from the perspective of individuals living with the condition. The identification of a misalignment between the care provision and cultural identity and preferred lifestyle habits is useful to inform cultural competency development to enhance the provision of person-centred diabetes care for those of Black African and Caribbean heritage. It highlights the need to develop a shared understanding of the explanatory models for diabetes and to recognise that powerful cultural drivers intersect with biomedical guidance and can limit engagement. Furthermore, the theory identifies the practical difficulties faced by individuals for
whom the knowledge provision is insufficient to enable them to fully engage while also following community situated normative behaviours. These findings will be useful to help diabetes care teams understand the patient perspective and provide useful insight for the development of culturally salient self-management education.

Application of the COM-B behaviour change framework successfully identified key culturally salient behaviour change techniques to address key determinants of health behaviour to support individuals in these communities. The key determinants identified were identity beliefs and outcome beliefs (influencing intention). Knowledge and skills (influencing capability) and social norms (influencing opportunity). The identified behaviour change techniques, may be used to theoretically inform interventions to support T2D management, support weight management and physical activity and they can be used to adapt diabetes education to increase saliency. The development of the evidenced-based taxonomy of BCTs can be justifiably criticised for its lack of robust evidence amongst minority ethnic groups. These findings demonstrate the potential utility of the taxonomy and the COM-B/BCW approach. Although, as discussed further below, the findings also highlight how important it is to use inductive qualitative methods in parallel, to improve cultural saliency. This approach helped identify wider social constructs shaping “worldview”, such as the relevance of spirituality and communalism. The analysis also identifies value placed on experiential learning and the importance of relationship building, reinforcing data from African American communities (Di Noia et al., 2013). These constructs can be employed to help shape intervention design and messaging and improve salience.

More distal determinants of self-management behaviour were also identified. The importance of trust and the value of healthcare teams following the person-centred guidance in nurturing engagement, for example. In addition, wider psychosocial factors which may negatively impact upon engagement with health care in general, were also identified. These distal determinants are potential targets for policy interventions, to shape guidelines, service provision, legislation, and communication.
My thesis adds to the current literature base by developing our understanding of current self-management behaviour patterns amongst South London Black African and Caribbean communities and constructively identifies how support may be developed and targeted in a culturally salient manner. This knowledge has potential value for different Black African and Caribbean communities around the country and for developing a range of culturally salient lifestyle interventions, including supporting weight management and physical activity as well as diabetes self-management.

4.2 Discussion of results

Each of my chapters has discussed the findings individually in the context of the current literature. Here then, I focus on exploring the utility and of the collective findings and how they add to the literature.

4.2.1 Understanding intersectionalities for improving intervention targeting.

4.2.1.1 The behaviour typologies – where and when to focus support

The grounded theory analysis identified trust in healthcare (determined by personal experience and biomedical knowledge) and cultural affiliation as key intersecting factors that influenced self-management behaviour. Within this framework (summarised visually in Figure 3-26, page 197), those with lower trust showed either a pattern of traditionalism or detachment. This resulted respectively in either, the rejection of self-management advice that was not compatible with cultural identity or illness representations, or in detachment from the intention to actively engage in self-management at all. These groups showed less adherence to self-management advice and so should be key targets of interventional support. In the context of healthcare literature that often determines minority ethnic groups as ‘hard to reach’ (Hou and Cao, 2018, Bodewes and Kunst, 2016), this puts the onus back upon healthcare teams to be providing care that has compatibility with cultural habits and beliefs, and that helps build trust and engagement. The diabetes-related patient journey for each
typology is different. The patient journey is defined as ‘the entire sequence of events that the patient experiences within a given healthcare system’ (Groszewski, 2020). The data suggest that for the Traditionist and Detacher particularly, the moment of diagnosis is crucial; it presents an opportunity to develop trust, shared understanding, self-efficacy and to develop appropriate knowledge and skills. Conversely, many of the participant narratives highlighted the alienation, despair, and lack of cultural competence they felt at diagnosis, resulting in disengagement. Currently self-management education is the key first-line recommendation at diagnosis (National Institute for Clinical Excellence, 2020), yet it is acknowledged as less engaging and effective for minority ethnic groups (Winkley et al., 2015). Developing culturally salient self-management education interventions, offered at the time of diagnosis as well as improving the cultural competence of the diagnosis experience maybe helpful to engage and support the Traditionalist and Detacher typologies. Understanding this granularity is important and the data suggest that these factors transcend ethnicity groupings – with the typologies being equally represented across the diverse African and Caribbean sample.

**4.2.1.2 The lens of intersectionality**

This study was not designed with a focus on intersectionality. The retrospective consideration of an intersectionality framework, however, can provide depth to the data and further highlight how different groups could benefit from different recruitment methods where and how interventions can be targeted for maximum salience. I have considered the intersections of gender, age, ethnicity, socioeconomic position with my experiences of recruitment, findings from the grounded theory and the behavioural analysis, to further identify how to reach and engage different groups (this approach is adapted from Bilge 2009, see section 1.3.2). The full framework is shown in Table 6-11. Thinking about intervention design and targeting, the intersectionality framework highlights the following:

- **Gender:** Male participants generally struggled more across the process of integrating perspectives, than females. Cultural constructions around male pride made it more difficult for men to come to terms with diabetes and to
generally discuss it within their social support group. They also struggled to make dietary changes with food and large portion sizes tied up with beliefs about what it meant to be an African man, for example. Men also showed limited self-efficacy over dietary choices and cooking at home. BCTS associated with social support were likely to be helpful for people of both genders, however, more so for women; women accessed support to exercise in groups and shared dietary advice and cooking tips, as well as weight-loss successes. Caring roles amongst women, increased their burden and reduced flexibility to focus on self-management.

- **Ethnicity**: for the Black African participants the impact of diabetes-related cultural stigma, attachment to cultural foods and a particular lack of information on African cultural starches, highlighted their unique challenges.

- **Socioeconomic position**: Lack of flexibility in schedules for those in unskilled jobs significantly impacted their ability to engage with self-management education classes and other groups that required an advanced time-commitment. This suggests that intervention design (and services) need to offer flexibility and sessions timed appropriately. Financial stress was apparent for many. Interventions therefore, need to be sensitive to minimising the financial burden – for example, by providing equipment needed. In addition, biomedical knowledge was lower in those with lower educational attainment, suggesting that the BCTs *information about health consequences*, and *instruction* may be particularly useful for these groups.

- **Religion**: Faith in general was positive for diabetes management and faith settings useful for health education. Differences in religious festivals and teachings surrounding health and diabetes suggest that targeted intervention in both mosques and churches would best capture the different religious groups.

- **Age**: Older participants were less likely to source information on-line and to use digital technologies. This meant it was harder for them to access information. Furthermore, this has implications for the current move towards centralising...
diabetes care monitoring with the use of online apps. The older participants particularly benefited *demonstration* and *instruction* BCTS which helped develop self-efficacy (for example, increasing confidence to engage in physical activity). Participant narratives also suggested that the health care provision could be ageist, with older participants being offered limited information or support to make dietary and lifestyle change.

This analysis adds depth to my main findings, exploring nuances that can improve targeting and development of interventions but also supporting general equitability of BCTS across the intersectional frameworks.

**4.2.2 Determinants of behaviour and relevance within the typologies**

**4.2.2.1 Identifying target determinants of behaviour**

The grounded theory analysis suggested that key determinants shaping different behaviour patterns were knowledge, cultural affiliation, and trust. The COM-B analysis identified key determinants to support behaviour change as knowledge and skills, identity beliefs, and outcome beliefs. These broadly map onto each other, highlighting capability and motivation to being key targets for intervention. Trust identified in the grounded theory, included *faith in healthcare* which incorporates outcome beliefs, although is a wider more elusive theme and also *bonding* which does not map onto the COM-B framework, but will indirectly influence motivation (see Figure 4-1).
The Committee on the Communication for Behaviour Change in the 21st Century was formed to improve the health of diverse populations. This group developed a consensus opinion on the key constructs determining behaviour, based on existing models. The key findings of their consensus report are shown in Table 4-1, and conclude that key determinants of behaviour in general are intention, having appropriate skills and that there are no barriers in the environment preventing the behaviour (Committee on Communication for Behavior Change in the 21st Century: Improving the Health of Diverse, 2002).

Table 4-1: Consensus opinion on key determinants of health behaviour (modified from (Bartholomew et al., 2016))

<table>
<thead>
<tr>
<th>Consensus opinion on eight key determinants of health behaviour</th>
<th>Priority</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. A strong positive intention to perform the behaviour.</td>
<td>Key</td>
</tr>
<tr>
<td>2. Has the necessary skills to perform the behaviour.</td>
<td>Key</td>
</tr>
<tr>
<td>3. No environment constraints make it impossible to perform  behaviour.</td>
<td>Key</td>
</tr>
<tr>
<td>4. Believes that the advantages of performing the behaviour outweigh the disadvantage (attitude).</td>
<td>Influences strength and direction of intention</td>
</tr>
<tr>
<td>5. Perceives that there is more normative pressure to perform the behaviour than not.</td>
<td>Influences strength and direction of intention</td>
</tr>
<tr>
<td>6. Perceives that performing behaviour is more consistent than inconsistent with his own self-image.</td>
<td>Influences strength and direction of intention</td>
</tr>
</tbody>
</table>

Figure 4-1 Comparing behaviour determinant-identification across methodologies

** poorer knowledge did influence motivation via faith in healthcare, although outcome beliefs were not specifically identified as a key determinant in the grounded theory analysis

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142 Models identified and assessed were the theory of planned behaviour, theory of subjective culture and interpersonal relations, transtheoretical model of behaviour change, information-motivation-behavioural skills model, Health belief model, social cognitive theory and theory of reasoned action.
7. Emotional reaction to performing the behaviour is more positive than negative.
8. Believes that has capability to perform the behaviour.

The findings of my collective analysis identify determinants related to determinants 1 (intention), 2 (skills), 4 (attitude towards the behaviour), and 6 (consistency with self-image) from this consensus opinion. This is illustrated further in Figure 4-2, together with the BCTs identified to shift behaviour for each of these determinants.

- **Intention**: is limited for some both by their illness representations being misaligned with biomedical understanding, so the value of performing the behaviour is not well understood (point four in the table above), and by the belief that some of the recommendations are not compatible with their cultural identity (self-image) (point six in the table above). In addition, intention may be limited by a lack of generalised trust in healthcare.

- **Necessary skills**: is limited by the lack of a culturally appropriate knowledge provision, which leaves individuals unable to translate the advice to the foods they want to eat and to the type of physical activity they feel comfortable with (point three in the table above).

This suggests the mapping analysis did identify culturally relevant, effective and acceptable BCTs that addressed key factors which are likely to be most relevant in behavioural terms. The grounded theory did suggest similar determinants of behaviour, although they were less clearly classified in terms compatible with traditional established psychological models of behaviour change.

Compared to the established models of behaviour change described above, my findings emphasise that culturally situated knowledge and cultural identity played a more central role in shaping behaviour. Most behaviour change models either do not consider culturally related constructs or allocate them a distal role. Social norms may be considered in a general way based on perceived normative pressure to engage or disengage with a behaviour, such as in the theory of planned behaviour (Ajzen, 2011),
or, as in the case of social learning theory, social norms are considered only to play an indirect role by influencing outcome beliefs (Bandura and Hall, 1997). I will discuss these social influences in the next section.
DISCUSSION

Figure 4-2: Summary of theoretical constructs influencing key determinants of behaviour and associated behaviour change techniques identified.

Key determinants:
- Healthcare context:
  - Trust & patient-centred care: promotion of related positive and neutral behaviours that are culturally valued
  - Reinforce or reduce engagement in behaviour
- Cultural factors:
  - Is behaviour compatible with cultural identity?
  - Is behaviour perceived to be supported by others in community?
  - Does behaviour fit with culturally situated diabetes understanding and experience?
- Psychological factors:
  - Attitudes: will outcomes be worth engagement?
  - Self-efficacy: will I be able to perform behaviour?
- BCTs:
  - Modelling
  - Role models
  - Credible sources
  - Social support
  - Social comparison
- Knowledge:
  - Information on health consequences
  - Reinforce or reduce engagement in behaviour
- Community context:
  - Social networks & faith networks

INTENTION

BEHAVIOUR

SKILLS
4.2.2.2 The importance of socially situated cultural influences

The two methods of data analysis concurred on the importance of socially situated influences as moderating forces on self-management behaviour. The need to provide support to allow individuals to adapt to diabetes in a way that fits within this social context was evident, for example being able to eat foods that are shared socially. In addition, as many individuals sought knowledge from trusted community sources, there is potential to support engagement from within the community, especially given the valued nature of community networks and faith institutions. This may be particularly true for the Traditionalist and Detacher typologies who have less generalised trust in healthcare.

Social influences on health knowledge

It is useful to consider how social influences shape health knowledge. As evidenced in the data, biomedical and cultural health knowledge coexist, with cultural health knowledge predominating in most of the participants in this study. Studying migrant and non-migrant Ghanaian populations, de Graft et al. were able to compare how diabetes knowledge shifted with migration from rural to urban Ghanaian settings and from Ghana to Europe, which provides insight into my data (de-Graft Aikins et al., 2019). The study identified four types of health knowledge in Ghanaians living with diabetes: cultural knowledge (core beliefs around health and spirituality); religious knowledge; scientific knowledge (biomedical); and common-sense knowledge (social observation, communication and everyday experience of sources in the public domain, like the media). Their analysis suggested that as individuals moved from the rural to urban setting in Ghana and to high income settings in Europe, their knowledge shifted with exposure to different influences, gradually becoming more biomedically aligned as more scientific sources were available both within the social informal networks as well as through healthcare exposure. The study concluded that core representations from culture and religion were stable with migration and peripheral representations from common sense and scientific sources changed with length of time in new countries. This change occurred through access to healthcare knowledge and common-
sense knowledge becoming more scientific with exposure to community and media sources, that reflect biomedical views. This is process is illustrated in Figure 4-3.

Figure 4-3: Modified from de Graft et al., to explain cognitive polyphasia and developments in health knowledge (de Graft et al., 2019)

This resonates well with my data and suggests that misalignment may become less of a challenge as successive generations assimilate knowledge from the UK context. This gradual shift towards biomedical health knowledge is also supported by studies amongst African Americans living with diabetes. These studies suggest that while knowledge continues to be developed through social contacts and lived experience, it is eventually becomes more aligned with biomedical understanding because of increased exposure of the population to these ideas. (Skrine Jeffers et al., 2019, Skelly et al., 2006).

### 4.2.2.3 Accommodating cultural identity

As discussed in Chapter 3.5, the theory of *Integrating Perspectives* builds upon theories of adaption that highlight that self-management behaviour needs to be compatible with the social context of the individual (Pollock et al., 1989, Roy, 2011). For individuals with strong cultural affiliation (the Accommodators and the Traditionalists in my analysis), self-management advice was seen to conflict with cultural identity. This
creates considerable challenge in supporting engagement, particularly with weight management, carbohydrate reduction and changes to cooking habits, all of which are central to supporting diabetes control. Supporting engagement in these behaviours begins with respectful understanding of these cultural influences, recognition of where there are positives and understanding of the cultural and historical context influencing value, beliefs and behaviours (Andrews et al., 2017).

The findings that body image beliefs and dietary habits are influenced by normative cultural influences is supported in the literature. For all participants there was a complex interplay of factors influencing how biomedical knowledge was assimilated in the context of normative social influences. Most participants (apart from some older male individuals) recognised the health implications of being overweight, even if they didn’t necessarily pin-point weight as a key contributor to diabetes. The socially constructed beliefs amongst women that the larger body size was a symbol of social position (being cared for, wealthy, mature), health and attractiveness, was also powerful. This was particularly true for those of African heritage; amongst Black Caribbean women these views were evident although there was more variation. These deep-seated beliefs, coupled with worry about the perceptions of others, highlight the real challenge in addressing weight issues and may help explain why supporting weight loss amongst Black populations has proved difficult in interventions (Wingo et al., 2014). In my analysis cultural perceptions about body size were given weight over biomedical knowledge, in guiding behaviour in some of the typologies. My analysis concurs with the body of literature from the US setting which highlights normalisation of a larger female body shape within Black African and Caribbean communities (Lau, 2011, Andrews et al., 2017, Kumanyika et al., 1993). Andrews et al., exploring the clinical encounter in relation to weight amongst Black women, highlight the bias associated with the “medical gaze” in presenting the body as an object of scrutiny for classification by such tools as BMI charts and the risks of shaping knowledge based on biomedical understanding, marginalising other forms of understanding (Andrews et al., 2017). It was only amongst those of the Adapter typology that pursuit of health was a
strong motivator, overcoming cultural influences on body image beliefs. Shoneye et al., who compared motivations for weight management between Black and White women note that weight management was more likely to pursued for health than for aesthetic reasons in Black women compared to White (Shoneye et al., 2011). The women in the Adapter typology had a higher level of health literacy and biomedical knowledge than other types. Nevertheless, this group still rejected the use of BMI charts as inappropriate and considered a larger body to be less susceptible to illness, highlighting that even amongst those with good health knowledge, biomedicine was only one of the lenses through which individuals judged health and illness. The finding that diabetes dietary advice was perceived to conflict with valued cultural habits has also been reported in UK South Asian communities with diabetes, resulting in disengagement with advice not compatible with cultural identity (Patel et al., 2021). In my analysis attachment to cultural foods was strong, even amongst second generation individuals. Dietary change is hard for all individuals as diet is one of the early learnt habits (Hellman, 2007). For immigrant communities the literature confirms that food can play a symbolic role in maintaining cultural identity (Wright et al., 2021) which can increase the challenge of self-management (Osokpo et al., 2021). The role of food culture is considered crucial in the diasporic experience (Tat Shum, 2020). It can help delineate ethnicity creating a sense of “us” (Kershen, 2017), maintains a link with homeland (Gunew, 2000) and, as my data concur, can provide comfort and security (Ore, 2018). My analysis particularly highlights the role cultural foods have in creating and maintaining social bonds, as reported for the African diaspora in other countries (Tat Shum, 2020) as well as in other immigrant cultures (Lin et al., 2020). The strong reliance on starchy staples and oil and salt in cooking means that some dietary change is warranted to support diabetes management, although it does not require cultural foods to be eliminated from the diet. Given the important and symbolic role foods play in immigrant communities, however, we can expect that making changes may be difficult. Providing social support for change, for example by developing group interventions or situating interventions within the social context, such as amongst faith or other community groups, is therefore likely to be helpful. The analysis also
demonstrated the benefits of involving credible role models from the community to shift identity beliefs, with regards to the compatibility of self-management recommendations.

Finally, a cultural conflict associated with engagement in purposeful exercise was highlighted by some participants. These were primarily those of West African ethnicity. This reflects a similar finding in the study of UK West African immigrants by Alloh et al., (Alloh et al., 2019a). The lack of cultural relevance leading to limiting physical activity engagement in minority ethnic communities, has been reported in two systematic reviews (Koshoedo et al., 2015, Ige-Elegbede et al., 2019) however the lack of data from Black African and Caribbean communities is noted (Ige-Elegbede et al., 2019).

It is significant that the behavioural analysis and BCT evaluation, indicated perceptions about the incompatibility of self-management behaviour and identity could be shifted with appropriate BCTs that involved cultural role models (credible sources, modelling, providing information about health consequences, social support). This finding highlights how valuable it is to engage the community and community leaders in endorsing shifts in behaviour in order to demonstrate that these changes can be made in a way that is compatible with normative influences. Engaging community role models has been demonstrated to be effective in lifestyle intervention to support African Americans, endorsing benefit in this approach (Kong et al., 2014).

4.2.2.4 Determinants and the typologies

Finally, it is useful to draw out here that the behavioural analysis suggests a slightly different focus may be warranted for different sections of the population. For those with faith and trust in healthcare, improving cultural competency within the current care pathway is likely to provide sufficient support. For example, by adapting existing self-management education to offer pertinent knowledge and guidance such as appropriate portion sizes for cultural carbohydrates. For those with low trust in healthcare, working within established medical care pathways is less likely to be beneficial, because of the lack of trust. Interventions are likely to be more effective if
run in settings where trust is already established, such as in the community. Support for these groups needs to include strategies to develop knowledge as above, but also to shift intention. To improve intention, strategies need to shift outcome and identity beliefs. Interventions need to highlight benefits of following self-management guidance, including developing knowledge about the metabolic perturbations of diabetes and how different aspects of self-management may act to improve outcomes. The use of cultural role models is likely to be particularly important for this groups.

4.2.3 Leveraging cultural assets and experiences to improve saliency and outcomes

4.2.3.1 Building on positive behaviour

Recognising and reinforcing current positive behaviours is an important part of designing culturally appropriate care (Airhihenbuwa, 1995). My behavioural analysis identified several positives to support self-management. Regarding physical activity there was a broad belief in the importance of being active and most had grown up leading very active lives in African and Caribbean settings. Furthermore, the need to continue to be active was well accepted, with walking and dancing enjoyed by many individuals. In London walking associated with use of the bus network was described, which included setting oneself small goals like getting off a few stops earlier. Walkability rating for London is high, as highlighted in section 3.2 (Stockton et al., 2016), suggesting that promoting walking would have high acceptability compared to other physical activity options. The care provision still needs to include further specific instruction on how to meet the physical activity guidance in terms of time and intensity nevertheless, as this guidance seemed poorly understood. High regard was given to treatments and approaches that were natural. This meant that relative to intervention with medicines, individuals would prefer to control diabetes naturally with diet and physical activity. This does present opportunity to motivate engagement with lifestyle management, although my findings suggest participants were only motivated to make necessary changes when they were equipped with biomedical knowledge about exactly how foods and exercise affected blood sugar. This preference
for natural approaches extended to the use of natural remedies, which were used by all but the Adapter types, who were more strongly motivated by biomedical knowledge. Concomitant use of natural and allopathic approaches to treating diabetes has been identified as a common in many cultures (Singh et al., 2012). Several natural remedies have been evaluated and have been found to have potential positive effects on blood glucose (Salimifar et al., 2013). While this is a difficult issue for doctors to navigate, the data suggest there would be value in developing our medical understanding of some of these natural treatments and where they might be used safely, respecting the desire of patients to continue use of some natural remedies.

4.2.3.2 Empowering trusted community sources to improve knowledge

Information seeking occurred within established trusted community networks amongst both Black African and Caribbean ethnicities. This reliance on familial and social networks for health information was also reported by Scott et al. in UK Caribbean communities (Scott, 1998) and is evident in studies amongst African American communities (Woodward et al., 2008, Chao et al., 2006), with church networks in particular being highly supportive (Taylor et al., 2005). This reliance on trusted community networks to build knowledge presents an opportunity to engage community leaders in supporting the care provision. Community partnerships with Black majority churches have also been suggested as a valuable approach to supporting Black British communities (Harding et al., 2018). In the US leveraging community networks to develop understanding of diabetes, has proved effective in diabetes prevention (Kitzman et al., 2021) and diabetes management education (Samuel-Hodge et al., 2009, Ammerman et al., 2002) and shows potential for supporting lifestyle change (Bopp et al., 2012, Lancaster et al., 2014), with interventions in faith settings being particularly helpful (Summers et al., 2013, Ammerman et al., 2002, Newlin et al., 2012, Thompson et al., 2009).

Importantly, culturally specific nutritional information was until recently difficult to access, with little scientific evaluation on the glycaemic index and other relevant analysis on traditional African foods carried out. Fortunately, more data are now accessible in the public domain to facilitate training and empowerment of lay
educators in the community setting as well as dietitians in the medical setting (Mehar et al., 2019).

4.2.3.3 Building ‘deep structure’ sensitivity

Identifying core cultural constructs

My analysis adds to the literature concerning deep structures which may help to shape the cultural saliency of interventions to support engagement with self-management behaviours. The finding that individuals placed particular importance on kinship, connecting with and caring for others in the community, adds to the literature previously discussed which suggests that communalism is valued in UK Black African and Caribbean communities (Ochieng, 2011a, Osei-Kwasi et al., 2019, Koffman et al., 2011) (see section 1.3.4). In addition, my data reinforces the importance of religiosity and religious coping strategies previously reported in UK studies conducted amongst non-diabetic Black African and Caribbean adults (Alidu and Grunfeld, 2020, Mulugeta et al., 2017, Akinlua et al., 2017, Wagland et al., 2020, Koffman et al., 2008). The church and mosque settings were considered important places to learn about health, as has also been previously reported in UK studies (Rawlins et al., 2013, Heward-Mills et al., 2018, Koffman et al., 2008). These findings would suggest that engaging friends and family in interventions, using spiritual messaging and considering faith venues for sharing health knowledge may be useful strategies to increase the saliency of interventions. My study builds on existing literature regarding two core constructs identified from American literature that have not been clearly reported in UK studies to date. These were priority being given to experiential learning and interpersonal contact to develop knowledge (Anderson-Loftin et al., 2002) and the importance of emotional cues and relationship building (Di Noia et al., 2013). These factors may shape the choice of the most appropriate BCTs and suggest the importance of supportive relationships in developing engagement.

The influence of other social and structural factors

Resnicow et al., highlight the need to understand the wider socioeconomic, structural factors and historical factors (Resnicow et al., 1999). My analysis builds on existing
literature by describing the social contexts within which individuals are managing their diabetes more fully than in previous published studies. The findings highlight wider social determinants of health that may limit engagement, such as psychosocial stress and financial constraints. Structural issues associated with extended periods of travel to native countries and inflexible working timetables may limit engagement with care, particularly attendance at long structured education sessions. It is important that these factors are recognised as part of a person-centred care provision and in intervention design. Marginalisation and discrimination, though not a major focus of exploration in this study, are likely to influence trust in healthcare, which did influence engagement more specifically in my theory. As previously highlighted, experiences with UK establishment as well as historical experiences in health care interactions will shape generalised trust. Recent publication of the NHS Race and Health Observatory report, highlights the pervasive racism which still exists within the NHS (Kapadia et al., 2022) and suggest urgent need for policy change, at a societal level, before inequities can be more fully addressed.

4.2.4 Trust and the therapeutic alliance

Whilst my focus has been primarily of supporting health behaviour change at an individual level, the data also provide data about how the healthcare interaction may be improved. These factors are important to consider, both because minority ethnic groups have a right to the provision of person-centred, culturally appropriate care but also because any culturally salient interventions developed are likely to be more effective in the context of a trusted healthcare provision. Person-centred care is a cornerstone of the guidance for supporting individuals living with chronic conditions, in order to guide self-management (section 1.2.1.2). The theory of Integrating Perspectives highlights the presence of barriers to achieving a therapeutic alliance with the healthcare team. This includes a lack of shared understanding about the condition of diabetes, failure to provide culturally salient knowledge and lack of inter-relational trust. The COM-B analysis reinforced the fact that these barriers reduced both capability and motivation to engage with behaviour change to self-manage diabetes.
4.2.4.1 Negotiating shared understanding

Developing shared understanding is imperative to avoid stereotyping. There is likely to be considerable intrapersonal variation in health beliefs and behaviours within communities based upon countries of origin, generation, immigration status, acculturation, and education (Betancourt et al., 2003). Even in my study, participants included both first- and second-generation, of wide educational attainment, with different religions and originating from several different countries. In my analysis some individuals (Adapters and Accommodators) in fact had a good understanding of diabetes, which reflected biomedical understanding to a large degree. These individuals engage and work in partnership with their healthcare team. Those holding traditional beliefs and whose explanatory models for illness and treatments diversify from the biomedical perspective (Traditionalists) were less well-supported. As the intersectionality framework indicated, this group were more likely to be older and to have lower educational attainment and health literacy. The data suggest that healthcare professionals in the main, are not addressing these different beliefs and perceptions, thus are not meeting the objectives of providing person-centred care for this group of patients. This creates disengagement.

Failure to recognise these differences in the cultural perceptions of illness, was identified in a realist review as one of the key problems in communication between healthcare and patient in the intercultural scenario (Paternotte et al., 2015) and has been reported in observational study of intercultural healthcare interactions in the European context (Paternotte et al., 2017). Key communication skills for healthcare professionals to address differences in perceptions of illness and disease have been identified from observation of multiple healthcare interactions. Strategies include: recognising that misunderstandings are caused by cultural differences; recognising the patients’ expectations of healthcare; being aware of one’s own culture; empathetic communication; demonstrating trustworthiness; giving appropriate information; becoming familiar with the situation and context of the patient and respecting their
habits norms and values (Paternotte et al., 2015, Paternotte et al., 2016). My analysis suggests that addressing these factors is likely to increase trust and engagement.

4.2.4.2 Addressing psychosocial needs

Significant psychosocial factors were evident in the everyday lives of individuals which have potential to limit the attention given to diabetes self-management and engagement in healthy lifestyle change. These factors included stress associated with working patterns, financial worries, safety fears for children and caring responsibilities.

A qualitative study amongst healthcare professionals in London highlighted the perceived impact that significant social challenges affecting their Black African and Black Caribbean patients had upon the centrality and priority given to managing diabetes (Goff et al., 2020). In fact, a wider narrative of displacement, educational disparity, change in social status, financial pressures, stress and discrimination is recognised to impact diabetes care across minority ethnic communities in the UK (Greenhalgh et al., 2011). These are not easy issues to resolve. Being responsive to psychosocial needs, however, is a key part of the provision of person-centred care (Hudon et al., 2012). My analysis highlights that when healthcare teams related individuals on a personal level, were interested in them as an individual and related to some of these difficult issues listed above, the quality of engagement improved (see Figure 3-25, in the theoretical findings chapter 3.5).

4.2.4.3 Cultural competence or cultural humility?

When healthcare practitioners showed awareness of cultural factors and provided knowledge salient to cultural habits and beliefs, trust and engagement were increased (see Figure 3-25, in chapter 3.5). Cultural competence has been described as “an ongoing process in which the healthcare provider continuously strives to effectively work with the cultural context.” (Campinha-Bacote, 2002). It is a process that involves cultural knowledge (health related beliefs, values, worldview), cultural skill (being able to interact to collect relevant data), cultural encounters (seeking out interaction), cultural desire (the desire to learn) and having awareness of one’s own culture (Campinha-Bacote, 2002). Providing care that is sensitive to individual preferences and
culture is a key facet of NICE guidance (National Institute for Clinical Excellence, 2020), however, the data evaluating the effectiveness of cultural competency on patient outcomes are limited. While it appears to improve patient satisfaction, evidence from systematic reviews that this translates to improved outcomes is not convincing (Renzaho et al., 2013, Horvat et al., 2014, Chae et al., 2020, Lie et al., 2011). Further analysis of the Cochrane review data suggests health behaviour improved significantly, as did mutual understanding and perceptions of healthcare but that the heterogeneity of studies and the particular outcome measures chosen (LDL cholesterol and weight – both of which are difficult outcome measures to shift) meant the analysis did not reach significance (Horvat et al., 2014). These studies conclude that more data is required to make robust conclusions about the impact of cultural competence on outcomes.

With the increasing diversity of the UK population, especially in cities like London, the challenge of providing culturally competent care to people from a range of ethnic backgrounds is not insignificant. My findings suggest, however, that the general attitude of the healthcare practitioner in terms of being empathetic and building trust can positively influence engagement. This general attitude includes the use of affective relationship-building communication and showing respect for cultural traditions. This was the case even if the healthcare practitioner was not able to give detailed, culturally specific knowledge. This finding is supported by other authors; two studies investigating how to improve engagement in the intercultural healthcare interaction have highlighted how general affective communication is more important for patients than culturally competent communication (Jager et al., 2020, Paternotte et al., 2017). Affective communication including empathy, respect, being interested in the individual as a person have been highlighted as key determinants of satisfaction amongst patients generally (Saha et al., 2008). As far as the healthcare interaction is concerned, my analysis suggests that individuals valued “cultural humility” - not necessarily cultural competence - in the process of trust and engagement. Lekas et al. (2020) have described cultural humility as follows:

“Cultural humility refers to an orientation towards caring for one’s patients that is based on: self-reflexivity and assessment, appreciation of patients’ expertise on the social and cultural
context of their lives, openness to establishing power-balanced relationships with patients, and a lifelong dedication to learning. Cultural humility means admitting that one does not know and is willing to learn from patients about their experiences, while being aware of one’s own embeddedness in culture(s). While competence suggests mastery, humility refers to an intrapersonal and interpersonal approach that cultivates person-centred care.” (Lekas et al., 2020)

Despite this, individuals do need practical, culturally salient advice to enable successful self-management which is compatible with cultural identity. This can be achieved by signposting to an appropriate provision, be that a figure in the community, a specialist dietitian in the healthcare team with knowledge of specific cultural foods, or a diabetes education session specifically tailored towards the needs of Black African and Caribbean individuals.

4.2.5 Exploring the findings in the context of current literature

Developing theory can add depth to the understanding of a phenomenon as it assists in exploring the complexity of links between different themes and in understanding the behavioural patterns in the data (Glaser, 1998). This knowledge is particularly valuable if an aim of the research is to support behaviour change as it helps elucidate determinants of behaviour. To date, however, there has been little work to theorise diabetes related health behaviour in immigrant Black African or Caribbean adults in the UK or other high-income countries. Other thematic qualitative studies from the UK have reported some elements similar to the concept of misalignment, indicated in the theory Integrating Perspectives. Brown et al., (2007) and Scott et al., (2001) identified the health beliefs and normative influences on behaviour in Black Caribbean individuals which made self-management difficult. Similarly, Omodara et al., recently presented a qualitative study amongst sub-Saharan African participants in the UK in which culturally situated beliefs were noted to differ from the biomedical perspective in several respects, particularly concerning beliefs about the causes of diabetes (Omodara et al., 2021). My theory goes beyond this heuristic understanding to provide important insight in how individuals navigate these issues, which is absent from the current body of work. The theory also explores the diversity amongst individuals and the factors which moderate beliefs and practice; it hypothesises how intragroup differences in the degree of cultural affiliation shape behaviour with four key
behaviour patterns evident in the data. Understanding these nuances is helpful to avoid stereotyping (Purnell, 2002). In section 3.4.5, page 207, I suggest that key constructs in the theory *Integrating Perspectives* are supported by other grounded theories of diabetes self-management in different populations and contexts. Absorbing diabetes into the sense of self and into the social context was a key theme of a number of studies (Page-Carruth et al., 2014, Hernandez et al., 1999, Fink et al., 2019), as was the value of social support (Nantha et al., 2021b, Ligita et al., 2021) and information seeking from trustworthy sources and through an experiential process (Low et al., 2016, Ligita et al., 2019, Smith-Miller et al., 2020). The use of the theory and the data to inform a theoretical understanding of how to support positive engagement in self-management behaviour can help to ensure that support provision is responsive to needs and is culturally salient. Evaluation of the COM-B framework in UK minority ethnic populations is novel. Identification of culturally relevant BCTs to increase culturally salient knowledge and skills and support adaptation to diabetes in a way that is compatible with cultural identity adds to the current theoretical understanding of supporting behaviour change amongst Black African and Caribbean adults. This can help to counter the criticism that many diabetes support interventions are "evidence-inspired" rather than "theory-driven" (Anand et al., 2015). The COM-B framework was recently used to evaluate and specify BCTs for people in the general UK population who are living with type 1 diabetes and several selected BCTs are common to my analysis, highlighting particularly the common value of social support to manage a chronic condition. The key differences were in the selection of credible sources as a BCT and the particular value placed upon participatory approaches to learning from social interactions, demonstration and instruction in my analysis (Stanton-Fay et al., 2021). COM-B and the behaviour change wheel has not yet been used to develop many culturally tailored interventions. Two systematic reviews have retrospectively identified BCTs in health education interventions for culturally diverse populations with chronic conditions (Lambert et al., 2021) and interventions to reduce soft drink consumption in adolescents from minority ethnic groups (Shagiwal et al., 2020). These reviews identify benefit in BCTs associated with self-regulation (feedback, goal setting,
action planning and self-monitoring) for both these objectives. Additionally, BCTs associated with social support and shaping knowledge were also commonly used in the educational interventions. Shagiwal et al., (2020) demonstrated a positive effect of self-regulatory BCTs, however, the review by Lambert did not find any modifying effects between the BCTs, which authors considered was due to the limitations of the sample size (Lambert et al., 2021). The interventions amongst minority ethnic communities, which have been developed using COM-B to specify BCTs, include one to reduce smoking in Australian indigenous women who were pregnant (Gould et al., 2017) and one support gestational diabetes in Latina pregnant women (Handley et al., 2016). These interventions included more of the additional BCTs identified in my analysis – for example, credible sources, social comparison, demonstration, and information about health consequences (Gould et al., 2017, Handley et al., 2016). Additionally, Van der Veen et al., using the intervention mapping approach (Bartholomew et al., 2016) identified active learning, peer stories and modelling as key BCTs in their intervention to support engagement with hepatitis screening in Turkish Dutch communities (Van Der Veen et al., 2014). These BCTs map broadly to social comparison, demonstration and role modelling in the V1.0 BCT taxonomy used in my analysis (Michie et al., 2013). Collectively, these findings in other culturally tailored interventions and outside the UK setting, give some credibility to the findings of my analysis.

I would like to specifically reflect upon the theory of Integrating Perspectives, compared to the one published theoretical study of self-management amongst the African diaspora in the UK setting, which was conducted recently in West African individuals (Alloh et al., 2019a). This study used constructivist grounded theory methods (Charmaz, 2014). The published paper presents data largely descriptively, therefore I have reviewed the PhD thesis in order to further understand this work (Alloh, 2020). This analysis supports elements of my findings but there are notable differences. In the study by Alloh, the category Finding out describes diabetes diagnosis as shocking and burdensome as my data suggested. A key difference,
however, was that this study did not find the related dissociation and denial which was evident for several of my participants. I discuss potential reasons for this below. The second main theoretical category Striving to adapt describes efforts to adjust diet and to change activity levels, and the associated support systems. Difficulties were noted in reducing portion sizes and maintaining an active lifestyle, the latter being due to migration, the typical UK lifestyle being generally less active than that of the participants’ countries of origin. Misalignment or conflict, however, is not identified in Alloh’s work. In fact, the challenges with healthcare provision which formed such a key part of the discussions with my participants is not noted in this analysis. As discussed previously (see 3.4.5.2) there is a lot of supporting data to corroborate misalignment as a challenge both for African heritage individuals with diabetes in the UK (Brown et al., 2007, Scott, 2001), other minority ethnic groups in UK (Wilson et al., 2012) and in other high income settings (Zeh et al., 2014). I suggest that the differences between the work of Alloh and the present study may be due to recruitment in the latter being primarily from diabetes support groups, as well as the fact that the majority of participants were tertiary educated. It is likely that biomedical knowledge will be higher in these individuals, like the Adapters and Accommodators in my analysis who also experienced less misalignment. The final category Living with it mirrors some parts of my category Reconciling, as individuals describe a process of coming to terms with the condition. The primary difference between this category and my data is that in my study participants emphasised that coming to terms with diabetes involved a process of filtering so that behaviour was consistent with the individuals’ normative beliefs and identity. Constructivist methodology encourages the development of “storyline” to explain the links between categories and this study identifies Normality as the linking storyline. The products of constructivist and classic grounded theory are slightly different; classic grounded theory has roots in quantitative analysis and is therefore focused on understanding interactions and moderating factors, encouraging the development of understanding of different patterns in the data. Therefore, whilst there are some similarities between the two theories, my theory of Integrating Perspectives differs in some areas of the findings and in the development of typologies.
It is also developed from a diverse participant group, comprising both Black African and Caribbean individuals, from a range of educational backgrounds.

**4.2.6 Summary**

In this section I have considered how the findings of the grounded theory analysis and the behaviour change analysis collectively shape our understanding of how engagement with diabetes self-management guidance can be supported. This included identifying intervention points within the patient journey, exploring key determinants of behaviour and potential BCTs which could act as mechanisms of change, how a therapeutic alliance between healthcare providers and patients may be improved, and what cultural assets, beliefs and experiences are important building blocks to support engagement. In my analysis I have used two approaches to determine strategies to support healthful behaviour change for diabetes self-management specifically amongst Black African and Caribbean individuals. I would like to begin the next section, which reflects upon the methodologies used, by considering the contribution of each approach and how successfully the combination of these two methods helped identify routes to developing culturally salient support.

**4.3 Reflecting on the methods**

**4.3.1 My choice and combination of methodologies**

**4.3.1.1 Grounded theory methods**

Grounded theory methods have been identified as being valuable for cultural exploration of a health-related issues, because of the methodological framework which guides the researcher to explore the participant voice and minimise pre-conceptions (Draucker et al., 2014).

“The emergent, inductive, comparative nature of grounded theory renders it particularly well-suited to uncover processes by which factors related to ethnic diversity influence health-related problems.” (Draucker et al., 2014)

Certainly, I found this to be the case. For example, the concept-indicator model used to build up theoretical concepts helped me to avoid an impressionistic response to the
data and to consider deeply what participants were expressing throughout the data. The focus on theory generation was also useful in encouraging careful consideration of how the concepts in the data interacted. This assisted me in identifying the key factors that influenced health behaviour at the individual level, giving perspective to the COM-B analysis, as it allowed me to understand which were the principal proximal determinants of behaviour. In addition, the focus on explaining variability in interactions and the resulting typologies which emerged from the analysis provided, I would argue, a more realistic picture of the complexity of the social environment than would have been evident from a standard thematic analysis. Grounded theory is not without critics, however. The process of grounded theory is criticised for several reasons: the methods are complex yet there is a lack of standard rules for developing theory; it is challenging to integrate abstract concepts into a unified theory and requires a certain level of theoretical knowledge, however, reading relevant theoretical literature is discouraged; and the denseness of the theoretical data can be difficult for the reader to absorb (Wells, 1995). There is also some debate around the value of generating middle-range theories which only apply to a limited context, with some researchers saying this fragments knowledge (Wells, 1995). While others argue they these theories are important to develop our understanding, bridging a gap between empirical research and formal theory which is more general in nature (Kaidesoja, 2019). I support the latter perspective. Nevertheless, increasing generalisability by continuing to explore theoretical understanding and testing in other contexts is important and can increase the utility of a middle-range theory.

A comment on the relative advantages of the different approaches to grounded theory is warranted given the comparison with the constructivist theory developed by Alloh et al., which addressed a similar substantive area (Alloh et al., 2019a). The constructivist grounded theory approach used by Alloh has advantages, perhaps, over classic grounded theory in that it is a less rigid approach which encourages the development of a storyline to bring together all the different concepts in the data loosely surrounding the phenomenon in question. I personally found, however, that the lack of explicit instruction became a challenge to developing a practical parsimonious theory.
The classic approach, on the other hand, is well-defined and promotes the discipline of identifying the main concern from participants and selectively coding only the behaviour that resolves the main concern to generate a tight theory. However, this meant that more distal influencers such as psychosocial challenge were relegated to the category of “context” with minimal involvement in the theory. This does belie the importance of these factors in framing behaviour, which is why I took the decision to present the descriptive data of the social context as a stand-alone chapter in my thesis. Also, there may be more than one theory in the data, but only the most prominent is developed. For example, my analysis did not fully explore the challenges surrounding maintenance of self-management as these issues were presented with less prominence by the participants. Advantages in the classic approach, however, include the coding discipline supporting the emergence of patterns in the data, for example allowing me to identify the behaviour typologies which are useful in elucidating the diversity in the data. The resulting theory Integrating Perspectives is relatively concise and has practical value for identifying practical steps that can be addressed to help improve outcomes for participants.

4.3.1.2 COM-B and the behaviour change wheel

The behaviour change wheel and COM-B frameworks were accessible and facilitated the application of theoretical constructs to the mechanisms of change. Use of this kind of framework has the potential to be helpful for the health promotional designer uninitiated to behaviour change theory as it simplifies the complexity of health behaviour and behaviour change theory in favour of a step-by-step methodology to guide intervention development. The framework helped to identify a range of BCTs which translated into acceptable intervention components and appeared to support change effectively as intended. Lifestyle-related health behaviour change is, however, by its nature complex, being enacted by the individual embedded within a social and physical environment which also may exert strong influences. The COM-B analysis therefore unsurprisingly identifies many barriers to change. I found it gave little support in highlighting which of these determinants should be prioritised as the key causal antecedents of behaviour; the addition of the grounded theory helped to
facilitate understanding the key factors influencing behaviour. Secondly, the menu of BCTs provided in the taxonomy is large and the theory underpinning each is not provided in the behaviour change wheel taxonomy, creating a “leap of faith” scenario that the techniques chosen will directly instigate change in the target determinant. It has been argued that a taxonomy created to categorise and code interventions, such as the V1.0 taxonomy used here (Michie et al., 2013), fulfils different objectives to a taxonomy created to support intervention design. The former aims to create “clear mutually exclusive definitions for reliable coding” whilst, in reality, BCTs from different theories overlap and encompass each other. Detail on the parameters for action - the conditions under which theory-based BCTs are effective - are also necessary in creating a toolbox for intervention designers, so they can ensure the conditions for effectiveness are met (Kok et al. 2015). For example, the parameter for the BCT action planning to be effective is that there is an existing positive intention to perform the behaviour, limiting its likely effectiveness until intention is addressed by other BCTs (Bartholomew et al., 2016). Finally, the behaviour change wheel framework does not give specific guidance on translating BCTs into specific applications or intervention components. Other qualitative data beyond the learning achieved in the COM-B analysis was necessary to design appropriate components. In complex interventions, in which multiple BCTs are targeting multiple determinants, it is possible for detail of the theoretical underpinnings and preservation of key parameters to be lost in the process of translating the BCTs into components.

4.3.1.3 Combining deductive and inductive approaches

Understanding the lived experience of self-management from the participant perspective using grounded theory methods facilitated a wide consideration of factors which individuals considered to be priorities. The approach to building theory then allowed me to consider how these factors influenced behaviour across the participants. In this way I was able to identify the role misalignment played in influencing self-management behaviour self-management behaviour, with cultural affiliation, health knowledge and trust being important predictive factors within the model. The grounded theory approach also meant that more peripheral factors were
captured within the analysis and facilitated understanding of wider social constructs, such as spirituality and connectedness, which is an important part of developing deep structure sensitivity to improve cultural saliency of interventions (Resnicow et al., 1999). Whilst constructs such as spirituality, valued social support and the importance of faith networks as trusted sources of health knowledge, identified as part of the category Connectedness, were distal factors in terms of influencing engagement in a particular behaviour. This important ecological understanding is a central part of what Resnicow et al., (1999) determined as deep structural sensitivity (see section 1.3.2) and these factors are important improve cultural salience by helping to shape messaging, determining the nature of intervention components, and identifying appropriate settings for interventions. The COM-B approach, on the other hand, is the application of a deductive framework to a well-specified behaviour. The framework was successful in identifying key determinants of certain specific behaviours and mapping these theoretical constructs to BCTs which were effective and acceptable. There was much overlap between the two methods in the identification of key determinants of behaviour. Some of the rich data described above, however, would not have been captured if the COM-B framework alone had been used. The COM-B approach suggests a consideration of the system in which the behaviour occurs (Michie et al., 2014), however, because of the strict focus on an individual specified behaviour the methodology does not easily capture wider socio-ecological constructs not specific to the behaviour in question. This is a fundamental challenge for individuals designing lifestyle behaviour change interventions, as most lifestyle behaviour is influenced significantly by wider social factors. Despite the acknowledged importance of social factors, behaviour change theory largely focuses on the psychology of the individual. COM-B and the behaviour change wheel have been developed to consolidate 19 behaviour change theories, including several social theories such as social cognitive theory and social learning theory, yet in my experience the approach was less successful at capturing some of the wider social influences. Having used two methods to explore behaviour, I consider that the findings are far richer and more helpful because of the combination of the two approaches. Furthermore, the wider ecological
understanding from the grounded theory helped prioritise the choice of BCTs, for example highlighting the relative importance of factors such as cultural identity.

The focus on behaviour change at an individual level facilitated by the behaviour change wheel, does have potential to miss wider socioecological factors which would be evident if a more ecological approach were taken. Having done this analysis I recommend that in developing culturally tailored interventions COM-B and the behaviour change wheel are used together with a wider inductive methodology to identify deep structures. Grounded theory worked well in combination as it helped elucidate these wider social factors, facilitated understanding of which of the COM-B findings were the most pertinent determinants of behaviour to address and most importantly gave a deeper understanding of the values and social structures that would help improve saliency for these groups. Combining the two approaches to analysis also provided the opportunity to consider how the determinants of behaviour differed across the different behaviour typologies identified in the grounded theory analysis. This understanding may help to inform targeting of interventions towards different sub-groups within these communities.

4.3.2 Engaging communities in the research process

Engaging members of minority ethnicities in medical research in the European and US contexts has been identified as challenging (Hussain-Gambles et al., 2004). Data from the Wellcome Trust indicate that in the UK those from minority ethnic groups were 87% less likely to participate in medical research than White British, with willingness to participate being higher amongst those in managerial and professional roles (Beach et al., 2005). These studies would suggest potential challenges for this study of recruiting an inclusive sample from Black communities in deprived London Boroughs. In fact, recruitment was relatively easy, but required time to build relationships. I would suggest therefore, that it is not appropriate, nor helpful, to label minority ethnic groups as hard to reach. It is in fact the case that people need to be approached in a manner that is culturally appropriate and that builds trust, and that includes encompassing community groups and ensuring that the research is giving back to the
community. This is particularly the case for Black populations, which have been unethically treated in medical research historically (Reverby, 2001) and for whom racism and discrimination within the medical setting are particularly apparent (Kapadia et al., 2022).

There were some key learning points during the process of recruitment which are pertinent to record. As KCL is well-placed centrally in Southwark it does have an existing reputation within local communities for research. For the Phase I focus groups, recruitment was enhanced by approaching those who had taken part in the large SOUL-D study and had agreed to be contacted for further relevant research (Winkley et al., 2013). Given the desire to access as wide a diversity as possible it was also necessary to build relationships within the communities. Working with advocates was an important part of my success in doing this. Once introduced via an advocate to mosques in the area, for example, I was given the opportunity to present the study and engage individuals during a religious service. This would have been much more difficult without advocate support. Even so, as a female researcher and female advocate, we were both barred from interacting directly with men in the mosque setting, so also had to liaise closely with the Imam and other leaders to facilitate the collection of contact information from the male participants. Having gone through this process subsequent engagement was more straightforward within this setting. Recruiting Caribbean men was a particular challenge and again working with an advocate (a male in this case) in the Black majority church setting was pivotal in accessing this group. Building these trusted relationships, however, took a considerable investment of time. This meant that recruitment began slowly, and the initial groups were smaller than intended. It then began to accelerate at the point I needed to finish, meaning a few individuals who wanted to take part in discussions could not. Ethical approval also took much longer than predicted due to NHS procedures, preventing early discussion of the study in local communities. Building in more time to develop relationships would have been helpful. Using focus groups and holding some in the faith setting was successful in securing involvement of individuals with a range of levels of health literacy and integration into
UK society. This was valuable to the credibility and representativeness of the data. I also feel that holding a discussion group, as opposed to one-to-one interviews, encouraged participation amongst those who may have been less trusting of research. This was particularly true in the faith settings when participants got the confidence to engage, as they knew one another. Phase II recruitment focused more on recruitment from the primary care pathways. While recruitment was successful, use of the primary care channels as well as recruitment being to a clinical trial meant that the second cohort of participants tended to be more health literate with a greater willingness to engage in medical research. The combination of both Phase I and Phase II cohorts add to the strength of the analysis.

4.3.3 Quality and rigour

The procedures put in place to ensure the study was undertaken rigorously are discussed in detail in the methods section 2.2. In this respect the fact that my PhD study was nested within a large funded study meant that I benefited from having structures in place not normally afforded to a PhD study. This was particular the case as far as credibility is concerned, as there were many triangulation procedures adopted. Having data collected at multiple points from the same individual was useful as it allowed the opportunity to revisit and clarify some points and because the study had a participant steering group there was an opportunity to seek clarity and confirm findings. I found the triangulation between qualitative methods to be interesting and valuable. This group of participants really enjoyed the interaction of the focus groups. The groups were very humorous and warm, and the discussion was frank, in a way that the interviews did not achieve. Furthermore, it was possible to engage participants who may not normally get involved in research, in community settings, such as the mosque because the groups were seen as an informal chat. On the other hand, the interviews were nested in the feasibility trial, so those participants were more medically literate but added less insight into the more culturally situated beliefs. In the private one-to-one context, however, they were open to discussing personal life challenges in a way that was less evident in the groups. So, the two methods complemented each other. Having data from other stakeholders (community leaders
and healthcare professionals) was useful to provide insight into the diversity in the community, for example highlighting that faith in natural remedies, supernatural beliefs about diabetes and detachment from the diabetes diagnosis may be more common in the community than the data suggest. The peer review data sessions were also helpful to ensure credibility, especially as one of my supervisors was able to discuss first-hand perceptions of the data, having co-facilitated the initial focus groups. The rigidity of the grounded theory method enhances dependability, particularly with the process of memo writing to record key decisions. I really valued the concept-indicator model for building up concepts in the data and have confidence that there is high dependability in the analysis. I do think the norm of reporting classic grounded theory with little data reduces confirmability and I tried to ensure others could confirm my findings by choosing to illustrate the findings fully with participant quotes. I sought expertise and oversight from both a COM-B specialist and a grounded theory mentor to ensure the methods were correctly applied. I also attended a UCL summer school on COM-B and a grounded theory seminar. Overall, I think procedures ensured the study was conducted with adequate rigour.

4.3.4 Representativeness of the sample

The decision to include Black African and Black Caribbean participants can be seen as both a strength and weakness of this analysis. There is much diversity within UK Black communities and inevitably considering how to collectively support a more diverse group of individuals may limit how tailored and culturally sensitive the findings are. Kreuter et al. (2003), have written extensively on cultural tailoring in healthcare and they note that while detailed understanding of the heterogeneity within the populations can enhance sensitivity, it is important to balance this with reflection on how efficiently the findings can be applied in the public health context. In this regard there is therefore value in structuring the research design to compare the findings across the two ethnicities and across genders to find common constructs, which may be practically applied in a healthcare setting. Guidance on developing culturally sensitive support, suggests that heterogeneity within a sample is assessed and that adaptations are made to interventions at a sub-level (Liu et al., 2012). For example,
this would include ensuring that whatever geographical origins of intervention participants, their cultural foods were represented within the general knowledge provision.

I made considerable effort to engage a diverse range of participants and recruitment achieved an adequate spread of educational attainment. As discussed above, the demographic profile of the interview participants and focus group participants was slightly different, certainly the interview participants alone would not have provided the cultural depth that was evident from the focus group discussions. Triangulation with community leaders added further depth and suggests that there is more disengagement with diabetes advice than was evident in my analysis; the detachment behaviour typology, for example, was identified in the analysis but there were too few of these individuals to make meaningful conclusions. This suggests those with less faith in biomedical approaches were under-represented.

4.3.5 Challenges & limitations

The limitations of the study primarily relate to the research design adopted, much of which was dictated by the fact that this PhD was nested within an NIHR funded medical study, which shaped some of the methodological choices. I will also briefly discuss the potential influence of ethnicity differences between researcher and participant.

With a focus on implementation in the healthcare setting it was important that the findings had practical utility in the real-world setting. Researchers such as Kreuter highlight that when designing for healthcare it is a pragmatic decision about the degree of granularity that is practical – picking out the common things that individuals recognise and identify with, even though they will do so differently (Kreuter et al., 2003). Therefore, despite recognising that there is considerable cultural diversity within and between communities of Black African and Black Caribbean heritage, my study investigates diabetes-related health behaviour across these groups to explore where there are synergies and differences. Whilst there was never an intention to treat these groups as homogeneous, it is likely that the resulting conclusions do so to a
degree, compared to focusing on groups from specific geographical areas and cultural background for example. It is encouraging however, that synergies are evident with studies that have treated these population groups separately (Alloh et al., 2019a, Brown et al., Scott, 2001). Exploring behaviour patterns evident across the data, highlights common challenges that transcend ethnic groupings, such as the poor provision of culturally appropriate dietary information and failure to acknowledge and understand personal diabetes experiences and knowledge. These present important intervention points to improve care generally, for these groups. Adaptations can then be introduced to address heterogeneity at a sub-level within interventions, such as in the development of culture-specific dietary resources.

The structure of the HEAL-D data collection was governed by the funding requirements. This meant that focus groups were used for much of the primary data collection, whilst it is most common in grounded theory studies to use interviews. The suitability of the focus groups for grounded theory analysis was considered as the initial data were collected, the prerequisites being that the personal descriptions gave enough depth to the analysis to allow the patterns of behaviour to be identified and the development of a parsimonious theory. On reflection, I feel that the combined use of focus groups and interviews was appropriate for the needs of this study. There was considerable value added by the group discussion in terms of generating free and natural expression of subjects which may have not been so forthcoming on a one-to-one basis. Developing trust was important both in achieving recruitment engagement and facilitating honest and open discussion. I felt that the focus group methodology was particularly valuable in this regard, enhancing feelings of security for the participants and creating a relaxed setting enabled the engagement of a diverse group of participants who otherwise may have been reticent to engage in research. Additionally, theoretical sampling was guided by the need in HEAL-D for the phase II interviews to be representative of participants, limiting my ability to sample for diversity to develop the theory. In this case the interviews were analysed individually to develop the theory and further fieldwork was not considered necessary as each of the key categories was considered
saturated. This approach was pragmatic, but it is possible that had theoretical sampling been expanded to include a wider diversity of individuals, further depth could have been added to the theory.

Whilst the findings highlight the influence of both trust in the healthcare interaction as well as wider social and environmental pressures, the focus of the data collection in this study was primarily centred on health behaviour. Further research would be necessary to fully elucidate the impact of these factors. In addition, adopting an intersectional approach in the design of the study could have added more depth to the findings.

Considering the transferability of the findings more widely in the context of the dynamic nature of cultural influences and the fluidity with which acculturating factors influence health behaviour, it is also important to note that the findings largely relate to first generation Black African and Caribbean adults. From a public health perspective the cultural influences on beliefs and habits within the population are likely to shift over time, as the number of people emigrating from the African continent to the UK continue to grow and those from the Caribbean decline. This is commonly recognised as a challenge of designing culturally sensitive care, and as researchers such as Liu et al., point out, it is important to acknowledge shifting characteristics, trends and patterns and revise interventions to maintain relevancy (Liu et al., 2012).

Finally, I would like to reflect upon the impact of my healthcare role and White ethnicity on the knowledge generated from this study. The contribution of ethnic concordance within the research-participant relationship is much debated. While it may help recruitment, ethnic concordance may not negate the influence of other facets of social identification, such as age, class, education, roles according to Fryer et al. (2016). In fact, Fryer et al. suggest that the primary factors in building research relationships were reflecting values of the community, trustworthiness, actively listening, expressing empathy, reciprocity, transparency, and humility, rather than
DISCUSSION

General Discussion - Conclusions

I made effort to develop rapport with participants to mitigate barriers created by my ethnicity and healthcare role. Certainly, by the time the final data collection was done I had interacted with some individuals over the three-year period of the study, so had formed a trusting bond. I was invited into the homes of several of these participants to conduct the final interviews, highlighting the level of trust. Shared gender and being a similar age helped create a shared bond with the women in the sample. Where possible I tried to minimise barriers, such as in the choice of community venues, wearing casual clothes and creating a relaxed friendly atmosphere. Nevertheless, it is possible that being of White ethnicity and been seen in the role of healthcare may have acted as a barrier to a freely open dialogue for some participants. Certainly, the data do suggest some reticence of expression about views about healthcare and doctors, with participants often referring to disengagement with doctors in the third person. Triangulation with the community leader data suggested a reluctance to seek help from healthcare was more common in the general community than was found in my analysis. This reflects other studies from the UK context that highlight distrust of doctors and diabetes-related healthcare more explicitly than my data indicated (Brown et al., 2007, Scott, 1998).

4.4 Conclusions

4.4.1 What are the implications of the findings?

4.4.1.1 Implications for Black African and Caribbean communities

These findings can contribute to policy and practice to improve equity of access to diabetes-related healthcare for people of Black African and Caribbean heritage.

- Specifically, the findings highlight that for those that are not reached by the current healthcare support, situating interventions in faith and community settings, involving credible role models is likely to improve engagement.
- Within the healthcare setting and the current structured education, the need to provide carbohydrate portion guidance pertinent to the cultural diet is highlighted. Even second-generation individuals, born in the UK, wanted advice
pertinent to their traditional diet. The evaluation of the data from the HEAL-D trial in this thesis, highlighted how empowered people felt when they were given the dietary tools they needed. Given that dietary resources were developed in HEAL-D in partnership with Carbs and Cals (Mehar et al., 2019), these resources can be made readily available as well as being incorporated into future interventions and culturally salient interventions for diabetes. In addition, the findings highlight that many were excluded from attending structured education because of their socioeconomic position and the type of jobs they held and suggest flexibility of sessions would be warranted.

- The findings highlight the theoretical constructs that may be effective to underpin lifestyle intervention design for this target population – namely participatory learning, social support and social comparison, use of role models and credible sources, and information about health consequences. These mediate change in outcome beliefs, self-efficacy, and identity beliefs. Similar BCTs may also be useful for diabetes prevention and other lifestyle interventions targeting UK African and Caribbean populations in the urban context.

- There may also be transferability of these findings to other sectors of these communities – such as pregnant and post-natal women to reduce risk of gestational diabetes and subsequent T2D. However, because of the different age demographic it would be necessary to do some further formative evaluation to assess relevancy and what adaptations needed to be made.

- The issue of maintaining relevancy, previously mentioned, is pertinent to highlight, as the population demographics shift amongst UK Black African and Caribbean communities, with young African immigrants making up an increasingly larger percentage of the British Black population. Recommendations from the Liu et al., RESET tools would suggest that interventions designed from these findings are revised depending on shifting patterns, characteristics, and trends within the population, to maintain relevancy (Liu et al., 2012).
• From a policy point of view, the findings present concrete suggestions for healthcare providers to improve trust and engagement with their Black patients living with T2D.

4.4.1.2 Clinical implications

• The current self-management education provision is not meeting the needs of Black communities. Most individuals were motivated to manage their diabetes but there is an urgent need for the provision to include scientifically reliable guidance that addresses cultural diets, of different groups, for them to be able to follow guidance.

• The data highlight relationship building, empathetic communication and person-centred care are both particularly valued and effective in supporting engagement with self-management guidance. It is important that clinicians recognise that first-generation immigrants are likely to hold illness representations that differ from the medical perspective. Taking measures to explore these experiences and beliefs, alongside diagnosis may prevent disengagement with recommendations and sourcing of alternative advice.

• There are parts of this target group that are unlikely to be well-served by interventions within the current care pathway. Developing community-clinician partnerships and situating self-management education within a community context, offers potential to reach and support those with less trust and faith in healthcare.

• The findings also highlight persistent inequities socially and within the NHS care provision, which need to be addressed at a policy level.

4.4.1.3 Design of culturally salient interventions

My findings indicate that there is advantage in employing inductive methods, alongside a behaviour change framework when developing culturally salient interventions. An inductive approach facilitates a wider exploration of behaviour and of other social influences, such as cultural constructs. Responding to these wider cultural constructs is necessary to improve cultural saliency of interventions.
The COM-B and behaviour change wheel analysis was appropriate and successful in identifying culturally acceptable BCTs to support self-management behaviour change for UK African and Caribbean adults at the individual level. BCTs to engage credible sources, build social support and develop learning in a participatory way were identified and proved to be effective.

4.4.2 Future research

There are several avenues suggested for the next stages of this research. These focus on translating these findings into targeted culturally salient interventions.

- The first is using this theoretical understanding to develop T2D interventions to support the groups with the traditionalist and detachment behaviour patterns, who were less likely to find salience in the current healthcare offering. This includes developing and evaluating interventions to support positive diagnosis, and to offer self-management education in trusted community settings, such as faith institutions.

- The second is to consider how these findings can be incorporated into diabetes prevention initiatives for Black communities.

- Finally, the findings may inform diabetes interventions at other stages in the life course. In particular, gestational diabetes (GDM) is highlighted as a key potential point of intervention to reduce diabetes prevalence in Black communities. Black women are six times more likely to enter pregnancy obese than white women, the rate of GDM is 5-8% (compared to 2% in White women) and 40% of those who develop GDM will progress to T2D within 5 years (Maitland et al., 2014, Kim et al., 2002, Nishikawa et al., 2017, Chu et al., 2009). Intervening either to reduce GDM or to target those who have GDM to reduce their risk of developing T2D, should be further explored.

In terms of the need for wider research, the findings highlight certain areas where further research is warranted:
- There is urgent need to communicate and further explore glycaemic load of cultural carbohydrates consumed traditionally in Black communities, to provide clinicians with robust guidance to make salient dietary recommendations for those following traditional diets.
- Given the current climate of evident discrimination against minority ethnic groups in the NHS (Kapadia et al., 2022), it is important to explore further how trust can be improved for some individuals living with diabetes. This is particularly urgent given the move towards use of apps and online record-keeping for diabetes patients given there is evidence that, due to lack of trust, those of Black ethnicity are less likely to use these digital platforms (Diabetes UK, 2021b).

4.4.3 Dissemination plans

To date the COM-B analysis and some of the grounded theory analysis has been published (Moore et al., 2019, Moore et al., 2022). Two more academic publications are planned. The first, an evaluation of COM-B and BCTs identified and the second, describing intervention opportunities from the behaviour pattern typologies and the identified Integrating Perspectives process. The opportunity to present the findings have been severely limited due to COVID and it is intended that the content of these papers will also be presented at academic conference in 2022/23. A monograph of the grounded theory is also being considered.

With regards to dissemination within the community, I am working on an ongoing basis with several community groups, to help disseminate the findings. For example, I am a regular speaker at health events with the Muslim Association of Nigeria and Black majority church leaders (via the charity Food for Purpose). I also sit on the research advisory group for South London charity which is developing community capacity to attract research funding for targeted, community driven interventions. The Let’s Talk Sugar! initiative was an early dissemination activity based on preliminary findings from this analysis, which showed how children could act as credible sources, to shift intention to engage with positive lifestyle change to reduce risk and manage existing
diabetes. This was an art/science collaboration, and I was funded by the KCL Cultural Institute to work with artist The Fandangoe Kid (www.fandangoekid.com). The initiative won the KCL Cultural Institute Early Career Researcher award for impact.

4.5 General conclusion

My thesis explores how to support engagement with self-management behaviours for T2D amongst diverse Black African and Caribbean adults, in an inner-city London setting. The thesis offers novelty around the development of theoretical understanding of the population sub-groups that are important to target, what time points in the patient journey present intervention opportunity, and the identification of culturally appropriate BCTs to form the basis of intervention. It identifies sociocultural factors that can be incorporated in intervention design and delivery, to improve cultural salience. Original findings also suggest ways that the healthcare provider-patient therapeutic alliance may be improved.


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### 6.1 Key studies

Table 6-1: Studies exploring diabetes self-management practices and perceptions in UK Black African and Caribbean adults

<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Population</th>
<th>Country</th>
<th>Methodology</th>
<th>Focus</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abubakari et al., 2013</td>
<td>n=359 White, BA, BC</td>
<td>UK</td>
<td>Survey</td>
<td>Knowledge and illness perceptions</td>
</tr>
<tr>
<td>Alloh et al., (2019)</td>
<td>n=34 West African</td>
<td>UK</td>
<td>Interviews</td>
<td>Lived experience</td>
</tr>
<tr>
<td>Alloh et al., (2021)</td>
<td>n=34</td>
<td>UK</td>
<td>Interviews</td>
<td>Diagnosis</td>
</tr>
<tr>
<td>Brown et al., (2007)</td>
<td>n=16 BC</td>
<td>UK</td>
<td>Interviews</td>
<td>Lived experience</td>
</tr>
<tr>
<td>De-graft Aikins et al., (2019)</td>
<td>n=180 Ghanaian</td>
<td>London, Amsterdam and Berlin</td>
<td>Focus groups</td>
<td>Explore knowledge about T2D</td>
</tr>
<tr>
<td>Goff et al., (2020)</td>
<td>n=11 HCP</td>
<td>UK</td>
<td>Interviews</td>
<td>Service provision</td>
</tr>
<tr>
<td>Harrison (2014)</td>
<td>All BME</td>
<td>UK</td>
<td>Narrative review</td>
<td>Health beliefs</td>
</tr>
<tr>
<td>Noakes (2010)</td>
<td>n=24 (BA and BC)</td>
<td>UK</td>
<td>Focus groups (x2)</td>
<td>Insulin treatment</td>
</tr>
<tr>
<td>Omodara et al., (2020)</td>
<td>n= 36 sub-Saharan immigrants</td>
<td>UK</td>
<td>Interviews</td>
<td>Explore diabetes-related health beliefs</td>
</tr>
<tr>
<td>Scott (1997)</td>
<td>n=37 12 BC 12 White</td>
<td>UK</td>
<td>Interviews</td>
<td>Diet &amp; culture</td>
</tr>
<tr>
<td>Scott (1998)</td>
<td>n=24 White &amp; BC patients n=13 HCP</td>
<td>UK</td>
<td>Interviews</td>
<td>Self-management</td>
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*BC Black Caribbean BA Black African SS sub-Saharan HCP health care professional*
6.2 Theoretical models

The following health behaviour models are referred to in the text.

Figure 6-1: Theory of Planned Behaviour. Modified from Ajzen (2011).

Figure 6-2: The common-sense model. Modified from Leventhal et al., (1992)
6.3 Study sample characteristics

Table 6-2: Participant characteristics (Focus group 1 dataset n = 41)

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*Living alone and benefits calculated for a sub-sample only; ** Missing data for 1 participant; N/C not collected
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*Living alone and benefits calculated for a sub-sample only; ** Missing data for 1 participant
Table 6-4: Participant characteristics (focus groups Phase II n = 20)

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**Table 6-5: Details of individual participants including the unique identifier**

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<th>Age</th>
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## 6.4 Behavioural analysis

### Table 6-6: BCT mapping for daily medication

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<td>Understand that in order to support diabetes medication is needed everyday.</td>
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<td>Understand the how medication helps reduce complications</td>
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<td>Feel confident to have tests and take insulin if needed.</td>
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</tr>
<tr>
<td>Lack of knowledge of specifics of guidelines, rationale behind them and how to meet them</td>
<td>State what the guidelines are, why intensity and frequency are important and how that impacts on blood glucose.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Information on health consequences (E) Instruction on how to perform behaviour (T)</td>
</tr>
<tr>
<td>Other competing priorities and tiredness</td>
<td>Prioritise physical activity over other activities, overcome tiredness.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Feedback on outcome of behaviour (E) Self-monitoring of Behaviour (E) Goal setting (behaviour) (E) Action planning (En)</td>
</tr>
<tr>
<td>Normative influences not supporting purposeful activity</td>
<td>Express confidence that it is socially acceptable to engage.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Social support - unspecified (En) Restructure social environment (En)</td>
</tr>
<tr>
<td>Lack of affordable, safe accessible facilities</td>
<td>Choose activity that is safe, affordable and accessible</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Social support - unspecified (En) Restructure physical environment (En)</td>
</tr>
<tr>
<td>Low self-belief in personal ability to follow guidelines (due to mobility issues primarily)</td>
<td>Express confidence in ability to follow guidance.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Credible sources (P) Social support - unspecified (En) Info about health consequences (P, E) Demonstration of behaviour (M)</td>
</tr>
<tr>
<td>Not feeling purposeful activity is aligned with cultural identity</td>
<td>Recognise that respected others follow guidance.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Credible sources (P) Info about health consequences (P, E) Identification of self as role model (P) Social support - unspecified (En)</td>
</tr>
<tr>
<td>Don’t believe that engagement in activity will reduce blood glucose (or medication)</td>
<td>Be able to explain how activity impacts on blood glucose and medication use.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Info about health consequences (P, E) Salience of health consequences (P, En) Credible sources (P) Social support (P)</td>
</tr>
<tr>
<td>Not an intention to meet the guidelines</td>
<td>Make it a goal to do 30 mins MVPA pd</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Social support - unspecified (En) Goal setting (En) Action planning (En)</td>
</tr>
<tr>
<td>Fear of injury or other poor outcome</td>
<td>Recognise that the guidelines can be followed safely</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Demonstration of behaviour (M) Social support - unspecified (En) Credible sources (P)</td>
</tr>
</tbody>
</table>
### Table 6-8: BCT mapping for dietary change

<table>
<thead>
<tr>
<th>Identified determinants of behaviour</th>
<th>Outcome objectives</th>
<th>Educate</th>
<th>Enable</th>
<th>Train</th>
<th>Model</th>
<th>Persuade</th>
<th>Identified potential BCTs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unable to accurately identify which traditional foods are carbs and the appropriate portion size. TDF: knowledge</td>
<td>Be able to state how carb guidelines relate traditional starches and natural sugars. Be able to state what carb portion size is appropriate. Understand what fats are helpful/harmful and what foods contain them. Be able to identify high salt foods (including traditional)</td>
<td><img src="https://via.placeholder.com/15" alt="" /></td>
<td><img src="https://via.placeholder.com/15" alt="" /></td>
<td><img src="https://via.placeholder.com/15" alt="" /></td>
<td><img src="https://via.placeholder.com/15" alt="" /></td>
<td><img src="https://via.placeholder.com/15" alt="" /></td>
<td>Information on health consequences (E)</td>
</tr>
</tbody>
</table>
### Table 6-9: BCT mapping for measuring waist circumference

<table>
<thead>
<tr>
<th>Identified determinants of behaviour (TDF Domain)</th>
<th>Outcome objectives</th>
<th>Educate</th>
<th>Enable</th>
<th>Train</th>
<th>Model</th>
<th>Persuade</th>
<th>Identified BCTs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not practised at measuring waist. (TDF: Skill)</td>
<td>Know how to measure waist.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Instruction on how to perform behaviour (T) Demonstration of behaviour (T)</td>
</tr>
<tr>
<td>Unsure of what waist circumference indicates risk, (TDF: Knowledge)</td>
<td>Be able to identify whether personally at risk of abdominal obesity.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Information on health consequences (E) Self-monitoring of behaviour (E) Feedback on outcomes of behaviour E</td>
</tr>
<tr>
<td>Waiver in attention given to weight, (TDF: Memory, attention; Behaviour regulation)</td>
<td>Check waist circumference each month.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Action planning (En) Goal setting (En)</td>
</tr>
<tr>
<td>Social pressure not to lose weight. (TDF: social opportunity)</td>
<td>Be able to resist social pressure.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Social support (unspecified) (E) Problem solving (En)</td>
</tr>
<tr>
<td>Do not own tape measure. (TDF: Environment, context, resources)</td>
<td>Have a tape measure at home.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Restructure physical environment (En)</td>
</tr>
<tr>
<td>Belief that larger shape associated with health and prosperity (TDF: Identity)</td>
<td>Recognise that respected others engage in weight management. Hold belief that it is beneficial to reduce abdominal obesity.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Credible sources (P) Social comparison (En) Social support - unspecified (En) Identify self as role model (En)</td>
</tr>
<tr>
<td>Low belief in own ability to lose weight. (women) (TDF: Belief in capability)</td>
<td>Feel confident in own ability to meet the waist circumference targets.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Problem solving (En) Information about health consequences (P) Action planning (En) Social support - unspecified (En) Feedback on outcomes of behaviour (E, P, T)</td>
</tr>
</tbody>
</table>
### Table 6-10: Detailed description of potential BCTs

<table>
<thead>
<tr>
<th>Identified BCT</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Action planning</td>
<td>Prompt detailed planning of performance of the behaviour (at least one of context, frequency, duration and intensity).</td>
</tr>
<tr>
<td>Credible sources</td>
<td>Present verbal or visual communication from a credible source in favour or against the behaviour.</td>
</tr>
<tr>
<td>Demonstration of the behaviour</td>
<td>Provide observable example of the performance of the behaviour, directly in person or indirectly via film, or pictures. Includes Modelling.</td>
</tr>
<tr>
<td>Feedback on outcomes of behaviour</td>
<td>Monitor and provide feedback on the outcome of performance of the behaviour.</td>
</tr>
<tr>
<td>Goal setting – behaviour</td>
<td>Set or agree a goal defined in behavioural terms.</td>
</tr>
<tr>
<td>Graded tasks</td>
<td>Set easy to perform tasks, making them increasingly difficult but achievable until behaviour is performed.</td>
</tr>
<tr>
<td>Habit formation</td>
<td>Prompt rehearsal and repetition of the behaviour in the same context repeatedly, so that the context elicits the behaviour.</td>
</tr>
<tr>
<td>Information on health consequences</td>
<td>Provide information (written, verbal visual) about health consequences of performing the behaviour.</td>
</tr>
<tr>
<td>Instruction on how to perform the behaviour</td>
<td>Advise or agree on how to perform the behaviour (including skills training).</td>
</tr>
<tr>
<td>Problem solving</td>
<td>Analyse or prompt the person to analyse factors influencing the behaviour and select strategies to overcome barriers.</td>
</tr>
<tr>
<td>Adding objects to the physical environment</td>
<td>Add objects to the environment to facilitate the behaviour.</td>
</tr>
<tr>
<td>Salience of health consequences</td>
<td>Use methods specifically designed to emphasise to consequences of performing the behaviour with the aim of making them more memorable. (Goes beyond informing about consequences).</td>
</tr>
<tr>
<td>Identification of self as role model</td>
<td>Inform that one’s own behaviour may be an example to others.</td>
</tr>
<tr>
<td>Self-monitoring of behaviour</td>
<td>Establish a method for the person to monitor and record their behaviour as part of the behaviour change strategy. (For outcome of behaviour the same except monitoring the outcome)</td>
</tr>
<tr>
<td>Social comparison</td>
<td>Draw attention to others’ performance to allow comparisons with person’s own performance.</td>
</tr>
<tr>
<td>Social support - unspecified</td>
<td>Advise or provide social support (from peers, friends, family etc).</td>
</tr>
</tbody>
</table>
### 6.5 The lens of intersectionality

#### Table 6-11: Intersectionality framework

<table>
<thead>
<tr>
<th>Recruitment</th>
<th>Ground theory analysis</th>
<th>Behaviour analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Taking it in</strong></td>
<td><strong>Finding a sense of knowing</strong></td>
<td><strong>Choosing a path</strong></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cultural constructions around gender contributing to men being more reluctant to talk about their health, and particularly difficult to recruit to a discussion group. Successful strategies highlighted the role of trusted male advocates from within the community.</td>
<td>Male pride was a key part of the social construction of gender amongst both African and Caribbean men. The vulnerability associated with the diabetes, therefore seemed to shock men more and this good lead to denial.</td>
<td>Those of the Traditionalist type sought information from the community. Because many of the men were stoic and reluctant to talk about their health, this limited access to shared community knowledge.</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No obvious impact on recruitment</td>
<td>The accounts from the older participants suggested a particularly difficult diagnosis experience, with little self-management information given. The data suggested the healthcare practitioners assumed older patients would not make any dietary changes, therefore did not offer it.</td>
<td>All participants engaged in information seeking to help fill gaps in healthcare guidance. Older participants showed reluctance to use online sources, which limited</td>
</tr>
<tr>
<td>Recruitment</td>
<td><strong>Ground theory analysis</strong></td>
<td>Behaviour analysis</td>
</tr>
<tr>
<td>-------------</td>
<td>-----------------------------</td>
<td>--------------------</td>
</tr>
<tr>
<td><strong>Taking it in</strong></td>
<td><strong>Finding a sense of knowing</strong></td>
<td><strong>Choosing a path</strong></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More stigma was evident amongst African participants, and they generally reported taboo would prevent them speaking openly to others about their diabetes. It is not clear that this made an impact on recruitment, however, it does highlight the importance of building trust as part of the recruitment process.</td>
<td>The data suggest that the stigma associated with diabetes may be greater for the African participants. This made the diagnosis harder to absorb for some.</td>
<td>The data suggest the BCTS were appropriate across ethnicities to the same degree.</td>
</tr>
<tr>
<td>Socioeconomic position</td>
<td>Access to care was reduced for those in low skilled work. Thus, it was harder for them to attend self-management and lifestyle related classes (like weight management groups) as they were unable to take unscheduled time off work and to commit in advance to the sessions.</td>
<td>Socioeconomic pressures did impact on the focus that could be given to diabetes. Where people could, they would buy foods for diabetes that were more expensive. Costs associated with leisure facilities and gym were, however, prohibitive for some.</td>
</tr>
<tr>
<td>Working patterns and less skilled job roles had potential to limit access to engagement as it was hard to get time off work. Recruitment strategies needed to be flexible to allow participation at weekends and in the evenings.</td>
<td>Those with lower educational attainment were less likely to have good biomedical understanding of diabetes, they were therefore more likely to follow traditionist or detachment patterns of behaviour.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Recruitment

Faith settings were helpful to facilitate recruitment so attending faith institutions was helpful to improve reach. However, it was challenging for a female researcher to recruit men from the mosque. In addition, those of Muslim faith talked about the particular stigma of diabetes, which could reduce the number of people willing to step forward and engage.

### Ground theory analysis

<table>
<thead>
<tr>
<th><strong>Religion</strong></th>
<th><strong>Taking it in</strong></th>
<th><strong>Finding a sense of knowing</strong></th>
<th><strong>Choosing a path</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>The stigma associated with diabetes in the Muslim faith, made absorbing the diagnosis harder for some individuals.</td>
<td>Faith groups provided a supportive environment to learn and share knowledge in both Muslim and Christian faith settings. There was some indication that there was more stigma</td>
<td>Religious factors were likely to shape some dietary choices. In some cases, this could be positive, such as using Lent as a catalyst for change amongst those following Christian faiths. However, regular fasting could present some challenges for those following Muslim traditions. Faith in general was a positive support.</td>
</tr>
</tbody>
</table>

### Behaviour analysis

No obvious impact on BCT choices but interventions components need to be sensitive to religious differences.