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## **UNIVERSITY OF SOUTHAMPTON**

FACULTY OF HEALTH SCIENCES

# School-based Intervention to Improve Self-Management among Adolescents with Type 1 Diabetes Mellitus

By

### Raya Said Al Habsi

Thesis for the degree of Doctorate of Philosophy

July 2019

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July 2019

#### **UNIVERSITY OF SOUTHAMPTON**

#### **ABSTRACT**

### FACULTY OF HEALTH SCIENCES Thesis for the degree of Doctorate of Philosophy School-based Intervention to Improve Self-Management among Adolescents with Type 1 Diabetes Mellitus By Raya Said Al Habsi

**Background:** Type 1 diabetes mellitus (T1DM) is a long-term condition that can lead to serious complications in adolescents, due to poor metabolic control. Selfmanagement is a key component in diabetes care. However, this can be challenging in adolescence, as this period includes physical, psychosocial, and emotional strains. As with other adolescents, those with T1DM spend long hours in school. Therefore, they are expected to manage their complicated diabetes requirements while they are engaging in other school activities. Consequently, the school is a critical environment for adolescents with T1DM. Thus, school-based interventions intended to improve self-management among adolescents with T1DM should be available in a form suitable to the understanding and age-specific demands of adolescents through recognising their needs and priorities. Adolescents should have the chance to make informed decisions about their treatment and care, in cooperation with their health care specialists.

**Aim**: to develop a school-based intervention to promote self-management (i.e. physical and psychosocial management) among adolescents with T1DM aged 11 to 15 by exploring their needs and priorities regarding the intended intervention.

**Method**: exploratory, qualitative research using an applied thematic analysis, structured into four stages. In the first stage, face-to-face semi-structured interviews were conducted with 18 adolescents to gain more understanding of their needs and priorities,

in order to enhance self-management in schools. The second stage involved using the findings from the first stage to guide and shape the intended intervention. In this stage, the intervention mapping framework was used to guide the development of the intended intervention. In the third stage, health care professionals from the paediatric diabetic team were interviewed to provide recommendations about the scientific content and relevancy of the developed intervention based on the findings of the study and their expert views. Finally, data regarding the appropriateness of the developed intervention's content and materials were collected from another ten adolescents with T1DM.

**Results**: the findings of the first stage revealed how adolescents with T1DM wanted to be supported in school. They wanted their peers and teachers at school to know more about T1DM. Thematic analysis was used to identify the content of the intervention. The data collected from the first stage has identified specific information that, if known by peers and teachers, can reduce some of the physical and psychosocial challenges and consequently improve self-management among adolescents with T1DM in a school setting. The findings from the first stage were used to develop the intervention (animated video). Intervention mapping protocol was utilised to ensure a systematic and evidence-based approach for the development of the intervention. The results of the third and fourth stages of this study indicated that the developed intervention was relevant and appropriate to be used in school.

**Conclusion:** the findings of this study helped to develop well-informed evidence-based interventions, ready for pilot testing in the future, that can enhance self-management in adolescents with T1DM in school settings.

iv

## **TABLE OF CONTENTS**

| ABSTR  | АСТ II                                                                 | I |
|--------|------------------------------------------------------------------------|---|
| LIST O | F TABLESX                                                              | I |
| LIST O | F FIGURESXI                                                            | I |
| DECLA  | RATION OF AUTHORSHIP XII                                               | I |
| ACKNO  | WLEDGEMENTSXIV                                                         | 7 |
| DEFIN  | TIONSXV                                                                | 7 |
| ABBRE  | VIATIONSXVI                                                            | I |
| СНАРТ  | ER 1: INTRODUCTION & BACKGROUND                                        | 1 |
| This s | ECTION OF THE CHAPTER CONSISTS OF A BRIEF DISCUSSION OF T1DM INCIDENCE |   |
| AS WE  | LL AS AN EXAMINATION OF THE NATIONAL AND PROFESSIONAL CONTEXT AND THI  | Е |
| THESI  | OUTLINES                                                               | 1 |
| 1.1    | INCIDENCE OF T1DM                                                      | 1 |
| 1.2    | NATIONAL AND PROFESSIONAL CONTEXT                                      | 2 |
| 1.3    | CHILDREN'S INVOLVEMENT IN THEIR HEALTH CARE DECISIONS                  | 2 |
| 1.4    | THESIS LAYOUT AND CONTENTS                                             | 3 |
| 1.5    | BACKGROUND                                                             | 1 |
| 1.6    | DIABETES MELLITUS                                                      | 4 |
| 1.6.   | Classification of diabetes mellitus                                    | 4 |
| 1.6.   | 2 Type 1 diabetes mellitus (T1DM)                                      | 5 |
| 1.6.   | 3 Diagnosis of type 1 diabetes                                         | 5 |
| 1.7    | MANAGEMENT OF T1DM                                                     | 5 |
| 1.8    | Insulin Therapy                                                        | 7 |
| 1.9    | Monitoring                                                             | 3 |
| 1.9.   | Blood glucose                                                          | 8 |
| 1.9.   | 2 Urine glucose10                                                      | 9 |
| 1.9.   | 3 Glycated haemoglobin (HbA1c)10                                       | 9 |
| 1.9.   | 4 Nutrition1                                                           | 1 |
| 1.9.   | 5 Exercise                                                             | 2 |
| 1.9.   | 5 Sick day management1.                                                | 3 |

|            | 1.9. | 7 Diabetes education                                                  | 14 |
|------------|------|-----------------------------------------------------------------------|----|
|            | 1.9. | 8 Behavioural interventions                                           | 15 |
|            | 1.10 | COMPLICATIONS OF TYPE 1 DIABETES AND ASSOCIATED CONDITIONS            | 16 |
|            | 1.10 | 0.1 Short-term complications                                          | 17 |
|            | 1.10 | 0.2 Long-term complications                                           | 19 |
|            | 1.11 | Adolescents and Type 1 Diabetes Mellitus                              | 20 |
|            | 1.11 | 1.1 Physiological changes and adolescents with T1DM                   | 21 |
|            | 1.11 | 1.2 Cognitive changes and adolescents with T1DM                       | 24 |
|            | 1.11 | 1.3 Psychosocial changes in adolescents with T1DM                     | 25 |
|            | 1.11 | 1.4 Peer support and adolescents with type 1 diabetes                 | 27 |
|            | 1.11 | 1.5 Self-management and glycaemic control among adolescents with type | 1  |
|            | diał | betes 29                                                              |    |
|            | 1.12 | STRESSORS IN THE SCHOOL SETTING                                       | 31 |
|            | 1.13 | CONCLUSION                                                            | 36 |
| C          | НАРТ | TER 2: LITERATURE REVIEW                                              | 38 |
|            | 2.1  | INTRODUCTION                                                          | 38 |
|            | 2.2  | LITERATURE SEARCH                                                     | 38 |
|            | 2.2. | 1 Study selection                                                     | 40 |
|            | 2.2  | 2 Search results                                                      | 40 |
|            | 2.2  | 3 Quality assessment                                                  | 41 |
|            | 2.3  | SCHOOL-BASED INTERVENTION                                             | 43 |
|            | 2.4  | Study Justification                                                   | 56 |
|            | 2.5  | AIM OF THE STUDY                                                      | 57 |
|            | 2.6  | THE RESEARCH QUESTIONS                                                | 58 |
| <b>C</b> ] | НАРТ | TER 3: METHODOLOGICAL APPROACH                                        | 60 |
|            | 3.1  | Paradigms                                                             | 60 |
|            | 3.2  | RESEAECH WITH CHILDREN                                                | 61 |
|            | 3.3  | RESEARCH APPROACH                                                     | 64 |
|            | 3.3. | 1 Phenomenological approach                                           | 64 |
|            | 3.3. | 2 Ethnography approach                                                | 64 |
|            | 3.3. | <i>3 Grounded theory approach</i>                                     | 65 |
|            | 3.3. | 4 Applied thematic analysis                                           | 65 |

|   | 3.4   | RESEARCH DESIGN                                                 | 67 |
|---|-------|-----------------------------------------------------------------|----|
|   | 3.5   | QUALITY IN QUALITATIVE RESEARCH                                 | 68 |
|   | 3.6   | CONCEPTUAL FRAMEWORK                                            | 70 |
|   | 3.6.  | 1 The Intervention Research Framework                           | 70 |
|   | 3.6.  | 2 Medical Research Council Complex Intervention Framework       | 72 |
|   | 3.6.  | 3 The Theoretical Domains Framework                             | 73 |
|   | 3.6.  | 4 Behaviour Change Wheel                                        | 74 |
|   | 3.6.  | 5 Intervention Mapping Protocol                                 | 74 |
| C | СНАРТ | <b>TER 4: METHOD</b>                                            | 77 |
|   | 4.1   | STAGES OF THE STUDY                                             | 77 |
|   | 4.1.  | 1 Stage 1: Exploratory stage (Need Assessment)                  | 78 |
|   | 4.1.  | 2 Stage 2: Intervention development stage                       | 79 |
|   | 4.1.  | 3 Stage 3: Health care professionals' consultation              | 80 |
|   | 4.1.  | 4 Stage 4: Feedback stage                                       | 81 |
|   | 4.2   | DATA COLLECTION                                                 | 81 |
|   | 4.3   | SEMI-STRUCTURED INTERVIEWS                                      | 82 |
|   | 4.4   | The study setting                                               | 85 |
|   | 4.5   | THE STUDY SAMPLE AND RECRUITMENT                                | 85 |
|   | 4.6   | RECRUITMENT PROCESS PLAN FOR STAGE 1                            | 88 |
|   | 4.7   | RECRUITMENT PROCESS PLAN FOR STAGE 3: HEALTH CARE PROFESSIONALS | 92 |
|   | 4.8   | RECRUITMENT PROCESS PLAN FOR STAGE 4                            | 92 |
|   | 4.9   | ETHICAL CONSIDERATIONS                                          | 92 |
|   | 4.10  | THE PARTICIPANT INFORMATION SHEET                               | 94 |
|   | 4.11  | Consent                                                         | 94 |
|   | 4.12  | DATA PROTECTION                                                 | 96 |
|   | 4.13  | DATA ANALYSIS                                                   | 97 |
|   | 4.14  | FAMILIARISATION WITH THE DATA                                   | 98 |
|   | 4.15  | Coding                                                          | 98 |
|   | 4.16  | SEARCHING FOR THEMES                                            | 98 |
|   | 4.17  | REVIEWING THEMES                                                | 98 |
|   | 4.18  | DEFINING AND NAMING THEMES                                      | 99 |
|   | 4.19  | WRITING UP                                                      | 99 |

| СНАРТ | TER 5:        | FINDINGS OF STAGE 1,2,3&4                                             | 101 |
|-------|---------------|-----------------------------------------------------------------------|-----|
| 5.1   | Finding       | GS OF STAGE 1 (EXPLORATORY STAGE)                                     | 101 |
| 5.1.  | 1 Da          | ta Analysis of Semi-Structured Individual Interviews for Stage 1      | 101 |
| 5.1.  | 2 The         | e findings from the demographic data of the study sample              | 101 |
| 5.1.  | 3 The         | emes                                                                  | 102 |
| 5.1.  | 4 Sur         | nmary of stage one                                                    | 117 |
| 5.2   | Finding       | GS OF STAGE TWO: INTERVENTION DEVELOPMENT                             | 121 |
| 5.2.  | 1 IM.         | P Step 1: Need assessment                                             | 121 |
| 5.2.  | 2 IM.         | P Step 2: Identity outcomes and change objectives                     | 122 |
| 5.2.  | 3 The         | e theoretical framework for the intervention                          | 130 |
| 5.2.  | 4 IM.         | P Step 3: Choosing theory-informed intervention methods and           |     |
| pra   | ctical ap     | proaches                                                              | 138 |
| 5.2.  | 5 IM.         | P Step 4: Producing intervention components and materials             | 141 |
| 5.2.  | 6 Sur         | nmary of stage two                                                    | 146 |
| 5.3   | Finding       | GS OF STAGE 3 (INTERVIEWS WITH HEALTH PROFESSIONALS)                  | 148 |
| 5.3.  | l Acc         | ceptance of the intervention regarding the format of the video (white |     |
| anii  | mated vid     | deo)                                                                  | 149 |
| 5.3.  | 2 Acc         | ceptance of the intervention regarding the relevancy of the content   | 149 |
| 5.3.  | 3 The         | e most helpful parts of the video                                     | 149 |
| 5.3.  | 4 Mo          | difications to some of the video content                              | 150 |
| 5.3.  | 5 The         | e desire to use the video during educational school tours             | 155 |
| 5.3.  | 6 Sur         | nmary of stage three                                                  | 155 |
| 5.4   | Finding       | gs of Stage 4 (Interviews with a second group of adolescents          |     |
| WITH  | T1DM)         |                                                                       | 159 |
| 5.4.  | 1 Da          | ta analysis of semi-structured individual interviews for Stage 4      | 159 |
| 5.4.  | 2 The         | e findings from the demographic data of the study sample              | 159 |
| 5.5   | SUMMA         | RY OF STAGE FOUR                                                      | 167 |
| СНАРТ | <b>TER 6:</b> | DISCUSSION AND CONCLUSION                                             | 168 |
| 6.1   | THE RE        | SEARCH QUESTIONS                                                      | 168 |
| 6.2   | ADOLES        | SCENTS' ABILITY TO DEPEND ON THEMSELVES IN MANAGING THEIR             |     |
| DIABE | TES IN SC     | CHOOL                                                                 | 169 |
| 6.3   | PHYSIC        | AL AND PSYCHOSOCIAL CHALLENGES IN MANAGING T1DM IN SCHOOL             | ,   |
|       | 170           |                                                                       |     |

| 6.4         | PEERS AND TEACHERS IMPROVE THEIR KNOWLEDGE AND UNDERSTAND  | DING      |
|-------------|------------------------------------------------------------|-----------|
| ABOU        | лт Т1DM                                                    |           |
| 6.5         | INTERVENTION DEVELOPMENT                                   |           |
| 6.6         | ACCEPTANCE OF THE INTERVENTION REGARDING THE FORMAT OF THE | VIDEO     |
| (WHI        | TEBOARD ANIMATED VIDEO)                                    | 177       |
| 6.7         | THE MOST HELPFUL PARTS OF THE VIDEO                        |           |
| 6.8         | SUGGESTION FOR MODIFICATIONS                               |           |
| 6.9         | ACCEPTANCE OF THE APPROPRIATENESS OF THE INFORMATION       |           |
| 6.10        | ACCEPTANCE OF THE FORMAT 'SIMPLE AND ENJOYABLE'            |           |
| 6.11        | APPROPRIATE SPEED (VIDEO PACING) AND APPROPRIATE LENGTH    |           |
| 6.12        | Easy language                                              |           |
| 6.13        | CONTRIBUTION TO KNOWLEDGE                                  |           |
| 6.14        | RECOMMENDATIONS FOR THE FUTURE MANAGEMENT OF ADOLESC       | ENTS WITH |
| T1D         | M IN A SCHOOL                                              |           |
| 6.15        | IMPLICATIONS FOR CLINICAL PRACTICE (DIABETIC TEAM)         |           |
| 6.16        | Study Strengths and Limitations                            |           |
| 6.17        | IMPLICATIONS FOR FURTHER RESEARCH                          |           |
| 6.18        | Personal Reflection                                        |           |
| 6.19        | CONCLUDING COMMENTS                                        |           |
| <b>REFE</b> | RENCES                                                     |           |
| APPE        | NDICES                                                     |           |
| Appe        | endix 1: Interview guide                                   |           |
| Appe        | ENDIX 2: INTERVIEW GUIDE (HEALTH CARE PROFESSIONALS)       |           |
| Appe        | ENDIX 3: INTERVIEW GUIDE FOR FOLLOW-UP STAGE               |           |
| Appe        | ENDIX 4: COLLABORATION EMAIL FROM PAEDIATRIC DIABETIC TEAM |           |
| Appe        | endix 5: Invitation Letter                                 |           |
| Appe        | ENDIX 6A: PARENT/GUARDIAN INFORMATION SHEET                |           |
| Appe        | ENDIX 6B: PARTICIPANT INFORMATION SHEET                    |           |
| Appe        | endix 7: Parents/Guardian Consent Form                     |           |
| Appe        | ENDIX 8: RESPONSE CARD                                     |           |
| Appe        | ENDIX 9: INVITATION LETTER (HEALTH CARE PROFESSIONALS)     |           |
| Appe        | ENDIX 10: INFORMATION SHEET (HEALTH CARE PROFESSIONALS)    |           |

| APPENDIX 11: CONSENT FORM (HEALTH CARE PROFESSIONALS)                | . 263 |
|----------------------------------------------------------------------|-------|
| APPENDIX 12: INVITATION LETTER FOR FEEDBACK INTERVIEW                | . 265 |
| Appendix 13A: Parent/Guardian Information Sheet (Feedback Interview) | 267   |
| APPENDIX 13B: PARTICIPANT INFORMATION SHEET (FEEDBACK INTERVIEW)     | . 271 |
| Appendix 14: Participants' Assent Form                               | . 275 |
| Appendix 15 (coding frames of interview data for stage 1, 3 & 4)     | . 276 |
| Appendix 16: Demographic Data Information Sheet                      | . 290 |
| Appendix 17: HRA Approval Letter                                     | . 292 |
| APPENDIX 18: LETTER OF AGREEMENT                                     | . 300 |
| Appendix 19: Preliminary questionnaires                              | . 301 |

## LIST OF TABLES

| Table 1: Keywords                                                                  | 39  |
|------------------------------------------------------------------------------------|-----|
| Table 2: Inclusion and exclusion criteria                                          | 40  |
| Table 3: The intervention studies included in the reviews of Edwards et al. (201   | 4)  |
| and Pansier and Schulz (2015)                                                      | 50  |
| Table 4: Study overview (the four stages of the research aligned with the steps of | f   |
| IMP framework)                                                                     | 77  |
| Table 5: Demographic elements, showing demographic characteristics of              |     |
| adolescents with T1DM (n=18)                                                       | 102 |
| Table 6: Programme and performance objectives for the organisational level         |     |
| (peers and teachers)                                                               | 124 |
| Table 7: Selected determinants and related theories                                | 130 |
| Table 8: Matrix for peers and teachers at the organisational level (school)        | 135 |
| Table 9: The theoretical methods and applications for attaining the change         |     |
| objectives at the organisational level                                             | 141 |
| Table 10: Initial video content                                                    | 143 |
| Table 11: Modifications to the video suggested by health care professionals        | 156 |
| Table 12: Matrix for peers and teachers at the organisational level (school)       | 157 |
| Table 13: Theoretical methods and applications for achieving the change            |     |
| objectives at the organisational level                                             | 158 |
| Table 14: Findings from the demographic data of the study sample                   | 160 |

## **LIST OF FIGURES**

| Figure 1: Literature search flow chart for search method and results |    |
|----------------------------------------------------------------------|----|
| Figure 2: Recruitment process                                        | 91 |

### **DECLARATION OF AUTHORSHIP**

I, Raya Said Al Habsi, declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

## School-based Intervention to Improve Self-Management among Adolescents with Type 1 Diabetes Mellitus

I confirm that:

This work was done wholly or mainly while in candidature for a research degree at this University;

Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated; Where I have consulted the published work of others, this is always clearly attributed;

Where I have quoted from the work of others, the source is always given. With the

exception of such quotations, this thesis is entirely my own work;

I have acknowledged all main sources of help;

Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;

None of this work has been published before submission

Signed:

Raya Said Al Habsi

September 2018

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### **DEFINITIONS**

Adolescents: young people between the ages of 10–19 (World Health Organisation, 2013).

**Diabetes UK**: a British-based patient, health care professional and research charity that describes itself as the leading UK charity that cares for, connects with, and campaigns on behalf of all people affected by and at risk of diabetes (Diabetes UK 2017b). The charity campaigns for improvements in the care and treatment of people with diabetes.

**Diabetic ketoacidosis**: a severe lack of insulin means that the body cannot use glucose for energy, and it starts to break down other body tissues as an alternative energy source. Ketones are the by-product of this process; they are poisonous chemicals that build up and, if left unchecked, cause the body to become acidic, hence the suffix 'acidosis'.

**Gillick competence**: a term originating in England and used in medical law to decide whether a child (16 years or younger) can consent to his or her medical treatment without the need for parental permission or knowledge (Cornock 2007).

**Health and well-being**: reflect a person's health and lifestyle according to four factors: physical, intellectual, emotional, and social.

**Haemoglobin A1c**: glycated haemoglobin is a form of haemoglobin that is mainly measured in order to detect a three-month average plasma glucose concentration. The test is restricted to a three-month average, as that is the lifespan of a red blood cell.

**Heidegger's hermeneutic phenomenological approach**: a qualitative research methodology that arose out of, and remains closely tied to, phenomenological philosophy, a strand of continental philosophy (Kafle 2013).

Hyperglycaemia: refers to chronically high blood glucose levels.

Hypoglycaemia: refers to dangerously low blood glucose levels.

**Interpretive phenomenological approach**: 'an approach to qualitative psychological research with an idiographic focus, which means that it aims to offer insights into how a given person, in a given context, makes sense of a given phenomenon. Usually, these phenomena relate to experiences of some personal significance' (Callary et al. 2015).

**NVivo**: a qualitative data analysis computer software package produced and designed for qualitative researchers working with very rich text-based and/or multimedia information, where deep levels of analysis on small or large volumes of data are required.

**Type 1 diabetes mellitus**: a chronic condition that classically develops in childhood as a result of the destruction of B-cells within the pancreas, causing a lack of insulin production (Gordon - Dseagu et al. 2013).

## **ABBREVIATIONS**

**T1DM**: Type 1 diabetes mellitus.

**T2DM**: Type 2 diabetes mellitus.

**HbA1c**: Haemoglobin A1c

WHO: World Health Organisation

### **CHAPTER 1: INTRODUCTION & BACKGROUND**

This section of the chapter consists of a brief discussion of T1DM incidence as well as an examination of the national and professional context and the thesis outlines.

#### **1.1 Incidence of T1DM**

T1DM is defined as a chronic condition that classically develops in childhood and, as a result of the destruction of B-cells within the pancreas, causes a lack of insulin production (Gordon - Dseagu et al. 2013). T1DM is one of the most common endocrine-metabolic disorders in children and adolescents worldwide (Casqueiro et al. 2012), corresponding to 5–10% of all chronic diseases in children and adolescents (Almeida et al. 2013). From 1990 to 2008, the global incidence of T1DM among children aged under 15 increased by 2.8% to 4.0% per year (Patterson et al. 2012; Dabelea et al. 2014). T1DM represents at least 85–90% of all diabetes cases in adolescents under the age of 20 worldwide (Maahs et al. 2010; IDF 2013). A recent analysis revealed that the UK ranks fifth out of 88 countries for the incidence of T1DM in children (Iacobucci 2013). The most up-to-date information about the total number of children and adolescents with diabetes in England is found in Diabetes: Facts and Stats (2017), which refers to approximately 31,500 children and adolescents with diabetes under the age of 19. The current estimate of the prevalence of T1DM in children and adolescents in England and Wales is 187.7 per 100,000 (Diabetes UK 2017a). These global and national figures signify an alarming increase in the prevalence of T1DM among adolescents worldwide, which indicates the continual need to focus attention on adolescents with T1DM.

#### **1.2** National and Professional Context

According to the UK Children and Families Act 2014, schools have a legal duty to support pupils with medical conditions such as T1DM. The Department of Health and the Department of Education initiated the National Health Schools Programme (NHSP) in 1999, with the aim of supporting schools in taking a whole-school approach to the promotion of children and adolescents' health and well-being (physical, mental, and social). The school environment influences an adolescent's life and can lead to the enhancement of health and well-being outcomes (Guffey 2012). T1DM is a life-threatening medical disorder, which can seriously affect the health and well-being of the children and adolescents with T1DM can effectively manage their disease. According to a survey by Diabetes UK conducted in 2015, involving 409 parents of children and adolescents with T1DM, one-third of children and adolescents with T1DM were not receiving satisfactory attention in school. These findings highlight how support at school remains a major concern for many children and adolescents with T1DM.

#### **1.3** Children's Involvement in their Health Care Decisions

The UN Convention on the Rights of the Child states that children and young people have the right to contribute in decisions about their care, including their health care. In this sense, children and young people have the right to voice their views on all matters that affect them (Weil et al. 2015). In the UK, the National Health Service (NHS) clearly emphasises that, in order to be completely involved in decision-making about their treatment choices, all patients need information (Noyes et al. 2014). One review of children and adolescents' NHS services in England (Kennedy 2010) explained the importance of integrating children and adolescents' views on aspects related to their

health and the delivery of health services. The American Diabetic Association (ADA) has emphasised that diabetic support and education should be patient-centred, respectful, and responsive to individual patients' preferences and needs (Wiley et al. 2014; American Diabetes Association 2015b). Dickinson et al. (2014) and Amiel et al. (2015) highlighted that understanding children's requirements could provide health professionals with the ability to communicate with children and deliver child-centred services more efficiently. In addition, Foot et al. (2014) stated that the policy had tended to focus mostly on, or express patient involvement in, the form of rights, but that associated responsibilities are inherent in this. Healthwatch England has emphasised the rights and responsibilities of health and social care in order to ensure that the voice of patients, including children and the public, are heard in the health care system.

Reflecting on these recommendations in the school context, there is importance in providing school-based interventions based on the perceptions, needs and priorities of adolescents with T1DM in order to support them in maintaining their health and well-being at school; also, to empower them to take responsibility for their care while they are at school.

#### **1.4 Thesis Layout and Contents**

This thesis will consist of seven chapters, a brief outline of which is presented below. **Chapter 1** provides the introduction and the background. **Chapter 2** addresses the literature review as supporting evidence for the study. **Chapter 3** explains the choice of methodology and methods used to pursue the research aim, questions and objectives. **Chapter 4** presents the findings of the first stage of the study. **Chapter 5** will be divided into three parts, with Part 1 providing details of the intervention development using intervention mapping protocol and findings from stage 1. Part 2 presents the findings of stage 3, and Part 3 presents the findings of stage 4. **Chapter 6** discusses the

findings of stages 1, 2, 3 and 4 in the light of existing evidence. **Chapter 7** concludes the thesis and sets out the study limitations, recommendations, implications, suggestions for future research, and personal reflection.

#### 1.5 Background

In order to understand T1DM's complexity, its classification, management, and complications are explored in this section. Moreover, developmental changes, self-management, and glycaemic control in adolescents with T1DM are outlined. In addition, stressors in the school setting faced by adolescents with T1DM are discussed in more detail.

#### **1.6 Diabetes Mellitus**

Diabetes is a group of metabolic disorders categorised by hyperglycaemia resulting from defects in insulin secretion, insulin action, or both (Thorve et al. 2011). The chronic hyperglycaemia of diabetes is associated with long-term damage, dysfunction, and failure of different organs, especially the eyes, nerves, blood vessels, kidneys, and heart (American Diabetes Association 2010).

#### 1.6.1 Classification of diabetes mellitus

Diabetes can be categorised into four main categories:

- Type 1 Diabetes: This is one of the most common autoimmune disorders affecting children and adolescents. It is caused by damage to the pancreatic βcells, resulting in complete insulin deficiency (Tao et al. 2015).
- Type 2 Diabetes: This type of diabetes was formally known as non-insulindependent diabetes. It involves people who have insulin resistance and usually have relative (rather than absolute) insulin deficiency (TA 2014). Type 2

diabetes is more common in adults; however, there is an increasing incidence of type 2 diabetes mellitus among children and adolescents around the world (Reinehr 2013).

- Gestational Diabetes; This type of diabetes is diagnosed during pregnancy (American Diabetes Association 2014b).
- Other types of diabetes may be due to other reasons, for example, genetic defects in insulin action or genetic defects in β-cell function (ibid.).

The study outlined in this thesis focuses on T1DM in adolescents.

#### 1.6.2 Type 1 diabetes mellitus (T1DM)

The autoimmune destruction of pancreatic β-cells causes a deficiency of insulin secretion, which leads to metabolic imbalances associated with T1DM. The absence of insulin leads to uncontrolled lipolysis and elevated levels of free fatty acids in the plasma, which defeat glucose metabolism (Ozougwu et al. 2013; Noor et al. 2015). This damage to glucose consumption and insulin deficiency also reduces the expression of the genes essential to target the tissues that normally respond to insulin, such as glucokinase in the liver and the glucose transporter type 4 in adipose tissue. The main metabolic imbalances that result from insulin deficiency in T1DM are impaired glucose, lipid, and protein metabolism (Cryer 2006). Insulin has a vital function in the breakdown of carbohydrates, fats, and proteins by reducing the concentration of glucose in the blood and enabling the transportation of glucose into the cells. In the case of total insulin deficiency, glucose is unable to pass into the cells, thus raising glucose concentration in the blood (hyperglycaemia). Initial signs and symptoms include polyuria (increased urinary frequency), polydipsia (increased thirst), fatigue, and weight loss due to the breakdown of fat and muscle (Usher-Smith et al. 2015).

#### **1.6.3** Diagnosis of type 1 diabetes

The medical diagnosis of T1DM is verified by finding a significant rise of random blood glucose of  $\geq 200 \text{ mg/dl}$  (11.1mmol/L), in addition to polydipsia, polyuria, tiredness, and weight loss (Beckles et al. 2016) with hyperglycaemia, glycosuria (excess of sugar in the urine), ketonemia (presence of high concentration of ketone in the blood), and ketonuria (presence of ketone in the urine) (Usher-Smith et al. 2015). Further investigation includes a fasting plasma glucose (FPG) of  $\geq$  126mg/dL (7.0mmol/L) and a two-hour plasma glucose of  $\geq$  200mg/dL (11.1mmol/L) during a 75g oral glucose tolerance test (OGTT) (American Diabetes Association 2010). Random glucose of  $\geq$ 200mg/dl (11.1mmol/L) should be repeated on the second day to confirm the diagnosis. Additionally, elevated glycated haemoglobin (HbA1c) above the normal range of 20–41mmol/mol (4–5.9%) is a valuable diagnostic test. HbA1c provides an index of the average blood glucose levels over the 120-day lifespan of erythrocytes (John 2012).

#### 1.7 Management of T1DM

T1DM management involves permanent administration of exogenous insulin. The purpose of T1DM treatment in adolescents is to maintain near-normoglycemia through rigorous insulin treatment, prevent acute and chronic complications, and promote normal growth and development (Malik and Taplin 2014). Management of T1DM comprises different self-care activities, including insulin adjustment and administration, blood glucose monitoring, regulation of dietary intake, and consistent physical exercise to regulate glycaemic control. In adolescence, insulin regimens should be individualised to fit lifestyles and to enhance adherence while promoting glycaemic control that meets age-specific goals. Also, the emotional and psychosocial needs of adolescents with T1DM should be considered. Autonomy is a vital issue of diabetes self-management

that needs particular attentiveness (Wiley et al. 2014). Autonomy in diabetes management is associated with improved metabolic control (Comeaux and Jaser 2010). Management plans should be framed collaboratively between patients and other members of the health care team, taking into consideration patient preferences and priorities (American Diabetes Association 2013).

#### **1.8 Insulin Therapy**

Insulin dosage differs significantly between individuals and changes over time. Therefore, it requires regular review and reassessment (Danne et al. 2014). Glycaemic control should be evaluated by regular measurement of HbA1c levels. Optimal glycaemic control can be reached by checking blood glucose levels regularly and adjusting insulin dosages accordingly (Ergun-Longmire and Maclaren 2014). Insulin can be administered either by basal-bolus regimens or pump therapy. Basalbolus regimens comprise the administration of subcutaneous insulin through an insulin pen or syringe for both long-acting (basal) and rapid-acting (bolus) insulin. Basal insulin, given in the long-acting form as glargine or detemir, or in the intermediateacting form as neutral protamine Hagedorn (NPH), is injected into the subcutaneous tissue one or two times per day; it emulates the physiologic basal insulin secretion that inhibits hepatic glucose production. The patient may also use bolus insulin, given as rapid-acting aspart, glulisine, or lispro, a minimum of three or four times a day to cover mealtime and snack time carbohydrates and to correct for hyperglycaemia (Dayton and Silverstein 2016).

Continuous subcutaneous insulin infusions (CSII) are a frequently used alternative to multiple daily injections in the treatment of T1DM (Phillips 2016a). CSII is a small programmable pump, including a reservoir of short-acting insulin, that is joined to a cannula placed beneath the skin by a thin tube. The amount of the insulin can be altered

at any time by the user. For instance, mealtime doses are delivered by the initiation of a booster dose by the user (Majedah et al. 2015).

The benefits of CSII over multiple daily injections in adolescents with T1DM include lower insulin requirements and greater glycaemic control (Shalitin and Peter Chase 2011; Hofer et al. 2012; Brancato et al. 2014). On the other hand, Maahs et al. (2010) point out some disadvantages of insulin pump use in adolescents, such as weight gain, insulin unavailability and instability, skin infections, and infusion site dislocation. However, Pozzilli et al. (2016) found that the association between CSII and reduced hypoglycaemic risk is more consistent in children/adolescents with T1DM, in addition to there being a positive influence on quality of life, as CSII provides adolescents with better lifestyle flexibility, particularly with regard to concerns about food and socialisation (Alsaleh et al. 2012).

#### **1.9 Monitoring**

#### 1.9.1 Blood glucose

Self-monitoring of blood glucose (SMBG) is considered as a vital device for T1DM management and essential for enhancing and improving the safety and effectiveness of complex insulin regimens (Czupryniak et al. 2014). SMBG offers information concerning the blood glucose profile that can help with the proper planning and scheduling of medication, diet, and physical exercise (Kirk and Stegner 2010). Most patients with T1DM on intensive insulin therapy should consider SMBG before mealtimes and snacks, postprandial, before any physical exercise, and at bedtime. Although individual needs may differ, for many patients this will necessitate checking six to ten (or more) times daily (American Diabetes Association 2016). More frequent SMBG is required during illness or periods of glycaemic instability. Compared to SMBG once a day, SMBG four times a day or more is linked with a decrease in HbA1c

of about 1% in adolescents with T1DM. This reduction could significantly contribute to reducing the incidence of acute diabetic complications (Formosa 2013).

Continuous glucose monitoring (CGM) is a sensor inserted into the subcutaneous tissue that estimates interstitial fluid glucose levels to give semi-continuous data regarding glucose levels. CGM can recognise fluctuations that would not have been identified with standard self-monitoring (Langendam et al. 2012), which helps to enhance diabetes self-efficacy, increase flexibility in daily living, decrease anxiety about unexpected hypoglycaemia, and improve motivation towards improved glycaemic control (Schwartz and Scheiner 2012). The use of CGM can improve glycaemic control in children and adolescents with poorly-controlled diabetes (Lewis et al. 2016). However, CGM use can cause possible psychological and behavioural side effects, for instance, through raising the overall burden of diabetes management by yielding an overwhelming amount of glucose data, generating unrealistic expectations about CGM benefits, and aggravating conflict between parent and adolescents regarding glycaemic control (Patton and Clements 2016). The National Institute For Health and Clinical Excellence (NICE) recommends CGM for adolescents with T1DM who have severe hypoglycaemia or hyperglycaemia or an inability to communicate or recognise the symptoms of hypoglycaemia because of cognitive or neurological incapacity (NICE 2015).

Flash technology relates to newly introduced devices for monitoring blood glucose, which allows for the screening of blood glucose via a sensor attached to the skin, generally on the upper arm. The patient can observe a sensor measuring glucose in the interstitial fluid under the skin in order to give a glucose reading (Phillips 2016b), the accuracy of which is comparable to other continuous glucose monitoring devices (Kropff et al. 2015). Such devices are becoming more accessible on the market, but they are, as yet, unavailable on prescription in the UK.

#### **1.9.2** Urine glucose

Urine tests are sometimes used to investigate the presence of ketone bodies if the blood glucose level is more than 250mg/dl (14mmol/L). Moderate or large ketone levels in the urine in the presence of hyperglycaemia suggest insulin insufficiency and the risk of metabolic decompensation, which can lead to ketoacidosis. The presence of vomiting with hyperglycaemia and large urinary ketones must be assumed to be due to a systemic acidosis, requiring further evaluation (Rewers et al. 2009).

#### **1.9.3** Glycated haemoglobin (HbA1c)

A glycosylated haemoglobin (HbA1c) test indicates the level of blood glucose for the previous two to three months in addition to evaluating the amount of glucose that is being carried by the red blood cells in the body (Sacks 2011). HbA1c monitoring, when added to conventional blood glucose monitoring, has shown improved glycaemic control, and it has become a standard practice in managing patients with T1DM (Cutfield et al. 2011). A HbA1c goal of <7.5% (58mmol/mol) is suggested for children and adolescents under 18 years of age without frequent disabling hypoglycaemia (American Diabetes Association 2015c). The NICE (2015) guidance identifies even tighter HbA1c recommendations, with a goal determined for 6.5% (48mmol/mol). Better metabolic control in adolescents, as measured by a lower HbA1c level along with intensive management, is associated with fewer diabetic complications (Rewers et al. 2014). However, health care teams should consider the age of adolescents when setting glycaemic goals, specifically those with hypoglycaemia unawareness (i.e. unable or not experienced enough to recognise the signs and symptoms of hypoglycaemia) or those with episodes of severe hypoglycaemia. They should be guided to increase their glycaemic goals to prevent more hypoglycaemia and reduce the risk of future hypoglycaemic incidents (American Diabetes Association 2014a).

#### 1.9.4 Nutrition

Nutritional management is one of the bases of diabetes management in adolescents with T1DM (Smart et al. 2009). Dietary advice should be adjusted to cultural, ethnic, and family traditions, as well as the cognitive and psychosocial needs of the individual adolescent (Craig 2014). The goals of nutritional management of adolescents with diabetes include achieving and maintaining glycaemic control, maintaining body weight, and promoting regular physical activities, in addition to providing appropriate energy and nutrient intake (Gray 2015). There are several meal-planning approaches, including individualised menus, the exchange list approach, and basic and advanced carbohydrate counting.

Individualised menus are when the dietitian creates an individualised list based on the nutritional counselling plan chosen and the patient's preferences. The idea of the exchange list approach is that foods are categorised according to similar dietary values, and they can be switched or exchanged for portion sizes listed within the same groups (Gray 2015).

Carbohydrate counting has become a popular method for diabetes management and education, as carbohydrates have the biggest impact on postprandial blood sugar levels when compared with fats and proteins (Bell et al. 2014). Carbohydrate counting is a planned approach that stresses consistency in the timing and amount of carbohydrates consumed (Hall 2013). It is used by the Dose Adjustment for Normal Eating (DAFNE) programme, which is a structured diabetes education programme for people with T1DM. DAFNE aims to improve overall glycaemic control, to minimise hypoglycaemia, and to enhance the quality of life for patients with T1DM (Mansell 2012). Through this programme, people with T1DM can estimate their carbohydrate

intake based on 10g portions and then calculate their short-acting insulin doses as a ratio to carbohydrate consumption (Dunning 2013).

Bishop et al. (2009) found that adolescents with T1DM do not count the carbohydrates of regularly consumed foods with sufficient accurateness. Therefore, adolescents with T1DM and their families should be trained on carbohydrate counting so that either carbohydrate exchanges or insulin-to-carbohydrate ratios can be used to achieve optimal glycaemic control (Danne et al. 2014; NICE 2015). NICE (2015) recommendations have also emphasised that children and adolescents with T1DM have the same basic nutritional requirements as other children and adolescents, and they should be provided with sufficient energy and nutrients for optimum growth and development either at home or school. In this sense, healthy, well-balanced meals should be available for all students in school. However, there has to be a special consideration for adolescents with T1DM, such as providing nutritional information about foods served and portion sizes so that they can make the necessary adjustments to their insulin dosage.

#### 1.9.5 Exercise

Exercise is essential in the management of T1DM. Regular exercise enhances lipid profiles, cardiovascular health, psychosocial well-being, and glycaemic control in adolescents with T1DM. The International Society for Paediatric and Adolescent Diabetes (ISPAD) advocates that all adolescents with T1DM participate in a minimum of one hour of daily physical activity (Robertson et al. 2014). However, exercise for adolescents with T1DM can be challenging because glycaemic excursions usually happen during and after exercise and may raise the hazard of severe hypoglycaemia (J Roberts and E Taplin 2015). Fright of hypoglycaemia has been considered a significant obstacle to physical activity and it may influence adolescents' performance in relation to exercise, particularly in reference to insulin adjustment and additional

carbohydrate intake to avoid severe hypoglycaemia (Roberts et al. 2016). In some poor control diabetic situations, exercise stimulates high ketone body formation. Ketone bodies joined with impaired muscle glucose uptake may precipitate ketoacidotic abdominal pain and vomiting. Therefore, physical activities should be avoided if blood glucose is high and ketones are present in the urine (Craig 2014).

Adolescents with T1DM should be encouraged to take part in routine exercise. However, they need to take precautions to avoid hypoglycaemia. Blood glucose levels must be checked before, during, and after physical activity in order to maintain normal blood glucose. When participating in prolonged physical activities, they may need to consume more carbohydrates or lower their insulin dosage. Also, carbohydrate-based foods should be available during and after exercise. Adolescents with T1DM should be educated to identify the glycaemic response to different exercises and determine any changes in insulin or food consumption (Pivovarov et al. 2015). Adolescents with T1DM are expected to participate in physical education (PE) in school. However, PE teachers and other school personnel should understand how to support adolescents with T1DM before, during, and after sessions in order to achieve stable glycemia during physical activity (Nadella et al. 2017).

#### 1.9.6 Sick day management

Illness and infection can change diabetes management and blood glucose control. Illnesses associated with fever can lead to high blood sugar levels because of increased stress hormones, promoting gluconeogenesis and insulin resistance. Illnesses associated with diarrhoea, vomiting, and loss of appetite may cause low blood sugar levels and cause hypoglycaemia. Disease increases ketone body production due to inadequate insulin levels (Brink et al. 2014). Adolescents with T1DM who are unwell may need to manage hypoglycaemia and hyperglycaemia, as well as watch for signs of diabetic

ketoacidosis (Choudhary 2016). The ultimate goals for sick day management are to prevent hypoglycaemia or hyperglycaemia and dehydration. These goals can be achieved by adjusting insulin doses depending on the degree of hyperglycaemia and ketosis and by treating the underlying illness, checking blood glucose and ketone levels (every two hours), and keeping the body well hydrated by drinking lots of fluids (Soni et al. 2016). If vomiting and diarrhoea happen more than once and blood glucose levels remain higher than 250mg/dl, in addition to ketones remaining high, adolescents with T1DM should contact those responsible for their care, which may be the parent or carer (e.g. teacher or school nurse), depending on where they are (Brink et al. 2014).

#### **1.9.7 Diabetes education**

Diabetic education is the foundation of diabetes care, and structured self-management education is essential for successful diabetic management (Swift 2009). It is defined as the process of providing the person with the knowledge and skills needed to perform diabetes self-care, manage crises, and make lifestyle changes to manage the disease successfully (Clement 1995).

Such education relates to facilitating the knowledge and skills necessary for diabetes self-management. It should include the needs and experiences of the person with diabetes and is guided by evidence-based standards (Funnell et al. 2010). Educational programmes should be carefully designed, and appropriate goals and objectives should be shared with people with diabetes, care providers, and their families (Lange et al. 2014). The aims of diabetes education include information on diabetes, the management and prevention of complications, motivating positive attitudes to self-care, and identifying potential barriers. In addition, diabetes education endeavours to identify personal health care targets and build up strategies to meet these targets, adapt behaviours to interact with diabetes management and empowerment in self-

management, and ensure effective communication with health care teams (Cameron et al. 2014).

Educational programmes in adolescents with diabetes have a positive effect on glycaemic control and psychosocial outcomes (Danned 2014). Adolescence is a time during which rigorous education may ward off or delay the onset and progression of complications in later adult life (Donaghue et al. 2014). Moreover, interventional studies in respect to effective and behavioural aspects show better results than educational intervention only (Abualula et al. 2016). They have been found useful in enhancing metabolic control and decreasing inpatient admissions among adolescents with chronic poorly-controlled T1DM (Ellis et al. 2005; Delamater et al. 2014).

#### **1.9.8** Behavioural interventions

Behavioural interventions are intended to enhance levels of self-management by incorporating psychological principles to help people with diabetes make modifications to their behavioural patterns and lifestyle. These interventions are broad and may focus on knowledge and skills, psychological issues (e.g. self-efficacy), and behaviours (e.g. eating and physical activities) (Hampson et al. 2000). Behavioural interventions for adolescents with T1DM that focus on teaching problem-solving skills and improving coping have been found helpful in tackling the psychological obstacles to self-management (Hackworth et al. 2013). Coping skills training (CST), which focuses on managing diabetes in stressful social situations (Hilliard et al. 2016), is one of the most explored areas. Some studies have examined the effect of CST in adolescents with T1DM, indicating that CST, along with intensive diabetic management, has resulted in improved glycaemic control (Grey et al. 1999; Grey et al. 2000; Serlachius et al. 2012). Motivational interviewing is another approach that has been found effective in improving glycaemic control in adolescents with T1DM. It is defined as a collaborative

conversation style that produces internal motivation and reinforces obligation to behaviour change (Powell et al. 2014), and it has been found to have effects on diabetic outcomes among adolescents with T1DM, such as decreased A1c (Huws-Thomas 2007). However, there is still inadequate evidence to recommend the adoption of a particular educational programme. Well-designed trials of such interventions are needed, and the evidence suggests that interventions are more likely to be effective if they demonstrate the inter-relatedness of the various aspects of diabetes management. There is increasing evidence encouraging the usage of behavioural interventions. National guidelines recommend that adolescents and their families should receive ongoing education about the prevention and examining of the microvascular and macrovascular complications of diabetes (American Diabetes Association 2004; NICE 2004; ISPAD 2014). Understanding and accommodating the perspectives of adolescents with T1DM about how to enhance their self-management either at home or school is essential in order to maximise the suitability and efficacy of interventions (Yardley et al. 2015).

## **1.10** Complications of Type 1 Diabetes and Associated Conditions

Complications are linked to blood glucose control, with acute complications presenting as hyperglycaemia and diabetic ketoacidosis with associated mortality and low blood glucose concentrations resulting in hypoglycaemia (Forbes and Cooper 2013). Longterm micro- and macrovascular complications can lead to retinopathy, nephropathy, neuropathy, and cardiovascular disease (Frohlich-Reiterer and Borkenstein 2010).

#### **1.10.1 Short-term complications**

#### Hyperglycaemia

Hyperglycaemia, a preventable short-term complication of T1DM, occurs when the blood glucose is >270mg/dl (15mmol/L) (Dunning 2013). Early signs of hyperglycaemia are increased thirst, frequent urination, fatigue, blurred vision, and headache. These symptoms, if not treated, can progress to fruity-smelling breath, nausea and vomiting, shortness of breath, confusion, and coma (American Diabetes Association 2013). Reasons that can add to the development of hyperglycaemia in adolescents include insufficient insulin, not following diabetes eating plans, and lack of physical activities. Illness or psychological and emotional stress can also trigger hyperglycaemia, as the hormones produced to fight disease or stress might cause the rise of blood sugar levels. Hyperglycaemia should be treated to prevent the development of diabetic ketoacidosis and reduce morbidity and mortality associated with acute illness. Hyperglycaemia can be self-treated by adjusting insulin dosage and diet plans as well as the frequent monitoring of glucose and ketone levels (every two hours). However, if the patient's symptoms progress to persistent vomiting and diarrhoea, severe abdominal pain, or loss of consciousness or blood glucose <4mmol/L or >15mmol/L + ketones and dehydration, admission to the hospital is required (Dunning 2013). As adolescents with T1DM attend school, and hyperglycaemia might happen at any time, it is essential for school personnel to understand the basic management of hyperglycaemia, e.g. by testing blood glucose to confirm hyperglycaemia or allowing the student free use of the bathroom or to drink more water if needed. Schools must be sensible in assisting the special needs of students with T1DM diabetes.
#### Hypoglycaemia

Hypoglycaemia is one of the most common complications of T1DM. It occurs when the blood glucose level is  $\leq 3.9$  mmol/L (70 mg/dl) (Dunning 2013). It can happen suddenly and, if not treated immediately and appropriately, it can progress within a short period of time to unconsciousness and seizure. In addition, hypoglycaemia can lead to cognitive defects or even directly cause death (Bin-Abbas and Al Qahtani 2014). The signs and symptoms of hypoglycaemia include trembling/shaking, sweating, palpitations, pallor, hunger, and nausea (IDF 2013; Rewers et al. 2014). Hypoglycaemia has been categorised as mild, moderate, or severe, based on the patient's ability to treat him/herself. Mild and moderate hypoglycaemia is when blood glucose is 3.5-3.9mmol/L, which can be treated by taking carbohydrates immediately, such as glucose tablets or a sweet drink. Severe hypoglycaemia is characterised by a loss of consciousness, with or without convulsions. It is considered as life threatening and requires immediate emergency transfer to hospital, where glucagon should be given intramuscularly or subcutaneously. If glucagon recovery is insufficient, intravenous dextrose should be administered slowly (Clarke et al. 2009). According to NICE (2015), urgent treatment of hypoglycaemia should be performed immediately by family members or school personnel to prevent further life-threating complications. In such cases, schools need to ensure the provision of emergency transfer services. In addition, hypoglycaemia can affect the cognitive function of a student with T1DM several hours after a hypoglycaemic episode. Therefore, students with T1DM may not achieve as expected educationally. NICE (2015) highlights that schools need to grant special considerations for students with T1DM before and during examinations, for example, by checking blood sugar levels before exams and making food and drinks available during the exam in case of hypoglycaemia. NICE (2015) has also emphasised the need

to continue educating families or carers and school personal about recognising and managing hypoglycaemia.

### 1.10.2 Long-term complications

Prevention of diabetes complications is of vital importance for children and adolescents. Diabetic vascular complications are asymptomatic during their early stages, and once symptoms develop, it can be difficult to reverse them. Therefore, early implementation of preventive and therapeutic strategies, which could change the progression of diabetic-related vascular complications and improve the prognosis of adolescents with T1DM, is crucial (Marcovecchio et al. 2010; Chiarelli and Marcovecchio 2011). Long-term complications can be divided into macrovascular disease and microvascular complications (Fowler 2008). Micro- and macrovascular complications affect both quality of life and life expectancy in diabetic patients (Demirel et al. 2013). Risk factors for the development of complications are a longer duration of diabetes, older age, and puberty (Frohlich-Reiterer and Borkenstein 2010). Long-term vascular complications of diabetes include retinopathy (which can cause visual impairment and blindness) and nephropathy (persistent albuminuria leading to renal failure and hypertension), neuropathy (pain, paraesthesia, and muscle weakness), and macrovascular diseases (cardiac disease, peripheral vascular disease, and stroke) (Ly et al. 2014). Peripheral sensorimotor neuropathy is symmetrical and commonly affects the feet, leading to diminished sensation that can alter the perception of foot pressure and alter foot architecture. This change can result in injury, non-healing wounds, and eventual amputations (Moore et al. 2009).

In adolescents, microvascular complication incidence is more than the expected in two to five years' time following initiation of T1DM (Kim et al. 2012). Adolescents with diabetes have a much higher albumin excretion, and it is suggested that they will have

more advanced microvascular and macrovascular disease, probably because of poorer metabolic control. Poor diabetic management in adolescents with T1DM could lead to further complications in the future (Gerstl et al. 2008; Anderzén et al. 2016).

Persistent poor diabetic control makes it more challenging to reverse the original factors of poor diabetes management. Kim et al. (2012) suggest that strategies to improve diabetic control in adolescents with T1DM, along with an emphasis on changes that result in improved diabetic control, are critical.

According to IDF (2013) and ISPAD (2014) recommendations, adolescents with T1DM should be offered screenings for blood pressure at least annually. In addition, screening for retinopathy, microalbuminuria, and peripheral and autonomic neuropathy should start from the age of 11 and after two years of diabetes duration. Further, screening for thyroid dysfunction and celiac disease should be considered (American Diabetes Association 2015a; NICE 2015).

The following section presents the developmental changes in adolescents with T1DM. It also provides information about self-management and glycaemic control in adolescents with T1DM. Furthermore, stressors of adolescents with T1DM in the school setting are discussed in more detail.

## **1.11** Adolescents and Type 1 Diabetes Mellitus

Adolescence is known as the critical transitional period of development and growth between childhood and adulthood (Silverstein et al. 2005). The World Health Organisation (WHO) has defined adolescents as individuals between the ages of 10–19 (WHO (2015)

This transitional period can result in issues of autonomy from family, more personal independence, and self-identity (Remschmidt 1994). Adolescents start to develop

stronger reasoning skills and moral and logical thinking, in addition to becoming more skilful in abstract thinking and making rational decisions. The most important cognitive changes in this period of life are adolescents' ability to think abstractly, a growing concern about other people's opinions, mostly those of their peers, and the frequent desire to do something about the social issues that they encounter in their lives (WHO 2015). Many adolescents and their peers face difficult choices regarding many issues, such as school work, sexuality, relationships, drugs, alcohol, and social life (Casey et al. 2008). Adolescents with T1DM encounter the extra challenge of trying to improve glycaemic control while experiencing the physiological and psychological changes of puberty (Ridge et al. 2014). They need to control their blood glucose to prevent serious short- and long-term complications of the condition (Helgeson and Palladino 2012). Adolescents are set to face physiological and psychosocial changes, including rapid cognitive, emotional, physical, and social changes (Frydenberg 2008). As each of these is key to adolescents' experiences of diabetes, the following sections will explore each element in more depth.

#### 1.11.1 Physiological changes and adolescents with T1DM

Puberty indicates the commencement of adolescence (WHO 2015). Puberty is defined as the biological time frame in which a child's gonads (testes or ovaries) are started, producing definite hormonal changes. During the pubertal growth spurt, the rate of growth in adolescents might double (Richardson and Glasper 2010). These hormones are androgens for males and oestrogens and progesterone for females, and they commence physical and psychological changes to achieve reproductive competence. Puberty precedes adolescence, with the typical age of onset at 7–12 years for females, and between 8–13 years for males (Cohen and Ball 2007). Adolescence signifies the period in which puberty has begun (Gluckman et al. 2011). In males, early onset of

puberty has been related to an increased risk of health-compromising behaviours including increased aggression, substance abuse, sexual activity, depression, anxiety and suicidal tendencies (Mendle and Ferrero 2012). In females, the completion of puberty is considered as the onset of menarche. An earlier occurrence of menarche is also associated with an increased likelihood of engagement in health-compromising behaviours, for example, the beginning of sexual activity, smoking, alcohol consumption, drug use, aggression and eating disorders (Hales and Barker 2012). Therefore, it is indicated that early onset of puberty is linked with an increase in adolescent morbidity and overall poorer health decisions (Mendle and Ferrero 2012). Chronic illness has the potential to have a significant influence on this process of maturation and the transition of this population into adulthood. Evidence for this is clear in diabetes, in which increasing hormone levels cause insulin resistance (Suris et al. 2004). Physical development includes noticeable changes to the body and increased growth of hormone secretion that causes insulin resistance (Al-Agha 2014). Therefore, insulin requirement increases during puberty. Adolescents with T1DM might need intensive insulin therapy with multiple doses of insulin or Continuous Insulin Infusion Therapy (CIIT) to achieve optimal glycaemic control (Patton and Viner 2007; Tfayli and Arslanian 2007; Bhakthavalsala 2008). In addition, adolescents with T1DM may experience growth delay and/or pubertal delay as a result of poor glycaemic control and associated complications (Assar et al. 2015; Virmani 2015). Furthermore, there are significant insulin differences between adolescent boys and girls due to pubertal hormones (gonadal) (Weisfeld 1999). Due to body composition changes and an increased percentage of fat, girls develop a greater insulin resistance than boys (Greene and Greene 2008). Usually, adolescents experience increased hormonal levels and emotional difficulties that change their behaviour and may result in denial, indifference

or depression about their chronic condition, placing them at increased risk of poor glycaemic control and neglecting their self-care (Carroll and Marrero 2006).

Eating disorders are more prevalent in the presence of T1DM (d'Emden et al. 2012; Young et al. 2013), particularly in female adolescents, when compared with the general population (Markowitz et al. 2010). This is partly due to the loss of weight before diagnosis and subsequent (and often unwelcome) weight gain after initiation of insulin, and the focus on diet, e.g. carbohydrate content of food, in the management of T1DM (Peterson et al. 2014; Smart et al. 2014). Co-existence of eating disorders and T1DM can deteriorate glycaemic control (d'Emden et al. 2013). In addition, a diabetes-related 'eating disorder' is well recognised, where intentional omission or under dosing of insulin is used as a weight control strategy (Young et al. 2013; Cameron et al. 2014).

Weisfeld (1999) states that as adolescents move into reproductive maturity, they tend to become preoccupied with the opposite sex and focus on their physical and social attractiveness due to mate selection and these factors can have a positive or negative effect on their self-esteem. Generally, adolescents with T1DM behave similarly to other young people but their sense of independence, body image, identity, sexuality and self-esteem may be adversely affected by the development and treatment needs of T1DM. Their self-image issues may conflict with the demands of diabetes self-management, such as administering a lunchtime injection and testing blood glucose or not wanting to test themselves when out with friends (Mulvaney et al. 2011). Restrictions on food or social activities may mean they are treated differently from others in the family, which increases the negative effects and conflicts that trigger psychological problems (Caccavale et al. 2015).

### 1.11.2 Cognitive changes and adolescents with T1DM

The physical changes associated with puberty also affect the brain, aiding cellular signalling pathways and increasing numbers of vascular cells (Krause et al. 2006). Therefore, puberty is also associated with brain development, and in particular enhanced cognitive function. Blakemore et al. (2010) have suggested that hormonal events during puberty may also affect the structure and function of the human brain. The prefrontal cortex – where executive control is observed including decision-making, multitasking and self-awareness, planning and emotional regulation – undertakes the most prolonged development. These changes may be able to clarify the gradual rise in self-control as an adolescent (Shaw et al. 2008). Conversely, the limbic system, the system that is accountable for reward processing, appetite and pleasure seeking, develops far earlier (Casey et al. 2008). The imbalance in the development of the prefrontal cortex and limbic system occurs during adolescence. The observed increase in risk-taking behaviours, some of which may be health-compromising, may be attributable to a discrepancy that would favour emotion and reward over the rational decision (Casey et al. 2008).

During this period, adolescents can gain and consolidate many positive health behaviours, such as nutrition and exercise; however, they may also gain negative health behaviours, such as smoking, alcohol and drug use, and unsafe sexual practices. With cognitive development, adolescents with T1DM are usually able to use a future perspective and can consider the long-term implications of their behaviours. However, evidence shows that many adolescents have poor glycaemic control (Chaney 2012). They become less dependent on their families and more competent in making their own decisions (Chaney et al. 2010). Furthermore, adolescents often show a combination of three skills when using formal operational thought: they emphasise possibilities rather

than realities; they use scientific reasoning to solve a problem systematically; and they combine ideas logically and skilfully (Seifert et al. 2000). Consequently, they become more able to solve their diabetes problems in relation to self-care management. However, short-term cognitive impairment, due to hypoglycaemia and hyperglycaemia, affects self-management behaviour, such as the adjustment of insulin doses (Williams et al. 2002). Although it is essential to provide adolescents with information regarding the importance of self-management and adherence to a diabetes regimen, may be insufficient in leading them to adopt optimal diabetes management (Cameron et al. 2014). Other factors that influence self-care, emotional well-being, and glycaemic control are environmental support, motivation, encouragement for learning, and physical growth processes (Channon et al. 2007).

### 1.11.3 Psychosocial changes in adolescents with T1DM

Psychosocial development is a critical period in adolescence. During this stage, adolescents are expected to discover their identity, obtain a stable personality, and learn to cope with different behaviour problems (Meeus 2016). Adolescence is also a time when adolescents are seeking autonomy.

Erikson (1968) theory describes the impact of social experience across the whole lifespan. Erikson was interested in how social interaction and relationships played a role in the development and growth of human beings. In Erikson's theory, the psychosocial developmental stage (identity vs confusion) plays a significant role in developing a sense of individual identity, which will continue to influence behaviour. The content of identity and identity achievement depends on experiences and opportunities within the social environment (Saewyc 2007). Zimmer-Gembeck and Collins (2003) define autonomy as self-governance or self-determination. Karabanova and Poskrebysheva (2013) explain the accomplishment of personal autonomy as the ability to set life goals,

carry out personal, free choices and gain self-confidence, which are seen as essential tasks of adolescence.

Adolescents with T1DM are at higher risk of psychological problems, particularly internalising behavioural problems, such as depression (Maas-Van Schaaijk et al. 2013). Diabetes mellitus and depression often co-occur in adolescence. Diabetes significantly increases the risk of depressive symptoms, even in adolescents with good diabetes control. Depressive symptoms have been associated with poor diabetes-related health outcomes, such as less effective glycaemic control and frequent diabetic ketoacidosis (Hood et al. 2006; McGrady et al. 2009; de Wit et al. 2012). Stress also has a particular impact on the diabetic outcomes of adolescents with T1DM. Stress can affect diabetic control both directly and indirectly: directly through its influence on cortisol and other catabolic hormones that interfere with insulin metabolism, and indirectly by interfering with the completion of self-management responsibilities (Ashraff et al. 2013).

Moreover, emotional problems such as distress, anxiety, and anger have also been found to produce negative diabetes outcomes (Adal et al. 2015). Adolescents who have T1DM as well as emotional problems and depressive symptoms are at a high risk from poor coping and problem-solving skills, problems with self-management and, consequently, poor diabetes outcomes (Helgeson et al. 2009; Zheng and Chen 2013). These psychological problems and their negative consequences in adolescents with T1DM necessitate special attention to understand how these problems effect self-diabetic management in schools. Other psychological challenges include teasing, bullying or feeling isolated from their non-diabetic peers, eating disorders, fear of hypoglycaemia, and family conflict.

Adolescents with T1DM encounter several other challenges in the different areas that can affect diabetes outcomes, such as the medical and academic domains. Medical

challenges include carbohydrate counting and medication administration, multiple daily insulin injections or continuous subcutaneous insulin infusions (via an insulin pump), and regular monitoring of blood glucose. Academic challenges include specific attention in the classroom and during examinations, planning extracurricular events, and weakening of cognitive function during episodes of hypoglycaemia or hyperglycaemia (Storch et al. 2006; Wagner and James 2006; Kakleas et al. 2009; Jaser 2010; Young et al. 2013).

### **1.11.4** Peer support and adolescents with type 1 diabetes

A peer is an individual who is of equal standing with another and who belongs to a specific social group, sharing distinct characteristics with this group (Doull et al. 2005). For the purposes of this study, peers are all adolescents who share the same school. Peer relationships are considered to be one of the most important elements of adolescence (Brown and Larson 2009). However, it can be difficult for adolescents with T1DM, since adolescents like to be seen as the same as their peers and not be treated differently because of their diabetes (Damião and Pinto 2007). Fear of non-acceptance by the peer group may make adolescents hesitant to reveal their condition. This fear may also cause adolescents with T1DM to intentionally neglect their insulin injections or blood monitoring (Grey 2011). Peer relations in adolescence often constitute the socialisation that they build and in which they express their identity. The communication of adolescents and their stylistic practices and experiences with each other is called peer culture. The use of language is a key feature of peer culture that creates in-groups and out-groups (Thurlow 2005). Peer culture is defined as a stable set of activities or routines, things, principles and concerns that adolescents produce and share in contact with peers (Qvortrup et al. 2009)

Peer relationships depend on the appearance, popularity and leadership of dominant adolescents (Weisfeld 1999). However, body image is a primary element of adolescent peer evaluation. Therefore, adolescents whose pubertal development is delayed or who feel unattractive may tend to have severe psychological problems (Moules and Ramsay 2008) Similarly, insulin injections and blood glucose testing affect adolescents' perceptions of their body image, and because insulin requirements and glucose profiles may vary on a day-to-day basis, these routines place significantly greater demands on adolescents with T1DM (Berg et al. 2014). Commonly, adolescents may experience anger or denial regarding the restrictions that differentiate them from their peers, as well as emotional difficulties regarding the condition and its management at school. These difficulties may cause psychosocial problems, such as isolation, rebellion and risky behaviour that reduces adherence to management schemes (Tilden et al. 2005). Thus, many adolescents with T1DM have a higher risk of longer-term psychiatric morbidity, such as depression and eating disorders, compared to their peers (Kyngäs 2007).

Peer relationships are linked to diabetes outcomes in adolescents with T1DM. The instability of peer relationships during adolescence could be a source of stress that has an immediate effect on metabolic control (Helgeson et al. 2009). Positive relationships and greater participation and caring from peers can lead to improved glycaemic control among adolescents with T1DM (Helgeson et al. 2007). Friends and peers have been found to be an essential resource of emotional support for adolescents with diabetes, which can lead to better adherence and metabolic control (Ashraff et al. 2013). Boosting the contribution of peers and friends leads to raising self-confidence and social acceptance in adolescents with T1DM, which can result in better regimen adherence (Kazemi et al. 2016).

# 1.11.5 Self-management and glycaemic control among adolescents with type 1 diabetes

Self-management is an active process in which individuals actively manage a chronic illness (Schulman-Green et al. 2012). The main concept in self-management is self-efficacy, which is the confidence and belief in one's ability to perform the behaviour necessary to reach the anticipated goal (Bodenheimer et al. 2002). Self-efficacy is enhanced when patients succeed in solving patient-identified problems. Self-management has become a popular term for behavioural interventions as well as for healthy behaviours. It comprises three self-management tasks: medical management, and emotional management. It also comprises six self-management skills: problem-solving, decision-making, resource utilisation, the formation of a patient-provider cooperation, action planning, and self-tailoring (Lorig and Holman 2003).

Throughout the diabetes literature, self-management is often used interchangeably with such terms as adherence. Schilling et al. (2009) explain the differences between the two concepts to clearly understand how adolescents with T1DM care for their disease. Adherence is defined as the extent to which an individual follows medical guidance (Brown and Bussell 2011), whereas self-management has several dimensions that include activities and processes of collaboration among adolescents, parents, and care providers that help adolescents to move toward the goal of assuming full responsibility for managing their diabetes. Self-management also extends to comprise knowledge and self-regulation, beliefs, skills and abilities, and social facilitation (Grady and Gough 2014).

Self-management is an essential component of diabetes care. However, this can be challenging in adolescence, as this phase includes physical, emotional, and social

pressures. Adolescents' self-management of T1DM requires them to check their blood glucose levels on a continual basis, monitor their diet, increase their physical activities, and administer and adjust their insulin dosages. These diabetes-related stressors can cause emotional distress, such as feelings of anxiety and frustration (Grylli et al. 2005; Helgeson et al. 2012; Nieuwesteeg et al. 2012). Stress may affect an adolescent's ability to perform self-management tasks, resulting in poor metabolic outcomes (Jaser et al. 2012). Therefore, self-management has also become a common phrase for health and emotional management and comprises behaviour modifications and learning problemsolving skills as well as how to cope with stressful circumstances (Lorig and Holman 2003). Shrivastava et al. (2013) have identified vital self-management attributes in patients with T1DM that can lead to favourable diabetic outcomes, including healthy diet, exercise, regular monitoring of blood sugar, adjusting and administering insulin dosage (via injections or an insulin pump), healthy coping skills, problem-solving skills, and risk-reduction behaviours. These attributes are important in achieving health and emotional management.

Petitti et al. (2009) point out that self-management tasks are not easily achieved or maintained by adolescents. For adolescents with T1DM, adolescence is often linked with poorer self-management and worsening metabolic controls (Greening et al. 2007; Delamater 2009; Hsin et al. 2010; Murphy et al. 2012). At this age, the prefrontal cortex, the area of the brain that controls judgement, reasoning, decision-making, and problem-solving, is still developing, which may explain why many adolescents react inadequately to complex diabetes self-management circumstances (Wang et al. 2010). The capacity of adolescents to make sound judgements amid difficult situations will not be at the maturity level of an adult, as the prefrontal cortex that controls many higherorder skills is not yet completely developed until the third decade of life (Siddiqui et al. 2008). Moreover, the critical transition to adolescence has the possibility of negatively

affecting self-care management because of increasing independence from the family (Rausch et al. 2012).

Another reason for self-management tasks not being easily achieved or maintained by adolescents with T1DM is, according to Borus and Laffel (2010) and Peters et al. (2011), often due to fatigue from taking care of a chronic illness and major psychosocial issues, which generate obstacles to diabetes self-care. Pyatak et al. (2014) found that adolescents with T1DM with a history of major psychosocial life stressors, such as anxiety disorders or unstable interactions with family and peers, may be more likely to experience deterioration in glycaemic control. Adolescents with T1DM encounter the extra challenge of trying to improve glycaemic control while experiencing the physiological and psychological changes of puberty (Ridge et al. 2014). Many adolescents still do not achieve HbA1c levels low enough to prevent diabetic complications. Data from the UK National Diabetes Audit indicates that around 17.7% of children and young people with T1DM have an HbA1c below 7.5%, and approximately 30% have an HbA1c >9.5% (Marcovecchio et al. 2010). The following section will focus on the stressors faced by adolescents with T1DM in the school setting in more details.

## **1.12** Stressors in the School Setting

As with other adolescents, those with T1DM spend long hours in school and, therefore, diabetic self-management at school needs to be optimal in order to prevent deterioration in metabolic control. An integrative review conducted by Tolbert (2009) examined 11 research studies that explored the care of students with T1DM in school (aged 3 to 18) in the USA. The findings identified a need for improvement in the following areas: communication between school staff and parents, after-school support, education of staff, education about managing students with T1DM, school nurse availability, and

lunch choices. A descriptive qualitative study conducted by Freeborn et al. (2013) in the USA used focus groups of parents with children and adolescents with T1DM to understand their experiences in the school setting. The study identified a number of school challenges faced by children and adolescents with T1DM, including a lack of school staff cooperation, a high level of carbohydrates offered in the school cafeteria, hypoglycaemia during physical education classes, and the unfamiliarity of classmates with T1DM. Another study, conducted by Schwartz et al. (2010), sought to evaluate the experience of children and adolescents with T1DM and involved the participation of 20 schools in the USA. The study surveyed school-age children and adolescents with T1DM (kindergarten to 12<sup>th</sup> grade), their parents, and the school staff (e.g. school nurses, educators, and administrators). The study identified several issues, including a lack of diabetes training in educators, a shortage of trained personnel, a lack of standardisation related to individualised diabetes care plans for each child or adolescent with diabetes in certain school systems, embarrassment and emotional distress due to diabetes-related issues, such as checking blood glucose or taking insulin injections, feelings of disconnectedness, and a lack of nutritional information provided to parents by schools in order to assist parents in planning insulin-dosing requirements. Schwartz et al. (2010) also highlight the need to continue improving the experiences of children and adolescents with T1DM in the school setting and recommend that schools conduct diabetes education programmes for school personnel on an annual basis. They also recommend considering the special physical and psychological needs of children and adolescents with T1DM.

A qualitative study, using Heidegger's hermeneutic phenomenological approach, was carried out by Wang et al. (2013). Semi-structured interviews were used to collect data to explore the school-based experience of 14 Taiwanese adolescents with T1DM. The participants' ranged between 12 and 16 years old and were studying either at a public or

private junior high school. The study indicates a number of interrelated themes including adolescents with T1DM being confused about their identities and whether they are similar to or different from their peers/classmates (similar yet different), adolescents with T1DM having doubts about whether or not to tell their peers about their diabetes mellitus, whom to tell, how much to tell, how to tell, and how to answer others' enquiries (covert and overt), adolescents expressing concerns that parents were not happy about their children having complete autonomy over their diabetes management (independent and dependent), and, finally, adolescents' awareness that many distractions might have resulted in them not following the diabetes management guidance, particularly related to foods and especially sweets (being derailed and being on track). These challenges lead to some adolescents mishandling their conditions, such as delaying checking their blood glucose, neglecting insulin injections at the required time, following unreliable diabetes meal plans and physical exercise routines, and engaging in high-risk behaviour (Abualula et al. 2016).

Wang et al. (2013) recommended that significant work still needs to be carried out to enhance school management sufficiently in order to support adolescents with T1DM. In this sense, they state that considerable effort remains to be made in order to improve the experience of adolescents with T1DM in school.

A recent qualitative study was conducted in the UK (Spencer et al. 2014) to investigate the influence of the social environments of adolescents with T1DM and their possible impact on glycaemic control. An interpretive phenomenological approach using indepth interviews was used to explore the experiences of adolescents with T1DM and their parents. The study focuses on the school setting as well as three others (the home, clinic, and social settings) and provides discrete information regarding challenges faced by adolescents with T1DM in schools in the UK. Twenty-seven adolescents with T1DM aged 13–16 from a paediatric diabetes clinic were interviewed about their experiences

in defined environments, such as home, school, the diabetes clinic, and with friends. The study highlights the importance of understanding the environmental facilitators and boundaries to self-management in order to comprehend the difficulties related to adolescents' self-management behaviour and its influence in glycaemic control. In the school setting, adolescents with T1DM and their parents expressed that more awareness from teachers about diabetic self-management would make it easier for adolescents with T1DM and would allow parents to feel confident that their child was in a safe and supportive environment when at school. The interview findings regarding the school environment also revealed that performing diabetes tasks caused adolescents with T1DM to feel different from their friends. Many adolescents described situations in which they had been questioned over treating an episode of hypoglycaemia. Furthermore, adolescents with T1DM explained that a hypoglycaemia episode had affected their concentration in school and affected their motivation towards taking part in school activities. Understanding the lived experiences of adolescents with T1DM within the social and cultural contexts of school offers a good opportunity to learn about the important factors that may influence adolescents' self-management in school. Adolescents spend a considerable amount of time at school. As a result, it is important to ensure that diabetes self-management can occur safely within school settings (Silverstein and Patrick 2007), as the school environment may have a significant impact on overall diabetes control (Faro et al. 2005). According to Melton and Henderson (2007), schools are important settings for secondary prevention interventions to assist children and adolescents reduce the risk of complications from diabetes. Some policy documents in the UK from Diabetes UK, the National Institute for Health and Clinical Excellence (NICE, 2015) guidelines, and the International Society for Paediatric and Adolescent Diabetes (ISPAD, 2014) set clear frameworks within which schools can work safely with students with T1DM. These guidelines provide general information

about diabetes mellitus in addition to providing a set of responsibilities for the headteacher, teachers, and school personnel towards children and adolescents with T1DM. However, unfortunately, a significant disparity in practice has been found among schools and between care providers themselves (Boden et al. 2012; Matyka 2014). It may be that diabetes management in educational settings can be a significant source of worry for children, adolescents, and their families. An exploratory study conducted by Fisher (2006) to measure school nurses' perceived self-efficacy in providing diabetes care and education to students with T1DM found that the surveyed school nurses perceived a moderate level of self-efficacy in caring for children and adolescents with T1DM. In addition, Fisher (2006) argues that, since the number of children and adolescents with T1DM continues to increase, it is important to assist school nurses in developing the confidence and skills to care for children with diabetes in the school setting. In addition, Marshall et al. (2013) studied the role of school nurses in supporting the care of children with diabetes in schools in the UK, with 47 nurses representing all four countries of the UK and a range of rural and urban settings involved in the study. The researchers found that there was uncertainty and inadequate legal and other national guidelines produced by Diabetes UK and the Royal College of Nursing. Moreover, there was irregularity in schools' responses towards the level of collaboration that should be provided by teachers to support diabetic care in schools, problems in creating support for diabetic children, a lack of evidence-based practice regarding diabetes management, and differences emerging from variabilities regarding best practice in the UK. Dowling (2014) also highlights that, although some schools in the UK have good procedures in place, there are still too many examples of children with T1DM not getting the support they need at school. This can include a lack of support during the administration of insulin or checking their blood glucose level or not being allowed snacks in class to treat low blood glucose levels. She also emphasises that

it is important for students with T1DM to be as healthy and safe as possible at school, given that T1DM is a serious medical condition and, if not managed carefully, it can lead to the blood glucose levels going either hazardously high or hazardously low.

The findings of the above studies imply that not all schools are equipped to support students with T1DM. Diabetic care for adolescents with T1DM in schools may vary by country, but the emergence of similar issues from various countries suggests that this needs more in-depth exploration. Moreover, diabetes care has changed considerably over recent years. Extra frequent testing and injecting, as well as an increased usage of insulin pump therapy, demands more support in schools than ever before. Therefore, it is important to continue working on how to improve diabetic management in school settings. Understanding the most pressing challenges, needs, and priorities of adolescents with T1DM in schools will direct professionals to plan more effective interventions in order to enhance self-management in school settings. The Children and Young People's Health Outcomes Forum published a report in 2015 that suggests critically evaluating the specific needs of children and young people. In addition, the forum recommends involving children and adolescents when designing health services, as children and adolescents can provide useful insights into their social worlds (Gardner and Randall 2012). Glasper (2012) points out that new approaches are necessary in order to confirm that the opinions of children and adolescents are recognised throughout the whole of the health system.

## 1.13 Conclusion

Physical, psychosocial, and emotional challenges play significant roles in adolescents' diabetes outcomes. Diabetes care, in particular, is greatly influenced by these challenges when they affect adolescents' abilities to self-manage the disease and reach metabolic control. Moreover, these challenges can increase the disease load and can cause even

more distress, leading to increased risk of diabetic complications. The school is a critical environment for adolescents with T1DM. Enhancing self-management in school is important in order to empower adolescents with T1DM in managing the day-to-day requirements of their disease. Understanding and incorporating adolescents' needs and priorities and involving them in decision-making regarding their health is important for improving the quality of the health care experience among adolescents with T1DM in schools.

# **CHAPTER 2:** LITERATURE REVIEW

# 2.1 Introduction

This chapter explains the process of the literature search strategy and then provides a detailed critical evaluation of the papers selected in addition to a brief set of conclusions resulting from the literature analysis. Finally, the research justification, questions, aim, and objectives will be stated.

## 2.2 Literature Search

A literature review is a vital step for any academic research in order to identify all of the published literature relating to a particular area (Levy and Ellis 2006; Machi and McEvoy 2016). The initial steps before starting a literature review include creating a well-focused question, finding the sources of information, and selecting a suitable critiquing tool (Havard 2007).

The search strategy was influenced by the need to explore the current literature on interventions that have been developed for adolescents with T1DM in school. The literature review methodology involved targeting national and international English language peer-reviewed literature for the period spanning 2000 to the present.

The literature review commenced by asking questions followed by defining a search strategy to include search terms and inclusion and exclusion criteria. To ensure an adequate review was carried out, the researcher first engaged in a scoping exercise to determine the search terms, recording and collating all the terms that could be relevant. The researcher then identified and selected potentially relevant studies. Following this, the selected studies were appraised based on four questions:

- 1. What school-based diabetes interventions have been developed?
- 2. What are the components of the school-based diabetes interventions?
- 3. To what extent were adolescents with T1DM involved in the development of the school-based interventions?
- 4. To what extent were the needs and priorities of adolescents with T1DM addressed in the developed interventions?

Different electronic databases were searched, including PubMed, PsycINFO, Cochrane Library, CINAHL, Social Science, Delphis, Medline, and different search engines (e.g. Google Scholar). Further searches were based on bibliographical information from relevant articles and 'grey literature', e.g. conference papers and unpublished reports. Furthermore, manual searches of journals and articles were undertaken in order to gather all relevant reviews. The database was searched using the Medical Subject Headings (Mesh) and keywords and their combinations (see Table 1).

The main keywords used were: type 1 diabetes, adolescents, schools, and intervention

| Торіс        | Keywords                                                                                                                                                                                                                                                                | Database                                                 |  |
|--------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------|--|
| Condition    | 'Type 1 diabetes mellitus', 'Type 1 diabetes', 'Type 1<br>diabetes mellitus in children adolescents', 'Diabetes',<br>'Diabetes mellitus', 'Type 1', 'Diabetes mellitus Type 1',<br>'Diabetes Type 1', 'T1DM', 'Diabetes insipidus', or<br>'Insulin-dependent diabetes'. | PubMed, PsycINFO,<br>Cochrane Library,<br>CINAHL, Social |  |
| Population   | 'Adolescents', 'young people', 'young adults or<br>teenagers', 'youth', 'children', 'juvenile', or 'school age'.                                                                                                                                                        | Science, Delphis,<br>Science Direct,                     |  |
| School       | 'School', 'educational setting', 'secondary school', or 'school-based'.                                                                                                                                                                                                 | Medline, and different<br>search engines (e.g.           |  |
| Intervention | 'Intervention' or 'programme'                                                                                                                                                                                                                                           |                                                          |  |

### Table 1: Keywords

### 2.2.1 Study selection

Although the search terms were very precise, the search still identified a large number of studies. However, studies were screened and discarded based on the inclusion and exclusion criteria (see Table 2). Potentially relevant articles were retrieved and analysed for study eligibility (see Figure 1). Reference lists from potential articles were also considered and searched to find more information for answering the search questions stated above.

| Inclusion criteria                                                                                                                                                                                                                   | Exclusion criteria                                                                                                                                                                                                                                                                                                       |  |  |  |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--|--|--|
| <ul> <li>Studies published in English in peer-<br/>reviewed scientific journals</li> <li>Intervention focusing on type 1<br/>diabetes mellitus</li> <li>School-based intervention</li> <li>Studies focused on adolescents</li> </ul> | <ul> <li>Studies not published in English</li> <li>Studies focusing on outside the school setting, such as at home or paediatric centres or summer camps</li> <li>Studies focusing on other types of diabetes</li> <li>Studies focusing on diabetes prevention programmes, such as lifestyle or risk factors.</li> </ul> |  |  |  |

#### Table 2: Inclusion and exclusion criteria

### 2.2.2 Search results

The preliminary search generated a total of 398 studies across all databases, which were then subjected to further screening. Two hundred and fifty duplicates were removed, and 148 titles and abstracts were reviewed. The primary results were evaluated against the inclusion/exclusion criteria, with a review being identified from its title and abstract. Then, in the second phase, a full-text version (n=120) of the publication was obtained and checked. As a result, only 17 studies were selected: two systematic reviews Edwards et al. (2014); Pansier and Schulz (2015) and 15 primary studies. Although all

the primary studies identified were included in the systematic reviews, it was necessary to individually evaluate them in order to answer all the search questions stated above. However, care was taken not to 'double count' when reporting the study findings.

### 2.2.3 Quality assessment

The quality of the selected studies was evaluated by using the Critical Appraisal Skills Programme (CASP) framework, which helps to evaluate the validity, results, and relevance of the selected studies before using them as evidence. CASP was developed by the Public Health Resources Unit in 2006. It provides a set of high-quality appraisal tools to help practitioners develop the skills required to locate a sense of research evidence (Foyle and Hostad 2010).

CASP consists of different frameworks to critique various types of research (i.e. systematic reviews and qualitative or quantitative studies). The selection of the CASP framework depends on the type of research study being critiqued. It consists of ten questions to assist the researcher in making sense of systematic reviews as well as qualitative and quantitative research studies. In this study, the CASP framework for systematic reviews was selected as all the primary studies found were included in the systematic reviews.



Figure 1: Literature search flow chart for search method and results

## 2.3 School-Based Intervention

In this section, the researcher will begin to discuss the two systematic reviews conducted by Edwards et al. (2014) and Pansier and Schulz (2015). Edwards et al. (2014) performed a detailed mixed-method systematic review focusing on ways to achieve the most appropriate degree of self-management of T1DM in children and young people during their time in educational settings. The review objectives were as follows: firstly, to review the effectiveness of the interventions conducted to enhance management and care for children and adolescents with T1DM in the educational setting; secondly, to explore the experiences of children and adolescents and those involved with their care and management in the educational settings; and finally, to conduct an overarching synthesis of both the above-stated objectives to determine the level to which interventions tackle the challenges identified by children/parents or teachers and to build on the facilitators for offering optimum care and management for children and adolescents with T1DM. The review designs of the study of Edwards et al. (2014) were informed by the evidence for policy and practice information and coordination centre (EPPI-Centre), utilising a mixed-method triangulation approach (Oliver et al. 2005).

The systematic review of Edwards et al. (2014) was split into two main streams: stream one (intervention studies n=11) focused on studies reviewing the effectiveness of interventions; the focus of stream two (non-intervention studies n=55) was on the experiences and barriers faced by children with T1DM in schools.

The inclusion criterion for stream one (intervention studies) was that all interventions to promote the management of diabetes in a school setting in any country were considered. For stream two, all interventions that explored the views of participants (i.e. children, adolescents, parents, or teachers) were examined. In stream one, studies were excluded

if there were no before and after measures. For stream two, studies that did not obtain the views of children and adolescents, parents, or professionals were excluded.

The quality of the randomised studies included in stream one was assessed using the criteria developed by Kirk and Stegner (2010), which involves, for example, assessing the adequacy of randomisation, the blinding of outcomes, the use of power calculation, the length of follow-up, and the identification of confounding factors. The quality of non-randomised studies in stream one was assessed based on the work of Deeks et al. (2003), which involves, for example, assessing how the treatment group was created and assessing the comparability of the intervention comparison groups at the analysis stage. The quality of stream two (non-intervention) studies that utilised surveys was assessed by using a checklist developed by Rees et al. (2010). Other qualitative studies in stream two were assessed by using the appropriate checklist from CASP.

The 11 intervention studies in stream one (intervention studies) were further split into studies concerned with: 1) supporting children with T1DM (five studies); and 2) those focusing on the effectiveness of school personnel (six studies). The design of the studies conducted to support children and young people were two randomised controlled trials (RCTs) (Nguyen et al. 2008; Izquierdo et al. 2009), one controlled trial (Wdowik et al. 2000), and two before and after studies (Faro et al. 2005; Engelke et al. 2008). The design of the studies involving school personnel was one RCT (Husband et al. 2001), one before and after study (Siminerio and Koerbel 2000), two analogue experiments (Wodrich 2005; Cunningham and Wodrich 2006), one cohort study (Bullock et al. 2002), and one programme evaluation (Bachman and Hsueh 2008). Four of the studies focused on children and young people with T1DM, and the samples included children from 5–13 years old (Izquierdo et al. 2009), 5–19 years old (Engelke et al. 2008), 11–16 years old (Nguyen et al. 2008), and 5–11 years old (Faro et al. 2005). A further six

studies that focused on school personnel involved school nurses and school teachers (Bachman and Hsueh 2008), only school nurses (Bullock et al. 2002); (Bachman and Hsueh 2008), or only teachers (Siminerio and Koerbel 2000; Husband et al. 2001; Wodrich 2005). All intervention types (11 studies) had the common goal of optimising the self-management experience of children with T1DM in educational settings. Only two out of the 11 intervention studies were reported as theory-based intervention studies. The study of Faro et al. (2005) was based on developmental theory and social learning theory, while Wdowik et al. (2000) was based on social learning theory. Ten of the studies were conducted in the USA, and one was conducted in Canada.

Intervention studies conducted to support children and young people involved nurses assisting with the case management and supervision of glucose and insulin-dose adjustments, telemedicine and diabetes visit interventions, and the production of health plans, in addition to monthly visits by paediatric nurse practitioners and individual meetings with a diabetic educator.

Interventions delivered to school personnel involved online education about diabetes management, compact CD-ROM teaching tools, the '5Cs of diabetes' (cause, classification, complications [acute and chronic], care, and cure), and reading materials about diabetic mellitus or didactic lecture presentations delivered by diabetes educators. All the reviewed interventions in the above study had the overarching aim of supporting children to self-manage some specific aspects of their T1DM in schools, educating and raising awareness amongst school staff and related health care professionals, and improving communication channels between diabetes specialists. The review of intervention studies concluded that health plans and support from school nurses proved to be effective, while telemedicine also proved effective for individual case management. In the short term, education-based interventions were useful for

improving the confidence of school staff and children, but they needed to be followed up over a longer period to gauge their overall effectiveness.

It was not considered appropriate to undertake a meta-analysis in this instance, as the tools and study designs across the review were not undertaken in the same way, so heterogeneity was an issue. There was only a 'moderate' level of confidence in the ability to transfer the findings to settings other than those described in the studies (i.e. principally in the USA), which proved to be a significant restriction on the findings. In addition to this, concerns relating to methodologies, such as a lack of details in regard to the randomisation process or power calculations, made it harder for the findings to be transferred to other settings. Also, no details on whether an intention to treat (ITT) analysis was undertaken or identification of any confounding factors were included.

A review of the findings derived from the studies in stream two (focusing on the barriers and experiences of the children) indicated many barriers within the school setting, such as the absence of emergency plans to care for T1DM students, not having a designated person to check students' blood glucose throughout the school day and administering the necessary insulin or nurses to supervise children during physical education lessons. Further, diabetic children also reported negative emotional and social experiences, such as feeling different from their peers, experiencing embarrassment in the event of hypoglycaemia (Tang and Ariyawansa 2007; Schwartz et al. 2010), having to check their blood glucose or take medication at school, and being bullied for their condition (Wilson and Beskine 2007). Despite that the review concluding that stream one's studies' findings were not transferrable, quite the opposite was found with the studies in stream two.

After conducting the systematic review, Edwards et al. (2014) noted significant gaps between children's and parents' views on the barriers to the desired degree of self-

management in schools, which are explained in the diabetes guidelines for schools to support children and young adolescents with T1DM, in addition to their evaluations of the various interventions designed to remove or break down these barriers. There was no feedback system to ensure compliance with the guidelines, and there was a lack of the translation of guidelines and monitoring of school practice towards children and adolescents with T1DM. The school interventions provided additional support for children with T1DM in the school setting and increased the knowledge and awareness of school personnel and nurses but not school peers. However, the review has limitations, as none of these studies explored cost effectiveness. The review highlights the need to identify more cost-effective solutions, such as providing additional school reading materials or peer support in the school setting. Also, all the intervention studies have been implemented either in the USA or Canada. Further, the psychosocial issues and negative emotional thoughts and experiences that students had reported were underrepresented in school-based interventions.

Pansier and Schulz (2015) conducted a systematic review of 15 studies focusing on school-based diabetes interventions, nine of which were also referred to in Edwards et al. (2014), and their outcomes during the period 2000–2013. The key questions at the centre of the review were twofold: the school-based diabetes interventions that had been applied in that period and their results. Studies involving educational interventions on diabetic management to school staff and studies focusing on children with diabetes to enhance their well-being were brought to the forefront.

Similarly, the review by Pansier and Schulz (2015) distinguished between intervention studies targeting school personnel in focusing on diabetes knowledge and diabetes education (n=7) and studies focusing on improving the health and well-being of children with T1DM (n=8). All the studies in this review were conducted in North America. The main objectives of the studies focused on school personnel (i.e. school

nurses or school teachers) were to increase confidence in caring for students with T1DM and to improve diabetic knowledge. These interventions included continuing diabetes education via face-to-face training and CD-ROM computer-based or online-based education. All the studies reported an overall satisfaction with the training provided and demonstrated gains in perceived knowledge.

The other eight studies in this review offered a more inclusive approach to enhancing management in school and creating a safe environment for students with T1DM. These interventions included case management, telemedicine, collaborative approaches to diabetes management, and counselling and coordinating with families. Indicators such as quality of life and HbA1c levels were used, as these intervention studies intended to enhance the diabetes management and well-being of students with T1DM in their school. Studies that measured HbA1c levels in children noted that there had been a shift towards improving children's lives. This review highlights the importance of evaluating school-based interventions. The more reviews that are conducted in this area, the better the platform will be to influence diabetic management in schools.

This systematic review experienced similar transferability restrictions due to large heterogeneity issues, as a mixture of quantitative and qualitative methods were used for a range of different designs. Heterogeneity of measured outcomes and measurement tools did not allow for the statistical pooling of results. In addition, the use of nonvalidated scales and small sample sizes do not provide enough evidence on the effectiveness of the interventions. All studies having been conducted in North America make it difficult to generalise findings to other parts of the world.

The systematic literature review by Pansier and Schulz (2015) does not ultimately offer direction towards the best school-based diabetes interventions because of the methodological issues. However, it demonstrates that growing efforts are being made

and highlights the importance of conducting detailed planning and evaluations of school-based interventions for students with T1DM as well as the necessity for additional thinking about long-term outcomes that reflect the nature of the interventions and how they can best be measured.

In this section, a summary of all the primary studies included in the aforementioned systematic reviews by Edwards et al. (2014) and Pansier and Schulz (2015) were evaluated by the researcher in order to explore further the intervention purposes, attributes, targeted group(s), outcomes, and the main focus of the interventions. This evaluation was also carried out to determine the extent to which adolescents with T1DM were involved in developing these interventions or whether their priorities and needs for the components or approaches were considered. Characteristics of the intervention studies included in both Edwards et al. (2014) and Pansier and Schulz (2015) are presented in Table 3. This table was formulated to synthesise the studies included in the systematic reviews of both Edwards et al. (2014) and Pansier and Schulz (2015), and to draw a conclusion about the above-mentioned characteristics (i.e. purposes, attributes, targeted group(s), outcomes, focus, and the extent of the involvement of adolescents with T1DM).

| Author and<br>date/place                                 | Name of the intervention                                         | Purpose of the<br>intervention                                                                                                                                                          | Attributes of the intervention                                                                                                                                                                                                                                       | Targeted<br>group   | Intervention outcome                                                                          | Main focus of the<br>intervention/extent of<br>involvement                                                                                              |
|----------------------------------------------------------|------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------|-----------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------|
| (Siminerio and<br>Koerbel 2000),USA                      | A diabetes education<br>programme for school<br>personnel.       | To assess the knowledge<br>level and needs of school<br>personnel and implement a<br>comprehensive education<br>programme.                                                              | Called the '5Cs of<br>diabetes', which<br>highlighted new<br>information in the areas<br>of cause, classification,<br>complications (acute<br>and chronic), care, and<br>cure.                                                                                       | School<br>personnel | Efficacious in educating school personnel.                                                    | School personnel<br>knowledge/teachers<br>needs were assessed.                                                                                          |
| (Bobo et al. 2011),<br>USA                               | The Healthy Learner<br>Model for Chronic<br>Condition Management | To support school nurses<br>and facilitate collaboration<br>between the family, school,<br>and healthcare provider.                                                                     | The programme<br>consisted of seven<br>elements: leadership,<br>evidence-based practice,<br>capacity building, the<br>chronic disease resource<br>nurse, healthy learners,<br>partnership with<br>families, and partnership<br>with health care.                     | School nurses       | Development of a<br>standardised approach and<br>website on diabetes<br>management at school. | Coordination and<br>collaboration between<br>staff, family, and<br>healthcare<br>providers/views of<br>parents, school nurse,<br>and students assessed. |
| Maibach EW et al. (;<br>Bachman and Hsueh<br>(2008), USA | Online diabetes<br>management education.                         | To pilot and evaluate an<br>online continuing<br>education programme for<br>school nurses about<br>diabetes management for<br>children in schools using<br>current practice principles. | Consisted of three<br>lessons: an overview of<br>diabetes in children and<br>an update on diabetes<br>management in the<br>school setting;<br>managing students with<br>insulin pumps; and the<br>role of the school nurse<br>in managing children<br>with diabetes. | School nurses       | Enhanced the nurses' ability<br>to manage the care of<br>children with diabetes.              | School nurse support;<br>management/<br>professionals and<br>school nurses were<br>involved.                                                            |

# Table 3: The intervention studies included in the reviews of Edwards et al. (2014) and Pansier and Schulz (2015)

| Bullock et al. (2002),<br>USA | Continuing education<br>programme          | To determine if attendance<br>at particular continuing<br>education courses<br>increased the perceived<br>competence of school<br>nurses who enrolled and<br>completed these courses,<br>compared with the<br>perceived competence of<br>school nurses who did not<br>participate. | The questionnaire<br>contained specific<br>learning objectives<br>based on the content of<br>continuing education<br>courses.                                                 | School nurses             | School nurses who attended<br>felt more competent than<br>school nurses who had not<br>attended the particular<br>offering.                                              | Competence of the school nurses involved.                                                  |
|-------------------------------|--------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------|
| (Engelke et al. 2011),<br>USA | Case management                            | To describe the care<br>provided to children with<br>diabetes by school nurses<br>using case management.                                                                                                                                                                           | School nurses<br>completed an expanded<br>health assessment.<br>Individualised goals<br>were established and<br>interventions were<br>provided on the basis of<br>a protocol. | School nurse/<br>children | Enhanced the health and<br>wellbeing of children with<br>diabetes. Improved quality<br>of life, particularly the<br>ability to communicate with<br>health professionals. | School nurses'<br>management/no<br>involvement.                                            |
| Engelke et al. (2008),<br>USA | School-based case<br>management            | To examine health and<br>academic outcomes for<br>children with chronic<br>illness who received case<br>management from school<br>nurses.                                                                                                                                          | Case management<br>included nursing care<br>directed towards the<br>child and coordination<br>and communication with<br>parents, teachers, and<br>other care providers.       | School nurse/<br>children | Improvement in academic measures.                                                                                                                                        | Role of school nurse in<br>relation to children<br>with chronic illness/no<br>involvement. |
| (Faro et al. 2005),<br>USA    | Periodic diabetes care<br>visits in school | To examine health and<br>academic outcomes for<br>children with chronic<br>illness who received case<br>management from school                                                                                                                                                     | 20 to 30-minute school<br>visits. The emphasis of<br>the conversations was<br>on the extent to which<br>blood glucose goals                                                   | Children                  | School nurses gained better<br>understanding of disease<br>management.                                                                                                   | Glycaemic control of<br>students with<br>T1DM/no involvement.                              |

|                                            |                                                                          | nurses. To perform<br>episodic diabetes care<br>visits in school, with the<br>aim of promoting optimal<br>management of diabetes<br>for high-risk youths.                                       | were being achieved<br>and, if not, how to<br>problem solve solutions,<br>including adjustments in<br>insulin dose.                                                 |                                        |                                                                                                 |                                                                       |
|--------------------------------------------|--------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------|-------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------|
| Husband et al.<br>(2000), Canada           | CD-ROM teaching tool                                                     | To increase knowledge about T1DM.                                                                                                                                                               | Knowledge about<br>hypoglycaemia and<br>hyperglycaemia.                                                                                                             | Teachers                               | Increased confidence in teachers' ability to care for a student with diabetes.                  | Teacher knowledge/not<br>clear.                                       |
| Izquierdo et al.<br>(2009) ,USA            | School-centred<br>telemedicine                                           | To improve education and<br>support for school staff<br>caring for children with<br>T1DM.                                                                                                       | Telemedicine unit in the<br>school nurse's office to<br>hold a video conference<br>between the school<br>nurse, the child, and the<br>diabetes team every<br>month. | School nurse/<br>children aged<br>5–14 | A school telemedicine<br>programme can improve<br>diabetes care.                                | School-based care<br>diabetes-related<br>education/no<br>involvement. |
| Nguyen et al. (2008),<br>USA               | School nurse<br>supervision of glucose<br>and insulin-dose<br>adjustment | To examine if supervised<br>blood glucose monitoring<br>and insulin injections at<br>school will improve<br>glycaemic control in<br>children and adolescents<br>with poorly controlled<br>T1DM. | The school blood<br>glucose records were<br>reviewed weekly, and<br>the subjects' insulin<br>doses were adjusted as<br>necessary.                                   | Children aged<br>11–16                 | Improved HbA1clevel in<br>children and adolescents<br>with poorly controlled<br>T1DM.           | HbA1clevel/not<br>mentioned.                                          |
| (Nimsgern and<br>Camponeschi 2005),<br>USA | A Resource Guide for<br>Wisconsin Schools and<br>Families                | To improve the school<br>staff's knowledge of<br>diabetes and its<br>management, as well as<br>their awareness of the<br>benefits of maintaining<br>glucose control.                            | Training sessions for<br>school professionals<br>were developed and<br>conducted around the<br>state.                                                               | School<br>professionals                | Identified concrete<br>solutions to deliver the best<br>diabetes management care<br>in schools. | Diabetic knowledge,<br>resources, and<br>policy/no involvement.       |
| (Radjenovic and<br>Wallace 2001), USA      | Computer-based<br>remote diabetes<br>education                           | To improve teachers'<br>knowledge about diabetes                                                                                                                                                | Web-based diabetes information using                                                                                                                                | School<br>teachers                     | Training via a web-based<br>system resulted in<br>significantly higher                          | General diabetic<br>education/not<br>mentioned.                       |

|                                          |                                                                         | management using computer audio and video.                                                                                                 | computer audio and video.                                                                                                                                                                                                                      |                                  | knowledge than a paper system.                                                                                                     |                                                                    |
|------------------------------------------|-------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------|------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------|
| (Smith et al. 2012),<br>USA              | Diabetes Education<br>Curriculum                                        | To evaluate the<br>effectiveness of a T1DM<br>education programme for<br>school personnel.                                                 | The 60-minute<br>educational session had<br>four main components:<br>overview of diabetes<br>pathology, monitoring<br>and treating diabetes<br>and hypoglycaemia,<br>dietary considerations in<br>diabetes, and exercise<br>and blood glucose. | School<br>personnel              | Increased knowledge and<br>confidence in caring for<br>students with diabetes.                                                     | General diabetes<br>information/school<br>nurse.                   |
| (Peery et al. 2012),<br>USA              | Nurse interventions in<br>children's self-<br>management of<br>diabetes | To examine the<br>relationship between<br>school nurse interventions<br>and parent/teacher<br>perceptions of a child's<br>self-management. | Case management from<br>school nurses. Class<br>visits to collaborate with<br>the student, parents, and<br>teachers to help the<br>child manage his/her<br>diabetes effectively.                                                               | Children                         | Improvement in a child's self-management.                                                                                          | Collaboration to<br>enhance self-<br>management/no<br>involvement. |
| Cunningham and<br>Wodrich (2006),<br>USA | Packet of information<br>about T1DM                                     | To examine the effect of<br>providing teachers with<br>varying levels of<br>information about T1DM.                                        | Basic summary of the disease and its effects on children in a school setting.                                                                                                                                                                  | Elementary<br>school<br>teachers | Providing teachers with<br>more information about<br>T1DM increased their<br>ability to accommodate a<br>student's learning needs. | Teachers' knowledge<br>about T1DM/no<br>involvement.               |
The researcher relied on published systematic reviews, Edward et al. (2014) and Pansier and Schulz (2015), as they provide recent and high-quality reviews. The researcher's search started in 2014 and it was updated in 2017 to see if any new pieces of evidence on this specific topic had emerged. All of the new studies found were on diabetes risk reduction or enhancing self-management in children and adolescents out of the school setting; therefore, they are outside of the focus of this study.

Another reason why the identified reviews were relied on is that the mixed-method systematic review conducted by Edward et al. (2014) was a comprehensive review that was informed by the mixed-method synthesis approach that was developed by the centre of Evidence for Policy and Practice Information (EPPI). The EPPI mixed-methods triangulation technique enabled the appropriate mapping of evidence from effective research studies (stream one: quantitative data) together with evidence from research findings reporting the experiences and attitudes of research participants (stream two: non-intervention studies, including qualitative studies and surveys). This approach permitted the creation of a detailed and comprehensive protocol and provided an overarching narrative synthesis from both stream one and two to determine the level to which interventions to improve T1DM self-management in the educational setting tackled the barriers and built on the facilitator. Edward et al. (2014) sought to conduct a mixed-method systematic review that used a complete and systematic search strategy and evaluated the methodological quality of the incorporated studies.

Another review used in this current study is Pansier and Schulz's (2015) review, which confirms that there is a cumulative effort concerning school-based diabetes interventions. However, the review accentuates that using a clear framework to develop school-based interventions is important in order to achieve the desired outcomes.

Both systematic reviews brought together all of the available published evidences related to this research topic. The identified reviews focus on the self-management of T1DM within educational settings. In addition, they comprise a critical discussion of the included literatures, providing detailed scrutiny and analysis of all published literature. Further, they identify the methodological problems and the research gaps concerning school-based interventions for adolescents with T1DM.

It is acknowledged that it is usual practice for a researcher to conduct their own systematic review as the basis for identifying gaps in the literature and framing the research question. However, in respect of this study, while older and seminal literature has been searched as noted previously, the existence of two comprehensive, highquality and up-to-date search results on the topic meant that there was little to be gained from replicating this work. Literature searches revealed the same papers that these reviews had included. Thus, while some of these primary studies were scrutinised in their own right to provide added insight, there was little merit in constructing another systematic review (SR) using essentially the same papers. Consequently, careful prioritisation was given to vigilantly considering the quality of the two included SRs to ensure their robustness and to updating the search due to the two reviews' search cut-off dates. No recent relevant papers (up to the time when the data collection was started) that met the inclusion criteria for this literature review were found.

This review resulted in the identification that the school-based interventions developed to date have not attended to all the demands stated in previous studies; specifically, psychosocial aggravation has not been tackled. In addition, there is no clear indication of involving adolescents with T1DM in designing school-based diabetes interventions. Involving this age group when designing these interventions could enhance self-management skills. Furthermore, most of the included studies do not report using a

framework to guide their development of interventions and there was also a lack of detail in regards to the interventions development process.

Summary of the Gaps in the systematic reviews of both Edwards et al. (2014) and Panzer and Schultz (2015) are summarised as follow:

- No school-based intervention focused on the psychosocial issues that have been addressed in the literature review, such as feeling different or being bullied by peers. Adolescents with T1DM have an increased risk of developing psychosocial issues, leading to the deterioration of diabetic control (Kakleas et al. 2009). All the studies focused on training and continuing the education of the school nurse and school personnel only; school peers were not involved. In addition, studies focused on students with T1DM and aimed to promote collaboration, communication, and coordination between all caregivers.
- Some studies demonstrated the involvement of parents or school nurses in identifying some elements of the intervention chosen (e.g. Bobo et al. (2011). However, there was no clear evidence of including the voice, needs, or priorities of adolescents with T1DM during the development of school-based interventions.
- Most of the studies included in both reviews lack details on intervention development process.
- All studies were conducted in the USA or Canada (one intervention). Further research is needed in the UK.

# 2.4 Study Justification

The literature review concluded that, despite the ongoing progress that has been made to improve the self-management of adolescents with T1DM in schools, challenges still

exist. Furthermore, the review concluded that the school-based interventions developed to date mostly concentrate on improving care coordination and diabetic education/communication for both students with T1DM and school personnel. None of the interventions tackled other aspects, such as psychosocial and emotional challenges. Despite considerable literature about the negative effects of these symptoms on diabetes outcomes in adolescents with T1DM, a gap regarding the need to address psychosocial or emotional aspects in school-based interventions exists. This gap in the literature leads to the identification of another important gap: the extent to which the developed schoolbased interventions accommodate the perspectives, needs, and priorities of adolescents with T1DM while designing the interventions. Therefore, research is required to provide insight into the intervention components that might meet the physical, psychosocial, and emotional well-being needs of adolescents with T1DM, which have the potential to be effective in helping adolescents overcome the challenges they might face in school and offering clear guidance on the most important intervention components and how best to implement them in a school setting. This study seeks to obtain data that will help to address these research gaps. It seems clear that understanding the needs, priorities of adolescents with T1DM will provide a greater opportunity to develop well-informed evidence-based interventions in school settings.

# 2.5 Aim of the Study

The aim of the study is to develop and assess the appropriateness of a school-based intervention to promote self-management (i.e. physical or psychosocial) among adolescents with T1DM aged 11–15 by exploring their needs and priorities in terms of how they want to be supported in school settings. The researcher will focus on children between the ages of 11 and 15, as the adjustment through middle adolescence is rather difficult. This particular school age begins the phase of emotional separation from

parents and the possibility of developing increased health risk habits, such as smoking and drinking alcohol, as well as strong peer relations (Christie and Viner 2005). This critical development can place those in this age group category at possible risk, and it is imperative to offer them special attention, particularly with the presence of a chronic illness such as T1DM. Adolescents at this age are also developing the ability to create hypothetical solutions to difficult situations or problems and to evaluate which is best (Steinberg 2005). This means that they are assumed to have more understanding of their disease and are also able to understand what they need in order to support themselves.

# 2.6 The Research Questions

1. In adolescents aged 11–15 with T1DM, what are the needs and priorities for enhancing their self-management (physical or psychosocial) in the school?

2. In adolescents aged 11–15 with T1DM, what intervention components and approaches are required to enhance self-management (physical or psychosocial) in the school setting?

#### The Objectives of this Study

- 1. To understand the needs and priorities of adolescents with T1DM to enhance self-management in the school.
- To explore the barriers and facilitators of self-management among adolescents with T1DM in school.
- To explore what intervention characteristics may benefit adolescents with T1DM in enhancing self-management (physical or psychosocial) in the school setting.

- 4. To explore what intervention format or methods adolescents with T1DM would choose.
- 5. To assess the appropriateness of the intervention.

# **CHAPTER 3:** METHODOLOGY

This chapter focuses on the philosophical issues underpinning the methodology of choice for this research: exploratory qualitative research using a thematic analysis approach involving individual interviews with adolescents with T1DM and health care professionals. The intervention mapping protocol is also introduced to provide guidance on how to develop health intervention.

# 3.1 Paradigms

A paradigm is defined by Morgan (2007) as a system composed of beliefs and practices that impact the researchers' choice of study questions as well as the approaches that they use to study the chosen questions. The paradigmatic stance of interpretivism is adapted for this research. The position of interpretivism in relation to ontology (the nature of reality) and epistemology (how this reality is captured or known) is that reality is multiple and relative (Hudson and Ozanne 1988) and the meaning of experiences and events are constructed by people (Lauckner et al. 2012). Charmaz (2006) explains that, through participation, individuals can construct their realities. Guba and Lincoln (1994) argue that interpretivism perceives the world as dynamic and its interpretation as reliant on the experience of people and their interactions. An interpretive research paradigm is characterised by the need to understand the world as it is from an individual's perspective and to find an explanation within the frame of reference of the individual (Ponelis 2015). It also considers people as located in a social context and continually engaged in making sense of their experience (Magnusson and Marecek 2015).

Qualitative research is grounded in interpretive ontology, which suggests that there is no objective reality (Krauss 2005) or truth and, therefore, reality needs to be interpreted; from such a perspective, researchers are more likely to utilise a qualitative approach in order to access multiple realities. Bygrave (1989) points out that interpretive qualitative approaches can bring about a valuable understanding of important issues that can help to develop practical and theoretical knowledge or produce new and alternative theories and concepts. This study adopts the belief that the paradigmatic stance of interpretivism will help in gaining an understanding of the needs, and priorities, of adolescents with T1DM in their school settings, which will help to generate a patient-centred schoolbased intervention to enhance self-management.

## **3.2 Research with children**

The view that involving children as active participants in research is critically important for generating knowledge and understanding the issues and concerns that shape their lives is growing. Mack et al. (2009) highlight some considerations, such as designing developmentally appropriate questions, evaluating the adolescent's developmental level, and refining interviewing techniques to optimise the experience for the participants. Weller et al. (2014) explain that studies with children and young people have an overarching philosophical focus that direct research with child and young people research. This focus is grounded in the principles described in the Convention on the Rights of the Child and their unique voices and viewpoints. Article 12 and 13 of the Convention on the Rights of the Child states that children who are able to form their own views shall be assured the opportunity to express those views freely in all aspects affecting them. This right shall include freedom to request, receive and convey information and ideas of all types, either verbally, in writing or in print, or any other method of the children choice (Unicef 1989). Children's research requires that children be considered in their own right and that researchers interpret and explain the world through the eyes of children and adolescents (Dockett and Perry 2011).

Potential new approaches arise from two imperative arenas: power and emancipation. The emancipatory aspect argues that the legality of research does not empower groups (in this case, adolescents with T1DM) who are either unseen or burdened. Consequently, the interests of children and adolescents, as a relatively powerless category, are taken care of when they are offered the appropriate opportunities (Noel 2016). Emancipatory research has been defined as research for constructing knowledge that can be beneficial to disadvantaged individuals (Barton 2005). It is a general term that can incorporate many streams of critical theory-based research, such as disability/ ill health, feminist, gender, and race theory. One of the vital assumptions in emancipatory research is that there are many realities and that research is not only generated by the researcher given the expansion and development of various branches of research design, for example participatory design, inclusive design, and social innovation design. It is expected that the designer will interact with the designs with and for individuals who may be marginalised or discriminated for reasons of race, gender, sexual orientation, disability, or economic background in order for their voices to be heard and to enable them to share their insights on related issues that matter to them (Noel, 2016).

Behar-Horenstein and Feng (2015) highlight that engaging in emancipatory or participatory research drives researchers to be conscious of their taken-for-granted

assumptions and their central role in the research. Examining the power relations that are inherent in the researcher-researched relationship requires researchers to locate themselves theoretically and culturally and to ensure that participants and their voices are adequately represented. Bailey et al. (2015) explain that children and adolescents could be valuable colleagues in research, given their unique perspectives. However, children and adolescents with chronic diseases, for example diabetes, asthma, HIV, and autistic spectrum disorder, are less frequently involved in research than their nondiseased peers. This is possibly because of perceived difficulties with access and communication and negative assumptions regarding their ability to provide a valuable contribution. Mogensen (2010) addresses many challenges that can hinder children and adolescents with a disease or disability from being involved in research studies, including a lack of confidence, being unused to giving their opinion, feeling intimidated by professionals, unfamiliar working environments, and sensitive meeting contents.

Bailey et al. (2015) stress that using flexible methods is essential to support the involvement of children and adolescents with disabilities or chronic illness while maintaining power and control over how and when they are involved. In addition, researchers need to balance the right of children and adolescents to participate in research with the responsibility to protect them and ensure that they are not overstrained. Street and Herts (2005) suggest some ways to empower children and adolescents such as letting them take control over the research agenda and methods and define their own and others' roles in the project, which allows them to raise the issues that are important to them.

## 3.3 Research approach

The following paragraph will discuss the commonly used approaches to frame qualitative research

#### **3.3.1** Phenomenological approach

The purpose of phenomenological research is to describe phenomena from the participant's perspective or, as frequently stated, capture the lived experience (Gray et al. 2016). In principle, phenomenology focuses on peoples' perceptions of the world or the perception of 'things in their appearing'. The main philosophers who assisted in developing phenomenology are Husseral and Heidegger. The phenomenological (Husserl, Heidegger) approaches seek to both establish a whole, accurate, clear description and understanding of specific human experience. It attains its aim through the use of a particular researcher position and approach and through particular methods of participant selection, solicitation of information, systematic data handling, and accumulating of interview factors into a concluding report (Brown 2009). Phenomenology is worried about the completeness, with examining entities from many sides, viewpoints, and perspectives till a unified vision of the cores of a phenomenon or experience is attained. Phenomenology is committed to descriptions of experiences, not explanations or analyses.

#### 3.3.2 Ethnography approach

An ethnography approach is the study of social interactions, behaviours, and perceptions that occur within groups, teams, organisations, and communities (Reeves et al. 2008). The ethnographer observes participants in varying degrees of purpose and context, and interviews key cultural informants who can teach about their culture (De

Chesnay 2014). Ethnography requires spending considerable time in the setting studying, observing and gathering data. There are four schools for ethnography: classic ethnography, which seeks to describe culture through immersion in the culture for an extended period; systematic ethnography, which describes the social, organisational structure influencing a specific group; interpretive ethnography, which interprets the attitudes or values shaping the behaviours of members or groups to promote understanding of the context of the culture; and finally, critical ethnography, which examines the life of a group in the context of an alternative theory or philosophy (Gray et al. 2016).

#### **3.3.3 Grounded theory approach**

Grounded theory was developed by Glaser and Strauss (1967). The purpose of using grounded theory is to develop a theory, grounded in data gathered during a given study, rather than testing a theory developed by other scientists (Morse et al. 2016). Therefore, the main desired outcome of grounded theory is a middle range or substantive theory. Using the grounded theory, the researchers need to understand about the interaction of data collection and analysis as well as theoretical sampling (Holloway and Galvin 2016). Theoretical sampling is the method of data collection for producing or generating theory whereby the analyst jointly collects, codes, and analyses his data and decide what data to gather next and where to find them, to develop his theory as it emerges. This process of data collection is controlled by the emerging theory, whether substantive or formal (Ritchie et al. 2013).

#### **3.3.4** Applied thematic analysis

An applied thematic analysis approach has been selected for this study. There are many approaches in qualitative research that represent different epistemological, theoretical,

and disciplinary perspectives. The applied thematic approach is a poorly acknowledged yet widely-used qualitative analysis method (Guest et al. 2012). Braun and Clarke (2006) emphasise that because of the theoretical flexibility of thematic analysis, it can be considered as a methodology rather than just an analytical method, even though some researchers locate it as a process performed within other major approaches, such as grounded theory or phenomenology. However, Braun and Clarke (2006) argue that thematic analysis should be considered as an approach on its own.

Braun and Clarke (2006) broadly classify qualitative analytic methods into two groups, one of which involves analysis such as interpretative phenomenological analysis. This group is usually constrained to a specific theoretical or epistemological position. In contrast, the second group comprises all other independent methods that can be applied across a wide variety of theoretical and epistemological approaches. According to Braun and Clarke (2006), being flexible and compatible with the paradigms of both interpretivism and positivism means that thematic analysis belongs to the second group. A robust and granular account of data can be achieved through the theoretical independence that thematic analysis offers and, in this way, it serves as a flexible and valuable research instrument. Thematic analysis allows for a wide range of theoretical and methodological perspectives and is seen as a rigorous but inductive approach (Guest et al. (2012).

The inherent features of being independent and theoretically flexible elevates thematic analysis from being a mere analytical method to being a methodology. This was firmly emphasised by Braun and Clarke (2006), who argue that the search, examination, and patterning through language is not constrained to any particular theory of language, framework, experience, or practice. Apart from being flexible and independent, thematic analysis is valuable resource for researchers as: a) it helps to work with a wide

range of research questions, from those about people's notions or perspectives to those about the illustration and demonstration of particular phenomena in particular contexts; b) it can be used to analyse different types of data, e.g. from secondary sources such as media to transcripts of focus groups or interviews; c) the size of data-sets does not matter, and therefore it can be applied to both small and large data-sets; and d) it can be applied to produce data-driven or theory-driven analyses (Clarke and Braun 2013). Through the use of interpretations, thematic analysis deals with diverse subjects, and data can be illustrated in a detailed way (Boyatzis (1998). Thematic analysis is a valuable tool, as researchers can identify patterns and correlations between the data as well as evolving themes around the research interest (Alhojailan (2012). Therefore, exploratory qualitative research using a thematic analysis approach is adopted for this study.

# 3.4 Research design

The research design relates to the complete plan for collecting and analysing data (Polit et al. 2001). It guides the selection of a population and the sampling strategy for data collection and analysis (Grove and Burns 2005). When designing research, it is necessary first to select an appropriate method that will generate findings in order to address the research questions.

Exploratory qualitative research using applied thematic analysis is used in this study. Qualitative research attempts to explore the relative nature of knowledge that is subjective, unique, and context-dependent (Taylor and Francis 2013). It has been defined as a method of providing rich data that may be utilised to influence current standards of care, create theory and patient-centred outcome measures, and to confirm the acceptability of behavioural interventions (Meissner 2011). Gray et al. (2016)

explained that researchers who value the perspective of participants, to develop an intervention and evaluate the appropriateness of the intervention, can use qualitative exploratory research. Appropriateness examines how users react to interventions (Bowen et al. 2009). Qualitative methods can be used before the developmental phase of complex interventions in order to identify key issues and variables in the intended intervention (Murtagh et al. 2007). Moreover, qualitative research findings can offer initial data in support of the efficiency of a new intervention approach or add to further modifications of new or existing interventions (Akard et al. 2013).

# 3.5 Quality in qualitative research

Evaluating the quality of research is critical if findings are to be applied in practice and integrated into care delivery (Noble and Smith 2015). The criteria used to evaluate the findings of qualitative research are different from those used in quantitative research. In quantitative research, the criteria for evaluating research are reliability, validity, and generalisability. However, in qualitative research, different terms are used to better reflect the different nature of qualitative research. These terms are referred to as trustworthiness criteria, involving dependability, credibility, transferability, and confirmability (Ponelis 2015). Dependability can be addressed by reporting all the details of the research so that the study could be repeated by other researchers, if necessary (Shenton 2004). However, the qualitative research cannot be replicated in similar conditions with similar participants – as the researcher is the key research instrument in qualitative research, the research can never be wholly replicable. Other investigators have different accents and emphases, even when they use the same methods and select a similar sample and the same issue. The researcher's characteristics and background will also influence the research (Holloway and Galvin 2016). For the finding to be dependable, it means that the reader should be able to assess the suitability

of the analysis through following the decision-making progression of the investigator. The context of the research must be described to achieve some measure of dependability (Holloway and Galvin 2016).

Credibility refers to the adoption of a suitable, well-recognised research approach, in addition to denoting the level of confidence in the truth of the findings, including an accurate understanding of the context. Transferability means the provision of all the evidence to allow the reader to confirm whether the findings emerged from the data and not from the biases and subjectivity of the researcher. Confirmability refers to the use of triangulation to decrease the influence of researcher bias (Shenton 2004). To ensure high-quality qualitative research, trustworthiness criteria should be carefully considered while planning, conducting, and documenting a research project. Triangulation, which refers to the use of various methods, techniques, or data sources to gain a broad and deep understanding of an issue (Carter et al. 2014), is one of the methods used to increase the trustworthiness of qualitative research.

Accounting for any personal biases that may influence the findings is one of the most important strategies for ensuring the trustworthiness of qualitative research findings (Noble and Smith 2015). In the present thesis, it was essential to consider whether the presence of the researcher would affect or constrain the participants from sharing their perceptions. However, as the researcher is not a member of the paediatric diabetic team in the hospital, it would be easier for the participants (adolescents and health care professionals) to freely express their views. Therefore, the researcher's presence could not be construed as a weakness in the research. Burns and Grove (2005) go even further and explain that qualitative researchers have to think about the interaction between the self and the data during analysis. This process of critical examination is called reflexivity (Burns and Grove 2005). Also, carrying out a literature review before

commencing the study was important in understanding the research topic as well as helping to formulate the type of questions that would produce enough information for interpretation.

In this study, the researcher has maintained reflexivity and engaged in self-reflection by keeping a diary, in which regular entries were made throughout the process of collecting and analysing the data; this enabled the researcher to identify the influence that her beliefs and values may have had on the quality of the data collected.

# **3.6 Conceptual Framework**

Complex interventions are commonly used in the health sector. There are different approaches and frameworks of intervention development that can help researchers and intervention developers to adopt the proper framework, for instance the Intervention Research Framework (McBride, 2016), Medical Research Council Complex Intervention Framework (Richards and Hallberg, 2015), Theoretical Domains Framework (French et al., 2012), Behaviour Change Wheel (Michie et al., 2011), and Intervention Mapping Protocol Framework (De Craemer et al., 2014).

#### **3.6.1** The Intervention Research Framework

The Intervention Research Framework offers a scientific and systematic method for the development of evidence-based interventions in the health sector. It phases and processes the demonstrated impact on individual and community level behavioural outcomes. It consists of four phases: notification, development, assessment, and dissemination (McBride 2016).

The first phase of this framework engages the scientific notification of the research problem. This can be informed by aetiological and epidemiological studies to recognise significant areas of concern in order to come up with the scientific justification of the specific research focus. The notification phase identifies an existing gap in the research area and gaps in evidence-based policy and practice.

The development phase of this framework includes formative intervention research processes, including formative processes to make sure that an intervention is informed by different methods of critical input. This critical input includes earlier research studies in the field that have achieved behavioural influence, opinions from specialists and experts in the field, and guidance from theories and models. This phase also involves a pre-test of the intervention in the setting before progressing to the assessment phase.

The assessment stage of the Intervention Research Framework incorporates three forms of longitudinal behavioural assessment. These three assessments are: an efficacy assessment to determine how the intervention works and its behavioural effect under best circumstances, an effectiveness assessment to determine behavioural impact in real circumstances or the real world, and an efficiency assessment, which provides an opportunity for a research comparison of the intervention delivery using different approaches and includes costs analysis comparisons. However, it is uncommon for all three to be applied to an individual research programme.

Finally, the dissemination phase measures how extensively the intervention is used in different settings by practitioners and policymakers. The dissemination of the intervention into policy and practice organisations is determined by how academic researchers link and communicate with these professionals to disseminate the programme's development and findings and how easily the programme can be accessed and used by professionals (McBride, 2016).

## **3.6.2 Medical Research Council Complex Intervention Framework**

The Medical Research Council Complex Intervention Framework consists of four main phases, namely development, feasibility and piloting, evaluating, and implementing (Richards and Hallberg 2015). The development of the intervention involves three steps. Firstly, the existing evidence is identified by exploring what is already known about exciting interventions concerning the specific topic and the approaches used to evaluate them. Secondly, identifying and developing the theory involves gaining a theoretical understanding of how the expected changes are going to be achieved by drawing on existing evidence and theory. Thirdly, regarding modelling methods and outcomes, with some studies, progressively refining the design may be required before embarking on a full-scale evaluation. This is considered imperative before a full-scale evaluation as it can provide essential evidence concerning the intervention and the evaluation design.

The second phase concerns feasibility and piloting as the development stage may leave some uncertainties that could potentially undermine the conduct of a thorough evaluation of the planned intervention. Feasibility studies can be used to determine whether an intervention is appropriate for further testing. In addition, such studies may detect if anything in the research methods or protocols needs modification (Bowen et al. 2009). A pilot study should not be a scale model of the intended evaluation but should evaluate the major uncertainties that have been specified during the developmental phase (Bryman 2016).

Evaluating the complex intervention is the third phase of this framework. The key goal of this phase is to establish causality (the relationship between the intervention and the effect). Selecting the design strategy is a critical element with regards to determining

the ability of the evaluation to show the effect of the intervention at as good an approximation of the real effect as possible (Richards and Hallberg, 2015). Randomisation, for example individually randomised trials and cluster randomised trials, has to be considered because it is the most vigorous method of avoiding selection bias. If an experimental method is not possible because large-scale implementation is already underway or because the intervention essentially applies to the entire population, an observational or quasi-experimental design may be considered (Craig et al. 2008).

Implementation is the last phase of this framework. It involves the use of strategies to adopt and integrate evidence-based health interventions. The key aspect of ensuring that implementation progresses quickly is to have a strategic and systematic approach to the problem. The approach should be able to measure both the positive factors that would facilitate intervention adoption and the challenges to routinely embedding the intervention. An audit and feedback are examples of these strategies (Richards and Hallberg, 2015). Although this framework is a useful guide for the development of interventions within the healthcare system (Campbell et al. 2007), Wight et al. (2014) note that this framework provides little detail on intervention development.

## **3.6.3** The Theoretical Domains Framework

The Theoretical Domains Framework was developed to facilitate the use of theory in behaviour change and improve behaviour change theories' accessibility to researchers. A set of 12 domains covering the main factors influencing practitioner clinical behaviour and behaviour change were identified using expert consensus. These 12 domains offer a broad framework that has wider coverage of possible barriers to change and thus suggests a greater range of potential intervention components. It also

comprises environmental and social factors that can be used as an evaluation tool to assess how effective an intervention was at targeting specific behaviour determinants. In addition, it can serve as a tool to identify a planning tool to help identify determinants (and appropriate techniques) to address previously identified barriers and facilitators to positively impact the outcomes of an implementation strategy (French et al. 2012).

#### **3.6.4 Behaviour Change Wheel**

The Behaviour Change Wheel approach is grounded in a broad causal analysis of behaviour. It can be developed into a theory- or evidence-based permitting the development of interventions and policies that correspond to the analysis of the behaviour (Michie et al., 2011). It consists of specific activities, starting with behavioural target specification, which is followed by identifying what needs to be altered for the behaviour to change regarding capability, opportunity, and motivation, after which the intervention strategy, such as training, educational strategy or persuasion, is selected. Next, an implementation strategy is chosen and behavioural change techniques are selected, and finally, a detailed description of all the aspects of the intervention is developed (Michie et al. 2011). Barker et al. (2016) emphasise that the Behaviour Change Wheel allows intervention designers to systematically identify intervention functions and policy classifications that could bring about change. However, Ogden (2016) argues that the Behaviour Change Wheel is difficult to operationalise and test and that this is perhaps because of inconsistent nature of the data it produces.

#### **3.6.5 Intervention Mapping Protocol**

The Intervention Mapping Protocol (IMP) provides a structured framework to develop, implement, and evaluate complex interventions. It describes a process for developing

theory-based and evidence-based health education programmes. The IMP framework was used to guide the development of the intended intervention. The development of a relevant intervention is a very complex process, so the IMP framework will be used to direct the intervention development (Fassier et al. 2016). De Craemer et al. (2014) state that an IMP is a time-consuming process but that this systematic approach may lead to an increase in intervention effectiveness.

The framework consists of six steps: 1) need assessment; 2) preparing matrices and change objectives; 3) choosing theory-informed intervention methods; 4) creating intervention components; 5) programme adoption and implementation; and 6) programme evaluation. These steps are discussed in detail later in this section. Step 1 to step 4 of IMP will be integrated through the stages of this research as shown in Table 4. Step 5 and step 6 of IMP (Implementation and evaluation) are beyond the focus of this study.

All of the frameworks discussed above differ or overlap in terms of their elements or processes. For this study, the IMP was chosen and used to guide the development of the intervention. Although the IMP has been criticised as being a highly technical perspective and for taking a long time (Wight et al., 2014), it is a highly detailed and rigorous approach to intervention development (Bartholomew et al. 1998). The IMP has been shown to be feasible and effective when it comes to providing an evidence-based and theoretical structure to a health behaviour change intervention (Taylor et al. 2013). It is an extremely rigorous and elaborate approach to intervention development. Each step has very specific tasks that need to be accomplished. The specification of these tasks in each step helped the researcher to focus on the desired outcomes of the intervention. The completion of the tasks for each step creates a product that guides the subsequent step. Even though the IMP has six steps, the process is iterative rather than

completely linear. The researcher was able to move back and forth between tasks and steps as new information and perspectives were gained. However, the process is also accumulative; thus, the researcher was able to base each step on the previous step and most of the time, the researcher was able to backtrack and include, repeat, or elaborate on any step.

# **CHAPTER 4: METHOD**

This chapter focuses on the research method, including the stages of the study, data collection tool used, study setting, study sample and recruitment, ethical considerations, and data analysis tool used for this study.

# 4.1 Stages of the study

This research focuses on developing a school-based intervention that is aimed at enhancing self-management among adolescents with T1DM through exploring their needs and priorities, in addition to assessing the appropriateness and acceptability of the intervention's materials in terms of content and presentation. The research stages aligned with the steps of IMP framework are presented in table 4.

Table 4: Study overview (the four stages of the research aligned with the steps of IMP framework)

| Research stages                  | Specific objectives                                         | Intervention mapping<br>protocol framework (IMP)                                                                                                                                                              | Design                                                                                                                                                                                                                                                                       | Participants                          | sample size |
|----------------------------------|-------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------|-------------|
| Stage 1<br>(Exploratory<br>part) | To explore needs, priorities, and ideas                     | 1. Needs assessment                                                                                                                                                                                           | Semi-structured interviews                                                                                                                                                                                                                                                   | Adolescents with<br>T1DM (aged 11–15) | 18          |
| Stage 2<br>(Development<br>part) | <ol> <li>To develop a school-based intervention.</li> </ol> | <ol> <li>Preparing matrix of change objectives.</li> <li>choosing theory informed intervention methods and practical strategies.</li> <li>creating intervention components and choosing materials.</li> </ol> | Analysis of the interview findings<br>of stage 1.<br>Conducting a systematic review<br>of the existing evidence relevant<br>to the intended intervention.<br>The intervention development<br>will be guided using the<br>intervention mapping protocol<br>from steps 2 to 4. | Not applicable                        |             |

| Stage 3<br>(Health<br>professionals'<br>consultation) | To comment on the developed<br>intervention based on the<br>study's findings and the<br>experts' views.            | Not applicable                                                         | Semi-structured interviews with health professionals. | Health professionals<br>(e.g. diabetes nurses<br>and psychologists) | 6  |
|-------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------|-------------------------------------------------------|---------------------------------------------------------------------|----|
| Stage 4<br>(feedback stage)                           | To obtain validity and<br>acceptability regarding the<br>material produced and the<br>content of the intervention. | Not applicable                                                         | Semi-structured interviews                            | Another group of<br>adolescents with<br>T1DM (aged 11–15)           | 10 |
| Post-doctoral                                         |                                                                                                                    | <ol> <li>Adaptation,<br/>Implementation</li> <li>Evaluation</li> </ol> |                                                       |                                                                     |    |

## 4.1.1 Stage 1: Exploratory stage (Need Assessment)

Stage 1 of this research is aligned with step 1 of IMP framework. Adolescents with T1DM underwent a face-to-face interview in order to gain more understanding about their needs and priorities, to understand how they wanted to be supported in the school setting. It was also to gain more understanding about what intervention features, components, and methods were considered as a priority in enhancing their self-care (physical and psychosocial) in the school. Furthermore, the needs assessment was conducted through gathering information in the literature review regarding the problem and need as well as existing interventions and services.

The findings from the exploratory stage were used to guide and shape the intended intervention. Building an in-depth understanding of the viewpoints of the adolescents with T1DM guided the researcher to develop a school-based intervention to enhance their self-management.

#### 4.1.2 Stage 2: Intervention development stage

#### Preparing matrices of change objectives

The goal of this step is to state the outcomes of the behavioural and environmental changes, state the performance objectives, select relevant and changeable determinants, and create matrices of change objectives (De Decker et al. 2014).

In this step, a programme goal and objectives for the health outcome to be achieved through the intervention are formulated. Performance objectives are formulated to determine the behavioural and environmental outcomes that the intervention aims to achieve. These performance objectives state what the intervention users have to do, or how the environment has to be improved in order to achieve the outcome. Based on the information derived from the individual interviews and based on the literature review, elements of behavioural and environmental outcomes were enumerated. The list of potential elements was refined into a final list of elements by selecting each element in terms of relevance and changeability (i.e. the likelihood that the intervention could influence a change in the determinant). Finally, the selected elements were matched with the formulated performance objectives in order to generate matrices with change objectives. These change objectives specify what needs to be changed in the elements of behavioural or environmental outcomes in order to achieve the performance objectives (De Decker et al., 2014).

#### Choosing theory-informed intervention methods and practical strategies

Theoretical methods that can effect change in the selected elements were identified based on a list including all change objectives. Change objectives that had to do with specific elements were listed, and theoretical methods were then matched with the corresponding elements. After the theoretical methods were selected, they were translated into creative approaches (De Decker et al., 2014). The development of creative approaches was guided by the formulated change objectives in the previous step of the intervention mapping protocol and also be based on suggestions made by the adolescents with T1DM during the interviews.

#### Creating intervention components and choosing materials

The scope, sequence, and themes and a list of necessary intervention materials were completed. Suggestions made by adolescents with T1DM during stage 1 were used to prepare and design documents for the production of the intervention components and materials to meet the intervention objective. Once the design documents been developed, a review of available materials was carried out against the matrices (De Decker et al., 2014).

#### 4.1.3 Stage 3: Health care professionals' consultation

Health care professionals with experience of treating and supporting adolescents with T1DM, drawn from paediatric-diabetic workers in the local NHS trust (e.g. paediatric-diabetic nurses, paediatric-diabetic physicians, paediatric psychologists, paediatric dietician), were interviewed. Interviews with the health professionals were considered after the development of the intervention. A brief report about the findings of the interviews from the first stage with adolescents with T1DM was prepared. The report was presented to health care professionals, as well as the prototype of the developed intervention. The prototype of the intervention (video) was presented to the health care professionals using a laptop. They were instructed to stop, restart and turn forward and backwards at any parts of the video to give their comments. Face-to-face semi-structured interviews was conducted with the health care professionals, and they were

asked to give their recommendations about the developed intervention based on the findings of the study and their expert views.

## 4.1.4 Stage 4: Feedback stage

This stage begun after modifying the intervention based on the comments and suggestions provided by the health care professionals during stage 3. In the follow-up feedback stage, a new group of adolescents with T1DM was recruited and interviewed using a semi-structured individual interview in order to inform the validity and acceptability of the developed intervention. The modified intervention (video) was also presented to the participants using a laptop. The participants were instructed to stop the intervention or go forwards or backwards at any part of the intervention to give their comments. The adolescents with T1DM were asked to speak about their ideas regarding the intervention, such as what they like or dislike, what seems to be acceptable and usable. The results of this study are expected to provide a solid foundation for a newly developed school-based intervention for adolescents with T1DM that is ready for future testing.

## 4.2 Data Collection

There are several methods for collecting qualitative data, the most common of which are individual interviews and focus groups. Both methods provide an opportunity for discussion and interaction between the researcher and participants (Ayala and Elder 2011). Although individual interviews and focus groups can offer a depth of understanding, individual interviews are more appropriate for determining the emphasis of an issue. In addition, individual interviews are more appropriate for asking participants how firmly they feel as well as asking them to prioritise issues or give weight to certain aspects. As the researcher is intending to ask the participants about

their priorities and needs, focus groups are less appropriate for the exploratory part of this study in determining emphasis, as the participants may not share the same priorities. Moreover, the group dynamics may imply an emphasis that is misleading (Harrell and Bradley 2009). Therefore, in this study, the researcher will use semistructured individual interviews in all the study stages.

## 4.3 Semi-structured interviews

Research interviews can be divided into three types: structured, semi-structured, and unstructured. Structured interviews are verbally administered questionnaires with a list of prearranged questions, with no room for follow-up questions to responses that permit additional explanation. They are quick and easy to administer. Therefore, as they allow for limited responses from participants, they will not be used, as depth is required in this study. On the other hand, unstructured interviews tend to be more flexible, open-ended, and free-flowing. Rather than prearranged questions, however, there are usually certain topics that the researcher desires to cover. Unstructured interviews are usually very time-consuming and can be difficult to manage. This type of interview is used where significant depth is required or where almost nothing is known about the subject area (Gill et al. 2008b).

Semi-structured interviews are in-depth interviews where the interviewees have to respond to pre-set, open-ended questions. They are commonly used by different health care professionals in their research, and they provide participants with some direction regarding what to talk about. Semi-structured interviews comprise some principal questions that help to explain the areas to be explored, but they also permit the interviewer or interviewee to deviate in order to pursue an idea or response in more detail. They also allow for more elaboration of information important to participants

that may not have before been assumed as relevant by the research team (Jamshed 2014). Semi-structured interviews have been chosen as they provide more opportunity for the expansion of replies (Polit et al. 2001). They are used where depth of meaning is required, and the research is primarily focused on gaining insight and understanding. A semi-structured interview allows for the flexibility needed in qualitative research, and it is one of the most commonly used data collection methods in qualitative research (Bryman 2015). In addition, semi-structured interviews allow for areas of uncertainty or ambiguity to be clarified, as well as avoidance of any misunderstanding, due to the presence of the researcher. However, the effectiveness of an interview depends greatly on the interviewer's skills, which include the ability to structure clear questions, listen intently, pause, probe or prompt appropriately, and encourage the participant to speak freely (Newton 2010). Interpersonal skills, such as the ability to create a connection with the participant and use humour and modesty, can also enhance cooperation and elicit more information from participants (Grove and Burns 2005). Furthermore, the effectiveness and validity of an interview depend on the degree to which the participant's views are accurately reflected. Leading questions or the predetermined ideas of the researcher can be considered as threats to the validity of an interview (Zorn 2008).

In this study, the researcher carefully structured the questions so as to avoid leading the interview or imposing meanings. Furthermore, the researcher considered being an active listener in order to avoid influencing the participants' responses, as suggested by (Hammersley and Atkinson 2007). The researcher prepared interview guides for Stages 1, 3, and 4 (see Appendices 1, 2, and 3), which consisted of a number of questions to be covered with each participant.

The researcher informally piloted the questions by conducting five 'test' interviews with adolescents who were as close as possible to the target research group (i.e. same age and with or without diabetes). Doing this was very helpful in obtaining a general feel for how the interviews would go. In addition, it provided a better understanding of the clarity, wording, and understanding of the designed questions. The adolescents agreed that the questions were simple, straightforward, and easy to understand. Therefore, no significant changes were made to the interview guide.

It is important that researchers using interviews as a method of data collection have appropriate training, experience, and expertise (Gill et al. 2008a). In addition, interviewing adolescents requires particular skills, e.g. the interviewer needs to use language that adolescents are familiar with to describe their situations and experiences (Grove and Burns 2005). Therefore, as a novice researcher, specific activities about how to conduct qualitative interviews with adolescents were undertaken to ensure the researcher was able to generate an atmosphere within which the participants could communicate their views. The researcher has also had six years of experience working with children and adolescents in hospitals, in addition to having a specialised diploma in critical care nursing in paediatric settings. This experience generated valuable skills in how to communicate with adolescents with medical problems. Further, the researcher engaged in extensive reading in order to enhance her interviewing skills, and she also attended interviewing skills workshops.

The researcher audio recorded all the interviews in this study so that she could focus during the interview and avoid detracting from the development of understanding between the interviewer and interviewee (Cohen and Crabtree 2006). The interviews in stage one (exploration stage) and four (feedback stage) were conducted face-to-face (at the interviewee's home). As all of the interviews were conducted at the interviewee's

home, lone interviewing risk assessment guidance, the lone interviewing contact procedure and location form, and the loan interviewing checklist provided by the University of Southampton were followed. Stage 3 interviews were conducted at University Hospital Southampton (UHS).

## 4.4 The study setting

The study is being conducted in collaboration with the paediatric diabetic outpatient clinic in one local NHS hospital. In the hospital, the paediatric diabetic clinic is held two days per week.

# 4.5 The study sample and recruitment

A purposive sampling design is commonly applied when qualitative methods are used to collect data, and it is commonly used for exploratory work (Kelley et al. 2003). This involves identifying and selecting individuals or groups of individuals that are particularly knowledgeable about or experienced with a topic of interest (Palinkas et al. 2015). Purposive sampling was used in all study stages.

In qualitative research, the sample size is sufficient when additional interviews do not result in the emergence of new thoughts; this point is called data saturation (Sargeant 2012). Marshall and Rossman (2014) claimed that such data saturation is indefinable, only theoretical sufficiency is achievable. They explained that not one person can know a whole truth about the issue. Sample size should not be so small as to make it challenging to reach data saturation or informational redundancy (Onwuegbuzie and Collins 2007). However, if the sample is too large, data become monotonous and unnecessary (Mason 2010). There are a number of factors that can influence the amount of qualitative data researchers gather. Baker and Edwards (2012) explain some

examples of these factors, such as when participants are easy to reach and there are many of them, it may be suitable to find a larger number of participants when groups within the setting have different insights, roles, positions, or choices about the issue. The nature of the topic, the quality of the data, and the study design are also contributing factors that affect the sample size in qualitative research (Mason 2010). Malterud et al. (2016) suggest that qualitative interview studies may benefit from sampling strategies by shifting attention from the numerical input of participants to the contribution of new knowledge from analysis. Malterud et al. (2016) propose the concept of information power, which argues that the more information the sample holds, relevant for the actual study, the less participants are needed.

An initial approximation of sample size is necessary for planning, while the adequacy of the final sample size must be evaluated continuously during the research process. Advice regarding the sample size of qualitative studies using interviews is inconsistent. For example, Crouch and McKenzie (2006) explain that research based on interviews often seeks to penetrate the social life beyond appearance and manifest meanings, so a small sample size of fewer than 20 would be justifiable. In addition, the rule of thumb based on data collection methods suggest that 30 respondents would be sufficient for each stratum (Hill 1998). Looking at similar studies that used qualitative interview methods, the sample size in these studies ranged between 10 and 30 participants. In this study sample comprised three components: (a) 18 adolescents with T1DM (b) 6 Health care professionals, and (c) 10 adolescents with T1DM (different from the first group). Inclusion and exclusion criteria for Stages 1, 3, and 4 are described below:

Inclusion criteria for Stage 1:

a. Has been diagnosed with T1DM.

- b. Is aged between 11–15 years old (as this study focuses on adolescents with T1DM).
- c. Speaks and reads English (in order to facilitate comprehension and communication between the researcher and the participant).
- d. Is attending school (as the study is intended to help develop a schoolbased intervention).

Exclusion criteria for Stage 1:

- a. Not diagnosed with T1DM
- b. Is younger than 11 and older than 15.
- c. Does not speak or read English
- d. Is not attending any school.
- e. Parents have not provided written consent.
- f. Has not provided assent.

Inclusion criteria for Stage 3 (health care professionals)

- a. Experienced in treating and supporting adolescents with T1DM.
- b. Drawn from paediatric-diabetic or paediatric-specific services (e.g. paediatric-diabetic nurses, psychologists, or play services).
- c. From the same hospital.

Exclusion criteria for Stage 3 (Health care Professionals):

- a. Inexperienced in treating and supporting adolescents with T1DM
- b. Is not working at the University Hospital Southampton

Inclusion criteria for Stage 4:

same as stage one except adolescents must not have been part of the interviews in stage one of this study.

Exclusion criteria for Stage 4:

same as for Stage 1

## 4.6 Recruitment process plan for Stage 1

This section will present the recruitment plans for all stages, and the actual findings for Stage 1 will be presented in Chapter Four. The main aim of recruitment is to enrol the required number of eligible participants onto the study within an anticipated period. The procedure used to locate and recruit participants in a qualitative study is essential for efficiently obtaining a purposive sample and reducing bias (Arcury and Quandt 1999). In research, bias can arise at any stage, including study design, data collection, data analysis, and publication. Selection bias can occur when selecting participants, and therefore it is necessary to use rigorous criteria to avoid confusing results; in addition, well-designed, prospective studies help to avoid selection bias, as the outcome is unknown at the time of enrolment (Pannucci and Wilkins 2010).

Although the researcher is focusing on adolescents with T1DM in a school setting, the participants were recruited from a paediatric diabetes clinic, as this environment is more accessible. In addition, recruiting from a clinic also allowed different views regarding various schools to be identified. The researcher started building relationships and communicating with the paediatric diabetic team before starting the recruitment in order to ensure collaboration during the recruitment process. The study proposal was presented and explained to the paediatric-diabetic team members. The team were made

aware of the proposal and were enthused by the purpose of the research (see Appendix 4).

Recruitment took place after gaining approval from the Ethics Committee at the University of Southampton, as well as from the National Health Service (NHS) approval system and receiving the research passport. The researcher met with the paediatric diabetic team members once again at the hospital and discussed the recruitment plan in more detail. The researcher was located in the diabetic assessment rooms, where adolescents with T1DM come and are assessed before seeing the doctor. The diabetic-paediatric nurse identified the eligible participants for the first stage of the study, according to the inclusion criteria, and introduced a brief idea of the study to adolescents and their parents/guardians. Interested potential participants and their parents were then approached by the researcher, and the study was further discussed with them. Complete disclosure regarding what would happen during the research and what was expected of the research participants was essential during the recruitment process in order to help alleviate parent and adolescents' uncertainties (Pickler and Martin 2010). Care was taken by the researcher to eliminate or reduce the risk of coercion that might have affected patients' participation in the research. Complete disclosure about the aims and objectives of the research and what is expected from the research participants was presented to the potential participants. Participants were given the opportunity to question and receive accurate information before committing themselves to the study. An information pack was also given out, consisting of an invitation letter (see Appendix 5), an information sheet for both parent(s)/guardian(s) and adolescents (see Appendices 6A and 6B), a consent form (Appendix 7), and a response card (Appendix 8). A minimum of 24 hours was given in order to decide whether they wanted to take part in the study. After receiving the response cards by
post, the researcher contacted the potential participants by telephone or email (based on the information on the returned response cards), confirmed their agreement to participate, and arranged a date for the interview. On the date of the interview, participants also had the opportunity to ask further questions about the study, and they were reminded that they could withdraw at any point. The consent form was signed by the parents/guardians, and the adolescents signed an assent form before the start of the interview. The ground rules regarding confidentiality and the purpose of the study was explained again by the researcher. The patient demographics were checked before commencing the interview questions.

The recruitment process regarding identifying and approaching participants is shown in Figure 2.



Figure 2: Recruitment process

# 4.7 Recruitment process plan for Stage 3: Health care Professionals

Health care professionals were identified by the researcher, as she becomes familiar with the team members. Six health care professionals who met the inclusion criteria were interviewed. The health care professionals were approached face-to-face by the researcher and the study was discussed with them. After showing interest to participate in the study, a study pack including an invitation letter (see Appendix 9), information sheet (see Appendix 10), and consent form (see Appendix 11) were supplied to the potential participants by the researcher. A minimum of 24 hours was given to decide on whether they want to take part in the study. After that the interested potential participants sent an Email to confirm their willingness to participate in the study. The researcher then called the participants back to decide the date of the interview. Experts were interviewed in a reserved room within the diabetic clinic.

## 4.8 Recruitment process plan for Stage 4

The recruitment process in this stage was similar to that used for the first stage. An information pack was also given to the interested potential participants in this stage. The information pack consists of an invitation letter (see Appendix 12), an information sheet for both parent(s)/guardian(s) and adolescents (see Appendices 13A and 13B), a consent form (Appendix 7), and a response card (Appendix 8).

### 4.9 Ethical Considerations

It is good research practice for all studies involving human participants to be ethically reviewed. This research study involved human participants and, therefore, the researcher adhered to policy on the ethical conduct of studies involving human

participants. To protect the rights of the participants, the study was submitted for ethical approval through the University of Southampton's electronic document management system: Ethics and Research Governance Online (ERGO). Following approval from the University's Ethics Committee, the researcher sought permission from the NHS approval system, as the research study involves NHS patients and health professionals. Health Research Authority (HRA) approval and a research passport were obtained. According to the British Psychological Society Code of Human Research Ethics (2010), participants should not be subjected to harm more than that to which they are exposed in their normal life. According to Medical Research Council's, MRC Ethics Guide: Medical Research involving children, MRC (2004), children are considered to be a vulnerable group and, therefore, researchers are required to assess the potential benefits and harm to children at all steps of the research study. The benefits and risks ratio has been fully considered in this study, and the possibility of risk for all participants is believed to be minimal. The researcher took precautions to avoid physical or psychological harm, such as hypoglycaemia, distress, or anxiety being experienced by the participants during the data collection process. The researcher ensured that all appropriate precautions were taken to ensure that, as a result of participating in interviews, no participants were at any additional risk of hypoglycaemia. The participants were allowed to bring suitable snacks and they were permitted to eat and drink during the interviews. As qualitative research attempts to gain an in-depth understanding and exploration of certain issues, this may lead to anxiety or distress in participants, depending on their personal experience (Richards and Schwartz 2002). Participants were given the opportunity to ask questions and receive accurate information before committing themselves to the study. The researcher ensured a comfortable conversational setting for the interviews. In addition, the researcher

reminded the parents to use the 24-hour urgent call service at the paediatric clinic if any unforeseen situations arose. The 24-hour urgent call is already available and accessible for patients and their parents.

The participants' right to confidentiality and to withdraw from the study were assured at all stages. To maintain confidentiality, the participants were assured that any data collected during the research stages will be used for the purpose of this research only, including personal, demographic, or any other data. The participants were also assured that their identity is confidential. Each participant's information assigned a code number, and the list that links the names of the participants to the codes kept in a locked file (more details regarding this procedure are given in the data protection section below). It was explained to the participants that they have the right to withdraw from the study at any stage without penalty, as their participation is voluntary.

### 4.10 The participant information sheet

Participant information sheets for all stages have been prepared for the participants and parents/guardians, and detailed information about the study, as well as the researcher's contact details, are included.

### 4.11 Consent

Informed consent has been defined as the process of confirming that research participants fully understand what is being done to them and the limits to their participation, and it should alert them to any possible hazards they may experience (Wiles et al. 2007). Informed consent from research participants is regarded as central to ethical research practice in the social sciences. Gaining consent from children or adolescents is more complicated than gaining consent from adults, however, because children and adolescents are commonly characterised as 'vulnerable' (Wiles et al. 2007). According to the MRC (2004), children should be involved in decisions that are related to their health and well-being. However, it is necessary to employ an appropriate process that is suitable to the child's age and cognitive ability in order to obtain consent. Adolescents aged 16 and above are competent enough to give consent unless they are not able to understand and weigh up the options. The MRC (2004) has also stated that any child under 16 is defined as a minor, who cannot give consent for medical treatment or research. However, according to Gillick, with regard to competence, which is concerned with determining a child's capacity to consent to medical treatment (Wheeler 2006), a child under the age of 16 can give consent on his or her own if he or she has enough understanding of the treatment choices provided. However, due to the complex nature of research, there is ambiguity about the extent to which the Gillick principle can be applied to this research. As many minors are expected to participate in research studies, further protection rules for children under 16 have been considered. These rules stipulate that informed consent, which allows for the withdrawal of a child at any time and without giving any reason, must be obtained from the parents or guardians (MRC 2004). The MRC guidelines also emphasise encouraging parents or guardians to stay with the child during the data collection. Although, Gardner and Randall (2012) discussed the impact the presence of the parents in the interview between the child and the researcher. They explained that influences of parents on views of the children during the interview is complicated as their presence may hinder or help children's opinions being heard. For some children, the chance to provide their views without attendances of their parents can lead to the gathering of more profound and more precious data. However, where parents act as substitutes for researchers, the parents understanding of their children can lead to the collection of rich data. Parents may help or limit children

contribution. Gardner and Randall (2012) emphasised that any influences by the parents on the interviews should be reported so users of their research can reach an informed judgment. In this study, during the interviews, some parents excused to do some other work and left us alone, some other parents asked their adolescents about the preference of their presence during the interview, and most adolescents did not mind their parents to be around. There was no observed influence on adolescents from parents during the interviews. However, there was occasional influence from the parents during the recruitment process, where two mothers were happy for their children to participate in the study whereas the children were hesitant. Therefore, the researcher gently focused on the adolescent's opinion on their participation, and after confirming their refusal, they were thanked for their time. The researcher is also expected to respond to any questions that the parents or guardians may have during the study, in order to reduce any concerns that may arise. However, it has also been emphasised that a child's ability to give consent depends on the understanding and intelligence of that child in respect to what is proposed. Researchers must respect the autonomy of adolescents (those under the age of 16) by ensuring that children or adolescents can freely participate, at the same time as allowing for the parental obligation to safeguard their children's safety and well-being (Powell et al. 2012; Huang et al. 2014). Therefore, in this study, initial consent from parents or guardians was obtained at all stages, followed by a written assent form (see Appendix 14) from the adolescents who take part.

## 4.12 Data protection

The researcher followed the University of Southampton's policy for research data management (Section IV: Research Data Management Policy). The researcher transcribed the audiotape data as soon as possible. All personal data was then held securely in order to prevent any unauthorised access or accidental loss, particularly when using a laptop and removable flash discs or CDs. In order to maintain confidentiality, a password was used to protect all the information, and all paper records are stored in locked cupboards within the Faculty of Health Sciences (Building 45) at the University of Southampton. In accordance with the University of Southampton's policy for research data management, all forms of data will be stored securely for ten years in the Faculty of Health Sciences after the study has ended.

# 4.13 Data Analysis

Thematic analysis was utilised for the interviews in this study, using computer-assisted qualitative data analysis software (NVivo). Data analysis is the most complicated and essential aspect of qualitative research. Qualitative research usually produces large amounts of textual data in the form of transcripts. The systematic and difficult preparation and analysis of qualitative data is usually time-consuming (Zamawe 2015). Therefore, computer-assisted qualitative data analysis software (NVivo) was used to assist in data analysis. One of the main advantages of using computer software is that it can offer greater analytical flexibility and transparency to a research process when compared to manual methods (Siccama and Penna 2008). Software such as NVivo provides transparency mechanisms that can help make the methodological and analytical processes more understandable and easier to trace. However, it is essential to understand that these kinds of software do not analyse data but facilitate data analysis by managing, sorting, and organising large volumes of qualitative data (Burnard et al. 2008). In this thesis, transcription is being done by means of professional audio player software such as Express Scribe, which assists in the transcription of audio recordings. The researcher is utilising the six phases of thematic analysis framework (Clarke and Braun 2013) for stages 1, 2 and 4 as follows:

### 4.14 Familiarisation with the data

To be familiar with the data, the researcher immerses herself in the interview transcripts, reading and re-reading the participants' experiences. In addition, the researcher listens to the recordings to identify any initial analytical observations.

# 4.15 Coding

Coding of content begins by reviewing the analytical objectives, reading the text to be analysed, and indicating the type of meaning that the text may potentially represent (Guest et al. 2011). The researcher codes every data item, and this stage ends by collating all the codes and relevant data quotations.

## 4.16 Searching for themes

A theme is defined as an expression or sentence that indicates what the unit of data is about or what it means (Saldaña 2015). Searching for themes is similar to categorising codes in order to identify similarities in the data. The researcher organises items relating to similar topics into categories in order to create the themes. This phase ends with the collation of all coded data relevant to each theme.

## 4.17 Reviewing themes

The data is explored for similarities and differences and codes are developed and applied to extracts of the data in order to identify their links to one or more of the themes. Although each category is coded separately, some textual extracts can be applicable to more than one category. Therefore, it is necessary to keep the text intact throughout. To facilitate this, the researcher uses NVivo software for data organisation. The use of NVivo software enables the coding process to record codes into the software's coding system automatically, in addition to allowing for the retrieval of coded text that is linked to the individual source data. This permits a checking back and forth between the analysis and the source data to identify the most frequent terms. In addition, it enables the researcher to read the content line-by-line and identify salient coding themes. The researcher then reads the data repeatedly to gain a complete sense of the themes. Preliminary categories and themes are then discussed with the researcher supervisors in order to ensure the rigour of analysis.

### 4.18 Defining and naming themes

The researcher writes a short description that highlights the key feature of the theme or theme components. This is achieved by asking, 'What does this theme tell me?' and 'How does this theme fit into the overall data?'

# 4.19 Writing up

Writing-up involves merging the analytic narrative and data extracts to tell the reader a logical and convincing story about the data. Vaismoradi et al. (2016) suggest that researchers eventually link their storyline to the literature around which the content of themes in the study revolves. This will indicate how the study has progressed and also enable more understanding of the study topic for readers.

In this study, the semi-structured individual interviews conducted in all stages were based upon open-ended questions and were recorded using compact recording technology. The audio files were professionally transcribed using a professional transcribing service. A confidentiality agreement was obtained before sending the audio files. The researcher checked the transcripts alongside the initial audio recording in order to ensure accuracy. Data analysis was carried out using thematic analysis, which involves six main stages: familiarisation with the data, coding, searching for themes, reviewing themes, naming themes, and writing up. The researcher spent time familiarising themselves with the data by reading and re-reading the transcribed data. NVivo software was utilised to code each of the participant's transcribed interviews. This phase resulted in a long list of different codes.

The researcher read the codes from each participant's interview and then started to search for themes by re-reading and refocusing on the broader level of themes, instead of the codes. The codes were then sorted into potential themes. The use of NVivo enabled the researcher to check back and forth between the analysis and the source data in order to read the content line-by-line and code the salient themes. The researcher reviewed the textual data to make sure that the themes were clearly stated by the participants. Peer debriefing was carried out to increase the trustworthiness of the findings. Holloway and Galvin (2016) explain that debriefing is when competent personal in qualitative research reanalyse the raw data, listen to the researcher's concerns and discuss them. This could detect bias or inappropriate subjectivity. In this study, peer debriefing was performed by the researcher's supervisors and colleagues.

# CHAPTER 5: FINDINGS OF STAGE 1, 2, 3 & 4

This chapter presents the findings of all the stages of this study including stage one (exploratory stage), stage two (intervention development), stage three (interviews with health professionals), and stage four (interviews with the second group of adolescents with T1DM).

## 5.1 Findings of Stage 1 (exploratory stage)

The qualitative findings of this stage explore the needs and priorities of how adolescents with T1DM wanted to be supported in a school setting. This information will also contribute to determining which intervention's elements that can help adolescents with T1DM to improve their diabetes care in schools.

# 5.1.1 Data Analysis of Semi-Structured Individual Interviews for Stage 1

Eighteen participants were interviewed individually. For reasons of confidentiality, participants are referred to by abbreviation: adolescent (A=Adolescent), number (1–18), and gender (M=male, F=female).

### 5.1.2 The findings from the demographic data of the study sample

The demographic data of the participants were collected by the researcher before each interview, consisting of the participants' gender, age, ethnicity, family structure, duration of T1DM, and type of insulin therapy (see Table 5).

|                         |                                    | Ν  | %     |
|-------------------------|------------------------------------|----|-------|
| Candar                  | Male                               | 11 | 61.1% |
| Gender                  | Female                             | 7  | 38.9% |
| Age                     | 11 – 12 years                      | 7  | 38.9% |
| Age                     | 13 – 15 years                      | 11 | 61.1% |
| Ethnicity               | White British                      | 14 | 77.8% |
|                         | Black African                      | 3  | 16.7% |
|                         | Asian                              | 1  | 5.6%  |
| Living with             | Parents and siblings               | 9  | 50.0% |
|                         | Parents without siblings           | 1  | 5.6%  |
|                         | Mother and siblings                | 4  | 22.2% |
|                         | Mother without siblings            | 3  | 16.7% |
|                         | Others (living with foster mother) | 1  | 5.6%  |
| Number of family        | 1 – 2 members                      | 4  | 22.2% |
| members                 | 3 – 5 members                      | 14 | 77.8% |
| Guardians/Carers        | Mother                             | 7  | 38.9% |
|                         | Father and Mother                  | 10 | 55.6% |
|                         | Others (foster mother)             | 1  | 5.6%  |
| Duration of the disease | 1 – 4 years                        | 8  | 44.4% |
|                         | 5-8 years                          | 4  | 22.2% |
|                         | 9 – 12 years                       | 6  | 33.3% |
| Type of insulin         | Injection                          | 9  | 50.0% |
| therapy                 | Insulin pump                       | 9  | 50.0% |

 Table 5: Demographic elements, showing demographic characteristics of adolescents with T1DM (n=18)

# **5.1.3** Themes

The data was analysed and categorised into themes to ensure clear accounts from adolescents (See Appendix 15 – coding frames of interview data for stage 1, 3 and 4

and thematic mapping). Appendix 15 is a newly added appendix that contains the coding frames of the interview data for stage 1, 3 and 4. It also comprises the thematic mapping for each stage, which was formulated to show the relationship between the codes and themes identified in each stage.

The adolescents accounts have many similarities and differences, which are fully explained in this chapter. The final analysis revealed seven themes:

1. Adolescents' ability to depend on themselves in managing their diabetes in school.

- 2. Challenges in managing T1DM in the school setting.
- 3. Peers and teachers to improve knowledge and understanding about T1DM.
- 4. Suggestions in which knowledge and understanding of T1DM can be enhanced.
- 5. Approaches to informing peers and teachers about T1DM.
- 6. Willingness to learn problem-solving and coping tips/skills.
- 7. Approaches to learning coping tips.

# 5.1.3.1 Adolescents' ability to depend on themselves in managing their diabetes in school

All adolescents explained that they depended on themselves for all of their diabetes management tasks and they understood how to do their daily tasks, such as checking their blood sugar, adjusting insulin doses, administering insulin injections, and counting carbohydrates. The following interview extract demonstrate some of these behaviours:

*Um*, *I just do it, like, normally, I do my blood sugar map and checking every two hours, so when I get to school, it'll be around 8 o'clock, so I wait until* 

9, which is during registration, and I'll check my sugar levels then. Then, I check again at 11, which is break time, and then 1 o'clock, which is the end of lunch, and then at the end of the day, which would be 3 o'clock. That's when I do my final one for school (A4-F-15yrs).

Sixteen of the adolescents were also aware of what to do before engaging in different school activities, such as physical education (PE) or swimming, e.g. checking blood sugar before and after, adjusting insulin dosage, or having extra carbohydrates:

Well, if I am going to PE, then I would have to check my blood, and then have something high in carbs to account for the exercise I am about to do (A1-M-11yrs).

In contrast two of the adolescents expressed that they do not do any preparation before PE or swimming.

No, I am not taking more carbs or checking my blood sugar before doing that (A16-F-15yrs).

No, I do not check my blood sugar before swimming. No, I do not take extra carbs (A14-F-13yrs).

#### 5.1.3.2 Challenges in managing T1DM in a school setting

Although all adolescents demonstrated their ability to take responsibility for their diabetes management in school, when asked about their feelings regarding managing their diabetes in school, the adolescents explained that it could be difficult and challenging. The challenges were categorised into physical challenges, psychological challenges, and social challenges.

### **Physical challenges**

Two of the adolescents stated that managing diabetes can be physically hectic because, in secondary school, they have to move from one class to another and they need to take their equipment along with them:

Sometimes, it's kind of hectic because I'm obviously doing, like, moving around the school because it's secondary school instead of primary school. just staying in one class. Sometimes I forget to put an injection (A4-F-15yrs).

Two of the adolescents explained that managing diabetes in school could be timeconsuming.

It just takes time [diabetes tasks] (A1-M-11yrs).

Probably finding the time to do it, because if you don't have a lot of time, and then, obviously, when we have to wait for the lesson to finish, and then go back to tutor, and eat, and everything, in like, 10 or 15 minutes (A9-F-15yrs).

All but one described some other physical challenges associated with signs and symptoms of hypoglycaemia, such as general weakness, agitation, thirst, and shakiness.

Just, if I'm low [low blood sugar], I feel a bit, I feel hungry, sometimes thirsty. I might feel a bit sick and weak (A8-M-13yrs). Normally, like, I can't really move myself very well. I shake a lot (A17-M-14yrs).

### **Psychological challenges**

Sixteen of the adolescents described some psychological challenges associated with signs and symptoms of hypoglycaemia, such as a lack of motivation and a lack of concentration.

*Like, my blood goes low, and I don't want to do anything (A3-F-11yrs).* 

I can't concentrate half the time when I'm low [low blood sugar] (A6-M-13yrs).

Another psychological challenge facing adolescents with T1DM as a result of fluctuating blood-sugar levels is mood swings, which can result in a flare-up in temper or other less-than-desirable behaviours. Four of the adolescents expressed consequences of fluctuating of blood sugar:

When my blood sugar is high, sometimes when I am talking to people in school, I can come across quite abrupt with quite a bad attitude, and that has upset some of my friends, but they didn't realise what is going on with me (A11-M-13yrs).

When I'm high [high blood sugar], my mood just goes off slightly (A10-M-12yrs).

Fifteen of the adolescents also expressed that diabetes management can be frustrating, as they have to miss some fun activities or miss part of an important class or break time.

it's kind of frustrating when, like, my blood sugars are high or my blood sugars are low, and I do miss the lessons that are really quite fun and, like, because sometimes I feel like I am missing out on a lesson, like, if it is something that I have never done before or it is something completely brand new that I really wanted to learn about, and I have to miss it. It is a bit annoying, yeah (A11- M-13yrs).

Two of the adolescents asked, 'Why me?' The following extracts demonstrate this type of worry:

Sometimes, it makes me upset because, sometimes, it's just, like, I ask my mum why it happened, even, because no one in our family has it, so it just, it kind of, it was kind of strange to us how it came to me (A4-F-15yrs). Obviously, you're different, but you don't want to be different, and it's obvious, I think (A9-F-15yrs).

#### Social challenges

Adolescents expressed some social challenges, such as their uncomfortable feelings and embarrassment due to carrying out diabetic-related tasks in front of their peers, especially if their peers did not know anything about the duties of managing T1DM, such as checking blood sugar or administering insulin injections.

I think the fact that you have to inject yourself in public, and things like that, is just a bit, like, you don't want to do. It's almost a bit embarrassing, you know? Like, not the fact you have to inject yourself. It's the fact that there are other people (A9-F-15yrs).

In addition, some of the adolescents stated that they did not like being repeatedly asked about it. Therefore, such feelings of unease can cause them to delay their diabetes management in the classroom and, instead, do it in the medical room, which may be far from their class: I prefer doing it in my medical room because, like, not very many people go in there. I prefer to go to the medical room, although I don't have to, but people ask questions otherwise. It is just annoying (A16-F-15yrs).

One adolescent described how his peers bully him by messing with his diabetes medication backpack:

But they've picked mine up before, the whole backpack. took it over the room and chucked it, and then someone pushed it off the table. but they wouldn't do that to him because they'd know if he did, well, if they did it to him, he'd punch them, or do something like that, because he's larger than them, and they think I'm an easy target, sort of (A8-M-13yrs).

# 5.1.3.3 Peers and teachers improve their knowledge and understanding about T1DM

When asked about how adolescents with T1DM wanted to be supported, to make their self-management better in school, sixteen of the adolescents would want their peers and teachers to know more about T1DM.

Diabetes and things to do with diabetes so all teachers and my friends should know, you know? Everyone at school to know about it [diabetes] (A18-M-13yrs).

Four participants stated that more understanding about T1DM from teachers and peers may help adolescents with T1DM to improve their self-management around the school.

Maybe help my teachers, also schoolmate to know what is going on...will help me manage my diabetes better around the school (A11-M-13yrs).

Six of the adolescents specified that more knowledge about T1DM among peers and would make them to feel more comfortable being around their peers, they would not feel awkward, and they would stop being hesitant performing the tasks required.

I'm sat with people [peers] that don't know about it, so it's, kind of, I feel to step back a bit, instead of doing it in front of them, and to be asked questions about it, but if they know[peers], it will make me to feel more comfortable to go on with my diabetes tasks (A4-F-15yrs).

# 5.1.3.4 Suggestions in which knowledge and understanding of T1DM can be enhanced

All of the adolescents suggested that their peers and teachers to become more familiar with diabetes as well as signs and symptoms of hypoglycaemia, and its management so they will be able to manage in emergencies

*Umm, know the symptoms of feeling low [low blood sugar] and feeling high [high blood sugar], and know how to act in case of emergencies (A2-F-11yrs).* 

Seven of the adolescents reflected that if their peers and teachers knew about diabetes, they would understand the effect of hypoglycaemia on their mood and changes in their behaviours, so they would not get angry.

...understand how it affects my temper and not getting angry with me. Just to genuinely, like, understand what people with diabetes go through, like my attitude changes quite drastically, and just don't get angry at me, in a way, and wait till I'm alright again (A17-M-14yrs). Half of the adolescents also specified that teachers and peers to know about the effect of blood fluctuation on behaviour, therefore, they would be able to remind them to test their blood sugar.

If I start acting weird in a class before lunch and no-one encourages me to do a blood test, then I come after lunch, my sugar could be all over the place, and it could escalate into something a lot more that could have been prevented, really (A15-M-15yrs).

Six of the adolescents would like peers to know about their diabetes because their understanding of the disease could allow adolescents with T1DM to manage their tasks without having to answer many questions, and it would give them space to do their tasks.

To understand that I need some space to do my diabetes tasks (A10-M-12yrs).

Because then people actually understand it [diabetic management]. They don't ask a load of questions (A13-M-11yrs).

Two of the adolescents explained that because peers do not know about insulin injection, they had to inject themselves under the table because they thought that some of their peers would become scared or misunderstand the purpose of injections.

Kind of, do it [injecting insulin] under the table where no one can see it, or something, because I think some, you know, like, some people can be a bit funny about, like, needles and stuff like that, and blood. Because I am, which is quite ironic, being diabetic, but, like, if I mean, I know if I saw someone injecting, I'd be like, 'Oh my God.' (A9-F-15yrs) Three of the adolescents also explained that their peers and teachers do not understand why they need to eat during the lesson to treat their hypoglycaemia.

Because I went in the lesson one time, and I was eating my dextrose, and she [teacher] told me, 'Spit your chewing gum out' (A7-M-12yrs).

It's just a bit annoying that people [teachers and peers], it's like, stereotypes of why diabetic people, eat in the class (A8-M-13yrs).

One adolescent explained that he had to wait for 15 minutes to be allowed to go to medical room to treat his hypoglycaemia.

I went up to the reception desk to say I felt low, and she [receptionist] made me wait for about 15 minutes or something before she'd let me go and get my medication (A6-M-13yrs).

Two of the adolescents stated that some peers do not know the actual cause of T1DM and they think it happens because eating so much sugar or because being overweight or drinking alcohol. The misconception about the causes of T1DM can be frustrating.

Make them [peers] aware, maybe explain what it is. Like they said, 'How did you get it? Eating too much sugar? Are you eating too much? Are you fat?' It is frustrating and annoying, and I went, 'Um, oh, yeah, my pancreas stopped working'. They [peers] were searching up something about alcohol, and he went, 'Oh look, it could give you diabetes'. I went, 'Yeah, it's not how I got it'. And then I said, 'It's where I got a cold, and it stopped my pancreas' (A18-M-13yrs).

Eight of the adolescents expressed that there was lack of awareness regarding what T1DM is and how it differs from T2DM. They expressed that more knowledge can lead to better understanding of the tasks of T1DM:

So, I think the biggest problem is the awareness in the school. Teachers and students are, actually, should be made much more aware of what is type 1 diabetes. It is not like type 2 diabetes. It [type1] needs much more care (A4-F-15yrs).

One of the adolescents stated that some of their peers need to know the importance of carrying their diabetes bag (a bag containing an insulin pen and a blood glucose meter) at all times:

Yeah, I've had issues with boys, like, taking my diabetes bag. Just boys are messing about it in the classroom, throwing the diabetic bag around. So, I had to tell the teachers because I need that kit on a daily basis. They're not, very, um, good at dealing with it. I guess they need to know how the kit is important to me (A8-M-13yrs).

Six of the adolescents expressed that, some peers and teachers had no idea what the insulin pump is. They thought it was an MP3 player or a mobile and tried to pull it off:

One teacher tried to pull it off of me. Well, in a sort of way, they won't help me because they don't know how much it means to you to have an insulin pump (A15-M-15yrs).

One adolescent stated that the teachers could provide more support:

Well, maybe for the teachers just to give a little bit of like, support, like it's okay and stuff, so we feel good (A1-M-11yrs).

Five of the adolescents stated that some teachers do not know that they have students with diabetes in their class. The participants expressed frustration of having to repeat telling the teachers that they have diabetes: Teachers, they can make them more aware, maybe, because some teachers just don't know. Like, my English teacher, she'd asked me to take this band off before that says 'diabetic', and I've explained to her, I think two weeks ago. It was the third time she asked. It is annoying, repeating the same thing over and over, so, she wasn't aware that I actually had diabetes (A8-M-13yrs).

Three of the adolescents suggested some ideas for how their teachers could know that they have students with medical problems, such as names on the staffroom board or documentation on each child for the teachers.

To have, like, a sheet of paper with a photo of us and then, like, the medical condition we have, and this will be better, so they [teachers] know about us and support us (A14-F-13yrs).

Also, the lack of knowledge about how to support adolescents with diabetes during specific activities can cause adolescents to drop important activities, such as PE, specifically for those who need more support to do their tasks. Three out of 18 adolescents expressed this sentiment:

I do not do PE; they [PE teachers] have allowed me to drop PE instead of putting someone to support me, to actually check my sugars, through the PE, half-way through it, to check it again (A5-F-13yrs).

Four of the adolescents suggested that the canteen should provide more information about carbohydrates, so they can adjust their insulin dosage:

The canteen at school doesn't have anything on show about how many carbs and stuff. I think that would be helpful, though, if they did (A16-F-15yrs).

If the school could label food, they sell at break/lunch time with how many carbs that will be helpful to adjust our insulin dosage (A6-M-13yrs).

### 5.1.3.5 Approaches to educate peers and teachers about T1DM

Adolescents suggested different ways to educate peers and staff about diabetes, such as during enrichment days at school:

At my school, we have enrichment days, where we have a day full of activities to do with our learning. I think, maybe, on one of those days, or maybe on a Friday afternoon, we could do, like, and activity where people [teachers and peers], like, become familiar with diabetes (A4-F-15yrs).

Or tasks and pop quizzes:

Tasks and pop quizzes about it [diabetes] (A14-F-13yrs).

One suggested using posters:

Have posters up at school about what is type 1 diabetes, because people just aren't aware of that, or how you help someone with diabetes, maybe (A17-M-14yrs).

Few participants suggested PowerPoint or short video presentations to be watched during a tutor session:

Maybe they could have someone make a PowerPoint or short video, which they [teachers] then can show to the whole school during tutor session. Well, our years are split into French and Spanish, and all me, x, and y are all diabetic; we're all on the Spanish side so that the French side wouldn't know anything about it (A8-M-13yrs).

### 5.1.3.6 Willingness to learn coping skills

Fifteen adolescents expressed their interest in learning tips/skills in order to feel better about caring for their diabetes. The words tips or skills were explained by giving examples, such as tips on how to solve problems that may arise during managing diabetes in school or how to change unsettling thoughts to more positive thoughts:

Yeah, I would like to learn these kinds of tips [coping tips] (A2-F-12yrs). Yes, it will be interesting to learn these tips in school [coping tips] (A4-F-15yrs).

Adolescents stated that these tips (tips to solve problems or change unsettling thoughts to more positive ones) could help them to calm down:

It's not good to keep your feelings inside because you can get frustrated, and it could lead to something worse, and, just being able to be calm in some situations would make it easier, instead of making it hard on yourself (A4-F-15yrs).

One adolescent explained that changing negative thoughts to more positive thoughts can make her feel relaxed:

To help me, sort of, sometimes relax (A2-F-11yrs).

One adolescent stated that changing negative thoughts to more positive thoughts can help to not be negative about having diabetes:

If I am more prepared with these tips, then I could control myself better rather than, maybe, not be negative with being diabetic, but a bit straight with it, you know? (A15-M-15yrs) One adolescent expressed that problem-solving tips can help him to be able to solve problems without being panicked:

I'll be able to solve any problems without panicking (A6-M-13yrs).

However, three of the adolescents were not interested in learning these coping tips because either their teachers could solve the problem for them:

The school knows how to solve problems [related to diabetes selfmanagement]. If not, they would ask me, and even if I'm stuck with something, I would get them to ring mum (A10-M-12yrs).

Or they had their own ways to feel positive about themselves:

I wouldn't really want to be told how to do things at the moment. Well, I wouldn't like to learn new things because I've just kind of found out a really good way of dealing with everything. I have a really good way of feeling quite positive; it's just to think of something you're looking forward to after school (A17-M-14yrs).

#### 5.1.3.7 Approaches to learning coping skills

Five adolescents suggested some approaches to learning these tips, such as getting trained one-to-one or with other peers:

*Maybe, like, one-to-one, or groups, like, your friendship groups, so that they can understand as well (A4-F-15yrs).* 

Two of the adolescents suggested learning the coping tips by using cards with pictures:

*Like, laminated cards and stuff with maybe a picture on it (A1-M-11yrs).* 

However, eight of the adolescents would prefer to learn these tips using something they can read:

Anything I can read (A6-M-13yrs).

*Oh, for me, oh, um, I mean, I think online is quite good, but, to be fair, I mean, brochures and leaflets, as well, like, I wouldn't mind, like, reading, yeah, I mean, I wouldn't mind really (A9-F-15yrs).* 

### 5.1.4 Summary of stage one

This stage has presented interview data from the study's first stage. The adolescents, responding to semi-structured questions, described a variety of experiences and suggestions of how they wanted to be supported in school.

The findings indicate that adolescents with T1DM were actively managing their health conditions at school. However, there are areas of concern. The findings indicate that adolescents face some challenges in managing their diabetes in school. These challenges can be categorised into physical challenges due to fluctuations of blood sugar levels (such as weakness and shakiness), psychological problems (such as frustration, lack of motivation, and mood swings), and social challenges (such as embarrassment, feeling different, uncomfortable feelings related to being around peers, and bullying). In addition, a further challenge is the lack of awareness among teachers and peers regarding T1DM and its management.

The findings also explored how adolescents' with T1DM wanted to be supported in their school. Most adolescents wanted their peers and teachers to know more about the requirement of managing T1DM. Improving teachers and peers' understandings about T1DM and its management was seen as an area in need of attention. Adolescents gave many suggestions of the type of the information that they need their teachers and peers to know and how improved knowledge could facilitate diabetes management in school and reduce some of the physical and psychosocial challenges such as conflict, embarrassment and frustration resulted from lack of knowledge. The respondents felt that improved knowledge about diabetes among teachers and peers could help the adolescents with T1DM to feel more comfortable and not feeling embarrassed in managing their diabetes in school since it would help to correct the misconception about injections and insulin pumps. The findings also indicated that knowledge and understanding may enable teachers and peers to act in emergency situations, such as hypoglycaemia. In addition, it will offer more space for adolescents to carry out their diabetic tasks without feeling frustration caused by having to answer many questions, allowing peers and teachers to understand the effects of blood sugar fluctuation on adolescents' moods and behaviour to avoid conflict. In addition, teachers and peers can remind diabetic students to check their blood sugar if they notice any changes in their behaviour. Moreover, peers may understand the importance of carrying a diabetic bag. Furthermore, more knowledge may allow peers and teachers to understand the importance of sometimes eating in class, which is necessary to treat hypoglycaemia and avoid threatening complications. Additionally, physical education teachers can adequately support adolescents with T1DM during other school activities, such as physical education and swimming class. Also, school canteens can provide more nutritional information for the food they serve so adolescents with T1DM can adjust their insulin dosage. The findings also indicate some suggestions regarding how to educate peers and teachers about diabetes and its management. Adolescents suggested utilising enrichment days or tutor's sessions in school to inform others (peers and teachers) about the T1DM. Other suggestions were posters and PowerPoints or short videos about T1DM and how to support those with diabetes in school.

Although the main emphasis of the research is to know how adolescents wanted to be supported in school, however, a back-up question, regarding the adolescents' interest to

learn some coping skills in school, was asked. The findings showed adolescents' willingness to learn coping tips/skills, particularly problem-solving skills and tips with regard to changing unsettling thoughts to more positive ones. The participants stated that such tips could help them to voice their feelings, relax, and be better problem solvers, in addition to assisting them in not being negative about their diabetes. The adolescents suggested a number of approaches to learning these tips/skills, such as one-to-one or group training. However, most adolescents would prefer readable materials, such as laminated cards with pictures, leaflets.

The adolescents showed interest in learning some coping skills; however, this was not found as a priority when adolescents asked about how they wanted to be supported in school. Knowledge and understanding of peers and teachers about T1DM was specified as a priority by majority of the participants (16 out of 18). Also, the suggestion of what to include in the intervention was derived from the findings in this stage. Therefore, the researcher will pay attention to develop an intervention that meets the needs and the priority identified by the participants in this research.

The suggested information about T1DM (as obtained from data) for peers and teachers to be included in the intended intervention is summarised as follows:

- Information about diabetes mellitus and its causes.
- Information about the differences between T1DM and T2DM
- Information about signs and symptoms of hypoglycaemia to act on in an emergency
- Knowing that fluctuation of blood sugar can cause mood swing
- Knowing to remind someone with diabetes if their behaviour has changed
- Information about insulin pens

- Information about insulin pump
- Information about the need to eat in class
- Information about the importance of carrying the diabetes bag
- Knowing that teachers can give emotional support
- Knowing about a student with diabetes in the class will help a student with T1DM not to repeat information about themselves over and over
- Information about teachers to keep a register for students with diabetes
- Information about how hypoglycaemia should be treated immediately
- Information about how PE teachers can support a student with T1DM during a PE lesson
- Information about the importance of providing nutritional information.

### **5.2** Findings of stage two: Intervention Development

The following section provides details of the intervention development (stage two) using intervention mapping protocol and findings from stage one. It escribes the systematic development of an intervention programme (video) to be used in schools to improve knowledge and understanding of T1DM among peers and teachers in the school.

### 5.2.1 IMP Step 1: Need assessment

The need assessment was conducted via a literature review and semi-structured interviews with adolescents with T1DM (stage one of this study). The literature review was done to provide information about the prevalence of T1DM in adolescents, stressors facing adolescents with T1DM in school and how these stressors affecting the self-management in a school setting (see Chapter 1). Also, the literature review was conducted to provide information about the existing school-based diabetes interventions (see Chapter 2). The review revealed that the prevalence of T1DM is increasing among adolescents. Adolescents with T1DM are facing extra challenges with experiencing all the rapid physical, psychosocial and cognitive changes while trying to maintain good metabolic control. Also, adolescents are facing physical and psychosocial difficulties that can lead to poor management in school. School-based interventions established previously predominantly centred around enhancing education/communication and care coordination for both students with T1DM and school staff. No intervention focused on diabetic knowledge among the school peers. Also, other aspects such as psychosocial and emotional challenges were not presented. Moreover, there was no clear indication of involving the voice and priorities of adolescents with T1DM during the development of school-based interventions.

The semi-structured interviews were conducted to explore needs and priorities for adolescents with T1DM in the school settings and to understand how adolescents wanted to be supported in schools to enhance their diabetic self-management. The results indicated that adolescents with T1DM are still facing physical and psychosocial challenges that negatively influence their self-management in school. The findings also suggested how adolescents with T1DM wanted to be better supported in school. Most of the participants felt that their teachers as well as their peers needed to gain more understanding of T1DM and its management. All participants felt that enhanced knowledge and understanding of T1DM and its management among their teachers and peers could help to reduce psychosocial challenges and consequently promote their selfmanagement. These findings influenced the intervention development, specifically the content. According to the findings, the adolescents with T1DM suggested specific knowledge that should be included in the intervention (as discussed in Chapter 4).

### 5.2.2 IMP Step 2: Identity outcomes and change objectives

Results from IMP step 1 were used to identify the intervention objective. The programme objective was formulated for the organisational level (peers and teachers in the school environment). The overall aim of this intervention is to enhance self-management of adolescents with T1DM in school through improving the knowledge and understanding about T1DM among school peers and school teachers. This step of the intervention mapping involves **firstly**, a specification of objective that include a clear description of the target population's behaviours. The finalised programme objective for the organisational level is: to *Improve peers and teachers' knowledge and understanding of T1DM and its management*.

**Secondly**, objectives must specify what individuals (peers and teachers) need to learn to change their behaviour and what the expected changes are (Eldredge et al. 2016). Based on the programme objective, different performance objectives were formulated at the organisational level of peers and teachers. An overview of the programme objective and performance objective can be found in Table 6.

# Table 6: Programme and performance objectives for the organisational level (peers and teachers)

| Level of the intervention | Target group                                    | Programme objectives                                                                                                             | Performance objective                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
|---------------------------|-------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Organizational level      | Peers and teachers at the<br>school environment | <ol> <li>To improve Peers and<br/>teachers' knowledge<br/>and understanding<br/>about T1DM and how it<br/>is managed.</li> </ol> | <ol> <li>Peers and teachers know the difference between type 1 diabetes and type 2 diabetes.</li> <li>Peers and teachers correct the misconception about the causes of T1DM.</li> <li>Peers and teachers recognise the causes, signs and symptoms of hypoglycaemia.</li> <li>Peers and teachers know what to do if someone develops signs and symptoms of hypoglycaemia.</li> <li>Peers and teachers understand the effect of hypoglycaemia on the mood of someone with diabete:</li> <li>Peers and teachers recognize the causes, signs and symptoms and treatment of hyperglycaemia.</li> <li>Peers and teachers understand the different modalities of insulin therapies(injection-pens-pump)</li> <li>Peers understand the main diabetic tasks and why a student with T1DM carries their diabetic bag.</li> <li>Peers and teachers understand that a student with T1DM needs some time to eat in class to treat thypoglycaemia.</li> <li>Teachers keep and maintain a register with all students who have diabetes.</li> <li>Teachers will support students with diabetes emotionally</li> </ol> |
|                           |                                                 |                                                                                                                                  | <ol> <li>Physical education teachers remind students with T1DM to check their blood sugar before, during<br/>and after sport.</li> </ol>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |

Thirdly, after all, performance objectives were formulated for the organisational level (peers and teachers at school environment), the personal determinants for peers and teachers to improve knowledge and understanding of T1DM were listed (see Table 6). The following section describes how learnings from the literature review were used in the intervention development. In addition, the search for determinants and associations with teachers and peer's knowledge of T1DM will be explained.

The background and literature review chapters helped the researcher to identify the health problem by identifying the prevalence of T1DM among adolescents and whether this specific group (adolescents with T1DM) has additional burdens due to the disease. The literature review also provided an understanding of the impact that T1DM has on school-going adolescents with T1DM's quality of life. In addition, the behavioural and environmental factors that lead to poor management when it comes to school-going adolescents with T1DM were also ascertained, as well as an understanding of the behavioural and environmental contributors related to poor self-management. This information guided the intervention development by first isolating the problem of interest that the intervention should focus on (poor self-management among adolescents with T1DM) and it helped to narrow down the context in which the proposed intervention needs to be developed (school settings).

The literature review also provided a more thorough understanding of the school-based interventions that have been developed to date. The results of previous intervention research studies conducted in schools were explored with regards to their focus. They mainly centred on enhancing diabetic knowledge among school staff and school nurses; there were no interventions targeted at school peers. In addition, previous intervention research studies focused on enhancing collaboration/communication among caregivers and assisting children and adolescents to manage some aspects of their diabetes. There
was no focus on other aspects such as the psychosocial challenges that have been described in research studies. The literature review also showed a lack of involvement of the population at risk (adolescents with T1DM) when designing school-based interventions to understand more about their perspectives and needs. The viewpoint of adolescents with T1DM is critical for developing effective interventions. This gap in the literature helped to determine the fact that adolescents with T1DM needed to be included when developing the intervention in order to develop specific intervention components that are consistent with these adolescents' needs and perspectives.

The literature review on school-based interventions provided minimal understanding of how intervention developers translated their theory into school-based interventions. In addition, there were no details about the usage of specific frameworks to guide intervention development. Researchers in this study's literature review (Chapter 2) rarely provide a clear theoretical basis for developing an intervention. Most of the time, they do not even describe the intervention in detail or address the issue of why or how it is expected to bring about the desired change. This gap helped to determine the use of a clear theoretical framework to create a well-designed, theory-driven intervention to allow a greater level of understanding of how the intervention might affect the target population.

A variety of factors influence health status and these are known as determinants. These determinants can be classified as personal, social, economic, and environmental. Personal determinants are those factors that rest within individuals (agent in the environment). These factors can be changed or influenced by an intervention that involves how people think or have the capacity to change their behaviour. Personal determinants usually include cognitive factors such as knowledge, attitudes, or self-efficacy. The various determinants are not independent of each other, for example

knowledge is the basis for many other determinants such as attitudes and self-efficacy (Eldredge et al., 2016).

The determinants and the related theories were identified from the literature. To identify these determinants, a review of the literature was undertaken to find empirical studies, theoretical concepts related to the topic, and general theories that include some of the identified determinants as constructs within those theories (Eldredge et al., 2016).

For this study, in order to come up with an appropriate set of evidence and theoryinformed determinants, the process started with asking questions, generating lists of answers, and validating these answers against the literature (Chapter 1 and Chapter 2). The researcher asked questions like: what are the environmental factors that contribute to the presence of the problem and why would people perform the performance objectives or why would certain environmental agents make environmental modifications. Then, the researcher undertook a review of the literature to find studies and theoretical concepts associated with the topic at hand and theories that include some of the identified determinants. The literature review (Chapter 2) provided the researcher with the informed relationships that these personal determinants have with the behaviour of the environmental agents (teachers). The researcher included determinants that are well supported by literature and the determinants that have the strongest relationship with the behaviour as described in the following paragraphs. Peer support in the school setting was suggested by adolescents with T1DM in the first phase of this study; however, there was not enough literature discussing the proposed determinants for the effectiveness of peer support in schools. Thus, the researcher needed to collect evidence on peer support effectiveness in other settings such as the home or at camp as explained later on in this chapter.

Based on the literature search for school-based intervention targeted knowledge of school teachers (see chapter 3). Seven studies focused on improving school personnel's knowledge. Only three of the seven studies were reported as theory-based intervention studies (Husband et al., 2001; Bachman and Hsueh, 2008; Smith et al., 2012). The studies by Husband et al. (2001) and Smith et al. (2012) are based on Bandura's theory (social cognitive theory). They assumed that, in keeping with Bandura's theory of self-efficacy, knowledge and confidence would translate to a positive action with regard to caring for the student with T1DM. These studies reported changes in outcome measures of determinants of behaviour change (such as teacher's knowledge, teacher's confidence and attitudes towards caring for students with T1DM), while Bachman and Hsueh (2008) reported the use of Rogers' theory of diffusion of innovations in the development, implementation and evaluation of the intervention. Teacher's involvement within each study intervention was high as teachers were exposed to intervention components.

There was no evidence of peer involvement in any of the school-based interventions. However, this study data derived from the semi-structured interviews indicated that peers' understanding of T1DM could enhance T1DM self-management in school. Therefore, it was necessary to conduct another literature search regarding effectiveness of the peer-based intervention in managing T1DM among adolescents. Different electronic databases were searched, including PubMed, PsycINFO, Cochrane Library, CINAHL Social Science, Delphis, Medline, and different search engines (e.g. Google Scholar). The database was searched using the Medical Subject Headings (Mesh) and keywords and their combinations such as peer, friend, group, class, school, diabetes type 1, diabetes mellitus, children, adolescents, teen, youth, young people, interaction, effectiveness, interaction. A systematic review by Kazemi et al. (2016) evaluated the

effectiveness of peers-based intervention in managing T1DM among children and adolescents. The setting of the studies was home, camp, clinic, or community. The review included five randomised controlled trials, two were trials pre-post, and one was a controlled trial. All studies included were theory-based including social support theory, social learning and self-efficacy and problem-solving. The study outcomes focus on knowledge, attitudes, self-confidence, self-efficacy and social support. Studies focusing on knowledge and attitudes showed that more support from peers could lead to better metabolic control and better adjustment to diabetes tasks. There was a positive effect on peers' knowledge in the self-efficacy of the adolescents and children with T1DM. Positive impact on peers' attitudes showed a significant increase in self-esteem and social acceptance for adolescents with T1DM. Also, La Greca et al. (2002) and Wysocki and Greco (2006) found that there is an encouraging relationship between social support and its influence on diabetes health outcomes. Wysocki and Greco (2006) indicated that friends provide social support distinct from parents' contribution and provide an important source of emotional support. The provision of this support appears to improve adherence to self-management in general. They recommended that interventions aimed at involving friends in a positive, helpful manner seem to increase support from friends and to improve adolescents' self-management of diabetes. The determinants were selected based on their changeability and strength of the relationship with the behaviour. For this intervention, the personal determinants selected for peers and teachers at the organisational level were: self-efficacy, knowledge, attitudes and social influence. The related theories which address these determinants were selected accordingly as shown in Table 7.

| Determinants of peers and teachers | Related theory              |
|------------------------------------|-----------------------------|
| Self-efficacy                      | Social cognitive theory     |
| knowledge                          | Health belief model         |
| Attitudes                          | Health belief model         |
| Social influence                   | Theory of planned behaviour |

### Table 7: Selected determinants and related theories

### 5.2.3 The theoretical framework for the intervention

The theoretical framework of the present intervention consists of three theories: social cognitive theory, health belief model, and the theory of planned behaviour.

### 5.2.3.1 Social Cognitive Theory (SCT)

Bandura's (1986) social cognitive theory (SCT) is one of the most highly influential and widely celebrated theories in the field of social psychology. SCT is an interpersonal theory that involves together determinants of the behaviour and the process of behaviour change. SCT describes a person's behaviour as a model of reciprocal determinism. Both behavioural and environmental factors work as interrelating determinants of each other (Mohebi et al. 2013). SCT suggests that whether a person will change behaviour depends on self-efficacy, goals, and outcome expectations. If individuals have a great level of confidence, they can change even when they are confronted with many obstacles. If they are not confident about the behaviour in question, they will be less motivated to act or to persevere through obstacles or challenges as they arise.

Behavioural capacity described in SCT refers to a person's actual ability to perform a behaviour (improved knowledge and understanding) through essential knowledge and skills to successfully perform a behaviour. A person must know what to do and how to do it. Self-efficacy refers to the individual's belief in his or her ability to perform and succeed in specific situations or activities, and the individual's confidence that he/she can change his/her behaviour (Bandura 1997). According to Bandura, people with greater levels of self-efficacy will be more likely to engage in a specific behaviour, carrying on until they manage it, and maintain the behaviour. The concept of self-efficacy has been among the most studied concepts in the diabetes school-based intervention studies. According to Bandura (1997), individuals form self-efficacy beliefs by interpreting information regarding their capabilities.

Self-efficacy is an important factor influencing diabetes management behaviours either for patients or the care providers (Mishali et al. 2011; Pfitzner-Eden 2016). Social cognitive theory is useful in conceptualising strategies to enhance support from peers and teachers towards adolescents with T1DM. Setting realistic goals when aiming at changing behaviour (i.e. improve knowledge and understanding of T1DM and its management) can increase the peers' and teachers' sense of self-efficacy. Knowledge about T1DM can improve confidence among peers and teachers and this could be translated into positive behaviour (action) in regard to better supporting adolescents with T1DM to enhance their self-management in school; for example, allowing the student with T1DM to eat in the class if he/she needs to, without asking them to spit the food out, or being able to support students with T1DM during hypoglycaemia.

#### 5.2.3.2 Health Belief Model (HBM)

Health belief model (HBM) has been used in a wide range of health-related contexts (Skinner et al. 2015). HBM found to be effective in improving the knowledge and attitude toward health issue (Strecher and Rosenstock 1997). Originally HBM consists of the following psychological concepts: Perceived susceptibility, Perceived severity, Perceived benefits and Perceived barriers. Also, according to HBM, decision making is triggered by cues to action, which may be internal such as disease or external such as health education message or a friend with the disease (Eldredge et al 2016). In this intervention, the researcher suggests that perceived susceptibility refers to the teachers and peers believe that they have lack of knowledge about T1DM and its management. Perceived severity refers to the peers and teachers believes that their lack of knowledge can hinder or delay the self-management of adolescents with T1DM in school which can lead to serious diabetic complications. Perceived benefits refer to the teachers and peers believe that more knowledge and understanding might help to enhance selfmanagement among adolescents with T1DM in school. Perceived barriers refer to the personal barriers of teachers and peers in understanding more about T1DM such as lack of available educational recourse. Cues to Action refers to teachers and peers receive reminders for the action needed which is more knowledge about T1DM. In later application of HBM, researchers incorporated the concept of self-efficacy. In this intervention, self- efficacy suggest that teachers and peers are confident in supporting adolescents with T1DM in schools by receiving appropriate information about T1DM.

#### 5.2.3.3 Theory of Planned Behaviour (TPB)

The theory of planned behaviour (TPB) is based on the assumption that individuals usually behave sensibly, that they take account the available information and implicitly or explicitly consider the implications of their action (Ajzen 1991). TBP suggests that

intention is the most important determinant of behaviour. (Ajzen 2005) elaborated that, according to TPB, intentions and behaviours are the foundation of three main determinants: attitude, subjective (social) norms, and perceived behavioural control.

The attitude toward the behaviour is determined by salient beliefs about that behaviour. Each behavioural belief links the behaviour to a certain outcome or to an attribute. The construct of subjective norms (perceived social expectations) is a function of beliefs by people that specific, important individuals or group (social influence) approve or disapprove of their performance of behaviour and how important that opinion is to them (Eldredge et al. 2016). Social influence is important within the TPB and dismisses the belief that norms cannot play a steadily impactful role in the relationship between attitudes and action (White et al. 2009).

The final determinant is perceived behavioural control, which refers to an individual's perception of their ability to perform a given behaviour. It is assumed that perceived behavioural control is determined by the total set of accessible control beliefs. Perceived behavioural control is believed to moderate the relationship between intention and behaviour, i.e. intention will convert to behaviour when perceived behavioural control is high (Schifter and Ajzen 1985). In general, individuals intend to perform the behaviour if they have evaluated it positively, when they experience social pressure to perform it and when they have the chance to do it. However, the theory assumes that the relative importance of the attitudes toward the behaviour, subjective norm, and perceived behavioural control depends on the intention under investigation. In some instances, only one or two of the determinants are needed to clarify the intention. The theory has been successfully used with other health behaviour changes' educational interventions such as improving oral health knowledge (Dumitrescu et al. 2011) and educating teens to improve dietary and physical activity-related behaviours (Pooreh and

Nodeh 2015). The TBP has been found useful to guide diabetes self-management and diabetes education programmes (Lee et al. 2017). Daley (1992), Pendley et al. (2002), and Békési et al. (2011) found that peers' attitudes towards diabetic self-management influence adolescents' diabetic outcomes positively. They found that knowledge about T1DM led to a positive attitude and consequently higher peer support. The effect of knowledge on peers' attitude change resulted in better understanding and greater support. These findings highlighted the important role of knowledge on peers in attitude formation and attitude change toward supporting adolescents with T1DM, as well as the necessity of considering the determinants of attitude in this study. For this intervention, social cognitive theory, health belief model, and the theory of planned behaviour are applied as a basis for the intervention. These theories are based on the concepts of self-efficacy, knowledge, attitudes and social influence.

After selecting the theoretical framework for this intervention, the performance objectives were crossed with the determinant and resulted in the change objectives. The formulated change objectives were stated with an action word, followed by a statement of what is expected to result from the intervention. A matrix for the organisational level is shown in Table 8.

| Performance objectives<br>(Peers and Teachers)                                                                                          | Personal determinants                                                                                                              |                                                                                                                                                                                          |                                                                                                                                         |                                                                                                                                                                                                                            |  |
|-----------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--|
| (i cers and i caeners)                                                                                                                  | Self-efficacy                                                                                                                      | knowledge                                                                                                                                                                                | attitudes                                                                                                                               | Social influence                                                                                                                                                                                                           |  |
| <b>PO.1</b> . Peers and teachers know the difference between type 1 diabetes and type 2 diabetes.                                       | Peers and teachers express<br>confidence in differentiating between<br>T1DM &T2DM.                                                 | Peers and teachers differentiate between T1DM &T2DM.                                                                                                                                     | Peers and teachers express positive<br>feelings about the importance of<br>knowing the differences between<br>T1DM&T2DM                 | Peers and teachers able to show<br>concerns by knowing more about<br>T1DM even if others do not show                                                                                                                       |  |
| <b>PO.2.</b> Peers and teachers correct the misconception about the causes of T1DM                                                      | Peers and teachers express<br>confidence that they understand the<br>cause of T1DM.                                                | Peers and teachers know that the cause of T1DM is because of pancreas dysfunction. Peers and teachers express positive feelings about the importance of understanding the cause of T1DM. |                                                                                                                                         | Peers stop annoying students with<br>T1DM that they have diabetes<br>because they eat too much sweet<br>or they are overweight. Even if<br>others do.                                                                      |  |
| <b>PO.3.</b> Peers and teachers recognise the causes signs and symptoms of hypoglycaemia                                                | Peers and teachers express<br>confidence in ability in identifying<br>hypoglycaemia causes, signs and<br>symptoms                  | Peers and teachers list different<br>causes, signs and symptoms of<br>hypoglycaemia                                                                                                      | Peers and teachers express positive<br>feelings about the benefits of<br>recognising causes, signs and<br>symptoms of hypoglycaemia.    | Peers and teachers can recognise<br>someone with symptoms of<br>hypoglycaemia. even if others do<br>not do                                                                                                                 |  |
| <b>PO.4.</b> Peers and teachers know<br>what to do if someone develops<br>signs and symptoms of<br>hypoglycaemia                        | Peers and teachers express<br>confidence in the ability to respond<br>to someone with symptoms of<br>hypoglycaemia                 | Peers and teachers describe ways to<br>help someone with hypoglycaemia                                                                                                                   | Peers and teachers express positive<br>feeling about the necessity and<br>benefits of helping someone with<br>symptoms of hypoglycaemia | Peers and teachers are encouraged<br>to support and act assertively and<br>efficiently if someone develops<br>hypoglycaemia. Even if others do<br>not support                                                              |  |
| <b>PO.5.</b> Peers and teachers<br>understand the effect of<br>hypoglycaemia/hyperglycaemia<br>on the mood of someone with<br>diabetes. | Peers and teachers express<br>confidence that they understand that<br>blood fluctuation can cause mood<br>swing and cause conflict | Peers and teachers describe the effect<br>of blood sugar fluctuation in mood                                                                                                             | Peers and teachers express positive<br>feelings about understanding the<br>fluctuating of blood sugar can avoid<br>unnecessary conflict | Peers and teachers are more<br>understanding and not getting<br>angry instead they remind<br>someone with T1DM to check<br>their blood sugar gently. Even if<br>others do get angry and don't<br>remind student with T1DM. |  |

### Table 8: Matrix for peers and teachers at the organisational level (school)

| <b>PO.6.</b> Peers and teachers recognize the causes, signs and symptoms of hyperglycaemia.                                                   | Peers and teachers express<br>confidence in ability in recognising<br>causes, signs and symptoms of<br>hyperglycaemia.               | Peers and teachers list different<br>causes, signs and symptoms of<br>hyperglycaemia                                            | Peers and teachers express positive<br>feelings that knowing the causes,<br>signs and symptoms of<br>hyperglycaemia can help them to be<br>more supportive | Teachers are more flexible and<br>understanding if students with<br>symptoms of hyperglycaemia<br>wanted to go to the toilet more<br>frequently or need to drink more<br>fluid or take an extra dosage of<br>insulin. Even if other teachers do<br>not show understanding.    |
|-----------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>PO.7.</b> Peers and teachers<br>understand the different<br>modalities of insulin<br>therapies(pens-pump) and<br>blood monitoring          | Peers and teachers express<br>confidence in the ability to describe<br>different modalities of insulin<br>therapy                    | Peers and teachers list different<br>modalities of insulin therapy                                                              | Peers and teachers express positive<br>feelings about the importance of<br>knowing different modalities of<br>insulin therapy.                             | Peers are not staring when a<br>student with diabetes take an<br>injection or check blood sugar.<br>Peers give more space and don't<br>ask many questions. Even if<br>others stare.<br>Peers and teachers are not<br>confused about insulin pump to<br>think its MP3 or iPod. |
| <b>PO.8.</b> Peers understand the main diabetes tasks and why a student with T1DM carries their diabetic bag.                                 | Peers express confidence about<br>knowing why a student with diabetes<br>carries their diabetes bag.                                 | Peers describe what is inside the<br>diabetic bag.<br>Peers describe why a student with<br>diabetes carries their diabetic bag. | Peers express positive feelings of<br>taking care of the diabetes bag for a<br>student with diabetes and not<br>throwing it around.                        | Peers do not bully someone with<br>diabetes and throw their bags.<br>Even if others do.                                                                                                                                                                                       |
| <b>PO.9.</b> Peers and teachers<br>understand that a student with<br>T1DM needs some time to eat<br>in class to treat their<br>hypoglycaemia. | Peers and teachers express<br>confidence they understand why<br>students with diabetes need to eat a<br>snack in the class sometimes | Peers and teachers state situations<br>where students with diabetes need to<br>have snack in the class.                         | Peers and teachers express positive<br>feelings of the importance of student<br>with diabetes to eat a snack in class.                                     | Peers will not be surprised if<br>student with diabetes has to eat in<br>the class some time even if others<br>were surprised<br>Teachers will encourage a student<br>with hypoglycaemia to eat in the<br>class if needed. Even if other<br>teachers do not encourage         |
| <b>PO.10.</b> Teachers keep and maintain a register with all students who have diabetes.                                                      | Teachers express confidence in the ability to maintain records about the students with diabetes.                                     | Teachers list the students with diabetes.                                                                                       | Teachers express positive feeling<br>that keeping record students with<br>diabetes can help them not to forget                                             | Teachers will be able to remember<br>why students with diabetes have to<br>make some tasks without causing<br>them repeat about their condition                                                                                                                               |

|                                                                                                                                |                                                                                                                                                      |                                                                                                                                        | about them and their individual needs.                                                                                                      | over and over. Even if other teachers do not remember.                                                                                                                                                                       |
|--------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>PO.11.</b> Teachers will support students with diabetes emotionally                                                         | Teachers express confidence in the ability to give emotional support.                                                                                | Teachers know that they have to give<br>emotional support to students with<br>diabetes.                                                | Teachers express positive feelings<br>about giving more emotional<br>support to students with diabetes.                                     | Teachers are encouraged to give<br>emotional support to students with<br>diabetes. Even if other teachers do<br>not give emotional support.                                                                                  |
| <b>PO.12.</b> Physical education teachers remind students with T1DM to check their blood sugar before, during and after sport. | Physical education teachers express<br>confidence in the ability to support<br>students with diabetes before, during<br>and after sports activities. | Physical education teachers describe<br>what to do for students with diabetes<br>before, during and after physical<br>education class. | Physical education teachers express<br>positive feelings about the<br>importance of checking blood sugar<br>before, during and after sport. | Physical education teachers<br>encourage students with diabetes<br>to check blood sugar before,<br>during and after sport. Even if<br>other PE teachers do not<br>encourage student with T1DM to<br>check their blood sugar. |

### 5.2.4 IMP Step 3: Choosing theory-informed intervention methods and practical approaches

Theory-informed methods are the techniques used for influencing changes in determinants that are selected for the targeted group (peers and teachers). Methods of the theory that is capable of influencing changes in the determinants were chosen during the third step of the IMP. First, all determinants included in the matrices at the organisational level were listed and were matched with methods derived from a theory. These methods were carefully considered for use in the intervention. For example, the formulated change objective 'Peers and teachers express confidence in their ability in recognising hypoglycemia causes, signs and symptoms' was the result of crossing the performance objective 'Peers and teachers recognise the causes, signs and symptoms of hypoglycaemia' with the determinant 'self-efficacy'. The selected theoretical method that corresponded with the determinant 'self-efficacy' to reach the change objective was 'verbal persuasion'. After the theoretical method was chosen, theoretical parameters and characteristics of the context were checked, and the selected method was translated into a creative application Eldredge et al. (2016). See Table 9.

The summary of the theoretical method provided by Eldredge et al. (2016) was used to complete this selection process. The methods were applied in this intervention including, first, verbal persuasion. Verbal persuasion is when other people are encouraged to perform a task – in other words, using messages that suggest that the participant possesses specific capabilities. Second, consciousness raising or providing information that aims to enhance the knowledge and attitudes of the particular needs of a group of people. In this case, it is raising consciousness of T1DM and its management among peers and teachers. Finally, resistance to social pressure, which stimulates building skills for resistance to social pressure – such as identifying symptoms of hypo-

or hyperglycaemia or how to support someone with hypo- or hyperglycaemia. Applying these methods is hypothesised to change peers' and teachers' self-efficacy, knowledge, attitudes and social influence. All of these methods were derived from the theories that have been selected in IMP step 2.

Next, these methods were put in to practice by selecting a practical application that fitted with the theoretical methods and specific programme goals. This selection was guided by suggestions from a few participants in the first phase of this study and suggestions from the literature review. A few participants highlighted an interest in using a video to explain about T1DM and its management. Some other participants highlighted the use of posters and PowerPoint presentations to improve the awareness about T1DM among peers and teachers. Posters provide a logical and cost-effective way for communication. However, posters require reduced content as well as getting to the point. Selecting what has to be included or omitted is not always easy. In contrast, PowerPoint can produce better visual effects and leave a deeper impression. However, it can be dull, not interesting, contain lots of information and be boring (Xingeng and Jianxiang 2012). On the other hand, videos can become a powerful technological tool in education. Several benefits of using videos are reported in the literature. Lopes and Soares (2016) explained that video could present in a clear and remarkable way descriptions to convey tacit information and knowledge that is hard to describe through text. The creative application for this intervention is a whiteboard animated video that can be used for peers and teachers. Whiteboard animation include simple and yet engaging videos that show someone drawing images on the whiteboard. In this intervention, the video is combined with a voiceover to make the presentation even more informative and interesting. It is one of the new emerging sources for engaging a potential audience with less span of time, although some studies in the field of media

psychology have shown that recipients can deal with media-based information with noticeable ease regardless of whether they are in the form of static pictures and photographs or dynamic movies and video clips (Schwan and Riempp 2004). However, Skouteris and Kelly (2006) found that watching the animated video can improve understanding and grasping of information. Jones and Scaife (2000) and Lowe (2004) explained that animations could show situational dynamics clearly, and can help recipients build comprehensible, high-quality mental models of complex change processes. Animation, consequently, may be anticipated to enhance learning, especially when illustrating dynamic processes, as motion is shown to be more visually explicit, thus reducing cognitive processing. De Lepeleere et al. (2016) clarified other benefits of using video such as the 24-hour availability of information, and the possibility to reach a broader audience and to raise access to organisations without an increase in the coast. Table 9 provides an overview of all the methods and application (a video) that were selected and used to achieve the change objectives for the organisational level of the intervention.

| Level of the intervention | Determinant         | Change<br>objective | Method                                           | Related<br>theory | Application                |
|---------------------------|---------------------|---------------------|--------------------------------------------------|-------------------|----------------------------|
| Peers<br>Teachers         | Self-efficacy       | 1-9<br>1-7,9-12     | Verbal persuasion                                | SCT               | video                      |
| Peers<br>Teachers         | Knowledge           | 1-9<br>1-7,9-12     | Consciousness raising<br>(providing information) | HBM               | Elements of the same video |
| Peers<br>Teachers         | Attitudes           | 1-9<br>1-7,9-12     | Consciousness raising<br>(providing information) | HBM               | Elements of the same video |
| Peers<br>Teachers         | Social<br>influence | 1-9<br>1-7,9-12     | Resistance to social pressure                    | TPB               | Elements of the same video |

### Table 9: The theoretical methods and applications for attaining the change objectivesat the organisational level

### 5.2.5 IMP Step 4: Producing intervention components and materials

Step 4 utilised the information from the previous steps to develop the video. The intervention is developed specifically to be used in schools. In particular, the results of the first phase of this study (interviewing adolescents with T1DM) provided information on how adolescents with T1DM wanted to be supported by their peers and teachers. Thematic analysis of the data from the first stage directed the content and the information that needed to be included in the video. The organisation or the flow of the information included was adopted from a school-based intervention developed by

Siminerio and Koerbel (2000). It targeted school personnel and showed significant improvement in staff knowledge. Their programme is entitled the '5Cs programme' and highlighted information of the causes, classification, complications, care, and cure of T1DM. In this study, the researcher followed the 5Cs only for the flow of the information as it shows the logical sequence of the information. However, the specific content was based on the thematic analysis of the first stage of the study. All the scientific content is based on updated information from Diabetes UK (2017a), American Diabetes Association (2010), IDF (2013), NICE (2015), ISPAD (2014), and JDRF (2017).

The information was used by the researcher to draft a script that was then used to develop the animated video. To determine whether the script content is appropriate, the researcher reviewed the script content against the programme objectives. The match was almost perfect, and gaps were filled. Also, all the messages that needed to influence the change objectives were included (see Table 10).

### Table 10: Initial video content

| Performance objectives                                                                                                        | Main Comment                                                                                              | Script                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
|-------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Introductory comments                                                                                                         | Introductory comments about diabetes (how insulin<br>is important for the body)                           | Diabetes is a permanent health condition that happens when the amount of sugar in the blood is too high because the body cannot use it properly. High sugar levels in the blood can cause serious health problems. After having a meal, the body starts to digest carbohydrates and breaking them down into sugar. Insulin, which is a hormone produced by a part of our bodies called pancreas, helps to move the sugar out of the blood and into the body's cells to be used as energy for the body. |
| Peers and teachers know the difference between type 1 diabetes and type 2 diabetes.                                           | Two main classifications of diabetes mellitus                                                             | There are two main types of diabetes: Type 1 diabetes and type 2 diabetes. These two types are entirely different from each other.                                                                                                                                                                                                                                                                                                                                                                     |
| Peers and teachers know the difference between<br>type 1 diabetes and type 2 diabetes                                         | A brief introduction to Type 2 diabetes                                                                   | Type 2 diabetes happens when the insulin does not work properly, causing sugar to build up in the blood.<br>This type of diabetes can be treated by diet, exercise, or pills.                                                                                                                                                                                                                                                                                                                          |
| Peers and teachers correct the misconception<br>about the causes of T1DM                                                      | Causes of T1DM                                                                                            | Type 1 diabetes does not happen because you are overweight or because you eat too many sweets. It happens to people because their bodies cannot make insulin at all because the cells that are producing insulin in the pancreas are damaged or destroyed. So, they will need insulin to allow their bodies to process sugar and avoid further complications from high sugar in the blood.                                                                                                             |
| Peers and teachers understand the different<br>modalities of insulin therapies(injections-pens-<br>pump) and blood monitoring | The different modalities to treat T1DM (injection, pen, and pump)                                         | The insulin can be taken by either insulin injection, insulin pens or insulin pumps. Insulin pens include an insulin holder, a knob to measure insulin amount, and a one-use needle. The insulin pump is a small device used to continuously inject the insulin. It is attached to the skin and can be easily carried on the belt or inside the pocket.                                                                                                                                                |
| Peers and teachers recognise the causes, signs and symptoms of hypoglycaemia                                                  | Complications of T1DM: low blood sugar (hypoglycaemia)                                                    | Low blood sugar, also known as hypoglycaemia, is one of the complications of diabetes. It happens when blood glucose level goes too low                                                                                                                                                                                                                                                                                                                                                                |
| Peers and teachers recognise the causes, signs<br>and symptoms of hypoglycaemia                                               | Causes of hypoglycaemia                                                                                   | <ul> <li>Skipping or delaying a meal.</li> <li>Not having enough carbohydrate.</li> <li>Doing a lot of exercise without having extra carbohydrate</li> <li>Taking insulin more than needed</li> </ul>                                                                                                                                                                                                                                                                                                  |
| Peers and teachers recognise the causes, signs<br>and symptoms of hypoglycaemia                                               | The importance to act fast during hypoglycaemia<br>and signs and symptoms hypoglycaemia                   | Hypoglycaemia can happen so quickly. So, it is very important to know its signs and symptoms, and what<br>to do if someone has a hypoglycaemia<br>Feeling shaky, sweating, being nervous, getting angry, going pale, a fast heartbeat, lips feeling tingly or<br>numbness, blurred sight, feeling hungry, mood swings, tiredness, having a headache, and lack of<br>concentration.                                                                                                                     |
| Peers and teachers understand the effect of<br>hypoglycaemia/hyperglycaemia on the mood of<br>someone with diabetes.          | How hypoglycaemia affects mood and what to do if<br>a student with diabetes started to behave differently | Hypoglycaemia can also cause quick changes in a person's behaviour, which explains mood swings. So, if a student with diabetes starts to behave differently, please gently remind him to check his blood sugar.                                                                                                                                                                                                                                                                                        |
| Peers and teachers know what to do if someone<br>develops signs and symptoms of hypoglycaemia                                 | How to help someone with hypoglycaemia                                                                    | It is important to act fast to avoid more complications. You can start by reminding the person to check his blood sugar. As a quick treatment, try giving food containing a small amount of carbohydrate. Here are some examples of foods containing carbohydrate:                                                                                                                                                                                                                                     |

|                                                  |                                                   | 1. Glucose tablets,                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|--------------------------------------------------|---------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                                  |                                                   | 2. Fruit juice,                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
|                                                  |                                                   | 3. <sup>1</sup> / <sub>2</sub> cup of non-diet soft drink                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
|                                                  |                                                   | • Milk                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
|                                                  |                                                   | and DO NOT FORGET TO CALL FOR HELP FROM TEACHERS OR THE SCHOOL NURSE                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| Peers and teachers recognise the causes, signs   | Complications of T1DM- high blood sugar           | High blood sugar, also known as Hyperglycaemia, is another complication of diabetes. It happens when                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| and symptoms of hyperglycaemia.                  | (hyperglycaemia)                                  | the blood sugar level goes too high.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
|                                                  |                                                   |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| Peers and teachers recognise the causes, signs,  | Causes of hyperglycaemia                          | Not taking insulin                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| symptoms, and treatment of hyperglycaemia.       |                                                   | Having more food than needed                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
|                                                  |                                                   | • Stress                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
|                                                  |                                                   | Sickness or feeling unwell                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
|                                                  |                                                   | Doing everyises less than planned                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| Poors and teachers recognise the causes signs    | Signs and symptoms of hyperglycaemia              | Fraguent urination                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| symptoms and treatment of hyperglycaemie         | Signs and symptoms of hypergrycacinia             | Interprete the set of the se |
| symptoms, and treatment of hypergrycacinia.      |                                                   |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
|                                                  |                                                   | • Blurred vision                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
|                                                  |                                                   | Weakness and headache                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| Peers and teachers recognise the causes, signs,  | How to treat hyperglycaemia                       | Normally, short time hyperglycaemia does not require an emergency or any immediate treatment. But if it                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| symptoms, and treatment of hyperglycaemia        |                                                   | stays high for a long time, it must be treated by drinking lots of sugar-free fluids or taking extra insulin.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| Peers and teachers understand the main           | Diabetes tasks (administration of insulin and     | Diabetic students will need to have insulin pens with him. These pens contain medication used to control                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| diabetes tasks and why a student with T1DM       | checking blood sugar)                             | their blood sugar. They also have to prick their finger to test their blood sugar levels using a special blood                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| carries their diabetic bag.                      |                                                   | sugar meter                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| Peers and teachers understand the different      | Do not be confused about insulin pump             | Some diabetic students are using an insulin pump instead. It may look like an iPod!! So, do not be                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| modalities of insulin therapies(injections-pens- |                                                   | confused                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| pump) and blood monitoring                       |                                                   |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| Peers and teachers understand the main           | Help student with diabetes to take care of his    | It is very important for diabetic students to always have their diabetes medication bag with them. This bag                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| diabetes tasks and why a student with T1DM       | diabetic bag                                      | contains their equipment and medication, so please help them to take care of it.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| carries their diabetic bag.                      |                                                   |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| Peers and teachers understand that a student     | Eating during the lesson                          | Sometimes they will also need to have a snack during the lessons to keep their blood sugar at normal levels                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| with T1DM needs some time to eat in class to     |                                                   |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| treat their hypoglycaemia.                       |                                                   |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| Teachers keep and maintain a register with all   | Keep records of students with diabetes            | It is so frustrating when diabetic students repeat about his condition over and over. So, it is much helpful if                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| students who have diabetes                       |                                                   | teachers can keep and maintain a register with his students who have diabetes.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| Teachers will support students with diabetes     | Teachers have to give emotional support           | Diabetic students will need your emotional support as much as your academic support                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| emotionally                                      |                                                   |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| Physical education teachers remind students      | PE teachers to support student before, during and | Physical education teachers to make sure of blood sugar levels of their diabetic students before, during,                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| with T1DM to check their blood sugar before,     | after sport                                       | and after doing any physical exercises. This will avoid a student having sudden drops in blood sugar level.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| during and after sport                           |                                                   |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |

| School canteen to provide nutritional                              | School canteen to provide more information about | School canteens can also provide students with information on how many carbohydrates in each portion      |  |
|--------------------------------------------------------------------|--------------------------------------------------|-----------------------------------------------------------------------------------------------------------|--|
| information about the food they provide the food that they provide |                                                  | size of food they sell. This will help students with diabetes to adjust their insulin dosage accordingly. |  |
| Closing remarks                                                    |                                                  | Remember                                                                                                  |  |
|                                                                    |                                                  | Your help and support can make a massive difference in someone's life                                     |  |
|                                                                    |                                                  |                                                                                                           |  |

For the video production, the researcher contacted the production company to agree to the contract. The contract and the budget included a rough cut of the video for the researchers pre-testing, reviewing and approval. A rough cut is an initial edit of the production before final editing. The researcher pre-tested a rough cut with the diabetes health care professionals (during stage 3). After making the amendments suggested by a health care professional (details are in part two of chapter 5), the script was reviewed and compared with intended change objectives and sent for video production to be ready to be tested with adolescents with T1DM in Stage 4 of this study (details are in part three of chapter 5). It is suggested that peers and teachers watching the video will learn about T1DM and be aware of its management and be more supportive to the adolescents with T1DM and consequently self-management among adolescents with T1DM will be much easier in schools. Furthermore, self-efficacy, knowledge, attitudes and social influence may be enhanced. Given that the peers and teachers watching the video will have no opportunity to discuss its content, the researcher considered it essential that the key messages were integrated explicitly in the script, and that video was educational and self-explanatory. The video was designed to teach explicit information related to T1DM and its management and how to support someone with T1DM in school.

### 5.2.6 Summary of stage two

This stage described in detail the theoretical basis, intervention techniques and strategies of a video-based intervention programme that is focusing on improving the knowledge and understanding of the teachers and peers about T1DM in schools. By increasing teachers' and peers' knowledge of T1DM, the intervention also aims to improve teachers' and peers' self-efficacy, attitude and social influence, identified as key determinants of health behaviour change.

A description of the different steps towards the development of the intervention using the IMP is provided, including detailed information about the preparation of the matrices with change objectives, the selection of methods and applications and about the production of the intervention materials. A literature search and results from individual semi-structured interviews with adolescents with T1DM were used as a guide during the development of this intervention. The development of an intervention using IMP is complex and time-consuming, but provide a comprehensive framework for effective decision-making at each step.

# 5.3 Findings of Stage 3 (Interviews with Health professionals)

The qualitative findings of this stage explored the health care professionals' (HCPs) opinion of the developed intervention based on their expert views and the findings of the first stage. This information will contribute to determining the content appropriateness of the developed intervention. This stage explores the findings of six HCPs (two Paediatric Diabetes Nurse Educators, one Paediatric Psychologist, one Paediatric Diabetes Dietician and two Consultants in Paediatric Diabetes and Endocrinology).

The participants' information in the data extracts is coded to protect their confidentiality. The researcher refers to the speciality by abbreviation and number (1–2) as (PDNE1) = Paediatric Diabetes Nurse Educators, PS = Paediatric Psychologist, PD = Paediatric diabetes dietician and CP = Consultant in Paediatric Diabetes and Endocrinology.

The findings were analysed and organised into several themes. Insights gained from exploring these perspectives will provide suggestions to inform further modifications to the intervention. The themes that emerged from the data are outlined as follows:

- 1. Acceptance of the intervention regarding the format of delivery.
- 2. Acceptance of the intervention regarding relevance.
- 3. The most helpful parts of the video.
- 4. Suggestion for modifications
- 5. The desire to use the video during educational school visits.

### 5.3.1 Acceptance of the intervention regarding the format of the video (white animated video)

All six participants felt that all the format of the video is good. They have expressed their positive feelings about it by saying words such as 'good' and 'brilliant'. One participant commented specifically about the drawings and the sound of the narrator explaining the content of the video and the short duration of the video:

I think the findings of your study are really helpful. I liked the style of the video a lot. it catches your attention, the pictures, the sounds [narrator] (PC1).

## 5.3.2 Acceptance of the intervention regarding the relevancy of the content

All six participants found most of the contents of the video relevant and an appropriate level of information is included and needed to support someone with diabetes in school:

Most relevant, differentiating type 1 and 2 diabetes, showing that meters/pump/injections/bag are part of daily life, hypoglycaemia symptoms and how a friend or a teacher can help, advice to teachers to maintain a record and check blood sugars during PE. Good job, excellent (PC2).

### 5.3.3 The most helpful parts of the video

Three of the participants mentioned specific content that they found really important. For example, the differences between type 1 and type 2, stating the signs and symptom of hypoglycaemia and gently reminding someone with T1DM to check their blood sugar: Yeah, I think that's important. That's good that the first thing you said was to get someone to remind them to check their blood sugar if they notice changes in the mood (PDNE1).

### 5.3.4 Modifications to some of the video content

Two participants suggested adding more pauses between the elements of the video and make the narrator speaks in a slower manner. They have explained that this might enhance the comprehending of the information:

> And even though we know this information, I still find it's quite quickly, so I think just slowing down this whole speed of the video, it's just getting that changing the delivery slightly so that it has time to sink into the brain (PS).

One participant suggested adding more description of the pump, and this can help to understand the differences between pump and pens:

The video particularly has emphasised the differences between pens and pumps, just like key ones like that the pump is attached to the skin, for example, as this can give a better understanding about the pump (PD).

Three participants suggested changing some medical terms used in the video into more informal language, for example, to change hypoglycaemia to low blood sugar and urination to peeing. They explained this might help them to remember the information presented:

Although I can see that you tried to make it simple, I think that some of the content is a bit over-complicated. The terms hypoglycaemia and hyperglycaemia are easily mixed up by lay people – why not just call them low blood sugar and high blood sugar – it will be easy to remember (CP).

One participant explained that it would be helpful to make it clear that, usually, four millimoles per litre or below is considered as low blood sugar. So, teachers and peers are aware when to support a student with T1DM:

And mainly this is coming but is it worth having low means four or below, just in case anyone, if they, if a friend or a teacher was looking at the sugar level, is it worth having a number in there... so they know when to interfere (PD).

In the video content, there is a part that states that one treats hypoglycaemia by offering a small amount of food containing carbohydrate. Two participants suggested changing this sentence to fast-acting sugar. As fast-acting sugar such as non-diet soft drink is more effective in case of hypoglycaemia than just food containing carbohydrate, such as a piece of bread, as this takes longer time to act. So, teachers and peers will not be confused and will act appropriately in case of emergencies:

> When you're saying that, what I would say is, rather than 'containing carbohydrates', to me, that could mean a piece of bread or something; I would maybe put in 'quick acting' or 'fast acting', to differentiate between the two, 'cos some people still get it wrong and if someone's going hypo – they'll give them a piece of bread, because they think that will work. It's necessary to make it clear so people in school can act properly in case of hypoglycaemia (PDNE2).

As part of the video, low-fat milk was explained to be one of the choices of treating hypoglycaemia; three participants suggested to remove it (milk) because it is not

recommended anymore, like a fast-acting sugar – it takes a longer time to treat hypoglycaemia, and it is considered a carbohydrate:

We do not recommend milk anymore for hypoglycaemia treatment – just fast acting sugars. like the rest mentioned [glucose tablets, fruit juice,  $\frac{1}{2}$ cup of non-diet soft drink] (CP2).

In the presented video, there was information about the different modalities of administration of insulin. One of them is a 1ml injection. Two participants suggested removing this kind of modality (ml injection) as it is not used anymore. They explained that a 1ml injection could provide a minimum dosage of 1 unit whereas pens can give a minimum dosage of half a unit, which is necessary when children or adolescents do their carb counting.

> The only thing I would say about that is that I would take out the insulin injection completely. Because I don't think – well, in children, nobody ever uses injections anymore. No, nobody, because the dosage you can give on a syringe, the minimum dosage you can give is probably about one unit because the marks are so small; you couldn't give a half a unit. Most of the children now, because they're doing carbohydrate counting, the doses are always counted in half units. (PDNE2).

In the video, there was information about adjusting the insulin dosage before sport. One participant suggested to remove this information. She explained that this might lead teachers to manipulate the insulin dosage:

Drop it. I mean if adjusting insulin dosage is needed before the exercise, it would all come up in a written care plan if the parents want to do that, but I don't know that they would. You don't want the teachers to go messing around with their insulin dose. Do you know what I mean? (PDNE1)

One participant suggested adding that hyperglycaemia can happen because of illness or infection:

And, actually, you probably need to have one about, infection. There isn't one for infection. So, if they are feeling a bit poorly or they've got a cold, that might be why they've got high sugar as well (PDNE1).

In the video, it was stated that hyperglycaemia could be treated by either drinking lots of sugar-free fluids OR taking extra insulin. One participant recommended changing that to drinking lots of sugar-free fluids AND taking extra insulin, as only drinking plenty of water will not be enough to treat hyperglycaemic episodes:

> On that one, I'd say 'and taking' because you would have to do both, because just drinking the fluids wouldn't bring the blood sugar down. So, it definitely has to be both and out of the two of them, the most important one would be in the insulin, because the taking the fluids is more because you get very, very thirsty, it's more for the person's comfort; it's not a medical necessity to necessarily drink plenty of fluids. It helps, but the only way you're going to solve the problem is with the insulin, so the insulin would have to be the main part of that one (PDNE2).

One participant recommended changing the term 'diabetic' to 'someone with diabetes'. He suggested that as it sounds incorrect to label people by their disease, as some people may feel insulted: But when you say, 'some diabetics', it's incorrect to call people with diabetes as 'diabetics'. We do not practice this anymore and some people will feel offended – they don't like to be labelled as a diabetic person. You would need to say something like, 'A person with diabetes'.

Three participants suggested that to make it clear that fluctuation of blood sugar can happen even if someone manages his diabetes well. So, peers and teachers will not judge someone with T1DM if they are hyperglycaemic or hypoglycaemic:

> It's sort of out of their control. So, I don't quite know how you could word it or get it in there but there is some sort of message of sometimes people are hypo and it's not their fault, or sometimes they're hyper despite doing everything correctly or something like that because otherwise, people might say, 'Ooh, you're eating a big lunch, you shouldn't be having that because you've got diabetes' (PS).

Two participants recommended adding a sentence about understanding the different preferences among adolescents with T1DM of where to undertake the diabetes tasks. Some will prefer to do it in the classroom, and some will prefer to go to the medical room for more privacy:

Sort of in that last line saying something about everyone with diabetes is different to each other, and wants different things, if they [adolescents with T1DM] want to stay in the class or to go away for their injection or to check blood glucose or whatever, like basically honouring the difference in some way (PS).

### 5.3.5 The desire to use the video during educational school tours

Two participants asked for the possibility to have a copy of the video to use it during their school educational visits to educate about diabetes. They highlighted that the video is very professional and can be useful. They explained that they could send it to teachers via email, so teachers can have an idea of the visit. Or they can show them during the visit itself:

> Can we have a copy of this when it's finished, it's very professional and can we have a copy as soon as possible, That would be quite useful to take in to schools before we – when we start. Because what we can do is we can actually email it to some of the schools before we go to the school, if we're going in for a new child, and then they can have a look at it themselves (PDNE1).

### 5.3.6 Summary of stage three

This stage of the study has presented the qualitative data from six health care professionals who are involved directly in managing adolescents with T1DM. The participants gave their overviews about the developed intervention (video) based on their expert opinion and the data provided from Stage 1 of this study. The findings of this stage were used to make the necessary amendments in the developed intervention to be ready to be shown to the adolescents with T1DM in the fourth stage of this study to check the appropriateness of the intervention produced. To conclude, all the modifications suggested by the participant in this stage of the study are summarised in Table 11 below.

| Changes suggested                                                                                                                        | Specific alteration to the video content                                                                                                            |
|------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------|
| Speed and pauses                                                                                                                         | The speed of the flow of the information will<br>be reduced, and more pauses will be added                                                          |
| Add more information                                                                                                                     | More description about the insulin pump will be added                                                                                               |
| Change some medical words to informal words                                                                                              | Hyperglycaemia will be changed to high<br>blood sugar<br>Hypoglycaemia will be changed to low blood<br>sugar<br>Urination will be changed to peeing |
| Specify what low sugar is with number                                                                                                    | Information that hypoglycaemia is usually below four millimoles per litre will be added                                                             |
| Change the term 'food containing<br>carbohydrate'                                                                                        | 'Food containing carbohydrate' will be<br>changed to 'food containing fast-acting sugar'                                                            |
| Remove low-fat milk as treatment of hypoglycaemia                                                                                        | Low-fat milk will be removed                                                                                                                        |
| Remove information about the ordinary injection                                                                                          | Information about 1ml injection will be removed                                                                                                     |
| Remove the information about adjusting the insulin dosage before exercise                                                                | Information about adjusting insulin before exercise will be removed                                                                                 |
| Add that hyperglycaemia can happen because of illness                                                                                    | Information that hyperglycaemia can happen<br>because of illness will be added                                                                      |
| Add that treatment of hyperglycaemia<br>should include not only taking more fluid<br>but also having an extra dosage of insulin          | Hyperglycaemia should be treated by having<br>extra fluid <b>and</b> extra insulin dosage will be<br>added                                          |
| Change the term diabetic to someone with diabetes                                                                                        | Any diabetic term will be changed to someone with diabetes                                                                                          |
| Add that fluctuation of blood glucose level<br>can happen even if someone with T1DM<br>does everything right                             | The statement explains that fluctuation of<br>blood glucose level can happen even if<br>someone with T1DM does everything right<br>will be added    |
| Add something about understanding the<br>differences in the preferences of where to<br>manage diabetes tasks among students<br>with T1DM | Statement to understand different preferences<br>among adolescents with T1DM will be added                                                          |

 Table 11: Modifications to the video suggested by health care professionals

Based on the expert feedback, two objective performances have been added as follows:

- Peers and teachers understand that complications of T1DM can happen for no obvious reason
- 2. Teachers recognise that students with diabetes have different preferences. Some will like to manage their diabetes in class, and some will prefer to go to the medical room.

The two added performance objectives have been included in the matrix as shown in the

Table 12.

| Performance objectives                                                                                                                                                                                  | Personal deterr                                                                                                                                                                 | ninants                                                                                                                          |                                                                                                                                                                              |                                                                                                                                                                         |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| (Peers and Teachers)                                                                                                                                                                                    | Self-efficacy                                                                                                                                                                   | Knowledge                                                                                                                        | Attitudes                                                                                                                                                                    | Social influence                                                                                                                                                        |
| 1. Peers and<br>teachers understand<br>that complications can<br>happen for no obvious<br>reason                                                                                                        | Peers and<br>teachers<br>express<br>confidence<br>that they<br>understand<br>that<br>fluctuation of<br>blood sugar<br>can happen no<br>matter how<br>careful the<br>person with | Peers and<br>teachers know<br>that fluctuation<br>of blood sugar<br>can sometimes<br>happen without<br>understandable<br>reasons | Attitudes<br>Peers and<br>teachers<br>express<br>positive<br>feelings for<br>not judging if<br>blood sugar<br>fluctuation<br>occurs for any<br>reason                        | Peers and teachers<br>support someone<br>with blood sugar<br>fluctuation without<br>unnecessary<br>comments on their<br>self-management<br>even if others do<br>comment |
|                                                                                                                                                                                                         | diabetes is                                                                                                                                                                     |                                                                                                                                  |                                                                                                                                                                              |                                                                                                                                                                         |
| 2. Teachers<br>recognise that students<br>with diabetes have<br>different preferences.<br>Some will like to<br>manage their diabetes in<br>class, and some will<br>prefer to go to the<br>medical room. | Teachers<br>express<br>confidence in<br>the ability to<br>respect the<br>student's<br>preferences<br>about where<br>they prefer to<br>manage their<br>diabetes tasks            | Teachers know<br>where a student<br>with diabetes<br>can perform<br>their tasks<br>(class or<br>medical room)                    | Teachers<br>express the<br>positive<br>feeling of<br>respecting and<br>allowing the<br>student with<br>diabetes to<br>choose where<br>they like to<br>perform their<br>tasks | Teachers<br>encourage students<br>with diabetes to<br>choose where to<br>perform their task.<br>Even if other<br>teachers do not<br>understand.                         |

 Table 12: Matrix for peers and teachers at the organisational level (school)

After that, the theoretical methods and application for the two added performance objectives have been selected and included in the table of theoretical methods and applications for achieving the change objectives at the organisational level, as shown in Table 13.

| Level of the intervention | Determinant         | Change<br>objective    | Method                                           | Related<br>theory | Application                |
|---------------------------|---------------------|------------------------|--------------------------------------------------|-------------------|----------------------------|
| Peers<br>Teachers         | Self-efficacy       | 1–10<br>1–8, 10–<br>14 | Verbal persuasion                                | SCT               | Video                      |
| Peers<br>Teachers         | Knowledge           | 1–10<br>1–8, 10–<br>14 | Consciousness raising<br>(providing information) | HBM               | Elements of the same video |
| Peers<br>Teachers         | Attitudes           | 1–10<br>1–8, 10–<br>14 | Consciousness raising<br>(providing information) | HBM               | Elements of the same video |
| Peers<br>Teachers         | Social<br>influence | 1–19<br>1–8, 10–<br>14 | Resistance to social pressure                    | TPB               | Elements of the same video |

Table 13: Theoretical methods and applications for achieving the change objectivesat the organisational level

# 5.4 Findings of Stage 4 (Interviews with a second group of adolescents with T1DM)

This stage was conducted after making all the modifications in the video suggested by the HCPs in Stage 3. The modified video was presented to another group of adolescents with T1DM who were not participants in Stage 1. Please click below link to watch the video, or copy the link and past it to an internet browser

https://www.dropbox.com/s/yavnjfrweg13f69/Diabetes%20Intervention-Final%20version.mp4?dl=0

The qualitative findings of this stage explored the acceptability of the intervention.

### 5.4.1 Data analysis of semi-structured individual interviews for Stage4

Ten participants were interviewed individually. For reasons of confidentiality, participants are referred to by abbreviation: adolescent (A=Adolescent), number (1–10), and gender (M=male, F=female).

### 5.4.2 The findings from the demographic data of the study sample

The demographic data of the participants were collected by the researcher before each interview, consisting of the participants' gender, age, ethnicity, family structure, duration of T1DM, and type of insulin therapy (see Table 14 below).

| Gandar                   | Male                     | 5 | 50.0% |
|--------------------------|--------------------------|---|-------|
| Gender                   | Female                   | 5 | 50.0% |
| Ago                      | 11 – 12 years            | 4 | 40.0% |
| Age                      | 13 – 15 years            | 6 | 60.0% |
|                          | White British            | 9 | 90.0% |
| Ethnicity                | Black African            | 1 | 10.0% |
|                          | Asian                    | 0 | 0.0%  |
|                          | Parents & siblings       | 8 | 80.0% |
|                          | Parents without siblings | 1 | 10.0% |
| Living with              | Mother & siblings        | 0 | 0.0%  |
|                          | Mother without siblings  | 1 | 10.0% |
|                          | Others                   | 0 | 0.0%  |
| Number of family members | 1-2 members              | 1 | 10.0% |
| Number of family members | 3 – 5 members            | 9 | 90.0% |
|                          | Mother                   | 1 | 10.0% |
| Guardians/Carers         | Father & Mother          | 9 | 90.0% |
|                          | Others                   | 0 | 0.0%  |
|                          | 1-4 years                | 7 | 70.0% |
| Duration of the disease  | 4-8 years                | 3 | 30.0% |
|                          | 9 – 12 years             | 0 | 0.0%  |
| Type of insulin therapy  | Insulin pen              | 7 | 70.0% |
| rype of insum merapy     | Insulin pump             | 3 | 30.0% |

| Table 14: Find     | ings from th | e demograpi | hic data of a | the study sample |
|--------------------|--------------|-------------|---------------|------------------|
| 1 0000 1 10 1 0000 |              | e wennes up |               | ne strug sumpte  |

\* Results of demographic elements, showing the demographic characteristics of adolescents with T1DM (n=10)

The findings were analysed and organised into several themes. The themes that emerged from the data are outlined as follows:

- Acceptance of the format
- Acceptance of appropriateness of the information
- Simple and enjoyable

- Appropriate Speed and appropriate background music
- Appropriate length
- Easy language
- Most liked parts
- Things to add
- Usability of the video

#### Acceptance of format

All ten participants liked the format, which is whiteboard animation video. They agreed it is more interesting than the video with real character and makes the information easy to understand. They also explained that the video with real character could be boring:

> I like how it's like animated, so it's not like, um, something that is serious, but you can relate to it because it relates to young people with diabetes. Because, like, say if it were like an interview with real people, people wouldn't listen because it's like boring, whereas animated pictures are interesting and I like the different drawings coming in (A4-F-15yrs).

#### Acceptance of appropriateness of the information

All ten participants expressed that the information included in the video covers everything about T1DM that is needed to help someone with diabetes in school.

I think it was good, it was very descriptive, it tells you everything you need to know about it [T1DM], and, honestly, I don't really know what to say because it tells you all that you need to know to help someone with diabetes in school, so – yeah (A2-M 14yrs).
#### Simple and enjoyable

Four participants expressed that the video is simple, and their friends can enjoy it and understand it:

Yeah, simple to understand. I think my friends would enjoy it (A1-F-11yrs).

#### Appropriate speed and appropriate background music

All ten participants agreed that the speed of the video was just appropriate and not too fast. The video was also accompanied with low music as background. The participants found it not very loud, calming and not distracting:

I could hear it all and, well, the music wasn't distracting, it was the right speed, you can listen and process it in your head. It's completely fine (A8-M-14yrs).

#### Appropriate length

The video was about 6:36 minutes. All participants found the length of the video to be appropriate and not too long. Three participants particularly explained that an audience might get distracted if they watched a long video:

It was the right kind of length; you don't want anything too long because, after sort of ten minutes or something, they [peers] start getting distracted and mess about (A2-M-14yrs)

#### Easy language

All participants agreed that the language used in the video is easy and understandable:

I like how, um, it explains it well even that younger people would be able to understand all what is presented can be understood definitely. That's good and simple because they [teachers] teach it in science or whatever some of these terms like cells and pancreas (A9-F-13yrs).

#### Most liked parts

When the participants were asked about their most liked parts, six participants found the part about differentiating type 1 diabetes from type 2 diabetes helpful. They expressed that this information will help teachers and peers to understand more about T1DM:

It's understandable, the differences between type 1 and type 2 is good? Because people in school does not really know. Some people mistake with type 1 about how they think, 'Oh, is it type 2, which is worse? I mean, they're both bad but they [teachers and peers] need to understand. (A3-M-14yrs)

Four participants found one of the most liked parts is the part that is explaining about understanding the preferences of where adolescents with T1DM wanted to do their diabetes tasks. They expressed that some teachers are asking them to do their diabetes tasks in the toilet or the hallway, which is not hygienic:

> I like the bit about understanding our preferences. A lot of the teachers have told me, 'You have to go and check your blood in the hallway or in the toilets'. This is not hygienic (A2-M-14yrs).

One participant expressed that she should not be separated from her classmates, because having diabetes is not her fault:

They [teachers] shouldn't separate me from other students and ask me to go and do it [check blood sugar] out just because I have diabetes; it's not my fault (A1-F-11YRS).

Two participants expressed that they liked the information about blood sugar monitoring because some teachers do not understand the importance of checking blood sugar:

They [teachers] were like, 'Can you put that away?' and I was like, 'I'm doing my blood', and they were like, 'No, just put it away' (A4-F-15yrs).

Also, information about blood sugar monitoring will educate peers about not making unnecessary hassle if students check blood sugar in between:

It is good to know that I check blood sugar sometimes, so they don't make a big fuss if they [peers] suddenly notice that I am testing my blood sugar in class because that's just what I have to do (A7-M-12yrs).

Three participants liked the information about the insulin pump as this will make teachers and peers understand that it is not a phone or iPad but for medication. Also, it will help them to know more about the insulin pump:

I liked when it says about that the pump looks like iPod – don't be confused, it's happened to me. It was my mock exam. Like, my pump started beeping at me and someone [another student] would be like, 'Oh, whose phone's that?' The teacher came and said, 'I need to take this in', and she wanted to take it and put it in the phone tray, so I was explaining this is my pump... that all was not necessary during my exam (A2-M-14yrs). One participant expressed that emphasising about teachers having a register will be good, so they will understand what it takes having diabetes:

Yeah, but that's a problem in my school, they don't – you talk about registers in there; I like it, I don't think every teacher in my school is aware of the student in their classes who have medical conditions. Um, I think this will be useful, so they [teachers] will always remember who have diabetes and they [teachers] will understand why we have to do specific things (A8-M-15yrs).

Two participants expressed that information about the diabetes bag is important, so teachers can understand why they have to carry it during the examination:

But, not – I appreciate not everyone will. Like my maths teacher – the examinations lady told him about me taking my diabetes kit in the exam and everything. But, he wouldn't have necessarily put all that together, and he told me all that you could only take a pen and a pencil and so... I have to explain. Yeah, I don't think all the teachers are aware of it [diabetes bag] so that would be good (A3-M-14yrs).

One participant liked the information presented in the video about PE teachers ensuring blood sugar before, during and after exercise. He expressed that his PE teacher does not do that, and it will be good if they help them to remember to check their blood sugar:

Right, but he [PE teacher] doesn't say to me to test it before I start and halfway through he doesn't make me stop and test it, so, maybe that's something that they [teachers] should start to remind us to do (A5-M-14 yrs.).

One participant liked the information that someone with T1DM may have to eat in the classroom. He expressed that could make them understand the reason for doing so:

Hmm, well, I liked the bit when they were saying like, erm, that you're allowed to eat in the classroom, so they understand (A9-F-13yrs).

One participant liked how the video is specifying how much low blood sugar is, so they do not worry unnecessarily:

I like when you put a number beside low sugar, most people [teachers and peers] ask me, like, 'Are, your blood okay and what do they need to be in range with?' So, like seven and four, So now they know if it is only below four (A10-F11yrs).

#### Things to add

All participants agreed that they like everything in the video:

Well, it explains it quite well, and it's quite simple so that people can understand. Yeah. There was nothing I didn't like (A6-F-11yrs).

However, one participant suggested adding a sentence explaining that T1DM is not contagious, as some peers think that they can catch it if they touch someone with T1DM:

Yeah. That you can't catch it because my little sister [has T1DM], erm, had this friend come round and she's like, 'I don't want to go near her because I might catch it,' and she was like so scared and my little sister got really upset (A10-F-11yrs).

#### Usability of the video

When participants were asked if this video will be easy to be used in school, nine participants answered that it could be used during a tutor session, where they normally share information or discuss matters: Well, yeah, I know some of the teachers in my school that would be happy to show that in a tutor or something before school (A3-M-14yrs).

I think tutor sessions. I mean all the teachers would say, 'We've got to watch a video', and everyone will watch it. (A7-M-12yrs)

Yeah, it's what they [teachers] do at our school if there's something that they [school] need to send around, they'll send it to the tutors and then the tutors share it in tutor sessions, so that's what they normally do, send a link to the video by email, so that's what they'd do with this (A4-F-15yrs).

# 5.5 Summary of stage four

This stage has presented the interview findings of ten adolescents with T1DM. All participants have expressed their positive attitudes in regard to the appropriateness of the information, format, simplicity, appropriateness of speed and length and the usage of easy language. They have also communicated their most liked parts. There was nothing that they disliked in the presented video. One participant has suggested adding information about T1DM not being contagious. They also suggested that this video can be shared during a tutor session, where they usually meet in the class as groups.

# **CHAPTER 6: DISCUSSION & CONCLUSION**

This chapter brings together the qualitative findings reported in Chapter 5 (stage 1, 2, 3, and 4). These findings are discussed in relation to the literature review. In addition, the study's contribution to knowledge is highlighted. Following this, recommendations and implications for practice are discussed. In addition, the strengths and limitations of the study and suggestions for areas of future research are provided, along with a personal reflection.

### 5.6 The Research Questions

1. In adolescents aged 11–15 with T1DM, what are the needs and priorities for enhancing their self-management (physical or psychosocial) in the school setting?

2. In adolescents aged 11–15 with T1DM, what intervention components or characteristics and approaches are required to enhance self-management (physical or psychological) in the school setting?

The findings of the first stage of this study answered those research questions, and suggest that the adolescents with T1DM are still confronting physical and psychosocial challenges in managing their diabetes in school. The findings also identified the priorities of how adolescents with T1DM wanted to be supported in school. It indicated that adolescents with T1DM wanted their teachers as well as their peers to improve their knowledge about T1DM as this can lead to reduced psychosocial challenges and consequently improved their self-management in their schools. The thematic analysis of the data has also enabled a greater understanding of what intervention content that has been pointed out by the participants is required to enhance the knowledge and understanding of T1DM among peers and teachers.

The study aims to develop and assess the acceptability and appropriateness of a schoolbased intervention to promote self-management (i.e. physical or psychosocial) among adolescents with T1DM aged 11–15 by exploring their needs and the priorities of how they want to be supported in school settings.

The study aim was met. This study resulted in the development of a school-based intervention that reflected the voice of the adolescents with T1DM, which could enhance self-management in school settings. Intervention mapping protocol was used to guide the development of the intervention. The developed intervention is also associated with delivery and evaluation plans for future testing. The developed intervention has been evaluated to ensure its content relevancy and appropriateness. Semi-structured interviews with health care professionals showed that the intervention is relevant to be used in schools to enhance knowledge and understanding of T1DM among peers and teachers. However, some modifications were suggested. After making all the suggested amendments, feedback regarding the appropriateness of the intervention was also gathered by conducting semi-structured interviews with adolescents with T1DM. The results showed that the intervention content is appropriate to be used in a school setting.

# 5.7 Adolescents' ability to depend on themselves in managing their diabetes in school

Cognitive changes during adolescence improve complex thinking, and previous life experiences help adolescents develop new knowledge (Moyse 2009). Therefore, they are usually able to understand the complexities of their disease and can assert their independence by recognising the changes in their physical and mental health that constitute a threat (Upton and Thirlaway 2014). As children enter adolescence, they become less dependent on others and more competent in making their own decisions

(Chaney et al. 2011). Consequently, they become more able to solve their diabetes problems with self-care management tasks (Thomas et al. 1997).

# 5.8 Physical and psychosocial challenges in managing T1DM in school

T1DM is a very demanding and challenging condition. Some challenges explained in this study were associated with the nature of T1DM and its management but also arose as a result of the social difficulties that restricted them from managing their diabetes within the school environment. These study findings explained some physical challenges that can be caused due to fluctuations in blood sugar levels such as weakness and shakiness. However, these physical challenges can lead to social challenges such as embarrassment.

The findings of this study reinforce the findings reported by (Schwartz et al. 2010), who evaluated the experience of children and adolescents with T1DM in school by surveying them. They found that 23% of the surveyed children felt embarrassed at school after experiencing a hypoglycaemia episode.

Feeling of the embarrassment of managing diabetes in school was indicated in this study. The result of this study concurs with Ye et al. (2017) study, which aimed to understand issues that concern teens to develop more successful interventions to improve diabetes self-management. Teens reported being embarrassed about blood glucose monitoring and insulin injections in public. Comparable findings were also reported by Lu et al. (2015), who asked teens about barriers to self-care. They found that adolescents were embarrassed managing their diabetes in front of their peers.

Adolescents in this study reported that diabetes makes them feel different from their peers. The findings of this study are similar to Wang et al. (2013) study, which

investigated the school experience of adolescents with T1DM. They found that adolescents were often confused about their identity and hesitant of whether and how much they were similar or different from their classmates. None of the participants in Wang et al.'s (2013) study was happy to perform their diabetes task in front of others because of associated unwanted attention, which emphasises the sense of being different. Charmaz (1995) discussed that identity is made up of various factors including self-concept, personal values, self-efficacy, relationship roles, and opportunities for the future. These factors are affected by a chronic condition such as T1DM, as the illness will affect how adolescents view themselves, and how they want others to view them or the priorities they assign to managing the illness.

Rapid physical development, hormones and taking responsibility for managing their diabetes may cause psychological and emotional problems in adolescents with T1DM (Abolfotouh et al. 2011). These findings are also supported by other studies, which found that blood glucose fluctuation, particularly hyperglycaemia, has affected the mood and motivation towards different activities of the adolescents in school (Spencer et al. 2014).

Storch et al. (2006) indicated that there is an association between diabetes-related bullying and diabetes self-management. They found that children with T1DM who are bullied about their medical condition may avoid engaging in self-management behaviours that are easily observable by peers and, by virtue, have a higher likelihood of being targeted. Similarly, Greening et al. (2006) and Horton et al. (2009) stated that diabetes and negative life events (bullying) are chronic stressors that harm children's behavioural adjustment. Understanding the physical and psychological challenges that might face adolescents with T1DM might provide better ways to support adolescents with diabetes in school. Also, it might help adolescents with T1DM to respond to these

challenging situations properly without compromising their diabetes self-management in school. In this current study, bullying was specified (messing with the diabetes bag); knowing what type of bullying adolescents with T1DM are facing in school could help in finding some strategies that might tackle this problem such as increasing the awareness of the importance of the diabetic bag.

# 5.9 Peers and teachers improve their knowledge and understanding about T1DM

Similar to the findings of other research (Huus and Enskar 2007; Wang et al. 2013; Commissariat et al. 2016), this thesis demonstrated the reluctance of some adolescents with T1DM to reveal their condition to their peer group, because they fear that their diabetes identifies them as different. Similarly, Balfe et al. (2013) found that adolescents with T1DM, confronting the challenge of feeling self-conscious about their diabetes and its management, were concerned about how other people viewed them. They found that adolescents with T1DM have strong stigma-related perceptions of other people and tended to sidestep activities that they felt would highlight or disclose their diabetes to others. Many adolescents with T1DM fight with body image, self-esteem, and peer-related issues. During adolescence, peer relations and acceptance by friends are vital. Therefore, adolescents with T1DM may engage in inactive coping approaches, for example, avoiding diabetic-related activities such as testing blood sugar or even injecting insulin to avoid being different to others (Brazeau et al. 2018).

Despite that, the data reported by most of the participants in this study recommended that peers and teachers know more about T1DM and its management. These findings are supported by Brooks et al. (2015), who concluded that a supportive peer system could be a valuable source in good management of T1DM in adolescents. Also, Lu et al.

(2015) suggest that sharing knowledge about diabetes with friends allowed them to overcome the social embarrassment related to diabetes-related tasks. Irani et al. (2014) also emphasised that to overcome T1DM-related social stigma, community-based strategies including education, advocacy, and interaction should be introduced. However, the above studies focused on other context and not in school. The uniqueness of this current study is that the participants wanted that all peers as well as teachers, in school particularly, to know about their diabetes.

More knowledge about diabetes and its management could prevent adolescents with T1DM receiving unwanted attention when testing or injecting in public or carrying an insulin pump treating their hypoglycaemia. Unwanted attention can hinder their ability to fulfil their self-management routines as a result (Spencer et al. 2014).

It was important for the participants in this study to know that they will be properly supported. Many studies had suggested teachers improve their knowledge or receive a basic knowledge of diabetes ((Vimalavathini et al. 2008; Aycan et al. 2012; Pansier and Schulz 2015) so they can act in case of emergencies such as hypoglycaemia. Having reliable, knowledgeable support within school is helpful to give adolescents with T1DM a sense of security in managing diabetes (Pinelli et al. 2011). In this study, participants with T1DM had recognised the importance and the need to have peers in school around them who knew about their diabetes, to feel more secure, even if they felt confident about their own ability, meaning that they are less alone with this condition.

Knowledgeable peers and teachers in school will be helpful to reduce some of the psychosocial challenges as indicated in this study. Malik and Koot (2009) found that protective factors such as self-worth and social support may mediate the effects of psychosocial stressors with adolescents with T1DM and thus should be encouraged.

It was also found that good knowledge about diabetes will allow PE teachers to adequately support and remind adolescents with T1DM to do the necessary task before engaging in any physical education classes. These findings are comparable to MacMillan et al. (2014) study, where adolescents with T1DM were excused participating in PE sessions due to a lack of diabetes knowledge among PE teachers. MacMillan et al. (2014) highlighted the necessity to improve support for adolescents with T1DM in schools in general and specifically in PE lessons.

#### Willingness to learn coping skills

Although the focus of this study is not on developing an intervention linked to coping directly, it is important to keep these thoughts in mind, to ensure greater openness and acceptance to establish these insights in the future. However, the priority was for an intervention that has been chosen by the participants in this study. Whittemore et al. (2012) study compared an internet coping skills training intervention to an internet educational intervention for adolescents with T1DM. They found that children with T1DM transitioning to adolescence may benefit from both internet diabetes education and coping skills to maintain HbA1c, reduce stress and improve quality of life.

This study was able to gather in-depth information about needs and priorities that could enhance self-management among adolescents with T1DM in school settings. This can be used to inform the development and design of the school-based intervention better. In this study, participants preferred more information and education to peers as teachers; they considered knowledge and understanding as significant factors that can enhance their self-management in a school setting. They also explained that knowledge of T1DM could also facilitate some social and psychological challenges that can hinder their self-management in school. Adolescents with T1DM need to feel confident and

comfortable with their self-management in school. Christie et al. (2009) argue that complete autonomy in diabetes self-management requires social and emotional support because adolescents will face social and emotional constrictions in school.

#### **5.10 Intervention development**

As discussed in chapter 4, this study used the first four steps of the intervention mapping protocol to develop an evidence-based intervention to improve awareness about T1DM among teachers and peers in a school setting. The resource addresses prominent determinants that have been identified to enable knowledge and understanding of T1DM.

To the researcher's knowledge, this is the first intervention to use an IMP to improve teachers' as well as peers' knowledge and understanding about T1DM in a school setting. Findings from Stage 1 of this study have suggested the content of the intervention as summarised in Chapter 4.

Findings from the literature indicated the importance of supporting students with T1DM to optimise their self-management during school hours (Edwards et al., 2014). School teachers play an important role to support students with T1DM. Therefore, many studies focused on the education of school teachers about T1DM. Diabetes training and continuing education of school teachers have reported that school personnel have gained knowledge and improved their self-perceived ability to support students with T1DM (Pansier and Schulz 2015). A recent systematic review by Kazemi et al. (2016) revealed that peer-based interventions could help to manage diabetes. Despite widespread literature searching, no studies have emerged involving peers in diabetes education in a school setting. Most of the studies involving peers-based intervention were conducted at home, clinic or in the community. Findings from the first stage of

this study indicated the need for involving the teachers as well as peers in the process of diabetes education, as this could help to enhance diabetes self-management among adolescents with T1DM in school settings. Key determinants of improving knowledge and understanding among teachers and peers that have been found in the literature review include: self-efficacy, knowledge, attitudes and social influence. A video-based intervention was developed based on the needs and priorities of adolescents with T1DM and the literature review (see Chapter 4 stage one).

It can be argued that the intervention excludes those with T2DM despite the increasing prevalence of adolescents with T2DM around the world and in the UK. A total of 106 cases were reported, giving a UK incidence of 0.72/100 000 (Candler et al. 2018). However, T2DM remains far less common than T1DM diabetes in childhood in the UK. Also, many studies suggested that adolescents with T1DM experience higher A1C, and poorer blood glucose control, suggesting that it is those adolescents with T1DM who need the most help (Clements et al. 2014; Costa and Vieira 2015; Liu et al. 2017). In addition, T1DM takes a more intense effort to manage, including, for example, multiple insulin injections or insulin infusion and carb calculation whereas T2DM may not need the injecting of insulin. Furthermore, T1DM is not reversible or preventable whereas T2DM can be prevented or reversed with a healthy diet and keeping weigh control. This does not mean that T1DM is more 'critical' than the other. It will be beneficial to be aware that both adolescents with T1DM or T2DM live with a chronic disease and that that takes a toll, just in different ways. Whether it is T1DM or T2DM, appropriate measures should be adopted to handle each of them. Each type should be tackled in its own way. Both are complicated, and it is not the case that one is worse than the other. However, the focus of this study is T1DM.

# 5.11 Acceptance of the intervention regarding the format of the video (whiteboard animated video)

In this research, the findings gathered through open-ended interviews (first stage) have been translated and communicated to others, such as HCPs, via whiteboard animation video format. Whiteboard animation has been considered as a feasible, practical and culturally-appropriate method of communicating research results back to communities. It can encourage insight and new ways of coproducing knowledge, which communicates knowledge to a broader audience (Bradford and Bharadwaj 2015). The dynamic contrast created by moving elements of animation may be more appropriate at capturing attention than the non-dynamic (de Koning et al. 2009). Türkay (2016) investigated the impact of whiteboard animated video on retention and subjective experiences of enjoyment, engagement, and challenge. They compered whiteboard animation to other ways of learning, including slideshow (i.e. sequential images with narration), audio only, and text only. Türkay (2016) found that whiteboard animations have a positive effect on retention, engagement and enjoyment. Whiteboard animations are more engaging, improving retention compared to only text and audio formats. In this current study, the health care professionals were interviewed (Stage 3) to assess the appropriateness of the content of the video produced. The analysis enabled the researcher to verify the suitability of the video and identify areas for improvement.

The participants in this stage agreed upon liking the format of the intervention, specifically, the drawing, the sound of the narrators (which helped in following the information), keeping videos brief, and the focus on learning aims. Combining visual and auditory features can maximise the learning from the video content (Brame 2016).

#### 5.12 The most helpful parts of the video

All the participants in Stage 3 of this study agreed upon the relevancy of most of the content of the video, explicitly stressing on how T1DM is different from T2DM. Understanding the discrepancies between type 1 and T2DM is essential as both have different treatment routines. Also, recognising the complexity of T1DM management can help teachers and peers to provide better support and allow students with T1DM to manage their diabetes tasks in a safe and supportive environment (Lawrence et al. 2015). Stating the signs and symptoms of hypoglycaemia was one of the things that was found most helpful. For students with diabetes, hypoglycemia is the greatest immediate danger and often leads to interruptions in learning, other school-related activities and more serious threatening complications such as comas. Therefore, it is important that teachers and peers be aware of the signs and symptoms of hypoglycaemia in order to provide the proper support, if needed (Kadohiro, 2009).

### 5.13 Suggestion for modifications

It was suggested to reduce the speed of the narration and introduce more pauses for the video developed in this current study. Narration has been defined as spoken text that accompanies the dynamic display of the actions (Sheridan 1983). The dual coding theory was suggested by Paivio (1990). Paivio attempts to give equal weight to verbal and non-verbal processing. Therefore, text and pictures can thus strengthen each other. Mayer and Anderson (1991) showed in their experiment that presenting verbal and visual explanations without connecting them is much less helpful than coordinating verbal narration simultaneously with animation, which supports Paivio's theory. The results of their study support the claim that synchronised presentation of speech and animation results in improved problem-solving. In this study, the narration in this video

comes from the human voice, and there was synchronisation between narration and the animation.

Video pacing means the speed of the video. The video tutorial should show and explain tasks at just the right pace for the learner (Foust et al. 2017). The pacing of the video might influence the learner attention process. If the pace is too slow, the learner may become uninterested and pay less attention, while if the pace is very fast, the learner may experience cognitive overload (Teng 2015). Micklewright et al. (2012) found that learner cognitive ability was one of the elements to be taken into account in choosing a suitable video pace. Greater cognitive ability students required a quicker pace. Swarts (2012) examined what could be an effective pace. He suggested using medium conversational speed. On the other hand, Ten Hove and Van der Meij (2015) suggested quicker conversational speed can be more engaging.

Pause refers to a short-term stop or break in a demonstration. During a pause, the visual image is kept static, with no narration (Teng 2015). Mercer (2015) found that a break had an extended positive effect on the learner retention. Similarly, Spanjers et al. (2012) found that introducing a pause in the animated video had a positive effect in cognitive load and enhance learning. Therefore, and based on the suggestion of this stage, medium conversational speed to suit different cognitive abilities and more pauses were introduced to the current video.

One of the suggestions was using more accessible language instead of using the medical terms (jargon) such as hypoglycemia, hyperglycaemia and urination and replace them with low blood sugar, high blood sugar and peeing. Jargon has been defined as especially the terms that are used in a particular trade, profession, or groups such as among doctors and engineers. Patoko and Yazdanifard (2014) investigated the impact of using jargon during communication. They found that jargon tends to negatively impact

the effectiveness and efficiency of the communication causing misunderstanding of the communicated message. Gharabaghi (2013) expressed the importance of understanding the undesirable influence of the jargon usage while interacting with children and adolescents. He explained that jargon could lead to misleading and misinterpretation of the communicated matters to children and adolescents. All medical terms have been changed to more accessible terms, as suggested by participants in Stage 3.

Information related to 1ml syringe injections was removed as this is not practised anymore, because the 1ml syringe injection does not provide an accurate tiny dosage as the case with the insulin pens. Similarly, Pfützner et al. (2008) and Asakura et al. (2009) found that the insulin pen was easier to handle and preferable to use compared to a conventional syringe and vial. Also, insulin pens were significantly more accurate than syringe injections. Insulin pens, in addition, were found to facilitate adherence to intensive insulin therapy, decrease injection pain, and help improve lifestyle flexibility when compared to a conventional syringe (Hanas et al. 2011). Therefore, the information about the 1ml syringe injection was removed from the video.

It was also suggested that milk as a treatment of hypoglycemia be removed as more fast-acting sugar should be given in the case of hypoglycemia. According to NICE (2015), regarding treating hypoglycemia, it can be treated immediately by eating or drinking 15 to 20g of fast-acting sugar. This could be three glucose or dextrose tablets or a small glass of a sugary (non-diet) drink. Milk was only recommended after treating hypo as a slower-acting sugar. Food containing fat or protein such as milk can slow how quickly the body absorbs sugar (NICE 2015). Therefore, milk was removed from the developed video in this study.

Other suggestions were to make it clear that hyperglycaemia can occur because of sickness as that was not clear in the video. Also, if hyperglycaemia occurred in the

school, it is necessary to have an extra insulin dosage and not only having extra fluid. Insulin therapy should be taken along with fluid to reverse the symptoms of hyperglycaemia (NICE 2015). Therefore, sickness was added as another cause of hyperglycaemia.

To enhance understanding and support from teachers and peers, more description of the insulin pump should be added, as expressed by one of the participants. Increasing levels of medical diabetes information presented to teachers promoted correct acknowledgements of classroom problems with health (Cunningham and Wodrich 2008). Therefore, a description of an insulin pump was added into the developed intervention.

The term 'diabetic student' from the video was suggested to be changed. According to the American Diabetes Association (2016), the word 'diabetic' should no longer be used to label people with diabetes. The term 'diabetic' is an adjective and it should be used to refer to complications related to diabetes (e.g. diabetic neuropathy). Referring to someone as diabetic suggests that they are nothing more than their disease, and their diabetes defines them as a person. Labelling them with their disease can stigmatise them. Brazeau et al. (2016) found that adolescents with T1DM are particularly vulnerable to stigma and this can lead to non-adherence to treatment regimens. Therefore, the term 'diabetic student' was replaced with the term 'someone with diabetes'.

Another suggestion was to add that fluctuation of blood sugar can happen even if someone with T1DM does everything right. The fluctuation of blood sugar can go beyond the adolescent's control no matter how much he/she tries to be careful. Glycemic control worsens during puberty as the lean body mass doubles, mainly over a period of two to five years, which increases the insulin requirement. Also, there is an

increase in insulin resistance over the period of puberty because of growth hormone (Moran et al. 1999; Chowdhury 2015). Furthermore, adolescents with T1DM are at increased risk of problematic psychological functioning such as depression and anxiety. These are found to be associated with suboptimal glycemic control in adolescents with T1DM (Herzer and Hood 2009). Also, stress has the potential to influence metabolic control directly, causing blood glucose fluctuation through its impact on cortisol interfere with insulin metabolism (Jaser and White 2011; Ashraff et al. 2013). All of these physical and psychosocial changes happening during adolescence further worsen glycaemic control. Therefore, the suggested sentence was added to the developed video. Finally, it was suggested to add the following sentence 'understand the differences in the preferences of where to manage diabetes tasks among students with T1DM'. Adolescents with T1DM need to inject their insulin and check their blood sugar frequently and at any time. They should be able to do these tasks where they feel relaxed and safe. This can be a classroom or medical room. Lawrence et al. (2015) explained that schools must provide all students with a clean, suitable and safe area for diabetes self-management, and respect students' personal preference for privacy. Similarly, Forsander et al. (2018) suggest that understanding more about how adolescents manage their disease and their wishes and attitudes towards treatment aspects will enable improvements in the support provided.

All the suggestions by the HCPs were taking into consideration, and all the suggestions have been implemented. The following paragraphs discuss the findings of the follow-up stage that was conducted with another group of adolescents with T1DM (Stage 4), in order to explore the acceptability of the developed and modified intervention.

The findings of Stage 4 showed how adolescents with T1DM feel about the developed intervention in regard to the format of delivery, the content, what they like, what they

do not like, what seems usable, and what to change. All ten participants showed positive attitudes about the intervention, as discussed below.

## 5.14 Acceptance of the appropriateness of the information

Acceptability is dependent on the individual's attitude towards care options and their judgement of perceived acceptability. Factors that influence an individual's perceived acceptability include the intervention's 'appropriateness in addressing the problem' (Sekhon et al. 2017). This stage of the study showed that the video is appropriate in regard to the information about T1DM. Care providers require appropriate knowledge about diabetes to empower young people in promoting self-management (Lange et al. 2014). Appropriate information on T1DM should include information such as an overview of diabetes, recognise and respond to emergent situations such as hypoglycaemia and hyperglycaemia, and care during sports activities. Typical needs of a student with diabetes should be taken into consideration when educating about T1DM in school (Jackson et al. 2015).

## 5.15 Acceptance of the format 'simple and enjoyable'

Whiteboard animation had translated the information in a simple way, not boring and easy to understand. Wafi and Keshta (2013) explained that animation has the potential for not only presenting information but also for holding a viewers' attention while it is being presented. Moreover, using animation in education is more satisfying and engaging than traditional learning modalities (Barak and Fisher 2001).

# 5.16 Appropriate speed (video pacing) and appropriate length

The video speed was appropriate (after adjustments), as expressed by all participants in this stage of the study. Video length means the duration of an instructional video. The optimum video length is six minutes or shorter. In fact, the average engagement time of any video maxes out at six minutes, regardless of its length (Guo et al. 2014). In the present study, the average video length is 6:36 minutes. To improve retention, the learner motivation will be enhanced via motivational processes. Motivation generally means an internal state that initiates and maintains goal-directed behaviour (Mayer 2008). According to Bandura (1986), motivation processes increase learners' active engagement. A higher level of motivation causes more attention, more retention of the behaviour, as well as more reproduction of demonstrated performance afterwards. People with higher motivation in observational learning are more likely to achieve the targeted learning objectives (Salas et al. 2009). Instructional features used to enhance learners' motivation in this video include using the spoken human voice and narration in a conversational style and user control. The conservational style was also reflected in the narration, such as 'you can start with reminding' or 'your help and support can make a massive difference in someone's life' or 'in your school', which directly addresses the learners as 'you'. Also, asking a question to stimulate their motivation, such as 'how to treat and help someone with low blood sugar?' It matches with the personalisation principle, which claims that learners are more likely to follow a narration presented in conversation style and more motivated to learn (Kurt 2011).

Also, the instructional feature of user control provides just an option for learners to actively acquire and process information, which further increases learners' comprehension and motivation. In this video, learners can start, pause, stop, restart and

move the video backwards or forwards. The control enables learners to adjust their viewing to their attentional processes. The user-control strategy in showing animation has an advantage in minimising cognitive overload and improving learning performance, especially for learners without previous knowledge of the content (Hassan and Ali 2014). Moreover, more pauses have been added to this present video, as suggested by HCPs. Studies found that animations with pauses are less difficult and require less mental effort than animations without pauses (Spanjers et al. 2012; van der Meij and van der Meij 2016).

#### 5.17 Easy language

The existing literature on jargon use in health-related communication focuses on what laypersons understand (LeBlanc et al. 2014). Using jargon in communication means that you want to reach a specific audience that already understands the terms. This can exclude many other people who might not understand the jargon used. As this video is targeting people out of the medical field (peers and school teachers), all the jargon was replaced with more informal terms, as suggested by HCPs. A large body of research shows that when people use language in different contexts, they make different choices of vocabulary. In turn, this gives rise to different varieties of language. Varieties are sets of human speech patterns exceptionally associated with situations, geographical areas or social groups (Sharon and Baram-Tsabari 2014).

#### Usability of the video during tutor session

Tutor session is also called vertical tutoring, which means organising students into mixed age groups for 20 minutes per day, tutor time. Schools in the UK have adopted vertical tutoring, which is believed to be helpful to provide more personalised support for all students as well as reduce poor behaviour, bullying and exclusions. The vertical tutoring system enables students to learn from others and share information of different aspects. Moving towards a vertical tutoring model is believed to generate a desire for high-quality dialogue between peers and teachers (Barnes and Kent 2011). Also, it is believed to improve levels of teamwork and communication between teachers and students. Baumgartner et al. (2004) found that vertical tutoring made tutees help each other with tasks, share information, reassure each other, stick up for each other and stick up for their tutor.

#### 5.18 Contribution to Knowledge

School is a critical environment in influencing the health and safety of adolescents with T1DM. Adolescents with T1DM need to manage daily tasks of medication, with regular monitoring of blood sugar, balancing food intake and physical activity. Given the importance of school-based diabetes self-management, this study sets out to develop and assess the appropriateness of a school-based intervention to enhance selfmanagement in school for adolescents with T1DM. The findings of the initial stage of the study supported earlier work in identifying the challenges of self-management among adolescents with T1DM in school and added to the literature by also identifying key points related, including the adolescents expressing how they wanted to be supported in school. A precise need emerged from the findings of the first stage, which is improving knowledge and understanding of T1DM and its management among teachers and also peers. All previous diabetic school interventions that were identified focused on educating school staff or supporting the adolescents with T1DM. There was no school intervention focused on educating peers in school about T1DM. Therefore, this study highlighted the importance for peers in conjunction with teachers to understand about the disease. The first stage also identified a key point regarding specific information about T1DM, which was suggested by the participants, to be

known by peers and teachers and assumed by the participants to be helpful to reduce some physical and psychosocial challenges and thus enhance self-management at school. Consequently, an intervention in the form of a whiteboard animated video was developed.

The outcomes of the first stage of this study were used to develop the intervention using intervention mapping protocol (IMP). IMP assisted with the development of the intervention that addresses elements that were suggested by the participants in the first stage. A key characteristic of IMP is the determination of desired outcomes at the beginning of the planning process, which ensures these outcomes are focused on throughout the intervention development process. The application of IMP resulted in an evidence-based intervention informed by the requirements of adolescents with T1DM in school. Theory- and evidence-based development interventions increase the likelihood of an intervention being effective (Wight et al. 2015). However, following the IMP steps, although time-consuming, can ensure that the change objectives selected, and which the intervention is targeting, are appropriate and likely to be effective. The findings of the third and fourth stages in this study also showed that the participants in the third stage (health care professionals) and fourth stage (a new group of adolescents with T1DM) positively valued the developed intervention. They suggested that the intervention is a promising education programme that could help to improve diabetes knowledge among teachers and peers in school. The diabetic health care professionals who participated in this study have expressed their desire to use the intervention in their school visits as soon as it is ready.

This study contributes by providing more insight into the systematic development of diabetic school intervention and more detailed description of the behaviour change methods and strategies used. The developed intervention (video) is a rigorously

researched intervention in terms of approach, content and construction, and the consequence is that in stages 3 and 4 the viewers responded very positively – validating the decision-making and the building and adapting of this video on a very firm foundation.

Although this intervention is developed based on theory and evidence, its effectiveness still needs to be evaluated in an evaluation study (suggestion for implementation and evaluation is provided in the future research section). Evidence from evaluation study will provide information on the efficacy of the intervention. If the evaluation study proves that the intervention is effective, a well-developed intervention will become available for teachers and peers in school that might have an impact on teachers' and peers' understanding about T1DM.

# 5.19 Recommendations for the Future Management of Adolescents with T1DM in a School

Teachers' and peers' knowledge and understanding about T1DM in school is important for adolescents with T1DM. It can minimise some physical and psychological challenges and consequently improve their self-management in school.

- Adolescents at school should be able to manage their diabetes and participate in school activities. Thus, teachers and peers should support adolescents to be empowered and overcome common social difficulties in schools.
- Students with T1DM are vulnerable to hypoglycaemia, mainly during or after exercise. Therefore, to keep students safe, physical education teachers must be aware of T1DM and understand what to do before, during and after the PE lesson.

- 3. Schools may need to consider implementing educational programmes that provide school teachers and school peers about type T1DM and other health problems on a regular basis, recognising the increasing incidence of diabetes and the importance of diabetes control during school hours.
- 4. The source of knowledgeable and practical support for adolescents' diabetic management may enable adolescents with T1DM to feel secure during emergencies within the school environment. It is therefore recommended that information about how to act in emergencies should be known among teachers and school peers. It is difficult to expect teachers to master all diabetes treatment as they are not health care providers. However, it is important for teachers of students with T1DM to identify signs and symptoms of hypoglycaemia and hyperglycaemia and to know what to do and how to call for an emergency if needed.
- 5. As misconception about the causes of T1DM and the confusion of the treatment modality among teachers and peers causes frustration to the students with T1DM, it is recommended to have a procedure in place to educate peers and teachers about T1DM, causes, and treatment modalities.
- 6. Information about T1DM and its management can be shared during school events such as assembly or tutor sessions, as suggested in this study.
- 7. Given general frustration and stress involved with repeatedly telling teachers about having diabetes, it is recommended to have a procedure in place in school to remind teachers about their students with diabetes. This would appear to be something that adolescents with T1DM would find beneficial.
- Emotional support should be given by teachers if needed for adolescents with T1DM.

- Students with T1DM should be given the choice of where they like to perform their diabetes tasks; their preference should be respected.
- 10. Students with T1DM should be able to treat hypoglycaemia with glucose tablets and/or food, in class if needed; therefore, understanding and flexibility is required from teachers.
- 11. School canteens can also provide students with information on how many carbohydrates there are in each portion size of food they sell. This will help students with diabetes to adjust their insulin dosage accordingly.
- 12. An overall recommendation would be for school peers and teachers to be knowledgeable and more accommodating of each individual's diabetes management.

### **5.20** Implications for Clinical Practice (Diabetic Team)

The findings of this study identified several implications for professional practice that are pivotal to meet the enhanced management of adolescents with T1DM in school.

- Adolescents with a chronic disease such as T1DM should always be encouraged to participate in their health choices. Their participation is likely to yield essential information for the effective and important insights in how they want to be supported in their school.
- 2. Health care professionals must provide continuous and accessible support to assist with the needs and priorities of adolescents with T1DM. The assessment should investigate the perception of school support. It should involve asking adolescents with T1DM what they feel is supportive and what could be done to improve a sense of support if it is lacking or how support can be enhanced.

- Interventions should be designed to enable others (peers and teachers) to successfully fill their roles in supporting adolescents with T1DM in a school setting.
- 4. The diabetic team need to ensure that schools are aware of the existing guidance in supporting students with T1DM. They should ensure that schools understand its implications and are implementing the guidance.
- 5. Teachers and peers in school need adequate knowledge and appropriate attitudes to become more competent in supporting adolescents with T1DM in school. Therefore, effective policies should be available to improve school awareness about different chronic diseases.
- 6. All schools' policies need to ensure that teachers know about their students with chronic illness and their particular needs.

#### 5.21 Study Strengths and Limitations

As with other research projects, this study has particular strengths and limitations. One strength is what has been learned about support needed in school from adolescents with T1DM themselves, which was a particular gap in existing knowledge. The themes emerged from this study were used to develop a school-based intervention that could enhance self-management among adolescents with T1DM in the school setting.

Another strength of this study is that due to the use of IMP and a very robust and wideranging review of the existing literature, the intervention is strongly based on theory and evidence. A key strength of this intervention is that the content of the intervention depended on what adolescents with T1DM wanted their teachers and peers to know about T1DM. Listening to and incorporating adolescents' voices could discover components they see as affecting their well-being (Dex and Hollingworth 2012). By using IMP as the conceptual framework for developing this intervention, the researcher offered involved adolescents a systematic and evidence-based approach. Furthermore, the transparent description of the development of the intervention may be helpful for the design and evaluation of future health interventions.

In addition, the third stage of this study (interviewing health care professionals) was a strength in validating the research findings by including them in the development of the intervention that ensured expert input throughout. Secondly, it was an opportunity to influence local practice through the dissemination of the research results of this current study to get their feedback in the developed intervention. As a consequence, the health care professionals were happy to use the intervention developed in this study in their school visits. Further, by adopting the intervention materials developed in this current study to the adolescents with T1DM feedback, the quality and effectiveness of the intervention were likely to increase. Finally, the plan to pilot a cluster randomise trail pre-test-post-test design (details are provided later in this section) could ensure the potential efficacy of the intervention will be thoroughly tested. Also, the use of CCA can analyse the cost-effectiveness of the intervention.

Some limitations of this research need to be acknowledged. This study was using a sample of mainly white British adolescents. Findings are based on the experiences and perceptions of the adolescents involved and might therefore not be reflective of the view of other people within the school environment. Further research involving a larger and more diverse sample (diverse ethnicity) would be justified, and perhaps including staff, peers and other school personnel experiences will provide a balance to the overall picture.

This study involves only adolescents (11–15) who attended one teaching hospital, representing one city in the UK. Consequently, the self-reporting and experiences of

participants in this study cannot be assumed as representative of all adolescents with T1DM attending other schools in different regions of the UK.

One of the limitations is that only steps one to four of the IMP were completed; however, the time focused on intervention development was critical. In addition, the rigour of the first four stages in developing robust material on which to build and the complex process of intervention development, of which this study has reported, should be acknowledged.

Intervention development led to a video-based intervention focused on teachers and peers at school and contained specific information that was perceived to be important to enhance self-management among adolescents with T1DM, and that was supported by the existing evidence base. However, the lack of available research specific to the effectiveness of peer knowledge about T1DM in school in particular meant evidence was sometimes drawn from the literature on peers' effectiveness in different community sites but not the school.

Despite these limitations, the study findings appear promising and pave the way for the importance of piloting the results of this study.

#### **5.22 Implications for Further Research**

This study points to some possibilities for further research. First, an essential source of support that emerged from the result was that of peers' support along with the teachers' support; however, there is no information on the views of peers themselves about their own roles and associated support needs to support someone with T1DM in school. Research in exploring the views of the school peers in this regard is needed.

Second, this study focused on the development of the school-based intervention; however, the researcher developed a plan that includes ideas in how this intervention can be implemented and evaluated. Programme implementation is the fifth step of the IMP. Developing an implementation plan will enable adaptation and implementation and maintenance of the designed health programme (Eldredge et al. 2016).

Step 5 focuses on planning the programme adoption and implementation. Normalisation process theory suggested some aspects to be considered during the implementation of a programme or an intervention (May et al. 2018). To establish leadership and support, key decision-makers regarding the adoption and implementation of health education programmes in schools should be contacted to gain their approval for the new programme. In addition, it needs to be ensured that key individuals within the school are able and willing to get others involved in the intervention and that the intervention is sufficiently supported by the hosting organisation. Staff training by reliable professionals has proven to be a successful implementation should have a clear understanding of the aim and objectives of the intervention so that they understand its value and benefits. Many implementation options can be adopted, for instance running a video-based intervention during school assembly or during tutor sessions or distributing it via school emails to all students and teachers.

The last step of IMP included the development of a plan to evaluate the intervention effectiveness and assess the quality of implementation (Eldredge et al. 2016). To conduct a process evaluation, important enhancers and barriers related to the implementation should be identified by the researcher. Therefore, it is necessary to conduct a pilot study. Pilot studies fulfil a range of essential functions and can provide valuable insights and obtain valuable information where modifications in the sampling

plan or data collection instruments can be introduced before the actual study (Polit and Hungler 1994).

The effectiveness of a video intervention can be tested using a cluster randomised controlled trial (pre-test and post-test design). Cluster randomised trials comprise the randomisation of groups of people, for example health system catchment areas or schools. They are generally used to evaluate non-drug interventions such as the delivery of interventions or the evaluation of policy (Eldridge and Kerry 2012). Random allocation is the most efficient and reliable approach to reducing confounding factors (Bryman 2016). This can be done by selecting a small cluster of schools, for example one school from each cluster selected by random sampling. Secondary schools will be invited to participate. Data can be gathered at four time points: baseline (T0), one week after the intervention (T1), three months post-baseline (T2), and six months after the intervention (T3). Teachers and students will be asked to fill in an online questionnaire in which four outcome measures will be studied, namely self-efficacy, knowledge, attitudes, and social influence, at the baseline time point.

Teachers' online questionnaire and peers' online questionnaires will be developed to investigate the changes in self-efficacy, knowledge, attitudes and social influence among school peers and school teachers. The preliminary questionnaires and tests have been developed by the researcher (see Appendix 19). Before using the preliminary questionnaires, their validity will be investigated using the cognitive interviewing method.

### 5.23 Personal Reflection

The process of undertaking this PhD has considerably impacted my thinking and my practice in many areas. It has given me confidence in exploring an area of practice in

depth; learning how to critically analyse all of the evidence, and synthesise the findings, to have an up to date and informed opinion on the subject. Also, I learned more about the policies and regulations that needed to be navigated, which could be time consuming without adequate preparation. This gave me an understanding of the need to promote working relationships with stakeholders within the health care field. For the future, such relationships would contribute in developing a various net system of support when involving with such studies.

This can be used both to provide information for my employer (Ministry of Health) in order to help them with decisions about school health in my country, but also in confident discourse with peers and colleagues. Furthermore, these skills have developed my ability to present evidence at network level, in order to have an impact on policy development locally, as I am a member of the Nursing and Midwifery Council in my country.

In terms of research practice, it has enhanced my knowledge of research methodology and principles, in particular, maximising rigour through a systematic approach to research design, data collection and analysis; acknowledging the effect of preconceived assumptions; the importance of listening to the adolescents' opinion and including their needs before developing any intervention – all of which aim to reduce sources of bias. For example, I now have more awareness of the impact of preconceived assumptions. Before conducting this study, I assumed that coping skills in school is the highest priority for adolescents with T1DM. This was based on my past reading and findings of the favourable effects of coping skills to enhance self-management among adolescents with T1DM outside the school setting. I did not expect that they would prefer for their teachers and peers to have more knowledge and understanding about specific aspects of T1DM.

Being an international student, it was a privilege to conduct this study in the UK. It was a great opportunity to learn about new cultures in the UK. I was especially struck by the generally supportive nature of the participants in giving their time to further this work. The semi-structured interviews with adolescents with T1DM allowed me to gain valuable experience and skills in interviewing adolescents with chronic disease. Also, it allowed adolescents to raise their issues of concern, acknowledging adolescents as experts on their own health needs.

During recruitment, I spent time in the assessment room where I got the chance to meet health care professionals from a diabetes clinic and learn more about the health system protocol regarding caring for children and adolescents with T1DM either in the hospital or outside the hospital.

### 5.24 Concluding Comments

This study aimed to develop a school-based intervention to promote self-management (physical and psychosocial health) among adolescents with T1DM aged 11–15 by exploring their needs and priorities of how they wanted to be supported in school. The aim was achieved, and well-informed evidence-based intervention was developed by actively incorporating the specific knowledge about T1DM that has been suggested by the adolescents and the wider literature review in this study. The relevance and appropriateness of the intervention's materials were verified in Stages 3 and 4 of this current study. This thesis also outlines the conceptualisation, design and development of an evidence-driven and theoretically-informed school-based intervention. The adolescents wanted an intervention that can enhance the knowledge and understanding of teachers and peers in school about T1DM. It is hoped this work has the potential to make a real difference to reduce some of the physical and psychosocial challenges
among adolescents with T1DM and accordingly help to enhance their self-management in school.

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## **APPENDICES**

### **Appendix 1: Interview guide**

### School-based Intervention to Enhance Self-Management among Adolescents with

### **Type 1 Diabetes Mellitus**

### **Interview guide**

Researcher: Raya Al Habsi Ethics number: 17/EE/0050

### Welcome

### Introductory remarks to explain the nature and purpose of the study.

- Introduce self to patient.
- Check patient demographics (name/age/duration of the disease/ mode of treatment (injection or pump).
- Explain purpose of study.
- Set ground rules regarding confidentiality.
- The researcher will not tell anyone what participants tell her unless she thinks someone might be hurt. If so, the researcher will talk to the participants and their parents first about the best thing to do.

### **General open-ended questions**

1. Tell me about how you manage all the things that you have to do as a result of your diabetes when you are at school?

### Probes to elicit more information

Things like managing insulin/pump, breaks, lunch, sport/PE/swimming etc.?

2. How do you take care of your diabetes while doing other activities at school?

### Probes to elicit more information

During physical activity or studying or going to school trips, or swimming? What makes it easier to fit it all in? What makes it harder? What happens? Can you give me some examples?

3. How do you feel about having to manage your diabetes at school?

#### Probes to elicit more information

Comfortable, easy, sad, angry, embarrassed, frustrated etc. How did you deal with that? What has led you to feel like that? Can you give examples of times when you have felt this way? Have any school staff/other children made you feel this way? What did they say/do to make you feel like that?

4. Is there anything you would like to see/feel could make your diabetic caring at school better in the future?

### Probes to elicit more information

In what ways these changes should happen? Such as be able to talk to someone in school, social media (apps, site or text messages) etc.? Would you like to tell me about that?

- 5. Do you have any ideas about things that teachers, classmate or nurses could do to make things better in school for pupils like you who have diabetes?
- 6. What would make the idea that you have mentioned better or easier to manage at school?
- 7. There are some good tips/skills that help kids with diabetes to care /feel better about caring of their diabetes, tips of how to solve problems, or how to change upsetting thoughts to feeling better thoughts... etc. Would you like to learn some of those tips? What would make those tips better or easier to use at school?

### Probes to elicit more information:

Can you explain more/ give me some examples?

e.g. talking to someone in school, social media (apps, site or text messages).

Thank you for your help

## **Appendix 2: Interview Guide (Health Care Professionals)**

### School-based Intervention to Enhance Self-Management among Adolescents with Type 1 Diabetes Mellitus

# Participant Interview Template (Participants-health professionals)

- 1. Introductory remarks to explain the nature and purpose of the study.
- 2. Set ground rules regarding confidentiality. The researcher will not tell anyone what participants tell her unless she thinks someone might be hurt. If so, the researcher will talk to the participants first about the best thing to do.

### 3. General open-ended question

The interview will contain two main questions:

- Are there any components included in the program, which you consider as irrelevant for this patient group? And if so, why do you consider these irrelevant?
- Are there any components missing from the program that you consider as relevant?
   And if so, why do you consider them relevant?

### 4. Use probes to elicit more information.

Would you like to tell me more about that?

5. Summarise the issues raised during the interview

We have gone through the components of the program and you have told me about those that you believe were the most relevant/important to adolescents with type1 Diabetes in school such as......

You told me about things that you thought were not at all important to adolescents with type1 Diabetes in school such as .....

Is there is anything else you wish to add?

Thank you for your help.

### **Appendix 3: Interview Guide for Follow-Up Stage**

### School-based Intervention to Enhance Self-Management among Adolescents with

**Type 1 Diabetes Mellitus** 

### Follow-up Interview guide

Researcher: Raya Al Habsi Ethics number: 17/EE/0050

### Welcome

### Introductory remarks to explain the nature and purpose of the study.

- Introduce self to patient.
- Explain purpose of study.
- Check patient demographics (name/age/duration of the disease/ mode of treatment (injection or pump).
- Set ground rules regarding confidentiality

### **Guiding questions**

1. What do you think about the overall presentation of the intervention?

### **Probes:**

- Tell me more about that.
- Describe that for me.
- What do others think about it?
- What are your thoughts on the content?
- What are your thoughts on how it looks (the format)?
- 2. What did you like best about each part?

### **Probes:**

• Tell me more about that.

- Describe that for me.
- What do others think about it?
- Give me an example.
- 3. What did you not like about each part?

### **Probes:**

- Tell me more about that.
- Describe that for me.
- What do others think about it?
- Give me an example.
- 4. What seems acceptable and usable?

### **Probes:**

- How is that?
- What do others think about it?
- 5. How easy or difficult is it to use its parts?
  - Please explain your response.
  - What do others think about it?
  - What else do you have to say about it?
- 6. How would you change it?
  - Are there ways that could have been introduced to make it easier/better for you?
  - More pictures/more or less information, colours, the title?
  - Who can add more to this idea?
  - Now let us hear some different thoughts.
- 7. Would you feel comfortable about using this intervention in school?
  - How would you make it easier to use/implement?

### **Concluding questions**

Of all the things we have discussed today, what would you say are the most important issues you would like to express about this intervention?

Is there anything I didn't ask that you'd like to discuss about this intervention?

### Thank you

### **Appendix 4: Collaboration Email from Paediatric Diabetic**

### Team

From: Davis, Nikki [mailto:<u>Nikki.Davis@uhs.nhs.uk</u>] Sent: 13 May 2016 14:35 To: Trevelyan, Nicola; Fall C.H.; Davies, Justin; Deamer, Susannah; Summerton Joanne (SOLENT NHS TRUST); Crouch, Gillian; 'Whiteside John (SOLENT NHS TRUST)'; Weeks, Rebecca; Hunt, Heloise Cc: Darlington A. Subject: RE: Diabetes research project looking at support in schools

Dear team

Dr Anne-Sophie Darlington is a contact I met from the university whilst developing computer games to support learning in adolescents with chronic disease. She has a new PhD student from Oman who is interested in how we can better support adolescents with T1DM in school eg use of social media, peer support, increased awareness in staff or other children etc (see email below). I think we would also be interested in the views of young people in this regard. They would like to meet the team and talk about accessing the views of our young people. My feeling is that this does not necessarily need full ethics if we are only collecting information we would use for service improvement eg PREM. Anne-Sophie may contact the team to come to a Thursday meeting while I am away for the next 3 weeks

BW

Nikki

------ Forwarded Message ------ From: Darlington A. <<u>A.Darlington@soton.ac.uk</u><mailto:<u>A.Darlington@soton.ac.uk</u>>> Cc: Rushforth H.E. <<u>her@soton.ac.uk</u><mailto:<u>her@soton.ac.uk</u>>>, AI Habsi R.S. <<u>rsah1g14@soton.ac.uk</u><mailto:<u>rsah1g14@soton.ac.uk</u>>> Date: Thursday, 28 April 2016, 00:18pm +01:00 Subject: FW: RE:

A reply for the Paediatrician:

We can discuss this when we next meet.

Anne-Sophie

From: Davis, Nikki [mailto:<u>Nikki.Davis@uhs.nhs.uk]</u> Sent: 28 April 2016 11:04 To: Darlington A. Subject: RE:

Hi there

She is welcome to come and invite our T1DM children to take part in a focus group or just talk to them as long as our team is around to support her and the patients. We run quite large clinics on most Thursdays and would be interested in this sort of information ourselves. Alternatively Diabetes UK would be a good place to start. Or she could try accessing some more vocal groups through there own social media platforms e.g. 'ninjabetic' on facebook is well known amongst our local youngsters I believe

BW

Nikki

### **Appendix 5: Invitation Letter**

## School-based Intervention to Enhance Self-Management among Adolescents with Type 1 Diabetes Mellitus

#### Invitation letter to adolescents/parents/guardians for the interview

Researcher: Raya Al Habsi Ethics number: 17/EE/0050

Dear adolescent/parent(s)/guardian(s),

I would like to invite you/ your child to take part in my research study.

I am currently a PhD student at the Faculty of Health Sciences at the University of Southampton. The purpose of the study is to gain information about needs, priorities and preferences of adolescents with Diabetes at school setting. Taking part of this study involves talking to me about what your child needs and preferences. The interview will take up to 20 minutes but no longer than 1 hour and could be conducted at the paediatric diabetic clinic at University Hospital Southampton or at your home (as you prefer). The information can then be used to develop a programme that can make self-care among adolescents with Diabetes better at school.

If you are interested in this study, please read the information sheet enclosed with this letter. This will help you to decide whether you would like your child to take part or not. If you would be happy for your child to participate in this study, please discuss it with your child and ensure that your child is happy to participate.

If your child would like to participate in this study, please provide your child's name, your phone number (parent's/guardian's number), your email and your address in the attached stamped, self-addressed envelope and return it to me. You will be given a minimum of 24 hours to consider the information and respond so I can contact you to arrange for an interview. If you have any questions, please do not hesitate to call me on 07752157341 or email me at: rsah1g14@soton.ac.uk. If you have any concerns or anxieties about participating in this study, please feel free to contact my supervisor: Dr Anne-Sophie Darlington, Associate Professor, Tel: +44(0) 23 8059 7888 or email: a.darlington@soton.ac.uk

<u>I hope you find this study interesting and thank you very much in advance for your</u> <u>cooperation.</u>

Yours sincerely,

Raya Said Al Habsi,

PhD student, Faculty of Health Sciences

University of Southampton, UK

Tel: 07752157341

Email: rsah1g14@soton.ac.uk

### **Appendix 6A: Parent/Guardian Information Sheet**

## School-based Intervention to Enhance Self-Management among Adolescents with Type 1 Diabetes Mellitus

### Parent/Guardian Information Sheet (Interview)

### Researcher: Raya Al Habsi (PhD student at UoS) Ethics number: 17/EE/0050

We would like to invite your child to take part in a research study to help us understand which issues are important to adolescents with type 1 Diabetes in school. The information will be used to design a programme to make self-care for adolescents with Diabetes in school better. Before you and your child decide, we would like you to understand why the study is being done and what it will involve. Take time to make the decision. The researcher will give you a minimum of 24 hours to decide.

### Does my child have to take part?

No, it is up to you and your child. If your child decides not to take part, this will not affect his/her care or treatment.

# What will happen if my child takes part?

Taking part involves your child talking to a researcher at the hospital or home about what they need and prefer to be done for them in school.

# Why do we want to know what issues are important to your child?

- To find out the issues that make diabetes self-care of adolescents easy or what makes it hard in school.
- To understand the needs and priorities of adolescents with Diabetes in a school setting.
- To find out what programme features might benefit the Diabetes self-care of adolescents in school.
- To find out what ways that adolescents with Diabetes would

247

prefer to help them make their Diabetes care in school better.

### Who can take part?

We are asking anyone with Diabetes who is between 11 and 15 years of age to take part, who can understand, speak and read English.

### How to contact us

If you have any questions, please contact **Raya Al Habsi**, the researcher of the study.

Tel: 07752157341

Email: rsah1g14@soton.ac.uk

### What happens next?

If you do not wish your child to take part, you do not need to do anything. If your child decides to take part, you will be asked to sign a *consent* form and your child will be asked to complete an assent form to check that he/she is happy to take part.

- We will arrange a time to meet your child when he/she is visiting the hospital (so you don't have to organise an extra visit). Or we will arrange a time to meet your child at home. You can choose a time that is convenient for you and your child. You can choose to be with your child during the interview.
- First, the researcher will ask your child a few questions about him/herself and will then be asked about what makes his/her self-care in school easy or difficult. He/she will also be asked about what changes he/she would like to see in school to make Diabetes care better. He/she will also be asked whether he/she would like to learn some skills/tips to help him/her better

handle his/her diabetes care in school.

- The study involves your child having a one-off chat with the researcher. There will be no followups and it is likely to take up to 45 minutes but no longer than 1 hour.
- With permission, the interview will be audio-recorded. The recorder can be stopped at any time. Once we have listened to the recording, it will be deleted and the anonymised transcriptions or notes will be retained.
- Access to your child's medical records will be purely for research audits.
- We hope that your child will find taking part in the research interesting but he/she is free to stop the interview at any time, and will not need to explain why

## Will my child's involvement in this study be kept confidential?

Yes, all information collected about your child during the course of the study will be kept strictly confidential. Some of what your child says during the interview may be taken as direct quotes and included in research reports or publications. These quotations will be completely anonymous, so no one will be able to tell the words came from your child. The researcher will not tell anyone what your child tells her unless she thinks someone might be hurt. If so, she will talk to you and your child first about the best thing to do.

# What are the possible risks of taking part?

Your child will be asked to think about things relating to self-care in school and what he/she needs and prefers to be done for him/her. Your child might find this upsetting. If your child becomes upset, we will stop the interview.

#### What are the benefits of taking part?

We cannot promise that this study will help your child personally. It is hoped that the

information will help us understand what is important to adolescents with diabetes in school. This will help us to design a programme that can make selfcare among adolescents with Diabetes better in school.

# What will happen to the results of the study?

The study results are likely to appear in the researcher's thesis, presentations and publications.

## Who is organising and funding this study?

The Chief Investigator for this study is Raya Al Habsi. The study is sponsored by the University of Southampton.

### Who has checked this study?

Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee (East of England – Cambridge East Research Ethics Committee).

What if there is a problem?

If you are unhappy with anything about this study, please let us know. If you have any concerns, you may also contact:

Patient Advice and Liaison Service Southampton General Hospital

**Tremona Road** 

Southampton, SO16 6YD

Tel: 23 8120 6325, Email:

patientsupportservices@uhs.nhs.uk

### Or

**Research Governance Office** 

**University of Southampton** 

Building 37, Room 4079

**University Road** 

Highfield

Southampton, S017 1BJ

Tel: 023 8059 5058

Email: Rgoinfo@soton.ac.uk

### **Appendix 6B: Participant Information Sheet**

School-based Intervention to Enhance Self-Management among Adolescents with Type 1 Diabetes Mellitus

### Participant Information Sheet (11–15-year-olds) (Interview)

We would like to invite you to take part in a research study to help us understand which issues are important to adolescents with type 1 Diabetes in school. The information will be used to design a programme to make self-care for adolescents with diabetes in school better. Before you and your parents decide, we would like you to understand why the study is being done and what it will involve. Take time to make the decision. The researcher will give you a minimum of 24 hours to decide.

### Do I have to take part?

No, it is up to you and your parent or guardian. If you choose not to take part, this will not affect your care or treatment.

# What will happen if I agree to take part?

Taking part involves talking to the researcher at the hospital or at home about what you need and would prefer to be done for you in school to make your Diabetes care better in school.

## Why do we want to know what issues are important to you?

 To find out the issues that make diabetes self-care of adolescents easy or what makes it hard in school.

2. To understand the needs and priorities of adolescents with Diabetes in a school setting.

2. To find out what programme features might help adolescents with Diabetes make their diabetes care in school better.

 To find out what ways that adolescents with Diabetes would prefer to help them make their Diabetes care in school better.

### Who can take part?

We are asking anyone with Diabetes between 11 and 15 years of age to take part, who can understand, speak and read English.

### How to contact us

If you have any questions, please contact **Raya Al Habsi**, the researcher of the study.

Tel: 07752157341

Email: rsah1g14@soton.ac.uk

### What happens next?

- If you do not want to take part, you do not need to do anything. If you choose to take part, your parent or guardian will be asked to sign a consent form and you will be asked to complete an *assent* form. By signing this form, you are saying that you are happy to take part.
- We will arrange a time to meet you when you are visiting the hospital (so you don't have to organise an extra visit). Or we will arrange a time to meet you at home. You can choose a time that is convenient for you and for your parent or guardian. You can choose to have someone with you in the interview.
- First, the researcher will ask you a few questions about yourself and you will then be asked about what makes your self-care in school easy or difficult. You will also be asked

about what changes you would like to see in school to make your diabetes care better. You will also be asked whether you would like to learn some skills/tips to help you to better handle your diabetes care in school.

- The study involves you having a one-off chat with the researcher.
   There will be no follow-ups and it is likely to take up to 20 minutes but no longer than 1 hour.
- With permission, the interview will be audio-recorded. The recorder can be stopped at any time. Once we have listened to the recording, it will be deleted and the anonymised transcriptions or notes will be retained.
- Access to your medical records will be purely for research audits.

We hope that you will find taking part in the research interesting but you are free to stop the interview at any time, and will not need to explain why

# Will my taking part in this study be kept confidential?

Yes, all information collected about you during the study will be kept strictly confidential. Some of what you say during the interview may be taken as direct quotes and included in reports or publications. These quotes will be completely anonymous, so no one will be able to tell the words came from you. The researcher will not tell anyone what you tell her unless she thinks someone might be hurt. If so, the researcher will talk to you and your parents first about the best thing to do.

# What are the possible risks of taking part?

You will be asked to think about things relating to self-care in school and what

you need and prefer to be done for you. Some people may find this upsetting. If you do become upset, we will stop the interview.

### What are the benefits of taking part?

We cannot promise that this study will help you personally. It is hoped that the information will help us understand what is important to adolescents with diabetes in school.

# What will happen to the results of the study?

The study results are likely to appear in the researcher's thesis, presentations and scientific journals.

# Who is organising and funding this study?

The Chief Investigator for this study is Raya Al Habsi. The study is sponsored by the University of Southampton.

### Who has checked this study?

Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee (East of England- Cambridge East Research Ethics Committee)

### What if there is a problem?

If you are unhappy with anything about this study, please let us know. If you have any concerns, you may also contact:

Patient Advice and Liaison Service

**Southampton General Hospital** 

**Tremona Road** 

Southampton, SO16 6YD

Tel: 023 8120 6325

Email:

patientsupportservices@uhs.nhs.uk

### Or

**Research Governance Office** 

University of Southampton

Building 37, Room 4079

**University Road** 

Highfield

Southampton, S017 1BJ

Tel: 023 8059 5058

Email: <u>Rgoinfo@soton.ac.uk</u>

### **Appendix 7: Parents/Guardian Consent Form**

## School-based Intervention to Enhance Self-Management among Adolescents with Type 1 Diabetes Mellitus

Researcher: Raya Al Habsi Ethics number: 17/EE/0050

Participant's study number

### **Consent form for parents/guardians**

You need to agree to all the points below if you want your child to take part in this study. Please put your initials in each box if you agree.

- I confirm that I have read and understood the information sheet version1 dated ---/-for this study and have had the opportunity to think about the information and ask questions, and that I am happy with the answers.
- I confirm that my child's participation in this study is voluntary and that he/she is free to leave the study at any time, without giving any reasons and without my child's medical care or legal rights being affected.
- I understand that relevant sections of my child's medical notes and data collected during the study may be looked at by individuals from the University of Southampton, or from the University Hospital Southampton NHS Foundation Trust. I give permission for those individuals to have access to my child's records.

- I understand that access to my child's medical records will be purely for research audits.
- I understand that any information or direct quotations used from this study in a report or publication will be completely anonymous and my child will not be able to be identified.
- I give permission for the interview to be audio-recorded

| I agree to my child    | (name) taking j | (name) taking part in this study |  |  |
|------------------------|-----------------|----------------------------------|--|--|
| Parent/guardian's name | Signature       | Date                             |  |  |
| Researcher's name      | Signature       | - Date                           |  |  |

### **Appendix 8: Response Card**

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School-based Intervention to Enhance Self-Management among Adolescents with Type 1 Diabetes Mellitus

Response card for the potential participant's answer

| Please complete the following and return this slip using the stamped, self-<br>addressed envelope. Your participation is very much appreciated. |
|-------------------------------------------------------------------------------------------------------------------------------------------------|
| I would like my child to participate in the study. (Please tick the box)                                                                        |
| My child name is                                                                                                                                |
|                                                                                                                                                 |
| My phone number is                                                                                                                              |
| My e-mail address is                                                                                                                            |
| My address is                                                                                                                                   |
| (Please list your child's name and your phone number and email so that I can                                                                    |

### **Appendix 9: Invitation Letter (Health Care Professionals)**

School-based intervention to enhance self-management among adolescents with Type 1 Diabetes.

### Invitation letter for health professionals

Researcher: Raya Al Habsi Ethics number: 17/EE/0050

Dear health professional(s),

I would like to invite you to take part in my research study

I am a PhD student at the Faculty of Health Sciences at the University of Southampton. I am interested in understanding how adolescents manage their Diabetes in school. The purpose of this study is to gain information about needs, priorities, and preferences of adolescents of type 1 diabetes in schools. This information will help to develop a schoolbased programme to enhance self-management among adolescents with type 1 diabetes in schools. Therefore, I would like to invite you to be interviewed (individually or within a group) to give your recommendation about the intended developed programme based on the findings from the study and your expert views.

If you would like to participate in this study, please email me at <u>rsah1g14@soton.ac.uk</u> or call/text me on 07752157341.

Thank you for taking the time to read this letter. If you have any questions, please do not hesitate to call me. If you have any concerns about the participation in this study, please feel free to contact my supervisor Dr Anne-Sophie Darlington, Associate Professor on Tel: +44(0) 23 8059 7888 or E-mail: a.darlington@soton.ac.uk

Yours sincerely,

Raya Said Al Habsi, PhD student

Faculty of Health Sciences

University of Southampton, UK

Tel: 07752157341

### Email: <u>rsah1g14@soton.ac.uk</u>

## Appendix 10: Information Sheet (Health Care Professionals)

School-based Intervention to Enhance Self-Management among Adolescents with Type 1 Diabetes Mellitus

part?

### Participant Information Sheet (Health Professionals Interview)

Researcher: Raya Al Habsi (PhD student) Ethics number: 17/EE/0050

We would like to invite you to take part in a research study to help us understand which issues are important to adolescents with type 1 diabetes mellitus in school. The information will be used to design a programme (intervention) to enhance self-management for adolescents with type 1 diabetes in school. Before you decide, we would like you to understand why the study is being done and what it will involve. Take time to make the decision. The researcher will give you a minimum of 24 hours to decide.

### Do I have to take part?

No, it is up to you.

Taking part involves talking to the researcher individually or within a group about your recommendation about the intended developed programme based on the study findings and your expert views. **Why do we want to know what issues are important to adolescents with diabetes?** 

What will happen if I agree to take

- To understand the needs and priorities of adolescents with type 1 Diabetes in a school setting.
- To find out what intervention features might help adolescents with type 1 Diabetes to make

their diabetes care in school better.

 To find out what intervention ways or approaches that adolescents with type 1 Diabetes would prefer to help them make their diabetes care in school better.

### Who can take part?

We are asking anyone who has experience of treating or supporting adolescents with type 1 diabetes.

### How to contact us

If you have any questions, please contact **Raya Al Habsi**, the researcher of the study.

Tel: 07752157341

Email: rsah1g14@soton.ac.uk

### What happens next?

- If you do not want to take part, you do not need to do anything. If you choose to take part, you will be asked to sign a consent form. By signing this form, you are saying that you are happy to take part.
- We will arrange a time to meet you in the hospital. You can choose a time that is convenient for you.
- First, the researcher will present a prototype of the program, which will be developed based on the study findings derived from patient interviews and the literature review.
- You will be asked about 1) the component included in the programme, which you consider irrelevant for this patient group and if so, why do you consider these irrelevant? And 2) are there any components missing

from the programme that you consider relevant and if so, why do you consider them relevant?

- You will be asked to comment and give your recommendation based on the study findings and your expert views.
- The study involves you having a one-off chat with the researcher.
  There will be no follow-ups and it is likely to take up to 45 minutes but no longer than 1 hour.
- With permission, the interview will be audio-recorded. The recorder can be stopped at any time. Once we have listened to the recording, it will be deleted and the anonymised transcriptions or notes will be retained.
- We hope that you will find taking part in the research interesting but

you are free to stop the interview at any time, and will not need to explain why.

# Will my taking part in this study be kept confidential?

Yes, all information collected about you during the study will be kept strictly confidential. However, confidentiality cannot be guaranteed if the interview been conducted as a group. If so, the researcher will address the group and ask each participant to maintain confidentiality of other participants in the group.

Some of what you say during the interview may be taken as direct quotes and included in reports or publications. These quotes will be completely anonymous, so no one will be able to tell the words came from you. The researcher will not tell anyone what you tell her unless she thinks someone might be hurt. If so, the researcher will talk to you first about the best thing to do. What are the possible risks of taking part?

What are the benefits of taking part?

No risk is anticipated.

We cannot promise that this study will help you personally. It is hoped that the information will help us to develop a programme to enhance self-management among adolescents with type 1 diabetes in school.

# What will happen to the results of the study?

The study results are likely to appear in the researcher's thesis, presentations and publications.

# Who is organising and funding this study?

The Chief Investigator for this study is Raya Al Habsi. The study is sponsored by the University of Southampton.

### Who has checked this study?

Before any research is allowed to happen, it has to be checked by a Research Ethics Committee (East of England – Cambridge East Research Ethics Committee).

### What if there is a problem?

If you are unhappy with anything about this study, please let us know. If you have any concerns, you may also contact:

Patient Advice and Liaison Service

**Southampton General Hospital** 

**Tremona Road** 

Southampton, SO16 6YD

Tel: 023 8120 6325 / Email:

patientsupportservices@uhs.nhs.uk

Or

**Research Governance Office** 

University of Southampton

Building 37, Room 4079

**University Road** 

Highfield

Southampton, S017 1BJ

Tel: 023 8059 5058

Email: Rgoinfo@soton.ac.uk

### **Appendix 11: Consent Form (Health Care Professionals)**

Study title: School-based Intervention to Enhance Self-Management among Adolescents with Type 1 Diabetes Mellitus

Researcher: Raya Al Habsi Ethics number: 17/EE/0050

Participant's study number

### **Consent form for health professionals**

## You need to agree to all the points below if you want to take part in this study. Please put your initials in each box if you agree.

- I confirm that I have read and understood the information sheet version1 dated --/--/-for this study and have had the opportunity to think about the information and ask questions, and that I am happy with the answers.
- I confirm that my participation in this study is voluntary and that he/she is free to leave the study at any time, without giving any reasons.
- I understand that data collected during the study may be looked at by individuals from the University of Southampton, or from the University Hospital Southampton NHS Foundation Trust.
- I understand that any information or direct quotations used from this study in a report or publication will be completely anonymous.

| • | I  | give p | ermission   | for the | interview | to be | audio-recorded |  |
|---|----|--------|-------------|---------|-----------|-------|----------------|--|
| - | τ. | 51 V P | CIIIISSIOII | ioi uit |           | 10 00 | uuulo recorded |  |

• I agree to take part in this study

Participant's name----- Date----- Date------

### **Appendix 12: Invitation Letter for Feedback Interview**

School-based Intervention to Enhance Self-Management among Adolescents with Type 1 Diabetes Mellitus

Invitation letter to adolescents/parents/guardians for feedback interview

Researcher: Raya Al Habsi Ethics number: 17/EE/0050

Dear adolescent/parent(s)/guardian(s)

I would like to invite you/ your child to take part in my research study.

I am currently a PhD student at the Faculty of Health Sciences at the University of Southampton. I am interested in understanding how adolescents manage their Diabetes in school. The purpose of the study is to develop a programme to make self-care among adolescents with Diabetes better at school. Taking part of this study involves talking to me about what is liked or disliked about the programme components, what seems acceptable, how easy or difficult it would be to use its components, and whether they feel it would be helpful. The interview will take up to 20 minutes but no longer than 1 hour and could be conducted at the paediatric diabetic clinic at University Hospital Southampton or at your home (as you prefer).

If you are interested in this study, please read the information sheet enclosed with this letter. This will help you to decide whether you would like your child to take part or not. If you would be happy for your child to participate in this study, please discuss it with your child and ensure that your child is happy to participate.

If your child would like to participate in this study, please provide your child's name, your phone number (parent's/ guardian's number), email and your address in the attached stamped, self-addressed envelope and return it to me. You will be given a minimum of 24 hours to consider the information and respond so I can contact you to arrange for an interview. If you have any questions, please do not hesitate to call me on 07752157341 or email me at: rsah1g14@soton.ac.uk.\_If you have any concerns or anxieties about participating in this study, please feel free to contact my supervisor: Dr Anne-Sophie Darlington, Associate Professor, Tel: +44(0) 23 8059 7888 or email: a.darlington@soton.ac.uk

I hope you find this study interesting and thank you very much in advance for your cooperation.

Yours sincerely,

Raya Said Al Habsi, PhD student Faculty of Health Sciences University of Southampton, UK Tel: 07752157341 Email: rsah1g14@soton.ac.uk

## Appendix 13A: Parent/Guardian Information Sheet (Feedback Interview)

## School-based Intervention to Enhance Self-Management among Adolescents

### with Type 1 Diabetes Mellitus

### Parent/Guardian Information Sheet (feedback interview)

Researcher: Raya Al Habsi Ethics number: 17/EE/0050

We would like to invite your child to take part in a research study to help us with the design of a programme about self-care for adolescents with type 1 Diabetes in school. Before you and your child decide, we would like you to understand why the study is being done and what it will involve. Take time to make the decision. The researcher will give you a minimum of 24 hours to decide.

### Does my child have to take part?

No, it is up to you and your child. If your child decides not to take part, this will not affect his/her care or treatment.

# What will happen if my child takes part?

Taking part involves your child talking to the researcher at the hospital or at home to talk about his/her opinion of the designed programme. The discussion will be organised by the researcher.

# Why do we want to know what you think of our programme?

- To find out how easy or difficult it would be to use the programme components in school.
- To find out what is good and what is to be improved about the programme.
- To find out if the programme needs to be changed to be more relevant for it to be used by

adolescents with Diabetes in school.

#### Who can take part?

We are asking anyone with Diabetes between 11 and 15 years of age to take part, who can understand, speak and read English.

### How to contact us

If you have any questions, please contact **Raya Al Habsi**, the researcher of the study.

Tel:07752157341

Email: rsah1g14@soton.ac.uk

#### What happens next?

If you do not wish your child to take part, you do not need to do anything. If your child decides to take part, you will be asked to sign a consent form and your child will be asked to complete an *assent* form to check that he/she is happy to take part.

- We will arrange a time to meet your child when he/she is visiting the hospital (so you don't have to organise an extra visit). Or we will arrange a time to meet your child at home. You can choose a time that is convenient for you and your child. You can choose to be with your child during the interview.
- First, the researcher will ask your child a few questions about him/herself. The researcher will then show and explain the programme to your child. The child will be asked about his/her opinion and understanding of the programme. The child will also be asked about what he/she like or dislike about every component of the programme. He/she will also be asked about how easy or difficult is it to use its components, if he/she feels comfortable using this

programme in school and what changes they suggest.

- The study involves your child having a one-off chat with the researcher. There will be no followups and it is likely to take up to 20 minutes but no longer than 1 hour.
- With permission, the interview will be audio-recorded. The recorder can be stopped at any time. Once we have listened to the recording, it will be deleted and the anonymised transcriptions or notes will be retained.
- Access to your child's medical records will be purely for research audits.
- We hope that your child will find taking part in the research interesting but he/she is free to stop

the interview at any time, and will not need to explain why.

# Will my child's involvement in this study be kept confidential?

Yes, all information collected about your child during the course of the study will be kept strictly confidential. Some of what your child says during the interview may be taken as direct quotes and included in research reports or publications. These quotes will be completely anonymous, so no one will be able to tell the words came from your child. The researcher will not tell anyone what your child tells her unless she thinks someone might be hurt. If so, she will talk to you and your child first about the best thing to do.

# What are the possible risks of taking part?

Your child will be asked to give his/her opinion about the programme. If your child becomes upset, he/she can leave the group.
#### What are the benefits of taking part?

We cannot promise that this study will help your child personally. It is hoped that the information will help us understand the programme that has been developed to enhance self-care among adolescents with Diabetes in school.

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

The study results are likely to appear in the researcher's thesis, presentations and scientific journals.

## Who is organising and funding this study?

The Chief Investigator for this study is Raya Al Habsi. The study is sponsored by the University of Southampton.

#### Who has checked this study?

Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee (East of England-Cambridge East Research Ethics Committee).

#### What if there is a problem?

If you are unhappy with anything about this study, please let us know. If you have any concerns, you may also contact:

Patient Advice and Liaison Service Southampton General Hospital Tremona Road Southampton, SO16 6YD 023 8120 6325 patientsupportservices@uhs.nhs.uk

#### Or

Research Governance Office University of Southampton Building 37, Room 4079 University Road Highfield Southampton, S017 1BJ Tel: 023 8059 5058 Email: Rgoinfo@soton.ac.uk

## Appendix 13B: Participant Information Sheet (Feedback Interview)

School-based Intervention to Enhance Self-Management among Adolescents with Type 1 Diabetes Mellitus

#### Participant Information Sheet (11–15-year-olds) (feedback interview)

| Do I have to take part?                  | 1. To find out how easy or difficult     |
|------------------------------------------|------------------------------------------|
| telephone or email in one day.           | are important to you?                    |
| a researcher can contact you by          | Why do we want to know what issues       |
| time to make the decision. If you wish,  | facilitated by the researcher.           |
| done and what it will involve. Take      | programme. The discussion will be        |
| to understand why the study is being     | talk about your opinion of the designed  |
| Before you decide, we would like you     | researcher at the hospital or at home to |
| diabetes mellitus better in school.      | Taking part involves talking to the      |
| make self-care for teenagers with type 1 | -                                        |
| programme that has been designed to      | part?                                    |
| understand more issues about a           | What will happen if I agree to take      |
| in a research study to help us to        | treatment.                               |
| We would like to invite you to take part | this will not affect your care or        |

Researcher: Raya Al Habsi Ethics number: 17/EE/0050

No, it is up to you and your parent or guardian. If you choose not to take part,

it is to use the programme in school.

- To find out what is good and what is to be improved about the designed programme.
- To find out if the designed programme needs to be changed to be more relevant for it to be used by teenagers with type 1 diabetes mellitus in school.

#### Who can take part?

We are asking anyone with type 1 diabetes mellitus between 11 and 15 years of age to take part, and who can understand, speak and read English.

#### How to contact us

If you have any questions, please contact **Raya Al Habsi**, the researcher of the study.

Tel: 02381947576/ 07752157341

Email: rsah1g14@soton.ac.uk

#### What happens next?

- If you do not want to take part, you do not need to do anything. If you choose to take part, your parent or guardian will be asked to sign a *consent* form and you will be asked to complete an *assent* form. By signing this form, you are saying that you are happy to take part.
- We will arrange a time to meet you when you are visiting the hospital (so you don't have to organise an extra visit). Or we will arrange a time to meet you at home. You can choose a time that is convenient for you and for your parent or guardian. You can choose to have someone with you in the interview.
- First, the researcher will show and explain the programme to you. Then you will be asked about your opinion and understanding of the developed programme. You will

also be asked about what you like or dislike about every part of the programme. You will also be asked about how easy or difficult is it to use the parts, if you feel comfortable using this programme in school and what changes you suggest.

- The study involves you having a one-off chat with the researcher.
  There will be no follow-ups and it is likely to take up to 20 minutes but no longer than 1 hour.
- With permission, the interview will be audio-recorded. The recorder can be stopped at any time. Once we have listened to the recording, it will be deleted.
- We hope that you will find taking part in the research interesting but you are free to stop the interview at any time, and will not need to explain why.

## Will my involvement in this study be kept confidential?

Yes, all information collected about you during the study will be kept strictly confidential. Some of what you say during the interview may be taken as direct quotes and included in reports or publications. These quotes will be completely anonymous, so no one will be able to tell the words came from you. **What are the possible risks of taking part?** 

You will be asked to give your opinion about the designed programme. Some people may find this upsetting. If you do become upset, you are free to leave the group.

#### What are the benefits of taking part?

We cannot promise that this study will help you personally. It is hoped that the information will help us understand the designed programme that has been made to make diabetes self-care among

273

teenagers with type 1 diabetes mellitus better in school.

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

The study results are likely to appear in the researcher's thesis, presentations and publications.

## Who is organising and funding this study?

The Chief Investigator for this study is Raya Al Habsi. The study is sponsored by the University of Southampton.

#### Who has checked this study?

Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee.

#### What if there is a problem?

If you are unhappy with anything about this study, please let us know. If you have any concerns, you may also contact:

#### Patient Advice and Liaison Service

**Southampton General Hospital Tremona Road** Southampton, SO16 6YD Tel: 023 8120 6325 **Email:** patientsupportservices@uhs.nhs.uk Or **Research Governance Office** University of Southampton Building 37, Room 4079 **University Road** Highfield Southampton, S017 1BJ Tel: 023 8059 5058 E-mail: Rgoinfo@soton.ac.uk

## **Appendix 14: Participants' Assent Form**

### School-based Intervention to Enhance Self-Management among Adolescents

### with Type 1 Diabetes Mellitus

Researcher: Raya Al Habsi Ethics number: 17/EE/0050

Participant's study number

### Participants' (11-15 years of age) Assent Form

### Please circle the answer you agree with:

| • Have you been given the information sheet for this study?       | Yes/ No |
|-------------------------------------------------------------------|---------|
| • Has someone explained this study to you?                        | Yes/ No |
| • Do you understand what this study is about?                     | Yes/ No |
| • Have you asked all the questions you want?                      | Yes/No  |
| • Do you understand that it's OK to stop taking part at any time? | Yes/ No |
| • Do you understand that our discussion will be recorded?         | Yes/ No |
| • Do you understand that quotations (the exact words) you use in  |         |
| our discussion may be used in publications and presentations by   |         |
| the research team but that no one will be able to tell the words  |         |
| came from you?                                                    | Yes/No  |
| • Are you happy to take part?                                     | Yes/ No |

If any of your answers are 'NO' and you don't want to take part, please don't sign your name. If you want to take part, please sign your name and add today's date:

| Print name: |
|-------------|
| Signature:  |
| Date:       |

The researcher who explained this study also needs to sign:

| Print name: |
|-------------|
| Signature:  |
| Date:       |

# Appendix 15 (coding frames of interview data for stage 1, 3 & 4)

Qualitative thematic analysis

This section is showing how different codes were sorted into themes in the study stages (1,3&4)

## Coding frames of interview data

First stage (exploratory stage): interviews with Adolescents with T1DM

Theme 1. Adolescents' ability to depend on themselves in managing their diabetes in school.

- a) Understand how to do their daily diabetes tasks
- b) Able to check their blood sugar
- c) Able to adjust insulin dosage
- d) Administer insulin injections
- e) Counting carbohydrates.

Theme 2. Challenges in managing T1DM in the school setting.

- a) Physical challenges associated with blood sugar fluctuation:
  - Shacking
  - General weakness
  - Agitation
  - thirst
- b) Psychological challenges associated with blood sugar fluctuation:
  - Lack of motivation
  - Lack of concentration
  - Mood swing

- Frustration
- Feeling Different
- c) Social challenges:
  - Embarrassment due to carrying diabetes tasks
  - Bullying
  - Uneasy being around peers

Theme 3. Peers and teachers improve their knowledge and understanding of T1DM.

- Peers to know more about T1DM
- Teachers to know more T1DM

Theme 4. Improved knowledge and understanding of T1DM can enhance self – management by:

- Becoming more comfortable and less hesitant to perform diabetes tasks if they know more about T1DM
- Feeling more secured during emergencies such as hypoglycaemia
- Avoid unnecessary conflict caused by fluctuation of blood sugar
- To be reminded to test blood sugar if behaviour changed.
- Allow more space to perform the diabetes tasks and not to be bombarded with many questions (if they know more about T1DM)
- Feeling less awkward using insulin injections in front of others
- Less frustration and distribution if they eat in the class to treat hypoglycaemia
- Correcting the misconception about the causes of T1DM l lead to less frustration

- Less bullying about carrying the diabetes bag
- Correcting the misconception about insulin pump lead to more understanding
- Knowing about the differences between T1DM and T2DM lead to a better understanding of the tasks
- Verbal, emotional support from teachers
- Less repeating (to teachers) about having diabetes over and over
- Teachers to keep a register to know about their students with diabetes
- Avoid unnecessary delay in treating hypoglycaemia
- Provide better support during PE lesson
- Better adjustment of insulin dosage

Table below concluded the suggested knowledge (as obtained from theme 4) for peers and teachers to be included in the intervention:

Suggested information to be included in the intended intervention.

| Theme                   | Suggested knowledge to be    |
|-------------------------|------------------------------|
|                         | included in the intervention |
| Becoming more           | information about T1DM       |
| comfortable and less    |                              |
| hesitant to perform     |                              |
| diabetes tasks (if they |                              |
| know more about         |                              |
| T1DM)                   |                              |
|                         |                              |
|                         |                              |
| Feeling more secured    | information about signs and  |
| during emergencies      | symptoms of hypoglycaemia to |
| such as hypoglycaemia   | act in an emergency          |
|                         |                              |
|                         |                              |

|                          | 1                               |
|--------------------------|---------------------------------|
| Avoid unnecessary        | Knowing that Fluctuation of     |
| conflict caused by       | blood sugar can cause mood      |
| fluctuation of blood     | swing                           |
| sugar                    |                                 |
| To be reminded to test   | Knowing to remind someone       |
| blood sugar if           | with diabetes if behaviour      |
| behaviour changed.       | changed.                        |
|                          |                                 |
| Allow more space to      | information about T1DM          |
| perform the diabetes     |                                 |
| tasks and not to be      |                                 |
| bombarded with many      |                                 |
| questions (if they know  |                                 |
| more about T1DM)         |                                 |
| Feeling less awkward     | Information about insulin pens  |
| using insulin injections |                                 |
| in front of others       |                                 |
| Less frustration and     | Information about the need to   |
| distribution if they eat | eat in the class                |
| in the class to treat    |                                 |
| hypoglycaemia            |                                 |
|                          |                                 |
| Correcting the           | Information about the causes of |
| misconception about      | T1DM                            |
| the causes of T1DM l     |                                 |
| lead to less frustration |                                 |
| Less bullying about      | Information about the           |
| carrying the diabetes    | importance of carrying the      |
| bag                      | diabetes bag                    |
| Correcting the           | Information about insulin pump  |
| misconception about      |                                 |
| insulin pump lead to     |                                 |
| more understanding       |                                 |
|                          |                                 |

| Knowing about the       | information about the             |
|-------------------------|-----------------------------------|
| differences between     | differences between T1DM and      |
| T1DM and T2DM lead      | T2DM                              |
| to better understanding |                                   |
| of the tasks            |                                   |
| Emotional support       | Knowing that teachers can give    |
| from teachers           | emotional support                 |
|                         | ·····                             |
| Less frustration of     | Knowing about a student with      |
| repeating (to teachers) | diabetes in the class will help a |
| about having diabetes   | student with T1DM not to          |
| over and over           | repeat about themselves over      |
|                         | and over                          |
| Taaahars to keep a      | Information about teachers to     |
| reachers to keep a      | Information about teachers to     |
| register to know about  | keep a register for students with |
| their students with     | diabetes                          |
| diabetes                |                                   |
| Avoid unnecessary       | Information about how             |
| delay of treating       | hypoglycaemia should be           |
| hypoglycaemia           | treated immediately               |
|                         |                                   |
|                         |                                   |
| Provide better support  | Information about how PE          |
| during PE lesson        | teachers can support a student    |
|                         | with T1DM during PE lesson        |
|                         | T. C                              |
| Better adjustment of    | Information about the             |
| insulin dosage          | importance of providing           |
|                         | nutritional information           |

Theme 5. Approaches to informing peers and teachers about T1DM

- Enrichment day
- Tutor session
- Tasks and quizzes
- PowerPoint
- Short video

Theme 6. Willingness to learn problem-solving and coping tips/skills

- Interest to learn coping skills
- Help to feel relax
- To feel calm down
- Feel positive about being someone with diabetes
- Solving problems without unnecessary panic

Theme 7. Approaches to learning coping tips.

- One to one training
- Group training
- Laminated cards with pictures
- Readable material.

## Qualitative thematic analysis

## Coding frames of interview data

Third stage: interviews with Healthcare professionals.

Theme 1. Acceptance of the intervention regarding the format of delivery by expressing positive attitudes about the format.

- Style good and brilliant
- Format of the video is good
- Drawings and the pictures catch attention
- The sound of the narrator explaining the content of the video is good.
- The short duration of the video.

Theme 2. Acceptance of the intervention regarding relevancy.

- Contents of the video are relevant
- The appropriate level of information is included and needed to support someone with diabetes.

### Theme 3. The most helpful parts of the video.

- The differences between type 1 and type 2
- Stating the signs and symptom of hypoglycaemia
- Reminding someone with T1DM to check blood sugar gently.

Theme 4. The desire of healthcare professionals to use the video during educational school tours.

- The video is very professional and can be useful.
- They explained that they could send it to teachers via email, so teachers can have an idea
- We can show them during the educational visit to educate about T1DM

Theme 5. Suggestion for modifications

a) Reduce the speed of the narration of the information and add more pauses.

- b) Add more information about insulin pump
- c) change some medical words to informal words
- d) Specify how much is low sugar with number
- e) Change the term food contains carbohydrate to fast-acting sugar.
- f) Remove low-fat milk as treatment of hypoglycaemia
- g) Remove information about the ordinary injection
- h) Remove the information about adjusting the insulin dosage before the exercise.
- i) Add "hyperglycaemia can happen because of the illness".
- j) Add that "treatment of hyperglycaemia should include not only taking more fluid but having an extra dosage of insulin".
- k) Change the term diabetic to someone with diabetes.
- Add that "fluctuation of blood glucose level can happen even if someone with T1DM does everything right".
- m) Add that "to understand the differences in the preferences of where to manage diabetes tasks among students with T1DM".

## Qualitative thematic analysis

## Coding frames of interview data

**Fourth Stage:** interviews with a new group of adolescents with T1DM to get their feedback of the appropriateness and acceptance of the intervention.

Theme 1. Acceptance of appropriateness of the information

• The information included in the video covers everything about T1DM that is needed to help someone with diabetes in school.

Theme 2. Acceptance of the format

- Whiteboard animation video is more interesting than the video with real character.
- Whiteboard animation video makes the information easy to understand.
- Better than the video with the real character which can be boring.

Theme 3. Simple and enjoyable

- The video is simple
- Friends can enjoy
- Friends can understand it.

Theme 4. Appropriate speed and appropriate background music

- The speed of the video was just appropriate
- Not fast.
- The background music is not very load, calming and not distracting.

Theme 5. Appropriate length

- The length of the video appropriate and not too long.
- The audience may get distracted if they watched a long video.
- •

## Theme 6. Easy language

- The language used in the video is easy
- Understandable.

## Theme 7. Most liked parts

- Differences between type 1 and 2
- Respect the preferences of students with T1DM
- o Information about blood sugar monitoring
- Information about insulin pump
- Information about having a register about students with T1DM
- Information about diabetes bag
- Information about PE teachers to ensure the level of blood sugar before, during and after exercise.
- Information about eating in class
- Information about specifying the range of low blood sugar

Theme 8. Things to add:

• T1DM is not contagious

Theme 9. Usability of the video:

Video can be used during tutor session

Initial thematic mapping for first stage (exploratory stage): interviews with Adolescents with T1DM



Final thematic mapping for first stage (exploratory stage): interviews with Adolescents with T1DM







Suggestion for modifications

- Reduce the speed of the narration of the information and add more pauses.
- Add more information about insulin pump
- change some medical words to informal words
- Specify how much is low sugar with number
- Change the term food contains carbohydrate to fastacting sugar.
- Remove low-fat milk as treatment of hypoglycaemia
- Remove information about the ordinary injection
- Remove the information about adjusting the insulin dosage before the exercise.
- Add "hyperglycaemia can happen because of the illness".
- Add that "treatment of hyperglycaemia should include not only taking more fluid but having an extra dosage of insulin".
- Change the term diabetic to someone with diabetes.
- Add that "fluctuation of blood glucose level can happen even if someone with T1DM does everything right".
- Add that "to understand the differences in the preferences of where to manage diabetes tasks among students with T1DM".



## **Appendix 16: Demographic Data Information Sheet**

School-based Intervention to Improve Self-Management among Adolescents with Type 1 Diabetes Mellitus.

Demographic information of the participants

**Participant Code:** 

## **Demographic factors:**

Age: -----

Gender: -----

Ethnicity: -----

### Who does the participant live with?

a) Both parents and siblings. ()

b) Both parents, siblings and other relatives (e.g. grandmother). ( )

c) Father and other relatives (e.g. siblings, grandmother). ()

- d) Mother and other relatives (e.g. siblings, grandmother). ()
- e) Other .....

#### **Disease-related characteristics:**

Age at onset of disease: -----

Type of therapy: insulin injection ----- insulin pump -----

### What are the types of insulin used?

- a) Rapid-acting insulin. ()
- b) Short-acting insulin. ( )
- c) Intermediate or medium-acting insulin. ( )
- d) Long-acting insulin. ( )
- e) Short-acting and intermediate-acting insulin. ()
- f) Other (please state) .....

#### How many insulin injections are prescribed a day?

- a) One per day ()
- b) Two per day ()
- c) Three per day ()
- d) Four per day ()
- e) Other ( )

## **Appendix 17: HRA Approval Letter**



Email: hra.approval@nhs.net

Ms Raya Al Habsi Ministry of Health Sultanate of Oman

20 February 2017

Dear Ms Al Habsi

**IRAS project ID:** 

**REC** reference:

Letter of <u>HRA Approval</u>

Study title:

Sponsor

School-based Intervention to Enhance Self-Management among Adolescents with Type 1 Diabetes Mellitus 210934 17/EE/0050 University of Southampton

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

#### Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

*Appendix B* provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read** *Appendix B* **carefully**, in particular the following sections:

- Participating NHS organisations in England this clarifies the types of participating
  organisations in the study and whether or not all organisations will be undertaking the same
  activities
- Confirmation of capacity and capability this confirms whether or not each type of participating
  NHS organisation in England is expected to give formal confirmation of capacity and capability.
  Where formal confirmation is not expected, the section also provides details on the time limit
  given to participating organisations to opt out of the study, or request additional time, before
  their participation is assumed.
- Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Page 1 of 8

#### Appendices

The HRA Approval letter contains the following appendices:

- A List of documents reviewed during HRA assessment
- B Summary of HRA assessment

#### After HRA Approval

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

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

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

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as
  detailed in the After Ethical Review document. Non-substantial amendments should be
  submitted for review by the HRA using the form provided on the <u>HRA website</u>, and emailed to
  hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the <u>HRA website</u>.

#### Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

#### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at <u>hra.approval@nhs.net</u>. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

#### **HRA** Training

Page 2 of 8

|                                     |                                                                                       | IRAS project ID         | 210934     |
|-------------------------------------|---------------------------------------------------------------------------------------|-------------------------|------------|
| We are plea<br>details at <u>ht</u> | ased to welcome researchers and research managem<br>tp://www.hra.nhs.uk/hra-training/ | ent staff at our traini | ing days – |
| Your IRAS                           | project ID is 210934. Please quote this on all correspo                               | ondence.                |            |
| Yours since                         | erely                                                                                 |                         |            |
| Miss Laure                          | n Allen                                                                               |                         |            |
| Assessor                            |                                                                                       |                         |            |
| Email: hra.a                        | approval@nhs.net                                                                      |                         |            |
| Copy to:                            | Mrs Diana Galpin (Sponsor contact)                                                    |                         |            |
|                                     | Miss Jennifer Peach, Trust management offices (Le                                     | ad NHS R&D conta        | act)       |
|                                     |                                                                                       |                         |            |
|                                     |                                                                                       |                         |            |
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|                                     |                                                                                       |                         |            |
|                                     |                                                                                       |                         |            |

#### Appendix A - List of Documents

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

| Document                                                               | Version | Date              |
|------------------------------------------------------------------------|---------|-------------------|
| Interview schedules or topic guides for participants [Interview guide] | 1.0     | 19 October 2016   |
| Interview schedules or topic guides for participants [Focus group      |         |                   |
| IRAS Application Form [IRAS_Form_23012017]                             |         | 23 January 2017   |
| Letter from funder [Funding Confirmation]                              |         | 05 August 2014    |
| Other [DBS certificate]                                                |         |                   |
| Other [University Hospital Southampton R&D letter]                     |         | 02 September 2016 |
| Other [Response card]                                                  |         |                   |
| Other [Supervisor's CV]                                                |         |                   |
| Other [Collaboration Email]                                            |         |                   |
| Other [Consent form for Health professionals]                          |         |                   |
| Other [indemnity (amended)]                                            |         |                   |
| Other [Indemnity]                                                      |         | 6                 |
| Other [2nd supervisor's CV]                                            |         |                   |
| Other [Focus group interview guide V2.0]                               | 2.0     |                   |
| Other [Health professional invitation letter]                          | 2.0     |                   |
| Other [Interview guide (Health professionals)]                         | 2.0     |                   |
| Other [Interview guide V2.0]                                           | 2.0     |                   |
| Other [Invitation letter for focus group V2.0]                         | 2.0     |                   |
| Other [Invitation letter for interview V2.0]                           | 2.0     |                   |
| Other [Parent information sheet (interview) V3.0]                      | 3.0     |                   |
| Other [Parent's consent form V2.0]                                     | 2.0     |                   |
| Other [Parent-guardian information sheet (Focus group) V3.0]           | 3.0     |                   |
| Other [Participant Assent form V2.0]                                   | 2.0     |                   |
| Other [PIS (Focus Group) V3.0]                                         | 3.0     |                   |
| Other [PIS (Health professional) ]                                     | 2.0     |                   |
| Other [PIS (Interview) V3.0]                                           | 3.0     |                   |
| Other [Changes outline]                                                |         | 12 February 2017  |
| Participant consent form [Parent's consent form]                       | 1.0     | 19 October 2016   |
| Research protocol or project proposal [Research protocol]              |         |                   |
| Summary CV for Chief Investigator (CI) [Chief investigator CV]         |         | 03 December 2016  |
|                                                                        |         |                   |

Page 4 of 8

#### Appendix B - Summary of HRA Assessment

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

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Mrs Diana Galpin Tel: 02380595058 Email: rgoinfo@soton.ac.uk

#### **HRA** assessment criteria

| Section | HRA Assessment Criteria                                                   | Compliant with<br>Standards | Comments                                                                                                                                                |
|---------|---------------------------------------------------------------------------|-----------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1.1     | IRAS application completed<br>correctly                                   | Yes                         | No comments                                                                                                                                             |
| 2.1     | Participant information/consent<br>documents and consent<br>process       | Yes                         | No comments                                                                                                                                             |
| 3.1     | Protocol assessment                                                       | Yes                         | No comments                                                                                                                                             |
| 4.1     | Allocation of responsibilities<br>and rights are agreed and<br>documented | Yes                         | No study agreements are required as<br>this is a single NHS site study where<br>the single NHS site's partner University<br>is the study sponsor.       |
| 4.2     | Insurance/indemnity<br>arrangements assessed                              | Yes                         | Where applicable, independent<br>contractors (e.g. General Practitioners)<br>should ensure that the professional<br>indemnity provided by their medical |

Page 5 of 8

| Section | HRA Assessment Criteria                                                                  | Compliant with<br>Standards | Comments                                                                                  |
|---------|------------------------------------------------------------------------------------------|-----------------------------|-------------------------------------------------------------------------------------------|
|         |                                                                                          |                             | defence organisation covers the<br>activities expected of them for this<br>research study |
| 4.3     | Financial arrangements<br>assessed                                                       | Yes                         | No comments                                                                               |
| 5.1     | Compliance with the Data<br>Protection Act and data<br>security issues assessed          | Yes                         | No comments                                                                               |
| 5.2     | CTIMPS – Arrangements for<br>compliance with the Clinical<br>Trials Regulations assessed | Not Applicable              | No comments                                                                               |
| 5.3     | Compliance with any<br>applicable laws or regulations                                    | Yes                         | No comments                                                                               |
| 6.1     | NHS Research Ethics<br>Committee favourable opinion<br>received for applicable studies   | Yes                         | No comments                                                                               |
| 6.2     | CTIMPS – Clinical Trials<br>Authorisation (CTA) letter<br>received                       | Not Applicable              | No comments                                                                               |
| 6.3     | Devices – MHRA notice of no<br>objection received                                        | Not Applicable              | No comments                                                                               |
| 6.4     | Other regulatory approvals<br>and authorisations received                                | Not Applicable              | No comments                                                                               |

#### Participating NHS Organisations in England

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

There is one site type. This is a non-commercial single site study where the single site's partner University is the study sponsor.

If this study is subsequently extended to other NHS organisation(s) in England, an amendment should be submitted to the HRA, with a Statement of Activities and Schedule of Events for the newly participating NHS organisation(s) in England.

The Chief Investigator or sponsor should share relevant study documents with participating NHS

Page 6 of 8

organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at <u>hra.approval@nhs.net</u>. The HRA will work with these organisations to achieve a consistent approach to information provision.

#### **Confirmation of Capacity and Capability**

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

This is a non-commercial single site study taking place in the NHS where the single site's partner University is the study sponsor. The participating NHS organisation will therefore be expected to formally confirm their capacity and capability to host this research according to local requirements.

 Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capacity will be confirmed is detailed in the Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) section of this appendix.

The <u>Assessing</u>, <u>Arranging</u>, <u>and Confirming</u> document on the HRA website provides further information for sponsors and NHS organisations on assessing, arranging and confirming capacity and capability.

#### Principal Investigator Suitability

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

A Local Collaborator should be identified at the site to facilitate access arrangements for the external research team where needed and assist with recruitment of participants.

GCP training is not a generic training expectation, in line with the <u>HRA statement on training</u> expectations.

#### **HR Good Practice Resource Pack Expectations**

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

External staff (e.g. University) will be expected to obtain Letters of Access to conduct study activity at the site which involves direct contact with patient participants or is conducted in patient care areas of

Page 7 of 8

| IRAS project ID 210934 | IRAS project | tID | 210934 |
|------------------------|--------------|-----|--------|
|------------------------|--------------|-----|--------|

the site. Letters of Access will need to confirm enhanced Disclosure and Barring Service checks and Occupational Health clearance.

#### Other Information to Aid Study Set-up

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

 The applicant has indicated that they <u>do not intend</u> to apply for inclusion on the NIHR CRN Portfolio.

## **Appendix 18: Letter of Agreement**

|                               |                                   | NHS                                                                              |
|-------------------------------|-----------------------------------|----------------------------------------------------------------------------------|
|                               |                                   | NHS Foundation Trust                                                             |
|                               |                                   | Clinical Governance<br>R&D Department                                            |
|                               |                                   | Mikayala.King@uhs.nhs.uk<br>Tel: +44-(0)23 8120 8689<br>Fax: +44-(0)23 8120 8678 |
| To whom it may concern,       |                                   | 2 <sup>nd</sup> September 2016                                                   |
|                               |                                   |                                                                                  |
| Please take this letter as co | firmation that, when is the       | e only NHS site involved in studies                                              |
| either sponsored by, or invo  | ving                              | , a                                                                              |
| Statement of Activities and S | schedule of Events will not be re | equired.                                                                         |
|                               |                                   |                                                                                  |
| There exists a high level agr | eement between the Trust and      | the University which sets out the                                                |
| way in which joint studies ar | e managed.                        |                                                                                  |

Yours Faithfully

Dr Mikayala King Research Governance and Quality Assurance Manager

## **Appendix 19: Preliminary questionnaires**

| Centre: |                                |
|---------|--------------------------------|
| Title:  | The attitudes change for peers |

|     |                                                                                                                         | strongly<br>agree | agree | uncertain/<br>not | disagree | strongly<br>disagree |
|-----|-------------------------------------------------------------------------------------------------------------------------|-------------------|-------|-------------------|----------|----------------------|
| 1.  | I feel it is important to know the differences between type 1 diabetes<br>and type 2 diabetes                           |                   |       |                   |          |                      |
| 2.  | I feel it is important to understand the cause of type 1 diabetes                                                       |                   |       |                   |          |                      |
| 3.  | I feel it is important to recognize symptoms of low blood sugar.                                                        |                   |       |                   |          |                      |
| 4.  | I am interested to help someone with symptoms of low blood sugar                                                        |                   |       |                   |          |                      |
| 5.  | I feel it is important to know that blood sugar can goes up and down for no reason sometimes                            |                   |       |                   |          |                      |
| 6.  | I feel it is important to know that changes in blood sugar can cause<br>changes in the mood with someone with diabetes. |                   |       |                   |          |                      |
| 7.  | I feel it is important to know signs and symptom of high blood sugar                                                    |                   |       |                   |          |                      |
| 8.  | I am interested to know about insulin pump and insulin pens                                                             |                   |       |                   |          |                      |
| 9.  | I feel it is important to help someone with diabetes to take care of his diabetes bag and not to through it around      |                   |       |                   |          |                      |
| 10. | I feel it is important to know why someone with diabetes has to eat in class sometime.                                  |                   |       |                   |          |                      |
|     |                                                                                                                         |                   |       |                   |          |                      |
|     |                                                                                                                         |                   |       |                   |          |                      |
|     |                                                                                                                         |                   |       |                   |          |                      |
|     |                                                                                                                         |                   |       |                   |          |                      |
|     |                                                                                                                         |                   |       |                   |          |                      |

| Centre: |                               |   |
|---------|-------------------------------|---|
| Title:  | Attitudes change for teachers | ] |

|     |                                                                                                                       | strongly<br>agree | agree     | uncertain/<br>not | applicable<br>disagree | strongly<br>disagree |
|-----|-----------------------------------------------------------------------------------------------------------------------|-------------------|-----------|-------------------|------------------------|----------------------|
| 1.  | I feel it is important to know the differences between type 1 diabetes<br>and type 2 diabetes                         |                   |           |                   |                        |                      |
| 2.  | I feel it is important to understand the cause of type 1 diabetes                                                     |                   |           |                   |                        |                      |
| 3.  | I feel it is important to recognize symptoms of low blood sugar.                                                      |                   | $\square$ | $\square$         |                        |                      |
| 4.  | I am interested to help someone with symptoms of low blood sugar                                                      |                   |           |                   |                        |                      |
| 5.  | I feel it is important to know that blood sugar can goes up and down for no reason sometimes                          |                   |           |                   |                        |                      |
| 6.  | I feel it is important to know that changes in blood sugar can cause changes in the mood of a student with diabetes.  |                   |           |                   |                        |                      |
| 7.  | I feel it is important to know signs and symptom of high blood sugar                                                  |                   |           |                   |                        |                      |
| 8.  | I am interested to know about insulin pump and insulin pens                                                           |                   |           |                   |                        |                      |
| 9.  | I feel it is important to know why a student with diabetes has to eat in class sometime.                              |                   |           |                   |                        |                      |
| 10. | I feel it is important to allow a student with diabetes to choose where<br>they like to perform their diabetes tasks. |                   |           |                   |                        |                      |
| 11. | I like to keep a record of students with diabetes so I can always remember their individual needs.                    |                   |           |                   |                        |                      |
| 12. | I like to give emotional support to students with diabetes.                                                           |                   |           |                   |                        |                      |
| 13. | I feel it is important to remind student with diabetes to check their blood sugar before, during and after sport.     |                   |           |                   |                        |                      |
|     |                                                                                                                       |                   |           |                   |                        |                      |
|     |                                                                                                                       |                   |           |                   |                        |                      |

| Centre: |                                   | Enquiry No: |  |
|---------|-----------------------------------|-------------|--|
| Title:  | Self-efficacy change for teachers |             |  |

|     |                                                                                                                                             | strongly<br>agree | agree | uncertain/<br>not | applicable<br>disagree | strongly<br>disagree |
|-----|---------------------------------------------------------------------------------------------------------------------------------------------|-------------------|-------|-------------------|------------------------|----------------------|
| 1.  | I am confident in my ability to differentiate between type 1 diabetes and type 2 diabetes                                                   |                   |       |                   |                        |                      |
| 2.  | I am confident in my understanding of the causes of type 1 diabetes                                                                         |                   |       |                   |                        |                      |
| 3.  | I am confident in my ability in recognising low blood sugar symptoms in students with diabetes                                              |                   |       |                   |                        |                      |
| 4.  | I am confident in my ability to help a student with diabetes with symptoms of low blood sugar                                               |                   |       |                   |                        |                      |
| 5.  | I am confident in my understanding that blood sugar can go up and down for no reason sometimes                                              |                   |       |                   |                        |                      |
| 6.  | I am confident in my understanding that changes in blood sugar<br>can cause changes in the mood with someone with diabetes.                 |                   |       |                   |                        |                      |
| 7.  | I am confident in my ability in recognising symptoms of high blood sugar                                                                    |                   |       |                   |                        |                      |
| 8.  | I am confident in my understanding about insulin pump and insulin pens.                                                                     |                   |       |                   |                        |                      |
| 9.  | I am confident in my understanding of why students with diabetes need to eat a snack in the class sometimes                                 |                   |       |                   |                        |                      |
| 10. | I am confident in my understanding of why to allow a student<br>with diabetes to choose where they like to perform their diabetes<br>tasks. |                   |       |                   |                        |                      |
| 11. | I am confident of my ability to keep records about the students<br>with diabetes so I can always remember their individual needs.           |                   |       |                   |                        |                      |
| 12. | I am confident of my ability to give emotional support.                                                                                     |                   |       |                   |                        |                      |
| 13. | I am confident of my ability to remind students with diabetes to check their blood sugar before, during and after sports activities.        |                   |       |                   |                        |                      |
|     |                                                                                                                                             | 1                 |       |                   |                        |                      |

| Centre: | Enquiry No:                    |
|---------|--------------------------------|
| Title:  | Self-efficacy change for peers |
|         |                                |

|    |                                                                                                                               | strongly<br>agree | agree | uncertain/<br>not | applicable<br>disagree | strongly<br>disagree |
|----|-------------------------------------------------------------------------------------------------------------------------------|-------------------|-------|-------------------|------------------------|----------------------|
| 1. | I feel confident in my ability to differentiate between type 1 diabetes and type 2 diabetes                                   |                   |       |                   |                        |                      |
| 2. | I feel confident in my understanding of the causes of type 1 diabetes                                                         |                   |       |                   |                        |                      |
| 3. | I feel confident in my ability in recognising low blood sugar symptoms in students with diabetes                              |                   |       |                   |                        |                      |
| 4. | I feel confident in my ability to help a student with diabetes with symptoms of low blood sugar                               |                   |       |                   |                        |                      |
| 5. | I feel confident in my understanding that blood sugar can go up<br>and down for no reason sometimes                           |                   |       |                   |                        |                      |
| 6. | I feel confident in my understanding that changes in blood sugar<br>can cause changes in the mood with someone with diabetes. |                   |       |                   |                        |                      |
| 7. | I feel confident in my ability in recognising symptoms of high blood sugar s                                                  |                   |       |                   |                        |                      |
| 8. | I feel confident in my understanding about insulin pump and insulin pens.                                                     |                   |       |                   |                        |                      |
| 9. | I feel confident in my understanding of the importance of carrying diabetes bag                                               |                   |       |                   |                        |                      |
| 10 | . I feel confident in my understanding of why students with diabetes need to eat a snack in the class sometimes               |                   |       |                   |                        |                      |
|    |                                                                                                                               |                   |       |                   |                        |                      |
|    |                                                                                                                               |                   |       |                   |                        |                      |
|    |                                                                                                                               |                   |       |                   |                        |                      |
|    |                                                                                                                               |                   |       |                   |                        |                      |
|    |                                                                                                                               |                   |       |                   |                        |                      |

| Centre: |                            |
|---------|----------------------------|
| Title:  | Social influence for peers |
|         |                            |

|     |                                                                                                                                                                                                                                                  | strongly<br>agree | agree | uncertain/<br>not<br>applicable | disagree | strongly<br>disagree |
|-----|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------|-------|---------------------------------|----------|----------------------|
| 1.  | I am happy to show concerns by knowing more about T1DM even if others do not show                                                                                                                                                                |                   |       |                                 |          |                      |
| 2.  | I will not annoy students with diabetes by repeating that they have diabetes because they eat too much sweet or they are overweight. Even if others do.                                                                                          |                   |       |                                 |          |                      |
| 3.  | I will be interested to recognise someone with symptoms of low blood sugar even if others do not do.                                                                                                                                             |                   |       |                                 |          |                      |
| 4.  | I will support and act properly if someone develops low blood sugar, even if others do not support                                                                                                                                               |                   |       |                                 |          |                      |
| 5.  | I will support someone with blood sugar changes without judging his self-<br>management of his diabetes even if others do.                                                                                                                       |                   |       |                                 |          |                      |
| 6.  | I would not be angry if the mood of a student with diabetes changed suddenly.<br>Instead, I will remind them to check their blood sugar gently. Even if others do<br>get angry and don't remind student with diabetes to check their blood sugar |                   |       |                                 |          |                      |
| 7.  | I will be interested to recognise symptoms of high blood sugar even if others do not show interest.                                                                                                                                              |                   |       |                                 |          |                      |
| 8.  | I will not stare when a student with diabetes take an insulin injection or check<br>blood sugar instead I will give more space and don't ask many questions. Even<br>if others stare and ask so many questions.                                  |                   |       |                                 |          |                      |
| 9.  | I will not be not confused about insulin pump to think its MP3 or iPod. Even if others got confused.                                                                                                                                             |                   |       |                                 |          |                      |
| 10. | I will not bully student with diabetes and throw their bags around even if others do.                                                                                                                                                            |                   |       |                                 |          |                      |
| 11. | I would not be surprised if a student with diabetes has to eat in the class sometimes even if others were surprised.                                                                                                                             |                   |       |                                 |          |                      |
|     |                                                                                                                                                                                                                                                  |                   |       |                                 |          |                      |
|     |                                                                                                                                                                                                                                                  |                   |       |                                 |          |                      |
|     |                                                                                                                                                                                                                                                  |                   |       |                                 |          |                      |
|     |                                                                                                                                                                                                                                                  |                   |       |                                 |          |                      |
|     |                                                                                                                                                                                                                                                  |                   |       |                                 |          |                      |
| Centre: |                               |  |
|---------|-------------------------------|--|
| Title:  | Social influence for teachers |  |

Please complete the following questionnaire with specific regard to the above enquiry, by placing a CROSS (X) in the appropriate box

|   |          |                                                                                                                                                                                                                                                            | strongly<br>agree | agree | uncertain/<br>not<br>applicable | disagree | strongly<br>disagree |
|---|----------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------|-------|---------------------------------|----------|----------------------|
|   | 1.       | I am happy to show concerns by knowing more about T1DM even if others do not show                                                                                                                                                                          |                   |       |                                 |          |                      |
|   | 2.       | I will be interested to recognise someone with symptoms of low blood sugar even if others do not do.                                                                                                                                                       |                   |       |                                 |          |                      |
|   | 3.       | I will support and act properly if someone develops low blood sugar, even if others do not support                                                                                                                                                         |                   |       |                                 |          |                      |
|   | 4.       | I will support someone with blood sugar changes without judging his self-<br>management of his diabetes even if others do.                                                                                                                                 |                   |       |                                 |          |                      |
|   | 5.       | I would not be angry if the mood of a student with diabetes changed suddenly.<br>Instead, I will remind them to check their blood sugar gently. Even if others do<br>get angry and don't remind student with diabetes to check their blood sugar           |                   |       |                                 |          |                      |
|   | 6.       | I will be more flexible and understand if students with symptoms of high blood<br>sugar wanted to go to the toilet more frequently or need to drink more fluid or<br>take an extra dosage of insulin. Even if other teachers do not show<br>understanding. |                   |       |                                 |          |                      |
|   | 7.       | I will not be not confused about insulin pump to think its MP3 or iPod. Even if other got confused.                                                                                                                                                        |                   |       |                                 |          |                      |
|   |          |                                                                                                                                                                                                                                                            |                   |       |                                 |          |                      |
|   | 8.<br>9. | I would be flexible if a student with low blood sugar wanted to eat in the class.<br>I will not ask the student with diabetes to spit the food from the mouth if I see                                                                                     |                   |       |                                 |          |                      |
|   |          | them eating in the class sometimes even if others do.                                                                                                                                                                                                      |                   |       |                                 |          |                      |
|   | 10.      | I will encourage students with diabetes to choose where to perform their diabetes task even if others do not encourage that.                                                                                                                               |                   |       |                                 |          |                      |
|   | 11.      | I would keep records of students with diabetes so I can remember their individual needs even if others did not keep a record.                                                                                                                              |                   |       |                                 |          |                      |
|   | 12.      | I will give emotional support to students with diabetes even if others do not give.                                                                                                                                                                        |                   |       |                                 |          |                      |
|   | 13.      | I will encourage students with diabetes to check blood sugar before, during and after sport even if other teachers PE teachers do not encourage that.                                                                                                      |                   |       |                                 |          |                      |
| L |          |                                                                                                                                                                                                                                                            |                   |       |                                 |          |                      |

## A knowledge test for teachers

- 1. Diabetes is
  - a) Temporary health condition
  - b) Permanent health condition
  - c) Semi-permanent health condition
- 2. Insulin is produced by the
  - a) Liver
  - b) Heart
  - c) Pancreas
- 3. Insulin helps to
  - a) Move sugars out of the blood to the cell
  - b) Move the blood cells
  - c) Remove the sugars out of the body

## 4. There are two main types of diabetes

- a) Type 1 diabetes and type 2 diabetes
- b) Gestational diabetes and monogenic diabetes
- c) Chemical-induced diabetes and disease of pancreases
- 5. Type 2 diabetes is
  - a) Exactly the same as type 1 diabetes
  - b) Similar to type diabetes
  - c) Completely different than type 1 diabetes
- 6. Type 1 diabetes happens because
  - a) Overweight
  - b) The body cannot make insulin at all
  - c) Eating too many sweets
- 7. How can someone with T1DM take insulin
  - a) Insulin pens or insulin pumps
  - b) Insulin pens only
  - c) Insulin pumps only

- 8. Insulin pens include
  - a) Only a knob to measure insulin
  - b) A knob to measure insulin and a one-use needle
  - c) Only a one-use needle
- 9. What is an insulin pump
  - a) Pills that can be taken
  - b) Same as insulin pens
  - c) A device that continuously injects insulin
- 10. Diabetic tasks involve
  - a) Checking blood sugar by using blood sugar meter
  - b) Administration of insulin using insulin pens or insulin pump
  - c) All of the above
- 11. What causes hypoglycaemia?
  - a) Taking insulin more than needed
  - b) Not taking enough insulin
  - c) Having too much sugar
- 12. Which of these are not symptoms of hypoglycaemia?
  - a) Feeling shaky, sweating, being nervous
  - b) Getting angry, going pale, having headaches
  - c) Feeling energetic, calm, being bored
- 13. How do you treat someone with hypoglycaemia?
  - a)  $\frac{1}{2}$  cup of non-diet soft drink
  - b) Glucose tablets or fruit juice
  - c) Any of the above
- 14. What is hyperglycaemia?
  - a) Low blood sugar
  - b) High blood sugar
  - c) Stress

- 15. What causes hyperglycaemia?
  - a) stress
  - b) Feeling unwell
  - c) All of the above
- 16. What are the signs of hyperglycaemia?
  - a) Blurred vision and frequent peeing
  - b) Increased thirst
  - c) Weakness and headache
  - d) All of the above
- 17. High blood sugar can be treated by
  - a) Drinking lots of sugar-free liquids and taking extra insulin
  - b) Taking extra insulin only
  - c) Drinking lots of sugar-free liquids only
- 18. A diabetes medication bag contains:
  - a) Medication
  - b) Equipment
  - c) All of the above
- 19. A student with diabetes has to eat in class some time to treat low blood sugar
  - a) True
  - b) false
- 20. type 1 diabetes can cause mood changes
  - a) true
  - b) false
- 21. what to do if a student with diabetes got angry
  - a) to be angry from them
  - b) start a conflict
  - c) Ask them to check their blood sugar gently
- 22. If you find someone with diabetes unconscious
  - a) Try to weak him up
  - b) Give insulin
  - c) Call 999

- 23. Physical education teachers should remind students with diabetes to check their blood sugar:
  - a) During class
  - b) After class
  - c) Before, during and after class
- 24. Students with diabetes can take their medication or check their blood sugar
  - a) In class only
  - b) In medical rooms only
  - c) Wherever they wish/prefer

## **Knowledge test for peers**

- 1. Diabetes is
  - a) Temporary health condition
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- 3. Insulin is produced by the
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- 19. A diabetes medication bag contains:
  - a) Medication
  - b) Equipment
  - c) All of the above

- 20. Student with diabetes has to eat in class some time to treat low blood sugar
  - a) True
  - b) false
- 21. type 1 diabetes can cause mood changes
  - a) true
  - b) false

## 22. what to do if student with diabetes got angry

- a) be angry
- b) start conflict
- c) Ask them to check their blood sugar gently
- 23. If you find someone with diabetes unconscious
  - a) Try to weak him up
  - b) Give insulin
  - c) Call 999