# Designing, Developing and Evaluating an Age-appropriate Digital Educational Tool for Younger Children with Type-1 Diabetes

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## Previously Published Work

Research in this thesis has been published at the following venues, using only the parts of these papers that are directly attributable to the author:

- Charalampos Kyfonidis and Marilyn Lennon. 2019. Making Diabetes Education Interactive: Tangible Educational Toys for Children with Type-1 Diabetes. In Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems (CHI '19). Association for Computing Machinery, New York, NY, USA, Paper 441, 1–12. DOI: `https://doi.org/10.1145/3290605.3300671`
- Charalampos Kyfonidis. 2017. Tangible Educational Toys for Children with Type-1 Diabetes. In Proceedings of the 2017 CHI Conference Extended Abstracts on Human Factors in Computing Systems (CHI EA '17). Association for Computing Machinery, New York, NY, USA, 291–296. DOI: `https://doi.org/10.1145/3027063.3027139`
- Charalampos Kyfonidis and Marilyn Lennon. 2016. Mummy, Why Do I Have Diabetes? A Tangible Interface For Educating Children With Type-1 Diabetes. In Proceedings of the 15th International Conference on Interaction Design and Children (IDC '16). Association for Computing Machinery, New York, NY, USA, 524–528. DOI: `https://doi.org/10.1145/2930674.2935979`

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# Abstract

Younger children (under 9 years old) with type-1 diabetes are often very passive in the management of their condition and can face difficulties in accessing basic information about their condition. This can make transitioning to self-management in later years very challenging. Previous research has mostly focused on educational interventions for older children who have literacy skills. In order to create an educational tool that can effectively support the education of younger children with diabetes and be feasible for adoption in the local context, we conducted a multi-phase and multi-stakeholder human-centred design process. The process entailed a review of the relevant literature, in-context qualitative enquiries for requirements gathering, an iterative design process with stakeholder participation, multiple prototyping and evaluation stages, development and a final large-scale evaluation. The result of this process is an interactive digital tool that illustrates diabetes concepts in an age-appropriate way with the use of tangible toys as input devices. The tool was evaluated in-context with children, parents and clinicians against the stakeholders' requirements. The results showed the effectiveness of the tool in enabling clinicians to convey the educational message in a fun, age-appropriate and memorable way. The results also informed about the feasibility of the tool to be adopted in standard practice. This thesis illustrates in detail the aforementioned process and its results and also syntheses the findings in order to inform more generally the design and development of other educational tools for younger children with complex educational needs.

# Chapter 1

# Introduction

## 1.1 Motivation

In 2015 the number of children having type-1 diabetes globally exceeded, for the first time, half a million [72]. In the UK there are about 31,500 children with type-1 diabetes and a total expenditure by the NHS for type-1 diabetes of £1.802 billion (children and adults) [85]. Moreover, the UK has the world's fifth-highest rate for children up to 14 years old diagnosed with type-1 diabetes [72]. All those children, living with diabetes, can experience psychological disturbance [151] and periods of struggling to cope with the condition [63], due to the intensity of diabetes management.

Type-1 Diabetes (T1D) is a serious long-term condition whose management is continuous and requires decision making by balancing several factors [63]. Due to the high risk of serious consequences, the management of younger children's diabetes is solely the parents' responsibility [150]. Hence, most current diabetes educational programs for a younger age group (9 years and younger) target their parents [97, 161]. Children learn about their condition informally, mostly through their parents, and often with the use of age-inappropriate materials [103]. Moreover, they are often discouraged from taking initiatives in the management process [97], a fact that does not allow them to put into practice any education they have received and subsequently does not prepare them adequately for the transition to essential self-management practices in later years [133]. Without the appropriate education and skills, children entering a state of autonomy (like adolescence) are unable to effectively manage diabetes [133, 158]. As a consequence they can have serious long-term health complications [173].

To date most educational materials for T1D are focused on self-management, target older children (usually 9 and older) and require literacy skills. This approach is not suitable for younger children who have limited or no literacy skills [102] and who do not solely manage their condition. The lack of age-appropriate educational materials for T1D creates a burden on those responsible for younger children's education, as they cannot easily and effectively convey T1D educational messages to children.

## 1.2 Project Outline

This research aimed to provide a viable solution to the lack of age-appropriate educational materials for children with T1D, through the use interactive technology. We explored a T1D ecosystem through a multi-stakeholder and multi-phased human-centred process. In sum 8 clinicians, 1 national T1D coordinator, 27 parents and 21 children were involved in the different stages of the process and their input guided the design of an educational tool. Based on a series of interviews, focus groups, observations and co-design sessions in the clinical setting we extended the current educational approach of plastic food toys for nutrition education by making them interactive.

The outcome is an educational tool which uses tangible food toys as input devices. Children use the tangible food toys to feed and provide insulin to a virtual diabetic character. The virtual character gives them feedback about their choices. This tool illustrates diabetes concepts in an age-appropriate way and helps clinicians to tailor T1D education to the individual. The tool provides a way for children to test their preconceptions without putting themselves at risk.

The tool was evaluated inside a paediatric diabetes clinic with 17 children, their parents and 4 clinicians. The educational sessions in which the tool was evaluated were co-designed with clinicians in order to meet the educational targets of the clinic. The tool was assessed through observations; questionnaires to the children about its acceptance and enjoyment; interviews with parents and clinicians about its perceived educational effectiveness and its appropriateness.

This work has implications for the design of interactive tools that can support the education of children with complex information needs. We also reflect on the challenges of designing in a clinical context for a vulnerable user group. This work can inform the broader Human-Computer Interaction (HCI) community about the holistic co-design approach in the field and the importance of designing tools that fit into current clinical work practices.

## 1.3 Research Aim

The overall aim of this doctoral project is to design, develop and test an age-appropriate digital tool which can effectively support the education of younger children with T1D and can actually be adopted by the educational practice in diabetes clinics for young children.

This is done through a human-centred design process with multiple stages of input from the different stakeholders in order to be based on the needs and requirements of the T1D ecosystem without perturbing it.

## 1.4 Main Contributions

1. With respect to understanding the current educational practices for children with T1D, this thesis presents an in-depth contextual analysis of a series of qualitative enquiry stages

with multiple stakeholders linked to the education of children with T1D. The results identified the current challenges faced by the different stakeholders and how these challenges are related to the health system's approach to diabetes education. These results are presented in Chapters 4 and 5. Also, the aforementioned results were further analysed in order to identify the needs and requirements for an age-appropriate T1D educational tool. These needs and requirements are presented in Chapter 6.

2. A novel interactive prototype tool (see Section 7.3.4, page 105), is shown to be effective in supporting younger children's T1D education (see Chapter 8, page 112). The tool proposes a viable solution for the in-clinic education of younger children and is designed to be easily replicated and rapidly manufactured. Moreover, the tool has the potential to support a formal T1D curriculum as an effective and age-appropriate medium.

3. A digitally supported educational session and supporting materials were co-designed with clinicians. These assets were designed to be used alongside the tool as the basis for diabetes education. These assets are presented in Section 7.4 on page 107.

4. In regards to methodology, this thesis presents a complete and effective case study of Human-Centred Design (HCD) in the clinical context. The greater HCI community can be informed about the adaptation of the HCD principals for a complex context with different stakeholders and many limitations. This contribution is set out mainly in Chapter 3, where the methodology is presented.

## 1.5 Research Question

According to the research aim, this thesis is trying to answer the following research question (RQ):

> **RQØ: Is an interactive -digital- educational tool for younger children with T1D, developed through a HCD process, a viable solution that could effectively support the educational practice?**

# Chapter 2

# Background Research

## 2.1 Introduction

The purpose of this chapter is to give the reader a general understanding of the topics related to this thesis. To that end, this chapter presents a non-exhaustive review on the topics of children's diabetes, educational tools and design of interactive tools. Many of the presented theories and approaches about educational tools were not directly used in this thesis. However, because all of them have similarities and/or they build one upon the other, they are presented in order to help the reader understand the importance of educational tools and the different perspectives on how tools can be used in children's education. The theories used in this thesis (*Zone of Proximal Development* in Section 2.3.5 and *Activity Theory* in Section 2.3.6) have not been used in their entirety or exclusively. Because these theories are not analytical tools or methodologies [81], but rather descriptive tools [115], they are used at different stages of the thesis to either explain the current educational context or to deepen the discussion on the findings.

## 2.2 Children with Type 1 Diabetes

### 2.2.1 Type 1 Diabetes Management

Diabetes mellitus type 1, or Type-1 diabetes (T1D), is an autoimmune condition where the immune system attacks the pancreas and destroys the beta cells (produced by the pancreas). Without the beta cells, the body cannot produce insulin. Insulin is a hormone that enables the cells to absorb glucose. Glucose is the main source of energy for our bodies; it is produced when carbohydrates are broken down during digestion and is transferred to cells through the blood. With a lack of insulin, the body cannot function properly, since it cannot absorb the energy necessary to survive.

The main goal of T1D management is to achieve the restoration, as much as possible, of the carbohydrates' metabolism to a normal state. However, this process is constant and requires frequent management steps and adjustments, including blood glucose monitoring (even during the night), insulin dose calculations, insulin provision (via injection or pump) and carbohydrate counting. Apart from its continuous demand T1D management is also a very complicated and laborious procedure which requires decision making by balancing several factors (e.g. food intake, exercise, insulin type), some of which are unpredictable [63]. If not properly managed, T1D can give rise to very serious short and long-term health complications, such as heart disease, stroke, foot and circulation problems, sight problems and blindness, pain and loss of feeling (nerve damage), kidney problems and even mortality [106].

The seriousness of the condition and the complexity of its management make T1D impossible for younger children (under 9) to manage alone [150]. Children at a younger age do not have the cognitive skills to deal with such an advanced task and their parents have to take the responsibility of doing so [132]. Children's T1D needs to be effectively managed in order for them to safely participate in everyday activities like other children [53, 108]. Poor management can negatively impact the health and well-being of the child and increase the financial costs to the health system [147].

### 2.2.2 Transition to self-management

Proper management of children's T1D by their parents is essential for the child's health and well-being but it does not guarantee that the child will get the appropriate skills to manage the condition alone. The transition to a state of self-management, when a child enters a stage of independence such as adolescence, is very important [147]. Children need to have the appropriate skills in order to manage their condition when they are entering a state of autonomy [174]. Hence, exposure to management through age/developmental-appropriate education is of paramount importance [147].

Children should be part of their condition management from as young as 5 years old [113]. However, due to complex socio-cultural factors, children have limited meaningful engagement with the management of their condition and generally with their care [113]. As a consequence children end up having serious gaps in knowledge and misconceptions about their condition which prevents them from smoothly entering self-management [147]. As a result, a considerable number of children sooner or later face serious irreversible health complications.

### 2.2.3 Importance of T1D Education

T1D education is the practice that can give the knowledge and understanding to the children and their family [160] and thus it is very important [27, 57, 71, 103, 161]. Children with T1D need to understand their condition in order to later be able to deal with everyday challenges and thus enjoy physical health and emotional well-being [161].

T1D education should start from a very young age [97], even when there is no clear or directly measurable clinical improvement from this education [91]. This education has to be continuous and must start from day 1 of diagnosis [161].

### 2.2.4 Challenges with T1D Education

The ability of children to understand and manage T1D depends on their developmental stage [78,147]. The developmental stages of children are not strictly bound to age [78] and are heavily influenced by experience [108]. Hence, different children with T1D develop management skills and understanding at different times and at different levels [147]. These facts make children's T1D education a difficult task.

Because young children's diabetes is managed by their parents, most of the currently available educational programs target parents [97, 161]. Moreover, the educational resources are often not age-appropriate for younger children (those under 9 years) [161]. As a consequence children do not always receive formal diabetes education and their parents have to become the lead educators [161].

Even paediatric clinics with formal diabetes educational programmes face difficulties in educating younger children. Clinicians may have available educational guidelines on how to educate children about the condition but it is usually not clear how these can be applied as they do not provide practical advice [64, 107]. Martin et al. [103] evaluated how existing T1D education guidelines were implemented in 14 paediatric diabetes centres in the EU. They found that parents and children are educated with the same materials and that this approach does not work for every child.

### 2.2.5 Recommendations for T1D Education

T1D education should be delivered through age-appropriate materials and media, by taking into account the child's age and maturity [71]. Written materials, which are passive by nature, are not easily understood by younger children [30]. For example, Tsvyatkova et al. [161] present the example of an illustrated book for diabetes education which was found to be "too general and does not seem to speak the language of the user". Interactive learning has been shown to be more suitable for young patients [91] who can get bored easily if education is lacking fun and interaction [7]. Apart from being age-appropriate, diabetes education also to be tailored to the individual to be most effective [97, 147, 160]. The international diabetes federation points out that "Diabetes education needs to be learner-centred and thus be adaptable to suit individual needs" [71].

Another key element to diabetes education is the clinician responsible for educating the child [97]. Education should be through someone who is experienced and expert in diabetes management [71]. Diabetes educators are very good at providing tailored education [27] which takes into account the personality, the social and the behavioural characteristics of the child [38]. However, diabetes educators have to be motivated to encourage better adherence to management [91].

## 2.3 Educational Tools

The impact of concrete educational tools for children has long being studied, even from the nineteenth century. Throughout this period many educational theories and approaches about the use of tools in education have been proposed. The way children create mental models and the way they assign meaning to actions and concepts is gradual. Children start by automating processes which gradually enter them to the symbolic level and eventually enable them to create mental models [100]. Through these mental models, children can assign different meanings to objects, things and beings [100]. The focus on the symbolic level accompanied with the idea that young children construct knowledge through physical interactions with the world (*hands-on activities* with tools) has long being studied, even from the early 1800s.

The following sub-sections outlines in chronological order some of the most influential theories and approaches to children's knowledge construction through the use of tools. The focus of this presentation is to illustrate the importance of concrete educational tools and the role of the educator in the process.

### 2.3.1 Pestalozzi's pedagogy

Pestalozzi (1746-1827) was the first pedagogist to point out the advantages of hands-on activity and learning by doing; he stated that "things should go before words and concrete before abstract" [126]. His doctrines emphasised that children should proceed to new knowledge by combining familiar things, through a gradual progression from observation to comprehension and to formation of clear ideas [149]. In his pedagogy the developmental stage of the child should be taken into consideration; the younger the children are, the more concrete, tangible and immediate education should be [26].

### 2.3.2 Fröbel's gifts

Pestalozzi's disciple, Fröbel (1782-1852), extended his mentor's ideas, organised them and created his own pedagogy [33]. Fröbel recognised the child's desire to play as nature's way to stimulate the brain to grow; hence, his approach was centred on self-activity and play [25]. In order to provide the right tools that empower children to explore and create meaningful connections, he created a set of tangible educational toys, called "Fröbel Gifts" [55] (Figure 2.1). These gifts are divided into 10 sets, each one for a different age group; *gifts 1* to *6* are solids, *gift 7* contains surfaces, *gift 8* consists of lines, *gift 9* contains points and *gift 10* is a framework for creating solids. These gifts encourage children to explore the world through design, by allowing them to freely build real-world objects and structures [180].

Apart from the mere use of the gifts, Fröbel also stressed the importance of the adult's role in the child's play with these gifts; adults should support children's play and join in appropriately [95] without invading and taking over the children's learning [159]. This kind of play promotes close relationships between adults and children and helps adults gain insight into the children's thinking and understanding. Even though play is a central to Fröbel's approach, the availability of the *gifts* or other educational resources alone is not enough. Novel and meaningful experiences need to be planned carefully by the educator in order for the children to extend their understanding between the outer world of new experiences and the inner world of ideas and feelings [159].

Figure 2.1: A reproduction set of Fröbel gifts. Image source: wikimedia.org[1]

### 2.3.3 Montessori's materials

A similar approach was developed by Montessori (1870-1952). She created a set of modelling materials/toys (Figure 2.2), with the difference that they focus on modelling conceptual and abstract structures [109]. These toys encourage limited exploration as they have a predetermined way in which they can be used, in order to make abstract concepts more salient [180]. Many of Montessori's materials were initially developed by Edouard Seguin for mentally disabled children and were adapted by Montessori [96].

Similarly to Fröbel, Montessori's pedagogy sees the child as an active agent of the environment and the adults as the facilitators of the child's education. She stressed the importance of an accessible environment that provides a wide range of accessible activities, in which children can move freely and find what they need to "satisfy their inner drive" [110]. This "inner need" was conceived by Montessori as the main motive for learning that children develop when they are situated in properly constructed learning environment [17].

Hence, she believed that children can reach their potential in a developmentally appropriate environment, where adults add, complement or develop educational materials according to the individual child's needs [76]. So the adult is seen more as a facilitator for the exploration and not so much as an instructor. Teacher-directed lessons for the introduction of new concepts are recognised as necessary but not as important as the discovery leaning [17].

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[1] `https://upload.wikimedia.org/wikipedia/commons/c/c8/Friedrich_Fr%C3%B6bel-_Construction_kit-_1782-1852-_SINA_Facsimil-dhub.jpg`

Figure 2.2: Some of Montessori's many manipulatives. Image source: wikimedia.org[1]

### 2.3.4 Piaget's theory of constructivism

Piaget (1896–1980) was the first cognitive psychologist to formulate an epistemological foundation around the concept of learning through concrete operations [136]. According to his theory, children learn by interacting with the environment and must first construct knowledge through concrete operations and, based on those, build formal operations [128]. Piaget also believed that knowledge is constructed when learners build their own mental models based on what they already know [68]. His theory, referred to as *constructivism*, distinguished children in four stages of cognitive development: sensorimotor (birth-2), pre-operational (2-7), operational (7-11) and formal operational (11+).

In his theory [127], objects alone do not have a meaning until they are used. Human knowledge comes as a result of the actions we do while using the objects. In that sense, knowledge is an assimilation or interpretation of actions and is continually created by organising, structuring and re-structuring our existing knowledge.

A lot of people have challenged Piaget's theory and his experiments (e.g. [105, 142]). Even though the developmental stages he proposed seem to exist, they do not necessary occur in the exact age spans he proposed for every child or in different cultures [35]; it seems that he has ignored not only the context in which learning takes place but also the way education is delivered [69].

### 2.3.5 Vygotsky's Socio-Cultural Theory

Another interesting theory, related to the social aspect of learning, is Vygotsky's socio-cultural approach. Vygotsky (1896-1934) believed that children construct knowledge through a network of social interactions [167]. Cultural and social background play an important role, since the child's understanding about the world and knowledge are built based on their experience of the world. He also argued that "play is the leading form of development in young children" [167].

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[1] `https://en.wikipedia.org/wiki/File:Maria_montessori_per_soc._falegnami_gonzaga,_scatola_dei_solidi_geometrici,_cilindri_colorati,_cilindri_dei_rumori,_1907.jpg`wikimedia.org

Vygotsky introduced the idea of *psychological tools* to describe conceptual tools, such as a map or an algebraic notation, whose purpose is to help people affect others and themselves [168]. Vygotsky distinguished the psychological tools in physical artefacts (e.g. maps, diagrams, blueprints) and symbolic systems (e.g. languages, numbers, mathematical notations) and after empirical studies on the former found out their importance in learning [86]. He observed that psychological tools with physical form enhance the performance of their user, when they are used repeatedly as mediators for solving a task and then stopped [169]. Vygotsky attributed this phenomenon to *internalisation*, a process by which external physical mediators are replaced by internal/mental mediators [86].

The Zone of Proximal Development (ZPD) is probably Vygotsky's most well-known and influential concept for education. ZPD is what a child can only achieve with the instruction and guidance of an adult or a more knowledgeable peer [167]. When children are provided with the appropriate tools, when entering their ZPD they can accomplish a new task or acquire a new skill [119]. This process is known as scaffolding [176]. For Vygotsky, there is a distinction between spontaneous and scientific concepts learning. Spontaneous are everyday concepts that the children can perceive and learn through independent exploration. However, scientific concepts can only be understood and learned through assisted discovery [171].

Fröbel, Montessori and Piaget described specific sequential developmental milestones for the children, in which they transition from one stage to the next. From one stage to the next the mental capabilities of the child increase. All three based their pedagogy on these stages [17]. While Vygotsky agreed that these stages exist, he thought that they were relevant only with the lower mental functions. His research focused more on higher mental functions, unique to human beings, which saw the individual as an actor of a greater, interactive social construct [17, 167, 170].

### 2.3.6 Activity Theory – Construction of knowledge through tools

Many theories about the way human beings learn have been proposed by the research community. Some of the best known are behaviourism[1], cognitivism[2], constructivism[3] and constructionism[4] [50]. Only one theory, however, interlinks organically the way we learn with the way we interact with the world through tools. This theory is *Activity Theory* and was first conceptualised by Aleksei Leontiev [92, 93], a colleague of Vygotsky. After the early death of Lev Vygotsky (aged only 37), Leontiev continued and built upon the work of Vygotsky. Through his research, Leontiev, extended socio-cultural theory and studied the way people interact with the world around them. Activity theory was unknown to the Western academic community for

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[1] Behaviourism: learning by reacting with the environment and providing response to stimuli; learning occurs by reinforcement of behaviours.

[2] Cognitivism: learning by processing information and constructing schemas or symbolic mental models; the mind is seen as a "black box" which receives, organises, stores and retrieves information.

[3] See Section 2.3.4

[4] Constructionism: constructing knowledge by combining existing knowledge and stimuli. See Section 2.3.7.

many years, until in 1987 Yrjö Engeström, an educational researcher from Finland, came across it.

According to his research [92, 93], Leontiev concluded that all human interactions with the world are performed through *activities*. An activity is a meaningful process that relates the *subject* (the actor) of the activity with the *object* (prospective outcome, objective) through the use of tools [52, 86]. During the *activity*, both the subject and the object are influencing and changing one another [92]. Hence, the subject and the object should not be analysed separately but instead as part of the activity [86]. Mediation is also a key notion for activity theory, as all our actions are mediated by tools or sign systems (e.g. language) [92]. These mediating tools are not simply mediums through which experience is transferred; they also connect us organically and intimately with the world [115]. Figure 2.3 presents Leontiev's model of activity and illustrates the interrelation between the subject, the object and the tools.

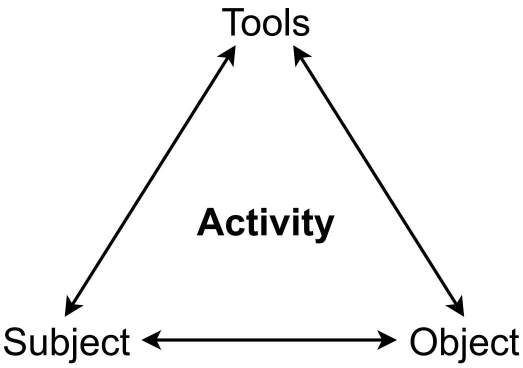

Figure 2.3: Leontiev's model of activity.

According to Leontiev, activity is a high-level process driven by a motive and consists of a chain of actions which are used to accomplish the object [81]. Actions can subsequently be decomposed into concrete routine processes called operations. Each action is bound to specific goals and each operation to conditions (see Figure 2.4). All new operations when performed for the first time are actions and through experience are internalised and become operations [81].

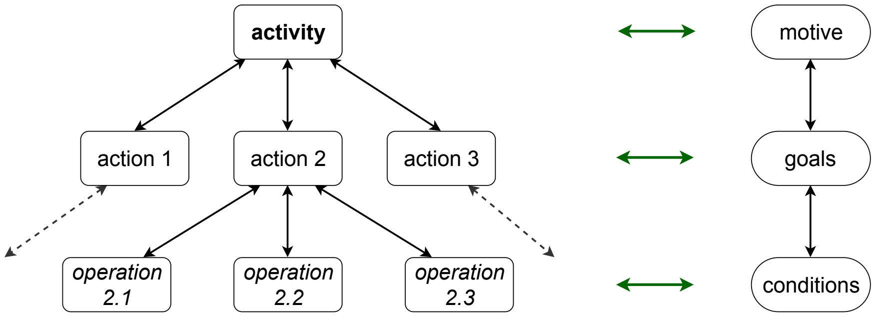

Figure 2.4: Leontiev's decomposition of activity in actions and operations.

The model Leontiev proposed for activity theory was focused on individual activities rather than on collective or socially influenced activities [86]. Engeström [47] extended the work on activity theory and proposed an enhanced model describing the activity as a system [47,48,49]. Engeström added the notion of the general social context in which the activity takes place, the *community*. The way the other two basic elements of activity (subject and object) interact with the community is again through mediation. The subject interacts with the community through the mediation of *rules* and the community interacts with the object through the *division of labour*. Rules refer to norms (explicit and implicit), customs and social behaviour within a community; division of labour covers the way a community is organised in order to transform the object into the outcome [89]. Engeström's *Activity System Model* is presented in Figure 2.5.

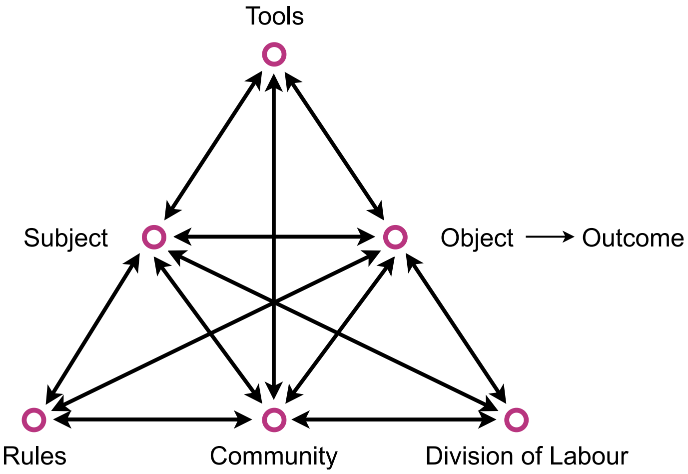

Figure 2.5: Engeström's *Activity System Model* with the six elements and their interactions.

Activity theory presents a great tool for understanding, analysing and describing human interactions, especially in education [62]. Activity theory understands actors in the objective reality; when they are exposed to an objective experience (created in an objective way), they translate that experience into a subjective experience and in this way understand and assimilate it (internalisation – see Section 2.3.5 on page 9) [92]. In that sense individuals can only understand something if they act on it [80]. Knowledge is not transmitted but instead is constructed based on the socio-cultural context and the tools mediating the process [81]. Activity theory is not an analytical tool or a methodology that can be used to design learning activities [81]. Instead, it is more of a descriptive tool for explaining and understanding how and why learning occurs rather than predicting it [115].

### 2.3.7 Papert's Constructionism

Building upon Piaget‘s work, Papert (1928-2016) proposed a theory called *constructionism*. This theory builds on the constructivist idea that learning occurs through reconstruction of existing knowledge (concrete to abstract) rather than being transmitted. Papert suggested that the academic community should reconsider the importance of concrete operations and stop regarding them as inferior to abstract operations [162]. Also, Papert was highly critical of traditional education and argued that it makes children believe that "learning only happens by being taught" and this is the opposite of empowerment [124]. Instead, according to Papert's constructionism, the best way learning can occur is when the learning activity involves the construction of a meaningful product [123].

Paper in 1986 [123] stated:

> – *From constructivist theories of psychology we take a view of learning as a reconstruction rather than as a transmission of knowledge. Then we extend the idea of manipulative materials to the idea that learning is most effective when part of an activity the learner experiences as constructing a meaningful product.*

Papert believed that the most beneficial learning was Piaget's concept of "learning without being taught" [122]. This form of learning can occur with novel and authentic learning materials (tools) used in realistic contexts through authentic learning tasks [144]. Such tasks make learning more "transparent and perceivable" and are better achieved through play and experimentation [144]. Papert envisioned an educational reform in which children are self-motivated learners who solve problems and think critically. Moreover, they are provided with tools that can empower them to take ownership of their learning process [125]. In his vision of an educational reform where learners own the learning process and learn by constructing meaningful products [123], the computer was the appropriate tool through which to achieve such a reform [125]. He saw the computer as the right tool for manipulating abstract concepts such as mathematics, and for building meaningful products. As a demonstrator of his theory, in 1967 he developed a programming language for children called *Logo*[1]. Through simple mathematical statements in Logo, children can construct shapes and two-dimensional structures.

### 2.3.8 Guided and exploratory learning

The influential views of Papert and his vision of learners owning the learning process may have inspired many researchers who believe that discovery learning is a "panacea" because students are active and participate in problem-solving activities [32]. However, learning paradigms where children are left without guidance, hints or coaching in "pure" discovery activities has been demonstrated to be ineffective [104]. Research comparing guided and free discovery of students working with Logo has disproved the superiority of the latter [104].

These findings are aligned with Vygotsky's ZPD theory. Moreover, they are relevant to Engeström's model where each activity exists at a greater community level. The tools provided in an isolated activity (without the community element) may not be enough or appropriate to help the learners enter their ZPD. A good exemplar of this is Piaget's notion of conservation.

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[1] `https://el.media.mit.edu/logo-foundation/what{_}is{_}logo/history.html`

One of the things Piaget was critiqued about (see Section 2.3.4 on page 9) was conservation[1], because in his experiments the children could not alone understand/perceive the concept. However, researchers found that children can learn to solve conservation problems through guided learning [60, 104].

Discovery learning is a strong tool to enable children test their hypotheses and be involved in problem solving [112]; however, without appropriate tools, free exploratory learning can lead the children to quickly abandon the task and even be unproductive [129]. On the other hand, with the addition of even basic verbal feedback one can increase the potential of children's learning [104].

Vygotsky's view on discovery and adult guided learning expresses the middle ground between the different theories. He initially distinguished learning tasks into *spontaneous* (simple) and *scientific*. The former can be achieved through free discovery but the latter need the guidance of an educator [171]. Children, sooner or later, will need to transition to this new type of leaning, better described as *assisted discovery* [17, 171].

## 2.4 Digital Educational Tools

The theories and pedagogies described in the previous section (2.3) lead to the recognition and widespread adoption of concrete educational tools, such as Montessori's materials, Fröbel's gifts and others, for children's learning [136, 143]. Despite the fact that through these tools children can learn and experience simple cognitive constructs (e.g. numbers, length, geometry), it is very hard through them to explore more complex notions and constructs such as dynamic systems [136]. As a result complex notions and constructs are accessible only by older students who possess the literacy and the cognitive development to manipulate abstract symbols in order to understand them [140]. This is particularly important for children with T1D, as they have to understand and balance a complex and dynamic system – their body [63] (see Section 2.2.1, page 4).

Interactivity is key in making dynamic-system related concepts more salient to children [136]. Digital technology can add computational and communication capabilities to educational tools and make them interactive, enabling children to manipulate complex system concepts and thus understand them [136]. But it was not until the end of the 1990s that the idea of embedding computational and interactive capabilities to physical objects was formulated [179]. Before that seminal work from the MIT Media Lab (see Ishii's *Tangible Bits* [77] and Resnick's *Digital Manipulatives* [136]) the main educational digital tools were video games. Educational video games continue to be a very popular means of delivering education, both by the research community and by the industry [39].

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[1] Conservation refers to a way of induction thinking which allows a person to perceive that a certain quantity of an object (e.g. volume) will remain the same despite adjustments of its container, shape, or apparent size.

Despite the fact that the outcome of this thesis is not a game, its design entails game elements. Moreover, most educational tools available to date for children with T1D are video games. Hence, the following sections will provide a basic background for digital educational games (serious games) and video games for T1D.

### 2.4.1 Gamification and Serious Games

A game is defined as "usually a contest of physical or mental skills and strengths, requiring the participant(s) to follow a specific set of rules in order to attain a goal" [67]. In another definition [130], a game is described as a form of organised play containing the following structural units: rules, goals and objectives, outcomes and feedback, conflict/competition/challenge/opposition, interaction and representation or story [87]. However, when it comes to a digital context, not all forms of playful interaction can be considered games [154]. Hence, the digital media industry in 2008 [39], created the term *gamification*.

Gamification is an umbrella term describing the use of game design elements in digital non-game contexts [40, 41]. Gamification is widely used nowadays to make non-game *serious* products and services more attractive to their users [39]. However, the concept of using game elements for serious purposes (i.e. to make education more interesting to the learner) is not new and dates back some millennia [9]. With its roots in military purposes, starting around 70 years ago, the concept of *serious games* has been also applied to education [43, 130]. Serious games can be defined as "any form of interactive computer-based game software for one or multiple players to be used on any platform and that has been developed with the intention to be more than entertainment" [139].

Serious games have widely been used for the education of children with health conditions [29], as they can overcome barriers of health behaviour promotion [99]. According to Baranowski et al. [120], there are four basic categories for health related serious games:

1. Games to increase knowledge;
2. Games to change behaviour;
3. Games to involve behaviour change in the game play;
4. Games that influence health precursors.

Apart from their potentiality to be engaging, fun and promote learning [29, 120, 132], one of the main advantages of serious games for health is that they allow learners be safely *exposed* to situations which otherwise would be impossible [154].

More generally, any gamified educational tool or serious game can also have negative effects if not properly designed. Specifically, there needs to be a balance between fun and learning outcomes during a learning task, because extensive fun can make children focus on this aspect and thus not learn [7, 143]. Moreover, if rewards are involved, trivialising the rewards for learning and making them too frequent can risk making children expect immediate rewards in order to do everything [66]. Hence, designers should be very careful when designing gamified educational tools or serious games.

### 2.4.2 Gamified Educational Tools for Children with T1D

The main digital educational resources created for T1D children's education are video games. These tools are recognised as one of the favourable ways to provide hands-on and individualised education [7], allowing children to test their preconceptions without putting themselves into harm [23].

One of the earliest studied educational games for children with T1D was *Captain Novolin.* It was released in 1992 by RayaSystems for Nintendo SNES$^{TM}$platform. The game was academically evaluated by children in the 8–14 age range and their parents for its usability but not directly for its educational aspects [94].

A more sophisticated video game for T1D than Captain Novolin, *Packy & Marlon*, was released in 1995 for Nintendo SNES$^{TM}$from the same company. It was evaluated academically with children 8-16 years old with T1D and was found to increase self-efficacy, communication with parents, disease management and decrease urgent doctor visits [23].

*Starbright Life Adventures* and *Dbaza Diabetes Education for Kids* were interactive CD-ROM tools launched in 1999 and 2003 respectively. *Starbright* was tested with children aged between 5 and 10 and was found to improve knowledge and disease self-management against the control conditions (an interactive group class and *Packy & Marlon*) [65]. A pilot study for *Dbaza Diabetes Education for Kids* was conducted with 83 children in the age range from 8 to 11 years. The study showed a significant increase in the knowledge immediately after the use of the tool. Moreover, it was further evaluated though a 19-children randomised trial in the clinical setting. The participants, who were children aged from 8 to 14, were randomised between using the tool and using a workbook. A pre-post-test was conducted and the results (preliminary and 30-day post) did not show significant difference in in the knowledge between the two groups [38].

In 2004 Kumar et al. [88] conducted a study with a game for a PDA hand-held device that they designed for children with T1D. The study was testing how a simple game for predicting the blood glucose levels could increase knowledge of and compliance with T1D management. The study was a four-week randomised control trial with 44 children aged between 8 and 18. The game group uploaded significantly more glucose values, had significantly less hyperglycemia and displayed a significant increase in diabetes knowledge than the control group.

Comprehensive work was done by Aoki et al. [7, 8] who created a series of four educational games for T1D patients. The first game, *Egg Breeder*, was designed for recently diagnosed patients with T1D and illustrates the relationship between blood glucose, insulin, food intake and exercise. *Egg Breeder* was developed for PC users. The second game, *Detective*, was again focused on the relation between blood glucose, insulin, food intake and exercise. It was developed for GameBoy Advance$^{TM}$. *Magic Toom* (Buildup blocks) is their third game, which focused on the food categories and how they should be selected from a diabetic patient based on the situation. It was developed for GameBoy Advance$^{TM}$. The last game by Aoki et al. is *Insulot* – a slot-machine game teaching children about the interaction between insulin and carbohydrates. It was developed for feature phones. It is not clear if the first three games specifically target children. They were evaluated with 58 "testers" and they were found to be entertaining, usable and with potential "clinical usefulness" [7]. *Insulot* was evaluated with 30 diabetic patients aged between 12 and 24. It was found to be "interesting", usable and a useful as a learning tool [8].

Another video game for children with T1D is *L'Affaire Birman* ("Mr. Birman's File") by Joubert et al. [82]. This game was designed by a multidisciplinary team of academics and developed by a multimedia development company. The game was designed according to Thompson et al.'s [156] framework, for the design of T1D serious games, and was intended to promote *flexible intensive insulin therapy* [145]. The game was designed for children between 11 and 18 years of age and the goal was to manage the main character's T1D and learn through problem solving. The authors conducted a six month multi-centre evaluation study with 38 children aged between 11 and 18. They found that the game was used with low frequency by the children (average 3.3 ± 2.8 times), it had good acceptance, mild usability, moderate improvement in knowledge and low motivation for intent to change behaviours.

In 2019 Rafeezadeh et al. [132] conducted a randomised clinical trial of an educational video game for T1D that they had developed. The game was designed to educate children between 8 and 12 years of age about self-management and adherence to a self-care regime. It was evaluated in a controlled experiment with 68 children (34 with the game and 34 without the game). The results showed a significant increase in the knowledge about adherence to management and self-care regimes. The results did not show a significant change in the clinical indicators of management adherence (HbA1c).

Another interesting example of T1D education through gamification, used during the ALIZ-E project, is the use of robots. During the course of the project a multidisciplinary team of researchers and diabetes clinicians studied the effects of a robotic companion for motivating and supporting children (9 to 12 years old) with T1D (e.g. [36,114,164]). The results of this project indicated the competence a social robot could have and how it can support the management of T1D. Unfortunately, the project did not directly study the educational capabilities of such robots.

Despite the successes or failures to prove educational effectiveness in the aforementioned studies, most of these tools target older children (8 and older); they require literacy skills and they focus on the management aspect of the condition, rather than education about the basic concepts of the condition. Another limitation in the existing gamification tools for T1D is that they are not designed to be integrated into existing educational pathways and hence they risk failing to be adopted by the context [83]. In the literature there are also examples of gamified tools related to T1D which are not educational (dealing with issues like glucose logging – e.g. *Glucoboy* [38], or exercise – e.g. [157]) and also gamified tools for children's T2D[1] (e.g. *Monster Manor* [59]). These tools were not presented in this section because they either do not have educational content/purpose or because they are targeting a group with different characteristics (T2D).

### 2.4.3 Tangible User Interfaces for education

An interface modality that can combine interactivity through concrete operations and gamification is Tangible User Interfaces (TUIs). TUIs are real-world objects coupled with digital information or controls. They allow users to effect functionality through physical manipulation [177]. It has been observed that children can perform better in problem solving when using tangible materials rather than illustrations [3]. This phenomenon has been described as the "tools of mental sight" [28].

TUIs do not require literacy skills (reading and writing) and thus are more accessible to preschool children, people with learning disabilities and novices [180]. Moreover, TUIs as learning tools can enable children to combine and recombine the known and familiar in unfamiliar ways, which can promote reflection, awareness and in turn reinforce learning [131]. TUIs can be used for illustrating domain-specific concepts more explicitly [51] and allow the more shy and restrained learners to contribute to the activity [51]. When combined with learning, these digital manipulative elements are thought to provide different kinds of opportunities for improving the child's reasoning about the world, by means of examination, exploration and participation [152]. TUIs have also been shown to be good for promoting social interaction and collaboration, which in turn can promote or provide fun in a group play session [177]; have been shown to allow users to be more aware of the actions of others [155]; and allow sharing of control and promote parallel interaction [180]. As a result, TUIs make a very good candidate for the specialised education of a younger age group with complex educational needs, such as younger children with T1D.

## 2.5 Design of Interactive Tools

The most comprehensive theory, which has also been recognised as the most appropriate paradigm for HCI research, is activity theory [89, 115]. However, as mentioned before (see Section 2.3, page 7), activity theory is not an analytical tool or methodology that can be used for designing learning activities, but rather a tool for understanding and explaining learning

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[1] Type 2 Diabetes is a similar condition to T1D but it is only a result of a non-healthy life style resulting in, for example, obesity.

activities [81, 115]. Hence, a more design-focused methodology is needed for creating educational tools; one that can support the design of an intervention and is rooted in the theories and practices of HCI.

### 2.5.1 Human-Centred Design

The philosophical movement of modernism late nineteenth and early twentieth centuries) was the first to consider the use of objects as a subject of design [135]. Human-centred design (HCD) is an approach to the design of an artefact which considers the satisfaction of potential users' needs as the key priority. The term HCD was first used in the 1980s by Donald Norman [117] and it signified the designer's honest commitment to centre the design on the actual human/user needs [101]. HCD has emerged as concept from the fields of ergonomics, computer science and artificial intelligence [61]. Since its first appearance in the literature it has gained much attention from the community (both research and practice) and has been studied in depth.

### 2.5.2 HCD as an ISO standard

The importance of the HCD process has led the *International Standard Organisation (ISO)* to standardise the process. *ISO 9241-210:2010* [74] (a revised version of ISO 13407:1999 [73]) provides the standards for the human-centred design of interactive systems. According to the ISO [74], in order to employ an HCD process, one needs to implement the following activities:

1. understand and specify the context of use;
2. specify the user and organisational requirements;
3. produce design solutions; and
4. evaluate designs against requirements.

The standard specifies that these activities should be iterated until the objectives (requirements) are satisfied [12]. The activities are presented in Figure 2.6 .

ISO 9241-210 gives flexibility to its implementers, by allowing to change the order of the activities and the effort put into each of them, depending on the context and the stage of the design [12].

### 2.5.3 Focus and Use of HCD

The main focus of HCD is to make products usable [34]. According to *ISO 9241-210:2010* [74], usability is "the extent to which a product can be used by specific users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use" [34].

According to Daly-Jones et al. [34] the benefits of a HCD are:

- reducing training costs;
- improving users' quality of life and satisfaction;
- reducing stress related to the use of the product;

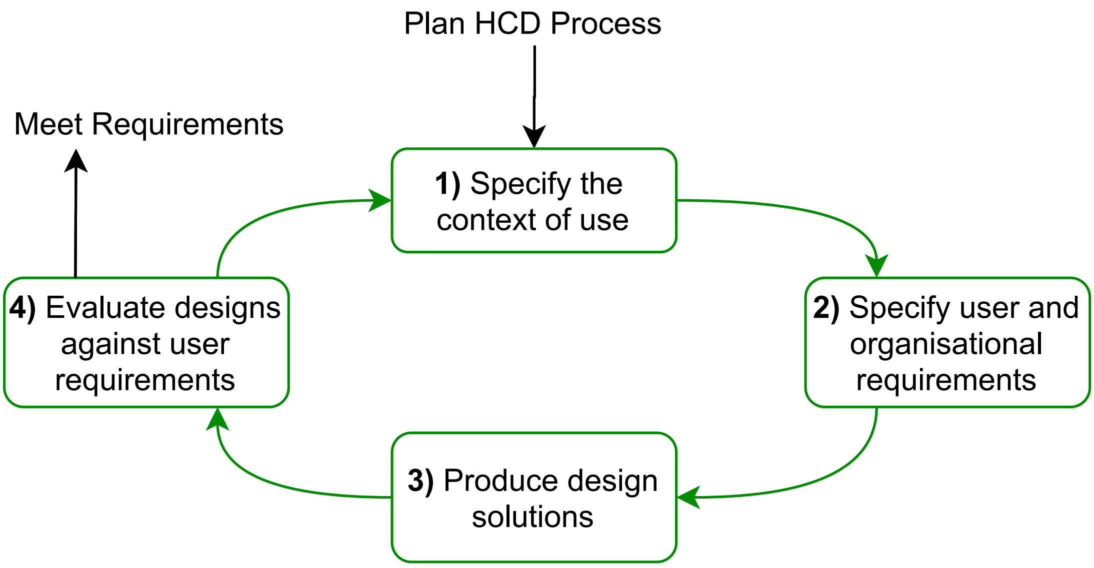

Figure 2.6: Human-centred design process activities.

- improving the productivity of users and consequently impacts the general context; and
- helps to identify problems early on the process and thus reduce development costs.

HCD stresses the importance of utilising people who have real insights into the context (users) and the problems the designer is trying to solve. By involving users into the design process, HCD also enhances acceptance and commitment to the product [34].

The literature suggests that during the design of an HCD process, cheap and quick prototypes should be developed as soon as possible. These prototypes should be evaluated by potential users [34, 101] when ready and a cycle of redesign and evaluation should continue until the prototypes meet the users' requirements [34].

### 2.5.4 HCD and Participatory Design

During the early years of HCD, users were conceptualised as subjects of the design, and the design team would involve them as informants to or testers of the process [101]. More recently, the design practice has started to understand the value of more active user participation in the design process. More and more the design community is starting shifting from HCD to participatory design, where users are seen as design partners rather than just subjects [37]. The design perspective has also moved from a focus on usability to a focus of designing for experiences [135].

This shift has occurred after extended debates about the subjectivity and the "expertise" of the designer and the effectiveness of guidelines (*human factors*) in the development of interactive systems. These critical discussions questioned the "design for the users" with insufficient or no input from users [45]. The design community understood that designs cannot be based on knowledge about the potential usage and the users [45,135]. Instead we, as designers, can only predict use and even if we do it well, it will always be different from actual use [135].

### 2.5.5 Challenges with HCD

Nonetheless, even after the shift to a more active user involvement, the participation of users is not recommended in all circumstances [37]. For example Webb [172] argues that user involvement might not be "feasible because the design environment is new, innovative, creative and dynamic and users are heterogeneous and difficult to access. Not desirable because user involvement itself may constrain creativity". Another aspect of the challenging nature of HCD has to do with the analysis of users' the requirements. According to Maguire et al. [98] the following problems are faced during this task:

- complex organisational contexts with many and diverse stakeholders;
- users and designers trying to resist innovation;
- difficulty of the users to know their needs of a future system;
- time limitations restricting the analysis of the users' needs; and
- representing effectively user requirements.

Lastly, the designer at specific points of the design process needs to act as an expert, by taking the decisions. However, taking all the decisions is not professional and can lead to mistakes. When there is a need for the users to decide, the designer should change their role from an expert to a facilitator [45].

## 2.6 Conclusion

This chapter had presented the basics of children's diabetes and the importance of education; on theories, approaches and limitations of educational tools; on the strengths of digital educational tools and how these have been used specifically for diabetes; and on a widely accepted and adopted methodology for interactive tool design. As mentioned before, not all the theories presented have been directly used in this thesis. The theories used in this thesis (*Zone of Proximal Development* in Section 2.3.5 and *Activity Theory* in Section 2.3.6) have not been used in their entirety or exclusively but have instead been used to either explain the current educational context or to deepen the discussion on the findings.

The next chapter presents the methodology used in this thesis.

# Chapter 3

# Methodology

## 3.1 Introduction

This chapter describes the methodology used to achieve the aim of this thesis. It starts by explaining the research approach and the intentions behind it, which underpin the methodological choices. The rest of the chapter presents the methodology from a *top-down* perspective, where the higher-level phases of the methodology are presented first and then each phase with its stages in more detail.

This chapter serves the purpose of presenting the methodology as a whole in order to align the reader with the author's research approach. Thus, it does not go into much detail about each phase of the methodology; this will be done in the following chapters each of which describes a phase of the methodology.

## 3.2 Research Approach

The aim of this thesis is to provide an age-appropriate digital educational tool which can effectively support the education of younger children with T1D and can potentially be adopted by the educational practice in diabetes clinics for young children. The two constituent elements of this aim's fulfilment are *effectiveness* and *feasibility for adoption*. Both effectiveness and feasibility are highly sensitive/dependent on the context in which the technology will be situated [10] and the age-appropriateness of the tool [71, 147, 161]. Thus, it is crucial that the design and development of the technology is based on the understanding of all the relevant contextual information about user characteristics, the tasks the users will perform, and the environment [34].

A well-defined, standardised and widely used methodology for the design and development of meaningful and successful technological solutions is HCD [153]. HCD has proved to be effective for the design of technological solutions which are highly contextualised and thus successful. Moreover, HCD does not bound its implementers on specific methods, but allows them to use any methods that they consider appropriate, depending on the project and their research profile [12, 13]. Hence, HCD was selected as the core methodological framework and was adapted to meet the needs of this project.

More generally, effectiveness and feasibility for adoption were considered interconnected with and dependent on each other. Hence, we centred the approach around the belief that in order for the solution to be effective it needs to be feasible for adoption and vice versa. At every stage we tried to assess the fit of the solution for the context. As mentioned above, this required a deep and rigorous understanding of the context – achieved through the HCD process.

### 3.2.1 Main axes of the approach

Before describing the methodology phases in more detail we should explain the axes on which the HCD methodology was adopted. Three main axes were selected and are presented below.

**Maximise stakeholder involvement:** The first axis was the continuous input from the stakeholders. This is in line with HCD practices but it was also promoted by the author, because of his lack of insight for the T1D context. Moreover, by maximising the involvement of stakeholders, problems related to the effectiveness and appropriateness of the solution could had been spotted early on and thus be resolved before the solution was finalised. The author tried to include as many different stakeholder groups as possible, with multiple representatives from each group. As a result, 9 health professionals, 27 parents and 21 children were involved in the different stages of the process, providing valuable data which were used to iteratively design and evaluate the solution and hence support the thesis.

**In-context enquiries:** The second axis was the situation of most of the enquiry inside a real-world clinical setting. This approach was inspired by the *contextual enquiry* practices [14, 15, 175] and was aimed at getting a deeper understanding of the context by experiencing its specificities while being as *embedded* to it as possible. Moreover, with the continuous presence of the author in the clinical setting, an interpersonal relation of trust with the clinical stakeholders was built, which in turn maximised their engagement to the project. Throughout the enquiry process the author was in close collaboration with the local clinical team in order to delve into their practices and understand their approach to T1D education. All enquiry stages, apart from one, were conducted inside the clinical context. For the whole project we partnered with Yorkhill paediatric diabetes clinic in Glasgow. This is the only paediatric diabetes clinic in the area of greater Glasgow and Clyde and is the largest, in terms of number of patients, in the whole of Scotland.

**Iterative process:** The final axis was the iterative nature of the design process. Multiple stages of qualitative enquiries held and based on these prototype designs were created by the author and evaluated by the clinicians before the solution was finalised. This axis empowered the other two axes by involving the stakeholders at more stages and keeping a connection with the clinical setting. Hence, the solution was assessed by the stakeholders and refined accordingly, but also this process enabled their continuous engagement.

These three axes enabled us to overcome the challenges and the limitations faced at the different stages by a constant calibration of our data based on the context's facts [61]. By having as many stakeholders involved as possible, placing most of the enquiry inside the clinical setting and by iterating the process we managed to triangulate each stage's outcomes [37] and validate the findings before implementing them.

### 3.2.2 Subjectivity of the approach

The author's involvement in the process certainly impacted its exploration and solution because of subjectivity during the gathering and interpretation of data. Nonetheless, we tried to reduce as much as possible the effects of subjectivity through the aforementioned three axes of the research approach which ensured the triangulation of the each phase's outcomes. Whenever decisions were taken based on the author's research interests this is made clear in the thesis (i.e. Sections 4.2.1 and 6.3.2),

### 3.2.3 Challenges

Designing for and in such a complex context proved to be challenging at times due to poor stakeholder engagement, time constraints, legal and procedural constraints. Because of these challenges some enquiry methods had to be altered or even cancelled. Nonetheless, due to the flexibility of the HCD methodology, these enquiry methods were replaced with others more suitable, providing equivalent depth of insights. More details on the challenges and their resolutions are provided in the chapters of each methodological phase.

## 3.3 Phases of the methodology

Before going into details about the phases it may be helpful for the reader to explain the difference between the terms *phase*, *stage* and *step*. By *phase* in this thesis we will be referring to higher level methodological units of the project. These units can be conceptually described as the sum of multiple *stages*. Each *stage* has a set of coherent goals that help in the completion of the phase's goal. Lastly, each *stage* will be composed of one or more *steps*. Therefore, by *step* we mean a specific action (e.g. enquiry, analysis or design) with a distinct combination of inputs, method and outputs.

To illustrate these concepts, let us give an example. In a bread-baking recipe the first phase would be the preparation of the dough. The first stage of this phase would be to measure the ingredients, the second to mix them and the third to knead the dough. The first stage would have four steps; measuring water, salt, flour and yeast.

Coming back to the methodology, it consisted of four phases – the same as the HCD process:

1. Specify the Context

2. Specify the Requirements

3. Design and Development

4. Evaluate the Solution

These phases are depicted in Figure 3.1.

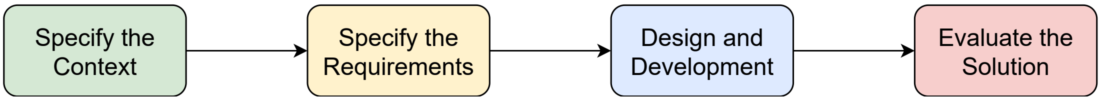

Figure 3.1: The four phases of the research methodology.

### 3.3.1 Phase 1: Specify the context

The first phase of the methodology was about the specification of the context. At the beginning of the project very few insights about the specificities of the context were known and the scope was not yet defined. Therefore, an enquiry stage was conducted to explore the context and understand its specificities and challenges. At this stage different stakeholder groups were invited to participate but, as explained later, only two T1D health-care professionals and one T1D government official responded to the call and were interviewed. The results of this stage were analysed and synthesised in order to provide an initial understanding about the context from different perspectives locally and regionally. This stage is presented in Chapter 4. Based on the results of the aforementioned stage, another enquiry stage was conducted, which was more focused and well-defined. It was designed to illustrate existing educational practices mentioned in the previous stage and to get the perceptions of parents on them (who did not take part in the previous stage). The result of this stage completed the picture of the context by providing more detailed information to the insights of the previous stage. The results of these two stages were analysed and synthesised in order to provide the relevant contextual information needed for the project. This stage is presented in Chapter 5.

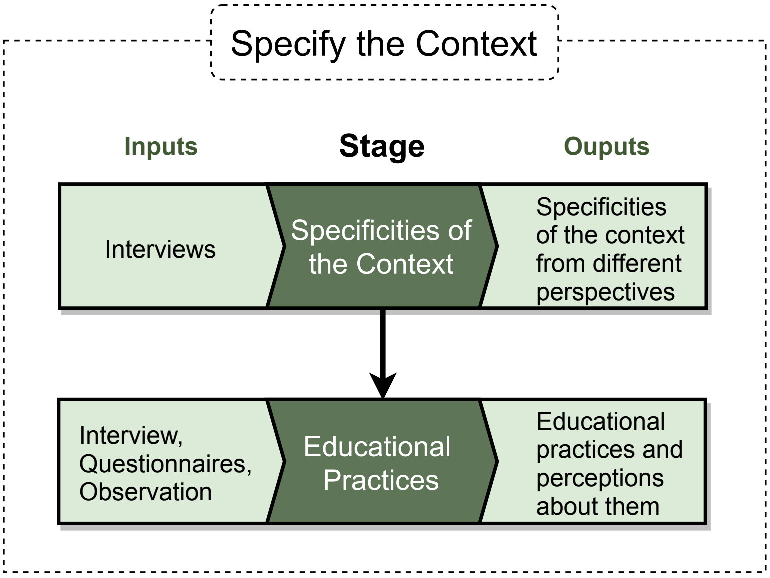

Figure 3.2: The first phase of the evaluation, "Specification of the context", with its two stages. The first stage is presented in Chapter 4 and the second in Chapter 5.

### 3.3.2 Phase 2: Specify the requirements

The second phase of the methodology was about the specification of the requirements. Based on the synthesised results of the previous phase, the challenges of the context were identified and from them we derived the needs of the stakeholders. According to the needs and the research aim a set of requirements was formulated, and these were iteratively broken down to more concise requirements and design decisions. The final stage was about validating the formulated requirements and design decisions, and also determining the requirements for the educational content of the tool. This phase is presented in Chapter 6.

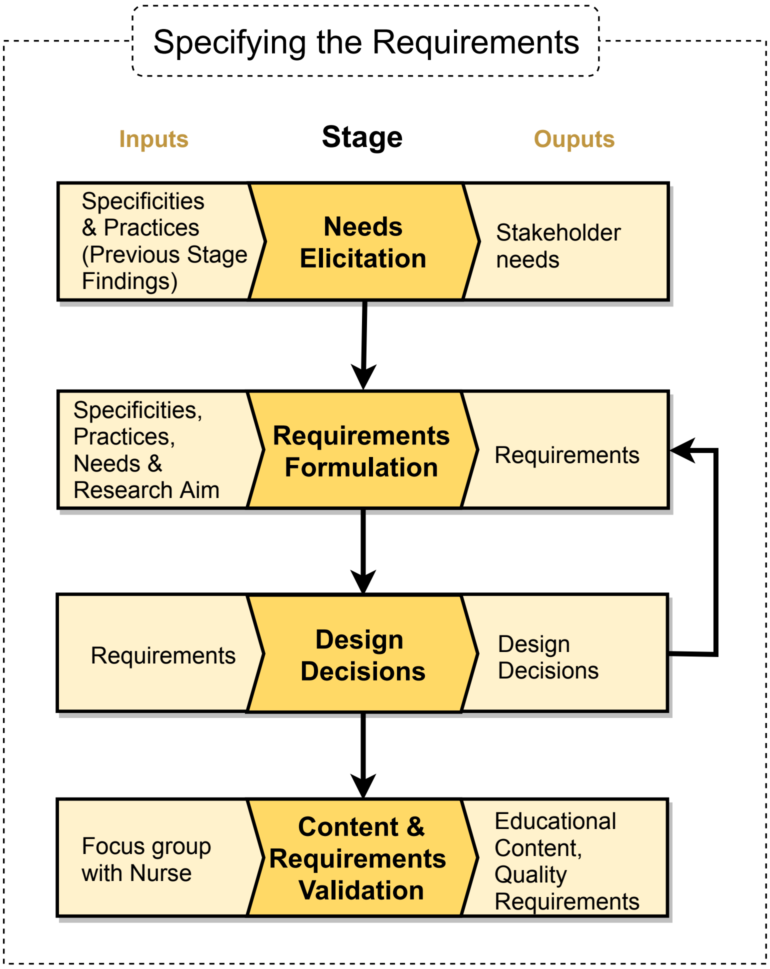

Figure 3.3: The second phase of the evaluation, "Specification of the requirements", with its four stages. This phase is presented in Chapter 6.

### 3.3.3 Phase 3: Design and development

The third phase was devoted to the design and development of the solution. The analysed results were fed into the design process and some initial paper prototypes were created. These paper prototypes were formatively evaluated by clinicians. Then they were refined based on the evaluation and a series of development stages was conducted. When the designs were finalised and the final prototype was developed, a set of helping materials and an educational process were co-designed with stakeholders in order to ensure fit with the current practices and targets of the context. This phase is presented in Chapter 7.

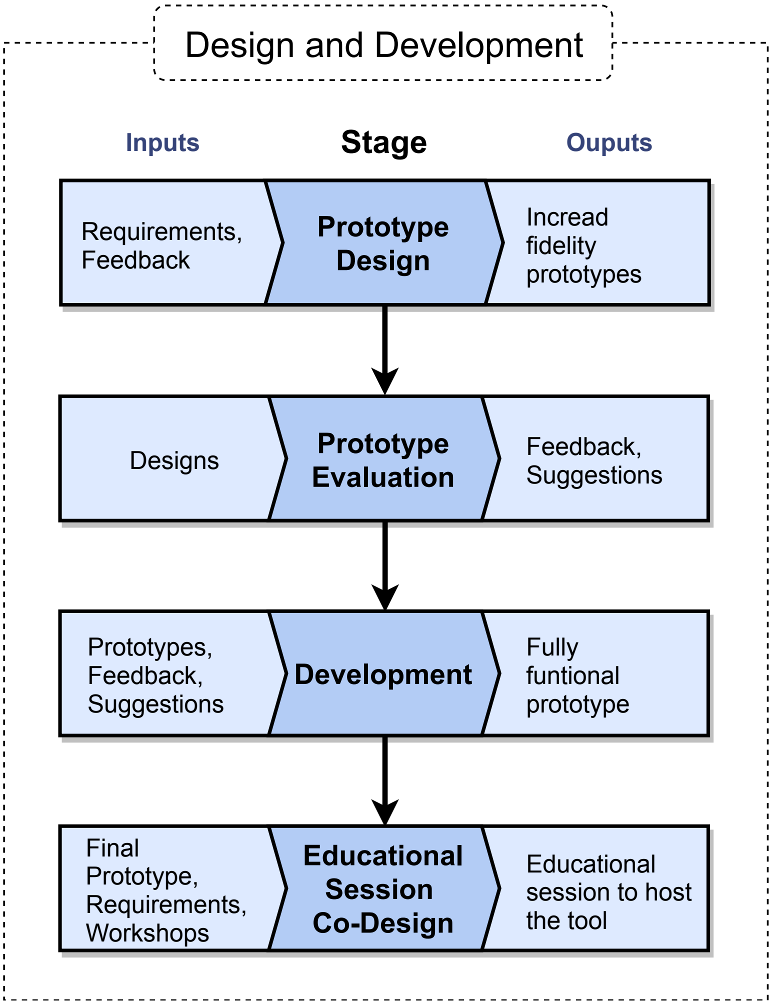

Figure 3.4: The third phase of the evaluation, "Design and development", with its four stages. The first two stages were iterative. This phase is presented in Chapter 7.

### 3.3.4 Phase 4: Evaluate the Solution

During the final stage of the methodology the solution was evaluated against the requirements and research aim, in order to provide an answer to the research question. A large-scale evaluation study was conducted, where children and clinicians used the tool and they –along with parents– provided their insights about it. This phase is presented at Chapter 8.

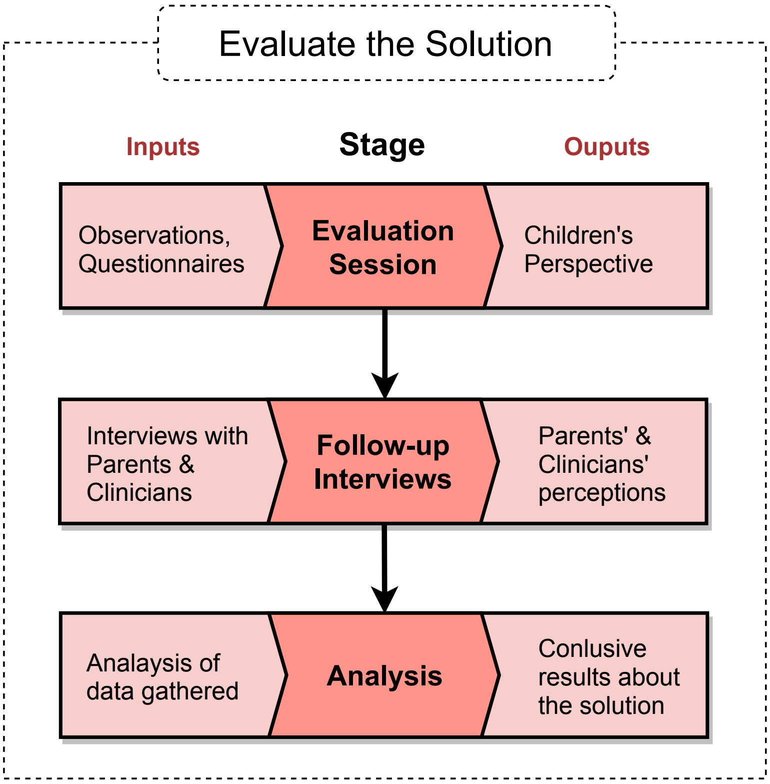

Figure 3.5: The final phase of the evaluation, “Evaluate the Solution”, with its three stages. This phase is presented in Chapter 8.

## 3.4 Ethics

For the stages of the project which contained qualitative enquiry stages (interviews, observation, evaluation) ethical approval was acquired. For the steps that children were not involved in the enquiry the ethics committee of the Department of Computer and Information Sciences of the University of Strathclyde provided the ethical approval of the procedures (Ethics Approval ID: 286). For the two enquiry steps that included children, the Research Ethics Committees of the National Health Service (NHS) provided ethical approval for the procedures (IRAS Project IDs: 193038, 209708, 231365).

All four ethics applications contained a detailed description of the protocol, information sheets and consent forms. The committees which reviewed the ethics application consisted of experienced academics and researchers who provided feedback on the procedures which was used to refine each procedure and make them more robust.

## 3.5 Conclusion

This chapter described the methodology that was used in order to achieve the aim of this thesis. It described the methodological approach and the different phases of the process.

The methodology used is an adaptation of the HCD process with a focus on effectiveness and feasibility of adoption of the solution. Multiple enquiry stages were used in order to understand the context in depth and evaluate the solution against the requirements and the research aim. The main axes of the approach were explained and also there was an introduction to the challenges faced.

The next chapter presents the first stage of the context's specification.

# Chapter 4

# Specificities of The Context

## 4.1 Introduction

This phase of the methodology was devoted to gaining an understanding of the context. Through two stages (Figure 4.1), with multiple steps of qualitative enquiries in each, we managed to gain deep insights on the specificities of the context, the educational practices and the challenges faced in the current clinical set up and system of practice.

Due to limited insights about the context, extracted mainly from the literature, this phase was conducted using a deductive approach; starting from the general and moving to the specific. At the first stage, presented in this chapter, we conducted a set of exploratory enquiries and tried to approach as many stakeholder groups (involved in diabetes education and care for younger children) as possible. The results were analysed qualitatively and a first understanding of the general context was formed. Subsequently, based on these results, we enquired about specific practices and perceptions in order to deeply understand the context (Chapter 5). Hence, this chapter illustrates the steps that were taken to understand the specificities based on the different stakeholders' perspectives.

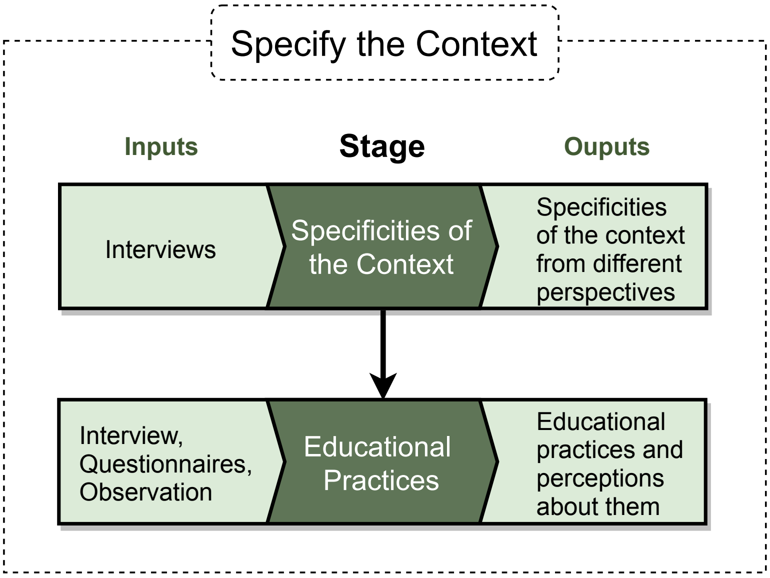

Figure 4.1: The phase "Specification of the context" with its two stages. The first stage is presented in this chapter and the second stage is presented in the next chapter (Chapter 5).

## 4.2 Specificities of the Context

By *specificities* we mean the basic frame on which the context is structured. In a more simplified way, how the context works and the reasons why it works like that. This includes the roles of the stakeholders, the available resources, the strategies, the needs, the challenges and limitations along with the influence each has on the others.

### 4.2.1 This stage's steps

At the beginning of this stage few elements of the solution had been decided. Some of these elements were derived from the research aim (see Section 1.3, page 2) and others based on the author's research interests. Namely, it was only clear that:

- the solution will target young children with T1D;
- it would be an age-appropriate educational tool or system;
- it would use digital technology; and
- it would have gamification elements.

Specific elements of the solution, such as the exact age group, the setting in which it will be situated (home or clinical setting), its educational style (e.g. solo or group), the platform that would host it (e.g. smartphone or other device) and its *usecases* were not yet defined. Any decision about these missing elements could only be made once the specificities of the context were clearer. Hence, the first stage was decided to be exploratory in order to prevent us focusing on specific elements for the solution and specific stakeholders; this way we wanted to capture the bigger picture by not narrowing our exploration.

An initial call to different T1D professionals and charitable organisations was made. After a search on the internet a few local and national organisations, related to children's T1D were identified and contacted through emails. These organisations included the local T1D clinic and T1D charities. The first person to respond to the call was a T1D consultant, leading the local T1D clinic (Section 4.2.4, page 34). He also introduced us to a T1D nurse specialist, responsible for children's education in the clinic, who was later interviewed (Section 4.2.6, page 36). After getting a basic insight into the context through the initial interviews, we extended the call to parents of children with T1D – a step that was cancelled due to zero responses (Section 4.2.5, page 35). At the same time a T1D government official responded to the call and agreed to be interviewed (Section 4.2.7, page 36).

Lastly, all the data gathered from the interviews were synthesised, through a thematic analysis, in order to provide deeper insights and help the production of requirements. The steps of this stage, in the sequence that that they were conducted, are depicted in Figure 4.2.

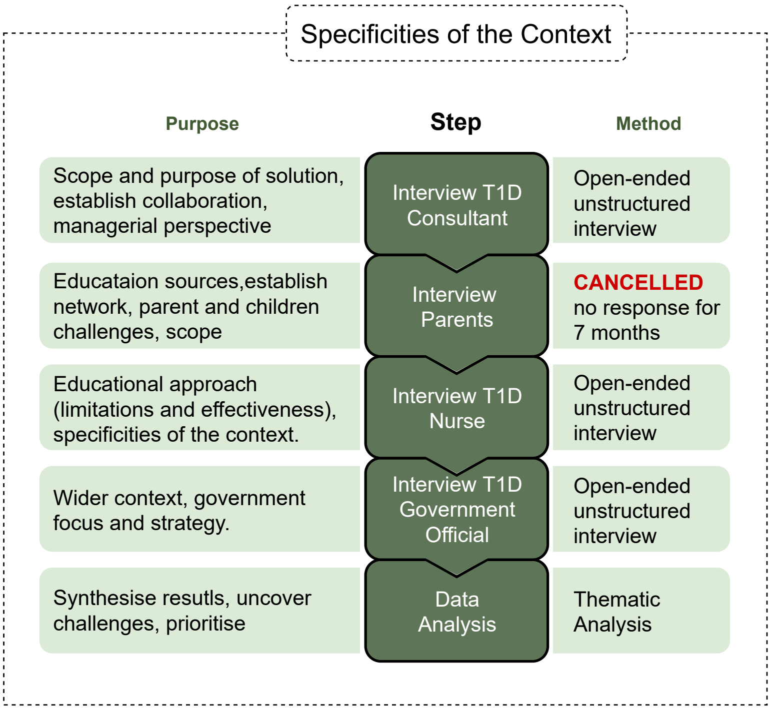

Figure 4.2: The steps of this stage, presented in the sequence that they were conducted, their purpose and the methods used.

### 4.2.2 Data Collection Protocol

Due to the exploratory nature of the process and the different perspectives of the participants, a discussion-based open-ended unstructured interview protocol was selected. This way the interviewees had the freedom to guide the interview to the aspects they considered important. However, from one interview to the next the author was gaining more insights into the context – a fact that influenced the flow of the interviews. Even without analysing the data, the author started forming a mental model about the context; this fact was inevitably raising new questions on previously mentioned aspects, but also helped to uncover new aspects.

At the beginning of each interview, the author made an introduction to the project, informing the interviewee about the base of the proposed solution (*decided elements* in Section 4.2.1, page 32). He then asked the participants to explain their role in relation to T1D education for younger children. Subsequently, he asked their perspective on the existing formal education of children with T1D and how an educational tool might help. The rest of the discussion was mainly driven by the interviewees and the author asking explanatory questions.

The first interview (with D1 – see Section 4.2.4, page 34) was not audio recorded because it was arranged at an early stage of the project when audio recording equipment was not yet purchased; instead notes were taken during the interview. The other two interviews (nurse and government official) were audio recorded. When all three interviews were conducted, they were transcribed verbatim and analysed for emerging themes. The transcribed interviews were analysed through a thematic analysis. More details on the coding strategy and the rationale behind it are presented in the *Data Analysis* step (Section 4.2.8, page 37).

### 4.2.3 Participants

For the sake of presentation clarity the participants of this stage are shown in one table so that the reader can easily refer to it. The participants of this stage are listed in Table 4.1.

Table 4.1: Profiles of the clinicians and the government official who participated in the stage.

| ID | Role | Gender | Experience |
|---|---|---|---|
| D1 | Consultant Paediatrician | Male | 25 years |
| N1 | Nurse Specialist | Female | 8 years |
| G1 | National T1D Coordinator | Male | – |

### 4.2.4 Interview with T1D consultant

The first person (D1) was the head of the only paediatric diabetes clinic in Glasgow. He was an experienced type-1 diabetes paediatrician who has been involved in national committees about T1D (such as "My Diabetes My Way"[1] and as clinical lead for information technology for Scottish Government).

D1 started by suggesting that we should focus on very young children (e.g. 3 to 5 years old) who had limited or no literacy and had difficulties accessing information about their condition. According to his experience, these children are the hardest to educate and are one of the largest age group proportions. He was convinced that we should only focus on the educational side of the management and not connect it with the day-to-day monitoring, as some smartphone applications do. He thought that T1D education for such an age group should only cover the

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[1] https://www.mydiabetesmyway.scot.nhs.uk/

basic aspects of the condition and present them in the simplest form. In his opinion, T1D children's education should focus more on simplified 'cause and effect' learning, where they can learn the outcome of each management action – e.g. insulin reduces blood glucose and food increases it.

D1 also proposed a short life-cycle for our educational solution; in an era where games and applications arise every day, children would otherwise easily be distracted and switch to something new instead of our solution. Hence, he supported the idea of a simple tool that would be used once and its messages would stick in the children's minds. Lastly, he thought that in order to evaluate an educational solution one needs to refer to the adults; children cannot easily express themselves and parents and clinicians can more decisively come to conclusions about children's knowledge and preferences.

All these insights and suggestions –about the scope, the purpose of the solution and the context– set a basis for the rest of the exploration. Moreover, this interview established a connection with the local T1D clinic, which was later transformed into a collaboration that lasted until the end of the project.

At the end of the interview D1 also suggested that we should interview one of the nurses responsible for T1D education of young children. He brought us into contact with her and an interview was arranged (see section 4.2.6, page 36).

### 4.2.5 Parents Interviews: Cancelled

After the interview with D1 and since a further interview with a clinical member of staff was planned, we wanted to extend our participant pool to include parents as well. Parents are key stakeholders as they are responsible for longer-term day-to-day education and condition management (see Section 2.2, page 4). Hence, we compiled a semi-structured interview protocol and submitted it for CIS department ethics. A semi-structured interview protocol was chosen because we were expecting around 10 participants and thus we wanted to keep the interviews slightly more focused. The interview topics covered the sources of education, existing educational materials, challenges in education and management, how the child's personality affects management and education and children's motives. The semi-structured protocol would also have allowed the interviewees to discuss other topics that they considered important, thus still promoting a certain level of exploration.

After the ethical approval, we started asking for participants through an online local patient group and through all the T1D charitable organisations working in the local area. Unfortunately, after seven months of multiple posts no parents stated their interest. It was decided to re-promote participation of parents in the next stage of this phase (section 5.2.4, page 65) in order to obtain parental insights.

### 4.2.6 Interview with T1D Nurse Specialist

The second person (N1) to be interviewed was a diabetes nurse specialist working in the diabetes clinic in Glasgow. As it was mentioned earlier (section 4.2.4, page 34) D1 suggested that we should interview N1 as she was one of the key nurses responsible for T1D education of young children within the clinic.

During the interview, N1 provided insights, briefly explained the current educational approach of the clinic, gave information about available resources and discussed the limitations of the current educational context in the clinic. N1 explained that parents are the focus of T1D education in the clinic and that there is nothing age-appropriate for the younger children (10 years old and younger). N1 mentioned the struggle that families are going through with the management and that parents are mainly managing the condition for the younger children. The clinic does not have access to age-appropriate educational materials and nor do the staff have explicit knowledge on how to educate children of a younger age. Over the years they have created some educational materials for parents and they are running one educational session for the parents, which older children can attend. The only material they use that may be considered age-appropriate is a set of plastic food toys to illustrate the different food groups.

Throughout the interview N1 highlighted the need for an interactive educational resource, one that could help clinicians include younger children in the educational process and empower them (the clinicians) to convey educational messages to the children effectively during the sessions.

### 4.2.7 Interview with T1D Government Official

The third person interviewed (G1) was the National T1D coordinator at the Scottish Government's Health Department. He was responsible for coordinating the different T1D stakeholders who work across Scotland in order to achieve the government's goals. G1 was suggested by a charitable organisation and we contacted him to gain a deeper understanding of the national approach to educating children in the clinical context.

G1 informed the enquiry about strategic directions and focus on a national scale. Through this perspective he illustrated the bigger picture of T1D education in Scotland and helped us to grasp the current policies, demographics, strategies and the feasibility of an educational tool.

According to G1, the government is not currently looking at this age group because there is no identified problem with their T1D management outcomes. He considered younger age children as a neglected group because they do not receive formal education and they are called to suddenly learn everything when they have to take care of their condition, i.e. when they transition into teenage years and then adulthood. The older children have been observed to have a knowledge gap which is rooted in the lack of formal education at younger ages. This gap leads many older children to poor management choices and as a result long-term health complications. Lastly, he acknowledged that parents are struggling to deal with their dual role as educators and managers of their child's condition.

### 4.2.8 Data Analysis Protocol

In order to dig deeper into these three interviews and uncover all the key contextual information about the specificities of the current educational context within the clinic, we decided to synthesise the results through a qualitative data analysis. *Thematic Analysis* (TA) was chosen for the data analysis, as it poses a strong and yet flexible methodological approach for the analysis of qualitative data [18]. TA can be used even by only one researcher [19] and it is suitable for HCI research [16, 22]. However, TA is not a single methodology but rather an umbrella term covering a set of methodological approaches to coding [16]. In our case *Reflexive TA* was used for the analysis of the data. Reflexive TA was introduced by Braun and Clarke in 2006 [18] and it presents an iterative process of coding in which codes are generated dynamically (changing with each iteration) until they converge [19]. Reflexive TA consists of six phases [16]:

- Familiarising yourself with the data
- Generating initial codes
- Searching for themes
- Reviewing themes
- Defining and naming themes
- Producing the report

Themes are then generated by clustering together codes which have the same underlying meaning [20]. More on the exact process and on what a code and a theme consist of can be found in the following section (Section 4.2.8.1). Our approach to the analysis sat between a realistic and a constructionistic perspective. We tried to analyse the data based on the meanings and the reality the participants are experiencing (realistic) but also how these affect, influence or form the context (constructionistic) [18]. We chose an inductive approach to the theme generation due to the lack of pre-existing knowledge or theory about the context. Hence, the themes generated are strongly linked to the data and derived from the data. However, the process was not a pure induction, as any subjective interpretation of qualitative data is influenced by the experience, perspective and interests of the researcher [18].

#### 4.2.8.1 Coding Strategy

In our coding strategy, a *quote* is a sentence or a statement or a paragraph which clearly describes an experience, a perspective, an event, an effect or a fact. As a *code* we conceptualised a part of the data (a collection of quotes) with a single meaning or point important in understanding the context. As a *theme* we conceptualised a coherent set of codes that form a fact or a perception about the context.

The themes were developed in an inductive way through a deep familiarisation with the data and many iterations of reading the transcripts to identify codes from the quotes and subsequently form the themes. The analysis was done *by hand* – without the use of specialised software (e.g. NVivo). From the transcripts, specific quotes describing the specificities of the context[1] were identified and extracted into a separate text document. Subsequently, the quotes were grouped into codes based on their thematic congruence. Some of these codes had already been partly developed during the interviews in the form of mental models of understanding (see Section 4.2.2, page 33). From iteration to iteration the codes were refined by re-examining their quotes and ensuring they fitted in the codes; some additional quotes were added to codes later during further reading and analysis as codes developed and some quotes were re-assigned to other codes due to a deeper familiarisation with the data. Figure A.1 in Appendix A (page 165) shows a screenshot of a coding table used during the process.

The final codes were given a descriptive name, based on the meaning they were conveying. Due to the small number of interviews (N=3) some codes were based only on one person's quotes. This was the only way, with the existing data available at the time, to understand the key opportunities and challenges of the context. Such codes were carefully examined and selected only on the premises of the participant's expertise (e.g. G1 informing about policies or N1 informing about educational sessions). The codes created were mostly on a semantic or explicit level, summarising their underlying quotes.

The next step was to identify influences or interactions between the codes. Some of these influences were easily extracted as the interviewees were clearly mentioning them; the rest were extracted by cross-checking between different interviewees' quotes (i.e. one interviewee mentioned something and another interviewee mentioned something related and explained why). The influences were iterated and checked many times (more than 8) and when no other influences emerged they were finalised. A figure representing them was then created (see Figure 4.3 on page 41). In the same way that the quotes merged into codes, the codes were merged in *themes*.

In contrast with the codes, which represent an explicit meaning, the themes (Figure 4.4 on page 42) present a higher level of understanding about the context, and represent the central meaning of the codes of which they consist. The influences between the themes (seen as arrows connecting them in Figure 4.4) were extracted from the influences between the codes; the reader can observe that the connections in Figure 4.4 are drawn from the connections/influences of Figure 4.3. In summary, the themes are deeper analytic insights developed to summarise the specificities of the context examined during this phase of inquiry.

In total, 8 themes and 33 codes were generated during the coding process.

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[1] For example, the roles of the stakeholders, the available resources, the strategies, the needs, the challenges and limitations along with the influence each has on the others – see Section 4.2 on page 32

### 4.2.9 Findings

This section briefly describes the themes and the codes consisting them. Table 4.2 presents a summary of the themes and the codes under each one of them. The order by which the themes and their codes are presented is arbitrary and implies nothing about their importance.

#### 4.2.9.1 Theme 1: Targets are measurable outcomes

There was much discussion about the way the government and the NHS approach effectiveness of care in younger children's T1D. Effectiveness of care is based only on measurable outcomes of management (*Hb1Ac*[1]), which helped to clarify why there is no standard education for this age group. This approach focuses on solving observed problems rather than preventing them from arising in the first place.

> – *Scottish Government's current focus is on an older age group, because there's an identified problem that they need to sort out.* [G1]

**Younger age-group management targets are met**

The health system and the government in Scotland seem to focus only on measurable outcomes about T1D and measure effectiveness only based on these. According to their figures, the targets for the management of younger children's T1D are met.

> – *The only way we can measure our effectiveness is the HbA1c. This is the measure of overall diabetes control.* [N1]

> – *At the moment that younger age group is being, if you like, managed by parents and by health-care and actually it's not looking too bad.* [G1]

**Government not looking at that age group**

According to the government's figures, the targets for the management (in terms of Hb1Ac) of younger children's T1D are met. Hence, they are not looking at that age group.

> – *At that particular age group it's not something that is currently one of the biggest issues that [government] are looking at. The Scottish Government's current focus is on an older age group, because there's an identified problem.* [G1]

**No standardised education across Scotland**

There is no formal education for younger children with T1D across Scotland. Instead, each service is free to develop its own educational package.

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[1] *HbA1C* (hemoglobin A1c) is a test that informs about how effective the management of T1D has been by measuring the average level of blood sugar over the past two to three months. The results can be compared to standard expected/optimal figures.

Table 4.2: The themes and codes of this stage's interviews.

| **Targets are measurable outcomes** |
|---|
| Younger age-group management targets are met |
| Government not looking at that age group |
| No standardised education across Scotland |
| Clinicians not trained on education |
| **Clinicians are left alone in education** |
| No educational resources provided by NHS or government |
| All materials produced and paid by them |
| Materials created based on their experience |
| **Challenges of T1D and children** |
| Complexity and severity of management |
| Children harder group to educate |
| Children have limited processing |
| Children quickly speak about concepts but may not understand them |
| **Focus is on the parents** |
| Parents manage the condition |
| Try to make sure parents are safe and able to manage T1D |
| Education targets parents |
| All written materials for parents |
| **Parents fight an unfair battle** |
| Parents educate children |
| Not all parents are capable of educating their children |
| Parents background, interest and understating |
| Most child patients not in management target range (HbA1c) |
| **Children are a neglected group** |
| Children are passive in management |
| No formal education for children |
| Observed gap in knowledge at teenagers |
| No formal approach to help them enter self-management |
| Struggle to manage when they take control of management |
| Long-term complications |
| Assumption that having T1D for a long time means you understand |
| **Perceptions of effective education** |
| It's about keeping it simple |
| Need for practical sessions and interactive tool |
| Children learn through play |
| Only plastic food toys for children |
| **Need for T1D children's education** |
| Children have to know the basics (e.g. for when tech fails) |
| Better knowledge from younger age can help |
| Need to gradually enter self-management |

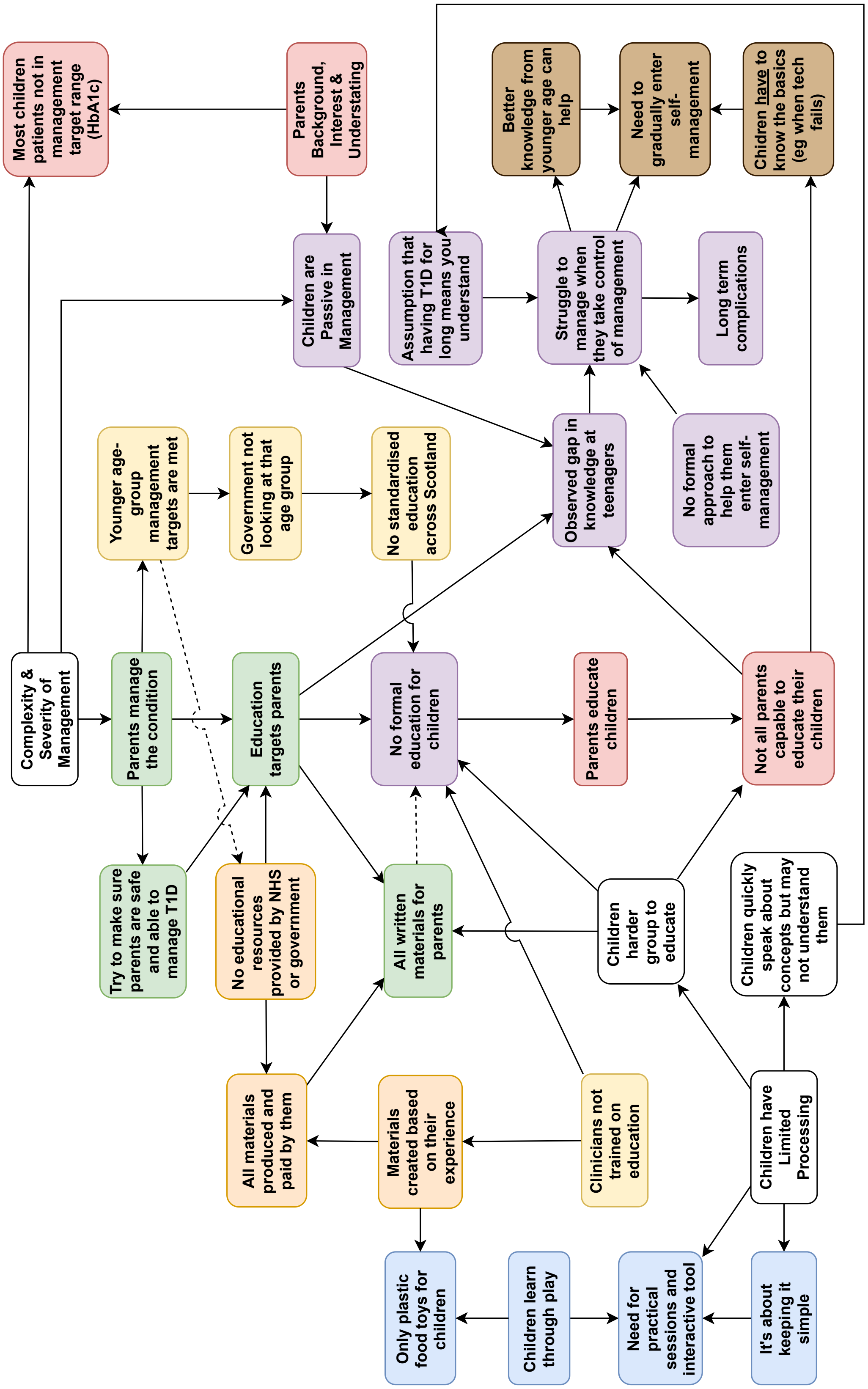

Figure 4.3: The resulting codes of the thematic analysis of the first stage's interviews. The arrows in the figure represent influence, with the pointed being influenced. The dotted arrows represent influences that were not clear on the data but are based on the author's understanding. The different colours represent themes which are represented in Figure 4.4 on page 42

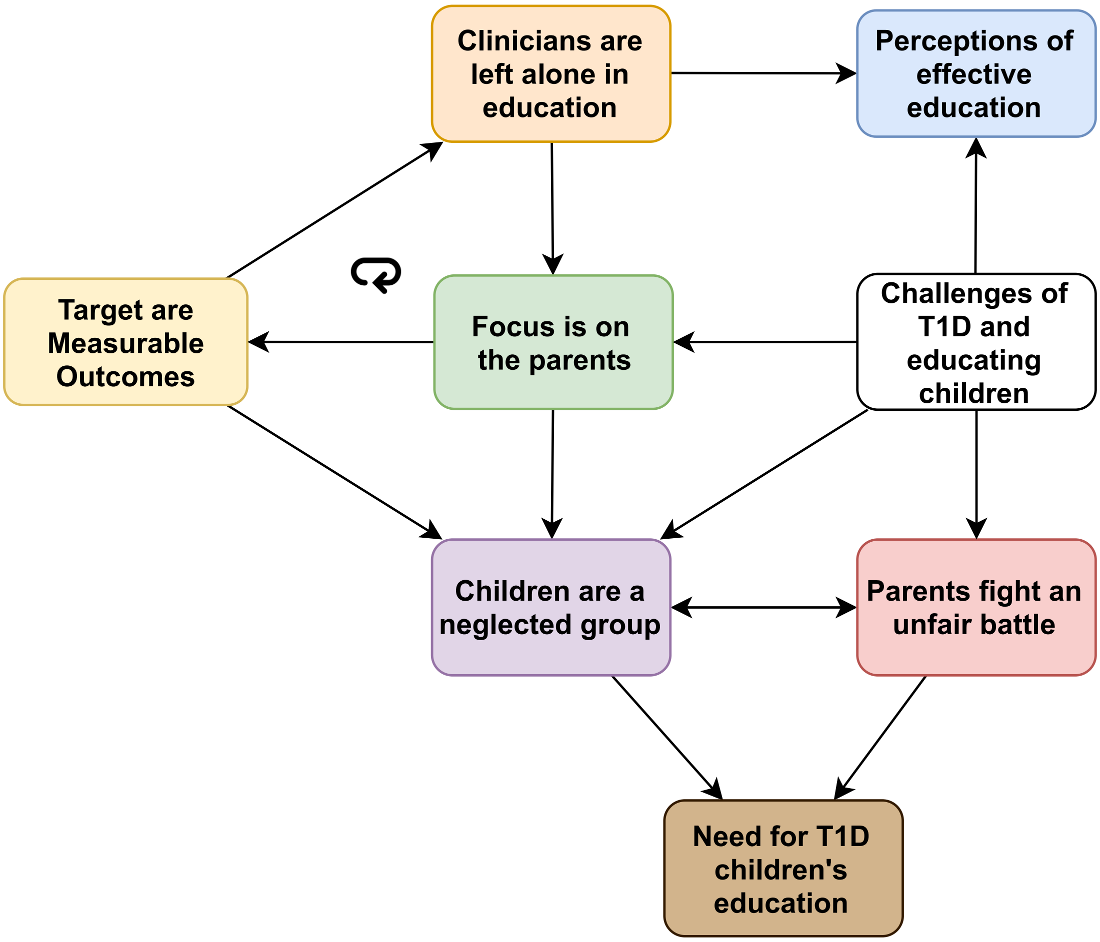

Figure 4.4: The themes and the influence they have on each other

> – *Most people [clinics] have their own formal education. So, in different places they would have their own formal education packages, they might be slightly different to this [Yorkhill's]. I think most places in the NHS give some kind of written education. (...) Each service is very different.* [N1]

**Clinicians not trained on education**

The clinicians are not trained by the health-care system on education. Hence, educating younger children is not easy for them.

> – *From an NHS point of view, there isn't any guidelines about how to do education; anything. (...) It's hard for us, 'cause we are not educationalists, we are nurses.* [N1]

#### 4.2.9.2 Theme 2: Clinicians are left alone in education

As education is not a priority, clinicians are not supported in any way to educate younger children. The lack of educational resources and funds means that clinicians are alone in producing the materials they need, based on their understanding and capabilities.

**No educational resources provided by NHS or government**

The clinicians are not supported by the health system or the government in providing education to the families.

> – *The NHS don't really provide anything [educational materials].* [N1]

**All materials produced and paid by them**

According to N1, all the materials are produced by them and funded by a charity stand in the clinic selling toys to patients.

> – *We had to create all the educational materials 'cause the NHS don't really provide anything. (...) All the educational materials we use was developed by the diabetes team, ourselves; our team. (...) We run a small charity stand on the entrance [of the clinic] and with the money we gain we print the booklets.* [N1]

**Materials created based on their experience**

Because clinicians are not trained in children's education, any materials created were based on their experience and were iterated throughout the years to end up in their current form.

> – *It's all based on our experience. We just have to, we just kinda learn over time.* [N1]

#### 4.2.9.3 Theme 3: Challenges of T1D and Children

The complexity of T1D was mentioned many times by all three participants. It was made clear that the complexity and the seriousness of T1D management, along with the limited processing capabilities of younger children, are two of the main reasons that the context is facing many challenges.

**Complexity and severity of management**

The complex and continuous management process of T1D makes it very challenging. Poor management should be avoided because of the short-term (Hypoglycemia) and long-term (e.g. damage to eyes and feet) health complications.

> – *Everything is going to affect your blood glucose. (...) It's a really really hard thing to manage. It's day in day out and you really can't take your eye off the ball –at all. (...) If they don't manage it they will become unwell very quickly or would affect them later on in life.* [N1]

**Children harder group to educate**

The complex concepts of diabetes are very hard for young children to understand. Moreover, children get very quickly disengaged during education.

> – *We try and talk with the [younger] children as well, as it's age-appropriate. You know, but they're not gonna understand that [things taught to parents], so it's not really appropriate to do all of that with them. (...) They very quickly get bored [during education].* [N1]

**Children have limited processing**

Children cannot deal with diabetes management due to their limited understanding and capacity to process all relevant information.

> – *Most of the children in such young age cannot even compare numbers e.g. what is 8 compared to 7. Imagine now what happens when it comes to decimal numbers. They need simple depictions like a scale comparing two different things, or bars that represent a number visually.* [D1; indirect quote]

> – *They do actually understand quite a lot, but what kind of processing do they have at that age?* [N1]

**Children quickly speak about concepts but may not understand**

The fact that children quickly mention and recognise T1D concepts does not mean that they understand them.

> – *They recognise the carbs, they talk about injections, they talk about their jags, so they do at really young age become familiar with this. (...) Diabetes is such a huge condition that they might understand that they have to take their insulin injection but they might not understand the complications and problems later on in life.* [N1]

#### 4.2.9.4 Theme 4: Focus is on the parents

The participants clearly stated that parents are the priority for the provision of T1D education. Because parents are the ones who manage the condition, they need to be properly informed and equipped in order for the children to be safe.

**Parents manage the condition**

It became clear that it is the parents who almost entirely manage their child's condition.

> – *At the beginning they have to []take control of management].* [N1]

> – *They are almost entirely managed by their parents.* [G1]

**Try to make sure parents are safe and able to manage T1D**

Parents have to be properly equipped and informed in order to cope with the management.

> – *We have to make sure that parents are safe and able to carry through.* [N1]

**Education targets parents**

Because parents are responsible for the management, then T1D education is primarily targeting them.

> – *We aim the education at the parents (...) The most important thing they [children] have to learn at the beginning is blood finger testing and insulin injection. Everything else is directed to parents.* [N1]

> – *The danger is that age – most of the education that goes out from the health-care professionals goes to parents.* [G1]

**All written materials for parents**

No written materials are produced by clinicians for the children; everything targets the parents.

> – *Obviously the majority of this [booklet] is for parents to read. It's their book and they can go onto it, but there is nothing really that a child could read through this. It's really more for the parents (...) We don't have anything for the wee ones.* [N1]

#### 4.2.9.5 Theme 5: Parents fight an unfair battle

Parents are not just managing their child's T1D but they are also responsible for educating them. This dual role is very important and continuous and not all parents are capable of coping with it. Some parents do not have the background, the interest or motivation to constantly keep their child's T1D management on target.

**Parents educate children**

The parents are the main educators of their child.

> – *We aim the education at the parents and (...) the parents will then educate their children.* [N1]

**Not all parents are capable of educating their children**

Not all parents are capable of educating their child at the same level.

> – *Some people do it really well and some people don't. (...) It comes down to each parent; everybody gets the same information from us. Parents who are more proactive take the education from us and other sources and they continue to educate their children at home.* [N1]

**Parents background, interest and understating**

The effective management of the condition does not depend on the parents' background but rather their interest and motivation.

> – *When it comes to management, it doesn't really matter what background you come from. (...) Others might not see that as a priority. (...) People put things into practice day-to-day but then, maybe they are not as strict as they were at the beginning. (...) They have the knowledge, but it's the motivations to put is into practice.* [N1]

**Most child patients not in management target range (HbA1c)**

Unfortunately, most of the child patients in the area covered by the clinic are not in the target range for management goals.

> – *Unfortunately, the majority of our patients aren't in the target range (of HbA1c); 'cause diabetes is really really hard to manage.* [N1]

#### 4.2.9.6 Theme 6: Children are a neglected group

The passive role of children in management, the lack of education, their subsequent struggle to enter self-management and the health complications arising as a result of these factors make children a neglected group.

**Children are passive in management**

Most children are passive in the management process, as parents do not include them in the process.

> – *At that age so much is done for them.(...). Some parents will try and include the children all along, but then a lot of parents don't. (...)I would say that 70% of the parents have more control on management and 30% of the parents help children have a more active management role.* [N1]

> – *They are almost entirely managed by their parents. (...) The children have been sort of, on the receiving end of whatever management they get.* [G1]

**No formal education for children**

There is no formal or standardised way to educate children for their condition.

> – *We don't have formal education based at the children. As we go along we teach the children, but we don't actually do teaching sessions.* [N1]

### Observed gap in knowledge at teenagers

The passive role of their children and the lack of education result in a knowledge gap, which has been observed by the government.

> – *There are kids who had diabetes for years and still are not putting things into practice. (...) They might been doing injections for 10 years, but they still don't do it properly. A lot of that may be related to early stage education. I know an adult who has diabetes. She didn't have good education when diagnosed and she has really bad practice and she doesn't want any advice now.* [N1]

> – *The lack of knowledge that you see in a teenager, 11 to 12 year old, is usually due to the fact that the information is being given to the parents and they were too young to understand it.* [G1]

### No formal approach to help them enter self-management

Children have to transition from a state of passiveness in the management to a self-managing state without any guidance.

> [When asked about gradual transition into self-management] – *That's what we want them to do, but we have no formal approach to how/when they step that up.* [N1]

### Struggle to manage when they take control of management

When children are entering the self-management state it is very hard for them to cope with the condition's management.

> – *A problem is found in children who start going to secondary school. When they get to their teenage years they don't want to look different.* [N1]

### Long-term complications

As a result of the knowledge gap and the struggle to manage their condition, children are having serious health complications later in their lives.

> – *They sort of disengage in their mid-30s and there is a big issue where people who should be getting screening for eyes, get their blood sugar measured they don't, they just disengage and get lost; and the next time you see them is 10 years later when they come in for laser in their eyes – it's a real issue.* [G1]

### Assumption that having T1D for a long time means you understand

Adults falsely assume that children have the knowledge and skills to manage their condition based on the fact that the children have had diabetes for a long time.

> – *As it's gone through the assumption has been made that they know, because they've had diabetes for years.* [G1]

#### 4.2.9.7 Theme 7: Perceptions of effective education

The clinicians expressed their understanding of effective education. Their perceptions are based on their experience as parents and their interactions with children on a daily basis. Play and interactivity are recognised as the cornerstones of effective and engaging children's education.

**It's about keeping it simple**

Participants considered simplification of T1D concepts very important for conveying educational messages to children.

> – *I think the problem with diabetes is that you can quickly confuse children. You need to keep it simple. (...) There is a lot of information, but how much do they need to know.* [N1]

> – *They need simple depictions like a scale comparing two different things, or bars that represent a number visually.* [D1; indirect quote]

**Need for practical sessions and interactive tool**

Hands-on activities with interactive elements were pointed out as being a good approach for learning sessions.

> – *It would be good if we had practical sessions. (...) We used to do a stand up on board and talking to people, but this is outdated now. This isn't the way children learn, it's not even the way adults learn.* [N1]

**Children learn through play**

The participants spoke about playful interaction as an effective way of educating children.

> – *Learn through play is how pre-schools are educated. (...) Playing a game about diabetes familiarises them with it. (...) We would want to have an app up in the whiteboard so we can show it to the children.* [N1]

**Only plastic food toys for children**

The only age-appropriate material used for the children by the clinicians is a set of plastic food toys. These toys are used to initiate discussions between the children and the clinicians.

> – *We run a group and spend a lot of time with the parents and then I'll take some of the younger children out, 'cause we found out that the wee ones get bored very quickly. We would take them to the plastic food toys and we would say "This is an orange. Do you know what is this? Is this healthy?".* [N1]

#### 4.2.9.8 Theme 8: Need for T1D children's education

The need for education was pointed out many times. The importance of education in helping children to set a basis for coping with their condition later in life was recognised by the participants.

**Children have to know the basics (e.g. for when tech fails)**
Technology simplifies many things nowadays in diabetes management, but children still need to know the basics about their condition.

> – *Technology is playing a more and more of a role in diabetes now. (...) But actually, you still need to understand the basics; you still need to understand how your body works and why you're doing what you're doing; and it will never replace that.* [G1]

> – *There is a need for a diabetic patient to always be aware of the manual alternative of this [monitoring and managing] process, because technology failures are possible, and might have serious consequences.* [D1; indirect quote]

**Better knowledge from younger age can help**
Knowledge from a younger age was thought to be very important for gaining understanding about the condition later in life.

> – *Kids need to have that basic understanding for themselves, but a lot of the time that comes later. (...) If you've actually grown up and got education from the time you were youngster and it's developed with you, you've then sort of progressed.* [G1]

**Need to gradually enter self-management**
To prevent a hard transition to self-management children need to gradually enter this state.

> – *When children go to high-school they need to take more responsibility and this transition is hard. (...) We want them to gradually get into the full management each step at a time.* [N1]

### 4.2.10 Suggestions for the solution

Apart from the results mentioned in the previous section, there were some results from the interviews which do not describe the context but are rather suggestions about the solution. These suggestions can be categorised as scope-related or evaluation-related. These two categories of quotes were very important for the determination of requirements in the next phase and so they were included in the next phase's analysis.

#### 4.2.10.1 Scope

All the interviewees discussed aspects related to the scope of an educational intervention. The main axes of the discussions were about the ages of the target group, the content, individualised education and the interaction life-cycle.

> – *We want them [children] to have a greater understanding of what is healthy eating and what is carbohydrate and be able to put than into practice, so maybe they've seen something with us and they've said "Oh, that's a healthy food" and then they might be in the supermarket with their mom and they might say "Oh, apples are healthy, grapes are healthy". (...) If they had, maybe, a game that they did at the beginning at diagnosis, but then it was an app they could go back to. You know, a game that you can go back to later.* [N1]

> – *You cannot do many things in an academic project. That's why I am suggesting you to work only in the educational aspect [nothing about monitoring]. Also try to create something that is going to have a life-cycle. I mean something that will target to change a behaviour, rather than something that will be used forever and make it attractive! (...) Create a simple game that will help them understand the basic concepts that interact with their condition. (...) Maybe an avatar representing the child. Also, use colours; e.g. red for hyperglycemia and pale orange for hypoglycemia. (...) Maybe try to show how the different factors like insulin, exercise and sugar interact using scales. For example exercise reduces the sugar in your blood, so by adding more exercise to the scale the sugar is reduced, some scales that reduce and increase stuff like that and sees the results in the avatar.* [D1; indirect quote]

#### 4.2.10.2 Evaluation

The participants discussed the evaluation of the final educational tool. The discussions were mainly about the importance of the evaluation, ways to evaluate such an intervention and what could make it effective.

> – *I suppose you could get the parents to evaluate the children's understanding of it [the educational tool]. (...) I would find it [an educational tool] successful if they enjoyed it and they engaged with it and parents said "They learned something from it", they were able to recall something taught them.* [N1]

> – *Ability to learn, engagement, how long people play with it [educational tool].* [When asked about evaluation] *Probably educational outcomes; learning-educational outcomes are probably your easiest ones. Health outcomes, you need longer time.* [G1]

> *– I think that you can refer to parents, clinicians and teachers rather than children themselves. The children will reply in question like "What do you think about the system?" saying "It's good" and nothing more. From adults you can get an insight of whether the intervention/game was effective. They can monitor the process of the children and report for the general outcomes.* [D1; indirect quote]

### 4.2.11 Discussion

The central point made at this stage's enquiry was the lack of formal education for younger children with T1D (see Figure 4.3, page 41). This fact is not a choice for the local clinic but rather a consequence of the health system's choices not to support education and to focus only on measurable outcomes. With the lack of appropriate resources (materials, knowledge, curriculum) clinicians are left alone to deal with education and they prefer to put all their effort on educating parents whose role is irreplaceable for the management. These results (summarised by the three themes "Target are Measurable Outcomes", "Clinicians are left alone in education" and "Focus is on the parents") seem to reinforce one another and create a loop (see Figure 4.4, page 42) that prolongs/sustains the lack of education for younger children.

Without formal education for the children, the parents are –almost entirely left alone in educating their children while managing their children's condition. The challenging nature of diabetes management and the difficulty of educating younger children puts a huge pressure on their shoulders and they very frequently fail to educate their children adequately. Hence, children are entering self-management (even from high school) without appropriate knowledge and skills and thus fail to meet the management objectives. The result is high prevalence of long-term irreversible health complications. All these factors call for an age-appropriate T1D education for younger children that could equip them with the necessary knowledge about their condition and also take some pressure off the parents.

An interesting observation was the mismatch between what G1 and N1 reported about the management targets of the younger age group. G1 said that the management figures are on target, whereas N1 said that their younger patients were not meeting target levels. This might be due to a difference in the target set by each party or because this clinic might not be performing well. Nonetheless, N1 later reported that they are one of the best areas in terms of management levels.

### 4.2.12 Limitations

The number of participants of this phase might be considered as its main limitation. Due to the lack of parent participants the enquiry was limited only to the three professionals who agreed to be interviewed. These three participants, however, were all key stakeholders, experts in their fields and they represented three different perspectives of the children's T1D educational *ecosystem.* Hence, we managed to get deep insights about the general educational context, both locally and nationally, which was the goal of this stage. Finally, in order to gain more detailed insights about the context, we planned and conducted more targeted enquiries in the next stage, including also parents.

## 4.3 Conclusion

This chapter described the enquiry process and the analysis conducted in order to understand the specificities of the context. The results pointed out the need for an age-appropriate T1D education for younger children, which could potentially alleviate some pressure from both parents and clinicians. The next chapter presents a more focused enquiry, targeting current educational practices in order to deeply understand the context. After the presentation of the findings at the end of the next chapter, Section 5.3 presents a general discussion on the context by summarising results from both Chapter 4 and Chapter 5. The results of this phase (this and next chapter) are used in Chapter 6 to generate the requirements, which guided the design of the tool.

# Chapter 5

# Educational Practices of the Context

## 5.1 Introduction

This phase of the methodology was devoted to the understanding of the context. Through two stages (Figure 5.1), each with multiple steps of qualitative enquiries, we managed to gain deep insights on the specificities of the context, the educational practices and the challenges faced in the current clinical set up and system of practice.

Due to limited insights about the context before the start of this phase, which were mainly extracted from the literature, this phase was conducted using a deductive approach (general to specific). In the first stage (presented in the previous chapter) we conducted a set of exploratory enquiries and tried to approach as many stakeholder groups (involved in diabetes education and care for younger children) as possible. The results were analysed qualitatively and a first –general– understanding about the context was formed. Subsequently, based on these results, we enquired about specific practices and perceptions about them in order to deeply understand the context (this chapter).

Hence, this chapter explains the methods for capturing specifically the current educational practices and the perceptions about them, and presents the results. Moreover, this chapter summarises the findings of this phase through a general discussion on the findings about the context (Section 5.3).

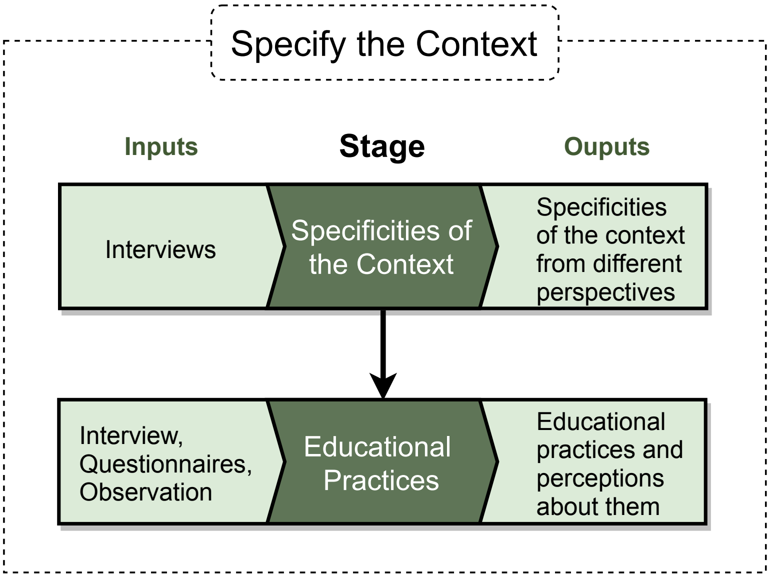

Figure 5.1: The phase “Specification of the context” with its two stages. The first stage is presented in the previous chapter (Chapter 4) and the second stage is presented in this chapter.

## 5.2 Educational Practices

After gaining a basic understanding of the clinical context’s specificities, we wanted to gain a deeper insight into the practices currently used specifically for education within the clinic. We were very interested in the main educational tool used currently by the clinicians – the plastic food toys (see Figure 5.4 on page 59). Also, we wanted to understand the targets of T1D education along with any existing approach in educating children (verbal or through the toys), to determine how this approach could potentially be enhanced through technology. Lastly, we were very keen to understand the parents’ point of view on education, the materials they use and their perception of formal diabetes education.

### 5.2.1 This stage’s steps

The three steps of this stage are presented in Figure 5.2 in the sequence they were conducted. In the first step of this stage a new interview with N1 was conducted (see Table 4.1, page 34), in order to find out in more detail how education is provided to each family from the point of diagnosis on-wards. N1 was selected for this interview as she is one of the main nurses responsible for running the sessions with the families. She was asked about the tools and techniques used in the clinic for educating children, and also about targets for any education provided to the children. The second step was to observe an educational session and understand the way clinicians try to educate children using the current approach. Another, equally important target of the observation, was the way children react to this education.

These first two steps were planned according to the second axis of the research approach, about in-context enquiries (Section 3.2.1, page 23). The main idea was to partner with an expert (N1 in this case), interview them and observe their working practices in a similar way to the master-apprentice practice (a *contextual enquiry* practice [14, 15, 175]). This was aimed at getting a deeper understanding of the context by experiencing its specificities while being as *embedded* to it as possible.

The last step was to distribute an online questionnaire to parents to get their perceptions on T1D education and find out what materials they currently use.

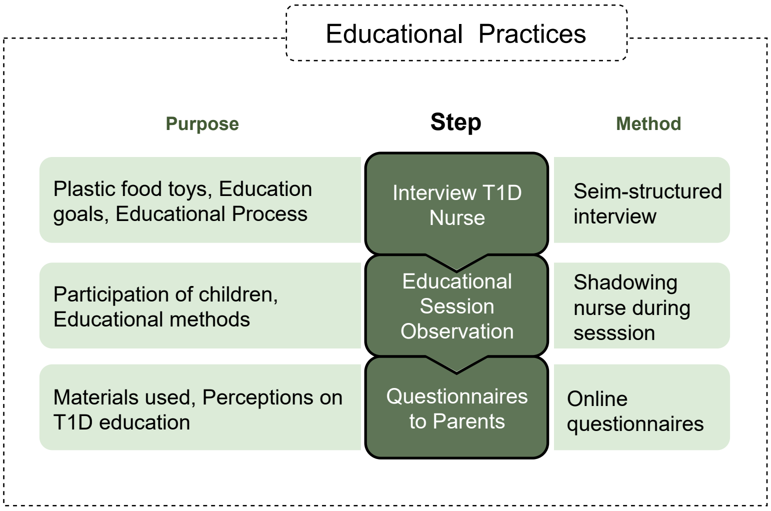

Figure 5.2: The steps of this stage, presented in the sequence that they were conducted, their purpose and the methods used.

## 5.2.2 Interview with T1D nurse

### 5.2.2.1 Protocol

A semi-structured interview protocol was chosen to guide the discussion on specific topics about the educational practices and also allow the participant to mention other aspects she considered important. The aim was to get more insights about the current educational practices and clarify things that were mentioned but not explained in detail during the previous stage (e.g. New Starts Group and plastic food toys).

The interview was audio recorded and then transcribed verbatim. The interview was not analysed for emerging themes as the target was only to summarise and describe the educational practices rather than synthesise them analytically. A service map of the educational practice, a description of the current educational sessions and the use of the plastic food toys were the outputs of this interview.

The main topics of the discussion were selected before the interview and were based on things about the educational pathway not clarified at the previous stage. The topics were the following:

- Educational pathway
- Educational sessions

- Plastic food toys
- Problems and challenges of the existing approach

#### 5.2.2.2 Findings

**Finding 1: Summary of the process – Care and educational pathway**

The educational and care process, from the point of diagnosis and on, is summarised in Diagram 5.3.

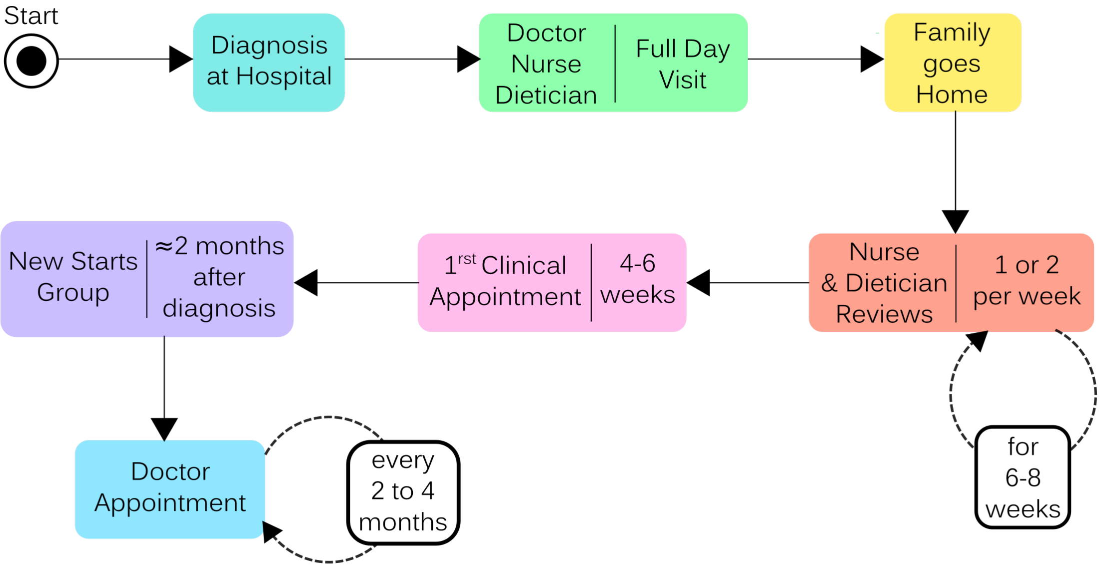

Figure 5.3: Process of the clinical service delivered to newly diagnosed families.

Children are diagnosed in hospital, when they become hospitalised with serious symptoms. After the diagnosis, a team consisting of a Diabetes Paediatrician, a Diabetes Nurse Specialist and a Diabetes Dietitian visit the family in the hospital. This visit lasts for a full day and the clinicians give as much information as possible to the parents, in order to get them started with the management of T1D. The clinicians hand the parents two educational booklets, one with information about management and one with information about nutrition. The clinicians also speak to the child, but the level of interaction depends on the age of the child and their post-diagnosis shock. Subsequently, the family is dismissed from the hospital and they return to their home and start putting the things learned about management into practice. The booklets given to the parents were created 15 years ago by two members of the team, a consultant paediatrician and a dietitian, and have been refined throughout the years to meet the needs of families.

or the next 6 to 8 weeks, the family meets a nurse and a dietitian 1 or 2 times per week. The clinicians have a set of educational targets for the basics of T1D management that they want the parents to achieve; namely, learn about carbohydrate counting, insulin types and dosages, hypoglycemias and hyperglycemias, and blood glucose measuring. During these meetings, the clinicians go into more detail about diabetes concepts and management. They also review parents' management understanding and practices and help them to improve. If parents after the 6 to 8 weeks are still not coping with the management, or if all the educational targets have not been met (according to the nurse's and dietitian's judgement), this period is extended as needed.

The first clinical appointment with a diabetes paediatrician occurs 4 to 6 weeks after the diagnosis and reoccurs every 2 to 4 months, depending on the management outcomes. During these appointments the doctor performs some clinical checks on the child and guides insulin dosage adjustments or points the parents to a dietitian or a nurse for further assistance.

After around 2 months after the diagnosis, all the recently diagnosed families are called in an educational session in the clinic, named "New Starts Group" (NSG). This educational session lasts about 2 to 3 hours and targets mainly parents and older children (aged 10 or older).

#### Finding 2: Educational Session – New Starts Group

According to N1, NSG is directed to parents and children 10 years or older. Parents can bring even younger children if they think they will benefit. The threshold of 10 years was set because it was observed by clinicians that younger children cannot be engaged for such a long period of time [N1]. The attendance at the NSG is variable, depending on many factors, such as the availability of parents, number of diagnosed children or season of the year. Some NSGs do not have any child participants and there is no guarantee about the child's age group uniformity.

NSG is the only educational session about management that children can attend. All the other education delivered to children is on a discussion basis during clinical appointments where clinicians assess the children's knowledge through questions and try to educate them by initiating discussions.

The NSG consists of three parts. The first part is introductory to the session and a few ice-breaker activities take place. The second part is the core of the session where parents and children split and are in separate rooms. The nurse asks if the children want to follow her and the children chose if they want to join or stay with the adults. Then the nurse takes the children to a separate room from the parents. The dietitian might join the children's group if the number of children is more than four. If the children are more than 2 the clinicians split them into groups in order to increase involvement and engagement. The clinicians (in the room with the children) have a predefined set of topics about diabetes and they ask each group of children to choose one. These topics are the following:

1. Food and healthy eating

2. How to treat hypos[1]
3. Counting carbohydrates
4. Exercise
5. Coming to clinic
6. Doing an injection
7. Being ill

After each group chooses a topic, then the nurse asks them if they want to create a poster, make up a play or tell a story about it. According to N1, almost all of the time the children choose to do a poster. The nurse tries to educate children verbally, during the poster creation, by initiating discussions about diabetes. The main focus is to find out what the children's understand about diabetes. Because it is hard to keep children engaged for an hour the clinicians have the set of plastic food toys ready to use in the session. If children are not interested in drawing posters or learning about carbohydrates and healthy foods (through the plastic food toys), the clinicians might read a book or a story to them.

For the third part, parents and children gather together again in one room. Initially, the nurse with the help of the children presents to the whole group the materials they have created. Then children and parents get mixed up by the clinicians and are split into groups. These groups try to solve a worksheet, about a boy with diabetes. After this exercise, the NSG is over and the families are dismissed.

#### Finding 3: Plastic Food Toys

The plastic food toys which are used by the clinic are shown in Figure 5.4 on page 59. N1 refers to the toys as the "food models" because they are not used in any pretend play scenario and thus the term toys was not considered accurate by her. Rather, they are used to depict real-world foods (like photographs of the foods) and initiate discussions about carbohydrates and healthy foods. Usually these toys are used by a dietitian, who joins the session when there are more than four children attending, and tries to initiate discussions about the nutritional aspects of foods and their impact on diabetes through the plastic food models (Figure 5.4). These models are used infrequently and there are no specific (predefined) educational scenarios for them; the choice if the food toys will be used and how they will be used depends entirely on each clinician.

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[1] Hypo is a shorter form of the term Hypoglycaemia. It means low blood sugar levels. Results in dizziness, confusion, blurred vision. If not treated quickly can lead to seizures or loss of consciousness.

Figure 5.4: Plastic food models used to illustrate food groups when educating about nutrition.

#### 5.2.2.3 Finding 4: Problems and Challenges

According to N1 all T1D education targets parents and is not directly tailored to the children. Nonetheless, they try to include the children in the process, but without educating them about the diabetes concepts. The main things the clinicians try to pass to the children are related to the way management is delivered, rather than the rationale behind the management's decision making.

> – *We don't directly tailor our sessions to the children, but through the parents, they get a lot of that education. (...) Generally it's always with the parents, but through that (NSG) we are trying to talk with the children as well - as it's age-appropriate.* [N1]

A major problem of the current approach is to keep the participants engaged during the educational sessions. Children and even parents tend to get bored and disengage very soon during educational sessions.

> – *We find very quickly the way we're educating people, they are not engaging with us a lot of the time. (...) It gets very boring if someone is talking to you for an hour. And the wee ones we see them very quickly to get bored, definitely (...) We know the way we deliver education is not the best way; we do it because we have to give out so much education.* [N1]

Lack of interactivity has been identified as a barrier to conveying knowledge effectively and clinicians have taken steps to increase interactivity. Nonetheless, even the introduction of more interactive tasks (as the drawing of posters or the worksheets) have not proved very helpful to the clinicians, who are not experts in education.

> *– The children like the interactive; e.g. the food models and when they are chatting back to you. We have though the years improved the approach by removing more slides and adding more interactive tasks. Not all of us are good at talking in front of big groups, nor we like it. Some are good and engaging, some are not. (...) We try and do worksheet, we try and brake them up and make it more interactive, but it's hard.* [N1]

Interactivity and fun are targets of the existing educational approach towards children and clinicians look forward to adopting a way to achieve these targets.

> *– So I think it would be really really good if we had or could have a different way to go with them. (...) If it's something that can make it more fun, to make them think about it again, that would be excellent, that's what we try to do. If you have them up in their feet playing with the things it would be definitely much more receptive to that.* [N1]

Simplification of the concepts was again mentioned as a very important feature of effective education for children. N1 gave specific depictions of how they describe the concepts to children and the level of detail that is appropriate for them to understand.

> *– I try to keep it simple. I talk about being healthy: "If you wanna grow big and strong you need to eat all your dinner and take your insulin; it's your insulin that keeps you healthy". (...) There is the door, you can't get the sugar in. I try to explain insulin to them as the key that lets sugar into their body. The tummy a bit like a washing machine mixing all up.* [N1]

#### 5.2.2.4 Interpretation of findings

Throughout the care and educational pathway of a family there is a lot interaction with the clinicians in a clinical setting. Parents are educated from the first day of the diagnosis and until the clinicians are sure that they comprehend the basics of the management. The only educational session that younger children can attend is NSG, even though it targets parents and older children. Younger children are not encouraged to attend because the clinicians do not have an effective way to educate and keep them engaged while the parents are educated. Any education delivered to children is though the clinicians talking to them. Also, the clinic lacks interactive and age-appropriate materials and even the ones that could support age-appropriate educational scenarios (the plastic food models), are not used in play scenarios. Interactive education through simple and clear educational messages is considered as the key to effective T1D education.

### 5.2.3 Observation at the NSG

#### 5.2.3.1 Goal

According to the findings of the interview with N1 (previous section), the New Starts Group (NSG) was found to be the only educational session that younger children can attend. Because the NSG played such an integral role in the education process we considered it very important to conduct an observation in an NSG and get a deeper understanding of the process and its educational impact. Due to the long time span between two NSGs (4–6 months) and the variable attendance (some have no young children attending) only one observation was conducted. Nonetheless, the results were very informative and illustrating.

#### 5.2.3.2 Protocol

The author silently observed the NSG session, taking notes. At the start of the NSG the author introduced himself as a university student studying the educational practices of the clinic. After the beginning of the session the participants were split into two groups; adults and children. The author followed the nurse and the children's group to another room. He sat on the same round table with the children and the nurse and was focused on taking notes, without interacting with the children at all and without taking part in the process. For this observation NHS ethics approval was granted.

#### 5.2.3.3 Participants

The nurse that took part in the NSG was again N1, as she is mainly responsible for running the NSG. The other two clinicians who took part were D1 and T1; their profiles are shown in Table 5.1. In total 6 children were in the NSG and from these the two older boys (12 and 16 years old) did not want to split from the parents group. The profiles of the children observed are presented in Table 5.2. The participants were recruited by the clinicians through the standard NSG recruitment process – all families of newly diagnosed children with T1D were called to the session.

Table 5.1: Profiles of the clinicians who were present in the NSG. Please note that only N1 was present in the room with the children when the observation took place.

| ID | Role | Gender | Experience |
|---|---|---|---|
| D1 | Consultant Paediatrician | Male | 25 years |
| N1 | Nurse Specialist | Female | 8 years |
| T1 | Clinical Specialist Diabetes Dietitian | Female | 27 years |

Table 5.2: NSG Child participants

| ID | Gender | Age | School Grade | Diagnosis |
|---|---|---|---|---|
| C1 | Girl | 10 | P6 | 3 months |
| C2 | Girl | 5 | P1 | 1.5 months |
| C3 | Girl | 5 | P1 | 2 months |
| C4 | Girl | 9 | P5 | 2 months |

#### 5.2.3.4 Findings

The session began with a quick introduction from the nurse and the dietitian, explaining the session's goals and some housekeeping. Afterwards, one parent from each family introduced the child and the rest of their family members who were present. They shared the diagnosis date and how well were they coping with diabetes so far. Subsequently, N1 asked the children if they wanted to follow her to the other room to discuss diabetes and draw posters. From the six children who were in the room with the parents, only the four younger ones agreed to follow N1. Two boys, aged 12 and 16, stayed in the room with the parents. T1 and D1 stayed in the room with the parents and gave a presentation on diabetes.

The four children who followed N1 to another room sat at a round table. N1 brought coloured markers and two poster sheets. She sat on the round table and began speaking with the children. The author sat next to N1 and during the session was silent, taking notes. N1 started asking general diabetes questions of the children and explained basic diabetes concepts related to those questions. Some of these questions were: "Which nurses have you seen so far?" and "Do you have a relative with diabetes?" Then she explained some basic diabetes concepts and asked the children related questions.

Throughout the discussions (e.g. about hypoglycaemias or difference between T1D and T2D) the two older children C1 and C4 were more active; C2 and C3 did not answer questions unless these questions were explicitly directed to them. During the discussions C2 was skittish and seemed to be bored. She looked in different directions, she was not staying still on her chair; she seemed to be bored as soon as she stood on the chair. C3 was very calm and paid attention to the discussions, without participating unless she was directly asked something.

About 15 minutes after entering the room (around 10 a.m. – half an hour after the beginning of the session), C1, C2 and C4 took a snack out of their bag to eat. C1, before having her snack, confidently tested her blood glucose. After the initial discussions, N1 suggested that they should start drawing the posters. She asked the children if they wanted to draw posters about the things they were discussing or about something else. C1, C3 and C4 agreed to draw about the things they were discussing.

N1 split the groups as following; C1 with C3 formed group 1 and C2 with C4 formed group 2. This split was also according the way children were sitting around the table. N1 assigned the older girls the role of the "poster designer" and to the younger ones the role of the "helper".

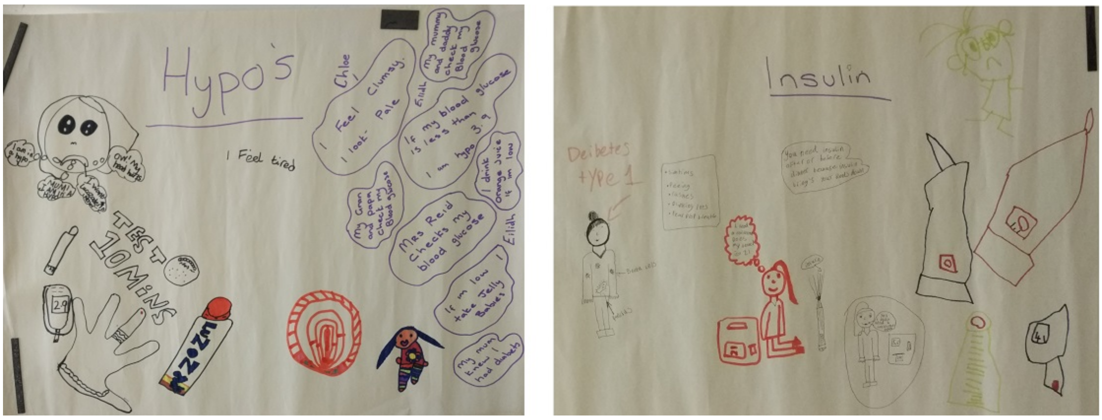

Figure 5.5: Posters drawn by children in the NSG. Left: Group 1, Right: Group 2

According to the discussions, N1 set the theme for each poster, and group 1 was assigned to draw about hypoglycemias and group 2 about insulin.

C1 and C4 were more active, talking while drawing and constantly coming up with ideas about things they should draw in the posters. For a long time C3 drew only a girl (Figure 5.5: left poster bottom right), and thus N1 started asking C3 about her experiences and (N1) wrote down these experiences on the poster (Figure 5.5: left poster text 'bubbles' on the right).

C3 drew something that even she, when asked, was not sure what it was. C2 drew two insulin pens, a glucose monitor and an old person. C1 and C4 drew more complex and illustrative pictures, related to the theme they were assigned (see Figure 5.5, page 63). When the time came to merge with the parents group, the children stood up and C2 and C4 approached the table having the plastic food models on it (see Figure 5.4, page 59). C2 asked if the food toys were real. C4 said that they were too accurate in their depiction; that they looked weird. C1 and C3 approached the models and started touching them. N1 said that it was time to go to the other room, and the children left the foods and went to the other room.

When the children rejoined their parents, N1 took the two posters and stuck them to a whiteboard. C2 ran to her parents and pointed at the things she had drawn. N1 asked the children to come to her to help her present their posters. N1 explained who the two groups were and what the theme for each poster was. Then C1 started presenting her drawings and explained the rationale behind them. C3 hesitated about talking in front of all the parents, so N1 started explaining the drawings and the things that were written. C3 was constantly nodding positively when N1 was presenting her drawings. The same thing happened with C2 and C4. C4 presented her drawings and N1 presented for C2. Nonetheless, C2 seemed to be very proud of her drawings when N1 presented them.

After the presentation of the posters, T1 split the parents and the children into four different groups. All the groups were given a worksheet with a few practical exercises about diabetes. The worksheet was based around the daily life of a diabetic boy, and most of the exercises were about insulin dosages and carbohydrate counting. During these exercises C1 and C4 were actively involved in the group assessment. C4 wrote answers on the worksheet. C2 and C3, on the other hand, did not participate at all. Specifically, C2 lay on a chair, seeming very bored, and then played with a doll; C3 was most of the time playing with her mother's phone.

After each exercise, N1 and T1 discussed the answers with the groups and gave them more information when needed. At the end of the group assessment, T1 thanked the families for taking part, and the meeting ended.

#### 5.2.3.5 Interpretation of findings

The ages of the children clearly impacted the level of involvement they had in the poster task and in the worksheet group activity. The younger children seemed to focus more on objects related to diabetes (e.g. insulin pens) and were not able to synthesise depictions or stories about the concepts. The older children, though, were very engaged and were seriously trying to draw and explain the theme they were assigned. All children, though, seemed to enjoy drawing something about their condition. Younger children were very quickly disengaged when there was nothing that they could contribute to, or when there was nothing going on that interested them. Moreover, the older children seemed to dominate the discussion in the room with N1; many times they interrupted C2 and C3 in order to say something. Lastly, the children seemed to be interested in the plastic food toys and were curious to see what they are and how are they used.

In terms of educational effectiveness, the session did not seem to have an impact at all on the children. During the split, children were engaged to a drawing exercise which was mainly about reflecting on their experiences rather than learning something new. The older children seemed to have an adequate knowledge for the management of their condition for their age. The nurse tried to initiate discussions and understand the depth of the children's knowledge, and tried to explain things that they did not know. This was done while the children were drawing and it was only based on discussion. The only part that children were engaged on as a hands-on learning task was during the worksheet task after the groups were merged. However, the younger children could not participate at all as the worksheets required numeracy and literacy skills. The older children participated actively but it was not clear if they managed to learn anything, because all the tasks on the worksheet were solved collaboratively with the parents. After observing the session, it was clear to the author why clinicians think that the session is appropriate only for children aged 10 and older. The way the session was organised, its goals and the way clinicians approached education, was not appropriate for younger children.

The fact that only one NSG was observed, in which the children were all girls, does not allow us to generalise the results with confidence. More information would need to be collected from different groups as well, of other ages, larger groups and containing boys also in order to be able to generalise with confidence. This is very hard, though, due to the limited number of NSGs taking place each year and to the variable attendance. These limited results do, however, provide a valuable insight into how the sessions with the children run. Moreover, they illustrate the approach of the clinic and the use of the existing materials available. Even though the data were limited, they provided key insights about the process and confirmed many of the conclusions from the previous enquiry stages. N1 explained after the session that most NSGs with children of younger ages run similarly to the one that was observed. When older children or adolescents take part they mostly prefer to discuss rather than draw.

### 5.2.4 Questionnaires to parents

#### 5.2.4.1 Goal

Due to the extended enquiry in the context up to that point, a first (sufficient for our project) understanding of the context had been formed. Up to that point, however, we were not able to obtain parents' insights (despite the attempt to recruit them for interviews; see Section 4.2.5 on page 35). Nonetheless, in order to have an even fuller picture of the context, we wanted to have the parents' perspective as well and see if the findings were aligned with what they were experiencing. Hence, we decided to approach them again, this time through a more flexible enquiry method. Due to time limitations (it was decided and conducted at the end of this phase, right before the design phase), the uncertainty of getting enough participation and the existing deep insights acquired about the context, this enquiry was designed to give more descriptive rather than reflective results.

#### 5.2.4.2 Protocol

In order to ease participation (considering time and scheduling constraints the parents might have had) we decided to use a questionnaire survey as the most appropriate method for this group. A questionnaire was distributed through a social media local support group page. This group, when the questionnaire was distributed, had 230 members.

The survey had 25 questions in total, 8 of which were open-ended. From the 25 questions, 4 were about demographics; 4 about the educational practices; 6 about perceptions of education; and 5 about the perceived outcomes of current educational approaches; 1 about existing educational materials; 5 about other challenges related to T1D education. The questions can be found in Table A.1 on page 166 (Appendix A)

The surveys were not analysed for emerging themes as the target was only to summarise the parents' perspective, in order to see if it is in alignment with the existing findings, rather than synthesise their perspective analytically.

#### 5.2.4.3 Participants

Participants of this stage were parents of children with T1D from the local community, covered by the *Children's Diabetes Service of Greater Glasgow and Clyde*. The inclusion criteria were parents whose children had been attending the local diabetes service. The inclusion criteria were not bound by the child's age, for two reasons: 1) to have more participants, and 2) to observe any differences or similarities to the challenges faced by different age groups.

In total 22 parents, translating to almost 10% of the online group's members, completed the questionnaire. Their profiles are shown in Table5.3

Table 5.3: Profiles of the parents who completed the questionnaires.

| ID | Age | Child's gender | Child's age | Age of diagnosis |
|---|---|---|---|---|
| P1 | 30 - 40 | Girl | 4 | 2 |
| P2 | 40 - 50 | Boy | 5 | 2 |
| P3 | 40 - 50 | Boy | 7 | 4 |
| P4 | 25 - 30 | Girl | 7 | 6 |
| P5 | 30 - 40 | Boy | 7 | 6 |
| P6 | 40 - 50 | Boy | 7 | 4 |
| P7 | 40 - 50 | Girl | 7 | 6 |
| P8 | 40 - 50 | Boy | 7 | 7 |
| P9 | 30 - 40 | Boy | 8 | 7 |
| P10 | 40 - 50 | Boy | 8 | 6 |
| P11 | 50 or older | Girl | 9 | 5 |
| P12 | 40 - 50 | Boy | 9 | 8 |
| P13 | 18 or younger | Boy | 9 | 9 |
| P14 | 40 - 50 | Boy | 10 | 10 |
| P15 | 40 - 50 | Girl | 11 | 7 |
| P16 | 40 - 50 | Boy | 11 | 10 |
| P17 | 40 - 50 | Girl | 12 | 1 |
| P18 | 40 - 50 | Girl | 12 | 12 |
| P19 | 30 - 40 | Boy | 14 | 4 |
| P20 | 40 - 50 | Girl | 14 | 11 |
| P21 | 40 - 50 | Boy | 15 | 14 |
| P22 | 50 or older | Girl | 17 | 4 |

#### 5.2.4.4 Results

**Question 1**

**Who is mostly teaching your child about diabetes? [1=Never . . . 5=Mostly]**

Table 5.4: Descriptive statistics for the first question.

| Order | Answer | Average Score | Standard Deviation | Responses |
|---|---|---|---|---|
| 1 | Me and/or spouse/partner | 4.64 | 0.66 | 22 |
| 2 | Clinicians | 3.44 | 0.92 | 18 |
| 3 | Other family member/s | 1.77 | 0.72 | 13 |
| 4 | Other | 1.7 | 0.95 | 10 |
| 5 | School teacher | 1.13 | 0.35 | 15 |

The responses from this question were in accordance with the outcomes of the previous stage's interviews; the parents are the main source of education for the children. The second source of education for the children was the clinicians. It was also important that parents were almost sure that their children are not being educated by their school teachers.

### Question 2

**Have you and your child attended any educational session for diabetes in Yorkhill?**

From the responders, only 13 families (63.6%) had attended educational sessions in Yorkhill clinic.

### Question 3

**Have you or your child ever been to any formal educational sessions anywhere else?**

From the parents who responded, 4 had been educated in other clinics in Scotland, 2 had been educated abroad and 5 stated that they had not been educated in other setting. Interestingly enough, 4 parents had not attended an educational session in Yorkhill or in any other clinic.

### Question 4

**Did you find it useful? (the educational session)**

All parents (18) who had attended an educational session found it useful. These sessions, at least at Yorkhill clinic, are conducted close to diagnosis; hence, they provide helpful information in the beginning when parents are still not experienced.

### Questions 5 & 6

**5: How engaging did you find it? & 6: How engaging did your child find it? [1=Not at all ... 5= Very much]**

All parents who had attended educational sessions replied to both these questions, which implies that their children had joined them. Question 5 (about the parent) had an average score of 4.39 (SD=0.78) and Question 6 (about the child) received a 3.39 (SD=1.29) score. The average score for those who had attended an educational session in Yorkhill diabetes clinic was 4.14 for the parents and 3.5 for the children. The responses for the parents were more uniform, in the sense that the standard deviation was low and the lowest score was 3. The responses for the children were lower, with a larger standard deviation and with two parents giving *1* as their score. These results seem reasonable, as these sessions are designed for parents.

### Question 7

**Did you learn anything useful? (from the educational session)**

In this question 14 parents replied in total. Of them, 4 parents replied just “Yes”, 6 parents mentioned specific management guidance and advice (like carbohydrate counting) that they had learned and 1 parent replied “Nothing much I didn’t know from initial diagnosis” [P17] and 1 parent said ”It was interactive so get our attention” [P1]. Lastly, two parents, who were more enthusiastic, wrote:

– *Everything! Well as much you can tell at the training but it's never enough... I'm always learning about this disease*" – [P11]

– *Everything, we were newly diagnosed.*" – [P16]

**Question 8**

**Did your child learn anything useful? (from the educational session)**

In this question 13 parents replied. Out of all the responses 2 were simply 'Yes', 3 mentioned specific skills that their children learned (carbohydrate counting [P22], injections [P19], blood testing-[P16]), 3 were neutral in tone and 4 were negative. Two of the 3 neutral mentioned that the social aspect of the education was important. The 4 negative focused on the lack of engagement or interest and the other two on the effectiveness.

– *He hasn't really taken it in.* [P4]

– *you get Lego if you sit nicely during diabetes sessions...*" -– [P9]

– *No he was bored.* [P15]

– *Not sure...just confirmed what I have taught her.* [P18]

– *Not so much useful but it was good to be able to train with other kids and together.*"
– [P10]

– *Learned about pancreas and why it does the work anymore.*" – [P7]

**Question 9**

**Educational sessions help children change their behaviour towards better diabetes management [1=Disagree ... 5=Agree]**

This question received 20 responses and got an average score of 3.85 with a standard deviation of 1.09. Even though the average score is relatively high, the standard deviation points towards a disagreement. Specifically, 9 parents gave a score of 2 or 3 – including all those who replied negatively to the previous question. Maybe these scores are influenced by their bad experience expressed in the previous question. Also, 3 parents gave a low score even though they haven't been to an educational session. On the other hand, 11 parents gave a score of 4 or 5. Some of these parents (2) had not responded to the previous question and some of them (4) replied without having been to an educational session. The next questions can shed more light to these answers, as they are related to this question.

### Question 10

### Can something be improved in the way children are currently educated about their diabetes?

The response rate for this question was 16 out of 22 parents. The parents suggested many interesting things and their responses were grouped. The results are as follows:

**Age**: 6 parents mentioned the need for more sessions targeting younger children, more sessions where children get to play and learn with other children of the same age and more sessions closed to the diagnosis.

> – *More sessions with other children same ages*" – [P16]

> – *More targeted at under 12s would be good*" – [P4]

**Hands-on / Interactivity**: 4 parents suggested that the education should use more interactive and hands-on techniques and some connected it to the introduction of technology.

> – *More hands-on, taking get in to account on their ages.*" – [P15]

> – *Definitely more interactive - especially games through electronics (iPad) were to be used.*" – [P9]

> – *More engaging, more interaction.*" – [P12]

**Fun**: 3 parents considered fun and engagement to be important elements of the education.

> – *Make it more fun.*" – [P6]

> – *More tech hands on, maybe apps that are fun but educational.*" – [P8]

**More sessions**: 3 parents suggested more educational sessions.

> – *(...) I guess on-going training not just the initial diagnosis.*" – [P11]

> – *Perhaps more sessions at diagnosis in how best to manage the condition as felt once we left hospital we were on our own*" – [P21]

> – *more time with the children and more training for them to understand the importance of their diabetes and the obvious life changing emotions for all that entails - it's not just training on diabetes it's training on coping that would help too for all parents and children - it's the biggest thing trying to keep positive! I guess on-going training not just the initial diagnosis.*" – [P10]

**Current environment**: 3 parents mentioned the current environment in the clinic. Two of them mentioned their positive experiences with education and the third stated that her child has not yet received education.

– *There can always be improvement.. Our family learnt everything in a two day period and then came home...nervous to say the least. D1 phoned us on the first morning... Yorkhill Diabetes Service are outstanding.*" – [P12]

– *They did their absolute best with the facilities and tools available.*" – [P10]

– *My child is aged 5 and was diagnosed at age 2, since that time he has received no offer of educational training to help him understand his diabetes.* [P2]

**Group Learning**: 2 parents suggested group learning as a positive improvement.

– *more sessions with other children same ages.* [P15]

– *Clinic appointments with others the same age.* [P16]

**School**: Lastly, one parent mentioned that schools should teach more about diabetes

**Question 11**

**Diabetes education is important for children [1=Disagree ... 5=Agree]**

All parents replied to this question and apart from 2 who gave a score of 4 all the rest gave a 5 and hence the average score is 4.9 . Clearly, all the parents considered diabetes education to be of paramount importance for their children.

**Question 12**

**Do you think that experience is a better teacher or do you believe that formal education is more useful? [1=Experience is better ... 5=Formal Education is better]**

The response rate for this question was 21 parents. The average score was 2.86 and the standards deviation was 1.28. The parents' opinions did not seem to be in alignment in this question. This question was designed to elicit the perceptions about formal T1D education, mainly in relation to their children. However, this might not had been clear from the question text and thus some parents might have answered about their own education. Therefore, some parents might have replied based on the way they have learned. Still, the split of opinions seems to be expressing a need for both formal but also practical education. Interestingly enough, all the parents who thought that experience was more important than formal education (scores 1 and 2) had attended educational sessions. Again, we cannot conclude with confidence about this fact, as it is not clear if they were referring to their child, themselves or both.

### Question 13

**Do you have any educational game, video programmes or any other kind of educational artefact for T1D?**

This question received 16 responses and 11 of them were a simple “No”. There was a parent who replied “Yes” and the remaining 3 parents mentioned leaflets and books/booklets and one mentioned that they have ”various educational DVD’s”. These results present evidence about the lack of age-appropriate materials, especially interactive ones, even in the home setting.

### Questions 14, 15 & 16

**14: Diabetes educational games can help children learn more efficiently. 15: Diabetes educational games are going to be more enjoyable than other educational methods.**
**16: Technology can help children learn more about diabetes.**
**[1=Disagree . . . 5=Agree]**

For question 14, 21 parents replied. The average score was 3.95 and the standard deviation was 0.92. Both the number of responders and the relatively high average score indicate a positive belief about the value of games for T1D education.

For question 15, only two of the 22 parents did not answer. The average was 4.1 and the standard deviation was 0.91. Similar to the previous question, this question supports the value of games for T1D education and indicates their preference over other educational materials.

Question 16 received 21 responses. Its average score was 4.52 and the standard deviation was 0.75. Most of the parents agreed with confidence to this statement. This perception of theirs might be influenced by the relationship that children have with technology but also the fact that technology is engaging for children.

These three questions –jointly– suggest that the combination of educational games and technology can be an effective and enjoyable medium for children’s T1D education.

### Question 17

**What is the most difficult concept for your child to understand?**

The answer rate for this question was 17 out of 22 parents. Parents’ responses were grouped as follows:

**Life-long condition**: 4 parents stated that their child could not understand the fact that diabetes is a life-long condition that “never goes away” [P10] and that it will “never get better” [P4].

**Insulin**: 3 parents agreed on the fact that insulin is a hard concept that is not easily understood by children (along with calculations of insulin dosages).

– *My son is only five just now , he doesn't really understand yet how his body works and how insulin works to help him.* [P2]

**Why me?**: The question "Why me?" was mentioned by 3 parents. Their children could not understand why they were different from the other children.

**Food intake**: 2 parents found that for their children it was hardest to understand that they cannot eat *freely.*

The remaining 4 answers by one parent each mentioned: other factors that affect diabetes [P3], importance of equipment [P5], poor management has long-term effects [P22], child diagnose old enough and understands everything [P21].

From the parent responses it seems that children cannot understand that diabetes is a lifelong condition. To them it does not make sense that they have to act differently from others and that they are the only ones to have T1D. It is hard for them to comprehend the complex functioning of their body and the role of insulin.

#### Question 18

**What is the most difficult question your child has asked you about diabetes?**

Only 3 parents did not respond to this question. The answers emphasise the challenges that the parents and their children are facing when it comes to diabetes.

The answers can be grouped as following:

**Why me?** 8 parents mentioned this question as the most difficult question asked by their child.

– *Why do I have diabetes and my sisters don't.* [P1]

**When will I stop having diabetes?** 6 parents mentioned this as the most difficult question. Their children were asking them if they will get better any time in the future.

– *When will I get better?* [P4]

– *Why did I get this disease? Can my blood be fixed? Why can't they fix my pancreas?* [P10]

**Will I die?** 3 parents mentioned this question as the most difficult.

– *why me? will I die young* [P15]

– *What's the worst thing you have ever heard about diabetes Mum? Can you die?* – P5]

Also, one parent was not comfortable sharing such details and 2 parents mentioned the disappointment of the child with the following quotes:

> – *the phrase of "never let it stop you". He has found that it can, and does stop him, at times and this kind of language – whilst mainly positive, can belittle how difficult it can be to manage on a daily basis.* [P19]
>
> – *He would rather die than have diabetes – why should he keep going?* [P14]

All these strong and emotionally intense quotes graphically capture the challenges that these people are going through. Moreover, they are in alignment with the responses to the previous question. Children seem to be lost in their condition and their lack of understanding appears to create a state of fear and uncertainty.

#### Question 19

#### Is the child cooperative when it comes to the management of the disease?

20 parents answered this question. The responses were grouped as follows:

**Yes / Cooperating**: 12 parents replied that their child is cooperative and (s)he gets involved in the management.

**No / Refusing**: 1 parent stated that their child is refusing to cooperate.

**Sometimes**: 6 parents stated that their children do not cooperate all the time.

Lastly, P19, who has a 14 year old child stated:

> – *at this age, he is struggling with the transition of parental control and help and autonomy* [P19]

#### Question 20

#### Is it easy for children to access diabetes related information? [1=Disagree ... 5=Agree]

18 parents replied to this question. The average score was 3.17 and the standard deviation was 1.3. The relatively low score and the high standard deviation might be influenced by the different parents' profiles and the challenges they are facing when it comes to educating their children. It is not clear if the parents who replied more positively to this question considered themselves as the source of diabetes education and thus, even subconsciously, connected their response with their efficacy as parents/educators.

#### Question 21

#### Anything else you want to add, share or suggest?

The last question received 7 answers from the parents. These answers were about motivation, education of younger children and teenagers, the importance of familiarising with concepts from a young age and, lastly, personal experiences.

– *Kids need constantly motivated to keep on track and not get depressed and uninterested. Support and not criticism essential. Healthy and happy for life..not just for a short time.* [P17]

– *I think educational games for younger children would really help with their understanding of diabetes.* [P2]

– *No more sleepovers with friends and most of family. Someone once described it as watching someone's goldfish when they are on holiday. (...) When you get diabetes it's not just the disease it's the exclusion the birthday invites they no longer get they go from being one of the popular kids in P3 to being the kid with diabetes who no-one invites, the kid who can't go anywhere :(* [P15]

– *Education for younger children is so different for those of teenagers. I see the need for smaller children to engage with more game play, designed at their level of understand, to help take the fear away from the condition.* [P19]

#### 5.2.4.5 Summary of results

Parents are the main source of education for the children; clinicians are the second most important source. Most of the parents (18) had attended educational sessions and all of them found it useful and quite engaging. They were not so confident about their children being engaged during these sessions, though. A similar pattern occurs with the learning outcomes of these sessions, where parents reported that they have learned something from the sessions, whereas only a few (5) children learned something.

All parents considered diabetes education to be important for children and were generally positive about the value of educational sessions. They suggested many improvements to the current approach, mostly about including younger children, more interactivity and hands-on education, fun and group learning.

There was a split of opinions with regards to whether experience is a better teacher than formal education. This result might had been influenced by the way they themselves were educated, and their negative or positive experiences with formal educational sessions. Moreover, their perceived self-efficacy might have influenced their responses. Despite this split, all parents agreed that technology and games can help children learn effectively about their condition.

Most families do not possess educational materials for their children. The educational materials owned by families are not interactive. Parents perceive games for T1D as an effective and enjoyable medium for education and also think that technology can effectively support children's education.

Children with T1D are struggling to understand their condition and why they are the ones who have it. For them, it is very hard to conceive that diabetes is a life-long condition without a known permanent cure. The severity of T1D accompanied by their difficulty to understand it, seems to create a state of fear and uncertainty. There was a split of opinions about how easy it is for the children to access T1D related information.

All these results seem to be in alignment with the previous enquiry stages and demonstrate the struggle of parents in educating their children while at the same time managing their child's condition.

### 5.2.5 Discussion

This stage's outcomes had a threefold role in the methodology, in that they helped us to: 1) understand the current educational practices; 2) complete the picture about the context; and 3) triangulate the findings of the previous stage. The first aspect was made possible by gathering concrete information about the educational practices (e.g. plastic food toys or how the NSG is conducted) and the clinic's approach to them. The second aspect was made possible by gaining input from parents (through questionnaires) and children (through the observations). These insights were crucial for understanding the education's impact on the family. These first two findings were combined and analysed and are presented in the next section (5.3). The third aspect was made possible by combining insights from all the enquiry steps of this stage. For example, the inappropriate nature of the current educational sessions for the children and the focus on educating the parents were made clear by the observations and the questionnaires. Another example is the parents' responses to questions that show them fighting alone an unfair battle. A third example is the lack of available appropriate resources for the education, made clear in all three enquiries.

#### 5.2.5.1 Limitations

The fact that the first two stages of this enquiry were based on one interview with one clinician and one observation might be considered as limitations of this stage. Despite the low number of enquiries, the data gathered from these two steps were very rich and insightful. Specifically, both of these enquires are used as basic steps for other HCD methodologies (e.g. *contextual enquiry* [14, 15, 175]) and thus are designed to extract highly contextual and deep insights. Moreover, they were not conducted as isolated enquiries, but as parts of a methodology. Their findings were cross-triangulated with the other stages' findings and also their outcomes were communicated to the stakeholders[1] who gave feedback on them.

## 5.3 General Discussion on the Context

In order to understand the context and come to an even deeper understanding about its complex structure, including the dynamics between the stakeholders and the challenges faced, we decided

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[1] See Section 7.2.1 on page 94, Section 6.4 on page 92 and Section 7.4 on page 107

to use activity theory (Section 2.3.6, page 10) as an analytical tool. Activity theory is a strong descriptive tool for explaining and understanding how and why learning occurs [115] and for describing human interactions, especially in education [62].

The main **activity** this thesis is looking at is the education of younger children with T1D. The main **subject** of this activity is the individual child learner. In younger ages (below 10) children are discouraged from participating, as there is nothing developmentally appropriate for them. Moreover, the youngest children (pre-school) face even more serious challenges due to their lack of literacy skills and their limited developmental and cognitive skills (due to their young age). The **object** of the activity is the understanding of the basic T1D concepts which are needed for the management of T1D.

This activity is situated within a social context, with the **community** being the clinicians responsible for the child's education, the parents and other children with T1D. This community is mediated by some **rules**, such as the responsibilities of each stakeholder, the frequency in which one stakeholder interacts with our subject and the authority each stakeholder might have. The aforementioned community is trying to achieve the object of the activity through a **division of labour**. Namely, the parents are the day-to-day educators of the children and are at the same time responsible for the management of the condition; the clinicians are responsible for educating and guiding the parents and trying to educate the children when possible; the other children, during group leaning tasks, are interacting with the subject.

According to the results of this phase, it seems that most children at a younger age are struggling to enter their ZPD. This is particularly interesting, considering that there are always adults responsible for educating them, who –in general terms– are not effectively helping them enter their ZPD. The only weak element of this particular activity system described earlier is that of the **mediating tools**. The main tools currently available across the different subjects are language and the plastic food toys. Language is the basic tool mediating every interaction with the community and enables thinking, but is apparent in every social activity irrespective of the context and the object of the activity. Hence, it is not something that can alone crucially influence the outcome of the activity, especially in a younger group. The plastic food toys on the other hand are a more appropriate tool which, however, is limited in terms of scenarios where it can be used. The clinicians use them in some hands-on tasks (e.g. sort the foods into categories) but not systematically or with a specific underlying curriculum. These tools, and any other tools used currently, seem to be inadequate in enabling children to understand their condition. These tools also seem inadequate in enabling the community to help children; otherwise, children would more easily be entering their ZPD and would be able to understand more about their condition.

The elements of this activity are influenced by a number of factors which cannot be changed. For example, the workload of clinicians influences the division of labour; the educational skills of each member of the community influences the tools (e.g. the way each member uses language to educate a child); the family background influences the subject; the way the health-care system works influences the rules mediating the community and the subject, etc.

Since this project's main aim is to provide an educational tool to support this activity, if the tool is effective and appropriate for this activity it will effectively mediate the process and will help in the production of the desired outcome. Such a mediation could potentially influence different parts of the activity (e.g. change the division of labour by helping clinicians effectively educate children) and thus enable the community to better help children enter their ZPD.

## 5.4 Conclusion

This phase of the process was about understanding the context through two stages of enquiry: process and an initial analysis. The previous chapter (Chapter 4) presented the initial exploratory enquiry targeting the general specificities of the context. This chapter presented a more focused enquiry targeting current educational practices in order to complete the picture and understand the context. According to the results, the different specificities and their interactions form a context that is not effective in educating younger children with T1D. A need for age-appropriate education is prominent as neither the clinicians nor the parents can succeed with the resources they currently have.

The next chapter describes the specification of the requirements based on this phase's results (this and previous chapters).

# Chapter 6

# Specifying the Requirements

## 6.1 Introduction

This chapter describes the second phase of the methodology by which decisions about the solution were made and the results of the previous phase were translated into requirements. The decisions and the requirements were used for framing the design of the solution in the next phase.

This chapter is split into three sections; the first section describes the elicitation of the stakeholder needs based on the previous stages' results; the second section describes the iterative process of the requirements formulation and design decisions based on those needs, and presents the results; the third section presents the validation of the requirements produced in the previous stage and the decisions about the educational content of the solution.

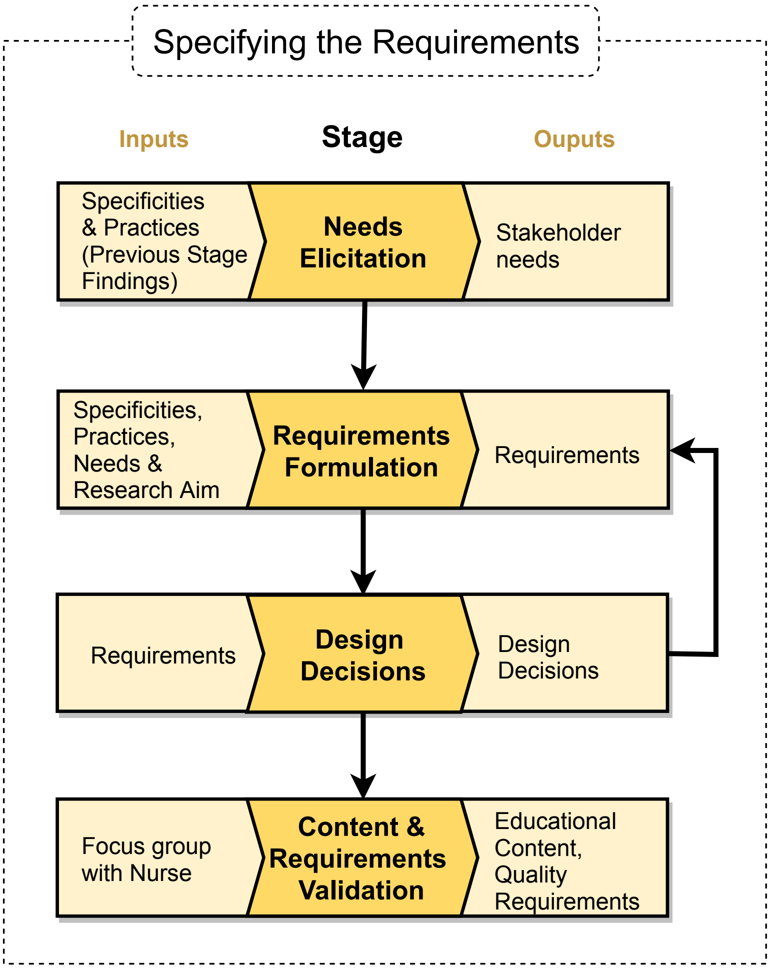

Figure 6.1: The phase "Specifying the requirements" with its four stages.

### 6.1.1 Requirements, needs and decisions

Before we dig into this chapter it might be helpful to explain how the terms *Requirements*, *Needs* and *Decision* are used.

By *needs* of the stakeholders we are referring to the essential elements missing from the current context, the fulfilment of which can potentially give a solution to the challenges the stakeholders are facing.

By *requirements* we mean the objectives that need to be satisfied in order for the solution to be successful. A special category of requirements are *non-functional requirements*, which refer to quality attributes (e.g. *The tool should be engaging*) and usually it is difficult to conclude on whether they have been satisfied, as there are not always objective or clear metrics available. The rest of the requirements are mainly functional or behavioural requirements and their lowest-level is almost equivalent to design decisions as they describe very specific features (e.g. "Tool should be used by different clinicians").

Lastly, with the term *decisions* we allude to the choices made by the author in order to advance or finalise the requirements elicitation process. More on the decisions and their purpose will follow on the next sections.

It might also be helpful to explain that the requirements presented in this chapter are not detailed software technical specifications (such as, e.g., ISO-25010 [75]), and nor do they result in an exhaustive list of features for the solution. Such a presentation would have required extensive space and would had changed the scope of this thesis, which is to present the research with a focus on the process rather than the technicalities. Instead, the requirements are high-level representations of the things required to fulfil the stakeholders' needs. Along with the requirements, this chapter also presents the way they are decomposed to lower-level (more precise) requirements and decisions.

## 6.2 Needs Elicitation

### 6.2.1 Procedure

To elicit the needs of the stakeholders a further analysis was conducted on the results of the previous phase (Chapter 4 and Chapter 5). First of all, based on the results of the previous phase, we identified the main stakeholders whose problems need to be tackled by the educational tool. Then we identified the main challenges faced by these stakeholders. These challenges were then translated to specific needs for the stakeholders. The needs we ended up with are a subset of all needs the stakeholders have expressed and were chosen based on the challenges identified and the aim of the research (Section 1.3, page 2). The needs elicitation process is diagrammatically presented on Figure 6.2.

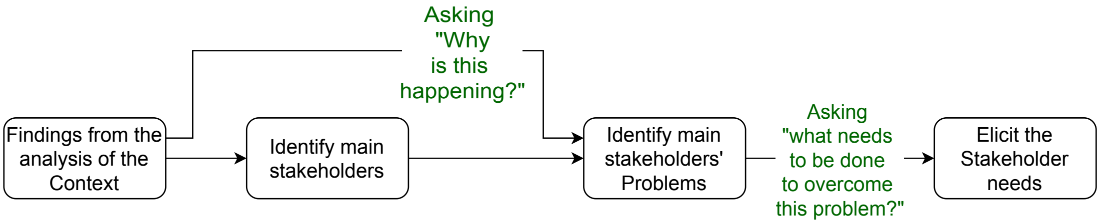

Figure 6.2: The procedure for eliciting the needs of the stakeholders, based on the findings from the analysis of the context.

### 6.2.2 Stakeholder identification

The first step into identifying the challenges was to identify the main stakeholders based on the previous stages results. According to the results there are four main stakeholders involved in the education of younger children with T1D:

1. Clinicians
2. Parents
3. Children
4. Policy makers (NHS and Government)

From these four stakeholder groups, clinicians, parents and children are actively involved in T1D education of children, whereas the policy makers are not. Hence, any educational technological solution introduced would target to reduce the challenges of those actively involved in T1D education of children. The policy makers, according to the way they currently approach education (see Section 5.3), might be interested in such a solution only after it had been proven effective. Therefore, even though their perspective was acknowledged during the previous phase's analysis (see Section 4.2.8), we decided not to take into account their needs during the elicitation of the requirements.

### 6.2.3 Identify Stakeholder Problems

**Identify themes related to problems**

As described earlier (Section 6.2.1), the first step in the requirements elicitation process is to identify the problems of main stakeholders. The starting point for identifying the problems of the three main stakeholders (clinicians, parents and children) were the results of the specificities (section 4.2.11, page 51) shown in Diagram 6.3. According to this diagram, only three themes describe problems faced by the main stakeholders, namely: 1) "Clinicians are left alone"; 2) "Children are a neglected group"; 3) "Parents fight an unfair battle".

Another theme that refers to one of the three main stakeholders is "Focus is on the parents". This theme describes a fact that is not necessarily a challenge/problem for the context. Because the management is very challenging and younger children cannot manage their condition alone (see Section 2.2, page 2.2), the focus of T1D education has to be on the parents. This fact, however, does not mean that children should be excluded from education or be under-educated. Hence, this is something that should continue (parents need to remain the main target of the T1D management education), but also children should be included in the educated.

The theme referring to the policy makers ("Target are measurable outcomes") is not considered, because it was decided not to include the policy makers' needs during for the requirements elicitation process (as described previously on Section 6.2.2, page 80).

The two *leaf* themes (those that are only influenced and do not influence), "Perceptions of effective education" and "Need for T1D children's education", do not describe any challenges, but can rather propose approaches to solving the problem, and thus they will not be used for the needs elicitation (this stage) but for the requirements elicitation stage (Section 6.3, page 6.3).

Finally, the theme "Challenges of T1D and educating children" can be helpful in understanding some of the causes of most challenges (e.g. Complexity and severity of management) but does not inform about the problems themselves that the stakeholders are facing. Hence, it will not be considered for the needs elicitation process.

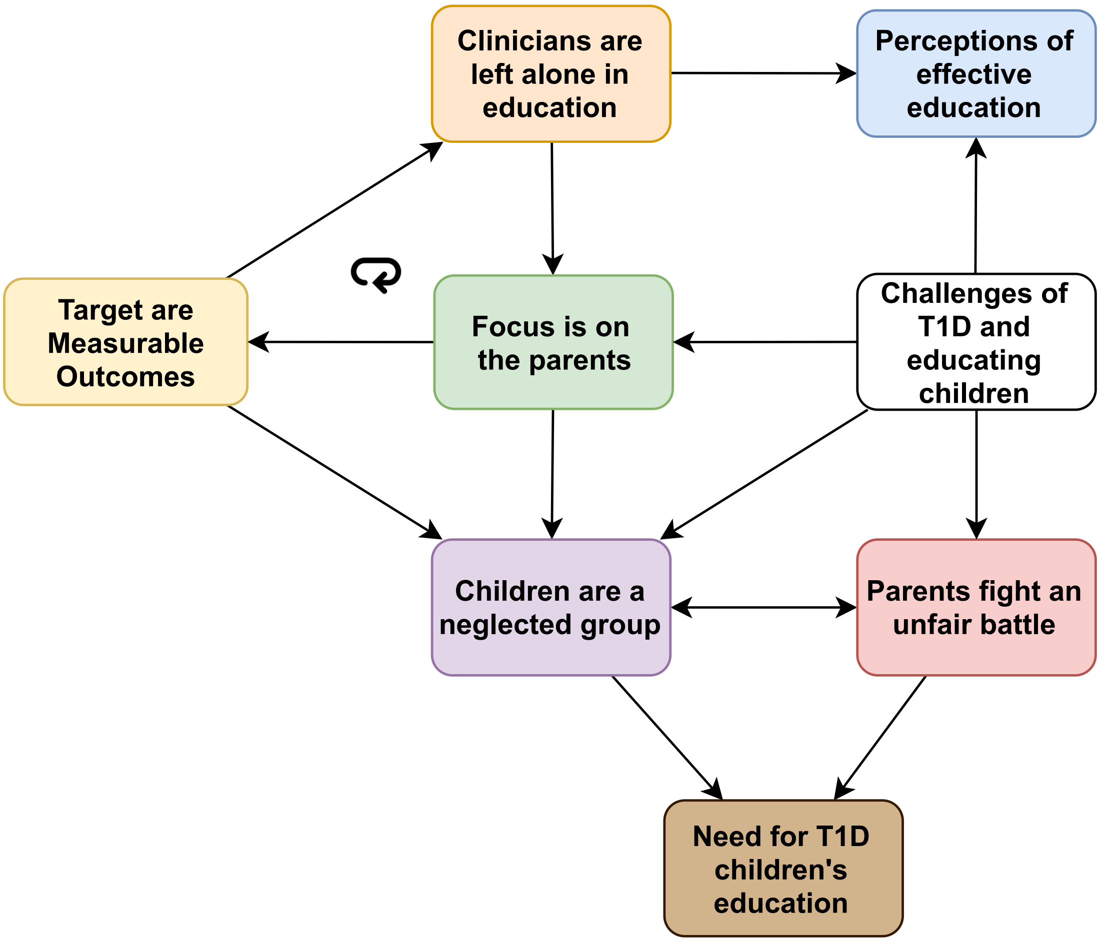

Figure 6.3: The *themes*, which were extracted in the previous phase (Section 4.2.8, page 37), and the influence each has on the others.

### Identify problems from the relevant themes

From the three themes referring to the problems the stakeholders are facing ("Clinicians are left alone", "Children are a neglected group", "Parents fight an unfair battle") we can extract the problems by asking "Why is this happening?"[1].

1. For the theme "Clinicians are left alone" the underlying problem is that the clinicians do not receive any help in educating children (lack of appropriate educational resources) and do not receive pedagogical education. Because the education of adults is outside of this project's scope, we will only focus on the lack of appropriate educational resources.
2. For the theme "Children are a neglected group" the underlying problem is that children do not get any formal, standardised or age-appropriate education; as a result they do not understand their condition and they lack basic skills.
3. Finally, for the theme "Parents fight an unfair battle" the problem is that parents have to educate the children and at the same time constantly manage the T1D condition.

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[1] Asking the *why* is a technique called *abstraction* and is widely used in Requirements Engineering to validate requirements [42, 165].

All the problems are summarised on Diagram 6.4 bellow.

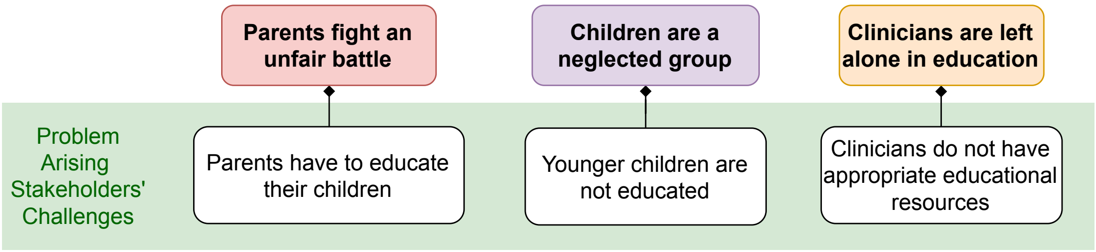

Figure 6.4: The *themes* related to the main stakeholders and their underlying problems.

### 6.2.4 Identifying Stakeholder Needs

The problems identified on the previous section can simply be translated to needs by asking "What needs to be done, through a technological solution, to overcome this problem?". The needs extracted by asking this question are presented in Diagram 6.5. These are not all the needs of the stakeholders, in relation to the problems identified, but are the subset of needs which a technological solution can deal with.

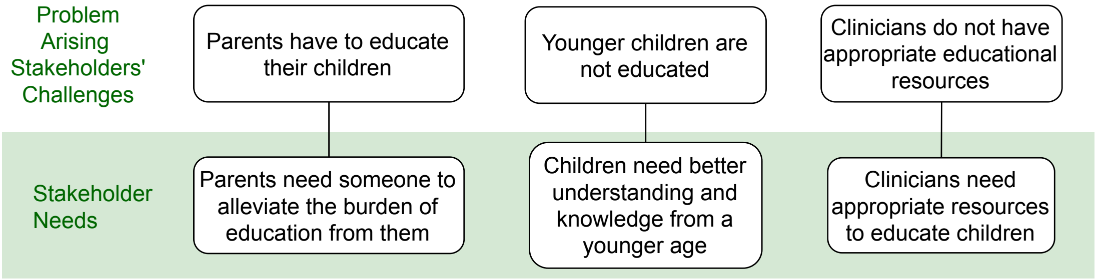

Figure 6.5: The needs of the stakeholders and the problems they are elicited from.

## 6.3 Requirements Formulation and Design Decisions

### 6.3.1 Procedure

At this stage of the project, the needs of the stakeholders, identified at the previous section, had to be used as a starting point for the requirements formulation. The requirements formulation process as described by Bashar Nuseibeh [118] is not a sequential procedure where requirements and design decisions are separately chosen. In real-world projects, requirements and design decisions have to be addressed simultaneously as specific decisions can constrain the meeting of particular requirements, and the requirements formulated can influence the design. Hence, Bashar Nuseibeh proposes an iterative model, called "the twin peaks model" (see Figure 6.6, page 84), by which requirements and design decisions are progressively refined into more detailed requirements and design decisions. In his model, design decisions influence the requirements formulation and vice versa.

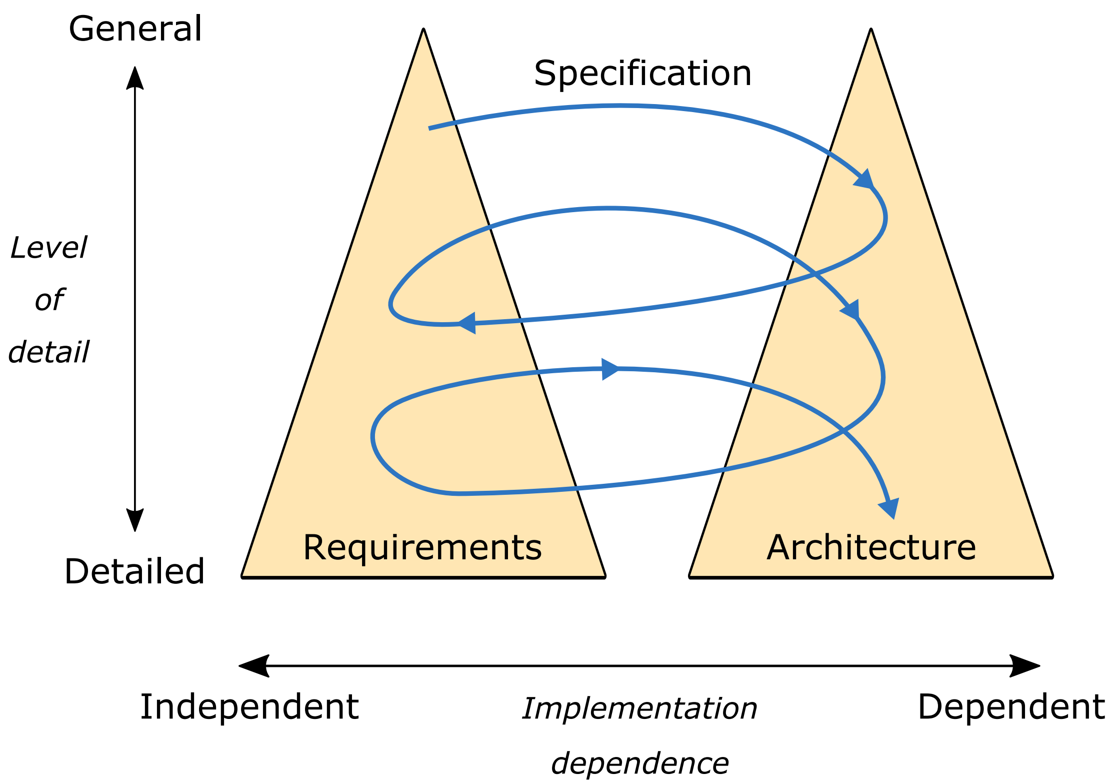

Figure 6.6: The twin peaks model by Bashar Nuseibeh [118], depicting the progressive and iterative formulation of requirements and design decisions, with one influencing the other.

The twin peaks process was used for formulating the requirements and design decisions of this project. The first iteration started with the stakeholders' needs, the requirements of the research aim (Section 1.3, page 2) and some of the initial design decisions (Section 4.2.1, page 32) as inputs. All these inputs were initially refined into one specific highest-level requirement, which then was further refined into lower-level requirements and design decisions. All the requirements (that will be presented in later sections) were formulated by asking the "How?" [1] question on their higher-level requirements, needs and decisions.

### 6.3.2 Highest-level requirements and decisions

As mentioned earlier (Section 4.2.1, page 32), the very first design decisions were taken even before the first enquiry[2]. Namely these were:

1. solution will target young children with T1D;
2. it would be an educational tool or system;
3. it would use technology; and
4. it would have gamification elements.

---

[1] Asking "How?" is a technique called *refinement* and is widely used in Requirements Engineering to break down requirements into more detailed ones [42, 165].

[2] Some of these elements were derived from the research aim (see Section 1.3, page 2) and others based on the author's research interests.

Moreover, three non-functional requirements were formulated from the research aim[1]:

1. Tool should effectively support education
2. Tool should be age-appropriate
3. Tool should be viable for adoption

The first two non-functional requirements can be refined based on the literature, where many proposed theories, approaches and techniques have proved to be related to effective and age-appropriate education (see Section 2.2.5 on page 6 and Section 2.3 on page 7). For the "viability for adoption" we consulted the data from the previous phase's interviews (Chapter 4 and Chapter 5). From the inquiry about the practices we found that the current educational approach of the clinic has been evolved throughout the years and is constantly adapted based on experience and feedback [N1]. This fact signifies an approach that is adjusted the local context. Moreover, the interpersonal relationship between children and the clinicians is one that can last up to 18 years [N1]. Hence, in order to target potential adoption we decided not to disturb the existing practices but rather enhance them and design something that could be integrated into the current work practices.

By combining these initial decisions, the stakeholders needs[2] (Section 6.2.4, page 83) and the non-functional requirements, we compiled the overarching requirement for the solution:

> **Enable clinicians to educate effectively younger children with T1D through an age-appropriate digital tool.**

The way the overarching requirement was formulated is diagrammatically depicted in in Diagram 6.7.

---

[1] The two constituent elements for the aim's fulfilment are effectiveness and feasibility for adoption and they are both influenced by age-appropriateness. See Section 3.2 on page 22

[2] The needs were distilled for the formulation of the overarching requirement by asking "How would the needs of the stakeholders be fulfilled?"

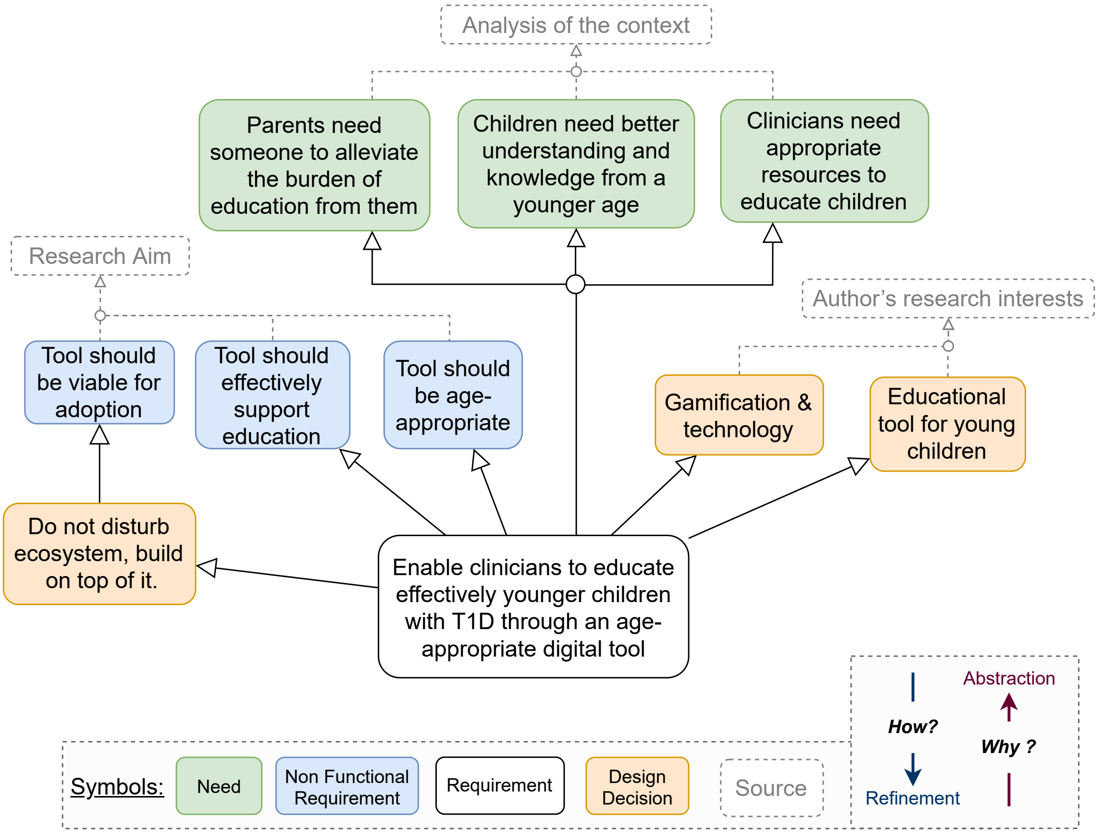

Figure 6.7: The overarching requirement formulation based on stakeholder needs and the initial design decisions. The grey dotted boxes contain the source of each requirement or decision. Note that by moving from top to bottom following the connections we are refining by asking “How?” and moving upwards we are abstracting by asking “Why?”.

### 6.3.3 Lower-level requirement and decisions

The lower-level requirements and design decisions were produced in an iterative way by refining the highest-level requirements and decisions presented in the previous section (Section 6.3.1). Figure 6.8 presents the final set of requirements and design decisions. The diagram is structured in the same way as the requirements from which they were formulated (child node was formulated by refining parent node(s)).

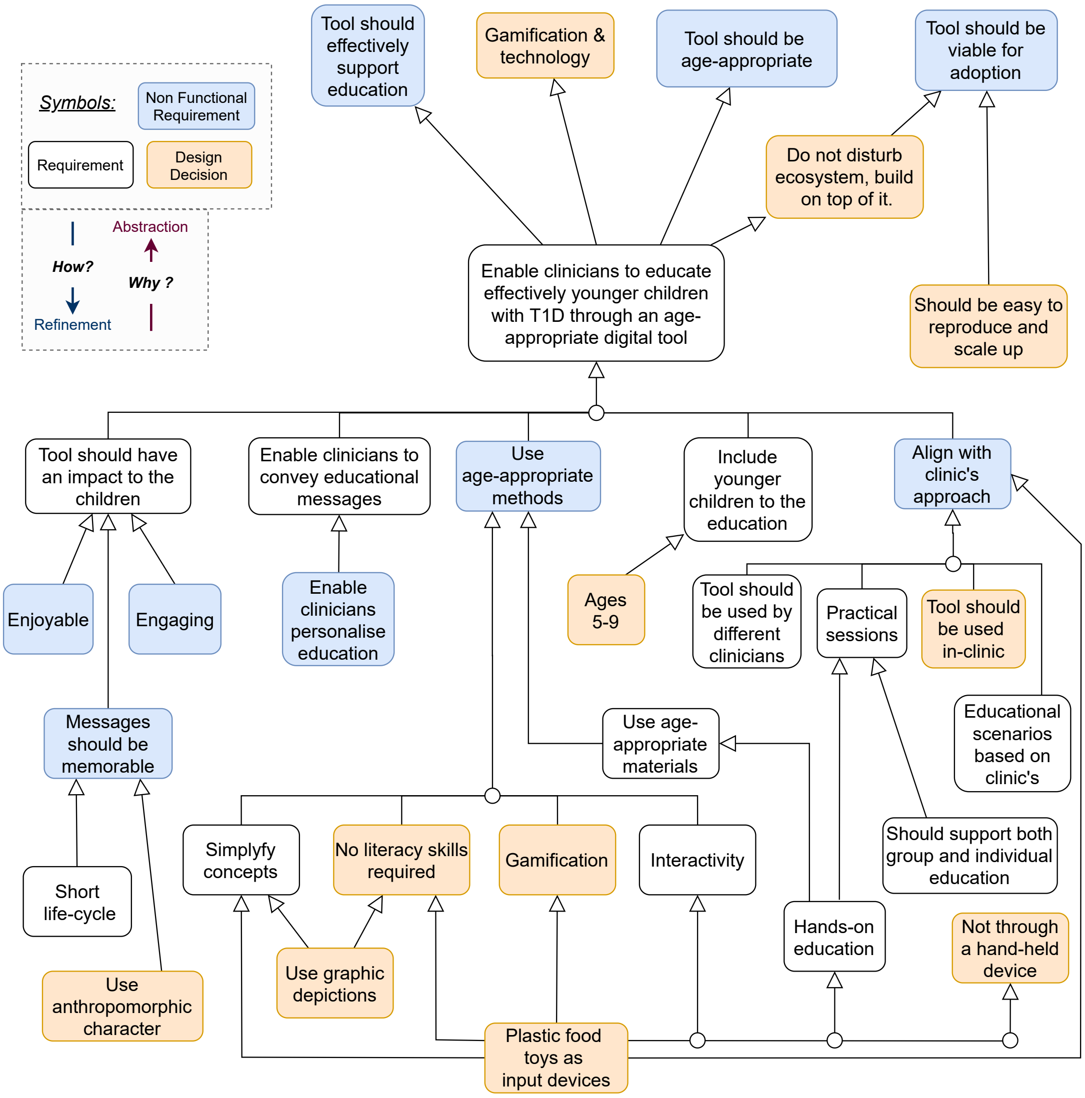

Figure 6.8: The full set of requirements and design decisions. The structure shows the way they were formulated (child node was formulated by refining parent node). Note that by moving from top to bottom following the connections we are refining by asking “How?” and moving upwards we are abstracting by asking “Why?”.

#### 6.3.3.1 Lower-Level non-functional requirements

By refining the highest-level non-functional requirement “Tool should effectively support education”, with the use of the literature, we manged to formulate four lower-level non-functional requirements: “Tool should be enjoyable”, “Tool should be engaging”, “Educational messages should be memorable” and “Tool should enable clinicians personalise education”. Factors that influence the effectiveness of a learning tool and are closely related to the adoption are: enjoyment and engagement [54, 70, 141] (which are missing from the current approach); the ability of the tool to individualise T1D education [71, 97]; and the things that the children actually managed to put into practice after their education with the tool [90].

The lower-level non-functional requirement “Align with clinic’s approach” was mainly a refinement of the highest-level requirement about viability of adoption. We believe that if the tool is aligned with the clinic's approach only then it will not disturb the ecosystem and will enable clinicians to enhance their approach. As a consequence of it being appropriate for the context, it will be feasible for adoption [46].

Lastly, the lower-level non-functional requirement "Use age-appropriate methods" and its decompositions (e.g. "Use age-appropriate materials") were derived from the highest-level non-functional requirement "Tool should be age-appropriate", which in turn was derived from the research aim.

#### 6.3.3.2 Lower-level design decisions

The rationale behind the design decisions, chosen during the refinement process, is explained bellow:

1. **Age group:** Because most existing educational games (Section 2.4.2, page 16) and the existing in-clinic diabetes education (NSG; see Section 5.2.2.2, page 57) target children older than 9 we decided to work with children up to 9. We decided to align with the school curriculum [148] (suggested also by the clinicians) and chose to work with children aged between 5 and 9 (attending Primary 2 to Primary 4) who belong to the same level; the "First Level". According to the national curriculum [148] this level has specific learning goals about health and nutrition, which are in line with the education children with T1D should have.

2. **Not through a hand-held device:** The widespread adoption hand-held devices (smartphones and tablets) is increasingly making them a preferable medium for interventions. Creating an interactive educational intervention for such a device, though, may potentially increase the exposure of the child to a screen, something that is not recommended [5,11]. Moreover, it places the app as an antagonist to the other games available for the device (installed or to be downloaded) and thus does not ensure usage. Lastly, a hand-held device has limitations on the number of people who can use it simultaneously and thus poses the risk of being controlled by only one child.

3. **In-clinic with clinicians:** We decided to build a tool for use in the clinic with clinicians. This way children can be educated from someone with experience and training on diabetes [71]; away from parents who might act paternalistic; learn with peers in a collaborative environment and view of the other's perspective; make visits to clinic more enjoyable; relieve the burden of parents who have to both manage the condition and educate children. Moreover, a clinicians can easily tailor the feedback to the individual [27], something not easily achievable by a standalone educational tool [63].

4. **Use of the plastic food:** The plastic food models were the only artefacts currently used that could support interactive scenarios, gamification and hands-on education. Their tangible aspect and the fact that they look like toys provide a potential age-appropriate medium for this age group. Hence, it was decided, based on the requirements, to use the plastic food toys as input devices for the interactive tool.

5. **Anthropomorphic character to present feedback:** Chomutare et al. [31] found that children preferred anthropomorphic characters for T1D education, as an indication of themselves as the protagonists. Based on that example and the recommendation of D1, we decided to provide the feedback through an anthropomorphic character with whom the children could potentially relate. Moreover, by managing the character's diabetes, children can test their preconceptions about the management of T1D without putting themselves at risk.

6. **Use graphic depictions:** Visual/graphic depictions are very good at gaining children's attention and initially attract them to learning [58, 137]. If combined with verbal cues, graphics increase the likelihood of information recall [6,138]. Moreover, graphics provide a dynamic and spatial form of feedback which is more efficient for abstract concept learning (such as diabetes) [21, 111]. They pose a more natural expression of spatial relations (eg. food contents) for children 5 and older, even in different cultural backgrounds [163].

7. **No literacy skills required:** It was also decided that the tool should not require literacy (reading or writing) skills so it can be used with confidence uniformly by the age group we chose. Moreover, if the tool is proved to be effective and does not require literacy, it could in the future be also tested with even younger children (below 5 years old).

8. **Should be easy to reproduce and scale-up:** We wanted the tool to be easily reproducible and scalable in order to be able to be disseminated to other clinics or other places where children can be educated about T1D.

### 6.3.4 Who is the user – Whom is the tool targeting

Up to this point, the requirements and the design decisions define a tool which will be used in the clinic at dedicated educational sessions with clinicians and younger children. More specifically, according to the overarching requirement (Section 6.3.2, page 84), the tool will be designed to help clinicians educate children. However, according to the lower-level requirements and design decisions, its input is going to be manipulated by children and its output is targeting children. Hence, the tool is aiming to help the children through the clinicians and the clinicians will have a secondary experience [4] of the tool through the children's interactions with it. This shared nature of the tool creates a complex usage pattern where it is hard to clarify whether children or clinicians are the tool's primary user group. In order to clarify the tool's usage and understand who is actually the main group of focus we depicted the usage, according to the requirements and design decisions, in Diagram 6.9; it presents the flow of actions during a potential educational session where the tool would be present.

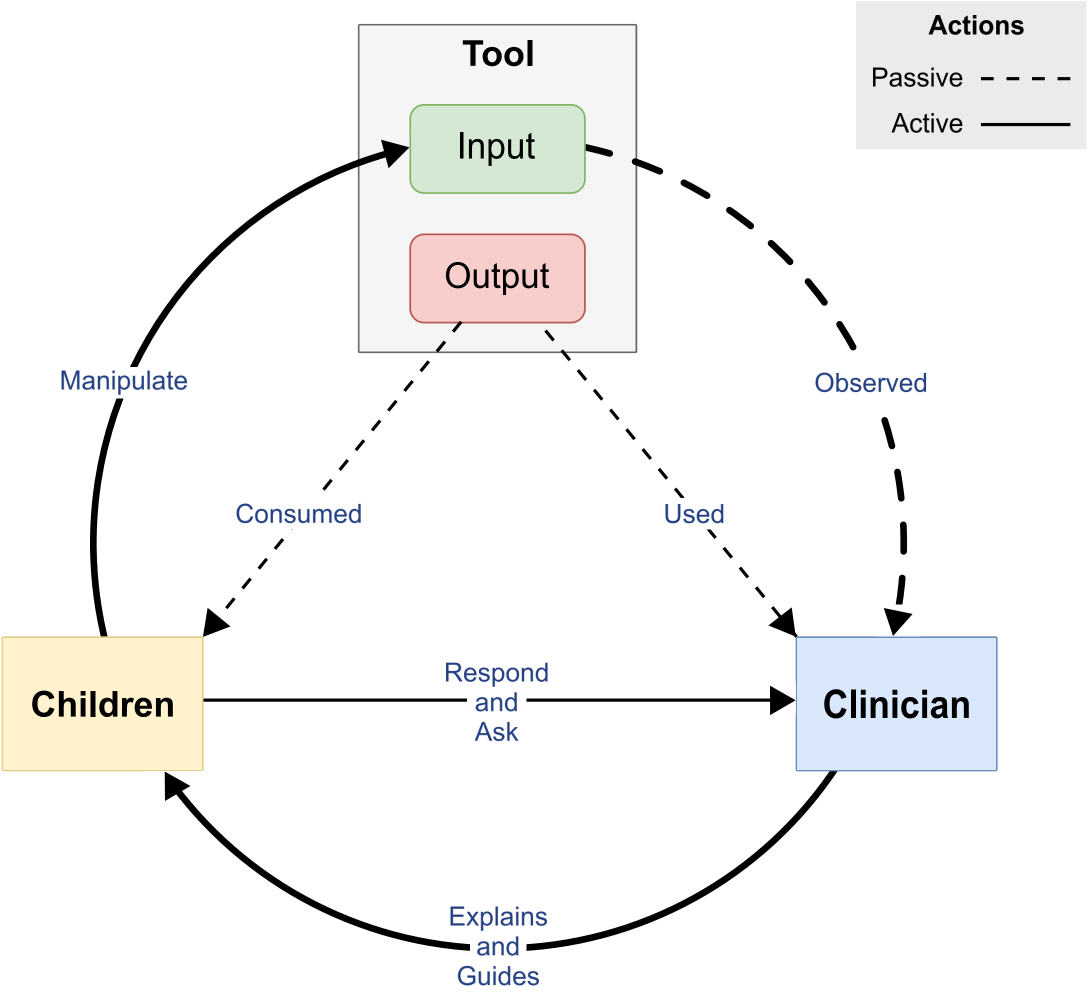

Figure 6.9: The flow of actions during the educational session between children, clinicians and the tool. Solid lines represent the active actions and dashed lines the passive actions.

During the educational session described in Diagram 6.9, there are three interactions[1] taking place, observed as inner *circles* in Diagram 6.9; two of them are direct and one is indirect:

1. The first and most prominent is the one where the children interact **directly** with the tool. The children use the tool by manipulating its input and by “consuming” its output. Hence, the children have the primary role in the tool’s usage.
2. The second one is the **indirect** interaction of the clinicians with the tool. It is indirect because they interact with the tool through the children. MMore specifically, the clinicians would be observing the children’s input choices and would use the tool’s output to further explain the concepts. This way they would be prompting the children towards good and

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[1] Interaction: a mutual or reciprocal action or influence; source: *thefreedictionary.com*

bad choices. The children will be combining the tool's output, their existing mental models and the clinician's feedback in order to choose and test their new choices. Hence, even though the clinicians would not directly be using the tool, they would be influencing its use.

3. The other **direct** interaction is the interpersonal interaction between children and the clinician. During the session, children and the clinician would be interacting verbally; the clinician would explain and guide the children, and the children would respond back to the clinician or would ask questions. This interaction would be influenced and informed by the other two interactions. Any sequence of input-output from the tool and feedback from the clinician can trigger discussions between children and the clinician.

According to the analysis of these interactions, the children have the primary role in relation to the tool's usage. They would have a more active role in the session as they would be directly interacting with the tool and the clinician. It is also important to mention that if more than one child was present in the session, another interpersonal interaction − between children − arises. This interaction is a part of the third interaction described above, as the clinician would be monitoring such discussions and would be intervening in order to explain or guide the children towards the learning goal.

As we can observe from the interactions mentioned above, the clinicians would have a multi-faced role to play − equally important to that of the children. The clinicians would indirectly use the tool as an aid for (1) understanding the children's perceptions but also (2) as an aid for explaining the concepts to the children. Despite the fact that clinicians will not have a direct interaction with the tool, they would be using it as a medium for conveying knowledge to the children.

The usage pattern described above cannot strictly be classified under existing categorisations by the literature, such as those by Eason[1] or Ågerfalk[2]. This is because these classifications assign a single role to each user ( i.e. the children being the "primary" users and clinicians having the meta-role of the "interpreter") and in our case that might restrict our view on the usage. To add more, even though the children can be considered as the "primary" users in terms of immediacy of use, they would use the tool probably for only one session, whereas the clinicians will use it an as an aid to their job and will have a long-term exposure it. Hence, they would have a long-term user experience that would probably change over time, as they would adjust and improve their methods with time.

Hence, in such a complex context, it is probably wiser to consider both children and clinicians as equally important users of the tool, each group for a separate reason and with a separate use

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[1] Eason [44] distinguished users into three categories according to frequency and immediacy of interaction ; primary users: those who mainly and frequently use the tool; secondary: those who use the tool occasionally or use it through someone else; and tertiary: those who are affected by its use or decide about its acquisition.

[2] Ågerfalk [2] specifies the usage based on the type of actions performed by users in a secondary level of examination. The three meta-roles they propose are, the performer (performs the action), the interpreter (receives and decodes the action) and the communicator (communicates the action).

case. On this premise, the tool should focus on making the input and output for the children as clear as possible; and the tool should focus on enabling the clinicians to understand the children's preconceptions and also enable them to convey the educational messages.

## 6.4 Requirements Validation and Educational Content

In order to determine the educational content of the tool and get feedback on the requirements and design decisions, we conducted an informal requirements validation session with N1.

### 6.4.1 Educational content

Initially, the requirements and design decisions were presented to N1 in the form of a list. She considered all of them to be reasonable and well-aligned with the needs but she preferred not to express a detailed opinion until she had seen how these would be translated to actual prototypes for the system. After the decisions were presented, N1 was asked to determine the educational scenarios that the tool would support. Based on this age group, N1 proposed five educational scenarios:

1. "What is insulin?"; Insulin is one of the most important concepts in T1D. Nonetheless, according to N1, insulin is a very difficult concept for the children to understand. They learn that it is necessary component of the management, but they cannot understand what it is actually doing and why it is so important.

2. "Nutritional content of foods"; Different foods contain different proportions of the three main nutrients related to diabetes (carbohydrates, proteins and fat). Children with T1D need to learn what nutrients are in each food because, depending on the proportions, different management choices have to be made.

3. "Which foods are healthy?"; Even though children with T1D can eat whatever they want, as long as they take the proper amount of insulin at the right time, that does not mean that everything is healthy. The area covered by the clinic, according to N1, has a very high consumption of non-healthy foods and thus, the tool should tackle this matter.

4. "How exercise impacts T1D?"; Exercise is another concept that influences T1D management significantly. Children should know that exercise impacts the levels of blood glucose in their body and it requires careful management options before being conducted.

5. "Blood glucose monitoring"; Proper blood glucose monitoring is the basis for T1D management. Anyone with T1D needs to carefully monitor the levels of glucose in their blood regularly in order to take management-related decisions and also learn how their body reacts to the management.

### 6.4.2 Suggestion of Non-functional Requirements

During the focus-group N1 also expressed the following non-functional requirements for the tool to be built. These were taken into account during the crafting of the tool.

- **Robustness**: the tool should not be easily damaged and has to last long. It needs to be sturdy because otherwise children can easily break it.
- **Portability**: it should be easy to move the tool from one room to another. Because different rooms are available at different times, the tool should be easily moved from one room to the other.
- **Safety**: it has to be safe when used by children. Material that might harm the children should be avoided; all components have to be safe for this age group.

## 6.5 Conclusion

This chapter described the analytical process by which the requirements and the design decisions were elicited. The process was split in three parts. Initially, we translated the insights from the previous phase (Chapters 4 and 5) into detailed needs of the stakeholders. Afterwards, based on these needs, we formulated requirements and the design decisions deductively, through an iterative process. Lastly, we validated these requirements with a clinician who also provided the quality requirements and educational content. The results of this phase will be used in the next phase to guide the actual realisation phase – the design and development of the prototype tool. Moreover, the lower-level requirements will also be used in the evaluation (Chapter 8) to assess the effectiveness of the tool against the stakeholder requirements.

The next chapter presents the design and implementation phase where the requirements and the decisions guided the design and the development of the tool.

# Chapter 7

# Design and Implementation

## 7.1 Introduction

The third phase of the methodology was about envisioning and developing the solution. As soon as the requirements and the design decisions were finalised we started rapidly developing paper prototypes. The prototypes were based on the design decisions and the requirements. The two main non-functional requirements that guided the design were “Tool should be age-appropriate” and “Align with clinic’s approach” because these two were decomposed into the lowest-level requirements (equivalent to design decisions which describe very specific features).

This phase consisted of four stages. The first was to translate the results of the previous phase (Chapter 6, page 78) into low fidelity[2] prototypes. The next stage was to evaluate the prototypes with the clinicians and get feedback about things that need to be changed for the next iterations of the prototypes. Subsequently, the tool was gradually developed, through prototypes of incremental functionality. Finally, when the tool was ready, a series of co-design sessions was conducted in order to determine the educational session in which the tool could be evaluated.

## 7.2 Prototyping

### 7.2.1 Paper prototypes

The initial prototypes were developed in low-fidelity (paper) for two reasons. Firstly, in order to be quickly developed and receive early feedback. Secondly, in order to prompt the clinicians to critically evaluate them. The lower the fidelity of the prototypes, the easier it is for the evaluators to be more critical about them [166].

The first set of prototypes that were produced were all on paper and were the following:

**A tool outline**: A paper sheet representing the tool (Figure 7.1); it was used to provide an understanding of the tool’s components, its inputs and its outputs.

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[2] With limited or no functionality acting as illustrations of the tool to be built.

**Educational Scenario Designs**: 2D graphics and UI elements of the scenarios (Figure 7.2); used to illustrate the way the output of the system could be delivered for each educational scenario. Many of these graphical representations were based on depictions that N1 mentioned, which are currently used by clinicians when they try to explain diabetes to children (e.g. insulin being the key and food digested and broken into pieces).

**Storyboards:** Drawings about the process/story for each scenario(Figure 7.3); used to explain the way the interaction will happen using small story plots based on the educational scenarios (Section 6.4.1, on page 92).

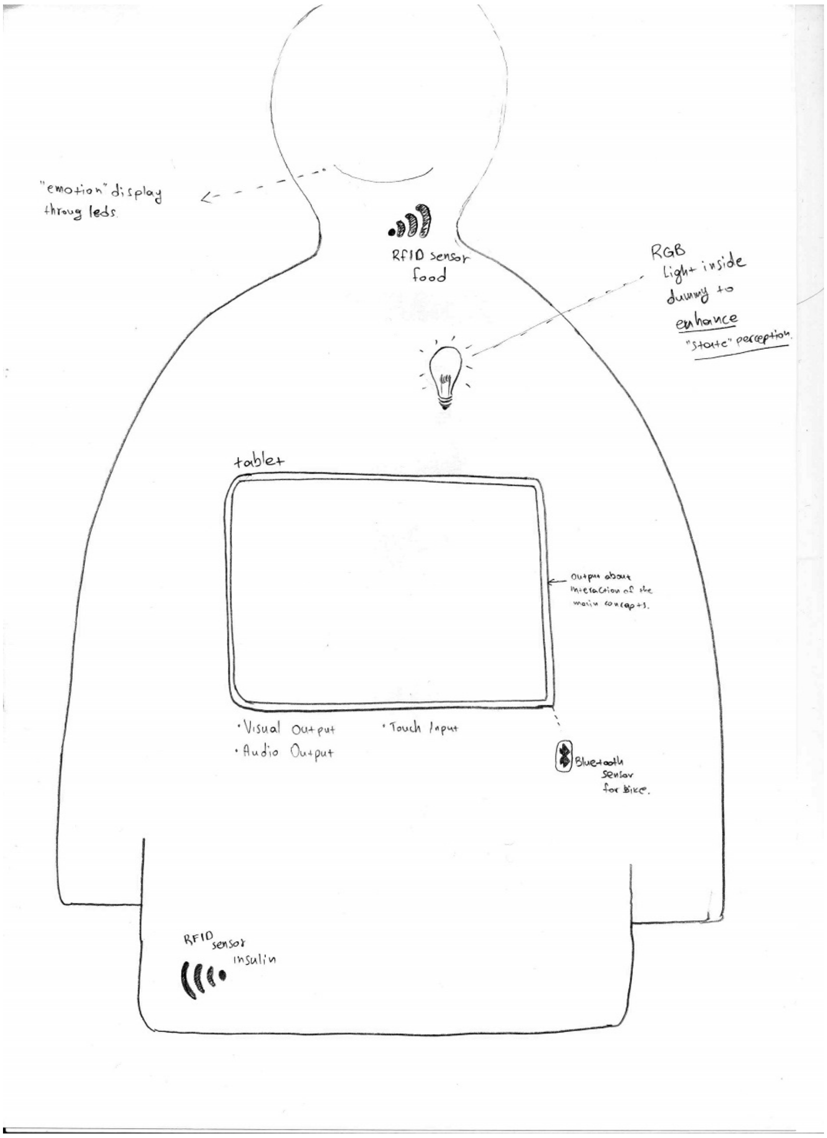

Figure 7.1: Paper prototype of tool's outline. It shows the tool's potential physical appearance.

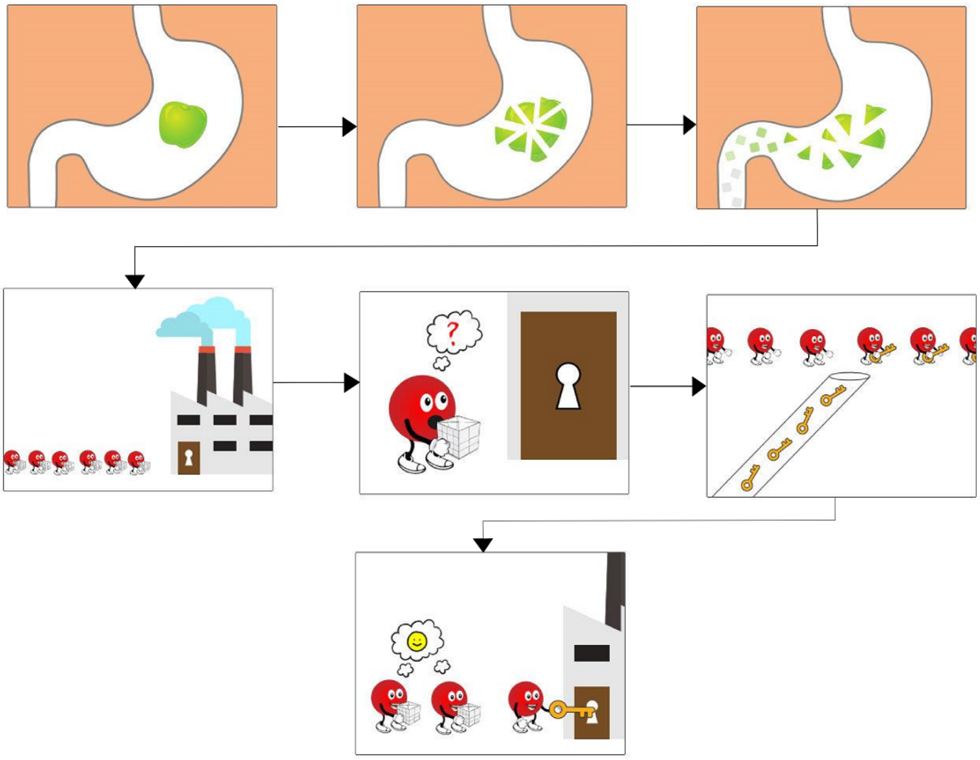

Figure 7.2: Prototypes of the tool's 2D graphics created in Inkscape. They represent what the 2D graphical output would look like.

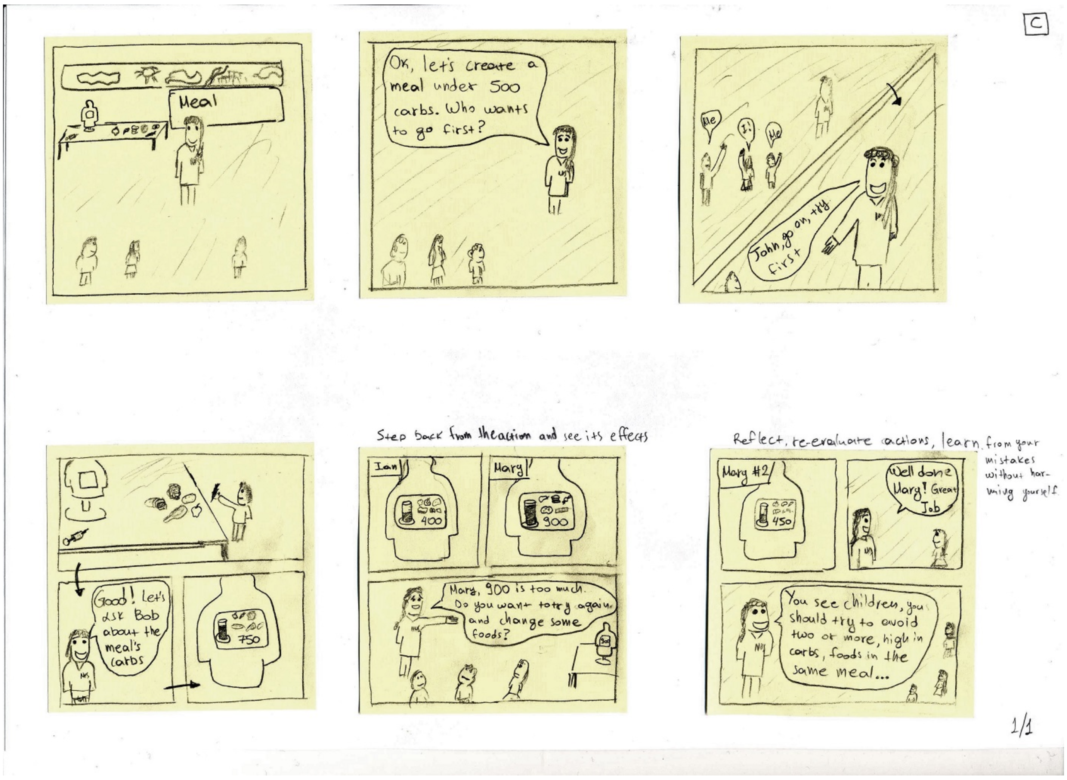

Figure 7.3: Storyboard prototype of educational scenarios. They were used to represent how the tool would be used during the different educational scenarios.

### 7.2.2 Evaluation of paper prototypes

The evaluation of the paper prototypes was initially conceptualised as a workshop with clinicians, parents and children. Due to the complex ethics approval process (form with up to 30 pages and 78 fields, and many accompanying documents – especially if the study involves children), the long waiting time for acquiring the ethics (3 months for the NSG observations) and the limited time of parent availability, it was decided not to work with children and parents for this stage, even though it was on the initial plan (children and parents are included in later evaluation – Chapter 8).

An evaluation workshop was conducted with 3 clinicians; D1 and N1 who participated in previous phases as well and T1 who was new to the study. Their profiles can be found in Table 7.1.

Table 7.1: Profiles of the clinicians who participated in the evaluation workshop for the paper prototypes.

| **ID** | **Role** | **Gender** | **Experience** |
|---|---|---|---|
| D1 | Consultant Paediatrician | Male | 25 years |
| N1 | Nurse Specialist | Female | 8 years |
| T1 | Clinical Specialist Diabetes Dietitian | Female | 27 years |

The evaluation was through pluralistic walk-throughs [116] with the clinicians on the educational scenarios. The participants went through each storyboard and 2D graphics of each scenario, expressing their thoughts and suggesting alterations or improvements on them. Then a discussion about the steps and the value of each scenario was conducted. During the evaluation the clinicians also commented on the properties of the tool's outline and proposed changes. Throughout the evaluation the *Keep-Lose-Change* [56] annotation technique was used, where the clinicians annotated the prototypes about features or elements that they liked (*keep*), thought they should be altered (*change*) or did not think appropriate (*lose*).

Figure 7.4: Pluralistic Walk-through evaluation of the paper prototypes. The green, red and yellow post-it notes are used to annotate the prototypes according to the keep-lose-change methodology.

### 7.2.3 Outcomes

The changes suggested were mostly about graphical representations (e.g. icons for carbohydrates, no sad faces but rather worried) and language used (e.g. use “unhealthy” instead of “bad”). The clinicians also expressed their worries about the physical aspect of the prototype. Namely, the interaction was designed to be through a mannequin with a tablet in the abdominal area (see Figure 7.1, on page 95). The mannequin would represent a diabetic child and the tablet would show feedback on the children’s choices. The clinicians were afraid that this setup was not robust enough for the setting. They preferred something that would be less likely to be damaged, like a projection of the character onto the wall. Moreover, they suggested that the tool should be able to be moved from room to room depending on the availability of space in the clinic.

All three agreed that the prototype tool was aligned with the existing educational goals and that it added the level of interactivity needed. Through the storyboards they recognised some flexibility in the scenarios (about changing the flow and tailoring education to the participants). Finally, they all agreed that there were too many scenarios and suggested reducing them to the three most important scenarios: “What is insulin?”; “Nutritional content of foods”; and

"Which foods are healthy?".

Lastly, the clinicians liked the choice to use of an anthropomorphic character and suggested calling the character "Mee" – a name that can ambiguously make children relate to the character.

## 7.3 Development

The tool went through three development phases, each one with increased fidelity.

### 7.3.1 Making food toys interactive

The first stage of the development was devoted into making the plastic food toys interactive. Many different techniques for achieving interactivity were identified (e.g. camera sensing, touch-screen patterns) but in the end Radio-Frequency Identification (RFID) [1] was chosen, due to its low cost, high reliability and distant interaction (no touch needed). RFID technology uses electromagnetic fields to identify tags attached or embedded into objects. Whenever the object with the RFID tag approaches the RFID scanner, the scanner reads the information stored in the tag. Hence, by embedding RFID tags (see Figure 7.5) in the food toys, the tool could identify each food toy. For the scanning of the RFID tags we used Arduino[2] (see Figure 7.6) microcontrollers connected to RFID scanners.

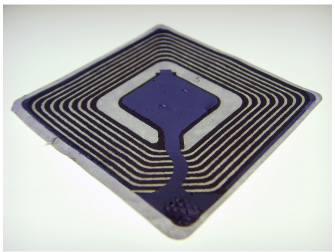

Figure 7.5: An RFID tag. *Image source: wikimedia.org*[3]

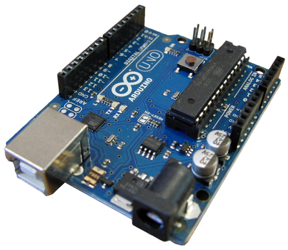

Figure 7.6: The Arduino Uno microcontroller. *Image source: wikimedia.org*[4]

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[1] `https://en.wikipedia.org/wiki/Radio-frequency_identification`

[2] `https://www.arduino.cc/`

[3] `https://commons.wikimedia.org/wiki/File:RFID_Chip_004.JPG`

[4] `https://commons.wikimedia.org/wiki/File:Arduino-uno-perspective-transparent.png`

Once the prototype interactive food toys were tested and proved to work, the list of the food toys was finalised (see Section 7.4.2) and the author started crafting them. In total 85 plastic food toys were used. Most of these toys were standard plastic food toys available in toy stores; 21 toys were hand-crafted by the author, because they were not available in the market. Those crafted toys were created to look like foods that are locally available and to which children in Glasgow are exposed (e.g. fish and chips, oatcakes, Chinese take-away). Also, an insulin pen used for providing insulin to the character was embedded with an RFID tag. The insulin pen, without a needle, was a standard plastic insulin pen. Figure 7.7 shows the initial set of plastic food toys with the RFID tags and the Arduino used during the development of the sensing technique. Figure 7.8 shows some plastic food toys and the RFID tags attached to them. Figure 7.9 presents all the final food toys used.

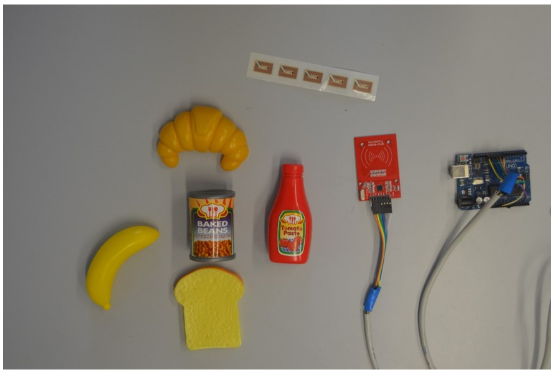

Figure 7.7: Initial food toys, RFID tags (a strip with small orange squares on the top of the image) and the Arduino microcontroller and the RFID sensor (red wired square next to the Arduino) used when the sensing technique was developed.

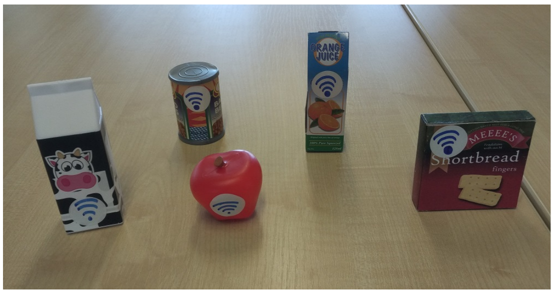

Figure 7.8: Some plastic food toys with the RFID tags attached to them. The white circle stickers with the *WiFi-like* symbol are the RFID tags.

Figure 7.9: The food toys used for the evaluation.

### 7.3.2 2D graphics and logic

The next stage of the development was to create the 2D graphics for the tool and make them interactive. More specifically, the 2D graphics had to become animations and these animations needed to be triggered by input from the RFIF scanners. Hence, whenever a food toy was moved closer to the RFID scanner the respective animation with the respective food had to be triggered.

The 2D graphics of the tool were designed with Inkscape[1] and the animations with Blender3D[2] and Synfig Studio[3]. The graphical interface and the coordination of the sensors with the graphics was done in Unity3D[4]. Figure 7.10 shows examples of the animations for two scenarios: "What's in my food?" and "What is insulin?". Figure 7.11 shows the main screen of the tool's User Interface.

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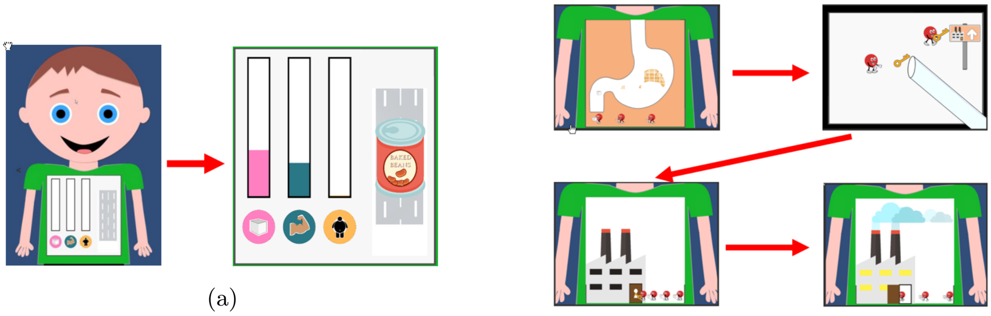
[1] `https://inkscape.org/`

[2] `https://www.blender.org/`

[3] `https://www.synfig.org/`

[4] `https://unity3d.com/unity`



(a)

(b)

Figure 7.10: (a) The animation shown for “What’s in my food?” scenario when a can of baked beans is scanned to the RFID scanner. (b) The animation shown to explain what insulin is. First a food is scanned and then the insulin pen is moved closer to the scanner.

Figure 7.11: The main screen of the tool’s User Interface. The three buttons on the right take the user to each educational scenario.

### 7.3.3 Tool outline and experimental prototypes

After much consideration about the layout of the tool and the way it will be used to give output to the children and get input from the RFID tags, without making the process very unrealistic, the final tool outline was designed. It was decided to host the tool inside a movable station/kiosk with a projection screen on its back. It was decided to place the RFID sensors behind the projection screen, so that the children would move the food toys towards the mouth of the main character, as if they were feeding him, and move the insulin pen towards his thigh (typical insulin injection site), as if they were injecting the insulin. Inside the main station, a projector would project the 2D graphics to the screen through a mirror. The outline is graphically depicted in Figure 7.12. Also, Figure 7.13 presents an outline of the digital components used.

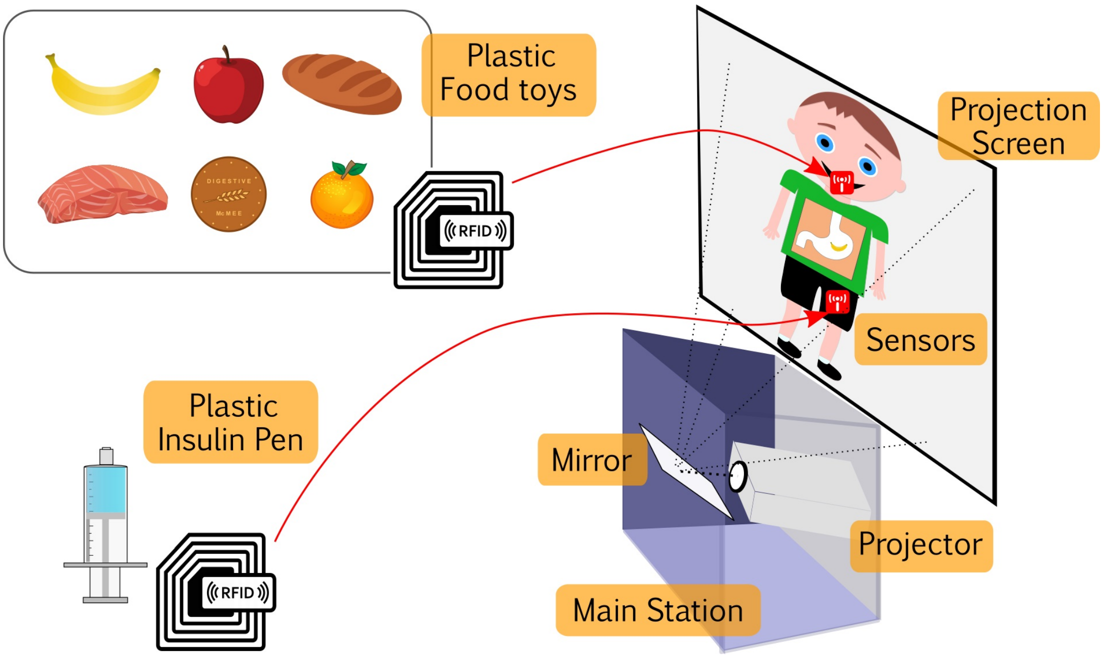


Figure 7.12: The educational tool comprises a projection that interacts through RFID sensors with the plastic food toys and the toy insulin pen.

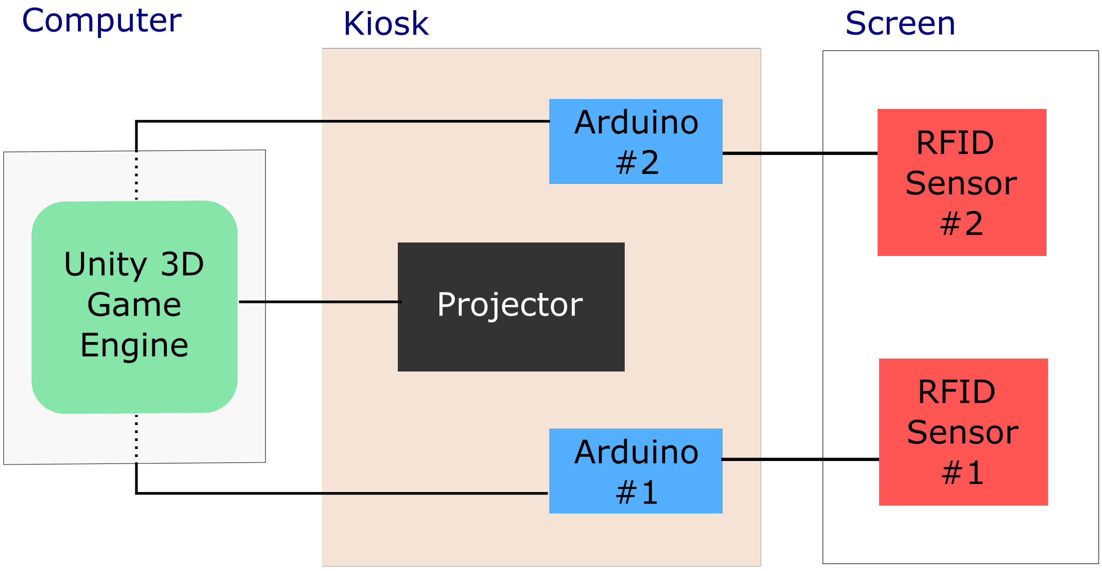
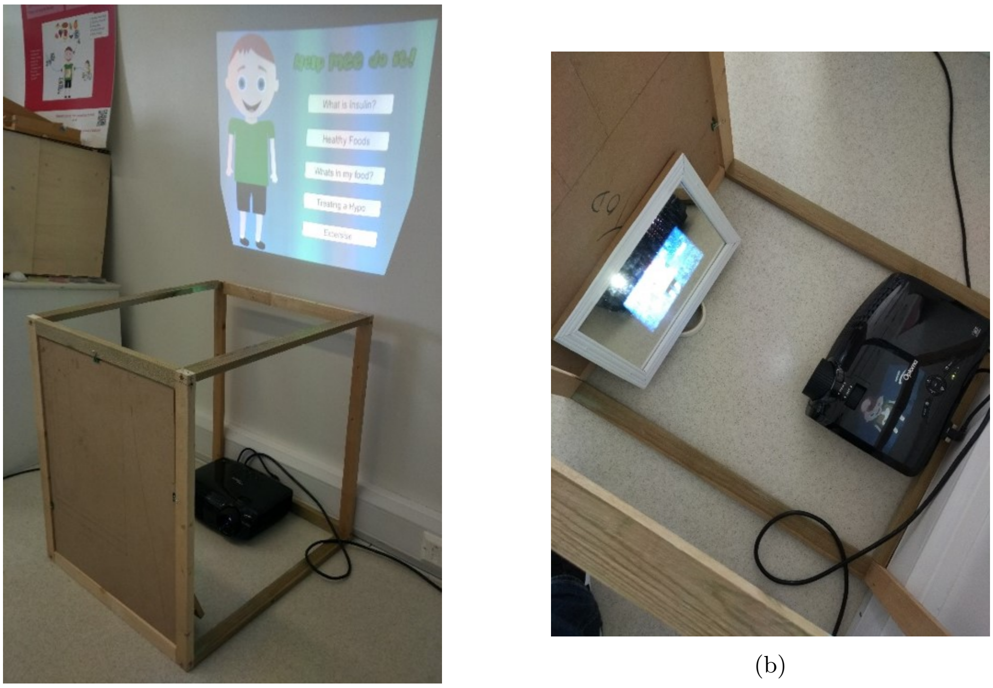


Figure 7.13: The digital components used and how they were connected. Two Arduinos were used, each one connected to an RFID sensor. The Arduinos and the projector were connected to an external computer and whoever – through Unity3D game engine – was controlling the input and the output.

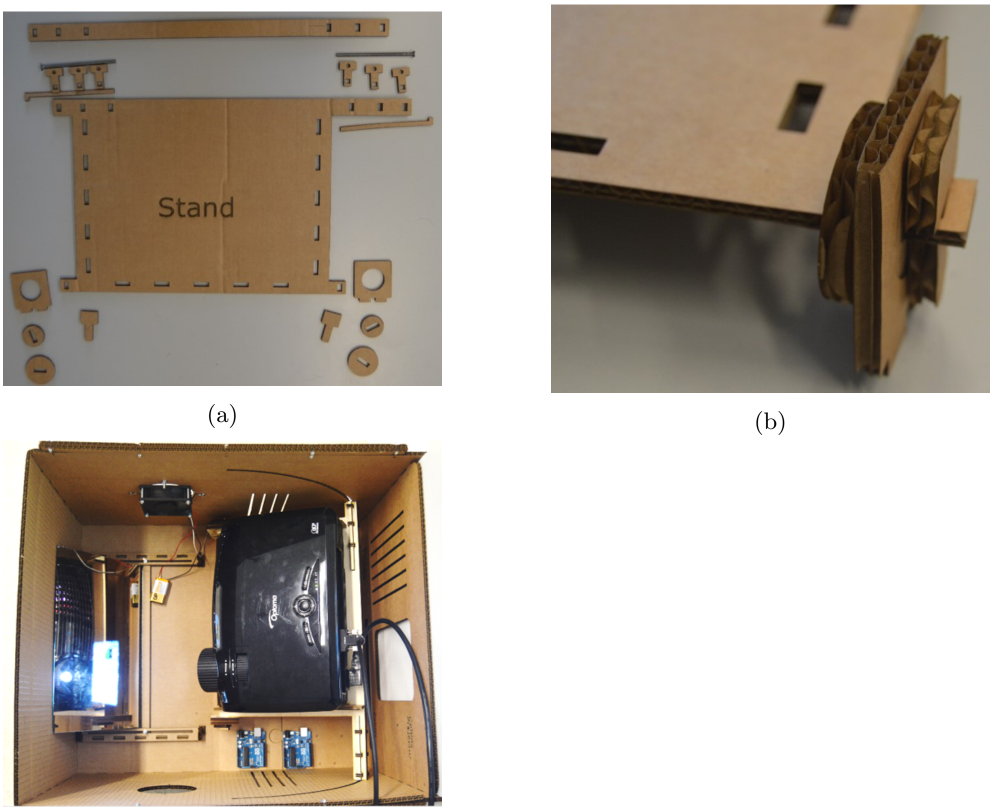
At this stage, a series of prototypes with different techniques was used to build the main station and the screen. Initially, an experimental frame from hardwood was developed by the author (Figure 7.14).



(a) (b)

Figure 7.14: Two photos of the initial experimental hardwood frame for the main station.

The idea of the hardwood frame for the main kiosk was not adopted because it was heavy and it was hard to reproduced it. Hence, laser cut plywood was chosen as an alternative. Laser cut plywood is a cheap and easy to handle material that can easily be used in reproduction allowing an easy scale-up. Wood was chosen in the first place in order to give a more natural and environment friendly feeling to the tool. Hence, a new design cycle begun; instead of plywood, carton was used for experimenting with the exact design, because of its lower cost and its ability to be also cut by laser cutters. Figure 7.15 shows some carton prototypes of the tool.



(a)

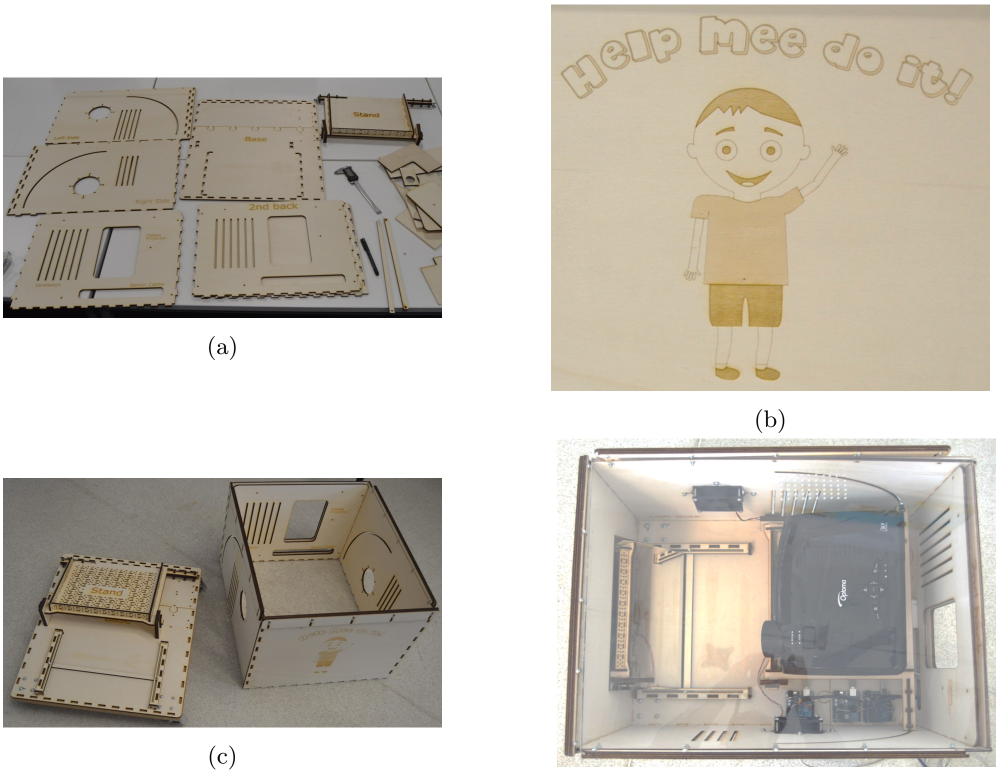
(b)

(c)

Figure 7.15: Experimental carton prototypes, cut with a lase cutter.

### 7.3.4 Final prototype

After a fully-functional carton prototype was ready and all the details were finalised, the next step was to make the prototype with plywood. Figure 8.5 shows some of the plywood components of the main station.



(a)

(b)

(c)

(d)

Figure 7.16: Plywood components of the main station (a, b and c) and the tool from seen from the top (d).

For the projection screen, corrugated plastic[1] sheets were used due to their durability, low cost and low weight. The RFID sensors were attached to the back of the screen as shown in Figure 7.17

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[1] `https://en.wikipedia.org/wiki/Corrugated_plastic`

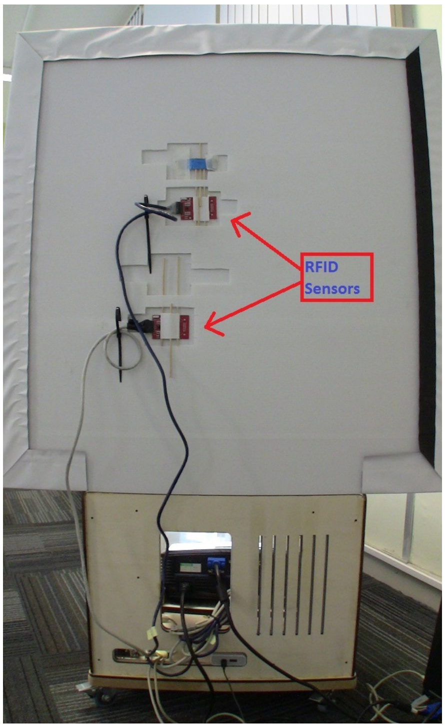

Figure 7.17: The back of the projection screen with the two RFID sensors attached to it.

The final tool is presented in Figure 7.18.

Figure 7.18: The final educational tool and the plastic food toys.

## 7.4 Co-Design of the Educational Sessions

The lack of a formalised education dedicated to children between 5 and 9 meant that we could not compare with existing practices or any existing educational criteria. A new educational session had to be created from scratch, one that could fit the educational goals of the tool and the educational style of the clinic, and support the requirement for group learning (see Figure 6.8, page 87). This session could then frame and contextualise the evaluation. Four co-design sessions were conducted with a total of 5 clinicians (3 of whom were new to the study – T2, D2 and T3). Their profiles can be found on Table 7.2.

During each co-design session the author presented the outcomes up to that point; then clinicians and the author collaborated in the design of the educational session through discussions. Throughout the co-design session the author took notes of the discussions and at the end he summarised the decisions to the clinicians, in order to finalise them. At the end, all the decisions were gathered and presented to the clinicians, who used them for the educational sessions.

Table 7.2: Profiles of the clinicians who participated in the co-design sessions.

| **ID** | **Role** | **Gender** | **Experience** | **Session(s)** |
|---|---|---|---|---|
| N1 | Nurse Specialist | Female | 8 years | 1 |
| T1 | Clinical Specialist Diabetes Dietitian | Female | 27 years | 2 |
| T2 | Clinical Specialist Diabetes Dietitian | Female | 8 years | 3 and 4 |
| D2 | Paediatrician | Female | 2 years | 2 |
| T3 | Clinical Specialist Diabetes Dietitian | Female | 6 years | 3 |

### 7.4.1 First co-design session

The first co-design session was conducted with N1. The purpose was to shape the educational session and decide upon its procedure. It was decided to have *pre* and *post* discussion between the children and the clinician for each scenario. This way the clinician could understand what children already know (to tailor education) and what they learned after using the tool for each scenario. Also, it was decided that the session should not exceed 1 hour and had to be run by either a nurse or a dietitian or both, depending on availability. Finally, it was decided that the number of children per session and the age span of the children attending should be flexible. This would simulate participation to the NSG where all newly diagnosed families are called but there is no guarantee as to how many will actually attend, nor that the children would be of the same age.

### 7.4.2 Second co-design session

The second co-design session was conducted with T1 and D2. The purpose was to compile a food list for the toys that will be used. In total, 95 foods were chosen, based on the dietary habits of the local community covered by the clinic. The foods that were chosen for the "Healthy Foods" scenario, were grouped into triads of "Healthy", "Not So Healthy" and "Not Healthy" alternatives (e.g. salmon, canned tuna and fried fish, respectively). It was decided that the children would frame their options based on three meals: breakfast, lunch and snack. For the

"What's in my food?" scenario, the foods chosen were balanced between carbohydrates, protein and fat-based foods.

### 7.4.3 Third co-design session

At this stage T1, who was the main point of contact for dietitian-related aspects of the study, retired. Two other dietitians volunteered to help. This session was conducted with T2 and T3. Initially, they were presented with the co-designs of the previous sessions and they refined them.

It was decided that children would test the foods freely, without framing them around specific meals (e.g. breakfast or lunch) because different families have different eating habits. The foods were reduced to 85 by removing 10 foods that were not available as food toys and were very hard to craft. Moreover, the "Not So Healthy" food category was removed for two reasons. Firstly, to avoid confusion by the younger children and secondly because some of these foods may be considered a healthy option by some families and an unhealthy by other families (e.g. home-made pizza versus take-away pizza). For the "What's in my food?" scenario, a fourth category was added, the "More than one" that could cover the foods that comprise by different nutrient categories (e.g. pizza which has protein, carbohydrates and fat).

In relation to the order of the educational scenarios, it was decided to have a story-like continuum. Namely, first the children would be educated about insulin. Based on that, they would then learn which foods need insulin and which do not (which foods have carbohydrates and which do not). Finally, the children would have to understand that from the foods they had chosen previously not all are healthy. This way the T1D education would have a story-like continuum.

### 7.4.4 Fourth co-design session

The final co-design session was conducted with T2 to finalise the procedure. T2 observed that there was a need to visually summarise children's food options for the second and the third scenario (group foods by category and separate healthy and not so healthy foods respectively). This way they would be able to see an overview of their choices and the outcomes in the end of each scenario. Hence, two paper boards were designed which children would use to place the plastic food toys on, according to the feedback they get from the tool. One board would be used to distinguish the foods in "Count" and "Don't count" (based on the carbohydrate content) and children will place foods on it after they get feedback from the tool on the second scenario. This was suggested by T2 because the main educational message of this scenario for the children is whether or not they need to count a food. The count and don't count areas are further split into the different nutrient groups (proteins, carbohydrates, fats, more than one) so the educator can speak about these as well with children in the older age group. The other board would be used to distinguish the foods as “Healthy” or “Less Healthy”, based on the feedback from the third scenario. The boards are shown in Figure 7.19 and Figure 7.20

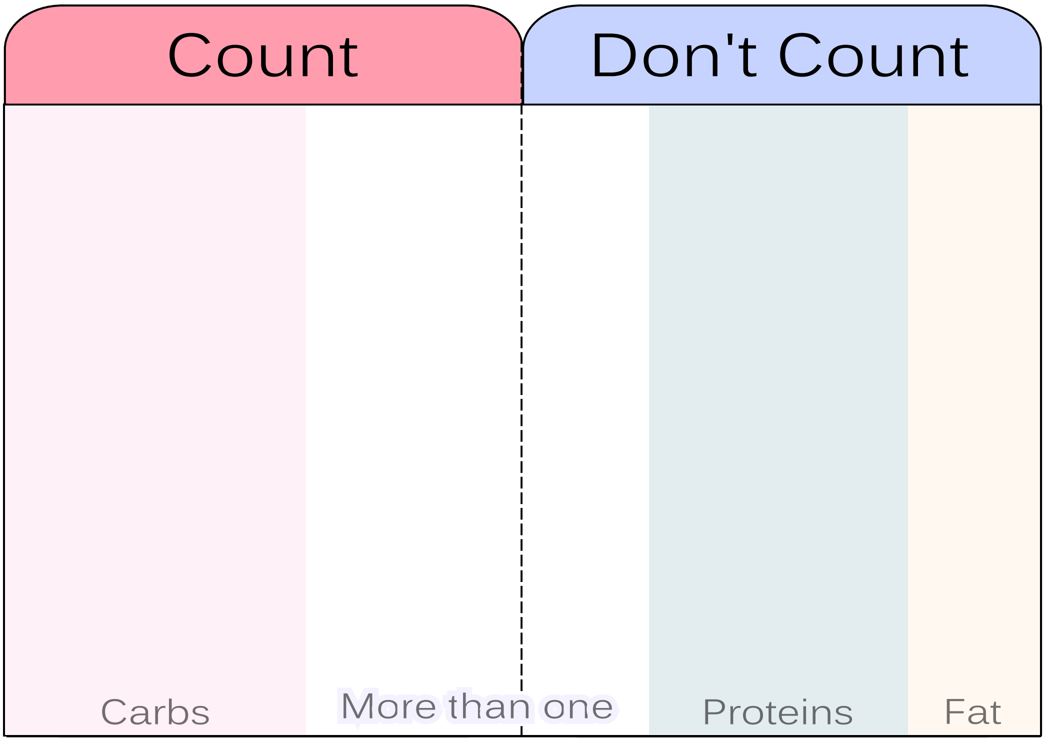

Figure 7.19: The paper board used for placing the foods of the “What’s in my food?” scenario.

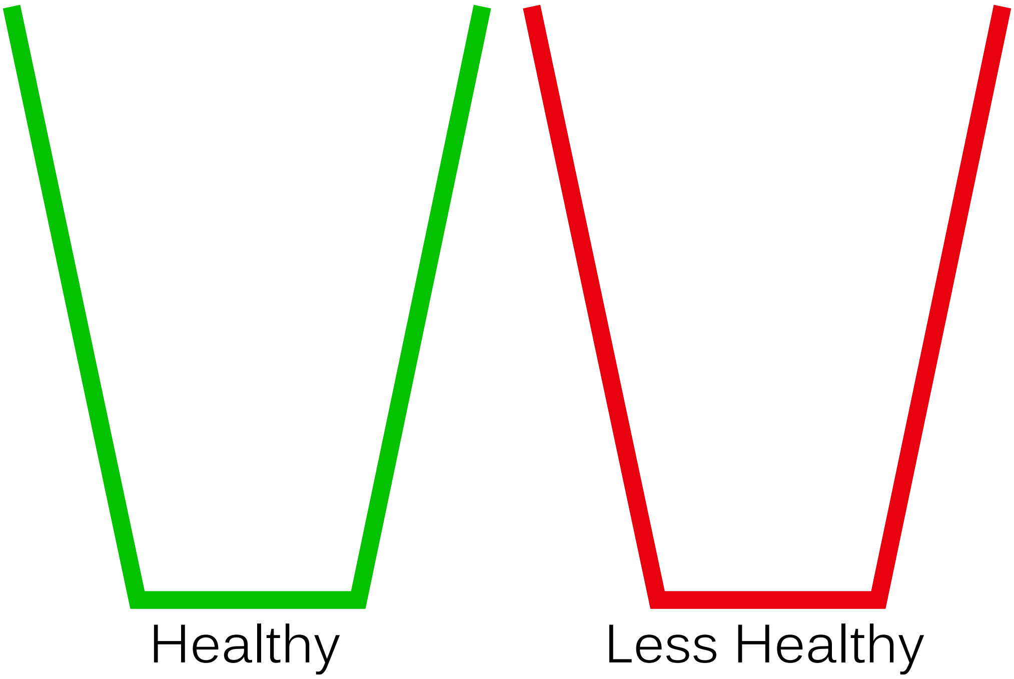

Figure 7.20: The paper board used for placing the foods of the “Healthy foods” scenario.

## 7.5 Conclusion

This chapter presented a series of steps undertaken to design a tool based on the requirements of the context (Chapter 6). The result was a set of designs for a tool which extends the existing approach of the clinic, the tangible food toys, by adding interactivity. The designs were then implemented and a prototype tool was produced. Even though the tool was based on the existing approach of the clinic, it was targeting an age group that previously was not adequately catered. Hence, a series of co-design sessions were conducted in order to frame the T1D education in a dedicated session, one that could also be used for the summative evaluation of the tool. The resulting tool and the bespoke educational session, which are based on the requirements, propose a new way to enhance the existing educational approach by making it interactive.

The next chapter presents the evaluation of the tool in the context with children, clinicians and parents.

# Chapter 8

# Evaluation of the Solution

## 8.1 Introduction

The fourth phase of the methodology was to assess the effectiveness of the educational tool created. This phase was conducted in order to test the developed tool against the requirements and more generally the research aim[2].

The chapter starts by explaining the rationale behind the evaluation (aims, measurements), continues with the procedural aspects (procedure, participants, data gathering and analysis) and finishes with the results for each participant group.

## 8.2 Aim and Methods

### 8.2.1 Aim

The aim of the final evaluation was to measure success of the tool in supporting T1D education of younger children with T1D in the clinical setting. This way we could answer the research question of this thesis.

### 8.2.2 Measurements

The result of the requirements formulation process was a set of requirements and design decisions. The design decisions and the lowest-level requirements, because they are very detailed and purpose-specific features (see Section6.1.1, page 79), guided the design of the tool and were fulfilled when they were implemented. The highest-level non-functional requirements (see Section 6.3.2, page 6.3.2), derived from the research aim, characterise the target qualities that the tool should have in order to be successful. These are “Tool should effectively support education”, “Tool should be age-appropriate” and “Tool should be viable for adoption”. Hence, in order to conclude on the tool’s success and be able to respond to the research question, we had to assess the fulfilment of these three requirements. Since these three highest-level non-functional

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[2] Research aim: To design, develop and test an age-appropriate digital tool which can effectively support the education of younger children with T1D and can actually be adopted by the educational practice in Diabetes clinics for young children

requirements are quite vague and thus hard to conclude about, we decided to assess their fulfilment by assessing their decompositions (lower-level non-functional requirements derived by them).

### Educational effectiveness

The concept of educational effectiveness during the requirements formulation was decomposed, using the literature, into four non-functional requirements; namely: “Tool should be enjoyable”, “Tool should be engaging”, “Educational messages should be memorable” and “Tool should enable clinicians to personalise education” (as described in Section 6.3.3.1, page 87). By measuring these aspects (**enjoyment**, **engagement**, **things children put into practice**, **enabling individualised education**) we could make some reasonable conclusions about the potential educational effectiveness of the tool in a summative way.

We decided to assess ***engagement*** through the clinicians and parents who would observe the session and would be able to see if the children were engaged; ***things children put into practice*** through the parents who would observe the children’s reactions after the session and would be able to compare these reactions before and after the session; ***enabling individualised education*** through the clinicians who would have the role of the educator during the session; and ***enjoyment*** by asking both parents and clinicians to express how they perceive the children’s enjoyment during the session.

Moreover, because ***enjoyment*** is a more subjective concept we wanted to also measure it more directly by asking the children. Hence, the children were asked to complete a four-page questionnaire about enjoyment and emotional stage during the session with the tool. To measure enjoyment from children we chose to use standardised techniques used in the literature. Namely, we measured enjoyment using the *smilometer* (Figure 8.1) by Read et al. [134] and emotions during the session through the *emotional response tool* (Figure 8.2) by Agarwal et al. [1]. Both the smilometer and the emotional response tool have been shown to be age-appropriate for young children in system evaluations.

Figure 8.1: The *Smilometer* [134].

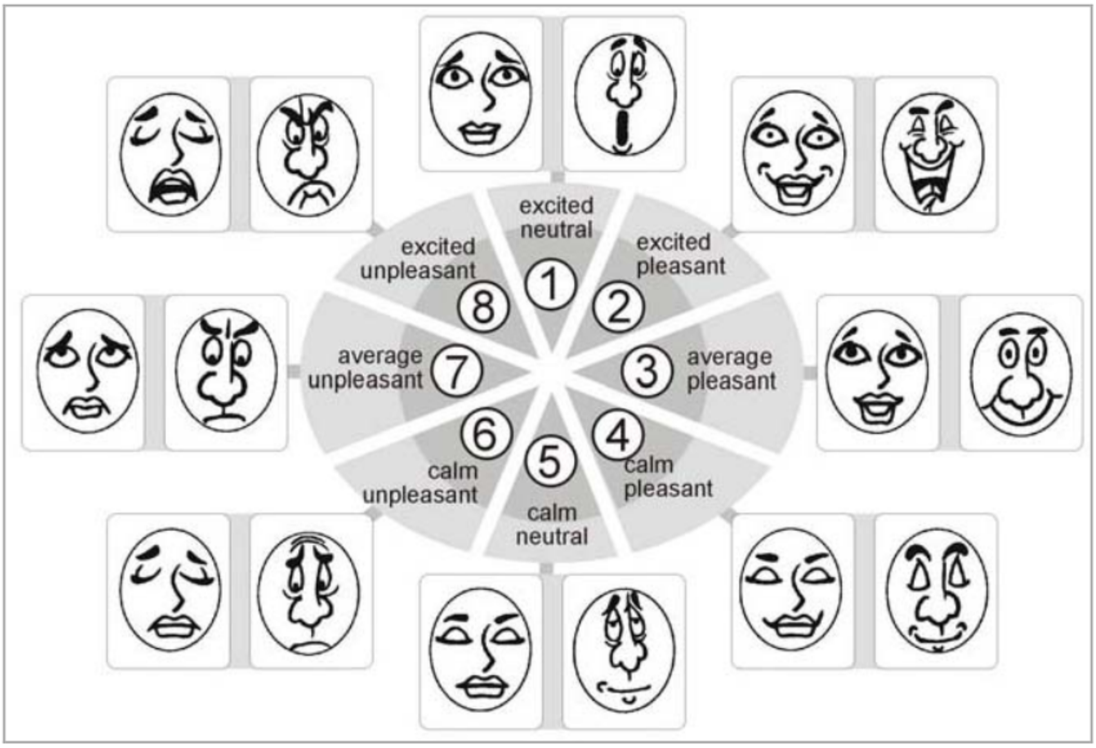

Figure 8.2: The emotional response tool [1].

Apart from the decomposition of educational effectiveness in the four non-functional requirements, we also considered measuring educational effectiveness more directly from the children. Namely, we considered measuring it through pre and post tests/quizzes to the children. However, we decided not to measure it this way for the following reasons:

- The first was due to the specificities of the context, namely the different clinicians (nurses, dietitians, support workers), the limited participation to the research and the diverse patient profiles. To accurately measure educational effectiveness, one must control many different variables (e.g. prior knowledge, learner's ability and style, instructor effect, number of participants) [84]. Controlling all the variables may have excluded some children from the sessions (due to availability limitations), and would had been contrary to the clinicians' requirement that the session should be flexible and simulate participation to the NSG.
- The second reason was to avoid putting stress on the children and making them feel questioned or assessed for their knowledge with pre and post questionnaires [146, 178].
- The third reason was to avoid capturing indicators of current performance (i.e. achievement-based indicators), which are mainly influenced by past experiences and are not useful for assessing future assimilation of knowledge [86].

Moreover, we decided not to use control and test group (with and without the tool) for the following reasons:

- There was no real alternative to test against. The lack of other materials and the lack of an alternative session for children at that age group did not allow for such an option.
- We did not want to *disadvantage* some children by not letting them play and experience the tool.

### Feasibility for adoption

To assess the fulfilment of the non-functional requirement “feasibility for adoption”, we enquired about the sub-requirements derived from it; namely, we asked the adults about:

1. Alignment with clinic’s current approach – Clinicians.
2. Tool’s ability to educate groups – Clinicians and parents.
3. Feasibility for implementation in educational practice – Clinicians and parents.

### Age-appropriateness

Even though the non-functional requirements “alignment with clinic’s approach” and “age-appropriateness” were partially assessed during the design phase, through designing the tool based on their sub-requirements and sub-decisions (see Section 7.1 on page 94), we also asked the adult participants about them. We asked both parents and clinicians their opinion about the age-appropriateness of the tool and the stage(s) and age(s) it could be used for.

### General opinion

Apart from all the previous constructs related to the requirements, we wanted to understand more generally the opinion of the participants about the session and the tool. Hence, we asked the adult participants to explain their personal experience. This was particularly important for the clinicians [97] because, as mentioned before, the effectiveness of diabetes education relies on their motivation [91].

### Conceptual constructs of the interviews

Table 8.1 presents a summary of the four concepts (effectiveness, feasibility for adoption, alignment with clinic’s approach and general opinion) of the evaluation, that adult participants were asked about (during the interviews).

Table 8.1: The conceptual constructs of the final evaluation that parents and clinicians were asked about during the interviews.

| **Parents** | **Clinicians** |
|---|---|
| ***Educational Effectiveness*** | |
| Enjoyment | Enjoyment |
| Engagement | Engagement |
| Memorable | Personalise Education |
| -Learning outcomes | Learning outcomes |
| -Change in behaviour | |
| ***Age-appropriate*** | |
| Age group | Age group |
| Stages | Stages |
| ***Adoption*** | |
| Implemented in educational practice | Implemented in educational practice |
| Group Education | Group Education |
| | Align Clinic's Approach |
| ***General Opinion*** | |
| Opinion session | Opinion session |
| Opinion tool | Opinion tool |
| Interaction Style | Interaction Style |
| | Enjoyed taking part |
| | Motivate clinicians |
| | Improvements |

## 8.3 Procedure

In total five evaluation sessions were conducted on days where children between 5 and 9 were already having clinical appointments with the doctor. All parents were informed prior to the study by the clinicians through emails. In those emails the clinicians explained that a one-hour educational session will run before their appointment with the doctor, and that this is part of a research study. All the families called had already been provided with the appropriate education according to the current practices (see Section 5.2.2.2 about the educational pathway on page 56 and Section 5.2.2.2 about the New Starts Group on page 56).Only one child, CF13, had not been to the clinic before, as he was close to diagnosis and an NSG had not yet been conducted, but his family had followed the educational pathway. The emails sent to the families included information sheets for the parents and the children. The emails were sent at least a week before their appointment with the doctor.

On their arrival at the clinic, those who had agreed to participate (and their children) had to fill in consent forms: one assent form for the child (Figure B.2, page 169) and one consent form for the parent (Figure B.1, page 168). The clinicians, as participants of the study, also had to complete consent forms (Figure B.3, page 170).

After completing the forms, children were taken to another room by the clinician, where the tool and the author were. In that room and before the start of the session, the clinician introduced the author as the *inventor* of *Mee* and informed the children that he would be present during the session, observing and helping with any technical issues. The author was silent throughout the evaluation, did not interact with the children and only looked at the tool. During the session the children were educated by the clinician (nurse and/or dietitian), with the use of the tool, on the three main topics that the educational scenarios were covering: insulin, carbohydrate counting and healthy food options.

Parents, from the waiting room that they were in, had the chance to watch the session through a monitor connected to two cameras. This way they could see what the tool was doing and observe how their children were being educated. This was done in order for the parents to know what was happening in the evaluation room and thus be able to later reflect on the use of the tool, the session and their children's experience.

At the end of the session the children were asked to complete an age-appropriate questionnaire asking the following: 1) Their emotional state during the session (Figure 8.2), 2) how much they liked previous visits to the clinic (5 point smilometer), 3) how much they liked this visit to the clinic (5 point smilometer), 4) to draw or make something (using plasticine) that described their experience with the tool. For both the smilometer and the emotional response tool the children were asked to circle their preference. The session, including completion of the children's questionnaires, lasted on average one hour.

At least one week after the session the participant parents were also interviewed about the tool and their child's reactions to it. The one week gap was chosen to allow the parents to spend enough time with their children after the session and thus be able to observe any changes of behaviour or knowledge. Finally, a few weeks after the end of the study, all four clinicians who took part in the evaluation were interviewed and asked to reflect on the appropriateness, feasibility and effectiveness of the tool. The evaluation procedure is diagrammatically depicted in Figure 8.3.

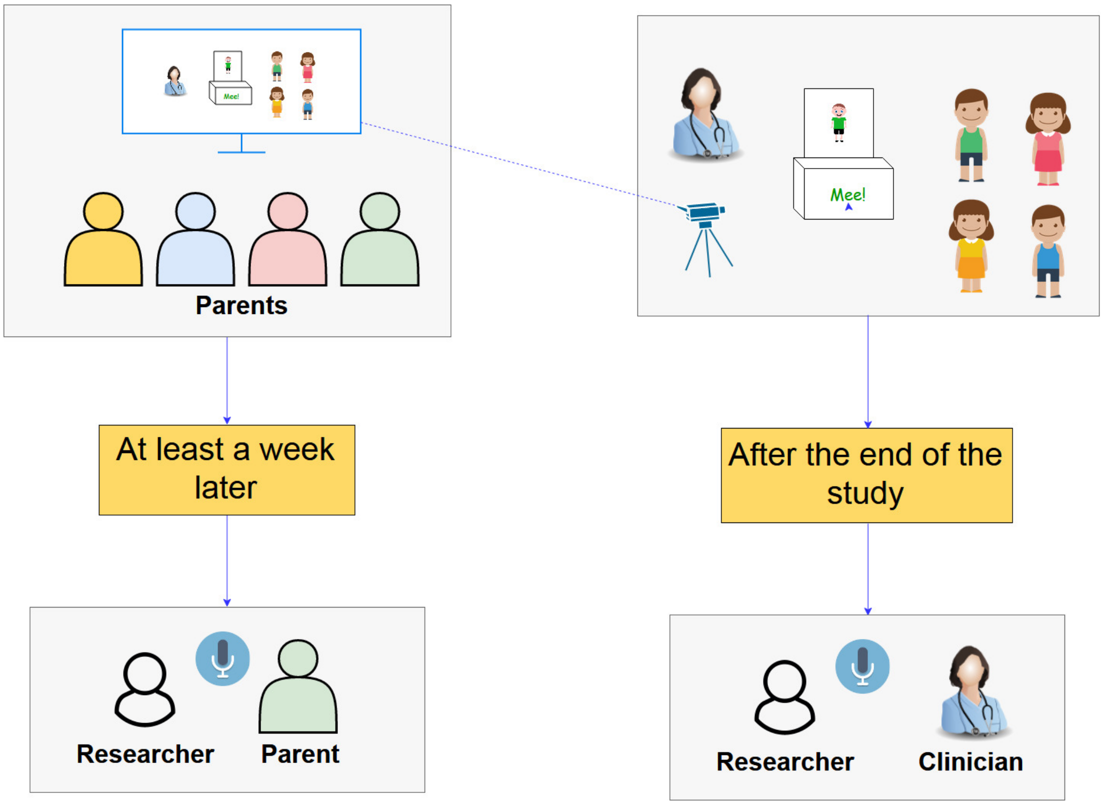

Figure 8.3: Diagrammatic representation of the final evaluation procedure. The clinician(s) educated the children in one room and the parents, who were in another room, observed the session through a monitor. At least a week after the session the parents were interviewed. At the end of the study the clinicians were interviewed.

The full evaluation protocol was presented to the Scottish Children's Research Network (ScotCRN)[1] who gave feedback about the procedure and the appropriateness of the methods for the age group. Also, ethics approval was provided by the NHS for the evaluation.

## 8.4 Participants

In total 17 children (mean age = 7, deviation = 1.3, 7 boys and 10 girls) and 4 clinicians (N1, T2 , T3, T4; see Table 8.3) participated in the evaluation. All 4 clinicians had previously taken part in NSGs. The number of children participants translates to 11% of the total number of children (154) between 5 and 9 years with T1D in the area covered by the clinic. All the children were new to the study and were not involved in previous stages nor had seen the tool before. The profiles of the children who participated are presented in Table 8.2.

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[1] A team of researchers, clinicians and children experienced in research who provide support and advocacy for the set up, research governance and conduct of trials involving children. `https://www.scotcrn.org/`

Table 8.2: Children participants of the final evaluation

| ID | Age | Gender | Diagnosis Age | Session |
|---|---|---|---|---|
| CF1 | 8 | Girl | 7 years | 1 |
| CF2 | 8 | Girl | 7 years | 1 |
| CF3 | 5 | Boy | 3 years | 1 |
| CF4 | 6 | Girl | 15 months | 1 |
| CF5 | 8 | Girl | 6 years | 2 |
| CF6 | 9 | Boy | 18 months | 3 |
| CF7 | 8 | Boy | 2 years | 3 |
| CF8 | 8 | Girl | 8 years | 4 |
| CF9 | 9 | Girl | 9 years | 4 |
| CF10 | 6 | Girl | 6 years | 4 |
| CF11 | 7 | Boy | 2 years | 5 |
| CF12 | 5 | Boy | 2 years | 5 |
| CF13 | 7 | Boy | 7 years | 5 |
| CF14 | 7 | Boy | 5 years | 5 |
| CF15 | 5 | Girl | 4 years | 5 |
| CF16 | 6 | Girl | 4 years | 5 |
| CF17 | 8 | Girl | 7 years | 5 |

Table 8.3: Profiles of the clinicians who participated in the final evaluation.

| ID | Role | Gender | Experience | Session(s) |
|---|---|---|---|---|
| N1 | Nurse Specialist | Female | 8 years | 1 |
| T2 | Clinical Specialist Diabetes Dietitian | Female | 8 years | 1, 2, 3 |
| T3 | Clinical Specialist Diabetes Dietitian | Female | 6 years | 5 |
| T4 | Clinical Specialist Diabetes Dietitian | Female | 18 years | 4 |

Four children (CF1 to CF4), N1 and T2 participated in the first session; 1 child (CF5) and T2 in the second; 2 children (CF6 and CF7) and T2 in the third; 3 children (CF8 to CF10) and T4 in the fourth; 7 (CF11 to CF17) children and T3 in the fifth. The participants were assigned to a session based on the date they had their clinical appointments with the doctor. One child (CF14) participated in the session but had to leave before the end of the session and thus did not fill in the questionnaire. In total 5 parents (CF5's, CF6's, CF7's, CF8's and CF12's) agreed to participate in the interviews after the evaluation. For CF5 and CF7 both parents attended the interview and in the quotes mentioned, as M stands for mother and F for father. All four clinicians were interviewed 2 to 4 weeks after the session, depending on their availability.

## 8.5 Data Gathering and Analysis

The session was video recorded by two video cameras for referencing and analysis of the children's actions and responses. For the interviews with the parents and the clinicians a semi-structured protocol was used. The topic guides can be found in Appendix B (page 167). The interviews were audio recorded and transcribed. Due to the more structured and focused protocol of this evaluation the interviews were analysed based on the conceptual constructs of Table 8.1. Since the conceptual constructs had been predefined, a deductive coding approach was used to summarise the results and each conceptual construct was translated into a theme. Hence, the analysis presented in this chapter is more descriptive than reflective. A reflective interpretation of the evaluation results is presented in the next chapter (9).

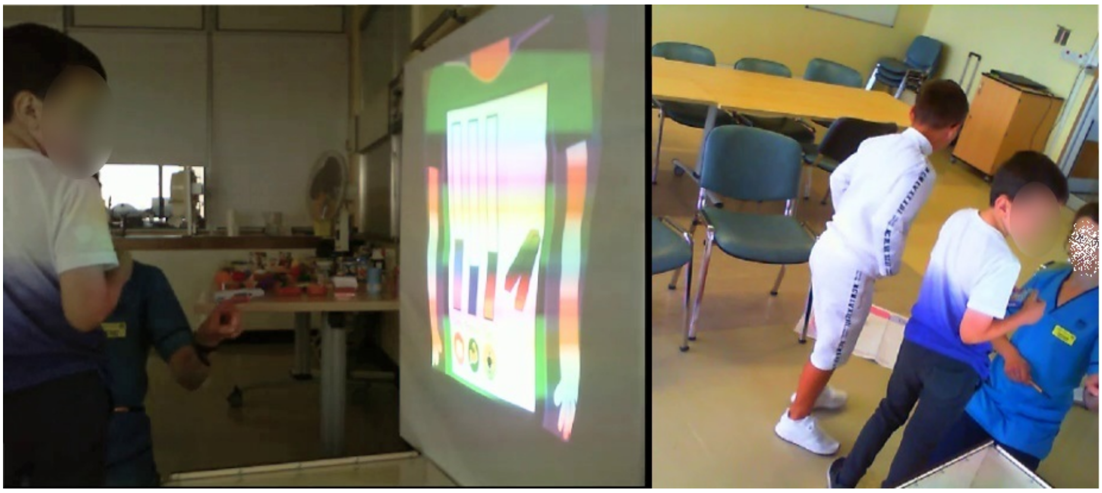

Figure 8.4: Snapshot of the third session with CF6, CF7 and T2.

(a)

(b)

Figure 8.5: The two helping boards with the plastic food toys of the 3$^{\text{rd}}$ session, after the child's exploration. The children put the food toys to the correct paper (or side of the paper), depending on the feedback they got from the tool. (a) shows the results of the "Healthy foods" scenario and (b) of the "What's in my food?" scenario.

## 8.6 Results

### 8.6.1 Parents

#### 8.6.1.1 Construct 1: Effectiveness

Parents were certain of their children's enjoyment during the session. All of them reported that the tool was engaging and enjoyable for their children. Some of them were surprised by the level of engagement and enjoyment, as they had lower expectations from the tool and the session. Not all parents were sure about the actual educational effectiveness of the tool. Those who were positive about the educational effectiveness observed explicit and apparent learning outcomes and they even reported that they observed a change in their child's behaviour and awareness in relation to the condition and its management.

**Enjoyment**

All parents thought that their children enjoyed interacting with the tool. Some of them were more enthusiastic than others, but all were very positive about the enjoyment their children experienced.

> – *Oh, he loved it! I thought that him and the other wee boy (C7) weren't gonna come out. They were having a great time! (...) My son was actually in a wee high in that room, he was loving it.* [P6]
>
> – *M: But also how pleased when it finished; how pleased my son was having taking part. He clearly enjoyed it.* [P7]

**Engagement**

All the parents thought that the tool was very engaging for their children. They commented on the fact that their children were not "pushed" to be involved during the session and were very engaged throughout the session.

> – *M: They [C6 & CF7] were very involved, they didn't need to be encouraged to take part. (...) You weren't trying to force information on them, they were actually eager to find out what each food group had.* [P7]
>
> – *They all certainly paid attention. (...) Nobody happened to be told to sit down or pay attention. So I think they found it engaging enough.* [P8]

**Memorable**

Four parents mentioned specific learning outcomes, but it was not clear if all parents had actually observed these outcomes or not.

> – *M: He remembered an awful lot of what was said from that session and talked about it (...). Yesterday he was talking about the "insulin is like a key".* [P7]
>
> – *When we've asked him what do you feel you've learned he said "basically, I've learned more about healthy eating, I've learned about healthy foods". So, we quizzed him on a couple of foods, for example hamburgers and pizza vs fruit and cereals and low carb foods. He could tell us whether he should eat a lot of or will have some times.* [P12]

Two parents observed, as a result of the session and the tool, that their children started talking more about their food choices at home.

> – *He's constantly since the session talked about what's in his food (...) He started discussing the difference between soy and real milk and how soy milk had have any carbohydrate and "may have a bit of fat", he said "but I think it's mainly protein"; that kind of thing. Maybe that's better to have or he could have that all the time.* [P7]

One parent, P8, was sure that her child had not learned anything new from the session. This parent, throughout the interview, focused more on the social aspect of the tool rather than its educational impact. Another parent, P6, also could not name a specific thing that her child learned from the session. Whenever asked about learning outcomes she was replying about the enjoyment and the engagement in a very positive way.

> – *I guess, our children have had a wee bit of education on that already. They knew more about carbohydrates than a children just who's never ever had a conversation really.* [P8]

There was a change in the behaviour of three children. P7 and P12 spoke about very specific incidents where their child acted more maturely than usually and considered that a result of the session and the tool. P5 talked about a general change in the behaviour.

> – *M: She's now starting to think what she didn't. Before she would just pick up a snack on anything. (...) She's now saying "Oh actually, I'll have a bit of cheese rather than having a packet of crisps".* [P5]

> – *He'll talk about the carbohydrate, he'll also list all the facts and the things and then say "Oh, there's more than you would think now, wouldn't you?" and he wasn't doing that before in that way at all, I feel it's very beneficial for him.* [P7]

> – *He was at a party for the first time (after the session) and he's been given a bag of sweets. And he said that he understood that it was ok to have them sometimes and he would eat a wee bit there, a wee bit tomorrow! So I thought that was quite responsible (...). I was quite interested to see - especially at a party. It obviously had an impact and stuck in his mind what he looked and learned.* [P12]

Some parents mentioned that the tool reinforced their children's current education. Parents found the tool not only helpful in reminding the children of the basics to also in preparing them for more advanced knowledge.

> – *I think it's a good way for the children to learn about what's in what and also to kinda cement their understanding of it.* [P8]

> – *It covers topics that we talk about at home; we don't really explicitly cover the concepts of counting carbs, we kinda enforce healthy food choices and maybe don't discuss them as much. (...) The tool reinforces some of the things we've been saying to him as parents.* [P12]

#### 8.6.1.2 Construct 2: Age-appropriateness

The parents perceived the tool and its educational content as very appropriate for this age group. Also, they thought it could be used for other age groups and even other user groups (e.g. parents). Parents also thought that the tool would be most useful close to diagnosis, when children struggle to understand what diabetes is.

**Appropriate for the age**
Four parents commented about the appropriateness of the tool for this age group. They all spoke about the educational content and how it was suitable for their child's age group.

> – *Pitched just right, given the kind of ages of the children(...) I don't know the ages of the other children, but my son is 5 and a half and he's generally has a good attention span, but I thought all the children totally had well, obviously the content was interesting to them. (...) I mean, he clearly understood it and discuss it afterwards.* [P12]

Four parents commented on the potential of the tool to be used for other age and user groups as well.

> – *I thought it would be even good for his brother, to learn about what was happening with his wee brother. (...) I think I would had learned through that (tool), when CF6 was diagnosed. Than would had been much easier for me. I wouldn't had felt that pressure reading that red book (provided by the clinic).* [P6]

> – *I think that's gonna be beneficial not only for the children but also for the parents.* [P7]

**Stage used**
When it comes to the stage of the diabetes journey that it would be more appropriate for, most parents thought that it would be most suitable close to diagnosis.

> – *I think it is particularly useful when there are nutritionists involved and very likely early after diagnosis. (...) once they've accepted the diagnosis and they understood that it's something that has a life-long impact and requires day-to-day constant attention. I find at that time of acceptance, that's a good time to reinforce it: "Here's why you should eat healthy".* [P12]

Two parents suggested the tool could be used in other educational settings as well. Namely, they suggested usage inside school classrooms as a general tool for nutritional education, or as a tool for diabetic children to educate their peers about diabetes.

> *– We were talking about that and he was like "This would be great", because he had given a few assemblies at school (...) he talked about the fact that he is diabetic to the school (...) he was like "Could you imagine if you could take that up to the school and let the other kids see it..".* [P6]

> *– M: because I work in schools, I was thinking about it as a general nutrition point of view in classrooms and thought it was already good way of doing it (...). But to involve them in a way that they were involved, even as a bigger class lesson it would still be more engaging that a lot of things you're doing.* [P7]

#### 8.6.1.3 Construct 3: Adoption

The parents compared the tool to the current educational practice by the clinic. They mentioned the barriers and the limitations of the current approach and contrasted it with the educational session and the tool. They discussed the feasibility of adopting the tool within the regular practice and they also mentioned the importance of their child being educated with peers.

**Implementation in educational practice**

Four parents compared the current educational approach of the clinic and available educational resources with the session and the tool.

> *– The diagnosis, the process afterwards is very obviously about them but it's not fun; it's not material that's presented in a way that particularly necessarily to learning, it's basically "here's a bunch of things you need to do, here's a bunch of books you need to read, here's a bunch of numbers you gonna have to start worrying about". For kids it's not necessarily something to absorb easily. Whereas I think this exercise [session with the tool] maybe drives home the why.* [P12]

All parents answered positively and thought that the tool can be implemented for educating young children with diabetes.

> *– Yeah, definitely could do that as part of the clinic because they do that (NSG). (...) So I think it would probably fit inside of that.* [P8]

### Group education

There was an interesting alignment of thought in relation to the importance of the social aspect of learning. All parents acknowledged the significance of education in groups after observing the session. They mentioned the value of looking at the other's perspective but also the value of connecting with other children like them.

> [Asked if better for child to be educated alone] – *M: For CF5 I think it worked better because she is quite shy. I don't know if would had come out of her shell quick enough in a group setting. F: There is that, but the certain point in a group setting usually find that you learn little snippets from each other. M: Aha.* [P5]

> – *M: If they see other children who are the same age group or similar observing that information and making decisions based upon it, it might encourage them to do. And also emphasises the fact that they are not on they own.* [P7]

#### 8.6.1.4 Construct 4: General opinion

Parents expressed very positive opinions about the tool and the session. They found the interactional and educational style of the tool to be very effective. Moreover, they thought that the session was well-structured and they mentioned that even they personally found it interesting and learned from it.

### Opinions about the session

Two parents commented positively on the structure of the session.

> – *I think it was well-structured obviously.* [P8]

> – *I thought it was very useful, very well organised.* [P12]

Some parents talked about the session's impact on them personally. Two mentioned that they enjoyed observing the session and it also brought them in contact with other parents. Two also mentioned that they could assess their children's knowledge and also they themselves learned about nutritional aspects that they did not know already.

> – *It was good for us to hear how much they did understand, when they were answering stuff. (...) And it's funny because things that at sometimes seem obvious to us but wasn't obvious to them (...) And we [P6 and P7] were quite surprised with a couple of things, we not known. (...) So that was good for us.* [P6]

> – *M: Watching the two of them discussing it brought up an awful lot of points for me and the other lady [P6] to talk about. We were constantly trying to watch what they were doing but we start talking about an issue that we had, it was that kinda*

> *interaction for parents, it brought up a lot points for discussion. (...) If you are in the waiting room you don't much talk to the other parents, you have to seek out one of the support groups.* [P7]

### Opinions about the tool

Almost all parents mentioned that the educational style of the tool is relaxing, without scaring the children and uses simple terms. They found this fact very important, in comparison with other education that their children had received in the past.

> *– M: There's a fun and a relaxed element too; I think it's really important that it is not formal. (...) When I watched him from the monitor you could see that he was not that comfortable straight off (...). When he was sitting there, his legs were swinging forward constantly (...) but you could see that only lasted till he realised what was wanted of him and he understood the situation and he was perfectly comfortable. (...) D: I think for children is really important that they get the information about diabetes in a safe, careful and fun way and sounds like your tool does that.* [P7]

Four parents thought that the tool had everything that it required for educating their children.

> *– F: For what it is set out for it has everything it needs.* [P5]

Two parents found important that their children could test their hypotheses freely during the session and could get constructive feedback about their wrong preconceptions.

> *– M: The fact that it was a bit like a game where they were discussing what they thought first, and then it was the process of finding out. (...) There was a few things that they discussed, like olive oil, and we use that all the time in the house and he didn't know what it was (when asked if it was healthy or not).* [P7]

### Interaction style

Three parents explicitly mentioned the physicality and the tangible interaction of the tool as an important factor for the enjoyment.

> *– F: (...) The interface; the nice way that you can put the food to the mouth. It kinda go to the physically interacting with that. (...) It was all moving and... Whereas anything else is "click, click, click".* [P5]

Three parents considered the graphical representations and the visual feedback of the tool valuable. They found these drivers for the tool's impact on their children.

> – *M: The visual aspect of it. He spoke about that, about seeing the body inside there was a bit where it was talking about the insulin and the insulin being like a key. He's repeated that, yesterday he was talking about "insulin is like a key" and he hadn't mentioned that part since the study (a week before) – obviously that stays in his brain.* [P7]

Interactivity was also mentioned as a key element of the educational style that influenced children's experience and made the tool more engaging and enjoyable.

> – *I think kids at that age like the idea of interactivity and the fact that they can hold the things up to the boy's mouth and it changes the screen or whatever, so they would have enjoyed that.* [P8]

The elements related to the gamification nature of the tool (competition, reinforcing feedback) were mentioned as important aspects of the tool's educational style.

> – *I think he enjoyed it 'cause he was like showing off what he knows about his food. (...) They were quite competitive about getting what right.* [P6]

#### 8.6.1.5 Summary

All the parents expressed only positive or neutral comments about the tool and the session. They believed that the tool could be used in regular practice and they thought that it was more appropriate for children close to diagnosis. Also, they found the tool very engaging, enjoyable and beneficial for the children. Some parents mentioned the increase in their children's awareness and presented evidence of their children putting into practice the things that they learned. Moreover, they suggested that the tool can also be used in multiple stages of the diabetes journey and that it should also be used to educate siblings and even adults.

### 8.6.2 Clinicians

#### 8.6.2.1 Variable 1: Effectiveness

The clinicians were sure about the tool's ability to engage children in an enjoyable, fun and effective interaction. Both they and the children enjoyed the session and the tool. They reported that the tool was very effective and deeply engaged the children. When it comes to learning outcomes they were not sure about what specifically the children learned, but they observed instances where the children tested their preconceptions and got constructive feedback on them.

**Enjoyment**

According to the clinicians, children's enjoyment was obvious during the sessions. The clinicians explained that they know the children and could assess their enjoyment and that they were surprised by the level of enjoyment.

> – *Yeah, they enjoyed it. (...) The children we know already, so we've had interactions with them but you could see that they were enjoying it; it wasn't just another normal day at clinic.* [N1]

> – *I felt the children enjoyed using it, probably more than I expected they would.* [T2]

> – *I think the kids loved it (...) Even when I asked them at the end 'did you guys have fun?' they said 'Yes!' and they were going out telling their parents (...) they were excited about it.* [T3]

**Engagement**

All clinicians agreed that the tool was very successful in engaging children. The tool kept the children's attention for a relatively long time for their age group.

> – *The children engaged really well, more than I anticipated they would. (...) I was thinking they might need a bit of prompting or they might need to be coaxed along but I felt they were quite interested in going up and getting a food model and giving it to "Mee". (...) All wanted a go and they wanted another go and then I was actually thinking: "We're gonna have to end this".* [T2]

> – *I think an hour to hold some of their attention that was even too much... I think it was engaging them.* [T3]

**Personalise education**

The tool was reported to be capable of helping the educators personalise the education, mainly through enabling them to assess a child's knowledge and understanding.

> – *There were times when they got the answer maybe different from what the tool told them and that was a chance for us to talk about it so, you know, what is a healthy food and these kind of things. (...) The tool you've designed it's almost backing to what you have tried to teach. So it's actually a way of checking, 'Do they understand? Have they understood?' and it probably helps them understand.* [T2]

> – *I think you'd be able to individualise, it would allow you to see how somebody is in a group as well and where their knowledge lacks and then you could obviously see them separately. (...) I thing you could tailor it to the group and see where it goes (...) it's quite flexible what you could do with it.* [T3]

**Learning outcomes**

Not all clinicians could confidently answer whether the children learned something or not. One dietitian (T3) drew a conclusion about the learning effect of the tool by correlating the children's drawings and crafts with the learning goal of the healthy food scenario.

> – *They definitely learned I thing about healthy eating; was definitely, they said afterwards that they learned about healthy eating and a bit more about their insulin.(...) How can you assess what they learned, you know, 'did they learn?'. Because we all were really finally asking: 'Well, did they enjoy it?'. I don't know.* [N1]
>
> – *I think so, I suppose what we didn't do was assess what they knew before coming into the session but they certainly all, were keen to guess what was about to happen.* [T2]
>
> – *They all chose to make healthy foods (...) They've all kinda picked the healthy thing to talk about, which is quite interesting, because I wouldn't have thought kids would want to admit to what is healthy. (...) That's what helps in knowing that they've learned something.* [T3]

Hypothesis testing and learning by observing peers was mentioned as an element of learning that the clinicians observed happening.

> – *I think they probably learned from what each other learned. So, when one girl was talking about hypos she'd said, 'Oh, you use chocolate' and one of the other girls was like 'No! You don't'. So, I think they kind of learned from each other. (...) I think if you know that one person in the group has bad practice or poor knowledge you can get the other kids to almost empower them and tell them what they think.* [T3]

#### 8.6.2.2 Variable 2: Age-appropriate

The clinicians were sure about the age-appropriateness of the tool and also believed that it could be used to educate other age groups as well. Furthermore, they thought that it can be used in many stages of the diabetes journey. Lastly, they also thought that the tool could potentially educate other groups, such as parents and siblings and even be used in schools.

**Age group**

The clinicians thought that the tool is appropriate for this age group, but it could also be used with older or even younger children.

*– The age group you selected is a good age group for that. (...) It depends on the child (...) a lot of 11 and 12-year-olds that are quite immature for their age, and I think definitely it'll be good for them. And then you have some 3-year-olds you could use it with, but I think generally your age groups were good.* [T4]

They also commented on the age-distribution of a sessions participants.

*– So I think maybe the key is to keep the age group similar and have smaller groups.* [N1]

Parents and children without diabetes were the two proposed user groups that the tool could be used to educate.

*– I would probably as I said maybe try and use it with newly diagnose families, patients and parents.* [T2]

*– If you did it in like a primary class with no diabetes, I think that they would learn something form it absolutely, 'cause their general knowledge will be tested.* [T3]

**Stage used**

Clinicians proposed that the tool should be used near the diagnosis of a child with diabetes, but also used in later stages as well.

*– A couple of parents said 'This would have been great if you had this at diagnosis'. (...) I think it can be used at all stages. I think you could use it right at the beginning and then you could go back to it and you could assess their knowledge. (...) It would be good for a refresher as well. I think it could be used throughout.* [N1]

*– Maybe that first time they come up as an outpatient here, to make it a bit more less serious and more fun (...) and make them realise "it's not all hospitaly". It could be brought in again later, you know, a year down the line or something, if you are feeling some things needing to be gone over again.* [T4]

One clinician suggested that the tool could be used in school classrooms to educate other children about a newly diagnosed classmate.

*– If you're maybe educating a group of you were wanting to teach a class about diabetes because of a child in the class is diagnosed with diabetes.* [T2]

#### 8.6.2.3 Variable 3: Adoption

The clinicians discussed the potential adoption of the tool by the clinic and shared their thoughts on the ability of the tool to educate groups and/or individuals (when appropriate). They thought that the tool matches the clinic's approach and would enhance it.

### Implemented in educational practice

All four clinicians described the advantages of the tool versus the current educational approach and they were sure about its potential for adoption in the educational practice.

> *– Sometimes we run groups with children; we do a lot of group work (...) but we find very quickly they'll lose their interest, because we're just talking to them. (...) whereas if you had one of the dietitians or the support workers maybe doing 'Mee' with the wee ones you could move on and continue to do education with the parents.* [N1]

> *– We use resources like pictures or we do drawings but we don't aim it at the children at that age (...) I think we'd want to use something like this. (...) It would maybe give us a line of providing education to that age group, 'cause I think that's always the hold-back, you don't have the resources (...) so you're just teaching the parents.* [T3]

> *– I think it was teaching them things that we teach them, or try to teach them anyway, but in a more fun way.* [T4]

The clinicians were sure about the potential adoption of the tool. They thought it would be a valuable addition to the clinic's educational practice. They thought that the tool has the flexibility to be adapted for other age groups as well and also thought that with some additions it could be a whole educational package for the children.

> *– I think we'd want to use something like this. (...) I think it'd be a really good resource to use for education or even in-clinic, you could have it out in the waiting room and people can be learning without realising that they're learning things. (...) I think it'll be sure thing that we'd pick up and use it - definitely. (...) The food is one topic, insulin is one topic, but when we talk about exercise and glucose monitoring, it could be a whole package of diabetes education.* [T3]

### Group education

The number of children and the social aspect of learning in a group were commented on by the clinicians, who thought that during the session the children had the chance to learn through each other. The style of education each clinician was using seemed to impact their judgement about collaboration and managing group dynamics.

> *– I would personally use it whether I had one child or whether I had two or whether I had four and just adapt how I used it.* [T2]

> – *They interacted well with each other. (...) I kind of tried to pick out one of them each time or give them all a shot at something. I think maybe if I hadn't done that one might have dominated and could have answered everything.* [T4]

Because the number of children per session varied, the clinicians were asked to comment on the appropriate number of children per session. Their views were not similar, a fact that can be explained by the unique educational style each one has and their limited exposure to the tool and the session.

> – *I think 4 or 5 probably would be a little bit easier and at least 2 or 3 so that at least you've got they can work together.* [T3]

> – *I don't think I would do it with less than three children because then you usually find one as more dominant in the group (...) I think 3 was a minimum number I would do it with maybe a couple more, I think that would be enough. (...) Maybe you could use it in a bigger group and just pick up out one or two children to show how it worked and have it in front of a classroom setup.* [T4]

**Align Clinic's Approach**

The clinicians thought that the tool was in alignment with the clinic's approach to education and would enhance it.

> – *The three topics (scenarios) that we covered are very much what we'd try and cover in education normally. (...) I think it does match it (clinic's approach) very well and it kinda enhances it.* [T2]

> – *From a dietitians point of view I thought the topics were really good and I thought it was a good learning tool for food.(...) I think it is a really useful addition on what we try and teach them anyway, but gives them that very different way of learning.* [T4]

Moreover, all four clinicians thought that the tool matched their personal style, as all were keen on using materials during education and the tool was allowing them to take their teaching a step further.

> – *For me I liked using that; I don't really like to teach without resources and I usually would use at least drawing or images. So for me that was better, because I think it's easier to explain and it demonstrates what you've trying to say.* [T2]

#### 8.6.2.4 Variable 4: General Opinion

The clinicians, generally, expressed a very positive opinion about the tool and the session. They found the session to be very engaging and easy to run. They explained how they enjoyed the session(s) with the tool and explained that the tools presence in the clinic has motivated them. Lastly, they proposed improvements and extensions to the tool.

**Opinions about the session**

The clinicians perceived the session to run in an orderly fashion without problems and thought that it could even be prolonged for larger groups.

> – *I think it probably ran more smoothly than I anticipated.* [T2]

> – *I think they would just want more time, we probably could have done that for 3 hours; and the other bits maybe more with the drawing, you could easily turn it into a whole morning I think.* [T3]

**Opinions about the tool**

The tool was found to be very useful and helpful in educating the children. The clinicians stated that it gives a new way of learning that can be very effective. They thought it would add value to the educational service as a resource.

> – *I think it's been very effective; I think it's useful for teaching children. (...) I liked that [tool] because it's easier to explain and it demonstrates what you've trying to say. (...) Something like this would be beneficial.* [T2]

> – *I thought it was a good learning tool for food (...) I think it definitely could help and make the children more interested on what they've trying to get. And if they're more interested and involved in it, then they learn more.* [T4]

The clinicians presented specific cases of the way the tool affected the children. The shy kids felt very comfortable with the tool and opened up and also a child did not want to leave the session even though he had a hypoglycaemic episode [1].

> – *The wee boy [C7] who said [in the smilometer] he was shy normally, didn't come across as being shy when he was doing the session and didn't think he was able to put that down on paper.* [T2]

> – *One boy [C11] was hypo and didn't even say that he felt unwell, 'cause he didn't want to leave the session, whereas normally he would so and get his mom, but he*

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[1] When the sugar levels in the blood are too low. Results in dizziness, confusion, blurred vision and other symptoms. If not treated soon can lead to seizures or loss of consciousness.

> *didn't want, because he was watching, and he came back. So even after he had to treat his hypo he was wanting to play the game. I think that shows that they were engaged and found it fun; otherwise they'd all have been running off.* [T3]

> *– Interestingly enough her [C10] mother said at the end, she didn't think she would say much. She thought she would be too shy; she was the one who actually led most of the talking and had her hand up first and wanted to do all (...) She [mother] said "I was very surprised to see her getting so involved".* [T4]

The clinicians found the tool easy to use and thought that any member of a diabetes team would be able to use it. Moreover, they observed that clinicians and children can very quickly get familiar with using it.

> *– I think any member of staff could had done it. (...) I suppose because it was the first one we weren't really still kinda trying to get used to it. (...) Children quite easily, quite quickly were picking up the items, were putting it to the mouth.* [N1]

**Interaction style**

The physical aspect and the tangible interaction were mentioned by the clinicians as a positive aspect complementing the whole experience.

> *– They were interested on what was happening on the screen, plus they had the food models, so they were touching things, they were getting up and were... been more active.* [N1]

The visual/graphical and audio aspects were considered very important in the children's experience with the tool.

> [When asked about the children's drawings] – *I think it's amazing, like the visual literally is the exact same picture, that's the exact ice-cream [C17's drawing]; it's purple, that's what they've been remembered from it; so that's why they have been really engaged.* [T3]

The game elements of guessing correctly, turn taking and getting feedback on their choices was reported by two clinicians as an important factor.

> [Asked what makes it fun] – *I think the play side of things. It's all that they can pick the models; they were picking them up and looking at the event, obviously with the sound effects and things, I think that engages them and helps them.* [T3]

Interactivity, as a way of involving children to the learning process, was considered a significant factor in engaging and making the children enjoy the education.

> *– I think they liked it because it was interactive. Because we were watching at the screen and they were able to interact with it, so I think that was the most important think. (...) Because we got lots and lots of apps but we find people get bored of apps (...) whereas something quite practical I think is the key.* [N1]

**Clinicians enjoyed taking part**

Three clinicians clearly stated that they themselves enjoyed the session with the tool.

> *– I really enjoyed it, I thought it was good. I liked it.* [N1]

> *– I enjoyed when the children were in, it worked quite well I thought. (...) For me, I liked using that. (...) Overall I felt the sessions were really good, I enjoyed teaching with it the kids.* [T2]

**Tool can motivate clinicians**

The clinicians thought that the tool can actually motivate them to engage in learning activities which are more effective and enjoyable for the children.

> *– Yes definitely I think it has motivated us. When you came to the 'journal club' [a weekly seminar within the clinic] everybody was interesting in it and I think we were all talking about it at clinic days. We were all talking about and I think it has definitely motivated our people to teach, to learn, to practice more like that.* [N1]

**Improvements**

The clinicians reported specific issues that they had noticed. These include speed, size of the tool and number of food toys. Also, one clinician suggested future extensions for the session and the educational scenarios.

> *– I think the concept is really good; the problems were just practically, you know, sometimes when they were trying to go over to the box, the smaller [children] were maybe standing in front of it, so if it... could you have something that you could project on the screen... had the screen separate from the box?* [N1]

> *– Maybe the speed of it at times (...) there was maybe a delay on occasion. Actually, that didn't seem to bother the children.* [T2]

> *– Lots of things I think you could do with it that would be more collaborative. (...) [Asked about improvements] I think the way it looks like, because it's a big projector - isn't it? It might be ways of making that more kind of succinct and compact. (...) You might come up with different games or team games or whatever depending on what groups you're using it with.* [T3]

Two clinicians thought the tool would be eligible for use in other health promotion related topics.

> – *I think it's something that could be used in lots of different areas, you know teaching children for, you could see it in schools, teachers do teeth brushing or any kinda health promotion.* [N1]

#### 8.6.2.5 Summary

It became apparent from the interviews that clinicians considered the tool to be very helpful and capable of supporting different educational needs. All clinicians found the tool age-appropriate, good for assessing children's knowledge and very engaging. They were sure about its potential value if implemented to the standard educational practice.

### 8.6.3 Children

Most of the children (13 of 17) felt a pleasant emotion and the rest (3 of 17) felt a neutral emotion during the session. The results are shown in Figure 8.6.

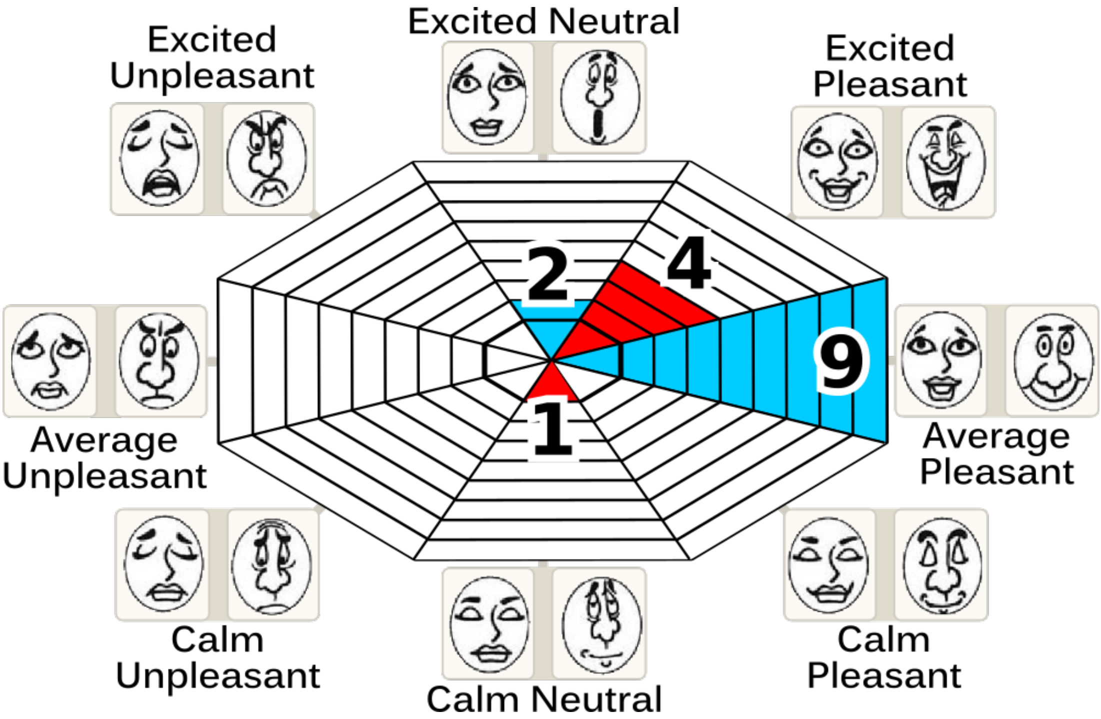

Figure 8.6: The emotions of the children while being educated with the tool.

The results from the smilometers (Figure 8.7) show a significant increase (p=0.022 – Wilcoxon Signed-Rank Test) in the experience during the evaluation compared to previous visits.

For one child (CF13) it was his first time to clinic so he only completed the smilometer about the evaluation day (no value on previous visit). Only one child (CF4) rated the evaluation session less preferable than the regular visits to the clinic. When this child was asked by the clinician if she could explain why, she did not provide an answer. Unfortunately, her parent did not reply for the interview and thus, no follow-up could be conducted in order to try to understand this child's experience. CF14 had to leave the session before the end so he did not complete a questionnaire. An interesting fact was that CF7 could not find a face from the smilometer to represent his previous visits to the clinic and instead, he draw a sad face with "shy" as caption and placed it in between 2 ("Not very good") and 3 ("Good"). Similarly, CF6 drew a face saying "bored" and chose 3 ("Good") for the previous visits.

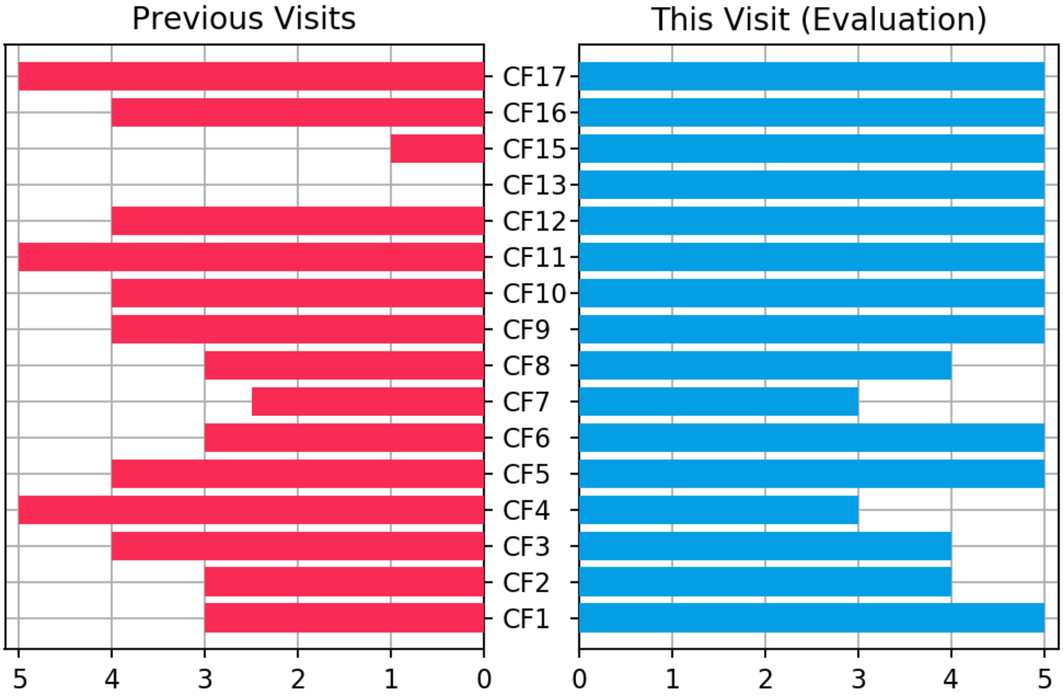

Figure 8.7: Results from the Smilometer (1=Awful ... 5=Brilliant). Comparing previous visits to the evaluation.

Finally, the drawings and crafts of the children about their experience (Figure 8.8) were as follows: 8 children included parts of the healthy foods scenario in their drawings or crafts (CF1, CF3, CF6, CF7, CF11, CF13, CF16, CF17), 5 children included *Mee* in their drawings (CF2, CF5, CF8, CF9, CF10), 5 children drew themselves (CF2, CF12, CF13, CF15, CF16), 1 child drew the session (CF2) and 2 children made random things (CF3: flower and CF4: smiley face).

After the end of all the sessions, we contacted the clinical psychologist who was working for the clinic and asked her to help us interpret the drawings and crafts. Unfortunately, she thought she did not have the knowledge to help us and she suggested we should speak with art therapists. Unfortunately, due to time constraints we did not manage to get in touch with an art therapist to further interpret the drawings and crafts.

All these results are in alignment with parents' and clinicians' answers about the acceptance

Figure 8.8: Drawings of the children describing their experience.

and the enjoyment of using the tool. The children were very engaged and seemed to enjoy it. An example is CF6 who during the session verbally stated "This is surprisingly fun". Another example of how engaged the children were is the fact that CF11 had a hypoglycaemia (hypo)[1] during the session. Nonetheless, according to T3, he did not report it because he wanted to stay in the session. His mother recognised the symptoms while observing him from the other room and came to treat the hypo. After his hypo was treated CF11 came back to the room to continue with the session.

Through the video footage of the sessions, it was observed that children were constantly performing positive non-verbal cues (smiles, dance moves, gestures) which signified a state of enjoyment. Moreover, the children who initially showed anxiety in the way they were sitting or acting, soon enough felt relaxed and opened up – a fact that was also pointed out by P7 for her own child

#### 8.6.3.1 Summary

The results from the children's questionnaires made it clear that the children had a very pleasant and enjoyable experience.

## 8.7 Conclusion

This chapter presented the rationale, the procedure and the results of the tool's evaluation. The requirements for the tool were used to compile the evaluation protocol and the tool was tested against the requirements. In total, 5 educational sessions with 17 children and 4 clinicians were conducted. Also, 5 parents whose children participated in the sessions and the 4 clinicians

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[1] When the sugar levels in the blood are too low. Results in dizziness, confusion, blurred vision and other symptoms. If not treated soon can lead to seizures or loss of consciousness.

were interviewed. The results were analysed qualitatively and quantitatively and showed that the tool is an effective and age-appropriate medium for the education of younger children with T1D. Moreover, it was perceived as feasible for adoption in the educational practice.

The next chapter synthesises results of the evaluation in order to answer the research question, and also reflects and provides deeper insights and implications.

# Chapter 9

# Discussion and Conclusion

The final evaluation, presented in Chapter 8 (page 112), highlighted the tool's appropriateness for this age group and the affinity of the children towards it. This chapter will start by responding to the research question of this thesis according to the results of the evaluation. Then it widens the discussion on the results of this project and its implications. It continues with the limitations faced during the project and then proposes future work. Lastly, it summarises the thesis and concludes.

## 9.1 Answer to RQØ

**RQØ:** ***Is an interactive -digital- educational tool for younger children with T1D, developed through a HCD process, a viable solution that could effectively support the educational practice?***

The educational tool presented in this thesis was designed and developed using the HCD process. This process entails all the steps needed to obtain an in-depth understanding of the context and the production of a solution based on its requirements. The final stage of the process is the evaluation of the solution against the requirements.

We started the process with an extended multistage enquiry with different stakeholders in order to understand the context in depth. The results of the in-context enquiry were analysed methodologically and combined with the research aim, in order to accurately formulate the requirements for the tool. Based on the formulated requirements and design decisions, and with multiple stages of inputs from the clinicians, we iteratively designed, prototyped and developed a novel tool. The final tool was assessed (with children, parents and clinicians) for its capacity to fulfil the requirements and as a result meet the research aim.

The results of the evaluation made it clear that the tool is an age-appropriate medium for enjoyable and engaging education of younger children with T1D. It can help clinicians effectively convey educational messages by allowing them to identify and target the educational needs of an individual, even during group learning. Moreover, the tool builds on the existing ecosystem, without perturbing it, by enhancing the existing approach of the clinic. It also can easily be reproduced and scaled up. Hence, the tool is feasible for adoption for in-clinic education of younger children with T1D.

All these facts combined provide a positive answer to the research question.

The following section will discuss some of these findings in relation to the existing literature and will mention the wider implications of this thesis for digital educational tools.

## 9.2 Summary of Findings

### 9.2.1 The missing elements of the current education

The lack of appropriate resources (materials, knowledge, curriculum) for the education of younger children with T1D was the main limitation for the delivery of age-appropriate education in the clinic. The clinicians who do not have training in education and access to age-appropriate materials were struggling to provide education to the younger children. Any attempt to educate them was not successful because children were quickly bored and disengaged from any educational process. As a result the clinicians shifted the focus to educating only the parents and expected the parents to educate children through the day-to-day management of the condition. However, this model was not effective as parents were struggling to educate children or did not have the capacity to do so.

Given the lack of centralised (national-level) T1D curriculum and training, the clinicians tried to improve the situation by introducing more age-appropriate tasks (e.g. poster drawing) and materials (plastic food toys). However, these remedies were still not enough to educate the children effectively. The combination of interactivity and fun, which are main elements of effective leaning (especially for diabetes education [7, 84, 91]), was still missing.

Even though the children seemed to be having fun during the poster-drawing session (see Section 5.2.2.2, page 57) they were not really interacting with or exploring their condition. The only feedback was through the clinician, who tried to initiate discussions during the drawing. This was more an expressive task (children showing their understanding) rather than a reflective task. On the other hand, even though the food toys were a main feature of a developmentally appropriate education –the concrete nature– the children were not engaged by them and thus clinicians were using them infrequently (see Section 5.2.2.2, page 58). Education through them had no interactivity or gamification, a fact that prevented exploratory, enjoyable and reflective learning.

### 9.2.2 Envisioning and designing the solution

It was clear after understanding the context that there was a need for more effective mediating tools. Such tools should mediate the learning activity and allow children to understand their condition by exploring it, but also allow the clinicians to guide children towards the activity's objective – learning.

During the design process, the tangible aspect of the food toys was conceptualised as an excellent age-appropriate vehicle for an interactive/gamified education, building on the current approach. The tool was designed based on the existing approach and added the missing elements of interactivity and fun. With the tool in place, the clinicians were able to design an educational session that could support the educational goals of the clinic and enable group learning – a step towards *standardised* education.

Even though educational games for health are a great means for behaviour change [153], we decided not target children's behaviour change. This choice was made because children do not manage their condition at that age; instead, we decided to help them understand the management *imposed* on them. On the same premise, instead of teaching children about how to manage their condition, we chose to educate them on the meaning behind the management decisions. This way we wanted to build a foundation for later self-management. Our tool did not provide a full diabetes curriculum but instead it focused on three key concepts of diabetes management, which according to the clinicians were the most important ones (Sections 7.2.1 and 6.4.1, pages 94 and 92 respectively).

### 9.2.3 Evaluation

The parents were interviewed at least a week after their child's session, so that they had time to observe and reflect on the child's acquired knowledge. Also, at the end of the study we interviewed the clinicians in order to capture also their insights on the tool and the educational process it mediated.

The results of the evaluation from all the stakeholders were very positive. The interaction technique, introduced by the tool, enabled children to participate more actively in the educational process by exploring their condition rather than being asked to reflect on it (done currently when clinicians assess their knowledge through questions - see Section 5.2.2, page 55).

The tool was found to be age-appropriate by bringing the information to the children's level and enabling them to explore and test their preconceptions. This age-appropriate and exploratory learning seem to have created a meaningful and enjoyable experience for the children, which is very important for an effective learning [62, 79]. This meaningful and enjoyable experience deeply engaged the children who were active during the session by moving, speaking, playing, learning by exploring, testing, observing others and reflecting. This was observed by the adults, who were surprised at the children's level of engagement.

Despite the difference in ages in each session, the children were very comfortable and engaged throughout. Even though a 5 year and a 9 year old child are very different developmentally, they all enjoyed the tasks and participated actively despite their developmental differences. This was also apparent from the responses of the adults, who thought that the tool could be used for a broader age group – even for adults.

The most solid outcome about learning was the fact that three children (CF5, CF7 and CF12), out of the 5 whose parents were interviewed, actually put into practice the things they learned. For example P12 reported that his child understood the fact that he can have non-healthy snacks "sometimes" and that he acted upon that by keeping some of the sweets given to him for another day. This fact was not a directly shown by the tool (which was showing if a food is "healthy" or "less healthy") but it was something T3 explained to the children during the session. Similar outcomes were reported also by T5 and T7, whose children started more critically looking at their food contents. Hence, the tool was used as a medium that helped clinicians convey the target messages to the children.

During the evaluation, the interaction through the food toys was very intuitive to the children, who used them as input devices very naturally and could focus on their representations and the tool's output rather than the interaction modality itself.

The tool showed a great potential in fulfilling the needs of the stakeholders (see Section 6.2.4, page 83) if implemented in standard practice. It can provide an appropriate educational resource to the clinicians, who can use it to educate younger children with T1D and thus alleviate some pressure from parents.

## 9.3 Discussion

The clinicians, during the session with *Mee*, had the chance to observe the children's misconceptions and gaps in knowledge which allowed them to guide the children towards specific learning outcomes. Such feedback helps clinicians understand the children's knowledge gaps, misconceptions and enables them to assess if the children are learning properly [147]. The clinicians through this process became informed observers who understood the children's knowledge gaps and thus managed to guide them appropriately [25]. This way the clinicians could effectively help children enter their ZPD, through an "Assisted Discovery" [17, 171] which focused the children's exploration to their needs/gaps of knowledge. This is probably the reason why all clinicians found the tool's ability to identify gaps in knowledge important in helping them tailor T1D education to the individual.

Through the tool, the children could easily externalise their knowledge and preconceptions without feeling judged, questioned or bored. They could focus on the graphics of the tool and the fun interaction, but at the same they were testing their hypotheses. This type of knowledge externalisation was also empowered by the fact that they did not have to recall all the possible food option they knew about (e.g. when asked to find a food belonging to a category). but instead had their options visually accessible and could compare and select. During this activity of food selection, feedback from the tool and the clinicians, observation of others and through multiple repetition of all these, children managed to internalise the learning objective (at least those whose parents reported learning – 3 out of 5 interviewed). This shows that the children managed to enter their ZPD and achieve what they could not achieve in the past. Moreover, the clinicians also managed to achieve what they could not achieve in the past; they manged to help the children enter their ZPD by being able to transmit the educational messages. Hence, the tool was effective for both its user groups.

The tool's effectiveness in helping clinicians convey the learning messages, and the enjoyment the children had during the session, shows a good balance between education and fun, not overly leaning towards one of the two directions. This is an important result from an educational perspective [143] as it does not trivialise learning by simply equating it with fun, but instead motivates the learners [121]. This motivation is particularly important for children with diabetes who have a *bad* experience (i.e. related to pain and discomfort) with the clinic and their condition (parents, clinicians and literature [7]).

We believe that the main factor for making the tool effective in conveying educational messages to children was the HCD methodology. This methodology allowed us to deeply understand the context and the needs of the stakeholders, and based on this understanding to design a solution that would enhance the context rather than perturb it. The continuous involvement of the different stakeholders, especially the clinicians, not only enabled us to understand the context but also allowed them to align with the aim of the project. Their participation in the design process provided valuable feedback that helped us refine the prototypes and align them with the requirements. Moreover, the co-design of the educational session was critical for the outcome, because the author could not alone design a session that would match the educational style of the clinic.

The way the HCD methodology was adapted and used in this project could inform other researchers or practitioners involved in the design of educational materials for children with complex educational needs (i.e. similar to children with diabetes). Even with limited involvement of children in the initial enquiry phase, HCD enabled the design of an effective tool suitable for the context.

The tool poses a viable and effective solution that can potentially be implemented. It can be used in regular practice, but actual long-term effects can only be observed through future work. More generally, the solution of providing interactivity through technology could reduce the high number of resources needed for the education of children with T1D [38]. The tool provides an affordable solution that can easily be replicated and introduced to multiple centres nationally. It could potentially support a formal T1D curriculum as an effective and age-appropriate medium.

An interesting outcome from the study was the interpersonal relationship between families and clinicians. P7 stated in the interview that they participated because they saw that the clinicians were on board in the study. This fact should be considered by other researchers who want to work with young children with similar conditions. Our team struggled to get participation from parents, a fact that is also pointed up by the literature [161]. Because the management outcomes of T1D are usually within the target range for younger children (since parents are managing the condition), many parents do not consider research to be important and this negatively impacts recruitment [174].

Parents and clinicians also found the tool flexible in educating different audiences (adults, siblings, older children) and suitable for different situations (one-to-one, free play in waiting room) and even for different contexts (schools). The potential of the tool to be used in schools was also mentioned by P6, whose child considered the tool to be a great way to explaining his condition to his classmates. Educational interventions can help children communicate more openly about their condition with peers, parents and health-care professionals [147]. This way they can let other children know why they might be acting differently, potentially destigmatise them [24], and also help them be more extrovert by discussing their condition.

## 9.4 Challenges

The main challenge faced during this project was the very time-consuming and inflexible ethics approval process of the NHS. The ethics approval process is built around quantitative studies that assess clinical outcomes such as randomised controlled trials. Following this process for small scale quantitative studies (such as user experience studies) proved in our case to be a burden because we had to complete huge forms with irrelevant questions. We believe that the approval processes should be updated and adapted by the health system to include qualitative, smaller scale and exploratory studies that involve user experience testing and evaluation of novel digital tools.

## 9.5 Limitations of the Project

The main limitation of this project is the fact that it was only evaluated in one setting. What works in one setting does not necessarily work in others as well [70]. Certainly, more settings have to be used for evaluation and even in different countries to see if the tool is more widely effective. Another related aspect is its evaluation with clinicians who helped in its design. This has a positive and a potentially negative side. The positive side is that clinicians were embedded in the project and thus could understand the goals and the challenges. On the other hand, they might be biased when evaluating the tool and lack objectivity. Also, the author who designed and developed the game and had been in contact with them for almost three years was also the one who interviewed them. Hence, they might have been reluctant to mention negative aspects. However, the questions of the interviews were designed so that they were not leading.

Another limitation in relation to the evaluation is an ordering effect based on previous visits. Specifically, we could not balance the fact that this session was compared to previous visits. Nonetheless, this way children had a clearer view for the previous visits as most of them had many. Moreover, the last two sessions were conducted when schools were open. Children might have responded positively in the smilometer just because they were drawn away from school for a day [177].

A third limitation of the evaluation was that we could not isolate the effects of the session to the assessed educational effectiveness. The session was designed to support the tool and its effects were not directly distinguishable. In future studies the tool could be used in different situations (as also proposed by parents and clinicians) in order to assess its effectiveness irrespective of the session.

On a final note, there was not much input from children during the design phase. It proved very challenging to recruit families, and also the ethics approval process was very time-consuming (i.e. three months for the NSG observations and three months for the final evaluation) for this project's time frame. However, we engaged as much as possible with people who are directly responsible for their education in order to design something that fitted the children's needs, and included them in the evaluation.

## 9.6 Future Work

Since the tool was effective in conveying educational messages to children, the first potential future plan would be to incorporate it into educational practice. Because the current version is a prototype tool it firstly needs extensive testing and further development in order to be more robust and stable. Another key element, also pointed out by the clinicians, would be to reduce its size. Apart from the technical improvements, the system can readily be used in the educational practice, as it is specifically designed for the context and also has a dedicated educational session designed for it. With a potential actual adoption more research opportunities can arise, mainly about assessing the long-term effectiveness of the tool and looking more closely to specific elements (e.g. the 'Mee' character). Also, adoption could create opportunities for co-design with children about further improvement of the tool.

Another option for the future of the tool is to create a standalone tablet version of it, which children can continue using at home. Such a scenario could potentially enable children to continue learning at home. This option needs a new HCD to clearly understand the home context and effectively design for it. This tool could have many different elements (e.g. be a game, have collaboration opportunities, have blood glucose logging capabilities) depending on the needs and requirements of the context. Such a standalone tablet version of the tool could create new research opportunities on the topics of children with chronic conditions and digital educational tools.

Based on the feedback from clinicians and parents from this study, a potential route that could be explored is the use of the tool with other age groups and in other settings. Specifically, the tool could be used in primary schools where students with T1D can educate their peers. Such sessions, where children explain their condition to their peers, are already taking place in schools but without any educational material. The interactive elements of the tool, which were found to be very engaging and enjoyable, could potentially help younger children to understand what their peer with T1D is going through. This was pointed out by P6; her child explicitly suggested such a usecase (see Section 8.6.1.2 on page 123).

Another research opportunity for the tool is that it could be used to educate families or adults and see if it can outperform any existing educational materials, in a controlled experiment. Other alternatives could include older children with T1D who are entering adolescence, who could educate younger children. This way adolescents could recapitulate basic diabetes messages and at the same time help the younger children. This could also be an interesting research opportunity as it can help explore more complex collaborative learning styles. Lastly, the tool could possibly be used for other nutrition-dependent conditions, such as obesity, or more generally about nutrition education. As it was stated by patents and clinicians, the tool could support such educational scenarios as they are very similar to its existing educational content.

## 9.7 Summary and Conclusions

A digital educational tool for younger children with T1D was developed following a rigorous development approach. This included a review of the literature in order to establish a basic understanding of children with T1D, educational tools (generally and about diabetes) and design of interactive tools. An HCD design process was chosen to design and develop the solution. The context of in-clinic education of younger children with T1D was explored in depth and the requirements for a digital educational tool were formulated. The tool was designed and developed iteratively and was evaluated in-context against the requirements with children, parents and clinicians. The results showed the effectiveness of the tool in enabling clinicians to convey the educational message in a fun, age-appropriate and memorable way. The results also informed about the feasibility of adopting the tool in standard practice. These findings are important and inform about the potential use of the tool in standard practice, and also inform more generally for the design and development of other educational tools for younger children with complex educational needs.

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## Appendix A

# Miscellaneous Documents

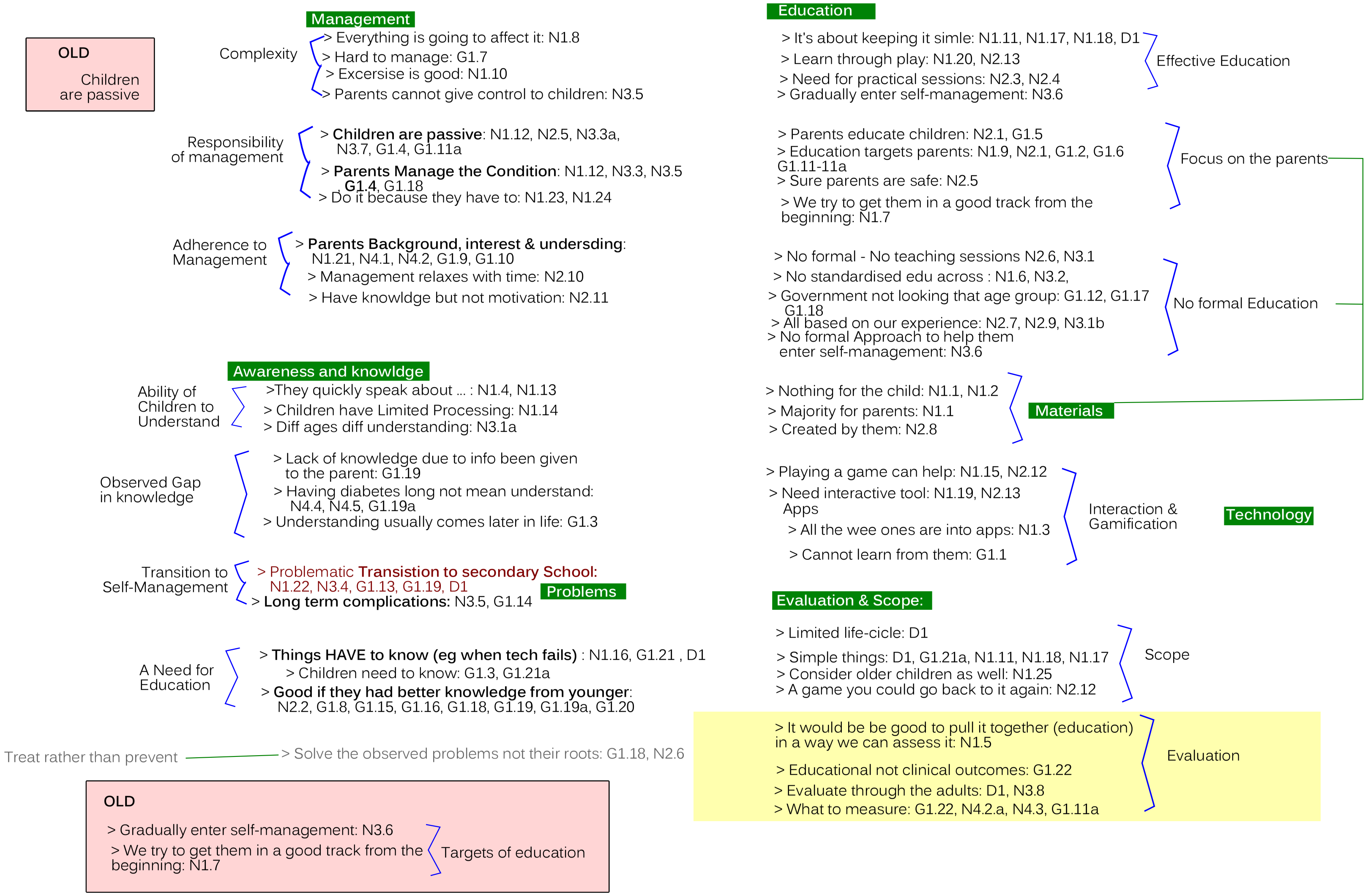


Figure A.1: An iteration of the coding table, used for the Thematic Analysis of the specificities specification stage (Section 4.2, page 32)

Table A.1: Questions and answer types of the questionnaires to parents.

| # | **Question** | **Answer Type** |
|---|---|---|
| | Your age | 18 or younger, 18 – 24, 25 – 30, 30 – 40, 40 – 50, 50 or older, Prefer not to say |
| | Your child's gender | Boy, Girl, Prefer not to say, Other |
| | Child's age | Number |
| | Age of diagnosis | Number |
| 1 | Who is mostly teaching your child about diabetes? | |
| 1a | [Me and/or spouse/partner] | 1-Never ... 5-Mostly |
| 1b | [Clinicians] | 1-Never ... 5-Mostly |
| 1c | [School teacher] | 1-Never ... 5-Mostly |
| 1d | [Other family member/s] | 1-Never ... 5-Mostly |
| 1e | [Other] | 1-Never ... 5-Mostly |
| 2 | Have you and your child attended any educational session for diabetes in Yorkhill? | Yes / No |
| 3 | Have you or your child ever been to any formal educational sessions anywhere else? | Free text |
| 4 | Did you find it useful? | Yes / No |
| 5 | How engaging did you find it? | 1-Not at all ... 5-Very much |
| 6 | How engaging did your child find it? | 1-Not at all ... 5-Very much |
| 7 | Did you learn anything useful? | Free text |
| 8 | Did your child learn anything useful? | Free text |
| 9 | Educational sessions help children change their behaviour towards better diabetes management? | 1-Disagree ... 5-Agree |
| 10 | Can something be improved in the way children are currently educated about their diabetes? | Free text |
| 11 | Diabetes education is important for children | 1-Disagree ... 5-Agree |
| 12 | Do you think that experience is a better teacher or do you believe that formal education is more useful? | 1-Experience is better ... 5-Formal Educ. is better |
| 13 | Do you have any educational game, video programmes or any other kind of educational artefact for T1D? | Free text |
| 14 | Diabetes educational games can help children learn more efficiently | 1-Disagree ... 5-Agree |
| 15 | Diabetes educational games are going to be more enjoyable than other educational methods | 1-Disagree ... 5-Agree |
| 16 | What is the most difficult concept for your child to understand? | Free text |
| 17 | What is the most difficult question your child has asked you about diabetes? | Free text |
| 18 | Technology can help children learn more about diabetes | 1-Disagree ... 5-Agree |
| 19 | Is the child cooperative when it comes to the management of the disease? | 1-Disagree ... 5-Agree |
| 20 | It is easy for children to access diabetes related information? | Free text |
| 21 | Anything else you want to add, share or suggest? | Free text |

# Appendix B

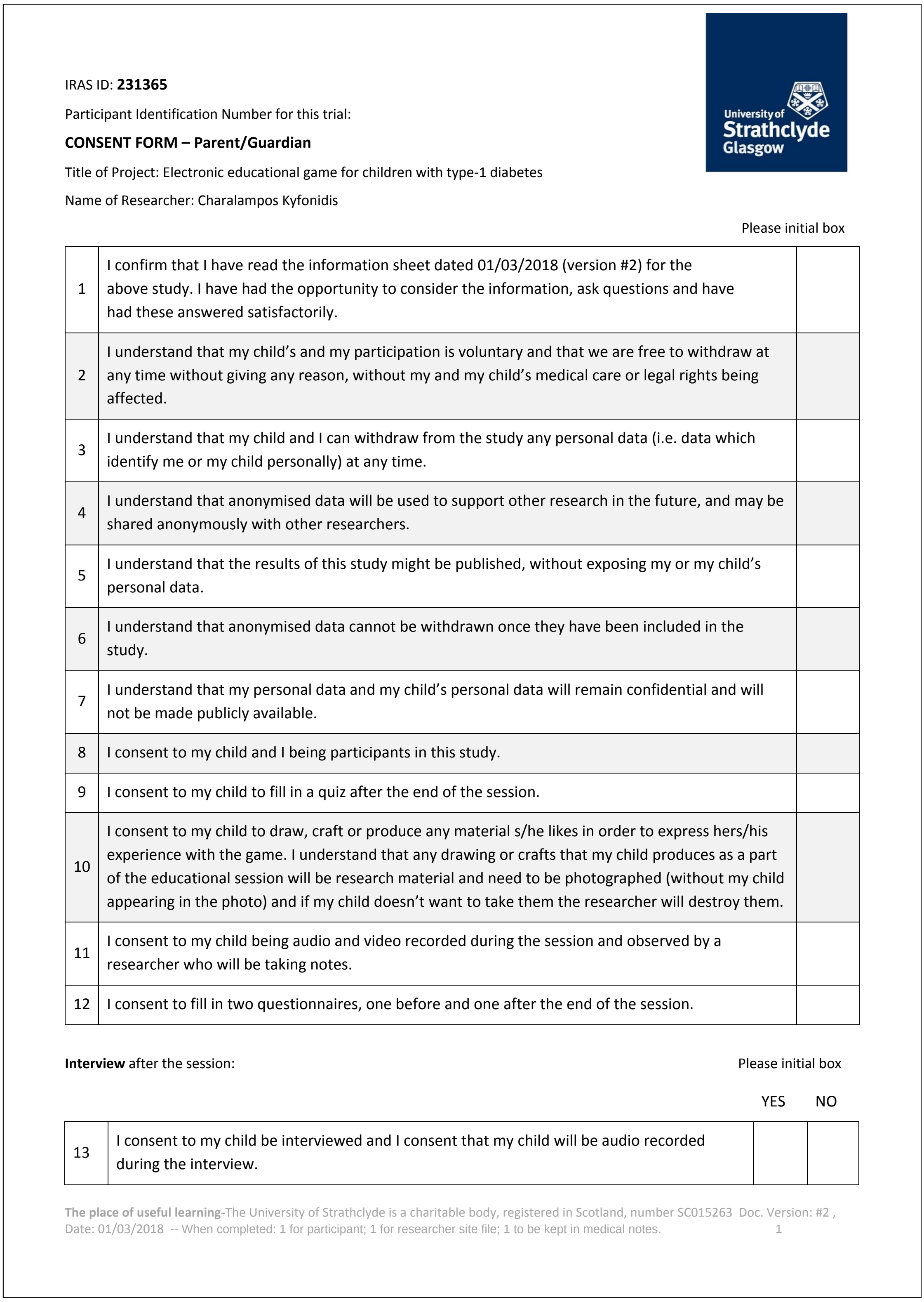
# Final Evaluation Documents

## B.1 Consent Forms

## B.2 Information Sheets

## B.3 Interview Scripts

## B.4 Questionnaires



IRAS ID: **231365**

Participant Identification Number for this trial:

**CONSENT FORM – Parent/Guardian**

Title of Project: Electronic educational game for children with type-1 diabetes

Name of Researcher: Charalampos Kyfonidis

Please initial box

| | | |
|---|---|---|
| 1 | I confirm that I have read the information sheet dated 01/03/2018 (version #2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | |
| 2 | I understand that my child's and my participation is voluntary and that we are free to withdraw at any time without giving any reason, without my and my child's medical care or legal rights being affected. | |
| 3 | I understand that my child and I can withdraw from the study any personal data (i.e. data which identify me or my child personally) at any time. | |
| 4 | I understand that anonymised data will be used to support other research in the future, and may be shared anonymously with other researchers. | |
| 5 | I understand that the results of this study might be published, without exposing my or my child's personal data. | |
| 6 | I understand that anonymised data cannot be withdrawn once they have been included in the study. | |
| 7 | I understand that my personal data and my child's personal data will remain confidential and will not be made publicly available. | |
| 8 | I consent to my child and I being participants in this study. | |
| 9 | I consent to my child to fill in a quiz after the end of the session. | |
| 10 | I consent to my child to draw, craft or produce any material s/he likes in order to express hers/his experience with the game. I understand that any drawing or crafts that my child produces as a part of the educational session will be research material and need to be photographed (without my child appearing in the photo) and if my child doesn't want to take them the researcher will destroy them. | |
| 11 | I consent to my child being audio and video recorded during the session and observed by a researcher who will be taking notes. | |
| 12 | I consent to fill in two questionnaires, one before and one after the end of the session. | |

**Interview** after the session: Please initial box

| | | YES | NO |
|---|---|---|---|
| 13 | I consent to my child be interviewed and I consent that my child will be audio recorded during the interview. | | |

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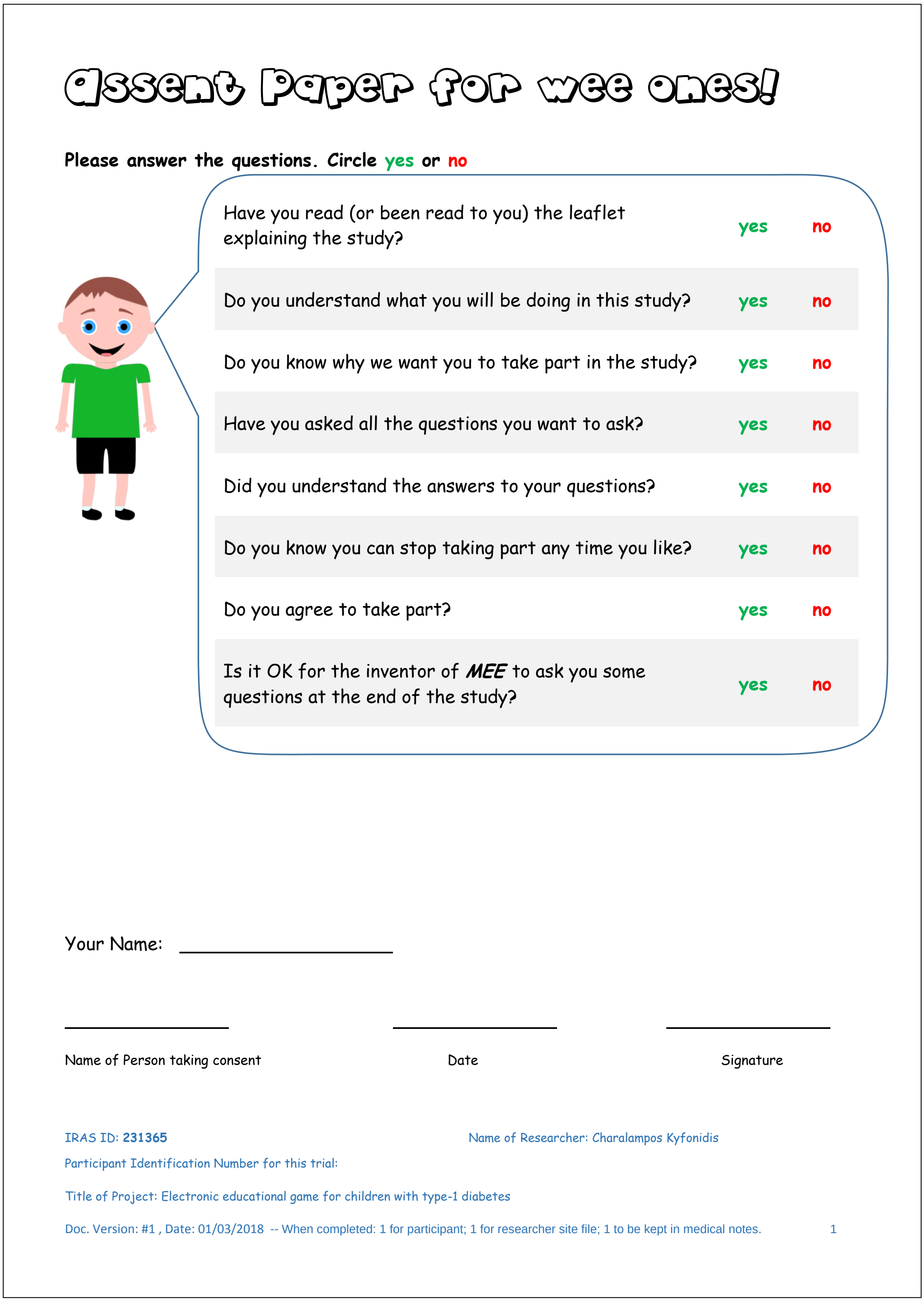
Figure B.1: Parent's consent form of the final evaluation.



# Assent Paper for wee ones!

**Please answer the questions. Circle yes or no**

| | | |
|---|---|---|
| Have you read (or been read to you) the leaflet explaining the study? | **yes** | **no** |
| Do you understand what you will be doing in this study? | **yes** | **no** |
| Do you know why we want you to take part in the study? | **yes** | **no** |
| Have you asked all the questions you want to ask? | **yes** | **no** |
| Did you understand the answers to your questions? | **yes** | **no** |
| Do you know you can stop taking part any time you like? | **yes** | **no** |
| Do you agree to take part? | **yes** | **no** |
| Is it OK for the inventor of ***MEE*** to ask you some questions at the end of the study? | **yes** | **no** |

Your Name: ____________________

| | | |
|---|---|---|
| Name of Person taking consent | Date | Signature |

IRAS ID: **231365**

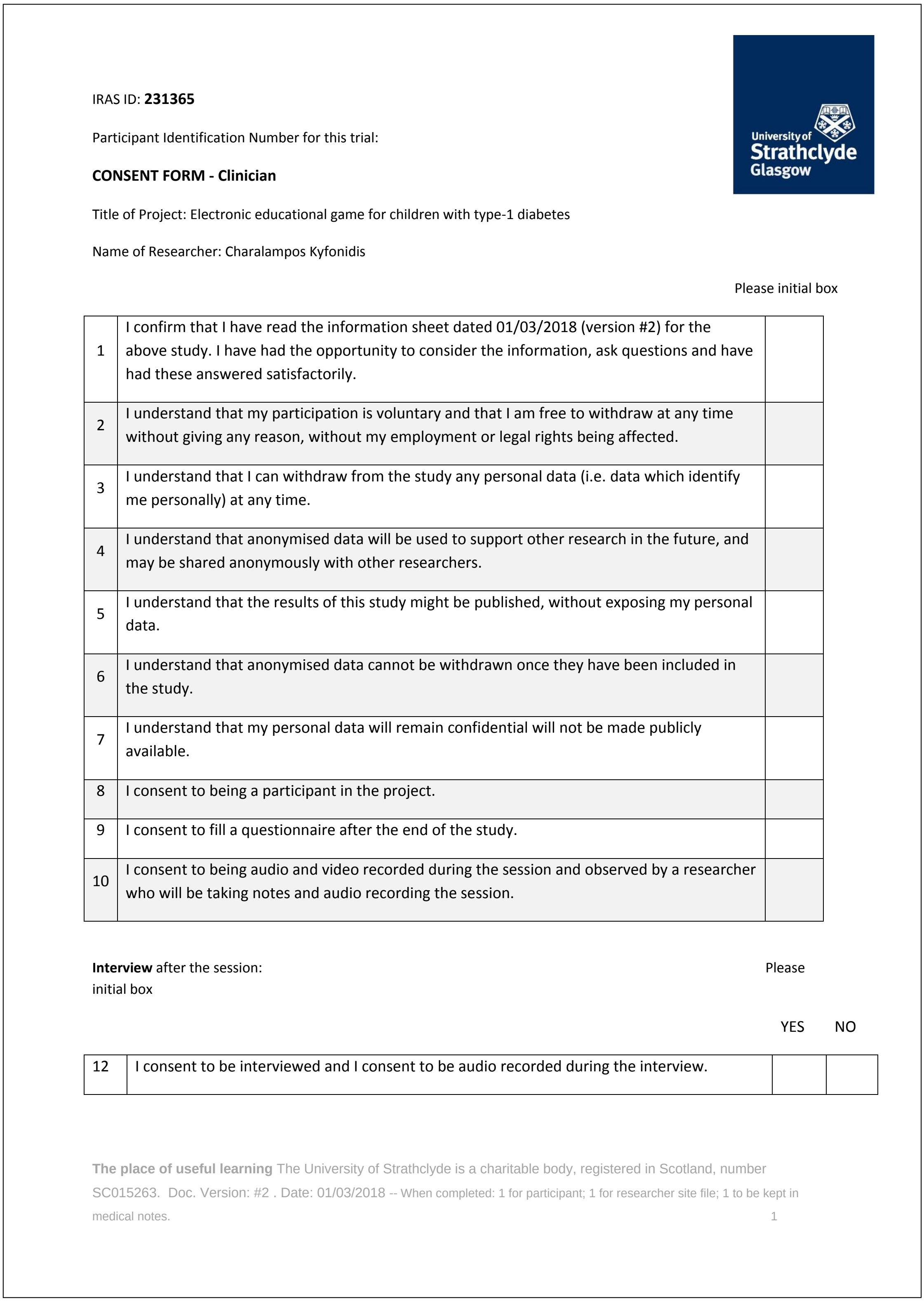
Name of Researcher: Charalampos Kyfonidis

Participant Identification Number for this trial:

Title of Project: Electronic educational game for children with type-1 diabetes

Doc. Version: #1 , Date: 01/03/2018 -- When completed: 1 for participant; 1 for researcher site file; 1 to be kept in medical notes. 1

Figure B.2: Children's assent form of the final evaluation.



IRAS ID: **231365**

Participant Identification Number for this trial:

**CONSENT FORM - Clinician**

Title of Project: Electronic educational game for children with type-1 diabetes

Name of Researcher: Charalampos Kyfonidis

Please initial box

| | | |
|---|---|---|
| 1 | I confirm that I have read the information sheet dated 01/03/2018 (version #2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | |
| 2 | I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my employment or legal rights being affected. | |
| 3 | I understand that I can withdraw from the study any personal data (i.e. data which identify me personally) at any time. | |
| 4 | I understand that anonymised data will be used to support other research in the future, and may be shared anonymously with other researchers. | |
| 5 | I understand that the results of this study might be published, without exposing my personal data. | |
| 6 | I understand that anonymised data cannot be withdrawn once they have been included in the study. | |
| 7 | I understand that my personal data will remain confidential will not be made publicly available. | |
| 8 | I consent to being a participant in the project. | |
| 9 | I consent to fill a questionnaire after the end of the study. | |
| 10 | I consent to being audio and video recorded during the session and observed by a researcher who will be taking notes and audio recording the session. | |

**Interview** after the session: Please initial box

| | | YES | NO |
|---|---|---|---|
| 12 | I consent to be interviewed and I consent to be audio recorded during the interview. | | |

**The place of useful learning** The University of Strathclyde is a charitable body, registered in Scotland, number SC015263. Doc. Version: #2 . Date: 01/03/2018 -- When completed: 1 for participant; 1 for researcher site file; 1 to be kept in medical notes. 1

Figure B.3: Clinician's consent form of the final evaluation.

## Electronic educational game for children with type-1 diabetes.

*Parent's Information Sheet*

**Invitation**

My name is Charalampos (Babis) Kyfonidis and I am PhD student in the Computer Information Sciences department at the University of Strathclyde. My supervisor is Dr Marilyn Lennon, a senior lecturer in Digital Health and Wellness.

We would like to invite you and your child to take part in our research study about an electronic educational game for children with type-1 diabetes. Joining the study is entirely up to you and your child. Before you decide, we would like you to understand the purpose of the research and what you and your child would be doing. We have also sent you an information sheet for your child. We are happy to go through the information sheets with you and your child if you want. This way we can help you decide whether or not you would like to take part but also answer any questions you may have. We suggest this would take 20 minutes. Please feel free to talk to others about the study if you wish. Please ask if anything is unclear.

**Summary**

Currently, there is no formal diabetes education for children aged 5 to 9 with type-1 diabetes in the West Glasgow ACH Children's Diabetes Service. For this age group, the clinicians have a one-to-one approach where they talk with the child, during the regular visits, and try to support and guide her/him. We created a novel educational electronic game to make the education interactive and collaborative. We created the game with the guidance of clinicians in the West Glasgow ACH Children's Diabetes Service and we included children and parents in the design process, in order to understand and meet their needs.

The game teaches children about carbohydrates, healthy foods and what is insulin, through a virtual diabetic character named 'Mee'. Children will be feeding 'Mee' and helping him make choices for his diabetes. This way the children can learn about diabetes in a more enjoyable and child-friendly way. In this study we want to see if the game is effective in teaching children, and how we can improve it. The study will be conducted in the West Glasgow ACH Children's Diabetes Service. Participants will be children between 5 and 9 years old who speak English, their parents and diabetes clinicians.

We would like to invite you to take part in our study and help us improve our game.

**What would taking part involve?**

If you and your child agree to take part in the study, we will ask you to bring your child only to one educational session which will last about 1 hour in total. During this hour your child will be playing with the game in a room with clinician, and I will be observing. There might be more children in this session, playing along with your child, depending on the participation. You will be waiting in another room and you will have the chance to see what is going on in the room that your child is being educated, through a monitor. At least a week after the session I will informally interview you about any changes in the management of diabetes and your child's understanding after the session.

At the end of the session the clinician will ask your child to fill in a quiz about his/her experience and what (s)he learned. Your child will not get a mark for his/her responses. The clinician will also ask your child to draw or craft things about his/her experience during the session.

**Why has my child chosen?**

Your child has been invited to take part because (s)he is aged between 5 and 9 and has type-1 diabetes. Participants will be children between 5 and 9 years old (English speaking, with type-1

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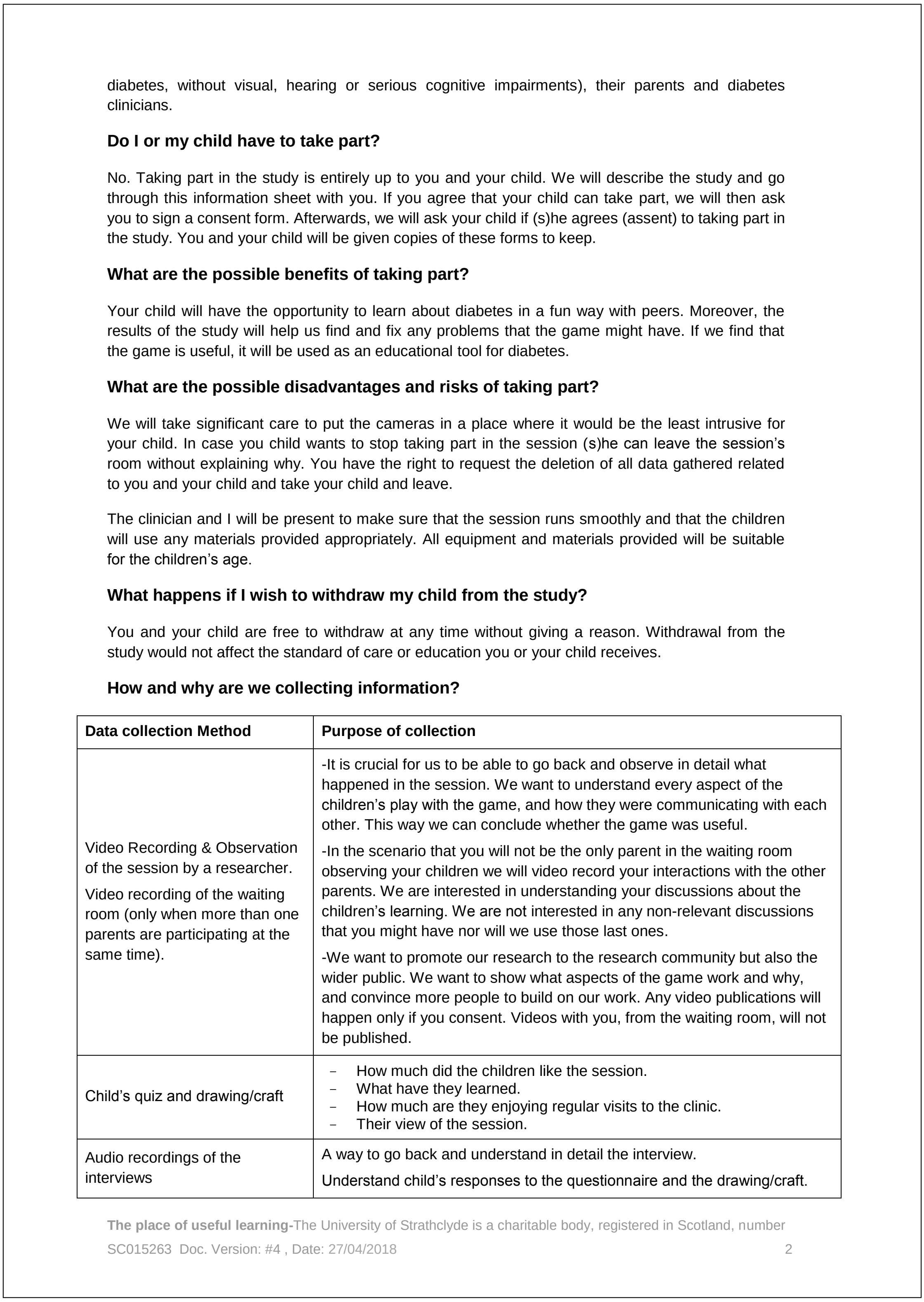
Figure B.4: Page 1 of the parent's information sheet of the final evaluation.



diabetes, without visual, hearing or serious cognitive impairments), their parents and diabetes clinicians.

**Do I or my child have to take part?**

No. Taking part in the study is entirely up to you and your child. We will describe the study and go through this information sheet with you. If you agree that your child can take part, we will then ask you to sign a consent form. Afterwards, we will ask your child if (s)he agrees (assent) to taking part in the study. You and your child will be given copies of these forms to keep.

**What are the possible benefits of taking part?**

Your child will have the opportunity to learn about diabetes in a fun way with peers. Moreover, the results of the study will help us find and fix any problems that the game might have. If we find that the game is useful, it will be used as an educational tool for diabetes.

**What are the possible disadvantages and risks of taking part?**

We will take significant care to put the cameras in a place where it would be the least intrusive for your child. In case you child wants to stop taking part in the session (s)he can leave the session's room without explaining why. You have the right to request the deletion of all data gathered related to you and your child and take your child and leave.

The clinician and I will be present to make sure that the session runs smoothly and that the children will use any materials provided appropriately. All equipment and materials provided will be suitable for the children's age.

**What happens if I wish to withdraw my child from the study?**

You and your child are free to withdraw at any time without giving a reason. Withdrawal from the study would not affect the standard of care or education you or your child receives.

**How and why are we collecting information?**

| **Data collection Method** | **Purpose of collection** |
|---|---|
| Video Recording & Observation of the session by a researcher.<br>Video recording of the waiting room (only when more than one parents are participating at the same time). | -It is crucial for us to be able to go back and observe in detail what happened in the session. We want to understand every aspect of the children's play with the game, and how they were communicating with each other. This way we can conclude whether the game was useful.<br>-In the scenario that you will not be the only parent in the waiting room observing your children we will video record your interactions with the other parents. We are interested in understanding your discussions about the children's learning. We are not interested in any non-relevant discussions that you might have nor will we use those last ones.<br>-We want to promote our research to the research community but also the wider public. We want to show what aspects of the game work and why, and convince more people to build on our work. Any video publications will happen only if you consent. Videos with you, from the waiting room, will not be published. |
| Child's quiz and drawing/craft | – How much did the children like the session.<br>– What have they learned.<br>– How much are they enjoying regular visits to the clinic.<br>– Their view of the session. |
| Audio recordings of the interviews | A way to go back and understand in detail the interview.<br>Understand child's responses to the questionnaire and the drawing/craft. |

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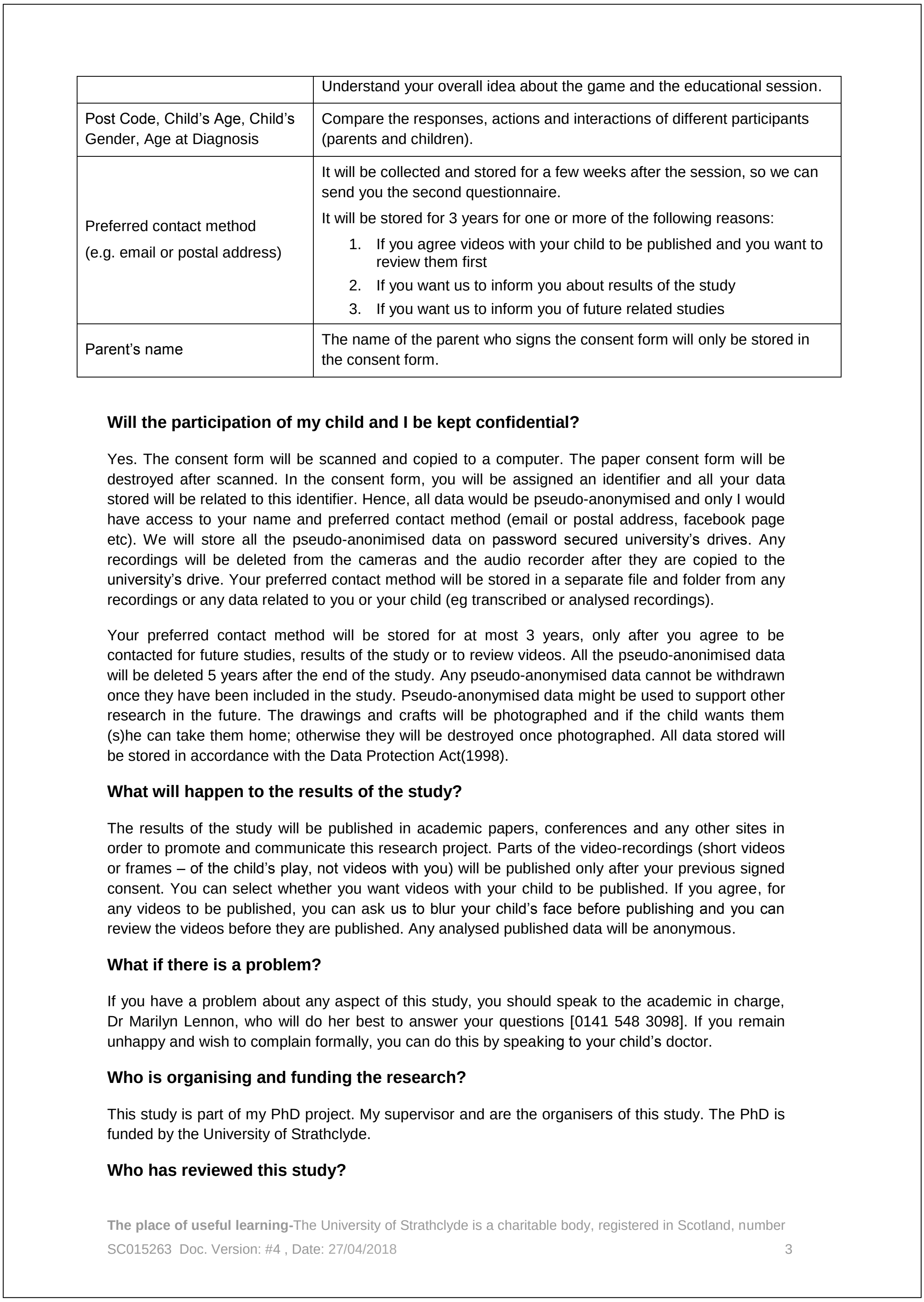
Figure B.5: Page 2 of the parent's information sheet of the final evaluation.



| | |
|---|---|
| | Understand your overall idea about the game and the educational session. |
| Post Code, Child's Age, Child's Gender, Age at Diagnosis | Compare the responses, actions and interactions of different participants (parents and children). |
| Preferred contact method<br>(e.g. email or postal address) | It will be collected and stored for a few weeks after the session, so we can send you the second questionnaire.<br>It will be stored for 3 years for one or more of the following reasons:<br>1. If you agree videos with your child to be published and you want to review them first<br>2. If you want us to inform you about results of the study<br>3. If you want us to inform you of future related studies |
| Parent's name | The name of the parent who signs the consent form will only be stored in the consent form. |

**Will the participation of my child and I be kept confidential?**

Yes. The consent form will be scanned and copied to a computer. The paper consent form will be destroyed after scanned. In the consent form, you will be assigned an identifier and all your data stored will be related to this identifier. Hence, all data would be pseudo-anonymised and only I would have access to your name and preferred contact method (email or postal address, facebook page etc). We will store all the pseudo-anonimised data on password secured university's drives. Any recordings will be deleted from the cameras and the audio recorder after they are copied to the university's drive. Your preferred contact method will be stored in a separate file and folder from any recordings or any data related to you or your child (eg transcribed or analysed recordings).

Your preferred contact method will be stored for at most 3 years, only after you agree to be contacted for future studies, results of the study or to review videos. All the pseudo-anonimised data will be deleted 5 years after the end of the study. Any pseudo-anonymised data cannot be withdrawn once they have been included in the study. Pseudo-anonymised data might be used to support other research in the future. The drawings and crafts will be photographed and if the child wants them (s)he can take them home; otherwise they will be destroyed once photographed. All data stored will be stored in accordance with the Data Protection Act(1998).

**What will happen to the results of the study?**

The results of the study will be published in academic papers, conferences and any other sites in order to promote and communicate this research project. Parts of the video-recordings (short videos or frames – of the child's play, not videos with you) will be published only after your previous signed consent. You can select whether you want videos with your child to be published. If you agree, for any videos to be published, you can ask us to blur your child's face before publishing and you can review the videos before they are published. Any analysed published data will be anonymous.

**What if there is a problem?**

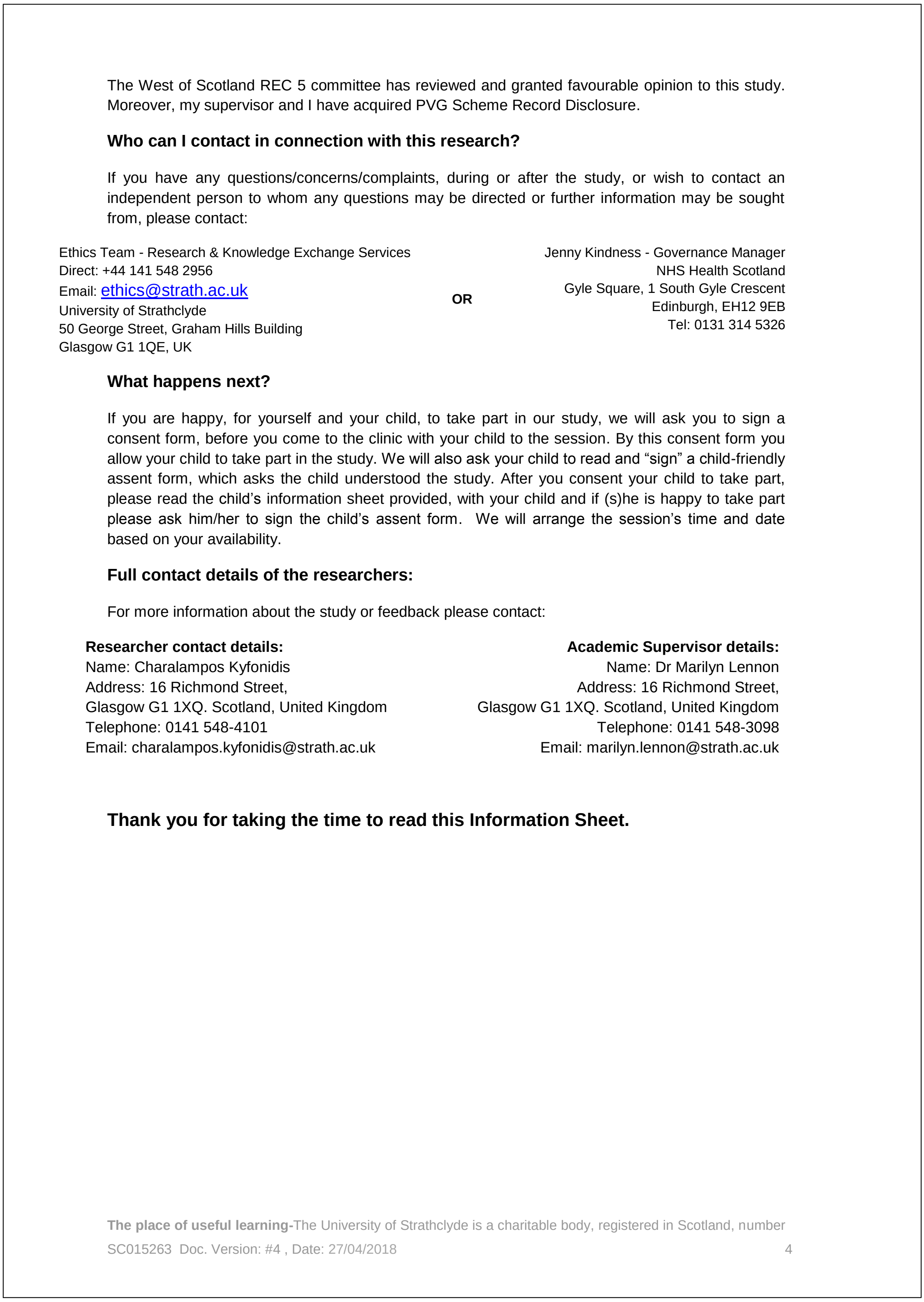
If you have a problem about any aspect of this study, you should speak to the academic in charge, Dr Marilyn Lennon, who will do her best to answer your questions [0141 548 3098]. If you remain unhappy and wish to complain formally, you can do this by speaking to your child's doctor.

**Who is organising and funding the research?**

This study is part of my PhD project. My supervisor and are the organisers of this study. The PhD is funded by the University of Strathclyde.

**Who has reviewed this study?**

Figure B.6: Page 3 of the parent's information sheet of the final evaluation.



The West of Scotland REC 5 committee has reviewed and granted favourable opinion to this study. Moreover, my supervisor and I have acquired PVG Scheme Record Disclosure.

**Who can I contact in connection with this research?**

If you have any questions/concerns/complaints, during or after the study, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Ethics Team - Research & Knowledge Exchange Services
Direct: +44 141 548 2956
Email: ethics@strath.ac.uk
University of Strathclyde
50 George Street, Graham Hills Building
Glasgow G1 1QE, UK

**OR**

Jenny Kindness - Governance Manager
NHS Health Scotland
Gyle Square, 1 South Gyle Crescent
Edinburgh, EH12 9EB
Tel: 0131 314 5326

**What happens next?**

If you are happy, for yourself and your child, to take part in our study, we will ask you to sign a consent form, before you come to the clinic with your child to the session. By this consent form you allow your child to take part in the study. We will also ask your child to read and "sign" a child-friendly assent form, which asks the child understood the study. After you consent your child to take part, please read the child's information sheet provided, with your child and if (s)he is happy to take part please ask him/her to sign the child's assent form.  We will arrange the session's time and date based on your availability.

**Full contact details of the researchers:**

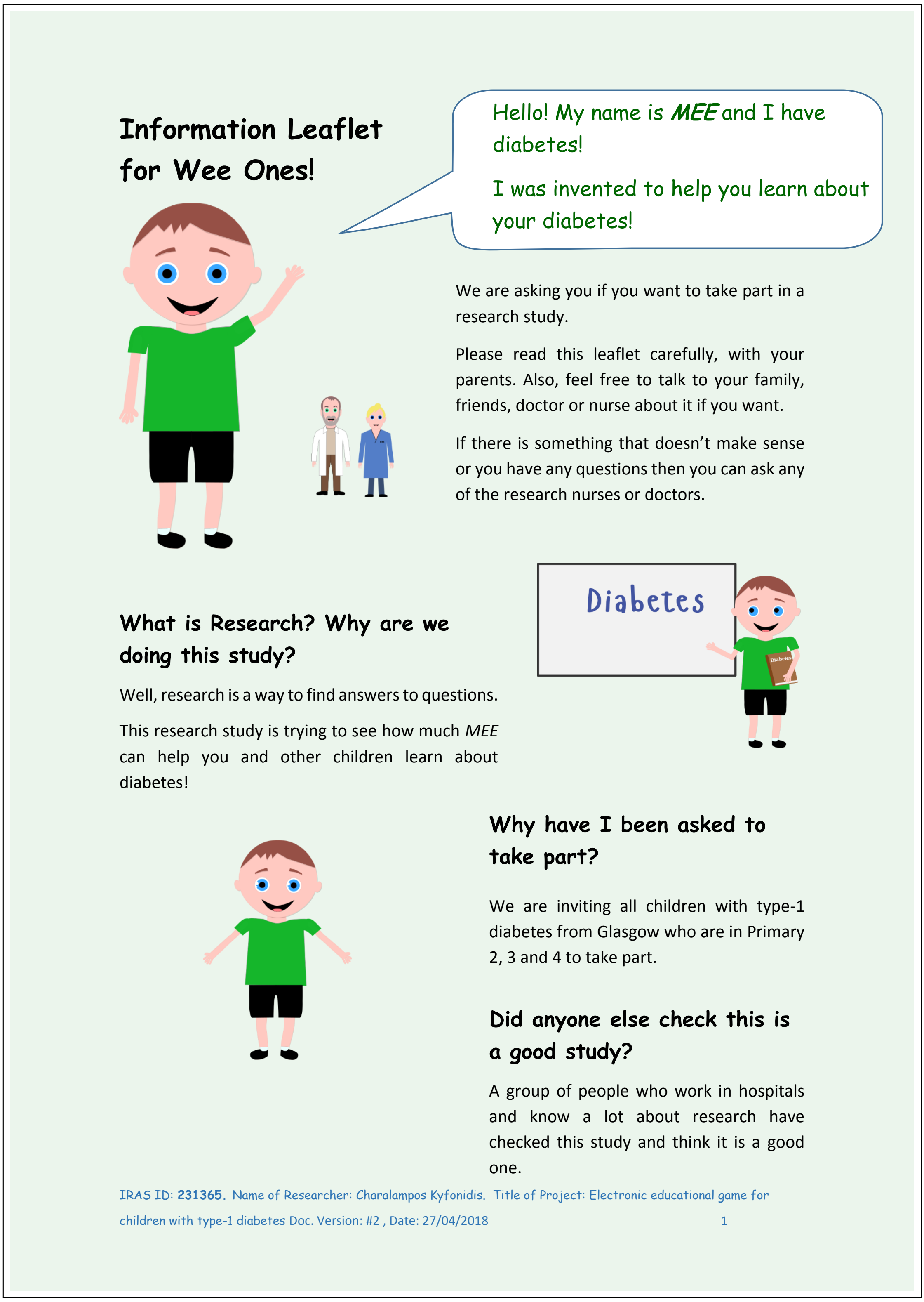
For more information about the study or feedback please contact:

**Researcher contact details:**
Name: Charalampos Kyfonidis
Address: 16 Richmond Street,
Glasgow G1 1XQ. Scotland, United Kingdom
Telephone: 0141 548-4101
Email: charalampos.kyfonidis@strath.ac.uk

**Academic Supervisor details:**
Name: Dr Marilyn Lennon
Address: 16 Richmond Street,
Glasgow G1 1XQ. Scotland, United Kingdom
Telephone: 0141 548-3098
Email: marilyn.lennon@strath.ac.uk

**Thank you for taking the time to read this Information Sheet.**

Figure B.7: Page 4 of the parent's information sheet of the final evaluation.



## Information Leaflet for Wee Ones!

Hello! My name is ***MEE*** and I have diabetes!

I was invented to help you learn about your diabetes!

We are asking you if you want to take part in a research study.

Please read this leaflet carefully, with your parents. Also, feel free to talk to your family, friends, doctor or nurse about it if you want.

If there is something that doesn't make sense or you have any questions then you can ask any of the research nurses or doctors.

### What is Research? Why are we doing this study?

Well, research is a way to find answers to questions.

This research study is trying to see how much *MEE* can help you and other children learn about diabetes!

### Why have I been asked to take part?

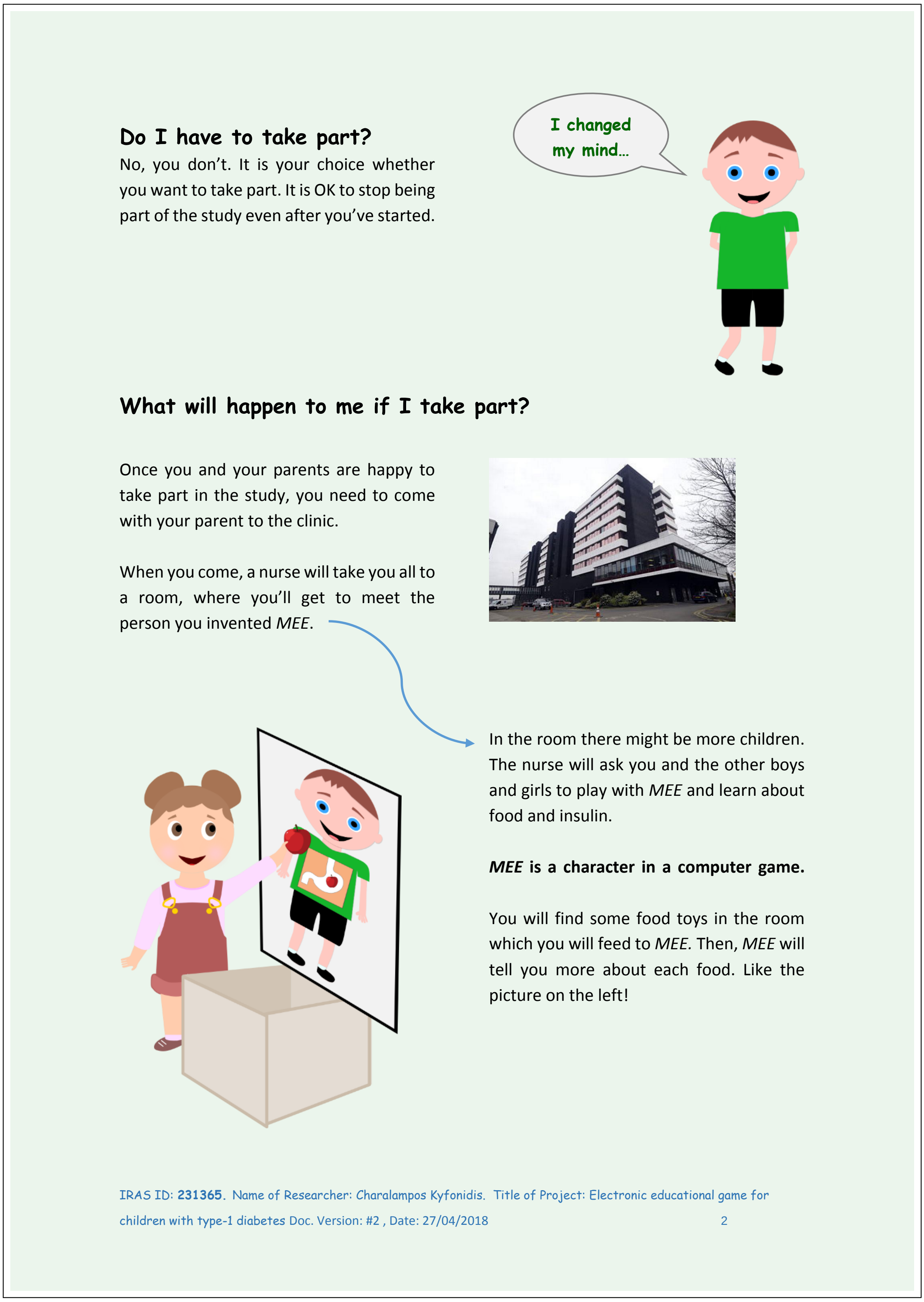
We are inviting all children with type-1 diabetes from Glasgow who are in Primary 2, 3 and 4 to take part.

### Did anyone else check this is a good study?

A group of people who work in hospitals and know a lot about research have checked this study and think it is a good one.

IRAS ID: **231365**. Name of Researcher: Charalampos Kyfonidis. Title of Project: Electronic educational game for children with type-1 diabetes Doc. Version: #2 , Date: 27/04/2018 1

Figure B.8: Page 1 of the children's information sheet of the final evaluation.



**Do I have to take part?**

No, you don't. It is your choice whether you want to take part. It is OK to stop being part of the study even after you've started.

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

Once you and your parents are happy to take part in the study, you need to come with your parent to the clinic.

When you come, a nurse will take you all to a room, where you'll get to meet the person you invented *MEE*.

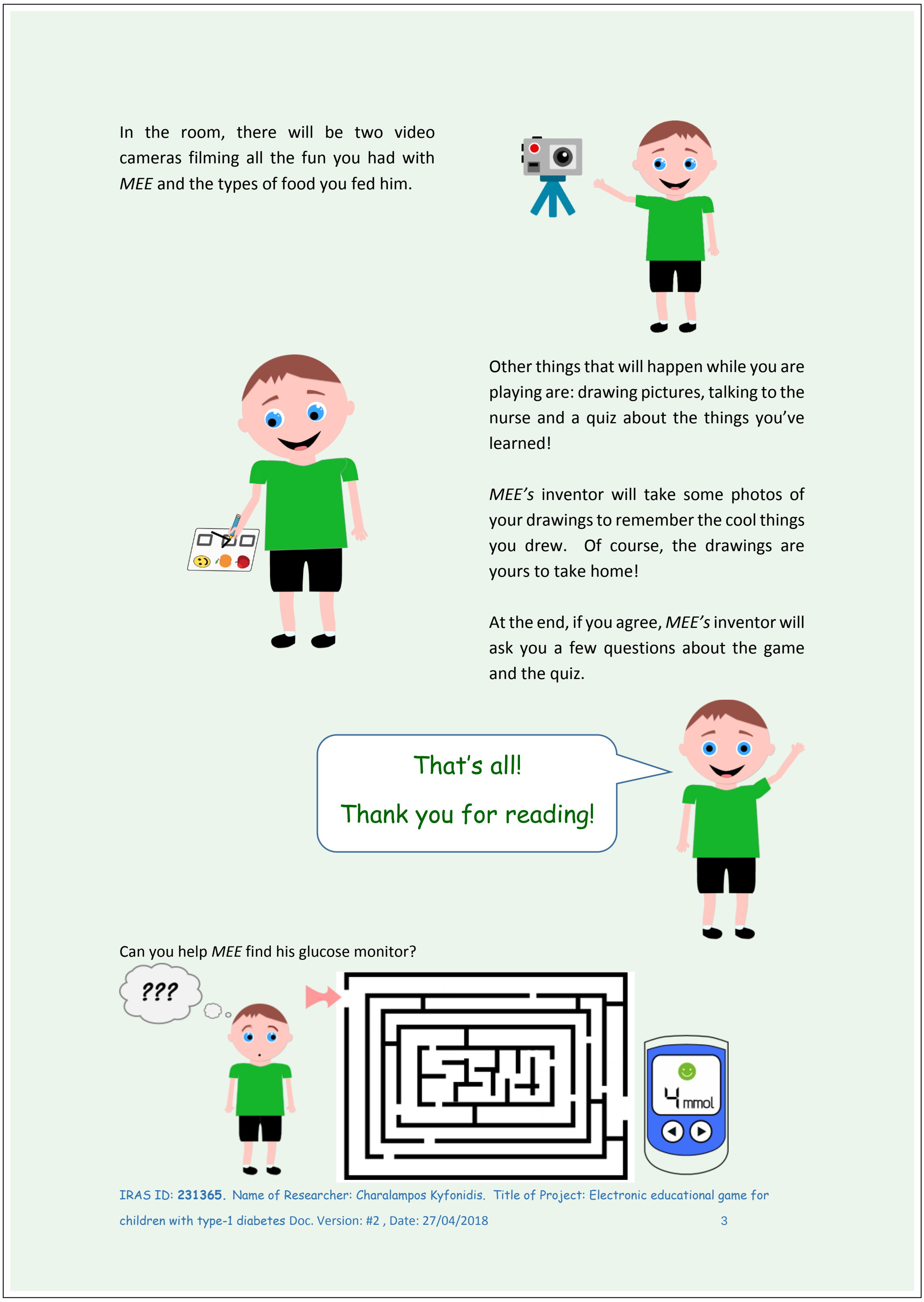
In the room there might be more children. The nurse will ask you and the other boys and girls to play with *MEE* and learn about food and insulin.

***MEE* is a character in a computer game.**

You will find some food toys in the room which you will feed to *MEE*. Then, *MEE* will tell you more about each food. Like the picture on the left!

IRAS ID: **231365**. Name of Researcher: Charalampos Kyfonidis. Title of Project: Electronic educational game for children with type-1 diabetes Doc. Version: #2 , Date: 27/04/2018 2

Figure B.9: Page 2 of the children's information sheet of the final evaluation.



In the room, there will be two video cameras filming all the fun you had with *MEE* and the types of food you fed him.

Other things that will happen while you are playing are: drawing pictures, talking to the nurse and a quiz about the things you've learned!

*MEE's* inventor will take some photos of your drawings to remember the cool things you drew. Of course, the drawings are yours to take home!

At the end, if you agree, *MEE's* inventor will ask you a few questions about the game and the quiz.

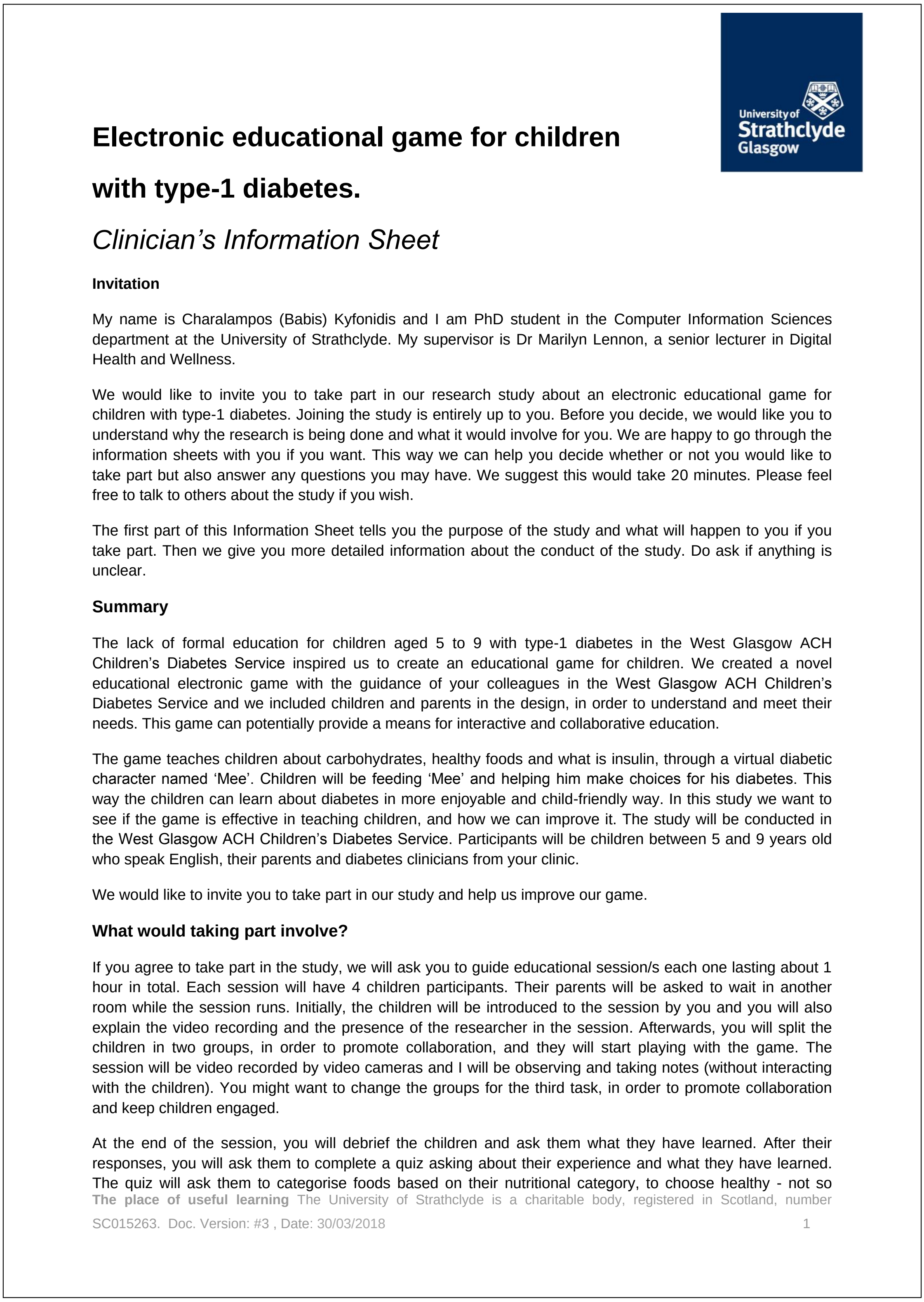
That's all!

Thank you for reading!

Can you help *MEE* find his glucose monitor?

IRAS ID: **231365**. Name of Researcher: Charalampos Kyfonidis. Title of Project: Electronic educational game for children with type-1 diabetes Doc. Version: #2 , Date: 27/04/2018 3

Figure B.10: Page 3 of the children's information sheet of the final evaluation.



# Electronic educational game for children with type-1 diabetes.

## *Clinician's Information Sheet*

### Invitation

My name is Charalampos (Babis) Kyfonidis and I am PhD student in the Computer Information Sciences department at the University of Strathclyde. My supervisor is Dr Marilyn Lennon, a senior lecturer in Digital Health and Wellness.

We would like to invite you to take part in our research study about an electronic educational game for children with type-1 diabetes. Joining the study is entirely up to you. Before you decide, we would like you to understand why the research is being done and what it would involve for you. We are happy to go through the information sheets with you if you want. This way we can help you decide whether or not you would like to take part but also answer any questions you may have. We suggest this would take 20 minutes. Please feel free to talk to others about the study if you wish.

The first part of this Information Sheet tells you the purpose of the study and what will happen to you if you take part. Then we give you more detailed information about the conduct of the study. Do ask if anything is unclear.

### Summary

The lack of formal education for children aged 5 to 9 with type-1 diabetes in the West Glasgow ACH Children's Diabetes Service inspired us to create an educational game for children. We created a novel educational electronic game with the guidance of your colleagues in the West Glasgow ACH Children's Diabetes Service and we included children and parents in the design, in order to understand and meet their needs. This game can potentially provide a means for interactive and collaborative education.

The game teaches children about carbohydrates, healthy foods and what is insulin, through a virtual diabetic character named 'Mee'. Children will be feeding 'Mee' and helping him make choices for his diabetes. This way the children can learn about diabetes in more enjoyable and child-friendly way. In this study we want to see if the game is effective in teaching children, and how we can improve it. The study will be conducted in the West Glasgow ACH Children's Diabetes Service. Participants will be children between 5 and 9 years old who speak English, their parents and diabetes clinicians from your clinic.

We would like to invite you to take part in our study and help us improve our game.

### What would taking part involve?

If you agree to take part in the study, we will ask you to guide educational session/s each one lasting about 1 hour in total. Each session will have 4 children participants. Their parents will be asked to wait in another room while the session runs. Initially, the children will be introduced to the session by you and you will also explain the video recording and the presence of the researcher in the session. Afterwards, you will split the children in two groups, in order to promote collaboration, and they will start playing with the game. The session will be video recorded by video cameras and I will be observing and taking notes (without interacting with the children). You might want to change the groups for the third task, in order to promote collaboration and keep children engaged.

At the end of the session, you will debrief the children and ask them what they have learned. After their responses, you will ask them to complete a quiz asking about their experience and what they have learned. The quiz will ask them to categorise foods based on their nutritional category, to choose healthy - not so

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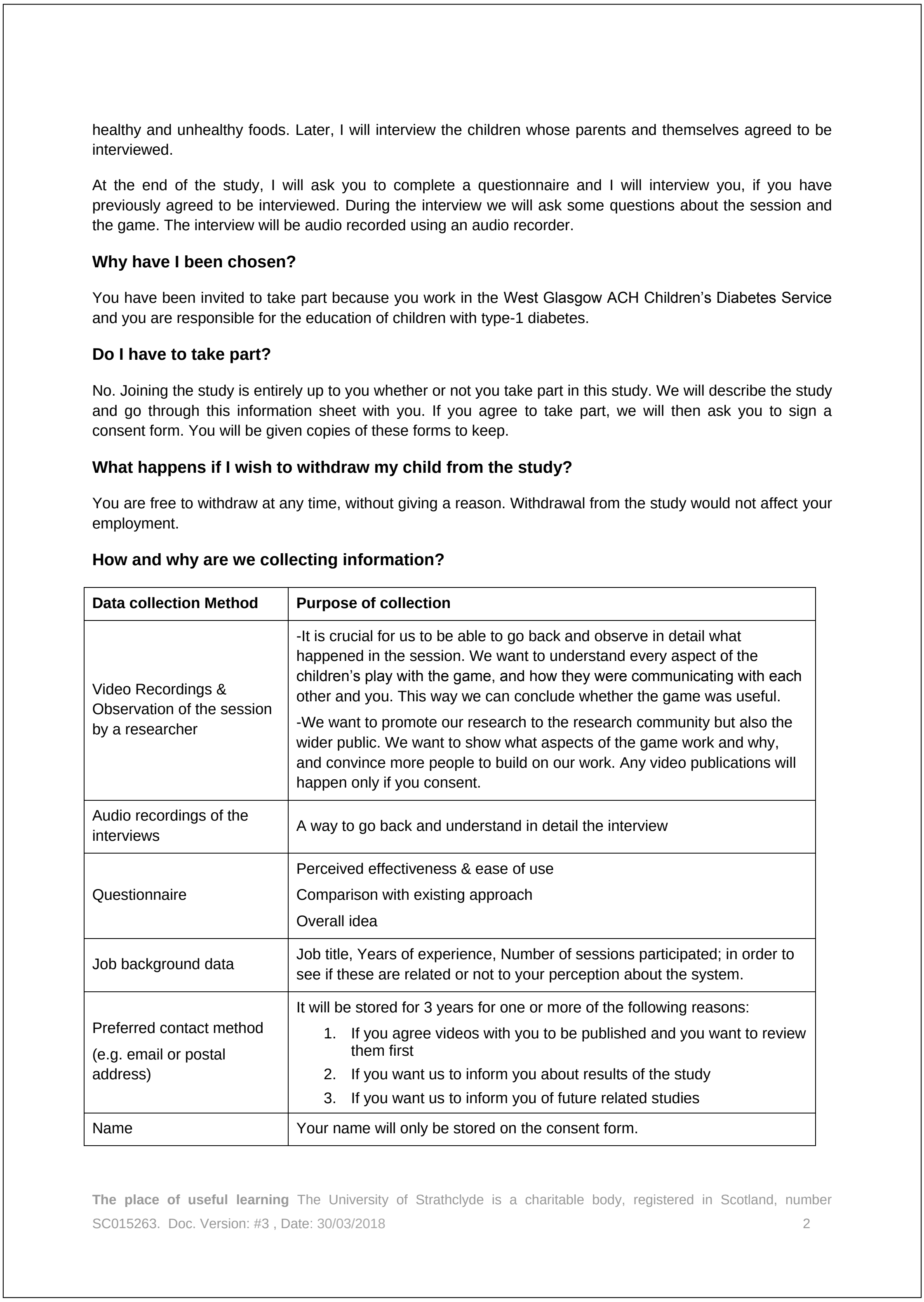
Figure B.11: Page 1 of the clinician's information sheet of the final evaluation.



healthy and unhealthy foods. Later, I will interview the children whose parents and themselves agreed to be interviewed.

At the end of the study, I will ask you to complete a questionnaire and I will interview you, if you have previously agreed to be interviewed. During the interview we will ask some questions about the session and the game. The interview will be audio recorded using an audio recorder.

**Why have I been chosen?**

You have been invited to take part because you work in the West Glasgow ACH Children's Diabetes Service and you are responsible for the education of children with type-1 diabetes.

**Do I have to take part?**

No. Joining the study is entirely up to you whether or not you take part in this study. We will describe the study and go through this information sheet with you. If you agree to take part, we will then ask you to sign a consent form. You will be given copies of these forms to keep.

**What happens if I wish to withdraw my child from the study?**

You are free to withdraw at any time, without giving a reason. Withdrawal from the study would not affect your employment.

**How and why are we collecting information?**

| **Data collection Method** | **Purpose of collection** |
|---|---|
| Video Recordings & Observation of the session by a researcher | -It is crucial for us to be able to go back and observe in detail what happened in the session. We want to understand every aspect of the children's play with the game, and how they were communicating with each other and you. This way we can conclude whether the game was useful.<br>-We want to promote our research to the research community but also the wider public. We want to show what aspects of the game work and why, and convince more people to build on our work. Any video publications will happen only if you consent. |
| Audio recordings of the interviews | A way to go back and understand in detail the interview |
| Questionnaire | Perceived effectiveness & ease of use<br>Comparison with existing approach<br>Overall idea |
| Job background data | Job title, Years of experience, Number of sessions participated; in order to see if these are related or not to your perception about the system. |
| Preferred contact method<br>(e.g. email or postal address) | It will be stored for 3 years for one or more of the following reasons:<br>1. If you agree videos with you to be published and you want to review them first<br>2. If you want us to inform you about results of the study<br>3. If you want us to inform you of future related studies |
| Name | Your name will only be stored on the consent form. |

Figure B.12: Page 2 of the clinician's information sheet of the final evaluation.

### Will my participation be kept confidential?

Yes. The consent form will be scanned and copied to a computer. The paper consent form will be destroyed after scanned. On the consent form, you will be assigned an identifier and all your data stored will be related to this identifier. Hence, all data would be pseudo-anonymised and only I would have access to your name and preferred contact method (email or postal address, facebook page etc). We will store all the pseudo-anonimised data on password secured university's drives. Any recordings will be deleted from the cameras and the audio recorder after they are copied to the university's drive. Your preferred contact method will be stored in a separate file and folder from any recordings or any data related to you (eg transcribed or analysed recordings).

Your preferred contact method will be stored for at most 3 years, only after you agree to be contacted for future studies, results of the study or to review videos. All the pseudo-anonimised data will be deleted 5 years after the end of the study. Any pseudo-anonymised data cannot be withdrawn once they have been included in the study. Pseudo-anonymised data might be used to support other research in the future. The drawings and crafts will be photographed and if the child wants them s/he can take them home; otherwise they will be destroyed once photographed. All data stored will be stored in accordance with the Data Protection Act(1998).

### What will happen to the results of the study?

The results of the study will be published in academic papers, conferences and any other sites in order to promote and communicate this research project. Parts of the video-recordings (short videos or frames) will be published only after your previous signed consent. You can select whether you want videos with you to be published. If you agree, for any videos to be published, you can ask us to blur your face before publishing and you can review the videos before they are published. Any analysed published data will be anonymous.

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

The children will have the opportunity to learn about diabetes in a fun way with peers. Moreover, the results of the study will help us find and fix the problems that the game might have. If we find that the game is useful, it will be used to help you and your colleagues educate more children in the future.

### What are the possible disadvantages and risks of taking part?

We will take significant care to put the cameras in a place where it would be the least intrusive for your child. My participation to the session would be mostly to help with the setup and function of the game and to observe. In case a child wants to stop taking part in the session (s)he can leave the session's room without explaining why. The parent has the right to take the child and leave.

You and I will be present to make sure that the session runs smoothly and that the children will use any materials provided appropriately. All equipment and materials provided will be suitable for the children's age.

There are no significant risks for you taking part.

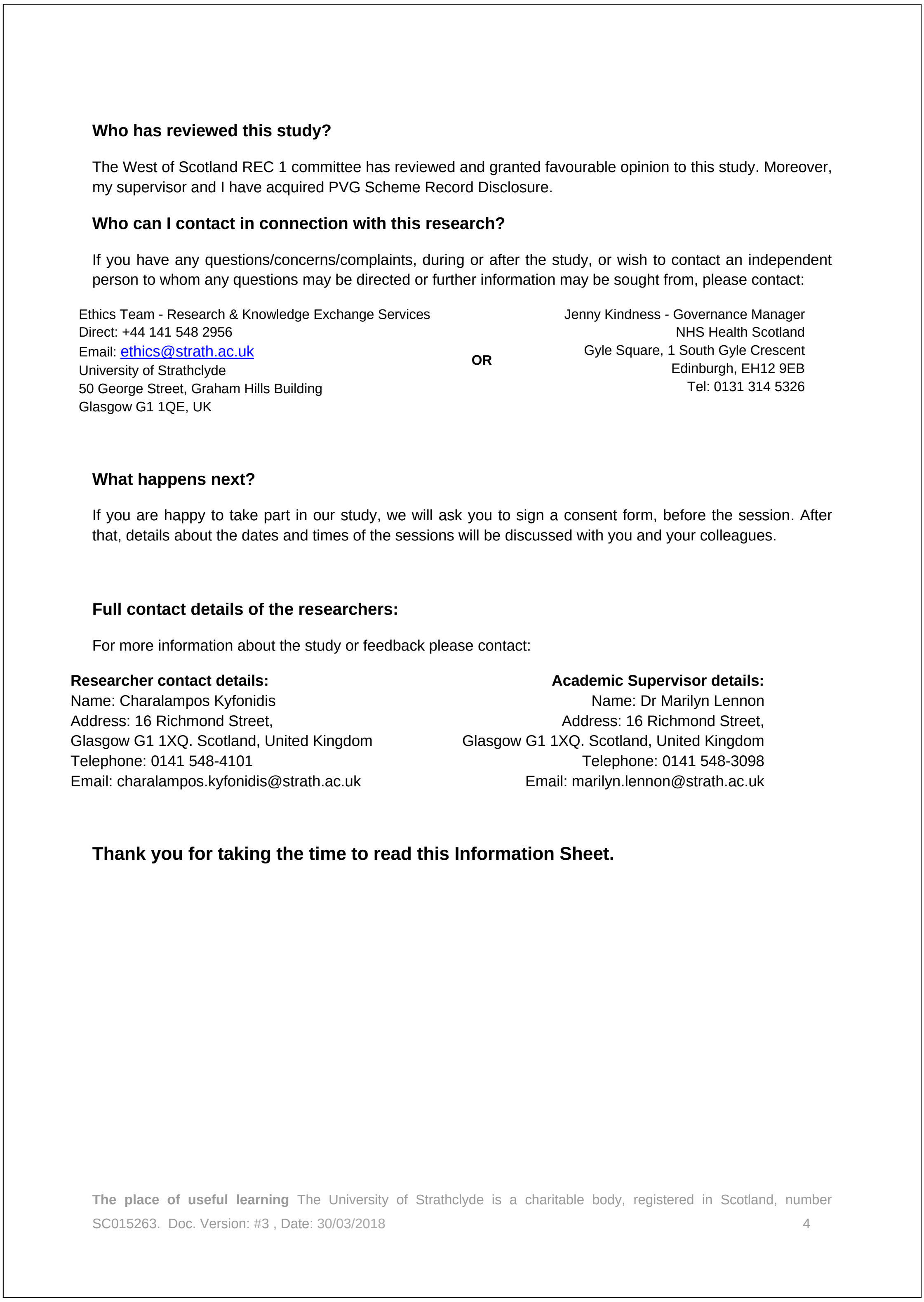
### What if there is a problem?

If you have a problem about any aspect of this study, you should speak to the academic in charge, Dr Marilyn Lennon, who will do her best to answer your questions [0141 548 3098]. If you remain unhappy and wish to complain formally, you can do this by speaking to the head of your clinic or one of the independent people listed in the next page.

### Who is organising and funding the research?

This study is part of my PhD project. My supervisor and are the organisers of this study. The PhD is funded by the University of Strathclyde.

Figure B.13: Page 3 of the clinician's information sheet of the final evaluation.



**Who has reviewed this study?**

The West of Scotland REC 1 committee has reviewed and granted favourable opinion to this study. Moreover, my supervisor and I have acquired PVG Scheme Record Disclosure.

**Who can I contact in connection with this research?**

If you have any questions/concerns/complaints, during or after the study, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Ethics Team - Research & Knowledge Exchange Services
Direct: +44 141 548 2956
Email: ethics@strath.ac.uk
University of Strathclyde
50 George Street, Graham Hills Building
Glasgow G1 1QE, UK

**OR**

Jenny Kindness - Governance Manager
NHS Health Scotland
Gyle Square, 1 South Gyle Crescent
Edinburgh, EH12 9EB
Tel: 0131 314 5326

**What happens next?**

If you are happy to take part in our study, we will ask you to sign a consent form, before the session. After that, details about the dates and times of the sessions will be discussed with you and your colleagues.

**Full contact details of the researchers:**

For more information about the study or feedback please contact:

**Researcher contact details:**
Name: Charalampos Kyfonidis
Address: 16 Richmond Street,
Glasgow G1 1XQ. Scotland, United Kingdom
Telephone: 0141 548-4101
Email: charalampos.kyfonidis@strath.ac.uk

**Academic Supervisor details:**
Name: Dr Marilyn Lennon
Address: 16 Richmond Street,
Glasgow G1 1XQ. Scotland, United Kingdom
Telephone: 0141 548-3098
Email: marilyn.lennon@strath.ac.uk

**Thank you for taking the time to read this Information Sheet.**

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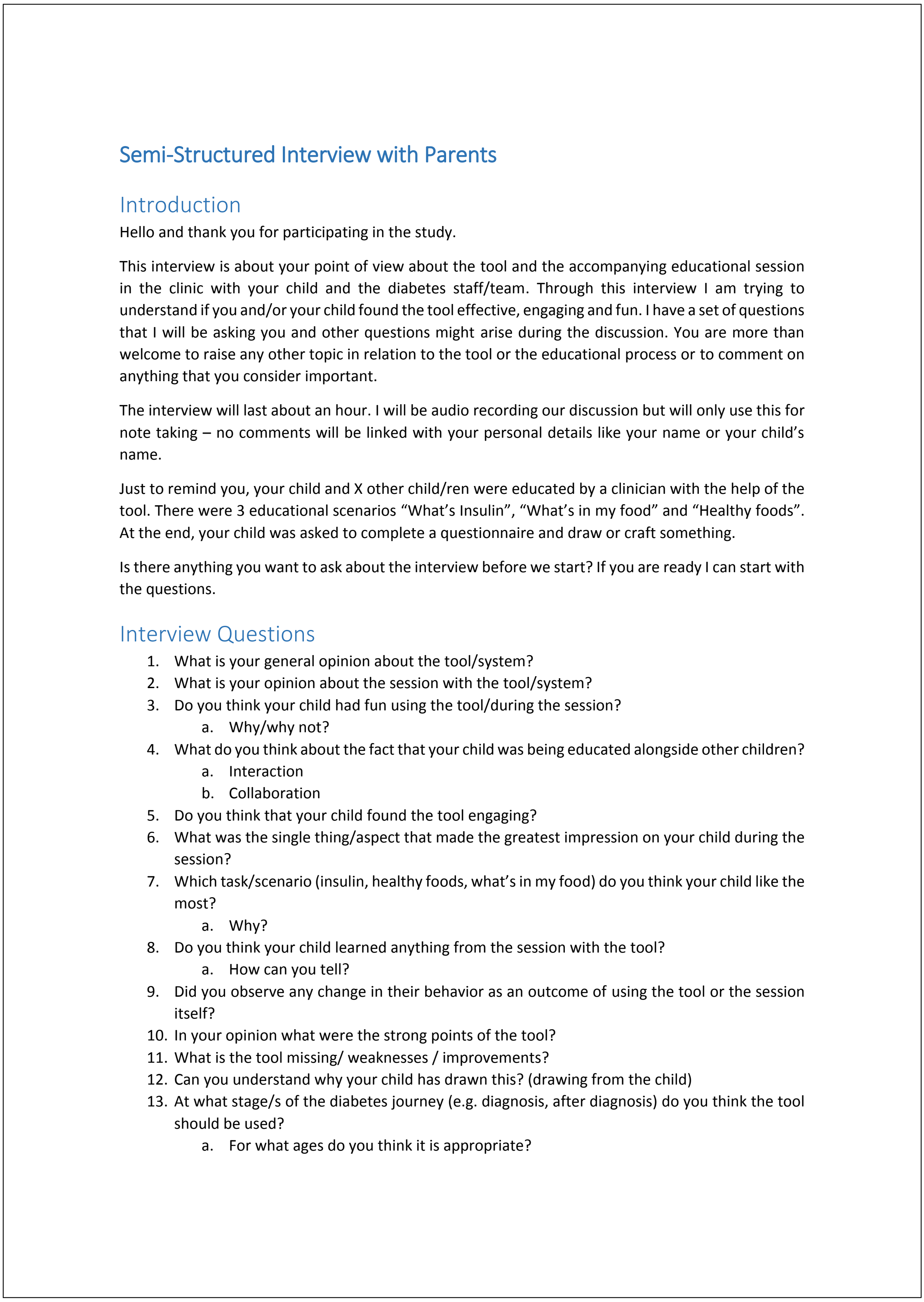
Figure B.14: Page 4 of the clinician's information sheet of the final evaluation.



# Semi-Structured Interview with Parents

## Introduction

Hello and thank you for participating in the study.

This interview is about your point of view about the tool and the accompanying educational session in the clinic with your child and the diabetes staff/team. Through this interview I am trying to understand if you and/or your child found the tool effective, engaging and fun. I have a set of questions that I will be asking you and other questions might arise during the discussion. You are more than welcome to raise any other topic in relation to the tool or the educational process or to comment on anything that you consider important.

The interview will last about an hour. I will be audio recording our discussion but will only use this for note taking – no comments will be linked with your personal details like your name or your child's name.

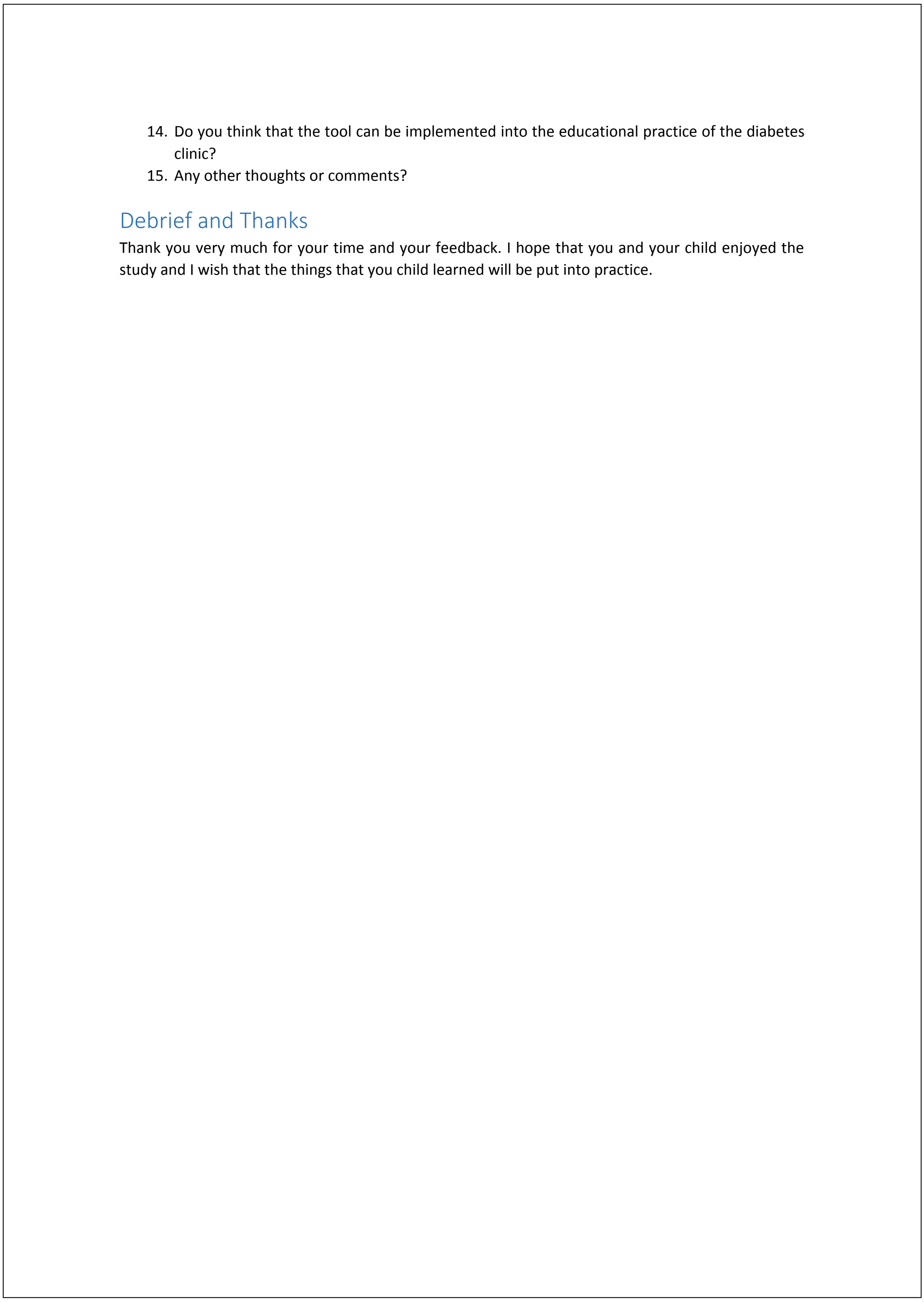
Just to remind you, your child and X other child/ren were educated by a clinician with the help of the tool. There were 3 educational scenarios "What's Insulin", "What's in my food" and "Healthy foods". At the end, your child was asked to complete a questionnaire and draw or craft something.

Is there anything you want to ask about the interview before we start? If you are ready I can start with the questions.

## Interview Questions

1. What is your general opinion about the tool/system?
2. What is your opinion about the session with the tool/system?
3. Do you think your child had fun using the tool/during the session?
    a. Why/why not?
4. What do you think about the fact that your child was being educated alongside other children?
    a. Interaction
    b. Collaboration
5. Do you think that your child found the tool engaging?
6. What was the single thing/aspect that made the greatest impression on your child during the session?
7. Which task/scenario (insulin, healthy foods, what's in my food) do you think your child like the most?
    a. Why?
8. Do you think your child learned anything from the session with the tool?
    a. How can you tell?
9. Did you observe any change in their behavior as an outcome of using the tool or the session itself?
10. In your opinion what were the strong points of the tool?
11. What is the tool missing/ weaknesses / improvements?
12. Can you understand why your child has drawn this? (drawing from the child)
13. At what stage/s of the diabetes journey (e.g. diagnosis, after diagnosis) do you think the tool should be used?
    a. For what ages do you think it is appropriate?

Figure B.15: Page 1 of the parent's interview script of the final evaluation.

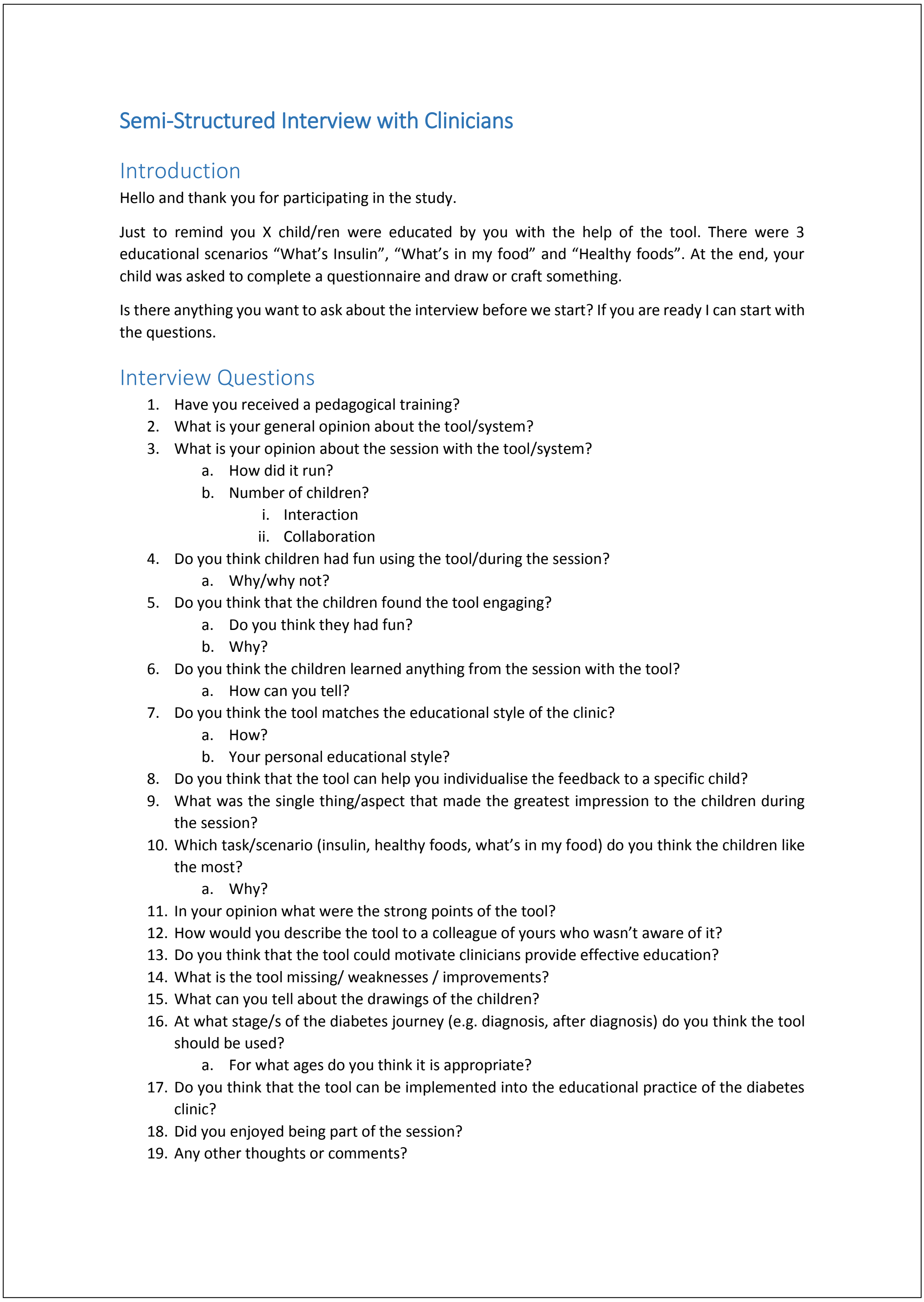


14. Do you think that the tool can be implemented into the educational practice of the diabetes clinic?
15. Any other thoughts or comments?

## Debrief and Thanks

Thank you very much for your time and your feedback. I hope that you and your child enjoyed the study and I wish that the things that you child learned will be put into practice.

Figure B.16: Page 1 of the parent's interview script of the final evaluation.



## Semi-Structured Interview with Clinicians

### Introduction

Hello and thank you for participating in the study.

Just to remind you X child/ren were educated by you with the help of the tool. There were 3 educational scenarios “What’s Insulin”, “What’s in my food” and “Healthy foods”. At the end, your child was asked to complete a questionnaire and draw or craft something.

Is there anything you want to ask about the interview before we start? If you are ready I can start with the questions.

### Interview Questions

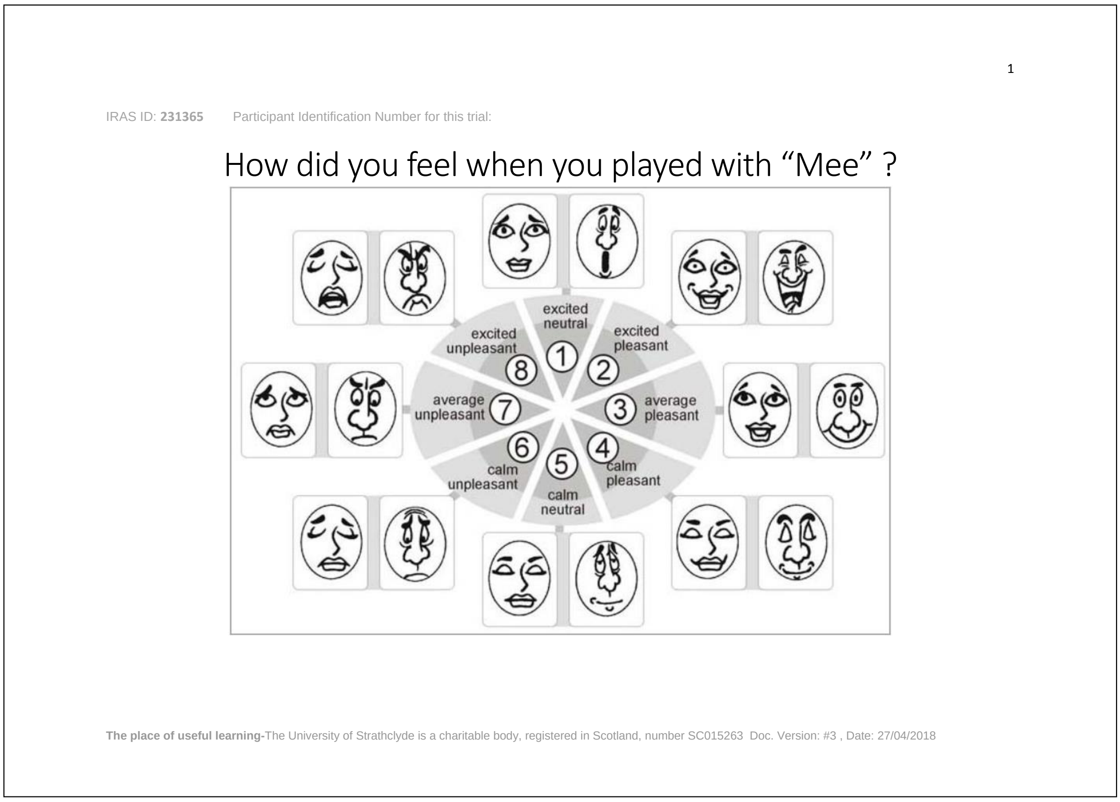
1. Have you received a pedagogical training?
2. What is your general opinion about the tool/system?
3. What is your opinion about the session with the tool/system?
    a. How did it run?
    b. Number of children?
        i. Interaction
        ii. Collaboration
4. Do you think children had fun using the tool/during the session?
    a. Why/why not?
5. Do you think that the children found the tool engaging?
    a. Do you think they had fun?
    b. Why?
6. Do you think the children learned anything from the session with the tool?
    a. How can you tell?
7. Do you think the tool matches the educational style of the clinic?
    a. How?
    b. Your personal educational style?
8. Do you think that the tool can help you individualise the feedback to a specific child?
9. What was the single thing/aspect that made the greatest impression to the children during the session?
10. Which task/scenario (insulin, healthy foods, what’s in my food) do you think the children like the most?
    a. Why?
11. In your opinion what were the strong points of the tool?
12. How would you describe the tool to a colleague of yours who wasn’t aware of it?
13. Do you think that the tool could motivate clinicians provide effective education?
14. What is the tool missing/ weaknesses / improvements?
15. What can you tell about the drawings of the children?
16. At what stage/s of the diabetes journey (e.g. diagnosis, after diagnosis) do you think the tool should be used?
    a. For what ages do you think it is appropriate?
17. Do you think that the tool can be implemented into the educational practice of the diabetes clinic?
18. Did you enjoyed being part of the session?
19. Any other thoughts or comments?

Figure B.17: Page 1 of the clinician’s interview script of the final evaluation.

## Debrief and Thanks

Thank you very much for your time and your feedback. I hope that you and your child enjoyed the study and I wish that the things that you child learned will be put into practice.

Figure B.18: Page 2 of the clinician's interview script of the final evaluation.



1

IRAS ID: **231365** Participant Identification Number for this trial:

How did you feel when you played with “Mee” ?

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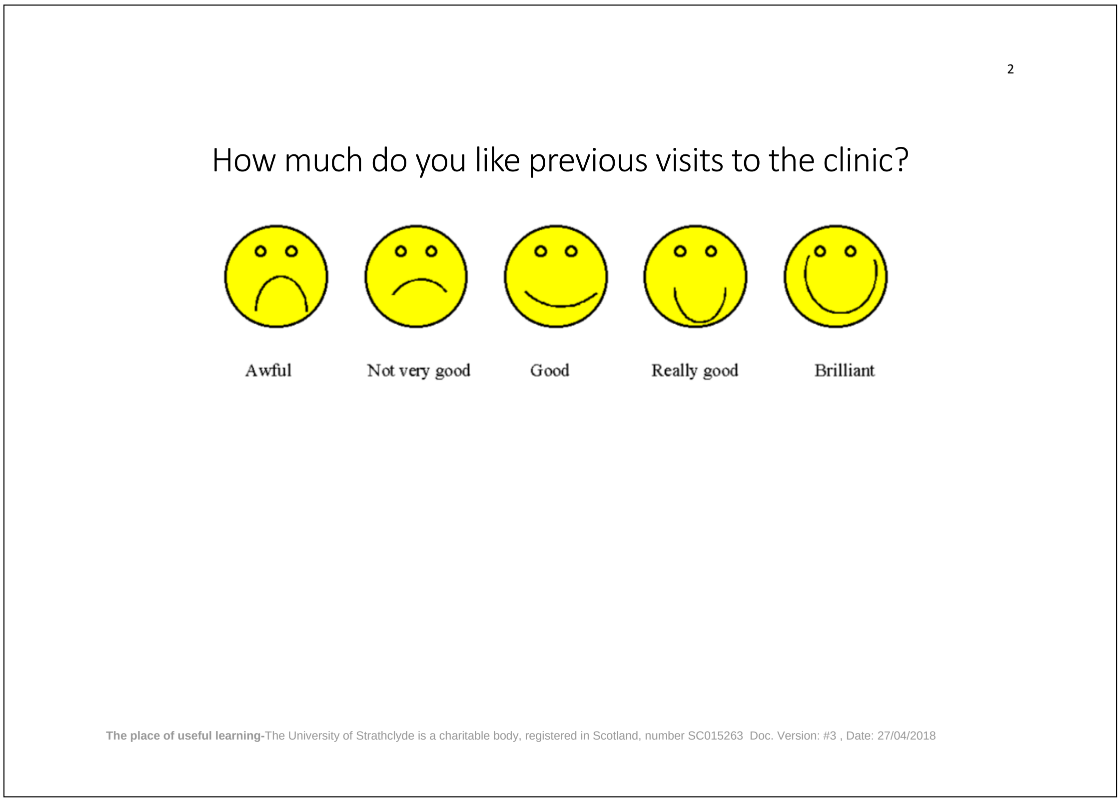
Figure B.19: Page 1 of the children’s questionnaire of the final evaluation.



2

How much do you like previous visits to the clinic?

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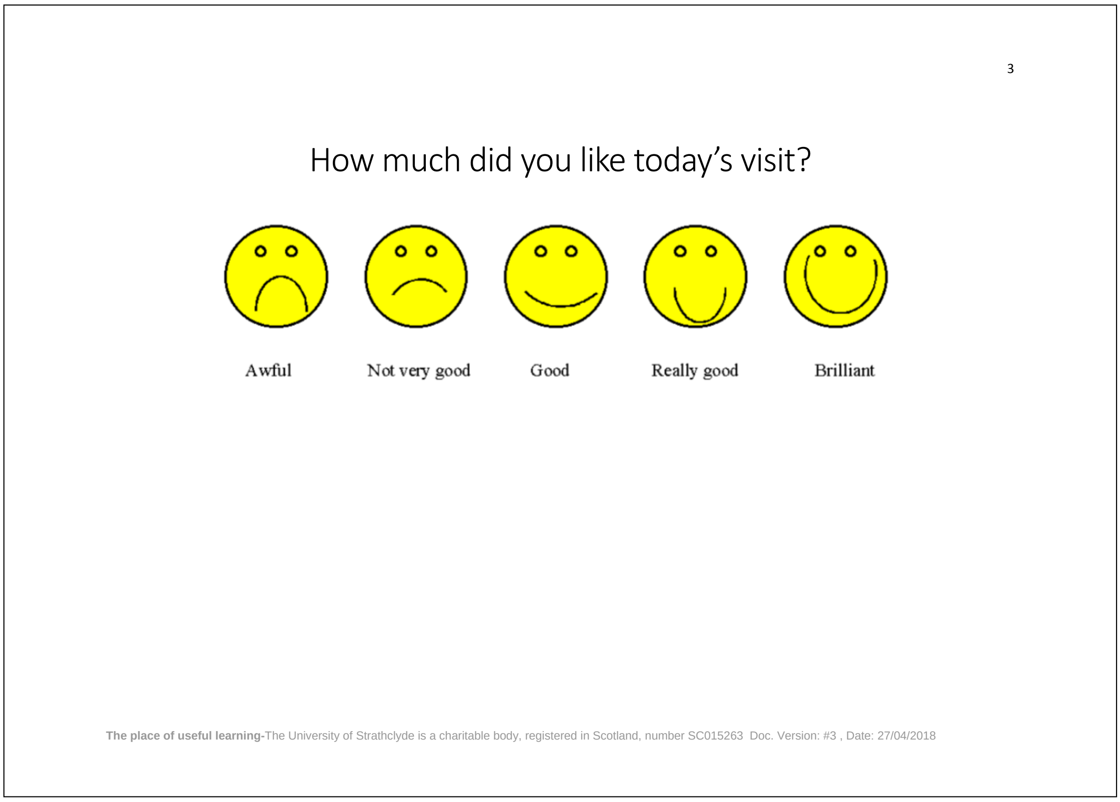
Figure B.20: Page 2 of the children’s questionnaire of the final evaluation.



3

How much did you like today’s visit?

Awful Not very good Good Really good Brilliant

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Figure B.21: Page 3 of the children’s questionnaire of the final evaluation.

4

Draw or craft something about today’s visit to the clinic!

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Figure B.22: Page 4 of the children’s questionnaire of the final evaluation.