

Making Diabetes Education Interactive: Tangible Educational Toys for Children with Type-1 Diabetes.

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ABSTRACT

Younger children (under 9 years) with type-1 diabetes are often very passive in the management of their condition and can face difficulties in accessing and understanding basic diabetes related information. This can make transitioning to self-management in later years very challenging. Previous research has mostly focused on educational interventions for older children. To create an educational tool which can support the diabetes educational process of younger children, we conducted a multiphase and multi-stakeholder user-centred design process. The result is an interactive tool that illustrates diabetes concepts in an age-appropriate way with the use of tangible toys. The tool was evaluated inside a paediatric diabetes clinic with clinicians, children and parents and was found to be engaging, acceptable and effective. In addition to providing implications for the design and adoption of educational tools for children in a clinical setting, we discuss the challenges for conducting user-centred design in such a setting.

CCS CONCEPTS

• **Human-centered computing** → **Interactive systems and tools**; *Empirical studies in HCI*; • **Applied computing** → **Interactive learning environments**.

KEYWORDS

Children, Diabetes Education, User-Centred Design, Tangible Interaction

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CHI 2019, May 4–9, 2019, Glasgow, Scotland UK
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ACM ISBN 978-1-4503-5970-2/19/05...\$15.00

<https://doi.org/10.1145/3290605.3300671>

ACM Reference Format:

Charalampos Kyfonidis and Marilyn Lennon. 2019. Making Diabetes Education Interactive: Tangible Educational Toys for Children with Type-1 Diabetes.. In *CHI Conference on Human Factors in Computing Systems Proceedings (CHI 2019), May 4–9, 2019, Glasgow, Scotland UK*. ACM, New York, NY, USA, Article 4, 12 pages. <https://doi.org/10.1145/3290605.3300671>

1 INTRODUCTION

Type-1 diabetes (T1D) is serious long-term condition whose management is continuous and requires decision making by balancing several factors [18]. Due to the high risk of serious consequences, the management of younger children's diabetes is solely the parents' responsibility [32]. Hence, most current diabetes educational programs for a younger age group (9 years and younger) target their parents [24, 36]. Children learn about their condition informally, mostly through their parents, and often with the use of age-inappropriate materials [26]. Moreover, they are often discouraged to take initiatives in the management process [24], a fact that does not allow them to put into practice any education they have received. Without the appropriate education and skills children entering a state of autonomy (like adolescence) are unable to effectively manage diabetes [29, 35]. As a consequence they can have serious long-term health complications [37].

To date most educational interventions 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 [25] and who do not solely manage their condition.

This research aimed to provide a viable solution to the lack of age-appropriate educational materials for children with T1D. We explored a T1D eco-system through a multi-stakeholder and multi-phased user-centred process. In sum 8 clinicians, 1 national T1D co-ordinator, 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 tailor the education to the individual. The tool provides a way for children to test their preconceptions without putting themselves into harm.

The tool was also evaluated inside the paediatric diabetes clinic with 17 children, their parents and 4 clinicians. The evaluation sessions 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 CHI community about the holistic co-design approach in the field and the importance of designing tools that fit into the current work practices.

2 RELATED WORK

Diabetes education

Diabetes education is very important [7, 14, 17, 26, 36] even from a very young age [24] and even when there is not a clear or directly measurable clinical improvement from this education [22]. Because young children's diabetes is managed by their parents most currently available educational programs target parents [24, 36]. Moreover, the educational resources are often not age-appropriate for younger children (those under 9 years) [36]. As a consequence children do not always receive formal diabetes education and their parents have to become the lead educators [36].

Even paediatric clinics with formal diabetes educational programmes face difficulties in educating younger children. Martin et al. [26] 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 is not working for every child.

Education should be given with age-appropriate materials and media taking into account the child's age and maturity [14]. Even more, written materials, which are passive by nature, are not easily understood by children [8]. For example, Tsvyatkova et al. [36] present the example of an illustrated book for diabetes education which is *"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

[22] who can get bored easily if education is lacking fun and interaction [2]. Apart from being age-appropriate, diabetes education has to be also tailored to the individual in order to be most effective [24]. The international diabetes federation points out that *"Diabetes education needs to be learner-centred and thus be adaptable to suit individual needs"* [14].

Another key element to diabetes education is the clinician responsible for educating the child [24]. Education should be through someone who is experienced and expert in diabetes management [14]. Diabetes educators are very good at providing tailored education [7] which takes into account the personality, the social and the behavioural characteristics of the child [11]. However, diabetes educators have to be motivated to encourage better adherence to management [22].

Edutainment tools for type-1 diabetes

Edutainment (education + entertainment) systems are recognised as one of the favourable ways to provide hands-on and individualised education [2], allowing children to test their preconceptions without putting themselves into harm [4].

The main edutainment resources created for T1D children's education are video games. Starting from 1997, a series of educational video games for T1D education have been created [3, 4, 6, 8, 10, 21, 23]. Despite the successes or failures to prove educational effectiveness in their studies, most of these games, are targeting older children (9 and older), they require literacy skills and focus on the management aspect of the condition, rather than education about the basic concepts of their condition. Games are a good candidate for T1D education [18] but there must be a good balance between education and entertainment (for effective diabetes education) [2].

Tangibles for education

An interface modality that can combine interactivity and gamification¹ 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 [38]. TUIs do not require literacy skills (reading and writing) and thus are more accessible to preschool children, people with learning disabilities and novices [39]. Moreover, TUIs as learning tools can empower children to combine and recombine the known and familiar in unfamiliar ways, which can promote reflection, awareness and in turn reinforce learning [28]. TUIs can be used for illustrating domain specific concepts more explicitly [13] and allow more shy and restrained learners to contribute to the activity [13]. 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 [38]; have been shown to allow users to be more aware of the actions of others [34]; allow sharing

¹Gamification: "use of game design elements in non-game contexts" [12]

of control and promote parallel interaction [39]. As a result, they make a very good candidate for the specialised education of a younger age group with complex educational needs.

3 METHODOLOGY

The methodology consisted of 3 phases, each with multiple stages (Figure 1). The first phase was about understanding the current educational practices and the requirements of the T1D eco-system. In the second phase the tool was designed, rapidly prototyped and implemented. The last stage was about the evaluation of the tool through a designated educational session. For the whole project we partnered with the *Children's Diabetes Service of Greater Glasgow and Clyde* in Scotland.

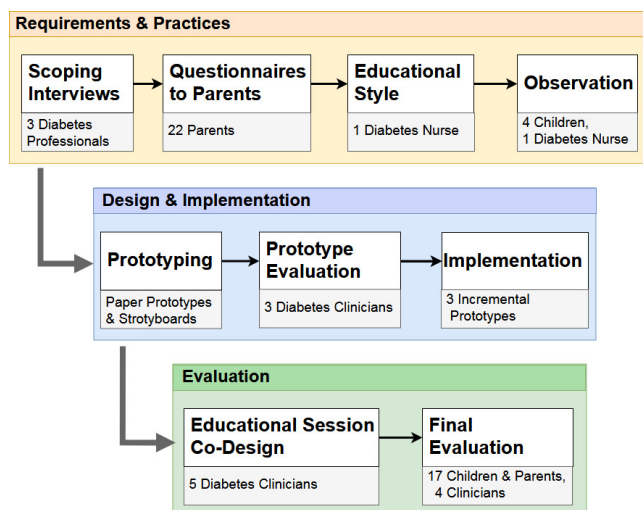


Figure 1: Research methodology.

4 REQUIREMENTS AND PRACTICES

In order to gather the requirements and understand current educational practices 4 qualitative enquiry stages were conducted. In the first stage, 3 key diabetes professionals (D1, N1, G1) were interviewed, in order to understand the specificities of the local T1D educational context. The interviews also aimed to frame the exact scope of the research by capturing information about the current policies, demographics, strategies and the feasibility of an educational tool. The profiles of the participants can be found in Table 1.

The second stage was aiming to capture parents' perspective about the challenges and importance of T1D education. A questionnaire was distributed through a social media local support group page. The survey had 25 questions in total, 8 of which were open-ended. The questions were about demographics, educational practices, perceived outcomes of current educational approaches, existing educational materials and challenges related to T1D education. In total 22 parents completed the questionnaire.

Table 1: Profiles of the clinicians and the government official who participated in the study.

ID	Role	Gender	Experience
D1	Consultant Paediatrician	Male	25 years
N1	Nurse Specialist	Female	8 years
G1	National T1D Co-ordinator	Male	-
T1	Clinical Specialist Diabetes Dietitian	Female	27 years
T2	Clinical Specialist Diabetes Dietitian	Female	8 years
D2	Paediatrician	Female	2 years
T3	Clinical Specialist Diabetes Dietitian	Female	6 years
T4	Clinical Specialist Diabetes Dietitian	Female	18 years

To understand the way education is currently delivered to children by the clinicians an unstructured interview was conducted, in the third stage, with N1.

In the fourth stage, an observation was conducted on the only existing educational session for children at the clinic.

All interviews were audio recorded, transcribed verbatim and analysed for emerging themes. The Framework Approach [33] for qualitative data analysis was used.

Current Educational Practices

Younger children are a neglected group when it comes to T1D education [G1, D1]; they do not receive formal education and there is a lack of age-appropriate materials [N1, G1, D1, Parents]. Most education comes though parents during the day-to-day management of the condition [D1, N1]. Parents are considered more important because they manage the condition [N1, D1]. Thus, education focuses primarily on the parents [N1]. Children are passive receivers of whatever management they get [D1, G1].

Not all families can support their children adequately [N1, G1] and most children who do not receive proper education eventually struggle with their condition during adolescence [N1, D1]. Not all families readily have access to educational materials and any educational materials owned by families are not interactive (DVDs, books, leaflets) [Parents].

All the education is delivered to parents the first months after the diagnosis. The education is supported by two booklets that the clinicians have been developing for 15 years. These booklets are distributed to parents and inform about management of T1D and nutrition. They include mainly textual information and graphs. These target the parents and they



Figure 2: Plastic food models used to illustrate food groups when educating about nutrition.

cannot be easily understood by children [N1]. More generally, it is not very easy for children to access diabetes related information [N1, Parents].

The only educational session that children can attend is called 'New Starts Group' (NSG) and is a few months after diagnosis. All the other education delivered to children is in a discussion-basis during clinical appointments [N1]. The clinicians assess the children's knowledge through questions and try to educate them by initiating discussions [N1].

Most of the parents (14 out of 22) and their children had attended NSG and found it useful. Nonetheless, their children found the sessions less engaging. 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]. An observation was planned and conducted in a NSG. Due to the long time span between two NSGs (4-6 months) and the variable attendance (some do not have young children) only one observation was conducted. Four children, all girls with ages 5, 5, 9 and 10 took part in the NSG. They were all been diagnosed between 1.5 and 3 months ago. The nurse who educated the children was again N1, as she is mainly responsible for running the NSG.

The children are educated by a nurse in a separate room from the parents. There is a set of predefined topics (e.g. carbohydrates, insulin, sick days) that nurses can discuss with the children, depending on what the children want to talk about. Then children are asked if they want to draw a poster, make up a play or tell a story about the topic they selected. Children almost always decide to draw a poster [N1].

The nurse try to educate children verbally by initiating discussions about diabetes. The main focus is to find out what is the children's understanding about diabetes. Because it is hard to keep children engaged for 1 hour the clinicians have also a set of plastic food models that they use in the session.

These models (Figure 2) are not used in any pretend play scenario. 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 dietician who joins the session when there are more than 4 children attending the session.

It was observed and confirmed by N1 that younger children seem to focus more on objects related to diabetes (e.g. insulin pens, glucose monitors) and are not able to synthesise depictions or stories about T1D concepts. Moreover, younger children are very quickly disengaged when there is nothing that they could contribute to or when there is nothing interesting to them. Finally, in a mixed group, the older children seemed to be dominating the discussions.

Requirements

Throughout the enquiry it was clear that, irrespective of what materials used currently for the children's education, the only way for the children to get feedback or information was through an adult. This fact might make children dependant to the adults and their capacity to transmit knowledge. Even though the clinicians constantly try to improve and are always receptive to feedback, more interactivity is still needed for children's education [N1].

The requirements about the T1D education can be summarised as following:

- Children need to know simple things about T1D [D1, N1, G1]. The following educational goals were proposed: *"what is insulin"*, *"nutritional content of foods"*, *"which foods are healthy"*, *"how exercise impacts T1D"* and *"blood glucose monitoring"* [N1, D1].
- Children should be educated with peers during educational sessions [D1, N1, G1].
- Children need take initiatives in diabetes management, without putting themselves into harm [N1].
- Children should be more active during education rather than just sitting and listening [N1].
- There is a need for an interactive learning tool, that should use symbolic language, be engaging and should align with the school curriculum [N1, D1, Parents].

Parents also provided their insights about things that can be changed in the current educational practice. 6 mentioned targeting younger ages; 4 wanted more interactivity and hands-on tasks; 3 commented on the lack of fun and engagement; 3 parents proposed more sessions; 2 parents mentioned their positive experiences with the clinical staff; and 1 parent wanted more T1D education at school.

The clinicians suggested that any evaluation of effectiveness should be conducted with and through the adults (parents or clinicians) because they can confidently explain children's reactions [D1, N1, G1]. Also, medical measurements are not appropriate as they are not influenced by children [D1].

5 DESIGN & IMPLEMENTATION

Design Decisions

Based on the outcomes of the previous phase's enquiry a set of design decisions were made. The fact that the educational approach of the clinic has been evolved throughout the years and has been constantly adapted based on experience and feedback [N1] signify 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, we decided not to perturb the existing practices but rather enhance them and design something that could be integrated into current work practices. Lack of interactivity and gamification was certainly a disadvantage and was constantly pointed by the different stakeholders.

- (1) **Age group:** The school curriculum groups children into 5 levels based on their age, each one with specific targets about health and nutrition. Hence, we decided to align with the school curriculum (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".
- (2) **In-situ 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; away from parents who might act paternalistic; learn with peers, promote collaboration and view of the other's perspective; make visits to clinic more enjoyable.
- (3) **Use of the plastic food:** The plastic food models were the only artefacts currently used that could support interactive scenarios. 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 to use the plastic food toys as input devices for an interactive tool.
- (4) **Feedback through an anthropomorphic character:** Chomutare et al. [9] found that children preferred anthropomorphic characters for T1D education, as an indication of their self as the protagonists. Therefore, we decided to provide the feedback through an anthropomorphic character with whom the children could potentially relate to.
- (5) **Enjoyment vs Education:** We tried to keep a balance between enjoyment and education. Thus we conceptualised an educational tool with some gamification elements but no rewards, levels, points etc. This way we wanted to ensure that children would be more focused on the clinician's feedback rather than any reward system.

Paper Prototypes

Subsequently, according to the design decisions and the proposed educational scenarios a set of paper prototypes were rapidly produced (Figure 3). The prototypes were:

A tool outline: A paper sheet representing the tool; used to provide an understanding of the tool's components, the inputs and the outputs.

Educational Scenario Designs: 2D graphics and UI elements of the scenarios; used to illustrate the way the output of the system is going to be delivered for each educational scenario.

Storyboards: Drawings about the process/story for each scenario; used to explain the way the interaction and the education will happen using small story plots.

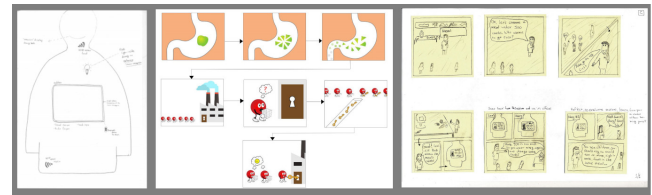


Figure 3: Paper Prototypes. Left: Tool Outline. Middle: 2D graphics of tool's output. Right: Storyboards of educational scenarios.

The prototypes were evaluated in a focus group 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 1.

The evaluation was through pluralistic walk-troughs [27] of the scenarios with the clinicians. 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 value of each scenario was conducted.

Throughout the evaluation the *Keep-Lose-Change* [16] annotation technique was used, where the clinicians were annotating the prototypes about features or elements that they liked (*keep*), they think they should be altered (*change*) or they do not think appropriate (*lose*), respectively.

The changes suggested were mostly about graphical representations (e.g. icons for carbohydrates, no sad faces but worried) and language used (e.g. use 'unhealthy' instead of 'bad'). The clinicians suggested a more robust setup than the initial proposed (a mannequin with a display in the abdominal area – Figure 3), maybe through a projection of the character to a screen or the wall. They also wanted the tool to be portable.

All three agreed that the prototype tool was aligned with the existing educational goals and that it was adding the level of interactivity needed. Through the storyboards they recognised some flexibility in the scenarios (about changing the flow and tailoring the education to the participants). Finally, they all agreed that the scenarios were too many and suggested to reduce to the 3 most important "what is insulin", "nutritional content of foods", "which foods are healthy".

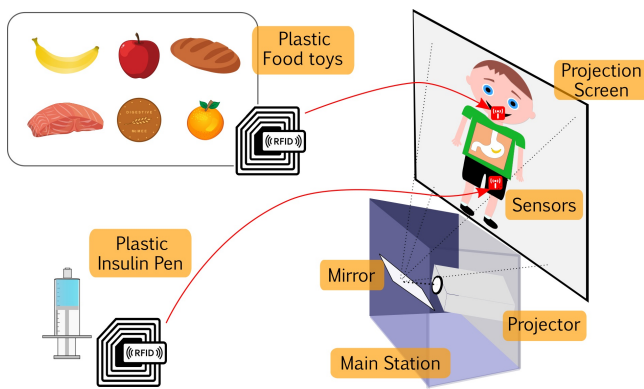


Figure 4: The educational tool comprises of a projection that interacts through RFID sensors with the plastic food toys and the toy insulin pen.

Implementation

The tool went through 3 development phases, each one with increased fidelity. Each prototype was formatively evaluated by the clinicians (N1 and T1) to see if it is aligned with their requirements. The final tool, shown in Figure 5, comprises three components; the main station/kiosk, the plastic food toys and an insulin pen.

In total 85 plastic food toys were used. Most of these toys were standard plastic food toys available in toy stores; 21 toys were crafted by the researcher in order to look like foods one can get in the local market. All the plastic food toys were embedded with Radio-frequency identification (RFID) tags, that could be read by approaching them to the main station's sensors (see Figure 4). The insulin pen is a standard insulin pen, without a needle, with an embedded RFID tag.

The main station is made by laser cut plywood. The lower part of the main station is a box that hosts a projector, a mirror and 3 Arduino units (responsible for controlling the sensors). The box is equipped with wheels so it can be carried around easily. The projector projects through the mirror to the screen. On the back of the screen 2 RFID sensors are attached. The RFID sensors are aligned with the mouth (for feeding) and the thigh (for insulin) of the virtual character. The graphical environment and the logic were developed in Unity3D.

6 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 scenarios designed in the previous stages. This session could then frame and contextualise the evaluation. Four co-design sessions were conducted with a total of 5 clinicians. Their profiles can be found on Table 1.



Figure 5: The educational tool comprises of a projection that interacts through RFID sensors with the plastic food toys and the toy insulin pen.

The first co-design session was conducted with N1. The purpose was to shape the session and decide upon its procedure. It was decided that the session should not exceed 1 hour and has to be run by either a nurse or a dietician or both, depending on the availability. Finally, the number of children per session was decided to be flexible, to simulate participation to the NSG where attendance varies.

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. The foods were chosen in groups of a healthy and a less healthy options – for the third scenario.

The third co-design session was conducted with T2 and T3. In this session the food list was finalising. Moreover, the order of the educational scenarios was decided. It was also 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 final co-design session was conducted with T2 in order to finalise the procedure.

7 FINAL EVALUATION

The final evaluation was designed to answer the following research questions:

- **RQ1:** Is the tool a viable and effective solution for supporting the current educational practice?
- **RQ2:** Is the tool an age-appropriate, engaging and enjoyable means of education?
- **RQ3:** Did the children put in practice things they learned?

For RQ1 we tried to assess how helpful the tool was in educating children; if can facilitate the clinician to individualise educational message [14]; if it fits the current educational

practices. It was answered qualitatively through interviews with the clinicians.

For RQ2 we tried to capture the tool's appropriateness for the age group [14]; how engaging it was; and children's reactions to it [19, 31]. To measure reactions, we used standardised and suitable techniques for this age group. Namely, we measured emotions during the session through the emotional response tool [1] and enjoyment using the smilometer [30]. Appropriateness for the age group was assessed through parents and clinicians.

For RQ3 we chose to assess educational impact through parents who can safely assess their children's knowledge and clinicians, as also proposed by D1 and N1. We tried to elicit cues observed by the clinicians that show a learning effect, and from the parents elicit any observed changes in children's awareness and/or initiatives in the management process.

Procedure

The evaluation ran for 5 weeks on days where children between 5 and 9 were having clinical appointments with the doctor. All parents were informed prior to the study by the clinicians through emails or phone calls. During their arrival, those who agreed to participate and their children had to fill consent forms. Children were taken to another room and were educated by the clinician through the tool. Parents had the chance to watch what was happening in the room with the children, through a monitor. This way they could see what the tool is doing and observe how their children were being educated. At the end of the session, children were asked to complete an age-appropriate questionnaire asking the following: 1) Their emotional state during the session, 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 describes their experience with the tool. At least one week after the session the parents who agreed were interviewed about the tool and their child's reactions to it. Finally, at the end of the study, the clinicians were interviewed about the appropriateness, feasibility and effectiveness of the tool.

Participants

In total 17 children (7 boys and 10 girls; mean age=7 and deviation = 1.3; mean years having diabetes = 2.3) and 4 clinicians (N1, T2, T3, T4) participated in the evaluation. The children participants translate to the 11% of the total number of children (154) between 5 and 9 years with T1D in the area covered by the clinic. All of them were new to the study and were not involved in previous stages nor had they seen the tool before.

4 children (C1 to C4), N1 and T2 participated in the first session; 1 child (C5) and T2 in the second; 2 children (C6 and C7) and T2 in the third; 3 children (C8 to C10) and T4 in the

fourth; 7 (C11 to C17) 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 (C14) participated in the session but had to leave before the end of the session and thus did not complete the questionnaire. In total 5 parents (C5's, C6's, C7's, C8's and C12's) agreed to participate in the interviews after the evaluation. Three of the four clinicians were interviewed (N1, T2, T3); T4 was not available the period after the evaluation.

Data gathering and analysis

The session was video recorded by two video cameras for referencing and analysis of the children's actions and responses. The interviews with the parents and the clinicians were semi-structured interviews. They were audio recorded and analysed using the Framework Approach [33] for qualitative data. From the interviews the codes that emerged were grouped and cross-analysed by two researchers. The results from the smilometers were analysed for statistical significance.

Results

Parents: All parents agreed that children found the tool very engaging and enjoyed both the educational session and the interaction with the tool. –*"They were just so engaged by it, they weren't bored at all through the whole. (...) You weren't trying to force information on them, they were actually eager to find out"* [P7]. –*"Oh, he loved it! I thought that him and the other wee boy weren't gonna come out. They were having a great time!"* [P6].

In terms of effectiveness, three parents (P5, P7, P12) observed an increase in their children's knowledge and awareness and all parents stated that their child had learned something (not all the same things though). –*"She now knows more about it (T1D). She can explain it to her friends"* [P5]. –*"He took away increased knowledge clearly. It sparked his interest"* [P7]. Also, two parents (P7, P12) reported that their children had put into practice the things that they've learned during the session. –*"He was at a party (...) and he'd been given a bag of sweets. He said that he understood that it was ok to have them sometimes and he would eat a wee bit there, and a wee bit tomorrow. (...) I was quite impressed. It obviously had an impact and stuck in his mind"* [P12]. –*"He started discussing the difference between soy milk and real milk (...) Maybe that's better to have or he could have that (soy) all the time"* [P7].

Two parents (P6, P8) stated that they as well have learned something new by observing the feedback the tool was giving. Four parents (P6, P7, P8, P12) commented about the social aspect of the session and found useful that their child was being educated with peers. –*"I think it was the interaction with the other children. I think that's what made a difference for them."* [P8]. Also they found the session helpful for them to come in contact with other parents. –*"It gives you that opportunity,*

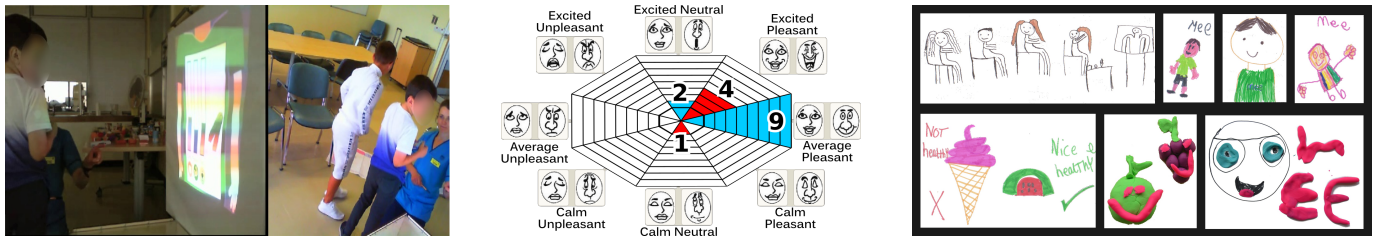


Figure 6: Left: Snapshot of the session with C6 and C7. Middle: The emotions of the children while being educated with the tool. Right: Drawings and crafts of children

to have those little discussion (with other parents)” [P8]. P5 thought as positive that their child was being educated alone and believed that for some children a one to one session might work better. – “For some children yes (being educated alone). For C5 I think it worked better because she is quite shy” [P5].

The tool's physical aspect was considered as one of its strong points by four parents (P5, P6, P7, P12). Also four parents found the graphical output useful (P5, P7, P8, P12). – *“They’ve particularly enjoyed the interactivity aspect of it; taking foods to the screen and pressing them against it (...) the physical activity so I think he appreciated it”* [P12]. – *“The visual aspect of it; he spoke about seeing the body inside. There was a bit where it was talking about the insulin being like a key. He’s repeated that yesterday (...) and he hadn’t mentioned that part since the study (a week) - obviously it stays in his brain”* [P7].

The tool's gamification elements were pointed out by three parents who saw their children wanting to compete (P6, P8) and answer correctly (P5, P6). – “*There is a bit of a competitive element as well (...) they like to compete with each other to see who's got the greater level of knowledge*” [P8]. – “*He enjoyed it because he was like showing off what he knows about his food*” [P6].

All parents believed that the tool can be used in regular practice, and they thought that it was more appropriate for children close to diagnosis. Moreover, they suggested that the tool can also be used in multiple stages of the diabetes journey and that it should be used to educate also siblings and even adults. Lastly, two parents stated that the tool could be used at schools. – *“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: 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].

Clinicians: All clinicians agreed that the tool was engaging and that children enjoyed the session. T2, who participated in 3 sessions, mentioned 7 times that she was surprised by how much the children enjoyed the session and how engaging the tool was. – “*They loved it, they thought it was great*” [T3]. – “*It*

actually surprised me how much they enjoyed it(...) surprised because I felt it was more engaging than I expected it to be" [T2].

All three considered the tool to be helpful and useful in educating young children. They thought that it was appropriate for this age group and that it can help the clinicians tailor the educational message to each child or each group. –*“It’s been very effective, I think it’s useful for teaching children (...) can be used (...) to illustrate very simple messages (...) or to help illustrate more complex information”* [T2]. –*“I think you would be able to individualise, it would allow you to see how somebody is in a group and where their knowledge lacks”* [T3]. All three clinicians also pointed out that the tool can be used to assess the children’s knowledge, by letting them test their preconceptions and initiate discussions about misconceptions. –*“There were times when they got the answer maybe different from what the tool told them and that was a chance for us to initiate discussions”* [T2]. –*“I thought it was really helpful (...) you could assess their knowledge”* [N1].

When it comes to learning N1, T2 and T3 thought that all children learned something – mostly about healthy eating; T3 reinforced this belief because all the children in her session included healthy foods in their drawings and crafts. – “*They all chose to make healthy foods (...) I think that’s what it helps in knowing that they’ve learned something*” [T3].

All three clinicians commented positively about the interactive elements of the tool. T2 and T3 considered that the tangible interaction and the visual feedback made education more enjoyable; N1 considered the tangible nature of the food toys and the fact that they had to get up and move around the most engaging elements. N1 though that social aspect of the session was an important aspect that had an impact to the children. – “*When you have more than one then there’s somebody else you can ask questions to. (...) They enjoyed it. Probably they like having a group*” [N1].

In relation to adoption, all of them thought that the tool can be implemented into the clinic's educational practice. N1 thought that the presence of the tool to the clinic had already motivated the clinicians. –*"Something like that would be very beneficial (...) It would be excellent to have something that we can use and it's there available any time we need it"* [T2]. –*"I think*

it would be something that we'd pick up and use definitely" [T3]. Lastly, all three thought that it would be more appropriate for children patients close to their diagnosis. N1 and T3 also thought that it could be used at different stages as well for refreshing knowledge or as a free play tool at the waiting room.

Children: Most of the children (13) felt a pleasant emotion and the rest (3) felt a neutral emotion during the session. The results are shown on Figure 6:Middle.

The results from the smilometers (Figure 7) shown a significant increase ($p=0.022$ – Wilcoxon Signed-Rank Test) in the experience during the evaluation compared to previous visits. For one child (C13) it was his first time to clinic so he only completed the smilometer about the evaluation day; the rest had their previous visits 2 to 4 months ago. Only one child (C4) rated the evaluation session less than the regular visits to the clinic. When this child was asked by the clinician if she could explain why, she did not reply. Unfortunately, her parent did not reply for the interview. Interestingly enough, C7 could not find a face from the smilometer to represent his previous visits to the clinic and instead, draw a sad face with 'shy' as caption and placed in between 2 (Not very good) and 3 (Good).

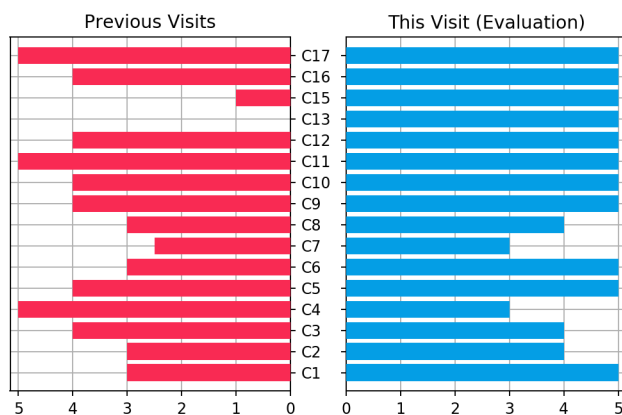


Figure 7: Results from the Smilometer (1=Awful ... 5=Brilliant). Comparing previous visits to the evaluation

The drawings and crafts of the children about their experience (Figure 6:Right) were: 8 children included healthy foods in their drawings or crafts, 4 children drew "Mee" in their final drawings, 4 children drew themselves, 1 child drew the session and 2 children made random things (flower and smiley face).

All these results are in alignment with parents' and clinicians' answers about the acceptance and the enjoyment. The children were very engaged and seemed to enjoy it. An example is C6 who during the session verbally stated "*This is surprisingly fun*". Another example is the fact that C11 had a Hypoglycaemia (Hypo)² during the session. Nonetheless,

²Low blood sugar levels. Results in dizziness, confusion, blurred vision. If not treated soon can lead to seizures or loss of consciousness.

according to T3, he did not report it because he wanted to stay in the session, indicating how engaged he was. His mother recognised the symptoms while observing him from the other room and came to treat the Hypo. After his Hypo was treated C11 came back to the room to continue with the session. By the video footage of the sessions, it was observed that children were constantly performing non-verbal cues (smiles, dance moves, gestures) which signified a state of enjoyment. Moreover, the children that were initially showing anxiousness in the way they were sitting or acting, soon enough felt relaxed and opened up (also mentioned by P7 for her own child).

8 LIMITATIONS

The main limitation of our study is that it was only evaluated in one setting. What works in one setting does not mean it will work in others as well [19]. Certainly more settings have to be used for evaluation and even in different countries to see if the tool is effective. Another related aspect is that it was evaluated with clinicians who helped in its design. This has a positive and a potentially negative side. The positive side is that clinicians are embedded in the project and thus can understand the goals and the challenges. On the other hand, they might be biased when evaluating the tool and lack objectivity.

Another limitation in relation to the evaluation is an ordering effect about the 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 of the previous visits as they had many. Moreover, the last two sessions were conducted when schools were open. Children (C8 to C17) might responded positively in the smilometer just because they were drawn away from school for a day [38].

On a final note, there was not much child input during the design phase. It proved very challenging to recruit families also pointed by the literature [36]. Also, the NHS ethics process was very time consuming (3 months for the NSG observations and 3 months for the final evaluation) for this project's time frame. However, we engaged as much as possible with people who are responsible for their education in order to design something that fitted the children's needs.

9 DISCUSSION

In relation to RQ1, it became apparent from the interviews that clinicians considered the tool to be a very helpful and capable of supporting different educational needs. All clinicians also, found the tool good for assessing children's knowledge. They were sure about its potential value if implemented to the standard educational practice.

For RQ2 the results from the children's questionnaires made clear that the children enjoyed the education. Also, both parents and clinicians were very confident about the tool's appropriateness for this age group and found it very engaging.

With regards to *RQ3* the most solid outcome was the fact that two children (C7 and C12), out of the 5 whose parents were interviewed, actually put into practice the things they learned. These children had similar profiles (both boys, diagnosed at 2 years old and had been living with diabetes since).

The decision of how to measure educational effectiveness of such a complex educational system (tool+session) was very difficult. We chose not to measure educational effectiveness directly for four reasons. The first was the specificities of the context, namely the different clinicians (nurses, dieticians, support workers), the limited participation to research and the diverse patient profiles. In order 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) [20]. Controlling all the variables may have excluded children from the session, contrary to the clinicians' requirement to simulate participation to the NSG. The second reason was that the session was designed around the tool and was not standardised or tested. It would not have been clear what the influences of the session to the results were. The third reason was to avoid stressing children and making them feel questioned or assessed for their knowledge. The final reason was that the clinicians considered more appropriate the assessment of knowledge through the parents.

Hence, we enquired about factors that influence the effectiveness of a learning tool and are closely related to the adoption, specifically: from the children – enjoyment and engagement [15, 19, 31]; from the clinicians – the ability of the tool to enable them individualise the education [24]; and from the parents – the things that the children actually managed to put into practice after their education with the tool.

All these factors were satisfied, showing a very promising age-appropriate medium for children's T1D education. Moreover, both parents and clinicians found value in a potential adoption of the tool in the educational practice and thought that it would easily be adopted, facts that again point towards effectiveness and fulfil our intention for a viable solution.

Interactivity and fun are key elements of effective diabetes education [2, 20, 22] and were missing from the current educational approach. The plastic food toys were identified by clinicians as an age-appropriate medium but were used without interactivity or gamification. This fact prevented children from feeling included in their care and be engaged during any education in the clinic (parents, clinicians and literature [2]).

During the design process, the tangibles were conceptualised as the ideal vehicle for an interactive gamified education, building on the current approach. During the evaluation, the interaction through the tangibles 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. This approach enabled children to participate more actively in the educational

process by exploring their condition rather than reflecting on it (see 'current educational practices'). This exploration seemed to create a meaningful and enjoyable experience, which in turn helped them internalise some key messages and put them into practice.

Interactivity through technology could reduce the high number of resources needed for the education of children with T1D [11]. 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. Parents and clinicians also found the tool flexible in educating different audiences (adults, siblings, older children) and to be used in different situations (one-to-one, free play in waiting room, schools). Hence, there is potential for the tool to be used in other contexts, for example in schools where students with T1D will be educating their peers. This way they can let other children know why they might be acting differently, potentially destigmatise [5] them and also help them be more extrovert by discussing about their condition.

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. The aforementioned fact should be considered by other researchers who want to work with young children with similar conditions.

A challenge that our team faced was the very cumbersome and non-flexible national health system's (NHS, UK) ethics approval process. The ethics approval process is built around quantitative studies that assess clinical outcomes like randomised controlled trials. Following this process for quantitative studies adds a burden to the researchers who have to complete irrelevant forms and questions. These processes should be updated and adapted by the health systems to include qualitative, smaller scale and exploratory studies.

10 CONCLUSION

This research aimed to provide a viable solution to the lack of age-appropriate educational materials for children with T1D. We employed an exploratory co-design approach in order to capture the requirements of the stakeholders and provide a solution that matches the clinic's approach to education.

The final tool can be used by clinicians to educate children under 9 with T1D inside the clinical setting. It was found to be useful and appropriate in supporting the education by the clinicians. The children enjoyed being educated through it and found it very engaging. Its perceived educational effectiveness was highlighted by parents and clinicians and examples of actual educational impact were reported by parents.

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