# Bodymapping: A Way To Engage Young People With Long -Term Conditions

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## Abstract
Growing up is a sensitive period for any young person and especially for those with long-term health conditions. Research shows different levels of young peoples participation. This paper focuses on a Bodymapping activity conducted as a part of a 10 month study developing services and technologies for better self-management young people with type 1 diabetes. With this activity they were able to engage with their condition, reflect on it and discuss it more openly.

## Author Keywords
Young people, Engagement, Probes, Diabetes

## ACM Classification Keywords
D.2.2 Design Tools and Techniques: Object-oriented design methods

## 1. Introduction
Adolescence is a sensitive period in a young person's life, as they have to deal with the challenges of exams, physical appearance, growing up and boyfriend-girlfriend relationships. Moreover, young people with long-term conditions such as Type 1 Diabetes Mellitus

(henceforth diabetes[1]) must also balance their physical activity, insulin and blood glucose levels (Glasemann and Kanstrup 2008). Young persons may feel frustrated, ashamed, afraid, or angry (ibid.) and may not want to talk about their condition to other people.

## 2. Literature review

More studies have been conducted concerning designing with children (Druin, 2002) than with teenagers; even fewer were identified which were conducted with young people with long-term conditions. The literature reveals different levels of participation in the design process: participating primarily as informants through surveys, questionnaires, interviews, and evaluating prototypes (Edwards et.al., 2011, Katterfeldt et.al., 2012); being engaged in making as a source of creative inspiration for designers who then develop their ideas (Katterfeldt et.al., 2012, Fitton, et.al. 2012, Service Innovation Corner, 2012); or being encouraged to design directly by proposing design concepts in workshops and prototyping (Glasemann and Kanstrup, 2008). However, only a smaller number of studies from the third group, designing digital products or services, was recognized. Katterfeldt et.al., (2012) designed a learning platform using workshops, role playing and paper prototyping. Iversen and Smith (2012) in designing an interactive museum exhibition, employed observations, interviews, informal conversations and collaborative mock-up prototyping.

[1] The term 'diabetes' is used to refer specifically to Type 1 Diabetes Mellitus which is a lifelong condition requiring indefinite treatment, usually by regular insulin injections, that is typically diagnosed in childhood or adolescence.

## 3. Case study

In this case study eight creative workshops were run from July 2011 to May 2012, following a process of: understanding and sharing experiences; exploring blue sky ideas; selecting and developing blue sky concepts; developing practical proposals; prototyping and evaluating. Each design stage involved one or two workshops depending on the design progress. A Diabetes Specialist Nurse, a project manager, and three designers/facilitators from User-centred Healthcare Design (UCHD) research group took part with occasional input from external specialists. The study participants comprised of young people with diabetes, their siblings, and parents who were members of two local support groups. 10 young people with diabetes (2 boys, 8 girls) were involved, predominantly in their mid-teens (from 12 to 17 years) and one 10-year-old boy also participated. Workshops were held at the conference facilities of a nearby shopping centre every 2 or 3 weeks as evening sessions lasting up to 2 hours.

### *3.1 Bodymapping*

At workshops, which supported the design process, various creative approaches were used to engage participants in the design process (Sustar, et. al., 2013). However, the Bodymapping method (Frankel, 2011) was only used at the second workshop titled *'What's it like?'*, which aimed to understand and share participants' experiences with diabetes. The Getting Sorted[2], who facilitated the parents' group, introduced the Bodymapping method. Participants were divided in:

[2] The Getting Sorted Enterprise Unit specialises in participatory research with children and young people with type 1 diabetes, their families and healthcare professionals.

Bodymapping poster with post-it-notes.

2 young peoples' groups and 1 parents' group. Facilitators supported all three groups; in addition to 1 young person's group where a young adult (studying nursing, age 21) with diabetes was also engaged. Participants were asked *"What is it like to be a young person with diabetes?".* Using a Bodymapping approach, facilitators drew an outline around a volunteer's body on a large sheet of paper. The young adult with diabetes asked specific questions related to the condition to prompt responses, e.g. *"How do you wear a pump in jeans?"*. Participants wrote their thoughts on post-it-notes and stuck them at the part of the body where they thought they belonged; for example, *"Finger-pricking hurts"* was placed where fingers were drawn. After 20 minutes working in groups, each group reported on their findings (Figure 1).

## 4. Discussion

Throughout the Bodymapping design activity young people were able to reflect on their condition. A 17-year-old boy commented, "*Bodymapping was ok. It opened my eyes that I have to improve it* [diabetes]*, because I was more held back in the past."* Post-it-notes and outlined body shapes distanced young people from talking about *their* condition. Additionally, when young people discussed their experiences with diabetes they made bonds with one other. A 13 year old girl said that she initially did not really like Bodymapping, as she did not like to talk about her condition, but, when she heard experiences from other young people, she felt quite comfortable and able to contribute her thoughts. The young adult acted as an effective role model.

**Figure 1:** Group discussion after the Bodymapping activity.

When groups presented their 'body maps' back to the larger group, several parents expressed they had learned what the children were really thinking about their condition and at times this was quite an emotional experience. One parent reflected on the Bodymapping session with the following words: *Yeah that was quite good, it showed different sorts of fears and apprehensions of different people* […] *and it's surprising how it affects different people in different ways and what their thoughts and ideas were."*

## 5. Findings

Using Bodymapping design activity reveals outlines of body shapes as highly effective mediators, which allowed young people to engage with their diabetes, gave them opportunity to talk more openly about it (some for the first time), and reflect on their self-management. Additionally, parents were able to hear what their children really thought about their condition.

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## 6. Author

Helena Sustar works as design-research associate at the UCHD in Healthcare Service Design. She has a background in product design and completed her BA and MA at the Academy of Fine Arts and Design in Ljubljana (Slovenia). At the beginning of her career she worked as an interior designer, journalist, editor and critic in the area of design and contemporary architecture. She was awarded a PhD at the Centre for HCI Design, City University London. The main focus was on adopting appropriate methods for designers and older people, and measuring their creative performance and final output. Helena believes in designing with people for people and her research interests have always related to different social groups; children, older people and people with disabilities.

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