

# Reconsidering what you think you know: exploring the lifeworld of a young person with type 1 diabetes

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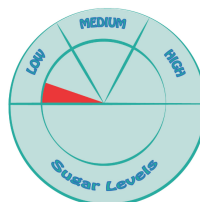
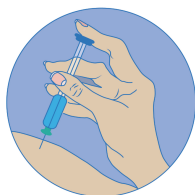
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## Introduction

Published research considering the lifestyle and views of young people aged between 18 and 21 with type 1 diabetes and their use of web and mobile technology to support their condition is sparse. This research aimed to develop a greater insight in these areas.

## Methods

Recruitment conducted at a district hospital in the South West (and a local university) with data collected by semi-structured, in-depth qualitative interviews ( $n=9$ ). Interviews were transcribed, loaded onto NVivo and analysed to gain a deep understanding of the perspective of a young person with type 1 diabetes and to construct a picture of their lifeworld.



## Results

Data analysis highlighted a number of themes and uncovered several interesting areas not yet noted in previous research with this age group, which benefit in being shared at this conference.

### Living with Diabetes

Concerning their type 1 diabetes, there was a strong feeling expressed that although the condition might be the same, the experience of living with it was completely different for each person.

**Isolation / Loneliness** - coping with type 1 diabetes can sometimes be a lonely experience for a young person - something which they felt they had to deal with on their own.

**Negativity** - these feelings sometimes being mixed in with adolescent angst, making discussing important issues concerning control and measurement exceptionally difficult with parents and clinicians.

**Fear** - (of poor control, needles, diagnosis, side-effects, dietary concerns) was an emotion continually expressed and experienced.

**Discomfort** - during interviews, there were a number of remarks referring to discomfort and pain as a part of QOL (like blood testing, injecting, post-injection).

*Reflecting on the fear, negativity, discomfort and isolation and loneliness that young people with type 1 diabetes sometimes feel now, will feel in the future and have felt before should be an important part of helping to influence future policy concerning improving their QOL via treatment and support and also play a part in helping to decide how the role of technology might help to improve these areas.*

### Feelings about Health Services

There was awareness in interviews that young people's point of view wasn't being taken into account in all aspects of their care - a lack of listening to the patient's point of view.

There was also a feeling that they were never asked for their opinion - rather discussion was mostly focused on telling them specific information.

*Reflecting on the many instances of poor service from NHS Direct and highlighting the rudeness and arrogance on display in some cases has a vital role to play in affecting future policy. This needs to be addressed immediately as it has obviously had a damaging impact on the relationship of the interviewees with this aspect of the health service.*

### Mobile Phones and Use of Apps

The age when most interviewees obtained their first mobile phone was quite young (as young as 9 or 10).

From a young age, this generation viewed their phone as a constant companion, accompanying them at play, through school, university and then work.

Newer smartphones have gradually started to replace other electronic media that interviewees owned like MP3 players, laptops, cameras and paper based systems like diaries.

In some cases, the closeness of technology to the young person had already led to it being used innovatively in relation to their condition such as using alarm functionality as reminders to inject.

Apps were quite a new development and for some they hadn't really made much use of them. One of the reasons for this was financial and because they were frightened about the implications of creating an account, or because there was a reluctance to pay for an Internet connection as a part of a mobile contract.

If cost wasn't an issue, some would be more likely to engage with using diabetes specific app related technology.

The main benefit mentioned by interviewees of using diabetes apps tended to focus on the ability for them to replace paper based information - like logbooks and books - which they had previously had to carry around with them.

There was a feeling that current apps, although helpful, weren't actually worth using. This could be due to the cost, the flexibility and usefulness of the apps themselves or the lack of a cohesive guiding framework for using them.

*Future developments concerning the use of mobile phones must reflect and focus on how this generation has become used to making use of them and where it might best fit - whilst acknowledging that this won't naturally work in every set of circumstances.*

### Use of Social Media

The general theory with social media is that it encourages people to use it. So, it's in stark contrast to note that there are reasons why this age group won't always feel inclined to use it as a mechanism for obtaining information and support for their LTC.

The belief that users of this age group were happy to share every aspect of their personal life on Facebook was contradicted. Some interviewees only wanted to use forums for talking to friends about their life outside of type 1 diabetes, rather than using it for diabetes related searches and communal group discussions.

It seemed as if the amount of discussion in the media about certain social media like Twitter was in some cases harming its ability to attract this age group toward using it.

Not all interviewees were desperate to engage with new social media tools if they didn't appeal to them.

### How Others Viewed Diabetes

Interviewees discussed instances in their life where they had come across older people who either had no idea about the differences between type 1 and type 2 diabetes - such as teachers; no awareness of possible complications which might affect individuals who had type 1 diabetes; and in some cases this lack of knowledge could have proved fatal or caused the wasting of ambulance/paramedic time as these circumstances could have been improved if the requisite knowledge was available at the time.

*It is necessary for future policy to include building a much greater awareness of the difference between type 1 and type 2 diabetes and education and training on the problems which may occur if someone has these conditions to certain groups - like school staff.*



### Picture Represented by Others

The way in which some groups expressed their opinions about diabetes was deemed to be overly positive by interviewees which had the effect of turning them away.

There seemed to be a perception with some organisations (including Diabetes UK) that these feelings weren't being properly expressed and it was almost taboo to be able to express negative opinions and discuss why their control and measurement wasn't as good as it could be.

*Policy concerns should focus attention on making the point of explaining that it is ok to be able to stress a negative view of having type 1 diabetes if that is what people want to do without fear of reprisal for doing so (or being made to feel uncomfortable about doing it).*

Type 1 diabetes friend:  
alcohol guide



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