

# Perceptions of the clinical usefulness of the Adolescent Diabetes Needs Assessment Tool

Helen Cooper, Joy Spencer, Gillian Lancaster, Mark Johnson and Rebekah Lwin

**The UK has one of the poorest levels of diabetes control in young people so helping them to learn how to effectively manage their condition is a matter of high priority. Guidelines for improving diabetes control and long-term health in young people advocate the tailoring of education. The online Adolescent Diabetes Needs Assessment Tool (ADNAT) was developed to meet this standard. This article assesses the perceptions of the use of ADNAT in clinical practice by young people, their healthcare professionals, and their parents or guardians. The authors explore the views on ADNAT's potential impact on diabetes care, ways of promoting and maintaining its use, and potential future developments.**

The Adolescent Diabetes Needs Assessment Tool (ADNAT) is aimed at improving the long-term health of young people living with type 1 diabetes. This is particularly important given the UK's 2009–2010 audit results, which reported that <15% are achieving the recommended blood glucose targets and >30% are at a high risk of developing future complications (NHS Information Centre for Health and Social Care, 2011). The Government's response has been to introduce a best practice tariff award, which specifies tailored education as a mandatory care standard, prioritising the need for interventions that can provide diabetes education and assessment of its outcomes (Department of Health, 2011). Such a standard fits with ADNAT, which integrates education and assessment through reflective questioning on diabetes self-management (Cooper et al, 2009; Cooper, 2010; Kennedy, 2010; Cooper et al, 2012). It was developed over a 3-year period following a six-stage approach, including item selection, item review, pre-testing, piloting and on-line

transfer. Statistical tests assessed the reliability of ADNAT using item–total correlations, inter–item consistency and test–retest reliability. The validity of ADNAT was tested using HbA<sub>1c</sub> levels and the self-management of type 1 diabetes in adolescence (SMOD-A) questionnaire. ADNAT consists of 117 questions divided between six inter-connecting domains, which are regarded as priority areas for educational purposes: “all about me” (demographic characteristics), physical activity, eating, medication, blood glucose monitoring and living with diabetes. Based on the underpinning theory (experiential learning), the questions in each domain aim to prompt critical self-awareness in recognition of learning being a continuous adaptive process triggered by personal learning experiences that requires young people to make connections so they can transfer their learning to other contexts (Cooper and Geyer 2007; Cooper and Geyer, 2008; Yardley et al, 2012). Twenty of the questions were chosen to represent each of the six educational areas, providing an overall self-care score, and 16 of the questions were

**Citation:** Cooper H, Spencer J, Lancaster G et al (2012) Perceptions of the clinical usefulness of the Adolescent Diabetes Needs Assessment Tool. *Diabetes Care for Children & Young People* 1: XXX

## Article points

1. The Adolescent Diabetes Needs Assessment Tool (ADNAT) is aimed at improving diabetes control in young people with type 1 diabetes.
2. The purpose of this study was to explore the perceptions of the use of ADNAT in clinical practice.
3. ADNAT was viewed as a communication tool that targets clinical conversation and promotes learning through reflection.

## Key words

- Experiential learning theory
- Education
- Needs assessment
- Type 1 diabetes

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## Page points

1. Three main themes emerged from the analysis of the Adolescent Diabetes Needs Assessment Tool (ADNAT): the benefits of ADNAT; the barriers to implementation; and the development of ADNAT.
2. ADNAT was identified by the participants of the study as a useful communication tool, as its format is based on the lived experiences of young people with diabetes and their healthcare professionals.
3. Young people with diabetes referred to ADNAT as providing a “vehicle” for driving the conversation with adults.

devised to provide a psychosocial “traffic light” health evaluation. Face and content validity of the self-care scoring items were all positively evaluated in terms of appropriateness and readability, and tests for validity found statistically significant correlations with SMOD–A ( $r=-0.41$ ,  $P<0.001$ ). There was also a weak correlation with HbA<sub>1c</sub> levels ( $r=0.14$ ,  $P=0.056$ ), but this compared favourably with SMOD–A ( $r=-0.06$ ,  $P=0.52$ ). The tool can be accessed via a PC or mobile device (online and offline), so that it can be used in a clinic or at home prior to a clinic visit. It provides “traffic light” feedback to young people and delivers data downloads for practitioners through the NHS email system. This article describes the findings of four focus-group interviews, which aimed to test respondent validity by exploring its potential utility for young people with diabetes, their parents or guardians, and their healthcare professionals.

## Methods

A semi-structured topic guide was designed and informed by the reach, efficacy, adoption, implementation and maintenance (RE-AIM) framework, which is a translational research tool used to enhance efforts to guide the adoption of new interventions in clinical practice (Glasgow et al, 1999). Two members of the research team conducted four interviews: one with young people at a university ( $n=5$ ); one with parents ( $n=7$ ); one with health professionals ( $n=8$ ); and one with young people ( $n=4$ ) at a hospital. In recognition of the different age groups and recommendations for good research practice (Gibson, 2007), the adults were sent instructions and an interview schedule prior to the meetings, whilst the young people were sent brief instructions only and then provided with seven vignettes at the beginning of the interviews. The vignettes were based on case histories taken from a previous research study. They included new diagnosis, transition, poor and good blood glucose control, weight gain, leaving home, and drinking alcohol (Spencer et al, 2012). The vignettes were used to provide a less threatening way of exploring the views of young people, allowing them to describe ADNAT’s potential in relation to defined situations in their own terms. The interviews, which lasted 90–120

minutes, were audio-recorded with participant consent and transcribed verbatim. Ethical approval was granted by the local research ethics committee (Liverpool, UK; Ref: 08/H1002/32).

## Sample

A maximum variation sample of 60 potential participants was selected based on their clinic, age, gender, blood glucose control and duration of diabetes. Their parents and 20 members of the healthcare teams were also invited to attend. Of these, 24 responded positively including nine young people, eight clinicians (five nurses, two medical consultants, one psychologist), and seven parents. All gave signed consent to participate and it was made clear at the beginning of the interviews that each person’s views were important, differing opinions would be valued and confidentiality was essential.

## Data analysis

Themes in each interview transcript were noted by highlighting the text and then these were explored to build an understanding of multiple perspectives, both within and between the groups. The data were then organised into themes and subthemes using NVivo software (QSR International, Australia) to ensure a composite interpretation was reached. To ensure reliability, expert review by members of the ADNAT Research Steering Group was used, alongside three different forms of triangulation including: theoretical (data analysed from different perspectives); source (data collected from three different groups of people); and investigator triangulation (more than one person interpreted the data).

## Findings

The researchers identified the initial themes from the analysis separately and then jointly agreed on three main themes. In this article, quotations are presented by participant (YP: young person, P: parent, C: clinician) and number.

### Theme 1: Benefits of ADNAT

#### Communication tool

All participants defined ADNAT as a communication tool. A key part of this was the

format of ADNAT, which was based on the lived experiences of young people with diabetes and their healthcare professionals, using their actual words to formulate the questions and answers (Spencer et al, 2010; Spencer and Cooper, 2011; Spencer et al, 2012). One clinician captured the importance of this when he described a typical clinical scenario:

*"I get lots of shrugging, so I quite like having a tool that I can do with a young person because it gives a starting point to some of those conversations that are not easy to engage them with at first...you would never get some of this information because you are asking open-ended questions."* (C4)

The young people in the group verified this when they talked about ADNAT improving communication with adults in providing a "vehicle" for targeting conversation. One young person said:

*"We had an actual area to talk on instead of going in, just having a chit chat about general health."* (YP2)

The young people felt that it provided them with a "safe place" to offload information and obtain support. Furthermore, it appeared to remove the perceived awkwardness from the clinical encounter and the need to lie, as described below:

*"It won't be as awkward when you go and see the doctors and stuff 'cause they'll already know...in advance before you go. You don't have to worry about the awkwardness of saying 'I haven't been doing very well'. They'll already know so you haven't got to lie or anything when you go to see them."* (YP2)

### Needs assessment tool

The parents in the study appeared to feel that ADNAT was valuable in providing another way to monitor the condition and a means of validating their concerns. Clinicians felt that it defined the needs of young people with diabetes better than the staff are currently able to, as well as complying with the recommended guidance. Moreover, there was a consensus that ADNAT was thorough, providing a wealth of information. For the parents, this appeared to be considered important as they felt it embraced the complexity

of their lives with diabetes. For the young people, the needs assessment was part of a process of awareness-raising, moving them from a state of pre-contemplation to contemplation (Prochaska and DiClemente, 2005). For example, one young person said:

*"I think it raised awareness cause obviously I know where I'm going wrong but I think it raised further awareness...you need to properly register and accept you need to change something about your diet or your lifestyle."* (YP2)

The feedback indicated that ADNAT encouraged critical self-reflection, allowing young people to take account of their own unique ways of managing their diabetes, as described by the following young person:

*"I know, personally, it's made me look over what I've done, 'cause I've looked at the questions and answers...it made me look over my diabetes, and that's a good thing."* (YP3)

Such feedback was the means by which consciousness was raised and behaviours were questioned, making ADNAT a tool that helps them draw connections. The word "engage" was frequently used by parents and healthcare professionals in relation to conscious raising for young people. One clinician saw ADNAT as a way of enabling this to happen and a few parents referred to "ownership" as being key to this skill.

Being able to return to ADNAT was considered a means of providing feedback to young people, which is imperative to experiential learning, as it supports self-reflection and provides a record of their progress (Kolb, 1984). Fostering good educational practice was discussed by the adults and young people alike, and their comments reinforced the findings from educational research that has shown feedback to be effective if it focuses more on what is "right" than what is "wrong" (Sutton Trust, 2011).

### Learning through reflection

In relation to ADNAT's educational potential, a variety of views were observed. The clinicians' comments supported the idea of learning through reflection, with ADNAT being the mediator to support this activity. The need for regular

### Page points

1. The tool was identified by clinicians as a mediator for supporting the process of learning through reflection.
2. In being catered to each individual, it was felt that the tool enhances the sense of ownership and self-management.
3. The tool was also described as a means of self-disclosure, providing an "ally" in the clinical environment to discuss personal and often sensitive information.

***“The need to change consulting styles was discussed, with the focus on allowing young people to set their own agendas, rather than waiting for adults to dictate the agenda and pass judgement.”***

educational updates was discussed by all the adults, who recognised the inherent difficulties associated with this age group. One case study (vignette) describing a girl with good blood glucose control, prompted one young person to summarise the link between reflection and learning and ADNAT’s place in the following way:

*“If it says ‘drinking alcohol’ and ‘binge drinking’, then that is going to affect her HbA<sub>1c</sub>, so by using ADNAT she’d know that’s not the thing to do. So even being perfect as herself, she can upload, input her information, and see if she’s still keeping on track, every time.” (YP7)*

### **Self-disclosure**

All participants recognised the importance of the clinical biomedical environment, characterised as controlled and orderly with a focus on blood glucose control. This system was recognised as not always being conducive to sharing personal and often sensitive information. ADNAT was frequently referred to as an “ally” in this environment through the use of words, such as “discrete”, “access” and “safe”. One young person referred to ADNAT as providing a place for disclosure:

*“It should be good to get it out to the people that you mostly know. More personal stuff, like about drinking and smoking, it’s hard to open it otherwise.” (YP8)*

Another young person described ADNAT as providing a private space for dealing with his condition:

*“..when I’m on the computer I feel as though it’s just me on that computer, not everyone’s got access to it....so I feel as though I’m safe.” (YP2)*

This view was reinforced by the adults who described ADNAT as something which young people can do for themselves, enhancing ownership of their own agendas to support meaningful conversation. The need amongst young people to develop autonomy and to stand up for themselves was frequently discussed by the adults. ADNAT was seen as a novel tool for promoting such independence, because it provided a better

forum for them to answer in their own way, and as one parent said:

*“..to say the truth if they don’t think their parents are going to find out what they are saying.” (P5)*

### **“Hard-to-reach” population**

Clinicians appeared to feel that ADNAT was good for the motivated, but for others, who were described as non-engaging, it was felt that it could be a “turn-off”, particularly if it was seen as an imperative. The importance of reaching this population was emphasised, leading to the comment that ADNAT:

*“..might reach those that we can’t reach any other way...by giving them a way into education that they may not have had before.” (C3)*

One clinician suggested that if ADNAT became part of the care pathway, then it could provide indirect information on the engagement of young people with their condition:

*“It would pick up more of those kids who would not go out of their way to do it”. (C4)*

## **Theme 2: Barriers to implementation**

### **Negative feedback**

ADNAT delivers visual (red, amber or green) feedback to provide users and carers with a framework on which to tailor education and support, and a personal profile that can be saved and reviewed. Negative feedback (red) was seen by the majority of the adults as a situation which was likened to the HbA<sub>1c</sub> scenario in the clinic. Such feedback was felt to reduce motivation, providing scope for dishonesty.

The need to change consulting styles was discussed, with the focus on allowing young people to set their own agendas, rather than waiting for adults to dictate the agenda and pass judgement. Such contrasting themes reflected a stereotypical view of adolescent transition from childhood to adulthood, a period where exploration of independence is the “norm” (Arnett, 2007). In contrast, the young people appeared to feel that negative feedback would acknowledge what they already knew and serve

to validate their perspectives, as one young person said:

*"If you had all reds, I think ADNAT would help. Like if you had just one red light, you could see where you were going wrong...you've got to make minor changes, but if you've got all red lights then I think it's pretty obvious...that you've got to change."* (YP6)

### Access and confidentiality

Key to the concept of self-disclosure was the question of who should access the data. The suggestion for having a tick-box, message option, or both, was unanimously agreed as the way forward. The idea of allowing parents to see the coloured outcome (red, amber or green) was acceptable but not the detail associated with the outcome. Whilst choice was accepted, the question of safety was raised with the young people by the interviewer. The consensus was for healthcare professionals to have access as this was seen as customary practice. The young people recognised the need for discussion on the basis that it might be in their best interests, and acknowledged that they had to be prepared to accept that someone would see their data. Parents reiterated much of what the young people said but also reflected on the fact that their children already have control over their data, so ADNAT would not change this, as the following conversation indicates:

Parent:

*"It is their right to give consent for other people to look at that information."* (P2)

Interviewer:

*"Would you be happy if they said they did not want to share it with anybody?"*

Parent:

*"Yes, well it wouldn't be any different to now would it!"* (P4)

Central to the theme of access was the problem of patient confidentiality. The use of secure username and password-protected email systems was discussed. Current ethical working practices were referred to, highlighting the fact that

protocols are already in place to safeguard the use of ADNAT. Unintended consequences were also discussed with reference to the emergence of safeguarding issues. Here, again, the use of set guidelines was mentioned.

Given the size of ADNAT (117 questions), the location for where it should be completed was also discussed. All the participants felt that lack of time could limit its use in the clinics, as this participant said:

*"It is probably something to do at home before they go to clinic rather than something that they would do in a clinic setting..."* (C6)

## Theme 3: Development of ADNAT

### Resources

All participants had development ideas: young people wanted ADNAT to be made available via mobile phones so they could choose when and where to complete it; parents wanted educational resources to be included in ADNAT, such as carbohydrate counting apps, checklists, YouTube videos and validated websites; and clinicians wanted better networked access in the clinics and money to buy updated technological equipment. For the clinicians and young people, real-life scenarios were considered useful for learning; for the young people, this took the form of positive role models, such as sports people living with diabetes:

*"There could be examples of celebrities who are all famous people, famous sports people who suffer from diabetes and also how they like still manage to maintain a career..."* (YP5)

### Social networking and peer support

The need for peer support was apparent amongst all the young people and supported by the adults. The use of mobile phones, instant messaging and social networking sites was viewed as a good way of "meeting up" with others with similar experiences. It appeared that what was important to them was not feeling isolated, and being able to ask sensitive questions privately. Navigating these sites was described by the young people as a way of being

### Page points

1. Social networking and peer support emerged as important amongst young people with diabetes as a means of sharing experiences.
2. The focus groups demonstrated agreement about how the Adolescent Diabetes Needs Assessment Tool (ADNAT) works in being an effective communication tool.
3. The use of technology in ADNAT was considered as key in terms of engaging young people and providing an organisational context.



***“ADNAT has the potential to provide a self-directed combined educational and assessment tool for young people to support the process of providing tailored education.”***

in constant contact with peers who share their experiences of diabetes with them, but within the context of their own familiar environments. This allowed then to explore options, find information and peer feedback as this young person describes:

*“...knowing that other people have had the problem and they can talk to you about what they’ve done, especially if they’re not doctors or like authoritative people. They’re people your age who have the same problem and what they did like, how they did it, is a good way to solve problems.” (YP2)*

Another young person described how this is a two-way process, as they also find opportunities to support others which, in turn, provides new forms of visibility, boosts confidence and supports the process of experiential learning:

*“You can get a commonality with them and talk about the same problems, and overcome them with each other.” (YP7)*

## Discussion

The poor blood glucose control during adolescence indicates a growing need for improving the way young peoples with diabetes manage their condition (Skinner and Cameron, 2010). Identifying individual needs is fundamental to care planning and ADNAT was developed to meet this priority. This study has described the perceptions of ADNAT amongst young people, parents and healthcare professionals to understand its utility to these groups. Whilst the findings relate to only a small sample of people who participated in the ADNAT study, some of the authors’ findings, such as the need for the involvement of young people in setting their own agendas in clinical consultations, have been reported elsewhere (Hawthorne et al, 2011). The authors of this article are also now piloting ADNAT in 10 different paediatric clinics to further support these findings.

The focus groups demonstrated agreement about how ADNAT works – as a communication tool to support clinical consultations and as a tool that “permits” self-disclosure and raises self-awareness for contemplating change. The

use of technology was seen as key to this process, providing an organisational context for structuring engagement with ADNAT (and therefore with diabetes). It was clear that the young people appeared to feel secure answering questions online as opposed to confronting adults in the clinic. The need to reconstruct consultation styles was also discussed, with a focus on adults becoming facilitators of tailored learning using technology to meet the needs of young people. In line with previous research, this study highlights how technology has altered the way young people socialise and learn, raising challenges for diabetes educators (Ito et al, 2008). The young people spoke about using technological tools to learn from their peers so that adults, as experienced role models, were able to set needs-based learning goals and provide feedback. In line with this, further developments were advocated, using methods such as social networking and virtual case scenarios of famous people, which reinforces the idea of learning through peers, perhaps vicariously, as well as learning from personal experiences.

## Conclusions

Findings from this study suggest that ADNAT has the potential to provide a self-directed combined educational and assessment tool for young people to support the process of providing tailored education. The authors are currently testing out these findings by evaluating the use of ADNAT within larger and more diverse populations of young people. Further to this study, the authors have also developed communication pathways for ADNAT via mobile devices and have submitted a new research proposal to expand the utility of ADNAT as an educational resources. ■

*The authors thank Diabetes UK which funded the ADNAT study; all the young people, parents, and healthcare professionals who contributed to the study; and the UK Medicines for Children’s Research Network and Non-Medicines Paediatrics Speciality Research Group, which supported the ADNAT study.*

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