

Institution: University of Chester
Unit of Assessment: 3 Allied Health Professions, Dentistry, Nursing and Pharmacy
Title of case study: The Adolescent Diabetes Needs Assessment Tool (ADNAT) Research Programme
<p>1. Summary of the impact</p> <p>An urgent need has been identified to redesign diabetes health services for young people in the UK, which has the fifth largest paediatric diabetes population in the world with no standardised approach to care. The Adolescent Diabetes Needs Assessment Tool (ADNAT) App is the first intervention of its kind filling a recognised gap in UK service provision. Evidence from the underpinning research programme that has studied adolescent diabetes self-care and explored technological methods of learning, has guided the development, validation and clinical evaluation of ADNAT which has now been included in the UK's 2013-2018 National Paediatric Service Improvement Delivery Plan.</p>
<p>2. Underpinning research</p> <p>The UK has one of the poorest levels of paediatric glycaemic control in Europe, particularly during adolescence. It was vital that services were changed to address this serious issue, and systematically identifying patients' needs was fundamental to this process.</p> <p>Previous research provided the groundwork for the ADNAT research programme. It includes a PhD study of a lifestyle intervention for adults with Type 2 diabetes (University of Liverpool, Cooper, 1997-2001) which validated the need for theoretical foundations and the use of combined research methods. It also includes a four year study of interprofessional education at the undergraduate level (University of Liverpool, Cooper (Chief Investigator), Spencer-Dawes (Researcher), McLean (Trainer), Carlisle (Researcher), 2003-2007,) which led to a developing expertise in complexity science as a new theoretical paradigm for the study of education, behaviour and health.</p> <p>This case study is centred upon the work of Cooper (Professor, University of Chester 2008-present). The ADNAT research programme [Cooper (Chief Investigator), Spencer (Researcher), Lwin (Senior Lecturer & Paed. Clin. Psychol.) & Wheeler (Researcher), University of Chester; Lancaster & Titman (Statisticians), Lancaster University; Johnson (Educational Technologist) University of Bolton - 2008-present] is focused on young people aged 12-18 years living with Type 1 diabetes (T1D). Following the Medical Research Council's framework for the design and evaluation of complex interventions, it includes a qualitative phenomenological PhD study of the experiences of adolescents with T1D and their families (Spencer, University of Liverpool, 2009), and their diabetes healthcare team (Spencer & Cooper, University of Chester, 2010); alongside two systematic reviews. The first examined educational technologies for young people living with T1D [Cooper H. (Principal Investigator), University of Chester; Cooper J. (Research Assistant) & Milton (Researcher), University of Liverpool - 2008-09], and another studied the qualitative literature on adolescence and T1D (Spencer & Cooper, University of Chester & Milton, University of Liverpool - 2008-09).</p> <p>This work highlighted the importance of needs assessment to guide tailored experiential learning and support for young people, but found no existing validated UK instruments to facilitate this process. This evidence guided the development, psychometric testing and clinical evaluation of ADNAT, which is a unique combined education and assessment tool.</p> <p>Methodology involved a five-stage intervention developmental phase, followed by a second phase to evaluate the tool's psychometric properties. A third phase evaluated perceptions of its usefulness with users and providers, and a fourth phase is currently re-testing the tool and evaluating its clinical utility. A fifth phase (in development) will utilise combined methods to determine the efficacy of the ADNAT App. Over 200 young people participated in the first three phases. ADNAT consists of 117 questions divided between six interconnecting domains of educational and psychosocial support needs. All the questions stimulate reflection on personal</p>

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experiences as prompts to integrated scored assessment of self-care and psychosocial health. Face and content validity of the scoring items were all positively evaluated in terms of appropriateness and readability. Tests for validity found significant correlations with the only other (non-educational) American self-care assessment questionnaire (Self-management of Diabetes in Adolescence - SMOD-A) ($r = -0.41$, $p < 0.001$). Correlation with glycated haemoglobin (HbA_{1c}) was weak ($r = 0.16$, $p = 0.056$) but this compared favourably with SMOD-A ($r = -0.06$, $p = 0.52$), indicating that ADNAT taps into the construct of 'self-care' more successfully.

The third phase of the study (evaluation of users' and providers' perceptions of ADNAT) highlighted the need to expand accessibility. Working with a technology company (*Healthlmo*), the ADNAT App and website, www.myadnat.co.uk, were built, alongside secure access through mobile devices, and delivery of assessment feedback to users and confidential patient data to providers. This work provided the foundations for the evaluation study [Cooper, Lwin, Lancaster, Ghatak (Consultant Paediatrician), Alder Hey Children's NHS Trust; & Waldron (NHS Paediatric Diabetes Education Lead, 2013 - present)] which is providing data for the fifth phase which will utilise combined methods to determine effectiveness. This study is being developed for NIHR funding in liaison with the NHS Paediatric Diabetes Education and Clinical Team and the Royal College of Paediatrics and Child Health with a view to integrating ADNAT into the National Paediatric Diabetes Audit.

3. References to the research

The programme has won two awards including the Diabetes UK Annual Professional Conference Education Award (2007), and 'highly commended' at the Royal College of Nursing International Research Conference (2010). The following six peer reviewed publications and their associated research grants provide evidence of the research's quality:

1. Cooper H., Spencer J., Lancaster G., Titman A., Johnson M., Wheeler S., Lwin R. (2013) Development and psychometric testing of the on-line 'Adolescent Diabetes Needs Assessment Tool' instrument. *Journal of Advanced Nursing*. Early on-line view. doi: 10.1111/jan.12235.
Grants to Cooper at University of Chester: (i) Diabetes UK, 'Development of ADNAT': £197,335 (2009-2012). (ii) National Institute for Health Research (NIHR) Cheshire, Merseyside and North Wales Medicines for Children's Research (CMNWMCRN) Network Trials Unit: 3 year secondment, £78,843 (2011-2014), funding for research equipment, £5,680 (2013-14), and funding to support Senior Researcher (Dr Joy Spencer), £19,589 (2011-2012).
2. Cooper H., Spencer J., Lancaster J., Johnson M., Lwin R., (2013) Perceptions of the Clinical Usefulness of the Adolescent Diabetes Needs Assessment Tool (ADNAT). *Diabetes Care for Children and Young People*, 1(2), 55-61. **Grants:** as for 1.
3. Spencer J., Cooper H., Milton B., (2013) A qualitative phenomenological study to explore the lived experiences of young people (13-16 years) with type 1 diabetes and their parents. *Diabetic Medicine*, 30, e17-e24. DOI: 10.1111/dme.12021. **Grant:** University of Liverpool (funder), £56,135 (2005-08).
4. Spencer J., Cooper H., Milton B.. (2010). Qualitative studies of Type 1 diabetes in adolescence: a systematic literature review. *Pediatric Diabetes*, 11(5), 364-375. DOI: 10.1111/j.1399-5448.2009.00603.x **Grant:** University of Liverpool (funder).
5. Cooper H., Cooper J., Milton B. (2009). Technology-based approaches to patient education for young people living with diabetes: a systematic literature review. *Pediatric Diabetes*, 10, 474-483. DOI: 10.1111/j.399-5448.2009.00509.x **Grant:** University of Liverpool (funder), £2,690 (2007-08).
6. Cooper H., Geyer R., (2008) Using 'complexity' for improving educational research in health care. *Social Science and Medicine*, 67, 177-182. DOI: 10.1016/j.socscimed.2008.03.041. **Grant:** Cheshire and Merseyside Strategic Health Authority, £404,018 (2001-05) to University of Liverpool.

4. Details of the impact

ADNAT supports the UK government's recommendations for tailored education based on needs assessment as part of its recently introduced 'Best Practice Tariff' strategy (DoH (2011) *Payment by Results Guidance for 2011-12*. London: DoH) and integration of technology into clinical practice (DoH (2010) *Delivering 21st Century IT Support for the NHS*. National Strategic Programme.

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London: DoH). ADNAT has been included in the 2013-2018 National Paediatric Service Improvement Delivery Plan (NHS Diabetes. (2013) National Paediatric Diabetes Service Improvement Plan 2013-2018. London: DoH) following uptake by the NHS Paediatric Team. In their letter of support they state,

“ADNAT provides an opportunity to improve care in this highly specialised field.... We are therefore happy to work with you and your team to take ADNAT forward within the clinical field and to further its research.”

This Team also includes the UK Project Manager for the international SWEET Project EU (www.sweet-project.eu) which is working to develop EU centres of reference for paediatric diabetes for which ADNAT has been recognised as having potential for future EU dissemination (<http://onlinelibrary.wiley.com/doi/10.1111/pedi.2012.13.issue-s16/issuetoc>).

ADNAT is also being discussed as a tool to provide data for the *National Paediatric Diabetes Audit*, with an invitation to present at the Royal College of Paediatric and Child Health in London in November 2013 (see email re: National Paediatric Diabetes Audit).

For researchers, ADNAT can provide both quantitative and qualitative information regarding adolescent diabetes self-care needs. This is an important outcome as evidence suggests that the relationship between educational outcomes and processes can provide an understanding of how interventions should be targeted.

The ADNAT study is registered with the National Institute for Health Research (NIHR) Cheshire, Merseyside and North Wales Medicines for Children's Research (CMNWMCRN) Network Trials Unit ([StudyID=6633](#)), and co-adopted by the Diabetes Research Network. In a letter of support, they wrote:

“...ADNAT has been one of the most successful studies within the MCRN portfolio with respect to both recruiting participants on time and the integration with research network resources”

As a result of this success, Professor Cooper successfully applied for a 2-day secondment to the CMNWMCRN, and funding to support the study's research associate. The CMNWMCRN funded research nurses are also supporting the delivery of the evaluation study in four hospitals, including service support activities, monitoring and recruitment.

Other beneficiaries include lay volunteers who participated in the study's Research Steering Group (n=16, 2005-2012). This group, which comprised 50% lay people including adolescents with T1D and their parents, ensured that the research was focused by sharing understanding of youth culture, identification of priorities, use of suitable research tools, and disseminated locally through peer dialogue.

Findings have been disseminated nationally and internationally at both professional and academic conferences and have included ten personal invitations including one to present at the International Diabetes Federation's World Diabetes Congress in Dubai, 2011, and three key-note lectures to National (2012) and Regional Paediatric Diabetes Professional Network (www.diabetes.nhs.uk/networks/paediatric_network) Meetings (South East of England, 2012, North West, 2012, and Yorkshire and Humber, North East and North Cumbria, 2013). Other presentations include Diabetes UK's Annual Professional Conference (2010, 2011, 2013), British Sociological Association Medical Sociology Annual Conference (2008, 2011), International Society for Pediatric and Adolescent Diabetes, USA (2011), Diabetes UK Major Supporter's Events (2011, 2011), NIHR Medicines for Children's Research Network Annual Conference (2010, 2011), NIHR Diabetes Research Network meeting (2010), Royal College of Nursing International Research Conference (2008, 2010), and the Royal College of Paediatrics and Child Health (2013).

Research work in both adult and paediatric diabetes has led to invitations to contribute to a number of national expert groups, as summarised in Table 1 below.

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Table 1: Contributions to national bodies

2013 - 2014	Expert Steering Group member: NHS National Peer Review Programme/Children and Young Peoples Transition Services (see: National Peer Review Programme support letter).
2013	Expert adviser: Juvenile Diabetes Research Federation's 2013 UK Type 1 Diabetes Research Roadmap (http://www.jdrf.org.uk/research/type-1-diabetes-research-roadmap).
2011-Present	Member: NHS Diabetes, Paediatric Sub-Group (www.diabetes.nhs.uk/networks/paediatric_network).
2007-2010	Member: DoH/Diabetes UK working group: 'Supported Self-Management' (http://www.diabetes.org.uk/Documents/Reports/Supported_self-management.pdf).
2005-2010	Member: MRC's College of Experts - Health Services & Public Health Research Board.
2006	Expert adviser: Update review of patient education models for type 2 diabetes, NHS R&D HTA programme (http://www.ncbi.nlm.nih.gov/pubmed/1840546).
2004-2005	Expert adviser: DoH Patient Education Working Group, National Service Framework for Diabetes (Department of Health/Diabetes UK. (2005) <i>Structured Patient Education in Diabetes. Report from the Patient Education Working Group</i> . Ref. 269106. London: HMSO).
2002	Expert advisor: Review of patient education models for diabetes, NHS R&D HTA programme (NICE. Technology Appraisal Guidance 60. <i>Guidance on the use of Patient-education models for diabetes</i> . April 2003. Ref No. NO213/ ISBN: 184257-287-3).
2002	Contributor: Joint DoH/MRC Research Advisory Committee on Diabetes: Subgroup 5: Service Organisation and Delivery (DH/MRC. <i>Current and Future Research in Diabetes</i> . London : Stationary Office, 2002. Ref. No. 29397).

5. Sources to corroborate the impact (indicative maximum of 10 references)

1. ADNAT website: www.myadnat.co.uk. Accessible via Internet Explorer (Versions 9 and above) and Google Chrome or Safari if using mobile technology devices. For access to the ADNAT tool and App.
2. UK Clinical Research Network Study Portfolio:
<http://public.ukcrn.org.uk/search/StudyDetail.aspx?StudyID=6633>
For project summary and status information.
3. Diabetes UK (Funding body for ADNAT Study): for patient/professional website and patients' bi-monthly magazine (Balance):
 - i. http://www.diabetes.org.uk/Get_involved/Volunteer/involvenewsletter/Issue-1/Research-Update/
 - ii. http://www.diabetes.org.uk/How_we_help/Magazines/Balance/Past-issues/Archived-issues-and-articles/2010/SeptemberOctober-2010/Teenagers-in-control/
 - iii. http://www.diabetes.org.uk/How_we_help/Magazines/Balance/Past-issues/November---December-2012/Funding-our-future/
4. Letters/emails of support:
 - NHS Paediatric Diabetes Team.
 - NIHR UK Clinical Research Network: CMNWMCRN.
 - NHS Diabetes, Yorkshire and the Humber and North West Paediatric Diabetes Network.
 - National Peer Review Programme.
 - National Paediatric Diabetes Audit.