Final Report

Diabetes UK requires that annual progress reports are provided as part of the Terms and Conditions of award. This report must be received for Diabetes UK to release the final quarter payment. Please take time to complete this form thoroughly and return an electronic copy to research@diabetes.org.uk and a signed hard copy to: The Research Team, Macleod House, 10 Parkway, Camden, London, NW1 7AA.

If you have any queries please contact us on the email address above or on 020 7424 1076.

Part 1: Project Details			
Project BDA number	UK 11/0004363		
Principal grant holder's name	Professor Jonathan Pinkney		
Contact email	Jonathan.pinkney@pms.ac.uk		
Contact telephone number	01752 763498		
Organisation where grant is held	Plymouth University		
Project title	User-led development and piloting of pre-clinic Internet applications enabling young people with diabetes to set the focus for their diabetes consultations		
Project start date	01.06.2012	**Project end date**	31.05.2013
Type of project (project, studentship fellowship)	Pilot study		
Date report due	12.07.2013		

Part 2: Progress report
Please provide a detailed report describing the progress of the research, the extent to which the original aims and objectives of the research have been achieved and the scientific and/or technological achievements of the research. This should be not more than six pages of A4.
The aims of this pilot study were to (i) facilitate and support YPD (young people with diabetes) in developing 'apps' (mobile or Internet based) that help prepare for and set the focus of clinic appointments, (ii) to assess the impact and usefulness of these apps by recording the views of YPD who trial them. And (iii) to discuss between YPD and advisory panel the most appropriate outcome measures and the possible design of a larger scale subsequent study with clinical endpoints. We invited YPD (aged 16-25) to enter a competition to design and develop an app for use by other YPD in clinic appointment planning and agenda setting. We did not define the specification beyond this but did include Sarah Youen's You + Your Diabetes website as an example of a pre-clinic note-making app (http://www.sarahyouen.co.uk/youyourdiabetes/letsgetstarted.html). We used various online methods to raise awareness and directed interested parties to our website for participant information, consent and registration. Methods included: (i) emails to 416 paediatricians and adult diabetes consultants and 160 computer science professors and lecturers of United Kingdom (UK) universities following an online search for contacts; (ii) 68 messages posted on university computer science, students union and diabetes relevant Facebook and Twitter pages; (iii) paid advertisements, targeting YPD and computer science students and developers, set up via Google AdWords (£800) and Facebook (£900) Campaigns; (iv) Diabetes UK postings on their website, Facebook, newsletters, press release and Balance and Update magazines; (v) project and personal Facebook and Twitter pages of the team,

project advisory group, and other supporting members; (vi) press releases and website posts by the host Universities; (vii) posts in diabetes discussion forums; (viii) emails to listserves and contacts of the team.

The competition ran for just under four months from 20th June to the deadline 14th October 2012. Contacts showing interest were received from 28 YPD and 28 others (including non-diabetic computer science students) via the website registration form and by email enquiry. Some YPD had computer science skills to create an app, some had teammate (TM) support, and others enquired about being teamed up with someone with app developing skills. We facilitated a 'match-making' service between those who requested it within the criteria that the team lead was a YPD, via email exchange following consent. Teams were given information and support from the research assistant (RA) and login details for accessing the project discussion forum for technical support, useful links and opportunity for discussion between developers.

23 YPD (with 19 TM) were potential app developers (excluding those who did not progress beyond initial enquiry), 19 (with 17 TM) continued correspondence, 8 (with 10 TM) indicated plans to develop an app, and 6 (with 8 TM) submitted an app. These were: (i) Diabetes Logger, an iOS mobile app for logging readings, setting target ranges and viewing trends on a graph; (ii) Diabetes Health Tracker, an Android mobile app also for logging readings and exporting data; (iii) You + You Diabetes, (Sarah Youen's original example website for making and printing notes under prompt categories); (iv) T1NDA, a mobile compatible website also for making notes and exporting via email; (v) cpSlider, a website with login for calculating insulin dose, logging calculations and viewing trends on a graph and chart; and (vi) Insulin Calc, an Android mobile app for calculating insulin dose, later also made available on iOS.

Apps were submitted by publishing to an app store or hosting as a website and details were emailed to the RA including links, screenshots and instructions for app use. The six teams were offered £65 towards the cost of publishing, £100 for maintaining the app over the course of the project and £6 per YPD who chose and reviewed their app in stage two (totalling £1,488). The project team, including our YPD advisory group panel appraised the submitted apps for suitability of use and the website was adapted in preparation for stage 2. We contacted the 28 who did not complete an app and 19 responded to a follow up questionnaire (£20 Amazon voucher incentive offered to each, totalling £380). Lack of time or other commitments (11/19) and breakdown of communication or conflict of ideas between TM (6/19) were the most commonly cited reasons for not completing their app. Nevertheless, we successfully achieved our first aim of facilitating and supporting YPD and teammates to design and develop their own apps.

In the second phase, we invited up to 200 YPD (aged 16-22) with a diabetes clinic appointment due within the review stage of 1st November 2012 to 28th February 2013, to sample the six apps available via website login, choose their preferred app and use it in preparation for their diabetes clinic appointment. Participants were asked to complete a questionnaire review and add comments in the forum discussion following their appointment. We advertised for and recruited nationally via the same channels as in the previous stage and in addition contacted 54 GP surgeries and 50 universities by email and other newly found relevant contacts by email, Facebook and Twitter. Interested parties were directed to our website for participant information, consent and registration (including baseline questionnaire). Registrants were given instructions from the RA, login details for accessing the app section of the project website and discussion forum.

Due to slow initial uptake, with ethical permission the age range was increased to 16-25. Interest

was received from 135 YPD, of whom 83 completed participation (62%), which following the app trial, included completing a review (including follow up questionnaire) and posting a minimum of 1 message in the discussion forum. For completing participation, a £20 Amazon voucher was offered (totalling £1,640, as 1 reviewer completed all but the discussion forum post). The most popular apps were Diabetes Logger (25 reviews), You + Your Diabetes (24 reviews), followed by Insulin Calc (17 reviews).

The 83 participants showed significant improvement ($p<0.001$) on a 5-item scale of impact on the consultation. This included improved confidence in dealing with diabetes ($p <0.001$), happiness with the way the clinic appointment went ($p =0.02$), and hospital doctors understanding their needs ($p = 0.03$). This was an important group to target as at baseline just over a third (31/83, 37%) reported that they had considered previously missing a clinic appointment.

Qualitative data were content analysed. Data were coded and frequencies of codes informed themes, identifying common issues of importance.
Most YPD felt their chosen app was useful for preparing for or setting the focus of their clinic appointment (n=53, 63%), in particular the notes/ agenda setting apps (positively correlated with ease of use) were considered useful for identifying issues normally forgotten that helped YPD feel more prepared and in control of the appointment. The data logging apps were useful for ease of recording and visually showing their doctor or nurse blood glucose trends for discussion. The insulin dose calculator apps were useful for raising concerns of insulin dose and carb calculations for discussion. Just over half of YPD (n=46, 55%) intended to use their chosen app again. They gave suggestions for features to be added or amended and most (n=67, 81%) would recommend the app to a friend as worth trying.

The features of most appeal to YPD reviewers were: (i) function for facilitating (a) data recording and overview, (b) assistance with carb counting and calculations and (c) help remembering what to discuss at appointments; (ii) ease of use and interface; and (iii) accessibility on device of choice (e.g. iOS, Android, PC).

Most (23/34, 68%) felt it was important that apps were designed and created by YPD, as only those with first hand experience of diabetes understood requirements, the difficulties living with diabetes and what can help. However, some YPD felt that as long as the apps looked professional, worked well and met their needs, then professionals consulting YPD would be adequate in app development. We also successfully achieved our second aim of assessing the impact and usefulness of these apps by recording the views of YPD who trialled them.

The project was very well received by all those involved. In follow up, all respondents (35/83) gave praise to the project including, “I think that the Diabetes App Challenge was a great idea, and I really enjoyed trying out free apps that were actually very helpful and helped me become more organised for my appointment with my DSN and doctor”, and 29/35 explicitly expressed an interest in taking part again or involvement in further study including, “I would definitely take part again - it was run smoothly and introduced me to a genuinely useful app”. Each YPD was emailed a copy of our recently published article (Jones R, Cleverly L, Hammersley S et al (2013) Apps and online resources for young people with diabetes: The facts. Journal of Diabetes Nursing 17: 20–26) to raise awareness of existing, reputable online resources for diabetes.

In the final stage, we invited YPD reviewers, YPD and TM developers (and developers from the Handihealth organisation), project team including YPD advisory group and other stakeholders to attend two online presentations and discussions to ascertain views on the future of the

submitted apps and further study. The first was for team members and project participants only, the second was opened to the wider audience. In this latter, a one-hour live webinar (mid-week evening), 22 viewed a presentation of the project summary, preliminary findings and discussed questions posed and responded to opinion polls via instant chat. Most (12/17) preferred, for future development a combined 'super app', of the three functions of the developed apps (note/ agenda setting, insulin dose calculator and data logging). Most (15/17) also felt that a panel of YPD working with a professional developer would be preferable for combining YPD needs and professional developer skills and that (10/15) Diabetes UK could support this development. For future research most (9/13) felt that health care professionals (HCP) should be included more so they can be part of monitoring impacts of apps on healthcare and be aware of current technologies so (4/13) YPD can be supported more in the use of existing apps. Therefore, we successfully achieved our third aim organising discussion between YPD and advisory panel about the outcome measures and design of a subsequent study.

Please describe the main conclusions you have reached from the research.

Supporting young people with diabetes and teammates to develop their own apps is a feasible alternative to professional developers engaging a user-panel to elicit their needs. We expected an agenda setting approach to focus the consultation but data logging and insulin dose calculation were equally developed and popular with YPD reviewers who considered the apps useful in preparing for and setting the focus of clinic appointments. YPD think that it would be worth merging the three functions into one app available across all platforms.

Have there been any deviations from the original research plan? If yes, please give details.

In recruiting YPD reviewers, the participant age criterion was extended from 16-22, to 16-25 (with ethical permission) due to initially low recruitment numbers.
The terms of submitting the apps under the 'creative commons' licence was used at developers' discretion. Some developers needed to use closed source coding in some elements of their apps, but overall, developers did not protect intellectual property and were open to the idea of their apps being used by others such as Diabetes UK or a communal interest group.

Please describe any problems you have encountered during the project.

Despite employing various methods of raising awareness to recruit YPD to review apps, we were unable to recruit our target maximum of 200; 135 registered of which 83 participated.

Part 3: Lay language progress report

Please summarise in one sentence the major outcome of the research.

Young people with and teammates developed and created six apps, two each of agenda setting, data logging, and insulin calculation, that were used, reviewed, and found useful by other young people with diabetes.

Please describe the progress of the research in lay language.

We invited young people with diabetes ("YPD") and teammates via an online competition (the Diabetes App Challenge) to create an 'app' (website or mobile application) to help others prepare for and get the best from clinic appointments. Some of these YPD 'developers' worked alone, others had friends' help and some were 'match-made' by us. They were given some minimal costs towards the cost of publishing the app or hosting the website and some reward for their work. We initially had interest from 28 YPD and 28 others including non-diabetic computer science students. By the end of the competition, 6 YPD (and 8 teammates) had submitted apps

that were designed as (i) note-making, (ii) data logging and (iii) insulin calculator functions. After the research team tested the apps for suitability of use, they were offered, via the project website, for other YPD to try out, choose one, use it in preparation for their upcoming clinic appointment and then give us their views. We had interest from 135 YPD, of whom 83 used and reviewed an app. The three functions were chosen in equal numbers by reviewers. However, the note-making apps were considered most useful for preparing for clinic appointment, the easiest to use, most likely to be used again and be recommended to a friend. Most of our participants felt that apps created by YPD was important, however discussions after the review stage of the project with a wide range of stakeholders suggested that as long as YPD were closely involved in the design process of apps, apps developed by professionals are acceptable. An app combining the three functions would be useful.

Part 4: Future Research

Please describe your future plans based on the outcomes of this research.

This research suggests that apps have the potential to enhance agenda setting and preparation for clinical appointments for young people with diabetes. We propose to use the understanding gained in this project (app features and the support required to develop and use apps, online recruitment and project management, outcome measurement etc.) to further test the use of apps as a self-management aid for young people with diabetes. One specific idea from another of our current research projects is to develop methods or guides to support the selection and correct use of good self-management apps, as this may be a current barrier to wider uptake. The principal options include trialling supported app use / app guide versus non-supported use of apps, and undertaking long term assessments of impact on clinical endpoints including glycaemic control.

Has the research led (or do you expect the research to lead) to other successful or pending grant applications? If yes, please provide details below.

We are very keen to develop a follow-on project, to develop and further apply what has been learned in this preliminary project. The further development of the DAC project will again be led by young people with diabetes, supported by the research team. Should the opportunity arise, we would be interested in developing a research partnership with Diabetes UK to take the work forward.

Has the research led to other academic or industrial collaborations? If yes, please provide details below.

We were approached by University of Hertfordshire for the Diabetes App Challenge project to be included in their evaluation study of research with patient and public involvement, RAPPORT. Chief investigator is Dr Patricia Wilson (p.m.wilson@herts.ac.uk).

Part 5: Outputs and outcomes

Please list all publications that have arisen from this grant to date, including any that are currently in press. If possible please send a copy of publications with this report.

Journal of Medical Internet Research – in development

Please list all oral and poster presentations that have arisen from this grant to date, including any that are currently submitted. If possible please send a copy of the abstracts with this report.

- Diabetes Technology & Innovation In Practice 2013: Role of technology in enhancing diabetes care, Manchester, 22nd October 2013 – *Confirmed*
- Medicine 2.0'13, London, 23rd September, 2013 – *Confirmed*
- PELeCON (Plymouth Enhanced Learning Conference), Plymouth University, 11th April, 2013
- HANDIHealth South West workshop, Plymouth University 19th November, 2012
- South West Paediatric Diabetes Network meeting, Taunton, 18th July, 2012

Has the research led to any commercial or potential commercial exploitations to date? If yes, please describe the nature of this and if patents have been filed please give details.

No

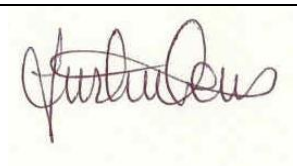
Please provide a full financial summary of this project. If additional rows for staff are required please insert these. Please provide a breakdown of materials and consumables cost.

	Year 1	Year 2	Year 3	Year 4	Year 5	Total
Staff costs						
Post 1 Basic salary (Emily Ashurst)	26,220.70					
Employers contributions	6,076.44					
Post 2 (Martin Jenner)	1,140.00					
Materials and Consumables: (please provide a breakdown)						
- Advertising	1,865.52					
- Software developer/ website	1,570.00					
Payments to participants						
- YPD consultancy	240.00					
- Technical support	100.00					
- Developer rewards	1,553.00					
- Tester rewards	1,640.00					
- Feedback incentives	360.00					
- RA travel / conferences	1,200.77					
- Reviewers Rewards	200.00					
- Publication costs	1,600.00					
Animal Purchase	n/a					
Animal Maintenance	n/a					
Other expenses – please detail						
Total	**43,766.43**					

Are there any variations between the original awarded costs and the full financial summary of this project? Please provide an explanation below.

Spare funds due to fewer than estimated for developers (budgeted for 10, 6 participated) and reviewers (budgeted for 200, 83 participated).

Spare funds due to staff costs of Ms Sarah Youen departing from project.

Part 6: Signature of principal grant holder and financial authority of your institute			
Print Name	**Signature**	**Date**	**Position**
J Pinkney		**03.06.2013**	**PI.**
Justin Crews		**24.06.2013**	**Finance Business Assistant**

Thank you for taking the time to complete this final report and informing us of your progress