

Whose  Diabetes is it?

# Final Report

October 2012

## Executive Summary:

This report captures the outputs of a project working with young people with type 1 diabetes and their families in Rotherham and Barnsley. It presents the findings through a proposed information and support service that puts young people at its centre.

This service was co-created by the young people, their families and key staff from the Rotherham Hospital Adolescent Diabetes Service through a creative design-led process.

The proposed service streamlines all that is positive about the existing provision into one brand and information resource "Whose Diabetes is it?" that brings in expertise from both inside and outside the NHS, in the form of peer support groups and clinical staff. This information is delivered via means that better fit young people's lifestyles such as text messaging, websites and in person. Finally it allows for young people and families to receive reassurance from others who know "what it's like".

This report is designed to be read alongside the service visualisation which can be found at [www.whosediabetesisit.org.uk/video](http://www.whosediabetesisit.org.uk/video)

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# Whose Diabetes is it?

## I. Whose Diabetes is it Anyway?

Staying well if you have type 1 diabetes means thinking about your diet, exercise, blood glucose levels and insulin (amongst other things). Teenage years can be difficult enough without this self-management work, and young people with type 1 diabetes may struggle. Help is available in the NHS and from others with diabetes but many teenagers do not engage with it, which could damage their long-term health.

In this project, User-centred Healthcare Design worked with young people with type 1 diabetes and their families, and Rotherham Hospitals to devise a new support and information service to help teenagers fit diabetes into their lives better.

We used creative design workshops to design an innovative service that:

- Focuses on young people's whole lives rather than just when they use health services;
- Joins up clinical expertise from inside the NHS and expertise in living with diabetes from outside the NHS;
- Explores new ways of interacting with a service that are more appropriate to teenage lifestyles and exploit the benefits of digital tools, such as text messaging and social networking websites.
- Encourages peer support both in-person and online.

As we approach the end of the project this report is a summary of what we have developed with the young people, it is also a suggested way forward if Rotherham hospital are keen to adopt the project and enhance their own service delivery.

We have also produced digital tools and printed materials to enable teenagers and their families to access help and support more easily.

All these resources and much more can be found at:

[www.whosediabetesit.org.uk](http://www.whosediabetesit.org.uk)



Figure 1. Participants in the Whose Diabetes is it? workshops.

## 1.1 Timeline of the project

UCHD started work on the project in early 2011, and spent some time understanding how best to engage with people from the diabetes community. We had explored a range of web based research tools and during this process had met and presented to the Rotherham and Barnsley peer support groups. See Appendix I on pages 18 & 19 for more details.

The workshops with RYDA, the Barnsley group and the Rotherham paediatric diabetes team started in July 2011. An overview of the process is shown in the figure below.

*“...and it just gives us opportunity to explain to people that don’t actually live with diabetes what it is like and explain to them how we feel living with..”(young person)*

*“...it was good to see the younger ones getting involved and seeing some of their ideas and it looks a bit futuristic at the moment but I suppose anything’s possible.”(parent)*

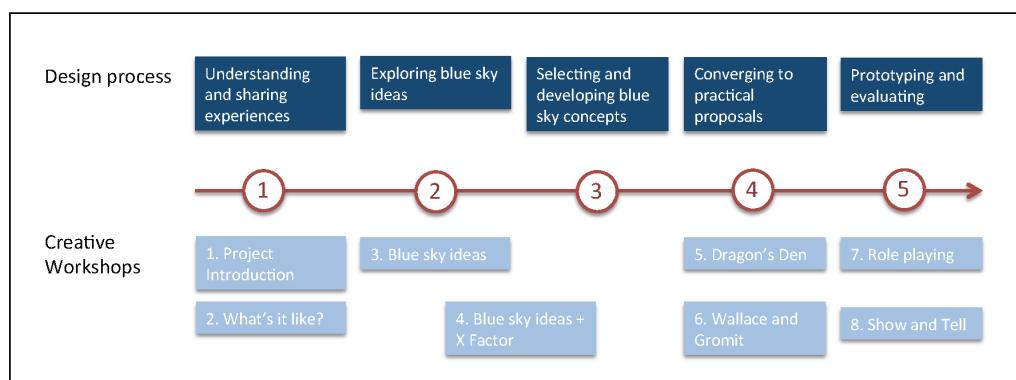


Figure 2. Project Summary Flowchart

## 2.The proposed service: Whose Diabetes is it?

### 2.1. Principles

*Whose Diabetes is it?* is based on three key principles:

#### 2.1.1. Expertise from inside and outside the NHS

Advice on living well with type 1 diabetes is available both from the NHS and from outside the NHS. Other people with diabetes and their families and carers have valuable experience on practical every-day aspects, which NHS services cannot always provide. The information and support provided to young people then needs to recognise both sources of expertise, and ownership of any such resources needs to be shared between clinicians and community experts.

#### 2.1.2. Access via means that better fit young people's lifestyles

Our participants have told us that clinic is not always the best place to get information and support. Issues that seem important in the moment are often forgotten by the time a three-monthly clinic comes around and, even if they are remembered, teenagers dislike discussing problems face-to-face and parents feel embarrassed asking questions that they think have previously been answered. Clinic remains a valuable source for support, but it should be complemented by other means that better fit the lifestyles of young people (e.g. text messaging, the web, and social media) and provides access between clinics.

#### 2.1.3. Reassurance from others who know "what it's like"

Support for living with diabetes is more than access to relevant information and advice. Sometimes it is just being able to talk to someone else who knows "what it's like". Our participants told us that they frequently felt misunderstood by their clinicians because they did not have type 1. Our project was also the first time several participants had spent time with other young people with diabetes, and they valued being able to talk to others (about anything) who "get what it's like". It is therefore important to create opportunities for socialising with those with shared experiences, whether they be in-person or online.

*Whose Diabetes is it?* demonstrates how these principles can be put into practice. It is an information resource bringing together clinical and community expertise, with shared ownership. It provides information to young people and families in a manner sensitive to the emotional journey they face in learning to live well with diabetes. It enables access to this information via means relevant to young people's lifestyles, and ensures the information is up to date and consistent through a common visual 'brand' and centralised web-based management of information (see figure 3). It also creates circles of support through the Welcome Event and social media functions.

Our participants told us of various significant points along their journey of learning to live well with diabetes, and these waypoints provide a useful framework for describing *Whose Diabetes is it?*.





Figure 4. 'Katie's' Facebook Page

## 2.3. Being Diagnosed

### 2.3.1. Information Pack

We were aware of the range and quantity of information available to young people and their families upon diagnosis. Often there was a sense of information overload during such stressful periods. *Whose Diabetes is it?* provides a simplified information pack and membership card at diagnosis (see figure 5). Giving families “the basics” (essential information with directions to sources of further information) potentially reduces information overload. The membership card provides a physical artefact to enable a young person to claim their diabetes as their own, and gives emergency contact numbers and the address of the service website in a practical, highly portable form (“just slip it in your wallet/purse”) affording quick access to help when needed.

Young people and their families were involved in developing both the contents and styling of the information pack. It represents all the essential information already provided by the Rotherham service but, through a clear visual ‘brand’ and high production values, gives the service a clear identity and reassures service-users of their importance and confidence in the professionalism of the service.

### 2.3.2. Home Visit

Ownership is a key issue in diabetes, “whose diabetes is it?” is a question for everyone who lives with, cares for and engages with young people with type 1 diabetes. By understanding the current clinical pathway we have been able to integrate the service into current practices.

A DSN home visit shortly following hospital diagnosis is already part of the service Rotherham provides. With *Whose Diabetes is it?* a DSN uses this visit to check a family’s understanding of “the basics” provided in the information pack and, using their home



Figure 5. Service membership card

# Whose Diabetes is it?

computer, guide them through the information available on the Whose Diabetes is it? website and set up their personal 'my diabetes' area.

### 2.3.3. School

Throughout the project, young people, parents and the participating DSN told us that school presents some of the biggest challenges for young people in managing their diabetes. As part of *Whose Diabetes is it?* we have rebranded the healthcare plan that is used in Rotherham schools. However, this document alone cannot deal with the issues young people and their teachers face at the moment they face them. Practical project constraints meant that we were unable to investigate this area further, but further funding would enable us to explore different ways of supporting young people and schools with more direct information and support.

For example, the principle of "access via means that better fit" could be applied to the working practices of the school. Such as using the electronic register systems\* that the majority of schools already employ to flag a pupil's health condition to their teacher and prevent misunderstandings about the use of blood glucose meters and pumps in classes (a common experience for our participants).

\* Rotherham Schools use the School Information Management System (SIMS), which is developed by Capita Group (<http://www.capita-sims.co.uk/>).

### 2.3.4. Website

There are many excellent sources of diabetes-related information on the internet (Diabetes UK, JDRF), many of which have had huge resources spent on them and are tailored to specific age groups and sub-populations. We were surprised to find that many of our participants did not access these sources to support their self-management and instead simply waited to speak to their DSN at the next appointment.

Expecting young people, parents and carers to access external sites (such as Diabetes UK) relies on their deliberate effort to search for and find relevant information. And such intentions, whilst firmly held face-to-face with a clinician, can soon get lost amidst everyday life.

*Whose Diabetes is it?* makes this information easier to access by making it part of the service itself – DSNs refer to the website in clinic, NHS guidance leaflets are stored on it, and printed materials reference further details on the site. As an information resource, the *Whose Diabetes is it?* website does not seek to re-create information shared on other sites rather, through collation and approval by DSNs and other clinicians, direct people to appropriate content on trusted external sites.

We have confidence that using the *Whose Diabetes is it?* website as a portal to these sources of information centralized (see figure 7) in one place with the assurance that the information has been approved by a DSN/clinician, will reassure people as to the relevance of the information and encourage more of them to access it.



Figure 6. Characters 'Katie' and 'Aaron'

The screenshot shows the 'Help and information' section of the website. It includes a list of topics like 'How to treat a hypo?', 'What is insulin and how does it work?', and 'How and when should I inject?'. There are also sections for 'Beyond the basics' and 'All the information given to you by your NHS Diabetes team is available for download here.'

Figure 7. Website help and information page

## 2.4. Going to Clinic

Clinic remains the single most identifiable interaction between young people and healthcare professionals. It is incredibly important for professionals, but we have evidence to suggest that young people do not always find it as useful. Whilst it currently provides the primary opportunity for young people to ask questions, many were unwilling to do so and certainly would not ask questions on sensitive subjects.

With our participants, we devised alternate ways of facilitating communication between young people and their healthcare professionals.

### 2.4.1. Action plan

Currently, diabetes clinics use a bubble diagram to provide a focus for consultation discussions. Although having an informal layout, this document still prescribed areas for discussion via the bubble headings. We have adapted this document into an Action Plan (see Figure 12) designed to be completed by the young person and their DSN in clinic then stored on the *Whose Diabetes is it?* web site for later access. This plan begins with an agenda for this discussion, completed by the young person, in three areas we identified as being of importance to them. The second part of the document enables young person and DSN to agree goals and actions each will complete to help attain them in the interval before the next clinic (typically three months).

Being a 'live' document on the personal area of the *Whose Diabetes is it?* website means that the action plan can be referred to by the young person and their DSN at any time during and between clinics, and in other electronic communications (email, text message etc.).

### 2.4.2. Bespoke text reminders

The screenshot shows the 'Katie's Personal Support Group' page. At the top, there's a green header bar with the website's logo and navigation links like 'About', 'News', 'My Diabetes', 'The Basics', 'Common Questions', 'Help and Info', 'NHS Diabetes Teams', and 'Support Groups'. Below the header, there's a profile picture of a cat and the group name 'Katie's Personal Support Group'. A sidebar on the left shows 'Hidden Group active 1 minute ago' and 'My little team to help me look after my diabetes.' Under 'Group Admins', there's a profile for 'Katie Riley'. The main content area shows a post from 'Katie Riley' about a hypo and another from 'Daren Gamble' about food. At the bottom, there are links for 'News', 'Support Groups', 'Members', and 'Activity'.

Figure 8. The social networking section of the site.

Personalized text messages can be configured to remind young people of items associated with their action plan. Such reminders can be programmed to coincide with important events, or times when motivation or memory needs a little help. These texts are agreed at clinic and are implemented by the service. There is a body of evidence building around the use of motivational texts and, if initiated by the young person, it is a way of them demonstrating ownership of their condition.

### 2.4.3. The 'my diabetes' section of website (social networking)

As well as being an information resource, the *Whose Diabetes is it?* website also has a personal, password-protected 'my diabetes' section (see figure 8). This feature enables private storage of a young person's action plan but it also provides social networking functionality similar to Facebook. That

is, young people, parents/carers and DSNs have online profiles, can choose to make 'friend' connections with each other, and create and join groups for discussion and sharing.

Our participants' experiences showed that young people have groups of people who provide support – their parents/carers, their health professionals, friends at school or through support groups such as RYDA. The groups aspect of 'my diabetes' enables such 'circles of support' to be created online. For example, a young person might join the RYDA group or a group of teenagers with type 1 in South Yorkshire. Crucially, 'my diabetes' enables personal support groups consisting of the young person and their parents/carers and DSN, which create private forums for discussion of personal issues related to a young

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person's wellbeing (including their action plan).

Facilitating several groups provides circles of support but also enables social interaction with others who "get what it's like" so that the website can be about more than diabetes. 'My diabetes' provides another incentive to use the site and be only a mouse-click away from information and advice.

## 2.4.4. Anonymous advice via text message

When asked how they would prefer to deal with diabetes-related issues rather than in clinic, our young people suggested a simple question and answer service via text message. We have trialed such a system, where young people sent questions to the service and received answers via text through an interface that allows them to remain anonymous. Text messages provide a limited space in which to give detailed answers, so short web links to fuller answers on the *Whose Diabetes is it?* website are included in answers (also reinforcing its role as centralized information resource). We recognize that anonymity could be problematic if serious health concerns or potentially harmful behaviour are alerted by young people's questions. We therefore propose that the anonymity feature of such a system could be 'unlocked' through the agreement of two DSNs to enable them to take appropriate action.

We suggest that this approach might allow young people to ask about sensitive subjects and for parents to ask questions that they 'should' already know the answer too.

See appendix 2 for a flowchart that outlines this process.

## 2.4.5. Seasonal text messages

Embracing text messaging as a means for the diabetes service to interact with young people enables more direct communication through a highly personal piece of technology (their mobile phone). It also means that a large group of service-users can be given specific information at relevant times during the year – e.g. advice about travel or the start of a new school year (again, linking to details on the *Whose Diabetes is it?* website). Such messages then provide opportunities for young people to re-connect with their diabetes and access information that empowers them to take greater ownership of their care.

## 2.4.6. Welcome event

As discussed above, clinical expertise is not the only form of knowledge. There is a huge amount of knowledge and experience available through peer support groups. However running peer support groups takes a lot of commitment with limited formal recognition from the NHS.

*Whose Diabetes is it?* makes explicit the link between clinical and peer expertise, through an NHS-supported, peer support group-led Welcome Event. Through this six-monthly event, new families are introduced to the range of support available both inside and outside the NHS in a way that shows all forms of knowledge as equal and allows young people and families to meet other living with diabetes in an informal and non-hospital-based setting. Together with the lead parents of local support groups, we have designed this event and produced guidance materials that enable parents to run this event independently. Parents have also run one such event and received positive feedback from the newly diagnosed families that attended.



Figure 9. Welcome event scene as depicted in the video.

### 3. Introducing the methods

There is a rich history of using design and particularly participatory design across a range of sectors. UCHD is researching the effectiveness of such methods in healthcare. This project deliberately set out to investigate type 1 diabetes from the perspective of the young person, and to work collaboratively to design a service that kept the young person at the heart of the experience.



Figure 10a.'Body-mapping' with the participants

We used a range of methods: some innovative to design and many innovative to traditional service improvement. We plundered popular culture finding success in using formats where young people knew how to behave and what was expected of them. These were not only fun and engaging but delivered valuable design insights that helped UCHD, the young people, Rotherham Paediatric diabetes service and our other partners develop an innovative service proposal.

We describe our methods in detail and discuss their effectiveness in several academic papers, which are listed at: <http://www.uchd.org.uk/uchd-in-action/publications>. We give some illustrative examples below.

*“Again it was surprising the different ideas that came out. I mean the younger ones had a lot more ideas than us. Some of the things that they were coming out with were quite enlightening; it shows they are taking interest in their life if you like. Probably more than we realise as parents.” (parent)*



Figure 10b.'Dragons den'

A workshop framed around TV programme “The X Factor” was used to help the young people prioritise ideas. Winners were announced using iconic “award show” props (gold and silver envelopes etc.). This made the activity both understandable and enjoyable for everyone.

In a subsequent workshop, young people and their families prepared to present their service innovations to a “Dragon’s Den”, following the format of the TV programme. Groups presented their ideas to four Dragons with relevant experience of where the ideas might be used: NHS Senior Manager Mark Cobb; Design and Technology Teacher Russell Fisher; Senior Diabetes Consultant Simon Heller; and Boots Superstore Manager James Stout.

Following the presentations and questions from the Dragons, each Dragon chose to “invest” in one group and spent time with them exploring the best features of their ideas, and identifying practical hurdles and possible improvements based on their experience.

In general the Dragons were very positive about the ideas and surprised about their innovativeness. The young people and parents were also encouraged by presenting their ideas to external experts and by hearing their helpful comments and suggestions.

*“Yeah it was quite fun, new experiences, it got people talking more and got us working in teams. It gave us the chance to speak to other young people about how they feel about diabetes and how they can change it.” (young person)*

## 4. Rotherham and Diabetes

Rotherham already provides good information and support for young people living with type 1 diabetes and their families. And further support on the day-to-day issues of living well with type 1 is provided by family support groups such as Rotherham Young Diabetes Association (RYDA). The majority of support from Rotherham’s paediatric diabetes service is currently provided via clinics, where young people have told us they do not find it easy to share their questions and concerns (if they attend at all). Also, not all young people and families are willing or able to participate in support groups. In summary, although excellent help is available from both healthcare professionals and expert patients, it is not being widely accessed.

Our related set of service improvements (titled “Who’s Diabetes is it?”) has three main benefits. Firstly, it makes information and support more accessible to young people and families by providing it in formats more relevant to their lifestyles (e.g. web, text messaging and email). Secondly, it encourages the development of a shared information resource by healthcare professionals and families living with type 1 that maximises the impact of their expertise by allowing it to be accessed 24/7. And thirdly it recognises that young people gain empathy and support from their peers as well as their parents and healthcare professional by enabling them to be part of different online “circles of support”.



Figure 11. Rotherham Hospital

## 4.1. 'Whose Diabetes is it?' response to Best Practice Tariff Standards

As described above the service allows the whole clinical team to add to and maintain a multi disciplinary, clinical repository of expertise that can instantly link to the latest research or service developments in Rotherham and across the world. It gives a clear professional image of the service and sets positive expectations for the relationship between young people and families with diabetes with the Rotherham paediatric diabetes Service.

We have evidence of periods of information overload especially around diagnosis that would prevent the expert advice being offered being internalised. Accessibility to this resource is not time limited and supports the current provision provided by the Rotherham team, but allows young people and families the opportunity to access information at a level and time sensitive to their progress through the journey that is diabetes.

Whose Diabetes is it?		Action plan
Name	Aaron Grant	Date 03/05/12
You fill this together before clinic.		
My current concerns	<p>How will it affect playing sport at school? What happens if I forget to test at school?</p> <p>E.g. How might stress of exams effect my diabetes?</p>	
School	<p>I don't want to be treated like I'm 'different' from my brother Will I still be able to play outside with my friends, what if it clashes with injecting or eating? E.g. growing up, brothers or sisters</p>	
Home	<p>What happens if I have a hypo and no ones around to help?</p> <p>E.g. social life</p>	
Out and about	<p>Is everyone at the clinic the same as me? What if I forget to ask something or I don't want to ask?</p>	
Clinic	<p>You complete this section with your DSN.</p> <p>I want to be able to continue to get better at football and make it onto the football team. E.g. I want to have good performance during exam time.</p>	
My goals	<p>I will regularly check my blood glucose levels throughout the day to ensure that I am ok to play my sports. E.g. I will check my blood glucose more regularly during exam period.</p>	
My actions		

Figure 12. A section of the Action Plan

An advantage of a web-based system is that once the information is present it can be accessed in different forms. It would be possible to create an interface that could track young people's progress through the content of the site, ask simple questions to test comprehension and deliver a reward in the form of a certificate or "badge" to show they had completed it. Diabetes staff could review the responses and identify areas where structured education needs to be strengthened or additional resources delivered.

*"I mean we are more aware now that more people are involved and there's a lot of other agencies and a lot of other things out there that are available to people with diabetes now." (parent)*

The web also allows the easy creation and dissemination of surveys, these could be around patient experience of the service through to psychological screening tools, able to be completed whenever and wherever the individual is and has access to a web enabled device.

*"There were bits that were quite good; I mean the website is good for some people. It's not something that I use, I think I've used it once or twice and it helps other young people with diabetes keeping contact with them. Like I said some people might find the messaging service quite good just for questions that they need to have answered and things like that." (young person)*

The system we propose would enable contacts between the young people and families with diabetes and the paediatric diabetes service to be far more frequent, by allowing different modes of communication through text messaging, not only from the service but from young people to the service. We have evidence to show that being able to text questions into the service is practicable but also allows people to ask questions on their own terms. Sending out newsletters and more targeted resources allows a different level of communication which delivers contact between clinics, when perhaps engagement might otherwise drop away.

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When 24 hour specialist cover is implemented, text messaging delivers a easy to triage means of fielding enquiries, freeing up busy clinicians to deal with emergency management.

Text messages are already used to remind people about appointments, with the service we propose this might extend to reminding people about specifics of their care, “remember to send your HbA1C in for clinic next week” or “ its your annual review why not pop to retinopathy screening first”. These simple reminders allow the service to deliver a better service for the patients by helping patients to help themselves.

The service exceeds the Best practice tariff in so much that it brings the peer support and lived experience expertise to young people and families in an accessible way. When the paediatric diabetes team is dealing with someone who is not engaged and is struggling to maintain their HbA1C it may be that another family or young person who has been through a similar situation may ‘reach’ them in a way that the clinical team cannot. Being able to access this expertise in a clinic setting might allow the clinical team to open up avenues for discussion that would otherwise be closed to them and offer young people and families a perspective on their own situation.

*“I think it’s given people knowledge coming from the voice of other people with diabetes of what can be changed in the future or how other people can be helped and it just gives them that bit more knowledge towards creating new ideas or new things that could help in the future.” (young person)*

Whilst we have designed the service with young people in the paediatric service, there is no reason that once you entered adult services that the service could not continue to support individuals with their information and support needs.

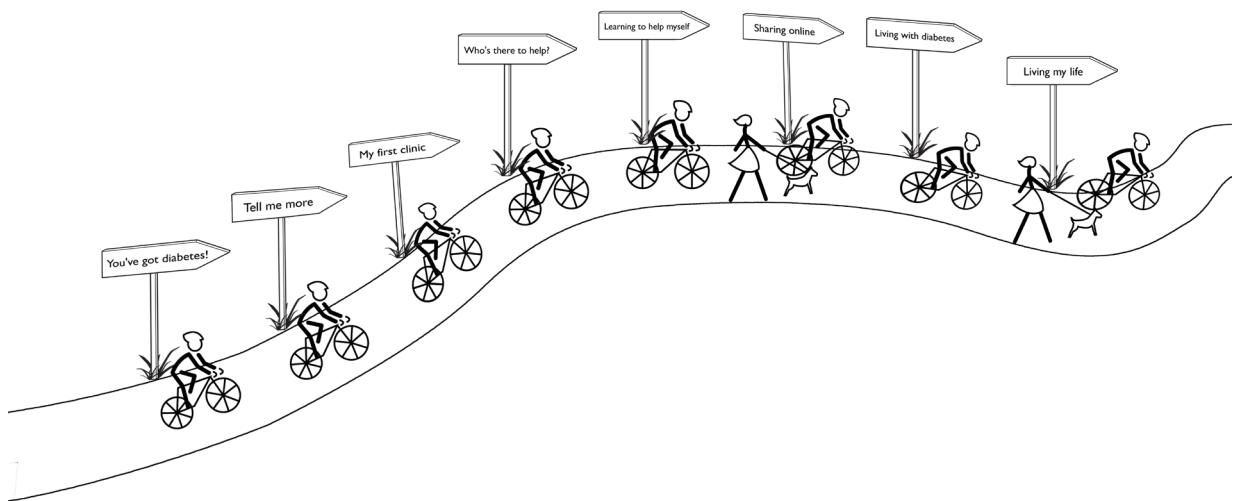


Figure 13. Journey Map

*“Watch this space. We’ll see what happens, I mean some of the ideas seemed really good, maybe not just for now but I think some of the ideas and that could appear in the near future.” (parent)*

## 4.2. Cost benefit analysis

Each Emergency Admission for DKA costs £1,250 (average across responses from 45 PCT's 2010) this pales into insignificance in the face of the long term implications of diabetic retinopathy or neuropathy, the incidence of which increases as engagement with diabetes decreases. Our proposed service has at its core the premise that by making the service easier to interact with young people will increase the number of occasions that they engage with both the service and their diabetes, increasing engagement and decreasing the incidence of long term implications.

It is our proposal that if the service was to be implemented in Rotherham we would undertake a research study of the effectiveness of the intervention to strengthen the evidence base of our assumptions.

One key part of this new service (entitled Whose Diabetes is it?) is a shared information resource and social media platform in the form of the web site: <http://www.whosediabetesit.org.uk>

This web site has been developed using the open-source 'blogging platform WordPress (<http://wordpress.org>) and social media extension BuddyPress (<http://buddypress.org>), plus a number of open-source plug-in extensions to these platforms. These technologies were chosen as they supported the rapid, cost-effective development and user-testing of a flexible and expandable web site, including all the necessary functionality, with access to a broad range of technical support from the open source development community.

## 4.3. Annual Costs of website

Costs can be broken down into four areas: hosting, maintenance, NHS user support, and site development. All these areas can be provided by Totaal, the external company who developed the site (<http://www.totaal.co.uk>) All costs exclude VAT unless otherwise noted, also see notes regarding non-VAT registered suppliers.

### 4.3.1. Site Hosting

The site is currently hosted by Yorkshire-based company Salt & Light Solutions, using their Mega hosting package with up to 1.5Gb web space and 12Gb/month bandwidth (see: <http://www.saltandlightsolutions.com/hosting&compare>).

Fixed cost of £50/year (company not VAT registered), already paid up to March 2013.

[Whosediabetesit.org.uk](http://www.whosediabetesit.org.uk) – already paid up to 19/6/2014

Zero (before March 2013),

£50 (March 2013-March2014),

£59.99 exc.VAT/£61.99 inc.VAT (after March 2014)

### 4.3.2. Site Maintenance

This consists of updating the relevant open-source software (BuddyPress, WordPress, and the associated 25+ plug-ins), including dealing with any conflicts that updates create.

6 person days per year at £350/day.

### 4.3.3. User Support

Training and ongoing support for the NHS users of the web site, specifically the Diabetes Specialist Nurses, Dieticians and Consultants of the Paediatric Diabetes service.

This option would involve Totaal providing training to all NHS users of the web site, with ongoing on-call support.

User training day(s) at £350/day\*

On-call support (banked time equivalent to 3 person-days extendable, as required)

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\* Totaal can accommodate up to 5 users per training session, but this depends on scheduling staff time, so additional days may be required.

## 4.3.4. Site Development

The web site, as it is, reflects the needs of the people we co-designed it with (young people with type 1 Diabetes, their families, and a Rotherham Paediatric Diabetes Specialist Nurse). However, as the number of users of the site grows, it is likely that it will need to develop to fit the way service-users and NHS staff use the site. It is difficult to put exact costs on any work that may be required, but we provide conservative estimates below.

Consultation with site users and site development equivalent to 10 days at £350/day.

## 4.4. Text Messaging Costs

Costs for the text messaging elements of the proposed service are in two parts: the cost of sending text messages; and development costs for a web-based system to manage the content and scheduling of these messages.

During user testing of the text messaging elements, UCHD used the Esendex service to send text messages with content and scheduling done manually for the small volumes involved. Esendex messaging costs are dependent on volume (further information at <http://www.esendex.co.uk/>), however Rotherham NHS may wish to use their existing text-messaging supplier to send messages. UCHD also have a working prototype of a text message content management/scheduling system, which could be customized for Whose Diabetes is it? Development costs would depend on the level of functionality and integration with existing systems required. Meaningful estimates are therefore difficult to provide here, but could be agreed if text messaging were to be adopted as part of the service.

**Total costs per year of £7500 (including development costs)**



Figure 14. Text messaging

#### 4.5. Gap analysis

As stated previously Rotherham provides a good service to young people with type 1 diabetes. The work we have undertaken in collaboration with the clinical team, peer support groups and young people has described a trajectory towards a new model of care.

The Rotherham NHS Foundation Trust has the opportunity to be at the forefront of diabetes service delivery, with a truly young person centred service, using innovative technologies. We hope this report provides the detail of what this service will look like and a sense of the excitement and enthusiasm that the young people and their families have contributed to its creation.

## 5. Acknowledgements

User-centred Healthcare design would especially like to thank the young people and families of RYDA and the Barnsley parents and carers group without whom the project would not have been possible and Sharon (Stone) Gamble whose enthusiasm and dedication inspired us to work with Rotherham in the first place.

This project would not have been possible without the following partners:

### Rotherham Young Diabetes Association

Is your child under 16 and has type 1 diabetes?

Would you like to meet other parents/carers of children with diabetes?

Would your child benefit from meeting other children with diabetes in an informal setting?

Would you enjoy fun/social activities as part of a group run by parents/carers of children with diabetes?

[www.ryda.org.uk](http://www.ryda.org.uk)



### Barnsley Support Group

Our group of parents and carers of children with type 1 diabetes is based in Barnsley, South Yorkshire. We meet 4 times per year to support each other in living with type 1 diabetes. We usually meet at The Emmanuel Church, Huddersfield Road, Barnsley.

[www.uchd.org.uk/](http://www.uchd.org.uk/)



The Rotherham NHS Foundation Trust

CLAHRC for South Yorkshire

#### Disclaimer

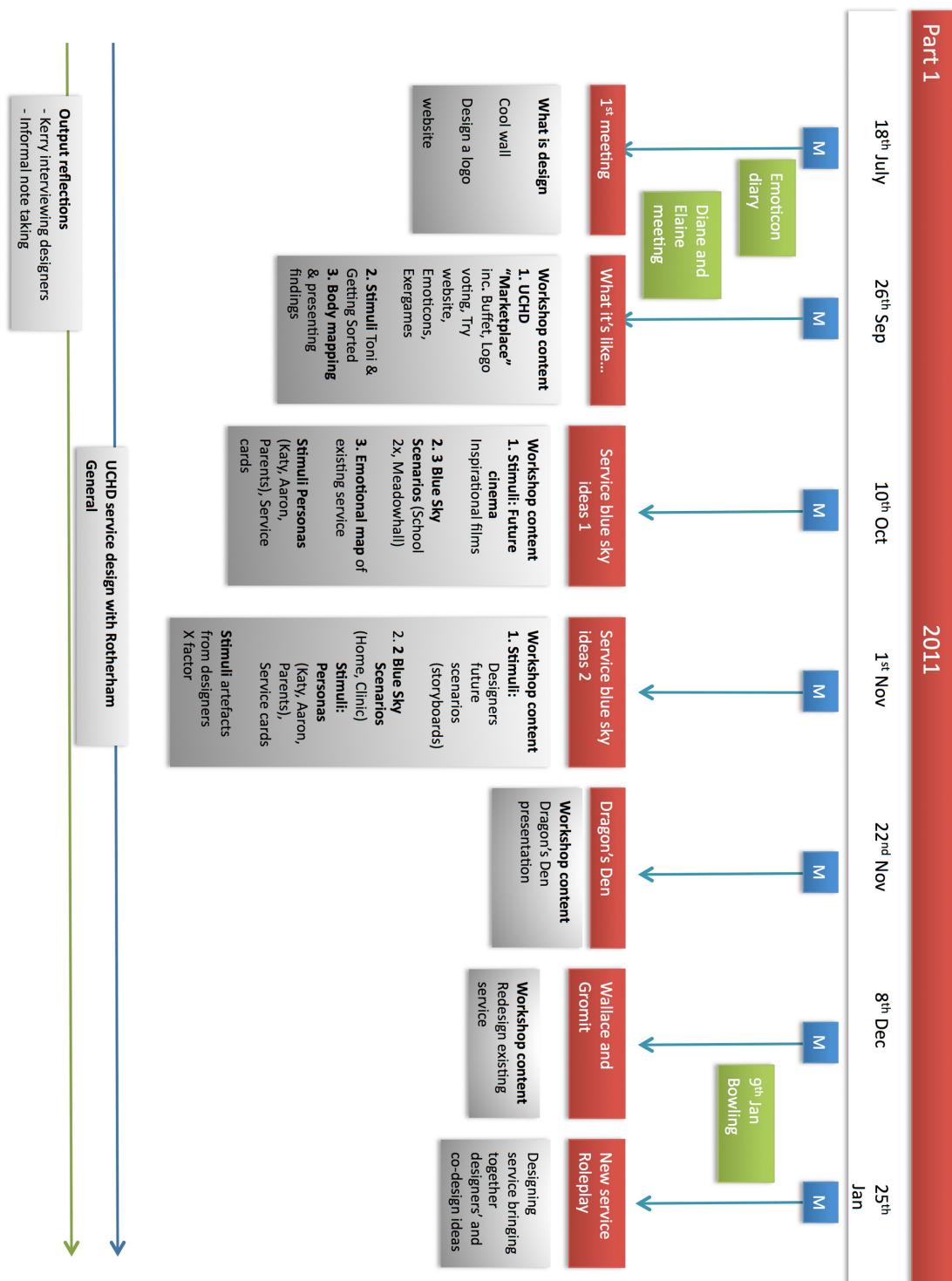
This report presents independent research by the Collaborations for Leadership in Applied Health Research and Care for South Yorkshire (CLAHRC SY). CLAHRC SY acknowledges funding from the National Institute for Health Research (NIHR). The views and opinions expressed are those of the authors, and not necessarily those of the NHS, the NIHR or the Department of Health.



CLAHRC SY would also like to acknowledge the participation and resources of our partner organisations. Further details can be found at: [www.clahrc-sy.nihr.ac.uk](http://www.clahrc-sy.nihr.ac.uk).

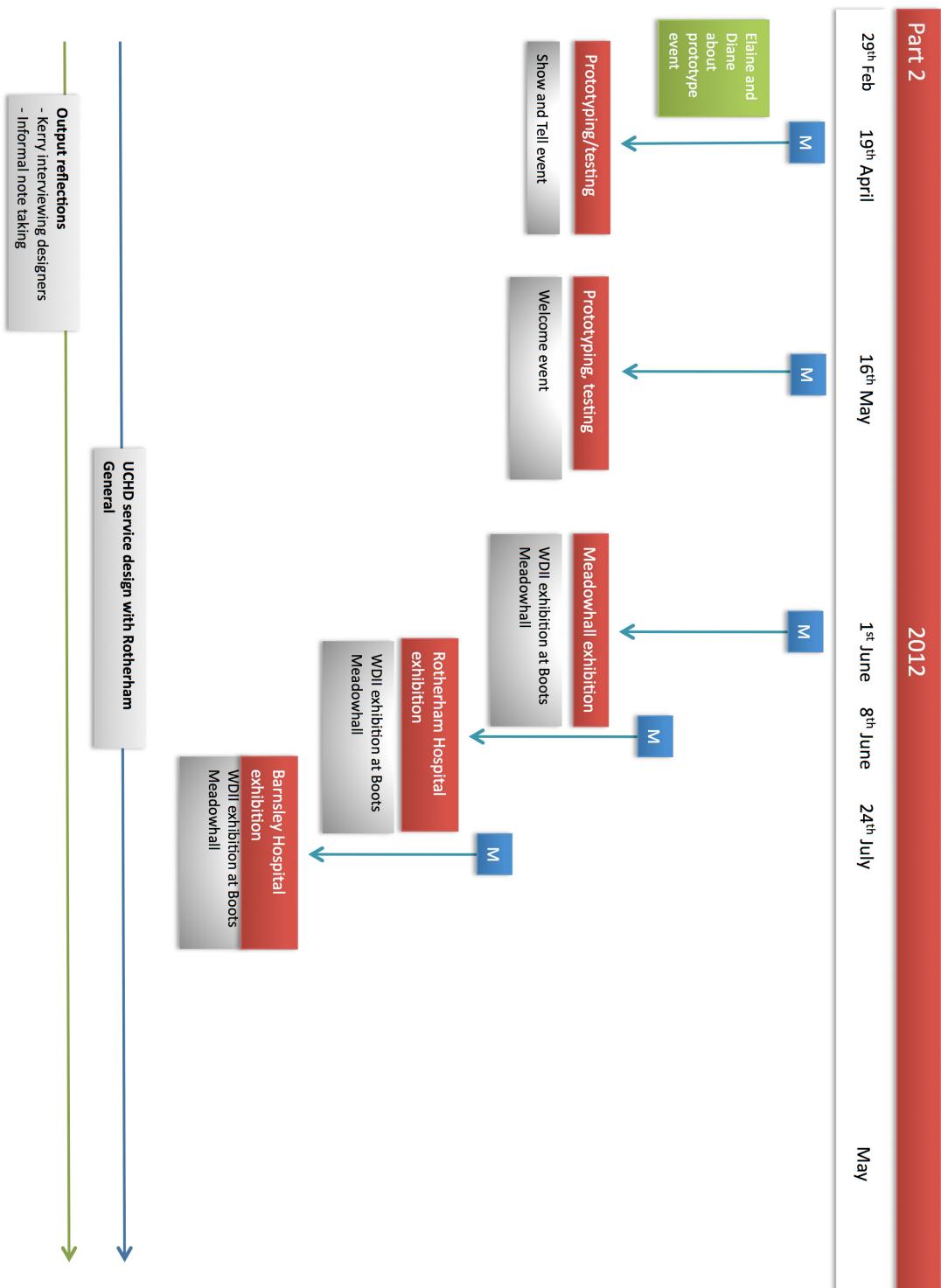
## Appendix I - Project timeline

### Part 1 of 2

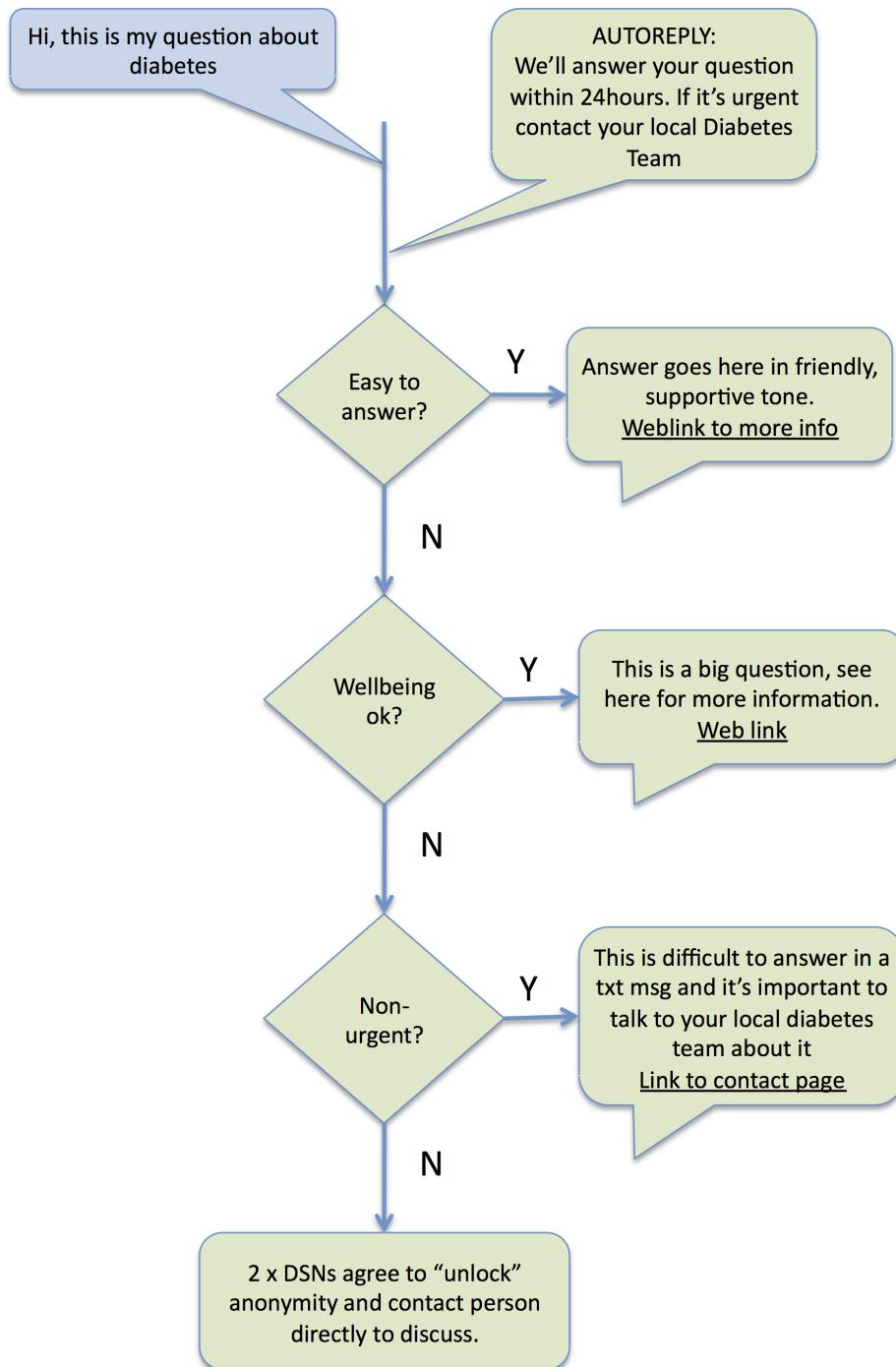


## Appendix I - Project timeline

### Part 2 of 2



## Appendix 2 - Automated Text Messaging System



*“Watch this space. We’ll see what happens, I mean some of the ideas seemed really good, maybe not just for now but I think some of the ideas and that could appear in the near future.” (parent)*