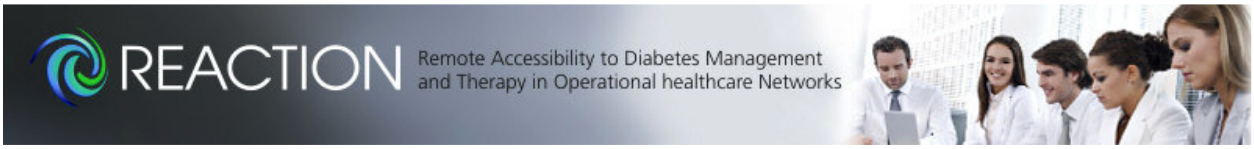

News from the REACTION project

Stay abreast with developments in closed-loop diabetes monitoring

Issue #1 - published by the REACTION project - November, 2010

First issue of the REACTION newsletter

We are very pleased to present this first issue of the REACTION newsletter. The REACTION project is committed to improve the daily life of diabetes patients across Europe with the aid of world class Information and Communication Technology (ICT). We are developing an integrated ICT platform that will improve long term management of diabetes based on wearable, continuous blood glucose monitoring sensors and automated closed-loop delivery of insulin.

The theme of this first issue is the potential benefits of the REACTION platform and how we have investigated disease management and clinical practise to derive the best possible requirements for the technical work that is already underway.

We look at how diabetic patients are coping with their condition on a daily basis and how healthcare professionals are struggling to manage the disease. We are seeking a solution that is equally valuable in the hospital setting and in the outpatient regime.

The newsletter will be circulated via e-mail, in PDF format, and will be posted on the REACTION web site as well: www.reaction-project.eu.

We hope that you will enjoy reading it!

Lydia Montandon, Project Manager
Atos Origin Research and Innovation

A life *not* governed by diabetes

Eight-year-old Villads Keiding from Denmark has had diabetes for two years. For him and his family the important point is not to let diabetes or blood glucose monitoring rule their lives.

“A big part of making the daily life with diabetes as easy as possible revolves around attitude, of not letting the diabetes take control of one’s life, but of having a few easy-to-use devices that efficiently help monitoring and controlling the blood glucose level.” The words belong to Johanne Keiding, mother of Villads Keiding who was diagnosed with diabetes when he was six years old.

In the following we have asked Johanne Keiding what it is like to live in a family with a child that has diabetes and what, in her opinion, can make the disease easier to manage.

The family

We are a family of five: Two grown-ups, Jens and Johanne, and three kids: Nora, fifteen, Marie, twelve and Villads, eight. Villads was six years old when he was diagnosed with diabetes. He had all the classical symptoms; he peed a lot, was thirsty and hungry all the time and generally in a bad mood, cranky and not happy.

How has diabetes affected your daily lives?

In the beginning it affected our daily lives immensely, so much that our other children asked whether we could talk about something other than diabetes, blood glucose values and carbohydrates once in a while.

But from very early on, we and Villads himself have been very aware of NOT letting the diabetes rule our lives. It has added an additional awareness; there are some things that we cannot forget and some things that we have to do but in general we have not changed our daily lives all that much.

Villads’ school and after-school care have both been a great help by taking an interest in and learning about diabetes and without a lot of fuss, they make us as well as Villads feel safe.

Describe a typical day

Villads has an insulin pump. A typical day is quite similar to before the diabetes, apart from the blood glucose monitoring and the weighing of some of Villads’ food. We/Villads himself measure the blood glucose seven times on an average day: morning, before lunch, when after-school care starts, in the afternoon, before dinner, when Villads goes to bed and before we go to bed.

Every third day we change the infusion set for the insulin pump.

In this issue

In other news

Future Dissemination Events:

MEDICA 2010
17-20th November 2010
The International Marketplace for Worldwide Medical Knowledge.

Healthinf 2010
26 - 29 January 2011
International Conference on Health Informatics , Rome

New Project Deliverables Released:

The following deliverables have been completed:

- D2.1 Scenarios for usage of the REACTION platform (Public)
- D2.4 Market and regulatory standards watch report (Restricted)
- D2.5 Initial requirements report (Restricted)
- D4.3 Technical requirements for medical data management (Public)
- D5.1 Communication standards within BAN and PAN (Public)
- D10.1 AmI test bed (Restricted)
- D12.1 Project website (Public)

Public deliverables can be downloaded from the project's website:
www.reaction-project.eu

Villads is a very active kid; he plays soccer twice a week and participates in a lot of sport activities in the after-school care. After school Villads often plays with his friends; we live in a neighbourhood where the kids can run around and visit each other without being accompanied by grown-ups. The other parents know of Villads' diabetes.

How much are you involved in the treatment?

We are responsible for most of Villads' treatment. Villads himself is getting more and more involved and we are very aware of the fact that he is actually the only one who really knows how it feels. We encourage him to trust his own feelings, because most of the time he is right about e.g. approaching hypoglycaemia. He has also very quickly acquired skills in counting carbohydrates and in using the bolus guide in the insulin pump. He also knows how to take off the pump and put it on again, for instance in connection with sport activities.

On the other hand, we are also aware of not putting all the responsibility on Villads and we talk to each other, Villads and the school and after-school people, about this balance once in a while.

How often do you visit the hospital and what do the visits consist of?

We go to consultations at a children's diabetes clinic every three months. The first year it was every month. At the consultation, Villads' average blood glucose level is measured, he is weighed and his height is measured. Our diabetes nurse looks at a transcript from our blood glucose meter and the settings of insulin doses in the pump. And we talk for around half an hour about how everything is going.

Where have you acquired knowledge on diabetes? And have you been satisfied with the information given by the health system?

The hospital and the clinic have both been immensely helpful. They have provided a vast amount of information. Apart from that, we have been talking to other people with knowledge of diabetes; a couple of our close friends are diagnosed with Type 1 diabetes and we are also in contact with some families with children having diabetes. We participate from time to time in events organized by the Danish Diabetes Association and JDRF - Juvenile Diabetes Research Foundation.

What could make the disease easier to handle on a daily basis?

I asked Villads this question and he answered that a cure for diabetes would be great. Apart from that, he would like an intelligent insulin pump paired with an intelligent blood glucose monitoring system so that he didn't have to do anything himself.

A smaller and more intelligent insulin pump linked to a continuous blood glucose meter with built-in configurability would work towards this goal but at the same time I think it is very important not to have one's life totally governed and monitored by devices.

What would you say if your son could carry an intelligent plaster that could monitor the blood sugar level continuously and advise on the administration of insulin?

I would be very aware of how much an intelligent band aid would affect living a 'normal' life, how much it would govern our as well as Villads' actions. I am a bit sceptical about the effect such a band aid could have on Villads' own sense of e.g. his blood glucose level. On the other hand, with the right monitoring balance and some clear agreements on when and how the people that have access to the data can react, such a band aid might work towards a more seamless and efficient monitoring and control of the diabetes/blood glucose level.

What is the greatest challenge in the management of diabetes in the future?

The balance between well-monitored blood glucose and a life not governed and controlled by blood glucose values and levels. The biggest challenge in future treatment of diabetes is to find a cure.

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The complexity of diabetes management

The REACTION project has investigated the clinical workflows in a general practice and in a hospital to close the gap between present practice and the potential of the REACTION platform. The results have been used to develop a set of initial requirements for the platform.

How do feel your diabetes management is currently being delivered? What problems are you facing? What do you think would help? Do you see any value in knowing what value your blood sugar is all the time?

These were some of the questions asked to diabetic patients participating in a workshop on diabetes management that took place earlier this year at the UK based general practice, Chorleywood Health Centre. Supplemented by a workshop at the University of Graz in Austria, the two sessions were held with the aim of identifying existing clinical routines in diabetes management outside and inside the hospital and

European Commission Information Society and Media

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Read more at:
www.reaction-project.eu

to determine the requirements of patients, informal carers and healthcare professionals. The results show a need to consider all the co-morbidities existing alongside diabetes when providing treatment and to develop a platform which supports the decision making process in a way that makes monitoring of blood glucose levels easy, efficient and less error-prone.

The co-existence of diseases

For diabetic patients in contact with the healthcare system outside the hospital, the goal for the REACTION service platform is to help the patients to better control their diabetes by giving them monitoring devices which continuously monitor the blood sugar level and give feedback on treatment.

One of the most significant outcomes of the five interviews conducted in Chorleywood Health Centre, a medium sized general practice in North-West London and partner in REACTION, was the fact that even if the participants were all at different stages of the disease, with different types of the disease, they had one thing in common. They all had complications and co-morbidities existing alongside their diabetes. Shona Thomson who is a Practice Nurse at Chorleywood Health Centre explains:

“Diabetes impacts on all systems of the body: Eyes, kidneys, cardiovascular system, endocrine and nervous system. Often eye disease is present at diagnosis and some men have been screened after presenting with erectile dysfunction and found to be diabetic. This means that patients with diabetes will rarely just have diabetes apart from the very young Type 1 insulin-dependent patients under 18.”

Since co-morbidities are present in practically every diabetic patient, clinicians need to look not only at blood sugar control but at the entire range of co-morbidities in order to give the best possible care.

“The co-morbidities associated with diabetes are serious. If patients with diabetes do not control their blood sugar well, they can develop renal disease, neuropathy, diabetic retinopathy and atherosclerosis, which is caused by narrowing of the arteries. If not looked for or monitored, this can result in heart attacks, strokes, gangrene in lower limbs, kidney failure and blindness. These are serious conditions often leading to premature death and disability which is why it is so important to ensure that all people with diabetes have regular check-ups, to ensure blood sugar levels are maintained within certain limits and ensure early detection of these possible complications, to avoid the poor outcomes associated with them. This will often entail lifestyle changes such as weight loss, more physical activity, no smoking and changes in diet including alcohol intake. There is good evidence that controlling blood sugar levels will reduce the incidence of these complications,” says Shona Thomson.

Monitoring can have a preventive effect

The REACTION platform will provide tools that support lifestyle changes and assist the patient in keeping the blood sugar level under control. For this purpose, REACTION aims to provide patients with a monitoring device such as a plaster with sensors that continuously monitor the blood sugar level of the patient and give feedback.

In general the patients were positive towards monitoring and feedback as a help to support lifestyle changes. One of the interviewed patients said that monitoring could actually help him understand how his blood sugar reacted when eating or doing exercise. Shona Thomson also believes in the preventive effect.

“I think that the platform would help the newly diagnosed understand which foods increase their blood sugar. If they keep a food diary, they can correlate this with the general trends. It will also help them to see how their medication helps to lower their levels so it may encourage them to participate more in their own care. The feedback the platform can offer will also be really useful to clinicians; it will show us when patients may need a bit more help and support.”

Diabetes management in hospitals

To approach diabetes management in hospitals, another workshop was held at the Medical University of Graz (MUG) in Austria, another partner in REACTION. MUG is a young university hospital offering a 20-bed in-hospital general ward with special expertise in the treatment of diabetes and associated metabolic disorders.

Since it is the nurse or the physician who controls the blood sugar levels in those hospitalised patients who are not able to control their blood sugar by him- or herself, the aim for the REACTION platform is to support the staff in improving glycaemic control of admitted patients using continuous blood glucose monitoring and therapy feedback.

Patients do not always know that they have diabetes

Unlike Chorleywood, most of the patients in Graz are not admitted because of diabetes or risk of diabetes but because of other diseases.

“Some patients do not even know that they have diabetes and others develop hyperglycaemia, also called stress-induced diabetes, caused by their primary illness. Unfortunately, patients with diabetes are more likely to suffer from other diseases hence the number of patients with diabetes in the hospital is large,”

explains Dr. Lukas Schaupp, a Senior Scientist at MUG.

Keep glucose levels within certain limits

In the hospital the aim is to cure the primary condition that caused the hospitalisation and to keep other complications within certain limits. However, there is a special interest in preventing hyperglycaemia since it can have considerable consequences for the health of the patient.

“Even if there is no clear evidence available, it is very likely that hyperglycaemia is not beneficial for the patient who can develop more complications, some of which can be life threatening. Our hypothesis is that keeping the glucose levels within certain limits is beneficial for the patients. However, this is labour-intensive and there is a risk of inducing hypoglycaemia in the patient, a state which is life threatening,” says Lukas Schaupp.

The system must support the decision on treatment

Since it takes a considerable amount of effort to control the blood sugar levels because of the frequent bedside glucose monitoring and decision making, it is crucial that information is readily available and adaptable and that the system streamlines the workflow processes and supports the decision on treatment.

“The relevant information must be available for the physician in a way that can be easily customised. The physician needs a visualisation of the relevant parameters, alarms/reminders for different tasks and finally decision support for dosing. Furthermore, the system should communicate with the hospital information system, with the laboratory system and also with the health record forms of the patient. Having the information available in an electronic form, it can be used simultaneously by different services, enabling also automatic processing of different tasks. This will mean less workload, fewer errors and easy archiving,” says Lukas Schaupp.

The system requirements are currently in the process of being implemented in REACTION and will be tested and developed during the project. For Lukas Schaupp, the potential of the project lies in proving that glycaemic control makes a positive difference and in applying the platform to other healthcare systems.

“Once the system is in place, it will be possible to conduct clinical trials to prove that glycaemic control is beneficial for the patients. In addition, the system which is going to be built for glycaemic management can be expanded to further applications, hence acting as an initial step towards a broader use,” concludes Lukas Schaupp.

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Making the REACTION platform work in different healthcare regimes

The REACTION platform has to work in all regions of Europe. To ensure this, REACTION is arranging four focus groups on technology and diabetes management in different European countries. The first two focus groups take place in November 2010 in Thessaloniki, Greece and Florence, Italy.

REACTION’s contribution to diabetes management is twofold. On the one hand, the REACTION service platform aims to help diabetic outpatients to better control their disease, with prompt feedback from formal carers and medical systems and appropriate risk assessment services. On the other hand, REACTION is expected to have an impact on formal carers in hospital wards by improving glycaemic control of admitted patients with diabetes using continuous blood glucose monitoring and therapy feedback.

REACTION has developed some initial requirements based on both settings earlier this year, one in Chorleywood Health Centre in England and the other at the Medical University of Graz in Austria. However, since the goal is to make the REACTION platform work in different healthcare regimes across Europe, there is a need to validate the requirements in more countries.

Understand in order to address

The objective of the workshops is to understand relevant personal, social and cultural factors related to potential REACTION services in order to be able to address ethical and social issues at the design stage of technology. Several themes will be addressed such as protection of personal data, the relationship between patient and healthcare provider and the level of self-management.

The aim is to establish what diabetic patients, nurses, doctors as well as healthcare professionals and administrators expect from technology and what values, beliefs, hopes and concerns are related to the use of REACTION services.

The results of the focus groups will be collected and analysed in order to give direction to the requirements

engineering process.

The focus groups are planned to take place between November 2010 and July 2011.

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