DR 2.3: Parental Monitoring Interface

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In this document we report on the work in work package 2 that relates to the development and pilot evaluation of the parental monitoring interface, *palInform*. *PalInform* enables parents (and health care professionals) to monitor the learning progress and the data entered by the children for whom they are responsible. The requirements for *palInform* have been based on input from the hospital partners of PAL project. The data - mainly when the child entered their glucose levels and activities with the PAL system - is provided in an aggregated manner, for which different time windows can be selected. Importantly, no private data of the child is presented in this overview, such as pictures or texts and diary entries. This is a design choice to balance between medically and system-usage relevant data and the child's privacy. In this deliverable we report on a pilot evaluation done with health care professionals. Initial analysis of the results are also presented in this deliverable. In D2.4 we report refinements based on these initial results and the evaluation with parents.

Executive Summary

The parental monitoring interface, *palInform,* is the software module in the PAL project that enables parents (and health care personnel) to get an insight into how their children use the system, their progress, and what dietic values they fill in. It provides a timeline of the most important events, based on system activity and the data the child enters, in an aggregated manner. palInform is integrated into the pal Control web application (see Deliverable 2.2). The monitor shows health, nutritional, activity and emotion related data for a child, as entered by the child via the timeline in the MyPAL app. The monitor is available for both healthcare professionals (HCP) and the parent(s). The child and parent can set agreements on what information will or will not be available. Requirements were developed together with the hospitals in the PAL project. We developed the prototype and report on the evaluation of this prototype with HCPs. In a later stage palInform will be coupled to the PAL system. It will make use of the general ontology underlying the data in the system (see appendix).

Tasks, objectives, results

1.1 Planned work

The work planned for this deliverable relates to Task 2.4. It consisted of the following items. The parent monitoring panel provides monitoring information to the parent. This module enables the parent to keep track of developmental and health related issues. First, it presents information on how well the child is doing with respect to achieving the self-management goals set by the health professional. Second, it presents physiological data of the child so that the parent can see how well the child is managing, for example, glucose levels. Third, it presents the parent with PAL usage data. Privacy of the child needs to be taken into account. We planned to develop a formal model for norms related to privacy.

1.2 Actual work performed

With the exception of the formal modelling of privacy rules, all planned work has been carried out or initiated. In the end, for this project, it was decided that the formal modelling of privacy was too much out of scope for the concrete requirements of the parental monitoring interface. We did analyze privacy concerns at multiple occasions (e.g. during PAL meetings and workshops), and it was concluded that a practical balance needed to be found between child privacy and monitoring. This resulted in taking the health requirements as leading but then removing the privacy related information such as diary entries, texts and pictures. The monitoring interface thus focusses on visualizing health relevant progress and

system usage. We specifically asked about privacy issues in the pilot evaluation. We detail the work done below.

1.2.1   Design of the palInform prototype

The first palInform prototype is a GUI based on the design specification from FCSR (Italian hospital partner). Currently it displays 'dummy' data of glycemic measures and insulin intakes in a graph, and registrations of meals, activities, emotion and goal/achievement attainment below. Each section can be hidden or shown using checkboxes at the top. The user can select a start date, and choose to show entries for a day, week, month or three months. We evaluated the design, usability and privacy concerns of this prototype. The next step is incorporating these evaluation results and coupling palInform to the PAL system so that real data are available.

1.2.2   Evaluation Method

palInform was evaluated in two hospitals in the Netherlands, with a total of three paediatric diabetic nurses. All healthcare professionals (HCPs) are involved in the PAL-project and have experienced working with palControl, but viewed palInform for the first time. During individual semi-structured interviews the representation of information, information needs, and usefulness in patient treatment and education were discussed.

Upon first seeing the interface showing the week-view, each HCP immediately, at their own initiative, started telling what they thought they were looking at. After this, each section was assessed in detail, discussing whether information was clear, relevant, and complete.
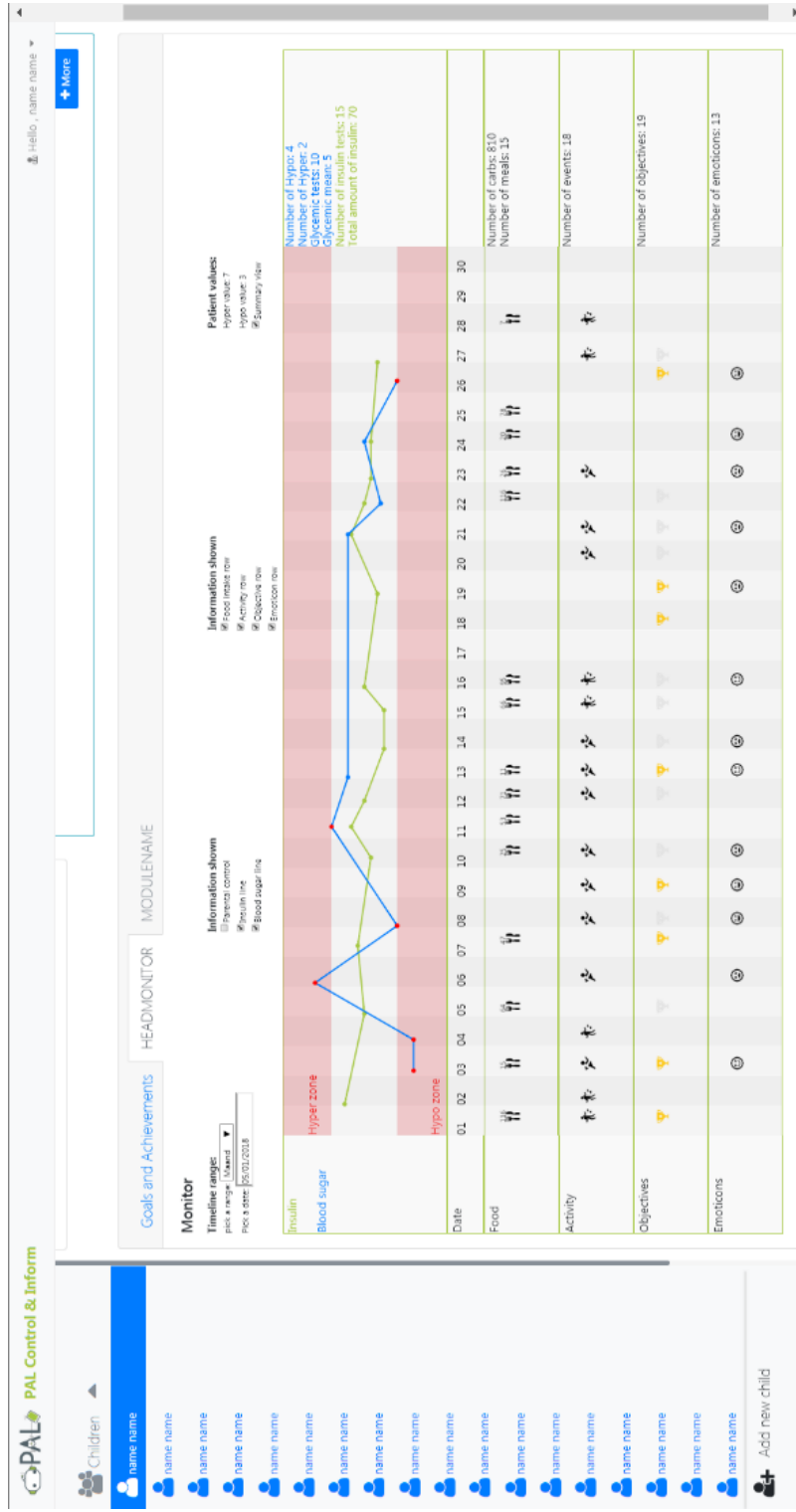
Figure 1 palInform interface for health and activity monitoring.

1.2.3 Evaluation Results

Overall the first palInform prototype was received positively. The required information was mostly present and the monitor gives an overview of the relation between activities and health status. This is considered an added value compared to current systems that are limited to presentation of health information. However, the trustworthiness, and thereby value, of the information is highly dependent on adherence to regular timeline entries by the child.

Information Representation

All HCPs immediately understood the type of information shown in each specific section of palInform. Two HCPs did not notice the date and, therefore, did not immediately understand the relation in time between entries in different sections. None of the HCPs attempted to click on any data element, all HCPs did hover over elements attempting to see more detailed information. One HCP showed active usage and expressed appreciation of the option to hide specific sections to support focus on certain sections.

All HCPs understood the blue graph to represent glycemic values and shortly noticed dots representing unique measurements showing the exact value when hovering.

In the glycemic quarterly-view the graph gives a quick overview of the frequency of and pattern in hypos and hypers a child has experienced. However, this graph can be very misleading, especially in the week-view, because a couple of good values do not tell what happened in between. Hypos/hypers may not have been entered into the timeline.

All HCPs understood the green graph to represent insulin intake, but were unsure about the meaning of the number shown upon hover. This will be made more clear in the next version. Although the insulin dosage –units- has a different scale then glycaemic values, none of the HCPs expressed to be hindered by their overlapping graphs. Nonetheless, two HPCs expressed a preference to show the insulin graph below the glycaemic graph instead.

All HCPs had some difficulty understanding that 'Food' displayed the carbohydrate intake. The label 'Food' differentiates from the HCPs usual notion of 'CHO' (or 'KH' in Dutch). Moreover the number for the amount of carbohydrates was relatively small and easily overlooked by the predominant cutlery-icon. Moreover, all HCPs expressed major concerns towards clarity and readability of this section when children do there timeline entries on a regular

basis; which may lead to up to eight meal entries a day. These issues will be taken into account in the next version.

All HCPs immediately grasped the idea of the activities section, and expected the icon to depict the type of activity undertaken by the child in correspondence with the icons in the MyPAL app.

All HCPs understood the emotion section to reflect the emotional status of a child. None of the HCPs were aware that these entries are always related to a specific activity – children can only report an emotion within an activity entry. This needs to be clarified in the interface.

All HCPs immediately understood that this section was related to the 'Goals & Achievements' set and monitored in palControl, but did not understand what the silver and gold cup represented. This was to some extend due to missing the description of the attained goal/achievement.

Information Needs

The current palInform GUI facilitated most of the HCPs' informational needs. The most important being the 'trinity' glycaemic values, insulin dosage and carbohydrate intakes, and their relation in time. This is well and clearly presented in the monitor. HCPs valued the additional insight in the child's activities. Specifically a medium-long term overview, may give insight into patterns of activities, emotions and education progress and how these relate to health status.

It is important to note that all professionals distinguished between health information and activity. Where health information are glycaemic values, insulin dosages and carbohydrate intake. HCPs are used to receiving this information via insulin pump reports. Activity information is information related to the child's sports activities, emotions, education efforts, but also irregularities such as illness, injury, exams or stressful events. Two HCPs expressed to be mainly interested in these irregularities but felt the tool does not support them in finding these.

All HCPs valued the monthly view for finding patterns in activities and relations with activities. The day view was valued if interested in details. The week view most closely resembled the period they reflect upon during consultations, which is a two-week period. The quarterly view was considered less valuable but might support finding more long term patterns in health status.

In general, the following summarizes the findings.

- Desired functionality
  - Glycaemic measurements and value per measurement.
  - Frequency of hypo and hyper vs within target values.
  - Insulin intakes and dosage per intake.
  - Carbohydrate intake (per meal).
  - Activities done.
  - Short-term overview of relations.
- Not needed
  - Quarterly view
  - Summary of carbohydrate intake
  - Summary of insulin total and amount
- Missing functionality
  - Two week overview
  - Personalised target values for glycaemia
  - Summary of average number of insulin intakes and dosage (units) per day
  - Summary of number of positive and negative emotions
  - Activity duration
  - Goal/achievement description
  - Goal/achievement activation date (and completion time)

Further, HCPs expressed interest in more than data points. For example, what caused a certain emotions, or, non-progressing learning would benefit from an option for the HCP to add a note to themselves after discussing it with the child.

Ethics

The summary data is relevant only when entries have been done on a regular basis. Moreover, to decide the patient treatment and education plan the HCP needs to have a complete view of the child's health status. The monitor only shows the data entered in the timeline by the child – it is not connected to the insulin pump that already holds the medical information. Commonly, children show weak adherence to these type of tasks. Therefore the monitor is not usable as a medical aid. However, it can give insight on the relation between health status and activities. Noticed patterns or particularities may be useful as an entry point for conversations.

All HCPs expressed concerns with respect to making the monitor available to parents. It should be transparent to the child –and the HCP– which information is shared with whom. Moreover the child should have control over this. Especially

during puberty, health information becomes more confidential between the child and the HCP. This might result in children not sharing any data.

Discussion of the option to allow children to limit what their parents can see to some degree remained inconclusive, especially regarding the required policies. Issues such as a hypo or hyper are rarely an immediate treat and sharing that kind of information with parents is not necessary and in some case even may make things worse (overly worried parents).

Summary of the possible adjustments for the next version

- Add a two-week range.
- Show the insulin graph below the glycemic (instead of overlapping)
- Enlarge glycemic and insulin points (so it is easier to hover over them).
- Set glycemic default range to 4-8 (preferably possibility to personalize this range).
- Show number of units taken when hovering an insulin data point.
- Color hypo (low) blue instead of red.
- Make lines in graphs optional.
- Rename 'Food' to 'CHO' (and Dutch/Italian counterpart for carbohydrates abbreviation).
- Remove the cutlery-icon for meals, only display the amount of carbohydrates per meal (or present a meaningful icon; distinguish between type of meal and show different icons for each meal).
- Reorder sections, show emotion under activity and remove border between these rows (to emphasize relation between activity and emotion report).
- In summary for range day show number of insulin intakes, and total units
- In summary for range > day show average number of insulin intakes per day, and average units per day.
- Show details of elements upon hover (instead of click).
- In details, show duration of activity.
- In details, show description of goal/achievement.

Conclusion, relation to milestones and feedback

The palInform is a well-designed and helpful tool. It clearly presents the trinity carbohydrates, glycaemia and insulin. However, it can only be used to inform treatment and education plans if data is entered on a regular basis. Alternatively, data obtained from a sensor and/or pump could be connected. Nonetheless, the tool can serve as an entry point for conversions about wellbeing or activities. In

the current version information representation was sometimes confusing; this can be improved by some minor adjustments to the interface, and presentation of actual child data obtained from timeline entries. Based on this evaluation minor adjustments will be made to the GUI for release in the pal3.5 experiment cycle.

POST REVIEW FEEDBACK NOTE: please note that the refinements made and the parent evaluation are reported upon in D2.4 section *palInform prototype Integration*, reflecting the correct period in which this work has been executed.

References

1. Neerincx, M., Kaptein, F., van Bekkum, M., Krieger, H. U., Kiefer, B., Peters, R., Broekens, J., Demiris, Y., & Sapelli, M. (2016). Ontologies for social, cognitive and affective agent-based support of child's diabetes self-management. Artificial Intelligence for Diabetes, 35.

Annex 1

Ontologies for social, cognitive and affective agent-based support of child's diabetes self-management

Bibliography Neerincx, M., Kaptein, F., van Bekkum, M., Krieger, H. U., Kiefer, B., Peters, R., Broekens, J., Demiris, Y., & Sapelli, M. (2016). Ontologies for social, cognitive and **affective** agent-based support of child's diabetes self-management. *Artificial Intelligence for Diabetes*, 35.

Abstract The PAL project is developing: (1) an embodied conversational agent (robot and its avatar); (2) applications for child-agent activities that help children from 8 to 14 years old to acquire the required knowledge, skills and attitude for adequate diabetes self-management; and (3) dashboards for caregivers to enhance their supportive role for this self-management learning process. A common ontology is constructed to support normative behavior in a flexible way, to establish mutual understanding in the human-agent system, to integrate and utilize knowledge from the application and scientific domains, and to produce sensible human-agent dialogues. This paper presents the general vision, approach, and state of the art

Relation to WP This paper shows the current progress and vision of the PAL-system. The development of ontologies facilitates the development of strategic goal selection, and normative behavior. Furthermore, the ontologies facilitate mutual understanding between the **different** users and the PAL-agent. This paper shows the high level design of the PAL-system, and how the ontologies support the development and intelligence of this system.