

A Health Monitoring Application to Support Informal Caregivers of People with Cognitive Impairment

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Abstract — Informal caregivers of people with cognitive impairment are often concerned about the health and wellbeing of their loved ones, leading to frequent care-related visits, check-ups, and conversations. Results from focus groups we held in daily care showed a strong need for support in terms of information about the health and wellbeing of the person with cognitive impairment (PwCI). The health monitoring application developed in this study, called HELMA, aims to offer a solution by monitoring the health and wellbeing of the PwCI in the long term and informing the informal caregivers. HELMA is an eHealth application that uses short frequent online monitoring questions to provide informal caregivers with information about the following health and wellbeing domains: physical; mental; social; and environmental. The next step is to evaluate HELMA on a large scale with end-users in daily practice.

Keywords – cognitive impairment; informal caregiver; eHealth; health informatics; health monitoring system

I. INTRODUCTION

The growing prevalence of people with cognitive impairment (CI) poses a significant public health challenge. CI is a common disorder, which, in the case of dementia, affects approximately 47 million people worldwide [1]. In the Netherlands, 70% of people with dementia live at home and are cared for by their informal caregivers. More than half of these caregivers are overburdened [2], as they face multiple tasks and experience physical, emotional, and economic pressures [3]. This is also related to the fact that people with CI remain at home longer, while the availability of professional care decreases [2]. This leads to increased responsibilities being imposed on the informal caregiver. In daily practice, we observe that informal caregivers are often concerned about the *health and wellbeing* of the person with CI (PwCI), leading to frequent care-related visits, check-ups, and conversations. Results from focus groups we held with caregivers showed a strong need for support in terms of information about the health and wellbeing of the PwCI, and especially which aspects of health and wellbeing need attention (e.g., loneliness). However, so far, support for informal caregivers is mainly focused on supportive interventions such as psycho-education, respite care, cognitive behavioral interventions, and occupational therapy [4]. In the current literature on

informal caregivers' care needs, we clearly see a need for: dementia education; managing, and coping with, symptoms of dementia; dealing with behavioral problems; assistance with (Instrumental) Activities of Daily Living; and access to care support [5]–[7]. In cases where health and wellbeing were mentioned this often concerned the health and wellbeing of the informal caregiver, and not our identified need for information about the health and wellbeing of the PwCI. The same problem applies to existing ICT solutions that support informal caregivers of people with CI. The ICT solutions found in literature focus on areas such as: education; consultation; social support; and monitoring health and safety [8]–[12]. Monitoring of health however mainly focuses on implementing detection devices and alarm systems, and not on our identified care needs.

To monitor health and wellbeing, eHealth could provide support. It can frequently monitor the health and wellbeing of the PwCI at a distance and in the long term. This could give peace of mind to the informal caregiver and improve the quality of life for both the informal caregiver and the PwCI. The assumption is that an increased peace of mind for the informal caregiver positively affects his or her quality of life, and that additional information could lead to earlier detection and anticipation of changes in the health and wellbeing of the PwCI.

As such, our aim was to develop an unobtrusive remote health monitoring application to monitor the health and wellbeing of the PwCI in the long term and inform the informal caregivers. In this paper, we describe the development and concept of this application, called *HELMA (Health Monitoring Application)*.

II. METHODS

This study takes a user-centered iterative design approach, as shown in Fig. 1, to maximize the usability and usefulness of the application to be developed. In the development process of the application, focus groups, interviews, and expert meetings were held to elicit requirements (see Section III). Participants were people with CI, formal and informal caregivers of people with CI (in this paper referred to as “*caregivers*”), and experts from various fields.

Phase 1: A semi-structured focus group was held to discuss what caregivers of people with CI (would like to)

monitor in terms of the health and wellbeing of people with CI in regular care. In addition, caregivers were asked how (eHealth) technology could facilitate this, and what its functionalities should be. The focus group consisted of ten caregivers of people with CI.

Phase 2: Requirements were elicited and prioritized during expert meetings. These meetings also discussed the content of the monitoring questions (in this paper referred to as “questionnaire”). The meetings involved two to six experts in the fields of biomedical engineering, movement science, health science, and professional caregiving.

Phase 3: A low-fidelity prototype of HELMA was developed with the health and wellbeing questionnaire incorporated.

Phase 4: Semi-structured interviews were held with four caregivers of people with CI to evaluate the low-fidelity prototype in terms of comprehensibility and completeness, content (e.g., clarity, brevity, ambiguity, and specificity), structure (e.g., order and length), and frequency (e.g., how often should the questionnaire be completed). In addition, the System Usability Scale (SUS) [13] was administered.

Phase 5: Two semi-structured focus groups were held to evaluate current, and elicit future, user interface (UI) requirements. The focus was on the content of the questionnaire and the display of results, but also on additional functionalities to be included. One group consisted of five caregivers of people with CI, and the other group of five people suffering from CI (total n=10).

Phase 6: The UI findings were evaluated and supplemented during an expert meeting. The meeting focused on how to display the results of HELMA and involved four experts in the fields of biomedical

engineering, movement science, professional caregiving, and computer science.

Phase 7: A high-fidelity prototype of HELMA was developed.

Phase 8: Two semi-structured focus groups were held to evaluate the high-fidelity prototype in terms of overall acceptance (semi-structured interviews), usability (SUS, observations, and semi-structured interviews), and questionnaire validation (semi-structured interviews on content, structure, and frequency using a think-aloud protocol). One group consisted of ten caregivers of people with CI, and the other group of ten people suffering from CI (total n=20).

Phase 9: The final version of HELMA was developed.

III. REQUIREMENTS

This section presents the requirements defined during the various phases of the development process. Requirements that are marked with an asterisk (*) are implemented in the final version of HELMA (see Section IV), based on the outcomes of the various phases, and their necessity and feasibility in this stage.

A. Health and Wellbeing

Table I shows the health and wellbeing related requirements, resulting from phases 1 and 5.

An important finding was that formal caregivers assess health and wellbeing once every half year using validated assessment tools such as the Omaha System [14]. Omaha is a subjective classification system for care and wellbeing. It gives structure to the daily practice of formal caregivers, and is a tool to better select, sort, and capture actions and outcomes of care for patients. The health domains used in

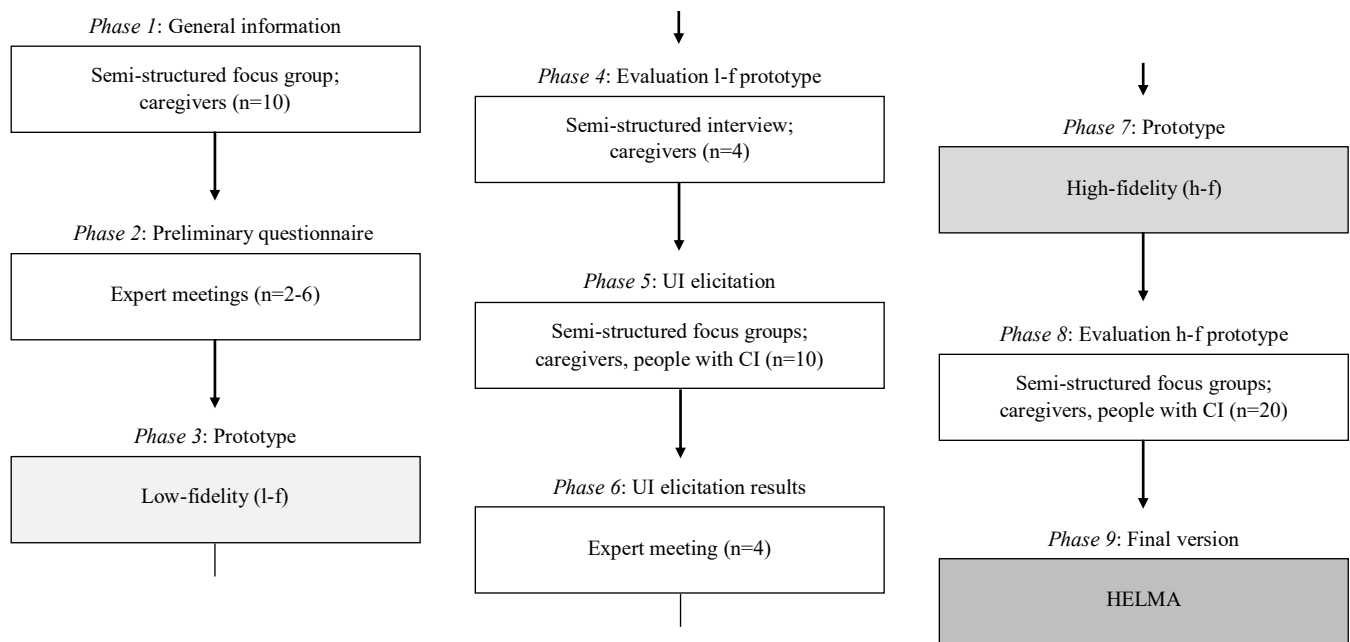


Figure 1. Iterative development of HELMA

Omaha (i.e., environmental, psychosocial, physiological, and health-related behaviors) seemed to correspond well with the outcomes in this focus group. However, to be able to apply Omaha in the context of this study, it should become more compact, specific, and efficient. This is necessary to enable more frequent monitoring, minimize the user burden, and utilize the short care visits of caregivers.

Additionally, to minimize the burden for the PwCI, a decision tree should be used to shorten the questionnaire where possible.

TABLE I. HEALTH AND WELLBEING RELATED REQUIREMENTS FOR HELMA

#	Health and wellbeing related requirements
<i>Phase 1 (focus group; n=10)</i>	
<i>HELMA should monitor:</i>	
H1*	Health status
H2*	Deviations in health patterns
H3*	User's first impression when visiting the PwCI: <ul style="list-style-type: none"> Alertness (i.e., mental sharpness) Environment (e.g., temperature of the room) Wounds/bruises Appearance (e.g., personal care, skin tone, looking tired)
H4*	The following health domains: <ul style="list-style-type: none"> Environmental Social Physical Mental
H5*	Medication intake
H6*	Eating patterns (e.g., forgetting breakfast)
H7*	Fatigue (e.g., feeling tired; is the person lying on the couch or in bed)
H8*	Changes in day-night rhythm
H9*	Social activities
<i>HELMA should include:</i>	
H10	A digital diary (e.g., for a grocery list, planning, reminders, and checklists)
H11	Chat functions (e.g., video calling)
H12	Modules for measuring vital functions
H13	Coaching (messages/notifications)
H14	A calendar function
H15*	A notification system to notify the caregiver when deviations in health occur
H16	Objective monitoring (e.g., to monitor day/night rhythm and physical activity)
H17*	An option to give the PwCI insight into his or her health results
<i>Phase 5 (focus group; n=10)</i>	
<i>HELMA should include:</i>	
H18	A calendar to support people in remembering, for example, their daily activities

B. User Interface

Table II shows the UI-related requirements and functionalities, resulting from phases 1, 5, and 6.

TABLE II. UI-RELATED REQUIREMENTS AND FUNCTIONALITIES FOR HELMA

#	UI-related requirements and functionalities
<i>Phase 1 (focus group; n=10)</i>	
<i>HELMA should:</i>	
U1*	Use different interfaces for the PwCI and caregivers
U2*	Be simple (e.g., short questions and a minimum number of functionalities)
U3*	Be user-friendly (e.g., large icons and font size)
U4*	Be capable of being used on a tablet
U5	Actively trigger the PwCI to respond to the questions
U6	Include the opportunity to respond to open questions and add remarks
U7*	Visualize results to caregivers graphically
<i>Phase 5 (focus group; n=10)</i>	
<i>HELMA should:</i>	
U8	Use a combination of text ("yes" and "no") and icons (e.g., emoticons) to provide clear answer options to the user
U9	Use a doctor-like avatar for asking questions, to support the serious context of the questions
U10	Allow the user to customize the application to personal preferences (e.g., background color)
U11*	Include a maximum of three answer options per question
U12*	Use a simple background to prevent overstimulation and distracting the user
U13*	Keep the application as simple as possible
U14*	Allow the user to see his or her health results
U15	Let the users have control over their data (i.e., to choose whether and with whom data is shared)
U16	Use text-to-speech
U17	Use pictures of family/friends/fun activities in, for example, a photo gallery
<i>Phase 6 (expert meeting; n=4)</i>	
<i>HELMA should:</i>	
U18*	Use various layers to display the results of the questionnaire, in which the PwCI should only be able to see his or her own information. Each layer should follow the UI guidelines as indicated by the experts (see Section IV)

C. Content, Structure, and Frequency

Table III shows the content, structure, and frequency related requirements, resulting from phase 4.

The SUS outcome from four caregivers in this phase showed a median score of 68.75 (range: 45-85), meaning the usability scored between "OK" and "Good" and therefore could be improved.

TABLE III. CONTENT, STRUCTURE, AND FREQUENCY RELATED REQUIREMENTS FOR HELMA

#	Content, structure, and frequency related requirements
<i>Phase 4 (interviews; n=4)</i>	
<i>Content</i>	
<i>HELMA should:</i>	
C1*	Use emoticons (or images) for results
C2*	Always ask about physical activity
C3	Provide a results overview every two months
C4	Ask for the reason when someone answers that he or she feels fine
C5*	Always ask about medication intake
C6	Add a final question to the questionnaire for the PwCI to end positively (e.g., whether the PwCI did something special today)
C7*	Ask the PwCI about whether he or she has been outside today
C8*	Add the option to give a neutral answer
C9	Allow to compare between how the PwCI feels now and just after waking up
C10	Add the cause of the pain and its location when the PwCI is in pain
<i>Structure</i>	
<i>HELMA should:</i>	
S1*	Include a user guide describing how the caregivers should complete the questionnaire
S2*	Allow the family of the PwCI to complete the questionnaire to add other perspectives
S3	Add the aim of some appointed questions to the user guide
S4	Add an example to some appointed questions
S5*	Rephrase some appointed questions
S6*	Change the order of some appointed questions
<i>Frequency</i>	
<i>HELMA should:</i>	
F1	Encourage the PwCI to complete the questionnaire
F2	Limit the frequency of completing the questionnaire to maintain motivation among users in the long term
F3	Adjust the frequency of completing the questionnaire based on the degree of CI
F4*	Allow the user to complete the questionnaire at any preferred moment
F5*	Limit the length of the questionnaire for formal caregivers due to time constraints

D. Evaluation High-fidelity Prototype

Table IV shows the emerged high-fidelity prototype evaluation requirements, resulting from phase 8.

Overall, the main outcome of this phase indicated that the questions, answer options, and results section of HELMA were all clear and complete, and that the length of the questionnaire was good. The SUS outcome from the ten caregivers in this phase showed a median score of 81.25 (range: 57.50-100), meaning the usability scored between “Good” and “Excellent”. The outcome also suggests that the usability of the high-fidelity prototype is to a large extent improved compared to the low-fidelity prototype.

TABLE IV. HIGH-FIDELITY PROTOTYPE EVALUATION REQUIREMENTS FOR HELMA

#	High-fidelity prototype evaluation requirements
<i>Phase 8 (focus group; n=20)</i>	
<i>HELMA should:</i>	
P1*	Include a user guide, including the aim of the questionnaire and each question, and how to respond to questions
P2	Explain to its users in the user guide that it is not mandatory to look at the results
P3	Provide training on how to handle a tablet
P4	Request that the questionnaire is completed no more than once a day
P5	Send a reminder to complete the questionnaire
P6*	Include a legend in the results section to explain the meaning of the colored emoticons
P7	Display in the results section the whole main domain question instead of the keyword (i.e., physical, mental, social, and environmental)
P8*	Include both frontal and dorsal animated bodies for pointing out the location of felt pain (and allow for adding multiple marks)
P9*	Allow the user to go back to previous answered questions when completing the questionnaire

IV. FINAL VERSION

The final version of HELMA is a health monitoring application that aims to monitor the health and wellbeing of the PwCI in the long term and inform the caregivers. It uses short frequent online monitoring questions to provide caregivers with the necessary information about the following health and wellbeing domains: physical; mental; social; and environmental.

A. Architecture

HELMA has a web-based architecture, that is built on the Continuous Care and Coaching (C3PO) platform [15] which has been frequently used for online health monitoring applications (e.g., [16]). HELMA is subdivided into a server and a user device. The server consists of a database, questionnaire results visualization, user interface, and questionnaire decision tree. Fig. 2 shows all the components and their mutual connections.

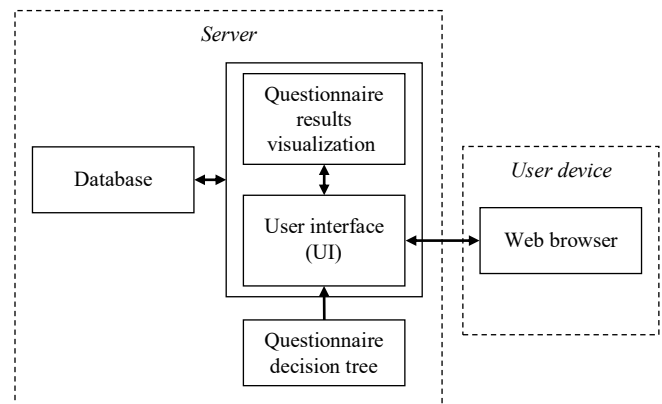


Figure 2. Architecture of HELMA

B. Use in Daily Practice

HELMA can be used by the PwCI and his or her caregivers. Each of them can fill in the questionnaire and view the questionnaire results. The PwCI is asked to complete the questionnaire daily, whereas the caregivers are asked to complete the questionnaire during or after a visit. Using HELMA, informal caregivers gain better insight into the health and wellbeing of the PwCI, the formal caregivers are better able to provide support to the informal caregivers, and changes in the health and wellbeing of the PwCI can be detected and anticipated on as early as possible.

HELMA will be displayed and used for the PwCI in a prominent in-home location (e.g., on the kitchen or living room table). It will be target-group-proof, meaning the tablet will always be on and unalterably run HELMA. For the caregivers, HELMA is available on a device of choice (e.g., computer, tablet, or smartphone). Users login to HELMA via a web browser. On the home screen, the user can either complete the questionnaire or view the questionnaire results.

C. Questionnaire

HELMA's questionnaire consists of straightforward health and wellbeing related questions, all concerning the PwCI. The questionnaire consists of 24 hardcoded questions, mainly divided over the following four health and wellbeing domains: physical; mental; social; and environmental. Essentially, HELMA contains two questionnaires: one for the PwCI; and one for the caregivers. The difference between both questionnaires is in the phrasing of the questions, and in the use of a decision tree for the questionnaire of the PwCI. Because both questionnaires correspond, HELMA can identify the similarities and discrepancies between the completed questions of the PwCI and the caregivers. In the long term, this may indicate a change in the PwCI's degree of CI.

To minimize the burden for the PwCI, a decision tree is implemented into the questionnaire of the PwCI. This means that HELMA will ask at the start of each questionnaire two questions: (1) "How are you feeling?" (see Fig. 3); and (2) "Did you use your medication?". If the first question was answered with: "Good", the PwCI will not be asked any further questions after the second question. If the answer was: "Not that good", a main question for each domain will be asked. For each main domain question to which the answer is worrisome, two to four in-depth sub-questions will follow. In this way, depending on the answers, HELMA can ask the PwCI 2 to 24 questions. Caregivers will be asked to complete all 24 questions.

D. Results Overview

The outcomes of the questionnaire are shown in the results overview. The results are divided into three layers, with each successive layer showing the results in more depth. For the PwCI, only the first layer is visible (similar to Fig. 4), whereas the caregivers can view all three layers. The PwCI also only has access to his or her own results,

whereas the caregivers can access both the results of the PwCI and themselves. The reason for this is to keep it simple and clear, and to prevent an overload of information for the PwCI. The overview uses emoticons to differentiate between positive, neutral, and negative outcomes.

Layer 1: The first layer of the results only shows the completed questionnaire of the current day and the previous seven days (see Fig. 4). For both the PwCI and the caregivers the results displayed in this overview are those of the PwCI. Whereas the PwCI can only view the outcomes from the first question (i.e. the header "General health") and the four main domain questions, the caregivers can view all questions using the expansion buttons.

Layer 2: The second layer shows a monthly overview of the completed questionnaires by the PwCI and caregivers. There are options to select a specific period, and options to view the questionnaire results from the PwCI, caregivers, or both combined. HELMA also highlights any discrepancies between the answers given by the PwCI and the caregivers.

Layer 3: The third layer allows the caregivers to view a single full questionnaire by selecting the relevant date.

Figure 3. HELMA's questionnaire; showing the first question for the PwCI

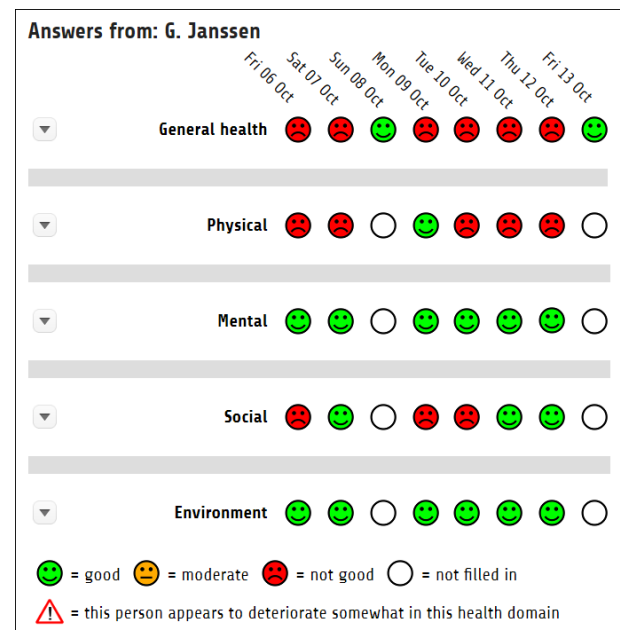


Figure 4. HELMA's results overview; showing layer 1 for the caregivers

V. DISCUSSION & CONCLUSION

This paper describes the development and concept of HELMA: a health monitoring application to monitor the health and wellbeing of the PwCI in the long term and inform the informal caregivers.

The user-centered iterative design approach of this study resulted in a set of requirements for: monitoring the health and wellbeing of the PwCI; UI and functionalities of the application; and content, structure, and frequency of the questionnaire. It is remarkable that the current literature offers little guidance on the identified need of informal caregivers to monitor the health and wellbeing of the PwCI. As a result, the requirements elicited in our study cover a wide monitoring range (e.g., in physical, mental, social, and environmental domains). Many of these requirements correspond with the aforementioned Omaha System, although the aim of the two systems differ greatly. HELMA focuses on short frequent monitoring, minimizing the user burden, and utilizing the short care visits of caregivers, whereas Omaha is intended as a comprehensive indication tool.

Three development iterations were performed in this study, resulting in a low-fidelity prototype, high-fidelity prototype, and final version. All requirements were assessed based on necessity and feasibility. The requirements that deemed important for a viable product were implemented in the final version of HELMA. The remaining requirements can be implemented in the next version of HELMA.

End-user evaluations of HELMA are needed to let users experience HELMA as part of daily practice and investigate the added value in this context. As such, a follow-up study has been conducted by Cossu-Ergecer et al. [17], who evaluated HELMA in terms of perceived usefulness, ease of use, and actual use. In addition, research needs to determine the validity of HELMA's results. Options are to compare these results to caregivers' findings in practice, or to results from validated tools such as the Omaha System. Besides, research should focus on investigating the real added value, including to what extent HELMA gives peace of mind.

Such follow-up studies are a necessary next step for further improvements of HELMA, and finally, to reach successful adoption in daily practice. We believe that when HELMA is implemented in an early stage of CI with sufficient training, the PwCI should be able to use HELMA independently. Implementation of HELMA in a later stage of CI may result in the PwCI requiring a lot of support or not using HELMA at all. These hypotheses should be tested in a large-scale evaluation with a special focus on possible service configurations (including training) in daily practice, to ensure adoption and added value.

HELMA is primarily intended for informal caregivers, but we foresee that formal caregivers will play an important role in supporting the informal caregivers in daily practice. HELMA's outcomes can also be used in their care plan. Interesting are for example the discrepancies between the questionnaire outcomes of the PwCI and the caregivers, which could indicate a change in the degree of cognitive

impairment of the PwCI, which could be used for clinical decision making. For example, if the PwCI reported that there were no visitors that day, but the caregiver reported that there were visitors, HELMA could indicate that the PwCI is beginning to forget recent events.

In conclusion: HELMA is a health monitoring application that aims to monitor the health and wellbeing of the PwCI in the long term and inform the caregivers. By using short frequent online monitoring questions, it provides caregivers with the necessary information about the following health and wellbeing domains: physical; mental; social; and environmental. Herewith, HELMA aims to give peace of mind to the informal caregiver and improve the quality of life for both the informal caregiver and the PwCI. The next step is to evaluate HELMA on a large scale with end-users in daily practice, and to improve HELMA with new, and yet to be implemented, functionalities.

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