

A collaborative patient-carer interface for the self-management of dementia

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Abstract. The wide spread prevalence of mobile devices, the decreasing costs of sensor technologies and increased levels of computational power have all lead to a new era in assistive technologies to support persons with Alzheimer's disease. There is, however, still a requirement to improve the manner in which the technology is integrated into current approaches of care management. One of the key issues relating to this challenge is in providing solutions which can be managed by non-technically orientated healthcare professionals. Within the current work efforts have been made to develop and evaluate new tools with the ability to specify, in a non-technical manner, how the technology within the home environment should be monitored and under which conditions an alarm should be raised. The work has been conducted within the remit of a collaborative patient-carer system to support self-management for dementia. A visual interface has been developed and tested with 10 healthcare professionals. Results following a post evaluation of system usability have been presented and discussed.

Keywords: self-management, visual interface, dementia, home based monitoring.

1 Introduction

Supporting self-management of chronic conditions is viewed as one way of alleviating the social and economic issues associated with an ageing population [1]. Indeed, one of the most common demands from a patient's perspective is the ability to live independently at home for a long as possible. This facilitates less time spent in the hospital and institutionalised settings, thus reducing health and social care costs. Recently, much consideration has been directed towards the use of home or

community based technology solutions that may be developed in order to assist in the self-management process [2, 3]. Remaining at home, may, however, require a degree of informal care from a family member or spouse. This may subsequently cause burden to the carer, placing further strain on their physical and mental health and wellbeing in addition to causing financial and social implications.

Cognitive impairments represent a significant challenge to older people. Difficulties can revolve around task completion or even commencing the task at all. For conditions such as dementia, the notion of self-management is a relatively new concept [4]. Traditionally, learning new tasks, such as remembering to take medications or remembering to schedule healthcare appointments, was perceived as beyond the ability of persons with dementia. Nevertheless, this represents a narrow view of self-management. A more contemporary view of self-management for dementia is considered as being a collaborative process between the person with dementia and their carer, which extends beyond traditional tasks and aims to improve personal resilience, quality of life, and increase levels of activity [4]. Technology has the potential to help individuals overcome the barriers associated with cognitive impairment in terms of performing activities of daily living and therefore help to maintain independence and enhance quality of life [5]. In particular, home based care, supported through a sensorized smart environment is considered as one way of supporting people with dementia and their carers [6]. The success of such an environment, however, relies on its ability to be customised and personalised to suit the needs of the user and the environment [7]. Many of the specific details required for the personalisation of the smart environment relating to the behaviours of the person with dementia are known only by the carer, who themselves may be older and not fully skilled in using technology. This poses a challenge given that a considerable part of the behaviour in smart environments relies on event-driven and rule specification [8]. The expressiveness of the rules available to users is usually either limited or the available rule editing interfaces are not designed for end-users with low skills in programming [8].

This paper presents HomeCI, a collaborative visual interface for the generation of machine interpretable rules to support self-management in dementia through remote monitoring of activities within a smart home environment. The ability to collaboratively generate rules through a simple visual interface allows the person with dementia and their carer to take a greater role in the provision and management of their own care. Specifically, this paper focuses on the process of designing, specifying and tailoring rules¹ to the individual through an easy to use visual editor. The aim of the research was to provide a solution which could involve those with the domain knowledge and the actual user in the process of creating the rules for home monitoring. Furthermore, a solution was desired which could generate rules that could be easily shared and reused by others and made available in the general research community through an online repository.

¹ A rule in this context is a set of guidelines on how data collected from sensors either on the person or within the environment should be interpreted and what feedback, if any should be provided by the environment itself. Rules define the sequence of sensor events that are expected for a certain activity, expected or desired behavior.

2 Background

Context can be described as the interrelated conditions in which something exists or occurs. From a computer science perspective, context awareness refers to the ability to sense and react to the environment. In this case sensors may gather information about the circumstances and based on rules or an intelligent response, react accordingly. In summary rule based languages preserve the natural essence of context aware applications “when something happens, if some facts are present then do something” [8]. Recently, visual methods of rapid programming, which require less technical knowledge, are becoming more popular. Graphical programming interfaces such as, Labview [9], BioMOBIUS [10] and MIT’s app inventor [11], allow users, with only a basic knowledge of the underlying system functionality, to effectively program complex systems. A growing number of visual methods for defining rules within a smart environment have also been presented within the literature.

SiteView, created by Beckmann and Dey [12], allows end-users to create and view automation control rules through an intuitive interaction method. The system relies on a small scale representation of the environment in which the user interacts with tangible objects. These objects represent rule conditions and may also have real-world counterparts (e.g., a thermostat or light bulb). The system was subsequently evaluated by generating a variety of rules using a combination of up to three conditions to produce predefined state changes in the environment. The interface was, however, limited to one environment (research lab) and as such the scalability and flexibility of the approach was not fully validated.

It has been said that users should be allowed to specify the behaviour of their own environment. When considering end-users, who may have little programming experience, the process of rule creation must be as simple and as intuitive as possible. iCAP [13], is a visual tool to facilitate the design of rules by end users with little programming knowledge. The iCAP interface comprised two main components. The first was a tabbed repository area which stored the user defined inputs, outputs and rules. These components could then be dragged onto the main canvas area where they were subsequently constructed into conditional rule statements. More recently, Bonino *et al.* [14] described a drag and drop visual interface that specifically targeted non-skilled or low technology skilled users. The system relied upon a rule format based on an IF-THEN structure with optional When and OR-IF blocks for expression of conditions and rule alternatives. Within this study, emphasis was placed on providing strong visual cues and suggestions to facilitate incremental rule construction by end-users.

HomeCI extends these works through the representation of objects in a simulated 3D environment. This allows for a more intuitive user interface in order to select objects for inclusion within rules. Furthermore, HomeCI represents a key component within an end to end system to support the creation, representation and storage of data and rules generated within a smart environment. Therefore, HomeCI relies heavily on established and open formats for storing and sharing data and rules. HomeCI is a companion to XML storage formats such as homeML and homeRuleML in addition to providing an intuitive interface [15]. The usability and usefulness of this interface is further validated within this paper.

3. Overview of HomeCI

The concept of a visual editor to support the capture of rule design within Smart Home environments was previously developed by the authors [16]. The solution was largely of a prototype nature and initial evaluations provided positive feedback. In the current study a fully functional version of the system has been designed and developed which produces, as an output, a set of rules conforming to homeRuleML [17]. This support the long term storage and exchange of the system’s output. The following Sections describe the structure of the visual interface.

3.1 The Visual Interface:

HomeCI is comprised of three separate main screens, each screen providing a sophisticated although user friendly interface. This interface supports users without prior experience or training to quickly and efficiently create complex rules. The first screen provides the user with an overview of the house (Figure 1). From this screen the user can select a room in which they would like to create a rule. Users can also select objects for use in the creation of a global rule. This screen is highly extensible, allowing for the addition of further rooms if required, therefore expanding the scope of this interface. A number of development languages including jQuery, PHP and HTML were used throughout the development of the HomeCI platform. This included libraries such as jsPlumb and MapHighlight. jQuery is a JavaScript library used to simplify the client side scripting of HTML and as such was used for the main content of each separate page.

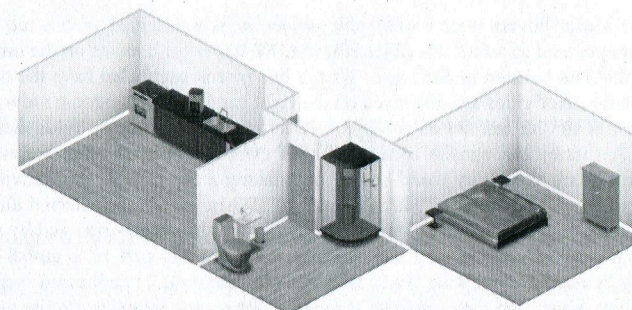


Fig. 1. Initial screen of the homeCI interface providing the user with the option to select a room within which rules can be specified for.

The level of detail provided is increased as the user progresses through the system. Within the room view, objects relevant to each specific room selected are presented to the user. Users can select objects they wish to include in either a local (single room)

or global (multiple room) rules. For example the activity of morning routine could be considered a global rule if the rule takes place in the bathroom for grooming and then the bedroom for dressing. During rule creation users are required to provide a "Rule Name" along with a "Rule ID". Users are also asked to set the "Rule Type" via a drop down menu. Rule Type selection specifies how the inference engine interprets the sensor data recorded. Two types of rules can be selected "Activity Rule" and "Intervention Rule". An activity monitoring rule selection instructs the system to trigger when a series of events have taken place based on the rule created. An intervention rule detects anomalies occurring within an expected flow of events, leading to a required intervention. Users are also expected to set the outcome, i.e. what should happen when a specific activity has been detected or completed. These are again set via a drop down menu offering the user two choices, "Activity Detected" or "Warning". In the case of an intervention rule, the outcome could be "warning" or something specific relating to the particular rule, such as "Breakfast Activity has been interrupted". Activity Rules would have a notification indication that the user has completed the task, such as "Breakfast Completed".



Fig. 2. Room view within the HomeCI interface. Details of each rule can be added on the left hand side of the interface.

When a user hovers over a selectable object, it is highlighted with a red outline. Users can proceed to select this object for use. No upper limit exists on the number of objects that can be used in each rule. Within this screen users also have the option to use activities. Activities are displayed on the right hand side of the room view and can be used in a similar manner as an object. Activities are pre-defined rules that can be reused. Activities can consist of a number of events, and even other activities. An example of such as activity could be that of "making a cup of tea", this activity could be integrated within a rule to "Make Breakfast". When users have selected all objects required they may create a rule immediately utilizing the objects selected by clicking "Create Rules". They can also use the selected events as part of a global rule by selecting "Create Global Rule". At this point, the user will be redirected back to the home view. Users can then navigate through other rooms selecting events until they are ready to create such a global rule.

The visual interface for creating rules relies heavily on established formats for storing and sharing data and rules, in addition to an intuitive interface that is easily accessed and easy to use. In previous work we have already investigated and established a format for storing and sharing data [18]. This format, referred to as homeML, is based on XML and supports data generated from a home or from mobile

and carried devices. We have also developed a format for storing and sharing rules [19] which is based on the homeML format and is extensible to support a great variety of different rules.

3.2 The workspace

The workspace is used to display to the user the objects and their inter-connections. This screen allows the user to combine the previously selected items in such a manner that a rule will be generated. The workspace allows users to drag and drop the objects and activities in any order. A distinguishing feature of HomeCI is the ability to include conditional expressions. When generating a rule, it is possible to specify that an activity should take "Less than 20 minutes" to complete or that a number of activities combined should not exceed a preset time limit. The use of such conditional expressions ensures users can easily connect the objects in an intelligent manner while retaining the user-friendly interface.

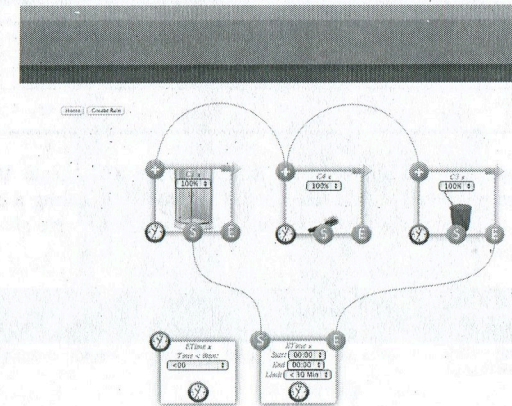


Fig. 3. Example of workspace and how objects selected from room view may be connected together.

4. Evaluation: Results and discussion

The evaluation was undertaken with 10 Nurses (Male n=2) recruited from Lulea Technical University. All participants were over the aged 45 and over. All users were experienced in working in the domain of elderly care and had good appreciation of the needs of technological solutions to be deployed in the home environment to support independent living. Participants were asked to complete two tasks. The first task requested the participant to create a rule from two pre-defined narrative for the activities of Grooming and taking medication. Participants were asked to use the homeCI interface and the visual notations to select the necessary objects and rooms

from the home view to build the necessary set of rules to monitor if a person had correctly undertaken the activities.

The average time for the 10 participants to complete the tasks was 118 seconds for grooming and 97 seconds for taking medication. Full results are presented in Table 1. Further testing is required to gain a deeper insight into exactly how much time is spent creating the rules; however, all participants were able to correctly define the rules in a reasonable period of time.

Table 1. Table showing task completion time for creating rules to represent grooming and taking medication for each participant.

Participant No.	Grooming	Taking medication
1	103	112
2	102	87
3	59	98
4	210	70
5	54	55
6	84	90
7	105	92
8	242	186
9	125	100
10	92	98
Mean	117.6	97.3
Std	61.4	36.4

The second task required the user to interpret rule and create the narrative. Participants were presented with a rule for the activity of preparing a drink (Fig.4.) and were asked to provide their interpretation. All participants were able to correctly interpret the rules.

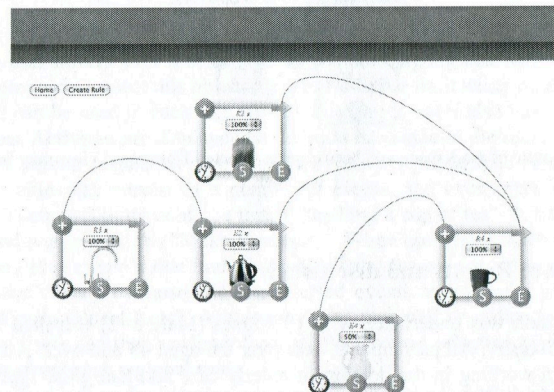


Fig. 4. Rule created for the activity of preparing a drink. This rule was shown to participants to interpret.

At the end of the both tasks each participant was asked to complete a post-evaluation questionnaire to gather feedback on their experience of using the system. Data was anonymized, with no identifiable information collected and participants were provided with the opportunity to complete the questionnaires in private. Questions were rated on a 10 point Likert scale (1- poor, 10 – excellent). Plots of responses by each participant, including the mean, for each question are presented in Fig. 5.

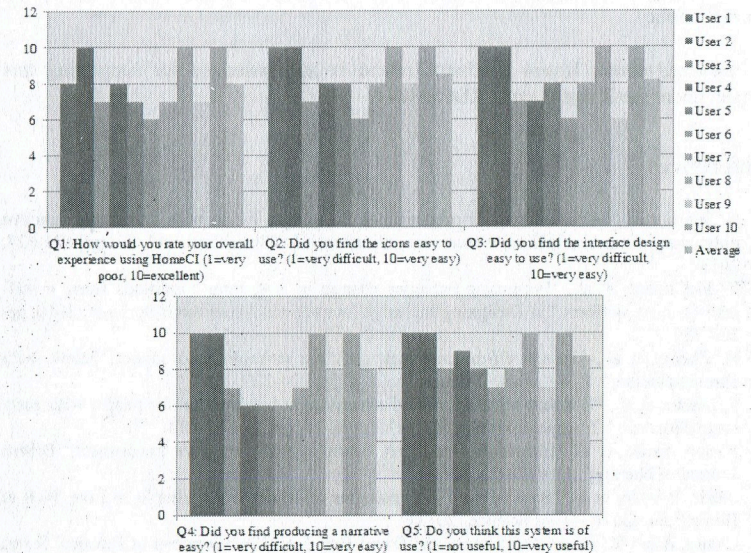


Fig. 5. Participant responses to questions investigating the system usability and usefulness.

6. Conclusions and Future Work

This paper presented an evaluation of HomeCI, a visual tool for the creation of machine visible rules for smart environments. It is envisioned that such a tool could be used within a self-management context by facilitating a collaborative creation of rules by the knowledge holders i.e. person with dementia and their carer. The visual interface was chosen as it is intuitive and allows for the creation and interpretation of rules with little technical knowledge. To test this theory, the interface was evaluated by 10 nurses who have a good knowledge of the requirements of older persons with chronic conditions. Over all the system was ranked highly on usability and usefulness by all participants and all participants completed the required tasks effectively. Although the healthcare professionals have a good insight into the needs of an older cohort, they may not necessarily have the same cognitive or technology ability as an older cohort with dementia. Future work will therefore investigate the usability and

utility of HomeCI to facilitate the collaborative creation of rules between persons with dementia and their careers as part of a self-management programme.

It is important that tools that allow for personalisation of rules are used within smart homes and that these rules are created in open formats that allow integration with other systems. Further work will seek to evaluate HomeCI with the dyad, including a person with dementia and their informal carer i.e. most likely the next of kin/ spouse. Further validation of such tools will allow for the creation of a black-box inference engine which will facilitate adoption of this advanced technology by the general public.

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