

# Managing Data in Help4Mood

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## Abstract

Help4Mood is a system that supports the treatment of people with depression in the community. It collects rich cognitive, psychomotor, and motor data through a Personal Monitoring System and a Virtual Agent, which is then analysed by a Decision Support System; analysis results are fed back to patients and their treating clinicians. In this paper, we describe how the complex data is managed and discuss ethical issues. Data is stored in functional units that correspond to treatment relevant entities. Custom XML DTDs are defined for each unit, which are used to exchange information between system components. As far as possible, observations and findings are coded using SNOMED CT to ensure interoperability with other applications such as Electronic Health Records.

**Keywords:** XML, depression, SNOMED CT, decision support

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## 1. Help4Mood—Supporting People with Depression

Depression is the main cause of disability worldwide [1]. It is characterised by a persistent and intense change of mood which affects behaviour, cognition, and physiology. Two types of depression can be distinguished, a melancholic form where patients' movements are significantly slowed down, and a non-melancholic form, where movements are not affected or agitated. Slowed movements are reflected in both gross motor function, such as gait, and fine motor function, such as movement initiation and reaction times [2, 3]. They also contribute to slowed speech and a flat intonation [4, 5]. Sleep duration can be either severely reduced (insomnia) or significantly increased (hypersomnia).

At the moment, recovery is monitored infrequently through self-reported patient questionnaires that require the person with depression to remember their symptoms over a period of time that can be as long as two weeks (e.g., PHQ-9 [6]). Those self-reports

can be unreliable, especially if the patient is not keeping regular notes or a diary.

Help4Mood enables patients to monitor selected cognitive, behavioural, and physiological aspects of their depression. Patients interact with the system every day to share how they are feeling and complete a few tasks that are informed by cognitive behaviour therapy, such as tracking and challenging negative thoughts. Help4Mood also collects activity and sleep data through a personal monitoring system.

Once every 1–2 weeks, Help4Mood generates a summary of the data that patients will then discuss with the clinician who treats them. This can be a family physician, a psychologist, a psychiatrist, or another health professional with mental health training. The summary includes overall mood, sleep and activity trends, and a list of frequent intrusive negative thoughts, which can be treated using cognitive behaviour therapy. The data generated by Help4Mood will also be useful for reviewing the effectiveness of medication. This design is based on extensive consultation with clinicians and patients in Spain, Romania, and the UK [7]

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In this paper, we describe our approach to data management in Help4Mood. We focus on the high-level data structures that form the basis for communicating with clinicians, patients, and other stakeholders.

In Section 2, we give an overview of the Help4Mood system. The basic high-level Help4Mood data structures are described in Section 3. Ethical issues are discussed in Section 4, and provisions for interoperability with Electronic Health Records are outlined in Section 5. Future work plans are summarised in Section 6.

## 2. Overview of Help4Mood

Help4Mood consists of a *Personal Monitoring System*, a *Virtual agent*, and a *Decision Support System*. Help4Mood is structured around patients' sessions with the Virtual Agent. Ideally, patients interact with their Virtual Agent daily. The Virtual Agent asks questions, sets tasks, and summarises the results of each session. Sessions can include summaries of activity and sleep patterns. Some of these tasks will yield cognitive data, such as relevant negative automatic thoughts, others are designed to capture relevant neuropsychomotor symptoms of depression.

The sensors of the *Personal Monitoring System* assess sleep and activity patterns using sleep sensors and a wrist actigraph. While sleep data is collected every night, the wrist actigraph will only be worn for 72 hours at a time. Sessions with the Virtual Agent can include summaries of activity and sleep patterns.

The *Decision Support System* plans and controls sessions with the Virtual Agent and converts data about the patient's sleep, motor, speech, and other psychomotor patterns into graphical, textual, and conceptual summaries that can be communicated to clinicians, patients, and electronic health records. As yet, there are very few rules for adjusting medications and interpreting data that could be implemented in a traditional decision support framework [7, 8]. Therefore, the decision support system focuses on trend analysis and planning the interactions between Help4Mood and the patient.

Figure 1 shows the internal structure of Help4Mood. On the left of the graph, we see the sensing / monitoring components, the Virtual Agent and the Monitoring System. The (Personal) Monitoring System includes the sensors and wireless communication infrastructure.

The structure of the Virtual Agent is more complex. The Virtual Agent consists of a Graphical User Interface (GUI) and a talking head (the "Agent"). Verbal messages are generated by the Natural Language Generation (NLG) component. These messages are displayed by the GUI and spoken by the Agent. Spoken messages are passed to a text-to-speech synthesis engine (TTS) that creates speech with annotations that help synchronise the Virtual Agent's head and facial movements. The

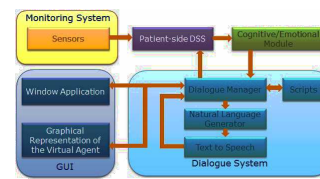


Figure 1. System Structure

Dialogue System controls the flow of messages, using scripts to ensure the correct wording where clinically relevant.

Data collected via the Virtual Agent and the Personal Monitoring System is processed by the Knowledge Engine. The Knowledge Engine creates summary reports and detects relevant trends about the patient's mood and behaviour. This information is passed on to the Cognitive/Emotional Model. This component is crucial for planning the interaction between Virtual Agent and user; it passes session plans and information about the intended affective behaviour of the agent on to the Dialogue System, which performs the low-level control.

Communication between the system's components is implemented using ICE (Internet Communication Engine) as middleware [9]. ICE, which is covered by the GNU public license, has several key advantages. It is independent of programming language and operating system, which is important on a project where components are developed by partners with different IT infrastructures. Since clients do not need to be aware of how the server implements their objects, the server implementation can be changed even after clients have been deployed. Communications between client and server are protected by using SSL (Secure Socket Layer). Last, but not least, ICE produces little overhead.

## 3. Core Data Structures

All data structures are described using XML. We chose this solution over a relational database, because Help4Mood has a highly modular architecture, and almost all inter- and intra-module communication is based on the exchange of XML messages. Elements are extensively cross-indexed to ensure flexible access to data. Individual components such as the Decision Support System may store data in an internal data base.

The XML elements that are used to capture relevant data are summarised in Table 1. They fall into four main categories, high-level tracking of patient and Help4Mood use, storing monitoring results, managing the interaction between patient and Virtual Agent, and storing the data collected during the interaction. Each set of elements is briefly explained below.

**Table 1.** Basic Elements of the Help4Mood data structure. Each one is defined using XML.

Element	Description
<i>High-Level Tracking of Patient and Help4Mood Usage</i>	
User Model	high-level summary of information about the patient
Adherence	adherence of patient to Help4Mood; can refer to sessions, tasks, and monitoring
Report	summary report for clinician
<i>Managing the Results of Monitoring</i>	
Monitor. Data	set of data points
Measure	high-level measure computed from monitoring data
Score	score on stand. questionnaire
<i>Managing the Interaction with the Virtual Agent</i>	
Session	content and results of a session with the Virtual Agent
Event	event triggered by the Decision Support System during a session
Task	task that is performed by the patient during a specific session
Emotion	emotion used by Virtual Agent during interaction with patient
<i>Storing Information Collected During Interaction</i>	
Diary	information on diary entries
Speech	changes in speech
Neg. Thought	frequency of negative automatic thoughts
Self-Report	results of self-report questions
Exercise	completion of exercise

### 3.1. High Level Tracking

The three high-level tracking elements in Table 1 summarise relevant information about the patient and system usage and store the regular reports generated by the system. Patient information, which is stored in the user model, includes basic demographics (occupation, gender, age) as well as current depression scores. The user model also includes information about the background photo chosen by the user, the avatar the user has chosen, and their preferred interaction style and personality (friendly or formal). As for reports, only official reports that are sent to the clinicians and can be discussed in patient/clinician meetings are stored. The feedback given to the patient at the end of each session is not saved, because it can be reconstructed easily.

### 3.2. Monitoring

The next two elements in Table 1 are used to describe high-level monitoring data. While the measure element covers specific analysis results, the monitoringdata element contains the measures obtained during a session.

The information contained in these elements is passed onto the Decision Support System, which processes them further. Sensor data are timestamped. Time stamp information is not just used to interpret the data, it is also used to prompt the patient to start a new round of data collection. Specific dialogues are encoded in the VA that tell patients when to put on the actigraph and when to take it off for data collection.

### 3.3. Managing the Interaction with the Virtual Agent

Sessions typically start with a daily mood check, followed by a diary task. Patients reflect on a specific prompt and write their thoughts into a text field. These entries are stored, but not analysed. Next, patients document negative thoughts relating to this entry, and Help4Mood provides guidance for challenging them. Other activities, such as speech tasks, relaxation exercises, or self-report questions, follow. Finally, the Virtual Agent bids the patient goodbye.

Interactive sessions in Help4Mood need to satisfy four constraints:

**Minimum Requirements:** Patients should complete a *daily mood check*, which is a validated four-item questionnaire, the CES-VAS-VA [10]. Every fortnight, patients also fill in a formal screening questionnaire, the PHQ-9 [6].

**Sustaining Interest:** Session structure should be varied, with some different tasks each time.

**Adapting To Stamina:** Patient state can vary greatly; on some days, all patients can do is a brief mood check, on other days, they are able to complete a session with four tasks.

**Ensuring Sufficient Data:** Subjective data about the patient such as self-reports and additional psychomotor data such as speech should be collected at least twice a week.

The Decision Support System controls the Virtual Agent's interaction with the user through events. Events are triggered when their preconditions are fulfilled. They are implemented as interaction tasks. Each task is associated with an emotion that controls the affective behaviour of the Virtual Agent [11] (c.f. Table 1).

The sequence of events and task/emotion pairs that occurred during a session and the data that was generated during a session is stored in a session element for easy reference. This data is used by the Decision Support System to plan further sessions and ensure regular coverage of relevant data.

Table 2 shows the structure of an event element. Each event is linked to a session, a patient, and a specific time within the session. A range of auxiliary elements

**Table 2.** The *Event* class

Attribute	Value	Description
⟨Type⟩	{1,2,3,4}	Event type as classified by data source
⟨Session⟩	timestamp	Session ID
⟨Patient⟩	alphanumerical	Patient ID code
⟨Description⟩	descriptor	Formal description of the event
⟨Generated⟩	timestamp	time at which the event was generated
⟨Preconditions⟩	list of conditions	pre-conditions that trigger the event.
⟨Postconditions⟩	list of conditions	findings or observable entities

is used to specify events. Descriptors link Events to a formal code that describes the underlying procedure and can be exported to external systems. Preconditions and postconditions are described using condition elements that consist of ⟨Property, Operator, Value⟩-tuples. Preconditions trigger events, postconditions describe the outcomes of an event.

During most tasks, the system collects rich information about the patient's cognition and current psychomotor functioning. Relevant high-level data is encoded in the diary, speech, selfreport and negative thought elements.

#### 4. Privacy, Security, and Ethical Considerations

The data that Help4Mood logs about a person's activity and mood is private and confidential. It is therefore imperative that it is stored securely. Since we do not assume that Help4Mood's users have a broadband internet connection, all data is initially stored in a single encrypted partition on a dedicated laptop, which can only be used to run the Help4Mood application. Raw data can only be accessed by the clinicians and technical support personnel that give out the Help4Mood kit, which consists of sensors and laptop.

The baseline solution for transmitting data to the relevant health care professionals is to send an encoded PDF with a summary of relevant trends via e-mail. This is the most portable solution, and it does not require the clinician-side Electronic Health Record / Electronic Medical Record system to support standards such as HL7. For systems that do support HL7, the PDF will be embedded in a HL7 CDA record.

The ethical considerations around the data that is collected can be summarised by one question: Will the system be able to pick up indications of suicide or self-harm, and if yes, what should the reaction be? Since the cost of failing to detect suicidal or self-harm tendencies far outweighs the cost of false alerts, it is highly likely

that many false alarms would be generated, which would increase the burden on the treating clinical team. Therefore, we decided to analyse only data that does not contain any unambiguous pointers to self-harm or suicide. This means that diary data is excluded from analysis, because people can explicitly describe suicidal ideation there. There is one exception: The PHQ-9 questionnaire, which is administered every fortnight, includes a question on self-harm or suicidal ideation; if the answer indicates cause for concern, users will be taken off the Help4Mood intervention immediately because they will need closer supervision.

#### 5. Electronic Health Record Integration

In order to foster interoperability with IT systems across the European Union, it is important to use a standard vocabulary to describe findings, procedures, and actions. For Help4Mood, we chose the international Core Release of SNOMED CT [12]. SNOMED CT is a highly complex, extendable clinical vocabulary that can be integrated with standards such as HL7 [13], which Help4Mood will support.

Most of the SNOMED-CT concepts used in Help4Mood come from the *Clinical Finding* hierarchy. Clinical findings are the outcome of assessments, observations, or judgements. For example, if the sleep sensor data indicate that the patient tossed and turned frequently at night, this can be encoded as the Clinical Finding "restless sleep".

Another class of concepts that are relevant to Help4Mood are *Procedures*. In SNOMED-CT, procedures are activities that occur at a specific time and involve the patient and include education and administration. Examples of procedures are guiding the patient through a relaxation exercise or showing the patient a list of activities that were identified as comforting.

A question or a procedure that produces a result is an *Observable Entity*. For example, "gender" is an observable entity, while "female gender" is a finding. While many demographic characteristics of patients are covered by Observable Entities, other information such as occupation is encoded using concepts from the *Social Context* hierarchy.

Modelling questionnaires in SNOMED-CT requires concepts from three different hierarchies. The questionnaires as measurement instruments are part of the *Staging and Scales* hierarchy. Questionnaire scores are modelled as observable entities, and the interpretation of questionnaire scores is encoded as a clinical finding.

For example, assessing a patient using the Beck Depression Inventory (BDI, [14]) is a procedure that has the Concept ID 446765009. The patient's score on the BDI is an observable entity with the Concept ID 446053003, and the BDI itself is an assessment scale with the Concept ID 273306008. The finding that

**Table 3.** Anchoring New Concepts in SNOMED-CT. H4M: Help4Mood concept, is-a: linked SNOMED-CT concept

Procedure	H4M	999991021	Assessment using PHQ-9
	is-a	445536008	Assessment using assessment scale
Observable Entity	H4M	999991022	PHQ-9 score
	is-a	363870007	Mental state, behavior / psychosocial function observable
Finding		999992011	Change of Score on Cognitive Game SIMON
	is-a	248536006	Finding of functional performance and activity

is associated with a patient's score is encoded using one of the subtypes of the clinical finding "Depressive Disorder" (Concept ID 35489007).

We defined our own codes only if the relevant findings, observable entities, or procedures were not included in SNOMED-CT. In all cases, these codes are linked to a parent concept in SNOMED-CT. For example, unlike the Beck Depression Inventory, none of our depression measures are modelled explicitly in SNOMED-CT, although they are well-known and validated. Therefore, we assigned system-specific codes to the resulting scores and linked them to relevant parent concepts. For example, the PHQ-9 score is an Observable Entity which is in an is-a relation with the SNOMED CT concept *Mental state, behaviour / psychosocial function observable*. The interpretation of cognitive games is also not covered. While the scores themselves are observable entities, changes in scores as well as relevant trends are modelled as findings. Table 3 summarises the implementation of these examples.

While information such as questionnaire scores can be stored more or less directly, concepts such as "restless sleep" require interpretations of sensor data. The Decision Support System will implement algorithms for mapping raw sensor data to these categories, which will be refined as data is collected in user studies and trials.

## 6. Taking Help4Mood Further

The data management approach outlined here provides a detailed, systematic representation of all of the relevant high-level information that Help4Mood collects about a patient with depression. It was designed for easy maintenance and maximum interoperability with Electronic Health Records. New sensors and interaction modules can be integrated easily. No new elements are required for additional sensor data, and we anticipate that for most exercises, we will only track completion.

We are planning three trials of the Help4Mood system. These will be iterative, starting with a bare-bones system and progressively adding functionality. At this stage, the most important function of the data structures is to make data readily accessible for future analysis. Given the relative lack of information on the sleep and activity patterns of people with depression in the community [8], one of the key important contribution of Help4Mood will be clean, usable data. Data will be summarised using visualisations and natural language summaries.

In future iterations of Help4Mood, the DSS will be extended to suggest activities or provide brief psychoeducation that reinforces the "homework" that clinicians often give to patients. We also plan to add HL7 integration, and refine the elements and clinical vocabulary described here to provide a more detailed ontology for interoperability.

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