

DMSS – a Dementia Management and Support System for providing Tailored Advice in the Dementia Workup

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Abstract The need for improving dementia care has driven the development of the clinical decision support system DMSS (Dementia Management and Support System). A sociotechnical approach to design and development has been applied, with an activity-centered methodology and user participation throughout the process. Prototypes have been developed based on the characteristics of clinical practice and domain knowledge, while clinical practice has been subjected to different efforts for development such as education and organizational change. A set of evidence-based clinical practice guidelines has been synthesized and integrated in DMSS to support clinical routines and reasoning processes as performed by individual health professionals in daily practice. DMSS-R provides advice, tailored to the individual and often exceptional patient case, to the user while providing guidance to the next step in the assessments and support for hypothesis generation and valuation throughout the process. This paper addresses the lessons learned and role and impact DMSS has had, and is expected to have on the clinical assessment of dementia in different clinics in Sweden, South Korea and Japan. Furthermore, it will be described in what way the development of DMSS and the development of dementia care in these three areas are interlinked. A recent evaluation study showed that the most important contribution of DMSS-R at the point of care, part from the tailored explanatory support related to a patient case, was the educational support that DMSS-R provided. This was partly manifested in a change of routines in the encounter with patients. Aspects regarding the individual health care professional's need for a personalized support system are discussed and put in relation to the team's need for support, and in relation to the diversity of disease manifestations in this group of patients, which enforces patient-centric assessments.

Keywords: Clinical decision-support systems; dementia; activity theory; continuing medical education; clinical practice guidelines; clinical practice; interaction design; activity-centered design; evaluation

1 The Sociotechnical and Situated Nature of Dementia Care

There is a common understanding that medical and health practices are fundamentally *socio-technical*, in that daily work involves a range of professionals and technical devices where all contribute to and put constraints on the outcome of care (Berg, 1999; Berg et al., 2003; Reddy et al, 2007). Clinical practice is also highly situated, where decisions often must be made based on the available limited knowledge and resources (Goorman & Berg, 1999). This poses demands on the different phases of computer system development for such use environment (Kaplan, 2001a; Kaplan, 2001b). It is argued that the sociotechnical perspective needs to be integrated from the early phases and evaluations should put focus on the change of work routines and culture that may affect the use of systems, just as the use of systems may direct changes in and development of work. It is also argued that development of health care systems should emerge within the health organization and daily practice instead of being something that is implemented by a third party into the daily work, for the system to become successful (Coiera, 2007).

Dementia care is a medical domain that is characterized by an incomplete and evolving domain knowledge, and complex disease manifestations in patients that both affect and are affected by the patient's environment. This complexity creates a need for assessing the patient's difficulties from different viewpoints and professional competences. The individual users of a decision-support system integrated in this context have different professional backgrounds, different preferences on, for example, which guidelines to use and different need for an individually tailored support. To approach this potential use situation we focus on what is to be accomplished in the clinical situation, which is providing optimal and tailored care to the individual patient considering the circumstances and available resources. This approach complies with the general view on activity in the cultural-historical research tradition (e.g., Engeström, 1999). Once we have the target outcome and motive set we can investigate in what way the contributing professionals best can work towards this goal with the support of a decision-support system. Physicians who have participated in earlier formative evaluation studies of a decision-support system for the domain (Lindgren 2008a; Lindgren, 2008b) tend to view more patients than expected as exceptions to the typical schoolbook cases of e.g., Alzheimer's disease, where a significant number has mixed etiologies. As a consequence, an optimally designed decision-support system should provide tailored support to not only the individual team member and the team as a productive unit, but also tailored support for the team to provide optimal care to the exceptional patient.

A clinical reality that adds complexity to the development of a decision-support system for the domain is the diversity in routines regarding how and by which professional categories patients with suspected dementia is managed. This diversity is seen within and between local care organizations in Sweden as well as in other countries such as Japan and South Korea. Depending on local organizations and individual preferences, the professionals who diagnose dementia in daily practice can be geriatricians, neurologists, primary care physicians, psychiatrists, physicians specialized in neurosurgery or internal medicine, etc. Consequently, their knowledge of dementia is often colored by their main professional domain, with the risk of overlooking important aspects related to other domains. On the other hand, dementia diseases affect several domains, which probably contributes to creating the special interest in individual physicians that is needed to develop the skills necessary for providing qualified care to dementia patients. To what extent the dementia workup includes additional professionals such as nurses, occupational therapists or psychologists, also depends on the local organization, priorities and individual preferences.

In clinical practice when investigating a suspected dementia disease, a range of additional medical conditions needs to be considered in a differentiation process. In addition, the assessment of the presence and severity of symptoms is crucial, especially since dementia diseases including their symptoms are progressive, and need to be continuously monitored in order to provide tailored and timely interventions. New cases of dementia are usually not frequent in the daily work of the general practitioner (e.g., in Northern Sweden typically 2-4 new cases a year), which prevents the physician to develop the skills needed for managing dementia in a satisfactory way. The Linköping study showed that only 25% of patients with a suspected dementia received a specific dementia diagnosis in the encounter with the primary care physician, which is not satisfactory, neither from the patient's perspective nor the society (Ólafsdóttir, 2001). Furthermore, the medical knowledge provided in clinical practice guidelines (CPGs) is incomplete and sometimes ambiguous. In order to capture the state of the domain knowledge a range of guidelines is required. These express the knowledge differently, sometimes with terminology that expresses the

underlying uncertainty of the domain knowledge. The knowledge domain is characterized by a continuous evolvement, where old “truths” are being replaced with new evidence-based and best practice knowledge. The investigation process is basically also a process of refinement of evidence, where evidence in difficult cases needs to be expressed using finer granularity compared to schoolbook cases that can be captured at coarser levels of granularity (Lindgren, 2007). Furthermore, the evidence used in the physician’s clinical reasoning process needs to be generated from different sources such as other professionals, the patient and the patient’s family members. Consequently, the evidence is of different granularity and reliability, depending on the source’s ability to account for specifics and their professional domain. When taking these characteristics of the decision-environment into consideration, methods that allow representing and visualizing uncertainty and defeasible reasoning in a process and teamwork perspective are required in order to provide a user of a decision-support system tailored support throughout the dementia workup. Furthermore, as a consequence of using a decision-support system that is tailored to a user who does not possess a complete knowledge, the user should develop his or her knowledge and skills in the process. To comply with this development the support provided by the system also needs to be flexible. Clinical use of CPGs seems to serve different purposes depending on prior knowledge in an individual (Patel et al., 2001), which consequently should be mirrored in the design of a CDSS.

The clinical decision-support system (CDSS) DMSS (Dementia Management Support System) is being developed for assisting medical personnel in the investigation of suspected cases of dementia (Lindgren, 2007). The main purpose of the system is to function as an extension of the individual actor’s cognitive ability and as a common ground for collaborative and distributed teamwork (Lindgren, 2007; Lindgren, 2008c). The system is designed to support higher-level cognitive functions such as reasoning, decision-making and learning in the sense of (Kaptelinin, 1995; Vygotsky, 1978). However, a critical functionality is also to collect patient data of high quality to be used to further develop the international evidence-based knowledge in the clinical domain as well as the knowledge integrated in the system. DMSS is designed to provide interactive support throughout the diagnostic process, giving reminders of what necessary evidence is missing, giving alerts when particular data requires alternative trails of investigation, giving suggestions of diagnosis, etc. This type of interaction behavior is also denoted mixed-initiative interaction in literature (e.g., Cortellessa & Cesta, 2006). While the system has been shown to be useful for capturing evidence in a patient case and for verifying and reconsider diagnoses, an earlier evaluation also showed that the system had limited support for diagnostic hypothesis generation and evaluation, which are important mechanisms in the reasoning process (Lindgren, 2008a). Therefore, DMSS-R (revised version) was developed with an extended support for handling hypotheses, which also highlights complexity in patient cases and provides tailored advices.

This paper presents the design of DMSS-R, the development process and results from clinical practice environments in Sweden, South Korea and Japan where DMSS has been or is integrated in controlled evaluation settings (Lindgren, 2007; Lindgren, 2008a-c; Lindgren, 2010). These use environments are characterized by an ongoing development for improving dementia care and the development of DMSS is integrated in this process. The sociotechnical nature of work has been in focus from the initial stage and throughout the development process of DMSS and this paper describes in what way sociotechnical and activity-theoretical aspects have been instrumental in this process.

The main purpose of the evaluation studies has been to explore phenomenon related to the use of DMSS-R qualitatively, that may be vital in the evaluation of quantitative data from evaluations in which the system is used during a longer period. Crucial factors in this context are misconceptions of terms and concepts in the system, routines that may generate questionable data, etc. The most important aspects concern the individual care professionals’ knowledge and skills, related to the individual and often exceptional patient.

The paper is organized as follows. In the next section the methods used and approach to development is described, followed by a section where the design and functionalities of DMSS-R are described. We focus in the summary of results from different studies on the following issues related to the use of DMSS-R in the clinical dementia workup:

- The quality of the tailored advice with respect to the patient case and with respect to the user,
- The user’s view on and adherence to suggestions and guidance provided by the system,
- The system’s support for teamwork,
- The support provided in situations with limited patient data, and
- Sources of questionable data and reasons for questionable or incomplete data.

Finally, the results are discussed and conclusions are drawn, providing implications for future work.

2 Methods and Study Design

DMSS-R is being developed as a multi-professional project involving experts in geriatrics, rehabilitation professional and computer scientists in an iterative, participatory design process. The approach taken in this work is activity-oriented rather than clinical practice guideline oriented, by embracing the whole dementia investigation process as the scope of analysis and environment to be supported. This wider, activity-centered approach is promoted in research in particular for developing systems to be integrated in complex knowledge intensive multi-professional and collaborative work environments (e.g., Engeström, 1999; Kuuti, 1995; Kaptelinin & Nardi, 2006; Norman, 2005; Berg, 1999; Goorman & Berg, 1999; Coiera, 2007; Kaplan, 2001a).

Prototypes have been developed for different purposes in the project and used as knowledge artifacts in the sense of (Singh, 2007) for creating a common perception of the knowledge to be integrated in the system (Lindgren, 2008b). In this process analyses of the domain knowledge have been done (Lindgren, 2007). Formative and qualitative evaluation studies in clinical practice have been done in order to capture the situatedness of the use environment, in which prototypes have been integrated (Lindgren, 2007; Lindgren, 2008a-c; Lindgren, 2010). The use environments have been clinics in Sweden, Japan and South Korea. The two phases of the development - system requirement phase and implementation phase - correspond to the increasing interest and development of dementia care in society. The following subsection describes in what way these processes have been interlinked.

2.1 Development of Dementia Care and the Integration of DMSS

During the initial period, development and evaluation focused organizational issues at local clinical practice as well as at a national and international level. Work was done to increase the awareness of the status of dementia care and the importance to improve the situation in Sweden and increasingly, also in South Korea and Japan. The members of the development team were during this period also active in this work, due to their expertise in the domain. Early prototypes of DMSS were demonstrated at the different levels and evaluated in order to gain responses and for discussing potentials of a decision support system in dementia care from different perspectives as well as obstacles that may prevent a successful implementation. Factors were identified, at personal use level as well as organizational and political levels. In parallel, DMSS was improved, with increasingly flexible and interactive support for managing both typical and atypical patient cases. A major obstacle found in both Sweden and Japan during this period was the unwillingness to change the routines for referrals of patients to specialist care, mainly due to the financial structure.

The next and current phase is characterized by an ongoing development of dementia care with a broad range of different efforts, such as educational support, extended support for consultation with experts in difficult cases, increased team work and engagement of specialized nurses and care personnel, increased efforts to distribute results from evidence-based medical research to clinical practice, support to patient's families and informal care providers, development of local and national practice guidelines and an increased willingness and incitements to change routines. Members of the development team have been involved also in these interventions. In this phase, DMSS-R (a revised version) is introduced and used in controlled settings, initially as a tool for collaboration and continuing medical education at the point of care.

DMSS has been developed in collaboration with specialists from the main geriatric clinic in Northern Sweden, and prototypes have been used by a range of professionals in evaluation settings. Currently, DMSS-R is available at two of the remote health care centers in Northern Sweden in daily practice and is used in distant consultations with geriatric specialists. In Northern Sweden the organization of dementia workup is centralized with the county council providing with specialized teams at the main hospitals as supplement to the health care centers distributed in remote areas. The purpose of the specialist teams is to provide with support in the difficult cases, although a large part has been also typical cases that has been referred from primary care. However, with the long distances to care, routines are currently being changed from referring patients to the specialist clinic to consulting the specialists using tele-medical equipment. This is a development that one of the expert physicians who participates in the development of DMSS has been leading. Education has been provided to personnel however, this has been difficult due to the high

turn-over of primary care physicians. The continuation of care typically relies heavily on nurses and occupational therapists in these locations. DMSS-R was introduced at the centers at the same time as one of the educational seminars was held. Current patient cases were discussed while introducing the system. Aspects regarding the local organization of the dementia workup were discussed and put into relation to current design of the system as well as possible future redesigns. The local organization differs significantly between the centers, and the introduction generated important aspects to be taken into consideration in the redesign of the system. The redesign was later presented at the clinics during another of the educational seminars, giving the professionals an opportunity to reflect on the design before a new version was installed. Currently, the new version is being used and evaluated in daily practice. A similar approach is being used in the implementation of the system into clinical practice in Japan and South Korea. Medical professionals who have the authority to and been assigned the task to develop dementia care, are integrating DMSS-R as one of the means to accomplish change, with a purpose of evaluating its potentials in the local environment. In practice, the involved domain expert physicians at the different locations are shaping their own and their collaborators' work organization, culture and processes while contributing to shaping the design of technology, in this case DMSS. We have found the approach to integrate system development into the development of practice highly valuable, by giving health professionals influence and control over the emerging content and design of the system, while they also work to develop their clinical practices (Lindgren & Eriksson, 2010).

The main aim of the development team in ongoing evaluations is to assess the development of attitudes and skills in direct and indirect novice users in the process of integrating the system into daily practice. This is done using formative and qualitative methods such as observation, interviews, focus groups and the use of the system in assessing and reasoning about familiar or new patient cases. The overall purpose is to provide optimal and tailored advice to the exceptional patient in order to increase the quality of the care provided to the patient. Using multi-professional evaluators who besides interaction design also know the disease domain, enrich the situated evaluation session with alternative ways of interpreting data in patient encounters. These can be used in interviews with the professional for the purpose of obtaining reasons for deviations from suggestions provided by the system, and most important, detecting ignorance and other reasons for errors. This also provides the patient who agrees on participating in evaluation a qualified second opinion, which increases the reliability in assessments.

2 DMSS-R

DMSS-R is built in an iterative process on the result of the formative evaluation studies and will be presented in more detail in the following subsections. In the first section an overview is given of the mechanisms that generate tailored support as a background to the following subsections, in which the functionalities of DMSS-R are described from a diagnostic reasoning process perspective, a knowledge and skill development perspective and a teamwork perspective.

2.1 Personalization of DMSS-R

DMSS-R is based on CPGs for dementia diagnosis and care with a primary focus on differential diagnosis and the physician's perspective, e.g., (American Psychiatric Association, 1994; McKeith et al., 2005; Neary et al., 2001). Additional support is integrated for assessing severity levels and for selecting interventions suitable for the individual patient. International terminologies and classifications are used for the concepts in the system, with associated terms and definitions to aid the user on what is being asked for. Inferences are implemented using production rules, with structures and ontologies based on formal argumentation theory (Lindgren & Eklund, 2006) and activity theoretical analyses of clinical practice (Lindgren, 2008c).

A model of the activity was created with the potential users and the patient's life situation as core parts (Lindgren, 2008c). Based on the model, the patients are by the system categorized into typical or atypical, based on their information's adherence to sets of CPGs. The distinction is made to lead the assessments in the atypical cases towards a finer level of granularity in patient information, in order to increase the reliability in hypothetical diagnoses. It should be noted that this distinction does not necessarily comply with the individual physician's view of the complexity of the patient case. Each patient is characterized by

the mixture of findings that is assigned the patient case, from which tailored advice and explanations are generated in the process of diagnostics and establishing interventions. The advices and explanations are selected from a repository of claims and synthesized based on algorithms crafted in the knowledge building sessions with expert physicians.

The user model emerged from the activities identified in the dementia workup, since what is interesting at execution time in the patient encounter is the available resources at the point of care. Three perspectives need to be taken into account in the creation of support for the user, that correspond to the interaction surfaces effectuated and visible in the execution of an activity, described by Engeström (1999); the *rules* that mediate the individual's interaction with coworkers and the patient's relatives, the *division of labor* that mediates the team's interaction with the patient case and the *tools* used by the individual and the team that mediate the interaction with the patient case. Firstly, we take into account the factor that responsibility and level of focus is different depending on professional category, and secondly, the factor that execution of sub-tasks differs depending on organization and personal preferences. Each task to be executed, regardless if it is a task at a basic operational level or a more complex decision making task, is dependent on certain resources and tools, such as assessment instruments, knowledge about and experience of observable phenomenon and associated terminology. Consequently, and thirdly, the need for support in the execution of a task differs depending on the skill and knowledge in the individual that has been assigned to the task. One basic assumption is made about the potential users of the system, and this is that the user has at least partial knowledge about dementia, either theoretical (factual or conceptual) from medical studies or experience-based from care situations during a longer period of time. In a teamwork setting and in the effectuation of the dementia workup, these two types of knowledge need to be synthesized. Therefore, the system includes what needs to be assessed based on the CPGs regardless whether the actor executing a certain task is certain type of physician or a nurse, or whether the person entering the obtained information into DMSS-R is the one who has executed the task. Consequently, in the use of the system, the direct or indirect user is provided with the information that is needed at different stages for the person to be able to assess what needs to be assessed in a patient case. The information about a certain concept includes both a definition as presented in terminologies that corresponds to the theoretical understanding, but also descriptions of manifestations and critical questions that support the assessment during observations of the patient, which also a person without the theoretical understanding should be able to use (Figure 3). An expected consequence of using the system would then be that in the latter case, the experience-based knowledge becomes enriched with the theoretical, explanatory knowledge, and vice versa in the case of the user with merely theoretical knowledge.

The interaction design of DMSS-R is tightly intertwined with the meta-level of the knowledge base, which directs the use of the system and provides the support that is needed at different points in the process. In Figure 1 the main form of the system is shown, in which the different categories of components correspond to different levels of activity in the investigation process. A major distinction is done between containers, or tools, for data capture and components for analysis and decision support, a distinction that mirrors the different levels of actions that are described in section 2.2 (Figure 4). Further distinctions and categorizations of data capture functionality are made based on sources of evidence and validated screening tools that are recommended to be used in order to obtain reliable data.

2.2 Interactive Support for Decision Making in a Diagnostic Process

DMSS-R essentially works as an interactive checklist of necessary and supplementary features to investigate, while providing analyses of the findings in a patient case. The user can choose to enter all information that is known and use the system to verify assessments and diagnoses, or let the system guide the process following a set of steps visualized by three critical questions (Figure 1). In this case, the system shows what information needs to be assessed and suggests conclusions, such as diagnoses based on the information. A suggestive diagnosis is provided in the typical patient cases, while in the atypical cases the system presents the features supporting different diagnoses possibly manifested in a patient case based on a set of certain CPGs, without suggesting one particular diagnosis the way the system does in the typical, unambiguous cases (Figure 2). Explanations are provided also when the information is insufficient for assessing a diagnosis.

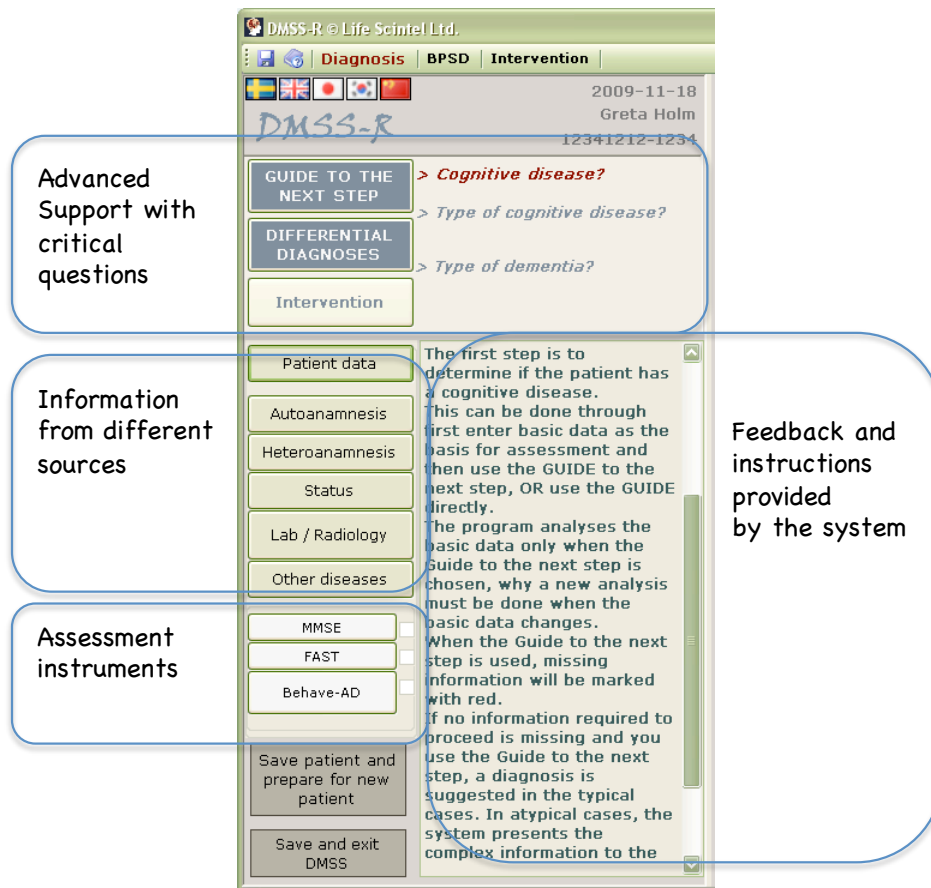


Figure 1. The main form of DMSS-R with its different categories of functionalities corresponding to different levels of activity.

The findings are interpreted using different sets of CPGs (i.e., *contexts* as defined in (Lindgren and Eklund, 2006) and different sets of values associated to the different contexts of interpretation. Each item (sign or symptom) with associated values in a patient case is treated conceptually as a piece of *evidence* and is used as argument in the reasoning process for establishing support or contradictions for diagnostic hypotheses. Different purposes of values are distinguished by whether they are included in a *reliability* scale (reliability of, or confidence in a certain finding or proposition), *severity* scale (severity of a symptom or disease) or an *influence* scale (the type of influence a finding has on a certain diagnosis or proposition). Evidence can have different associated values depending on the context of interpretation. All values are extracted from CPGs or assessment instruments. Therefore, they are typically qualitative, expressing modalities and degrees using expressions in natural language. The support is computed locally within each context. Therefore, in atypical cases different contexts may generate the same level of support for different claims. Furthermore, different contexts valuating the same claim may also generate different levels of support. An example is provided in Figure 2 where two different CPGs give the support *present* and *possible* respectively for the same hypothetical diagnosis. When using the extended information about the grounds for the hypotheses, the user will become aware of that due to the different characteristics of the CPGs, the value *possible* is the one to use in comparison with alternative hypotheses. The valuation between contexts in the atypical cases is in current version primarily done by the physician. This is mainly done by valuating the qualities of different contexts, adding personal preferences or preferences stated by the local organization or national guidelines. In the example in Figure 2 the support for the diagnosis Lewy body dementia is stronger (*probable*) than for Alzheimer's disease and vascular dementia (*possible*), and the grounds for the assessment is provided on the right side of the form in the example.

DIFFERENTIAL DIAGNOSES

Cognitive diseases Types of dementia

Confirm/assess diagnose(s):	Results of DMSS analyses:
<input type="checkbox"/> (Alzheimer's disease (DSM-IV	<input type="checkbox"/> <input type="checkbox"/> <input checked="" type="checkbox"/> PRESENT
<input type="checkbox"/> Alzheimer's disease (NINCDS (ADRDA	<input type="checkbox"/> <input type="checkbox"/> <input checked="" type="checkbox"/> POSSIBLE
<input type="checkbox"/> Alzheimer's disease (Dubois (criteria	<input type="checkbox"/> - / + UNKNOWN
<input type="checkbox"/> (Vascular dementia (DSM-IV	<input type="checkbox"/> <input type="checkbox"/> <input checked="" type="checkbox"/> PRESENT
<input type="checkbox"/> Vascular dementia (NINCDS (AIREN	<input type="checkbox"/> <input type="checkbox"/> <input checked="" type="checkbox"/> POSSIBLE
<input type="checkbox"/> Lewy body dementia	<input checked="" type="checkbox"/> <input type="checkbox"/> <input checked="" type="checkbox"/> PROBABLE
<input type="checkbox"/> Frontotemporal dementia	<input type="checkbox"/> - / + UNCERTAIN
<input type="checkbox"/> Corticobasal degeneration	<input type="checkbox"/> - / + UNKNOWN
<input type="checkbox"/> Semantic dementia	<input type="checkbox"/> - / + UNKNOWN
<input type="checkbox"/> FTD MND	<input type="checkbox"/> - / + UNKNOWN

Dementia due to:

<input type="checkbox"/> Parkinson's disease	<input type="checkbox"/> - / + UNKNOWN
<input type="checkbox"/> PSP	<input type="checkbox"/> - / + UNKNOWN
<input type="checkbox"/> Normal pressure hydrocephalus	<input type="checkbox"/> - / + UNKNOWN
<input type="checkbox"/> Creutzfeldt-Jacob disease	<input type="checkbox"/> - / + UNKNOWN
<input type="checkbox"/> MS	<input type="checkbox"/> - / + UNKNOWN
<input type="checkbox"/> ALS	<input type="checkbox"/> - / + UNKNOWN
<input type="checkbox"/> Huntington Chorea	<input type="checkbox"/> - / + UNKNOWN
<input type="checkbox"/> Other condition or disease	<input type="checkbox"/> - / + UNKNOWN

Close Save for analysis

Lewy body dementia

the symptoms support the syndrome or diagnosis to a certain degree.

Degree of severity

- Severe

- Moderate

- Mild

- Degree unknown or normal

Degree of reliability

- Probable

- Possible

- Uncertain

- Unlikely

- Excluded

Base for diagnosis

CORE DIAGNOSTIC FEATURES:
 State of dementia is present
 Extrapyramidal symptoms
 Fluctuating cognitive ability
 Visual hallucinations

CONTRAINDICATIVE FEATURES:
 Focal signs and/or vascular disease evident on radiology exam makes DLB less likely.
 Evidence fulfils the requirements for DLB according to consensusGL.

Figure 2. Example of support for differential diagnosis in DMSS-R in a patient case. Specific information related to the hypothetical diagnosis *PROBABLE Lewy body dementia* is shown.

In all patient cases the physician can anytime get an overview of the state of the knowledge at hand in the patient case, where hypotheses are presented with strengths, contradictions and support (Figure 2). Each potential diagnosis is then presented with the values for reliability (e.g., *uncertain*, *possible*, *probable*, etc.) as interpreted in different contexts of guidelines, together with a list of findings (present or absent) that supports or contradicts the diagnosis in the particular context. This way the physician may value the outcome of the use of different clinical guidelines and make a decision based on his or her preferences among the guidelines and screening tools. This overview is intended to increase transparency and consequently, promote trust and compliance with suggestions provided by the system, yet allowing for deviations from the suggestions when there may be reasons for valuating the findings differently. The alternative conclusions made by the physician are registered together with the system's suggestions in a patient case to enable analyses of the reasons for non-compliance. To be provided with an overview of different possible diagnoses is also important, since multi-diagnoses are common in the domain and the average primary care physician is rarely familiar with less common dementia diagnoses. Furthermore, a presentation is also given of what can be concluded based on limited information in a patient's case. If necessary information is lacking, the physician is made aware of this, and of possible weaknesses in his or her assessments that are due to limited information or imperfect domain knowledge.

2.3 Design for Supporting Knowledge and Skill Development

Since the system needs to support a continuing medical education and development of skills, the flexible support for the different levels of the activity in focus is essential in order to provide users of different levels of expertise appropriate support and guidance. A foundational view of skill development that is used

in the design of the system is the transformation of activities that requires cognitive effort to execute when unfamiliar, into operations that are executed with minor cognitive load, often accomplished with initial guidance from a more skilled peer (e.g., Kaptelinin & Nardi, 2006). Where experts reason at a higher level of abstraction, novices need support also for the operational levels of activity, such as gathering data using screening tools, refine and interpret low level data into observations and findings (Arocha et al., 2005; Lindgren, 2007). Reasoning activities are transformed along a hierarchy of activity in terms of activity theory with shifts of foci when breakdowns occur (Bødker, 1989). Causes of breakdowns can be absence of necessary data, conflicting guidelines, conflicting evidence, unfamiliar concepts, etc. If these breakdowns are interpreted as opportunities for learning and development, then providing support in these situations is expected to promote development of knowledge and skills in novice clinicians. In addition, creating use situations when existing routines or knowledge in a person is challenged, in order to create awareness about possible misconceptions is crucial in a system promoting learning and development (Kaptelinin & Nardi, 2006). One example of such mechanism in DMSS-R is that DMSS-R respond with an alert to an attempt to assess cognitive functions if the patient has been assessed to have a decreased level of consciousness.

An important component of support at the operational level is support for conceptualization of the clinical work including terminology (Arocha et al., 2005). A common understanding of the language used when describing vital signs in a patient needs to be continuously created and re-created in daily practice (Karlsson, 2001). This is particularly important when using a decision-support system for gathering data to be used for developing the knowledge domain in evidence-based studies. Consequently, reasoning about concepts and their relations is also part of the development of skills. DMSS-R supports this by providing definitions of concepts, information about the phenomenon and some examples of what to observe in a patient encounter. An example with information about memory functions is shown in Figure 3.

A vital component in teamwork is the collaborative reasoning, where individuals may contribute to the common reasoning and knowledge building. Therefore, the system allows and facilitates a shared representation of a progressive disease trajectory in a patient case, which may include different and conflicting views on how interpreting findings in a patient case. However, each may be fully motivated and analyzed from different professional perspectives. In a multidisciplinary setting each professional contributes with a supplementary view of a patient's situation and problems, in order to create a rich, holistic understanding for establishing interventions. In such collaboration the expert nurse for instance, contributes with a particular professional observational skill and experience-based knowledge (Benner and Tanner, 1987) and focus manifestations of symptoms instead of the pathology behind the symptoms (Leprohon and Patel, 1995), corresponding to the levels 1 and 2 in Figure 4.

Extensive investigations have been made by Patel and colleagues for the purpose to describe how clinicians perform the complex task of clinical diagnosis, summarized in (Patel et al., 2002). One of the strategies found is that working hypotheses are generated early in an abductive manner, when only a few facts have been collected, through some kind of pattern recognition. In pattern recognition a physician recognizes a particular sample of data as signifying a particular patient state, which is an ability that is developed with experience. Then the hypotheses are confirmed or rejected, while new information is gathered and new hypotheses are generated. Studies made by Patel and colleagues show that if an expert includes the correct hypothesis in the initial set of hypotheses, the remaining reasoning tends to aim at confirming the hypothesis instead of generating new hypotheses. A less experienced physician has more difficulty in evaluating hypotheses and therefore more difficulty in eliminating incorrect hypotheses. The less experienced also tend to continue generating new hypotheses, even after the correct diagnosis is produced. Thus, what seems to distinguish the expert from the novice is the knowledge of what *not* to do. In clinical practice experts put more effort on the representation of the problem by *sizing up* the situation rather than generating decision options, a process called *situation assessment*. Novices on the other hand tend to jump to generating hypotheses and implementing solutions, sometimes based on conflicting data, in situations where experts defer their decision until they have more evidence, while meeting the immediate need of the patient. The latter behavior is enforced by the system, by providing the status of the information including its limitations in an overview of hypothetical diagnoses, and by emphasizing lack of information.

Source → Heteroanamnesis (from relatives or other sources)

Category of evidence → Cognition **BPSD, ADL, social aspects**

Concept → Memory functions affected: significant

Term → Memory functions

Value: affected

The degree of the dysfunction is significant and does affect social and/or work ability.

Severity: significant

Degree of impairment?

- Severe Significant change, affects ADL and social ability (DSM-IV)
- Moderate
- Mild
- Degree unknown or normal

Definition/explanation/exemplification

Specific mental functions of registering and storing information and retrieving it as needed (ICF). Have next-of-kin the impression that memory ability has decreased lately, e.g., for events? If the decrease affects the ability to perform activities of daily living and social life then the severity is at least moderate. If the patient can do all things he or she can normally do, then the severity is mild.

Characteristics of the category of evidence

Cognitive functions

Mental functions of language aphasia- affected: mild

Interpretation of sensory impressions -agnosia normal

Performing practical tasks apraxia- affected: significant

Ability to plan and organize executive functions- affected: significant

Judgement normal

Understanding of instructions - / +

Orientation to time - / +

Orientation to place - / +

Characteristics of the cognitive deterioration

Onset Rapid onset -hours-days Insidious onset -months

Course Onset unknown

Slowly progressive deterioration during > 6 months yes

Stepwise deterioration yes

Fluctuating cognitive ability during the course of the day yes

Close Save for analysis

Figure 3. Example of information available in a patient case that is obtained from a relative or care personnel. Normal states are entered by buttons shifting to green color towards the left side next to a concept, and deviations from healthy, normal states are marked by buttons that shift to red color in a column towards the right side. Specific information about a concept is shown on the right side. Specifics about memory functions and the memory impairment is shown in this example, made visible by using the buttons next to the concept.

There are also differences between novices and experts in ways used to tackle daily clinical practice. Novices tend to use single purposes defined by official norms, single-layered surface relations and detailed actions. Experts handle several conflicting purposes while using official as well as unofficial norms and also personal judgment in the process. Other aspects of expertness are ability to handle complex multi-layered social relations and use high-level actions. This is for example shown in interactions with patients where data is collected. While the novice directs the conversation following an implicit or explicit manual or protocol, the expert is able to follow the patient's choice of subjects and still gather the information needed (Beuscart-Zèphir et al., 2001). A consequence that has been shown is that experts tend to be more reluctant to use computer applications that put constraints on the activity and reduce flexibility. Therefore, DMSS-R is designed to be used in a flexible way depending on the user and the patient case; as a guide with certain steps to follow, as a checklist to verify that nothing is forgotten, for challenging conceptual knowledge, but also as a tool for verification of assessments in difficult cases.

The dementia workup can be viewed as consisting of three levels of complexity in the activities, where the basic, or *operational* level constitutes the data gathering (Figure 4). This is preferable done using validated assessment instruments, clinical interviews, etc. The basic actions of collecting raw data are supported by the system in that suggestions are given of which methods or assessment instruments to use, of which selected instruments are integrated in the system as basic data collecting frames. These range over cognitive functions (MMSE, Folstein et al., 1975), behavioural and psychological symptoms (Behave AD, Reisberg, 1996) and functional levels related to daily activities (FAST, Reisberg, 1988).

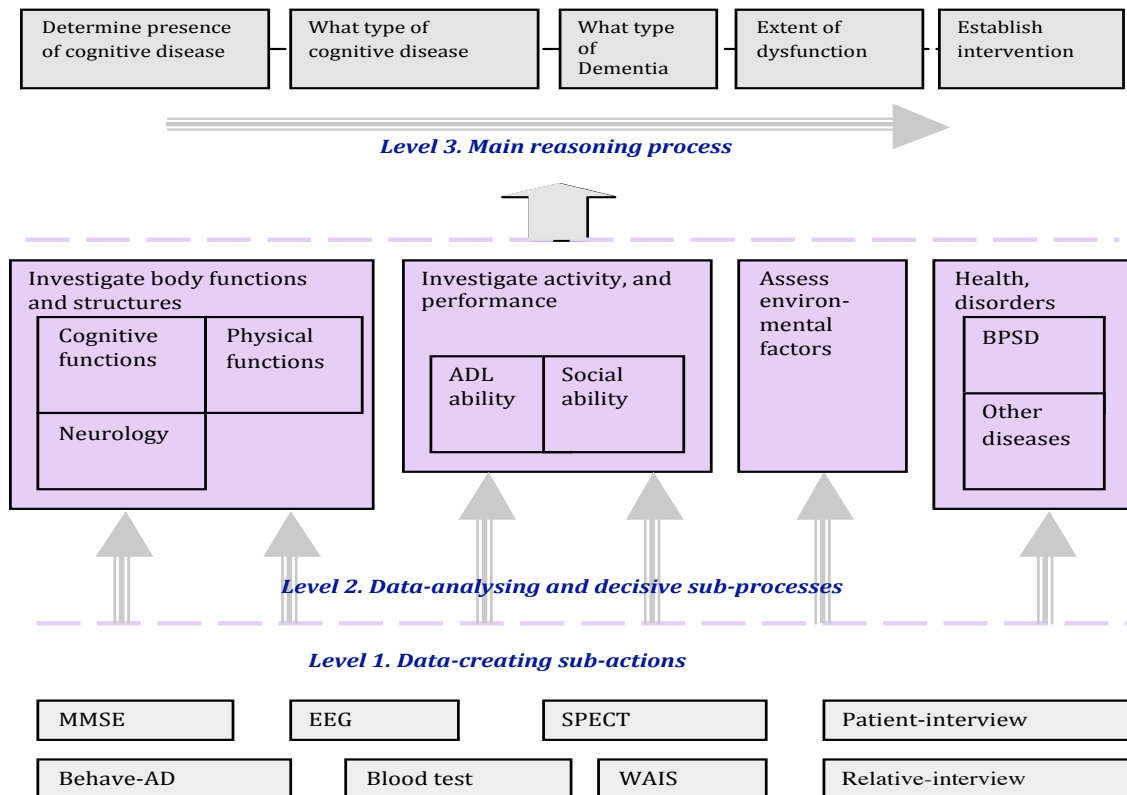


Figure 4. Different levels of complexity in the process of investigating cognitive diseases. BPSD is an abbreviation for Behavioral and Psychological Symptoms in Dementia, and MMSE, EEG, WAIS, SPECT and Behave-AD are abbreviations for clinical examinations, selected for exemplifying Level 1. (modified from Lindgren, 2008c).

In addition to the operational level, two levels of reasoning processes from a physician's perspective have been identified in the activity (Lindgren, 2008c). The *main reasoning* includes diagnostic reasoning and decision-making concerning interventions. This trajectory of reasoning is visualised by the critical questions visible in the user interface (Figure 1). *Supportive reasoning* processes involve investigations of specific domains in an individual, such as neurology, cognition, psychology, physiology, etc. (Figure 4) and involves refinement of data into findings. The different purposes of these processes can be summarised by viewing the supportive processes as investigating dysfunction per se, while the main reasoning relates the dysfunctions in the perspective of a dementing disease as a possible cause. The three views of the activity (operational level, investigation of specific domains and the main reasoning process) are executed in parallel, they are cross-fertilizing and dependent on each other, and are partly overlapping depending on circumstances in the environment.

The actions of higher complexity leading towards qualified decisions have been focussed in the development of DMSS. The advanced support for reasoning is based on the main reasoning process (Level 3 in Figure 4) since the clinical guidelines used in the system primarily provide support for this level. The system supports the supportive reasoning processes (Level 2 in Figure 4) by providing definitions of concepts, information about the phenomenon and some examples of what to observe.

A goal of the design of the system is to present the domain knowledge including its limitations. This is done by providing the user the evidence in a patient's case visualized and interpreted within different and sometimes conflicting frames of interpretations. The more complex actions are partly supported in the prototype system by the interaction design (integrating meta-level knowledge), and partly by production rules, based on clinical guidelines in the domain and formulated in knowledge-building sessions with domain experts.

2.4 Design for Supporting Teamwork and Consultations

The system is currently focusing the physician's task of diagnosing dementia and deciding on suitable interventions. From this perspective, and from the perspectives of the clinical practice guidelines, information about the patient needs to be obtained from different sources, such a person who knows the patient and is able to provide information about how the patient manages his or her daily life. DMSS-R structures information by category of source so that information about e.g., memory comes from assessment instruments, the patient, a relative or care personnel, and the physician contributes with his or her assessment in a dedicated status form. In practice, a large part of the information that the system requires is often obtained by a specially trained nurse or an occupational therapist, whom can account for specifics that the physician does not have the possibility to assess during an often brief encounter with the patient. Furthermore, some of the assessment instruments integrated in DMSS-R are in some clinics routinely used by a nurse or occupational therapist in the dementia workup. To facilitate the use of DMSS-R as a common tool for different professional categories, concepts from ICF (International Classification of Function, Disability and Health) (WHO, 2001) is used as basis for framing the patient's situation. The reason for this is that ICF covers most of what is occurring as observable difficulties for a patient with dementia, corresponding to the different fields of interest at Level 2, visualized in Figure 4.

In a current use setting, physicians at remote health care centers can use the system in their daily work, and in difficult cases discuss the cases using telemedicine techniques for sharing information and using DMSS-R as common ground for discussions with geriatricians. This facilitates consultation on distance preventing referrals of patients to hospitals situated a long way from their home, which may worsen their conditions. Integrating DMSS-R in distant consultations is part of a general effort in increasing the quality of dementia care in Northern Sweden where there is a high turnover of clinicians in primary care and long distances to specialist care.

3 Summary of Results from Evaluation Studies

When taking the sociotechnical and situated characteristics of the decision-environment into consideration, formative methods for translating these into requirements and interaction design are required. The aim has been to enrich the use environment with a tool that meets the immediate needs of a team of professionals while contributing to shaping their organization of work. The qualitative results that have been obtained in evaluations has been translated into requirements and fed into the development of DMSS, which have resulted in the design presented in the previous section (Lindgren, 2007; Lindgren, 2008a-c; Lindgren, 2010). In the following subsection, a summary will be provided of the combined quantitative and qualitative analyses that have been made. An overview of the evaluation studies is presented in Table 1 and Table 4. The summary will focus the studies III, IV, V (Table 1), VIII and IX (Table 4).

The second subsection describes in more detail a recent case study that provided insights in the impact DMSS-R may have on the whole use environment (Lindgren, 2010).

3.1 Summary of Results from Analyses of the System's Non-Compliance with Clinicians' Assessment

An early prototype was in the system requirements phase introduced to a network of physicians of different specialties for evaluation purposes (Study IV in Table 1). The prototype was also used by two experienced physicians during an evaluation period at a hospital, which managed referred patients with suspected dementia within this network (Lindgren, 2007) (Study V in Table 1). At this point, the organizational structure of dementia management posed limitations on the possible use scenarios in this use environment. The primary care physicians that were satisfied with the current organization were not interested in improving their skills in diagnostics, but needed support in assessing care needs in later stages of the disease, while the clinics that received the referred patients for diagnosis were not interested in changing these routines. However, the experienced physicians at the clinic viewed the system beneficial for verifying their assessments. The early prototype provided support for diagnosing the common types of dementia but provided no elaborated explanations in the atypical, ambiguous cases. As a result of this evaluation, the

interactive support was improved, partly to meet the needs that generated the “workarounds” that the two physicians developed who used the system in clinical practice during this period.

Table 1. Overview of evaluation studies made of early versions of the prototype in the requirements phase.

<i>Evaluation Study</i>	<i>I</i>	<i>II</i>	<i>III</i>	<i>IV</i>	<i>V</i>
<i>Prototype</i>	I	II	III	DMSS-SJ	DMSS-SJ
<i>Primary investigation focus</i>	Diversity in needs, user individuality aspects	Teamwork, consultation, reasoning model, argumentation functionality	System’s compliance with investigation process	Reasoning model, terminology, design and content, diversity in patients’ cases	Compliance with physician’s diagnosis and reasons for non-compliance
<i>Number of users</i>	6	6	1	7	1
<i>User characteristics</i>	GPs; geography, range in expertise	Experts, team; range of different expertise and work methods	Expert geriatrician	Experts, GPs; range of different medical expertise	Neurologist
<i>Number of patients</i>	6	5	5	21	34
<i>Patient characteristics</i>	Current patients	Current complicated patients	Range of typical and atypical patients	Range of typical and atypical patients	Range of typical and atypical patients
<i>Environment</i>	PCCs in a county of Northern Sweden	Geriatric clinic, PCC in Northern Sweden	Geriatric clinic in Northern Sweden	Different clinics in a county of Japan	Clinic in Japan
<i>Summary of results</i>	Socio-technical requirements, activity analysis. (Lindgren, 2007)	Validation of reasoning model, verification of argumentation approach, activity analysis. (Lindgren, 2007)	Need for support for hypothesis generation, activity analysis. (Lindgren, 2008a)	5 of 21 cases had diagnosis types not supported by the system. The 16 supported cases complied, of which 4 were atypical cases. (Lindgren, 2008b)	27 complied, 3 did not due to questionable data entry, 4 gave reasons to revise the knowledge base of which 2 were unsupported types.

Furthermore, when analyzing the responses obtained from the early prototype that was limited to the most common dementia diagnoses, it was found that the system behaved unsatisfactory in three of the six cases of rare dementia types (cases number 1, 15 and 17 in Table 2). The initial purpose of the system was to provide support only in the typical and “easy” cases, in order to prevent referrals of these to specialist care. However, the distinction between what cases were typical and not, proved to be subjected to biases. The perception on what cases were “difficult”, atypical cases did not necessarily correlate to the developers’ view or the system’s distinction. The described distribution of types of disease manifestations

in patients depended on the type of clinic and the physician's specialization. Four of the six rare cases were managed by physicians at a specialized psychiatric clinic or a pathology ward in Study IV (Table 3).

Table 2. Overview of patient participating in Study V and which response was given by the system, and whether the system was designed to handle the diagnosis. Cases with unsatisfactory responses are marked in bold face. AD: Alzheimer's disease, CBD: corticobasal degeneration.

Case	G	Age	Clinical Diagnosis	Prototype suggestion	Support not	
					Typ	Atyp integrated
1			Creutzfeldt-Jacob disease	Vascular dementia	X	X
2	M	69	Alzheimer's disease	Alzheimer's disease AD	X	
3	F	84	Lewy body dementia	Lewy body dementia DLB		X
4	M	58	frontotemporal dementia	frontotemporal dementia FTD		X
5	M	58	Vascular dementia	Vascular dementia VaD	X	
6	F	46	AD (chromosome 14)	AD/frontotemporal dementia		X
7		68	untypical AD->CBD	AD/frontotemporal dementia		X
8			Alzheimer's disease	Alzheimer's disease	X	
9	M	78	Lewy body dementia	Lewy body dementia	X	
10	F	76	Vascular dementia	Vascular dementia	X	
11		69	Alzheimer's disease	Alzheimer's disease	X	
12	F	79	Vascular dementia	Vascular dementia	X	
13	F	81	Alzheimer's disease	AD/frontotemporal dementia		X
14			Alzheimer's disease	AD/frontotemporal dementia		X
15			corticobasal degeneration	Alzheimer's disease	X	X
16	M	71	pick's disease	Incomplete data		X
17			corticobasal degeneration	Alzheimer's disease	X	X
18	F		Vascular dementia	Vascular dementia	X	
19	F	84	Alzheimer's disease	frontotemporal dementia		X
20	F	80	Parkinson dementia	Parkinson dementia	X	
21			mild cognitive impairment	mild cognitive impairment MCI	X	

Table 3. Demographic characteristics of the seven physicians participating in Study V and the clinical diagnoses of the 21 patient's cases. Unsupported cases are marked with bold face.

Physician	Type of Clinic	Pat 1	Pat 2	Pat 3	Pat 4	Pat 5
A	University hospital, Dept Neuropsychiatry	C-J Disease	-	-	-	-
B	University hospital, Dept Neuropsychiatry	VaD	DLB	FTD	VaD	-
C	University hospital, Dept Pathology	AD (Chr 14)	CBD	AD	-	-
D	University hospital, Dept Geriatrics	DLB	VaD	AD	VaD	MCI
E	PCC (patients in group home)	AD	AD	-	-	-
F	Psychiatry clinic	CBD	Pick's disease	CBD	-	-
G	PCC/private hospital (patients in group home)	VaD	AD	Park dementia	-	-

Supplementary data from Study V showed the same unsatisfactory results in the two unsupported corticobasal degeneration (CBD) cases. However, this study also revealed that the major reason for non-compliance in the three questionable cases was erroneous data entry where the core diagnostic symptoms for diagnosing Alzheimer's disease and frontotemporal dementia were not entered in accordance with clinical practice guidelines. As a consequence of the evaluations, support was integrated also for the rare cases in the revised version, and the explanations of concepts in the system were developed.

The main result from Study III was the observation that the system provided limited support for hypothesis generation and evaluation in the presence of incomplete data. The interaction design was enriched with a dynamic support for hypothesis generation and evaluation that also provides support in early stages of data collection.

Table 4. Overview of evaluation studies of DMSS-R, the revised version in the implementation phase.

<i>Evaluation Study</i>	<i>VI</i>	<i>VII</i>	<i>VIII</i>	<i>IX</i>	<i>X</i>
<i>Prototype</i>	DMSS-R (version 1)	DMSS-R (version 1)	DMSS-R (Version 2)	DMSS-R (version 2)	DMSS-R (version 3, ongoing)
<i>Primary investigation focus</i>	Compliance with clinical assessment, reasoning procedure	User interface and its components	Learnability, transparency, usability for novice users	System's compliance with assessment in clinical practice, usability	Comparison of diagnostic results, detect pattern of use, reasons for non-compliance
<i>Number of users</i>	1	10	6, distributed over different use environments	2 physicians, a number of nurses and care professionals	Ca 25 physicians, a number of additional professionals
<i>User characteristics</i>	Geriatrician, expert	8 medical candidates, 1 psychiatrist, 1 geriatrician; 9 novices, 1 expert in dementia	1 expert, 5 GPs; novice DMSS users; novice to highly skilled in dementia	Neurosurgeon, internal medicine, novice DMSS users; novice, resp. moderate skills in dementia	Experts, GPs; range of different medical expertise
<i>Number of patients</i>	3	11 and 7 fictive	9	41	300 - 350
<i>Patient characteristics</i>	Atypical patients	Typical	Range of typical and atypical patients	Range of typical and atypical patients, borderline cases	Range of typical and atypical patients
<i>Environment</i>	Geriatric clinic in Sweden	Sweden	Different clinics in a county of Japan	Clinic in South Korea, open ward, patient encounters	China, Japan, South Korea, Sweden
<i>Summary of results</i>	System provides satisfactory feed-back, contributes to second-opinion assessments	Evaluation of details in redesign alternatives (Larsson, 2008)	System complies with clinical diagnosis; terminology and other sociotechnical issues identified to be resolved	All but two complied with physician's assessment. Reasons for non-compliance assessed. (Lindgren, 2010)	To be analyzed.

The system has been introduced to novice users with different experience in computer use. In the evaluations of the revised version (Studies VIII, IX), the individuals with some experience with computer use, quickly manages the different interaction components and the user interface is found being intuitive and easy to use. The distinction between normal values and pathologic values is enhanced with colors, which users find pleasant and helpful. The slide bar for setting severity measures works well for the non-novice computer user, but was found less easy to use by physicians who are complete novice to computer use. The definitions and explanations of concepts were found helpful and trigger curiosity as expressed by a physician who was experienced in the dementia domain. The definitions and explanations were used extensively by physicians who were less experienced in the dementia domain. Concerning learnability, all physicians had after using the system in one patient case, grasped the different aspects of the system. The time spent on different components of the system, depended on the experience the physician had in the dementia domain. The less experienced seemed to take the opportunity to read more about concepts and instructions. The more experienced did not need much extra time to integrate the system into the routine of assessing a patient, in spite of the fact that he had not seen the system before the first patient encounter.

An evaluation period in a network of collaborating professionals distributed over different types of clinics has been recently initiated after an introduction made to a local doctors' society, in which physicians were testing the system with current and well-known patient cases (Study VIII in Table 4). The system responded in an accurate and satisfactory way to the nine patient cases and the professionals' response was very positive. As a result of the introduction, and before DMSS-R was made available in clinical practice, the explanations of symptoms by the system was further developed by the collaborating domain expert in this use environment. This development is also being made available to the users in the other environments since the extended explanations also respond to needs expressed in evaluations in these environments (e.g., in Study IX). Currently, ten primary care physicians and specialists have access to the system in daily practice for evaluation purposes as part of a general effort to find ways to improve dementia care in this region (part of Study X). The purpose is to increase the skills in dementia workup through the use of the system as a tool, and decrease the number of typical, "easy" patient cases that are referred for diagnosis to specialists in hospitals, which is also a motivation for the Swedish implementation.

To summarize the results, the evaluation studies using real patient cases in different settings have generated the following when analyzing the cases in which the system's suggestions do not comply with the physician's assessment:

- *The initial prototype* (Study IV, V): 55 cases of which seven suffered from unsupported dementia types (12,7%). When removing these cases from the sample the following analysis can be done based on the 48 remaining cases: In five cases the response from the system did not comply with physician's diagnosis (10,4%). Of these, two were caused by system failure (4,2%) and three by questionable data entry (6,2%).
- *DMSS-R* (Study VIII, IX): 50 cases of which all had diagnoses supported by the system. In two cases the system's response did not comply with the physician's assessment (4%). One case was caused by system failure (2%) and one by questionable data entry (2%).

The three cases of system failures were due to bugs in the system, which were removed as soon as they were detected. Subsequent re-runs with the patient cases in which the bugs had been detected provided with satisfactory results. The four cases of questionable data entries refer to cases when the distribution of signs in a patient that has been accounted for in the system, does not correspond to what the user meant to enter, his or her perception of the state of the patient and/or to prescriptions in clinical practice guidelines. A parallel process has been to validate the terminology used in the system, since the system is distributed in different language versions. Striving towards creating a mutual understanding of concepts has been vital, and some misunderstandings have been caused by imperfect translations. Since the patient samples are small, the quantitative analyses are merely indications of the improvements of performance between the versions of DMSS. The aim has been to minimize the cases of non-compliance due to questionable data entries. Therefore, the use context has been analyzed to identify causes. The purpose has been for improving the interaction design and preventing misunderstandings in the interaction with the system. A more detailed account for qualitative results in Study IX is provided in the next section, where factors such as stressful work situations and lack of knowledge have been identified as causes.

3.2 Case Study of DMSS-R in Clinical Practice

A case study was done in clinical practice for the purpose of evaluating the interaction with the system as taking place during patient encounters (Study IX in Table 4). The study design was qualitative, including for data collection observations of patient encounters where the DMSS-R was used, supplemented with interviews. Notes were taken during the observations and the sessions were videotaped. In addition, the patient information including stored assessments was used in the data analysis.

The head of the hospital selected staff members for participation in the study. The selection and booking of patients were done by the person in charge of patient bookings. The inclusion criterion was patients with a suspected dementia disease. 41 patients were scheduled to visit the out ward at the hospital, which was in practice all patients meeting the criterion that were able to come one of the selected days.

Two male physicians participated, of which one (Physician A) is a specialist in neurosurgery and one (Physician B) is a specialist in internal medicine with an additional degree in geriatrics, which were obtained the week before the evaluation sessions. Physician A had moderate experience of diagnosing dementia and assessed 38 of the 41 patients, while Physician B can be seen as a novice to the task and assessed three patients. Physician B was also guided by the more experienced physician in the assessment of his first patient case. A group of nurses and care personnel participated as well in the assessments.

Both physicians were skilled computer users. Regarding the use of DMSS-R, both physicians were novice users initially, and saw the system for the first time when they met their first patient within the study.

To contribute to observations and discussions in medical matters a geriatrician participated, who had also participated in the development of DMSS-R as a domain expert.

In the following subsections results are presented that regard; 1) DMSS-R as provider of tailored advice to manage an individual patient and its effect on the physician's decision making, 2) DMSS-R supporting knowledge and skill development, 3) DMSS-R supporting the dementia workup as a collaborative task involving additional professionals, the patient, relatives and care personnel, and 4) situations generating questionable patient information and breakdown situations.

3.2.1 Tailored Advice for Managing an Individual Patient

The patients that were assessed can be considered being typical visitors with suspected dementia to a non-specialized clinic. Based on the physician's assessments and the analyses done by DMSS-R, none of the rare types of dementia were represented in the group. 16 of the 41 patients were assessed having dementia, eight patients suffered from mild cognitive impairment, seven persons had cognitive symptoms correlating to normal ageing based on the physician's assessment and 10 persons did not have a cognitive disease.

17 patients who were themselves worried that they may have a developing dementia disease, were evaluated to have no cognitive disorder by the physician, including seven borderline cases with cognitive dysfunctions explained by the physician as "normal ageing". DMSS-R provided in 10 of the cases the information that the patient did not suffer from a cognitive disease, which complied with the physician's assessment. In seven cases, the system evaluated the information about the patient that had been entered in the system as being ambiguous and incomplete in the way so that it was impossible to assess the cause of the cognitive difficulties based on the information about cognitive symptoms that had been entered into the system. The physician was convinced that the patient was healthy, and only suffering from symptoms of "normal ageing". However, the information in the system about the patient did not correlate to what evidence-based studies define as normal ageing, and the information indicated a deviation from a normal state. When the data was discussed, the reason of the confusion was referred to the fact that the patient did not have a next-of-kin present that could confirm the presence or absence of a cognitive decline, i.e., a lack of information. Neither did the physician use any assessment instruments that could aid the distinction between normal memory and very mild memory impairment due to an early dementia. When the physician had become aware of this, he began to use MMSE in the questionable cases from case number 29 and onwards. In the remaining sessions three out of four cases with no cognitive disease were judged to be healthy partly based on MMSE and no additional case was considered being a borderline case, the rest was clear MCI or dementia cases.

A difficult task is to determine the cause of the cognitive deficits in the presence of vascular etiology. In one of the borderline cases, the patient had cognitive deficits, but they were assessed to be caused by a short confusional state related to a stroke and not caused by a progressive dementia disease. Another patient came to obtain a second opinion about diagnosis after the patient had received the diagnosis a mixed vascular dementia and Alzheimer's disease at another hospital. Physician A's assessment complied with the suggestion by DMSS-R that the diagnosis should be revised to be a pure Alzheimer' disease.

In a couple of cases in this group, the physician used the system to enforce his own assessment to the doubtful patient, by showing the patient what the system provided as suggestion on the screen, i.e., that the patient was healthy. The patient reacted in these cases in a positive way and with relief. Physician B expressed in one borderline case (his second case using the system) difficulties understanding what was the system's conclusion, since there was none. The patient information was sparse and ambiguous, and the system concluded nothing except that it ruled out dementia and MCI, and that more information was needed. When this was explored in an interview with the physician after the session, he was himself agreeing with the feedback provided by the system, but he had expected an explanation that he could provide the patient, which the patient would understand. He was then informed that providing with explanations suitable for the patient or relatives has not been the purpose of the system.

Eight patients were assessed to suffer from a mild cognitive impairment (MCI) by the system and by the physician, which, according to the physician, most likely was due to a progressing but still mildly manifested Alzheimer's disease. This group consisted of patients with a mixture of vague symptoms of different degrees. Five of these cases were considered by the physician as mixed cases with additional vascular signs. The physician's assessments in these cases correlated with the system's suggestion of a MCI diagnosis and a possible early mixed case according to the general overview in the system. The eight MCI patients were scheduled for a follow-up appointment within a few months.

The remaining 16 patients had different manifestations of one or more dementia diseases at different stages of progression. DMSS-R complied with the physicians' assessments in all of the cases, based on the information that was entered into the system. However, two of the cases illuminate the importance of the data gathering as a base for the providing of tailored advice. The two patients had a Parkinson's disease (PD) in their anamneses. Since this disease can be the cause of a state of dementia, the information about the time relation of PD with the onset of cognitive symptoms is important to assess. In DMSS-R this is done in an overview of other possible causes of dementia by first marking other diseases that are present, and then assessing whether the disease is a better explanation of the cognitive dysfunctions than a dementia disease, based on information such as time relations. In both cases the physician did not mark PD in the system, however, in one case he marked other diseases such as hypertension and arteriosclerosis. The physician was in general very careful in marking other earlier and existing diseases that he was considering in the differential diagnosis, where some were considered affecting the patient's cognitive state, such as depression and mild hydrocephalus. The physician assessed MCI in one of the two PD cases and a mixed Alzheimer's disease and vascular dementia in the other case. DMSS-R complied with the assessments, based on the information that was entered into the system. However, in at least one of the PD cases the patient showed symptoms of parkinsonism (assessed by the expert geriatrician), which was valued to be absent by the physician. In the other case, the physician expressed that he did not know about the Parkinson disease in this case, only that it was registered in the electronic health record. Since the information entered into the system in these cases was insufficient, consequently the tailored advices provided by the system were not optimal. Even more important, since in these cases the physician would have been given an opportunity to explore issues related to a disease he seemed to have limited knowledge of with the help of DMSS-R. The outcome with respect to diagnoses may have been the same, but a chance to adjust the conceptual knowledge and routines was missed.

3.2.2 Learning and Skill Development

There was a difference in how the two physicians approached the task of assessing the patient with the system as a tool. The more experienced Physician A was from the beginning of the first patient encounter fully focused on the patient that was entering the room and not on the to him new and unfamiliar system. He spent comparatively little amount of time to explore the definitions and additional information about concepts and phenomenon integrated in the system, which was interpreted as a sign that he was already familiar with the basic concepts. He also conducted a large part of the interview with the patient before he used the system to enter the information. When information requested by the system was missing, he turned

back to the patient and continued with the interview. The same pattern was seen when he involved care personnel or relatives in dialogues. Physician B was comparatively inexperienced in assessing dementia patients, and relied to a large extent on DMSS-R as a checklist and assessment protocol throughout the dialogue with the patient and care personnel. Part from the definitions and explanations provided by the system, he needed in a few occasions additional explanations to understand the meaning of concepts, which his colleague provided during the first patient encounter. This information was needed primarily in the assessments of levels of severities.

The participating physicians discovered the importance of involving care personnel and family members in the assessment, since the system enforces the obtaining of information from a person who knows the patient well, as well as from the patient him or herself. They also acknowledged the assessment instruments integrated in the system, and even if they are not obligatory, the physicians used them to an increasing extent during the evaluation sessions.

In the case of Physician A's limited understanding of how normal ageing is manifested, the system did not provide with suitable support to update his knowledge to what is known today. Instead, this was done by the participating expert geriatrician in one of the final the sessions, when this was identified as a source of a re-occurring and systematic misconception in the patient assessments.

The physicians and nurses organized during the evaluation study a series of meetings to take place after the evaluation study in which they were going to discuss and develop their understandings of the phenomenon and concepts defined and explained in the system.

3.2.3 The Dementia Workup

The patient encounters were organized as routinely done in the hospital. The time allocated for the encounters were limited, and the actual time spent on each patient ranged from 7-15 minutes in a majority of cases, and these time spans included the use of DMSS-R. A few more complicated cases took as much as 20-25 minutes, partly due to that a MMSE test were also done in these cases. Some patients were known since earlier encounters for other complaints and some had been subjected to radiology examinations, with information available in electronic health records.

The physician authored the patient encounters. The nurses organized the settings for the encounters and took part in the investigations when the patient was familiar to them, sometimes together with a relative or care personnel from special homes, when the physician requested their opinions. A transition was seen in how Physician A organized the encounters with the system integrated. From at first discovering that there are different sources to take into account, which seemed to become forgotten between the initial cases, he moved to integrating interviews systematically in the procedure according to the order of the sources in DMSS-R. After some encounters, the physician had become familiar with the structure of the information in DMSS-R and organized interviews with the patient, care personnel and relatives when available accordingly.

An increase in the use of MMSE was seen during the encounters, while the FAST scale was used in all cases and Behave AD in two cases. The physician involved the nurse or care personnel in the assessments using FAST and Behave AD.

Discussions about severity levels of symptoms were seen, where there was in some cases different opinions between the physician and nurses or relatives. The distinctions between thresholds as presented by the system were not clear to some of them, as also in what way some of the symptoms could be manifested and observed in a patient. This was confirmed in interviews with the physicians. While the possibility to assess severity levels was seen as very important, the support in the system for the distinction was considered insufficient. A clarification of one of the thresholds is integrated in the information about memory deficits in Figure 3.

The general view of the effects of integrating DMSS-R in the work was very positive, as expressed by the nurses. They saw an increase in the questions directed to the patient, and they also became more involved in the assessments. They also saw DMSS-R as a tool for learning more about the different symptoms commonly seen in dementia. The general view expressed by the physicians was that the system contributes to making the assessments more objective when the assessment instruments were used and when the levels of severities were assessed. They also mentioned the importance to schedule appointments with patients in which a person participates who knows the patient well, in order to obtain reliable information. Physician A was particularly pleased with the support for distinguishing between the borderline cases, partly since the system gave the physician support to provide an explanation to the patient

that the patient could understand and be satisfied with. He also found the explanations of concepts very useful, while he also thought that some of these needed to be developed further to provide sufficient explanations to persons with minimal experience.

Physician A was in all cases satisfied with and agreed with the explanations provided by the system, also when patient information was missing or ambiguous.

3.2.4 Situations Generating Questionable Patient Information

The patient encounters were rapidly executed, with a line of patients waiting outside the room. The work environment was judged by the observers to be highly stressful, which was noticeably decreasing Physician A's performance in periods. This was shown as an increase in mind slips, incorrect data entries, corrections, etc. The physicians experienced the setting as normal, with respect to time pressure and patient cases.

Two situations were observed in the case study, which generated a systematic entering of possible incorrect data into DMSS-R. These situations involve data that is required by the system at different stages. The first situation occurred in a few cases when the physician did not have a person available who knows the patient well. In some borderline cases he asked the patient about what relatives think about their condition in order to be able to enter data in the system. In other cases the physician himself assessed the information that should be provided by other sources. The second situation was when the physician assessed symptoms as absent by default, without a proper examination of the patient or assessment by a more elaborated interview. This behavior is similar to behavior observed in an earlier study, when the explanation was that there is no indication of presence in what the patient describes (Lindgren, 2008a).

The situation when other possible causes are to be assessed, this is highlighted in different ways to the user, but the granularity of the control whether the user has actually considered other causes is at a general level and it is up to the user to value all options and to enter the information. For instance, in the cases of the absent information about Parkinson's disease, the alert reminding the user of considering other possible causes re-occurred once in the process, however, this did not make him add the information. The reasons why the physician did not include the information of a co-occurring Parkinson disease were interpreted to be negligence and lack of knowledge about the relationship between Parkinson's disease and dementia. The stressful situation with more patient lining up, could also have affected the situation.

Physician B expressed concerns with the quality of the data that can be entered into the system, and views that the system should be used by qualified professionals only, in order to guarantee correct assessments. He viewed himself as qualified enough to use the system while any care personnel in elderly homes with questionable background and knowledge would not be qualified.

4 Discussion and Implications for Future Work

DMSS-R is a clinical decision-support system (CDSS) developed for supporting clinical assessments, knowledge and skill development in the dementia domain. The goal is to provide qualified assessments and optimal and individually tailored care to the exceptional patient. Due to the diversity in potential users, clinical settings, disease manifestations in patients and views on details in the evidence-based domain knowledge, a CDSS needs to be flexible in order to be useful for a broader range of users and use situations. First and foremost, a patient centric assessment needs to be supported, with tailored advice to how to manage the individual patient. In order to achieve this, tools for promoting a common understanding of a patient case among care professionals are needed in clinical practice. In this process, individual professionals need to develop their knowledge in interaction with colleagues and the patient, and also in the interaction with a CDSS. Essentially, the design of a CDSS in this context aims at creating advice tailored to an individual patient and to the understanding in an individual user as manifested by the information entered into the system and by his or her interaction with the system. This aim needs to be balanced to the contributions and needs of the additional professionals who are not directly interacting with the system.

The presented results from a case study of DMSS-R integrated in clinical use provide with insights in the potential influence the system may have on clinical practice. In the study an increase was seen in the use of assessment instruments in order to obtain objective measures. The involvement of the patient, relatives and other professionals increased in an unexpected but satisfactory way for the people involved in

our study. New insights were gained by the individuals who participated in the sessions and a strong interest in learning more about dementia was expressed, which was aimed to be accomplished partly by using DMSS-R.

The results also contain insights in the profound need to not only support what is focused in clinical guidelines for dementia diagnosis and management, but also for basic assessment of core symptoms and disease manifestations (corresponding to the Levels 1 and 2 in Figure 4). This was evident in the observed behavior of the two physicians with different level of expertise in the way they re-organized inquiries and data gathering with the system as mediator. A similar difference in behavior between levels of expertise was also observed in studies made by Patel and colleagues (e.g., Patel et al, 2000). These levels of activity are typically not a problem for the skilled and experienced professional. However, since a vast majority of the potential users of DMSS-R is similar to the professionals participating in this case study, these levels of activity also needs to be supported. Although there is no consensus to base CDSS support upon in evidence-based medicine on how to measure levels of severities and difficulties in order to compare information with what is required in CPGs, this type of support is highly valuable and critical in order to assess the patient in a satisfactory way. In order to extend the existing support in DMSS-R for the development of the conceptual and procedural knowledge, a larger emphasis has been put in the system on the use of assessment instruments, on how to interpret the generated data and by supplementing existing information, definitions and explanations of phenomenon with additional examples of typical scenarios of manifested symptoms at different degrees of difficulties.

Some concerns were expressed with respect to DMSS-R as a tool for less experienced users and the possibility to enter data that generates wrong suggestions. Based on the observations, the quality of the data that is entered into the system seems to be more dependent on to what extent validated assessment instruments are used, if persons are available who knows the patient well, and to which extent there is time allocated in the encounter for assessing details about the patient's situation. Incomplete knowledge in individual physicians that affects the quality of the data was seen in both the experienced and the novice physician in the case study (Lindgren, 2010), and in expert physicians in other studies (Lindgren, 2008b). Whether this observation is valid, needs to be further examined in larger scale evaluation studies. Meanwhile, the encouragement for using validated assessment instruments and for including persons who know the patient well will be increased in the installation of DMSS-R at new workplaces. In addition, a session of using the system in a couple of cases without the patient present, will be encouraged as an introduction for new users to the system and to the dementia workup as assisted by the system. This may decrease the impact that stressful encounters with patients may have on the learning pace of components in the system.

The system provides with information at appropriate level of granularity, when needed depending on the phase in the assessment process. Furthermore, the system can in some predefined general situations respond to misconceptions identified by ambiguous data entered into the system. However, lack of knowledge that is manifested as systematic errors generated by individuals in the assessment of patients other than those handled by the system, is currently not captured by the system. One such misconception observed in the case study was the knowledge that needed to be updated in an individual physician about what characterizes cognitive ability in normal ageing. Once identified, it is a trivial task to include clarification about the topic into the system. A desired property would be that the system tracks what the user does over a range of patients, match the data with the assessment done by the physician that deviates from suggestions by the system in order to discover systematic misinterpretations of, for instance, an essential type of memory such as the episodic memory function. Detection of such discrepancy between an expected behavior of a user and actual behavior could be a source for personalized support, corresponding to a particular need for knowledge development in an individual. Such functionality would be particularly useful in clinical settings where an individual physician is assessing the patient without support from additional professionals in a teamwork context and without consultation support from expert physicians. It is shown in studies that physicians' responsiveness to CPGs differ for many reasons (Patel et al., 2001), and we aim to capture the reasons in future studies. An initial mechanism for integrating such support is implemented in the system. Tracking deviations in physicians' assessments from suggestions provided by the system will be done in ongoing long-term evaluations with larger sample of physicians and patient cases. The results from these evaluations will form a base for the development of a web-based DMSS-R using semantic web techniques and argumentation schemes for personalization (Lindgren, 2009). When a physician assess a diagnosis that deviates from the suggestions from the system, a more alerting feedback can be given to the physician based on the patient information in the system about what is lacking in the

base of his or her assessment, before the assessment is stored. If the physician chooses to persist in his or her assessment without reconsidering the base for the decision, the possibility for the physician to also provide additional motivations for the decision can be included. In follow-up encounters with the patient new information may be added that validates the assessment. In a longer perspective, the motives may be discovered to be in compliance with new evidence-based studies in the evolving domain knowledge, or become an initiation of new studies.

One incitement for integrating DMSS-R into the context of electronic health care records is the opportunity to obtain information about investigations and other diseases from other sources. In our presented case study, the information about a pre-existing Parkinson's disease could have invoked a differential diagnostic process, where the physician had been given explanations about the relevance and impact of the information.

An interesting observation of the system in use was the way the physicians used or wanted to use the explanations provided by the system in the explanations given to the patient, and by showing the screen of the system to enforce the message. This was seen in patient cases with normal, or mildly affected cognitive ability, who were probably expected to understand the content of the message. The fact that this way of applying the system in the patient encounter happens, needs to be taken into consideration in future development, even if the original intention of the design of the system was not to provide with suitably formulated explanations to the patient.

5 Conclusions

In this paper DMSS-R is described, which is a clinical decision-support system that provides tailored support to health care professionals in typical and complicated patient cases with a suspected dementia disease. The support is based on a set of CPGs in the domain, synthesized to generate interactive and tailored support to a single physician or a team of professionals in the process of assessing dementia diagnosis and suitable interventions in a patient case. The system provides advice and explanations tailored to the often exceptional patient, timely and when requested by the user. Additional alerts are provided to create awareness about questionable or missing data and when the disease manifestations in the patient do not comply with clinical guidelines that often describes typical schoolbook cases.

The system has been shown to be useful for individual professionals as a checklist, validation of own assessments, for reconsidering diagnoses in ambiguous cases, and for checking one's understanding of phenomenon related to dementia diseases. Feedback provided by the system has in almost all cases been satisfactory, also when the patient case is ambiguous and the patient information is incomplete. When the system did not comply in early evaluation studies, this has been caused by systematic erroneous data entries caused by misconception of crucial concepts in the system or that the early versions of the system did not provide support for rare types of dementia. In evaluation studies of the extended and revised version DMSS-R, the system complies with physicians' assessments in a satisfactory way. A recent case study conducted in clinical practice showed that the system has the potential to increase the quality of the assessments of patient cases with suspected dementia. This includes an increased use of validated assessment instruments in order to obtain objective data, and an increased involvement of patient, relatives and care personnel in the assessments. This effect is partly explained by the enforcements by the system on the assessments in how to conduct the dementia workup, and partly by an increase in the knowledge about phenomenon related to the dementia workup.

The mechanisms in DMSS-R that provide personalization are mainly tailored to the need for support at different levels and stages of activity, by making relevant and tailored information, explanations and advices available when needed in the dementia workup process. The case study also provided with implications for developing the personalization of the system further, in order to capture and provide response to misconceptions tractable in the health professional's use of the system. This is suggested to be accomplished by exploring the physician's decision making and reasons for deviations from suggestions made by the system. This will partly be accomplished in ongoing long term evaluation studies in clinical practice, involving clinics in China, South Korea, Japan and Sweden. The results are expected to provide a base for the development of a web-based version of DMSS-R using techniques developed for the semantic web for personalization of the system.

The main lesson learned during the development of DMSS is that incitements for use are crucial, since the implementation of the system is expected to change work practices and individuals' knowledge and skills. The system needs to be approved and enforced to be used by both management of the local organization and the doctors' collegiums, with clearly stated expectations on how the system is affecting the quality, organization and cost for care. Furthermore, the individual user needs to envision immediate benefits of using the system in patient encounters, as a checklist or time saver, for verification of own assessments or for simply evoking the curiosity needed for developing his or her knowledge, which was an effect described by one of the experienced physicians.

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