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NEEDS ELICITATION FOR NOVEL PERVASIVE HEALTHCARE TECHNOLOGY

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1. Introduction

It is widely accepted that engaging with end-users to elicit their needs is beneficial when designing a new artefact. This can be particularly challenging, however, when end-users are limited in their ability to provide input. When there is broad variation in users' needs, a further challenge is to include the large number of users required to represent the entire population. Failure to do so may lead to a solution that is over specialised to fit the needs of only a small subset of users. Both challenges are common in healthcare applications in which the end-user is also care recipient (or patient). What if instead of trying to engage vastly many users in design activities, we could hear the voice of the patient by tapping into existing channels within the healthcare service system?

Many interactions between healthcare providers and patients involve knowledge transfer. Observing these could inform designers about patients' support needs and healthcare providers' information needs. Healthcare professionals offer a wealth of knowledge based on a clinical understanding of the condition as well as experience listening to patients' problems. Especially where patients are in denial about their condition, their healthcare providers might offer more detailed information than the patient themselves regarding their needs. Since each patient knows only their own experience, whereas healthcare professionals encounter numerous patients, their perspective is more robust against inter-patient variation, and they are able to comment on trends, scale or proportions.

We therefore explore how users' needs can be elicited by observing activities in which information is already being shared and discussed in the care process, and from the extensive knowledge of healthcare professionals. This is particularly relevant for pervasive healthcare technology, in which established methods for engaging users to elicit their needs can be difficult or even impossible to apply. In this paper we document our needs elicitation process in a relevant example as a method story, and present our findings and reflections on this as the key contribution of this work.

1.1 A new era in healthcare

Healthcare technology is undergoing a transition: from standalone devices operated in the clinic by experienced clinicians, to ubiquitous technologies that are integrated into people's home lives to provide pervasive support and feed information back to healthcare professionals. These ideas - of using technology for connected, personalised, and collaborative care - are encompassed in terms such as eHealth, mHealth or p4medicine (personalised, predictive, preventative and participatory), that all relate to this vision for the digitalised and data-driven future of healthcare. To enable this transition, we need design methods suitable for this emerging new context. So far, the healthcare sector is lagging in technology adoption compared with other sectors, and the needs of user groups such as the elderly or disabled are not being met by driving technologies such as smart wearables.

The field of engineering design research offers a rich source of methods and tools to support design in healthcare. User-centred design aligns with the personalised and participatory elements of p4medicine and its related concepts. Despite these parallels, there are pronounced challenges associated with the participation required from users when it comes designing novel, pervasive healthcare systems. Three challenging characteristics are highlighted:

- Pre-concept design phase: limited methods available for gathering needs where use of a prototype (or existing model) is not possible.
- Ubiquitous/pervasive use: wide range of use environments, potentially of an intimate nature, therefore the designer may not be able to observe users in a real-world use setting.
- Care recipient as end-user: condition from which the user suffers may limit their capacity to provide valid information about their own needs.

We therefore see a need for further experimentation to extend existing methods as we embark on a new era of design in healthcare. We address this by exploring an approach with which we can gather information about needs without relying heavily on directly engaging end-users. This is implemented in an example of smart technology tools for dementia that demonstrates the challenges described. The remainder of this section describes a selection of relevant literature to provide a background to the problem addressed in this work. Section 2 presents the research objectives and the example used in this study. Sections 3 documents the data collection activities, Section 4 the analysis and results, Section 5 a discussion of our findings and reflection on these, and we conclude in Section 6.

1.2 Related work

Methods for the healthcare domain

User-centred design is commonly employed in the healthcare application domain. For user-centred design, a needs analysis captures requirements for the system based on an understanding of the users and their tasks, goals and needs regarding both functions and information [Katz-Haas 1998]. This process translates the need (or user-expressed real requirement) to the system-expressed functional requirement [Soares et al. 2011], which brings us to the question of how to elicit needs from users in the first place?

Martin et al. [2008] describe seven methods for assessing user requirements in medical device development based on a review of ergonomics literature: cognitive inquiry, cognitive task analysis, usability tests, heuristic evaluation, cognitive walkthrough, focus groups and Delphi technique. Of these, only cognitive inquiry and focus groups are appropriate for the pre-concept phase, since all others rely on the use of a basic prototype at the very least. Moreover, certain methods may be particularly challenging to apply when the end-user is the care recipient rather than the care provider, since this has several implications. Due to the separation of operator (patient) and service provider (healthcare professional), information about both actors' needs is important, demanding greater needs-elicitation efforts. This also introduces additional environments which may not be accessible to the designer, such as those encountered in patients personal lives (home and beyond), especially where use of the device is of an intimate nature. This is problematic for methods such as cognitive inquiry that rely on shadowing the user. Perhaps most critical, however, are implications of the end-user's condition for which they are being treated, which are discussed below.

End-users' ability to provide information about their needs

The condition of the care recipient may affect their ability to provide adequate input regarding their needs. This could be due to physical or cognitive impairment (eg memory or language problems), or due to psychological factors associated with their health status (eg denial of one's condition or its severity). Progress has been made towards both. A recent CoDesign special issue focuses specifically on codesign with people with cognitive or sensory impairment such as autism or aphasia [Slegers et al. 2015]. Contributing authors describe approaches such as using high- and low-fidelity prototypes [Brereton et al. 2015], [Wilson et al. 2015], cross-modal interaction using audio-haptic objects [Metatla et al. 2015], abstract props and sensory preference cards [Gaudion et al. 2015] or argue for sharing method stories over general guidelines [Hendriks et al. 2015].

Regarding end-users' attitudes or perceptions (psychological influences rather than functional capabilities), Kelly and Matthews [2014] discuss this for hearing aids and insulin pens. Since there are certain negative stigmas associated with their use, uptake is postponed or avoided by many who could potentially benefit from using them (referred to as "not-yet users"). Their work proposes displacing use, placing more emphasis on relationships besides that between end-user and product, such as between the user and their condition, or healthcare professional and care recipient. This could be extended to include relationships between the patient and a caregiver (spouse, child or parent) who might encourages use.

End-users' functional limitations not only reduce their capacity to provide information about their needs, but also imply additional needs to be gathered and analysed: usability (non-functional) needs. Inclusive design methods have been developed over many years to address this, yielding a selection of tools for its implementation [Clarkson and Coleman 2015].

Summary and approach

While contributions from user-centred design (relating closely to inclusive design and participatory design) are highly valuable, their reach is limited under certain conditions associated with new pervasive healthcare technologies, particularly during the pre-concept design phase and where the end-user is also the care recipient. To address this, our approach reflects and builds upon the ideas and recommendations from the literature presented. As recommended by Hendriks, Slegers, and Duysburgh [2015], we present a method story. Our approach aligns with Kelly and Matthews' [2014] ideas by gathering information about users' needs through a variety of sources and interactions, thereby exploring other relationships than interaction between the device and end-user. Inclusive design concepts are also incorporated, since non-functional needs associated with end-users' condition are taken into consideration. We will tap into healthcare professionals' knowledge and activities in order to learn about and involve patients without demanding their direct engagement.

2. Research objectives

Our aim is to explore an approach for eliciting user needs when the patient view is difficult to ascertain. Information about all users' needs is gathered by observing interactions between care recipients and care providers, and interviewing healthcare professionals. Our main objectives are to:

- Determine whether these methods can be used to generate information about the needs of both healthcare professionals and care recipients
- Evaluate the validity of the information generated
- Describe our methods such that these might be implemented and built upon further by designers and researchers in future
- Reflect on our findings in terms of practical feasibility, advantages and limitations

To achieve these, we apply the approach in a relevant example, evaluate the information that is generated, and then discuss our experiences and results.

2.1 Case and problem framing

The example used in this study is the design of an intelligent aid for dementia based on smart technology. Technological aids (assistive technology) for dementia serve a wide variety of purposes (eg support with daily activities, safety, leisure, providing information) and range from mobile devices to smart homes, though very few show widespread acceptance. Existing solutions are highly fragmented despite the functionality they employ being commonly available in smart technology (eg digital calendars, reminders, location tracking). It is therefore of interest to design a solution based on common smart devices so that in future people could use technology they already own and are familiar with. The goals of the system are to:

- Support people with dementia to improve their independence and quality of life
- Reduce the burden on their caregivers
- Feed relevant information back to healthcare professionals to support care practices

These are based on the combined, broadest goals of current assistive technology and on the eHealth concept of connected, collaborative care. The users involved include the person with dementia (PwD), their caregiver (usually a spouse or child), and healthcare professionals. Clinic-based healthcare professionals include nurses, specialist doctors and neuropsychologists. There are also healthcare professionals within each municipality, eg dementia coordinators. A simplified overview of the proposed eHealth system is depicted in Figure 1.

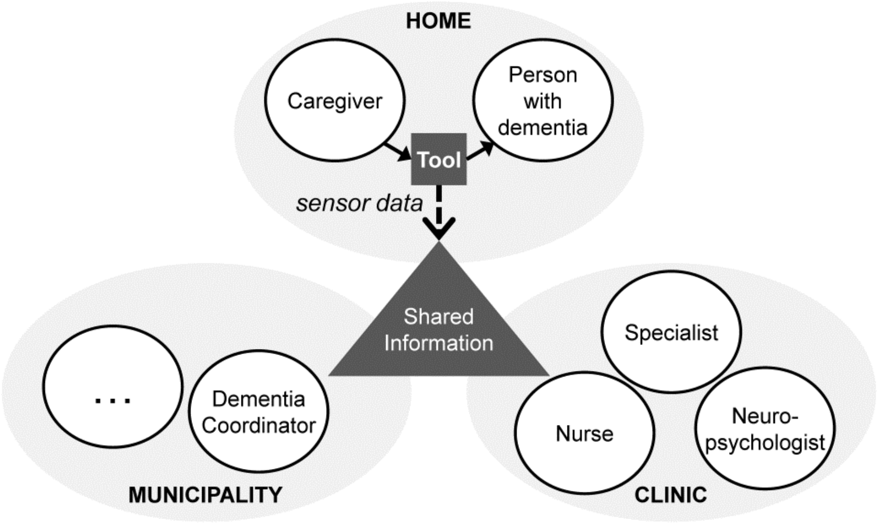

Figure 1. Example showing pervasive care in dementia using smart technology. End-users interact with the tool to enter information and receiving notifications (solid arrows)

This case exemplifies the needs gathering challenge introduced in the previous section, since the end-user (PwD) is the care recipient and functionally limited by cognitive impairment. Furthermore, smart-technology based aids are not in use, nor is data currently collected automatically from patients for clinical use. This means that the concept is unfamiliar to the potential users involved and there is no prototype or reference available for user-needs elicitation activities.

3. Data collection

Interviews and observation activities were employed with different combinations of stakeholders to gather information about all users' needs. Most activities were carried out in the dementia and memory clinic of a Danish hospital, with the exception of home visits and interviews with dementia coordinators, which took place at homes in the municipalities within which they operate. Overall, the data collection activities were implemented on approximately 14 days over a longer period of 9 months. A summary of the data collection methods and actors involved is provided in Table 1.

Table 1. Summary of data collection activities and actors involved

Activity	#	Description	Nurse	SD	NP	DC	PwD	CG
Interviews	6	Semi-structured, individual	x	x	x	x		
Observation (consultations, support services)	10	Nurse (includes testing)	x				x	
		Specialist doctor	x	x			x	x
	1	Neuropsychological exam			x		x	
	2	Home visits				x	x	x
	2	Caregiver education sessions	x			x		x

Abbreviations: specialist doctor (SD); neuropsychologist (NP); dementia coordinator (DC); person with dementia (PwD); caregiver (CG)

3.1 Interviews

A series of 6 semi-structured, individual (one-on-one) interviews were conducted with healthcare professionals working with the dementia clinic. These included clinic staff directly involved with examining, diagnosis and/or treatment of patients, such as nurses, a specialist doctor and a neuropsychologist, and dementia coordinators from municipalities covered by the clinic. Interview questions were tailored to the role of the interviewee, but used only to guide open discussion. Questions about their role in the care process covered topics such as: their tasks and responsibilities, information they need to do these, and challenges they face. Questions about their work with PwD and their caregivers covered topics such as: problems and concerns of these care recipients regarding many aspects of their health and wellbeing; their support needs in relation to both healthcare professionals and technological tools; and specific barriers and challenges faced in providing this support. Clinic staff interviews were brief (15-20 minutes), since these were supplemented by observation activities that enabled a more direct approach, whereas interviews with dementia coordinators were longer (35-45 minutes). All interviews were recorded and later transcribed and translated into English text to be analysed further.

3.2 Observation

Patient consultations and support services, including home visits and caregiver education, were observed. For these activities, the researcher remained uninvolved, even inconspicuous.

Patient Consultations

These were the primary focus of the observation activities. The patient is usually accompanied by their caregiver, thereby allowing insight into both perspectives. Depending on the type of consultation, these sessions can also involve several steps each with different combinations of people and activities. Examples of consultation types include:

- a first examination including thorough testing and discussion to gather as much clinically relevant information as possible
- an information meeting in which the patient and caregiver are informed about the diagnostic decision and a care plan is laid out
- follow-up controls to check up on the current status in relation to the previous, and make any necessary adjustments to their treatment

This is highly simplified, as in reality a patient's path through the system can vary depending on their individual case, and may involve additional steps and tests. Most observed consultations were first visits, since it is here that most information is collected. These include several steps, of which the two of interest were: functional testing facilitated by a nurse; and discussion with the specialist doctor. The testing is completed alone with the nurse and also includes background questions to gather information about the patient's history. The nurse passes notes and test scores over to the doctor for the discussion, which includes the nurse, patient and caregiver, and goes into more detail on symptoms and problems. Documentation related to these tests was also collected, including the MMSE (mini mental state examination) test instrument used by the nurse, and a checklist for doctors to help ensure that they do not miss any important details. Of 11 consultations in total, 9 were first meetings, 1 was a follow up, and 1 was neuropsychological testing. The neuropsychological testing is used when there is some doubt about the severity or type of dementia. These are far more thorough than the nurse's testing (can last over 2 hours) and go in depth into specific functional domains of the brain.

Support services

The clinic and partner municipalities together offer PwD and their caregivers various resources for support in dealing with their condition. Two activities of this nature were included to gain insight into problems experienced in daily life: home visits from a dementia coordinator; and caregiver educational courses. Dementia coordinators visit people's homes when the PwD or their caregiver has specifically requested this support. Visits to 2 homes were observed. The first involved a pair meeting with a dementia coordinator for the first time and was similar to initial consultations at the clinic. The other visit involved a second meeting between the pair and dementia coordinator. This went into more detail about a specific problem that the couple was experiencing in their home life, with the goal of eliciting the help of the dementia coordinator in finding a solution. The nature of each home visit is summarised in Table 2. The outcome from observing home visits was field notes on the care recipients' specific problems, details about their home lives, interaction with the dementia coordinator, and their various support needs.

Table 2. Home visits with dementia coordinators

	Care recipients	**Living status**	**Reason for visit**
1	PwD: Woman, 83yrs. Caregiver: Daughter	Retired. Husband passed away a year earlier, currently lives with her adult daughter in a house with a garden.	Daughter is concerned about her mother's poor memory and disorientation.
2	PwD: Man, 71 yrs. Caregiver: Wife	Retired, spends a lot of time gardening. Very active couple (socially, physically, travel). Live in a house with a garden.	Wife is frustrated with constantly being asked about schedule, would like to hear about possible solutions.

Caregiver educational sessions include a series of workshops in which healthcare professionals present a specific topic, answer specific questions, and encourage discussion among attendees on their own impressions and experiences. Attendees include primary caregivers as well as other family members (for a particular PwD, a spouse and 2 children might even attend the session together). Sessions cover topics such as basic information about dementia (clinical background, symptoms, treatment etc), what it means to be a caregiver (what this might involve, challenges and advice), administrative complications (personal finances, legal documentation) or other relevant interests. Two such sessions were observed: on the disease (presented by clinic staff); and on providing care (presented by a dementia coordinator). These were observed to collect data in 2 ways: from the material presented, and from the questions and discussion among caregivers.

4. Analysis and results

The data was analysed according to the goals laid out for the specific case: to support PwD and their caregivers in daily life and feed information back to their healthcare providers, which can largely be generalised to other pervasive healthcare applications. Transcribed interviews and field notes were analysed to find information that could be used to understand the needs of PwD, their caregivers and healthcare professionals. The following overarching themes were used:

- Clinical problems: can inform about functional and non-functional needs (eg qualities of the solution that would enhance acceptance)
- Caregiver burden: can inform about functional needs based on their role as a provider of support to the PwD; and as a receiver of support from healthcare professionals
- Clinically relevant information: can inform about needs regarding data to be generated that could aid healthcare professionals in providing care and support to PwD and their caregivers
- Barriers: Noteworthy challenges in the process/system to be considered

In the analysis, data from each activity was aggregated within these themes. This was then used to identify emergent categories to code the data. To assess the validity of the information generated, the results were reviewed to assess the level of agreement within the results. Additionally, the results were compared with existing knowledge available from scientific literature.

4.1 Generated information

Substantial information was generated within each of the themes targeted, as is described below and summarised in Table 3.

People with dementia's needs

Most of the information about PwD's needs related to their memory function, psychosocial needs, and support in activities of daily living (ADLs). This was expressed both according to the problem (eg "I forget what I heard a moment before ") and the need (eg "I need a way to remember information I am told"). Memory function needs could be remembering appointments (future events), faces and names, where they placed their belongings, or instructions their doctor gave them, to name a few. Psychosocial needs range from mood or behaviour related (eg apathy, aggression) to social inclusion and mental/physical stimulation. Of the non-functional needs, usability emerged as the most prominent, especially regarding the effort required to "learn to use" and "remember to use" a tool. The results also indicated that solutions should be familiar, adaptable and individualised.

Caregivers' needs

Information about caregivers' needs related to both the PwD and themselves. To care for the PwD, they need information about their medication adherence, wellbeing etc. Then there are various needs that relate to the impact their loved one's condition has on them psychologically (eg loneliness, fears for the future), on their time (extra household duties as well as new care duties), and their anxiety levels due to worries about safety (eg that the PwD will go missing).

Healthcare professionals' needs

These needs relate specifically to clinically relevant information. These included information about patients' behaviour, functional capacity, profile, medication and individual problems - largely depending on where the patient is in their journey through the system. For a new patient, expansive and detailed information is required to build up a profile (eg family/home situation, health background, lifestyle, personality) that is used towards both their diagnosis and treatment plan. Throughout the patients care, their functional capacity is of interest. This relates closely to "routine adherence" and deals with their ability to perform ADLs including basic tasks such as eating and washing, as well as memory function (self-reported or test results). The theme "information validation" refers to where information is sought from a secondary source as a confirmation (eg asking a caregiver about something the PwD told them). In general, there was a far greater emphasis on trends - changes and their rates - rather than on spot measurements.

Barriers

This information related to barriers that inhibit the care process for various reasons. Misinformation refers to the challenge of invalid or misleading information being shared, such as when PwD is delusional about their activities and consequently misinforms their caregiver (or healthcare professional) that they are taking medication or visiting friends when in reality they are not. These are especially pronounced when the PwD lives alone, but also arise when couples have become so interdependent that it is hard to distinguish their individual input into daily tasks (and thus the PwD's actual functional capacity). An example of a collaboration barrier is conflicting ideas about a treatment strategy - often the patient not desiring treatment. Process barriers include issues such as clinic staff's time being wasted by no-shows as a result of patients forgetting their appointments.

4.2 Validity of generated information

Existing knowledge on users' needs was sourced from scientific literature to provide a comparison against which to assess the generated information. A set of needs was selected from a review by Lauriks et al. [2007] that consolidates results from literature and 3 separate field studies involving a total of 617 people with dementia (PwD) and 322 carers. Considerable agreement was found between this collection and the results outlined in Table 3. These are summarised below, showing the corresponding themes and codes (see Table 3) in square brackets:

- General and personalised information on: dementia; service offerings; legal and financial issues; PwD's condition, care appointments and planning. [A7, B1,B3,B5]
- Support with: memory problems in daily life activities; coping with behavioural and psychological changes (PwD, carers); providing care; and emotional support. [A1-4,B3-4]
- The PwD's needs for social engagement/stimulation, to be cared for and safe. [A3,A5-6,B1]

This comparison focuses on the needs of PwD and their caregivers, comparing our results with those obtained through direct user involvement on a very large scale. Additionally, the collected data was examined to assess agreement across the different methods and sources. For each result (a stated clinical problem or need), at least two sources could be identified from the data.

Table 3. Elicitation of patients' support needs and healthcare professionals' information needs to develop a pervasive healthcare solution using smart wearable technology

A. Person with dementia	1. Memory function 2. Activities of daily living (ADL) support 3. Psychosocial/Behaviour 4. Orientation 5. Safety 6. Care 7. Information 8. Non-functional
B. Caregiver	1. Information about PwD and their safety (burden of worry) 2. Care burden (time and effort) 3. Care advice/training 4. Personal, emotional support 5. Information about resources
C. Healthcare professionals (information needs)	1. Behaviour 2. Functional capacity 3. Profile 4. Medication list and adherence 5. Individual problems/symptoms 6. Information validation 7. Routine adherence 8. PwD's and carer's support needs 9. General health and condition status
D. Barriers	1. Misinformation 2. Collaboration 3. Process

5. Discussion

The results from this study suggest that the data collection approach was successful in gathering information about users' needs. Our experiences carrying out the process also uncovered noteworthy insights and reflections on its practical application, interesting advantages and limitations.

5.1 Reflections on the process and its practical application

Overall, the data collection activities were straightforward to implement in practice. Two types of activities were employed in parallel: (i) interviews with healthcare professionals, and (ii) observations of interactions between care recipients and providers. The interviews provided rich output within a short time. Observing care interactions provided a broader range of perspectives and was minimally disruptive, since these did not require additional time or effort from stakeholders beyond normal care processes. The following key recommendations are made based on our experiences:

- Observation of care interactions should start prior to holding interviews, since the knowledge gained can enable more informed and targeted interviews. Thereafter, these activities should run in parallel, since during interviews healthcare professionals frequently refer to sequences, handovers, interactions and decision points or conditional steps/phases. This provides a detailed picture of the care network and patient pathway through the system.
- Where possible, different combinations of stakeholders should be observed, as information can be shared or withheld depending on the group/context

- Interactions in which care recipients openly discuss their problems should be included. Multidirectional communication was noted as particularly beneficial (eg discussions between patient, caregiver, doctor and nurse as opposed to a nurse testing a patient).

It should further be noted, that these activities take as a starting point some basic knowledge about the users involved (patients, healthcare professionals) and their interactions.

5.2 The value of a healthcare professionals' lens: Advantages and limitations

The primary motivation for eliciting needs of care recipients through observation rather than direct engagement was to circumvent specific challenges associated with the patient's condition, such as a denial of their needs or the impact of their cognitive impairment on their input. An advantage of including the healthcare professionals' perspective is that they encounter far more patients than the designer/researcher could typically engage with during the needs elicitation process. In this study, healthcare professionals described cases involving patients and their challenges extending well beyond those encountered among the group of patients that were observed in person. This is important considering how substantially patients' needs vary.

There are also several limitations to the approach used in this study. Observing interactions between care recipients and providers may not always be possible due to the privacy of information shared, or safety. Furthermore, patients do not necessarily discuss the problems they have at home in daily life with their doctor: depending on the context, these consultations may be brief and less directly related to the artefact to be designed. Finally, it should be emphasised that this approach does not obviate involvement from end users in the design process, as the voice of the patient is of significant importance. Rather, this provides an alternative approach to obtaining the patient's voice during the early phases of design before a prototype is available.

5.3 Going beyond: Extension to other design stages and application areas

The case presented here is within the context of dementia care and assistive technology. This was considered a valuable example in that it is comparable to other examples of pervasive technology-based services in healthcare. Specific characteristics of the example were noted in relation to how these might be generalised to other applications. The critical role of the caregiver in dementia was a strong element. This could be generalised to other applications with similar caregiver dependence (eg elderly, children or disabled users). The progression and treatment for dementia was also noted. Since there is not a cure, but rather a management approach, this might be similar to chronic conditions. We also observed that the kinds of needs in dementia concern the end-users' behaviour rather than physiological data such as blood or biosignals. This is comparable to other conditions that affect lifestyle, state of mind and behaviour.

6. Conclusion

This work addresses the challenge of gathering information about users' needs for new pervasive healthcare solutions such as those using smart wearable technology, particularly for a user group whose condition makes it hard for them to voice their needs, including people with dementia or other chronic conditions. We build upon relevant literature within topics related to user-centred design in healthcare, focusing on needs-elicitation in the pre-concept design phase. While closely engaging with end-users is generally considered beneficial, and an essential element of user-centred design, this may not be suitable when the target population are care recipients with broadly varying needs, and whose ability to provide input is limited by their condition. For such cases, we explore how this information could be gathered from a healthcare professional's perspective. The described approach involves observing healthcare professionals' various interactions with patients and their caregivers in which information is shared and discussed. Interviews are also used to tap into healthcare professionals' clinical knowledge and experience.

The approach presented in this work was implemented at a memory clinic in Denmark to gather information about the needs of people with dementia, their caregivers and healthcare professionals, regarding a smart technology based support system. Data was collected from 6 interviews with various healthcare professionals and observations of 11 patient consultations, 2 home visits with dementia coordinators, and 2 caregiver education sessions. This combined data was analysed according to defined goals for the type of technology to be designed, namely to support PwD and caregivers, and feed relevant information back to healthcare professionals. The themes for analysis included clinical problems, caregiver burden, clinically relevant information, and barriers (see Table 3). Within these themes, substantial information was gathered. The information aligned with current knowledge from scientific literature, and demonstrated consistent agreement across different collection methods and sources.

The study shed light on further insights and potential advantages concerning the practical feasibility of the data collection activities presented, and the value of a healthcare setting for needs elicitation.

The approach described here, and the insights uncovered through its application, show that it may be relevant for similar design challenges. We hope that this inspires other researchers and designers to explore and extend this work further in future.

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