

AreaAlzheimer: development process for a digital platform on Alzheimer's disease

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Background

- Dementia affects 55 million people globally [1]. In Spain, over 900,000 people are affected, including 93,700 in Catalonia [2], with informal caregivers (ICGs) providing care in more than 80% of cases [3].
- Technology can help provide access to services and support, but current digital tools often fall short in meeting caregiver needs [4] [5], highlighting the importance of co-designed, user-centered technologies developed with continuous end-user involvement.

Aim

To describe the development phases of AreaAlzheimer, a digital platform created to support family caregivers of people living with Alzheimer's disease (PwD).

Methods

Phase 1: Need Assessment

For the needs analysis, a quantitative research technique was used by designing an ad hoc survey of 27 questions. The anonymous survey was sent by email to an eligible population of 2,384 caregivers extracted from the Pasqual Maragall Foundation database.

By applying simple random sampling with a confidence level of 90% and a margin of error of 6%, a sample of 208 people is necessary to ensure a representative sample for the study. The data of the eligible people (n=210) were analyzed through a descriptive analysis and bivariate analysis carried out with the R software.

The structure of the survey has been formulated following the classification of needs based on the literature [6] and some categories of tasks and needs have been specified and added to facilitate and complete the self-administered survey in an online format.

Phase 2: Content Assessment

A quantitative ad hoc survey was designed for caregivers of adult family members with Alzheimer's who are current or former participants in the Pasqual Maragall Foundation's support groups.

The 32-question survey aimed to assess the usefulness of the proposed contents for each identified area of need, determine the preferred format, and gather suggestions for improvement. It comprised five sections: sociodemographic profile (with caregiver-specific fields such as length of caregiving and kinship); technological profile (digital familiarity, devices, and comfort with technology, given the digital divide among people over 65); contents (ranked by area of need, with open-ended questions); format (rated on a 1-to-5 scale); and a dedicated section on the person with Alzheimer's.

The anonymous survey was sent to an eligible population (N) of 494 caregivers from the Foundation's database, yielding 147 respondents at a 95% confidence level and an 8% margin of error.

The classifying criterion was assisting someone diagnosed with Alzheimer's who has difficulty performing normal vital or social activities, so temporal factors like years or hours of care were not considered. Univariate and multivariate descriptive analyses were then performed in RStudio to validate or reject relationships among variables, using two datasets by survey language.

Phase 3: Pilot Evaluation

A mixed-methods approach combined quantitative and qualitative techniques. The quantitative part was a structured survey in two sections: the first gathered caregivers' socio-demographic data (age, sex, education, marital and employment status, living arrangements, and relationship to the person with Alzheimer's); the second evaluated user experience using validated scales: the System Usability Scale (SUS, 10-item Likert) for usability, the Single Ease Question (SEQ, 7 items, 1–10) for accessibility, and the Perceived Usefulness Scale (PUS) and Behavioural Intention Scale (BIS) for usefulness.

The qualitative part involved two face-to-face focus groups exploring caregivers' experiences of the platform's content, usability, design, and relevance. Survey data were analysed in SPSS 23 (means and standard deviations), and the discussion groups via content analysis in Atlas 25. Participants were selected from the Pasqual Maragall Foundation's database using a purposive sample: over 18, caregiver of a relative with dementia, and prior participation in a Foundation programme. Recruitment ran October–November 2024. The pilot had two parts: an online evaluation and a face-to-face test, both with tasks (navigation, forums, programme registration, settings) plus the UX survey. Of the sample (n=40), 21 participated online and 19 attended in person, the latter joining the focus groups. All gave informed consent, with Barcelona residency required for this stage.

Results

→ 1 · Need Assessment: Top needs identified by ICGs

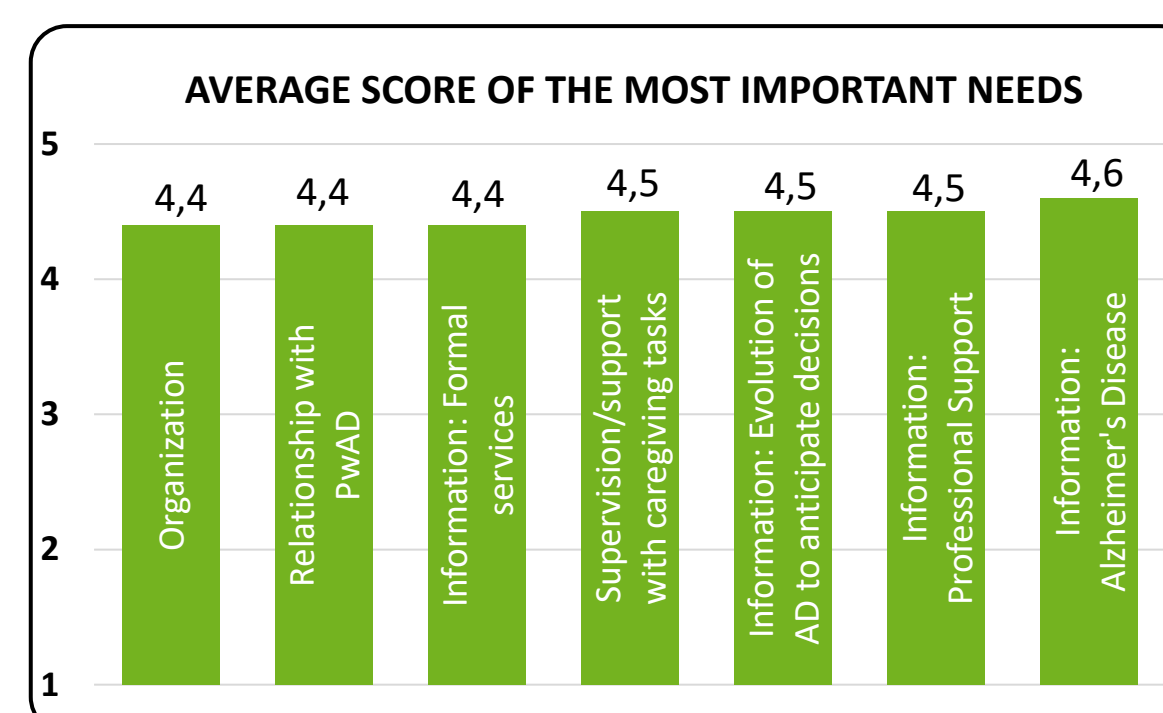


FIGURE 1. TOP NEEDS IDENTIFIED BY INFORMAL CAREGIVERS

→ 2 · Content Assessment

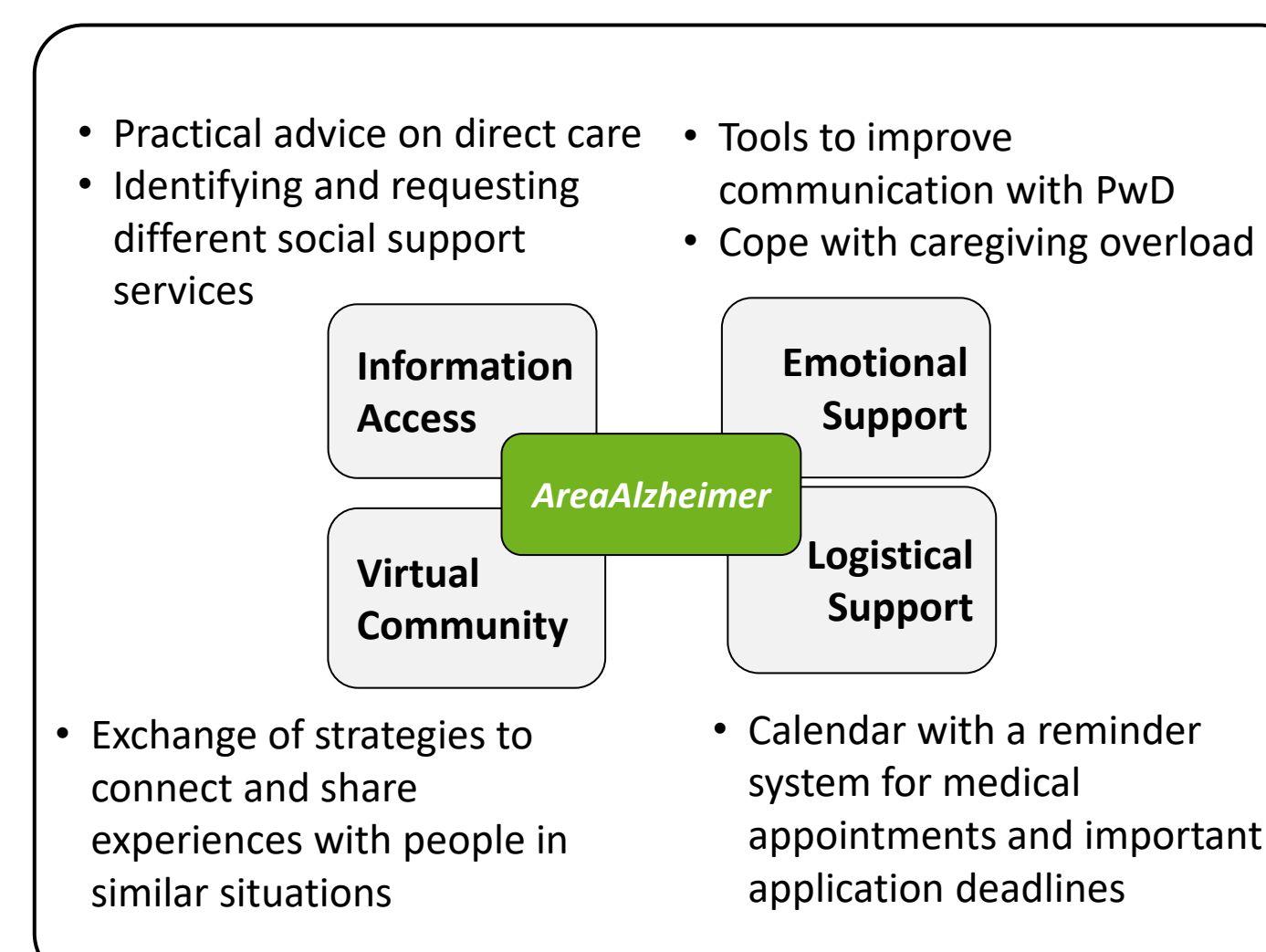


FIGURE 2. KEY AREAS OF NEED IDENTIFIED AND PREFERRED CONTENT.

→ 3 · Pilot Evaluation Accessibility

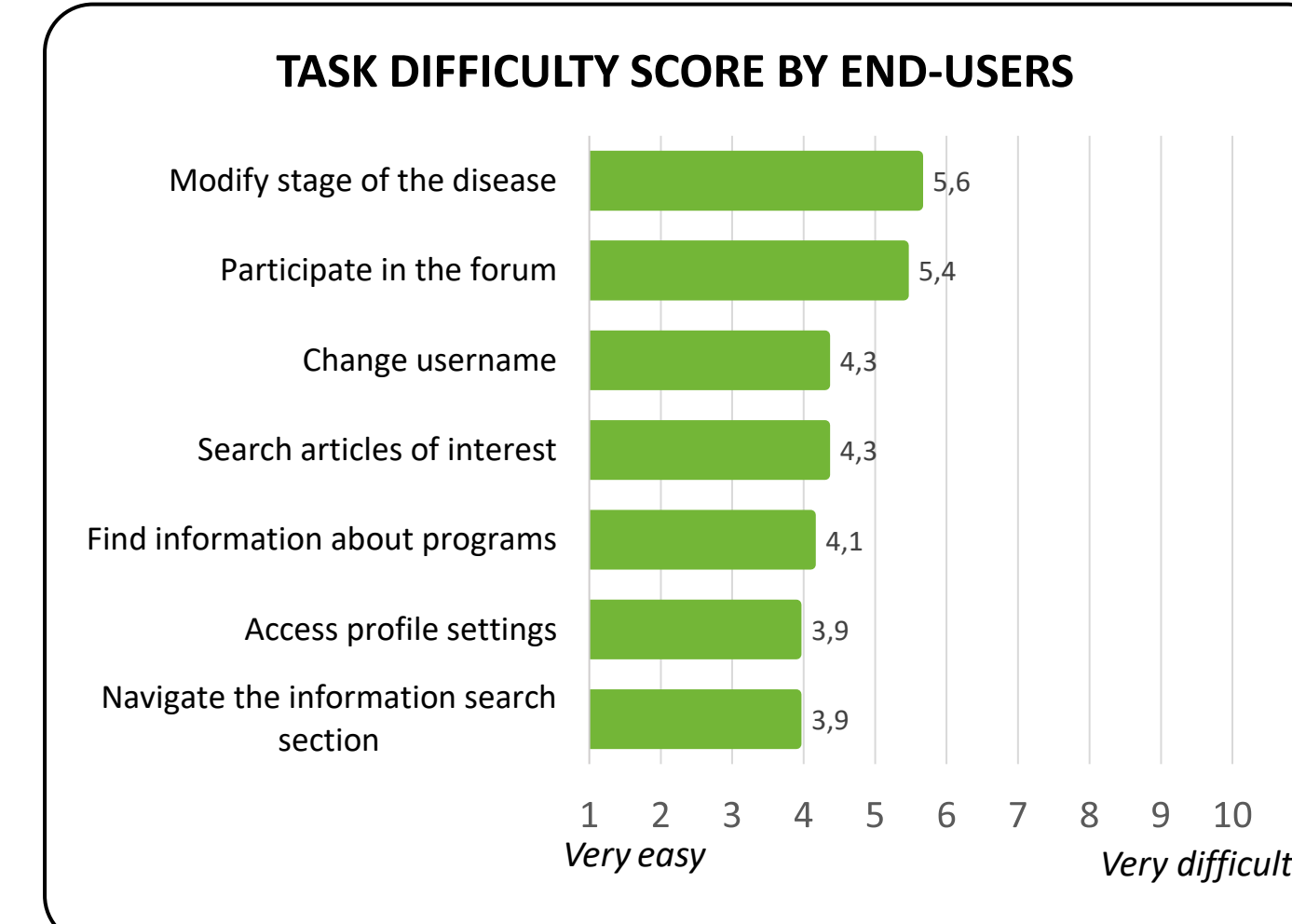


FIGURE 3. USER TASK DIFFICULTY ON AREAALZHEIMER PLATFORM MEASURED WITH SINGLE EASE QUESTIONNAIRE (SEQ)

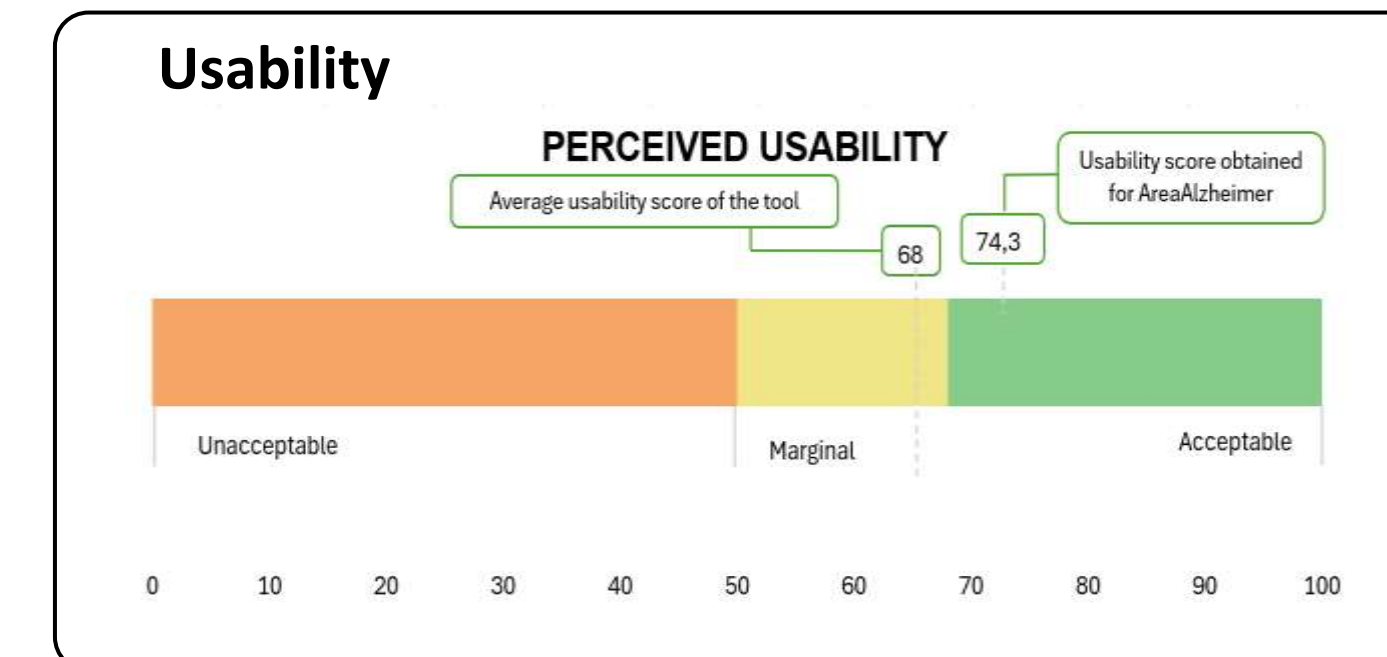


FIGURE 4. PERCEIVED USABILITY RESULTS ACCORDING TO THE SYSTEM USABILITY SCALE (SUS)

Conclusions

- User-centered design plays a pivotal role in bridging the gap between digital tools and caregiver realities.
- Digital resources tailored to caregivers' evolving needs can offer meaningful support, not only in managing daily care tasks but also in addressing emotional, social, and cognitive challenges associated with long-term caregiving.
- Continuous user feedback is crucial for refining and expanding the platform in future phases, ensuring it remains accessible, intuitive, and valuable for family caregivers, individuals with dementia (PwD), and healthcare professionals.

→ References

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