

The De-Sign Platform: An Online Psychometric Tool for Dementia Screening of Deaf Older Adults in two Sign Languages, GSL and ÖGS

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Abstract

This article presents the De-Sign platform, a web-based psychometric tool specifically designed for screening dementia in Deaf older adults (50+) who use Austrian Sign Language and Greek Sign Language hereinafter ÖGS and GSL respectively. The limited access to dementia services for these populations is primarily attributed to a scarcity of healthcare professionals fluent in sign language. Hence, enhancing access to relevant diagnostic services has become a priority. Currently, there is a significant lack of screening tools specifically developed to identify early signs of dementia that are compatible with national sign languages. To address this issue, the De-Sign Erasmus+ (2022-2025) project has employed suitable psychometric instruments that are adapted to the cultural contexts and linguistic norms of Deaf communities in Austria and Greece. The only existing Cognitive Screening Test (CST) for British Sign Language (BSL), used for diagnosing dementia in Deaf older adults, was initially adapted from English by Atkinson et al. (2015). The De-Sign platform hosts a cognitive screening test in ÖGS and GSL. Both were linguistically and culturally adapted from the BSL-CST test, providing two web-based versions of a psychometric tool that enables dementia screening within these populations.

Keywords: Dementia screening, Deaf populations, digital platform, psychometric tool, GSL, ÖGS.

1. Introduction

The De-Sign project “Raising Awareness for Dementia in Deaf Older Adults in Europe” (ERASMUS+, Project N° 2022-1-DE02-KA220-ADU-000088591) (<https://de-sign-project.eu/index.php/el/>) was an initiative aiming to meet an existing substantial lack in the field of mental health services, and particularly in the early detection of Dementia in Deaf and Hard-of-Hearing adult sign language users. Project partners included Germany, Greece, Austria and Italy, A German Sign Language (DGS) dementia screen had already been developed (Stockleben et al., 2025) and the Italian partners were not involved in the dementia screening part of the project. So, the study described here reports on the development of dementia screening tools for two of the partners' languages: Greek Sign Language (GSL) and the Austrian Sign Language (ÖGS) SLs. The De-Sign platform (https://sign.ilsp.gr/de_sign/) was one of the outcomes of the of the Erasmus+ funded project

“De-Sign: Raising Awareness for Dementia in Deaf Older Adults in Europe”.

1.1 Dementia Screening in Deaf Populations

Dementia is not a single disease entity but rather “a syndrome resulting from diseases of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, attention, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behavior, or motivation. This syndrome occurs in Alzheimer disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain” (WHO, 2019).

Alzheimer's disease is the most common form of dementia and accounts for over 50% of the cases (Alzheimer Europe, 2023).

Timely and accurate diagnosis of dementia is a health priority in many countries, as it enables access to a range of services that support a better quality of life, such as access to appropriate medication, time to plan future care preferences, and opportunities to express needs, wishes, and goals (NICE, 2018). Also, early diagnosis enables individuals to receive appropriate symptomatic treatment (e.g., cholinesterase inhibitors where indicated), engage in advance care planning, and participate in shared decision-making regarding future care preferences while decisional capacity is still preserved (Dubois et al., 2016). Recognition of early signs of dementia by family, friends, and communities plays a crucial role in facilitating help-seeking and referral to specialized assessment services (Alzheimer's Disease International, 2024).

However, there are few dementia awareness programs in sign languages worldwide (but see, e.g. <https://bda.org.uk/dementia/>). The absence of such programs contributes to low awareness of the early signs of dementia and underdiagnosis in Deaf communities around the world (Flower, Heferman & Dening, 2024; Ferguson-Coleman, Keady & Young, 2014). The aim of the De-Sign project was also to promote equal access of Deaf people to dementia information and diagnosis by raising awareness about dementia within Deaf communities in Europe.

The main innovation of this project was the creation of a digital platform for dementia screening, the De-Sign platform. The platform delivers an online digital administration of a neuropsychological test that screens for early signs of dementia in Deaf populations. The developed psychometric tool allows Deaf participants to be tested in their native language without the mediation of interpreters. A built-in evaluation section allows the health care expert to review the participants' answers. The De-Sign platform was developed in two different SLs, GSL & ÖGS.

2. Methodology

For the development and implementation of the De-Sign platform, Deaf communities, healthcare professionals, and academic experts were brought together, resulting in practical and accessible tools that directly address the needs of Deaf people.

At the time of the start of the De-Sign Project (2022-2025), except for the British Sign Language Cognitive Screening Test, hereinafter BSL-CST, there were no screening tools for detecting dementia in older Deaf adults, while none have

been implemented as a fully technology-assisted application.

The creation of a fully web-based screening test filled a gap that existed in the administration of such tests not only for the homogeneous parametrization of audiovisual materials but also in terms of the methodology of answer reception (answers are directly video-recorded and stored in a safe database), data protection, and classification as well as with respect to its potential remote use.

2.1.1 The BSL-CST Test

The British Sign Language Cognitive Screening Test (BSL-CST) is a screening tool for cognition assessment created and delivered in British Sign Language that is used to identify dementia and acquired cognitive impairment in older deaf individuals (Atkinson et al. 2015). It can be used to detect neurodegeneration or to provide a clinical baseline for a follow-up assessment. It is designed to screen all areas of cognition, with items relating to memory, language (BSL and British 2-handed fingerspelling), executive function, visuospatial ability, orientation, and attention

It uses standardized on-line video administration to screen cognition, using signed, rather than spoken or written, instructions and was normed on a sample of 226 deaf people aged 50-90o. This innovative testing approach transforms the ability to detect dementia in deaf people, avoids the difficulties of using an interpreter, and enables culturally and linguistically sensitive assessment of deaf signers, with international potential for adaptation into other signed languages. (Atkinson et al. 2015).

2.1.2 The Adaptation of the BSL-CST Into GSL and ÖGS

To obtain a highly efficient psychometric tool in the two SLs that are currently hosted on the platform, a series of methodological steps were followed for linguistic and cultural adaptation.

Two multidisciplinary teams of Deaf and hearing experts were brought together, one for each SL. In Austria this role was assumed by the Krankenhaus Barmherzige Brüder Wien¹. The expert group in Austria consisted of a Deaf social worker and a Deaf nurse, as well as a physician and four clinical psychologists with expertise in ÖGS.

In Greece two institutions were involved in the process, the Association of the Deaf Northern Greece (EKVE)² and the Greek Association for Alzheimer and Related Disorders (GAARD)³. The expert group in Greece consisted of two Deaf teachers of GSL with extensive teaching

¹Krankenhaus Barmherzige Brüder Wien (<https://www.barmherzige-brueder.at/portal/wien/home>)

² EKVE (<https://www.ekbe.gr>)

³ Greek Alzheimer Association and Related Disorders (<https://www.alzheimer-hellas.gr/index.php/en>)

experience and Deaf family backgrounds; a psychologist fluent in GSL with expertise in neuropsychological assessment; a linguist and GSL interpreter; a neuropsychologist specialized in dementia assessment; and a linguist specializing in SL research.

Athena RC⁴ was the institution that undertook the development of the platform and had regular communication with both teams.

The test contains 24 tasks, and each task contains several items. All test items of the BSL-CST were initially translated into the Austrian and Greek spoken/written language; they were then translated and adapted into the respective SLs, including thorough review to identify items requiring linguistic and/or cultural adaptation and to make decisions regarding the insertion of new items that were necessary for the efficacy of the test.

The main cultural adaptations were applied to items involving vocabulary, to ensure linguistic and cultural appropriateness. In contrast, visuospatial tasks did not require any modifications, as they were considered culturally neutral.

No new subtests were required. In some cases, existing items were modified to align with Austrian and Greek Deaf cultures. Variants of some tasks needed to be created to allow for fingerspelling particularities in both languages; in ÖGS, signers use either one- or two-handed fingerspelling, so two sets of elicitation material were created. The choice of which to use depended on information provided by the participants before the beginning of the test.

Similarly, for GSL, a limited number of alternative items were introduced in specific tasks. It had been expected that some elderly Greek Deaf participants might not know or use fingerspelling. Although in the course of testing it was found that most participants in the 50+ and 60+ groups could fingerspell, the platform provides an alternative option for those participants who cannot fingerspell: the Color Trails Test was administered in place of the Alternating Trails task to reduce language-related bias in executive function assessment.

Once agreement was reached on all items, a Deaf native signer of each of the SLs was video recorded signing all test instructions to create the pilot version of the test.

During the pilot phase, five Deaf experts provided detailed feedback. Their comments were discussed within each expert group, and appropriate amendments were implemented. Guidance and supervision on procedures for

adaptation of the BSL-CST were provided by the original authors of the BSL-CST.

Following finalization of the above-described procedures, each team recorded the final elicitation videos for all items in the test. The Austrian team recorded the videos with the support and equipment of the hospital's communication department, while the recording of the videos for GSL took place in the premises of ATHENA RC using high-quality audiovisual equipment.

A common methodology for creating the video materials was followed by both teams, and each elicitation item was filmed multiple times (2-3 times each). Afterwards, the videos were reviewed jointly by Deaf and hearing experts, and the best takes were selected.

3. The De-Sign Platform: Design and Implementation

Simultaneously with the procedures outlined above, the De-Sign platform was developed from the ground up. The platform currently hosts the adapted version of the BSL-CST test in GSL and ÖGS (https://sign.ilsp.gr/de_sign/). Both tests are constructed on a unified framework and design, incorporating parallel tasks to eliminate biases, ensure homogeneity in test administration and data acquisition across the two countries.

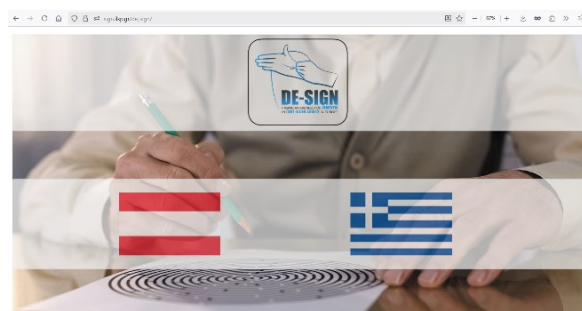


Figure 1: Initial page of the De-Sign platform

To facilitate the design of the platform, an initial blueprint was created to outline the methodological framework required for implementation. This step was crucial, as it enabled an examination of the technical specifications and accessibility standards that needed to be integrated into the platform.

The layout of the platform was designed with a primary focus on ensuring optimal test performance by incorporating adequate accessibility features for Deaf participants. These features include a comprehensive and user-friendly menu, instructions available in both video and written formats, a limited number and clearly identifiable buttons for advancing to the next task, pausing, and returning to the main menu, as well

⁴ ATHENA RC (<https://www.athenarc.gr/en>)

as options to skip tasks and navigate between them, along with the capability to record participants' responses.

A circular feedback strategy was implemented during the development of the platform, enabling the incorporation of insights from health and special needs experts. This approach facilitated the adaptation of the platform's functionalities to meet their expectations. As a result of this constructive dialogue, modifications and enhancements were made to the platform's features, overall performance, technical specifications, and testing flow. These improvements are intended to facilitate the administration of the tests and increase the usability of the tool itself.

Consequently, only essential navigation buttons were included to allow health experts to navigate between tasks.

The second pillar of the platform's architectural design was based on security and storage issues. Data storage and security issues are bound by local regulations in each country. To address this, ATHENA R.C collaborated closely with Krankenhaus Barmherzige Brüder Wien for the ÖGS and the EKVE and the GAARD for the GSL. They developed a suitable scheme for data transfer, storage, and security protocols tailored to each language set.

For the integration of video recordings, including both general and task-specific instructions, a

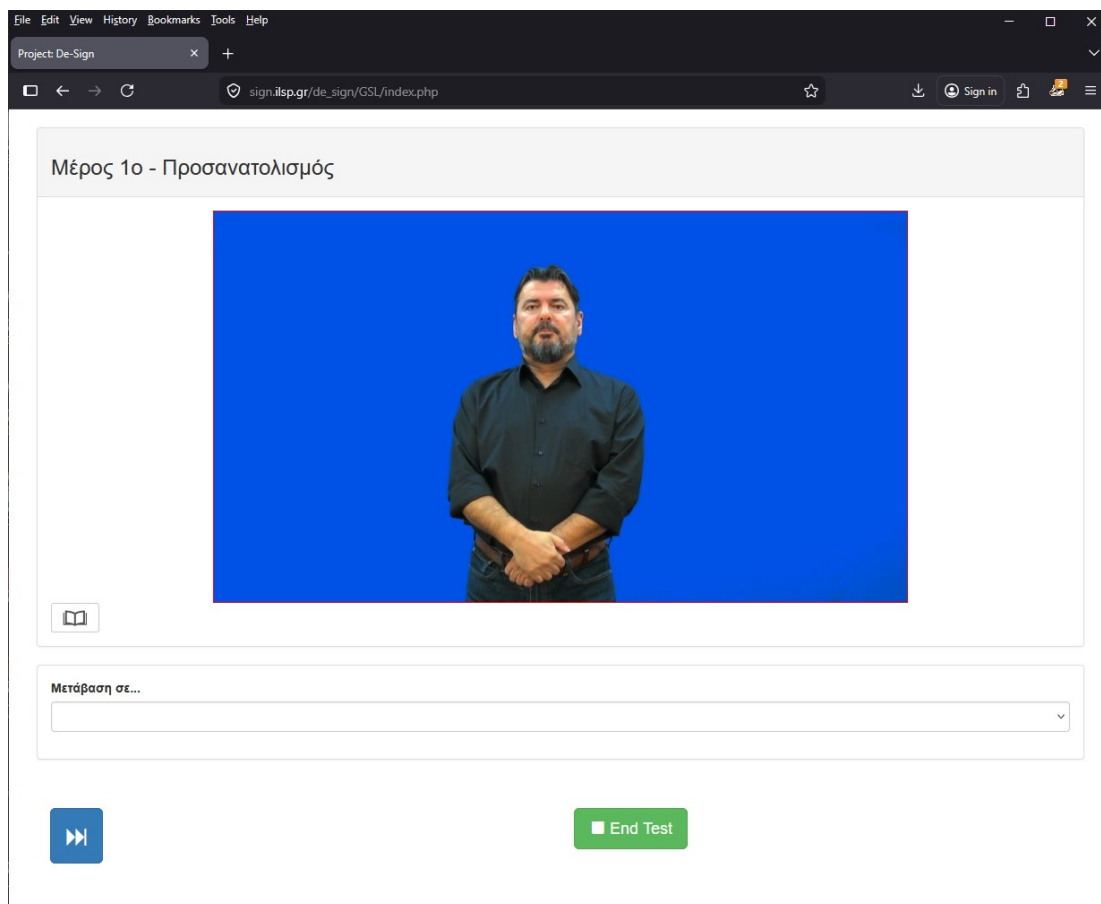


Figure 2: View of the layout pages on the De-Sign platform; the elicitation video of the orientation task on the Greek version.

Figure 2 illustrates the layout of the platform's pages which maintain a consistent design across both tests. The central area of each page features an elicitation video that provides instructions for each task, while a text version of the instructions is accessible beneath the video screen via a designated button.

The layout was intentionally designed to be minimalist, following recommendations that excessive visual stimuli could negatively impact on the efficacy of the tests, particularly for participants who may be prone to dementia.

flexible development and management approach (agile methodology) was adopted. This was necessary for the quick design, production, and delivery of subsystems within the project timeline. The use of proven technologies (JS, JSON, web services) allows usability, interoperability, and indexing requirements of audiovisual content. Content integration on the platform was carried out over the three years of the De-Sign project, with the content of both tests was available in both sign languages (ÖGS & GSL).

Testing and trial phases validated each development stage of the platform and confirmed its efficient performance.

3.1 Scoring, Result Reviewing and Final Evaluation Sheet

A significant aspect of the platform is the evaluation page, which serves as a distinct section within each language set. This feature enables health experts to simultaneously view video productions submitted for each participant and assess them on the platform. The final score for each task, along with the overall score for each participant, is calculated automatically, and a report is generated in .pdf format. Access to this section is restricted to the health expert responsible for each participant.

The result of the assessment is a total score, calculated by summing the scores across all items. Inter-rater reliability is typically examined in rating scales rather than in cognitive screening tools, as this type of reliability is less relevant when multiple cognitive domains are assessed rather than a single underlying construct.

Raters in Austria were not provided with additional training, as there was already a sufficient number of experienced health professionals, both Deaf and hearing, working in the field of dementia.

A comprehensive clinician User Manual has been developed and is available on the platform, outlining procedures and scoring guidelines. This manual is designed to assist new users in becoming acquainted with the tasks, the test flow, and the specificities of the digital test administration. It offers detailed instructions on biases to avoid during test administration and provides all necessary information regarding the use and scoring of the evaluation section.

3.2 Ethics and GDPR

The De-Sign platform is intended as a screening tool rather than a diagnostic instrument; it identifies early signs of dementia and facilitates referrals for further examinations by health experts. Although the data collected on the platform does not include medical information, it remains sensitive and personal, originating from individuals who may be at risk of dementia.

The platform adheres to strict GDPR regulations, and informed consent is obtained from every participant. Specifically, upon entering the platform for each language set, participants are presented with a general video outlining the project's objectives and the platform's purpose. Subsequently, each participant views two detailed videos: the first addresses the aims of the psychometric test, the research processes, and the management of their video recordings, while the second discusses GDPR considerations regarding their personal information on the platform. These videos are also available in written form. Participants have the option to either

read the informed consent documents or view them in sign language. The documents must be signed, and the corresponding box checked on the platform before the test can commence. Failure to accept the specified clauses constitutes an exclusion criterion, resulting in the cessation of the test.

Following this, each health expert must log into the platform using their personal credentials. The health expert is responsible for inputting the minimum required information for each participant, which includes their name, surname, date of birth, and the date of test administration. This information is utilized to create a unique identification sequence for each participant, which is subsequently employed to access the evaluation page containing performance scores for all tasks.

4. Results

Both the Greek and Austrian pilot versions of the psychometric test on the digital platform were administered to 20 Deaf individuals aged 50 or older who met stringent inclusion criteria. In Austria, there were no significant comprehension or technical issues, which allowed the pilot data to be incorporated into the final analysis. Conversely, minor adjustments were made in Greece.

For the purposes of developing test norms, 100 Deaf older adults from Austria and 70 Deaf older adults from Greece (with ongoing recruitment) have participated in the official administration of the test thus far. Normative samples from Austria and Greece were recruited from diverse regions to ensure representation of regional lexical variation. Participants provided informed consent and underwent screening for inclusion and exclusion criteria prior to engaging in one hour of video-based neurocognitive testing. As of the date of publication of the present paper, results for ÖGS are undergoing preparation for publication (Hoffmann-Lamplmair et al., in preparation); data are still being collected for GSL.

In Austria, four clinical psychologists fluent in ÖGS administered and scored the assessments using a structured scoring protocol. Approximately half of the scores were assessed through double rating to evaluate inter-rater reliability. In Greece, two clinical psychologists fluent in GSL administered and scored the assessments in accordance with protocol guidelines. Test administrators were members of the Deaf community who had received formal training in test administration under the supervision of one of the two clinical psychologists. They were health professionals, professional interpreters, or teachers. All were university graduates, used Sign Language as their primary means of communication, and self-identified as members of the Deaf community.

The outcome of this endeavor was the creation of a standardized web-based adaptation of the BSL-CST in two distinct SLs, which is characterized by high quality, linguistic precision, and cultural relevance.

5. Conclusion

The main target group of the De-Sign platform were Deaf older adults who use ÖGS and GSL.

This population has historically faced significant barriers in accessing linguistically and culturally appropriate cognitive screening tools, often resulting in underdiagnosis or misdiagnosis of dementia. By developing an adapted and web-based version of the BSL-CST, De-Sign platform effectively addressed this gap, offering an accessible, reliable, and standardized assessment mechanism tailored for these communities.

Consequently, the Deaf populations in Austria and Greece have been afforded access – for the first time – to a scientifically validatable cognitive screening tool that meets their linguistic and cultural requirements. This initiative marks a significant advancement toward achieving equity in neuropsychological assessment for Deaf individuals.

6. Acknowledgments

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