



ALS Community Support Assessment to Improve Online Access to Information and Resources in Italy

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Introduction

conSLAncio is a patient-led, non-profit Italian association founded in 2015 by Andrea Zicchieri (Fig.1). The association aims at supporting the Italian ALS community, informing the development and use of experimental ALS therapies.

Accessibility to real time ALS scientific research news and support resources in non-English languages is often a challenging endeavor for people living with ALS (PALS), families, and caregivers (1).

This project assessed the **ALS community needs to initiate a new series of virtual seminars** promoted by conSLAncio.

The Italian ALS community provided critical input in accordance with our Design-Build approach (Fig.2).



Fig.1. conSLAncio Founder, Andrea Zicchieri, with his son, Mattias, 2016

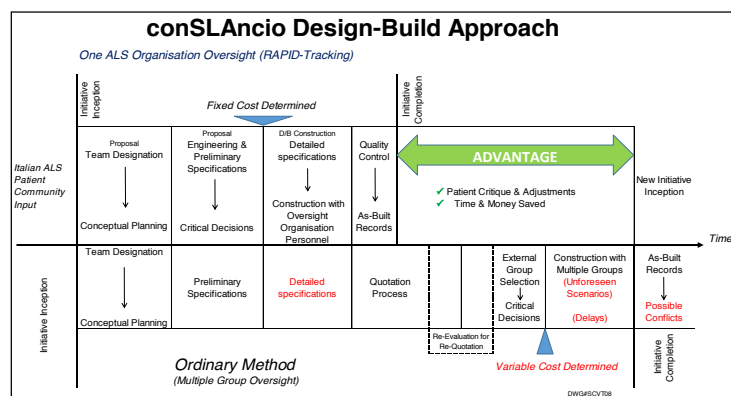


Fig.2. A timeline illustrating a comparison of the conSLAncio Design-Build approach versus an ordinary project delivery sequence.

Methods

To evaluate the interest in several ALS-related topics, PALS and PALS-related individuals (family members, friends and caregivers) were asked, upon consent, to fulfill a five-minute anonymous survey online (Fig.3). The survey included nine questions about: updates from clinical trials and scientific meetings, patient journey support, social supports, two open questions about scientific publications and other topics of interest. The survey was launched in May 2022. We present the results obtained until October 2022.

conSLAncio Seminar Series 2022 SURVEY

Answer to the following questions by expressing your interest:
Not interested 1 2 3 4 5 Very interested

Q1. Would you like a series of seminars on ALS organized by conSLAncio?

Q2. Which of the following topics would you be interested in?

- ☐ Update on the results of clinical trials launched in 2022
- ☐ Update on new clinical trials of 2022
- ☐ Learn about the disease diagnosis
- ☐ Information on how to participate in a clinical trial
- ☐ Information on care centers (at local or national level) and on offered services
- ☐ Update on current knowledge of genetic and sporadic causes of ALS
- ☐ Are you interested in receiving information from researchers about their studies?
- ☐ Updates on international congresses on ALS (e.g. ALS/MND Symposium, ENGALS...)

Q3. Personal Information:

- ☐ Are you a person affected by ALS (PALS)?
- ☐ Are you a relative or friend of a PALS?

Fig.3.

Results

The six-month survey (May 2022-October 2022) collected information from PALS and PALS-related individuals obtaining a total of n=65 answers. PALS represented the 31% of answers whereas the 69% of responses were obtained from PALS-related people (Fig.4A). More than 85% of participants were highly interested (a lot + very) in following a virtual seminar series produced by conSLAncio (Fig. 4B).

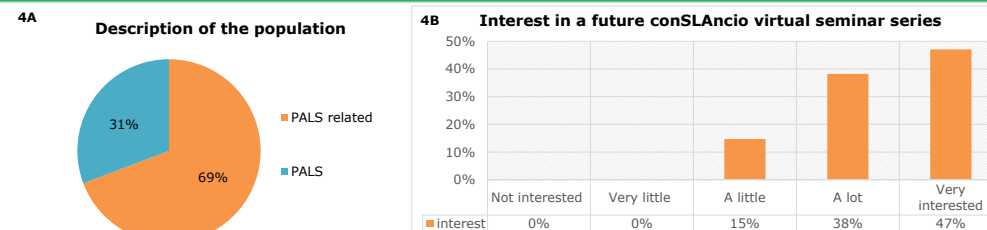


Fig.4. Description of the population that answered the survey (4A) and general interest in following a virtual seminar series produced by conSLAncio (4B).

Interest areas were evaluated according to the questions proposed; answers were collected and analyzed from both PALS and PALS-related individuals. Updates on clinical trials (Fig.5) obtained high interest in our population. 88% of individuals were a lot or very interested in trials results (5A), 90% of them were interested in updates on clinical trials recently launched (5B) and 78% showed interest in obtaining information about how to participate in ongoing clinical trials (5C). Information from clinicians about diagnosis and local or national support were topics highly appreciated from our population (Fig. 6). Indeed, 76% of our population showed high interest in diagnosis details (6A) and 90% of them would like to receive more information on local and national support for PALS and PALS-related and services offered (6B). Finally, updates on the ongoing research were considered favorably (Fig.7). In particular, 91% of PALS and PALS-related individuals expressed high interest in receiving information about the genetic and sporadic causes of the disease (7A), 91% of them would be interested in having meetings with researchers to know them more and discuss their studies (7B) and a general 84% of individuals were highly interested in having updates from national and international conferences (7C).

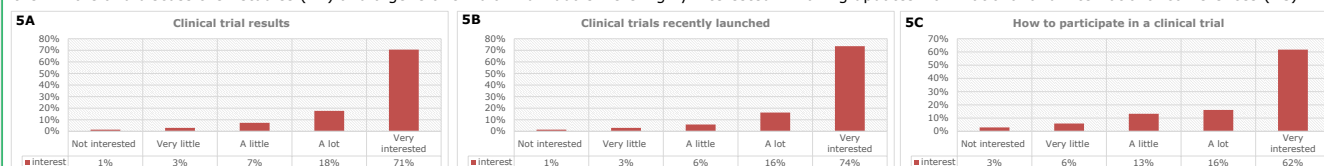


Fig.5. General interest in clinical trials. Responses were collected from questions related to clinical trials results (5A), newly launched clinical trials (5B) and how to participate in clinical trials (5C).

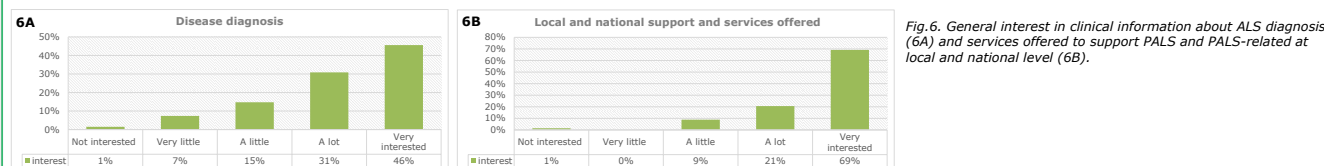


Fig.6. General interest in clinical information about ALS diagnosis (6A) and services offered to support PALS and PALS-related at local and national level (6B).

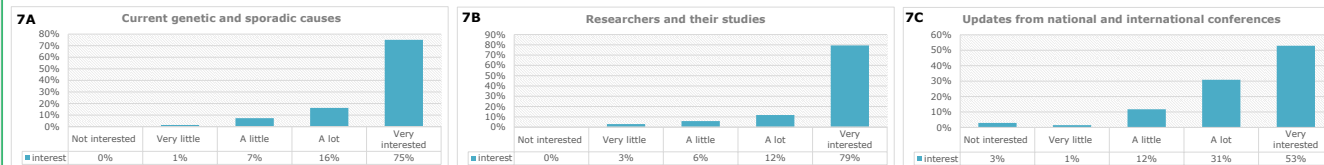


Fig.7. General interest in research related information. Responses were collected from questions related to current genetic and sporadic causes of ALS (7A), updates from researchers on their studies (7B) and updates from national and international conferences (7C).

Conclusion

The recent survey illustrated the **necessity of a new online ALS seminar series in Italy** promoted by conSLAncio. Results showed high community interest for a virtual seminar series covering numerous topics, including clinical trials and support services. These results support the usefulness of launching similar surveys in the future (as part of our **Design-Build** approach) to better support the ALS community. Accordingly, we are now building an online seminar series to address the interests expressed in this survey.

Reference

1. Zicchieri, A.D., Conte, S.F., De Rossi, N. (2020). CMS-27: Using a Design-Build Approach to Improve International ALS Research News Access in Italy. Poster presented at the Motor Neuron Disease Association Virtual 31st International Symposium on ALS/MND.

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