



Improving Online Caregiver Training for ALS and Complex Fragile Patients Using Design-Build in Italy



Zicchieri, A.D.¹, De Rossi, N.¹, Desiderato, A.¹, Conte, S.F.¹, Pozzi, S.¹, De Marchi, F.¹, Contessa, P.¹, Bedlack, R.S.¹, Ayala, J.C.¹, Ghio, I.¹

1. Associazione conSLAnCio Onlus – Terracina (LT), Italy



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

Introduction

This project improved **accessibility** to **online caregiver training courses** for ALS and complex fragile patients in Italy.

Previous caregiver training was sporadic, costly, and variable throughout Italy. Access to such training became further challenging due to the COVID-19 pandemic for caregivers, families, and healthcare assistants. In this project, the Italian ALS community provided critical input and was involved throughout. **Design-Build** (Fig.2) is a project delivery system in which a single entity oversees and executes a project from design to completion (1). Using Design-Build, conSLAnCio launched a new free online ALS caregiver training course available on demand, 24/7. In the first ten months, we saw widespread regional enrollment and overall positive feedback resulted.

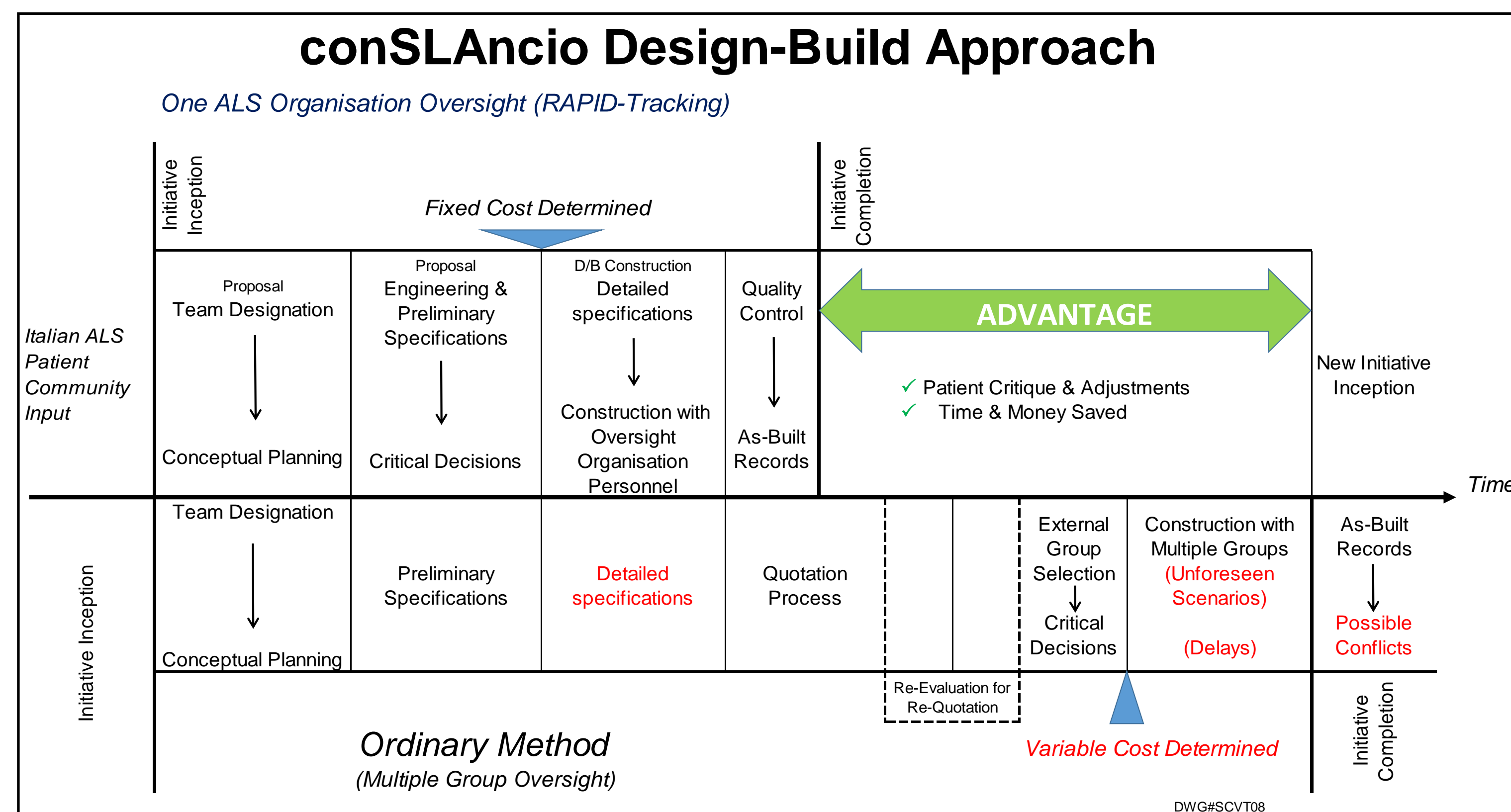


Fig.2. A timeline illustrating a comparison of the conSLAnCio Design-Build approach versus an ordinary project delivery sequence

Results

At the end of the 14 training course videos, users were requested to submit a survey for user data, feedback, and possible improvements to be implemented. From January 2021 to October 2021, we received 36 surveys from 136 users. Survey data received since course launch in January 2021 illustrate a widespread diverse course user background across Italy and Switzerland (Fig.4) consisting of caregivers (42%), healthcare assistants (39%), and other personnel (19%) (Fig.5). Most users discovered the course through Facebook (58%), and (18%) through the internet (Fig.6). Artificial Nutrition (72.22%), Alerts for Enteral Nutrition (66.67%), PEG and NG (61.11%), and Venous Accesses (61.11%) were found to be the most interesting, whereas Effective Communication (41.67%) was deemed the least interesting (Fig.8). The majority of users recommended the course to others (97%) and (3%) did not recommend the course although they found it to be useful, but too difficult (data not shown).

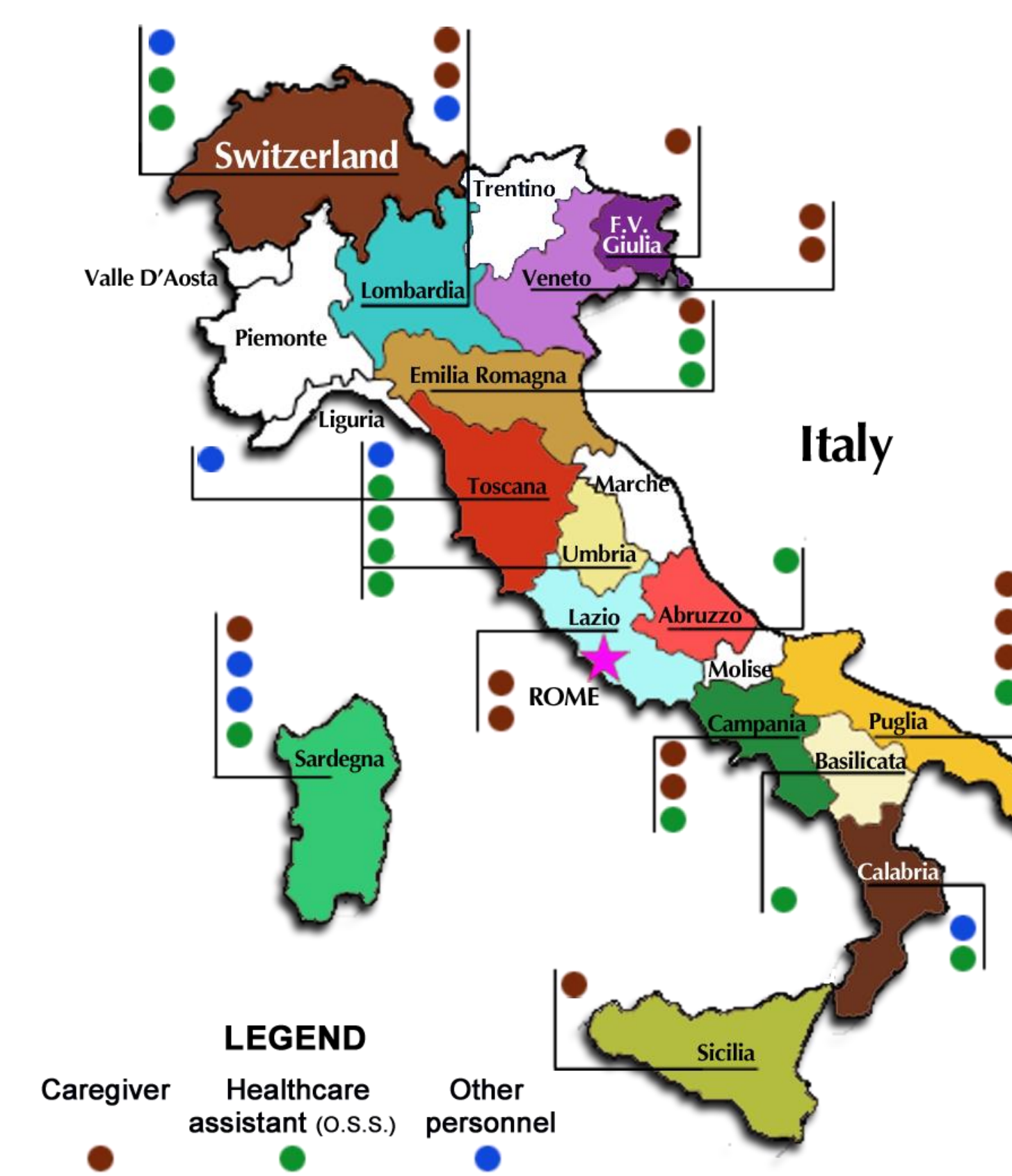


Fig.4. Geographical distribution of users

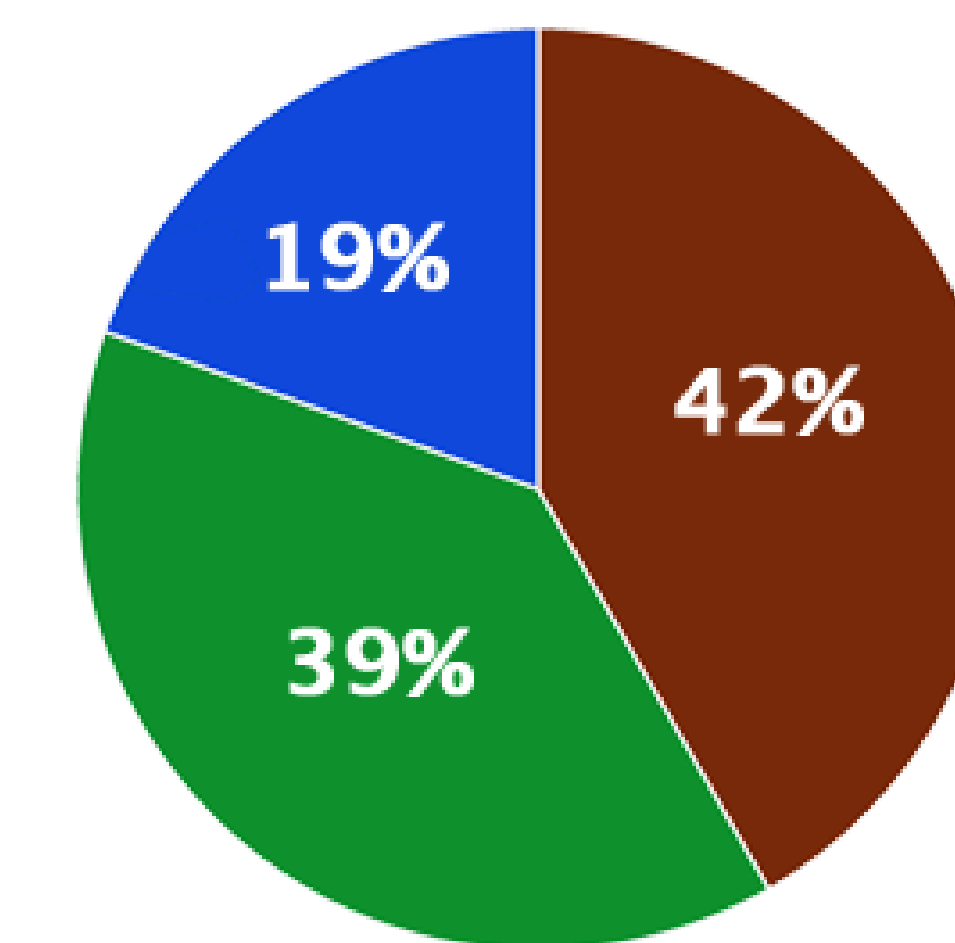


Fig.5. Type of users

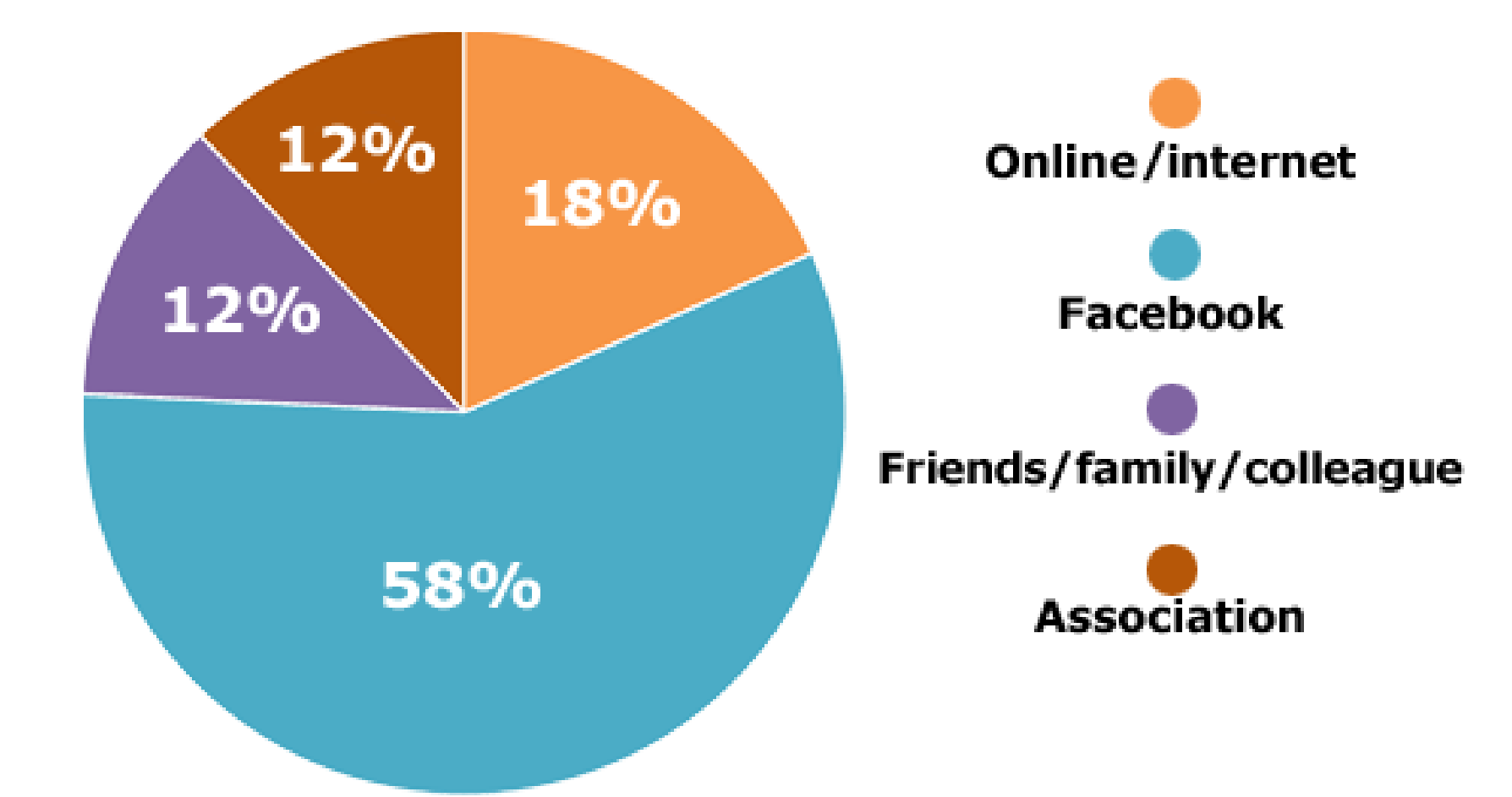


Fig.6. Sources of course discovery

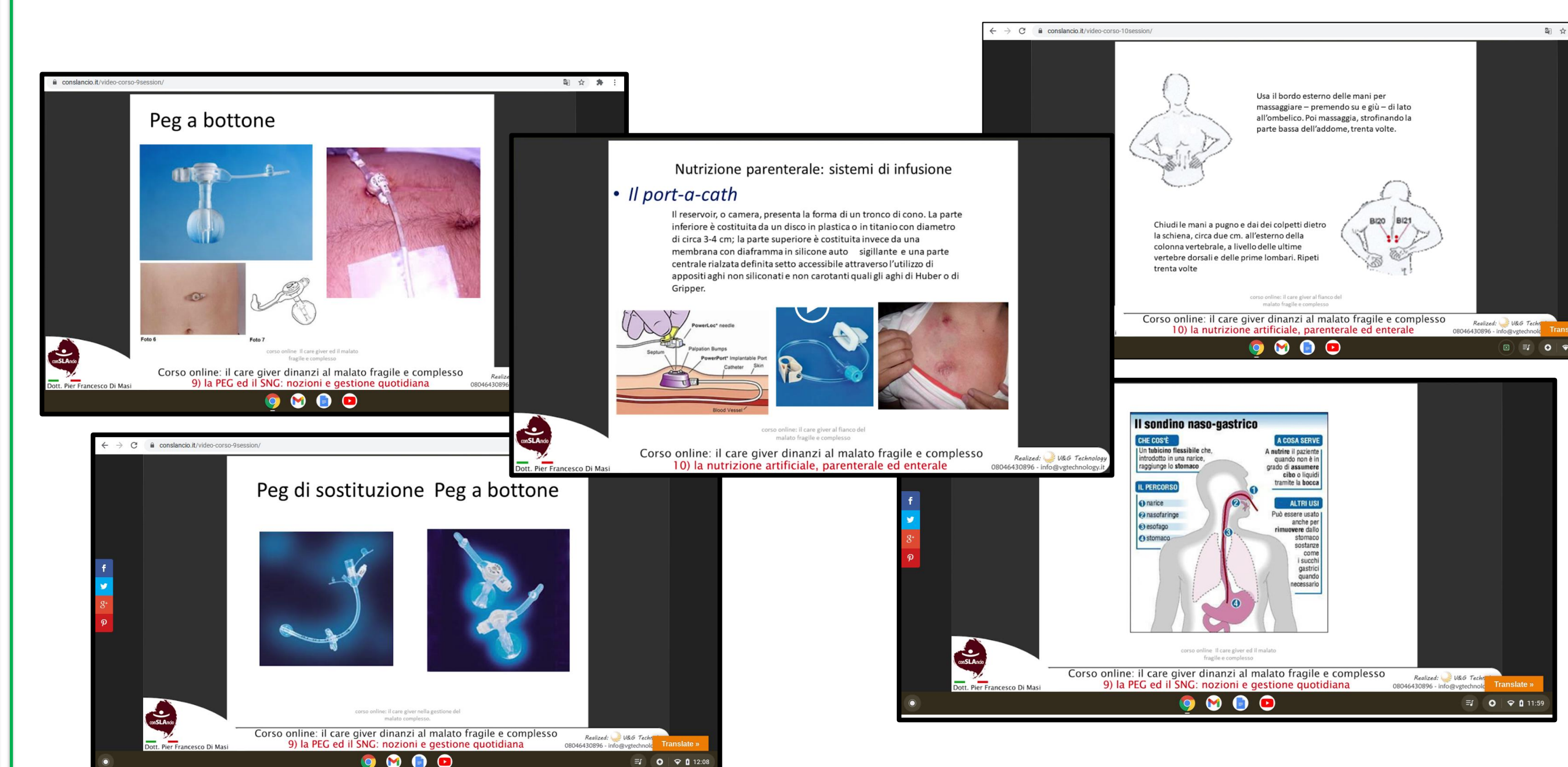


Fig.7. Representative screenshots of different slides present in the course session

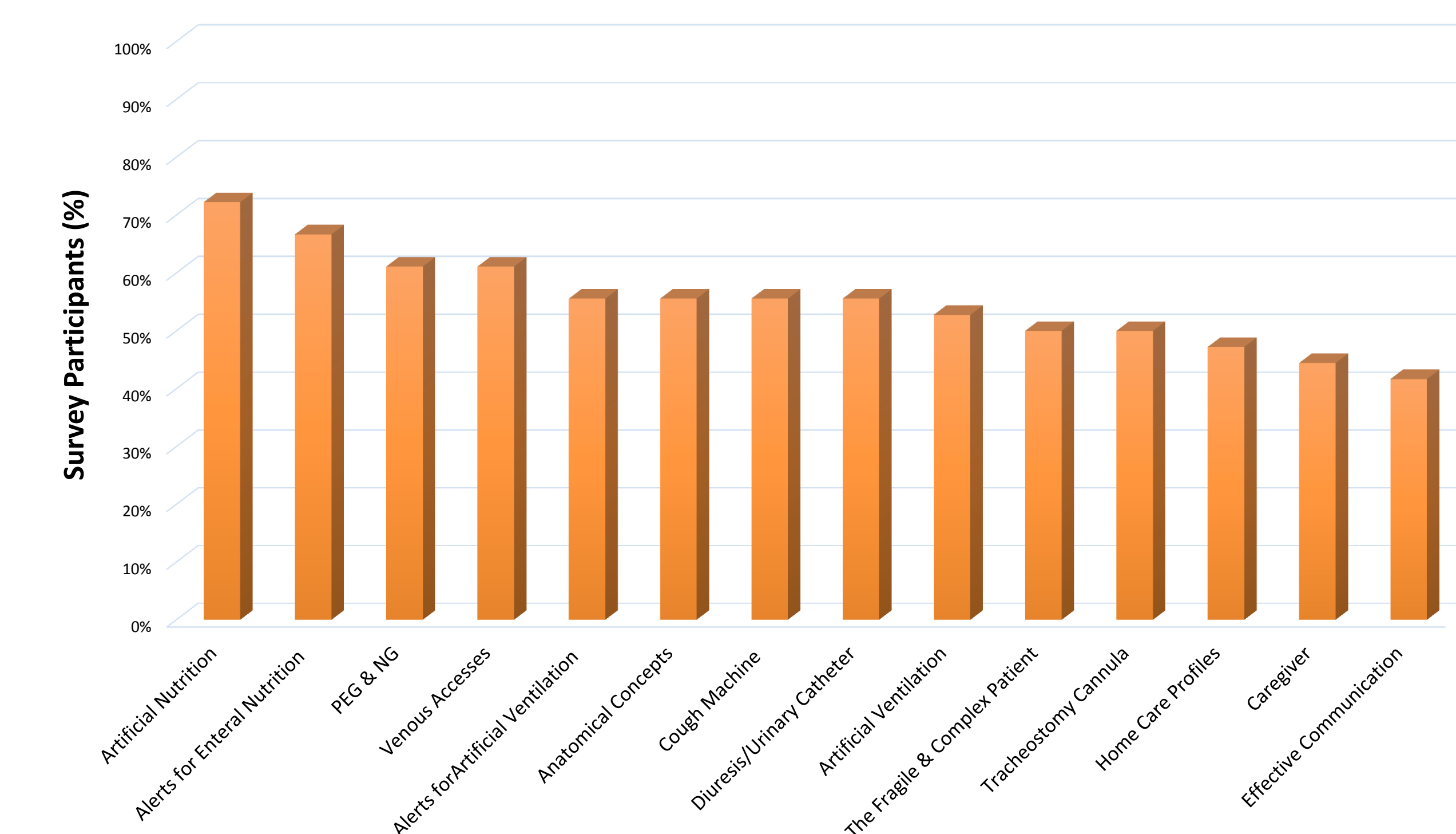


Fig.8. User interest per specific sessions

Conclusion

The conSLAnCio **Design-Build** approach has proven beneficial in improving **online accessibility** to **online caregiver training** for ALS and complex fragile patients in Italy.

Results highlight the widespread necessity of a free, on demand online caregiver training course for ALS and complex fragile patients across different care roles in Italy. Most users (**97%**) recommended the course to others. Additional reminders to users will be sent to obtain completed surveys. Although widespread enrollment across Italy and beyond, expansion of course offerings will continue while improving content based on feedback from the clinical and caregiver fields.

Italy's First Free Online ALS Caregiver Training Course

Designed by our team to precisely integrate with the specific mission of the Association to **support ALS caregivers and all personnel** when health institutions are unable to do so. The course is available in-person, and online.

Objectives of the course:

- Improve the qualitative processes of the procedures that caregivers have to manage, especially at home;
- Instruct caregivers on the latest best practices and guidelines that all medical professionals are obliged to adhere to in order to prevent free interpretation by healthcare providers themselves;
- Provide valuable training on effective communication for positive benefits in the care setting for the psychological well-being of all involved;
- Establish a bridge between families and conSLAnCio to develop better intervention protocols that are feasible in the home due to the actions of the healthcare professionals involved.

Online training course features:

- ✓ Course and technical support available 24/7;
- ✓ Covers 14 essential themes in video lecture format including concepts and practical demonstrations;
- ✓ User-friendly, fully compatible with desktop computers, tablets, and mobile devices and accessible anywhere worldwide;
- ✓ Self-paced and easy return access;
- ✓ Users receive a certificate of course participation.



Fig.3. QR code of the virtual course (<http://www.conslancio.it/corso01>)

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 Neurone Disease Association Virtual 31st International Symposium on ALS/MND.

Acknowledgements

We express our most sincere gratitude to the dedicated patients, families, caregivers, and volunteers from the Italian community for their involvement. Our team also appreciates the kind support and invaluable expertise of: Ilaria Barone, Mattia Belloni, Alessandro Boaro, Francesco Boccalatte, Lara Brambilla, Valentina Cattero, Simone Cimino, Pier Paolo Comida, Angelica D'Amore, Vittoria A. Farallo, Nicolò Giordano, Ester Luna, Ilaria Luna, Sean Mannion, Nicola Marinelli, Paola Mastracco, Deborah Metzel, Elisabetta Mezzalana, Ostap Nalysnyk, Cristina Onesta, Alessandra Pecora, Tiziana Petrozziello, Nicoletta Pireddu, Aleh Plotnikau, Elisabetta Pupillo, Giulia Supino, Luca Zampedri, and Cinzia Zicchieri.

Correspondence: Silverio Conte info@conslancio.it

