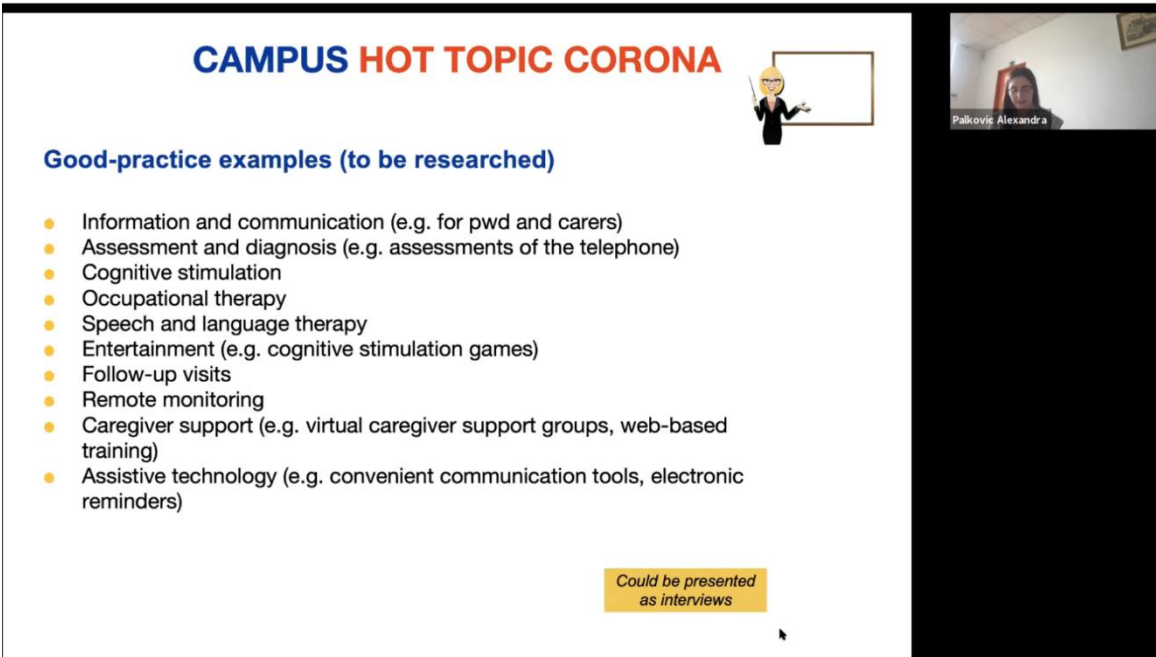


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## Short overview

The focus group took place on August 26<sup>th</sup>, 2021, via the online platform ZOOM. The decision to use a virtual format instead of hosting the focus group in person was based on very good experience with this platform in previous periods of the INDEED project (four INDEED pilot workshops took place in a fully digital format). Furthermore, group meetings were still not recommended at that time due to insufficient COVID-19 vaccination rates in participating countries. These preventative measures enabled us to proceed with planned activities within the INDEED Extension workpackage 8 “Hot Topic Corona” despite the persistence of the Corona pandemic crisis.



**CAMPUS HOT TOPIC CORONA**

**Good-practice examples (to be researched)**

- Information and communication (e.g. for pwd and carers)
- Assessment and diagnosis (e.g. assessments of the telephone)
- Cognitive stimulation
- Occupational therapy
- Speech and language therapy
- Entertainment (e.g. cognitive stimulation games)
- Follow-up visits
- Remote monitoring
- Caregiver support (e.g. virtual caregiver support groups, web-based training)
- Assistive technology (e.g. convenient communication tools, electronic reminders)

*Could be presented as interviews*

Palkovic Alexandra

## Preparatory steps

### Invitation process

We invited approximately twelve dementia experts from different countries to exchange their perspectives on alternatives and innovations that have been brought about by the pandemic and may sustainably improve dementia care. These included information provision, diagnosis and monitoring, treatment including assistive technology, and carer support. The experts were invited via email, which contained information about the INDEED project and what was expected from the online meeting.

### Participants

The invited experts were from Germany, Slovenia, Bulgaria, Romania, Moldova, Croatia, Czech Republic and Slovakia. The group consisted of neurologists, speech therapists, occupational and physical therapists and one University professor from Slovakia (Medical department).

To sum up, we had 9 experts who attended, presenting their opinions and sharing good practice examples at our online meeting.

### Structure of the focus group

The virtual focus group was hosted and moderated by the main project coordinator in Slovakia, Sabine Gergely and the project manager Alexandra Palkovič from the Memory Centre, n.p.o., in Bratislava, Slovakia. The moderators welcomed the participants and informed them about the agenda of the session. After a brief introduction round, Professor Nicola Lautenschlager from the University of Melbourne and co-moderator Alexandra Palkovič provided brief input presentations. Prof. Lautenschlager outlined her perspective and shared her experiences on strategies in dementia care for rural areas in Australia and on dementia care in times of lockdown as well as lessons learned during social distancing in the healthcare sector. In the second presentation, new ways of communication with patients with dementia and their caregivers which had been developed in the Memory Centre, n.p.o., were pointed out. Next, an overview on the topics was planned in the agenda and provided by moderators in cooperation with partners from TUM-MED. During the discussion participants shared their perspectives on detection and diagnosis, non-pharmacological interventions, caregiver support, assistive technology in times of restricted face-to-face contact, and discussed alternative ways of cross-disciplinary collaboration.

## Goals and findings

The overall goal of the focus group was to discuss the content of the additional chapter on management of dementia during the COVID-19 pandemic, particularly in times of social distancing, and develop ideas for the media formats to be used on the INDEED online learning platform.

We identified 3 key topics which were discussed during the focus group:

- 1) *How did the pandemic change dementia care?*
- 2) *Which strategies were developed to deal with the new situation?*
- 3) *Which strategies could possibly remain after the pandemic and create benefits in the care (or treatment) for people with dementia?*

Findings from the discussion were subsequently categorized into several additional sub-topics:

### Communication

- Digital devices used for communicating with people with dementia (pwd) and carers
- Communication via e-mail, phone, Facebook, online conferencing in the medical team and from the caregiver to the pwd
- A variety of educational and entertaining videos were produced (youtube, facebook) -> will be used after the pandemic, videos should be carefully selected / tailored to meet the capabilities of the individual person with dementia
- In times of lockdown/isolation/quarantine: Do pwd have the right to communicate with their families? E.g. must a nursing home provide communication tools?
- How can personal and confidential information be transferred in a safe (protected) way (GDPR)?

### Assessment and diagnosis

- Feasibility of neuropsychological assessments per phone / video using appropriate instruments with the assistance of carers, e.g. Addenbrooke Cognitive Examination, remote version -> continuation after the pandemic for people who cannot attend in person
- Protocols for these assessments are needed
- Billing methods for telemedicine are needed
- Virtual clinic visits are convenient for people with dementia, as they remain in their usual environment with a carer close by -> less stress and anxiety
- Remote examinations require clearer instructions and clearer communication for people with dementia (short sentences, loud voice) -> will continue after the pandemic

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- Pwd seem to be more comfortable because they can stay at home, i.e. in a familiar environment
- Usually, caregivers can manage the digital communication tool

Treatment delivery

- „Hospital in the home“ -> multiprofessional community teams conduct home visits -> may be practiced after the pandemic in special cases
- Short videos with suggestions for cognitive and physical exercises
- Short videos for carer education and support -> will be used after the pandemic
- Neurologists and psychiatrists on call for emergencies (in nursing homes)
- Group activities provided outdoors (distance)
- Occupational Therapy provided in small groups
- Exercises brought to peoples' apartments
- Communication training with carer and pwd per video
- Physical therapy provided by trainer in the garden with people watching from the balcony, also has a mental/social benefit
- Telehealth methods must be approved by authorities and must be reimbursed

Activity and participation

- Volunteer students sent to nursing homes
- Tablet computers programmed for gaming
- Useful items brought to the nursing home to enrich visits -> can be used after the COVID-19 pandemic
- Volunteer services in the community (e.g. shopping services) were expanded, increased involvement of medical students

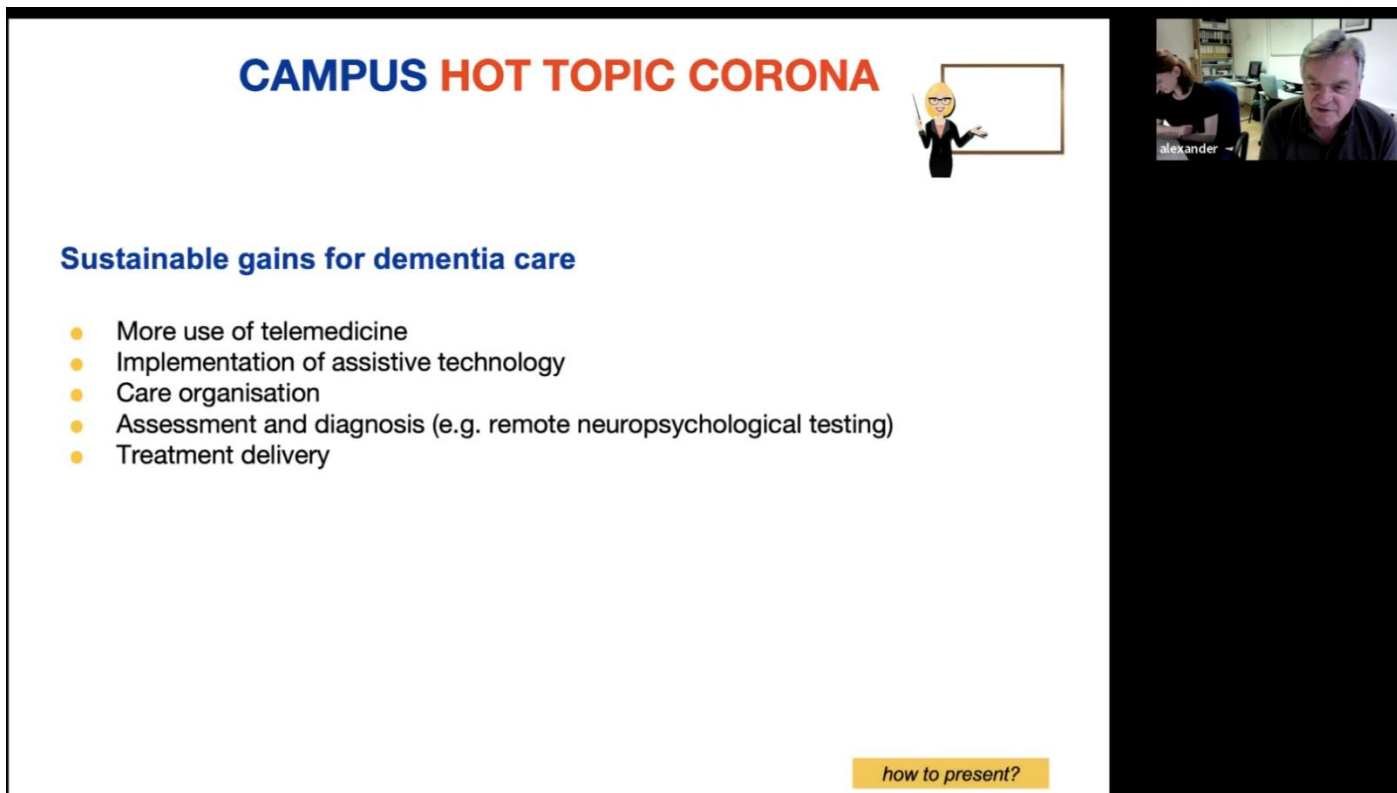
Interprofessional collaboration and coordination

- Virtual team meetings
- Written reports and handovers improve quality of collaboration -> may be continued after the pandemic


Additional aspects

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- Outward migration of medical staff + outward migration of workers who would be needed as informal caregivers in times of lockdown / isolation / quarantine (work-related migration from the Danube Region to central European countries)




**CAMPUS HOT TOPIC CORONA**



**Sustainable gains for dementia care**

- More use of telemedicine
- Implementation of assistive technology
- Care organisation
- Assessment and diagnosis (e.g. remote neuropsychological testing)
- Treatment delivery

how to present?



## Literature review

- *Hatcher-Martin JM, Adams JL, Anderson ER, et al.: Telemedicine in neurology: Telemedicine Work Group of the American Academy of Neurology update. Neurology 94:30–38, 2020*
- *Pappadá A et al.: Assistive technologies in dementia care: An updated analysis of the literature. Front Psychol 12: 644587, 2021*

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- *Adorjan et al.: Consequences of the COVID-19-Pandemic for People with Schizophrenia, Dementia and Substance Dependence Disorders-Nervenarzt 92: 571-578, 2021*
- *Manca R, De Marco M, Venneri A (2020) The impact of COVID-19 infection and enforced prolonged social isolation on neuropsychiatric symptoms in older adults with and without dementia: a review. Front Psychiatry 11:585540*
- *Wang H, Li T, Barbarino P et al (2020) Dementia care during COVID-19. Lancet 395:1190–1191*
- *Brown EE, Kumar S, Rajji TK et al (2020) Anticipating and mitigating the impact of the COVID-19 pandemic on Alzheimer’s disease and related dementias. Am J Geriatr Psychiatry 28:712–721*
- *Batty GD, Deary IJ, Luciano M et al (2020) Psychosocial factors and hospitalisations for COVID-19: prospective cohort study based on a community sample. Brain Behav Immun 89:569–578*
- *Simonetti A, Pais C, Jones M et al (2020) Neuropsychiatric symptoms in elderly with dementia during COVID-19 pandemic: definition, treatment, and future directions. Front Psychiatry 11:579842*
- *Canevelli M, Valletta M, Toccaceli Blasi M et al (2020a) Facing dementia during the COVID-19 outbreak. J Am Geriatr Soc 68:1673–1676*
- *Covino M, De Matteis G, Santoro M et al (2020) Clinical characteristics and prognostic factors in COVID-19 patients aged  $\geq$ 80 years. Geriatr Gerontol Int 20:704–708*
- *Tsapanou A, Papatriantafyllou JD, Yiannopoulou K, Sali D, Kalligerou F, Ntanasi E, Zoi P, Margioti E, Kamtsadeli V, Hatzopoulou M, Koustimpi M, Zagka A, Papageorgiou SG, Sakka P (2021) The impact of COVID-19 pandemic on people with mild cognitive impairment/dementia and on their caregivers. Int J Geriatr Psychiatry. 36(4):583–587*
- *Altieri M, Santangelo G (2021) The psychological impact of COVID-19 pandemic and Lockdown on Caregivers of people with dementia. Am J Geriatr Psychiatry 29:27–34*
- *Bianchetti A, Rozzini R, Guerini F et al (2020) Clinical presentation of COVID19 in dementia patients. J Nutr Health Aging 24:560–562*
- *Nalleballe K, Reddy Onteddu S, Sharma R et al (2020) Spectrum of neuropsychiatric manifestations in COVID-19. Brain Behav Immun 88:71–74*
- *Alonso-Lana S, Marquie M, Ruiz A et al (2020) Cognitive and neuropsychiatric manifestations of COVID-19 and effects on elderly individuals with dementia. Front Aging Neurosci 12:588872*
- *Gedde MH et al.: Access to and interest in assistive technology for home-dwelling people with dementia during the COVID-19 pandemic (PAN.DEM). Int Rev Psychiatry 33: 404-411, 2021*
- *World Health Organization: Infection prevention and control during health care when coronavirus disease (COVID-19) is suspected or confirmed: Interim guidance. WHO Online Reference number WHO/2019-nCoV/IPC/2021.1, 2021*

The COVID-19 pandemic creates particular problems for people living with dementia (but also for those who care for them = formal and informal carers + institutions), particularly in times of lockdown:

- They are at high risk for developing a severe course of the infection due to their age
- They often have comorbid conditions which makes it medically more difficult for them to deal with the virus and may cause an increased mortality

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- They are in need of continuous care provision, activity and participation
- They are vulnerable to the effects of inactivity and social isolation
- It is much more difficult for people living with dementia to understand and adjust to the changes and medical precautions due to the pandemic.

**Telehealth** and **assistive technology** are important strategies to maintain high-quality dementia care during the pandemic. **Telehealth** or virtual care uses digital information and telecommunication technologies to provide healthcare when participants are separated by distance or time. Participants include physicians, other qualified health care professionals, and additional members of the health care team connected virtually with patients, family members, and other care providers. Telehealth facilitates the exchange and interpretation of text, data, images, audio, or video with synchronous or asynchronous communication. Examples of telehealth services include real-time two-way interactive audio-video conferencing, mobile health applications and management services, virtual check-ins, electronic interprofessional consultations, telephone services and remote patient monitoring.

Benefits of telehealth include:

- Improved access to evaluation by a medical expert
- Enhanced comfort, convenience, and safety
- Reduced travel time and associated costs
- Decreased time away from work or other essential activities for patients and care partners
- Reduced caregiver stress
- Increased care partner and provider participation during a visit
- Better assessment of social determinants of health including the patient's home environment
- Early intervention prior to a scheduled office visit
- Protection of patient and providers from infectious disease exposure and reducing use of personal protective equipment

A general problem with telehealth and assistive technology in people with dementia is that actively operating technical appliances requires some computer / digital skills which many people with dementia may not have due to their age or due to cognitive impairment. Therefore, information and telecommunication technologies are likely to be handled by carers. There are two concerns associated with this:

- a) care must be taken to not overburdening carers with the operation of telehealth
- b) care must also be taken that people with dementia are included in the interaction (e.g. in terms of excluding them from communication and care planning).

The dramatic effects of the pandemic on social life particularly impact on the psychological and physical health of elderly people with cognitive impairment and dementia.

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- People with dementia have a significantly increased risk for an unfavourable course and outcome of a COVID-19 infection [23] including higher mortality (also due to comorbid conditions)
- Older age and dementia are among the most relevant mortality factors of a COVID-19 pneumonia.
- Diagnostic procedures which often involve several appointments are limited during the pandemic which impairs early recognition and treatment
- People with dementia have limited access to information about the Pandemic
- They have difficulty recalling safety measures against infection and adhering to quarantine regulations
- People with dementia also have difficulty following hygiene rules and other safeguarding procedures (masks, washing hands) or in understanding the public health information issued to them. Ignoring the warnings and lacking sufficient self-quarantine could expose them to a higher risk of infection.
- Hospital / emergency department admissions due to COVID-19 are likely to worsen cognitive impairment
- Since a major measure for fighting the pandemic is social distancing and replacing person-to-person contact through virtual meetings (e.g. teleconferencing - to which people with dementia rarely have access) people with dementia who depend primarily on in-person support and contact might feel lonely and abandoned, and become withdrawn.
- Another measure of disease control is banning visitors to nursing homes and long-term care facilities. As a result, older residents lose face-to-face contact with their family members.
- Group activities in nursing homes were also prohibited. As a consequence, residents in nursing homes become more socially isolated
- People with dementia usually know little about the options of telecommunication (and their digital competence is low) and therefore are particularly exposed to social isolation
- Social deprivation worsens neuropsychiatric symptoms and cognitive abilities
- During the COVID-19 pandemic, the frequency of neuropsychiatric symptoms increases
- According to family carers the time of lockdown is associated with general worsening of function, particularly with regards to communication, mobility, mood and cooperation
- As a consequence, the burden for carers increases, which is reflected in an increased incidence of depression and anxiety symptoms in carers
- Regarding staff, under the dual stress of fear of infection and worries about the residents' condition, the level of anxiety among staff in nursing homes has increased and many have developed signs of exhaustion and burnout.

As a consequence, special support for people with dementia and their carers is needed in crises such as the COVID-19 pandemic. In addition to **physical protection** from the infection, **mental health and psychosocial support must be delivered**. Mental health professionals, social workers, nursing home administrators and volunteers should deliver mental health care for people living with dementia collaboratively.

Good practice examples for telehealth and assistive technology; examples:



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- Information and communication
- Assessment and diagnosis
- Cognitive stimulation
- Entertainment
- Physical exercise
- Occupational therapy
- Speech and language therapy
- Monitoring
- Caregiver support
- Interprofessional networking

Assistive technology: In response to the COVID-19 pandemic, 17% of informal dementia carers show increased interest in technology. Being less familiar with operating a smart device and having higher cognitive functioning are both associated with increased interest.

Sub-heading missing here for the below list

- Manage your mental health and psychosocial well-being is as important as managing your physical health. Take care of yourself. Try and use helpful coping strategies such as ensuring sufficient rest and respite during work or between shifts, eat healthy food, engage in physical activity, and stay in contact with family and friends.
- Use easy to understand ways to share messages with people with intellectual, cognitive and psychosocial disabilities. Where possible, include forms of communication that do not rely solely on verbal information
- Focus on longer-term occupational capacity rather than short-term crisis responses. Ensure good quality communication and accurate information for the entire team. Build in time for colleagues to provide social support to each other
- Orient all responders including nurses, ambulance drivers etc. on how to provide basic emotional and practical support to people with dementia and their families

**Messages for older adults**

- Share simple facts about what is going on and give clear information about how to reduce risk of infection in words that people with cognitive impairment can understand. Repeat the information wherever necessary. It may be helpful for information to be displayed in writing or pictures.
- Activate your social contacts to provide you with assistance, if available
- Be prepared and know in advance where and how to get practical help if needed.
  
- Learn simple daily physical exercises to perform at home in order to maintain mobility and reduce boredom
- Keep regular routines and schedules, including regular exercise, cleaning, regular chores, hobbies such as singing, painting or other activities
- Keep in regular contact with loved ones via telephone, e-mail, social media or video conference

The COVID-19 pandemic is accelerating telemedicine and digital technology (DT) use for chronic neurological diseases management

**Teleneurology** may offer a cost-effective and practical method for delivering interventions to dementia patients and caregivers, especially during the COVID-19 pandemic, favouring the adoption of new ways to deliver medical care.

**Assistive technology** can become useful during further pandemic waves. Monitoring technologies, such as video cameras or GPS-based systems, meet the visit restrictions and thus reduce the risk of contagion by reducing the number of face to face visits both in residential settings and PWD's homes. Assistive technology can also compensate for the distress associated with the isolation through communication tools designed to keep remotely in touch. Phone calls, chat interfaces, videoconferences and remote therapies can connect family members, physicians / therapists and communities of peers. Telepresence robots may be useful surrogates during isolation by increasing daily stimulation activities. Apps offering interactive gaming or automatic prompting systems can either stimulate cognitive functions or support the daily routine and instrumental activities of daily living of PWD.

#### *Care organisation*

A follow-up visit via telemedicine approach may provide **timely referrals**, thus avoiding delays or build up of long waiting lists. Specifically, videoconferences and video monitoring have been shown to be as efficient as in-person visits in evaluating daily living activities and global cognition. The adoption of a **virtual clinic** is necessary to avoid traditional face-to-face visits for vulnerable patients, without diminishing the quality of neurological consultations. We recommend the use of electronic health record systems (that could be easily implemented through online tools, such as Google Forms) and e-mails for faster communication (e.g., report or visualization of diagnostic examinations and medical prescriptions). Then, after the first contact with patients and caregivers, we suggest to individually tailor the most suitable tele-medical support.

#### *Diagnosis and assessments*

The **diagnostic process** can be facilitated through telemedicine and DT. Indeed, although instrumental examinations are paramount for the detection of physiopathological biomarkers of disease (e.g., cerebrospinal fluid, amyloid PET), a preliminary telemedicine consultation could be helpful to identify those patients who actually need to be further assessed face to face.

**Accurate neuropsychological evaluations** are possible via telemedicine. Although further studies are needed to test the reliability of complex tasks requiring motor and visual abilities, there is growing scientific evidence supporting the use of videoconferencing technology in the remote administration of neuropsychological tests, particularly those that rely on verbal responses.

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There is preliminary evidence that smartphone-based assessment of episodic memory, cognitive processing speed, and visual attention are reliable tools to evaluate cognitive functions in preclinical populations and to monitor progression of cognitive decline in patients with cognitive impairment.

*Treatment delivery and follow-up*

Telemedicine and e-health services are also available to support care for older adults and family caregivers. Internet-based technology can support people at early stages of cognitive impairment via electronic reminders, daily activities, and cognitive stimulation games.

Even more important, most of the new DTs are devoted to support caregivers. Readily available **web-based training** and **psycho-educational programs** improve knowledge and competence for caregiving, while reducing caregiver psychological burden.

Also, mobile text messaging, video-recording, and chat forums can be useful for meeting specific caregiver needs. Crucially, there is an increasing demand and a high level of acceptance of technological support when assisting caregivers.

## **Conclusion**

Independently of the current COVID 19 pandemic, the application of technological devices and assistive technology in dementia care may lead to several advantages such as improving access and quality of care, servicing patients coming from rural communities, and supporting caregivers. The next step is to encourage a widespread adoption of telemedicine services promoted by healthcare board directives. The INDEED online platform will highlight these topics in new chapters with the ideas generated during the focus group:

The **CAMPUS** module will be complemented by a chapter on:

- 1) Challenges and changes in dementia care during the pandemic
- 2) Solutions to cope with these challenges in a professional way

The **CONNECT** module will be complemented by a chapter on:

- 1) Challenges and changes in interprofessional collaboration during the pandemic
- 2) Innovative approaches to facilitate teamwork during the pandemic

The **COACH** module will be complemented by:

- 1) a new subchapter in the “business development track” about “Innovation and crisis”

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2 ) a case study featuring a good-practice example

The content of these chapters will be shown in the Deliverable of workpackage 8 (DT6.1.1) and will be implemented on the following pages on the INDEED website:

<https://indeed-project.eu/campus/dementia-in-corona-times/>

<https://indeed-project.eu/connect/collaboration-in-corona-times/>

<https://indeed-project.eu/coach/business-plan-development/innovation-crisis/>

<https://indeed-project.eu/coach/good-practice-examples/>