# CUR TE-D



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This guide has been coordinated by the Panhellenic Federation of Alzheimer's Disease and Related Disorders, in close cooperation with the partners of Erasmus+ project "CURATE-D: A Game-based methodology for empowering Dementia friendly communities and equal access to Culture for people with Dementia".

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# L CHAPTER CURATE-D PROJECT OVERVIEW



#### The context

The main priority of the CURATE-D project is to promote equal opportunities, accessibility and Social Inclusion of people with Dementia (PwD) in cultural experiences. All the activities and WPs implemented and developed through CURATE-D project aim to train the people working in the cultural field on creating dementia friendly culture communities and to train professional carers of pwD to support pwD in cultural activities. Dementia currently affects around 10 million people in the European Region, and its prevalence is expected to double by 2030 (World Health Organization, 2023). Even though many researches confirm that it is very important for PwD to stay active and continue to do things they like or even search for new experiences, PwD are usually excluded from social activities and more specifically from cultural experiences. It is important to state the transformative effect which cultural experiences can have on the well-being of pwD and their carers when barriers to participation are removed (Genoe & Dupuis, 2014). Participating in cultural and other leisure activities has benefits beyond those associated with remaining physically active when one develops dementia (Bowes et al., 2013), in that leisure pursuits can promote both social (via interactions with others) and mental (via intellectual stimulation) well-being.

#### Aims - objectives - target groups and expected results

CURATE-D project aims to:

To promote social inclusion and equal accessibility to culture for People with Dementia To adapt vocational education training of professionals in cultural fields to today needs that includes the transformation of cultural experiences to be inclusive and accessible to PwD

To adapt vocational education training of professional carers to the needs of their patients (PwD) who can benefit a lot by getting involved in cultural activities

To create an innovative educational methodology and toolkit for VET education of professionals in the cultural fields and caring of PwD



The target groups of out project are:

the professionals in the field of culture such as curators, educators, trainers, facilitators, staff of cultural institutions etc. Our aim is to enhance their skills and competences through a game-based methodology that emphasises on developing their empathy, understanding and giving them the opportunity to create dementia friendly communities full of accessible experiences and activities for pwD.

professional carers of people with Dementia. Our scope is to enhance their understanding on the importance of involving pwD in cultural activities and empowering their skills in supporting pwD and their families to engage with cultural activities.

VET centers that offer education to professional cares or professionals working in the field of culture. Our objective is to provide them with a methodology and tools that will contribute to the adaptation of their VET training programs in the new labour market needs through an innovative way.

Other relevant stakeholders are:

Cultural institutions, museums, music-dance halls, cultural organisations. Our scope is to engage them to the new attitude and culture of Dementia friendly communities and provide to them training of their staff.

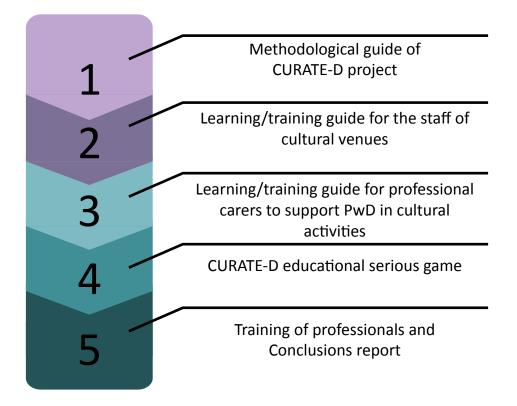
Alzheimer associations and carers associations. Our aim is to provide to their professional carers or to their network of carers the opportunity to VET education.

PwD are indirect target groups since the CURATE-D project promotes their inclusion in cultural activities



The main priority of the project CURATE-D is to promote equal opportunities, accessibility and social inclusion of People with Dementia (PwD) in cultural experiences. All the activities and WPs implemented and developed through the CURATE-D project aim to train people working in the cultural field how to implement dementia friendly culture communities and to train professional carers of PwD to support PwD in cultural activities. The CURATE-D project aims to develop a game-based methodology through which people working in the field of culture will improve their competences in creating dementia friendly communities and accessible cultural experiences while professional carers will empower their skills in supporting PwD in these activities.

The main results of the project will be:



The aforementioned results will be achieved through specific Work Packages (WP) and Activities (A) :

Work Package 2 – 'Initiation of project, conduction of research and Development of the CURATE-D methodology' will illustrate the innovative game-based

methodology of CURATE-D project on understanding dementia, making activities and experiences accessible and creating Dementia friendly communities within a cultural institution. Its main result would be the creation of the Methodological guide.

Work Package 3 – 'Development of Educational toolkit of CURATE-D project' will include the development of an innovative educational toolkit for VET education of professionals working in the field of culture and professional carers of pwD, based on CURATE-D methodology and training of staff of the partners on the educational tools. This educational toolkit comprises three discrete results: two training guides one targeted to professionals in the field of culture and the second one to professional carers of pwD and one educational serious game.



Work Package 4 – 'Training of professionals and exploitation'. During this WP the organizations of the consortium working with professional carers of pwD and professionals working in the cultural field will implement piloting workshops based on the methodology and tools generated in WP3 and will testthem in real conditions. After the implementation of the workshops, they collect their feedback and GSA will develop a report on final considerations on the methodology of CURATE-D project. This will be a helpful material for other organizations that want to apply the methodology and tools in their context.

#### The partnership

CURATE-D project's consortium consists of 5 organisations having complementary expertise so as to ensure the success of the development of the results of the project. More specifically, it is coordinated by CHALLEDU (Athens, Greece) and the partnership includes the Panhellenic Federation of Alzheimer's Disease and Related Disorders (Thessaloniki, Greece), The Gaiety School of Acting – The National Theatre School of Ireland (Dublin, Ireland), ASOCIACIÓN FAMILIARES ALZHEIMER VALENCIA (Valencia, Spain) and HERAKLEIDON MUSEUM (Athens, Greece). Below are some more information about each organisation and their mission:

#### 1. CHALLEDU- inclusion | games | education



is a non-profit organization that pioneers new models of learning, inclusion and engagement. CHALLEDU is one of the leading R&D experts in game-solutions for education and inclusion. Our team designs and implements playful experiences, games, formal and non-formal educational programs, tools, platforms and applications based on cross-sectoral, interdisciplinary approaches. We focus on 2 main sectors:

#### SOCIAL INCLUSION

The projects in this sector focus on inclusion and empowerment of marginalized groups, such as people with disabilities, people with health problems (i.e. dementia), older people, NEETs. The aims are: social inclusion, improved employability, development of skills and competencies, advocacy. The emphasis is given to create environments where people with different abilities, cultural backgrounds and skills, and different generations can interact with each other. The approaches in this sector involve non-formal and informal education, living labs, open co-creative workshops, game-based tools, and cross-sectoral approaches.

#### EDUCATION AND INNOVATION

We see education as a driver for positive societal, environmental, and innovative change. The projects developed in this sector focus on the promotion of entrepreneurship, STE(A)M education, civic and active citizenship, environmental challenges and agriculture, culture, and sustainable development. Our target groups include young people, adults, students, trainers and educators, professionals and institutions. Our approach encompasses forms of non-formal and informal education, game-based methodologies, role-model methodology, open-learning and digital tools, gamification, as well as cross-sectoral approaches.



2. The Panhellenic Federation of Alzheimer's Disease and Related Disorders



is a non-profit organization that was founded in 2007. The Panhellenic Federation consists of 39 linked Associations of Alzheimer's disease all over Greece. Its main objective is the coordination and cooperation of companies - members in the context of social contribution and awareness of people with dementia and their caregivers' needs. Its aims are the creation of structures, services and conditions that improve the quality of life of PwD and their carers, the promotion of research, the education and training for all the stakeholders, the provision of useful information and advice on dementia problems and the prevention of the marginalization of people with dementia. The federation hosts a Panhellenic conference every two years, as well as a 'train the trainers' programme for health care professionals and caregivers. The federation is also a member of Alzheimer Europe. Some of the other services provided by the federation include:

- Educational events
- Newsletter
- Resources (fact sheets, reading materials)
- Seminars/Webinars/Workshops
- 3. The Museum Herakleidon



Herahleiden science, art (8) Mathematics

is a Non Profit Cultural Organization, which was founded in 2004 and extends to two buildings in the historic district of Thissio (Athens). During the first decade of its operation, the museum focused on artistic activities and organised exhibitions with artworks of great artists such as M.C. Escher, Victor Vasarely, Carol Wax, Constantine Xenakis, Adolf Luther, Francesco Scavullo, Toulouse-Lautrec, Edgar Degas, Edvard Munch, Sol LeWitt and others. At the same time, a plethora of cultural activities allowed visitors to explore the essence of each artist's perspective.

Today the Museum Herakleidon has evolved to an interactive center of science popularization and to a technological museum that focuses on antiquity, with emphasis on the achievements of the ancient Greeks. Based on the philosophy of the educational programs that itself established, based in the triptych of Science, Art and Mathematics, continues to offer original educational programs motivated and inspired by its exhibition" EUREKA, Science, Art and Technology of the Ancient Greeks" to students, teachers and adults.

The aspiration of the museum's founders, the scientific advisors and all the staff, is the awakening of the research spirit of young people and their preparation in order to meet the growing demands of a rapidly changing world, taking advantage of the wealth of messages a glorious past can give in order to build a similar future.

#### 4. ASOCIACIÓN FAMILIARES ALZHEIMER VALENCIA (AFAV)



was founded in 1991 due to the concern of relatives to gather information from Alzheimer's disease and/ or other dementias and learn how to deal with the situation that arises in people and their relatives. It was declared of public utility by the Spanish Ministry of Interior in November 1998. AFAV has also won several awards: Award Valencianos del S.XXI Las Provincias for the best entity in 2005; Award Generalitat for the best social entity (2013); Award "Aquí newspaper" for the best social iniciative (2016); Award Valencia Town Hall recognition for 25 years of work career and Award of Federación Valenciana de Alzheimer for the best social work (2016).

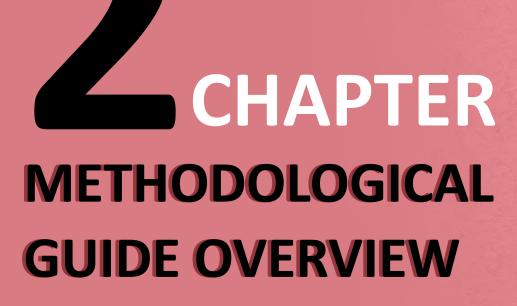
The association is formed by patients, relatives, professionals, volunteers and collaborators who strive to improve the quality of life of those affected (patients, relatives and caregivers) for Alzheimer's disease and other dementias. With this purpose, AFAV offers resources, services and activities, including training that try to meet the needs that arise at different stages. In the same way it makes a meticulous work of awareness and social awareness of the problems addressed both the affected and society in general.

#### 5. The Gaiety School of Acting – The National Theatre School of Ireland



is a Not for Profit organisation founded in 1986 by the internationally renowned theatre director, Joe Dowling, in response to the lack of full-timeactor training programmes in Ireland at the time. The school is now widely regarded as the country's premier training facility for actors. Our policy is to train actors for theatre, film and television. Through a committed and dedicated staff, the school has developed and expanded to its current position where over 5000 students are involved in a wide range of courses from our intensive two- year, full-time actor training programme to a range of courses available to students from overseas.







#### Scope of the guide

Panhellenic Federation of Alzheimer's Disease and Related Disorders is the leader of this result and all partners contributed. This guide will be a valuable tool for the implementation of our project since it illustrates the innovative game-based methodology of CURATE-D project on understanding dementia, making activities and experiences accessible and creating Dementia friendly communities within a cultural institution. Moreover, it will illustrate the basic structure of the learning training guides regarding the training of professional carers of pwD and professionals in the field of culture. Moreover, the notion of game-based learning is explored including best practices and will define the specifications of the CURATE-D methodology and toolkit. Developing the CURATE-D methodology was a collaboration among all partners based on the needs of their target groups, the objectives of the project and the expertise of each one. The cocreation of the project's methodology will enable the transnational impact of it and the direct connection with the needs of the target groups.

The main **objectives** of this methodological guide are:



#### Process of development of the methodological guide

The creation of the Methodological Guide was a collaborative process that engaged professionals with diverse expertise to address various challenges stemming from the innovative methodology to be followed.

The development of the guide was led by Panhellenic Federation following certain activities:

## 1

Creation of the template of questionnaires. The leading partner developed 2 questionnaires for research on needs of the target groups.

The key points to be investigated by the use of these questionnaires were:

-Which are the needs of target groups regarding the fields of the project? -Are there existing approaches, programs, applications and tools in partner countries for VET training of target groups?

-How can we utilise them in our project's methodology?

2

Partners with focus on cultural field responded to the relevant questionnaire while partners with focus to pwD responded to the other one. Also, professionals who do not work at partners' organisations, but have expertise on their respective fields were invited to respond to the questionnaires. All partners responded to general questions about the context in their country regarding dementia friendly policies.

## 3

Co-creation of CURATE-D methodology. All partners together developed the key points of the methodology, after discussion on the findings of their research.

#### 4

The Leader wrote the main theoretical sections of the guide, namely the introduction and the chapter about dementia. CHALLEDU wrote the chapter about gamebased learning. The Leader compiled all material of the research (in the form of a report) in one document in co-decided templates and style according to the visual identity of the project and produced the final guide in a pdf format.

#### 5

Feedback. The leader of this WP granted access to the English document of the methodology to the partners. A cycle of feedback/adjustments begun until it was agreeable by the partners.

6

Finalization. After the feedback of the partners, the leader developed the final version of the guide.



# **S**CHAPTER INTRODUCTION



#### Background

People with Dementia (PwD) constitute a significant part of the population with over 55 million people living with dementia globally, a figure set to triple by 2050, reaching 152 million people affected (WHO). Dementia currently affects around 10 million people in the European Region, and its prevalence is expected to double by 2030 (WHO).

Even though Accessible Tourism and Culture is a priority in Europe, it is mainly referred to accessibility to people with motor disabilities, enhancing physical accessibility neglecting non visible disabilities, such as dementia. PwD, like people with motor disabilities, face many structural barriers such as difficulty accessing transportation, accessibility of toilets, etc. However, the main barriers they have to deal with are also intrapersonal (psychological eg. fear of getting lost or feeling unsafe-no signs, no familiar faces, no trained staff), interpersonal (family and friends eg. perception of carers on their ability to participate in an activity), intrinsic (health, dependency on caregivers), environmental (attitude of others, stigma), interactive (situational), structural (external eg. busy places or a lot of echo due to the materials used) (Gladwell & Bendini, 2004). The results point to the potential to facilitate individualised opportunities The complex needs of PwD illustrate the importance of a transformational policy agenda focused on developing dementia friendly communities (DFCs).

Recent findings confirm the perceived benefits of meaningful activities for people's health and wellbeing as well as the potential barriers to overcome to facilitate participation. The results point to the potential to facilitate individualised opportunities for people living with dementia through participation in existing local activities and events. This engagement is presumed to be beneficial to health-related outcomes and fills a gap in the provision of activities and social participation (Tournier et al., 2023). Furthermore, offering personally tailored activities to people with dementia living in the community may be one approach for reducing challenging behaviour and may also slightly improve the quality of life of people with dementia (Möhler et al., 2020).



4. Photo by Steven HWG on Unsplash



#### 5. Photo by Robina Weermeijer on Unsplash

In recent decades, the cultural and heritage sectors have been increasingly providing spaces where people can go to improve their well-being and Quality of Life (Camic & Chatterjee, 2013). Thanks to changing conceptions, the community has become progressively aware of what these institutions can provide for them in terms of meeting their interests and, above all, their needs (Desmarais et al., 2018). In this way, museums and cultural institutions are proving to be competent and powerful allies for public health and wellness programs (Camic & Chatterjee, 2013).

Moreover, several studies have revealed the transformative effect that cultural experiences can have on the well-being of PwD and their carers when barriers of participation are removed (Genoe & Dupuis, 2014). In a study about the effects of the 'Arts & Dementia program' in the National Gallery of Australia, not only self-reported depressive symptoms decreased and memory and verbal fluency improved post intervention, but also quantifiable benefits were reported, including improved hypothalamic-pituitary-adrenal axis function (D'Cunha et al., 2019). Another recent study's findings demonstrate that PwD and caregivers highly valued heritage sessions and reported positively on their impact for their individual well-being and their relationships with one another (Innes et al., 2021). Also, multiple museum-based group object handling sessions showed a positive influence on the subjective wellbeing in people living with dementia (Camic et al., 2021). Another example is the Montreal Museum of Fine Arts' "Thursdays at the Museum" program, which showed positive effects on the mental and physical health of older people (Beauchet et al., 2020).



The COVID-19 pandemic has necessitated many museums and galleries to engage with people with dementia online, but further research is needed to improve the usability of online delivery platforms and a comparison of online and onsite delivery (Wiseman et al., 2023).

Regarding caregivers of PwD, in a study on impact of including carers in museum programmes for PwD, the impacts of including carers fell into seven broad areas – caring responsibility, session function, controlling access, preventing engagement, comparisons and losses, long-term impact of in-the-moment activities, and reducing social isolation and opening up the museum. Including carers may have both unanticipated benefits and negative consequences and greater attention is needed on how both carers and people with dementia can be supported in shared sessions. Carers should be viewed as participants of programmes, and can even be the main beneficiaries, even where the programme is ostensibly 'for' the person with dementia (Kinsey et al., 2022).

In conclusion, a recent systematic review of arts and culture-based interventions for people living with dementia and their caregivers showed improvements in well-being outcomes but no cognitive improvements except in some subscales in a music intervention (Letrondo et al., 2023) and another showed significant improvements in general cognition, quality of life, emotional wellbeing, socialization, and communication, with a reduction in depression symptoms (Delfa-Lobato et al., 2021). In accordance, a recent meta-analysis on the benefits of cultural experiences (in museums and other cultural institutions) on people with Cognitive Impairment revealed benefits in emotional well-being and social aspects, such as state of mind, socialization, self-esteem, or emotional well-being of PwD (Delfa-Lobato et al., 2023).

CURATE-D project emphasises on the development of a methodology that will enable people working in the cultural field to feel empathy, understand difficulties and develop experiences that are accessible to PwD. Moreover, it focuses on the professional carers of PwD learning how to support PwD in cultural activities and places. Inclusion of PwD in cultural experiences will align with two priorities of VET education: adaptation of vocational training and education to labour market needs and contribution to innovation. The 'accessibility agenda' within leisure, culture and tourism will evolve in the next few years and VET education should find a way to adapt to these new needs. Thus, CURATE-D project will address the need for an educational agenda focused on developing dementia friendly communities (DFCs) and accessible cultural experiences for Professionals working in the cultural field and Professional carers of PwD.

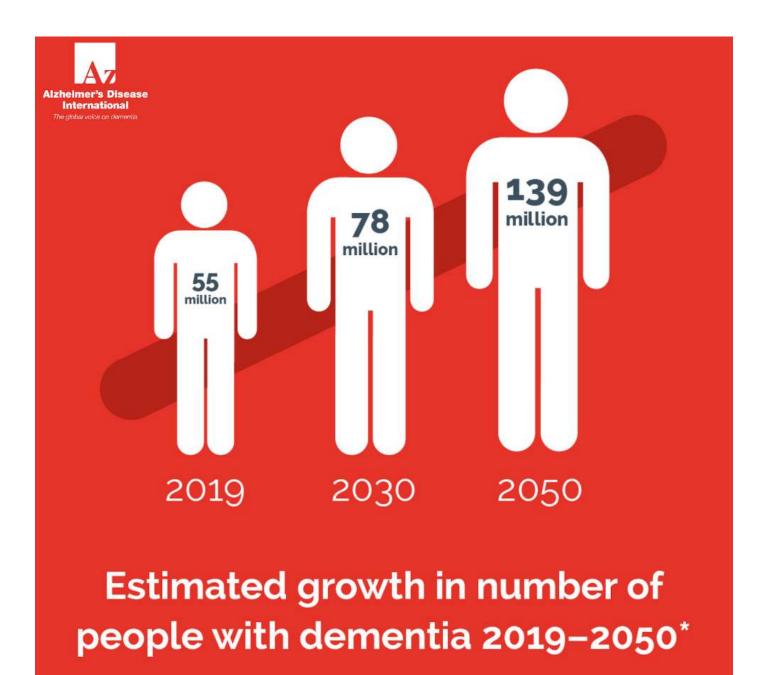
#### What is Dementia

According to WHO (2023), dementia is not a specific disease but is rather a general term for diseases that affect memory, thinking, and the ability to perform daily activities. Though dementia mostly affects older adults, it is not a part of normal ageing.

There were over 55 million people worldwide living with dementia in 2020. This number is expected to almost double every 20 years, reaching 78 million in 2030 and 139 million in 2050. Much of the increase will be in developing countries. (ADI, 2021)

The most common type of dementia is Alzheimer's disease (60–70% of cases). Other forms include Vascular dementia, Dementia with Lewy bodies, Frontotemporal dementia, Creutzfeldt-Jakob Disease, Huntington's Disease and Parkinson's Disease dementia. Dementia may also develop after a stroke or in the context of certain infections such as HIV, as a result of harmful use of alcohol, repetitive physical injuries to the brain (known as chronic traumatic encephalopathy) or nutritional deficiencies. The boundaries between different forms of dementia are often indistinct and mixed forms co-exist.





\*WHO Global status report 2021

**6.** Alzheimer's Disease International (2021), <u>https://www.alzint.org/about/dementia-facts-figures/demen-tia-statistics/</u>

Because of the nature of dementia, the symptoms can vary greatly and be very different from person to person. Dementia symptoms are progressive, which means that they usually start out mildly and gradually get worse over time. Depending on the severity of the symptoms, there are mainly three stages of dementia:

- mild
- moderate
- severe.

When communicating with PwD, it is very important to keep in mind that PwD in different stages have different communication needs.



In **mild dementia**, an individual is still able to participate in meaningful conversation and engage in social activities. However, he or she may repeat stories, feel overwhelmed by excessive stimulation or have difficulty finding the right word. Tips for successful communication:

**Discuss** which method of communication is most comfortable. This could include face-to-face conversation, email or phone calls. Speak directly to the person rather than to his or her caregiver or companion. Take time to listen to the person express his or her thoughts, feelings and needs. Don't exclude the person from conversations. Give the person time to respond. Don't interrupt unless help is requested. Don't pull away; your honesty, friendship and support are important to the person. Ask what the person is still comfortable doing and what he or she may need help with. It's OK to laugh. Sometimes, humour lightens the mood and makes communication easier.



**Moderate dementia** is typically the longest and can last for many years. As the disease progresses, the person will have greater difficulty communicating and will require more direct care. Tips for successful communication:





**Severe dementia** may last from several weeks to several years. As the disease advances, the person with dementia may rely on nonverbal communication, such as facial expressions or vocal sounds. Around-the-clock care is usually required in this stage. Tips for successful communication:

**Approach the person** from the front and identify yourself.

**Encourage nonverbal communication.** If you don't understand what the person is trying to say, ask him or her to point or gesture.

**Use touch, sights, sounds, smells and tastes** as a form of communication with the person.

**Consider the feelings behind words or sounds.** Sometimes the emotions being expressed are more important than what's being said.

It's OK if you don't know what to say; your presence and friendship are most important.

**Treat the person with dignity and respect.** Avoid talking down to the person or as if he or she isn't there.

According to the revised version of the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR) by the American Psychiatric Association (2022) there are six cognitive domains which may be affected in dementia:

COGNITIVE DOMAIN	AREAS AFFECTED	WARNING SIGNS /SYMPTOMS
Complex attention	Sustained attention, divided attention, selective attention and information processing speed.	Difficulty in environments with multiple stimuli (TV, radio, conversation), difficulty holding new information in mind.
Executive ability	Planning, decision making, working memory, responding to feedback, error correction, overriding habits and mental flexibility.	Difficulty to perform both familiar and complex tasks and projects, need to rely on others to plan instrumental activities of daily living or make decisions, problems with abstract thinking, loss of initiative, poor/decreased judgement.
Learning and memory	Immediate memory, recent memory (free recall, cued recall and recognition memory) and long term memory.	Learning and memory Repetitions, repetitive questions, confusion about time and place, repetitive behaviour, difficulty in keeping track of a short list of items when shopping or of plans for the day, requirement of frequent reminders to orient task at hand.
Language	Expressive language (naming, fluency, grammar and syntax) and receptive language.	Difficulties with expressive or receptive language, often use of general terms such as 'that thing' and 'you know what I mean'. In severe stages, PwD may not recall names of closer friends and family.
Social cognition	Recognition of emotions and behavioural regulation, social appropriateness in terms of dress, grooming and topics of conversation.	Changes in behaviour (e.g. insensitivity to social standards, or make decisions without regard to safety). Patient usually has little insight into these changes, social withdrawn or isolation.
Perceptual - Motor - Visual perception, praxis	Picking up the telephone, handwriting, using a fork/ spoon.	Difficulties with previously familiar activities (using tools or, driving a motor vehicle) and navigating in familiar environments.

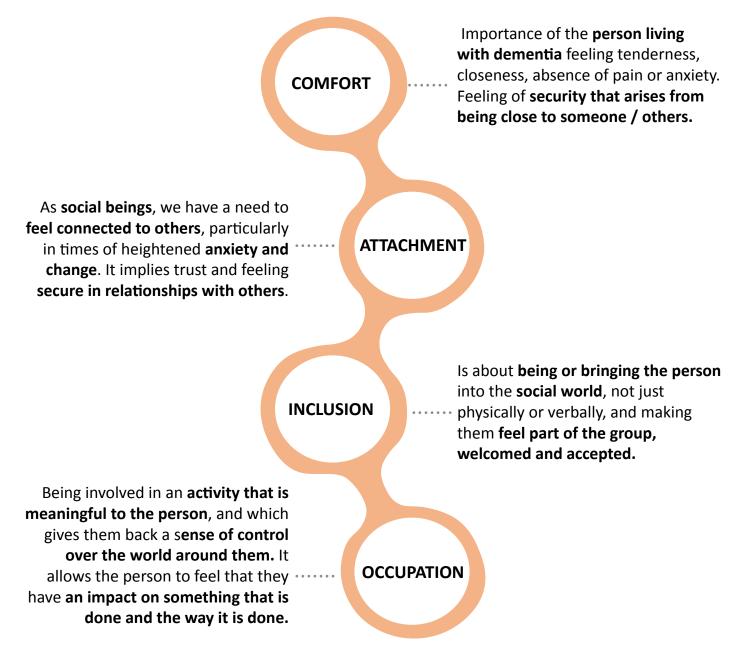
Dementia can also affect the senses. PwD may lose the ability to see in 3D, which affects their spatial awareness. The perception of colour can be diminished, as PwD may not see colour as brightly as before and without enough contrast in their environment, may have difficulty understanding where one thing ends and another begins. Hearing may be affected where sounds are perceived as much louder and often can become overwhelming and disrupt their ability to pay attention to anything else.



#### **Needs Of People Living With Dementia**

People with dementia state that they need professional multidisciplinary and psychological support, hope, the right to be included in society, destigmatizing the knowledge other people have about dementia and compassion (Orrel, 2008; WHO, 2012, Khanassov, 2016; Curnow, 2021). Coping with a chronic illness is not easy. Living with dementia changes not only the lives of those diagnosed with dementia but also the lives of their family members. That is why it is crucial to support PwD and their carers in a way that respects and includes their needs.

Person-centered care is a holistic and integrative approach designed to maintain the well-being and quality of life for people with dementia and it includes the elements of care, the individual, the carers, and the family. According to Kitwood's (1992) model of Person-Centered Care for People with Dementia, the following needs are present in all human beings, but they are intensified, and sometimes unanswered, in people with some types of dementia, as they are generally more vulnerable or less able to perform certain actions that allow them to satisfy these same needs. These needs include:







7. Photo by Astrid Schaffner on Unsplash

#### Meeting The Needs Of People Living With Dementia

According to Alzheimer's Disease International, a dementia friendly community can be defined as "a place or culture in which people with dementia and their carers are empowered, supported and included in society, understand their rights and recognise their full potential".

There are two different underlying objectives of dementia friendly communities:

Empowering **people** with dementia by recognising their rights ancapabilities so that they feel respected and, to the extent that they are able, empowered to make decisions about their lives.

Reducing stigma and increasing understanding of dementia by greater awareness and meaningful engagement for people with dementia of all ages

Below are some important key points to remember when working with PwD in order to support them using a dementia friendly approach:



#### CELEBRATION

**Recognize, support and join** in with something the **person is doing** (e.g. **clapping** and **smiling** while the **person sings**).

#### RECOGNITION

Address/greet the person by the name they prefer. Maintain eye contact during conversations.

#### TIMALATION

Give the person the opportunity to engage in activities that stimulate the senses and are not cognitively demanding.

# ALLOW TIME FOR THE PERSON TO PROCESS THE INFORMATION

Wait a few minutes and give the person an opportunity to ask questions.

#### VALIDATION

Being **empathetic** and **accepting** the **reality** of the person, even if it makes no sense (e.g. hallucinations).

#### HOLDING

Providing security and protection when the person is anxious, staying close to them, holding their hand and showing empathy and affection towards what they feel.

#### **EXPLAIN CONCEPTS AND INFORMATION IN A SIMPLE WAY**

Use **simple language** with **terms known** to the **person**, use **short sentences**, repeat the information.



#### FACILITATION

Support the person to engage in tasks that they cannot do alone, supporting them only when necessary.

#### PLAY

**Support** the person to **engage** in spontaneous and s**elf-expression activities** (e.g. painting using their hands, not the brush).

#### NEGOTIATION

Support the person to choose what they want to do at a given time.

#### USE IMAGES TO EXPLAIN CONCEPTS AND MAKE CHOICE EASIER

Showing pictures of activities, so that the person can choose what they would like to do.

#### COLLABORATION

Doing tasks together with the person, not for the person.

#### RELAXATION

Support the person to have a relaxing environment and moments, alone or with others (e.g. listening to music, sitting on a bench in a garden).

#### **BE MINDFUL OF NON-VERBAL COMMUNICATION**

Nodding the head can mean that the person is agreeing and understanding what is being said. Frowning could mean that they don't agree or don't understand.



Loaquin Sorolla

# **LEARCH METHODOLOGY**



#### **Data collection**

A mixed-methods research design, using both qualitative and quantitative methodologies, was used to meet the aims of this research to learn about the needs of partner organizations and target groups.

Firstly, interviews were undertaken in each of the three European countries that participate in this project (Greece, Ireland and Spain). Our participants were selected based on their professional expertise working either in the dementia or cultural field. We invited our participants to answer a sociodemographic questionnaire and then to participate in a semi-structured interview about dementia friendly policies. Both the questionnaire and the scenario for the interviews can be found in Annex I. Data collection was guided by ethical considerations, which included: informed consent; voluntary participation; confidentiality; anonymity; principle of the relevance of the information.

We also used data collected through secondary research: bibliographic research from books, journals, websites and other projects' published results, in order to find bibliographic sources relevant to our project. The aim of the secondary data collection was to explore existing dementia friendly policies and practices, to examine if they can be applied in cultural spaces, to understand what game based learning is and to explore if existing game based practices can contribute to our project methodology.



9. Image retrieved from Canva Pro

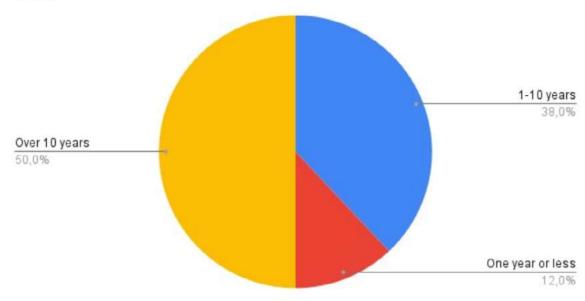


#### Data analysis and reporting

#### 1.Interviews

#### Participants' demographics

All partners invited professionals to participate in our interview based on their field of expertise. Panhellenic Alzheimer Federation and AFAV invited professionals working with people with dementia and their caregivers and CHALLEDU, Helakeidon Museum and GSA invited professionals working in the cultural field. All participants were selected because of their relevance to the subject of our research and their expertise in their respective field. As you can see in the graph below, most of the professionals have a long experience in their field:



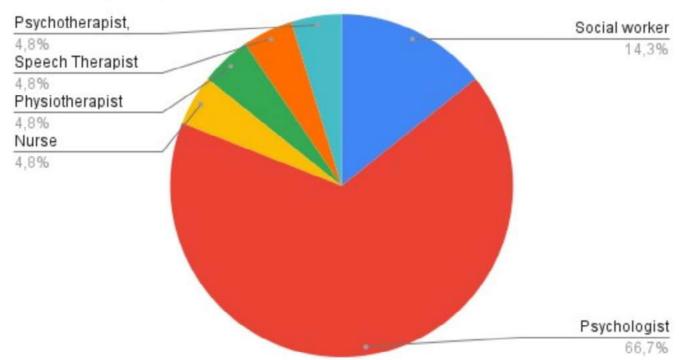
How long have you been working for your organisation / in your field?

#### 1.a. Professionals working with people with dementia

In total, 21 professionals from Greece and Spain working with PwD and their caregivers were interviewed. Most of the professionals work in day centres for PwD, some of them are healthcare professionals working in the private sector and one of them works in a nursing home.



The graph below explains the professional background of our interviewees:



### What is your job title/role?

#### Existing approaches, programs, applications and tools

Almost 40% of the professionals reported that they are not aware of any best practices for dementia friendly communities and inclusion of PwD in cultural activities. The rest of them reported that they regularly implement dementia friendly practices for raising awareness on dementia in the general public and not only family and professional caregivers e.g. activities with children, public authorities etc. However, COVID-19 was a main barrier for activities especially when they are intergenerational ones.

Some of the best practices the professionals mentioned include:

-"A walk together" (Greece): Alzheimer Hellas in collaboration with Museum of Modern Art (MOMus Thessaloniki) made specialised visits for people with cognitive impairments.

**-"Thāllo method" (Greece):** The company Seven eleven in collaboration with Niarchos Foundation developed a programme using a combination of recreational activities that take place using the Connotation Thought Principle and implemented in nursing homes. Indicatively, they include: Board games, Music, Musical-kinetics, Singing, Sensory memory, Cooking, Gardening, Crafts, the Isolated Listening Method and Virtual reality. https://seveneleven.me/en/thallo/

-The choir "Les Veus de la Memòria" (Spain): AFAV created a choir which aims at promoting the benefits of music for people with Alzheimer's who make up the choir and their families.

Professionals reported that existing or new dementia friendly policies could benefit PwD and their caregivers.



Firstly, these policies can have a positive impact on PwD due to socialisation, as PwD and the general public are mixed and they feel included in Also, such policies promote good treatment of PwD. Training society as a whole and specific groups that work more directly with people with dementia increases knowledge and empathy and makes them understand the difficulties encountered by PwD. In this way, it is more likely that they will be able to provide adequate response and support in situations that may arise, although this may require efforts on the part of all the actors involved (society in general, professionals, politicians, etc.). The connection between the general public and PwD through the implementation of dementia friendly policies can help the fight against stigmatisation towards PwD.

Another benefit that can arise from dementia friendly communities is the improvement of the quality of life of PwD. This can be achieved through training, awareness-raising, sensitization and activities that promote the participation of people with dementia in society. Moreover, when memories from the past are being used as a recreational method, it can have a positive impact on PwD's emotional well-being. Finally, especially during the first stages of dementia, early stimulation can slow down deterioration.

Furthermore, our interviewees reported that innovative dementia friendly policies can ease the process of talking to the family about the situation of their relative, including activities that are adapted to their situation. Sometimes, the lack of cooperation from the family and the user (unresponsive, aggressive behaviour) can make professionals' work more difficult, but having the right tools to adapt can be very helpful to them.

Even the interviewees who do not know or implement any policy about dementia friendly communities, agree that they are necessary and interesting because they would facilitate greater understanding and improve attention in many ways. A challenge for society would be to raise awareness and visibility of PwD, so our interviewees think that such policies are going to be needed more and more as the population pyramid is inverting and that new technologies and R+D+i (Research, Development and Innovation activities) can help to improve the quality of life of these people.

On the other hand, implementing policies about dementia friendly communities can be challenging. Participants to this study reported that a serious issue is getting the consent of PwD to participate and whether every PwD is in position to give their consent, especially if their caregivers have a different opinion. Also, organising and managing a mixed group in such activities can be challenging, as this would require creating an accessible space for PwD (trained staff, duration of stay, accessible artefacts etc). Finally, some professionals expressed their concern that if PwD are not able to follow the activity, they might feel sad or irritated.



10. Image provided by Asociación de Familiares de Enfermos de Alzhéimer de Valencia (AFAV)



# Support needed for dementia friendly communities

When asked what support they might require to take their work forward with practices about dementia friendly communities, most of the interviewees agreed that training from relevant professionals that implement such activities would be very helpful. Also, getting to know national or international best practices would be very helpful in order to assist them in organising relevant activities. A continuous collaboration and participation between dementia-friendly communities would also be preferred in order to ensure the exchange of best practices, as they require flexibility and constant change.

In addition, raising awareness in society and training to non-professional caregivers would be helpful in order for professionals to be supported in offering better services to PwD.

Greater collaboration from local, regional and national governments is also needed. The project will undoubtedly give visibility to the needs of people with dementia and the shortcomings we have as a society in this respect. It will also bring to the forefront the need to generate legislation that regulates and promotes good practices and dementia-friendly spaces. According to some participants, politicians should consider PwD as patients with functional diversity and not as elderly people. More responsibility and political commitment and more concrete proposals towards the collective are also important. Another proposal is the creation of a socio-sanitary structure with adequate synergies, with spaces far removed from the old forms of groups of elderly people and open spaces with adapted areas to facilitate access for people affected by dementia with the aim of integrating them into their environment. In conclusion, we should adapt resources to people and not people to the resources.



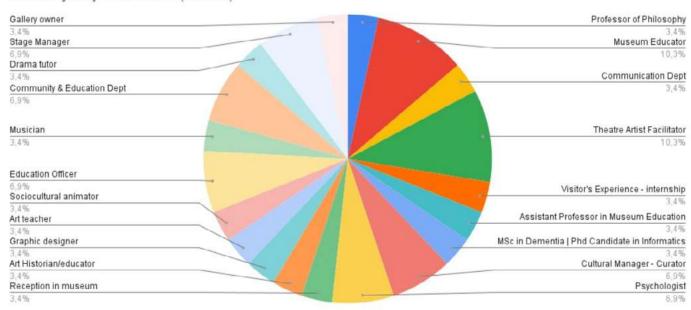
11. Image provided by Asociación de Familiares de Enfermos de Alzhéimer de Valencia (AFAV)



Finally, interviewees reflected on how they would try to overcome some challenges that may arise when including PwD in cultural activities. For example, travelling to cultural sites (especially when involving participants with dementia) might be troublesome, but with good organisation, adaptability and consent or even accompaniment from caregivers, it can be achieved. An interesting remark made by an interviewee is that culture is considered a luxury among seniors and PwD, so campaigns and policies should try hard to change this stereotype.

# 1.b. Professionals working in cultural field

In total, 29 professionals from Greece and Ireland working in the cultural field were interviewed. As the cultural field is a very broad field, the professionals we interviewed came from different backgrounds, as it is shown in the graph below:



What is your job title/role? (cultural)

# Existing approaches, programs, applications and tools

Most of the participants have implemented or currently implement best practices for the inclusivity and accessibility in cultural activities and/or spaces, but only a few have heard of or implemented best practices for people with dementia. There was one participant that expressed serious doubts about the possibility of host-ing activities for PwD. The majority, though, agrees that PwD are an overlooked population when it comes to cultural activities and should have tailor-made activities, as they could attract more specialised audiences creating a whole new dimension to their offered events. Some of them also reported that they would be very interested to be trained in techniques and ways to work with PwD in their own field.

They all reported that they would like more training on basic information about the nature of the condition and the challenges that the patient has to face on a day-to-day basis, as well as ways and techniques to approach such audiences more effectively. So, intense training and practice is what is needed.

Some of the best practices the professionals mentioned include:



Thallo program (Greece) that offered training for museum staff.

Benaki Museum (Greece) offers specialised visits for people with cognitive impairments.

**Informal network of Museums** in Portugal is a national network of museums for inclusion in Dementia:

https://accessculture-portugal.org/museums-for-inclusion-in-dementia/

Museum of Cycladic Art has created the "Wise Friends, Together at the Museum" program collaborating with a network of senior centres and nursing homes to give people over 65 a new way to visit its collection.<u>https://seveneleven.me/en/museum-of-cycladic-art/</u>

**Museum of London** (UK) - Creative Connections. The Museum of London offers Creative Connections sessions, designed for people living with dementia and their carers, which include multi-sensory activities and object exploration:

https://www.museumoflondon.org.uk/learning/schools-and-teachers/creative-connections

**The British Museum** (UK) - **Accessible Programs**. The British Museum provides dementia-friendly events and workshops, such as sensory tours and object handling sessions, to ensure a welcoming environment for people with dementia:

https://www.britishmuseum.org/visit/accessibility

Case studies on UK Caring culture by Alzheimer's Society: Museums reaching out to people with dementia.

https://www.alzheimers.org.uk/dementia-together-magazine-dec-20jan-21/caring-culture-museums-reaching-out-people-dementia

**Abbey Theatre** (Ireland): "An Old Song, Half Forgotten" is a play portraying the life of a character living with Alzheimer's, written for and performed by an actor who himself was recently diagnosed with Alzheimer's.

https://www.abbeytheatre.ie/whats-on/an-old-song-half-forgotten/



Theochraki foundation (Greece) offers specialised visits with emphasis on inclusivity.

**Collection of Aggelos Katakouzinos** in collaboration with Alzheimer Athens (Greece) have created a guide for dementia friendly museums and cultural sites in Greek.

**Goulandri museum** (Greece) has run/is running the first specialised program for people with mild cognitive impairment and third aged people. In 2019, Goulandri was nominated for good practice to European museum awards.

Dementia Action Alliance (UK) - Dementia-Friendly Museums Charter. The Dementia Action Alliance has developed a Dementia-Friendly Museums Charter, which outlines best practices and principles for museums to become more dementia-friendly: <u>https://www.dementiaaction.org.uk/museums\_charter</u>

House of Memories by National Museums Liverpool (UK) is a museum-led dementia awareness programme which offers training, access to resources, and museum-based activities to enable carers to provide person-centred care for people living with dementia: <u>https://www.liverpoolmuseums.org.uk/house-of-memories</u>

Smithsonian American Art Museum (USA) - Artful Connections: The Smithsonian American Art Museum provides Artful Connections programs, including engaging gallery tours and art-making activities for individuals with dementia and their caregivers: <u>https://americanart.si.edu/education/artful-connections</u>

The Museum of Modern Art (MoMA) (USA) - Alzheimer's Project. MoMA offers specialised programs for individuals with Alzheimer's and dementia, including interactive gallery tours and art-making sessions. A very interesting initiative that has to be adapted on local cultural context: <a href="https://www.moma.org/learn/accessibility/programs/alzheimers-project">https://www.moma.org/learn/accessibility/programs/alzheimers-project</a>

Azure network (Ireland) initiated through collaboration between Age & Opportunity, The Alzheimer Society of Ireland, the Butler Gallery, Kilkenny, and IMMA (Irish Museum of Modern Art) and delivers tours for people living with dementia – designed to improve access and enhance their experience of cultural initiatives in Ireland's galleries and museums. <a href="https://ageandopportunity.ie/engage/azure-dementia-friendly-tours/">https://ageandopportunity.ie/engage/azure-dementia-friendly-tours/</a>



Professionals reported that existing or new policies for PwD could benefit the cultural institutions, their staff, PwD and their caregivers.

Concerning cultural institutions, inclusivity and accessibility benefits focus on the wide range of audience they attract to the museum/organisation. In a country like Greece, for example, where museums and cultural institutes are often seen as a luxury for the elite, running inclusive, accessible and affordable programs is very important for the sustainability of the museum and its potential to survive, develop and expand. Furthermore, multi-sensory approaches create more engaging cultural experiences, so exhibitions can become more interesting, interactive and engaging, thus leading professionals to strengthen their knowledge and to offer better experiences and create a welcoming atmosphere for every target group. In conclusion, access to culture and arts is a universal need, so everyone should have access to them, especially since they might be used as non-pharmaceutical treatments.

Concerning PwD and their caregivers, interviewees agreed that keeping PwD connected to culture and community is important. Art based activities for seniors and PwD can have an impact on their quality of life, promoting the feeling of well-being, independence, creativity, self-worth and improving their mood. Also, supporting creativity in PwD can lead to a reduction of confusion and wandering, which are common symptoms of PwD. Finally, inclusion and active participation of PwD in cultural experiences can contribute to building a support system around caregivers.

Apart from benefits, creating a dementia friendly community or cultural site can also be challenging.

Concerning cultural institutions, some of the challenges that were mentioned most often are the lack of dementia awareness and the difficulty of catering to different types and stages of dementia. Many characteristics of PwD are different from what cultural staff is used to, namely different span of abilities, comprehension, different lifestyles, interests, and different attention span. Moderating their visits can be challenging in terms of building social bonds, keeping their focus, avoiding distractions, such as other paintings that aren't included in tour or other museum guests, and encouraging communication but also controlling it if there is too much. Other challenges, according to the museum educators, include the constant high demand for new ideas for events and workshops to keep the interest high and audience engaged.



**12.** Image provided by Asociación de Familiares de Enfermos de Alzhéimer de Valencia (AFAV)





13. Photo by Pawel Czerwinski on Unsplash

Organisational issues were also raised, as preparation and organisation for dementia specific activities/practices can require a lot of time and budget, which many times is limited, especially for small sized cultural spaces. Some of the participants mentioned they do not feel supported in taking initiatives regarding PwD, because not all relative stakeholders identify this issue as a problem to be solved. Another important challenge is the lack of flexibility of cultural spaces, especially in terms of non-accessible buildings architecture-wise and the barriers of the premises. Oftentimes, the solutions implemented to increase accessibility of such spaces are not working as they were supposed to. Cultural facilities are not willing to take many actions towards accessibility. For instance, many cultural spaces in Greece tackle only issues regarding accessibility in physical terms (ramps, barrier free spaces) but do not take into account people affected by cognitive or other physical impairments. Finally, advertising the events appropriately and reaching a wide and targeted audience can be challenging. Our specific target audience might not be able to reach that information through regular media / or forget that they participated in.

When asked about how they would face the aforementioned challenges, our interviewees proposed some solutions that either they have implemented or they think could help towards more dementia friendly cultural spaces. For example, exchanging experiences and ideas with other institutions can be very helpful. Participants in Greece and Spain claimed that they are not aware of existing databases where one could find other institutions that do similar programmes, as, e.g. in Ireland one can find the Azure programme which offers relevant training to cultural professionals. That is why follow up activities and reflection on results gathered may help us get acquainted with unprecedented challenges (from our main target group or caregivers). Train-ing staff of cultural facilities in order to be able to understand the needs of target groups facing additional difficulties and to adapt on the spot is essential. Moreover, PwD may forget their periodic participation in such activities. They need to be invited all over again by applying step by step approaches- an effective com-munication plan has to be designed. Constant reminders to be set via various media (radio, social media, mailing lists etc.).

From our interviewees' point of view, a cultural facility has to plan and organise in advance and to take some strategic decisions on certain inclusive activities in a cost effective and engaging way in the same manner, as they have to design multiple activities and provide time for participants to onboard. Finally, building relationships with target groups inside local communities may be difficult, but is very important in order to ensure high participation. For that reason, museums often use outreach programs techniques, collaborate with public services or offer free events to attract more people. For example, one museum in Greece offered specific complimentary tickets and a place to a kids' events to single-parent or refugee socially-challenged families, putting thus the museum in spotlight for its outreach programme. More actions such as these need to be done to open up accessibility and inclusivity.



## Needs towards dementia friendly communities

All participants reported that a specialised policy about PwD will be very helpful in their line of work. Such initiatives have a great impact on PwD, since it is estimated that a large percentage of the population is affected by dementia (PwD, caregivers, healthcare professionals etc). All participants who work with cultural institutions or teach art of any kind, reported that a specialised policy for PwD would be a very interesting idea and could attract more specialised audiences creating thus a whole new dimension to their offered events. Another benefit that makes specialised policies about PwD helpful to professionals working in the cultural field is the promotion of inclusivity in culture life.

In order for professionals to implement such policies, though, different types of support would be required. All professionals reported that they would like more training on basic information about the nature of the condition and the challenges that the patient has to face on a day-to-day basis, as well as ways and techniques to approach such audiences more effectively. Also, having experienced educators who can help them create proper tools and training in order to implement such activities (on how to approach PwD, how to help them, organisation and implementation of activities, duration of activities, etc.) preferably addressed to all of the staff of a cultural organisation. So, intense training, education and practice is what is needed both before implementing any policy and throughout its duration. Another proposal is to have the support of specially trained staff from dementia associations and/or other professions while implementing such practices in order to intervene and guide them if needed.

Financial support is equally important. Such initiatives require money, more time and more staff, so cultural sites will probably need funding from the state or EU. Another need is a regulatory framework that makes it easier to licence cultural spaces in means of accessibility.

Cultural sites may also need support from the community. Training of local communities towards dementia friendly communities can help de-stigmatise PwD and thus enable participation in new activities and practices. Furthermore, cultural sites should focus on the dissemination and promotion of relevant initiatives, in order for more and more PwD and their caregivers to know about them.

Our interviewees reported that during the implementation of dementia specialised policies, some challenges may arise. Challenges would include a lack of awareness around dementia and lack of training among cultural staff. As such initiatives may require a multidisciplinary group of people, communicating with everyone in the group and combining their particular fields of research and practice with these new practices that they will be trained in, can be difficult. Also, exchanging experiences and ideas with other institutions can be challenging, as there is no database where one could find other institutions that implement similar policies. Another common problem is that such initiatives are not easily funded, despite their impact. Finally, advertising and getting the information out to the right target audiences, as well as having the financial and other resources to create such events and services could be challenging.

When asked how these challenges may be overcome, all professionals agreed that efficient training and open access educational materials could help them to plan and implement innovative activities about PwD. Concerning the lack of funding, some professionals proposed the adaptation to low-cost initiatives, at least in the beginning. Finally, to overcome the communication challenges, professionals proposed promoting the activities to the public to raise awareness, while maintaining open communication with the families. Approaching the right audience through organisations would be a sensible way to go about as far as the promotion of such events is concerned.



# 1.c. Use of Game Based Learning

The majority of our interviewees reported that they prefer on-site hands-on experience seminars, when asked what their preferred method of learning is. A large number of them also mentioned online lectures, but some of them only prefer online seminars when a very important keynote speaker is available. Moreover, online courses offer the opportunity for a certification, which is needed when in search of employment. All of the interviewees agree that notes and handbooks or e-handbooks with as much information as possible on the subject and tips on how to apply the knowledge are equally important. Some of the interviewees reported that conversations with other professionals with expertise on the subject at hand can also be helpful. Finally, most of them stated that interactive methods of training/ learning are the best option.

Almost 80% of our interviewees reported that they know or incorporate game-based practices in their field of work. Notably, they mentioned theatre games, museum adventure games, role playing games, storytelling practices (e.g. drawing inspiration from folklore stories and myths), construction games, narrative techniques, experiential games. None of the participants use board games or serious games. Below are some serious games that our interviewees use and suggest :

 Legends of Disability game, which is an innovative project aiming to demonstrate the achievements of people with disabilities (PwD) in different fields (science, art, sport, entrepreneurship) and empower young and old PwD to become active and shape their own future through a role-model game-based approach:

 Legends of Disability EEA GRANTS | CHALLEDU .

 "WIZZLE" by isometrics (Greece) is a game of thought and creativity with a mathematical background that can be also used by people with cognitive impairments:

 https://sites.google.com/view/wizzle-en

 AdGaming is a platform with training materials and information about games useful to improve the quality of life of PwD: https://adgaming.ibv.org/en/training-content/

 Bridge is a platform with serious games aimed at supporting the treatment of cognitive and behavioral symptoms of dementia:

 https://projectbridge.eu/the-serious-game/

 Autistic Child with selective mutism talking for the first time in a group setting.

A game that consists of dice that have to be thrown into the air, when they fall some images appear with which PwD have to form a story.





14. Image provided by Asociación de Familiares de Enfermos de Alzhéimer de Valencia (AFAV)

Professionals who incorporate game-based practices reported that there are important benefits. First of all, game-based learning is more meaningful and more satisfying for the people involved, as the learning process becomes more enjoyable, more interesting and more appealing to audiences. Game-based learning can also have recreational purposes and, thus, improve the mood of the people involved. Usually, game-based practices take into account accessibility issues and make the games easy to participate in. Learning in groups through a serious game promotes socialising, as the participants connect in a comfortable relaxing and safe learning environment. Moreover, game-based learning can be more engaging and motivating to the person involved, so they would stay engaged for longer. Especially for PwD, taking part in personalised game-based learning can help stimulate areas that are still preserved and increase soft skills, which can help increase the self-esteem and confidence of PwD and slow down cognitive deterioration. For professionals, the immediate feedback received on designated training materials even with nonverbal cues is also very important. Finally, some interviewees highlighted that blended learning, which uses online and offline technologies, should also be an option.



Apart from the aforementioned benefits, game-based learning can pose some challenges for professionals, such as the stereotypes against using games. Although there are projects that work with serious games, there is not something standardised in order to use them as common tools. Furthermore, many professionals reported that serious games are not usually part of their training and there is a lack of experienced educators in game-based learning. While using game-based practices, some interviewees have faced stage fright or shyness of some participants that makes the process difficult. Especially with PwD, they often face communication challenges, as PwD may struggle to keep up with instruction and show a lack of cognitive flexibility on a large number of occasions. PwD at more advanced stages of dementia may not be able to follow such processes. In order to overcome these obstacles, professionals have to adapt on the spot and modify game rules at easier playing modes, to accommodate the needs of the group or individual. Many answered that you learn how to address the challenges with experience, for example, clearly explaining the game to be played, explaining it as many times as necessary and offering help and guidance where necessary.

When asked if incorporating game-based activities/ learning techniques for training would be interesting/ helpful, professionals, almost unanimously, answered yes. All participants reported that incorporating such activities would be very interesting and beneficial to their practices, with one stating that this may be the case more for PwD and their caregivers than creative staff. The majority of professionals believe that game-based learning practices are needed, especially in training, since people are more engaged, learn while having fun and are unobtrusively creating teams regardless of their background and abilities. In Spain, a professional answered that he does not know if they are necessary, but he thinks they are effective.



**15.** Photo by Milad Fakurian on Unsplash



# Quotes

Below, you can find some quotes from our interviews with the professionals that we consider worth mentioning:

CURATE-D project will be beneficial for its target group.A large amount of population is affected by dementia (including caregivers) and it is a pity for them to be excluded.

By being more inclusive we are improving ourselves,getting aware of ourselves and other people and we reconsider the world around us.

We have to face our existing stereotypes and reverse them if needed.

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# "

Using serious games is a very immediate way to target various groups of learners regardless of their abilities.

# "

Working in a cultural space cannot be considered as a job. It is a sharing experience with visitors and no one should be excluded from such experiences.

It is nice to share the same interests, values and goals with other organizations like you out there.

It is very nice to know that issues such as inclusion of people with dementia are starting to be discussed in Greece. It would be great If you could organize more activities and exchanges of good practices.

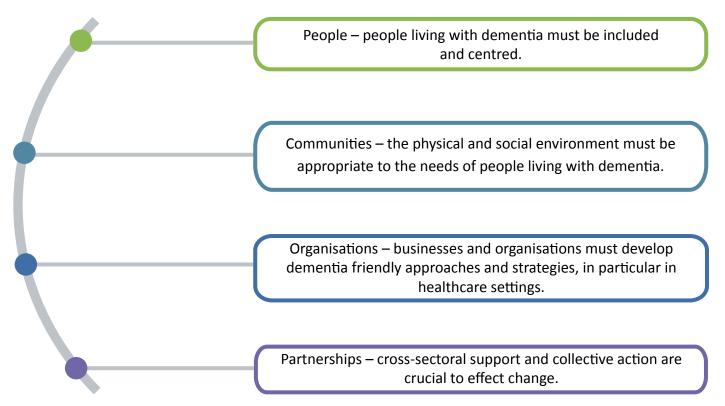
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# 2. Dementia friendly strategies/policies

Social stigma around dementia often leads to perceptions and behaviours that the person is helpless and unable to make decisions or participate in the activities they were involved in previously (Lion et al., 2015; Rewerska-Juśko & Rejdak, 2020). A practical initiative that seeks to support people with dementia and overcome misconceptions by building understanding, awareness and acceptance of dementia is a dementia friendly community (DFC). Dementia friendly communities were established with the aim of enabling people with dementia and their caregivers to feel empowered, supported and included in society (Lin, 2017; Lin & Lewis, 2015). The main characteristics of a DFC are to create a safe place where people with dementia can participate in community daily life, are able to access services and businesses, and feel valued and safe (Lin, 2017). The process of developing a DFC is secured in policy and planning that actively adopts a rights-based approach, recognising that people with dementia have a disability and are entitled to disability support (Shannon et al., 2019). The framework of dementia friendly has the power to change the way we think about living with dementia. It extends to areas such as language, improvements in social support, health and dementia services, and the physical environment. The concept has two different, but complementary, objectives: Firstly, to reduce stigma and promote awareness (i.e. the lived experience); and secondly, to empower people living with dementia to take decisions about their own lives (i.e. the rights approach) (Alzheimer's Disease International, 2011).

# Principles of a dementia friendly community

A dementia friendly community can be defined as: a place or culture in which people with dementia and their carers are empowered, supported and included in society, understand their rights and recognise their full potential. ADI (2011) suggests that the four essential elements needed to support a dementia friendly community are:



Despite dementia friendly communities being a global initiative and present in many developed countries (Alzheimer's Disease International, 2020).



# Case studies of dementia friendly policies and activities

# WHO's Global action plan on the public health response to dementia 2017-2025

# https://www.who.int/publications/i/item/global-action-plan-on-the-public-health-response-to-dementia-2017---2025

In May 2017 the WHO adopted the 'Global action plan on the public health response to dementia 2017-2025'. The Global plan contains seven action areas, the first of which is 'Dementia as a public health priority'. ADI is producing the 'From Plan to Impact' annual series of reports, monitoring the progress towards the plan's targets. The latest report calls for urgent action to develop, fund and monitor national dementia plans.

ADI also stays in touch with the UN, OECD, World Economic Forum, G7 and G20 (the governmental groups of, respectively, seven and twenty major economies) and other international and inter-regional bodies to develop policies that can be implemented in every country of the world.



16. Image provided by Asociación de Familiares de Enfermos de Alzhéimer de Valencia (AFAV)



# The 'Dementia friends' initiative

#### https://www.dementiafriends.org.uk/

## https://www.alzheimer-europe.org/news/global-dementia-friends-network-challenging-stigma-globalscale-mark-world-alzheimers-month

#### https://www.alzheimers.org.uk/about-us/policy-and-influencing/global-dementia-friends-network

In 2004, Japan's government announced the change of the word for 'dementia' from 'Chiho' which carried negative connotations to 'Ninchi-sho', meaning cognitive disorder. With this change, the country's government launched a nationwide campaign, '10-Year Plan to Understand Dementia and Build Community Networks', which stimulated the creation of various local activities centred around Dementia Friendly Communities. These included the Nationwide Caravan to train Ninchisho Supporters programme, an ambitious initiative to raise awareness of dementia and train various groups and individuals, in their personal or professional capacities, to best support people with dementia and carers to live well in their community.

Another crucial initiative is the Ninchisho Supporters training – a specialised 90-minute seminar for the public held at schools and offices and community settings across the country. The seminar covers the following key areas: recognition of the symptoms of dementia, diagnosis and treatment, the role of each health care professional, prevention, attitudes towards people with dementia, and understanding of the caregiver experience.

During the seminar, attendees learn about the disease itself, how it affects the lives of those living with dementia and what they should know in order to effectively support people with dementia. By the end of the programme, attendees are expected to have a good understanding of dementia and to become supporters and advocates for those living with dementia in their everyday lives. Those who attend the seminars become Ninchisho Supporters and receive an Orange Ring bracelet.

The Ninchisho Supporter concept was a key focus of research for Alzheimer's Society (England, Wales and Northern Ireland) during the development of their Dementia Friends programme, launched in 2013. Dementia Friends, which shares many of the elements of Japan's campaign, aimed to provide basic information about dementia, common misconceptions and a reminder that there is so much more to a person than the dementia. Individuals become a Dementia Friend by attending a face-to-face Information Session or watching an online video and registering for an information pack.

Inspired by the models in Japan and the UK, there are now 67 Dementia Friends programmes launched or in development in 56 countries and almost 19 million Dementia Friends worldwide (11 million of those in Japan).

# **Alzheimer Cafés**

https://www.alzint.org/what-we-do/policy/dementia-friendly-communities/alzheimer-cafes/

https://alzheimercafe.co.uk/



Founded in the Netherlands, Alzheimer Cafés – also known as memory or dementia cafes – have become a popular and easily transferable programme used to connect people, share information, and bolster support in many countries around the world. Alzheimer Café is a place with a welcoming atmosphere in an accessible location where all people affected by dementia could meet and feel at-ease.

The concept of Alzheimer Cafés has spread through the fabric of many societies, helping to overcome the stigma surrounding dementia by providing a social setting where people with dementia and carers can meet others in a similar situation and feel supported and encouraged to speak about their condition as well as their personal experiences.

Although people with dementia and their families, friends or carers are core attendees, others with an interest in dementia, such as students, nurses, people from other charities, local politicians, or those who want to find out more about dementia are welcome to attend an Alzheimer Café.

The Café event usually begins with a discussion or presentation on a particular theme, followed by a less structured session where those attending can share their experiences, thoughts and ideas with others. Moderators vary in their experience; some are from a counselling background with knowledge of dementia and experience with group work, while others are volunteers who have received specific training on how to run an Alzheimer Café and to actively engage with people living with dementia and their carers. To support the implementation of Alzheimer cafés and to ensure best practice and high standards, many countries have developed 'how-to' guides on developing and maintaining cafés.

Alzheimer Cafés share many of the same aims as global dementia friendly efforts; with a particular focus on reducing stigma, encouraging social engagement, and empowering people with dementia and carers. The success of Alzheimer Cafés is evident from the growing number of cafes world-wide.

# National dementia friendly policies and practices in Ireland, Spain and Greece

# Summary of national dementia friendly policies in Ireland

According to the Dementia Services Information and Development Centre, In 2017, it was estimated that around 55,000 people, approximately 1.1% of the population, were living with dementia in Ireland. In 2018, dementia was the fourth highest cause of death in Ireland.

At the moment, 11,000 new cases are diagnosed each year in Ireland and it is estimated that 141,200 people will be diagnosed with dementia by 2050. [source: <u>https://dementia.ie/lessons/irelands-dementia-sta-</u> tistics/]

In 2014, Ireland launched their National Dementia Strategy with the aim of improving dementia care so that people with the condition can live well for as long as possible and access services and support that are appropriate for their needs. It sought to promote a greater focus on timely diagnosis of dementia and on the value of early intervention, along with the long-term objective of making people in Ireland generally more aware and understanding of the needs of people with dementia, and of the contribution that those with dementia continue to make to our society.





These aims align well with a social inclusion agenda. Specifically, the Strategy identifies six priority areas for action:







17. Image provided by Asociación de Familiares de Enfermos de Alzhéimer de Valencia (AFAV)

To achieve this vision and implement the strategy over 2014-2017, the Department of Health and the Health Service Executive agreed a joint initiative with The Atlantic Philanthropies with initial funding of €27.5m. This highlights the substantial resources that have been allocated to addressing the challenge of dementia. In 2017, the National Strategy was reviewed and further outlined the need for primary prevention to be embedded in the Strategy as well as the requirement to provide a post-diagnostic system that emphasised knowledge, information, peer support, cognitive interventions and continuity of care and integration that would lead to higher levels of self-determination, choice and control on the part of people with dementia. It also argued for a personalisation agenda to be adopted that ensured the wishes and preferences of people with dementia were prioritised over the providers of care. To achieve this vision it highlighted the need for additional resources to be directed at dementia support and care as well as better education of dementia amongst health professionals, services providers, informal care partners and the general public. This again emphasises the need for a rights-based approach that draws from a wider social inclusion agenda.



# Case studies of dementia friendly activities in cultural spaces in Ireland

# Age & Opportunity

#### https://ageandopportunity.ie

Age and Opportunity is a national organisation that aims to inspire everyone to reach their full potential as they age. They work with people over 50 years old, including those living with dementia, and facilitate them to engage in cultural, sporting, physical and artistic activities, such as dance and writing. This provides opportunities to learn and be involved as active citizens. They work with public and private partners to deliver innovative programs such as the Bealtaine arts festival and Go for Life- a national sports program for older people. They have also commissioned a theatre play tour, which is a storytelling piece. Their two hour workshops with people with dementia are designed to enhance creative skills, support their interests and offer new experiences. In addition to this, they provide support to day care centres and offer artists' residencies in care homes. Evaluation feedback they have collected reports that their workshops have improved people's creative skills, participation and mood (Home, n.d.).

## **The Azure Project**

#### https://ageandopportunity.ie/engage/azure-dementia-friendly-tours/#phone

The Azure Project was born from the collaboration between Age & Opportunity; The Alzheimer Society of Ireland, the Butler Gallery, Kilkenny and IMMA (Irish Museum of Modern Art). It aimed at providing 'dementia-friendly' access to arts collections by incorporating elements of storytelling and creative arts to gallery tours. Age & Opportunity train tour guides to deliver tours specifically tailored to people with dementia by including activities focused on placing people with dementia 'in-the-moment' and storytelling in order to create conversation and self-reflection in an open and safe environment. The Azure tours aim at putting the person at the centre of the museum experience in order to create a sense of belonging, community and emotional connection.

The Age & Opportunity has trained facilitators and tour guides all over the country. Participating venue include (Azure, n.d.):

- Arts & Disability Forum, Northern Ireland
- Butler Gallery, Kilkenny
- Chester Beatty Library, Dublin
- Crawford Art Gallery, Cork
- DLR Lexicon, Dun Laoghaire Rathdown County Council Arts Office
- Galway Art Centre, Galway
- The Highlanes Gallery, Drogheda
- The Hunt Museum, Limerick
- Irish Museum of Modern Art (IMMA), Dublin
- The LAB, Dublin City Arts Office
- The Luan Gallery, Athlone
- The National Gallery of Art, Dublin
- West Cork Art Centre, Co. Cork



# An Old Song, Half Forgotten, The Abbey Theatre

#### https://www.abbeytheatre.ie/whats-on/an-old-song-half-fo rgotten/

In 2023, the Abbey Theatre, the National Theatre of Ireland, produced An Old Song, Half Forgotten by Deirdre Kinahan. The play portrays the life of a character living with Alzheimer's ; two actors play the Younger and Older version of the same character. The actor playing the Older version is himself at the early stages of Alzheimer's. As such, he was fed his lines through an earpiece by another actor.

The performance was accessible for People with Dementia and their carers. The theatre put in place a Information Pack specifically dedicated for People with Dementia and their carers. The Packs includes information about the venue, the play and the actors. Unlike other performances, audience members were allowed to leave the theatre and reintegrate the auditorium during the performance should they need to. The theatre staff followed a Dementia-awareness training and the team was accompanied by a Personal Support Assistant and Care Consultant (An Old Song, Half Forgotten, n.d.).

# Deirdre Walsh - Project Health "In the Kitchen" A community development project in Waterford

https://www.artsandhealth.ie/case-studies/past-times-community-choir-voices-of-spring/

Past Times and Voices of Spring are two large community choirs welcoming older people, including those living with dementia and other age-related illnesses. The choirs are supported by Kildare County Council (KCC) Arts Service and have been directed by Sharon Murphy and Sadhbh O'Sullivan since January 2015. They rehearse weekly in McAuley Place, Naas and The Mill Community Centre, Celbridge (Past Times Community Choir & Voices of Spring, n.d.).

## **Sharon Dipity**

#### https://www.artsandhealth.ie/case-studies/bridging-the-imagination/

Visual artist Sharon Dipity collaborated with a group of older people in Skibbereen Community Hospital in 2022 to explore task-based performance art around the theme of bridges, supported by an Arts Council Agility Award. Sharon received mentoring support from Dr. Katja Hilevaara, Department of Theatre and Performance at Goldsmiths College, University of London, and from Sarah Cairns, a dementia care specialist. Project support was provided by Sandya Zachariah, CNM2 at Skibbereen Community Hospital, and Justine Foster from Uillinn: West Cork Arts Centre (Bridging the Imagination, n.d.).

## **Dance Bualadh Bos**

#### https://www.artsandhealth.ie/case-studies/dance-bualadh-bos/

Dance Bualadh Bos is a creative performance project, led by dance artists Ailish Claffey and Philippa Donnellan, and developed for and with older age communities in County Kildare. The project culminated in the creation of an original dance performance, presented privately to participants and to public audiences (Dance Bualadh Bos, n.d.).



# **Dementia Hub Ireland**

#### https://dementiahubireland.ie/the-projects/

The work of ASI has had a powerful influence on the development of the National Dementia Strategy, its publication and its implementation to date. ASI continues to advocate for its progression and is calling for a second National Dementia Strategy. The work to encourage people with dementia to speak out for themselves has been instrumental in increasing public and political understanding, awareness and profile for the conceptualization of personhood in dementia. It has become recognised that people with dementia are able

The ASI continues to push for change through:

Enhancing the role and potential of the Dementia Working Group.	
	Strengthening the work on Dementia Friendly Communities.

# Summary of national dementia friendly policies in Spain

The Comprehensive Plan for Alzheimer's and other Dementias is based on a specific conception and consideration of the person: as a person with dignity and a citizen with full rights, towards whose maximum quality of life, participation, self-determination and autonomy the different actions in all its axes must contribute.

It also involves or reaches out to society as a whole, promoting progress towards the achievement of "Alzheimer-friendly environments", towards normalisation, avoiding situations of exclusion and rejection: spaces where people with Alzheimer's continue to live in an environment that does not exclude them, exercising their rights to participate in the society in which they used to live, staying in their natural environment as long as possible.

From this approach, the Comprehensive Plan for Alzheimer's and other Dementias is articulated in 4 Transversal Axes of Action. Each of these axes is interrelated and developed around the indissoluble binomial: person with Alzheimer's and family caregiver as the centre and meaning of all the actions it promotes.





18. Photo by Pawel Czerwinski on Unsplash

# Case studies of dementia friendly activities in cultural spaces in Spain:

# **CamDem project**

https://imserso.es/web/blog-ciudades/-/proyecto-camdem-sensibilización-del-voluntariado-con-las-comunidades-amigables-con-la-demencia

During 2022, the Spanish Confederation of Organisations for the Elderly (Ceoma) has carried out the Cam-Dem project "Raising awareness of volunteering with dementia-friendly communities", within the framework of the programmes of the Ministry of Social Rights and Agenda 2030 (Red De Ciudades Amigables - Blog De Ciudades Amigables - Instituto De Mayores Y Servicios Sociales, n.d.).

#### The Spanish Ministry of Social Rights and Agenda 2030

#### https://blogciudades.imserso.es/red-ciudades-amigables

The Spanish Ministry of Social Rights and Agenda 2030 is promoting the "dementia-friendly cities" initiative, which is aligned with the objectives of the 2030 Agenda. It is based on a focus on equal opportunities and access to inclusive services and environments. The initiative reflects a commitment to ensuring that all people, including those living with dementia, enjoy a dignified quality of life and participate fully in society (Red De Ciudades Amigables - Blog De Ciudades Amigables - Instituto De Mayores Y Servicios Sociales, n.d.-b)

## "Age-Friendly Cities" project

#### https://www.mdsocialesa2030.gob.es/en/el-ministerio/index.htm

The initiative, promoted by the Spanish Ministry of Social Rights and Agenda 2030, is aligned with the "Age-Friendly Cities" project proposed by the World Health Organisation (WHO) based on its paradigm of active ageing and the importance of the social participation of older people (Ministry of Social Rights and 2030 Agenda - the Ministry, in Depth, n.d.).

# Summary of national dementia friendly policies in Greece

In December 2014, the Greek Parliament enacted a law to ensure the implementation of the country's first national dementia strategy, which also saw the creation of the National Observatory for Dementia and Alzheimer's disease. A multidisciplinary group was involved in the drafting of the strategy and presented their final draft of the strategy to the Ministry of Health in September 2014. The Greek National Action Plan for Dementia was discussed during two subsequent sessions and approved by the Standing Committee of Social Affairs of the Greek Parliament on 22 March 2016.





Observatory's objectives, guided by the principles of respect, support and promotion of patients' rights, are:

**Ensure** the **implementation** and **subsequent updates** of the **National Dementia Strategy.** 

**Provide** official **guidance** to the Parliament, the Ministry of Health and other public authorities on legislative and **policy measures** related to **dementia.** 

**Coordinate** and **promote** the work of public and nongovernmental agents and associations, in order to **ensure efficient services** to **patients and their caregivers.** 

Provide specific guidance for organising and promoting the national policy in research and education.



19. Photo by Robina Weermeijer on Unsplash



So far, the implementation of the Dementia Action Plan includes the following:

A national dementia registry is underway by the Greek National Health Service Organization

> A rating system to measure the impact of dementia on families is being developed, taking into account the severity of the disease, socioeconomic status, access to health and social care services. This will be used by the State to establish financial benefits for persons withdementia and their families accordingly

Six Memory Clinics have been organised, in Psychiatric or Neurological Departments of General Hospitalsin Greek cities

> Seven new Dementia Day Care Centres in big cities and nine Day Care Centres in collaboration with Municipalities in smaller cities have been opened throughout the country

Five hospice care units in various locations throughout Greece.

More details on Greek National Dementia Action Plan can be found here: <u>https://www.alzheimer-europe.</u> <u>org/policy/national-dementia-strategies/greece</u>



Case studies of dementia friendly activities in cultural spaces:

# The project "Aeneas" https://pubmed.ncbi.nlm.nih.gov/32544079/

Dementia Friendly Communities" is a program of the EU as part of the Act on Dementia Joint Action, in order to advance common recommendations for the development of better services for people with dementia, which will improve their quality of life. The Dementia Friendly Communities involve four fields: the environment (places), the citizens (people), the networks and the resources. Based on this model, pilot actions have been developed in Greece (Municipalities of Athens, Byron and Vrilissia), Bulgaria and UK and it is expected to provide important guidelines for the development of Dementia Friendly Communities in the EU. In Greece, the goal of the Join Action on Dementia was to promote the development of strong alliances within the local communities (municipalities) and the networking of organizations (State, Municipalities, NGOs, enterprises etc) with dementia patients and their caregivers and to educate more people in the municipalities in order to fight stigma and understand dementia.

# Seven Eleven Theatre Company

https://seveneleven.me/en/thallo/

They are the first organisation in Greece to produce a theatrical play that is based on the experiences of people with dementia. Over the last six years, the company has worked as external activity providers for nursing homes in and around Athens. They have implemented the Thallo program tailored to the care partners in domiciliary care, although the majority of their end-users are people with dementia. They adopt a holistic approach to dementia care, where they integrate aspects of drama and use free association thinking to facilitate the complex needs that people with dementia might face. They also work alongside care partners to provide theatrical exercises, aimed at enhancing their self-confidence in a fun way that 'lightens their load.' These interventions have resulted in improvements in mood, stress reduction and self-expression in people with dementia.



# CHAPTER GAME BASED METHODOLOGY



The whole frameworks of educational results and activities developed under this project are based on using game based methodology.

Games have been used in the Vocational and Education training section (VET) for enhancing the skills of various learners, increasing their performance motivation as well as their engagement during educational activities. Adding to this, game-based learning is considered today one of the most effective methods for learning especially for skills that include empathy, understanding, communication, cooperation and generally soft skills. Soft skills and empathy are essential for creating a Dementia friendly community. For this reason, CURATE-D partnership has decided to use this kind of methodology.

In this chapter, readers can understand the theoretical framework of game based learning, its benefits for learners and on ways to implement it.

# Game based learning theory

## Game essentials-definition, types, game mechanisms etc

When it comes to defining games, there are many suitable definitions.Oxford Learner's Dictionaries, for instance, defines games as "an activity that you do to have fun, often one that has rules and that you can win or lose", or the necessary equipment for it. Laamarti et al. (2014) define games as "physical and/or mental contest that is played according to specific rules, with the sole goal of amusing or entertaining the participant(s)" Numerous methods exist for examining the classification of developed games. Taking into account the criteria of materiality: games can be divided (but not limited) into:

**Tabletop games** are typically played on a flat surface, such as a table, and often involve physical components like pawns, cards, or dice(s). Players adhere to specific rules while utilising these tangible elements. Examples of tabletop games encompass board games, card games, dice games, miniature games, and tile-based games.

**Digital games**, in essence, are games that incorporate digital technology, encompassing devices like computers, laptops, gaming consoles as well as smartphones and tablets. Throughout the evolution of digital gaming, various definitions have emerged, but they all revolve around the utilisation of digital technology for gameplay. Synonyms for digital games include computer games, electronic games, and video games.

The term **"phygital"** originally emerged in the marketing industry and has now found relevance in the gaming sphere. It describes efforts to blend the digital and physical realms. This fusion is achieved by using digital tools such as smartphones, tablets, desktop computers, and specialised software. Prominent examples of phygital games include well-known titles like Guitar Hero or Wii. Additionally, educational communities often recognize phygital games like Hunt Games, which utilise QR codes, and quiz games as effective learning tools.



**Group games**: in group games, participants are divided into two or more teams that function as cohesive units throughout the game. Each team competes against the others, and success is often the result of effective teamwork. Among the most popular group games are sports like football, basketball, and volleyball. Other notable examples include tug of war, musical chairs, hopscotch etc. In recent times, escape rooms have gained popularity among young people as engaging group activities. In these games, a group is confined to a room and must collaborate to solve a series of puzzles and riddles within a set time frame. Group games can be enjoyed both in outdoor and indoor settings, offering versatility in their location.

# Serious games

Even though serious games seem to have become more popular the past 2 decades, the initial appearance of this term with a meaning similar to its present usage can be traced back to "Serious Games," a book penned by Clark Abt in 1970. Abt was a researcher employed in a U.S. research laboratory during the Cold War era (Abt Associates, 2005).(Djaouti et al., n.d.)

There is no common definition of serious games. Some researchers limit it to solely digital games, whereas others also encompass physical games. What is commonly agreed, though, is that serious games are distinguished from entertainment games since they incorporate gameplay elements with their primary emphasis to lie on learning or training, with the knowledge acquired intended for practical application in real-world work scenarios. Serious games can be applied in various domains of expertise, such as education, healthcare, cultural heritage, interpersonal communication, manufacturing, etc (Wattanasoontorn et al., 2013).

# Game based learning

The gaming environment closely resembles the learning environment, encompassing cognitive, emotional, motivational, and sociocultural interactions (Plass et al., 2015, p. 258). At the same time, educational approaches are continually progressing. In conventional settings, learners typically assume a more passive role, primarily listening to the instructor, with limited chances to apply or experiment with their knowledge. Globally, in the field of education, there is a turn to more interactive, entertaining and participatory models of education e.g. game based learning (GBL).

GBL can be considered as an umbrella term that encompasses "the use of serious games, gamification and playful learning activities to denote a student-centred and creativity-orientated strategy: (GATE:VET Wiki, n.d.). GBL involves integrating game characteristics and principles directly into the learning activities (Whitton, 2012). In other words, "Game-based learning refers to the borrowing of certain gaming principles and applying them to real-life settings to engage users (Trybus, J. (2015). Game-Based Learning What It Is, Why It Works, and Where It's Going. Miami New Media Institute. - References - Scientific Research Publishing, 2015). Educators applying game based methods usually exploit existing games (digital or traditional) as an engaging learning tool as well as an effective evaluation tool for students. (Tobias et al, 2014;Plass et al., 2015). To put it differently this implies that the game serves as both the training and the lesson, emphasising a clear educational objective.

GBL is often associated with gamification. Gamification refers to the process of taking game design elements (e.g., collecting badges, breaking a task into smaller levels) and incorporating them into learning activities (Reinhardt & Sykes, 2014).



Implementation of GBL activities may lead to:

#### Increased Engagement:

Games make learning fun and engaging, capturing learners' interest and encouraging active participation.

#### Enhanced Learning Experience:

Interactive gameplay enhances the overall learning experience, helping students grasp complex concepts.

Provide a safe environment, free of the fear of failure.

#### **Improved Problem-Solving Skills:**

Games often present challenges that require critical thinking, problem-solving, and decision-making, enhancing cognitive skills.

#### **Promotes Teamwork and Collaboration:**

Multiplayer games encourage teamwork, cooperation, and collaboration among learners.

#### **Immediate Feedback:**

Games provide instant feedback, allowing learners to reflect on their mistakes and improve their performance.

#### **Increased Motivation:**

Game-based learning boosts intrinsic motivation, encouraging students to learn for the sake of mastering skills rather than simply for grades source.

#### **Customised Learning:**

Games can adapt to individual learning styles and paces, providing personalised learning experiences.

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21. Image retrieved from Canva Pro

Gameplay encompasses various aspects related to how players interact with a game, including its story, mechanics, and interactions with other players. Technopedia associates gameplay with the overall gaming experience, covering rules, plot, objectives, and strategies for achieving them. Technopedia associates gameplay with the overall gaming experience, covering rules, plot, objectives, and strategies for achieving them.

When examining the implementation of GBL in education one can identify the following types of GBL based on their gameplay (this list is not exhaustive)



Role playing games: Role playing games are the most popular simulation games. In a role-playing game (RPG), each player takes on the persona of a character and engages within the game's fictional universe. Ezquerro (Ruiz-Ezquerro, 2021) defines these games as "structured cooperative activity with predictable rules and an unpredictable outcome... where players are playing as characters they create in an open, interactive, responsive world facilitated by a game master". The game master in educational settings could be the educator.

Simulation games: Simulation games encompass a diverse range of gaming experiences where players can experiment with various aspects of life, ecosystems, cities, or entire worlds (Simulation Games - an Overview | ScienceDirect Topics, n.d.).

Storytelling games involve collaborative storytelling, with each player contributing characters and their actions.

**Puzzles games**: puzzle games necessitate players to solve problems in order to advance or complete the game. Typically, this involves arranging pieces of information logically to arrive at a correct or enjoyable solution. Such examples might encompass escape rooms, mystery games, and deduction games. Deduction games challenge players to apply deductive reasoning for victory, while mystery games often involve uncovering hidden scenarios like murder mysteries by discovering clues. These sub-genres appeal to players of all ages.

**Escape rooms** are games where people are locked into a room and have to find a way to escape by finding clues in it. **Creative Techniques**: they nurture and foster a fun and inclusive learning environment allowing space for improvisation, storytelling and makes information recall easier for participants. Creative techniques can be warm ups, energisers, improv games, drama based activity. They reflect the human desire to learn by inductive discovery, experiential experiences and collaborative teaching

**Cooperative Games**: Cooperative games, also known as coalition games, require players to collaborate, either online or offline, to achieve common goals, leading to group-based wins or losses. These games prioritize teamwork and social interaction. They can be used in team-building activities and educational contexts within business and academia. Semi-cooperative games represent a blend of collaboration and competition, potentially resulting in multiple winners or none at all.

The Benefits of Creative techniques are:

It fosters collaborative learning by helping to build trust, respect, and team spirit as well as listening, verbal and nonverbal communication, ad-libbing, role-playing, risk-taking and storytelling skills.

It taps into the learners' multiple and emotional intelligence. It promotes deep learning through active engagement with new ideas, concepts or problems, linking the activities or tasks to prior learning, applying the content to real-life applications, and evaluating the logic and evidence.

The aforementioned types of games fit more to the CURATE-D project's methodology. But, in this point, we would like to mention other types of games categorised by the type of gameplay they employ, that are the following:

Managerial Resource Management: Managerial resource management games task players with overseeing entities, involving activities such as collecting, monitoring, and leveraging resources. Often, players face incomplete information, making decision-making more challenging. These games can encompass a wide range of management scenarios, from daily life simulation to overseeing colonies, urban development, or financial resources.

Action and Adventure Games: Action games require players to surmount challenges, often demanding quick physical reflexes, rapid responses, and precise hand-eye coordination. Players control characters navigating through environments, collecting items, overcoming obstacles, and sometimes engaging in combat. Adventure games feature interactive narratives where players explore, gather items, and solve puzzles to accomplish quests. The term "adventure game" has evolved from text-based games into digital experiences.

**Sport Games:** Sports games are popular simulations, often mirroring real-world sports like basketball. Teams compete to score points, typically by throwing a ball into the opposing team's goal or basket.

Abstract Strategy Games: Abstract strategy games, primarily found in board games, often lack specific themes and rely solely on their rule sets to provide engaging gameplay. Games like chess are typically designed for two players or teams and include no elements of chance. They offer complete information without hidden variables and do not require specific physical skills, yet they provide captivating gameplay despite their straightforward rules.

By using game based activities, players are easily introduced also to empathy based learning. Empathy is the ability to not just recognise but also feel the emotions of others, putting oneself in their position to better understand what they're going through. It is important to note that this is very different from sympathy which is the feeling of sorrow for what someone else is experiencing. The reason that empathy is so important is that it allows a person to better connect with the core reason someone is feeling or behaving a certain way. The ability to put oneselves into another person's shoes will enable the participants to increase their capacity and understanding of PwD and make their participation in cultural life.



# **Case studies**

# Serious Games for raising awareness on dementia

# The iDO Serious Game



**22.** Outcome 3 – Serious Game – iDO Project. (n.d.). Retrieved October 9, 2023, from <u>https://idoproject.eu/outcome-3-serious-game/</u>

Evolved from a fusion of traditional e-learning and gamification, the iDO serious game offers unique training solutions for doctors, formal and informal caregivers, and individuals with dementia. This model complements the iDO massive open online course (MOOC) by introducing interactive scenarios achievable only through the serious game format. It aligns with three core objectives established based on best practices (Ranchhod et al., 2014) :

Enhancing Cognitive Skills: This model imparts dementia care concepts, enabling comprehension of distinctions among individuals with varying degrees of dementia. This empowers learners to apply these concepts to real-life situations, thereby reinforcing knowledge retention through in-game problem-solving.

Encouraging Positive Attitudes and Engagement: We aim to improve attitudes, motivation, and engagement in dementia care, ultimately enhancing overall job satisfaction. Cultivating Behavioral Skills: This model promotes the effective application of dementia care concepts, fostering practical familiarity with problems, outcomes, and consequences through in-game decision-making. This enhances situational awareness, analysis, and decision-making abilities.



The iDO education model introduces scenarios that demand the acquisition of specific know-how and background knowledge to address various gameplay situations. The game concludes when the quality of life bar reaches zero (0). Gameplay outcomes influence the pace and consequences of this outcome, simulating the caregiver's journey in learning how to care for elderly relatives or individuals with dementia. Each game outcome also unlocks a narrative element, employed to educate on specific aspects of dementia care.



# Intervention: SafeHome serious game

**23.** Appel, L., Peisachovich, E., Sinclair, D., Jokel, R., & Da Silva, C. (2020). SafeHome: A Serious Game to Promote Safe Environments for Persons Living with Dementia. Cureus. <u>https://doi.org/10.7759/cureus.6949</u>

This game was designed for caregivers of people living with dementia. SafeHome was designed to provide caregivers of people living with dementia with effective strategies to create a safe physical environment. The objectives of the SafeHome serious game are as follows:





The main task in the SafeHome game is to navigate through a representation of a typical kitchen that is designed to foreground the kinds of hazards that can be present to people living with dementia. The kitchen was chosen as the initial setting because many meaningful activities occur in this space, and all "homes" contain such a space (Fleming, 2010)..Also, the kitchen has the potential to model a wide variety of potential hazards for people living with dementia. Following the completion of the activities, the player encounters a knowledge assessment quiz. It becomes available once the player has successfully identified all the hazards. The player's task is to identify all the hazards without assistance. In essence, players are now expected to rely on their memory and quickly spot hazards within the room independently.

The SafeHome game demonstrates that it is feasible to convert content from an in-person caregiver education workshop to a digital format. It also illustrates that gamification along with visuals can provide a richer learning environment.

# The Dementia Game



24. Dementia Awareness. (n.d.). Www.dementiagame.com. <u>https://www.dementiagame.com/</u>

The Dementia Awareness game is the result of collaborative research conducted by Dr. Gary Mitchell, Dr. Gillian Carter, and Professor Christine Brown Wilson, who are affiliated with the School of Nursing and Midwifery at Queen's University Belfast. This project, financially supported by the Dementia Development Services Trust, involved active participation and input from individuals living with dementia and representatives from Dementia NI during the co-design process

This game is designed in order to:





The gameplay of the game are the following:

Players are using a board on which, according to the correct answers they give, they are able to move to the next step.At the beginning of each round, players are asked some questions which they have to answer, if they want to progress in the game.If the player gives a correct answer he/she can choose the next step.In case of a wrong answer, player has to try answer any question .One of the goals of the game is the players to build their path around the people they encounter. The main goal/achievement though, is to reach the finish line having made the highest score, and after that share it and challenge other players.In this way, players will have the opportunity to learn about dementia in a joyful way.

In order to have a clear understanding of the impact of using the Dementia Game on someone's attitude and understanding of dementia, those accessing the game were asked to complete a questionnaire before and after playing the game.

This approach is really helpful in understanding someone's attitude towards dementia by working out the extent to which those playing the game are recognizing people affected by dementia as unique individuals with the same value as any other person. It also highlights any sense of optimism or pessimism the person had about the abilities and the future of the person affected by dementia. Higher scores indicate more positive attitudes towards people with dementia.

## Communicare



25. Game. (n.d.). Communicare. Retrieved October 9, 2023, from https://ccare.aegean.gr/game/

This project is the result of the collaboration of 6 partners across Europe. The partners that cooperated for the development of the game are the following: Duale Hochschule Baden-Württemberg, Wohlfahrtswerk für Baden-Württemberg, COOSS, BFI, Frontida Zois and the University of the Aegean (UAegean).



The game aims to offer cognitive exercises while promoting communication between senior individuals and caregivers. It features everyday activities that can resonate with a wide audience, facilitating the integration of communication skills not only during gameplay but also in daily life. The game is available in four languages: Italian, Greek, German, and English.

There are six different sessions within the game, each set in various locations like the kitchen for preparing drinks or food, the bedroom for organising clothes and shoes, and the living room for sorting books or recalling images. These sessions can be completed in any order, and participants can choose to revisit a session if they wish. The primary objective is to encourage conversation between the senior person and the caregiver, fostering meaningful interaction while enjoying the experience.

## **Results - Curate-D methology**

CURATE-D project aims to develop a game-based methodology through which the people working in the field of culture will improve their competences in creating dementia friendly communities and accessible cultural experiences while professional carers will empower their skills in supporting pwD in these activities.

At national and international level, the CURATE-D project aims to develop tailored educational tools using game based methodologies so as to adapt the skills of its target groups to contemporary needs of the labour market that will contribute to the innovation practices of VET education and training.

The foreseen impact on CURATE-D target group would be:



In order to achieve these aims, the next steps after this methodological guide are described below:



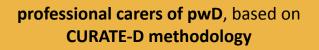
## WP3 'Development of Educational toolkit of CURATE-D project'

WP3 activities include the development of :



The **objectives** of this WP will have the following objectives :

the **development** of an **innovative educational** toolkit for **VET education** of professionals **working** in the **field of culture** and



training of staff of the partners on the educational tools

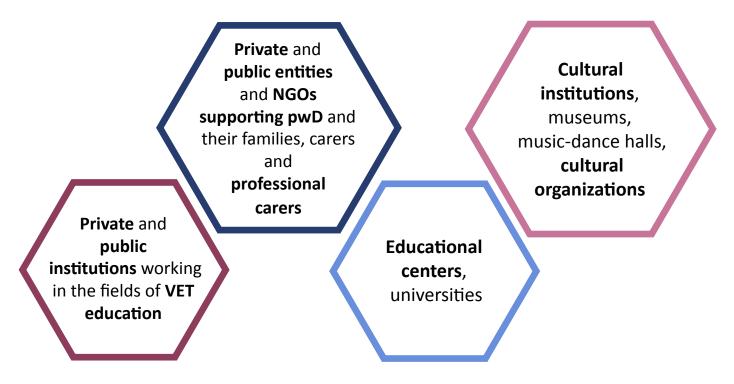
The target groups of this WP are :

staff of partner organizations professional carers

professionals working in cultural field



### Other stakeholders would be:

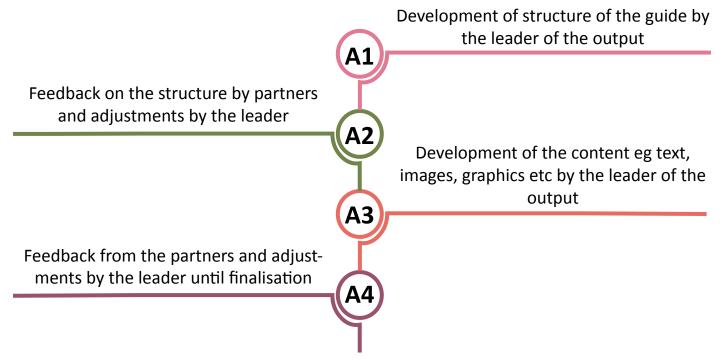


## **WP3 Expected results**

## WP3-R02: Learning training guide on training the staff of cultural venues

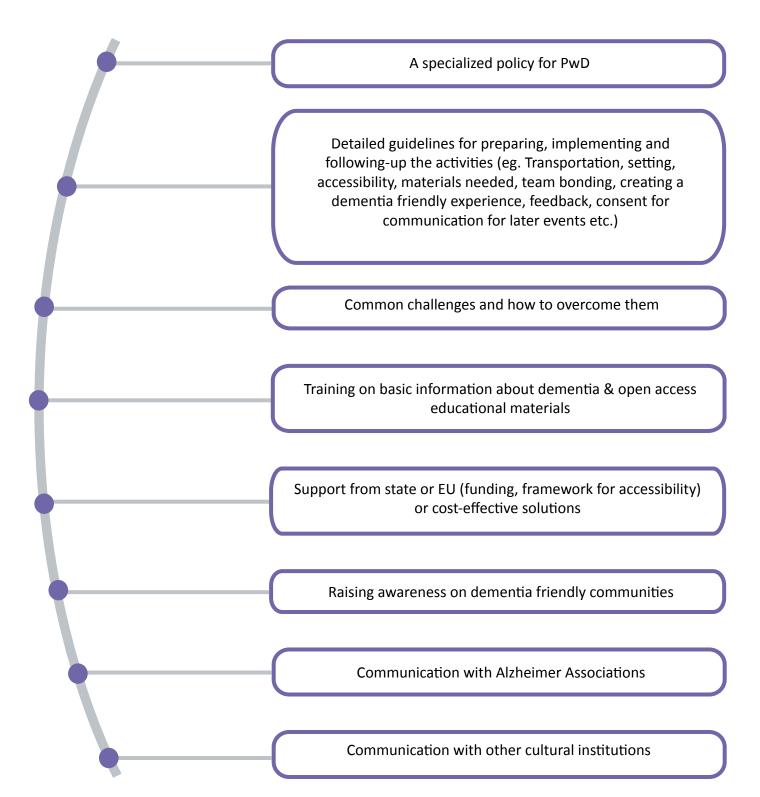
This guide will contain certain learning activities tailored to staff of cultural venues in order to train them under the objectives of this project.

The guide will be developed under the following steps:





## Needs derived from research:

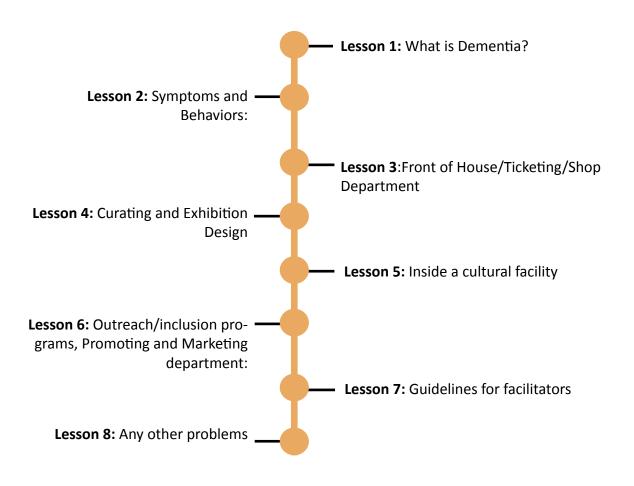




## **Main Contents**

The main contents of O2 would be

- A Brief introduction on CURATE-D approach
- Lesson plans



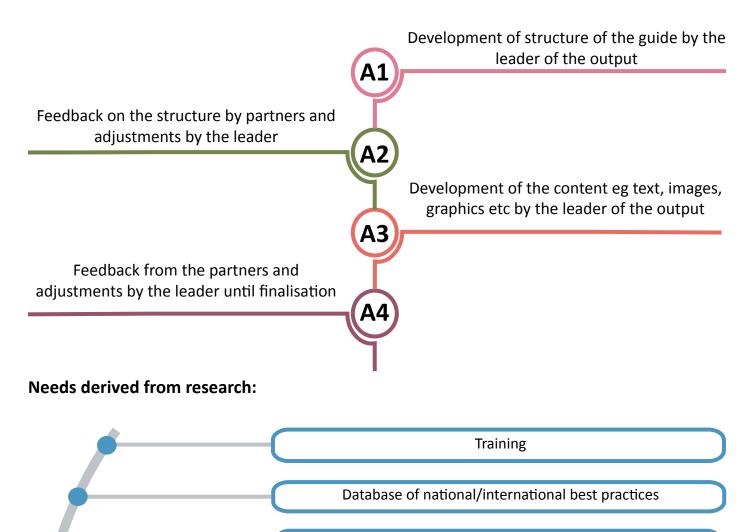
The titles are indicative. The topics selected for the lessons may be adapted after partners Feedback so as to assure the quality of the produced result.

## WP3-R03 -Learning training guide on training the professional carers to support pwD in cultural activities

This guide will contain certain learning activities tailored to professional carers in order to train them on how to support pwD in cultural activities



The guide will also be developed under the following steps:



Open communication with other professionals who implement such practices

Raising awareness on dementia friendly communities and the need of cultural experiences

Support from local, regional and national governments (legislation about dementia-friendly spaces)

Detailed guidelines for preparing, implementing and following-up the activities (eg. Transportation, setting, accessibility, materials needed, team bonding, feedback, consent for communication for later events etc.)

Common challenges and how to overcome them

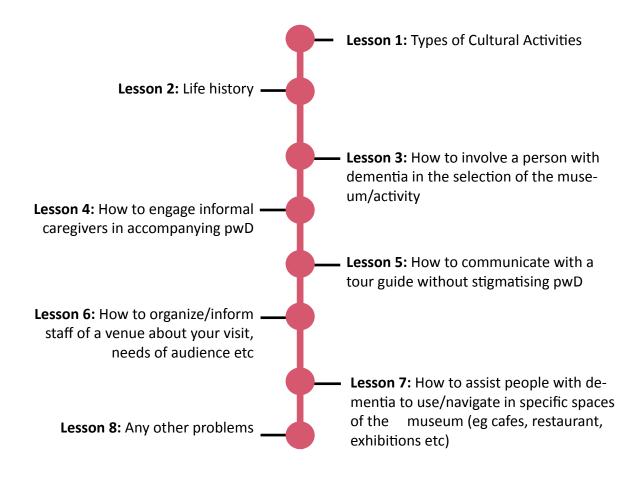
List of useful resources and organisations



## Main contents

WP3- O3 will contain

- A Brief introduction on CURATE-D approach
- Lesson plans (titles are indicative)

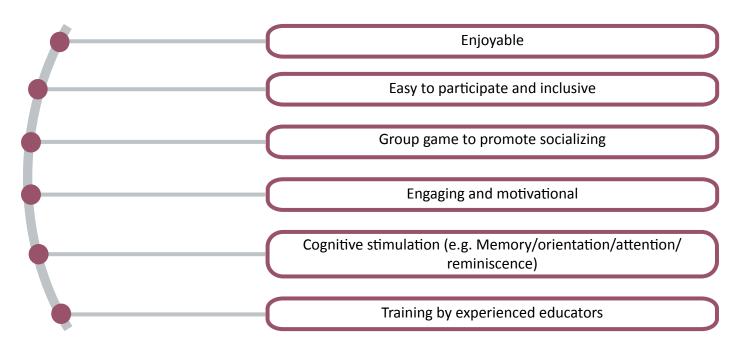


The titles are indicative. The topics selected for the lessons may be adapted after partners' feedback so as to assure the quality of the produced result.



## WP3-R04 Development of the Curate-D educational serious

game Needs derived from research:



## Main requirements of the game

The main purpose of the CURATE-D educational game would be to train staff of cultural organisations and dementia caregivers on how to create dementia friendly cultural experiences. While playing, learners will enrich their skills and/or develop relevant ones in the field of accessibility and dementia friendliness. Also, the game will act as a means of raising awareness on the issue of dementia.

The game will be based upon the research findings of this Methodological guide (RO1), and will be inspired from the needs of the project's target groups. Additionally, its content may build upon the activities included in O2 & O3 or address complementary ones.

The game will be a 1 player digital game (compatible with android devices). More specifically, at the beginning of the game players will have to choose between 2 profiles: staff of cultural organisations(profile 1) and professional dementia caregivers (profile 2). Thus, players will be immersed in various possible scenarios based on their expertise.

Profile 1 will target staff of cultural organisations. Players will be expected to address various scenarios regarding issues they may encounter when implementing activities for pwD. At the end, they will get an evaluation based on their performance and on some recommendations on how they could improve it.

**Profile 2** will target professional dementia caregivers. Players are expected to address various scenarios on how they can assist and support pwD to participate in cultural activities and on how they may cooperate with staff of cultural venues.



## WP4 'Training of professionals and exploitation'

During this WP the organizations of the consortium working with professional carers of PwD and professionals working in the cultural field will implement piloting workshops based on the methodology and tools generated in WP3 and will practice them in real conditions. The key content of the workshops will be the methodology and tools of CURATE-D project. GSA will develop a draft template on the agenda of the training and partners will adapt it to the needs of their target groups. After the implementation of the workshops, all partners will collect their feedback and GSA will develop a report on final considerations on the methodology of CURATE-D project. In the discussion between the partners for the development of the Report with the final considerations, partners will bring forward the adaptations as well as any feedback of them or of the participants to the methodology and tools. This will be a helpful material for other organizations that want to apply the methodology in their context. The report will include the following topics:

> How we implemented pilot workshops andwhich are the key findings?

Recommendations regarding the application of methodology Recommendations regarding the further exploitation of the produced material

The **objectives** of this work package are:

Training of target groups through the methodology of CURATE-D

Adaptation of the methodology to the labour market context and final considerations

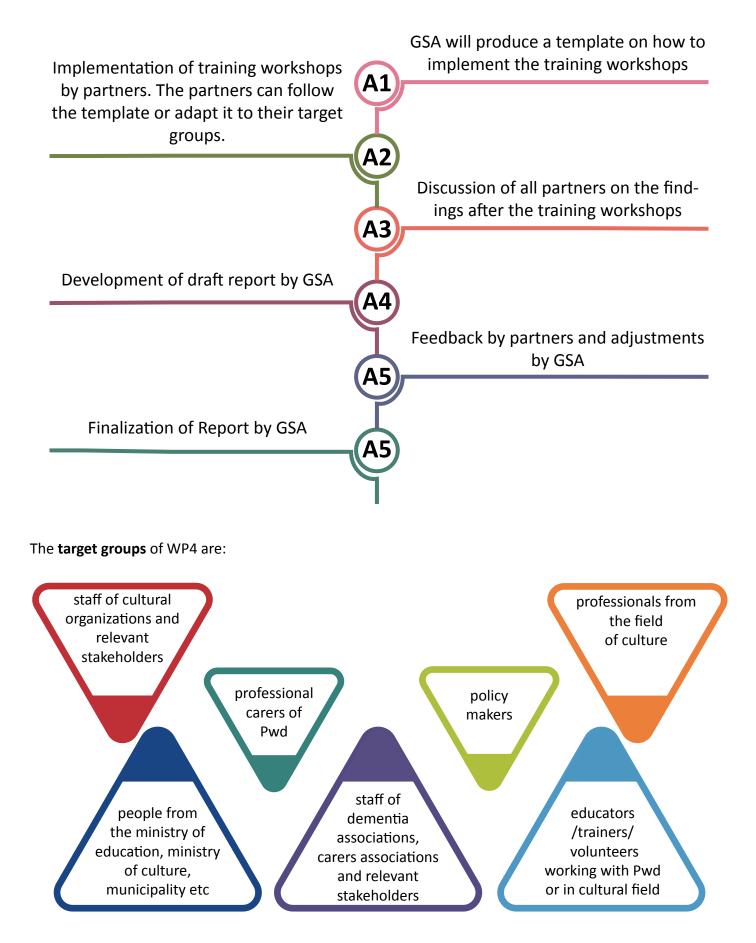
The main results of this WP will be:



Report with final considerations on the methodology of CURATE-D



This WP includes the following tasks:





## WP4-R05 Training Workshops

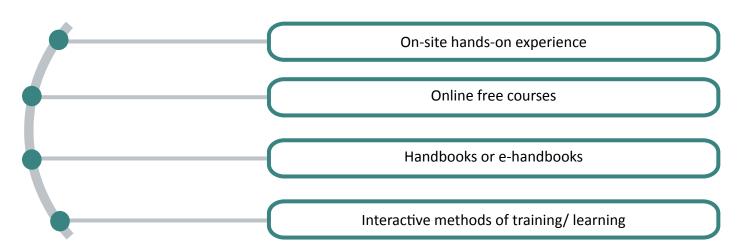
The Gaiety School of Acting will be responsible for monitoring the development piloting training workshops for professional carers and people working in the cultural field. All partners will be asked to implement pilot workshops using all the aforementioned material e.g. this methodological guide, activities included in two learning guides (O2 & O3), testing the Serious Game and activities stemming from.

GSA along with the template on how to implement the pilots, will give advice to facilitators on how to exploit these materials based on experiential learning focusing on empathy building, role playing activities and creative arts activities. After partners implement the pilot workshops, GSA will compile a report including the following topics:

How partners implemented pilot workshops and which were the key findings?

Recommendations regarding the application of methodology Recommendations regarding the further exploitation of the produced material.

Needs derived from research:







26. Image retrieved from Canva Pro



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## Photos/Images

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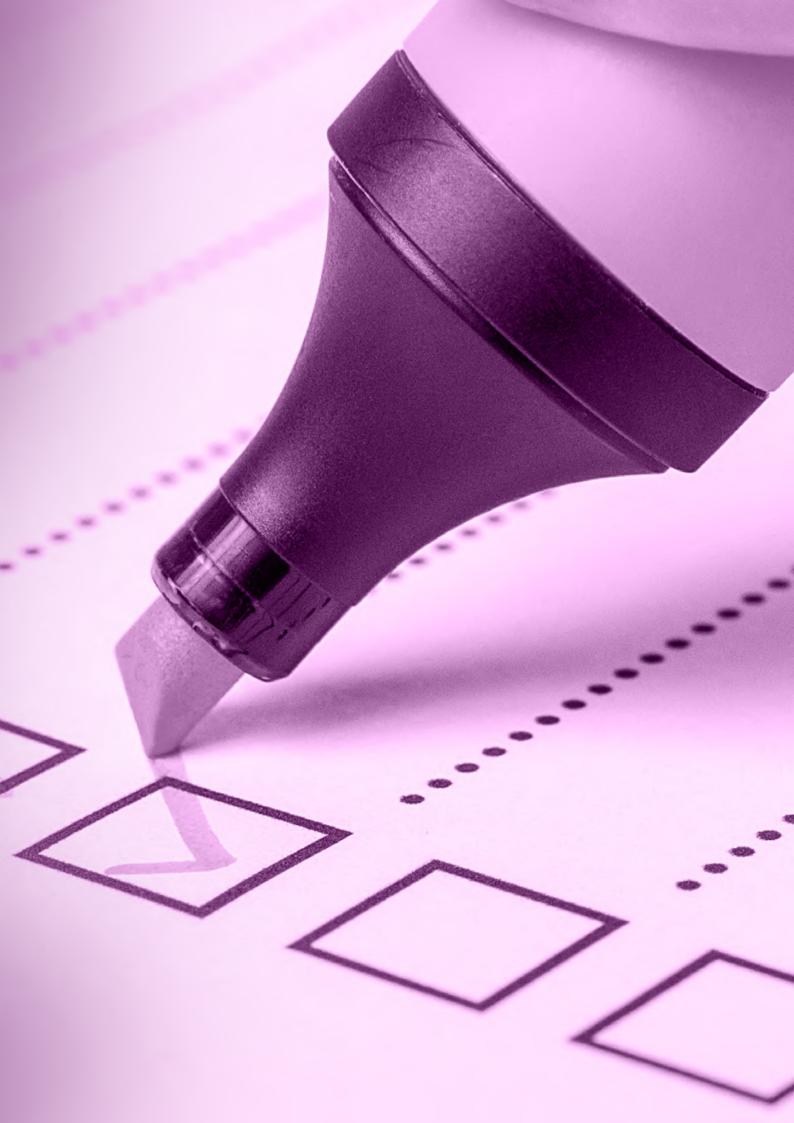
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## CHAPTER ANNEX I



## Questionnaire for research on needs of the target groups

## General questions (ON GOOGLE FORMS)

1. Background information

- •What is your job title/role?
- •What is your professional background? What did you train as?
- •How long have you been working for your organisation / in your field?

Now could you provide me with a bit of information on your work...

2. Your work

- •Could you please tell me a bit about what you do in your organisation / practice?
- •Who are your target groups?
- •What are the aims of the work you do with this target group?
- Do you have a theoretical framework that guides your work? (Please provide explanation)

## B1.Questions for partners associated with people with dementia

Introduction / Greeting

Thank you for agreeing to take part in the interview today. I expect that the discussion will last around 30 minutes. Will that be ok? I have a few questions that aim to understand who you are, the work that you undertake and the impact that you believe it has for people with dementia or their care partners.

So just to begin then...

3. Impact of your work

•Do you know / incorporate any best practices for dementia friendly communities in your work with PwD? •Any specific policies about PwD in cultural spaces / activities?

If yes:

- •What are the benefits?
- •Are there any challenges?
- •How do you address these?

•Can you provide a case study/case studies for some of the work you are doing that we can include in our work? Either highlighting positive benefits or challenges that needed to be overcome.

If no:

- Do you think they are needed?
- •Are there any challenges concerning them in your country / line of work?



## 4. Future impact of your work / Needs

•What support might you require to take your work forward with practices about dementia friendly communities?

- •What challenges might be encountered?
- •How might these can be overcome?
- •Do you think this project will be helpful? How?

## **B2.Questions for partners in cultural field**

### Introduction / Greeting

Thank you for agreeing to take part in the interview today. I expect that the discussion will last around 30 minutes. Will that be ok? I have a few questions that aim to understand who you are, the work that you undertake and the impact that you believe it has for people.

So just to begin then...

**3.** Impact of your work

•Do you know / incorporate any best practices for the inclusivity and accessibility in cultural activities/ spaces?

•What about people with dementia?

If yes:

•What are the benefits?

•Are there any challenges?

•How do you address these?

•Can you provide a case study/case studies for some of the work you are doing that we can include in our work? Either highlighting positive benefits or challenges that needed to be overcome.

If no:

•Do you think they are needed?

•Are there any challenges concerning them in your country / line of work?

4. Future impact of your work / Needs

• Do you think a specialized policy about PwD will help you in your line of work?

•What support might you require to take your work forward with practices about dementia friendly communities?

•What challenges might be encountered?

•How might these be overcome?

•Do you think this project will be helpful? How?



## Game based learning (Both)

What is your preferred learning/training method? (eg seminars, handbook with policies, MOOC etc)

Do you incorporate / know any game-based practices (role playing games, experiential games, storytelling games, board games, serious games etc.) in your field?

If yes:

- •What are the benefits?
- •Are there any challenges?
- •How do you address these?

•Can you provide a case study/case studies for some of the work you are doing that we can include in our work? Either highlighting positive benefits or challenges that needed to be overcome.

If no:

- •Do you think they are needed?
- •Are there any challenges concerning them in your country / line of work?

Do you think that incorporating game based activities/ learning techniques for training your staff would be interesting/helpful?

Thank you for giving up your time. Do you have any other questions/suggestions that we have not covered in the interview?



## **Participant Agreement Form**

**CURATE-D:** A Game-based methodology for empowering Dementia friendly communities and equal access to Culture for people with Dementia, an Erasmus+ project (**Project number: 2022-1-EL01-KA220-VET-000085409**)

This research study is part of CURATE-D project, which aims to develop a game-based methodology through which the people working in the field of culture and professional carers will empower their skills in supporting people with dementia in cultural experiences. You are invited to take part in this research study based on your expertise, in order to explore if there are existing approaches, programs, applications and tools in partner countries and what are the needs of professionals regarding the fields of the project.

The study will involve an interview that will take up to 30 minutes. During this interview you will be asked about the topics mentioned above. The interview will be recorded, so that it can be transcribed later.

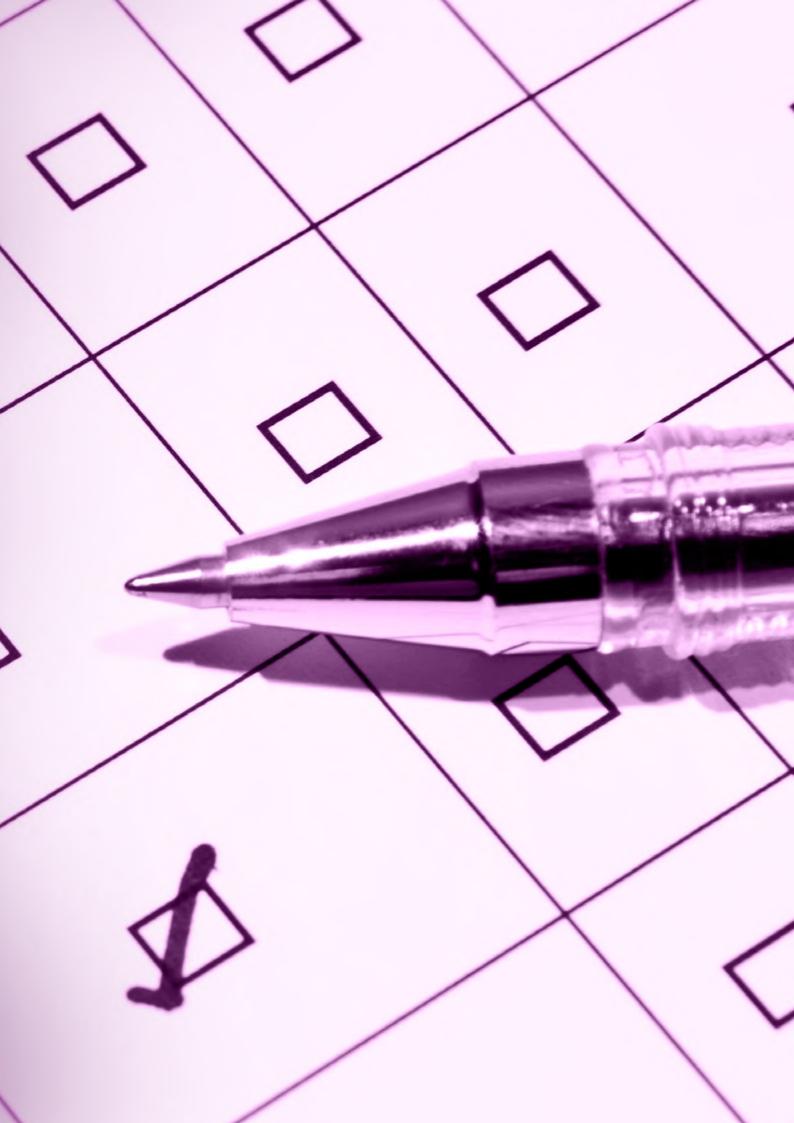
The interview data collected by recording will be processed (transcription). In accordance with the legislation on the protection of personal data,\* all those who have access to this data are obliged to keep confidentiality and sign a confidentiality statement. Your personal data will be collected under the responsibility of the researcher of the CURATE-D Erasmus + program (pr number **2022-1-EL01-KA220-VET-000085409**) and will be treated with confidentiality without disclosing the identity of the participant. None of the interview documents will include a reference to your name. In these documents your name will be replaced by a nickname. The final report will be published on an electronic platform and will be included in a methodological guide and / or announced in a scientific journal / scientific symposium, as it will be a product of the Erasmus+ CURATE-D project. The publication will not include the personal data of the participants, except if the participant asks for some information to be included. In addition, there is a commitment that the results obtained will relate exclusively to the specific project and in no case will serve other research. You may, if you wish, have access to the information concerning you and you have the right to request the correction of this information. We kindly ask for your consent in order to process your personal data in the manner described above. If you wish, you have every right to receive additional information about the processing of your personal data by contacting the Personal Data Protection Authority.

\*REGULATION (EU) 2016/679 OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL on the protection of natural persons with regard to the processing of personal data and on the free movement of such data (General Data Protection Regulation)

**Please Initial here** 



# CHAPTER ANNEX II



I have read and understood the participant agreement form for the above research project	
I confirm that I have had the opportunity to ask questions.	
I understand that my participation is voluntary.	
I understand that I am free to withdraw at any time up to the point of anonymisation	
During the discussion, I am free to withdraw without giving reason and without there being any negative consequences.	
Should I not wish to answer any particular question(s), I am free to decline	
I agree to the use of audio or video recordings during the discussion	
I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the outputs that result from the research.	
I agree to take part in the above research project.	

Name of Participant \_\_\_\_\_

Date \_\_\_\_\_

Signature \_\_\_\_\_

Name of Researcher\_\_\_\_\_

Date\_\_\_\_\_

Signature\_\_\_\_\_

This form should be signed and dated by all parties after the participant receives a copy of the participant agreement form and any other written information provided to the participants. A copy of the signed and dated participant agreement form should be kept with the project's main documents which must be kept in a secure location.





