



EDEN

**Community Collaboration
Concept**

**Identifying the
Participants**

The Project Partners in the Embracing DEmeNtia project are:



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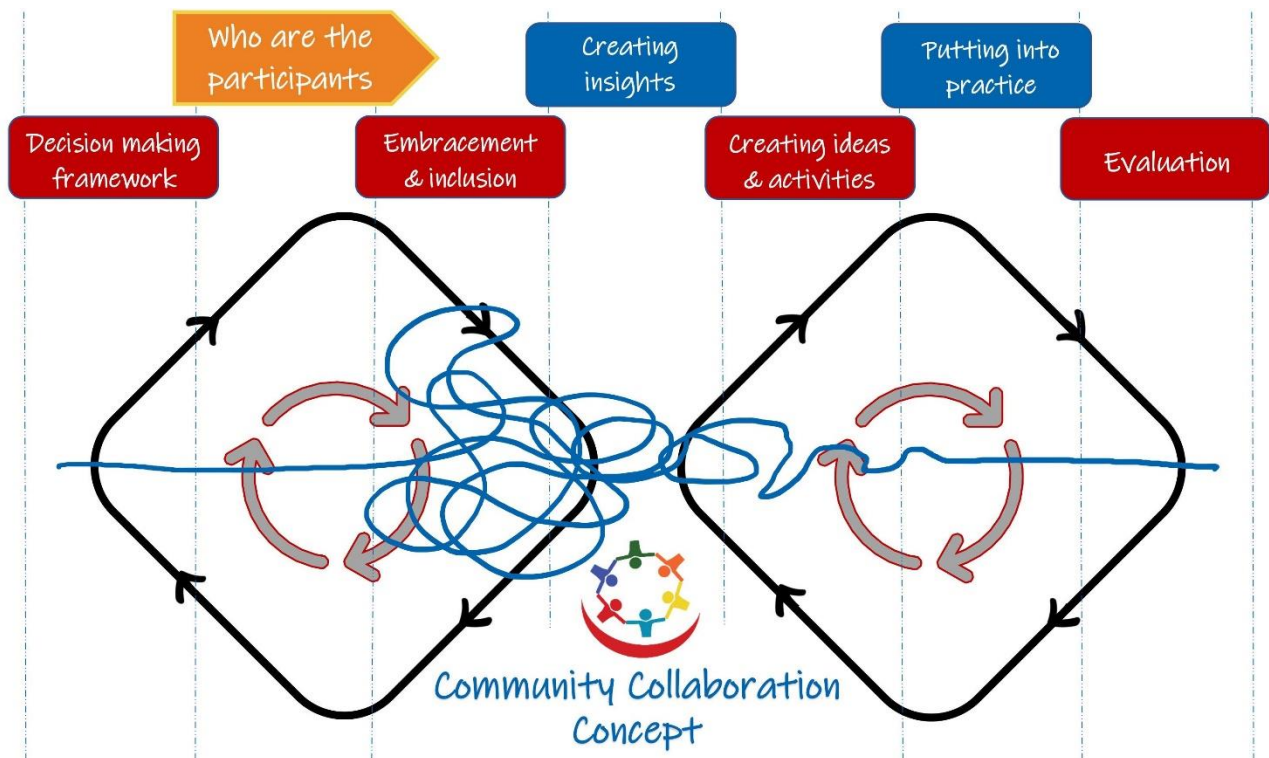
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Identifying the Participants



In this section of the model, it is important to create an overview of the relevant local and maybe national stakeholders that should be involved in the process of creating a community that embraces dementia. The stakeholders can be different from community to community, but for the purpose of describing the community collaboration concept and the process model, a list of 6 categories have been identified, these are;

- 1) Health and Social Care Professionals.
- 2) Relatives.
- 3) People living with Dementia (PwD).
- 4) Social Society Organisations and NGOs.
- 5) Volunteers, common people and schools.
- 6) Local businesses.

Health and Social Care Professionals

The Needs Analysis that was carried through in the EDEN project, shows that HSCPs are very attentive and engaged in establishing tailored care and continuity in the relationship and collaboration with PwD and the relatives. For these professionals the major obstacle in their work is the lack of time and resources combined with the roles of the formal care systems.

An intensified community collaboration combined with shared knowledge about dementia and how to deal with dementia, will support the professionals in taking care of PwD and relatives. The professionals can contribute to the collaboration with knowledge about dementia combined with competences in supporting local collaboration and co-creation.

Relatives

In general, relatives adapt their life and everyday activities and devote their time to the assistance of the PwD. The majority of the relatives has to manage not only PwD's needs but also other competing needs. These included, for example, manage other family necessities (e.g. children's and other family members' needs), face the relationships with multiple formal and informal caregivers, and find time for own needs regarding health, work and social activities. Many participants admitted that they did not feel adequate, ready and trained for their role of caregiver, as well as they needed for personal support to accept the diagnosis of dementia and to manage the difficulties of their life.



The relatives call for more information about the disease and how to support their beloved one. Furthermore, the relatives lack recognition, acknowledgement and understanding and often feel rather excluded from their former friends and relations.

Community collaboration is a way of practising social inclusion and will acknowledge the efforts given by the relatives. The connection between the Community Collaboration Concept and the learning and teaching materials also supports the relative's knowledge about the diagnosis and how to deal with the role as a relative and caregiver.

People living with dementia

Despite loss of cognitive abilities, PwD are still experts in their own life. They have, as everyone else, dreams and expectations for their life and know what brings quality and meaning into their everyday living. They are in the early stages of the disease able to participate active in local community activities and thereby contribute to the society. Therefore all activities for PwD have to be performed with the person. As the disease progresses they might lose ability to contribute and to express their wishes and desires in verbal, but it is still important to include them and their interests in the collaboration and activities.

Civil Society Organisations and NGOs

CSOs are usually psychological and social support organizations structured on a voluntary basis and are most often only partially publicly funded aimed at supporting PwD and their relatives. The Needs Analysis shows that despite services offered by the CSOs varied and the connection with public system/health and social care providers were different among the countries, their main and common role was support and help families by replacing the lack of official health care system support.

The CSOs have the ability to create "bridges" between the professionals and the relatives, not obliged to delivering professional care and not burdened by politically or legally decided tasks. By offering support, the CSOs also express understanding, compassion and acknowledge the relatives.

Volunteers, common people like neighbours and schools

Very often, the volunteers are engaged through the civil society organisations, that very often collaborates closely with local authorities in order to align the voluntary activities that is provided so that it supports and complements in the best way, the official and publicly funded health- and social care and cure interventions.

But volunteers can also be seen as common people like neighbours, colleagues and friends, as they can support and make the understanding of embracing dementia real, by doing little things in the daily life

such as showing compassion, empathy and understanding, and by listening and visiting the homes where dementia is a part of daily life.

Young people and schools can also become a resource. Since 2012, when the “European Year for Active Ageing and Solidarity between Generations”, was implemented, this theme has been high on the European political agenda, and member states and communities are encouraged to explore opportunities where generations meet activities, where generations support each other with their different resources to create win-win situations.

If you want to know more about good practices and stories in this field, we invite you to visit the AGE Platform Europe News section: <https://www.age-platform.eu/good-practices/intergenerational-solidarity>

In the tips and tricks section in chapter 6, posters are available which can be used to raise awareness on how neighbours and citizens can participate to assist PwD in their daily life.

Local Businesses

Collaboration with local businesses should be constructed with a win-win approach; by giving something to the local community, a local business should gain something else.

PwD and their relatives are consumers like all other citizens, but with special needs in relation to the fact that dementia is a very important part of their lives. Local businesses can therefore participate in creation local communities that embraces dementia, by e.g. sponsor ships to create physical environments that makes it easy for PwD and their relatives to participate in social and community activities. On the other hand, the local business can design physical and / or online structures which makes their business “dementia friendly”, which the local community is engaged to use and promote towards PwD and their relatives.

In the tips and tricks section in chapter 6, a lot of posters that can be used to raise awareness towards the different stakeholder that have been mentioned here, are available for download and adaption to the specific local community that wants to work with the Community Collaboration Concept.