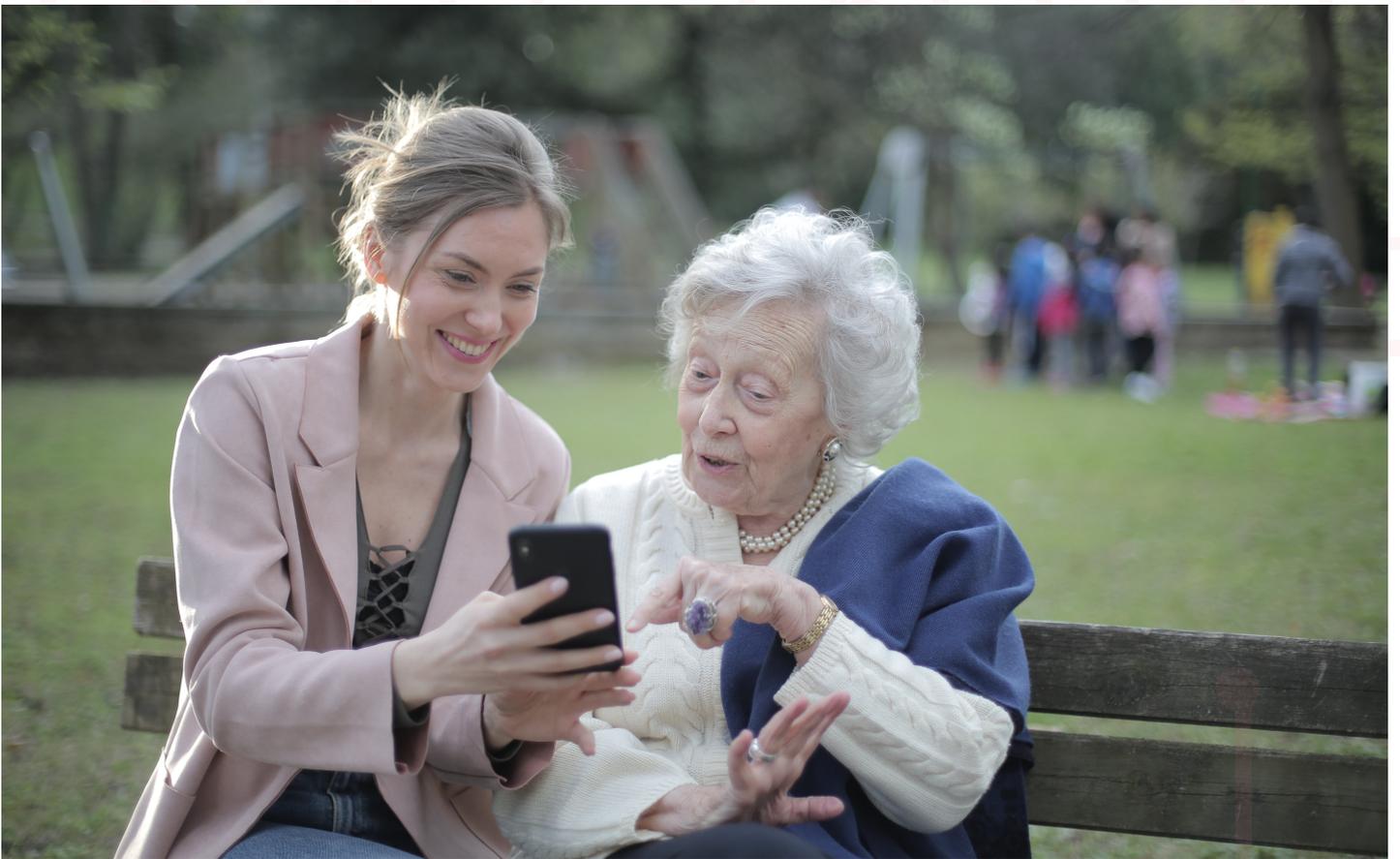


Co-Care

2020

# State of play report on co-created ICT-based Alzheimer care solutions



Co-Care

Co-created ICT solutions for Alzheimer's Informal Caregiving

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## List of terms and abbreviations

Instituto Politécnico de Setúbal	IPS
Non-Applicable	NA
Randomized Controlled Trial	RCT
Work package	WP



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## Executive Summary

This document reports the work implemented during WP 1, where a literature review was conducted in order to know the status of co-created ICT-based Alzheimer care solutions, specifically for Spain, Portugal and UK, in the last five years. It was intended to describe, analyse and classify solutions and the underlying process of design and development of those solutions.

The strategy adopted to conduct this literature review is described, specifying research questions, type of documents included, databases selected, and criteria for data extraction. A total of 174 documents have been collected and analysed. The documents spanned the period between January 2015 and April 2020 and were divided into five categories: journal articles, grey literature (including dissertations), policy documents, research projects, training, and experiences/actions. The key terms used in the search process were agreed between consortium partners and include among others: “Alzheimer”, “Caregiver”, “Support”, “Digital solution”, “Web application”, “Online community”, “Co-creation”, “Co-design”.

Two level analysis was carried out and results are presented according to the research questions that guided this literature review. Final results showed that there are already available solutions focusing on specific needs of caregivers, providing technological tools that may improve their practical life and well-being, however, we are still lacking technological/digital resources in many relevant domains.

Another relevant finding that emerged from this review, concerns the process followed for the design of solutions. Participatory methods are not yet implemented in this field of research and when caregivers are included in the process of design their involvement is mostly passive. Moreover, the available solutions are still at an early stage of development, since most of it are at the level of exploration and initial implementation. One can foresee that an actual development in terms of research methods and design can promote higher levels of implementation. In fact, WP1 findings suggest that there is space to improve user-led design and co-creation needs in the process of design of ICT solutions focusing the informal caregiving of Alzheimer patients.

## 1.- Introduction / About this document

One of the main goals of Co-Care is to develop design-enabled co-production of ICT-based Alzheimer care solutions for informal carers. Specifically, this project aims at preparing a training course for ICT, health & social care students and entrepreneurs, and developing a toolkit for informal caregivers, so they can choose technological tools that may help them in their daily life. However, to develop such tools, it is essential to have an overview of the already existing ICT-based solutions for the informal caregivers of people with Alzheimer's disease, designed through co-creation.

To obtain a detailed and comprehensive view of the current evidence and state of art, and map the existing national and European level actions on co-created ICT-based Alzheimer care solutions, a literature review was performed. This review is also intended to identify limitations and gaps regarding the caregivers' needs that are not yet supported, and to explore to what extent have these solutions been created integrating the caregivers into the design process.

This document is structured as follows:

- **Chapter 2** presents the methodology adopted to perform the literature review, where the guiding research questions, the type of documents, the databases selected, and the criteria for data extraction are specified.
- **Chapter 3** presents the results obtained from the literature review, where findings are synthesised both quantitatively and qualitatively. This section is structured according to the seven research questions that have guided the analytic approach.
- **Chapter 4** presents the main findings and conclusions about the caregivers needs and the development process of ICT-based solutions supporting informal caregiving of Alzheimer patients, and the main research gaps are identified.

## 2.- Methodology

To know the status of the co-creation ICT-based Alzheimer care solutions, a literature search was performed in different databases (e.g. EBSCO, B-On, PubMed, Medline, The Collection of Computer Science Bibliographies, Open Grey, Dart-Europe). The selection of databases was guided by the type of documents that were targeted (journal articles, grey literature, research projects, policy documents and existing trainings). A complete overview of the type of documents, databases and other sources are presented at Appendix 1.1.

The search spanned the period from January 2015 to April 2020, to ensure that the most recent digital solutions for Alzheimer's caregivers were captured. Search terms were selected taking into account four main questions: 1) the first refers to the context that solutions focusing on caregivers of people with Alzheimer's should address, therefore the disease needs to be present (Context/What? – Illness); 2) the second question refers to the target population of solutions (Target/who? – Carers); 3) the third question reflects the virtual / technological environment of solutions (Environment/where? – Technology); 4) the last question focuses on a collaborative creation process (Process/how?). A number of key terms associated with these questions were selected and agreed between consortium partners. Examples of key search terms included: "Alzheimer", "Caregiver", "Support", "Digital solution", "Web application", "Online community", "Co-creation", "Co-design". Searches contained a combination of key terms from these four domains, and were performed in English, Spanish and Portuguese. For a complete list of search terms, see Appendix 1.2.

Documents retrieved from each database were imported into Mendeley, and any duplicates were removed. Additionally, to avoid duplication, identification tables for each type of document were also uploaded at Teams platform.

Data extraction spreadsheets were designed according to the type of document to capture pertinent information for analysing the status of the co-creation ICT-based Alzheimer care solutions. Thus, four different spreadsheets were designed to collect information from journal articles, grey literature and research projects; experiences/actions; policy documents; and trainings. Initially, these spreadsheets were filled in at national level for first level data extraction and afterwards, all the spreadsheets were merged and harmonised for conducting second level data extraction and final analysis of results.

The next Gantt chart presents the schedule of activities conducted over the literature review.

	March	April	May	June	July
Planning search strategy					
Data collection					
First level data extraction by each partner					
Second level data extraction and final analysis by leading team					

Table 1. Gantt chart of literature review

The process of search and analysis of literature review was guided by seven research questions. The first two focused on the needs of caregivers and on the improvement of their quality of life since we wanted to learn more about the contribution and added-value of ICT-based Alzheimer care solutions in the concrete life of caregivers:

Q1. Are there technological/digital solutions designed to improve the life of Alzheimer’s (informal) caregivers?

Q2. Are the solutions designed to meet the needs of caregivers?

Because we wanted to explore and map the existing ICT-based Alzheimer care solutions according its purpose, level of implementation and also to analyse if the process used for design is user-centred, we raised the third question:

Q3. Can we classify these solutions according to the purpose of the solution, the process followed for the design and the level of maturity achieved?

The fourth question also focused on the design process of ICT-based Alzheimer care solutions, most specifically in the type of involvement that caregivers have during the process and at which stage:

Q4. Are the caregivers included in any step of the process? Which?

Because we were also interested in mapping the scientific status of ICT-based Alzheimer care solutions, we raised the next question:

Q5. Are the solutions evidence-based?

This review also focused on the level of expansion of ICT-based Alzheimer care solutions into different contexts:

Q6. To what extent these solutions have been scaled-up? (other organizations, contexts, countries...)

Finally, we were also interested in mapping the existing trainings in the field co-created ICT-based Alzheimer care solutions in Portugal, Spain and the UK, so the last question has been raised:

Q7. Is there any training for caregivers, designers/providers of technology (or students), healthcare professionals (or students) in the area of co-created ICT-based Alzheimer care solutions?

The presentation of results in the next chapter is organised according to the research questions mentioned above.



### 3.- Results

After completing the literature search, a total of 174 documents have been collected and analysed. Chart 1 presents the distribution of data in terms of percentages according to the type of document collected. Journal Articles represent the most frequent category, whilst policy documents and research projects are the least frequent.

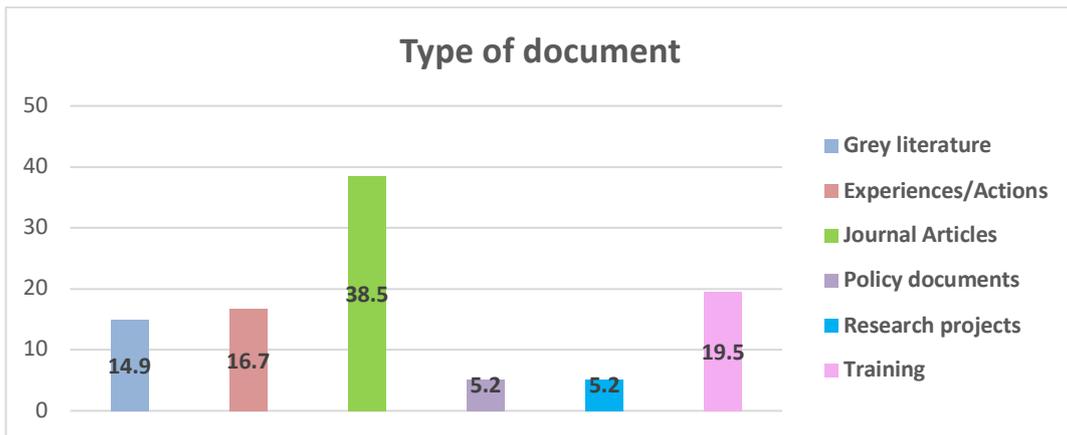


Chart 1. Type of document

Considering the year of publication or dissemination, chart 2 presents the distribution of documents in percentages throughout the time range of 2015-2020. 2019 reflects an increase in the number of publications.

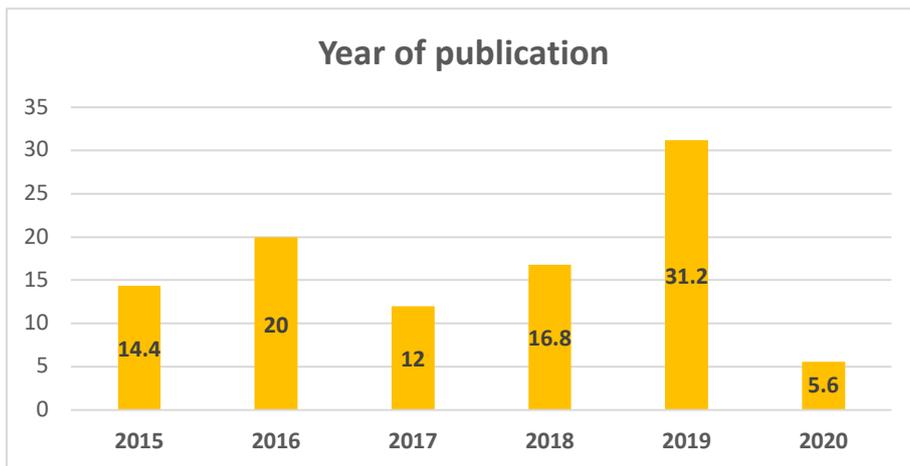


Chart 2. Year of publication

Considering experiences/actions, chart 3 presents the distribution of documents in terms of time range of publication or dissemination. Most of these examples are still current (75%).

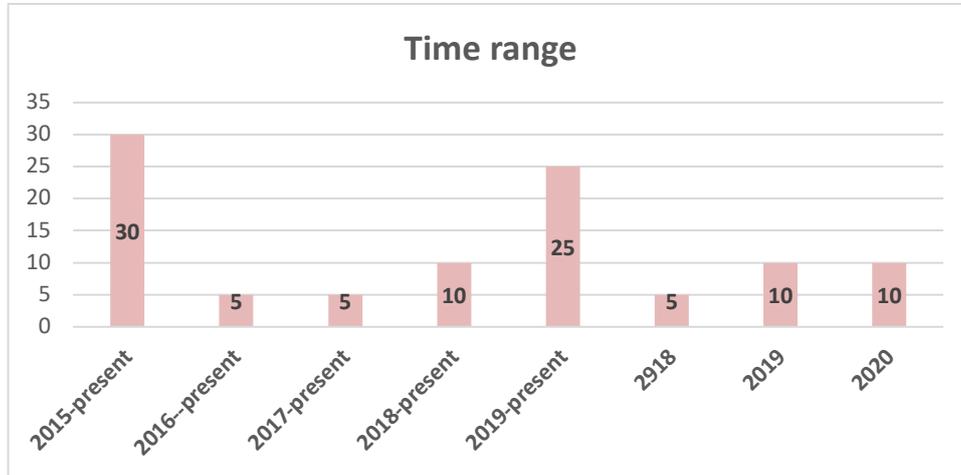


Chart 3- Time range of experiences/actions

Table 2 presents the distribution of documents considering the countries of origin of solutions. As expected, most of these solutions were developed in European countries, and Spain is the most frequent country in our sample. Among Non-European countries, USA is the most represented.

Countries of origin	N	%
European Countries	92	76
Netherlands	11	
Spain	22	
UK	18	
Non- European Countries	29	24
USA	19	
Total	121	100%

Table 2- Countries of origin of solutions, considering journal articles, grey literature and research projects.

the distribution of documents considering countries of application of solutions or implementation of policies is presented in table 3. As expected, most of these are related to European countries, and Spain remains the most represented country. Among Non-European countries, USA is the most frequent one.

Countries of implementation	N	%
European Countries	97	74,6
Netherlans	11	
Spain	24	
UK	19	
Non- European Countries	30	23,1
USA	19	
International	3	2,3
Total	130	100%

Table 3- Countries of application of solutions or implementation of politics, considering journal articles, grey literature, research projects and policy documents.

After the description of the sources that have been found, the research questions raised will now be addressed. The following sections of data analysis are organised according to our research questions.



### Q1: Are there technological/digital solutions designed to improve the life of Alzheimer’s (informal) caregivers?

To be able to answer the first research question we have analysed if solutions presented in literature are specifically focused on the needs and demands of Alzheimer caregivers’ life. As table 4 shows, most of the data collected is Alzheimer related (81%).

Specific for Alzheimer	N	%
Yes	79	80,6
No	19	19,4
Total	98 <sup>1</sup>	100%

Table 4 – Documents specific for Alzheimer, considering journal articles, grey literature and research projects.

A brief qualitative analysis of documents suggest that these solutions provide tools that may contribute to meet information needs and improve self-efficacy and competence of caregivers (e.g. care-giving tasks, manage dementia symptoms); improving accessibility to health professional without leaving the house; improving emotional support, reducing burden, anxiety, stress and its negative outcomes and increasing opportunities for positive interactions and support.

Results related to caregivers needs and the purpose of ICT solutions can give more information about specific areas of caregivers’ quality of life that are targeted in literature.

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<sup>1</sup> Missing data excluded.

## Q2: Are the solutions designed to meet the needs of caregivers?

To analyse this research question we have assessed if there is an explicit reference to the needs of caregivers in literature but also the type of needs which are addressed. According to table 5, the needs of caregivers are included in 65% of the data collected.

Talk about covering needs of caregivers'	N	%
Yes	71	64,5
No	39	35,5
Total	110 <sup>2</sup>	100%

Table 5 – Reference to caregivers' needs considering journal articles, grey literature, research projects and policy documents.

The type of needs that are covered by literature were classified according to the proposal of Queluz et al. (2020) and table 6 presents an overview of these results. Planning (mainly information about dementia and dementia care), personal health (mostly psychological health) and caregiving tasks (mainly physical/nurse care and supervision/support) are the most represented needs. Topics related to financial costs are the less frequent in literature, whilst housing matters and juggling responsibilities are absent from the documents collected by the different partners.

Classification of caregivers needs	N	%
<b>1. Caregiving tasks</b>	<b>25</b>	<b>25,2</b>
1.1 Physical/nurse care	10	10,1
1.2 Household work	1	1,0
1.3 Supervision/support	13	13,1
1.4 Coordination	----	----
1.5 Help received from others (informal/formal)	1	1,0
<b>2. Relationship with formal service providers</b>	<b>6</b>	<b>6,1</b>
<b>3. Housing</b>	---	---
<b>4. Juggling responsibilities</b>	---	---
<b>5. Financial costs</b>	<b>1</b>	<b>1,0</b>
<b>6. Personal Health</b>	<b>27</b>	<b>27,3</b>
6.1 Physical health	5	5,1
6.2 Psychological health, acceptance of changes to identity, sense worth/ self	22	22,2
<b>7. Relationships</b>	<b>9</b>	<b>9,1</b>

<sup>2</sup> NA excluded.

7.1 With care recipient		6	6,1
7.2 With family		3	3,0
<b>8. Planning</b>		<b>32</b>	<b>32,3</b>
8.1 Crises planning		---	---
8.2 Future planning		3	3,0
8.3 Information about professional support and formal services		7	7,1
8.4 Information about dementia and dementia care		21	21,2
8.5 Information about legal regulation in caring		---	---
TOTAL		99 <sup>3</sup>	100%

Table 6 – Classification of caregivers needs based on the typology of Queluz et al. (2020).

For a more descriptive view of caregivers’ needs found in literature some examples of each category are presented in table 7.

	Classification of caregivers needs	Description
1. Caregiving tasks	1.1 Physical/nurse care	. To support the caregivers and health professionals that direct nonpharmacological therapies in patients with early and moderate Alzheimer diseases;
		To provide caregivers access to exercises for patients; Medication, care and cures, pain management and symptoms.
	1.2 Household work	Support with shopping and on all aspects of meal making, particularly forms of shopping they are used to (online or accessed via car/transport).
	1.3 Supervision/support	to enhance the care recipients’ independence
Caregivers of people with dementia do not understand their needs correctly		
1.5. Help received from others (informal/formal)	To avoid carers getting exhausted	
	Receiving support when dealing with the difficulties of caregiving.	
2. Relationship with formal service providers		To improve information exchange between healthcare professionals and patients with dementia and their family caregivers to maintain autonomy and continuity in their lives.

<sup>3</sup> More than one category identified.

		Counselling multidisciplinary healthcare and communication between equals, avoiding the feeling of loneliness.
5. Financial cost		To plan and dimension resources, services, supports, solutions and treatments.
6. Personal Health	6.1 Physical health	To improve caregivers' physical health care as it has a negative impact on the quality of life and well-being of individuals.
		Participants found the ICT intervention empowering, valuable and acceptable in improving sleep. In addition, they formulated individualised strategies for self-care and relaxation as part of the sleep routine.
	6.2 Psychological health: acceptance of changes to identity; sense worth/ self	The need of improving psychological symptomatology among dementia caregivers through executive control improvement once caregivers appear to reduce learning, memory, attention and problem solving.
		The need of a psychological support for carers (e.g. negative emotions, burden, self-efficacy) through professional facilitated peer support virtual community.
7. Relationships	7.1 With care recipient	The need of caregiver put himself on patients position and improve their relationship.
		To improve the quality of live, wellbeing and medication adherence and enable to live well in the community for as long as possible.
	7.2 With family	The need of improving role and relationship changes to balance caregiving responsibilities.
8.Planning	8.2. Future planning	The need for alternative methods to presential (conventional) of delivering support once caregivers often has constraints of time, distance, etc.
	8.3. Information about professional support and formal services	The need of a close, easy, fast and accessible health professional contact without leaving the house.
		To provide easy access to communicate with health care professionals.
	8.4. Information about dementia and dementia care	Information about support services and local resources
The need for organized information about dementia and dementia care exposed in an interactive and easy way to access.		
		The paper identified the need for family caregivers to acquire skills and strategies to effectively manage dementia symptoms.

		The paper identified the need of an online resource for dementia caregivers that generates tailored support recommendations.
		To improve caregiver competence, e.g. being able to handle caregiving problems.

Table 7 – Description of the caregivers needs found in literature based on the classification of Queluz et al. (2020).



**Q3: Can we classify these solutions according to the purpose of the solution, the process followed for the design and the level of maturity achieved?**

To analyse this research question we have started to assess the main purpose of ICT-based Alzheimer care solutions found in literature according to the typology of Lorenz et al. (2019). As table 8 shows, ‘Support of self-care and activities of daily living (of the person with Alzheimer)’, ‘Care delivery, management and support’, and ‘Social interaction and networking’ are the most frequent categories in literature. On the other hand, ‘Self-care of carer’ is the less represented purpose.

Purpose of the ICT-based Alzheimer care solution	N	%
1. Support of self-care and activities of daily living (of person with Alzheimer)	21	18,6
2. Self-Care (of the carer)	3	2,7
3. Treatments and interventions delivery -	8	7,0
4. Safety, security, monitoring and reassurance	14	12,4
5. Training	16	14,2
6. Care delivery, management and support	21	18,6
7. Social interaction and networking	19	16,8
8. Other	11	9,7
TOTAL	113 <sup>4</sup>	100%

Table 8 – Classification of the purpose of the ICT-based Alzheimer care solution based on the typology of Lorenz et al. (2019)

Secondly, we have crossed the purpose of ICT solutions with caregivers needs to assess if there are any particular associations between these two dimensions of analysis. This way we can evaluate if there are specific needs being more covered through technological solutions and which type of answers or support do these solutions provide to caregivers. Table 9 shows that ‘Planning: Information about dementia and dementia care’, ‘Personal health: psychological health’, ‘Caregiving tasks: supervision/support’ and ‘Caregiving tasks: physical/nurse care’ are the needs with more ICT solutions available or under development. For the first need, the most frequent solutions are related to ‘Training’ and ‘Support of self-care and activities of daily living’. ‘Personal health: psychological health’ is mostly associated to solutions of ‘Self-care (of the carer)’. And for both categories of ‘Caregiving tasks’, the most common solutions are related to ‘Care delivery, management and support’.

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<sup>4</sup> More than one category identified.

Caregivers' needs	Purpose of the ICT-based Alzheimer solutions								Total
	Support of self-care and activities of daily living	Self-Care (of the carer)	Treatments and interventions delivery	Safety, security, monitoring and reassurance	Training	Care delivery, management and support	Social interaction and networking	Other	
Caregiving tasks: physical/nurse care	1	1	2	1	1	5	1	-----	12
Caregiving tasks: household work	1	-----	-----	-----	-----	-----	-----	-----	1
Caregiving tasks: supervision/support	3	1	4	3	1	6	-----	-----	18
Relationship with formal service providers	-----	-----	1	1	-----	2	2	----- -	6
Personal Health: physical health	1	1	-----	-----	-----	1	2	-----	5
Personal health: psychological health	2	8	-----	1	2	2	4	----- -	19
Relationships: With care recipient	1	1	1	1	1	2	1	1	9
Relationships: With family	1	-----	-----	-----	-----	-----	-----	-----	1
Planning: Future planning	1	-----	-----	-----	-----	1	1	-----	3
Planning: Information about professional support and formal services	1	1	-----	-----	-----	5	1	-----	8
Planning: Information about dementia and dementia care	5	1	-----	2	7	3	4	-----	22
Planning: Information about legal regulation in caring	-----	1	-----	-----	-----	-----	-----	-----	1
<b>TOTAL</b>	<b>17</b>	<b>15</b>	<b>8</b>	<b>9</b>	<b>12</b>	<b>27</b>	<b>16</b>	<b>1</b>	<b>105<sup>5</sup></b>

Table 9 – Caregivers needs by the purpose of the ICT-based Alzheimer care solution

<sup>5</sup> Some categories have been identified more than once.

To analyse the process followed for the design of ICT solutions, a number of key-terms focusing on a user-centred approach were searched in literature. As table 10 shows, these terms were absent from 85% of the documents found, but still, co-design was the most present search term.

Optional search terms	N	%
No	79	84,9
Co-production	1	1,1
Co-creation	2	2,2
Co-design	8	8,6
User-centred	3	3,2
TOTAL	93	100%

Table 10 – Optional search terms related to design process

We have also crossed the search terms with the methods identified in studies to assess particular associations between these two dimensions of analysis. As table 11 shows, co-creation, co-design and user-centred design were associated with twelve different methods and co-design reflects a larger diversity of methods used.

Optional search terms	Method	N
Co-Creation	Case study	1
	Qualitative design	1
Co-Design	Convergent parallel design	1
	Descriptive study	1
	Interventional study	1
	Lab study	1
	Qualitative study	2
	RCT	1
User-centred	Qualitative design	3
TOTAL		12 <sup>6</sup>

Table 11 – Search terms by method of study.

To evaluate the level of maturity of ICT-solutions, the level of implementation was also assessed. As table 12 shows, most of the solutions are still under development, either in a stage of exploration or at initial implementation.

<sup>6</sup> Reviews/revisions excluded.

Level of implementation	N	%
1. Exploration	24	34,8
2. Initial implementation	24	34,8
3. Full implementation	19	27,5
4. Expansion and scale up	2	2,9
TOTAL	69	100%

Table 12 – Level of implementation of ICT-solutions

We further explored the level of implementation by crossing it with the purpose of solutions to see if there are specific domains with more investment in terms of technological development, however no specific patterns are found as table 13 shows. As it has been seen before, ‘Support of self-care and activities of daily living’ and ‘Care delivery, management and support’ are the solutions more frequently found in literature and their level of maturity is distributed across levels 1, 2 and 3.

Level of implementation	ICT-solution purpose								Total
	Support of self-care and activities of daily living	Self-Care (of the carer)	Treatments and interventions delivery	Safety, security, monitoring and reassurance	Training	Care delivery, management and support	Social interaction and networking	Other	
1.- Exploration	7	6	1	1	3	3	1	2	24
2.- Initial implementation	3	4	2	4	2	5	5	2	27
3.- Full implementation	5	---	4	1	1	6	6	--	23
4.- Expansion and scale up	----	----	----	----	1	1	----	----	2
Total	15	10	7	6	7	15	12	4	76

Table 13 - Level of implementation of ICT solutions by ICT solution purpose

We also analysed if the level of implementation of solutions is more frequently associated with specific categories of caregivers needs by crossing these two dimensions of analysis. As table 14 shows, solutions in exploration stage are the most common (n= 31) and ‘Planning: Information about dementia and dementia care (8.4)’ and ‘Caregiving tasks: supervision/support (1.3) are more frequently developed at this level.

Level of implementation	Caregivers Needs												Total
	1.1	1.2	1.3	2	6.1	6.2	7.1	7.2	8.2	8.3	8.4	8.5	
1.- Exploration	2	1	6	1	1	4	2	1	2	3	7	1	31
2.- Initial implementation	2	----	2	1	2	9	2	----	----	1	4	----	23
3.- Full implementation	2	----	3	1	1	4	2	----	1	1	4	----	19
4.- Expansion and scale up	----	----	1	-	----	1	----	----	----	----	1	----	3
<b>Total</b>	<b>6</b>	<b>1</b>	<b>12</b>	<b>3</b>	<b>4</b>	<b>18</b>	<b>6</b>	<b>1</b>	<b>3</b>	<b>5</b>	<b>16</b>	<b>1</b>	<b>76<sup>1</sup></b>

Table 14 – Level of implementation of ICT-solutions by caregivers needs



**Q4: Are the caregivers included in any step of the process? Which?**

To analyse this research question we have focused on the participation of caregivers in the process of design, specifically in terms of frequency and type of involvement. As table 15 shows, caregivers are more often included in the process (52%) even if the difference is very small when compared to when they are absent.

Caregivers included	N	%
Yes	40	51,9
No	37	48,1
TOTAL	77	100%

Table 15 – Inclusion of caregivers in the process of design

Looking at how are caregivers included in the process, table 16 shows that they are mostly involved after the design stage. Giving feedback to refine and improve solutions is the most common way.

Caregivers included – How?	N	%
Design and future test	1	5
Analysis	1	5
Design and pilot	2	10
Giving information	2	10
Pilot/test	1	5
Contribute to refine the app and potential improvement	13	65
TOTAL	20	100%

Table 16 – How are caregivers included in process of design

A more detailed description of the way’s caregivers are included in the process of design is presented in table 17.

Caregivers included – How?
Informal caregivers contribute to refine the program through their feedback;
Caregivers could explain what the requirements they consider important in a technological solution for it be useful.
Caregivers gave information about what they want to learn and assess in an app.
Potential users’ views were integrated in the development and validation of the program content.
Informal carers were able to contribute with their opinions, needs and possible improvements.

Experts create a starting set of prototype images which are then culled and refined based on participant feedback.

Table 17 – Description of the ways caregivers are included in the process of design.

To further explore the involvement of caregivers in the process of design we have crossed this dimension with the purpose of the ICT-solutions. This way we can assess if there are specific domains where caregivers are more frequently included. As table 18 shows, caregivers are more frequently involved in the design of solutions related to ‘Care delivery, management and support’.

From the caregivers included (Yes), the purpose of the ICT care solution associated is:	N	%
1. Support of self-care and activities of daily living (of person with Alzheimer)	8	17
2. Self-Care (of the carer)	5	10,6
3. Treatments and interventions delivery	3	6,4
4. Safety, security, monitoring and reassurance	3	6,4
5. Training	5	10,6
6. Care delivery, management and support	15	31,9
7. Social interaction and networking	6	12,8
8. Other	2	4,3
<b>TOTAL</b>	<b>47</b>	<b>100%</b>

Table 18 – Distribution by the purpose of ICT-care solution when caregivers are included.

### Q5: Are the solutions evidence based?

To analyse this research question we have assessed the level of evidence of ICT-solutions found in scientific literature according to the SIGN grading system and afterwards a more detailed analysis of methodology was undertaken considering study method, sampling method, sample size and instruments used for data collection in each level evidence-based.

Table 19 presents the overall results of the level of evidence of the scientific literature. The most frequent level found corresponds to Expert Opinion (43%), however 48% of the literature found is evidenced based (1<sup>+</sup> to 2<sup>-</sup>). Considering the later, level 1 Meta-Analyses, systematic reviews or RCT's with a high risk of bias, are the most represented.

SIGN Level	N	%
1++ High quality meta-analysis, systematic review or RCTs with a very low risk of bias	0	----
1+ Well conducted meta-analyses, systematic reviews or RCTs with low risk of bias	4	6,7
1 <sup>-</sup> Meta-Analyses, systematic reviews or RCT's with a high risk of bias	13	21,7
2++ High quality systematic reviews of case control or cohort or studies	5	8,3
2++ High quality case control or cohort studies with a very low risk of confounding or bias and a high probability that the relationship is causal	----	----
2+ Well-conducted case control or cohort studies with a low risk of confounding or bias and a moderate probability that the relationship is causal	1	1,7
2 <sup>-</sup> Case control or cohort studies with a high risk of confounding or bias and a significant risk that the relationship is not causal	6	10
3 Non-analytic studies, e.g. Case reports, case series	5	8,3
4 Expert opinion	26	43,3
TOTAL	60	100%

Table 19 – Level of evidence of literature according to SIGN grading system

To further explore methodological aspects of evidenced-based ICT-solutions a comparative and more detailed analysis is presented in the following tables.

Looking at the research methods found in scientific literature evidence-based, table 20 shows that RCT's are most frequent in studies of level 1<sup>-</sup>, systematic reviews are similar in studies of level 1<sup>+</sup> and level 1<sup>-</sup> and scoping reviews more frequently chosen for studies of level 2<sup>++</sup>. Mixed methods are more present in literature of level 2<sup>-</sup>.

Research Method	Level 1 <sup>+</sup>		Level 1 <sup>-</sup>		Level 2 <sup>++</sup>		Level 2 <sup>+</sup>		Level 2 <sup>-</sup>	
	N	%	N	%	N	%	N	%	N	%
RCT	1	25	7	53,8%	-	-	-	-	-	-
Systematic Review	3	75	4	30,8%	1	20	-	-	-	-
Scoping Review	-	-	2	15,4%	4	80	-	-	-	-
Quasi experimental longitudinal	-	-	-	-	-	-	1	100	-	-
Quasi experimental design	-	-	-	-	-	-	-	-	2	33,3
Mixed Method	-	-	-	-	-	-	-	-	4	66,7
Total	4	100%	13	100%	5	100%	1	100%	6	100%

Table 20 – Research methods by level of evidence

Considering sampling methods used in research evidence-based collected for this literature review, table 21 shows that random sampling is most frequently chosen as a method (level 1<sup>-</sup>), however the total number of studies included in our sample is very small (n= 13).

Sampling method	Level 1 <sup>+</sup>		Level 1 <sup>-</sup>		Level 2 <sup>+</sup>		Level 2 <sup>-</sup>	
	N	%	N	%	N	%	N	%
Convenience Sampling	1	100	2	33,3%	-	-	2	40
Random Sampling	-	-	4	66,7%	1	100	1	20
Purposive Sampling	-	-	-	-	-	-	1	20
Snowball Sampling	-	-	-	-	-	-	1	20
Total	1 <sup>7</sup>	100%	6 <sup>9</sup>	100%	1	100%	5 <sup>8</sup>	100

Table 21 – Sampling methods by level of evidence

Regarding sample size, table 22 presents a distribution in terms of minimum, maximum and average sample considering participants included in studies and journal articles in reviews. For the former, the only RCT included in level 1<sup>+</sup> presents the largest sample of participants, for the later, reviews at level 2<sup>++</sup> reflect larger samples of journal articles.

<sup>7</sup> Systematic Reviews excluded.

<sup>8</sup> Missing data excluded

Sample	Level 1 <sup>+</sup>		Level 1 <sup>-</sup>		Level 2 <sup>++</sup>	Level 2 <sup>+</sup>	Level 2 <sup>-</sup>
	Participants	Journal articles	Participants	Journal articles	Journal articles	Participants	Participants
Minimum	438	14	27	6	5	145	11
Maximum		27	294	36	157		94
Average	438	19,7	104,9	16,3	31,4	145	44,7

Table 22 – Sample size by level of evidence

Looking at the groups of participants included in studies evidence-based across levels, table 23 shows that, as expected, informal carers are more frequently present when compared to formal carers or patients. Only at level 2<sup>-</sup> all groups are included.

Group of participants	Level 1 <sup>+</sup>		Level 1 <sup>-</sup>		Level 2 <sup>+</sup>		Level 2 <sup>-</sup>	
	N	%	N	%	N	%	N	%
Informal carers	1	100	6	75	1	100	6	60
Formal carers	-	-	2	25	-	-	2	20
Patients	-	-	-	-	-	-	2	20
TOTAL	1 <sup>9</sup>	100%	8	100%	1	100%	10 <sup>10</sup>	100%

Table 23 – Group of participants by level of evidence

Finally, table 24 presents the instruments used in studies across levels, which are quite diverse and include both quantitative and qualitative measures. Questionnaires, scales, surveys, interviews and focus groups are the main type of instruments used.

Level	Instruments
Level 1 <sup>+</sup>	Activities of Daily Living (ADL), Instrumental Activities of Daily Living (IADL), Short-form 12 Health Survey, Hospital Anxiety and Depression Scale (HADS), Multidimensional Scale of Perceived Social Support (MSPSS)
Level 1 <sup>-</sup>	The Structured Clinical Interview for DSM-IV with Psychotic Screen (SCID-I/P w/PSY Screen); Mini Mental Status Exam (MMSE); Penn Sate Worry Questionnaire (PSWQ); Perceived Stress Scale (PSS); Pittsburgh Sleep Quality Index (PSQI); Beck Depression Inventory (BDI-II); Hamilton Rating Scale for Depression (Ham-D); Hamilton Anxiety Scale (Ham-A); Impact of Events Schedule (IES); Multidimensional Rumination Questionnaire (MRQ).
	Six ADL tasks and six out of eight instrumental ADL; Revised Memory and Behavior Problems Checklist (R-MBPC); 5-item scale; 7-item short sense of competence questionnaire (SSCQ); Zarit Burden Interview; RAM Review checklist
	Usefulness, Satisfaction and Ease of use (USE) Questionnaire, Alzheimer's Disease Knowledge Scale (ADKS), Approaches to Dementia Questionnaire (ADQ), Interpersonal

<sup>9</sup> More than one category selected.

	Reactivity Index (IRI), Quality of life assessed with 2 distinct questions, Short Sense of Competence Questionnaire (SSCQ).
	Center for Epidemiologic Studies Depression Scale (CES-D), Caregiver Competence Scale (CCS), Revised Caregiving Satisfaction Scale (RCSS).
	Caregivers' perceived stress (PSS-14, primary outcome), self-efficacy, burden, perceived health status, and depression (secondary outcomes)
	QoI-AD; Short Sense of Competence Questionnaire (SSCQ); USE Questionnaire; Semi-structured interviews
Level 2+	Semi- Structured Interview; Interpersonal Reactivity Index (IRI); Caregiver Reaction Assessment
Level 2-	Functional Assessment Staging (FAST); Global Deterioration Scale (GDS); Interview
	Focus group and interviews
	WHO-Five Well-Being Index (WHO-5); Quality of Carer-Patient Relationship scale (QCPR); The Mutuality scale
	Pre and post paper-based questionnaire
	Questionnaires and Interviews; Preparation for decision making scale (PrepDM); Likert scale; EQ-5D-5L; Burden Scale for Family Caregivers (BSFC)
	Usability questionnaire

Table 24 – Instruments used for data collection by level of evidence

**Q6: To what extent these solutions have been scaled up? (other organizations, contexts, countries...)**

To analyse this research question we detail the ICT-solutions that have been already scaled-up and explore the level of implementation of the policy documents collected.

As table 12 has shown, only 3% of the ICT-solutions (n= 2) identified in this sample have been scaled-up. Solutions at level 4 are the following:

- . Web-Based STAR E-Learning Course Increases Empathy and Understanding in Dementia Caregivers. The STAR training portal is a useful and user-friendly e-learning method, which has demonstrated its ability to provide significant positive effects on caregiver attitudes and empathy.
- . Smart4md. This app aims at improving the quality of life of people with mild dementia and their carers. It will help patients to adhere to their treatment, reduce the progression of their illness and share data with their caregivers and doctors.

Considering the level of implementation of the policy documents collected, table 25 shows that all documents are already implemented.

Level of implementation	N	%
1. Development	0	---
2. Approved	0	---
3. Implemented	9	100
TOTAL	0	100%

Table 25 – Level of implementation of policy documents

The complete list of the policy documents collected is presented in table 26.

Policy documents
Dementia in Europe Yearbook 2018: Comparison of National dementia strategies in Europe
Dementia Apps Library
Crisis and Care Coordination
Towards a dementia plan: a WHO guide
Comprehensive Plan for Alzheimer and other Dementias (2019-2023)
Global action plan on the public health responde to dementia

Support strategy for people who care for sick and / or dependent relatives in the city of Barcelona 2019-2024
National Dementia Plan (Spain)
Alzheimer's Disease International - Strategic Plan 2019-20221

Table 26 – Policy documents collected



**Q7: Is there any training for caregivers, designers/providers of technology (or students), healthcare professionals (or students) in the area of co-created ICT- based Alzheimer care solutions?**

To analyse the last research question we have explored the existing trainings in the area of co-created ICT-based Alzheimer care solutions, in particular the following dimensions: specificity for Alzheimer or Dementia, profile of the targeted students, inclusion of staff from technology and health sciences, level of internationalisation of programs, year of last edition, participation of companies and consideration of users needs in the *curricula* of training programs.

As table 27 shows, a total of 34 trainings have been identified in Portugal, Spain and the UK and 56% of these are specific for Alzheimer/Dementia.

Specific for Alzheimer/Dementia	N	%
Yes	15	44,1
No	19	55,9
TOTAL	34	100%

Table 27 – Specificity of training programs (Alzheimer)

The targeted students of these trainings are diverse but the main fields of study are health sciences and engineering/informatics as it is presented in table 28.

Target students	N	%
Health sciences	10	47,6
Engineering/informatics	7	33,3
Psychology	1	4,8
Undergraduate students	2	9,5
Social workers	1	4,8
TOTAL	21	100%

Table 28 – Target students of training programs

Considering the staff, as table 29 shows, the majority of these training programs include teachers from health and technology sciences.

Staff from health and technology disciplines	N	%
Yes	28	90,3
No	3	9,7
TOTAL	31 <sup>11</sup>	100%

Table 29 – Inclusion of staff from health and technology in training programs

When we look at the level of internationalisation, as table 30 shows only five of these programs are international.

International program	N	%
Yes	5	31,3
No	11	68,7
TOTAL	16 <sup>11</sup>	100%

Table 30 – Internationalization of training programs

To analyse if these programs are current we have considered the year of the last edition and table 31 shows that most of these programs are recent or were still running in 2019/20.

Year of last edition	N	%
2020	1	6,3
2019/20	10	75
2017	2	12,4
2015	1	6,3
TOTAL	14 <sup>10</sup>	100%

Table 31 – Year of the last edition of the training programs

When we look at the involvement of companies, according to the available data, according to table 32 none of the trainings have the participation of companies.

Companies participation in the program	N	%
Yes	0	----
No	5	100
TOTAL	5 <sup>11</sup>	0%

Table 32 – Participation of companies in training programs

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<sup>10</sup> NA or missing data excluded.

Finally, considering the available data, caregivers needs are included in only 27% of the curricula of training programs as table 33 shows.

Caregivers needs are considered in the program	N	%
Yes	7	26,9
No	19	73,1
TOTAL	26 <sup>11</sup>	100%

Table 33 – Caregivers needs included in the curricula of training programs



## 4.- Discussion and conclusions

The main aim of this literature search was to know the status of co-created ICT-based Alzheimer care solutions in Spain, Portugal and the UK, considering the last 5 years. Results have provided relevant information to describe, analyse and classify solutions and their underlying process of design in those countries, but also at a broader European level.

In general, journal article publications are the most represented category in our sample and 2019 was the most productive year in terms of publications or dissemination related to the topic of research. Moreover, digital solutions collected as experiences or actions are mainly current, and European countries, specially Spain, seem to be fruitful in terms of conception and application of solutions, when compared to non-European countries.

Considering the first research question, if technological/digital solutions are designed to improve the life of Alzheimer's (informal) caregivers, results suggest that in the last five years there has been an investment from associations, companies and universities to address the constrains and difficulties felt by informal caregivers in their daily life but there is still room for further development. The solutions found in literature provide technological tools that may improve the practical life and well-being of caregivers, namely educational resources and development of competences, psychological health and social engagement.

Regarding the second research question, if solutions are designed to meet the needs of caregivers, results suggest that, in fact, there are already available solutions focusing on specific needs of caregivers, like planning, personal health, caregiving tasks, informal relationships and relationships with formal services providers. However, and considering the typology of caregivers needs of Queluz et al. (2020), we are still lacking technological/digital resources in many relevant domains, such as physical health of the carer, juggling responsibilities, crisis planning and information about legal regulation in caring, to mention some.

About the classification of solutions according to the purpose, process followed for the design and level of maturity achieved, results provide relevant insights for further reflection. Considering the purpose, and following the typology of Lorenz et al. (2019), most categories can be found in literature, however self-care of the carer and treatments and interventions delivery seem to receive less attention from stakeholders and developers.

Regarding the process followed for design of solutions, results clearly show that participatory methods and approaches centred in processes of co-creation are not yet implemented in this field of research. In fact, in 85% of the literature found, the key terms focusing on co-design processes are absent. On the other hand, it may be the case that researchers might involve users in designing but the associated concepts and terminology are not yet well established or applied in literature. Nevertheless, results focusing on how are caregivers included in the process of design also show that their involvement is mostly passive. In fact, when caregivers are included, they are mainly requested to contribute to aspects of refinement and potential improvement of solutions. The actual participation in design phase is still scarce.

Focusing on the level of maturity, it is clear that the available solutions are still at an early stage of development, since most of them are at the level of exploration and initial implementation. This is also a reason that may explain why the level of expansion of solutions is still residual. Hence, this is a relevant input to evaluate the actual state of technology development for Alzheimer care solutions.

Considering the level of evidence, around half of the articles are evidence-based, and most of it reflect meta-analytic studies and systematic reviews with high risk of bias. This result can be seen as a promising sign, considering that this is a recent field of research and development. Combining results related to level of maturity and level of evidence, one can foresee that an actual development in terms of research and design can promote higher levels of implementation.

Looking at the training programs available in the field of co-created ICT-based Alzheimer care solutions, results show interesting differences between the countries. In fact, there are already specific options in Dementia or Alzheimer studies but these are mostly offered by British institutions. Both students and staff involved in these trainings are mainly related to health sciences and engineering/informatics, nevertheless the participation of companies is still unclear and the consideration of caregivers needs remains unrecognised.

As concluding remarks, results from this mapping exercise can contribute with important input and insights for the next work packages. Specifically, it can provide relevant knowledge and further reflection that may help to fill in the gaps and current limitations found in this area of research and practice. In fact, there is space to improve user-led design and co-creation needs in the process of design of ICT solutions focusing the informal caregiving of Alzheimer patients.

## 5.- References

The Early Childhood Technical Assistance (ECTA) Center (2014). A Guide to the Implementation Process: Stages, Steps & Activities. <https://ectacenter.org/~pdfs/implementprocess/implementprocess-stagesandsteps.pdf>

Lorenz, K. et al. (2019). Technology-based tools and services for people with dementia and carers: Mapping technology onto the dementia care pathway. *Dementia*, 18(2): 725–741. Doi: 10.1177/1471301217691617

Queluz et al. (2020). Understanding the needs of caregivers of persons with dementia: a scoping review. *International Psychogeriatrics*, 32(1): 35–52. doi:[10.1017/S1041610219000243](https://doi.org/10.1017/S1041610219000243)

Scottish Intercollegiate Guidelines Network (SIGN). A guideline developer's handbook. Edinburgh: SIGN; 2019. (SIGN publication no. 50). [November 2019]. Available from URL: <http://www.sign.ac.uk>



## Appendix 1: Search strategy

### 1. Types of documents, databases and other sources for literature search

Type of document	Database and/or other sources
Scientific literature: Journal articles	EBSCO, B-On, PubMed, Scielo, Scopus, Web of Knowledge, Biomed, arXiv.org, CiteSeerx, Cochrane Library, Medline, Inspec, The Collection of Computer Science Bibliographies, ACM Digital Library, IEEE Xplore
Grey literature: Books, reports, conference proceedings	Google, Google Scholar, Open Grey <sup>11</sup>
Grey literature: Dissertations	OATD <sup>12</sup> - all languages, Dart-Europe <sup>13</sup> – all languages, PQDtopen <sup>14</sup> - English: UK, USA Teseo <sup>15</sup> - Spanish Tdx <sup>16</sup> - Catalan RCAAP (Portuguese)
Research Projects about the topic	European Union <sup>17</sup> , National entities (Recolecta <sup>18</sup> ) with funding
Policy documents	Local, national, European government sites
Experiences of possible existing actions at European level	Knowledge/contacts
Experiences of possible existing actions at Portuguese level	Knowledge/contacts
Experiences of possible existing actions at Spanish level	Knowledge/contacts
Experiences of possible existing actions at British level	Knowledge/contacts

<sup>11</sup> <http://www.opengrey.eu/>

<sup>12</sup> <https://oatd.org/>

<sup>13</sup> <http://www.dart-europe.eu/basic-search.php>

<sup>14</sup> <https://pqdtopen.proquest.com/search.html>

<sup>15</sup> <https://www.educacion.gob.es/teseo/irGestionarConsulta.do>

<sup>16</sup> <https://www.tdx.cat/>

<sup>17</sup> <https://cordis.europa.eu/projects/en> (english)

<sup>18</sup> <https://www.recolecta.fecyt.es/busqueda-avanzada> (spanish)

Existing trainings on these topics at Portuguese level	Knowledge/contacts/educational web
Existing trainings on these topics at Spanish level	Knowledge/contacts/educational web
Existing trainings on these topics at British level	Knowledge/contacts/educational web

## 2. Search terms

(1) Context/What? Illness	(2) Target/who? Carers	(3) Environment/where? Technology	(4) Process/how? Co-created
Alzheimer OR Dementia	Care OR Support OR Carer OR Caregiver	Technology solution OR ICT solution OR Digital solution OR Mobile application OR Mobile App OR Web application OR Web App OR Online community OR Virtual community OR Virtual environment OR Virtual reality	Co-production Co-creation Co-design User-led User-centred

## 3. Data Extraction: structure for spreadsheets

### 3.1 Table for Journal articles, Grey literature and Research projects

Year of the publication	YYYY
Authors	Surname/s, Name/s
Type of publication	Journal Article, Dissertation, Research Project
Title	Main title
Aim	Short aim
Talk about covering needs of caregivers'	Yes/No
Specific for Alzheimer	Yes/No

Purpose of the ICT-based Alzheimer care solution	Based on the classification of Lorenz et al. (2019) <sup>19</sup>	
Methodology	Sample (if applicable)	Type of sample and sampling method
	Participants	Target group
	Instruments (if applicable)	If they used instruments to collect information
	Method used	Research method used
Level of evidence (only scientific literature)	Scottish Intercollegiate Guidelines Network (SIGN) <sup>20</sup>	
Level of implementation	1) exploration, 2) initial implementation, 3) full implementation, 4) expansion and scale-up	
Caregivers included	Yes/No and When	
Description of caregivers needs	Brief description of the needs to cover	
Classification of caregivers needs	Based on the classification of Queluz et al. (2020) <sup>21</sup>	
Conclusions	Main conclusions	
Optional search terms	If the terms selected for process appear and which ones	
Country/ies of origin of the idea	Name of country/ies	
Country/ies where the ICT-solution is/will be implemented	Name of country/ies	

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<sup>19</sup> Lorenz, K. et al. (2019). Technology-based tools and services for people with dementia and carers: Mapping technology onto the dementia care pathway. *Dementia*, 18(2): 725–741. Doi: 10.1177/1471301217691617

<sup>20</sup> Scottish Intercollegiate Guidelines Network (SIGN). A guideline developer’s handbook. Edinburgh: SIGN; 2019. (SIGN publication no. 50). [November 2019]. Available from URL: <http://www.sign.ac.uk>

<sup>21</sup> Queluz et al. (2020). Understanding the needs of caregivers of persons with dementia: a scoping review. *International Psychogeriatrics*, 32(1): 35–52. doi:10.1017/S1041610219000243

The operationalization of the level of implementation was adapted from the proposal of ECTA Center (2014)<sup>22</sup> as follows:

Exploration	Focused on exploring potential practices, technologies or innovations to determine how well they fit with the goals and resources of the project/solution. The goals are to identify the need for change, determine what innovation or set of practices are likely to meet that need, and to decide whether to move ahead with the implementation process. It may involve stakeholders in assessing needs, identifying the innovation or practice that will address the needs, creating support for the needed innovation or practice, and deciding to move forward the change effort. Some experimentation is done, and data are analysed to make decisions towards the implementation of prototypes.
Initial implementation	Trying to come up with prototypes that are used to quickly solve problems and determine if adjustments are needed. Feedback is used to revise the written plans when necessary. During initial implementation, the new practices are at least partially in place. Data are used to inform all aspects of implementation. Training are adapted and strengthened according to evaluation results. Implementation of new practices began to show expected results. Evaluation of prototypes provide information to assist in expansion and scaling up to full implementation.
Full implementation	When solutions are being implemented with fidelity and are achieving the expected outcomes/prototypes. The goals are to assure practices used with high fidelity and are to achieve expected fully functional prototype to be used by end-users. Evaluation activities continue to monitor fidelity and outcomes of practice, so that "drift" (movement away from fidelity) in practices is quickly identified and addressed. Outcomes are measured to show intended results. Systemic issues were resolved, and the system/solution/prototype has the capacity to support its goals.
Expansion and scale-up	Scale-up refers to the adoption of policies, practices, and implementation strategies that promote widespread, sustained use of evidence-based practices first with-in the solution and then spread out across multiple programs, agencies, entities, end-users. Also referred as expansion. The goal is to increase the number of end-users, entities, agencies, etc., using the solution with fidelity.

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<sup>22</sup> The Early Childhood Technical Assistance (ECTA) Center (2014). A Guide to the Implementation Process: Stages, Steps & Activities. <https://ectacenter.org/~pdfs/implementprocess/implementprocess-stagesandsteps.pdf>

### 3.2 Table for Experience/Actions

Stakeholder/Entity	Name
Type of stakeholder/entity	If it is a company, government, user's association...
Time range	mm-yy; mm-yy
Title	Name of the product/solution
Type of experience/action	Yes/No
Specific for Alzheimer	Yes/No
Can it be used for caregivers?	Yes/No
Purpose of the ICT-based Alzheimer care solution	Based on the classification of Lorenz et al. (2019) <sup>23</sup>
Funding	Is there funding? In affirmative case where the funding comes from?

### 3.3 Table for Policy documents

Year	Of the publication (or range)
Authors	Organization Name
Type of publication	Policy Document
Title	Main title
Aim	Short aim
Talk about covering needs of caregivers'	Yes/No
Description of caregivers needs	Brief description of the needs to cover
Classification of caregivers needs	Based on the classification of Queluz et al. (2020) <sup>24</sup>
Specific for Alzheimer	Yes/No
Talk about any ICT-based Alzheimer care solution	Yes/No
Level of implementation	1) Development 2) Approved 3) Implemented
Caregivers included	Yes/No
Optional search terms fulfilled	Co-production, Co-creation, Co-design, User-led, User-centred, none
Country/ies of application	Name of the country
Level for the policy	Local/regional/national/EU/international

<sup>23</sup> Lorenz, K. et al. (2019). Technology-based tools and services for people with dementia and carers: Mapping technology onto the dementia care pathway. *Dementia*, 18(2): 725–741. Doi: [10.1177/1471301217691617](https://doi.org/10.1177/1471301217691617)

<sup>24</sup> Queluz et al. (2020). Understanding the needs of caregivers of persons with dementia: a scoping review. *International Psychogeriatrics*, 32(1): 35–52. doi:[10.1017/S1041610219000243](https://doi.org/10.1017/S1041610219000243)

### 3.4 Table for Training

Table for Training	
Institution	Name
Name of training	Title of course
Target students' profile	Area of knowledge and professional level
Specific for Alzheimer AND/OR Dementia	Y/N
Staff from health and technology disciplines	Y/N
Year of the last edition	Year
International program	Y/N
Companies participation in the program	Y/N
Users participation in the program	Y/N
Caregivers needs are considered in the program	Y/N
Description of caregivers needs	Brief description of the needs to cover
Classification of caregivers needs	Based on the classification of Queluz et al. (2020)



## Appendix 2: Training programs

### List of training programs by institution

Institution Name	Name of training - Title of course
Faculdade de medicina, Universidade do Porto	Mestrado em informática medica
Universidade Lusófona	Curso de Especialização dm intervenções nas demências
Instituto Politécnico de Leiria	Informática para a Saúde
Instituto Superior de Ciências da Saúde	Pós-Graduação em Doença de Alzheimer e Outras Demências
Instituto Superior de Engenharia do Porto	Pós-Graduação em Engenharia Informática Aplicada à saúde
Universidad de Burgos	Grado en Ingeniería de la Salud
Universidad de Málaga y Sevilla	Grado en Ingeniería de la Salud
Universidad de Alicante	Grado en Tecnologías de la Información para la Salud
Universitat Autònoma de Barcelona	Máster oficial en Internet de las cosas para la salud digital / Internet of Things for e-Health
CEU - Escuela Internacional de Doctorado	Doctorado en Ciencia y tecnología de la Salud
Universidad de Zaragoza	Experto Universitario en Nuevas Tecnologías y Emprendimiento en Ejercicio Físico, Nutrición y Salud
Universidad Europea Miguelde Cervantes	Máster en Salud Digital
Universitat de Girona	Máster en tecnologías inteligentes para sistemas de salud (smart healthcare)
Universitat Oberta de Catalunya	Máster universitario de Salud Digital / eHealth
Universidad Carlos III	Máster universitario en ingeniería de la información para la salud
La Salle - Universidad Ramón Llull	Máster en ehealth: tecnologías de la información y gestión sanitaria
University of Sheffield	MSc Neuroscience and Neurodegeneration
University of South Wales	MSc Dementia Studies
University of Hull	MSc Dementia (Online)
University of Stirling	MSc Dementia Studies (Online)
University College London	MSc Dementia: Causes, Treatments and Research
University College London	MSc Dementia: Causes, Treatments and Research
University of Worcester	PhD Dementia Studies

University of Bradford	MSc Advanced Dementia Studies
University of West London	MSc Dementia Care
Bangor University	MSc Dementia Studies
University of Worcester	PG Cert Person-Centred Dementia Studies
Brighton & Sussex Medical School	MSc Dementia Studies
University of Worcester	PG Award Professional Development: Expert Practice in Delivering Person-Centred Dementia Care
University of Limerick	MSc Nursing (Dementia Care)
Trinity College Dublin	MSc Dementia
University College Cork	MSc Dementia Care
Bangor University	MSc Ageing and Dementia Studies
University of St Andrews	The Psychology of Dementia Care PG Cert



## Appendix 3: Experiences/Actions

Name	Type of experience/action
Caregiver's Guide to Understanding Dementia Behaviors	Navigator lists programs for family caregivers.
Caregivers for Alzheimer's and dementia face special challenges.	Website with all kind of informations and support for caregivers
In person & Online Support for Those with Dementia & Persons Providing Care	Website with an organized list of support groups
Dementia Diaries	A UK-wide project that brings together people's diverse experiences of living with dementia as a series of audio diaries.
Innovations in Dementia	Working with organisations to help people with dementia to keep control of their lives and be happy.
AskSARA	Online self-help guide providing expert advice and information on products and equipment for older and disabled people
I'm with you	Improve the quality of life of informal caregivers of Alzheimer's patients
I take care of you	Help those affected and caregivers of people with Alzheimer's to overcome the daily challenges and doubts related to the disease
Twere - Autonomy for people with Alzheimer's disease and peace of mind for their relatives and caregivers	Allows caregivers to know where the affected person is, in case they go beyond the safety limits or don't come back home at the scheduled time.
I take care of you	Remotely monitor patients and empower caregivers
Purple	Comfort families and caregivers of people with Alzheimer's. Send them positive messages that remind them that they are not alone in the face of adversity.
People living with Alzheimer's	Virtual community for relatives of Alzheimer's patients
kNOW Alzheimer	Platform for info sharing
Dependence	Information sharing
MiMe & SuMe	To know where your loved one is at all times. As well as non-intrusively managing your medications, contacts, places of interest and being the first to know if you need help.
Safe365 - Eldercare App	Locate them in real-time, set up their daily routines, promote healthy habits, keep them safe and stay connected.
Come closer	Locator, notifications, privacy, sos buttons, telephone attention.

CRE de Alzheimer Imsero	View all the information available on the web and on the blog, as well as receive alerts on news and training courses.
SmartPanics	Improve the location of certain people who require passive tracking of their location at all times, such as people with dementia.
Super caregivers	To give information



## Appendix 4: List of publications and research projects

### Journal articles

- Anderberg, P., Barnestein-Fonseca, P., Guzman-Parra, J., Garolera, M., Quintana, M., Mayoral-Cleries, F., ... Berglund, J. S. (2019). The effects of the digital platform support monitoring and reminder technology for mild dementia (SMART4MD) for people with mild cognitive impairment and their informal carers: Protocol for a pilot randomized controlled trial. *Journal of Medical Internet Research*, 8(6), 1–12. <https://doi.org/10.2196/13711>
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