



**eDESDE-LTC**

*DESCRIPTION AND EVALUATION OF SERVICES AND  
DIRECTORIES IN EUROPE FOR LONG TERM CARE*

***EXECUTIVE SUMMARY***

***eDESDE-LTC Group***

*Executive Agency for Health and Consumers (EAHC)*

*Project Ref. 2007/116*



# eDESDE-LTC: Executive Summary

*eDESDE-LTC Group*

---

This document should be quoted as follows:

*eDESDE-LTC Group. eDESDE-LTC Executive Summary [Internet]. Jerez (Spain): PSICOST and Telnets; 2011. Available from: <http://www.edesdeproject.eu>*

---

**Edition:** January 2011

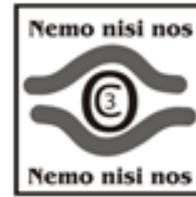
**Edits:** PSICOST

Pza. San Marcos nº 6, 11403, Jerez de la Frontera (Spain)

**Electronic edition and design:** Telnets Consulting S.L.

**ISBN:** (requested)





### **eDESDE-LTC Partners**

Asociación Científica PSICOST (Spain), London School of Economics (LSE) (UK), SINTEF Technology and Society (Norway), Catalunya Caixa (Spain), Družbenomedicinski inštitut ZRC SAZU (Slovenia), Public Health Association (PHA) (Bulgaria), University of Vienna (UNIVIE) (Austria), Izobraževalno raziskovalni inštitut Ljubljana (IRIO) (Slovenia)

### **Collaborating Partners**

Dept. of Mental Health Sciences, UCL (UK); ASL-4 Centro Studi e Ricerche (Italy), Dept Research & Development, Division of Mental Health Serv. Akershus University Hospital (Norway), ETEA University of Cordoba (Spain), University of Alacant (Spain), University Politecnica of Barcelona (Spain), OECD – Health Division (France), Ministry of Health. National Center for Public Health Protection (Bulgaria), Catalan Department of Health, DG de Planificació i Avaluació (Spain), Psychiatry Research Unit of Cantabria (WHO collaborating Centre) Univ. Hosp. "Marqués de Valdecilla" (Spain), Fundació Villablanca (Spain), Delegación Municipal de Igualdad y Salud. Ayto Jerez (Equity & Health Department. Municipality) (Spain).

### **Acknowledgements**

The eDESDE-LTC project has been funded by the Executive Agency of Health and Consumer (EAHC) Project Ref. 2007/116



**eDESDE-LTC Group** (*members<sup>1</sup>, collaborating members<sup>2</sup> and main subcontractors<sup>3</sup>*)

José Almenara (Spain) <sup>1</sup>	Rafael Martinez-Leal (Spain) <sup>1</sup>
Federico Alonso (Spain) <sup>1</sup>	Tihana Matosevic (UK) <sup>1</sup>
Jordi Balot (Spain) <sup>1</sup>	David McDaid (UK) <sup>1</sup>
Murielle Bendeck (Spain) <sup>3</sup>	Cristina Molina (Spain) <sup>2</sup>
Anne Mette Bjerkan (Norway) <sup>1</sup>	Valerie Moran (France) <sup>2</sup>
Barbara Brehmer (Austria) <sup>1</sup>	Carlos Mur (Spain) <sup>2</sup>
Angel Broshtilov (Bulgaria) <sup>1</sup>	Carmen Omist (Spain) <sup>2</sup>
Maria Dolores Crespo (Spain) <sup>2</sup>	Miriam Poole (Spain) <sup>3</sup>
Mojca Z. Dernovsek (Slovenia) <sup>1</sup>	Manuel Palomar (Spain) <sup>2</sup>
Hristo Dimitrov (Bulgaria) <sup>1</sup>	Rayna Popova (Bulgaria) <sup>1</sup>
Nikolina Djurova (Bulgaria) <sup>1</sup>	Eugeni Rojas (Spain) <sup>1</sup>
Mónica Duaigües (Spain) <sup>1</sup>	Maria Teresa Romá-Ferri (Spain) <sup>2</sup>
Josep Fuste (Spain) <sup>2</sup>	Cristina Romero (Spain) <sup>1</sup>
Ana Fernandez (Spain) <sup>3</sup>	Mencía Ruiz (Spain) <sup>1</sup>
Luis Gaité (Spain) <sup>2</sup>	Torleiff Ruud (Norway) <sup>2</sup>
Carlos García-Alonso (Spain) <sup>2</sup>	Jose Alberto Salinas (Spain) <sup>1</sup>
Juan Carlos García Gutierrez (Spain) <sup>1</sup>	Luis Salvador-Carulla (Spain) <sup>1</sup>
José García-Ibañez (Spain) <sup>2</sup>	Antoni Serrano (Spain) <sup>3</sup>
Juan Luis Gonzalez-Caballero (Spain) <sup>1</sup>	Daniela Seyrlehner (Austria) <sup>1</sup>
Karina Gibert (Spain) <sup>2</sup>	Josep Solans (Spain) <sup>1</sup>
Sonia Johnson (UK) <sup>2</sup>	Lilijana Sprah (Slovenia) <sup>1</sup>
Birgitte Kalseth (Norway) <sup>1</sup>	Giuseppe Tibaldi (Italy) <sup>2</sup>
Martin Knapp (UK) <sup>1</sup>	Jose Luis Vazquez-Barquero (Spain) <sup>2</sup>
Carolina Lagares (Spain) <sup>1</sup>	Britt Venner (Norway) <sup>1</sup>
Paula Llull (Spain) <sup>1</sup>	Germain Weber (Austria) <sup>1</sup>
Teresa Marfull (Spain) <sup>3</sup>	Elisabeth Zeilinger (Austria) <sup>1</sup>

## **EXECUTIVE SUMMARY**

### **ABSTRACT**

**BACKGROUND:** The European Commission is urged to provide comparable descriptions of care to facilitate patient mobility and equity. A common coding system and standard method of assessment is needed to overcome these terminology problems and to enable comparison of local data to generate informed evidence.

**AIM:** This project has been aimed to develop a standard classification and a related instrument to code services for Long Term Care in Europe (eDESDE-LTC), which incorporates basic descriptors and indicators in 6 European languages.

**METHOD:** The development of the eDESDE-LTC system involved an iterative process using nominal groups in the 6 participating countries (Spain, Austria, Bulgaria, Norway, Slovenia and the UK). A total of 41 European researchers and stakeholders in LTC health and social services participated in this process. The usability analysis has included an analysis of feasibility, inter-rater reliability in 170 services and a Boolean factor analysis in 1319 services for LTC. Following a pilot study has been carried out in the cities of Sofia and Madrid, and impact analysis of the instrument (screening, scoping and appraisal) was carried out.

**RESULTS:** The instruments show a high feasibility, consistency, inter-rater reliability and face, content and construct validity. The use of the instrument in Madrid and Sofia has allowed comparisons of service availability in both cities in spite of large differences in system, organisation and provision.

**CONCLUSION:** DESDE-LTC is ontology consistent and it is semantically interoperable. Its use will improve linkages between European Information Systems, service comparison and planning.

## **INTRODUCTION**

Health services are very difficult to compare across different territories particularly when they are aimed for long term care of complex health conditions. In the past service comparison studies failed to provide useful information for health planning in areas as diverse as mental health (Salvador-Carulla et al, 2006), ageing (Johri et al, 2003), or services for functional dependency in Europe (EUROSTAT, 2003). This could be attributed to several factors, such as the influence of historical and contextual factors in the development of local services, differences in organisation, increase complexity of integrative care arrangement and mainly to the fact that services with the same name perform different activities and vice-versa. This terminological variability appears across all levels of complexity of the care settings, from day centers and day hospitals to rehabilitation units. We even lack a common definition of 'hospital' and 'service'.

The European Commission is urged to provide comparable descriptions of care to facilitate patient mobility and equity. Although 'Having access to high-quality healthcare when and where it is needed' is a fundamental right of every European citizen (Charter of Fundamental Rights of the European Union, 2000), the fact is that mobility and access to health services across Europe is hampered by an inadequate framework and knowledge of available resources. The development of a common coding and assessment system is also relevant for harmonisation and equity or impartial allocation of care (resources, programmes and treatments) to different groups and individuals. Furthermore the growing linkage of European databases is accompanied by a parallel demand of 'semantic interoperability' or the development of a common language that can be used across different information systems and databases.

A common coding system and standard method of assessment is needed to overcome these terminology problems and to enable comparison of local data to generate informed evidence.

This project has been aimed to four main objectives: 1) To develop a standard classification system to code services for LTC in Europe; 2) To develop a related instrument (eDESDE-LTC), which incorporates basic descriptors and indicators in 6 European languages; 3) To improve linkages between national and regional websites, and EU health portals and the development of the eDESDE-LTC webpage, and 4) To

improve EU listing and access to relevant sources of healthcare information via development of a training package on semantic interoperability in eHEALTH (coding and listing of services for LTC).

## **METHOD**

The DESDE-LTC Team has been made by several major institutes in service research, provision and funding in Europe: PSICOST Research Association and the Foundation of Catalunya Caixa (Spain), the University of Vienna (Austria), the Public Health Association (Bulgaria), the Scientific Research Centre of the Slovenian Academy of Sciences and Arts and the IRIO Institute (Slovenia), SINTEF (Norway), and the London School of Economics and Political Science (UK). Collaborating partners included major experts in the development of the European Service Mapping System (S. Johnson, G Tibaldi and T Ruud), international organisations (OECD), health agencies at national level (Ministry of health Bulgaria), regional level (Regions of Cantabria, Catalunya and Madrid in Spain) and municipality level (Jerez in Spain). Other collaborating partners were main academic organisations in formal ontology (University of Alicante, Politechnical University of Catalonia) and support decision systems for health decision making (ETEA, Spain).

To produce the DESDE-LTC system and related products the eDESDE project followed a series of related steps:

1. Plans for Evaluation (UNIVIE) and Dissemination (LSE) of the eDESDE-LTC project were made and revised during the initial phase of the project
2. A review of the framework of coding and classification services for LTC in Europe. This review included previous studies (ESMS, DESDE) focused on evaluation of Mental Health, Disability, Ageing services.
3. The development of the eDESDE-LTC instrument and its related coding and classification system was coordinated by the working group. An iterative process was followed using nominal groups in the 6 participating countries. A total of 41 European researchers and stakeholders in LTC health and social services participated in this process. The different working versions of the questionnaire and

its related codes were translated in every country following a conceptual approach and reviewed by the nominal groups. Critical terms were identified in this process.

4. The usability of the eDESDE-LTC system was assessed in relation to a series of quality domains:
  - Feasibility: Applicability, Acceptability, Practicality and Relevance
  - Consistency: Ontology analysis and structure
  - Inter-rater Reliability
  - Validity (descriptive and Boolean factorial analysis)

The feasibility was based on the assessment made by an international panel of 51 experts in LTC with knowledge on the eDESDE-LTC or the parent instruments for mental health and for disabilities. The reliability analysis was made by two independent ratings on 170 services and the validity analysis was made on a database comprising 1319 services.

5. The eDESDE-LTC Toolkit incorporated the instrument, the coding system, a training package and an evaluation package. The toolkit has been incorporated to the eDESDE-LTC webpage.
6. A pilot study was designed in two macrouurban areas of countries with highly divergent health and social systems to demonstrate de practical usability of the eDESDE-LTC system. This study was carried out in Sofia (Bulgaria) and Madrid (Spain) in 2010.
7. The impact analysis of the eDESDE-LTC project was carried out in 2011, as part of the dissemination and evaluation activities. It comprised an analysis of three domains; Screening, Scoping and Appraisal of both the project and the assessment system.
8. The final version of the eDESDE-LTC toolkit (Instrument, Classification and coding, Training Package and Evaluation Package) as well as electronic versions of the different project documents were uploaded at the project's webpage

## **RESULTS**

### **SYSTEM DEVELOPMENT**

The eDESDE-LTC system (instrument and coding system) is a unique tool for assessing availability and use of services for long term care both in small health areas and at macro-level. It has been developed following a bottom-up approach in a process dating from the initial assessment of mental health services in Europe in 1997. It has evolved from the original system comprising 4 main branches and 33 final codes, to a highly comprehensive hierarchical system comprising 6 main branches and 89 final codes. The original instrument has also evolved to classification system which is ontology driven. The classification system includes a decimal identifier, its formal description, and a related label at the questionnaire or eDESDE-LTC code, as well as a glossary of terms. Therefore it allows for semantic interoperability in European health and social information systems and databases.

### **USABILITY**

eDESDE-LTC showed a high feasibility in its four domains: applicability, acceptability, practicality and relevance. It is important to note that previous expertise on the ESMS/DESDE system had a notorious influence on the assessment of feasibility. Every feasibility-dimension was better rated from participants with ESMS/DESDE experience, particularly acceptability and practicality. There were no major differences across countries in the rating of the practicality while significant differences were identified in the assessment of the acceptability, practicality and relevance of the eDESDE-LTC system.

The ontology analysis has allowed for the development of a decimal classification (Annex I). It is accompanied with a formal description and identification labels at the eDESDE-LTC instrument (Annex II). DESDE-LTC) is a system focused on the standardised description and classification of services for Long-Term Care (LTC) in Europe which has a high semantic interoperability and can be used in different information systems in this region.

Structural consistency is adequate according to the factor Boolean analysis. The

eDESDE-LTC codes are well defined and make a consistent structure within the instrument. This analysis confirmed that main branches and secondary of eDESDE-LTC are made by codes or items that measure independent characteristics of the services being assessed.

DESDE-LTC showed high inter-rater reliability for main branches. Reliability was also high for final branches which correspond to MTCs. The branches with lower inter-observer agreement were some Information and self-support codes and special forms of outpatient mobile care. These results are better than those of the parent instruments (ESMS/DESDE) (Salvador-Carulla et al, 2000, Salvador-Carulla et al, 2006), mainly due to the improvement of the training system which has added an online training toolkit, and to a better formalisation of the service assessment instrument and its coding system. Descriptive validity and the structural analysis of the system were appropriate.

## **EVALUATION**

The consortium fulfilled the tasks of the project. The translation process, the instrument and coding system, the website, and the training package and related toolkit have been positively evaluated. eDESDE-LTC is regarded as a very useful and promising instrument that provides relevant solutions targeted to the project's objectives. EQM and impact Analysis produced good results.

However further improvements need to be done in the next future to warrant its full implementation in Europe. EQM analysis produced good results and all planned deliverables were accomplished.

As regards to the project's impact analysis, decision makers and planners from the key international organisations have been contacted and have participated in eDESDE-LTC related international conference as well in eDESDE-LTC meetings. A major practical output of this awareness strategy has been the incorporation of the eDESDE reference to the pre-edited version of the new System of Health Accounts (v2.0) edited by OECD, WHO and EUROSTAT (OECD et al, 2011; p77). The inclusion of eDESDE-LTC

instrument in the 7th framework project REFINEMENT (2011-2013) may have large implications for the sustainability of the system.

Contacts with national and regional social and health planners have been made mainly in Spain, Bulgaria and Slovenia by all partners, main activities were recorded in Spain, Bulgaria and Slovenia. Whilst the awareness raised in Bulgaria and Slovenia did not developed into practical implementation, the results in Spain have been outstanding, particularly in the mental health and the disability sectors. The eDESDE-LTC instrument and its coding system have been used to describe the Mental Health system in the three Spanish regions or Autonomous Communities (Cantabria, Catalonia and Madrid).

## **TRAINING PACKAGE**

eDESDE-LTC could be satisfactorily used when adequate training is provided. However training requires a face-to-face intensive course conducted by experienced trainers. The eDESDE-LTC training package is a useful complementary tool but does not replace face-to-face training. Apart from the use of the instrument and the coding system it is necessary to provide complementary information on how to conduct a research in this area using the eDESDE-LTC system. This complementary information should address relevant issues such as contact with national and local public agencies, contact with local service managers, data collection and data interpretation. In the next future a computer completion of the questionnaire and the coding system using structured algorithms may facilitate the training and the use of the instrument.

## **eDESDE-LTC WEBPAGE**

The website was developed in English. Its structure and content management system is compatible with standard specifications. Changes were made following recommendations by the consortium and the evaluation report. The web analytics trends until January 2011 have been analysed and reported.

## **PILOT STUDY**

The standardized description of the services that comprise the LTC network through the DESDE-LTC instrument proved to be of great utility in understanding the care system and provision characteristics with regard to the main types of care (MTCs) in Bulgaria and Spain. Major differences in total availability and distributions of MTCs and both beds and places were found in the two catchment areas. Whilst a clear pattern of institutional care is shown in Sofia, the pattern of beds and places available in Madrid are closer to a community care model. The pilot study carried out in Madrid and Sofia shows that the eDESDE-LTC is an instrument that can be applied in very different environments and allows comparisons of availability of services in areas with distinct care systems.

## **CONCLUSIONS**

DESDE-LTC is ontology consistent and it is semantically interoperable. Its use will improve linkages between European Information Systems, service comparison and planning. It should be noted that eDESDE-LTC may have a significant impact in equity assessment in the next future. It should be noted that the main domains of health equity are: 1) Eligibility: Equal opportunity criteria to access care services. Specific groups are not excluded; 2) Availability: The care option is available in the catchment area 3) Accessibility: The care option is not influenced by restrictions and/or limitations in time, distance or information (e.g. user rights), 4) Utilisation: Available care alternatives are actually utilised by users; and 5) Mobility: When moving to a new placement users can access and utilise similar care alternatives to those available in the former location or basic care alternatives are available and comparable across two different territories. To adequately assess the different domains of equity a system such as eDESDE-LTC is needed as it incorporates a common terminology, a classification, a coding of LTC services in Europe, and a standard procedure for data collection and comparison (Roma-Ferri et al, 2005).

## REFERENCES

Charter of Fundamental Rights of the European Union (2007/C 303/01). Official Journal of the European Communities (18.12.2000).

EUROSTAT: Feasibility Study –Comparable Statistics in the Area of Care of Dependent Adults in the EU. Luxembourg: Office for Official Publications of the European Communities, 2003.

Johnson S, Kuhlmann R, and the EPCAT Group. The European Service Mapping Schedule (ESMS): development of an instrument for the description and classification of mental health services. *Acta Psychiatr Scand.* 2000; 405:14-23.

Johri M, Beland F, Bergman H. International experiments in integrated care for the elderly: a synthesis of the evidence. *Int J Geriatr Psychiatry.* 2003;18(3):222-35.

Organisation for Economic Co-operation and Development (OECD), World Health Organization (WHO) and EUROSTAT (European Commission). Pre-Edited Version. A System of Health Accounts Version 2.0. Paris: OECD, WHO and EUROSTAT, 2011 <http://www.oecd.org/dataoecd/27/51/47406956.pdf>

Romá-Ferri, M.T .; Palomar, M. "Interoperabilidad semántica de ontologías basada en técnicas de procesamiento del lenguaje natural (PLN)". En: Gascón, J.; Burguillos, F.; Pons, A. "La dimensión humana de la organización del conocimiento". 7º Congreso International Society for Knowledge Organization (ISKO)-España. Barcelona: Publicaciones de la Universidad de Barcelona. Departamento de Biblioteconomía y Documentación, 2005: 534-548.

Romero, C., Salvador-Carulla, L., Poole, M., Roma-Ferri, M. for the eDESDE-LTC Group. eDESDE-LTC: Classification and Coding System [Internet]. Jerez (Spain): PSICOST and Telnet; 2011. Available from: <http://www.edesdeproject.eu>

Romero C., Poole M., Ruiz M., Dimitrov, H., Martinez-Leal R., and Salvador-Carulla L., for the eDESDE-LTC Group. eDESDE-LTC Training Package [Internet]. Jerez (Spain): PSICOST and Telnet; 2011. Available from: <http://www.edesdeproject.eu/training.php>

Ruiz, M. Romero, C., Weber G et al for the eDESDE-LTC Group. eDESDE-LTC: Nominal Groups [Internet]. Jerez (Spain): PSICOST and Telnet; 2011. Available from: <http://www.edesdeproject.eu>

Salvador-Carulla L, Poole M, González-Caballero JL, Romero C, Salinas JA, Lagares-Franco CM. Development and usefulness of an instrument for the standard description and comparison of services for disabilities (DESDE). *Acta Psychiatr Scand.* 2006;114(Suppl. 432):19-28.

Salvador-Carulla L, Romero C, Martínez A, Haro JM, Bustillo G, Ferreira A, et al. Assessment instruments: standardization of the European Service Mapping Schedule (ESMS) in Spain. *Acta Psychiat Scand.* 2000; 405:24-32.

Salvador-Carulla, L., Romero, C., Poole, M., Ruiz, M. for the eDESDE-LTC Group.

eDESDE-LTC: Instrument-mapping tree [Internet]. Jerez (Spain): PSICOST and Telnet; 2011. Available from: <http://www.edesdeproject.eu>

Salvador-Carulla L, Romero R, Ruiz M, Poole M, for the eDESDE-LTC Group. eDESDE-LTC Introduction and Development of the Instrument [Internet]. Jerez (Spain): PSICOST and Telnet; 2011. Available from: <http://www.edesdeproject.eu>.

Salvador-Carulla L, Dimitrov H, Poole M et al. PILOT STUDY: Comparison of the availability of services for long-term care in Madrid (Spain) and Sofia (Bulgaria). eDESDE-LTC Evaluation Package. Jerez (Cadiz): PSICOST and Telnet, 2011.

Salvador-Carulla L, Gonzalez-Caballero JL, Ruiz M, et al. for the eDESDE-LTC Group. eDESDE-LTC: Usability of eDESDE-LTC [Internet]. Jerez (Spain): PSICOST and Telnet; 2011. Available from: <http://www.edesdeproject.eu>

Zeilinger, E., Brehmer, B. Seyrlehner, D. and Weber G. for the eDESDE-LTC Group. eDESDE-LTC: Quality Assessment and Evaluation Package [Internet]. Jerez (Spain): PSICOST and Telnet; 2011. Available from: <http://www.edesdeproject.eu>