eDESDE-LTC

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

NOMINAL GROUPS

Mencía Ruiz, Cristina Romero, Germain Weber, Hristo Dimitrov, David McDaid, Britt Wenner, Lilijana Sprah

for the eDESDE-LTC Group

Executive Agency for Health and Consumers (EAHC)

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eDESDE-LTC Group *(members[1], collaborating members[2] and main subcontractors[3])*

José Almenara (Spain)[1]

Federico Alonso (Spain)[1]

Jordi Balot (Spain) [1]

Murielle Bendeck (Spain)[3]

Anne Mette Bjerkan (Norway) [1]

Barbara Brehmer (Austria) [1]

Angel Broshtilov (Bulgaria) [1]

Maria Dolores Crespo (Spain) [2]

Mojca Z. Dernovsek (Slovenia) [1]

Hristo Dimitrov (Bulgaria) [1]

Nikolina Djurova (Bulgaria) [1]

Mónica Duaigües (Spain) [1]

Josep Fuste (Spain) [2]

Ana Fernandez (Spain)[3]

Luis Gaite (Spain)[2]

Carlos García-Alonso (Spain) [2]

Juan Carlos García Gutierrez (Spain)[1]

José García-Ibañez (Spain)[2]

Juan Luis Gonzalez-Caballero (Spain)[1]

Karina Gibert (Spain) [2]

Sonia Johnson (UK) [2]

Birgitte Kalseth (Norway) [1]

Martin Knapp (UK) [1]

Carolina Lagares (Spain)[1]

Paula Llull (Spain) [1]

Teresa Marfull (Spain) [3]

Rafael Martinez-Leal (Spain) [1]

Tihana Matosevic (UK) [1]

David McDaid (UK) [1]

Cristina Molina (Spain) [2]

Valerie Moran (France) [2]

Carlos Mur (Spain) [2]

Carmen Omist (Spain) [2]

Miriam Poole (Spain) [3]

Manuel Palomar (Spain) [2]

Rayna Popova (Bulgaria) [1]

Eugeni Rojas (Spain) [1]

Maria Teresa Romá-Ferri (Spain) [2]

Cristina Romero (Spain) [1]

Mencía Ruiz (Spain) [1]

Torleiff Ruud (Norway) [2]

Jose Alberto Salinas (Spain) [1]

Luis Salvador-Carulla (Spain) [1]

Antoni Serrano (Spain)[3]

Daniela Seyrlehner (Austria) [1]

Josep Solans (Spain) [1]

Lilijana Sprah (Slovenia) [1]

Giuseppe Tibaldi (Italy) [2]

Jose Luis Vazquez-Barquero (Spain) [2]

Britt Venner (Norway) [1]

Germain Weber (Austria) [1]

Elisabeth Zeilinger (Austria) [1]

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FOREWORD

The 'Description and Evaluation of Services and Directories in Europe for Long Term Care' (DESDE-LTC) is an instrument for the standardised description and classification of services for Long-Term Care (LTC) in Europe. DESDE-LTC has been designed to allow national and international comparisons.

The eDESDE-LTC Nominal Group Report includes the procedure and the results of the nominal groups carried out in Austria, Bulgaria, UK (England), Norway, Slovenia and Spain for designing and improving the eDESDE-LTC instrument and coding system for its use for service comparison within the European Union. This report is available at http://www.edesdeproject.eu[1].

Luis Salvador-Carulla
Coordinator of eDESDE-LTC Project

[1] If you want to provide us a feedback on the usability of the eDESDE-LTC system, please click on the link below to complete the online questionnaire (it takes less than 10 minutes):

http://www.unet.univie.ac.at/~a0305075/umfragen/index.php?sid=21575&newtest=Y&lang=en

LIST OF MAIN ABBREVIATIONS

BSIC	Basic Stable Inputs of Care
DESDE	Description and Evaluation of Services and DIrectories
EAHC	Executive Agency of Health and Consumers
EQM	Evaluation Quality Management
IRIO	Izobraževalno Raziskovalni Inštitut
LSE	London School of Economics
LTC	Long-Term Care
MTC	Main Types of Care
OECD	Organisation for Economic Co-operation and Development
QAP	Quality Assessment Plan
SHA	Public Health Association
UNIVIE	University of Vienna
WHO	World Health Association

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1. INTRODUCTION

The nominal group technique helps to deal with ill-structured domains while it allows a more structured approach than focus groups, as well as the use of prior information and knowledge. Once ideas and related questions are listed, its relevance to the central problem can be discussed following a question made by the facilitator, ideas can be re-formulated and clustered into coherent groups. All members are encouraged to participate in the discussion following a sequential order and every round is followed by a final debate (Bartunek & Murnighan, 1984). In the health sector nominal groups have been previously used to develop the preliminary taxonomy of health related habits and lifestyle (Alonso et al, 2010) and its integration into primary care (Grandes et al, 2008).

2. PROCEDURE

National nominal groups were gathered in every participating country (Austria, Bulgaria, Norway, Slovenia, Spain, United Kingdom). 3 rounds/sessions were designed lasting approximately 120 minutes. Groups were made of 6-8 participants plus a rapporteur, but variations were allowed depending on the country and the partner characteristics. They were intended to include health and social care professionals, providers, representatives from user organisations and decision makers, whenever possible. The nominal group should check the adaptation of national version, and contribute with their reports to obtain a first version of the instrument. It was agreed that points of disagreement should be solved by the working group. In the case that there is no agreement, a simple majority vote should be cast.

The regional mapping of LTC services completed at the Pilot study was presented at the third nominal group, to identify errors and to introduce final comments.

2.1. NOMINAL GROUP: SESSION 1

A number of comments and suggestions were provided for guiding the **first** nominal group session. One of the partners (LSE) was not able to organise the first session on time for the first review of the instrument. The aims of the first session were:

- To get acquainted with the problems of service research and comparability of services across different geographical areas.
- To know the EPCAT Approach to service research

- To know the DESDE-LTC instrument and coding system in order to prepare comments and amendments which will be discussed at Session 2

QUESTIONS RECOMMENDED

1. "How can we define a health service?"

a) Start an open discussion on the definition of services. Rise awareness on the lack of international standardisation on this critical concept. It may be interesting to provide examples to differentiate Services and other units of analysis in health service research such as Programmes, Procedures, Health Products and Health Functions. The additional material may help to orientate the discussion

b) Additional information and documents

- Johnson S, Salvador-Carulla L, EPCAT Group. Description and classification of mental health services: a European perspective. Eur Psychiat 1998; 13 (7): 333-341.
- Description of services in ESMS/DESDE-LTC:

Definition of long term care services:
Here a 'service' is defined as a Basic Input System (BIS) composed by the minimal administrative unit with an organised arrange of structures and professionals that provide care. Main Types of Care (MTCs) provide the essential descriptors and functions of a service.
The range of services to be considered includes those facilities that have as specific aim any aspect of the management of long term care and of the clinical and social difficulties related to it.

A "**service**" or BIS must fulfil one of the following criteria to be coded as a unit of analysis:

1- Criterium **'a'**
2- Criterium **'b**' AND 2 criteria from section **c**
3- 4 criteria from Section '**c'** (complementary criteria)

a) The service is registered and acknowledged as a legal organization (with its own company tax code) and not as a part of a meso-organization (i.e a hospital) and a separate official register in the Community.
b) To have its own Administrative unit and/or secretary's office.
c) Complementary criteria:
c.1 To have professional staff specifically for the aims of the service.
c.2 All activities are used by the same users.
c.3 Separate location (not as part of other facility i.e hospital)
c.4 Separate financing and specific accountancy)

Health and social services are the minimal micro-level functional systems of care organisation within a catchment area. Other organisation systems exist at meso-level (grouping of services or structures that compile different services within a larger organization such as General Hospitals) or at macro-level (i.e. large national or international Health Maintenance Organisations) are excluded from this classification. Health products are also excluded from this classification. The functions provided by the service "micro-organisation" can be described by smaller unit of analysis.

For example:

- *Modality of Care* is a main type of intervention (or activity) that can possibly be applied to achieve one of the restricted number of tasks that together comprise the whole range of Long-Term Care. (De Jong, 2000).
- *Clinical units* (or care units). Units of analysis that fulfil some of the criteria but do not fulfil overall criteria for being coded as a service (i.e a unit of eating disorders within an acute psychiatric ward in a General Hospital).
- *Main Types of Care* (see DESDE-LTC codes) (page 3).
- *Packages of Care*. A cluster or set of integrated care interventions designed for the same group of users.
- *Intervention Programmes*: a set of activities programmed within a limited period of time (normally less than 1 year, and no longer than 3 years) without a stable structure in time. In some occasions services develop from programmes which are reedited through the years.

2. "Is it necessary to develop standardized classification of services in long term care?"

a) In addition to the problems related definition of services there is a need to provide a classification system. It may be interesting to explain the available classification systems: The DESDE-LTC instrument provides links to available international classifications of services.

b) Additional information and documents:

- International classification Systems:
  - ICF. http://www.who.int/classifications/icf/en/
  - ICHA.http://ec.europa.eu/health/ph_information/dissemination/hsis/hsis_10_en.htm.
  - ICHI. http://www.who.int/classifications/ichi/en/

- Introductory comments at DESDE-LTC Instrument

Services are classified according to a number of descriptors, such as care typology, intensity, time of stay, and mobility. These atheoretical descriptors provide a classification based on the "Main Types of Care," including information/ accessibility, self-help, outpatient and community care, day care and residential care. Services are arranged or organised either as a single MTC or in cluster combination of MTCs.

There are some examples of types of care that can be classified in each code (in italics). This list of examples does not pretend to be exhaustive. Some instructions are also given for the cases where branches are mutually exclusive, i.e. pair of branches where a particular service never must be classified as part of both at the same time.
The coding system follows the original order used at the European Service Mapping Schedule (ESMS) (Johnson et al, 2000) and its adaptation for disability services (DESDE) (Salvador-Carulla et al, 2006), although the arrangement has been modified to make it suitable for the classification of LTC according to descriptor levels (page 3). Due to this rule the codes do not follow an ordinal arrangement in Branch "D" (Day Care).
The coding system should be filled after completing "Section D" taking into account the information provided there.

3. "Is the EPCAT approach useful for describing and classifying health & social services?

Methods (EPCAT Approach)

a) Here we explain and discuss the problems related to the data collection in service research. We explain and discuss the approach developed by EPCAT and based on the epidemiological approach developed by EPCAT which uses “Main Types of Care” for the description of services.

b) Additional documents: There is an extensive literature published in this area.

- Salvador-Carulla, L., Atienza, C., Romero, C. and the Psicost Group. (2000). Use of the EPCAT Model of Care for Standard Description of Psychiatric Services: The Experience in Spain. In. Guimon J, Sartorius N, eds. Manage or Perish: The Challenges of Managed Mental Health Care in Europe. New York: Plenum Press. **(chapter pdf)**

Tools (ESMS/DESDE)

a) Here we introduce the ESMS/DESDE literature and the DESDE-LTC instrument and coding system in order to facilitate full understanding of the approach and to enhance comments and modifications in the next session.

b) Additional documents

ESMS/DESDE

- 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 Psychiat Scand 2000; 102 (Suppl. 405): 14-23

http://www.ncbi.nlm.nih.gov/pubmed/11129094?ordinalpos=1&itool=EntrezSystem2.PEntrez.Pubmed.

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

- EXAMPLES OF PUBLISHED STUDIES AND EXPERIENCES

- Salvador-Carulla L, Saldivia S, Martinez R, Vicente B, García-Alonso C, Grandón P, Haro JM. Meso-Level Comparison of Mental Health Service Availability and Use in Chile and Spain. Psychiatric Services, 59 (4):421-8, 2008.

- Salvador-Carulla, L., Tibaldi, G., Johnson, S., Scala, E., Romero, C., & Munizza, C. Patterns of mental health service utilisation in Italy and Spain: an investigation using the European Service Mapping Schedule. Social Psychiatry and Psychiatric Epidemiology, 40(2):149-59, 2005.

2.2. NOMINAL GROUP: SESSION 2

The aims of the second session were specifically related to the preliminary version of the eDESDE-LTC developed by the working group:

- To get acquainted with the eDESDE-LTC instrument.
- To check the aim, structure and use of the instrument
- To check the cut-off points provided at the instrument

The questions recommended for this second session were:

- What is the main goal of the instrument?
- What are the reasons to exclude meso-organizations of the coding process?
- How were cut-offs derived?

The following key topics were discussed

- *Definition*
  - *Services*
  - *Main Types of care*
  - *Catchment areas / territorialisation*
- *eDESDE-LTC Instrument*
  - *Structure*
  - *Translation process*
    - *Use of the instrument*
    - *Cut off points*

2.3. NOMINAL GROUP: SESSION 3

The third session was intended to appraise the modified version of the instrument to check changes made and to assess its overall usability. Questions recommended were:

- Does the new version improve the beta version?
- Have your specific suggestions being incorporated in an adequate way?
- If not, do you understand the reason provided by the WP coordinator not to do so?

3. NOMINAL GROUPS: COUNTRY REPORTS

The total of participants in each country was: 8 in Austria, 7 in Bulgaria, 5 in UK, 6 in Norway, 12 in Slovenia and 8 in Spain. In all 46 participants attended the nominal group sessions.

All the reports of nominal sessions held in the six country partners have been gathered and are shown in the following lines. Table 1 shows nominal sessions dates.

Table 1. Nominal Sessions dates

COUNTRY	NOMINAL GROUP 1	NOMINAL GROUP 2	NOMINAL GROUP 3
AUSTRIA	Vienna 9th May 2009 (14.00 – 16.00)	Vienna, 22nd September 2009 (14.00 – 16.00)	Vienna 23rd June 2010
BULGARIA	Sophia 28th May 2009	Sophia 17th of August 2009 (90 min)	Sophia 10th January 2010
UK	London,9th November, 2009	London, 9th November 2009	London,January 2011
NORWAY	Trondheim ,February 2009	Trondheim 2nd December 2009	Thorndheim, 12th February 2011
SLOVENIA	20th May 2009	Ljubljana 12th of October 2009 (09.00 – 11.30)	Ljubljana, 13rd December 2010
SPAIN	Jerez, 26th February, 2009	Jerez 25th June 2010	Jerez, 26th October 2010

3.1. AUSTRIA

3.1.1. FIRST SESSION

Participants Experts:Tobias Buchner, Manfred Kornberger, Daniela Malfent, Germain Weber Moderator: Barbara Brehmer Observer: Elisabeth Zeilinger

Introduction by Barbara Brehmer Introduction of the participants, the project and the project-team.Quick overview about how this meeting will be done and how a Focus-Group works.

1. ***Question: How to define a „Health Service“?*** *Time for participants to think about it and take notes Statement from every participant; questions for understanding; short clarification and discussions if needed.*

Points of discussion: -Is the project about the psychological or psychiatric health care-services only, or does it cover services concerning physical health, too?
This question was raised because the provided literature was mainly about psychiatric health care. Participants were informed about the project covering all kinds of services concerning LTC.
-Discussion about financing health-care services:
In comparison to America, the government finances a lot of health-care services in Europe. Should one criterion of defining a health-service be: “being financed by the government”? It was decided not to add this criterion, because this would lead to disregarding all the privately financed clinics. A suggestion was made to create types of financing.

-Are private practices included in the definition of a “health service”?
Decision of the Group: Yes!
Accessibility for people with handicaps cannot be included as a criterion, since a lot of services don’t fulfill this criterion. This would rather be a requirement for a good health-service, and could be treated separately.

Result of the group: Features that describe a “Health Service”
-Kind of Financing

- There is a big range in financing: from totally gouvernmental to totally private
- Services should be affordable!

-Target-group

- People with special needs (psychological, social, physical) over the lifespan

-Different kind of services I:

- diagnostic, management, treatment
- prevention, treatment, after-care
- One can receive services that aim to achieve something like a good health (treatment, prevention, after-care) or a good quality of life
- Availability of services (urban/rural regions)

-Different kind of services II:

- Private practices included (e.g. psychologists)
- In-/out-patient
- Education of staff/ payment of staff (voluntary workers included)
- Duration of services (long-/short-term)
- Specific target-groups
- Open Access!

Definition of Long-Term-Care Introduction of criteria from the Instrument concerning services that can be coded (Criteria a, b, c)

2.Question: Need to develop Coding-System for LTC Services? This question was hard to understand for the participants. (Questions that were raised: do we need a definition of a Coding-System? What's included in LTC?) Time for participants to think about it and take notes Statement from every participant; questions for understanding; short clarification and discussions if needed.

Points of discussion: -Discussion about quality; kind of staff, possibility of self-determination? It would be important to code this.

-How can an evaluation be useful, if no information of quality of services is included?

-What can the Coding-System really do/achieve?

Mapping

quantitative and geographical data

This is a first step, but should not be the last.

What kind of people should get access to the system and itÄs results? (consumers, staff, …?)

Results of the group: “Need for Coding-System”

-Yes, a coding-system is needed

-Transparency / Function

-Researcher

-Politics

-Consumers (where can I go with my special problem?)

-People who work in the health-sector

-geographical

-knowlede can be used for building structures in new regions

-determination of over-/undersupply

-financial aspects(cost/benefit)

-develpoping minimalstandards of services

-Is the coding done by characteristics of quality (maintenance conepts) or by structure characteristics?

-It would be important to include aspects of quality

-Importance of knowing how services were developed.

- Various Needs > various kinds of services for different target-groups. It would be good to have an overview what kinds of services exist.

Aim of the Instrument Theoretical Input concerning the aim of the instrument and the aims of the project. What will/can the project achieve.

Intruduction to the coding-system and decision-trees. Instrument in the German draft-version was handed out to participants.

3.Question: “Model of EPCAT useful?” We used this question/part of the meeting to give an introduction to the instrument to participants.

Points of discussion -Situation in Austria, that could be a problem: Mostly, there are no records of the target group of the Instrument. (persons with ID, persons with mental health problems, …)

-Questions concerning translation:

Service: it will be mostly translated as “Dienstleistungen”, because it will be coded on Micro-Level.

Outlook to the next meeting The Instrument should be finished and translated until the next meeting. Important topics for the next meeting:
-Feedback and questions concerning the Instrument
-Vignettes
-Coding will be tried out (Micro-Level)

3.1.2. SECOND SESSION

Participants Experts: Tobias Buchner, Manfred Kornberger, Claudia Oppenauer, Germain Weber, Moderator: Barbara Brehmer, Observer: Elisabeth Zeilinger.

Introduction Aim of the Meeting. Introduction of the Project and current situation of project.

Discussion about the coding-system The following topics were discussed.

The three documents of eDESDE *Renaming branches/letters of coding-system: the main-branch should stay the same as in the original (English) version. This could cause confusion if using it in another language.*

New branches names have been added to make the toolkit clearer but they keep the same initials as in English for international use. As explained in the Reus meeting these codes will just be 'Labels' to identify the services which will be independent from the decimal code system that is being developed by Maite Roma.

What is the main goal of the instrument? Who will use the system and will benefit from it? This is not specified in the documents of the coding system. The whole coding-system is rather confusing. Words are not used consistently. The instrument will not be easy to use.

Main goal of the instrument and coding system has been clarified in the new version of the instrument. Instrument and Classification-system (previously called Coding system) are parts of DESDE-LTC Toolkit so they complement each other. In order to increase consistency a Ontology analysis of the system is being carried out by the University of Alicante and it was presented at Reus

Using the right words is very important to use the instrument in the right way! Concerning the

definitions it is very important that the meanings of words are thought of.

Key words have been reviewed: patients/users, services,..
Are there examples of the codes? This will be very helpful. Examples need and will differ between countries, due to the different service structures in the respective countries.

Some examples have been added to the instrument. A 'Casebook' with 30 examples has been prepared. The idea is to incorporate up to 60 examples in it.

The translation process, including problems with translation and their implications
Explanation of how the translation was done in Austria by Barbara Brehmer.
Discussed problems:

1) User/Client: both are used in the original documents, which caused confusion with translation.
Client and patient has been eliminated from the documents and they have replaced by 'user'

1) Community care / outpatient care: where is the difference in German language?
Community care has been eliminated and replaced by Outpatient care in the whole toolkit

3) The basic meaning of "care" is problematic concerning translation.
The basic term is BSIC with its definition: Basic Stable Inputs of Care
Will all the problems with translation being solved? > probably not! Pilots will help to solve /discuss some of these problems, but pilots will not be conducted in Austria, therefore **some problems with translation or meaning of specific words will not be solved.**

We will provide the result of pilot in Bulgaria and Spain when available. In the mean time we have prepared slides with data from Spain. All the translation problems cannot be solved. In any case this is a problem for any international instrument. The critical words will be identified and explained

Using the instrument: One service can get more than one code. The coding is done on the lowest level. Big organizations can get very many codes. Is this really practical to do? It makes the use of the coding-system rather difficult.

This is a misinterpretation of the assessment system when it is applied to a meso-organisation (ex. a hospital or a large NGO) instead to a BSIC. Remember that even the facilities called ‘Services’ should be explored to ascertain if they are BSIC where codes should be provided or larger systems. We have added a sentence to differentiate meso-organisations from ‘services’/BSIC and we expanded the description of BSIC as well as the description of MTC

In Austria there are a lot of big organizations (on a Meso level – which will not be coded by the system!), offering a lot of different services, and therefore get a lot of different codes. Is this helpful for anyone? **Will a user be able to get useful information out of these? There is a need to make information easy to understand for users!**

The system is intended to provide information for health and social planners and service researchers. Evidently users will not get any info from the coding: however the coding can be translated in relevant info on the existing services in a an area for a newcomer and improve information for mobility

How to detect and code services that are not documented somewhere? E.g. voluntary carers, that offer help to some people, but there is nothing written/documented about it. Not including them into the coding will lead to a flawed picture of the service-structure of an area.

You can use a census week and describe the care that they offer. Sometimes youdiscover these new services in the Service Inventory when you ask about services with which the described service has direct contact. We took out this question from section D but it could be added again if needed. In any case the system is intended for providing standard description of existing services and not to detect new services not identified by local authorities

Isn’t it useful to split up branches by the different target groups? Will it be useful for the users to know what kind of services exist for intellectual disabilities, what services exist for physical disabilities, etc.? This useful information is lost by coding all services together.

We can collect these data from additional codes and also from Section D. You have different ways of analyzing data from the instrument. The system is designed to identify FIRST the target group and then the services for this target group. Forexample services for Older people with intellectual disabilities (identified with capital letters before the desde coding. The

small letter at the end can be used to identify SPECIFIC services within an already defined target group

Will the instrument work at all in Austria? Is it possible to gather all the needed information? Not all of the information is documented. Some information will not be given by organizations, due to data protection.

When we cannot get the detailed information in a catchment area we can stop description at a higher level/ branch but we can obtain the services map. Of course the instrument will need to be tested in different countries. The case is that its former version ESMS was tested in 17 european countries so this coding should work in Austria as well. On the other hand DESDE-LTC will be used in Austria in the next REFINEMENT project for Mental health

Service-Definition (BSIC): ***Will meso-organizations be coded? If not, all hospitals (as an example) will not be coded. There should be the possibility to code these!***
Are there organizations, which only give information? (Branch "I"): Yes there are, but these are meso-organizations. Will they be coded?

What are the reasons to exclude meso-organizations of the coding process???
The eDESDE-LTC is NOT a system to code ALL the Care system (it does not code Meso-organisations at a higher level or activities at the lower level. This is explained at the instrument. DESDE-LTC is only intended to code the smallest service units (BSIC) using its main activity as descriptor (MTC). In any case previous research has provided evidence on the difficulty –not to say impossibility- of coding services/hospitals for international comparison. While this system has demonstrated its usability for international comparison at least in mental health. Hospitals as meso-organisations can be coded by aggregation of BSIC and MTCs (example Services for mental health in Cantabria)

It is important to have the possibility to code all available services, no matter if they are part of a meso-organization or not. Otherwise there will not be a sufficient coding of specific areas, and no comparisons between areas/countries will be possible.This can be obtained aggregating codes and BSIC: again example of cantabria

Importance for users: They need the information of the meso-level. If they want to use the services of the organization, they need to have the information of the meso-level to contact

the organization!

The contact with services is provided in section D. Section D provides aclassical approach to service localisation, and identification while it also provides the DESDE coding so it can be used both by users and by service researchers and policy planners
Catchment Areas and MTCs: ***No remarks or points of discussions by participants.***

Cut off points:

How were cut-offs derived? Example: Organizations with at least 20% of LTC are included. No explanation is given for using the cut-off of 20%? **There is need of an explanation for these cut-offs!**

All over, the definitions and cut-off are very complicated. Maybe it would be better to make these easier to understand.

Cut-offs have been produced by consensus trying to provide similar rates (ie 20%, 50%) for similar cut-offs to avoid excessive complexity in the system. We have tried to use a similar cut off point for similar levels of definitions

Confusion and discussion about the cut-offs relates to hospitals. Are hospitals included at all in the coding, besides not being on micro-level? There are organizations fulfilling criteria of “hospital” while not really being a hospital.

The code ‘Hospital’ does not refers to hospitals as meso-organisations but to BSIC which are in facilities: Residential, with 24hour physician coverage in a place defined as a ‘hospital’ by local authorities. In the previous version ‘hospital’ was in an upper level but we realised that there is huge variabilñity in what it is officially called a hospital in one country an another, and even in the same country (differences exist in Valencia and catalonia within Spain). As the local definition as ‘Hospital’ has legal and regulatory implications, we have to identify services or BCIS within ‘hospitals’ but this is now done at a lower level in the branches reducing interterritorial variance in the coding system.

3.1.3. THIRD SESSION

Participants *:* Experts: TobiasBuchner, Daniela Malfent, Germain Weber Moderator: Barbara Brehmer Observer: Elisabeth Zeilinger; Yvonne von Moy

Introduction*.* Aim of the Meeting. Introduction of the Project and current situation of the project. Resume of the past two Austrian nominal-group meetings. Experts were asked to discuss their questions or problems concerning the project and the instruments during the whole meeting.

Evaluation of translation The translational process and its evaluation were explained to the experts.

Discussion points

The use of the words “client” and “user” and its translation into German.

Different translators, with different educational background and knowledge concerning the topic were working on the instrument in the different partner-countries, which can raise problems.

Problems of translation and its implications in the different countries

Semantic interoperability: How can problems with translation and different translation strategies in different countries cause problems with semantic interoperability?

Usability of the instrument in the different countries: there are country-specific services that cannot be coded with the eDESDE-instrument. Should there be the possibility to add branches to the instrument, resulting in a coding system that is usable in every country?

Changes made concerning the instrument Explanation of changes concerning the instrument, that were made since the second nominal-group meeting, including explanation of the changes from BIS to BCIS and changes of BCIS.

Optional Codes

Optional Codes were explained to the experts. Examples for optional codes were explained and discussed.

Codes concerning target-population

Codes for additional characteristics

Important discussion about the coding system Generally, the whole instrument and the coding system were rated to be too complex with too many categories.

One expert remarked, that the codes are not easy to understand and don't follow a structure. The codes could have been designed in an easier way to make them easier to understand. You cannot see at first sight, what a code means. You always have to look it up in the coding system to know what the numerical/alphabetical code means. The design of the instrument should have followed a more user-friendly structure. It is only adequate for specialists, who have undergone intensive training concerning the instrument and the coding-system.

Who will be the users of this instrument in the first place (politicians, clients with LTC needs ...)? The system should be structured adequately for the target group of users!
Creating a more user-friendly instrument can save a lot of resources (money, time, etc.), since the trainings don't need to be that extensive and users can get access to and make use of the data that is gained by using the instrument. User-friendliness would make it easier to make the instrument acceptable by organizations, the public or users with LTC needs. The leader of the project should make a contribution and suggestion how the instrument could be changed and be made easier to use and understand. Suggestion by one expert to be more user-friendly: Using a computer for data processing and data-input.

On the other hand, as a first step it is acceptable to create a very complex instrument, but it should be adapted and changed in the future, so that users with LTC needs can make use of the data. Then a discussion arose about who will make use of the existing instrument or the data gathered by the instrument.

Vignettes and Coding Explanation of the Austrian vignettes. One vignette was coded by the experts. The coding and coding-problems of the vignette, as well as all branches of the coding systems were discussed. The coding was very difficult for the experts. The whole system seemed to be too complex to make an easy coding possible. One expert remarked that a lot of knowledge about the service is required to code the specific service. It may not be possible to get all important information for coding from the services easily.

Future use of the instrument A question was raised by the experts, if the instrument is used already and how it will be used in the future. It followed an explanation by Mag. Brehmer about the pilot study in two partner-countries and the training for persons that will use the instrument in the eDESDE-project. Concerning future use of the instrument there could not be any precise explanations, since the future use is not clear at this moment.

Final Remarks by the experts

final remark on the eDESDE project and the instrument

final evaluation of the nominal group meetings

Expert 1:

Ad 1)

Good project to achieve a mapping of services

Would be great if the quality of the services would be coded too

Currently not user friendly for non-project members – practicality of the instrument is questionable, especially if this tool should one time be used by clients with LTC needs or their carers!

Who will be the users when the project is finished? Where can it be available, how will this be disseminated?

Ad 2) Very good structured meetings, clear guidelines and tasks presented by a very good organized Austrian team!

Expert 2:

Ad 1)

Very interesting, background idea of the project is great

It would be even greater if the instrument would be improved concerning its usability and practicality

The instrument has the potential to improve the service structures and their availability in Austria

There are some translations (expert terminologies) that make the instrument hard to use for non-experts and not all branches are practicable for Austrian services

Ad 2) nice atmosphere – good for working together!

Expert 3:

Ad 1)

The project with the development of the eDesde Instrument gives for the first time the

possibility to evaluate services for different patient groups in different regions and countries. If the instrument manages to be used in practice, this project will have high implication on service development and improvement. Further, the instrument will have an impact on socio-political decisions on care services because service quantity and quality become evident with the instrument and related data.

With sufficient training and introduction of the instrument, the instrument will be highly relevant for international service evaluation and will show a roadmap for service development and maintenance as well as information about regional service gaps and which service structures have to be fostered. It will also give relevant information about used services related to different client groups and consequently will enhance service development for specific patient groups.

Ad 2) The meetings were very constructive and all experts contributed their knowledge to the development of the instrument. Because of the different professional backgrounds of the experts, different views could be discussed.

Expert 4:

Ad 1) The project is challenging, because the next steps are not always planned and known. It is not clear when to conduct the next step.
A general evaluation of the instrument has big innovation potential, because it tries to find a common structure to map the LTC-landscape for the first time and provides a structure for comparative analysis between EU-member states.

Ad 2) The nominal groups were always well organized, the moderation was very competent and the protocols very professional! The composition of the group was very productive!

Expert 5:

Ad 1) The project is very ambitious and continues the strategy of previous projects. Its goals are a welcome development on the way to a consumer-friendly European care system. Into the current instrument quality aspects/branches should be included to be more helpful for people with LTC needs, besides in future project the categories of branches should be evaluated and adapted by consumers. At the moment, the current instrument is only helpful

for policy makers.

Ad 2) The meetings were very constructive and it made fun working together. The participants with their different, individual backgrounds were perfectly chosen for the nominal group. All meetings were excellently moderated and tasks for the participants were always clearly structured – therefore good and intense discussions were possible.

3.2. BULGARIA

3.2.1. FIRST SESSION

Participants: Experts: Hristo Hinkow Head of department in National Centre for Public Health Protection, Ministry of Health Zahari Zarkov Epidemiologist. Vladimir Nakov. Private psychiatrist. Savka Angelova. Director of social home for children with intellectual disabilities, town of Elena, Bg. Angelina Petrova. Director of municipal department for social services – Stara Zagora municipality. S.P. Director – Project SANE (mobile social assistants to people with physical and intellectual disabilities). Moderator: Dr. Hristo Dimitrov Observer: Dr. Angel Broshtilov.

Method: asking preliminary agreed question-open discussion- brain storming- voting on the group's opinion and/or definition- next preliminary agreed question. Articles, provided by headquarters, were sent 1 week beforehand. Half of the participants admitted to have read some of the materials.

Procedure: The session started with participants receiving copies of the trees of social and health services, prepared during the service mapping exercise of mental health services in Stara Zagora- Bulgaria in 2006-2007. It was explained that what they see is one of the principle results of instruments, such as eDESDE-LTC and that the current instrument classifies services into these 6 main branches: Accessibility, Information, Self help, Outpatient care, Day care and Residential care. Participants were given 10 minutes to study the trees and ask some opening questions to the two members of the project team.

Discussion: From this, naturally followed a discussion as to the appropriateness and usefulness of the EPCAT differentiation and classification approach. Almost all of the participants approved of the method. Immediate applications were suggested: classification

is used during the planning process by a community planning group, classification is applied in the everyday networking and coordination activities of case managers, classification is used for evaluation of services for definite time periods, etc.

Then, the moderator presented eDESDE project, participating countries, as well as the main scientific purpose of eDESDE : to devise a comprehensive instrument for intranational and international comparison of services for a predefined target group, and agreed-upon catchment areas. This objective was highly appreciated; in the ensuing voting, all, but one participants voted in favor of EPCAT method and eDESDE in particular. The participant, voting against, stated that an instrument aiming to classify social AND health services in one system, is useless in a country where social and health services are managed by two agencies.

In this line, an opinion was shared that services, enlisted in the Self-help and Voluntary Care Coding Branch, are very unpopular in Bulgaria, and will remain unpopulated in a future mapping exercise. However it was agreed upon that such a branch is useful for politic purposes.

The discussion proceeded with participants trying to give a definition for health services. Despite heated arguments, such a definition was hard to reach. Participants reflected upon criteria A,B, C for a service, provided in the pre-final draft of DESDE.

The consensus was, that criteria A,B, C define comprehensively and operatingly the unit , which will be questioned with DESDE – service/agency/facility. With the help of DESDE this service/agency/facility will be further “broken into” Main Types of Care, present in the DESDE codification system.

A discussion ensued, focused on the translation into Bulgarian of particular DESDE terminology- Long term care, Main type of care, service, etc. Participants voted and reached consensus on the translations of terms, which will be of great practical value for the final Bulgarian version of DESDE.

As a whole, participants agreed upon and welcomed the philosophy, the purpose, definitions of DESDE with one important accent: the time delimitation between a “program” and a “service” should be shortened as far as possible in favor of the service. That is, for an activity

to be called a “service”, it should have been in existence at least one year before the time of the interview.

Participants also raised the question whether dementia should be mentioned exclusively in the target group definition.

Participants expressed satisfaction from the session and said they were looking forward to next focus group when details of DESDE instrument would be discussed.

3.2.2. SECOND SESSION

Participants: Experts: Hristo Hinkow Head of department in National Centre for Public Health Protection, Ministry of Health Zahari Zarkov Epidemiologist. Vladimir Nakov, Private psychiatrist. Savka Angelova, Director of social home for children with intellectual disabilities, town of Elena, Bg. Angelina Petrova, Director of municipal department for social services – Stara Zagora municipality. S.P. Director – Project SANE (mobile social assistants to people with physical and intellectual disabilities). Moderator: Dr. Hristo Dimitrov Observer: Dr. Angel Broshtilov.

Definition

-Basic Input Systems

The participants focused on the definition of “service” or “basic input system” and once again went through the definitions, provided by the headquarters. As it has been already pointed out by the different DESDE teams in the different countries, there are confounding terms for description of the PLACE which provides main types of care, and where the researcher goes, armed with a DESDE questionnaire to implement the DESDE classification and analysis.

There is a good term in Bulgarian to designate this PLACE (it is called СЛУЖБА). It is non-problematic to apply all three criteria to the СЛУЖБА without causing any confusion among researchers and services' staff. The criteria are easily understandable and applicable to the local context. Except, may be, for the criterion *c.3 Separate location (not as part of other facility i.e hospital)* ,since many Basic Input Systems in BG are situated inside hospitals and other facilities. Nevertheless, when we apply the other three complementary criteria, *c.1 To have professional staff specifically for the aims of the service. c.2 All activities are used by*

the same users.c.4 Separate financing and specific accountancy) the definition remains operative.

We have found examples which correspond either to criterion (a) OR to criterion (b) OR to criterion (c).

In conclusion, our group decided to use the Bulgarian term СЛУЖБА and put (in brackets!) the DESDE term “Basic Input System”, which is not easily grasped, when translated**.**

-Catchment area HEALTH

Catchment area in the Bulgarian HEALTH care system is never easy to delineate. All public health services, dedicated to people with long term care in BG follow the principle of “freedom of choice”. As an example, if a person, diagnosed with schizophrenia and registered as a person in need of LTC, decides to go and see a psychiatrist, he is free to go to whichever psychiatrist's office on the territory of Bulgaria, he'd like . The service will be costfree, provided that the psychiatrist is reimbursed by the National insurance Fund or by the state budget. The same holds true for other specialist HEALTH services.

Therefore the classification of catchment areas provided by the headquarters will look like the following in the Bulgarian context:

Territorialization levels

H0: International administrative territorial unit For example, European Union
H1: Country administrative territorial unit For example, Bulgaria
H2: Next territorial level before Country administrative territorial unit N/A
H3: Maximum administrative territorial mental health unit N/A
H4: Basic administrative territorial unit of specialized mental health N/A
H5: Basic administrative territorial unit of general health N/A

Discussion A discussion followed, concerning the cut-off point question “What criteria must a Basic Input System fall into, in order to be mapped as an LTC-BIS and mapped with DESDE?”

The group agreed that:

1. First, the BIS should be “designed” to provide services to people in need of LTC. This design ensues either from the current legislation which the BIS obliges, and/or the BIS internal regulation (statute, mission statement, scope of work, etc.).

This criterion was called by the group – Formal criterion.

2. Next, in order to be mapped, a certain BIS must follow the criterion that at least 20% of its users should have the statute of people in need of long term care.

The group understood this prerequisite as a Practical criterion. i.e. if a BIS is designed for people in need of LTC but practically does not service at least 20% of this population, it should not be mapped. An important exclusion will be if the BIS is not designed for LTC, but practically provides MTC to more than 50% of its clients with LTC.

Questions arised

Why, exactly 20 %; where does this figure come from ?

What is the time span for this 20%; Is it per/month, per/year or what?

In conclusion, if we are to follow both the Formal (1) and the Practical (2) criterion, very few health BIS in the pilot area in Sofia will be eligible for mapping. The reason is that health system in Bulgaria is not very much differentiated. For example, the BIS – group psychiatric practice can see 100% clients with LTC in May, but only 5% in June. Thus, this group practice can be said to provide only general MTC to its population.

-Catchment area social services However, the catchment area for social services is more clearly defined. In order to make use of social benefits, people with LTC need to have address registration in a certain municipality. Thus, they usually make use of social services, available within the administrative boundaries of a municipality.

-Specific cut-off points for the specific branches of MTC The participants in the nominal group went through the definitions and cut off points of MTC in the branches of the service tree, as provided by the Headquarters. The definitions were found to be clear and operative. The participants managed to think of an example for each particular MTC. Although services for people with LTC are still scarce and undifferentiated in Bulgaria, we managed to provide

examples. One big exception is The (S) branch (self help and voluntary services). At present, the group knows of no services where the work is done by unpaid, volunteers; specialists or non-specialists.

3.2.3. THIRD SESSION

Participants: One expert missing due to previous compromises. Experts: Zahari Zarkov Epidemiologist. Vladimir Nakov, Private psychiatrist. Savka Angelova, Director of social home for children with intellectual disabilities, town of Elena, Bg. Angelina Petrova, Director of municipal department for social services – Stara Zagora municipality. S.P. Director – Project SANE (mobile social assistants to people with physical and intellectual disabilities). Moderator: Dr. Hristo Dimitrov Observer: Dr. Angel Broshtilov.

Discussion on the results of pilot study (Madrid-Sofia) The discussion was centered mainly on the preliminary results of the comparison between services for long term care in Sofia and Madrid.

At first the participants were greatly astonished by the fact that an entire branch of the eDESDE classification system is missing in Sofia; i.e. the “Self Help” branch of services, where all types of care is provided to clients by professionals or non professionals, receiving no payment whatsoever. This proves that the self help and the voluntary sector in Bulgaria is in it primordial stage. People in need of long term care seldom organize themselves to create stable self- help services. It was noted that the existence of such services will increase the self consciousness of people with LTC- needs and perhaps will contribute for diversification of the range of services. Therefore clients and users need more help form the state and the professional organization.

In this respect the participants posed the question, what will be the picture if the stipulations for the “stability” of a certain service of eDESDE – LTC instrument are made more liberal. In other words, if mapping includes also programs of duration less than one year.

The number of services is not so drastically different between Sofia and Madrid, but participants pointed out the ratio community/residential services, which is very much in favour for the city of Madrid. This finding could become an additional proof to the statement that deinstitutionalization has not even commenced in Bulgaria. Obviously this will be an alarming

statement contrary to the political will for reforms, present in the official government documents. Thus the usability of the eDESDE instrument as a political tool was once again acknowledged by the nominal group members.

One of the participants said that the pilot data prove that the eDESDE instrument and the philosophy of Main types of care classification could be applied in the accreditation of Bulgarian health services. This is a process whereby different hospitals and other health care facilities receive a certain category according to the types and the complexities of services offered there.

Nominal group members asked DESDE team members how informants from the selected services reacted to the interview and the general context of the mapping exercise.
The answer was that some of the respondents were a little anxious, but generally eDESDE instrument was received quite well.
Then our participants suggested that the mapping process might have some beneficial effect on the service managers, and this should be taken into consideration by authors and developers of DESDE in the further elaboration of the instrument. All participants approved of the Beta version of the instrument.

3.3. UNITED KINGDOM

3.3.1. FIRST SESSION

Due to administrative problems the UK partner fully incorporated to the project activities with a fourth month delay. Due to that the first session was carried out in the UK not as a formal session.

Participants: Moderator: David McDaid Observer: Tihana Matosevic

Below we have summarised the key messages that came out of a discussion with a small nominal group of individuals working or researching social care services in England.

-How can we define a health/social service? The focus was on identifying the differences between health and social care services. Several possible dimensions and approaches, that

could be used in order to define health and social care services, were suggested: funding bodies, client groups, types of services, commissioning.
(**Note**: It was felt that the purpose of the additional information provided for this question was not very clear.)

Health services

- Formal diagnosis and treatment as essential part of health care;
- Treatment (medication, invasive);
- Delivered by qualified staff;
- Health services concerned with maintaining health;
- Health care delivered in specific locations (hospitals, GP practices, etc);
- Service rarely delivered in person's home;
- Fundamental difference between health and social care is in the focus of the assessment of needs (there is a lack of a holistic approach in health care);
- The health care approach appears to be largely problem orientated.

Social services

- Social care tends to pick up what health does not deem to be there (social service is whatever health service is not).
- Social care services support people living with their condition/ or frailty due to age; it can be about a diverse range of activities including banking, shopping, help with welfare benefits as well as personal care
- Often delivered by non-professionally trained staff (e.g. unpaid informal carers and volunteers;
- The objective is not to 'cure' but to help people to manage their difficulties and conditions;
- There is no pressure to improve health in a specific way;
- Holistic approach.

The group briefly discussed care services that are not only health or social care: these included intermediate care, extra care housing, and support services for carers of people with dementia.It was also noted that definitions of health and social care services depend on *location* and *purposes*.

The use of the term patient would not be appropriate when thinking about non-health

services: client would be a better term to use.

Similarities between health and social care services

- Both health and social care services are services delivered for people by people.
- Health and social care services are not scalable, i.e. handle one case at the time.
- Both services are delivered by structured organisations.
- Both are funded by the statutory organisations.

Key observations regarding health and social care services

-Social care services aim to promote quality of life in their daily living (3);

-Health services tend to be located within specific organisational units (2);

-Health services are largely staffed by professionally trained people with specific professional orientations (2);

-Diagnosis is a key component of health service (2);

-Health services are rarely delivered in the person's home (2);

-Social care services characterised by no need to cure but mainly to support people living with their condition or age;

-Social care services supported by unqualified people and informal carers (2);

-Social services characterised by one-to-one method of care delivery in peoples' homes rather than specific setting;

-In social care services there is no need to cure – no pressure to improve individual's health.

-Is it necessary to develop standardised classification of services in long term care?

-The participants pointed out that it depends on the intended use of the instrument. If the purpose of the standardised classification was to compare services then the answer is yes.

-The standardised classification would help to identify any gaps in long-term care services across Europe.

-Cultural differences between the countries might be so great that it might be not possible to develop such an instrument.

-There was also a question of the purpose of developing standardised classification of services? For instance, there was a question of the purpose of comparing services across Europe and their role in facilitating a cultural transfer of long-term care provision.

-A standardised instrument might be used for mapping services across Europe.

-Some participants pointed out that the standardised classification of long term care services is necessary in order to learn from different (successful) models of care.

-The need depends on *how* and *who* will get to use the standardised classification.
-The standardised classification might be used for informative purpose (as a tool for gathering data, and as a source of collected data using a standardised instrument).

Is the EPCAT approach useful for describing and classifying health & social services?

- Method based on Small Health Areas, Basic Types of care and use of standardised instruments
- DESDE-LTC instrument & Coding system: Open questions related to these tools.

Services and areas mentioned were difficult to fit into DESDE-LTC instrument and coding system. These included direct payments, leisure activities, home based care, community care and community day care.

One comment was that, as the services are organised now, the units seem to be measuring different things: some are in relation to location of care while others are in relation to remit of care.

3.3.2. SECOND SESSION

(1st Nominal group: London, 9th November 2009 [2])

Participants: Moderator: David McDaid Observer: Tihana Matosevic

General comments provided by D McDaid:

The instrument is mental health centered: This is true and it is recognised at the introduction. The system developed from the mental health area. In any case this has been considered as an advantage by the external assessment using an ontology approach (MT Roma – Univ Alicante) as it is bottom-up and it has been build up based on actual cases. Furthermore mental health care has been considered as a prototype of integrated care where social and health services and care systems interact closely. In any case the system was

[2] LSE has a four month delay in its tasks and it was agreed that Nominal session would be reduced to two instead of three. The first revision of the instrument developed after compiling the information of the 1st nominal group was used in the 1st session carried out in London, so this session has been grouped with the Second session in all other countries

later adapted and applied to social care (disabilities) and to ageing in Spain. It has been used to code all social services for disabilities in Spain in its former version

The instrument does not capture the characteristics of social care / social services and it is health focus The instrument is intended for describing, mapping and coding 'basic' or minimal units of services (BSIC) throughout different sectors, mainly health and social services, for territorial comparison. Evidently it does not captures all the subtleties of services within an specific area due to its broad scope. Therefore it cannot be used to describe to compare and to differentiate an specific type of care facility (for example to identify differences in special education services in schools or in mental health centers in the community). These services will mainly receive one or two codes. However it will be useful to count these services and to compare them to other services in the catchment area and to compera them to other catchment areas in other countries. Although the comparison of services in Madrid and Sofia may provide a demonstrations of its usability, the actual usability in social services should be tested in different countries in future studies in a following stage. It is also important to note that service research is laden by the underlying philosophy of care and the care models. It is common that systems that identify health services (ie Hospitals etc) are discarded in the social sector as 'health oriented' An integrative approach should provide a wide range of codes for the existing services and what is relevant is whether a facility/service can be described or not with the system

The instrument does not provide a description of financing, benefits and elegibility The instrument is not intended to provide a description of all the characteristics of the care system but simply to provide a consensus-based standard description of BSIC and MTC (see previous reply in Austria section). Of course financing, benefits, elegibility, rights and stigma should be described to understand a care system and for policy planning. DESDE-LTC just provide a part of the information required. The EPCAT battery incorporates other instruments for describing care activities and characteristics of small areas.

The coding listing of residential services is not appropriate/acceptable as it starts by secluded residential care Secluded care has been deleted from the eDESDE-LTC coding. An optional code of 'closed care' has been added to a listing of other optional codes using small letters in a separate coding system from the core eDESDE-LTC code

3.3.3. THIRD SESSION

Participants: Margaret Perkins, Research Officer, PSSRU, London School of Economics; Louisa Capitelli; informal carer, London; Catherine Henderson, Research Officer, PSSRU, London School of Economics.

A further two participants had agreed to take part in the discussion but due to unforeseen circumstances they were not able to attend the meeting.

Summary of the discussion

Compared to the earlier beta version, how does this current version of the main services tree reflects the long term care services in England, and the UK?

-There were still a few queries regarding the first branch in the mapping tree on the '*information for care*' where the participants asked whether the information referred to the information about services or whether it was the information as a service in its own right. Similar questions were raised with regards to the '*accessibility to care'* branch where it was not clear whether accessibility meant accessibility of care or access to care.

-We also asked the participants if they needed to map the services listed in the long-term care mapping tree, would they be able to do that.

-One approach to filling in the information on the services would be to ignore the top heading in the long-term care mapping tree and go down to the next level. Using the '*accessibility to care'* branch as an example, it was suggested to start with the '*communication*' sub-branch (are there services that belong to this category).

-As for the next level in this branch the '*personal accompaniment'*, it was not clear what services would count as part of this particular service branch (whether it referred to direct payments, attendance allowance or perhaps other services that could be labelled as personal accompaniment). In England, majority of long-term care services are provide by the informal carers which are not paid for the care they provide. It was also queried whether taking a taxi to go somewhere would be classified as personal accompaniment.

-There was also a question about whether the instrument is actually asking about the number of services available or is it designed for collecting information about the number of people receiving particular services.

-A point was also made about the differences between long-term care 'services' and 'benefits' that people with long-term care needs are entitled to. It was not always clear from the long-term care branches if they refer to services or benefits.

-It was further noted that some of the services included in the '*personal accompaniment*' branch are country-specific and they would make a complete sense in the context of that country but categories may not be easily transferable to the UK context. The semantic challenges of finding a common terminology for long-term care services across Europe were also recognised.

-The participants enquired about the way of entering the process of completing the eDESDE-LTC instrument. When suggested that a 'top-down' approach would be a way of gathering data, it was found to be quite difficult to follow. Taking a bottom-up approach may be an easier way of mapping the services.

-There are also services provided which are not recorded by the local authorities (e.g. services provided by voluntary organisations, respite services, sitting services, etc). Gaps in services not necessarily mean that services do not exist and are not provided.

-The quality of the information collected will depend on the resources, time, data available, and the experience of the person completing the instrument.

-Taking a '*Home and mobile'* and '*non mobile'* sub-branches as an example, it was pointed out that the definitions and descriptions of the services are quite detailed. When prompted if one person would be able to provide the information needed, the participants said that essentially the person who would know this is not the person you would pay to do this work. The amount of work to complete the survey was seen as overwhelming. So the only way to do it would be to hire an administrative assistant to code this. A person completing the survey would need to be familiar with the long-term care system and services.

-An importance of whether the services are mapped using a bottom-up or top-down approach was emphasised again. If there is a list of all available services in the area then it might be easier and more accurate to map the services rather than starting from the top and trying to fit in the services into the tree categories. It was also suggested that it might be helpful to add in a function with a list of the key words for each category and then using the search function to identify the services available under each of the branches. The services are also changing and it would be important to keep the list of services updated.

-In summary, the main queries were essentially around the level of detail, complexity and the time needed to complete the instrument. There were concerns that, considering the amount of resources needed to do this properly, it would be very expensive. This would mean that it would be unlikely that someone with these skills would be affordable, in which case it would be necessary to get someone with less knowledge and experience to do this and we would get very patchy information.

-There was also a question about the purpose of filling in the instrument and whether there are any incentives to do that. Why should these local service planners fill in the instrument, there was scepticism about the benefits of doing this, when essentially the purpose is to make cross-country comparisons.

-Another general point was that the language of the questionnaire still feels too psychiatric; the terms seem strange for someone working in social care and it would be helpful to have different versions of the questionnaire with different terms for these groups. It would also be helpful to have worked examples in the guide to help individuals understand how the coding process works in practice.

3.4. NORWAY

3.4.1. FIRST SESSION

Participants The participants came from different type of services. However, all of the services offered services for long term care for adult and elderly frail populations with:

1. Severe physical disabilities
2. Intellectual disabilities
3. Mental disabilities
4. Elderly with severe disability

Prior to the meeting the participants had received a translated version of the coding instrument. We also requested that they read the coding system while trying to categorize their services in this system. Furthermore they were told that the major objective with the focus group meeting was to discuss the applicability of the instrument in Trondheim Kommune, but also with respect to making national comparisons (i.e. between different catchment areas, both nationally and internationally).

Catchment area Trondheim is the third largest city in Norway with approximately 153 000 inhabitants. The health and welfare sector in Trondheim offers a wide range of services. Citizens in need of assistance from the local authority can contact their nearest Health and Welfare office which will offer advice and assistance and also determine what services you are entitled to.

-Health and Welfare Centres There are 24 Health and welfare centres in Trondheim that can offer the following services: Assisted living centres (nursing homes), Welfare housing facilities, Long-term stays, Day-centre activities, Respite care and assistance for inhabitants suffering from dementia.

-Health Houses There are four Health Houses in Trondheim, and one is also being built in Villajoyosa in Spain. These houses offer short-term stays and the following services: Treatment and medical observation, Relief assistance, Rehabilitation

-Home Care Home Care makes it easier for citizens with special needs to stay at home. This includes senior citizens, the chronically ill, patients recovering from surgery and the disabled. Home-care includes: Home nursing, Home help, Aid call alarm, Meal on wheels

***-The Health and Welfare offices can also assign the following services**:* Health assistance: physiotherapy, occupational therapy and psychiatric nursing care Day-time services for the occupationally disabled, Follow-up services for substance abuse problems, Individually adapted activities, Personal assistance, Welfare salary, Financial social assistance. Individually adapted activities are for inhabitants who are unable to participate in regular cultural activities. Organizations and institutions cooperate on adapting activities according to individuals needs and preferences. The aim is to increase the quality of life and promote good health through cultural activities.

Procedure Six participants from different services in the chosen catchment area (Trondheim Commune) were invited to participate in the focus group meeting in order to discuss the applicability of the e-DESDE coding system. The focus group meeting was arranged in February 2009 and lasted for three hours.

The focus group meeting started with a quick presentation from SINTEF regarding the instrument and the rationales behind the development of it. In this presentation the general guidelines for coding were presented as well as different examples of different services. The focus group members found the instrument to be quite long and complex and therefore also difficult to just read through, hence they found the initial presentation to be useful.

The next step was to discuss the instrument in terms of the existing services in the cathment area. We found it useful to show them the mapping trees and to discuss different examples of services under each branch. Before the mapping tree was shown a brief presentation was conducted to convey to the participants the rationale behind each tree.

In the focus group meeting we went through all the different mapping trees and categorized services in terms of relevant services. With regard to the first mapping tree concerning “accessibility to care coding branch” the focus group noted that a service should be able to be coded under several branches, and not be restricted to only one. Additionally some concerns were being raised regarding the interpretation of the accessibility term. The focus group ended up with a definition that included services that facilitate peoples own actions, and provides the information necessary for this goal to be achieved. Different types of services that could be coded under these branches were discussed. An example is advisory services for deaf and blind patients in need of long term care. This service could be placed under the accessibility mapping tree because it focuses on both information and accessibility

-Mapping tree Information on care coding branch The second mapping tree that were discussed was “information on care” coding branch. The members of the focus group had few problems in categorizing services under this coding branch, however it was noted that it was a problematic branch due to the fact that a service covers a number of areas and hence needs to be classified under different codes. This should be an available option in the coding system.

-Self help and voluntary care coding branch Again the members of the focus group had few problems to fit services under this coding branch. A discussion was raised whether it was possible to place crisis shelters for abused and battered women under this branch. This is a type of service that provides long-term care, however the users of this service are people in crisis, and could therefore not be categorized as people in need of long term care.

-Day care coding branch Day care services for people with developmental disorders should be placed under this branch, and also day care services for occupationally handicapped workers. The members of the focus group also placed day car services for people with psychiatric disorders as well as with physical disabilities under this coding branch. Some of the services that should be coded under this branch are sponsored by NAV (The Norwegian Labour and Welfare Administration) and intended to be practical help to rehabilitate workers or to activate workers as part of a “social” training programme.

-Outpatient care coding branch No specific problems were noted by the focus group with regard to services that should be categorized under this coding branch.

-Residential care coding branch The focus group would include nursing homes, but also some of the home based services under this branch. Some people with long term care needs live in facilities regarded as their own home (separate flats), but often in near location (sometimes in the same building) of a Welfare Center. Some of these people receive care with high intensity (both day and night). The cut off point between high intensity outpatient care and Recidential care can be a challenge.

General comments The members of the focus group noted that although the instrument was perceived as useful it was also difficult to use, they indicated a need to clarify the intentions and the aims of the coding system and furthermore why this system represents an

improvement from other systems. They also noted that it might be problematic with errors in the registration process. This was due to the fact that a service could be categorized under several different branches and it was difficult to determine what should or ought to be the correct code for different kinds of services. However, the members of the focus group thought that the instrument was useful in terms of stimulating discussions, and hence serve an important function with regard to make the service providers more conscious of the services they offer to the population of their catchment area. The structure of the coding system was compared to the structure in the locally used registration system for Health and welfare services.

The focus group members noted that a very important challenge is that some services cover many different areas and that the Norwegian system for long term care rarely covers one specific group of patients. Many services were organized under the same unit, but they provided different kinds of services.

3.4.2. SECOND SESSION

Participants Initially, six persons were summoned to the meeting. These are persons that have great knowledge concerning the services that are available for people with long-term care needs in Norway generally and in the catchment area of Trondheim specifically. However, at the meeting only four members participated.

Results The meeting started with a short introduction about the instrument, its purposes and its structure. Thereafter the following assignments were discussed:

- The service definition
- The territorial organisation of services within the health and social sector in Norway.
- Description of main types of care.
- Review of the list of cutoff points as presented in the eDESDE instrument.

General comments The nominal group used much time on the “confusion” in the instrument regarding the general term **service.** They felt that it was unclear whether the instrument sought to measure the **content** of the service (activities), i.e. the type of care that is being offered to patients with long term care needs, or the **organisation** of the services -the units that produces the service. The group can not see how the introduction of the term BIS (see later) solves this challenge.

The group members felt that the instrument was very complex and that the organisation of services could influence what is coded into the separate mapping trees. The latter was based on the criterias for inclusion of BIS (services). One group member said: “The instrument will generate random results, due to the fact that the organisation is different in different countries”. Related to this they also felt that the system was more designed to capture the structure/organisation of health care and social services in different countries than the total service supply to different target groups. However they all felt that the system could be more effective in mapping services for patients with long term care needs between different catchment areas in one country.

Service The group members were presented with the new term “basic input system” (BIS) and asked to discuss whether this was a more user-friendly term compared with the term service. The following description of a service/basic input system was provided.

A “service” or BIS (Basic Input System) must fulfil one of the following criteria to be coded as a unit of analysis:

- Criterium ‘a’
- Criterium ‘b‘ AND 2 criteria from section c
- 3 criteria from Section ‘c’ (complementary criteria)

a) The service is registered and acknowledged as a legal organization (with its own company tax code) and not as a part of a meso-organization (i.e a hospital) and a separate official register in the Community.

b) To have its own Administrative unit and/or secretary’s office.

c) Complementary criteria:

c.1 To have professional staff specifically for the aims of the service.

c.2 All activities are used by the same users.

c.3 Separate location (not as part of other facility i.e hospital)

c.4 Separate financing and specific accountancy)

-The group members felt that the term Basic Input System does not make more intuitive sense in Norway.

-The members were concerned that the instrument provided an overview over **BIS that provided services to specific target groups**, not a classification of services (in total) that were actually provided to the groups.

-They felt that the system could be effective in terms of comparing BIS (services) that provided the same types of care.

-Furthermore the group was concerned that the general definition of the BIS term was too restricted, therefore making it difficult to incorporate specific services into the general scheme of the eDESDE.

-Several of the nominal group members felt that the focus in the definition was on the smallest definable unit with the aim of incorporating it into the system.

-The definition also had the consequence that if several services within the same BIS were directed towards the same target group, the system required that this should be classified as one type of care.

-The group members also considered the possibility that because the services are differently organised in the different participating countries, the definition would be “reductionistic” in countries with a complex service structure such as Norway. Many services incorporate several target groups (also sometimes persons with drug/alcohol-problems) e.g work-related services, activity centres, home nursing.

Territorialisation levels The different territorialisation levels provided in the instrument were described at the nominal group meeting. Thereafter the levels were discussed and possible examples were provided.

Two territorial dimensions in Norway:

a) Territorial levels of the administrative responsibilities to provide services:
Before the Health Care reform in 2001, specialized health services were the legal responsibility of 19 counties. After 2001 the State took over as owner, and the country was divided in 5 (now 4) regional administrative units who are responsible for supply of specialized health services to the population in the regions. The municipalities have the legal responsibility for most social services and all primary health care.

b) Territorial levels for the catchment areas of services (BIS) are what we focused on at the nominal group meeting. The following section provides an account of the different levels and the discussion concerning which type of services these levels could incorporate.

- H0 International administrative territorial unit (*for example EU*)

  -EEA Agreement that provides access to services across Europe, but these are not necessarily services that offer long-term care.

  -Some Norwegian municipalities have built nursing homes in Spain, but it is the municipality in Norway that is the catchment area.

- H1 Country administrative territorial unit (*For example: Norway*)

  -In Norway, a few national services exists, these services provides specific services for the Norwegian population. A few such service exists, however they are not widespread.

- H2 Next territorial level before country administrative territorial unit

  -For *example: autonomous community, lander, federal state*

  -This would be Health Regions or counties in Norway.

  -Not very relevant for long term care services in Health care, but some rehabilitation wards are at this level

  -The group members could not identify this territorial unit concerning social services relevant to the specific target groups. Most services are at the municipal level

- H3 Maximum administrative territorial mental health unit

  -Eks: *mental health c area (covered by a reference general hospital)*

  -Helseforetak (localised hospitals).

- Generally, the group felt that it was difficult to make differentiate the levels represented by H2 and H3. The most relevant units in Norway are localised hospitals and the local level, i.e. the municipalities.

- H4 Basic administrative territorial unit of specialised mental health

  -For example: catchment area of a community mental health centre

- H5 Basic administrative territorial unit of general health

  -For example: territorial division for primary centres

We can sum up the Territorial levels for services (BIS) in table 2:

Table 2. Territorial levels for services (BIS)

Territorial levels	Level	Somatic Health Care	Mental Health Care	Social Care
Europe	H0			
Norway	H1	Not very relevant	Very little: care for highly dangerous persons	
Region	H2	Not very relevant, but some specialized rehabil.wards	Not very relevant	
County	H2	Not any more	Only a very few institutions left (some geriatric psychiatric wards)	Not for the target groups
Hospital catchment area	H3	Yes	Yes	
District (hospital) catchment areas	H4	In some geographical areas (e.g rehabilitation)*	Yes	
Municipality	H5	Most It services are here	Yes	Most It services are here

* A planned reform will probably make this level more relevant

Main types of care The nominal group members were asked to review the definition concerning **main types of care** and look for examples in the different cases.

- The members were provided with the following definition:

Operative description of MTC *MTC is a main part of care that is developed in a BIS. Many times, MTC is defined as a BIS. A BIS can also has various MTCs. In this case, it is very important distinguishing a MTC form other analysis units that are assessed for other kinds of instruments as IMHC.*

We will code a service with more than a MTC if the users of each MTC are different.
If all users that are attended in the two MTCs, we will think that one of them is an activity and the service will be coded with the main function.

Generally, the nominal group members felt that it was unclear how to deal with the systems that are subsumed under the heading of main types of care.

They were also concerned that the link between the BIS concept and the MTC concept was to diffuse to be user-friendly. Furthermore, in Norway one BIS may offer several MTC's. This

might in turn contribute to reducing the codings concerning the magnitude of services being offered to person's with long-term care needs if the services does not meet the criterias for BIS.

Cut-off points The following task were described and given to the nominal group members: Review the List of cut off points and discuss the adequacy of them.

Is it feasible to apply them to your country?

A series of cut off points have been set up to differenciate between generic services (i.e. gender, immigration, etc) and services for LTC. Cut off points have also been defined to differenciate among codes of eDESDE-LTC. We will like to know your opinion on the feasibility of the cut off points set up at the instrument.

We did not have time to discuss every cut-off point in detail, but the participants had prepared themselves before the meeting, and their comments can be summed up to the following:
The use of the cut-off points are dependent on which units that are supposed to be described. If the aim is to map the organisations (structure) of long term care services, the cut-off points generally represent "good" criterions. However, if the aim is to describe the service volume to specific target groups, they are more problematic (mainly due to the 20% rule).

3.4.3. THIRD SESSION

***Participants*:** Originally seven participants were invited to the meeting, and six of the invited participants showed up. The meeting lasted for approximately 2 hours, and it was arranged in Trondheim.

The meeting started with a quick review of the instrument. This was done to update the participants with regards to the aim of the instrument, the modifications that had been done during the project period and also to update the participants with regards to the status of the eDESDE project. During this introductory part of the nominal group session, the participants were invited to post general comments concerning the instrument. These comments will be outlined below.

Additionally, with regard to the aims of the third nominal group session, the following themes were discussed during the course of the nominal group meeting.

-Does the final eDESDE-LTC version improve the beta version?

-Have your specific suggestions being incorporated in an adequate way?

-If not, do you understand the reason provided not to do so?

-Is there a VERY relevant and elementary issue that must be incorporated to future version of the questionnaire?

General comments One of the participants in the nominal group session felt that the instrument had improved since the last version. More specifically the feedback was that the instrument had been clarified by better stating the aims and intention of applying the instrument to map health care services to people with long-term needs. The participant also noted that it was easier to see how it could be applied to the Norwegian context. However, the other participants still reported that the introductory part of the instrument still was too complicated and also somewhat confusing. They all viewed the instrument as useful in terms of research purposes; nevertheless they reported that a clarification needs to be done before it was possible to apply the instrument for practitioners operating in health and social services.

Additionally the group members noted that it was of essential importance to clearly define the aim and intention of the instrument before it could be applied. Several of the participants noted that the instrument could be useful in comparing services within a country over time. As an example they used the Norwegian health reform which was passed in April 2010. This is a reform that aims towards coordinating health services. The participants noted that data gathering with the use of the eDESDE instrument could form a baseline to be used to implement new reforms and interventions.

Another comment made by the nominal group members was that it could be difficult to apply the instrument in different countries due to heterogeneity in the way services are organised. This issue was exemplified by the term “catchment area”. The difficulty concerning this term mainly concerned whether it entailed supply of and responsibility for services or whether it should entail the producers of the services for patients with long-term care needs. It was noted that it was possible to compare these aspects within regions and within countries, however that the problems might arise when comparisons are to be made between countries.

This comment led to a discussion concerning the instrument and the purpose of it, and an agreement was made that the instrument should be used primarily to gain an overview of the *type* of services being provided to the population with long-term care needs.

It was also noted that the definition of the term "target population" was problematic. On page 4 in the final instrument it has been defined as:

- Adult (18+) and frail older people (65+) with
  - -Severe physical disabilities (registered in official, national, regional or local registers for this population group, or an equivalent system where registers are not available)
  - -Intellectual disabilities
  - -Mental disorders (ICD-10)
  - -Elderly/older people with severe disability (registered in official national, regional or local registers for this population group or an equivalent systems where registers are not available)

However, it was stated the definition of the target population was clarified at page 9 of the instrument, where it was defined in the following way: "target group is equivalent to people with long-term care needs".

Nominal group question number 1

-Does the final eDESDE-LTC version improve the beta version? Some of the participants felt that the instrument had improved since the last beta version. It was highlighted that the purpose and intention had been clarified, and that is was more clearly defined how the instrument should be used in practical research. Furthermore it was stated that the new beta version to a larger extent incorporates services that are available in a public health care system in Northern Europe. However, the same participants felt that the instrument still needed to be clarified due to the fact that they still felt that it was somewhat confusing – especially the introductory part – to be used by practitioners.

Several of the participants had concerns regarding the use of the instrument in different countries and comparisons between countries. One such difficulty that was highlighted concerns the use of different concepts and different definitions in the participating countries. With regard to this aspect they wanted more information regarding the pilots conducted as a part of the eDESDE project. The reason for this was that the nominal group participants felt that information concerning the pilot studies would yield important information regarding how

the instrument could be applied in countries with different types of health care systems.

The nominal group members agreed that the instrument was better applied within one country rather than as a comparison between countries, and that it was a useful instrument that could be used to describe health and social services provided for patients with long-term care needs within one country. The argument was that the services within one country were more homogeneous, and therefore more easily comparable. The point was that the instrument and applying the instrument was useful as a starting point for comparisons between services, meaning that the instrument was perceived as useful to say something about the scope of the services provided.

One group member also stated that the design of the instrument was able to map characteristics of the services provided, however it was more problematic to be used when the aim was to describe different levels of the services. However after reviewing the instrument some members raised concerns that there still were inherent problems within the model, and more specifically with regard to the criteria for inclusion which some of the members regarded as problematic.

A problem also arises when the scope of the services are to be seen in relationship with the target groups, and the challenge was seen in relationship the criterions for inclusions. For instance if the aim of the study is to map services provided for one specific group because the services provided in Norway are universal, and often not directed towards one specific group in the population.

Nominal group question number 2 and 3

Have your specific suggestions being incorporated in an adequate way? In the last nominal group (2009) conducted in Norway the members had some problems with the use of the term **Basic Input System.** The concern was that the term did not make intuitive sense in Norway, and that the use of this definition also provided an overview of specific care (særomsorg) and therefore did not yield an adequate classification of the services that were actually provided to people with long-term care needs in Norway.

The new version of the instrument provided a new term to classify services, namely **Basic Stable Inputs of Care.** The members of the nominal group did not feel that this definition of

a service was an adequate one, and that it still did not make intuitive sense in the Norwegian context. This is also the answer to the next nominal group question due to the fact that the nominal group members felt that it was important to gain a concept of the term service that would adequately reflect the Norwegian system.

When the term Basic Stable Inputs of Care (BSIC) is translated to Norwegian it does not make any sense. The group discussed different ways of defining it in Norwegian, but the general problem remained that it was difficult to understand what the concept should entail, and to grasp the meaning inherent in it. The group members also commented on the fact that this concept seem to lack face value, i.e. it does not intuitively make sense in the Norwegian context. Some discussions were also raised concerning why the concept should entail the wording "basic". The members of the nominal group suggested that the term should be replaced by the term "service providers", "service units" or unit for service production. The nominal group members agree that the BSIC concept is well defined in the instrument; however the argument is that using the BSIC concept does not intuitively make sense in Norway.

Nominal group question number 4

Is there a VERY relevant and elementary issue that must be incorporated to future version of the questionnaire? The members are not sure whether this question concerns specific items that should have been included in the instrument. The nominal group members are more preoccupied with the premises for the structure of the instrument. Generally the members agree that the usability of the instrument should be improved, and that it is very difficult to understand the instrument without applying the instrument.

3.5. SLOVENIA

3.5.1. FIRST SESSION

Participants Nadja Cobal – Ministry of health***;*** Zdravko Kaucic – Association of social institutions of Slovenia***;*** Andreja Peternelj – head nurse from the KOPA Golnik, the head of the committee for preparint the act on long term care and insurance for long term care***;*** Milka Krapez – free lance journalist for the health area ***;***Jelka Cernivec – The head nurse from Dom Danice Vogrinec Maribor – one of the biggest nursing home in Slovenia***;*** Darja Korva –

The Community of Centers for Social Work (CCSW)***;*** Agata Zupancic – Ministry of health

The following participants were invited and they could not come. They expressed interest in future group meetings. Barbara Strajner – Ministry for work, family and social affairs Martin Toth – Ministry of health

First research question There were some problems with the understanding the question. Participants were anoyed because they understood that we need to develop new definition. After clarifying the understanding the consensus statement was created immediately.
Definition of long term care: all services (social and health care) in local level to offer the long term care for different needs of users.

Second research question The participants were interested in instrument for coding long term care. They estimated that coding system should give the information to users and service providers. The coding system would allow us to see the accessibility of care in local level. The information is crucial for policy makers and service developing in regional and local level.

Third research question The presentation of the coding of two well known long term services (Altra and Hrastovec) was well accepted. Participants support the idea of coding and they like the EPCAT approach.

Participants were interested in future development of the project.

3.5.2. SECOND SESSION

Participants Nadja Cobal – Ministry of Health; Zdravko Kaucic – Association of Social Institutions of Slovenia; Darja Korva – The Community of Centres for Social Work (CCSW); Barbara Strajner – Ministry of Labour, Family and Social Affairs of the Republic of Slovenia,

Excused from attending due to illness and other obligations:

- Milka Krapez – Freelance Journalist in the Field of Health,
- Agata Zupancic – Ministry of Health,

The following participants were also invited, but they didn't take part:

- Andreja Peternelj – Head nurse from the KOPA Golnik; The head of the committee for preparing the act on long term care and insurance for long term care,
- Jelka Cernivec – The head nurse from Dom Danice Vogrinec Maribor (one of the biggest nursing home in Slovenia),
- Martin Toth – Ministry of Health,

Results of discussion

Service definition In Slovenia the criteria are not entirely applicable and some definitions are misleading. The group of experts proposed, that the **criterion "a"** should be modified. Official register number or licence for work on the field on long term care or health or social welfare or on any other similar area would be broad enough. Tax number is also enough.
Criterion "b" is also not clear since its service own administration is only a question of organisation. The definition would be clearer with incorporating that the documentation on cases or on work is separated from other activities in meso-organisation.
In **criterion "c3"** it also not clear whether location is meant as separated (dislocated) building (like structural) or department, section, separated service facility (like enterprise).
The differentiation from the part of meso-organisation is also important since in our country the department or a ward or program has its own account not its own accountancy (expand of **criterion "c4**") (for example: provided separate monitoring and financial control with respect to various findings and programmes costs).
The group of expert proposed criteria:
Licence for work and own tax number when not in meso-organisation.
Its own documentation and own account in meso-organisation.

Territorialisation levels In Slovenia we have different methods for calculating health and social care. There are statistical (between S/H2 and S/H3), health (S/H3) and local community administrative regions (in some cases S/H4 or S/H5 and even lower- ?S/H6. The experts could not find a consent which method would be the best for long term care since some of LTC services could be mapped only at S/H1 level. The most support got statistical region.

Description of MTC (Main Types of Care) The experts understood the MTC and the method used in the questionnaire. Two examples of services (BIS) were mapped according

to their MTC (BIS with one MTC and BIS with three MTC). There were no objections.

Review the List of cut off points and discussion about the adequacy of them

LIST OF CUT OFF POINTS

Self-help and Voluntary care

Non professional staff

'Facilities aimed at users with long term care needs, where professionals providing assessment, interventions or support to users with long term care needs are below 60% of the total personnel. The 100% of the staff is unpaid and has a voluntary association with the service'.

-The professional/non professional – misleading term.
It is not important the ratio between employed or unemployed (volunteers), important is how experienced the staff is. We can get extremely experienced volunteers.

Professional staff

'Services designed for users with long term care needs that regularly at least 60% of trained or specifically qualified staff for providing assessment, intervention and support to users with long term care needs. The 100% of the staff is un-paid and has a voluntary association with the service'

-The same comment:
It is not important the ratio between employed or unemployed (volunteers), important is how experienced the staff is. We can get extremely experienced volunteers.

Day care

Acute (for crisis care)

'Facilities where (i) users are regularly admitted because of a CRISIS: deterioration in physical or mental state, behaviour or social functioning which is related to his or her condition; (ii) alleviating this deterioration is a purpose of the programme; (iii) admission to the programme is usually (at least 20 of the users) available within 72 hours'.
-The threshold is too low. We propose 50%.

Work

High intensity

'High intensity facilities are available for users who attend for at least the equivalent of four half days per week. Not all the users need attend as frequently as this for the service to be classified as 'high intensity', but it should at least be possible for them to do so'.

-We propose 7 times per week at least 20 hours per week

Other work

'The organisation follows specific work regulations for users with disabilities. Users are paid at least 50% of the usual local minimum expected wage for this form of work. Where there is no minimum wage, we suggest calculating an expected level based on starting salaries for similar jobs advertised in the local press over the past month. The work may be in a sheltered setting or in a setting where some workers are not users with Long-Term Care needs'.

-We propose that is described that people in this service are not payed for their work. They are given a small amount of money for their needs.
-Underlined part is not valid for Slovenia.

Work related care

'These are facilities where users carry out an activity which closely resembles work for which payment would be expected in the open market, but where users are not paid or are paid less than 50% of the usual local expected wage for this form of work'.

In Slovenia we have enterprises for invalids and people are paid for their work.

Outpatient Care Continuing care – there is huge gap between high intensity (three times per week) and moderate intensity (once a fortnight) and we propose to increase the number of contacts of medium intensity to at least once per week. And low intensity once per 14 days.

3.5.3. THIRD SESSION

Participants: Nadja Cobal – Ministry of Health; Andreja Peternelj – Head nurse from the

KOPA Golnik; The head of the committee for preparing the act on long term care and insurance for long term care; Darja Korva – The Community of Centres for Social Work (CCSW).

Excused from attending due to illness and other obligations:

- Milka Krapez – Freelance Journalist in the Field of Health.
- Agata Zupancic – Ministry of Health.
- Zdravko Kaucic – Association of Social Institutions of Slovenia.

The following participants were also invited, but they didn't take part:

- Jelka Cernivec – The head nurse from Dom Danice Vogrinec Maribor (one of the biggest nursing home in Slovenia).
- Martin Toth – Ministry of Health.
- Barbara Strajner – Ministry of Labour, Family and Social Affairs of the Republic of Slovenia.

Participants of eDESDE-LTC project staff: Šprah Lilijana, Mojca Z. Dernovšek, Mateja Zorc

Have your specific suggestions being incorporated in an adequate way? Participants carefully studied the feedback from partners and they concluded that suggestions were incorporated when possible. The inclusions criteria in the new version of instrument are more applicable.

The answer on territorial level concerns was satisfactory.

The answer on professional/non-professional staff is still not clear. There could be at least two different translations in Slovenian language meaning either the profession (for example nurse, social worker, etc) or the employee (the team employed in service – for example medical staff). We decided to translate in the term meaning profession.

The term "acute" raised energetic discussion. The term "acute" is recognised in our culture as something strictly as urgent medical condition and one of the participants strongly disagree with expression, since she understands the term of long term care as something "not acute". In addition, in Slovenia we do not have outpatient/acute/home & mobile type of

care; from this point of view it is understandable that the term “acute” is viewed strictly in medical manner. We obviously should provide an additional explanation the term “acute” perhaps could be replaced in Slovenian language with something more recognisable and less misleading.

Participants agreed with comment regarding the suggestions on day care with work activities that were not incorporated because they were too specific for Slovenian situation.

In continuing care – there is huge gap between high intensity and moderate intensity and we proposed to increase the number of contacts of medium intensity to at least once per week. And low intensity once per 14 days. The response was that services with availability for once per week should not be classified in the same intensity that services that can attend every day if it is necessary. We do not understand this response.

If not, do you understand the reason provided not to do so? Overall, participants understood that the instrument should not be too specific and that all suggestions could not be included.

Does the final eDESDE-LTC version improve the beta version? Final version of eDESDE-LTC significantly improves the beta version.
Regarding the new term – BSIC, some of participants had a problem with understanding the concept of BSIC and how to translate it in our language in the way which could preserve the original meaning of BSIC.

Is there a VERY relevant and elementary issue that must be incorporated to future version of the questionnaire? The respondents had pointed out several problems with terms – for example the term »acute«.

The respondents also noticed that in the introduction there is a statement on the age of users of services (+18 to 65), but later in instrument, within optional codes - “C” appeared among different age groups – children adolescents, adults, older.

Another problematic term was »outpatient care«. In our language there are two different terms for outpatient care – one for medical care and another for social care.
One of the participants pointed out that medical care should not be included in long term care

(at least in Slovenia). There is a concept that even palliative care is not considered as long term care but it is considered as health care.

Respondents concluded that in Slovenia the major reason referring to the fact why there are so many not well understand terms and concepts within eDSDE-LTC methodology could be, that we are still at the beginning of developing the concept of long term care and even in proposal of the act for long term care and insurance for long term care there is no consensus between different actors engaged with LTC field. So the future version of eDESDE-LTC should be updated with norms and definitions of LTC accepted in Slovenia at that time in order to make it more understandable to stakeholders from social and medical sector (which are unfortunately at the time in the process of developing some new concepts and terminology of long term care, hopefully going beyond the old definitions and current system of organization LTC).

3.6. SPAIN

3.6.1. FIRST SESSION

This was the first group session carried out at the project.

Participants: Federico Alonso (Social Services Foundation and experienced on LTC mangement)***;*** José Almenara (University of Cádiz researcher on health issues)***;*** Carmen Omist (Equity & Health Department. Municipality)***;*** Juan Carlos García (psychiatrist)***;*** José Alberto Salinas (geographer)***;*** Cristina Romero (DESDE-LTC coordinator)

Definition of service The reviewing let us to make some changes in the service definition and the group proposed the following definition:

*A "**service**" or BIS must fulfil one of the following criteria to be coded as a unit of analysis:*

*-Criterium **'a'***

*-Criterium **'b'** AND 2 criteria from section **c***

*- 3 criteria from Section '**c'** (complementary criteria)*

a) The service is registered and acknowledged as a legal organization (with its own company tax code) and not as a part of a meso-organization (i.e a hospital) and a separate official register in the Community.

b) To have its own Administrative unit and/or secretary's office.

c) Complementary criteria:

c.1 To have professional staff specifically for the aims of the service.

c.2 All activities are used by the same users.

c.3 Separate location (not as part of other facility i.e hospital)

c.4 Separate financing and specific accountancy)

:

Definition of MTC

MTC is a main part of care that is developed in a BIS. Many times, MTC is defined as a BIS. A BIS can also has various MTCs. In this case, it is very important distinguishing a MTC form other analysis units that are assessed for other kinds of instruments as IMHC.

We will code a service with more than a MTC if the users of each MTC are different.
If all users that are attended in the two MTCs, we will think that one of them is an activity and the service will be coded with the main function.

Definition of Levels of care Descriptors that allow to classify services can be organized on levels as follows:

-First Level –Status of user. This level relates to the clinical status of the users who are attended in the care setting (i.e. whether there is a crisis situation or not).
-Second Level – Type general of care. This level describes the general typology of care (home & mobile/non-mobile, hospital/non hospital,..).
-Third Level – Intensity of care. This level refers to the intensity of care that the service can offer.
-Fourth Level – Subtype of care. This level provides a more specific description of the type of care at the setting.
-Fifth Level – Additional Qualifiers. This level incorporates additional qualifiers when needed to differentiate across similar care settings.

Definition of Territorialization levels The group discovered the difficulty of mapping catchment areas because there is not an operative definition of different territorialization levels. The following definition is proposed:

-H0: International administrative territorial unit For example, European Union

-H1: Country administrative territorial unit For example, Spain

-H2: Next level before Country administrative territorial unit For example, autonomous community, lander, federal state

-H3: Maximum administrative territorial mental health unit For example, mental health area (with a reference general hospital)

-H4: Basic administrative territorial unit of specialized mental health For example, catchment area of a community mental health centre

-H5: Basic administrative territorial unit of general health For example, territorial division for primary care centres

3.6.2. SECOND SESSION

(1st Nominal group: Jerez, 15th December 2009 [3]
2nd Nominal group: Jerez 25th June 2010)

Participants: Federico Alonso (Social Services Foundation and experienced on LTC management); José Almenara (University of Cádiz researcher on health issues)***;*** Carmen Omist (Equity & Health Department. Municipality)***;*** Juan Carlos Garcia-Gutierrez (psychiatrist)***;*** José Alberto Salinas (geographer)***;*** Cristina Romero (DESDE-LTC coordinator) Luis Salvador-Carulla (Observer); Miriam Poole (Observer)

Introduction The overall structure of the instrument has been reviewed taking into account the summary report based on the comments made by the nominal groups held in other countries as well as the experience got in the use of the beta version of the instrument in a) the Mental Health Atlas of Cantabria (Spain)[4], b) The official listing of services for disabilities in Spain (General Directorate on Disability, Spain), and c) the development of the Atlas of mental health services in Spain (Ministry of Health and Social Policy, Spain). Due to the fact that the first Spanish session was a focus group, and taking into account the tasks faced and the related questions it was decided that a 1st session would be devoted to analyse all the comments by other nominal groups and the on-going experience, then a thorough review of the questionnaire will be made by the PSICOST working group, and a second nominal group would be held in 6 months to provide a definite version for the pilot testing. The first session

[3] A Focus group was previosly held in 2008
[4] Vazquez-Barquero JL, Gaite L, Salvador-Carulla L, Salinas JA. Atlas de Salud Mental de Cantabria. Gobierno de Cantabria, 2010.

was hold on 15th December 2009 and the second session on the 25th June 2010. The comments made by other nominal groups were taken into account, on-going experience and the comments made at the training groups were taken into account for the second session (part 2). The minutes of both sessions were registered in Spanish. The final results are provide below.

Comments and results

Definition of MBICS and MTC Operational definition of Basic Input Care Systems (BICS) and Main Types of Care (MTCs)

The naming “Basic Input System” was judged confusing and “care” was added to this name, so the wording for “services” in DESDE-LTC would be: Basic Input Care System (BICS). The operational definition provided after Session 1 has been revised again and the need of algorithms for aiding the completion of the coding was also suggested.

As regards to the MTC, it was decided that an operational definition of MTC was required at the DESDE-LTC instrument. A definition was made and discussed at the 2nd nominal group. Inclusion and exclusion criteria were also discussed.

DESDE-LTC Instrument

-Additional codes A question raised by the group was the need to provide further identification of the characteristics of services apart from the core coding system of DESDE-LTC. The example of hospital services in institutions was reviewed. The final suggestion made by the group included the following additional codes and a paragraph which has been incorporated into de the section “B” of DESDE-LTC:
Explanatory Paragraph:

“These optional codes have been incorporated to facilitate a quick appraisal of those characteristics of BICS and their related MTCs which may be relevant to better define a subset of services within the same principal MTC code for local policy or for a specific research. These codes are part of the general description of the service provided at Section "D", and therefore they are not part of the core hierarchical tree structure of the DESDE-LTC system. These optional codes are small letters which can be added at the end of the numeral coding to provide an additional description about the location where the service is provided

(e.g. an institution "i", or care provided at a hospital setting "h"), the means by which the service is provided when this is a relevant descriptor (e.g. eHEALTH/telecare "e"), or for describing a specific activity within the service which implies an main organisation arrangement which is clearly different from other services sharing the same principal MTC code but without this activity (e.g. acute care provision in a non-acute care center "a"). These additional codes do not use cut-off points".

"A" Acute Care; "C" Closed Care; "D" Domiciliary Care, "E" Ecare; "H" Care Provided In A Hospital Setting; "I" Institutional Care; "J" Justice Care; "L" Liason Care; "M" Management Of Cases; "R" Reference Main Type Care In An Area; "S" – Specialised Care

Additional numerical qualifiers: It was suggested that when a service has two or more care units that provide separate care with similar characteristics it could be identified as a numerical code in brackets at the end of the core DESDE-LTC code (for example: a hospital service with 3 different units of time-limited care could be shown as R4[3])

-***Accesibility to care "A"*** The need to incorporate personal accompaniment and case management without actual care delivery was raised by the group. It was regarded as a service at the accessibility to care branch.

-Acute care It was suggested that branches O, D and R should follow a similar structure differentiating Acute Care and Non-Acute care. This suggestion has been added to the instrument

-Outpatient Care "O" Outpatient services are complex and they may provide acute care, non-acute mobile care and non-mobile-nonacute care at the same time. A risk of multiple coding which may reflect activities more than care functions may appear in this branch and therefore the rules for coding this branch should be made clearer. The problem identified in this branch was taken into account for improving the operational definition of MTC. This operational definition has incorporated Principal and additional MTCs.

A cut-off point of 50% has been incorporated to code mobile care as the principal MTC. Care units fulfilling the first three criteria of BICS could be coded as an additional MTC code.

A series of suggestions were made to improve the coding of services in this branch. However

it is not clear whether these recommendations should be incorporated into the instrument or they should be included in another document of the DESDE-LTC package

-Day care"D" Several problems were identified in this branch to properly describe acute day care. First a differentiation was made between a high intensity appraisal and front-line treatment of acute care episodes related to specific treatments such as Electroconvulsive Therapy (ECT) in mental health or chemotherapy in oncology in relation to other types of day care. A branch of acute episodic care was suggested to properly classify this type of interventions.

It was also necessary to differentiate between Acute day care of high intensity (High level day hospitals) and other intensity was discussed in the group. The current coding system classifies non high intensity day hospitals together with rehabilitation units at D4 while they are clearly different from these services. Therefore a new coding has been provided for coding Acute Day Care: admission within 72 hours from crisis onset (D1.1) and admission between 72 hours and 4 weeks (D1.2).

The ordering of day structured activities has also been changed to place health care in the first place. Therefore D4.1 is health-related and D.4.2 is education-related. The coding of high intensity education, social and cultural activities and employment has been questioned as services may vary in relation to their capacity of intensive care provision (hours per day). For example a D4.2 may assists students on a 1 hour daily basis or in a 6 hour daily basis.

-Residential care "R" The R1 secure code was regarded as stigmatising and not acceptable by one of the 1st nominal groups. Several strategies were reviewed such as replacing the content of R1 to other residential care and moving secluded care to code R14. However problems appeared in the use of this coding. It was non-sensical to use R1 for "other residential care". On the other hand, secluded care could be described using an additional letter "c" (closed) –see above-.

Replacing "hospital care" by "24-hour medical coverage" had problems for coding R3 and R5. Furthermore the wording "medical" could be understood as medical staff and not only physicians. It was decided to replace medical by "physician" (24-h physician coverage). There were residential care alternatives that were not properly described by the instrument such as the possibility of residential acute care with 24-h physician cover outside a registered

hospital or the high intensity acute care (e.g. acute intensive unit in a general hospital). Therefore residual codes were registered and a new structure was provided for residential care.

Cut off points (annex 1)

3.6.3. THIRD SESSION

Participants: Federico Alonso (Social Services Foundation and experienced on LTC management)***;*** José Almenara (University of Cádiz researcher on health issues)***;*** Miriam Poole (psychologist)***,*** José Alberto Salinas (geographer)***;*** Luis Salvador (DESDE-LTC Project leader)***;*** Cristina Romero (DESDE-LTC coordinator)

Summary Some changes have been added to the last version of DESDE-LTC Toolkit. Our group thinks that these changes clearly improve the beta version because they have tried to cover the difficulties founded and described for all the groups participants in the project.
The Spain suggestions have been incorporated in an adequate way. We will review all these changes included in every tool of DESDE-LTC Toolkit.

DESDE-LTC Instrument

We can find changes in:

-Structure

The structure of the Introductory questions has been made more user friendly.

Section B includes:

Optional codes: specifying target population and diagnostic groups

Additional codes for special cases

Structure of diagrams of this section has been modified:

-From: A. I, S, D, O, R

-To: I, A, S, O, D, R

-Concepts Inclusion and exclusion criteria are included for main concepts.

The concept BICU has changed to BSIC (Basic Stable Inputs of Care)

-Definitions The definition of “Hospital” has been reviewed and modified in a more comprehensive way. Some examples have been added. The definitive definition is:

“Hospitals are meso-organisations with a legal recognition in most countries. This legal recognition of registered hospitals can be used as the basis for identifying hospital BSIC. In those countries where there is no legal basis for deciding what are hospital services and in those cases where doubt exists, services should be classified as hospital BSIC if they have more than 20 beds and 24 hour resident physician cover. A stakeholder group and/or local or regional health officers should be consulted where there is doubt about which services should be viewed as hospital services or not. “

-New codes Total number of codes:

-From 74 to 88 codes

-11 optional codes: ‘a’, ‘c’, ‘d’, ‘e’, ‘h’, ‘i’, ‘j’, ‘l’, ‘m’, ‘r’, ‘s’

The definitive DESDE Coding follows next structure:

Target age [target diagnostic group] - [MTC code] additional code

C[ID]-D1.1s

New last branches included:

-Day tree These new codes (D0, D0.1, D0.2, D1, D1.1, D1.2) allow a more specific classification for day acute services that were included in the same branch but had different objectives (annex 2) .

-Residential tree

-Code R0: 24hours physician cover, Non-hospital/hospital. There was not exist the difference between hospital/non hospital.

-Code R14. Other non acute residential services. The code has been changed for a lower level according to the type of description that allows.

-Code R3: Non 24hours physician cover has been subdivided in two branches for making a difference between hospital and non hospital (annex 2).

Examples

New examples have been included in the codes definitions for claryfing the coding.

Spain and Bulgaria has applied the last version of the instrument for pilot study and we have been able of testing the improvement of the version.

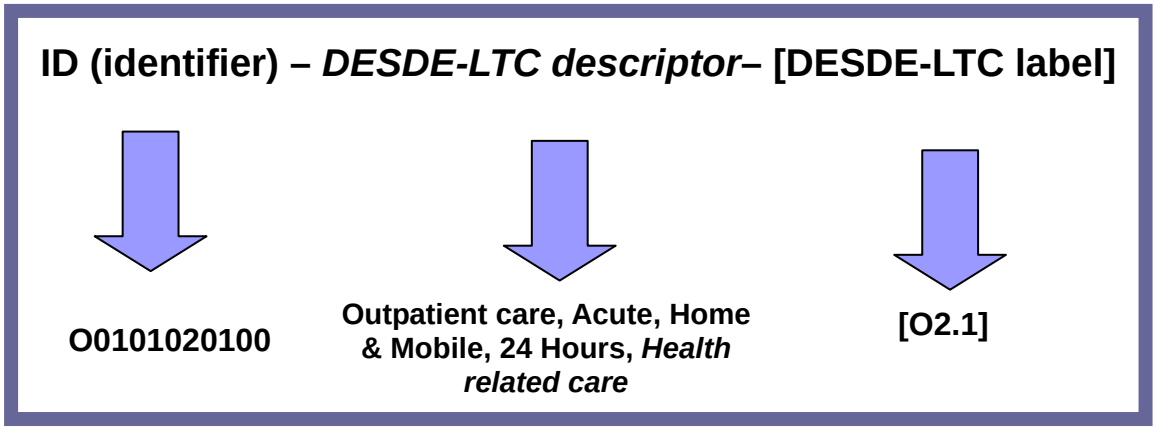
Desde-Ltc Clasificaction and Coding System The Coding System tool has been modified introducing the possibility of getting a formal classification that gets the semantic operability of DESDE system. Then this tool allows providing three types of results as follows:

-**DESDE-LTC Classification:** standard description of services organized into a classification scheme of hierarchy types (alphanumeric code or identifier). Formal ontology.

-DESDE-LTC Coding List: provides a code (label) also associated to DESDE-LTC descriptors.

-Glossary of Terms: compiles an alphabetical list of definitions of key concepts that appears on DESDE-LTC Instrument.

Figure 1. Classification and coding system



Desde-Ltc Forms And Templates No changes

Desde-Ltc Training Package Training package must update all the changes included in the Toolkit. Mainly, the following documents have been reviewed:

- General guide instructions.
- Case book

Desde-Ltc Web Page New documents including modifications must be uploaded

4. CONCLUSION

The nominal group methodology has proved useful for the development of the eDESDE-LTC system (instrument and coding). In all 18 session have been carried out in 6 European countries. A total number of 46 participants took part in the process of nominal groups held in the different country partners during the length of the project. They include clinicians, researchers, planners, and other stakeholders. The nominal groups allowed for major discussion and proposals of changes in the assessment system. Several members of the nominal groups participated also in the feasibility study.

5. REFERENCES

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ANNEX

1.1 ANNEX 1

LIST OF CUT OFF POINTS SPAIN
SECOND SESSION: NOMINAL GROUPS
(DESDE-LTC Beta1)

INTRODUCTION

Services could be included in the mapping and counting when, as a general rule, at least a 20% of their users are persons with long term care needs. Facilities provided by health services, social services, voluntary sector and private sector providers should all be included. However, generic services for the general population or large groups within it, (i.e. elderly people, immigrant population etc.) which are important for many users with long term care needs although they have not been specifically planned for this population, should not be included, with the exception of those services where more than the 50% of the users are people with long term care needs.

SELF-HELP AND VOLUNTARY CARE

NON PROFESSIONAL STAFF

Facilities aimed at users with long term care needs, where professionals providing assessment, interventions or support to users with long term care needs are below 60% of the total personnel. The 100% of the staff is unpaid and has a voluntary association with the service.

PROFESSIONAL STAFF

Services designed for users with long term care needs that regularly at least 60% of trained or specifically qualified staff for providing assessment, intervention and support to users with long term care needs. The 100% of the staff is un-paid and has a voluntary association with the service

DAY CARE

Acute (for crisis care)

Facilities where (i) users are regularly admitted because of a CRISIS: deterioration in physical or mental state, behaviour or social functioning which is related to his or her condition; (ii) alleviating this deterioration is a purpose of the programme; (iii) admission to the programme is usually (at least 20 of the users) available within 72 hours.

WORK

High intensity

High intensity facilities are available for users who attend for at least the equivalent of four half days per week. Not all the users need attend as frequently as this for the service to be classified as ‘high intensity’, but it should at least be possible for them to do so.

Other work

The organisation follows specific work regulations for users with disabilities. Users are paid at least 50% of the usual local minimum expected wage for this form of work. Where there is no minimum wage, we suggest calculating an expected level based on starting salaries for similar jobs advertised in the local press over the past month. The work may be in a sheltered setting or in a setting where some workers are not users with Long-Term Care needs.

Work related care

These are facilities where users carry out an activity which closely resembles work for which payment would be expected in the open market, but where users are not paid or are paid less than 50% of the usual local expected wage for this form of work.

Time limited.

These are facilities where users perform a work related activity that has a time limit.

It includes centres giving courses for Occupational Training with a continuity in time over 24 months. Programmes defined in page 7 which are aimed at occupational training are not included here.

Time indefinite.

Facilities where users carry out a work related activity that do not have a fixed time limit.

It includes other occupational centres and workshops with the aim of social and labour integration.

When a centre offers training or continuing occupational care to the same group of people during long periods of time (i.e. more than 2 years) the facility is not coded as "time-limited" even when it has different programmes with a time limit (i.e. users stay in the centre for a period of time longer than the duration of a course

Non-work structured care

These facilities provide structured activities different from work and work-related activity. Such activities may include skills training, creative activities such as art or music, and group work. These activities should be available during at least 25% of the service's opening hours.

Health related care

Facilities that meet the criteria for programmed availability day care whose main activity is to provide clinical long term care (physical, psychological and/or social). At least 20% of the staff has a qualified training on health areas (minimum graduated?).

Non structured care.

Facilities which fulfil criteria for non-acute day services, but where work or other structured activities are not available, or available only during less than 25% of opening hours, so that the main functions of the service are the provision of social contact, practical help and/or support.

OUTPATIENT CARE

Continuing care

O.5 **High intensity:** These are facilities which have the capacity to make face to face contact with users at least three times per week when clinically indicated.

O.5.1_ _ _ _ Health related care. (as in O.1.1)

O.5.1.1_ _ _ _ _3 to 6 days a week care. Facilities which main goal is the specific clinical care for users with a frequency lower than 7 days/week 3 hours/day.

O.5.1.2_ _ _ _ _7 days a week a minimum of 3 hours/day care. Facilities which main goal is the specific clinical care for users with a frequency of 7 days/week 3 hours/day.

O.5.2_ _ _ _ _Other care. Facilities that do not meet the criteria for health related care services.

O.5.2.1_ _ _ _ _ _3 to 6 days a week care. Facilities not intended to provide specific clinical care for users with a frequency lower than 7 days/week 3 hours/day.

O.5.2.2_ _ _ _ _ _7 days a week a minimum of 3 hours/day care. Facilities not intended to provide specific clinical care for users with a frequency of 7 days/week 3 hours/day.

O.6 **Medium intensity:** These facilities do not have the capacity to supply three times weekly contact to users, but which can provide contacts at least once a fortnight when indicated.

O.6.1_ _ _ _ _ Health related care (as in O.1.1)

O.6.2_ _ _ _ _ Other care (as in O.1.2)

O.7 **Low intensity:** These services do not have the capacity to see users as often as once a fortnight.

Mobile: In mobile facilities contact with users occurs in a range of settings including users' homes, as judged most appropriate by professionals and users. For a service to be classified as 'mobile', at least 20% of contacts should take place away from the premises at which the service is based. For some services, the main site of service provision may vary from day to day (e.g. services in rural areas which move from village to village) – this does not mean they should be classified as 'mobile' unless staff go and do work at locations away from that day's main site.

RESIDENTIAL CARE

ACUTE (Immediate Availability for Crisis) (R.2-R.3) Services where (i) users are admitted due to a deterioration of their mental state, behaviour or social functioning which is related to psychiatric disorder; (ii)admissions usually available within 24 hours; (iii) users normally retain their own accommodation during the admission.

Hospital: In most countries, hospitals are legally recognised, and this legal recognition should then be used as the basis for identifying hospital services. Exceptions are units that have fewer than 20 beds and/or no 24 hour medical resident cover (these should be

classified as non-hospital facilities even if they have the legal status of hospitals).

Time-limited: These are facilities where a fixed maximum period of residence is routinely specified. A facility should be classified as time-limited if a maximum length of stay is fixed for at least 80% of those entering the facility.

Daily support. Members of staff regularly on site at least five days a week for some part of the day, with responsibilities related to the monitoring and clinical and social care.

1.2 ANNEX

DESDE-LTC Instrument- Day care and Residential sections

DAY CARE

D0 EPISODIC ACUTE CARE

Facilities which usually provide day care to users with a deterioration of their health state on a single or a limited number of episodes of care during a defined period of time.

D0.1 **High intensity**

Facilities which usually provide high intensity day care to users with a deterioration of their health state on a single or a limited number of episodes of care during a defined period of time. The care episode last less than 24 hours and the user is admitted and discharged during the same day. The care episode includes complex and coordinated care activities such as diagnosis and assessment, interventions, and other type of health care which require highly trained professional staff and which is not limited to a single face-to-face contact such as in planned outpatient care. The complexity of the intervention is such as to assimilate it to a crisis care situation.

Examples of Acute episodic care are Day chemotherapy units in oncology or outpatient electroconvulsive therapy units in mental health.

D0.2 **Other intensity**

Facilities which usually provide episodic acute care but which do not fulfil high intensity criteria.

D1 CONTINUOUS ACUTE CARE

Facilities where (i) users are regularly admitted because of a crisis or a deterioration in physical or mental state, behaviour or social functioning related to their health condition; (ii) alleviating this crisis/deterioration is the main purpose of the facility; (iii) Care is provided on a continuous base –non episodic, at least 5 days a week- during a limited period of time. These day facilities are organised to provide an alternative to hospitalisation or to accelerate discharge from inpatient units before the crisis is ended or the user is stable.

Day hospitals are usually included in this section.

Admission to the facility is usually available within less than 4 weeks from the crisis onset for user discharged from an acute residential unit (R2 or R3). At least 80% of the users in the last twelve months are admitted within less than four weeks of the crisis onset (in any other case classify the facility as D4.2.).

D1.1 **High intensity**

Admission to the facility is usually available within 72 hours. At least 20% of the users in the last twelve months are admitted within 72 hours.

Day hospitals included in this section are focused on care for users with a crisis or significant aggravation of their health status which is associated to a risk for themselves, their family or others needing immediate care. These services are an alternative to hospital admission. The user would have needed hospitalisation in a catchment area without this facility.

D1.2 **Other intensity**

All day continuos acute care facilities that do not meet the criteria for acute care for crisis.

Day hospitals included in this section are also focused on care for users with a significant aggravation of their health status which is associated to a risk for themselves, their family or

others needing immediate care. These services are NOT designed as an alternative to hospital admission but as a complementary system to hospitalisation that allows early discharge before the crisis is over. The user would have needed a longer hospital stay in a catchment area without this facility. Intensive case management services may be coded here.

RESIDENTIAL

R3 Non-24hours physician cover

Facilities without 24-hour physician cover where (i) users are admitted because of a crisis, a deterioration in their physical or mental state, behaviour or social functioning which is related to the condition; (ii) admission usually available within 24 hours; (iii) users usually retain their own accommodation.

R3.0. Hospital

Acute care facilities without 24-hours physician cover in a registered hospital.

Example code R3.0: *Some registered hospitals may provide low intensity acute care without 24-hour medical cover (i.e. some acute wards at specialised psychiatric hospitals, some hospitals for geriatric users, or some hospitals for brain Injury). A hospital ward which does not have 24-hour medical cover but where this provision is available at the meso-organisation where the service is placed, this service should NOT be coded here.*

This is a residual code which should be registered only after a careful assessment.

R3.1. Non-hospital

Acute care facilities without 24-hours physician cover outside a registered hospital.

R3.1.1 **Health related care**

Residential settings aimed at providing specific clinical care, during the period described by the code, and where a part of the staff is qualified on health care (Psychology, Medicine, Physiotherapy, Nursing) or has the equivalent training, but which does not provide 24-hour physician cover.

Example branch R3.1.1 –It includes a range of non-hospital beds which may be used as alternatives to hospital admission. Facilities such as crisis houses, crisis hostels or emergency beds in community primary care or mental health centres should be placed here. "Residential facilities" with high intensity medical staff but without 24 hour medical cover are included here (i.e nursing homes)

R3.1.2 **Other care**

Facilities that do not meet the criteria for acute non-hospital health related care.